Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools

Facilitating Participatory Approach

Author: Damyanka Tsvyatkova
Supervisors: Dr. Cristiano Storni
Dr. Chris Exton

Thesis submitted to the University of Limerick for the degree of Ph.D.
November 2016
Declaration

*Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach*

By: Damyanka Tsvyatkova
Supervisors: Dr. Cristiano Storni
            Dr. Chris Exton

This thesis is presented as fulfillment of the requirements for the degree of Doctor of Philosophy, at the University of Limerick, Dept. of Computer Science and Information Systems, Faculty of Science and Engineering. It is entirely my own work and has not been submitted to any other University or higher education institution, or for any other academic award in this University. Where use has been made of the work of other people, it has been fully acknowledged and referenced.

Signed:

________________________________________
D. Tsvyatkova
Abstract

The central question of this thesis is: How to design Interactive Technology (IT) for/with children with Type 1 Diabetes Mellitus (T1DM) and their parents/guardians? To address this question, this research has two main goals: firstly to gain a deeper understanding of paediatric diabetes everyday care experienced by children and parents in domestic environments and to identify an application area to explore the potential role of IT in supporting (some) self-care practice, and secondly to explore a series of collaborative user-centred and participatory design approaches in an attempt to examine the participants’ role in design and to facilitate users’ participation (e.g. children and parents) better in the technology development and design. This investigation is heavily influenced by the design process; the second goal is central to framing the contribution of this study.

To help answer this thesis’ question, the investigation focuses on the four main phases of User Centred Design (UCD) (i.e. research, design, prototyping and evaluation) and explores a series of methods to investigate the role of the users in developing an IT interactive technology that may support diabetes education and sense-making in newly children and their families: Participatory Design (PD), Cooperative Inquiry (CI), and Informant Design (ID).

Based on the empirical results, I stress the benefits of employing a participatory approach in the design of IT for paediatric diabetes. In particular, I highlight the limitations of the current tools supporting education in newly diagnosed children (with diabetes), and how participation in the design contributed in identifying critical areas of potential intervention which resulted in the prototyping of an educational eBook for newly diagnosed children and their families. Two clear aspects emerged from reflection on and analysis of the design process: the first is that the emotional response of affected participants was a crucial factor during design and these potential responses need to be taken into account when planning participatory design activities; the second highlights the benefit of participatory approaches based on narratives and storytelling to support participants in communicating their concepts and knowledge successfully. It also became evident that applying UCD, PD and CI by involving both parents and children as design partners was essential for the interactive technology design; their contribution to the educational content and main
characteristics of the IT design was based on their distinct experience and acquired responsibilities in diabetes care (e.g. having diabetes and caring for a child with T1DM).
# Table of Contents

Declaration.................................................................................................................. iii  
Abstract..................................................................................................................... v  
Table of Contents ...................................................................................................... vii  
Table of Figures........................................................................................................ xiii  
Table of Tables ......................................................................................................... xvii  
Table of Graphics.................................................................................................... xviii  
Acknowledgements.................................................................................................. xix  
Glossary of Terms and Abbreviations ................................................................... xxi  

## Chapter 1: Introduction and Objectives ................................................................. 1

1.1 Introduction ......................................................................................................... 1  
1.2 Paediatric Diabetes: Challenges in Care and Education ...................................... 3  
1.3 Interactive Technology for Children with T1DM: Methodological Challenges and Users’ Roles in their Development and Design ......................................................... 6  
1.4 Research Questions ............................................................................................ 9  
1.5 Contribution of the Thesis ................................................................................ 11  
1.6 Thesis Outline .................................................................................................... 13  

## Chapter 2: Type 1 Diabetes and Educational Interactive Technologies: Challenges and New Perspectives ............................................................. 17

2.1 Introduction ...................................................................................................... 17  
2.2 Type 1 Diabetes Mellitus (T1DM): the Complexity of Diabetes Care and its Treatment ........................................................................................................... 18  
2.2.1 The Nature of Type 1 Diabetes and its Treatment ........................................ 18  
2.2.2 Diabetes Self-Care: the Complexity of the Terms in Paediatric Diabetes and the Value of Patient Education ................................................................. 21  
2.2.3 Model of Care in Ireland: Limitations in Paediatric Diabetes Education .... 26  
2.3 IT Interventions: Exploring Users’ Roles in Product Development and Design Interventions ........................................................................................................... 31  
2.3.1 Educational IT Interventions: Criteria for Selection and Data Analysis .......... 32  
2.3.2 Discussion: Advantages, Limitations and Future Perspectives ....................... 50  
2.4 Summary .......................................................................................................... 54  

## Chapter 3: Designing for/with Children with Diabetes: Challenges in UCD and CCI ............................................................................................................ 57

3.1 Introduction .................................................................................................... 57
3.2 Human-Computer Interaction and Children

3.3 User Centred Design (UCD) and Children

3.4 A Review of Selected Methods, Techniques and Tools in CCI Developed/Adapted to Support Children’s Involvement in Technology Development

3.5 Designing for/with Children: Challenges in CCI

3.5.1 The ID, CI and BRIDGE Methods: Critical Analysis

3.5.2 Three Studies with Children with Chronic Conditions and their Families: Design Activities, Various Actors and their Roles in Design

3.5.3 Participatory Approach: Age, Education and Families

3.6 Summary

Chapter 4: Research Methodology: Selecting Design Interventions to Support Users’ Participation in Design

4.1 Introduction

4.2 Empirical Methods

4.2.1 Understanding the Users’ Needs: Semi-Structured Interviews, Affinity Diagrams and DP

4.2.2 Designing: Collaborative Storytelling

4.2.3 Prototyping: Collaborative Storytelling, Personas, Problem and Activity Scenarios and their Storyboards

4.2.4 Evaluation Process: Layered Elaboration

4.3 People Involved in the Design Process: Ethical Approval and Participants Recruitment

Chapter 5: UCD and PD Approaches: Involving Participants in Design

5.1 Introduction

5.2 Stage One: Exploring Paediatric Diabetes Everyday Care

5.2.1 Qualitative Approach for Investigating Issues and Challenges in Paediatric Diabetes Practices Experienced in Domestic Environments

5.2.1.1 Sample and Data Analysis

5.2.1.2 Theme 1: Diabetes Education

5.2.1.3 Theme 2: Child’s Emotional State

5.2.1.4 Discussion: Interviews

5.2.2 Design Probes

5.2.2.1 DP: Participants’ Recruitment

5.2.2.2 Adapting Design Probe Materials for Children with Diabetes and their Parents

5.2.2.3 Distribution, Collection and Responses

5.2.2.4 First Iteration with Eight Activities: Collected Materials

5.2.2.5 Second Iteration with Four Activities: Collected Materials
Table of Figures

Figure 1: Screen capture of the Model of care by Porter and Thomas 2013  
(O’Riordan et al 2015, p 23) ...................................................................................... 28

Figure 2: Screen capture Patient Journey (O’Riordan et al 2015, p 24) .............. 29

Figure 3: Children’s role in the design process: Druin’s model ......................... 65

Figure 4: Screen capture of modified and tailored UCD for designing patient-centric self-help tools by Årsand and Demiris 2008, p 166 ................................................... 66

Figure 5: Affinity diagrams with two main themes, 19 + 5 sub themes and key empirical data .......................................................................................................... 129

Figure 6: Identified Themes .................................................................................... 130

Figure 7: ‘Pete the Pancreas’ set ............................................................................ 140

Figure 8: CHOICE materials used in the programme: First image - posters explaining some of the processes in the human body, Second Image - plastic food models with right sized portion circle graph, Third image - how to count the carbs in a plate and Fourth image - the use of glucagon ...................................................... 145

Figure 9: Instructions - Disposable camera ............................................................ 155

Figure 10: Disposable camera ............................................................................... 156

Figure 11: Technology Gadget design .................................................................... 157

Figure 12: Sent a postcard ........................................................................................ 158

Figure 13: Design Collage/Poster ........................................................................... 159

Figure 14: Kids diary .............................................................................................. 160

Figure 15: Superhero and a story of his/her power ................................................ 161

Figure 16: Design your own Recipe book ............................................................... 161

Figure 17: My problem solving diary ...................................................................... 161

Figure 18: Poster, T1DC4 (8-Year-Old) ................................................................ 164

Figure 19: Poster, T1DC7 (9-Year-Old) ................................................................ 164

Figure 20: Poster, T1DC8 (12-Year-Old) ............................................................... 165

Figure 21: Poster, T1DC9 (9-Year-Old) ................................................................ 166

Figure 22: Poster, T1DC10 (12-Year-Old) .............................................................. 166

Figure 23: Glucometer, T1DC8 ............................................................................... 166

Figure 24: Insulin pump, T1DC7 ........................................................................... 166

Figure 25: Insulin pump, T1DC9 ........................................................................... 166

Figure 26: Insulin pump, T1DC4 ........................................................................... 166

Figure 27: Hypo-Hyper Man, T1DC8 ................................................................. 167

Figure 28: Captain Baby, T1DC9 ........................................................................ 167

Figure 29: Helper D, T1DC4 .................................................................................. 167

Figure 30: Michael, T1DC7 ................................................................................... 167

Figure 31: Disposable camera ................................................................................ 168

Figure 32: Postcard to friends, T1DC8 ................................................................. 169

Figure 33: Postcard to the best friend, T1DC4 ...................................................... 169

Figure 34: Postcard, T1DC7 ................................................................................... 170
Figure 35: Detecting hyperglycaemia, T1DC8 ....................................................... 170
Figure 36: Pain in the stomach, T1DC8 ................................................................. 170
Figure 37: Diary, T1DC4 ...................................................................................... 171
Figure 38: Recipes, T1DC8 .................................................................................. 172
Figure 39: Problem solving diary ......................................................................... 174
Figure 40: Prick the finger (first image), Low results (second image), Sweet Dispenser (third image) and Light Indicators (fourth image), T1DC19 .............. 175
Figure 41: Wireless gadget, T1DC17 .................................................................. 175
Figure 42: Insulin pump similar to mobile phone, T1DC18 ................................... 176
Figure 43: Tele-transportation machine, T1DC16 .................................................. 176
Figure 44: Lighting girl, T1DC16 ....................................................................... 177
Figure 45: Debbie Diabetic, T1DC19 .................................................................. 177
Figure 46: Ailish Ryan, T1DC18 ........................................................................ 177
Figure 47: Information gin, T1DC17 .................................................................. 177
Figure 48: Poster, T1DC17 ................................................................................ 179
Figure 49: Poster, T1DC16 ................................................................................ 179
Figure 50: Poster, T1DC19 ................................................................................. 180
Figure 51: Poster, T1DC18 ................................................................................ 180
Figure 52: Brother and parents, T1DC16 ............................................................. 181
Figure 53: Mother and brother, T1DC18 ............................................................... 181
Figure 54: Mother, T1DC18 ............................................................................... 181
Figure 55: Two storytelling card decks: ‘Traveling through the human body’ and 188
Figure 56: Design of the story starters and picture cards of ‘Traveling through the human body’ ............................................................................................................. 188
Figure 57: Design of the story starters and picture cards ‘Superhero is sick’ ...... 188
Figure 58: Using glucometer ............................................................................... 191
Figure 59: Taking insulin by injections and insulin pump ...................................... 192
Figure 60: Food .................................................................................................... 193
Figure 61: Some of the scenarios produced in the first session ............................. 194
Figure 62: Story starter and Storytelling cards for describing characters .......... 196
Figure 63: Made suggestions ............................................................................... 196
Figure 64: Liam and Abbie ............................................................................... 196
Figure 65: Choose technology ............................................................................ 197
Figure 66: Submarine ......................................................................................... 197
Figure 67: Story telling cards on pancreas, stomach and heart ........................... 198
Figure 68: Lungs .................................................................................................. 198
Figure 69: Heart .................................................................................................. 198
Figure 70: Pancreas and stomach ....................................................................... 198
Figure 71: Position .............................................................................................. 198
Figure 72: Story starter and Storytelling cards for describing doctor .................. 200
Figure 73: Superhero’s House ............................................................................ 200
Figure 74: Anastasia .......................................................................................... 200
Figure 75: Dr. Jenny .......................................................... 200
Figure 76: Hospital .......................................................... 200
Figure 77: Doctor-Patient meeting ..................................... 201
Figure 78: Story telling cards and story starters on healthy food 201
Figure 79: Bad for you and Good for you categories .......... 202
Figure 80: Technology ....................................................... 202
Figure 81: Questions used in the prototyping session ........ 208
Figure 82: All prototypes developed by children ............... 210
Figure 83: Lizzie, T1DC20 ............................................... 212
Figure 84: Katie Cat, T1DC17 ......................................... 212
Figure 85: Sky master, T1DC21 ....................................... 213
Figure 86: Bella bendy, T1DC18 ..................................... 214
Figure 87: Bella's house, T1DC18 .................................... 214
Figure 88: Doctor, T1DC16 ............................................. 214
Figure 89: Doctor, T1DC17 ............................................. 215
Figure 90: Doctor, T1DC20 ............................................. 215
Figure 91: Story starters and picture cards for elaborating the dialogue .... 216
Figure 92: Story starters and picture cards for explaining the diagnosis and its treatment ........................................... 216
Figure 93: Dialogue, T1DC16 .......................................... 217
Figure 94: Dialogue, T1DC17 .......................................... 218
Figure 95: Dialogue, T1DC18 .......................................... 218
Figure 96: Dialogue, T1DC19 .......................................... 218
Figure 97: Dialogue, T1DC20 .......................................... 219
Figure 98: Dialogue, T1DC21 .......................................... 219
Figure 99: Dialogue, T1DC22 .......................................... 219
Figure 100: A watch, alarm clock and mobile phone, T1DC17 .... 220
Figure 101: Alarm clock and mobile phone, T1DC22 ........ 220
Figure 102: Example of healthy food discussion .............. 221
Figure 103: Healthy and un-healthy food, T1DC17 .......... 221
Figure 104: Images of healthy and un-healthy food, T1DC22 .... 221
Figure 105: Different sports, T1DC16 ............................ 222
Figure 106: To keep their sugars down, T1DC22 ............ 222
Figure 107: Interaction Doctor, T1DC21 ......................... 222
Figure 108: Constant image, T1DC19 ............................. 222
Figure 109: Personas: mother Anna and father Jonathan ... 243
Figure 110: Personas: teacher and nurse ......................... 244
Figure 111: Personas Liam, Daniel and Sarah ................... 250
Figure 112: Problem scenarios: Daniel and Anna ............. 252
Figure 113: Problem and activity scenarios: examples ...... 253
Figure 114: Some storyboards ......................................... 260
Figure 115: Story: screen capture .................................... 262
Figure 116: Mock-up prototype ................................................................. 265
Figure 117: Instructions and materials used for the test and evaluation sessions . 269
Figure 118: Questions used in the evaluation sessions with children with T1DM and their parents ................................................................. 275
Figure 119: Button and facts T1DC25 ...................................................... 281
Figure 120: Replace with real images when the user arrange them properly, Session 1 ....................................................................................... 281
Figure 121: Fappy/unhappy faces of the cells T1DC26 .............................. 281
Figure 122: Facial expression animation-Parent3 (Session 2) .................... 281
Figure 123: Describe child, but not his home life (Session 3) ................. 283
Figure 124: New questions for the page 10 (Session 2) .......................... 283
Figure 125: Technology Session 1 .......................................................... 283
Figure 126: Activating interactive elements ........................................... 286
Figure 127: Simultaneously adding ideas (Session 1) .............................. 286
Figure 128: Drawing mini-game idea (Session 1) ..................................... 286
Figure 129: Mother writing her ideas ...................................................... 286
Figure 130: Boy helping his mother ...................................................... 286
Figure 131: Draw dialogue bubble (Session 4) ........................................ 287
Figure 132: Several ideas on one page (Session 5) ................................. 287
Figure 133: Position of the transparent sheet (Session 5) ....................... 287
Figure 134: Child trying to insert the test strip into the glucometer (Session 3) ................................................................. 289
Figure 135: 6-year-old boy playing with the images of Superhero and Dr. Jenny (Session 2) ................................................................. 289
Figure 136: Session 1, rearranging images page 10 .................................. 291
Figure 137: Session 4, simulating submarine shrinking page 7 .................. 291
Figure 138: Session 5, page 8 simulating plop sound .............................. 291
Figure 139: ‘Pete the Pancreas’, page 30 ............................................... 292
Figure 140: Questions used for the evaluation sessions with healthy children ................................................................. 297
Figure 141: Suggestion for Page 3, 8 years old girl ................................... 302
Figure 142: Suggestion for page 3, 12 years old girl ................................ 302
Figure 143: Suggestion for Page 9, 8 years old ....................................... 303
Figure 144: Suggestion for page 9, 12 year old girl ................................. 303
Figure 145: Dialogue bubbles, page 5, HC9 ......................................... 304
Figure 146: Show and explain the object, page 5, HC2 ............................ 304
Figure 147: Tapping to change the size, page 7, HC11 ............................ 304
Figure 148: Add question, page 10, Session 10, 8 years old child ............ 305
Figure 149: Working in groups, Session 7 .............................................. 306
Figure 150: Writing question for page 10, Session 10 ............................. 306
Figure 151: Session 8, page 9 ................................................................. 307
Figure 152: Session 9, page 9 ................................................................. 307
Figure 153: Arranging the human organs, Session 9, page 10 ..................... 307
Figure 154: A girl explains diabetes to other children, Session 9, page 12 ....... 307
Figure 155: Finding submarine, Session 10, page 8 .................................................. 308
Figure 156: Liam drinks the water, Session 10, page 9 ............................................. 308
Figure 157: Playing the game, Session 10, page 10 ..................................................... 308
Figure 158: The correspondence between me and the community organizer .......... 337
Figure 159: Cancelling interview ............................................................................. 338
Figure 160: Returning DP ....................................................................................... 343
Figure 161: Formal Learning/Alone vs Informal Learning/Together ...................... 366
Figure 162: Medical perspective vs Patient perspective .......................................... 368
Figure 163: Prescription vs Narrative ...................................................................... 370
Figure 164: Static vs Interactive .............................................................................. 373
Figure 165: x-axis represents the merging of educational content, language and interactivity categories while the y-axis illustrates the opposition of individual/formal and collective/informal learning approaches ......................................................... 375
Figure 166: Transition to User Centred and Participatory Design model in the design of educational interactive technology for children with chronic disease .... 376
Figure 167: Word Puzzle ...................................................................................... 377
Figure 168: Colouring pages .................................................................................. 377
Figure 169: Instructions in bullet points .................................................................. 377
Figure 170: Insulin treatment .................................................................................. 377
Figure 171: Explaining what is diabetes .................................................................. 379
Figure 172: Using photos explaining the steps of using glucometer ....................... 379
Figure 173: Superhero's room, page 5 ...................................................................... 380
Figure 174: In a hospital waiting room, open a door and help the baby play with a toy, page 7 ................................................................................................................ 380
Figure 175: What is type 1 diabetes, journey with a magic submarine, page 7 ..... 380
Figure 176: Superhero's kitchen, page 8 .................................................................. 380
Figure 177: Superhero is sick, page 10 ..................................................................... 380
Figure 178: Measuring blood glucose level, page 9................................................... 381
Figure 179: Technologies: insulin pump and glucometer, page 11 ........................ 381
Figure 180: Digestive system, page 10 ................................................................. 382
Figure 181: Explaining diabetes, page 12 .............................................................. 382
Figure 182: Insulin treatment, page 13 ................................................................... 383
Figure 183: Balance between carb and insulin ....................................................... 383

Table of Tables

Table 1: A selection of IT developed to support children with T1DM ...................... 34
Table 2: Identified methods, techniques and tools in the evaluation and design ...... 47
Table 3: Participants: children with T1DM and their families ......................... 117
Table 4: Participants: healthy children ................................................................. 119
Table 5: Methods, techniques and tool applying UCD ....................................... 122
Table 6: Interviewed participants who have experience with T1DM .................... 126
Table 7: Participants in first and second iterations .............................................. 154
Table 8: Activities used in both iterations and users’ responses ......................... 162
Table 9: Design methods, participants, materials and place .............................. 187
Table 10: Participants in the prototyping session 4 ............................................. 209
Table 11: Users, users' roles, goals and factoids .............................................. 232
Table 12: The main user categories and personas names .................................... 241
Table 13: Antle's framework for developing child personas of Liam, Daniel and Sarah ........................................................................................................................ 247
Table 14: User requirements and the state of the art ......................................... 255
Table 15: Participants in the evaluation process ................................................. 270
Table 16: Participant's reflection on both prototypes ......................................... 278
Table 17: Using the materials supporting the layered elaboration technique ...... 284
Table 18: Participants' point of view on 'Pete the Pancreas' book ......................... 293
Table 19: Suggestions made by healthy children for both prototypes ................. 301
Table 20: Findings evaluating the prototypes with design partners and informants .............................................................................................................. 311
Table 21: Requirements at the level of Users, Educational content, Language and Interactivity .............................................................................................................. 359

Table of Graphics

Graphic 1: A map visualisation of the selection of methods, techniques and tools in CCI ............................................................................................................................. 73
Graphic 2: Performing UCD and participatory approach ................................... 99
Graphic 3: A map illustrating the places where various activities with participants have been carried out .............................................................................................................. 118
Graphic 4: Work completed in an iteration of the UCD .................................... 123
Acknowledgements

Over the past years I’ve spent on this research I had this great opportunity to have support from my supervisors Dr Cristiano Storni and Dr Chris Exton. I would like to thank you both for your valuable advice, trust in my research skills, support and motivation to continue my work.

I am very grateful to all fantastic lecturers in the Interaction Design Centre (IDC) as Dr. Gabriela Avram, Dr. Mikael Fernström, Dr. Nora O'Murchu and Professor Liam Bannon for their guidance regarding this research and for the wonderful learning environment. Also, to express my sincere thanks to Dr. Ita Richardson and Ms. Annette McElligott who work in the University of Limerick (UL) for their never ending support through my research. Special thanks to Alan Ryan for assisting me in proofreading my academic papers, for his continued help during the co-design sessions with children, for his patience in teaching me to use the Adobe Creative Suite (CS) and AXURE during the prototyping stage, and especially with his sense of humour in difficult times and always having a box of chocolate. Thanks to Laura Maye for discussing questions and issues related to the Ph.D. study, we both needed moral support during this long journey.

While working on this research, I have met many wonderful families who have children with diabetes, medical professional, people who were dedicated to help and support diabetics as Diabetes Ireland (DI) organization. I was impressed by their constant hard work, continuous effort and perseverance in their efforts to improve the lives of children who have type 1 diabetes. I would like to express my gratitude to all people who provided support for my research, who believed in me and my work, who actively participated in the design activities of the eBook. I would like to acknowledge the support, inspiration and great ideas I have received from the staff and children at ‘Sunflower’ voluntary group.

And finally, I would like to extend my sincerest gratitude to my husband and my daughters who always supported me in my willingness to help children with diabetes and their families. Their positive attitude in the hard times always encouraged me to continue my work, for that I was capable of accomplishing this research.
Glossary of Terms and Abbreviations

Within the content of this thesis, a number of terms, abbreviations and acronyms are used. These are explained below alongside with their shortened versions of words or phrases.

**T1DM:** Type 1 Diabetes Mellitus

**GP:** General Practitioner

**HbA1c:** Glycated Haemoglobin, accurate measurement of average blood glucose

**Insulin:** Is a hormone produced by the pancreas to regulate carbohydrate and fat metabolism

**Hypoglycaemia:** Technical term for low levels of blood sugar (glucose) in Diabetes Mellitus

**Hyperglycaemias:** Technical term for high levels of blood sugar (glucose) in Diabetes Mellitus

**Blood Glucose Meter:** Or Glucometer is a medical device used to measure the concentration of glucose (sugar) in the human blood

**Insulin Pump:** Is a medical device (mimicking the human pancreas) programmed to administrate human body with insulin

**Glucagon:** It consists of two hormones which have the opposite effect to insulin. Applied in an emergency, they boost blood glucose levels.

**Diabetic ketoacidosis:** The buildup of keytones in the body when the body cannot metabolise sugar (glucose) for energy because of a lack of insulin.

**Neuropathy:** Nerve damage as a result of type 1 diabetes

**CHOICE:** Acronym of the educational programme called Carbohydrate and Insulin Collaborative Education

**SWEET:** Acronym of Better control in Pediatric and Adolescent diabeteS: Working to crEate CEnTers of Reference

**DI:** Diabetes Ireland

**CBT** Cognitive Behaviour Therapy
**HCI:** Human Computer Interaction

**UCD:** User Centred Design

**PD:** Participatory Design

**CCI:** Child Computer Interaction

**CI:** Cooperative Inquiry

**ID:** Informant Design

**DP:** Design Probes

**IT:** Interactive Technology
Chapter 1: Introduction and Objectives

1.1 Introduction

According to The Lancet (2012) “all people are patients at some point of their lives”. However with some chronic diseases such as type 1 diabetes, the lives of affected young individuals and their families change forever, making them patients for the rest of their lives (Tsvyatkova and Storni 2015b). Unfortunately, the number of affected young individuals in the International Diabetes Federation\(^1\) (IDF) atlas shows the continuous increase in diabetes, for 2015 approximately 542,000 of the world’s children have Type 1 Diabetes Mellitus (T1DM) with approximately 140,000 (between 0-14 years) of them living in the Europe Region. The Europe Region has the highest number of cases of children with diabetes compared to other IDF Regions and each year about 20,000 new cases are reported (Aguiree et al 2013). It was also indicated that for 2013, one-quarter of global spending on diabetes care was in the Europe Region where the costs exceeded USD 147 billion (Aguiree et al 2013).

As users of Interactive Technology (IT), children with T1DM are entering in the vulnerable group because of their age (Child Care Regulations 2004\(^2\)) and diagnosis (Vines et al 2013). Very little research has investigated their and the designer’s roles in participatory Human Computer Interaction (HCI) (Vines et al 2012) involving young participants in the entire development process of application/technology that may support their paediatric self-care practices. There is no universal design approach that could be used in different healthcare domains facilitating the involvement of individuals with various health issues in the design of services. Further exploration of co-design practices in developing supportive technology for/with children with medical health problems and their parents is needed to explore not only how the theory best informs the design practices (Aldiss et al 2015; Isola and Fails 2012; Iversen and Dindler 2013), but also whether developed technology provides assistance to concrete users’ practices (Jahns 2014; Research2Guidance 2014a). Therefore, this opens up the opportunity for exploring the participation of this group of young individuals with T1DM and their parents in designing user-

centred activities investigating the most suitable methods supporting their participation in order to give them more control in choosing and creating IT that may better resonates with their needs.

The thesis is concerned with the design of IT for/with Children with T1DM in trying to explore User Centred Design (UCD) and participatory approach by examining different methods, techniques and tools supporting participants’ involvement and participation in the design process. The aim of this research is twofold:

1) On one hand to improve our understanding of every day self-care practices in paediatric diabetes and to explore the role of design and IT in supporting some of these practices.

2) On the other hand, to explore a series of collaborative user-centred (ISO9241 – 210:2010) and participatory design methods (Muller and Druin 2003; Mattelmäki 2006; Druin 2002; Scaife et al 1997) in an attempt to facilitate better involvement of the users (e.g. children and parents) in the IT development and design that might support newly diagnosed children and their family at home.

In my work as part of my initial investigation, I found that some of the problems experienced and identified by affected individuals were related to the diabetes education provided for newly diagnosed children and their families (Tsvyatkovala and Storni 2014a; Tsvyatkovala and Storni 2015b). This helped to narrow down and to find a specific focus for a design intervention that addresses a particular aspect in self-care, especially for newly diagnosed children and their families concerning their education and sense making on diabetes - an educational eBook for newly diagnosed children between 8-12 years of age with Type 1 Diabetes Mellitus. As the central goal of this study was to explore participatory design approaches aiming to involve individuals actively in the design process, the eBook was used as a tool to plan and examine a series of participatory activities as methods, techniques and tools and reflect on them, and to look at the role of IT in paediatric diabetes education. The children involved in the design had different “roles”- as “design partners” and “informants” - respectively qualified through their experiences of having diabetes and being healthy (Tsvyatkovala and Storni 2015b).

3 http://www.iso.org/iso/catalogue_detail.htm?csnumber=52075
This thesis begins with the Section 1.2 describing the challenges in paediatric diabetes treatment and the current state of care available for families who have children with T1DM in Ireland. Section 1.3 provides a discussion addressing the limitations in HCI, UCD and Child Computer Interaction (CCI) research areas by examining the involvement of children with diabetes and their participation in the design of IT. Section 1.4 presents the research questions this thesis strives to answer. The last two segments i.e. Section 1.5 introduces the contributions made based on empirical data and Section 1.6 offers the structure of the thesis and its content.

1.2 Paediatric Diabetes: Challenges in Care and Education

Diabetes is a non-communicable disease (NCDs) characterised by chronic high levels of sugar in the blood (World Health Organization 2008). With diabetes, the pancreas develops a total or partial inability to produce a hormone called insulin. The hormone’s main function is to help cells in the liver, fat tissues and muscles to take up the sugar from the blood stream for energy and also to control metabolic processes in the body (Holt and Kumar 2010; Lorig et al 2006; Weinger and Carver 2009). Self-management and self-care are terms explaining personal activities to control their chronic condition. In successful self-management, patients have the necessary knowledge to deal with prescribed medications, as well as skilled problem-solving abilities to engage and manage his/her own illness (Lorig et al 2006; Goodall and Halford 1991).

SWEET (2013) highlighted two major factors in paediatric diabetes treatment, 1) the inequality of access to “multidisciplinary diabetes care and education continue to exist across the EU” and 2) the overall quality of the care provided to the young patients (p 7). The systems of paediatric diabetes care are heterogeneous across the European Union (Cinek et al 2012). In 2009, only 7 of 26 EU countries had quality control systems (collecting data of glycated haemoglobin (HbA1c) and frequency of diabetic ketoacidosis (DKA)) in the delivery of paediatric diabetes care and only 20 EU countries had paediatric diabetes registers (Cinek et al 2012). Trying to improve

---

4 Diabetes itself has two forms and their cause and treatment are different: Type 1 Diabetes Mellitus (T1DM) or Juvenile Diabetes is an insulin dependent diabetes and Type 2 Mature Diabetes is a non-insulin diabetes. This project concerns only Type 1 Diabetes in children.

5 SWEET is an acronym of ‘Better control in Pediatric and Adolescent diabeteS: Working to crEate CEnTers of Reference’. The aim of SWEET project (April 2008 – March 2011) was to improve care, diagnosis and control in diabetes by developing Centres of Reference (CoR’s) for paediatric diabetes services in EU countries.
paediatric diabetes services (e.g. Centres of Reference (CoR’s)) across EU countries, SWEET developed a Paediatric Diabetes Toolbox with 3 key recommendations for “1) minimum treatment and care; 2) patient education programmes; 3) training programmes for health professionals” (SWEET 2013, p 7).

Children with diabetes are even more vulnerable; in a variety of ways and in relation with their age, kids are either unable to take care of themselves or need to rely on the help of family members, the medical staff and social services (Goodall and Halford 1991; Guthrie et al 2003; Smaldone and Ritholz 2011). Younger patients have limited communication and cognitive skills leading to difficulties in understanding all different aspects of diabetes and treatment (Guthrie et al 2003; Polonsky 1999; Smaldone and Ritholz 2011). Children need to learn how to make room for a huge amount of self-care practices: checking blood glucose, administering insulin injections (including counting the amount of insulin taken based on the blood sugar, food taken, and physical activities) or how to use an insulin pump, understanding what is healthy food (especially carbohydrates), and maintaining regular physical activities. They also need to learn how to recognize the symptoms of hypo- and hyper-glycaemia and gain skills of adequate action for these conditions (Polonsky 1999). Such knowledge is linked to their treatment and difficulties are influenced by children’s perception regarding the care, psychology factors and problem-solving experience (Roper et al 2009). Feelings of fear, self-doubt, adjustment to the illness, sharing diabetes-care responsibilities among the family members, as well as other issues, can be a challenge for every family who has a child with diabetes (Smaldone and Ritholz 2011). Parents are also worried about how much responsibility diabetic children will need to become more independent. Transition to a more autonomous life is concerned with the development of appropriate awareness, delegation of responsibility and independent activities of adolescents to live their own lives (Guthrie et al 2003; Smaldone and Ritholz 2011).

Education of children and parents is regarded as essential to establish an “effective medical home model” in domestic environments (Smaldone and Ritholz 2011, p 92); it is a long process that usually starts after the initial diagnosis (Martin et al 2012; Lange et al 2014; Swift 2009). Diabetes self-management education includes an acquisition of different practical skills and knowledge related to the chronic condition (Lange et al 2014). Usually, the education is supported by carefully
planned and organised structured programmes and materials that should be accessible for the families at different intervals (Lange et al 2014; Martin et al 2012; Swift 2009). The interdisciplinary team of medical professionals (e.g. endocrinologists, dietitians, diabetes nurses, etc.) should use age-appropriate language and educational resources as booklets, books, journals, pictures, posters, leaflets, DVDs, websites, games, devices, etc. in their secondary role as educators, facilitating the training and educative process (Lange et al 2014; Martin et al 2012).

Taking into consideration the “great diversity of educative practices across centers and countries”, the success of an educational programme depends on the national model of care for children with T1DM, the diabetes educational programmes used, local educational materials and health communities, and diabetes care centres and services (Martin et al 2012, p 25). This statement, together with the findings that have emerged in the empirical data applying semi-structured interviews with parents and children, led to a further investigation on paediatric diabetes services, educational procedures and materials available in Ireland for children with diabetes and their families. The results clearly indicated the shortage of teaching and learning materials and supports available and in use by children and educators (i.e. only the small booklet ‘Pete the Pancreas’ helps young patients learn about diabetes), as well as the lack of structured educational programmes outside clinical settings. According to the ‘Model of Care for All Children and Young People with Type 1 Diabetes’, 19 paediatric units provide care for 2,040 children and adolescents with Type 1 Diabetes Mellitus (T1DM). Developed by Dr Chaney (Chaney 2012; Chaney et al 2013), the CHOICE structured educational training programme for young individuals (aged 0-19 years) and their parents launched in Ireland in 2013, but it was available only in some paediatric centres. Unfortunately, this creates inequality in levels of access to this follow-up education, with many families not having this opportunity to refresh, update or improve their own knowledge and skills on diabetes treatment.

As one can easily imagine, maintaining a healthy behaviour can be particularly difficult for children. Many of them might find it too difficult to understand the nature of the disease and the need of continuous and consistent care. Others might

---

8 It is an acronym for carbohydrate and insulin collaborative education
fail to keep up with the demands of self-monitoring and self-medicating practices. In this context, the use of technology is seen as key to support the nature of care in chronic diabetes. Information Technology affords opportunities to investigate new methods in diabetes self-management and self-care practices, in addition to glucose meters, insulin pens and pumps, especially as the literature lacks reflections on how to design Information Technology and more importantly, how to evaluate its impact.

In relation to IT design, one of the opportunities for future research is through a HCI lens, suggested by Nunes et al (2015), focusing on the everyday life experiences of affected individuals by trying to investigate and become aware of their self-care practices and how technology may fit better to their routines contributing to their performance. And of course this could be happen when participants’ involvement starts from the early phases of IT design.

This project aims to improve our understanding of different issues and problems related to paediatric diabetes management outside the attention of the clinicians and to explore the potential of an IT design by involving users from the beginning of the design process and maintaining their participation throughout the entire product cycle. In striving to improve and facilitate their active participation in design, various participatory and user-centred design strategies were applied to increase creative collaboration, to support mutual learning and knowledge sharing and to explicit discussions that assist the development of interactive technology aiming to support more effectively the users’ needs. Taking into consideration parents’ shared experiences with the educational practices provided in the clinical and home setting, as well as the limitations of materials (e.g. book, video games, websites, etc.) supporting diabetes education, an interactive educational eBook for newly diagnosed children aged 8-12 was developed, thus enabling the examination of the role of the users (e.g. children and parents) during the design activities and to explore the role of technology in supporting diabetes education in children.

1.3 Interactive Technology for Children with T1DM: Methodological Challenges and Users’ Roles in their Development and Design

The interactive technology defined by Street and Rimal (1997) are “computer-based media that enable users to access information and messages in the mediated environment” (p 2). Assuming the significant role of technology in healthcare, many
new products were particularly developed to support people with chronic diseases as diabetes (Research2Guidance 2013; Research2Guidance 2014b). Unfortunately, the results indicated that these supportive tools still do not meet the requirements and subjective criteria of the individual users (El-Gayar et al 2013; Jahns 2014; Research2Guidance 2014a). El-Gayar and his colleagues (2013) highlighted that the Information Technologies interventions “did not achieve desired glucose management level, adoption and satisfaction” (p 643). They suggested that the best option “to incorporate users’ requirements is by involving end-users during system design and development (user-centered design)”, as well as the “research should pay particular attention to enhancing the usability and satisfaction of using IT for diabetes self-management through the understanding of the informational needs and characteristics of the end users as well as the social context in which the technology is applied.” (El-Gayar et al 2013, p 643-644).

Children with diabetes are not an exception as users of IT, as many different types of educational technologies were developed to support their daily self-care management (Aoki 2004; Bayer 2012; Belpaeme et al 2012; Brox et al 2011; Brox et al 2012; Bomark et al 2012; Gerber 2014; Glasemann and Kanstrup 2008; Henkemans et al 2013; Hockenson 2012; Kanstrup 2014; Lehmann 1997; Lieberman 2012; Looije et al 2008; Klingensmith et al 2013; Pentland 2004; Stiehl et al 2009; Van der Drift et al 2014). Some of these technologies are only prototypes (Aoki et al 2004; Brox et al 2012; Bomark et al 2012; Glasemann and Kanstrup 2008; Henkemans et al 2013; Looije et al 2008; Kanstrup 2014; Pentland 2004; Stiehl et al 2009). In the majority of these studies, the assessment process was mainly targeted at testing the design idea and identifying positive or negative results of using these artefacts. Most of the designers/researchers have given limited information on the criteria for informing the technology choice, what design interventions they used (i.e. methods, techniques, and tools) while they have developed these products/prototypes, and what was the role of the young individuals, their involvement and participation in the design process. Yarosh et al (2011) confirmed these gaps suggesting that researchers should “be more explicit about their theoretical perspectives and use more theories and models from other fields” (p 144). In a similar vein, Aldiss and her colleagues (2015) indicated two limitations based on the lack 1) of theory when designing supportive
technology for patients with chronic conditions and 2) of children’s participation and involvement in the design process.

As a sub-field within of HCI, CCI is a research area that studies the design of technologies and interactive systems for/with children, focusing on theory facilitating children involvement in the product design (Read and Bekker 2011; Read et al 2012). Of course, taking into consideration the child’s development (Piaget 1970) some of the design theories in HCI such as UCD (Norman 1998; International Organization for Standardization 2010), Contextual Design (CD) (Beyer and Holtzblatt 1998), Participatory Design (PD) (Ehn 1989; Ehn 1993; Iversen et al 2012; Muller 1993; Muller and Druin 2003; Robertson and Simonsen 2012; Sanders 2013), Design Probes (DP) (Gaver et al 1999; Mattelmäki 2006) and Learner-Centered Design (LCD) (Soloway et al 1994) have been adapted and adopted into new ones making them suitable for work with young participants i.e. Cooperative Inquiry (CI) (Druin 1999; 2002), Informant Design (ID)(Scaife 1997; Nesset and Large 2004), Bonded Design (BD) (Large et al 2006), BRIDGE (Iversen and Brodersen 2008), DP (Moser et al 2011; Iversen and Nielsen 2003; Wyeth and Diercke 2006), etc. Some of these methods as CI and BRIDGE were developed primarily to support the collaborative work between researchers and young individuals by examining children’s participation in developing interactive technologies as equal design partners (Druin 1999; Druin 2002; Iversen and Brodersen 2008). For example, many studies were focused on co-design with healthy children (Druin 2002; Scaife et al 1997; Guha et al 2012; Markopoulos et al 2008b) who cannot bring the same experiences as chronically ill children to bear on the challenges of being a design partner (Tsvaytkova and Storni 2015b). This clearly brings into question whether these techniques and methods developed for children’s participation in technology design - that are widely discussed in academic literature - are also appropriate for designing with young patients. What methods, techniques and tools may support participation and involvement of both children with diabetes and their parents in design? How does the designer select the tools that may facilitate children with T1DM to collaborate actively in the design process, by provoking children’s willingness to express their experience, ideas or to release their feelings without hurting young participants emotionally? Guha, Druin and Fails (2012) explained that children “at the beginning of their tenure as a design partner” need
training (p 5). Do children who have never been a design partner need education to work as equal stakeholders when they have to explain their own experience gained through living with the illness (Tsvaytkova and Storni 2015b)? Årsand and Demiris (2008) suggested a modification of UCD for developing self-help tools for people with chronic diseases; in their framework they illustrated methods for facilitating a patient-centric approach, but these have not been explored with young patients having T1DM by applying a participatory approach. All these identified gaps and limitations discussed above have indicated the direction of this investigation, opening the space of new research in the area of UCD, PD, and CI. Trying to answer these questions, I examined different participatory co-design methods supporting the work of children having T1DM (between 8-12 years of age) in the whole design process of the educational interactive eBook development as design partners (Tsvaytkova and Storni 2015b). As the technology is aimed at newly diagnosed children with diabetes, healthy individuals were also involved in the design process as their participation was as informants based on their knowledge as healthy children (ID) (Scaife 1997).

1.4 Research Questions

Having outlined the focus of this investigation, the main research question posed and considered throughout this study is:

How to design an Interactive Technology (IT) for/with children with T1DM and their parents/guardians?

As the question seems too broad, it was split up into a set of three concrete, clearly formulated sub-questions. They all help as a guide through the inquiry process, facilitating the discussion on problematic issues and challenges that emerged during the study, the selection of design activities enabling the IT development with the users.

- RQ 1: What are the problems, issues and practicalities experienced in paediatric diabetes self-care? What are the current limitations in the care provided for families who have children with T1DM? What is the role of IT in supporting paediatric diabetes care practices?
- RQ 2: How to design an intervention that would better resonate with their perspective and the practicalities of their everyday life?
RQ 3: How to design an interactive technology for/with children with diabetes and their parents? What are the issues experienced by designers working with this group of users? What combination of methodological strategies should be employed to overcome/avoid these issues when designing solutions for self-care practice of chronic paediatric conditions? Are co-design/participatory approaches adequate for this challenge? What combination of design principles and guidelines should be employed when developing interactive technologies that aim to facilitate diabetes education in newly diagnosed children with T1DM and their families?

The first question seeks to understand paediatric diabetes management and practicalities in domestic environment taken from the perspective of the users i.e. children with diabetes and their parents, as this helped to dig deeper into the paediatric self-care practices, focusing on the challenges and issues experienced by affected families applying semi-structured interviews (Section 5.2). Also, it addresses issues concerning the available services and paediatric diabetes care for children with diabetes in Ireland, focusing particularly on diabetes education, examining the potential of IT design to support children with T1DM (Section 2.2.3), gaining an understanding on how technology can help children with diabetes in Ireland. Answering this question identified the design of an educational eBook for newly diagnosed children with T1DM aged 8 to 12 years as a possible solution (Section 5.2.1.4).

The second and third questions are both linked to the process for developing the technology involving participants in UCD practices. The second question explores the roles of individuals who took part in the eBook design applying PD, CI and ID and whether their participation and contribution have impacted the quality of the product. The third question is the main question and it is twofold (WITH/FOR). On the one hand, it focuses on how to design WITH affected children and their family. This question reflects on collaborative and participatory methods, techniques and tool used to support, enable and facilitate the active involvement of affected children and their family in the design process. This concern is central to this thesis and it aims at offering contributions to anyone who wants to design in collaboration with children that are affected by a chronic illness and their families (regardless what is being designed). On the other hand, important elements also emerged in relation to
the specific design of the educational eBook in the context of paediatric diabetes education. In this sense, the third question also focuses on how to design educational technology (in this case an interactive eBook) FOR children that are diagnosed with type 1 diabetes. This aspect of the main research question aims at offering contributions to future researchers who need to engage in the design of digital educational support for children newly diagnosed with a chronic disease such as diabetes and their families.

1.5 Contribution of the Thesis

As discussed in Sections 1.3 and 1.4, this work is positioned in the field of HCI, UCD and CCI particularly exploring PD, CI and ID having two groups of participants in this study i.e. 1) children with T1DM and their families and 2) healthy young individuals. The involvement of these two groups was dictated by their different experiences of T1DM, e.g. having diabetes, caring for a child with this chronic condition, or being a healthy child. The thesis provides detailed information about the process including the organisational tasks and the performance of the UCD and participatory approaches in developing an educational interactive tool – an eBook assisting the exploration of a series of design activities aiming to identify their appropriateness in supporting young individuals in design. In addition, this research illustrates the design of an eBook and its associated educational content. The resulting design was founded on the data collected through the active collaboration of the children and parents involved in the study. Therefore, the main contributions of this study are:

a) The discussion of user’s challenges and issues experienced in paediatric everyday self-care practices, showing that the education in newly diagnosed children and thier families as a central concern.

b) Descriptions and reflections of methods to better understand their role in supporting active participation in the design process, and the role of the participants in developing IT tools.

c) A discussion of practical aspects of recruiting, involving, engaging, etc. identified as challenges experienced while organising and conducting co-design with individuals.

d) A series of design guidelines for a model based on the research findings to support future research in developing educational interactive technology for
newly diagnosed children with Type 1 diabetes (and possibly other chronic diseases and conditions) and their families.

Other contributions emerged primarily from participants’ involvement in design, they indicate 1) the benefits of repeating the recruitment process while performing different steps of UCD, as this helped to enrich data collection, which was important for the quality of design and 2) the new roles of the designer during the sessions in order to improve the active involvement and equal degree of participation of young individuals while using various co-design tools and materials.

Based on the evidence drawn from the empirical data collected throughout performing the UCD and PD approach, I argue that the participation of both children with T1DM and their parents was fundamental for the design of an educational interactive technology. Firstly, because involving users at the early stages of the product development by applying participatory design helped to address problems that seem particularly problematic in paediatric diabetes care; this shows the limitation of educational sources supporting diabetes education from the perspective of newly diagnosed children and their families. Therefore, this supported the circulation and justification of users’ needs and perspectives enabling to identify the area of potential intervention – the design of an educational interactive eBook. Secondly, parents and children have different experiences with diabetes self-care management practices; the expertise of young individuals was based on having and living with this chronic condition while the adults’ knowledge was acquired as caregivers. Playing the role of equal partners in the followed design process supported by PD and CI methods, their participation was important for identifying the educational content of technology, as well as to point out the characteristics and features that the new interactive product had to support. I also claim that working closely with this group of participants helped me identify the formation of negative emotions when discussing diabetes; this influenced the subsequent planning of design activities by indicating that careful consideration in the selection of methods, techniques and tools whose aim was to facilitate users’ active participation and involvement in design, was required. Many positive benefits have been identified by including healthy children as informants when applying ID; their participation enhanced the understanding of their practical skills, awareness about the human body and children’s language, facilitated the collection of requirements and creative ideas.
for the eBook design. Collaborative storytelling appears as a helpful narrative approach to support all participants by enabling, triggering and supporting the discussions and ideas elaboration, they emerged as a significant design tool when the design is revolving around the complex and sensitive context such as diabetes and the discussions are based on participants’ medical condition. The empirical evidence affirmed that UCD, PD, CI and ID facilitated the design process while working with these two groups of healthy individuals and those with diabetes; they seem to be very helpful when developing educational IT for newly diagnosed children with T1DM. Tailored to the individuals’ preferences for place and time when the meetings and workshops were scheduled, quite often these activities were carried out outside the University in very challenging workplace environments, adding extra levels of difficulty in organising events for diabetic children and their parents.

### 1.6 Thesis Outline

The thesis structure and content are composed of seven chapters that are organised around the research questions specified in this study. The following **Chapter 2** and **Chapter 3** include a systematic review of the literature, examining publications helping to frame the specific aspects that emerged in the research, and adequately positioning the research contribution in the available literature. **Chapter 2** examines the writings that include selected studies, addressing a wide range of important components outlining effective and efficient treatment of the life-threatening chronic condition called Type 1 diabetes. The literature review includes T1DM diagnosis and treatment strategies, explains the model of care and diabetes paediatric services in Ireland available for affected families and discusses a variety of challenges experienced in diabetes self-care practices. Additionally, it provides a review of 21 educational interactive technologies developed for young individuals with diabetes, aiming to examine particularly the state of art, the levels of children participation in their designs and the most common methods, techniques and tools used for their development. This exposed some of the gaps and limitations in supporting paediatric diabetes care and helped identify the lack of detailed descriptions of the methodology approach describing the design process of these IT, leading the direction of further investigation by exploring various CCI methods developed to support co-design practices with children. **Chapter 3** covers an examination of the academic texts, journal articles, books, reports and other published sources within multidisciplinary
studies identifying practices across HCI, UCD CCI, PD in the healthcare field and indicates the limitations, challenges, and strategies applied when involving young participants with medical health issues and their parents in the process of designing supportive IT. Furthermore, Chapter 3 suggests a map visualisation showing a selection of methods, techniques, and tools developed in CCI, helping to reflect critically on available participatory design practices and children’s role in design.

Chapter 4 offers information on the methodological approach aiming to investigate the research matter. Also, it illustrates the design of empirical process for performing one cycle of UCD exploring PD, CI and ID chosen for the development of IT - an interactive educational eBook for newly diagnosed children with T1DM, as well as justifying the selection of methods, techniques and tools used to facilitate participants’ involvement in the product design for collecting and generating empirical data.

Chapter 5 reports on the research phases of the project and details the results of research activities. The chapter describes the performed four steps of UCD aiming to specify the context of use and to explore the design space of IT, to elaborate on early design concepts, to translate developed ideas into a series of mock-up and digital prototypes and to evaluate the suggested ideas aimed at eliciting feedback and reaction from potential users. Also, the chapter explains the process of organising various activities for exploring the DP, collaborative storytelling and layered elaboration involving children and parents in the design process, and other methods - as affinity diagrams, personas, scenarios and storyboards - used to facilitate the designer’s work in building the prototypes.

Chapter 6 refers to the findings and results in performing the design process in its entirety. The chapter discusses the co-articulation and the co-identification of issues and problems related to paediatric diabetes management practices, exploring potential new avenues for the eBook to support everyday paediatric diabetes management and the outcomes of applying the selected activities supporting individuals’ input in product development and design. It also provides an abstract model supporting the design of an educational interactive technology for newly diagnosed children with chronic illnesses and their parents/guardians.
Chapter 7 presents the synthesis of various issues and limitations that arose in the discussion part (i.e. Chapter 6), and provides directions for future research in the field. Furthermore, it draws the attention on the conclusions aiming to reaffirm that the findings that emerged from in the empirical work offer the answers to the questions presented in this study.
Chapter 2: Type 1 Diabetes and Educational Interactive Technologies: Challenges and New Perspectives

2.1 Introduction

This chapter is a literature review that discusses two important, relevant themes to the research; they emerged from the initial investigation working with the first and second sub-questions exploring paediatric diabetes self-care practices in domestic settings and the role of IT in supporting some of these practices. In particular, I focus on and discuss educational issues as they clearly emerged as a recurrent concern in this study, helping to inform the future research in the available literature and publications in the fields, examining 1) the role of education in paediatric diabetes care and educational practices and 2) the educational interactive technology interventions developed to support children with T1DM. The first theme in Section 2.2 illustrates the nature of the chronic disease and its treatment (Section 2.2.1), together with a discussion on the self-care practices and the role of diabetes education in everyday diabetes management (Section 2.2.2), followed by the model of care and paediatric services that support newly diagnosed children and their families in Ireland (Section 2.2.3). The second theme in Section 2.3 addresses technologies designed to enhance diabetes education for diabetic children. It expands the focus by offering an extensive review of different interactive technologies (e.g. apps, wearable technologies, video games, robots, etc.) designed to support children with type 1 diabetes, by examining the latest technologies, the role of the users in their design processes and the design methodology applied in their development (Section 2.3.1 and Section 2.3.2).

These discussions on paediatric diabetes care and educational interactive technologies help to unpack some of the complex problems and issues in 1) diabetes care particularly for young patients in Ireland and 2) design practices with this category of users (e.g. children with diabetes and their caregivers), establishing reasonable grounds based on facts to ensure that the formulated research questions in Chapter 1 link to the available investigations of the theme.
2.2 Type 1 Diabetes Mellitus (T1DM): the Complexity of Diabetes Care and its Treatment

This segment examines literature discussing the nature of this life-long chronic condition called diabetes and its complicated means of treatment (Section 2.2.1). It also addresses various issues and challenges that may trigger psychological and emotional trauma in patients and illustrates how and why diabetes education in self-care practices is central to diabetes care for the healthy lifestyle-modifications in individuals. It critically exposes and juxtaposes the patients’ care to highlight the complexity of paediatric diabetes and the disparity of care systems between European countries in delivering paediatric diabetes care (Section 2.2.2). Furthermore, it sheds light on the current gaps in paediatric diabetes care provided in Ireland, primarily focusing on the diabetes education process and materials accessible for newly diagnosed children and their families (Section 2.2.3).

2.2.1 The Nature of Type 1 Diabetes and its Treatment

Non-communicable disease\(^9\) is a term which refers to a medical condition or disease which is not contagious. NCDs are cardiovascular diseases, cancers, diabetes and chronic lung diseases. These diseases are generally long in duration and have a slow progression. According to the Global status report on non-communicable diseases 2010 (World Health Organization 2011a), almost two thirds of the deaths that occurred globally for 2008 were caused by NCDs. In Europe, NCDs are the reason for nearly 86% of all deaths in the Europe region (Regional Committee For Europe 2011).

An example of NCDs is Type 1 Diabetes Mellitus (T1DM). People who suffer from diabetes vary in age: children, adults, elderly; all of whom need careful metabolic control by regular self-monitoring of blood glucose levels, physical activities (regular exercise) and nutritional care (flexible diet, monitoring the amount of carbohydrates) (World Health Organization 2011a; Holt and Kumar 2010). Diabetes is a common disorder where it is difficult for the body to metabolise glucose (sugar) in the blood. Usually the hormone insulin is produced by the pancreas and helps the body regulate glucose levels. In diabetes patients, the pancreas does not produce enough insulin or production does not work effectively. Diabetes in children and young people is

\(^{9}\)Non-communicable diseases definition http://www.biology-online.org/dictionary/Non-communicable_disease
usually Type 1\textsuperscript{10}, meaning they lack any insulin (known as insulin-dependent) (Holt and Kumar 2010; Lorig \textit{et al} 2006). Therefore, to manage this condition, diabetics need to check the glucose levels of their blood regularly, take daily artificial insulin, follow a diet (carbohydrates in the food) and take part in physical activities. Technical terms like hypoglycaemia (low blood glucose, below 4.0 mmol/L) and hyperglycaemia (blood glucose higher than 8.0 mmol/L) are used to describe glucose in the blood. To keep sugar levels within certain safe parameters (approx. between 4.0-8.0 mmol/L\textsuperscript{11}) it is essential to prevent the development of diabetes complications such as kidney failure, blindness, heart disease and amputations (Holt and Kumar 2010; Lorig \textit{et al} 2006).

Presently, the rapidly increasing number of T1DM among children and adolescents has become a serious global concern for our society. This ongoing problem led Patterson and colleagues (2009) to use statistical models to compile incidences of children with diabetes under the age of 15 in 17 European countries for a period of 25 years to predict the number of new cases in 2020. Their survey showed that a “doubling of new cases of type 1 diabetes in European children younger than 5 years is predicted between 2005 and 2020, and prevalent cases younger than 15 years will rise by 70%”, and all healthcare resources and services will have to be available and provide adequate care to meet children’s needs despite the rise in cases (Patterson \textit{et al} 2009, p 2027).

Diabetes care in young patients can be more difficult in two ways, firstly because they are often too young to understand the life-threatening nature of diabetes and secondly, because the illness changes young patients’ childhoods, their everyday lifestyles, schools and societies as a whole (Guthrie \textit{et al} 2003; Smaldone and Ritholz 2011). As children, age is a crucial factor for their communication and cognitive development and young patients may not understand the nature of the disease or the different aspects of diabetes care crucial for proper treatment (Guthrie \textit{et al} 2003, Polonsky 1999; Smaldone and Ritholz 2011). Children are not able to

\textsuperscript{10} There is evidence that children and adolescents can develop type 2 diabetes through risk factors such as obesity, a family history of diabetes, resistance to insulin, lack of physical activities. From 2002-2005, among children under age 10, the rate of new cases of Type 2 Diabetes was 0.4 per 100,000 whereas among youths between the ages of 10-19, the rate of new cases was 8.5 per 100,000. http://www.healthline.com/health/type-2-diabetes/statistics\textsuperscript{#2}

\textsuperscript{11} For children, these values may deviate. The safe parameters described in the educational book that is provided to the parents in Ireland ‘Pete the Pancreas: helping you and your child understand their diabetes’ are between 4.5-9.0 mmol/L.
deal with diabetes alone; they do not hold the same major responsibilities as they do not have the same “authority and moral significance” as adults (Schapiro 1999, p. 716). This strongly indicates that additional support is highly required therefore, their families, guardians and parents play a key role to help children adapt to new situations and to help them live with diabetes (Guthrie et al. 2003; Goodall and Halford 1991; Smaldone and Ritholz 2011). This will include help in checking blood glucose, taking insulin shots (calculating the dose of insulin needed which is based on the results of the blood sugar, carbohydrates in their food and physical activities at that particular time) or with using an insulin pump (learning to use the settings on the pump). Through engaging children in the self-care practices, this will gradually help them to manage the illness alone, learn to recognize the different symptoms of when hypo- and hyper-glycaemia occur and to gain the necessary skills to deal with these conditions should they arise (Holt and Kumar 2010). Additionally, care regimes that are complicated and hard to apply often need contingency strategies for adjustment to the diagnosis of diabetes and require support from professional teams (Guthrie et al. 2003).

Diabetes is an illness that brings significant physical, psychosocial and emotional challenges to young patients and their families. Families need acute attention from the health professionals to adjust their everyday life with the dynamic nature of treatment. Building trust and understanding by having continuous communication and open dialogue (Lowes et al. 2015; Wigert and Wikström 2014) could help to inspire confidence in the family with living with this chronic condition (Smaldone and Ritholz 2011). Unfortunately, the raising of children with T1DM is often difficult for parents; the challenges in diabetes care can be a daunting experience full of doubt about whether the care and attention they deserve is going to be offered by the healthcare team to support their hard work as caregivers (Lowes et al. 2015; Smaldone and Ritholz 2011). This creates the sense that they do not receive enough concern from their paediatrician, they feel they lack support and understanding from other family members, and of being alone and isolated (Smaldone and Ritholz 2011). As the children grow new issues emerge, so the parents need to constantly deal with new demands in diabetes management (Smaldone and Ritholz 2011). The ubiquitous nature of diabetes and the different problems linked to everyday management put young patients and their parents through extensive stress from both emotional and
psychological problems, of which some signs are irregular sleeping patterns, depression, eating disorders, negative emotions, doubting one’s ability to manage the illness, frustration, fear, etc. (Guthrie et al 2003; Polonsky 1999; Smaldone and Ritholz 2011). Therefore, they need both social and psychological support with adequate help and care (Guthrie et al 2003, Polonsky 1999). Unfortunately, many chronically ill people (children and adults) do not get enough medical care support, which fails to fulfil a person’s needs for better control of their illness (Wagner et al 2001). All the struggles connected with controlling diabetes and these stress responses may lead to a “diabetes burnout” (Polonsky 1999). This condition is described as a feeling of being overwhelmed, a form of desperation and helplessness in controlling diabetes, avoiding diabetes-related tasks that might show poor self-care inciting negative feedback, losing motivation for conscious self-management and self-care of the disease: “it is [a] destructive and deadly way of coping with diabetes” (Polonsky 1999, p X). These psychological, social and emotional aspects of course influence the patients’ quality of life, change patients’ educational requirements over time, as well as medical treatment and recommendations (Polonsky 1999; Weinger and Carver 2009). Diabetes education is a major factor in promoting adaptation and lifestyle modification to overcome these physical and psychological conditions to obtain better glycaemic control (Weinger and Carver 2009), sharing responsibilities with family members and motivation for continued care (Smaldone and Ritholz 2011).

2.2.2 Diabetes Self-Care: the Complexity of the Terms in Paediatric Diabetes and the Value of Patient Education

As the patients need to live with this chronic condition, the terms self-management and self-care refer to all the activities that individuals need to perform every day to manage their diabetes. Self-management and self-care skills are very important parts of treatment as they help patients to: a) manage the illness (by taking insulin, keeping a healthy diet, physical activities, deal with hypo- and hyper-glycaemia problems etc.), b) continue to lead a normal life (job performance, friendships, going to school, travelling etc.) and, c) deal with emotions (e.g. negative emotions related to the illness: anger, depression, uncertainty about the future, etc.)(Lorig et al 2006). In reference to diabetes treatment, particularly with the care provided outside hospitals,
self-care and self-management appear as the key mechanisms of affected individuals to live with this chronic, life-long condition.

The self-care concept was first defined in the 1970s by Levin and colleagues (1975): it is based on social theory and promotes active participation and autonomy of individuals through increasing their control over their health independently, outside of the clinic environment (Pelicand et al 2013; Shoor and Lorig 2002; Sidani 2011; Storni 2013a). Self-care is a broad theory; many different definitions are intended to provide a comprehensive view of self-care by focusing on the personal interventions for behavioural change and healthcare policy (Webber et al 2013; Sidani 2011; Pelicand et al 2013; Chambers et al 2006; Richard and Shea 2011). Within the self-care process, there are two main factors that the process is heavily concerned with: 1) the patient’s role in their treatment and decision making (Funnell and Anderson 2004; Lorig and Holman 2003) and 2) all the requirements necessary to ensure appropriate health care providers (Sidani 2011; Richard and Shea 2011). The active role of the patient constitutes a variety of actions in which individuals take ownership of their own health (activities that are specific to their chronic health condition); they can change their behaviour to improve their wellbeing, and make informed choices about treatment and medical care (Funnell and Anderson 2004; Lorig and Holman 2003; Barlow et al 2002; Wagner et al 2001). The individuals could be able to perform appropriate activities in different settings, either independently or with the help of medical professionals for effective changes in their health conditions (Sidani 2011; Richard and Shea 2011; Chambers et al 2006). Following these new demands in improving patient care, philosophically-oriented self-care brought changes for patients with chronic illnesses in the design of medical services (challenging the medical dominance) and in the interventions that would be effective in increasing patient satisfaction, well-being and quality of life (Sidani 2011; Richard and Shea 2011). Furthermore, self-care has become a fundamental component for chronic illnesses (Shoor and Lorig 2002; Barlow et al 2002; Wagner et al 2001; Chambers et al 2006), supporting diabetes care models which underline patients’ educational interventions as a fundamental aspect for acquisition of self-management skills, for optimizing disease control and for preventing complications (Wagner et al 2001).

Again, the self-care in children with diabetes is considered as a more complicated process than in adults (Kirk et al 2005; Schilling et al 2002). After examining the
diversity of self-care definitions for children and adolescents with T1DM given in the various literature, the subsequent definition was suggested by Schilling and her colleagues (2002) “…self-management of type 1 diabetes in children and adolescents is an active, daily, and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness-related activities” (p 92). In analysing the self-care concept for children with chronic diseases, Kirk and her colleagues (2005) have defined it as more complicated: they highlighted two main causes of the complexity of the term self-care. The first aspect is the inclusion of the parents’ crucial role in chronic disease management of their children, while the second element indicated the psychological consequences derived as a result of the illness care and their impact over the whole family, and the affected child (Kirk et al 2005). Therefore, the word “self” cannot be considered entirely individual, as this definition suggests a combination of the child’s and the parents’ efforts in care (Kirk et al 2010).

Also, as stated in Section 2.2.1, a decisive factor in determining different self-management skills and knowledge in children concerning diabetes is their age because it strongly influences their autonomy and the type of education that they need to obtain to perform different tasks related to their treatment (Goodall and Halford 1991; Kirk et al 2010; Kelo et al 2011). For example, only children who are of school age (approximately aged between 6 and 11 years) are capable enough to start learning self-care practices, develop the ability to understand and apply logical operations, discover things about cause and effect (of an illness) and attain the concept of past and future (Kelo et al 2011; Hannan 2011). Children in this age group may be more adept at recognizing the symptoms of hypoglycaemia, reporting and self-treating it, but they still need supervision from adults (Silverstein et al 2005). Other aspects influencing children’s self-care abilities can be the characteristics of the young patient, their living environment, professional support, physical and psychological aspects, the parents’ involvement in care practices, the children’s attitude concerning independence and the corresponding parents’ opinions (Goodall and Halford 1991; Kirk et al 2010; Kelo et al 2011). This highly indicates that it is vital to build a clear understanding of children’s “unique developmental needs” as they are caused by the illness having positive or negative effects that
impact the child’s development (e.g. cognitive, social and emotional) (Salkind 2002, p. 84).

As discussed, education appears as a very important factor in paediatric diabetes care. The care providers (local multidisciplinary teams) have to help parents and children using “motivational tools and education” to improve treatment of affected individuals (Williamson 2010, p 31). Diabetes education is “an active and proactive process” (Schilling et al 2002, p 87) helping to shift shared responsibilities between the young person and their parents (Schilling et al 2002; Christie et al 2014). It must be age-appropriate, adapted to each child by considering their cognitive development, social and emotional needs, family involvement, schools, and primary health care providers (Chaney 2012; Martin et al 2012; Swift 2009; Silverstein et al 2005; Yafi 2013). Health care delivery (e.g. education, funding, support services and qualified caregivers) for children with diabetes is quite different from adult diabetes care (Chaney 2012; Yafi 2013); the treatment of T1DM is always with insulin administered via injections, pumps or pens and blood glucose monitoring (Yafi 2013) which are invasive methods that require the development of skills in insulin injection techniques (or pump settings) and monitoring (Swift 2009). The affected children, adolescents, their families and health care providers should have easy access to the education and the process should repeat itself continuously (Silverstein et al 2005; Swift 2009). In the education for children with diabetes, the integration of appropriate learning styles (different for each child or adolescent, their personal attitudes, beliefs and goals)(Chaney 2012; Swift 2009) while having motivating, enjoyable and challenging activities, as well as supporting different teaching methods is important (Chaney 2012). Also, the education needs to help school age children to develop awareness or improve self-perception in hypo- and hyper-glycaemia symptoms recognition, to adapt to the school programme (meals, sports) and to increase their understanding of diabetes and its self-management (Swift 2009). The role of the educator is crucial (avoid didactic teaching through having open-ended, discussion-provoking questions) - the language used (should be appropriate for children, gradually adding new terms related to diabetes) in the educational sessions together with the content and materials (of text, images, videos, models, etc.) will have an impact on the children’s comprehension of the educational material (Chaney et al 2010; Christie et al 2014; Dunning 2013; Martin et al 2012, Swift 2009). For
measuring the effectiveness of structured education, the metabolic, psychological and long-term outcomes observed in the individuals after their attendance and participation in the education programme could be used (Chaney 2012).

In actuality, the first education provided (e.g. hospital inpatient education) on diabetes management is different from structured education (or education on self-care that occurs during a young patient's lifetime); it is started in medical settings after the child is diagnosed (Couch et al 2008; Gage et al 2008; Swift 2009). The interdisciplinary team involved in care usually helps the newly diagnosed child and his/her family to deal with the shock of diagnosis and the education starts, assuming a no-knowledge base of, or experience with, diabetes (Gage et al 2008; Couch et al 2008). These first days are a period of adjustment to the illness and are primarily concerned with acquiring and retaining relevant information while examining different aspects of diabetes and terminology (e.g. educational resources of written materials), treatment (having practical education on blood glucose monitoring, insulin and meal planning), sick day management (written guidelines and booklets), symptoms and daily life in home care (Swift 2009). As children mature, educational interventions are needed to offer them help to adjust their lives to the ongoing challenges caused by developmental change and psychological issues (Couch et al 2008).

Unfortunately, the variations in care across paediatric diabetes centres around the world discussed in IDF Diabetes Atlas\textsuperscript{12} indicate inconsistent access to proper care and education. For example, the EU has the highest regional number of children with T1DM (approximately 140,000) - there is an inequality in the access “to age-appropriate diabetes care and education across Europe\textsuperscript{13}” (Allgrove and Waldron 2009, p 32). The foundation of the SWEET project was prompted by these results and started in 2008; its aim was to improve the quality in diabetes treatment for children across the EU by developing 23 Centres of Reference (CORs). Investigating the current state of care provided for children and adolescents in different EU countries, they suggested guidelines through a Paediatric Diabetes Toolbox “with proven programs, concepts, devices and further material for education and care” as their main focus was to define the important components for appropriate educational

\textsuperscript{12}http://www.diabetesatlas.org/resources/2015-atlas.html
\textsuperscript{13}The results are taken form the IDF Diabetes Atlas, Seventh Edition 2015
practices for children with T1DM, their families, and health care professionals (Lange et al 2012, p 50). Despite the hard work of different organizations (e.g. SWEET, International Diabetes Federation (IDF), American Diabetes Association’s (ADA’s) and World Health Organization (WHO)) to increase the awareness of and attention to the growing rates of diabetes, to develop recommendations for standards of care and for improving education, to improve the access to quality care and support, problems concerning the heterogeneity among the systems for the delivery of paediatric diabetes care across the EU still exist (Cinek et al 2012; Lange et al 2012; SWEET 2013). Disparities in access to modern treatment, dissimilarities in medical infrastructure across countries, differences in cultures, limitations in educational materials and access to education are some of the issues that vary the quality and quantity in care available for people with diabetes (Cinek et al 2012; SWEET 2013). As this research is concerned with diabetes care in Ireland, moreover, to find the answer of the first sub-question posed in this thesis (Section 1.4) addressing the challenges and issues in paediatric diabetes care along with the early findings indicating - in particular - problems with diabetes education, further investigation on the medical infrastructure and model of care applied in the country was needed. This information is presented in the next section of this chapter, outlining some of the gaps identified in the old and new national clinical programmes in Ireland for paediatric diabetes, including the educational practices available and accessible for affected families.

2.2.3 Model of Care in Ireland: Limitations in Paediatric Diabetes Education

After discussing the complicated nature of paediatric diabetes care and self-care practices (Section 2.2.1 and Section 2.2.2), it is important to highlight that each country has a different approach to diabetes care based on the local factors and national healthcare system (Martin et al 2012). This section provides in-depth discussion on the self-care model and educational practices available for children with T1DM and their families in Ireland; this helped to reaffirm the initial results of paediatric diabetes exploration and to illustrate the shortage of educative materials used for the delivery of education at diagnosis and the shortage of available follow-up out-patient education programmes.
Diabetes Action in Ireland is an advocacy initiative of three organisations: Diabetes Federation of Ireland, Irish Diabetes Nurse Specialist Association and Diabetes Section of the Irish Endocrine Society. Approximately 3,500 children and adolescents are living with diabetes and they need to visit the hospital 4-5 times a year in order to monitor their diabetes. Ireland still has relatively poor paediatric diabetic care compared to the rest of Europe due to “over half [of] the patients having no access to a proper multidisciplinary team” and low access to proper treatment (many children living outside Dublin need to travel long distances for professional care to Dublin)(Diabetes Action 2011, p 2). Based on the age of children with T1DM, in 2012 a plan was developed in relation to the provision of continuous subcutaneous insulin infusion (CSII) in children by Dr. O’Riordan (Clinical Lead, Paediatric Diabetes) and Ms. Turner (Programme Manager). This model of care for children in Ireland states that the use of insulin pump therapy should be recommended to replace insulin injections given up to 5 times a day for children younger than 5 years of age with type 1 diabetes (O’Riordan and Turner 2012). Children at this early age of their development need access to thorough care, health resources and to people versed in diabetes management e.g. teachers, parents, childcare staff, relatives, etc. (O’Riordan and Turner 2012). At that time some critical reflections were made by Dr Moore (consultant endocrinologist of the Irish Endocrine Society). He pointed out that plans to “widen availability of insulin pumps for children under five years haven’t materialised”, mainly because of the lack of advertising job vacancies available to paediatric nurses and other diabetes related posts in Cork, Limerick and Galway (McDonagh 2012). This statement was confirmed by Hawkes and Murphy (2014) through their investigation on care services and positive outcomes in supporting children with diabetes and their parents/guardians by the national audit. Based on information from 2013, the aims of the first national audit were to identify the recommendations for improvement of the services provided to support paediatric diabetes care (Hawkes and Murphy 2014). The results indicated that nineteen centres support young individuals with this chronic condition, but only one has an appropriate patient ratio i.e. 70-100 patients per diabetes nurse, and in only 8 of the 17 centres the insulin pump therapy was available. They also reported that patients have “poor access to psychosocial services” and “many of the consultants delivering paediatric diabetes care in the Republic of Ireland as part of their general paediatric workload have no specific
training or ongoing Continuing Medical Education in paediatric diabetes” (Hawkes and Murphy 2014, p 103). Therefore, these results clearly show that the provision of care nationally requires more attention to improve its standards and quality.

Taking into consideration all these challenges and limitations discussed above, in November 2015 a model of care was suggested, which was developed to satisfy the requirements and meet the criteria of ISPAD (International Society for Paediatric and Adolescent Diabetes), BSPED (British Society for Paediatric Endocrinology and Diabetes), ADA (American Diabetes Association) and the European SWEET project (O’Riordan et al 2015). The Integrated Practice Units (IPUs) offer a more patient-centred system that supports “the full care cycle for a particular medical condition” (O’Riordan et al 2015, p 40). For instance, one IPU is an ‘umbrella’ having one Centre of Reference (CoR) (SWEET recommendations) and a number of additional units (Figure 1). By developing and integrating practice units (IPUs) (Porter and Thomas 2013 model), this could help to focus on paediatric care and on the needs of young patients (O’Riordan et al 2015).

![Figure 1: Screen capture of the Model of care by Porter and Thomas 2013 (O’Riordan et al 2015, p 23)](image-url)
The patient journey during and after diagnosis is also shown in Figure 2, which illustrates that the establishment of self-care, as well as diabetes education for parents and educators, is central; newly diagnosed young patients and their parents can be supported by 1) a centre of reference which provides 24 hours support and 2) the local unit.

One of the important objectives in this model is to “identify the structured education programmes to be used by multidisciplinary teams to optimise diabetes education, carbohydrate counting and insulin pump” (O’Riordan et al 2015, p 12). The educational process is composed of two phases that should be available and accessible for children and parents: 1) diabetes education (e.g. self-management of diabetes), usually after the diagnosis and 2) refresher education (e.g. updates on diabetes care). As examples of such programmes the authors highlighted those that

Figure 2: Screen capture Patient Journey (O’Riordan et al 2015, p 24)
suggest carbohydrate counting, pump education, FABB and CHOICE structured programmes, but it was also noted as a recommendation that “national, quality assured, educational programmes for children with type I diabetes and their families and carers should be developed” (O’Riordan et al 2015, p 34). Education provided to school staff is highly required as these practices have not yet been implemented (O’Riordan et al 2015). The lack of information on educational materials and tools (i.e. printed materials such as books, booklets, DVDs, websites, games, etc.) was not outlined in this report. Later it was identified that the only available educational material was a small booklet ‘Pete the Pancreas’ that is given to newly diagnosed children after the initial diagnosis.

As discussed, one of the diabetes-structured educational programmes for children and adolescents with T1DM mentioned in the report is the CHOICE programme (O’Riordan et al 2015). Available in Northern Ireland and developed by Dr. David Chaney (Western Health and Social Care Trust 2012), the name of the programme is an acronym of carbohydrate and insulin collaborative education (Chaney et al 2010). This structured education consists of programme sessions for a month, helping children and parents to obtain the necessary skills and knowledge needed to manage their diabetes effectively (Western Health and Social Care Trust 2012). The programme development was based on the German Berger programme (also used for the design of the DAFNE programme), but tailored to the needs of adolescents with diabetes (Chaney et al 2010) and later adapted for children and young people between 0 and 19 years of age. According to the problems observed in the clinical trial of the educational intervention, the programme was re-designed by adding new strategies for engaging young children. One of the issues identified was the problem for young individuals to do some of the calculations related to carbohydrate and insulin ratio alone, therefore the reason for the parents’ involvement and participation in the CHOICE programme was so they could “assist younger adolescents and improve their understanding of the skills needed to attain improved glycaemic control” (Chaney et al 2010, p 378). The CHOICE structured educational training programme has been available and accessible in some paediatric units in Ireland since 2013.

Education is a key element in paediatric diabetes care. The last part of this Section 2.2 helped to show that the new model of care (O’Riordan et al 2015) still needs to
reconsider some of the problems in 1) the identification of continuing refresher programmes for affected families, 2) the development of education/training at school and 3) the creation of new educational materials and tools that may support educational practices in hospital and in home settings. In the last two decades, the use of interactive technology in healthcare has shown promising results, and the development of efficient and effective tools that may improve diabetes education opens new areas of inquiry and discourses for many scientists wishing to explore many new forms of technology design in this field. The next section (2.3) discusses some of the types of educational interactive interventions developed for children with T1DM, as this helps to illustrate the recent trends of these products, as well as to explore the user’s role in their design and the methodological approach.

2.3 IT Interventions: Exploring Users’ Roles in Product Development and Design Interventions

To optimize diabetes care across multiple settings, children with T1DM constantly use technology to manage their diabetes. For example, some manage their blood glucose levels with monitoring devices called glucometers, and commonly use insulin pump\textsuperscript{14} technology for insulin administration - replacing the injections and pens, while some use Continuous Glucose Monitoring (CGM) devices that wirelessly monitor glucose in the blood, sending an alarm when the values are low, to prevent hypoglycaemia (Ratheau \textit{et al} 2011; Shalitin and Chase 2012; Kollipara \textit{et al} 2009). New modern everyday health interactive technologies for children with T1DM are also designed for helping young users to change their attitude towards their chronic condition, to modify and develop healthy behaviours, to educate users (e.g. to learn about the nature of the disease, different self-care practices, the relationship between medication, food and sport, etc.), to adopt healthy eating habits (count calories and carbs in the food), and to share data by mobile applications for decision-making in relation to dealing with their diabetes etc. These technologies can fall into different categories: Persuasive Technology (PT), educational video games, wearable self-monitoring technologies, robotic technologies, systems, etc., but they are all designed with the intent to help users to manage their diabetes effectively within their

\textsuperscript{14} Not all children are using insulin pump therapy. Personal preferences regarding treatment plans may be impacted by factors such as the available model of care, pump education, reimbursement of consumables, etc.
educational context (e.g. optimizing glycaemic control, avoiding severe hypoglycaemia and future diabetes complications).

As one of the questions in this thesis revolves around the role of IT in paediatric self-care developed to support children with T1DM, this justified the need to survey the latest developments of such technologies (Section 1.4). The review revealed the scarcity of a suitable IT. Furthermore, the empirical part of this research (Chapter 5) revealed the need for this IT to be an educational resource. I reviewed the design methods (not always fully articulated in these studies), because the main research question posed in my study considers the application of design interventions with diabetic children and their parents, therefore this review also helped to assess the limitations of this direction (Section 1.4). The focus of the second part of the literature review encompasses various educational ITs (e.g. products and prototypes) that facilitate diabetes education for children with T1DM, along with an analysis of the multiple approaches to users’ involvement (e.g. diabetic children and their parents/guardians) and design practices used in developing these technologies. The review starts with formulating the criteria used in selecting the 21 educational interactive technologies, and then provides an analysis of the collected data (Section 2.3.1), followed by a discussion of the findings and the gaps in the current research trends that helped to establish the developmental trajectories of this study (Section 2.3.2).

### 2.3.1 Educational IT Interventions: Criteria for Selection and Data Analysis

Educational interactive technologies developed for individuals with T1DM come in many different types of digital, computer-based technological interventions that facilitate the learning process by helping people to develop knowledge and improve their everyday self-care practices; they can take different forms and shapes - they can be wearable technology, robotic technology, video games, apps, websites, etc. Although literature offers some reviews of different types of IT to support paediatric diabetes (e.g. Lieberman’s (2012) discussion of video games developed to support children with diabetes education; Jahns’ (2014) survey of apps for people with type 1 diabetes mellitus in 27 countries are available for the iOS and Android operating systems (Research2Guidance 2014b).

---

15 More than 1.100 mHealth applications for type 1 diabetes mellitus in 27 countries are available for the iOS and Android operating systems (Research2Guidance 2014b).
diabetes), a comprehensive survey of the various systems developed to support paediatric T1DM, while offering an insight about their design, is not available. This motivated me to create and discuss a comprehensive selection of interactive technologies and prototypes that have been developed to support paediatric diabetes education for children and to illustrate the (not always fully articulated) methods, techniques and tools used for their designs.

As discussed, this review of selected educational interactive technologies had two aims. The first was to examine the variety of interactive technologies that were devised to support educational practices in paediatric T1DM, in order to identify their designs features, as well as their limitations. Secondly, this review supports the initial exploration of the (not always fully articulated) methodologies applied to facilitate the children’s and parents’ active participation in the design process.

In order to inform this review and acquire valuable information about design features, as well as design methods, I have referred to academic papers, books, websites and newspaper articles. The criteria for technologies to be included in this selection are only met if all of these three factors appear to be true: 1) the product is designed to support children with type 1 diabetes, 2) the design facilitates the educational process on diabetes care and 3) the technology is interactive. It is important to note that these technologies may have different levels of fidelity i.e. ranging from research prototypes to final products that have been released on the market. As result several type of technologies have been included in this survey ranging from video games to mobile apps, from robotic technology to wearables. The 21 identified technologies are presented in Table 1 where the first column reports the name of the technology and (when possible) the name of the designer or scholar who developed and studied it. The second column offers a brief description of the technology; the third includes information (where available) about the design methods, tools and techniques used to develop the technology. Finally, the fourth column lists the series of design features and design aspects that characterize the technology and that act as a first source of inspiration for the development of my interactive technology.

16 See also Research2Guidance 2014a
<table>
<thead>
<tr>
<th>Name of the IT and author</th>
<th>Description of technology</th>
<th>Participants &amp; Design Intervention (e.g. methods, techniques and tools)</th>
<th>Features used in design</th>
</tr>
</thead>
</table>
| 1) ‘BG Pilot’             | A three-day simulation course of flying an airplane. The airplane represented the blood glucose levels and its altitude corresponded with the player/pilot’s behaviour in taking insulin, food consumption and partaking in physical activities. | - | • Metaphors  
• Focus on balance  
• Fostering decision-making abilities  
• Challenging content  
• Simulation - visualisation – providing feedback on the progress in real-time when reflecting on a situation/scenario |
| For children (age is not specified) | IBM PCs | Final product (published, no longer available on the market) | Lehmann 1997 |
| 2) ‘Captain Novocare’     | An educational adventure in which children were asked to manage superhero Captain Novocare’s diabetes by making all health decisions for the character and observing the health consequences of the character. Later, the game was redesigned for the Super Nintendo platform with a new name: ‘Captain Novolin’. | Participants: 23 children age (6-16 years) with T1DM  
1 parent  
Preliminary Evaluation  
Interviews | • Adventure - fostering decision-making abilities  
• Challenging content  
• Uses fictional characters  
• Role-playing (the player assumes the role of a person or creature)  
• Metaphors  
• Score points for giving correct answers on questions related to diabetes  
• Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario |
| For children aged 8-12 | PC platform | Final product (published 1992, no longer available on the market) | Lehmann 1997  
Lieberman 1997  
Lieberman 2012 |
| 3) ‘Packy & Marlon’      | An action-adventure role-playing game in which two diabetic elephants Packy and Marlon are at a diabetes summer camp. They need to fight with rats and mice as part of their mission to save the camp, find food and diabetes-related supplies. | Participants: 59 children age (8-16) with T1DM  
Parents  
A clinical trial (Six months) for measuring the effectiveness of the game | • Story-based content  
• Adventure - fostering decision-making abilities  
• Challenging content  
• Role-playing (the player assumes the role of a person or creature) |
<table>
<thead>
<tr>
<th>Authors</th>
<th>Intervention Details</th>
<th>Study Details</th>
<th>Study Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>4) ‘Dbaza’&lt;sup&gt;17&lt;/sup&gt; For children (age is not specified) CD-ROM game Final product (published 2003) dbaza Inc 2012 Harkavy et al 1983 Johnson et al 1982</td>
<td>To play the game, users were asked to create their own character that would represent the player in the story and meet the storybook character Piper. In five chapters the game covered all issues related to diabetes care.</td>
<td>Participants: 83 children age (8-11) with T1DM Evaluation in a pilot study (for a month). Pre-test of diabetes knowledge - Modified version of the Test of Diabetes Knowledge: Revised-4 (Johnson et al 1982; Harkavy et al 1983) First post-test after using the game Second post-test after 17 days</td>
<td>Uses fictional characters Avatar – select a mission or role to play Story-based content Gradual progression – unlocking new levels/characters Short practical messages on diabetes Interactive quizzes</td>
</tr>
<tr>
<td>5) ‘Starbright Life’&lt;sup&gt;18&lt;/sup&gt; For children aged 5-13</td>
<td>XYLO was an alien, a cartoon fictional character whose spaceship had crashed on Earth.</td>
<td>Participants: 19 children age (8-14) with T1DM Randomized trial with two groups Pre-test of diabetes knowledge - Modified version of the Test of Diabetes Knowledge: Revised-4 (Johnson et al 1982; Harkavy et al 1983) First post-test after using the game Second post-test after one month</td>
<td>Metaphors Uses fictional character</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CD-ROM Final product (published 1999, no longer available on the market) Lieberman 2012</th>
<th>Earth. To return to his own planet the player with diabetes would be able to help XYLO to reassemble the craft only when he/she eats healthy food, knew how to take insulin and played quizzes, giving the correct answers on the questions related to diabetes.</th>
<th>–</th>
</tr>
</thead>
<tbody>
<tr>
<td>6) GetWellNetwork 19 ‘GetWell Town’ 20 For children of all ages Interactive Patient Care System Final product used in hospitals Kompany et al 1983 Marketwire 2013 Nash 2012 News-Medical 2009</td>
<td>It is based on the Interactive Patient Care™ (IPC) by providing two-ways of communication between patients and their health care team. “GetWell Town” is a part of the GetWellNetwork system. Playing with the animated character Moti, children have access to different educational tools (e.g. for asthma, diabetes, common hospital tests and procedures). Hollywood movies, can play video games, listen to music, search for their diagnosis or other information through the internet, as well as interact with other young patients in the clinic.</td>
<td>Participants: 15 paediatric facilities across the USA and other people working in multiple disciplines Design &amp; Evaluation Focus groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Design &amp; Evaluation Focus groups</td>
</tr>
<tr>
<td>7) maXi 21 project ‘MaXine’ For children (age is not specified)</td>
<td>Maxine22 (glucose simulator and learning system) representing simulation and visualisation of blood glucose level based on entered personal data in adding food, insulin</td>
<td>Participants: 60 participants (17 Danish families) age (4-68) 50% with Type 1 diabetes and 50 % Type 2 diabetes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>•Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario •Focus on balance</td>
</tr>
</tbody>
</table>

19 http://www.getwellnetwork.com/
21 Acronym of mastering chronic illness with information technology www.maxi-projektet.dk
22 Only MaXine and Food Quiz design are for education, so they are discussed in the table
<table>
<thead>
<tr>
<th>System</th>
<th>doses and physical activities (for newly diagnosed children).</th>
</tr>
</thead>
</table>
| **Prototype** | Glasemann and Kanstrup 2008  
Glasemann et al 2010  
Glasemann and Kanstrup 2011  
Kanstrup et al 2010  
Kanstrup 2014 |

| Participatory Design | UCD - Two iterations (8 families in the first iteration and 9 families in the second iteration)  
Interviews & visual tangible artefacts (e.g. laminated photographs of places (streets, sport, centres, nature, homes, cinemas, schools, workplaces, etc.) and seven postcards with pre-written questions “Where are you, and what would you like to know? Observations 3 hour workshop: Venn diagrams (Mukherjee 2002), sketching, design games (Brandt 2006) Design workshop 1 weekend exploring prototypes in a living laboratory |

| 8) ‘Didget®’- ‘GlucoBoy’ | The integration of the video game "GlucoBoy" for Nintendo DS with the glucometer called “Didget®” motivated children to regularly check and monitor their blood glucose levels. The frequency of using the meter, as well as the blood results are converted into extra reward points that children may transfer to the game and get access to mini-games or different levels. |

| Participants: | 174 subjects age (5-24) |
| A pilot study | -To assess the accuracy of the blood glucose meter |
| Participants: | 70 children parents |
| Evaluation study | - To assess HbA1c levels, but not on the game |
| •Gradual progression – unlocking new levels or games  
•Mini-games  
•Receive points for logging blood sugar and correct blood sugar levels  
•Several game levels |

For children aged 4-14  
Nintendo DS  
Final product 2004  
Brox et al 2011  
Lieberman 2012  
Klingensmith et al 2013  
Slater 2005
| 9) ‘Glucose Race’ | It is a social learning mini-game prototype using learning-by-doing concept in which users could choose between different transportation (a plane, car, motorcycle, on foot) to play a race. Fuel, oil/air and speed corresponded respectively with food, insulin and exercise levels as all of them needed to be in balance to win the race. | Participants: | • Metaphors
• Focus on balance
• Role-playing (the player assumes the role of a person or creature)
• Challenging content
• Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario
• Fostering collaboration and team work |
| For children aged 8-12 iOS platform Prototype Bomark et al 2012 Brox et al 2012 | | Children with T1DM Parents Diabetes nurses Healthy children aged (8-13) | |
| | UCD Interviews with diabetic children, their parents and diabetes nurses Work with healthy children Questionnaires and interviews Discuss design at it early stage Test the paper prototypes | | |

| 10) ‘Jerry the Bear’ | It is an interactive robotic toy, it has a chest display to show how the real digestive system worked when the bear takes insulin and food, as well as giving the blood glucose results. | Participants: | • Role-playing (the player assumes the role of a person or creature)
• Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario
• Balance
• Needle education
• The robot acts as an educator, motivator, buddy, companion
• The robot can speak |
| | Test and evaluation | | |

---

<table>
<thead>
<tr>
<th></th>
<th><strong>Tamagoya</strong></th>
<th><strong>Participants:</strong></th>
<th><strong>Development process</strong></th>
<th><strong>Evaluation</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>For children (age is not specified)</td>
<td>Diabetes specialists, Nurses</td>
<td>Only with medical professionals</td>
<td>with 58 individuals questionnaire with 14 questions to identify: Entertainment, Usability and Clinical</td>
</tr>
<tr>
<td></td>
<td>PC - GameBoy Advance</td>
<td>58 individuals (children with T1DM and Healthcare professionals)</td>
<td>Plan the game, Determine specifications for the game, Create the game, Adjust details of the game</td>
<td>Failure to control blood glucose level - the screen is fogged</td>
</tr>
<tr>
<td></td>
<td>Final product (published 2004)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aoki et al 2004</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lieberman 2012</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The Tamagoya (an egg breeder) game in which through raising the diabetic egg, the young user needs to provide appropriate care (e.g. food, insulin and exercises) that will help to keep the egg in a healthy condition to hatch a healthy baby chick.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Tantei</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>For children (age is not specified)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Advance game based on GameBoy Advance™</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Final product (published 2004)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aoki et al 2004</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lieberman 2012</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>In the game the player becomes a criminal-chasing detective who has T1DM. The detective must take food and insulin during the chase to maintain their sugar level.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Metaphors, Role-playing (the player assumes the role of a person or creature), Focus on balance, Fostering decision-making abilities, Challenging content, Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario, Balance</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Metaphors, Uses fictional characters, Role-playing (the player assumes the role of a person or creature), Challenging content, Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario, Balance, Fostering decision-making abilities, Story-based content, Quizzes on T1DM – the correct answer opens short cut, Failure to control blood glucose level - the screen is fogged</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 13) ‘Magic Room’
For children (age is not specified)
GameBoyAdvance™
Final product (published 2004)
Aoki et al 2004
Lieberman 2012

The game ‘Magic Room’ is designed to teach a child about healthy food (learn about carbohydrates) and appropriate food for hypo- or hyper-glycaemia.

usefulness

- Simulation - visualisation - providing feedback on the progress in real-time when reflecting on a situation/scenario
- Balance
- Quizzes on T1DM

### 14) ‘Carb Counting with Lenny’
For children (age is not specified)
iPhone, iTouch and iPad
Final product (published 2010)
Medtronic Inc. 2012

It is an app helping children count the carbs by presenting nutritious food choices and their carbohydrates values together with four interactive games

Participants:
- Accuracy strategy, see-and-guess strategy, compare carbs
- Time to give an answer limited


### 15) ‘Monster Manor’
For children aged 6-13
iPod, iPhone, iPad and Android
Final product (published 2012)
Ayogo Health Inc. 2014
Boulos et al 2014

This app helps children to engage in diabetes blood glucose monitoring by giving them rewards ‘piñata’ for their effort for testing and logging of their blood sugar. These rewards are used for unlocking rooms and for collecting different pets and objects.

Participants:
- Children with T1DM
- Their parents

Early evaluation to assess and refine the game’s user experience (UX) and design. Children tested the early prototypes

- Metaphors
- Uses fictional characters
- Adventure
- Collect the Monster
- Story-based content
- Gradual progression – unlocking new levels/characters
- Earn currency - allowing users to create new characters, unlock items, etc.
- Score points for correct answers logging blood sugar

| 16) ‘Mission T1D’ | A mobile game designed to help children with type 1 diabetes learning how to live with their chronic condition. The player could get messages and videos on some diabetes self-care practices only by completing levels and getting points to unlock these educational features. The app provides an option to use the game at school settings. | • Write notes  
• View logs |
|---|---|---|
| For children aged 8-12  
iPhone and iPad  
Final product (published 2014)  
Sanofi 2012 |  |  
*Scenarios – school setting  
*Story-based content  
*Short practical messages  
*Educational videos on T1DM  
*Interactive quizzes on T1DM  
*Receive points for completed levels  
*Several game levels |
| 17) maXi<sup>26</sup> project  
‘Food Quiz’ | *Food Quiz* is a mobile game that helps for carbohydrate counting (for children over 10 years of age). |  
**Participants:**  
**Design**  
24 age (10-16) with T1DM  
Exploring the prototype  
34 children age (10-15) with T1DM  
2 dietitians  
**PD and UCD-two iterations**  
Design  
• Theme posters  
• Discussions  
• Prototyping "creativity pack" (i.e. Polaroid camera, 3D paper prototype of a PDA, a stuffed animal, modelling clay, glue, paper and pens, scissors, prepared stickers, as well as blank stickers)  
Exploring prototypes  
• Interviews - dietitians  
• Children played with the game prototype followed by an informal conversation  
**Participants:**  
**Design**  
24 age (10-16) with T1DM  
Exploring the prototype  
34 children age (10-15) with T1DM  
2 dietitians  
**PD and UCD-two iterations**  
Design  
• Theme posters  
• Discussions  
• Prototyping "creativity pack" (i.e. Polaroid camera, 3D paper prototype of a PDA, a stuffed animal, modelling clay, glue, paper and pens, scissors, prepared stickers, as well as blank stickers)  
Exploring prototypes  
• Interviews - dietitians  
• Children played with the game prototype followed by an informal conversation |  
*Avatar – select character  
*Mini-games  
*Score points for correct answers, bonus points and magic points  
*Feedback on correct or wrong answer  
*Several game levels  
*Gradual progression – unlocking new levels  
*Accuracy strategy, see-and-guess strategy |
| For children over 10 years of age  
Mobile App  
Prototype  
Glasmann and Kanstrup 2008  
Glasmann et al 2010  
Glasmann and Kanstrup 2011  
Kanstrup et al 2010  
Kanstrup 2014 |  |  
*Scenarios – school setting  
*Story-based content  
*Short practical messages  
*Educational videos on T1DM  
*Interactive quizzes on T1DM  
*Receive points for completed levels  
*Several game levels |

<sup>26</sup> Acronym of mastering chronic illness with information technology www.maxi-projektet.dk
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>18) Teddy bear ‘Huggable’</strong>&lt;br&gt;For children aged 8-12 (powerful research platform)&lt;br&gt;<strong>Prototype</strong>&lt;br&gt;Stiehl et al 2009</td>
<td><strong>Children sketched new ideas</strong>&lt;br&gt;<strong>Children played mini-games</strong>&lt;br&gt;<strong>The prototype was explored as part of a regular diabetes lesson</strong></td>
<td><strong>Family and Friends Communication Channel</strong>&lt;br&gt;<strong>Daily lessons on T1DM</strong>&lt;br&gt;<strong>Needle education</strong>&lt;br&gt;<strong>The robot acts as an educator, motivator, buddy, companion</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Huggable offered a companion to children with diabetes in paediatric care. Huggable worked in a semi-autonomous mode, the doctors and nurses in the paediatric unit were the operators that controlled the toy (Wizard of Oz simulations). The bear-child interaction was carried out on a website allowing the operators (e.g. doctors, nurses) to playback animations, sound files, etc. to the child.</strong></td>
<td><strong>Participants:</strong>&lt;br&gt;Doctors&lt;br&gt;Nurses&lt;br&gt;Staff of HSR&lt;br&gt;<strong>Design</strong>&lt;br&gt;Brainstorm sessions (research scenarios on how the Huggable will used with children in the paediatric unit)</td>
</tr>
</tbody>
</table>

**Participants:**<br>24 healthy children age (8-9)<br>1 diabetic nurse<br>1 therapist<br>1 patient who acquired diabetes at a young age<br>1 game developer<br>**Design**<br>(with medical professionals and one patient (not a child) with T1DM)<br>Interviews to develop the educational quiz (e.g. movies and questions)<br>**Evaluation**<br>(with children)<br>Wizard of Oz<br>Questionnaire for examining fun, acceptance,<br>**The robot acts as an educator, motivator, buddy, companion** |

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>19) ‘pet-robot iCat’</strong>&lt;br&gt;For children aged 8-9&lt;br&gt;Robotic toy&lt;br&gt;<strong>Prototype</strong>&lt;br&gt;Looije et al 2008</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>The iCat had three roles of “educator” (helping to teach about diabetes), “motivator” (motivate to count carbs and take medication on time), and game “buddy” (as a companion in dealing with diabetes and for having fun).</strong></td>
<td></td>
</tr>
<tr>
<td><strong>20) ‘Nao’ humanoid robot</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>For children aged 8-12</td>
<td>Nao is a “programmable humanoid robot” which is easy to adapt to the child-robot interaction by playing a quiz covering a variety of topics e.g. maths, geography and for type 1 diabetes, dancing or imitating games.</td>
<td>Participants: Health care professionals (from WKZ children’s hospital) Diabetes nurse 5 children age (8–12) with T1DM</td>
</tr>
<tr>
<td>Robotic toy - ALIZ project</td>
<td></td>
<td>Design (only with Health care professionals and nurse) Developing the knowledge questionnaire with Professionals from the WKZ, reviewed by diabetes nurse</td>
</tr>
<tr>
<td>Prototype Henkemans et al 2013</td>
<td></td>
<td>Evaluation (for measuring fun, motivation and diabetes knowledge) A pilot study conducted in medical settings (one session) Partly Wizard-of-Oz simulation in home environment (two sessions) MIND Youth Questionnaire (MY-Q) that covers mental, physical and social well-being, and diabetes management (Wit and Snoek 2009) Five-point Likert scale using emoticons representing to measure fun Diabetes knowledge questionnaire (diabetes knowledge was measured before and after playing the quiz)</td>
</tr>
</tbody>
</table>

|  | empathy, trust and health intention Rating-smiley-o-meter (Read and MacFarlane 2006) |  |
|  |  |  |
|  |  |  |

• Quizzes on T1DM
• Dance
• Imitation
• The robot acts as an educator, motivator, buddy, companion
<table>
<thead>
<tr>
<th>21) ‘DiaBetNet’</th>
<th>It is a software system mobile game with standard wireless personal digital assistant (PDA) and a wireless belt-worn motion sensor (accelerometer). ‘DiaBetNet’ is a wireless and social game that encourages users to guess their blood glucose levels and compare their guess with the user’s given results with the readings from the wearable sensors and if the answer is accurate, the child gets a higher score. While predicting their glucose levels, users learn to detect high or low blood glucose levels.</th>
</tr>
</thead>
<tbody>
<tr>
<td>For children (age is not specified)</td>
<td><strong>Participants:</strong>  40 participants age (8-18) with T1DM</td>
</tr>
</tbody>
</table>
| | • By predicting the glucose levels, users learn to detect high or low blood glucose levels  
• Earn points  
• Community-based game |
For example, Brox and colleagues (2011) described educational games and suggested how educational material is integrated into the game content, helping the children to increase their knowledge of a variety of important health aspects; other technologies are presented as persuasive\(^{27}\) (Fogg, 2003) and aim at changing users’ behaviour in order to promote a healthy lifestyle and to educate users on different aspects of their health (Chan 2004; Brox \textit{et al} 2011). Smartphone applications were also developed for people with chronic diseases and are often designed to support remote monitoring of patients, and to facilitate self-medication (e.g. through reminders and journaling) and patient education (Moss \textit{et al} 2012). In some cases, wearable technologies that combine sensors (that can be incorporated into clothing) with a wireless Internet connection are explored, so that health data can be generated and shared (Pentland 2004; Kumar 2004).

Thirty-six sources were used to create this selection of 21 educational technologies. All these forms of educational interventions included different design features and elements that have been used as strategies to support better knowledge acquisition on diabetes (see fourth column). The use of metaphors (mostly visually rich) is quite recurrent (e.g. ‘BG Pilot’, ‘Captain Novocare’, ‘Packy & Marlon’, ‘Starbright Life’, ‘GetWell Town’, ‘Glucose Race’, ‘Tamagoya’, ‘Tantei’ and ‘Monster Manor’) and so is the use of quizzes and exercises (‘Dbaza’, ‘Starbright Life’, ‘Tantei’, ‘Magic Room’, ‘Mission T1D’ and ‘Nao’ humanoid robot). Reward systems based on points are also recurrent strategies to support engagement (‘Captain Novocare’, ‘GlucoBoy’, ‘Monster Manor’, ‘Mission T1D’, ‘Food Quiz’ and ‘DiaBetNet’). Some technologies offer information aimed at:

- Developing problem-solving skills (e.g. simulations of blood glucose levels, etc.), e.g. ‘BG Pilot’, ‘Captain Novocare’, ‘MaXine’, ‘Glucose Race’, ‘Jerry the Bear’, ‘Tamagoya’, ‘Tantei’ and ‘Magic Room’,

- Enhancing self-management skills (learning about healthy food, blood glucose monitoring, how insulin works), e.g. ‘Food Quiz’, ‘Carb Counting’

\(^{27}\) Captology is an acronym defined by Fogg (2003) from the phrase “\textit{computers as persuasive technologies}”. Functional Triads (a conceptual framework for three different functions of computing technology that influence people’s attitudes and behaviours) as explained by Fogg are ‘Tools’, ‘Media’ and ‘Social Actors’. 

45

- Supporting behaviour modification that results in good blood glucose monitoring (e.g. persuasive and wearable technology - ‘GlucoBoy’, ‘Jerry the Bear’, ‘Tamagoya’, ‘Tantei’ and DiaBetNet’),

- Enabling knowledge acquisition on symptoms of hypoglycaemia e.g. ‘DiaBetNet’, and

- Injection preparation and administration of insulin (e.g. ‘Jerry the Bear’ and Teddy bear ‘Huggable’).

Most of the academic sources cited in Table 1 reported good results that were observed in the evaluation procedures.

In terms of the design process, the overall age of participants involved in the design of the different technologies ranges between 4 to 18 years (Table 1, third column), while the adults that participated in the development process were diabetic adults (e.g. ‘pet-robot iCat’ and ‘MaXine’), parents (e.g. ‘Packy & Marlon’, ‘Didget®’- ‘GlucoBoy’, ‘Glucose Race’ and ‘Monster Manor’) and medical professionals such as doctors, nurses, a therapist, etc. (e.g. ‘GetWell Town’, ‘Glucose Race’, ‘Tamagoya’, ‘Tantei’, ‘Magic Room’, Teddy bear ‘Huggable’, ‘pet-robot iCat’ and ‘Nao’ humanoid robot). Other groups such as healthy children and adults also participated in the design process of ‘MaXine’, ‘Glucose Race’ and ‘pet-robot iCat’. For instance, based on their personal experience in playing games or being online interacting with similar technologies, healthy young individuals between 8 and 13 years of age contributed in the early stage of the ‘Glucose Race’ design by selecting the game requirements and by evaluating the low fidelity prototypes (Bomark et al 2012; Brox et al 2012), while in the ‘pet-robot iCat’ project 24 healthy children participated only as evaluators in the assessment activities (applying the Wizard of Oz method), and then they completed a questionnaire to rate fun, acceptance, empathy, trust and health intention perceived during their interaction with the artefact (Looije et al 2008). Kanstrup (2014) highlighted that in the ‘maXi’ project’s home interviews (aiming to identify daily activities in diabetes care), each diabetic individual’s family members (healthy individuals) also participated. Other valuable information indicated that the age of participants did not always correspond with the age group of the actual users that the technology was developed for. Here
are the few examples – ‘Glucose Race’, ‘Captain Novocare’, ‘Packy & Marlon’, ‘Didget®’- ‘GlucoBoy’, ‘MaXine’ - in which the age of the participants involved in their development is greater or less than the intended age range of the final users - these studies did not provide any information on whether this influenced the design or the evaluation practices.

The number of participants that participated in the technology evaluation or the design process varied considerably between 5 (e.g. ‘Nao’ humanoid robot) and 350 (e.g. ‘Jerry the Bear’) as usually more of the individuals took part in the evaluation practices. ‘Jerry the Bear’ was tested and evaluated by 350 children (Horowitz 2015) and 15 paediatric facilities across the USA. Other people working in multiple disciplines have been involved in the ‘GetWell Town’ design and evaluation whose objective was to improve its educational content (News-Medical 2009). There are also 5 educational tools for which information about the people involved in the product development (design procedure and implementation), was not found (e.g. ‘BG Pilot’, ‘Starbright Life’, ‘GetWell Town’, ‘Carb Counting with Lenny’ and ‘Mission T1D’).

Examining the data in the third column (i.e. Participants & Design Intervention), particularly the methodological approaches used for the final products and prototype designs; two themes emerged in the design interventions. The first theme describes only the evaluation practices while the second gives more information on the design processes, elaborating on the steps performed in order to understand the users’ needs for idea elaboration, prototyping and evaluation. Therefore, this helped to create Table 2 (i.e. identified methods, techniques and tools in the evaluation and design) with two columns illustrating the methodological approaches used in the design and development procedures (i.e. Design process: final products and prototypes) and in the evaluation process (i.e. Evaluation process: final products and prototypes).

<table>
<thead>
<tr>
<th>Design process: final products and prototypes</th>
<th>Evaluation process: final products and prototypes</th>
</tr>
</thead>
<tbody>
<tr>
<td>User Centred Design (UCD)</td>
<td>Interviews</td>
</tr>
<tr>
<td>Participatory Design (PD)</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Interviews</td>
<td>Questionnaires (at the start and at the end of the assessment and 3 and 6 months later)</td>
</tr>
<tr>
<td>Interviews &amp; Tangible artefacts (e.g. laminated photographs of places: streets, sport centres,</td>
<td>Pre-test of diabetes knowledge (Johnson et al 1982; Harkavy et al 1983)</td>
</tr>
</tbody>
</table>

Table 2: Identified methods, techniques and tools in the evaluation and design
Seven postcards with pre-written question “Where are you, and what would you like to know?”

First post-test after using the game

Post-test of diabetes knowledge (Second post-test after 17 days or one month)

Survey on diabetes knowledge (Johnson et al 2000)

Fill out a blood glucose logbook

Observations

MIND Youth Questionnaire (MY-Q) (Wit and Snoek 2009)

‘Creativity pack’ for producing prototypes (i.e. Polaroid camera, 3D paper prototype of a PDA, a stuffed animal, modelling clay, glue, paper and pens, scissors, prepared stickers, as well as blank stickers)

Workshops: Venn diagrams (Mukherjee 2002), sketching, design games (Brandt 2006)

‘Creativity pack’ for producing prototypes

Brainstorming

Theme posters

Fill out a blood glucose logbook

Workshops: Venn diagrams (Mukherjee 2002), sketching, design games (Brandt 2006)

Pay out (testing) prototypes (mini-games)

Wizard of Oz

Five-point Likert scale (emoticons)

Rating-smiley-o-meter (Read and MacFarlane 2006)

Exploring the prototype as part of a regular diabetes lesson

Five-point Likert scale using emoticons to measure fun

Quite often the clinical trials or pilot studies were used in the evaluation processes mainly to identify whether the design matched its intended purpose and how technology impacted the overall well-being of the users. This could also be seen in most of the final products on the market (e.g. Captain Novocare, Packy & Marlon, Dbaza, Didget®- GlucoBoy, Jerry the Bear, Monster Manor).

For example, with DiaBetNet, (as shown in the second column, Table 2), the evaluation procedures used were interviews, focus groups, questionnaires (at the start, at the end), pre-test of diabetes knowledge (Johnson et al 1982; Harkavy et al 1983), first post-test after using the game, post-test of diabetes knowledge, filling out a blood glucose logbook and a survey on diabetes knowledge (American Diabetes Association, Johnson et al 2000).

On the other hand, for most of the technologies that were in a prototype phase, some data was generated through the methods, techniques and tools applied while the artefact was developed (e.g. Glucose Race, pet-robot iCat and Nao humanoid robot), while for Teddy bear Huggable, only the design phase was discussed. For
‘pet-robot iCat’ and ‘Nao’ humanoid robot more detailed information was given on the evaluation process than on the design phase. For the design process of ‘pet-robot iCat’ and ‘Nao’ humanoid robot interviews were used to develop the educational quiz and knowledge questionnaire (Looije et al 2008; Henkemans et al 2013). The Wizard of Oz method was applied first for the evaluation process, and then a questionnaire was used with the Rating-smiley-o-meter (Read and MacFarlane 2006) to examine the fun, acceptance, empathy, trust and health, while the MIND Youth Questionnaire (MY-Q), together with the five-point Likert scale with emoticons were used to measure the fun. Only in the ‘Glucose Race’ did the researchers briefly explain their work in completing the first iteration of UCD; they used interviews with diabetic children, their parents and diabetes nurses, while healthy children were involved in completing the questionnaires, giving interviews, discussing designs and testing the paper prototypes (Brox et al 2012). Only for ‘MaXine’ and ‘Food Quiz’ did the authors provided rich data on the whole design process as they developed the ‘maXi’ project (Glasemann and Kanstrup 2011; Kanstrup et al 2010). Applying the UCD and PD approaches to the design of the ‘MaXine’ system and ‘Food Quiz’ game, the researchers gave comprehensive evidence on design interventions with users i.e. interviews and visual tangible artefacts, observations, theme posters, discussions, workshops, Venn diagrams, sketching, design games and prototyping with a "creativity pack" (Table 1) (Glasemann and Kanstrup 2008; Glasemann et al 2010; Glasemann and Kanstrup 2011; Kanstrup et al 2010; Kanstrup 2014). It was highlighted that the UCD process was performed in two iterations, as the evaluation processes of the digital prototypes of the ‘Food Quiz’ game (Glasemann et al 2010) and ‘MaXine’ system (Kanstrup 2014) were carried out in the second cycle. For example, the children played with the game prototype, had discussions, sketched new ideas, and explored the prototype as part of a regular diabetes lesson during a two-week summer camp for young individuals with diabetes in Germany, while other individuals assessed the simulation system prototype in a living laboratory for 1 weekend in Northern Denmark. Kanstrup (2014) outlined that this project “was rooted in participatory design research to explore how people affected by diabetes can contribute to expanding the solution space of digital diabetes technology” (p 51), therefore, the discussions on users’ participation and involvement revolved around users’ reflections on the design and the various prototypes, exploring where and how digital
technology may better support individuals’ needs and elaborating on how the
employed methods supported participants in the study. And last, only the three final
“edutainment” studies called ‘Tamagoya’, ‘Tantei’ and ‘Magic Room’, designed by
the same developer Aoki et al (2004), reported on their development and design
processes. According to the scarce information available in the article, the authors
briefly explained the design and prototyping steps that were carried out with medical
professionals without expanding upon what methods were used, but the explanations
were more detailed on the evaluation process by providing the questions used in the
questionnaire for identifying the Entertainment, Usability and Clinical usefulness
after the games were played by testers. Therefore, the first column of the Table 2
shows all the different design approaches found in the sources describing the design
process of these educational interventions.

2.3.2 Discussion: Advantages, Limitations and Future Perspectives

The educational interactive tools have shown promising results for education and
offer great potential in the design of new technology for young children with
diabetes. In general, all the results presented in the evaluations suggest that using
technology as an educational tool was a preferable alternative to the conventional
didactic method of education (dbaza Inc. 2012; Lieberman 1997; Henkemans et al

This review of 21 interactive technologies from 36 different sources helped to
categorize the most popular kinds of educational interactive tools developed in order
to improve and enhance the learning process on type 1 diabetes for young individuals
and secondly, to identify what design methods, techniques and tools (Table 1, p 34)
have been used to support the different roles of participants in the technology
development process. In addition, this review expanded my knowledge of
educational IT design; particularly regarding the features used to support and
facilitate the educational content on diabetes.

The results indicated that persuasion was the most common method, perhaps because
persuasion principles are used in many different types of technologies, such as video
games for Nintendo DS, platforms and robots, or maybe because they provide novel
and more enjoyable ways for patients to deal with their chronic condition. The most
frequently used interactive features were: reward systems based on earning points,
metaphors, simulations of blood glucose levels, and simulations and visualisation providing feedback on the metabolic processes as the user progresses through a scenario. However, these are all apps or video games, and not interactive eBooks. Interactively enhanced eBooks have become very popular among young individuals (IDC 2013), and this format’s potential in facilitating diabetes paediatric education has not been explored. Actually, there is one brief example suggesting such an eBook - Guía Diabetes²⁸ content - but more information on the design process was not found. The use of an interactive eBook has already been explored in asthma education. Wyatt and Hauenstein (2008) highlighted that having multimedia-rich environments with a high number of interactive features such as animations, mini-games, puzzles, videos, music, etc., within the digital stories could support children in the learning process about a specific health topic. Furthermore, they concluded that empirical data indicated the benefits of such IT in health education.

Different numbers and groups of individuals participated in the development process of the reviewed technologies covered in the selection; children and adolescents between 4 and 18 (i.e. healthy and those with T1DM), adults who were diagnosed with diabetes in their childhood (e.g. ‘pet-robot iCat’), family members (e.g. ‘maXi’ project), parents and medical professionals working in multiple disciplines. They were involved in various steps during the design process, for example, more often than not the diabetes specialists, nurses, and parents took part to determine user requirements and goals, to provide valuable data that facilitated the design of content and features and to explore possible solutions by generating many design ideas. The children’s input could be seen in many steps of the design, but more frequently in the evaluation process. Only one study discussed the parents’ involvement in the evaluation by applying questionnaires at the start of the study and 3 and 6 months later (e.g. ‘Packy & Marlon’); none of the technologies in the selection elaborated on either the parents’ or the children’s involvement in the assessment process and particularly on their work in performing different tasks while playing/testing the technology/prototype. Even at this stage of design (e.g. evaluation), it was still not very clear which of the methods, techniques and tools - excluding the questionnaires, sketches and discussions - would be best implemented to support both parents and children work in integrating the devices. Age was not seen as a very important

²⁸ http://www.panareadigital.com/content/diabetes/
criterion for participation. For example, it was indicated that in some studies the participants’ age did not correspond to the users’ age group. Unfortunately, the shortage of information on their contribution (except for the ‘Food Quiz’ (Glasemann et al 2010; Glaseemann and Kanstrup 2011) indicates some limitations, opening up new questions on this issue that need further investigation. A few of these questions are: whether the methods applied with younger children i.e. aged 8-11, would be suitable to apply to individuals at 12-15 years of age? What could be their contribution in the design and evaluation process? In Section 2.3.1, it was shown that healthy children were also involved, to contribute their knowledge as users of different interactive technologies such as games (e.g. ‘Glucose Race’), or to assess fun, acceptance, empathy, trust and health intention while testing the prototypes (e.g. ‘pet-robot iCat’), but their role as participants was not further discussed. Hence, it is not clear what role should they play if we include both healthy children and those with T1DM in the design process. Similar results were observed for other participants: the roles of health professionals, parents, dietitians, etc. that participated in some design activities were not explained. Only in the ‘maXi’ project (e.g. ‘MaXine’ system and ‘Food Quiz’ game) did the authors highlight that children and families (e.g. healthy family members and those with diabetes) were involved as equal stakeholders, because they used the participatory approach (Glasemann and Kanstrup 2008; Glasemann et al 2010; Glaseemann and Kanstrup 2011; Kanstrup et al 2010; Kanstrup 2014).

As it was shown in Section 2.3.1, reviewing these 21 types of educational technologies helped to illustrate applied design interventions and as a result, create a Table 2 (p 48) displaying the identified methods, techniques and tools in the evaluation and design processes. This demonstrated that a large variety of methods and techniques developed/adapted to support children’s and parents’ participation in technology design29 had not been explored, because most of the various sources used to find valuable data on the design process focused their discussion mainly on the evaluation procedures. For four of the educational tools (e.g. ‘Glucose Race’, ‘Tamagoya’, ‘Tantei’ and ‘Magic Room’), more information was given, but descriptions lacked detail. UCD was used for the development of ‘Glucose Race’, but the authors did not discuss what methods or tools facilitated the discussions on

29 Many of these design interventions are discussed in the next Chapter 3, Section 3.4.
design with healthy children or how they tested the paper prototypes (Bomark et al 2012; Brox et al 2012). Aoki et al (2004) did not specify the methods used to support their work with the medical professionals while they developed and built the prototypes of the persuasive games ‘Tamagoya’, ‘Tantei’ and ‘Magic Room’. Unfortunately, such information was found only for the design of the ‘Food Quiz’ mobile game and ‘MaXine’ system. Glasemann and Kanstrup (2008) highlighted that the aim of their work with young individuals in “the case study was to find out how young diabetics want to be supported with ICT in their everyday living, especially outside their home. Furthermore, we wanted to investigate if the participatory design method is applicable in the very early phase of a design process of mobile systems” (p 38). Based on their results, they argued that children can and should participate in the IT development process, particularly if their design solution aims to support these individuals in self-management practices (Glasemann and Kanstrup 2008). For example, they used a wide variety of design interventions (e.g. interviews & tangible artefacts, seven postcards with pre-written questions, a “creativity pack”, theme posters, design games, etc.) to support active participation of individuals, to give them freedom to explore, share and develop many prototypes of technologies that may better suit their everyday self-care practices. In regards to the applied method, they indicated that the “major challenge in using this method is to bridge the gap between visionary ideas of the users and possible implementations for the designer” (Glasemann and Kanstrup 2008, p 40). They also emphasised that girls aged between 12 and 15 were very productive in using modelling clay while developing their concepts. While they clearly explained the steps of identifying the users’ needs, the design and prototyping process and the evaluation of digital prototypes (Glasemann and Kanstrup 2008; Glasemann et al 2010; Glasemann and Kanstrup 2011; Kanstrup et al 2010; Kanstrup 2014), their work was more concerned with which “design concepts facilitate users’ interactions across boundaries in their everyday lives” rather than with exploring various methods, techniques and tools that may better facilitate the active users’ involvement in digital technology development and design (Kanstrup 2014, p 58).

In conclusion, from the above discussion it is very clear that only two (i.e. the ‘Food Quiz’ mobile game and the ‘MaXine’ system) of the studies dedicated to the 21 educational technologies gave detailed information on methods, techniques and tools
implemented for all the different phases (i.e. understanding users, design, prototyping and evaluation) completed while their designs were developed. Unfortunately, a large number of diverse research methods developed/adapted to support children participation in IT design have not been explored to test their feasibility when designing educational interactive technologies for children with diabetes. In the design process, the identification of the various roles that different groups of participants i.e. healthy children and healthcare providers, may play in the design was not the primary goal in any of these studies; further work is needed to explore the levels of involvement and design interventions that may support their participation for the better.

2.4 Summary

This chapter lays out some of the limitations and gaps found in the reviewed literature. The main focus is to examine two different themes which are both related to diabetes education; these are: 1) the complexity of paediatric diabetes care and the role of the educational process and practices in chronic disease self-management, and 2) the standard of technology, by reviewing 21 examples of educational IT for children with T1DM, along with the design practices and interventions used for their development and design. Regarding the first theme, the literature reviewed indicates the need for more attention on individual care: firstly, because of the growing number of new cases of diabetes among the young population, and secondly, because of the inability of young patients to control their diabetes alone without help from adults, as the self-care support model includes collaborative work between young patients, parents and care providers. A number of critical gaps have been identified in paediatric diabetes care in Ireland - a need for an adjustment of the healthcare system to better facilitate the self-care process for patient empowerment was observed. These modifications described in the Model of Care, 2015 include new approaches to improve the quality of national paediatric diabetes services by involving and working with highly educated staff, improving access to psychology services, identifying the structured education programmes and materials that will support affected families in order to acquire the knowledge and skills necessary for diabetes management, etc. Promoting self-care should deeply examine the assistive role of supportive services, schools, community organisations, and social networking in the self-management process and the role of interactive technologies supporting education for patients in
their daily life. For the second theme, the largest focus of the investigation was to examine the variety of interactive technologies that are designed to assist the communication of knowledge on diabetes self-care practices to young users with T1DM by creating a selection of 21 educational devices. Here the aim was to identify the most recurrent design features and to examine the methods, techniques and tools used for their development, in order to identify the roles of the diverse groups of participants involved in the technology design. Unfortunately, the results indicated that more attention was paid to the evaluation practices that examine the benefits of improving the self-care process and wellbeing as the result of using these technologies, than to describing the design process of the products, users’ involvement and their dissimilar roles in performing a series of design activities. Little is known on what theoretical framework is effective in designing good quality educational tools, tailored to fit user's actual needs, and what design interventions may support user’s active participation and involvement in technology design.

In summary, the findings from the literature helped to identify several gaps across different studies and how they are considered in this research:

- The limitations found regarding the educational materials and ongoing patient education in the national audit, 2013 (Hawkes and Murphy 2014) and new Model of Care, 2015 (O’Riordan et al 2015) reaffirm the initial findings from the qualitative investigation made in relation to the first-sub question asked in this thesis, therefore this direction was explored further in this research (Chapter 5).
- The potential of an interactive enhanced eBook as a technology that may facilitate diabetes education for children has not been fully explored. The identification of technology design in this research was partly based on this finding, as it was more concerned with the sensitive context of diabetes and the enormous stress after the diagnosis. Therefore, the design solution should address the learners’ engagement through fun, providing a relaxed interactive environment (Chapter 5).
- The lack of discussions on design approach and interventions used to support children with T1DM and their caregivers in developing educational interactive technologies was identified, hence these results suggest the need for further investigations in reviewing the literature on HCI in order to help
identify and explain various design methods, techniques and tools developed to support these users and designers in their collaborative work (Chapter 3).

The following chapter, Chapter 3, is a second literature review that critically discusses the human-computer interaction and children’s roles as users and designers, provides a map visualisation of selected activities developed/adapted to facilitate the involvement of young individuals in design and explores some of the challenges discussed when the participants are young individuals with diabetes.
Chapter 3: Designing for/with Children with Diabetes: Challenges in UCD and CCI

3.1 Introduction

Based on the identified limitations in Section 2.3.2 and Section 2.4, this chapter extends the discussions on the various design practices used for educational IT design with children with T1DM and their parents by examining different individual studies in the relevant literature on these broad areas of research of Human Computer Interaction (HCI), User Centred Design (UCD), Participatory Design (PD) and Child Computer Interaction (CCI). This approach helped 1) to address these issues in detail by providing an essential complement to the primary discussion on the design methodology, their current state of scientific knowledge, particularly examining the design practices with young users who have chronic diseases and 2) to position my research question in a background of already existing studies covering some of the limitations found in the publications describing the role of children and their families in the design of interactive technologies. Composed of four sections, the focus of Chapter 3 is to demonstrate critically some of the challenges and gaps identified in CCI and recognize factors that shaped the context of this research. Section 3.2 outlines the position of the CCI within the HCI, its focus on methodology along with four challenges related to the CCI community by showing how three of these challenges were considered to be examined in this thesis. Section 3.3 explains that 1) the child-centeredness in design differs from the suggested UCD framework for adults and 2) the modified UCD framework for designing patient-centric self-help e-health tools has not been explored with children’s participation in the design and prototyping processes. Section 3.4 provides a review and a map that visualises the selected methods, techniques and tools in CCI that identify current trends in design practices. These were used to guide the selection of the design interventions (Chapter 4) used for the empirical work in this research. In the last Section 3.5, by using three examples of IT design with chronically ill children to discuss applied design interventions, various actors and their roles in design alongside the critical discourses on the Informant Design (ID), Cooperative Inquiry (CI) and BRIDGE methods in CCI, I argue that UCD and the participatory approach have not been fully explored
with children with T1DM and their families, and identified limitations which helped to clarify the scope of the research.

3.2 Human-Computer Interaction and Children

CCI is a multidisciplinary area of research concerned with child-computer and communication technologies interaction that enjoys the contributions of development psychology, learning science, product and interaction design, computer science, etc. (Hourcade 2015; Read and Markopoulos 2012). As a research discipline within HCI, CCI is primarily focused on establishing the requirements for new methods to enable and facilitate the collaborative work for design and testing interactive technology with/for children. Therefore, this segment illustrates 1) the position of CCI in HCI and CCI’s dual role when examining methods i.e. for co-design activities with children and for the design of interactive technologies for young individuals (Read and Hourcade 2013), 2) the children’s development as a key factor in developing/adapting, selecting and applying various design interventions while working with these young participants and 3) how this thesis is positioned in the scientific field to address three of the challenges in CCI identified by Read and Markopoulos (2012) and to explore the design of IT in regards to the users’ “culture, socioeconomic status, or special need” (Hourcade 2015, p 121).

It is difficult to pinpoint the moment when the CCI was established, but having a greater number of studies and publications investigating children and technology officially laid the foundations of the first Interaction Design and Children (IDC) conference in 2002 (Markopoulos et al 2008b; Hourcade 2015). At the beginning, the CCI was more concerned with the technology used in education and later matured as a discipline focused on methodology, seeking out to find how to design and evaluate interactive technologies with and for children (Markopoulos and Bekker 2003; Markopoulos et al 2008b; Read and Bekker 2011). Read and Bekker (2011) proposed that the CCI is “a study of the Activities, Behaviours, Concerns and Abilities of Children as they interact with computer technologies, often with the intervention of others (mainly adults) in situations that they partially (but generally do not fully) control and regulate” (p 7). The “dual role” of CCI was pointed out by Read and Hourcade (2013): they believed that both roles are concerned with methods (p 2481). In the first role, all methods help to involve children in various design activities while in the second role, the methods facilitate the development of many
different types of interactive technologies, particularly for young users. As a growing and quickly transforming new discipline that supports the work between young users and researchers, CCI urgently needs “to start to develop a theory” (Read et al 2012, p 689). Design methods defined for adults in HCI would not be applicable for design with children because of the developmental differences between children and adults; they would need to be redesigned with children, for children (Chiasson and Gutwin 2005; Fails et al 2012; Read and Markopoulos 2012). There is a need for research aiming to understand children’s technology interactions in order to help develop appropriate guidelines and methods for the design process (Hourcade 2007; Markopoulos et al 2008b). Dissimilarity between CCI and HCI can be seen by examining the differences between children and adults and in the build of the CCI framework (Read and Bekker 2011). This refers to the process of biological growth and development which I will now discuss.

Actually, children’s development appeared as a very significant aspect not only in diabetes self-care practices, when the young patients need to manage their chronic condition (clearly discussed in Section 2.2), but also when children (i.e. healthy and those with medical health issues) are involved in the design of IT, mainly for two reasons. Firstly, this issue was pinpointed as a critical factor for the CCI theory when adapting or developing appropriate methods, techniques, and tools for designing with this group of users (Bruckman and Bandlow 2003; Hourcade 2007; Hourcade 2015; Markopoulos et al 2008b). Secondly, because children are more likely to use technology for playing, learning and communicating as opposed to doing work as adults (Read and Bekker 2011; Read and Markopoulos 2012). Based on their design experience with this young population, some researchers highlighted that designing products that do not take into account the child’s development (e.g. interface, task and features), may be ineffective in the context of use or even cause harm (Bruckman and Bandlow 2003; Hourcade 2007; Hourcade 2015; Markopoulos et al 2008b). Therefore, this strongly indicates its significance in developing recommendations in HCI when the adult participants are replaced by young individuals. For example, children develop their cognitive (gain new skills in areas of literacy, science or mathematics; their thinking abilities and intentional processes are different at different ages) and fine motor skills (actions performed with the small muscles in the hands, fingers and wrist that are controlled and used for holding a pencil, holding and
proficiency with a scissors or dressing a doll properly) (Kail 2009; Hourcade 2007; Bekker and Antle 2011; Bruckman and Bandlow 2003) at varying ages, explaining the disparity between children’s abilities to interact with technology. Consequently, this age diversity influences the guidelines for the design of applications and devices that could support better interaction with technologies targeting a specific age group of young users, as well as the selection of appropriate co-design activities that may support more effective child participation in the design of various products. Considering the child development, the fundamental nature of childhood and well-being, Markopoulos and his colleagues (2008a) have suggested that while “childhood is generally defined by biological age, the differences across cultures and societies that impact on children and childhood cannot be ignored” (p 4). Furthermore, they argued that the methods in HCI “need serious revision” when the participants are children (p XVIII). Children’s development, the way they learn and use technologies, could be taken as main factors when adapting existing methods in HCI or developing new ones that may improve children’s involvement as participants and users (Markopoulos et al 2008b). Therefore, the CCI explores the fundamental nature of children's growth and development, embracing the idea that children can develop their own technology working closely with researchers.

Unfortunately, quite often the researchers in CCI fail to expand upon the theory and motivation behind their work (Yarosh et al 2011). For example, Hourcade (2015) affirmed that technologies need to be adjusted in a way to respond to the local cultures, social and economic status of where children live, and this could be achieved by using PD techniques to further consider user interfaces and content for the product. Read and Markopoulos (2012) emphasised that CCI is still an ongoing process, and the needs of empirical work on different aspects of children’s technology design could help to develop new methods to explore and study CCI phenomena. The themes in CCI that are currently being discussed include interaction techniques, evaluation methods and design practice (Read and Markopoulos 2012). They outline four challenges related to the CCI community, children and future technologies.

a) The first challenge suggested a robust link between a wide range of theories on child development, education, etc. and interaction design practices. The described “scarcity of empirical research on children” highlights the need for
further exploration via practical approaches to facilitate the elaboration of guidelines and recommendations helping to “develop models that can guide design” (ibid, p 3).

b) The second challenge highlights the notion of children and their participation in the design process. Their involvement as social actors, as equal stakeholders and as users was “understudied and under explored in CCI” (ibid, p 3). More research in the area will open the doors for design of new IT supporting “varying groups of children”, their needs, participation and voice in technology development (ibid, p 3).

c) The emergence of many forms of technology for playing, learning and family communication was identified as a third challenge in CCI. It is focused on exploring the design space for development of appropriate technology “especially in the context of bringing families in the broadest sense into playful learning and communication spaces” by using suitable methods to help design needed applications (ibid, p 4).

d) And the last and fourth challenge is about stories in the digital space. “Storytelling has been a feature of CCI research” and exploration of a variety of technology for storytelling, communication with friends and families, and is a theme for many studies in this community. Privacy, security and trust are still major problems and challenges that will continue to exist in the development of new products (ibid, p 4).

The last three challenges are strongly related to this thesis and they fit into the main research question guiding this study. As a result, my work offers empirical material to shed more light on some aspects of what is missing in the CCI field. Applying the participatory approach for the development and design of IT that is relevant for children with T1DM, this research covers the aspects and challenges suggested by Hourcade (2015) and Read and Markopoulos (2012) in several ways. First, the young patients who are living in Ireland fall within the “vulnerable group” of users because of having Type 1 Diabetes (Vines et al 2013); therefore these users would have a chance to share their multiple perspectives by expressing their opinions in the decision-making process. Second, in the design process, not only are children involved, but also their families whose contribution to design has not been fully
analysed on a comparative basis. And third, by involving children with diabetes and their parents as a “different group” of users by emphasizing on their culture trait (i.e. local cultures, social and economic status) of individual and personal experience gained through living with the disease for exploring the digital space for storytelling within an educational context with this study, I am seeking validation by applying some of the existing methods supporting participatory design practices with families. Bearing in mind the limits and great demands in CCI (Markopoulos and Bekker 2003; Read and Markopoulos 2012; Read and Bekker 2011; Read et al 2012), as well as that “children are not a homogeneous group for which a single theory and practice may be recommended” (Markopoulos and Bekker 2003, p141), this research would provide avenues into new insights helping to confirm the applicability and usefulness of these user-centred design methods for researchers in the field who in the future may like to design IT for children with chronic illnesses. Furthermore, working closely with the users will increase our understanding on how to actively involve affected young individuals and their families in the design of educational interactive technology for young patients with long-term conditions. Viewing children as active agents in the design, the focus must be on the change to the potential benefits for the children themselves (Read and Markopoulos 2012) rather than on the benefits to technology design. Giving children voices to express their opinion on what technology could serve them best in their everyday care may bring new challenges in IT development, but of course, these can only emerge through working closely with participants. For that reason - designing for/with children with T1DM and their parents/guardians - this project could help to solidify the core knowledge of co-design with young chronically ill participants in CCI. For Read (2011), CCI “has not yet reached that level of maturity as an academic subject – there are neither enough people, nor is there enough knowledge to have that level of debate”, hence this suggests that further studies in the field of CCI are highly recommended (p 268).

3.3 User Centred Design (UCD) and Children

As noted in Section 2.3.1, UCD and PD were explored in the maXi project to support the work with various groups of participants in developing digital technology for diabetes, but the authors have not discussed the role of the individuals in the design process (Glasemann and Kanstrup 2008; Glasemann et al 2010; Glasemann and
Kanstrup 2011; Kanstrup et al 2010; Kanstrup 2014). Therefore, the following section first describes UCD, PD and then UCD with young participants as this helps 1) to outline the four different roles that young individuals can play in the design process defined by Druin (2002), 2) to illustrate some of the limitations that emerged when using the UCD framework, replacing adults with children and 3) to discuss how the UCD was tailored to facilitate the design of patient-centric self-help tools, but the children’s involvement in the design and prototyping steps had not been tackled by the authors (Årsand and Demiris 2008).

For Norman (1998), the Human-Centred Design (HCD) used in product development is an iterative “process” which “starts with users and their needs rather than with technology" (p.185). This process has two main concerns related to the users: “solving the right problem and doing so in a way that meets human needs and capabilities” (Norman 2013, p 219). Consisting of four different phases (Context of Use, User Requirements, Produce Design and Evaluation), HCD is a process that is trying to address, meet and serve users’ needs to optimize the product quality design by placing users at the centre of the design, which is one of the main objectives in this research. The HCD model of interactive systems follows the International Organization for Standardization for Standardization (ISO) – 13407 and was later on revised to the ISO 9241-210:2010 (International Organization for Standardization 1999; International Organization for Standardization 2010) which puts emphasis on user participation in technology development.

"ISO 9241-210:2010 provides requirements and recommendations for human-centred design principles and activities throughout the life cycle of computer-based interactive systems. It is intended to be used by those managing design processes, and is concerned with ways in which both hardware and software components of interactive systems can enhance human–system interaction.”

(http://www.iso.org/iso/catalogue_detail.htm?csnumber=52075)

There are a number of discussions about the concept of HCD and UCD which are based on the notion of people and their roles as users (Steen 2011); in practice HCD and UCD “are often used synonymously”\(^\text{30}\). The conventional UCD process

examines users as testers and evaluators after the technology or prototypes have been designed (Norman and Draper 1986). As a result, the involved participants have a very little or no control throughout the development process as the actual contribution or feedback will only shed light on the good or bad characteristics in the designs (Scaife and Rogers 1999). In contrast, adopting the ‘Scandinavian model’ for equal participation while the systems/products are developed, in participatory design individuals have a more responsible role, that stems from an assumption of equality because the participants work together with the designers, performing each stage of the product development as equal design partners (Schuler and Namioka 1993).

Similarly, the early discussions in UCD and children were focused on technology's impact on young individuals as users or as testers, evaluating some technology before being released to the public (Druin 2002). Based on “an analysis of the literature” and on her “own research experience with children”, Druin suggested a model that examines the roles of children in the design process as User, Tester, Informant and Design partner presented with four circles in Figure 3 (Druin 2002, p 3). In the article ‘The role of children in the design of new technology’, Druin (2002) highlights that each of these roles supports different levels/degrees of user contribution in design and children’s participation increases as we move from the inner to the outer circle. For example, playing the role of the user, children test a general concept by using a technology (e.g. final product that was released onto the market) with no involvement in its design. The role of adults is to collect data through observations, taking notes, pictures and videos as this will help to understand how the technology impacts the young user. Playing the role of tester, children test the initial prototypes of “emerging technologies” after they have been created, and the goal is to advise improvement to the technology interaction and to give future direction (p 9). Researchers or industrial professionals may do observations or ask questions related to technology features and use. The role of informants was influenced by the Informant Design (ID) (Scaife et al 1997); playing this role, young participants could suggest various input in the design process, participating

31 For the first time this approach of involving participants while designing technologies was used during the Utopia project in the 1960s and 1970s (Bødker et al 1987, Ehn 1989).
32 The PD method is discussed in the next Section 3.4
33 This method is discussed under the intersecting zones of UCD and PD
only at some stages of the product development, but their engagement is not as equal design partners: they are ‘native informants’. And in the final role - design partner - children are equal stakeholders throughout the entire UCD process of new technology design like adults in PD. For children each of these four roles (as users, testers, informants, or design partners) “offers a different degree of empowerment” (Druin 2002, p 29).

Figure 3: Children’ role in the design process: Druin’s model

In Section 2.3.2, by reviewing the selected 21 educational interactive technologies, this helped me to uncover some of the current problems in design, demonstrating that UCD and the participatory approach for developing such technologies have not be fully elucidated. Taking into consideration the limited information on the design practices, I am using Årsand and Demiris’ (2008) framework, which was developed particularly to design patient-centric self-help e-health\textsuperscript{34} tools for individuals with diabetes, including children, as this helped to explore the use of UCD in the healthcare domain. The suggested framework may also facilitate the design of educational interactive technologies for children with T1DM because it was grounded in data generated through three case studies (e.g. design automatic transfer

\textsuperscript{34} The use of Information Communication Technology (ICT) in healthcare is often referred to as eHealth, these are applications that can include decision support systems, national electronic registries, national drug registries, as well as telehealth which can provide reliable health information online (World Health Organization 2008). One of the new fields of eHealth is the use of mobile and information technologies in health services, mHealth applications working on health issues include mobile devices such as mobile phones, patient monitoring devices, personal digital assistants (PDAs) and other wireless devices designed to improve public health and patient care (World Health Organization 2011b).
of blood glucose data from children with T1DM, Information Communication Technology (ICT) self-help tool for people with type 2 diabetes and smart home features for the elderly), and the first one is for young individuals with type 1 diabetes. To facilitate patients’ involvement in the process of designing e-health technologies, some modifications in the UCD model have been recommended (Figure 4), as the patients’ participation early in the design process is required.

![Figure 4: Screen capture of modified and tailored UCD for designing patient-centric self-help tools by Årsand and Demiris 2008, p 166](image)

Self-helps tools are applications designed for chronically ill patients helping them to increase their self-efficacy in managing the illness. Authors identified that self-efficacy is a person’s belief in his/her capabilities to control and manage their illness and in dealing with different challenges. Internal (e.g. family and friends, healthcare services, access to health care, financial resources and ITC-infrastructure) and external (i.e. health status, motivation/attitudes, disease knowledge, education and physical abilities) attributes impact the sense of self-efficacy and both of these factors can increase the effectiveness of a self-help tool. The identification of these factors in stage one (i.e. understanding of the context of use and specification of patient requirements) of UCD “will drive the design decisions” (Årsand and Demiris 2008, p 166). The proposed design solutions could be evaluated against the earlier identified requirements and if the prototypes do not correspond and fulfil the requirements exactly, the procedure of understanding the context needs to be
recommenced. They also highlighted that the ISO\textsuperscript{35} standards do not cover in detail the methods and techniques required for human-centered design; hence in their framework they described them as follows, as they believe that these better support patient-centric approach in design:

- Workshops and focus groups (with approximately 5–7 patients) to involve users in the design process and to acquire information about users;
- Interviews and field studies to enable deeper understanding of the users. Field studies to gain insight into user’s every day practices or study assistive technologies;
- Scenarios and storytelling help to describe both the health problems experienced by the user and the technical solutions. Personas could be valuable for common understanding of the users;
- Paper prototyping and sketching helps to communicate design ideas and facilitate reflection;
- Thinking aloud in usability testing is focused on users’ expectations and feelings about the design;
- Questionnaires - using the 10-question Software Usability Scale (SUS), the Software Usability Measurement Inventory (SUMI) evaluation questionnaire, the Questionnaire for User Interaction Satisfaction (QUIS), the Computer System Usability Questionnaire (CSUQ), and the checkbox scheme Microsoft’s Product Reaction Cards;
- Logging and other observation methods used for collection and storage of data during the work with participants - video and audio recording and observations logs.

A more radical approach for young user participation in all phases of the UCD was suggested by Druin (2002): similar to adults in PD, children could participate in design as design partners. Based upon young users’ direct involvement with technology developers, Markopoulos and Bekker (2003) remarked that traditional UCD is more focused on the HCI principles related to adults and less on issues linked to children; they highlighted that the “standard user centred design approaches need to be adapted when we consider the specific needs of children”, as well as when the focus is on a special target of users such as the elderly, people with

\textsuperscript{35} International Organization for Standardization for UCD (ISO) – 13407, later on revised to ISO 9241-210:2010, \url{http://www.iso.org/iso/catalogue_detail.htm?csnumber=52075}
disability, to address their cultural influence, characteristics and needs (p 148). Applying UCD in the design process with children may bring some unique challenges regarding the levels of iteration needing to be adapted (Årsand and Demiris 2008; Markopoulos et al 2008a). More iteration is needed when designers develop software-based applications and products that have a higher level of interactivity, and the number of children involved in the evaluation practices must be planned carefully (Markopoulos et al 2008a).

Marti and Bannon (2009) reported that UCD approach with children was more complicated. Bearing in mind the defined four roles of children in the design process (Druin 2002; Scaife et al 1997), they found that not all children are open to participate as informants or creative designers when they need to talk with unfamiliar adults (designers). In the POGO project, children (6-8 years of age) who were constantly involved in the design process did not fully comprehend how ubiquitous technologies would support narrative activities. To overcome these obstacles, the design concepts were developed by designers taking inspiration from user observations and 14 visions of the narrative environment. Then children, teachers and technology developers were invited to evaluate the proposed solutions. This experience suggested that user-centred and user-involved design is highly influenced by the work environment, age and skills presented by the young users.

“User participation should always be regarded as a value; it should be tailored to the knowledge and the abilities of people involved in the design process. Users need to be prepared for playing their role effectively, for contributing with their domain knowledge to the project, for defining concepts, for evaluating and comparing solutions and identifying usage problems according to their abilities and possibilities to participate in the design process.”

(Marti and Bannon 2009, p 14)

Årsand and Demiris (2008) summarized that “the pitfalls when designing for a special user group may be many and difficult to predict” (p168). They believe that modification in UCD and an early focus on the users-patients and the proactive
user’s involvement could help to obtain good product design results. Unfortunately, their experience was based only on children who were involved in the project as test users and the “objective of this study was to determine how both children with Type 1 diabetes and their parents perceived a system that automatically transmits measured blood glucose data as text messages (SMS) to the parents’ mobile phone” (Årsand and Demiris 2008, p 160). The hypothesis that guided this study was more concerned with technology - how the system will support family disease management, decreasing the levels of conflict between children and their caregivers (Gammon et al 2005) – rather than focusing on the users i.e. how to involve them actively in the product development, what methods could better support their participation in that design process or what technology would resonate with the users’ needs better. Also, the role of the designers/researchers in selecting methods and techniques for users’ involvement (i.e. children with T1DM and their parents) in the entire design process was not clearly discussed, nor was the collaborative user-designer work using workshops, because their users were provided with a prototype to use at home. Marti and Bannon (2009) highlighted that some children have difficulties in communicating with unfamiliar adults and this challenged their participation as design partners and informants. What will the reaction of diabetic children be when they need to talk about their personal health experience (highly private and sensitive information) with people that they will meet for the first time - the designers? For many children, diabetes is a very sensitive theme (Guthrie et al 2003; Goodall and Halford 1991; Miller 1998); how do the designers overcome this problem throughout their collaborative work with young participants, or how will they deal with negative emotional states (if any) exhibited by the participants at the time of the design workshops? It is not clear what methods could help to deal with this emotional state and what the role of the designer would be. What will the group dynamics be like during the co-design process? More studies are needed to examine children’s role and the designers’ role during the design to consider users’ specific needs and characteristics. Adaptation of UCD for children can be achieved by not only placing young users at the centre of the design but by also selecting different methods and techniques aiming to actively involve users in all phases of product development. This will help to explicit users’ knowledge on their everyday life with the illness for mutual learning between different practices and to design products of high quality. Children with T1DM may need to be approached with a particular attitude stemming
from their personal needs to manage diabetes throughout the time of co-design, or the designers may need to pay attention to the emotions, feelings and other health issues, etc. that could possibly appear/present themselves while they are working with participants collaboratively. This study will help to clarify and summarise some of the key elements for safe and effective co-design with young patients and their families. To show, for example, what new coping strategies in dealing with any of the issues described above were used (if any) and to better describe the process in the selection of co-design activities aimed to facilitate children’s involvement in design (Chapter 4 and Chapter 5). As discussed, the involvement of young participants in all steps performing UCD is crucial; the next section illustrates some of the design activities adapted and developed for CCI enabling children and designers to work together.

3.4 A Review of Selected Methods, Techniques and Tools in CCI Developed/Adapted to Support Children’s Involvement in Technology Development

When the design teams plan design activities for/with children, it is important to look attentively at which of the existing design practices suggested in CCI would work best with the characteristics of the young users, their various needs, and roles in the design (Iversen et al. 2010). The gaps identified in Chapter 2, particularly in regard to the design interventions used in developing educational IT, indicated that further investigation in CCI is needed. However, the contribution of this section includes a review of the selected methods, techniques and tools within the area of CCI supporting young participants to play different roles in IT development by visualising them on a map (Graphic 1) and in a colour coded table (Appendix A). This work facilitates 1) the procedure of choosing and justifying the empirical data collection approach described in the methodology (Chapter 4), 2) the research in regards to the second and third sub-questions asked in this thesis examining the users’ role and design interventions in IT design and 3) the explication of some of the critical discourses on PD practices with young participants in Section 3.5, reflecting particularly on the design activities used with chronically ill children.

Taking the idea of Sanders (2008) to organise HCI design practices into a map, with Graphic 1 I am presenting a map visualisation of the selected design methods (big coloured circles), techniques (small black dots) and tools (small green triangles) in
CCI for co-design with children. They are arranged according to the various degrees of involvement the three roles have in co-design i.e. as Tester, Informant and Design Partner, (Section 3.3) (Druin (2002), so from left to right the user’s degree of participation increases (see the map legend). According to Druin’s model (2002), when children interact or use final digital products (i.e. technology that has been designed, released and distributed to the market) they play the role of Users, therefore this role does not afford any participation and input in the design process and is not included. In the map, the co-design approach refers to Sanders and Stappers’ statement (2008) that it is a process of collective creativity which includes both “designers and people not trained in design working together in the design development process” (p 6). Many of the design activities have been adopted to work with children applying UCD, Learner-Centered Design (LCD) and Participatory Design (PD) (Druin 2002; Good and Robertson 2006; Iversen and Brodersen 2008; Rode et al 2003; Van Kesteren et al 2003; Zaman and Abeele 2010), and for that reason, I am presenting the co-design in the map as the largest set that includes these main design practices. Within the zones of UCD, LCD and PD, there are zones in which selected CCI activities (i.e. methods, techniques and tools) fall. The proposed map does not include all methods, techniques and tools developed in CCI; it depicts a visualisation of selected methods, techniques and tools along with a colour coded table instead (Appendix A), developed to exemplify the collection by giving short descriptions at which stage of the design process the techniques and tools may be applied.

Similar to Fails et al (2012), the quantitative and qualitative methods are not entered into the selection or in the map as they are not confined to only the design process; they can be applied to social sciences and cultural studies. Before outlining a detailed description of the elements, I would like to offer definitions of the methods, techniques and tools that Sanders et al (2010) used in their PD framework, and which I have adapted for the CCI:

- **Methods**: a collection of techniques and tools used to design different technologies with children and that are linked to the large design philosophy of CCI.
• **Techniques**: Different techniques can be used while working with one tool. Usually the techniques give clear descriptions on how the tools are used in the design process with children.

• **Tools**: are different “material components” that are used in design activities (Sanders *et al* 2010, p 196).

In the following, I review the selection of design activities in CCI according to their visualisation in the map. As discussed, in the map the three zones of UCD, LCD and PD are illustrated, as well as their two intersections of 1) UCD and PD and 2) LCD and PD in which fall the selected methods, techniques and tools.

**UCD zone**

On the left side of the spectrum, indicating a lower degree of young users’ involvement is UCD. As discussed in Section 3.3, the key in UCD is the use of a variety of prototypes and physical artefacts for testing ideas with children. In this case participation is confined (limited) to the actual test of prototyped ideas and in this sense the child plays the role of what Druin labels as Tester. In this zone, under the **User eXperience** is the technique of Contextual Laddering (Zaman and Abeele 2010) and two tools, *Fun Toolkit* (Read 2006) and *This-or-That* (Zaman and Abeele 2007). For **Usability Evaluation**, I am reviewing six techniques (e.g. Co-Discovery, Peer Tutoring, Thinking Aloud, Active Intervention, Retrospection and Problem Identification Picture Cards (PIPC)) used to evoke verbal responses from children (Barendregt *et al* 2007; Van Kesteren *et al* 2003).

Based on the Means-end Theory (Gutman 1982), Zaman and Abeele (2010) proposed “a specific interview and data analysing technique” called Contextual Laddering for product evaluation to test User eXperience and to suggest design improvements. By explicating distinctions in two products (e.g. comparison) from the users, as well as the users’ product choice (e.g. why that product was preferred over another, overall judgment), designers can measure the individual experiences of children using different technologies. The researchers developed an interviewing tool called *This-or-That* which contains five questions aimed at finding out what children like or dislike after they have played with several prototypes (Zaman and Abeele 2007).
Graphic 1: A map visualisation of the selection of methods, techniques and tools in CCI
Fun Toolkit (Read 2006) is comprised of four instrument-tools: a Smileyometer, a Funometer, a Fun Sorter, and an Again-Again table that are designed to measure the fun aspects and a child's engagement with various interactive products while they play with them. Based on the Likert scale, a Smileyometer is a pictured representation of faces in a horizontal row together with text that explains the facial expression under each image. Children are asked to tick the face that corresponds to their opinion. Presented vertically, the Funometer (Risden et al 1997) is similar to the Smileyometer, but here children need to draw a vertical face to represent the experienced amount of fun. In the Fun Sorter technique, children are asked to measure the fun in activities that they have already completed; the provided images of items are sorted out by participants depending on what fun they experienced while they played with the products. And finally, the Again-Again table is for gathering children’s opinions on whether or not they would repeat a certain activity again.

In Usability Evaluation, Van Kesteren et al (2003) assessed five evaluation techniques: Co-Discovery, Peer Tutoring, Thinking Aloud, Active Intervention and Retrospection. In Co-Discovery, two children collaborate together performing different tasks having spontaneous verbalization (Kemp et al 1996). The Peer Tutoring evaluation technique is specifically developed for children to perform in two sessions, in which one child plays two roles: as a learner and as a teacher (Hoysniemi et al 2002). In the first session, the young individual plays with a product to get experience by practicing different tasks while in the second session the same participant teaches another child how to perform various tasks when they play with the product. For the last three (i.e. Thinking Aloud, Active Intervention and Retrospection) techniques, children perform the tasks individually - only one subject was involved per session. In Thinking Aloud, young participants were encouraged to verbalize their thoughts while doing tasks. The Active Intervention technique means that during the task performance, an evaluator would ask children questions formulated in advance and the given answers would reflect on the evaluation. In the Retrospection technique, during the Usability testing session, the child's actions were video recorded. After the child watched some parts of the recordings he/she was then questioned about his/her interaction with the product.

The PIPC technique (Barendregt et al 2007) is a combination of the traditional thinking-aloud method with eight pictures cards (e.g. difficult, don’t understand,
boring, fun, takes too long, childish, silly/strange and scary) that help to provide young children with the necessary vocabulary to express the usability, fun and problems in games with high levels of fidelity. If while playing a computer game the child detects a problem, the child can select a card related to this issue and place it in a box.

The intersecting zone of the UCD and PD

As we move from left to right on the map, the involvement of young individuals in the design increases as they can take part in more activities and not only in the evaluation. As a result of that, the UCD and PD intersection zone shows the intermediate position in which the positioned methods, techniques and tools suggest that the children’s involvement in the design is greater, because they can play the role of Informers (Scaife et al 1997) or of design partners. Large et al (2006) had some doubts on actual partnership with children “in all aspects of the design process”, because of “reservations about the extent to which full and equal cooperation can occur across the generational divide” (p 64). Therefore, these design activities do not fully support PD. The reviewed methods dropping into this intersecting zone are Informant Design (ID) (Scaife et al 1997), Bonded Design (BD) (Large et al 2006), Bluebells (Kelly et al 2006), Cultural/Design Probes (Wyeth and Diercke 2006), Mad Evaluation Session with Schoolchildren (MESS) (Read et al 2006), together with the technique called Obstructed Theatre (Read et al 2010). Storyboarding also falls into this zone, proposing a more active role in design. The technique was adapted for children to help in the brainstorming and evaluation sessions, so its four variations are Electronic (Hall et al 2004), Comicboarding (Moraveji et al 2007), Magicboarding (Moraveji et al 2007) and Emotional (Chung and Gerber 2010). Child-Personas is a tool that can be used for different users’ roles in different phases of UCD design; this actually sets its position in this intersection zone.

Informant Design can actually cover some limitations of UCD (children used only as evaluators or testers) and participatory design techniques (equality of all team members) effectively in regards to children (Nesset and Large 2004). ID is “for the design of interactive software for non-typical users or those who cannot be equal partners (e.g. children)” (Scaife et al 1997, p. 346). Facilitating children's effective
involvement in various stages in the design of interactive learning environments, ID increased the input of participants during the four phases of 1) emphasizing the learning goals which helped to identify the strengths and weaknesses of the teaching practices, 2) listing the problems from informants’ input to be used for the functionality specifications, 3) design low-tech prototypes by using the specifications, child suggestions and motivations for the design, and then test and evaluate and 4) design and test high-tech prototype in real settings (i.e. teaching context). These steps facilitated the development of high-fidelity prototypes that children and teachers evaluated. Each informant (child) shaped the design at different stages (at the beginning of the process they identified the problems, in the middle stage they reflected upon the design expectations and in the end, they evaluated the prototypes). This method doesn’t treat children as full partners because of the children’s limited knowledge, experience and time.

As described by Large et al (2006), Bonded Design is situated between ID and Cooperative Inquiry (CI), sharing a similar approach to CI - that children should be actively involved in technology development, and suggests an “intergenerational partnership working towards a common goal” (p 64). BD is based on the Zone of Proximal Development explained by Vygotsky (1978) in combination with 1) Contextual Design and PD for adults and 2) LCD, ID and CI methods for children. The name “bond” suggests that it “encapsulates the essence of what was experienced by all members of the design team” (Large et al 2006, p 78). Children and adults have an equal voice and unique individual expertise that is crucial to design successful IT. In Bonded Design, children can participate in all stages of the product development as design partners, but questions arise on how real the partnership with the adults is, positioning this method between ID and CI.

The Bluebells method is explained as a balance between child-centred design and expert design (Kelly et al 2006). Bluebells used British playground games to develop the activities used in the method; it had three design stages called before, during, and after play, with the first and third stages (i.e. before and after play) being only for designers. Designers worked in the first stage, aiming to identify the requirements and technology features and to produce sketches and technical specifications of the product. In the third stage, they worked with the data collected throughout different play activities with children during stage two to produce the initial prototypes.
Children were involved only in stage two (during play): this was the reason for not placing this method in the PD zone. Four different activities were designed for that stage, their names being taken from children’s playground games: 1) I-Spy to gather contextual information by observing children while they explore the context and environment, 2) Hide and Seek to collect information about product/application content, 3) Tig to collect information about children’s concepts of navigation, interaction and control across the interface and 4) Blind Man’s Bluff to gather information about the product interface.

**MESS** days method is very similar to Bonded Design and Bluebells; this places the method in the same intersection of the UCD and PD zone. In the MESS events for children, the organised activities fall into four categories, i.e. games, design, technology and experiments, but focusing more on the fun-suggesting activities and the evaluation practices with the young individuals (Horton *et al* 2012; Read *et al* 2006). During MESS days, children in the whole class participate in a series of design activities that were held at the University and planned by the researchers/members from the Child Computer Interaction (ChiCI) group. The Obstructed Theatre technique was used in the Usability of Music for Social Inclusion of Children (UMSIC) project in one of the MESS days; it is a modification of the same technique used with adults (Read *et al* 2010). The version for children had three stages. Stage one was for the creation of the video, writing a script explaining the essential aspects of the product - a mobile device. Then two children (aged 12) were video recorded while performing the script, the mobile device never being shown on the screen. Two video versions were presented at the start of the workshops: 2 groups of children watched the short version having scant information about the device and another 2 groups of children watched the normal video. After the film, the children were asked to design the mobile device using the provided art materials. At the end, children made small video cameos describing their ideas. The third stage was for the evaluation of the technique. The evaluation was based on the collected data and on the children’s opinions, which were based on what they had seen on film and the produced artefacts. This technique had prominent results in the design process, identifying the specifications of devices.

*Cultural probes* (CP) or Design Probes (DP) are described as artistic, playful and provoking processes aiming to empower designers’ imagination and knowledge.
Probes are a collection of physical objects and tasks. Considered as tools for design and understanding, the users can play/manipulate the suggested activities to record their own experiences, thoughts and ideas (Mattelmäki 2006; Wallace et al 2013). As a rational method, the probes’ main functions are to support UCD in collecting users’ requirements for inspiration, information, participation and dialogue, as well as to suggest similar participatory notion to PD by offering equality between the user and designer (Mattelmaki 2006). This statement determines the probes’ method position in the intersection zone of between UCD and PD. As tools, they can be used to build the concept of design at an early stage of technology development. The CP method was also adapted to children for various projects (Moser et al 2011; Iversen and Nielsen 2003; Wyeth and Diercke 2006) that are more concerned with the educational context in different settings. For example, the adapted Educationally-focused cultural probes contained open-ended activities (e.g. Technology Collage, Subject Ratings, Classroom Architect, Gadget Design, Brainstorming Bubbles, Excursion Plan, Science Toy, When I grow up and My Journal) trying to provoke and discover children’s personal interests and their ideas within an educational context (Wyeth and Diercke 2006). In the same vein, Iversen and Nielsen (2003) developed Digital cultural probes based on Nokia 7650 terminals and GPS technology for the NetWorking.Kids project, having a trial period of two months. They wanted to gain basic knowledge of children’s learning process outside the typical school environment - classrooms - and to follow and observe children’s activities when they finished with their school tasks and later in their homes. Probes were also used to guide the design phase in the Games4School project, by gaining a holistic understanding and generating requirements that helped the authors to understand the type of users and to create three Child-Personas of children who like to play games (Moser et al 2011). In this study, children from three classes were involved in the probes’ development process by using the W-question approach (Who? When? What? Where?). This helped to choose the context of qualitative and quantitative probe materials (e.g. postcards, a diary, maps, a collage and a disposable camera) for the study and helped to investigate a child’s personal perception, interest and needs (Moser et al 2011).

Storyboards is a technique in design that provides graphical narrative visualisations, usually including pictures, drawings, sketches, and words to illustrate a sequence of
envisioned scenarios (Truong et al 2006). Four variations of the technique can support children in design and evaluation. For instance, designed by Kar2ouche software, the Electronic storyboarding was described as a child-centred technique for virtual design of empathic characters used in a bullying scenario. Its design assists children in the process of “visualising agent design and verbalising opinions” (Hall et al 2004, p 125). This technique was used in two stages: to generate scenarios exploring bullying issues in a classroom in the UK and to evaluate storyboards by taking feedback on scenarios, empathy and emotions from children who lived in the UK and Germany and who watched the bullying storyboards. Comicboarding and Magicboarding were suggested by Moraveji et al (2007) to work with children. Comicboarding was designed especially for working with participants in the brainstorming sessions. Having a specific form along with the scaffolding - an artist who helped children by illustrating their concepts - the Comicboards generated ideas in small steps; it could possibly be an alternative to the traditional storyboard technique. In the Magicboarding technique, the researchers used two notebook computers (one for the child and one for the artist) for a simulation using PowerPoint. They combined the Wizard of Oz technique and the artist’s work to illustrate the children’s ideas using a Tablet PC and a digital pen. The images appeared magically on the child’s computer, and they could be moved and have dialogue added. In both the Comicboards and Magicboarding, scaffolding offered support for children who needed extra help in the brainstorming sessions. These techniques were not designed to be part of any particular method; they could be incorporated in other methods facilitating children’s contribution in design. Emotional storyboarding is the technique of telling stories with children by drawing emotional expressions (Chung and Gerber 2010). This is a face-to-face crowdsourcing approach to design with children using emotional-storyboarding for self-expression. Emotional-storyboarding encourages children to express their feelings to elicit emotionally inspired stories as a therapeutic practice; in design, they are used to generate meaningful content. Researchers asked children to draw four different emotions using pumpkin-shaped images in four different colours and then to tell the story, “The Tale of a Pumpkin,” for each pumpkin in the order of the emotion sequences.
**Personas** provide a vivid fictional archetype which is built on the collected knowledge of the real target group of users; it represents their needs, characteristics and goals. It is described as a “*design tool as well as a communication device*” in UCD that does not replace other activities in the design process (Guðjónsdóttir and Lindquist 2008, p 169). Personas can play different user roles in design, for example to suggest the characterisation of a typical user, to guide design in scenarios, to test prototypes by suggesting insights on persona behaviours, persona-centric usability studies, etc. (Pruitt and Adlin 2006), therefore it falls within the intersecting zone of the UCD and PD. The *Child-based personas* technique (Antle 2008) (modified from Cooper’s personas 1999) is for creating user abstractions of children aiming to understand them in a particular context e.g. as users of storytelling and news, online activities or in the context of their everyday activities. It was used to overcome the lack of access and work with children as design partners or informants supporting designers in child-centric design while they developed the CBC4Kids.ca website for the Canadian Broadcasting Corporation (CBC).

**The intersecting zone of LCD and PD**

LCD is similar to UCD, guided by the educational theory and assuming that everyone is a learner; the users were replaced by learners (Soloway et al 1994). Learners can be at different ages; they can be children, students or professionals. Scaffolding strategies in LCD suggest that the developed technology should work as a vehicle incorporating features that help learners to gain adequate knowledge and skills of a new work practice; it should be adapted to the learner’s needs, style of learning and environment. Having four dimensions - of tasks, interfaces, learner’s needs and tools, TILT is a LCD model in which the user participation in design was not considered (Soloway et al 1994; Soloway et al 1996).

The reason for including LCD in the selection, as well its position on the map was influenced by the methods Curriculum-focused design (Rode et al 2003) and CARSS (Context, Activities, Roles, Stakeholders, Skills) that suggest different roles for children-learners i.e. Testers and Design partners, so they are belonging to an LCD intersection with a PD zone.

The *Curriculum-focused design* method is a variation of CI; it has UCD and LCD elements where design and evaluation tasks are part of the lessons during school
days. It was designed to accomplish requirements in the National Curriculum in the UK and to work especially in school settings including staff work, timetable, etc. (Rode et al 2003). A Webkit project goal was to design tangible user interfaces (TUIs) for children in the classrooms, as well as to develop a method that would be easily deployed in other schools and could allow the performing of UCD in learning settings. Children were involved in “brainstorming, exploring of multiple options and testing of many low-fidelity prototypes” (Rode et al 2003, p 122).

**CARSS** is a method “for participatory, learner-centred design involving children”, wherein their involvement in the design is as a child-learner (Good and Robertson 2006, p 384). The method contains five main components: Context, Activities, Roles, Stakeholders and Skills and participants have to have specific skills to be a part of the team. Exploring the context, the authors identified five constraints (e.g. curriculum, timetable, environmental, commercial and legal, and ethical) that are related with children’s involvement in the LCD process. In the second category – Activities - in order to facilitate participants’ work on different stages of the educational software design, a series of different events were organised e.g. requirements gathering, design and evaluation of prototypes. The various functions that design team members have during product development are described through the roles category. All individuals - such as parents, teachers, children, industrial partners, etc. who participated in the study, belong to the Stakeholders category. The “personal attributes and dispositions necessary to conduct successful design sessions” in participants, alongside the skills of adult design partners are placed in the last category, Skills (Good and Robertson 2006, p 385).

**PD zone**

The PD zone contains all design practices that examine the design partnering role with children; here, they are involved in all stages of the technology design. The methods belonging to this zone are **Cooperative Inquiry (CI)** (Druin 1999; Druin 2002) and **BRIDGE**37 (Iversen and Brodersen 2008), along with their techniques and tools described below. Design Workshops cannot be considered as methods, techniques or tools, but they facilitate the performance of collaborative work between designers and stakeholders and need special attention from the design team.

---

37 BRIDGE is an abbreviation of Danish: BRuger Invol-vering i Design, GEntænkt
facilitators. The Design Workshops are positioned in the PD zone because they advocate participatory work with individuals and they are marked on the map with a black square.

In the late 1990s, the PD approach was adapted for young individuals to facilitate children’s involvement and work with designers. Grounded in the theories of cooperative design (Bjerknes et al 1987), contextual inquiry (Beyer and Holzblatt, 1998) and participatory design (Greenbaum and Kyng 1991, Schuler and Namioka 1993), Cooperative Inquiry is one of the most popular methods for design with children developed by Druin (1999; 2002). Druin (1999) affirmed that “while these methodologies offered an excellent starting point for us, we quickly found that they needed to be adapted and changed to suit our teams that included children” (p 592).

There are various techniques and tools that have been developed to support co-design practices in CI with children and they are described below.

The Bags of Stuff technique is based on bags filled with a wide variety of art and craft materials (i.e. glue, clay, string, markers, scissors, paper etc.) that children and adults can use together to suggest their ideas by sketching or building their low-fidelity prototypes (Guha et al 2012). Technology Immersion (Druin 2002; Nesset and Large 2004) is a technique for observing what children do with different technologies having unlimited access to various types of interactive products. Its implementation helps to see children’s decisions on technologies, as well as to identify roles and patterns at the beginning of the project. Composed of three stages, the Mixing of Ideas technique is used to design innovative new technology by engaging children in the collaborative design process (Guha et al 2004). In stage one, each child generates ideas by working one-on-one with an adult. In stage two, all ideas generated by the children that worked in one group are mixed, while in stage three, multiple groups’ ideas are mixed into one big idea. In the Sticky Noting technique, (Guha et al 2012) sticky notes are used to identify categories of likes, dislikes and design ideas while children examine an existing technology or prototype. All sticky notes are placed on the white board and organised into groupings of similar themes and the generated data is used by designers for formulating design requirements. Layered Elaboration is a paper-based prototyping technique enabling users to asynchronously “add and modify ideas without permanently destroying the original through the use of transparent materials”
(Walsh et al. 2010, p 1238). Using layers of transparencies placed over the original idea and coloured markers, children and designers draw new images or text to elaborate new ideas. Based on Layered Elaboration, the online tool DisCo (Walsh et al. 2012) enables asynchronously and geographically distributed, intergenerational co-design with children. Each design group can elaborate on requirements, annotate and critique the designs by adding different layers to create and evaluate multiple solutions. The Telling Stories technique (Alborzi et al. 2000; Druin 2002) supports collaborative storytelling with children in the brainstorming sessions. A magic plate and idea cards give children hints for telling stories, therefore each time a kid takes the card from the ‘magic’ plate, she/he needs to add something to the story, to draw and explain her/his idea. The Journals technique involves keeping an individual diary of ideas related to the design of new technology, to take some notes on sessions, to draw sketches, etc. (Fails et al. 2012). A note-taking technique for children called Pictorial Flowcharts was devised for taking notes while observing how other children use current technology; it uses a combination of small amounts of text and pictures (Druin 2002).

Iversen and Brodersen (2008) criticized the terminology used by Druin (1999), clarifying that CI is “a method rather than a methodology” and PD is a great example of a design methodology having many methods for design (p 84). Based on a socio-cultural theoretical framework and on their critique that many studies label young people as “cognitive incomplete” individuals when comparing them with adults, Iversen and Brodersen (2008) developed the BRIDGE method, facilitating work with children “as participants in meaningful communities of practice” (p 92). The difference with the “BRIDGE method is that it treats children as living their lives in meaningful socio-cultural dependant practices” and their participation is treated as “authentic stakeholders” (Iversen and Brodersen 2008, p 86). Applying many of the traditional methods used in PD, the authors developed a palette of design techniques for a period of no longer than 5 years, to facilitate their work on two projects i.e. NetWorking.Kids and the iSchool. These techniques are based on the video prototyping technique, technology immersion (Druin 2002) and fictional inquiry in a shared narrative space (Iversen and Brodersen 2008). Video Prototyping with children was influenced by the similar technique for adults (Mackay et al. 2000, 38)

38 BRIDGE is an abbreviation of Danish: BRuger Invol-vering i Design, GEntænkt
Ylirisku 2004); the use of physical prototyping materials and of acting out how they work while video recording. The technique was used to explore “how children in their existing school environment would appropriate the mobile technology” (Iversen and Brodersen 2008, p 89). The Probing Practice technique was explained as a continuation of the Technological Immersion technique with children in CI (Druin 2002) and CHIkids Newsroom (Boltman et al 1998). The aim was to find out how children in the school settings would appropriate the mobile technology. Fictional Inquiry in a shared narrative space is the third and last technique that was inspired by the “in-between’’ space for design collaboration by Muller and Druin (2003) and the technique used is called Mission from Mars (Dindler et al 2005). It was used to try to get access to the everyday life of children at school, to find out the children’s understanding of the schoolbag, and how they use it. In Mission from Mars, the Wizard of Oz technique was applied to simulate children communicating with Mars, creating a narrative shared space. The Martian would ask questions to learn about the children’s life, which helped to gather user requirements and understand the culture and knowledge within a practice.

**DESIGN WORKSHOPS**

Hanington and Martin (2012) explained Design Workshops as “a form of participatory design consolidating creative co-design methods into organized sessions for several participants to work with design team members” (p 62). During the time of these participatory sessions focused on co-designing with the participants, a variety of different methods, techniques and tools (collage, games, maps etc.) can be used, to generate an understanding of the users’ activities and their world. Usually, these workshops are planned ahead (i.e. time, place, materials, participants, etc.), run and documented by the design team facilitators. Their purpose is to engage participants by offering creative, fun activities focused on the selected problem/issue and to provoke individual ideas, group discussion or feedback necessary for design. Artefacts produced during the workshops (drawings, mock-ups, sketches, storyboards, role-playing, etc.) are analysed and used in the product development for different design stages. Under the focus groups, Fails and her colleagues (2012) addressed group activities with children working on these four requirements: data gathering, brainstorming, iterating and evaluating. They discussed some of the
considerations that could guide the design team facilitators when they plan focus groups with children (Appendix A).

With the above review, I have illustrated diverse methods, techniques and tools developed in UCD, LCD and PD to support children’s participation in technology design, playing the roles of Tester, Informant and Design Partner. Taking into consideration the findings illustrating the most common design approaches used by developers of educational interactive technologies for young individuals with diabetes in Section 2.3.2, along with the various examples of design activities described in this section, it is obvious that many of the design methods developed in CCI have not been explored and - neither have participants with diabetes - the roles that individuals may play in design. For that reason, the next section demonstrates some of identified and discussed challenges in the design process when participants are children with chronic diseases.

3.5 Designing for/with Children: Challenges in CCI

Divided into three segments, the role of this final piece goes beyond focusing on the participation of healthy children and those young individuals with medical health issues in the design of technology, enabling the demonstration of different discourses, particularly on the participatory approach in CCI. Section 3.5.1 critically discusses the roles of children as informants, design partners and authentic stakeholders when applying the ID (Scaife et al. 1997), CI (Druin 2002; Hourcade 2007; Guha et al. 2012) and BRIDGE methods (Iversen and Brodersen 2008). In addition, it introduces participatory epistemology (Iversen and Brodersen 2008; Iversen and Dindler 2013) to outline 1) children’s involvement in design as authentic stakeholders, 2) the designers’ role in selecting appropriate co-design activities for facilitating the articulation of children’s experiences based on socio-cultural practices and their everyday lives and 3) some of the challenges in applying this approach where the participants are young individuals with health issues. Section 3.5.2 considers the previously unaddressed issues of participatory epistemology with children with T1DM by examining three examples that discuss the involvement of chronically ill children and their families in the design of three different types of technologies, to explore 1) the design interventions supporting participation and active involvement of different groups of participants (i.e. parents and young healthy individuals and those with health problems) in design, 2) the various roles that they
could play in using the UCD and the participatory approach and 3) their diverse contribution in technology development. Finally, the last Section 3.5.3, pinpoints other important aspects in organising the participatory design process, such as age limits for participation, education of children in design, families as design partners, and selection criteria for co-design activities indicating the need for further research in the field. The limitations illustrated in the last two sections were taken into consideration by including them as the main objective(s) of this thesis - the second and third sub-questions in the research strive to explore these issues in the context of the empirical work in Chapter 5.

3.5.1 The ID, CI and BRIDGE Methods: Critical Analysis

Applying the PD approach with young individuals should not be considered unproblematic; it is simply not feasible to directly replace adults (workers) with children (Punch 2002; Iversen and Dindler 2013). In the literature exploring PD with children, native informants and equal design partners are the most common roles that young participants play in product development; this brought about some critical discussions between the scientists in the CCI field. ID and CI are the methods that see children either as informants or partners and several researchers indicated that these two roles facilitate the generation of different inputs while performing the UCD process (Druin 2002; Hourcade 2007; Guha et al 2012). For example, Scaife et al (1997) highlighted that “by ‘informant design’ we mean an interplay between privileged observations from potential users and ourselves with another set of skills” (p 344). The native informants’ contribution in design could be at any of the four stages of the UCD, as children may play multiple roles in the design process “as partners, users and evaluators, designing with and for us” (Scaife et al 1997, p 350), where by applying CI, the main contribution is only for fruitful design partnering with the “in-depth involvement” of children “over the long-term” by suggesting techniques, tools and guidelines for effective collaboration (Fails et al 2012, p 127) (Section 3.4, Graphic 1). To optimize design practices with children, researchers need to make clear distinctions when they work with children as informants and equal design partners (Guha et al 2012). Participating only in some stages of UCD, the role of informants in the design process is to support “a dialogue” (Guha et al 2012, p 5), more akin to consultants when their input is needed in the development process (Hourcade 2007). The equal design partnership suggests “elaboration” for
creating new ideas; children’s participation would be throughout the entire design process (Guha et al 2012, p 5), therefore to play this role these individuals would need education on the techniques and methods developed in CI, and this process is long, it “often takes months for a child to become true design partner” (Guha et al 2012, p 5). When young individuals are compared to adults, Iversen and Brodersen (2008) identified the assumption of a child’s “incompleteness” presented in the CI (Druin 1999) and in Piaget’s theoretical framework (1970). In contrast, arguing against this “incompleteness” in children, Iversen and Brodersen (2008) explored the role of equal partnership with these individuals in the BRIDGE method, where they embraced the idea that young participants are “able to make key decisions in the design process on the same terms as any other stakeholders” (p 85). They believe that children live in meaningful socio-cultural practices that make them experts in their everyday lives and these “practices can and should be the starting point for design” (Iversen and Brodersen 2008, p 86). The participation and involvement of these young individuals in design are as “authentic stakeholders” rather than cognitively incomplete human beings and engaging children with design with “legitimate access to their practice” is required (Iversen and Brodersen 2008, p 86). By legitimate they refer to the use of appropriate design interventions (i.e. tools and techniques) that could help to articulate and express children’s practices so these methods, techniques and tools could be built upon legitimacy. Also, they do not see the design as a symmetrical relationship between children and designers, but rather as a process of mutual learning between practices belonging to the young participants and designers. Similarly, criticising the Scandinavian PD tradition (UTOPIA project) that “takes as its basic assumption that knowledge is acquired through participation”, Iversen and Dindler (2013) believed that the PD approach is for “exchanging and negotiating values among participants in a highly dialogic and iterative process facilitated by designers” (p 26). The authors believed that in the design process, the “design activities that facilitate the negotiation of values constitute the participatory epistemology” (Iversen and Dindler 2013, p 26). Iversen et al (2010) pinpointed that applying and conducting participatory work is a constant divergent process for the negotiation of values among designers and children, where the value “refers what a person or group of people consider important in life” (p 92). This constant negotiation of values actually shapes the design process in terms of the dialogue, techniques and practices that will be employed. Iversen and Dindler (2013)
embraced the suggestion made by Iversen et al (2010) that participatory epistemology is a three stage process that facilitates “the negotiation of values” between participants (p 26). The first phase explains the emergence of values. It is a dialogical process between designers and users aiming to gain knowledge 1) on the everyday life of children and on the existing practices and 2) on the available CCI techniques that effectively may support this phase. The development of values is the second step which is related to the careful selection of appropriate methods, techniques and tools for the workshops to use as a “springboard”, through which the values that emerged are placed into a “particular digital trajectory” (Iversen and Dindler 2013, p.26). Here, the role of the designer is crucial: on one hand the knowledge of the existing collection of methods and tools is important, while on the other hand, he/she must have a clear understanding “on social dynamics underlying the design collaboration” (Iversen and Dindler 2013, p 26). The grounding on values - the third phase - is “when stakeholders can negotiate this newfound conceptualisation successfully within their everyday practice” (Iversen and Dindler 2013, p 27). In explaining the participatory epistemology process, Iversen and Dindler (2013) highlighted that each case is very specific, needs detailed attention, and an individual approach to design with children. The implementation of each one of these three stages can give rise to questions when the participants are children who have medical health issues. The example used in the paper examines the design of mobile support for intellectually disabled children in museum settings (Iversen and Dindler 2013). The authors suggested that in stage one, the emergence of values could not include a study on the children’s existing practices, as these values emerged in a dialogue between participants and designers. For the second stage, the questions that could generate the challenges and design judgement are: “How can we design the design activity for children with intellectual disabilities to express their values? How can we establish a democratic design space in which museum experts, designers and children with intellectual disabilities can get equal opportunities to express their values and to influence important design decisions?” (Iversen and Dindler 2013, p 26-27). For the third stage, it was emphasised that the design is successful only when these children and their families “are able to recognise their newfound values in their everyday life” (Iversen and Dindler 2013, p 27). Acknowledging all the above issues, this research further explores the participatory
epistemological values in CCI “in terms of their emergence, development, and grounding through design work” (Iversen and Dindler 2013, p 28).

One of the biggest challenges of undertaking participatory design with children is to optimize the collaborative work between designer/researcher and children, trying to “maximise children’s ability to express themselves at the point of data-gathering...enhancing their willingness to communicate and hence the richness of the findings” (Hill 1997, p 180). Iversen and Brodersen (2008) and Iversen and Dindler (2013) are probably right when they claim that the involvement of these young experts, i.e. healthy children and young individuals with medical health issues playing the role of authentic stakeholders, is essential. Still more, I could say that their participation is mandatory; particularly when we are developing interactive technology whose design aims to support some of their everyday practices. As discussed in Section 3.4, the suggested techniques and tools in the BRIDGE method support design with healthy participants, but it was highlighted that the application of this method “can potentially embrace all genres of technology” and “techniques must be revised according to legitimacy” (Iversen 2005, p 82). The legitimate access to their practice may occur when co-design activities have been appropriately chosen, helping children “to develop their own practice as an integrated part of the design process” (Iversen and Brodersen 2008, p 87).

3.5.2 Three Studies with Children with Chronic Conditions and their Families: Design Activities, Various Actors and their Roles in Design

Through the discussed above question, taking into consideration that the development of new IT in terms of the structures and processes is strongly individual, it is now time to pose the questions discussed by Iversen and Dindler (2013), replacing intellectually disabled children with young individuals who are diagnosed with type 1 diabetes: How can we design the design activity for children with Type 1 diabetes to express their values? How can we establish a democratic design space in which designers and children with T1DM can get equal opportunities to express their values and to influence important design decisions? Would Iversen and Dindler (2013) design approach work?

Actually, the questions above refer to the subject under investigation in this study, as these issues are addressed within the second and third sub-questions discussed at the beginning of this thesis in Section 1.4. Therefore, in trying to shed light on the
various co-design practices with young participants - children with chronic disease - and to support my work, I am examining three examples given in the CCI literature i.e. the Automatic transfer of blood glucose data from children with Type 1 diabetes (Årsand and Demiris 2008; Gammon et al 2005), the maXi Food Quiz game (Glasemann et al 2010; Glasemann and Kanstrup 2008) and the SISOM\(^\text{39}\) system (Ruland et al 2008), to furthermore add and expose a number of limitations, some of which I have remarked upon in this chapter and in Section 2.3.2. For example, in Section 3.3 I brought attention to the recommendations on user-centred methods suggested by Årsand and Demiris (2008) for the design of patient-centric self-help tools. Some of the activities, i.e. personas, paper prototyping and sketching, scenarios and storytelling were described by the authors as helpful co-design techniques, but they did not go further to discuss their exploration and results with the children and their parents because the individuals in the first case study (i.e. Automatic transfer of blood glucose data from children with Type 1 diabetes) participated only as “test users” (Årsand and Demiris 2008, p 161). The advantages of scenarios, storytelling, paper prototyping and sketching were observed respectively in SuperAssist (i.e. IT network application intended to assist in the supervision of patients) (Haan et al 2005) and Self-help through mobile ICT projects (Arsand et al 2007) as the studies were for/with people with diabetes type 2 and older adults, rather than with children with T1DM. In addition, by delving deeper into the CCI literature regarding adaptation and application of child personas, cultural probes and the narrative approach\(^\text{40}\) - particularly for children with T1DM - a lack of research in this domain was identified (Section 2.3.1). The use of cultural probes and child-personas in the CI and BRIDGE methods (Section 3.4) were not discussed; their work could have benefited from including cultural probes on the design side and techniques for data analysis from social science, such as affinity diagrams in the qualitative research. Therefore, it is not clear whether these design interventions (i.e. cultural probes, child personas, scenarios and storytelling) may support active participation of individuals (i.e. children and T1DM and their parents) in the design of educational IT, helping them to communicate their experience gained through living/managing diabetes.

---

\(^{39}\) Norwegian project SISOM is an interactive software solution for children with cancer between the ages of 6 and 12 helping children to cope with the illness, to articulate their thoughts and feelings for improving patient-medical professionals’ communication.

\(^{40}\) Prototyping and sketching were already explored for Food Quiz game design- maXi project.
In a similar manner, in Section 2.3 I have reviewed different types of educational IT developed for children with diabetes in trying to analyse other researchers’ work in terms of family involvement in educational IT development, as well as the applied PD approaches. Finally, there is only one example in which the whole design process was studied i.e. www.maxi-projektet.dk (Glasemann et al 2010; Kanstrup 2014). In the maXi study, the use of tangible methods facilitating family participation (i.e. children and their parents) in the development process aimed to explore “how people affected by diabetes can contribute to expanding the solution space of digital diabetes technology” (Kanstrup 2014, p 51) and whether the PD approach is applicable at an early phase of technology design (Glasemann and Kanstrup 2008), rather than exploring their role in design as equal partners. Summarizing the empirical studies with the families helped to build an understanding of everyday life activities when living with diabetes, as well as to develop four prototypes (Kanstrup et al 2010). One of the authors highlighted that the “designer’s ability to navigate and reflect on [her] position within this broad landscape of diabetes practice is important” (Kanstrup 2014, p 58). As mentioned, part of this project was to develop the design of a learning technology aimed at diabetes for young users in Germany, the methods and materials used are shown in Table 1, Section 2.3.1 (i.e. theme posters, discussions, "creativity pack" for prototyping, interviews, playing with the prototype, followed by discussions and sketching of new ideas), reaffirming that the child personas, cultural probes and storytelling were not explored in this study. Glasemann’s participants were 1) “24 teenaged diabetics (ages 10 to 16)” who “designed their own mobile diabetes supporter” in a design workshop (Glasemann and Kanstrup 2008, p 38) and 2) “young people with diabetes (ages from 10 to 15) 41, along with “two dieticians” for the exploration of the Food Quiz prototype process (Glasemann et al 2010, p 265). Both of these activities were conducted during a two-week German diabetes youth summer camp (2008–2010); the researchers noted that the planned settings were less difficult because they complied with some of the ethical principles and standards to work with chronically ill young individuals (Glasemann and Kanstrup 2008; Glasemann et al 2010; Glasemann and Kanstrup 2011). Therefore, the above discussion presented evidence illustrating that the

41 The number of children in the evaluation activities was not pointed out in the article but additionally, it was highlighted that 34 participants aged 10 to 15 explored the prototype as part of an educational diabetes lesson.
children’s families were not involved in these planned design activities. Hence, this obviously raises some questions about what methods and techniques may support the work of both parents and children with diabetes when applying the participatory approach in various settings (i.e. not only in camps or labs) and what would their contribution be to the design.

As the gap in the literature - particularly on the design practices with diabetic children - was clear (discussed in Section 2.3.1), similar studies with children having other chronic diseases have been explored. For instance, developing the application SISOM and involving seriously ill children posed some burden on working with only the system’s future users, and as a result, most of the time researchers worked with healthy children as informants and design partners (Ruland et al 2008). The authors pointed out that finding a balance in having children with cancer participate in all tasks as theoretically explained in PD was a challenge. For instance, children with cancer were involved in the interviews to help with child-friendly terms that would explain the physical, functional, and psychosocial symptoms of the health condition in the testing and evaluation phase, and in the usability testing of the system (Ruland et al 2008). Based on their experience, the authors highlighted that healthy children had difficulty in fully grasping the context and purpose of the SISOM, except for one healthy child who had a cousin with lymphoma. This young participant was able to share “knowledge of some aspects of cancer, through her life experiences with her cousin”, so the personal life experience was observed as a key factor for contribution (Ruland et al 2008, p 634). During the collaborative work with healthy children lasting over 3 months, the CI method had been applied and “both children and adults were considered experts” (Ruland et al 2008, p 627). Observations, note taking, role play, scenarios, low-tech prototyping and video-taping were the methods used by the researchers involved in this study. The participation of children-informants made significant contributions to icons, terms, usability testing, etc. related to the child-friendly SISOM graphical interface, with the healthy children contributing ‘considerably in the role as testers, informers’, but only to an extent as ‘partners’ as not all of their ideas were feasible for the design (Ruland et al 2006, p 80). PD was critical for the SISOM development and design; the limited involvement of children with cancer raised questions on “whether healthy children can conceptualize what it is like to be suffering from a serious illness and thus the degree to which they can
serve as proxies in participatory design and evaluations” (Ruland et al 2008, p 634). Consequently, the input and participation of healthy children (e.g. as informants) and the benefits they could provide to the design of educational technology for children with T1DM has not been explored. During the development process of educational IT for children with T1DM, the need for “healthy children’s” involvement in the design process emerged\(^4\), however, their role in UCD and how their input and participation would benefit the design context has yet to be explored.

### 3.5.3 Participatory Approach: Age, Education and Families

In this section, I juxtapose the findings that emerged in the three examples reviewed, along with some of the publication in CCI that discussed children’s participation and their families as design partners, because this helps to indicate additional influencing factors affecting the subject of this investigation. As noted at the beginning of this section, CI facilitates the partnership with children in the design of IT, but the young individuals need education on the design methods, which takes time (Guha et al 2012). Unfortunately, the education on design provided to the young children with T1DM that could help them play the role of real design partners, as well as the experience generated throughout the collaborative work with mixed-age groups of participants was not discussed in either of the above three studies. Do children with diabetes need training to work as equal design partners if they need to explain their experience and knowledge gained through living with the illness, or will their participation be based solely on how long they have this illness (Guha et al 2012)? If they do need education, how will this educational process be organised as these children do not live in the exact same location or attend the same school? Within the mixed-age groups of participants I worked with, there are children who fell into the required age category when the study started, but they grew up before the research finished. For example, if a developed technology is for children between 8 and 12 years of age, do designers only work with children that fall in this age group category? Some projects can last for a long period of time, from between three to four years (e.g. maXi-project\(^4\)) or even more (e.g. SISOM\(^4\)) and some participants, who were 11 or 12 when the project started, would no longer fall in the users’ age

\(^4\) The reasons for this approach are discussed and explained in Section 5.3 and Section 5.5.3
\(^4\) Participants - 17 families for the maXi-project were recruited between 2007 and 2011.
\(^4\) Cornelia Puland focused her work on developing the communication system, and the SISOM project started in the late 1990s by suggesting a number of prototypes on a PC, Palm Pilot and tablet and then with the precursor (or Choice system (Bratteteig and Wagner 2014).
category after two or three years of time. In addition, it becomes apparent that the PD approach in developing educational IT with families with chronically ill children is not fully explored. According to Isola and Fails (2012), only 4 papers from a batch of 84 papers selected from the IDC (2003-2011) and Human Factors in Computing System (CHI) (1996-2011) conferences, described the family’s involvement in the design process as equal stakeholders (e.g. participatory design) by using ethnography in the home, bonded design, technology and cultural probes\(^{45}\); none of these papers examines the design of interactive technology for children with diabetes. To give participants a voice in the design process, the authors of these studies suggested that the family involvement could be improved by developing methods and techniques that enable and facilitate their participation. More research is needed to explore these groups of users and their needs using a holistic approach focused on the individual members (Isola and Fails 2012). Yarosh and her colleagues (2011) highlighted five suggestions for the researchers in the CCI field, and most of them are taken into consideration in this study: 1) to involve children in the design at “a larger variety of ages”, not only those who fall in the age category of 6-12, 2) to use different theories and models suggested for the field and to be more precise when clarifying the theoretical perspectives, 3) to work closely with adults (e.g. parents/caregivers and teachers) who will know about the children’s interest in the technologies and their adoption, 4) to conduct a long-term evaluation of the designed product and 5) to be more reflective and explicit about the values that drive their research (p 144).

During these 25 years after the first PD conference (held in Seattle, Washington, 1990), many new PD methods, theoretical concepts and technologies have been explored to emphasise the need for full user participation in the design process and to expand the symbiotic pathways for collaborative work between users and designers. Moreover, these interests stemmed from adults’ technology development into the design of interactive technology for the younger population in our society - children - and ID, CI, BRIDGE, etc. found their place in CCI. There are no universal design approaches; children should not be forced to expose their personal knowledge and creative thinking, a way should be found instead to enabling effective communication to facilitate the sharing of information. Initiating participatory design

\(^{45}\) Here the probes were used in two different projects: digital probes to understand the potential for new technologies in supporting communication among multi-generational families and cultural probes to understand intimacy between children and parents.
with children with type 1 diabetes and their parents is a new challenge for CCI and the question asked by Rogers (2004) is still relevant today: “So how can theory best inform design?” (p. 32). She suggested that focusing more on the process of design, “engaged in ongoing dialogues rather than one based on the rhetoric of compassion”, will contribute to the theoretical knowledge (Rogers 2004, p 32). And this is what this study is set to do: to explore a series of methods, techniques and tools facilitating the collaborative work between this group of users and the designer in developing educational IT.

3.6 Summary

The goal of this discussion is 1) to show some of the identified gaps and limitations in the literature when applying UCD and the participatory approach in designing educational interactive technologies for children with T1DM and their parents and 2) to illustrate the great diversity of co-design activities adopted and developed in CCI, particularly to expose that many of them were not explored yet with this group of users. In addition, the described findings helped to justify the chosen design methodology presented in Chapter 4 that has been applied for the empirical part of this thesis presented in Chapter 5.

Taking into consideration Don Norman’s statement (1998) to focus on the users rather than on the technology, as discussed in Section 1.4, this research aims to gain a deeper understanding of everyday T1DM self-care practices in children and parents outside the attention of the clinics (i.e. in the real-world environment) and to explore the role of design and interactive technologies that could support these practices. In particular, in light of the literature reviewed in Chapter 2 and Chapter 3, I investigate and explore a series of collaborative user-centered design (UCD)(not HCD) and participatory design approaches, in the entire design process with active users - children with type 1 diabetes and their parents, avoiding the traditional cliché to only see the users as testers. Accepting children as “authentic stakeholders” (Iversen and Brodersen 2008) and the negotiation of values in participatory epistemology (Iversen and Dindler 2013) poses new questions for further exploration in CCI and this is a subject of examination justifying further study.
Chapter 4: Research Methodology: Selecting Design Interventions to Support Users’ Participation in Design

4.1. Introduction
This chapter outlines the strategy employed in constructing the research methodology applied to collect empirical data for this study. As discussed (Section 1.4), the goal of the research is to investigate how to actively involve children with T1DM and their families in the development of IT, aiming to design technology that could resonate with their self-care needs more effectively. Section 4.2 outlines the central methodological choices and explains the criteria used in choosing and applying other methods, techniques and tools to overcome the specific challenges of this field and to better facilitate users’ participation. Section 4.3 describes the procedure carried out to get access and ethical approvals to recruit participants, the number of individuals in the study, and the procedures used for collaborative work.

4.2 Empirical Methods
As discussed in Section 2.3.2, Section 3.3 and Section 3.4, UCD, PD and CI were developed to facilitate the partnership of potential users and to support their active role as design partners; the participants involved in this study are children with Type 1 diabetes and their parents/guardians. Adhering to the initial investigation results, along with the findings from the reviewed literature, the shortage of educational materials in the paediatric diabetes education process was identified as a problem (Section 2.2.3, Section 2.4 and Section 5.2.1.4); hence, the findings indicated the need for further exploration of possible alternatives in supporting this process and these methods i.e. UCD, PD and CI were selected to enable and afford the collaborative work with individuals in developing an educational IT. I had two reasons behind selecting CI (Druin 2002). Firstly, because the CI collection of various techniques and tools is very rich (Section 3.4, Graphic 1) from which I adapted and used two techniques for this study - i.e. telling stories and layered elaboration. Additionally, the storytelling was also discussed by Årsand and Demiris (2008), but not explored with diabetic children (Section 3.3). And secondly, because CI suggests that the following three aspects are important for this investigation i.e. “(1) a multidisciplinary partnership with children; (2) field research that emphasizes understanding context, activities, and artifacts; (3) iterative low-tech and high-tech
prototyping” (Druin 1999, p 593). Similar to the SISOM project (Ruland et al 2006) (Section 3.5.2), during the design process the need to involve healthy children in some stages (not all) of the UCD also emerged as an issue (Section 5.3 and Section 5.5). The role of ‘informant’ (Druin 2002) and ID (Scaife et al 1997) successfully facilitated such co-design practices with children (Section 3.3, Section 3.4 and Section 3.5.1) therefore ID was also explored in this study. As a result, two groups of participants took part in the IT design. To support their participation and different roles, UCD, PD and CI facilitated the involvement of children with T1DM and their families as “design partners” and ID assisted healthy children’s involvement as “informants”.

In relation to the close partnership with various groups of individuals, Robertson and Simonsen (2012) highlighted that PD is a process of “investigating, reflecting upon, establishing, developing, and supporting mutual learning between multiple participants in collective ‘reflection-in-action’” (p 2). The authors discussed that in this process, participants undertake two roles: as ‘designers’ they learn the real situation of the users and as ‘users’ they articulate their needs and learn about the technology that can effectively support these needs. In dealing with these two roles, Robertson and Simonsen (2012) outlined two fundamental aspects of PD: 1) to empower users to have their say in decisions about the design by using different tools to visualise technology functions without speaking the design language and 2) to help users define what type of device/tool they need, as they may have difficulties to “envisage future technology and the practices in which they can be embedded” (p 3). They also determined that the terms “users” and “designers” were respectively identified as participants who will use the technologies after being made, and as participants who are professionally responsible for the design project. With respect to these two aspects in PD, the roles of users and designers and the initial findings in this study, the process of selecting co-design techniques and tools was not based solely on the gaps identified in the UCD and CCI literature (Section 2.3.2, Section 3.3 and Section 3.5) - they were also impacted by the collected and generated data from/with the participants. Graphic 2 illustrates the pattern used in this research: it is composed of two main components assisting the collaborative work with participants as “design partners” and “informants”, applying PD, CI and ID.
The first component (yellow colour, Graphic 2) illustrates the four steps (i.e. 1, 3, 5 and 7) of the UCD that support the co-design process with participants, facilitated by different activities and materials in developing educational IT (e.g. Context of Use, Design, Prototype and Evaluate). The second component (green colour, Graphic 2) shows the four intermediate steps (i.e. 2, 4, 6 and 8) that assisted my work as a
designer - they were used to analyse the collected empirical data from each phase of UCD, to select and design activities for the work that followed with participants, to produce prototypes and to juxtapose and reflect on the evaluation results with the specified requirement identified at the start of the UCD regarding the close work with the involved individuals. This pattern was influenced by the objective to actively involve these two diverse groups of parents and children in design by exploring the sensitive topic of diabetes. For each of these four stages of the UCD denoted by the numbers of 1, 3, 5 and 7, I applied various design interventions which were carefully selected and designed in four intermediate steps (i.e. 2, 4, 6 and 8) influenced by the collected data.

The following is a detailed discussion of these 8 steps. In the next four sections, I outline 1) the purpose of each step of the UCD, 2) the methods, techniques and tools that have been selected and applied and 3) the work carried out in these intermediate steps by providing justification for the choice of design interventions that were adapted to facilitate co-design with children/parents. Section 4.2.1 discusses the approach applied to collect and generate data from the users needed to gain a deeper understanding on the paediatric diabetes practices and to identify an IT that may support some of these practices. Section 4.2.2 outlines the selection of collaborative storytelling in the design stage of UCD. Section 4.2.3 shows why the collaborative storytelling, personas, problem and activity scenarios and their storyboards were chosen for the prototyping stage. The last Section 4.2.4 describes the layered elaboration picked as a technique in the evaluation phase. The adaptation and application of all selected design interventions are illustrated in the empirical part of the thesis, Chapter 5, along with the discussions on the findings.

4.2.1 Understanding the Users’ Needs: Semi-Structured Interviews, Affinity Diagrams and DP

One of the key principles of UCD is to support “an early focus on users”, helping to build concepts about users’ needs that the design of the new technology intends to meet (Courage and Baxter 2005, p 6). This approach starts with a deep and qualitative investigation of potential users’ practices in an attempt to collect a robust and rich understanding of the users as a basis for the elaboration of the initial design requirements and the exploration of design possibilities.
Interviews and focus groups are two data gathering techniques that facilitate discussion of various problems with participants (Courage and Baxter 2005; Lazar et al 2010). Interviews encourage reflection by the individuals by giving them a chance to talk about their experience, thereby obtaining detailed information; they allow sharing insights by producing valuable and constructive data that is not possible to capture through other activities. The interviews can inform and guide the research in two ways: when exploring design concepts (Courage and Baxter 2005; Lazar et al 2010) and when selecting methods, techniques and tools supporting users’ participation in subsequent stages of designing products (Iversen and Brodersen 2008). In order to involve children with T1DM and their parents in design, these two ways played a significant role in applying UCD and a participatory approach (Graphic 2).

Interviews and focus groups were also discussed by Årsand and Demiris (2008) in their modified UCD framework (Section 3.3); I chose to use them both in this first stage of design, starting with semi-structured interviews, along with affinity diagrams and using MAXQDA software to analyse the collected data. The generated and collected data was analysed in the intermediate step 2 (Graphic 2) 1) to identify users’ needs and requirements, helping uncover design solutions (i.e. IT) that will meet these criteria and 2) to select and design appropriate methods/tools and materials that would help to facilitate the active involvement of participants in step 1 of UCD (i.e. design probes) and in the following step 3: Design (i.e. collaborative storytelling). The initial findings indicated the need for a less intrusive manner for collecting data on users’ daily activities related to diabetes management when exploring this sensitive domain. Therefore, these findings guided the initial selection of design probes. When the probe sets with the produced materials were returned to the designer, follow-up interviews and focus groups were scheduled. The sequence of applying these two tactics illustrates how the findings from the interviews were used to select and design the following activities aiming to generate more data for the same stage (i.e. understand users) by applying design probes, and for the design step 3 by using collaborative storytelling (Graphic 2); this process is discussed in Section 5.2.1.4 and Section 5.2.2.6.

**Semi-structured interviews, MAXQDA qualitative analysis software & affinity diagrams**
The semi-structured interviews were selected because they enable the designer “to dig deeper in search of critical comments, design requirements and other insights” and are “particularly helpful when you are unfamiliar with a problem domain” (Lazar et al 2010, p 190). Usually, some of the questions were pre-prepared, aiming to start a discussion and trigger new questions to facilitate the exploration of new topics that arose during the interview. Many of the scientists stated that they conducted interviews with children, parents, teachers, medical professionals, etc. (Fails et al 2012; Kanstrup et al 2010; Kanstrup 2014; Markopoulos et al 2008a; Ruland et al 2006; Scaife et al 1997), therefore in this study semi-structured interviews with children with diabetes were also applied. To analyse the collected data, I used the MAXQDA qualitative analysis software and the affinity diagrams method. MAXQDA is a professional computer program offering various analysis functions of qualitative and mixed methods data i.e. transcribing of audio and video files, creating and arranging different codes, visualising data by graphics, etc. Introduced by Jiro Kawakita in the 1960s (Scupin 1997) the KJ method, also known as affinity diagramming, suggests an inductive way (bottom-up approach) of analysing raw data (Holtzblatt et al 2004). It helps to organise large amounts of unstructured qualitative sources by creating/identifying groups that arose from the data instead of starting with categories established in advance (Holtzblatt et al 2004; Martin and Hanington 2012).

“The affinity diagram organizes the individual interpretation session, or affinity, notes into a wall-sized, hierarchical diagram grouping the data into key issues under labels that reveal the customer’s needs. The affinity shows in one place the common issues, themes, and scope of the customer problems and needs. The affinity acts as the voice of the customer and the issues it reveals become the basis for user requirements.”

(Holtzblatt et al 2004, p 160)

Affinity diagrams have been adopted and used by researchers in HCI for different purposes e.g. to analyse qualitative data, to build personas (Pruitt and Adlin 2010), in Contextual Design (Holtzblatt et al 2004), to evaluate interactive prototypes (Lucero 46 http://www.maxqda.com/
2015), to derive guidelines when designing healthcare games for toddlers with respiratory diseases (Høiseth et al 2012), etc. For example, Høiseth et al (2012) analysed the findings from a workshop session with experts - medical professionals – by applying affinity diagrams to create a “set of best practices” that later were “translated into design guidelines” and used to develop a healthcare game application (p 451). The use of affinity diagramming as a data processing method was strongly recommended by Pruitt and Adlin as a tool to help identify the highest priority items (2010); Martin and Hanington (2012) explained that “Affinity diagramming helps designers capture research-backed insights, observations, concerns, or requirements on individual sticky notes, so that the design implication of each can be fully considered on its own” (p 12).

As an inductive method for sorting data, the process of creating affinity diagrams starts when the collected qualitative data has been transcribed and is ready for analysis. By reading data sources, the identified important points i.e. factoids, are each transferred to a sticky note (Pruitt and Adlin 2010). The written down individual notes called “affinity notes” or “factoids” are sorted in a meaningful way, allowing a pattern to be identified i.e. to link to a similar problem or issue. When positioned near to each other, these notes create clusters or groups that are labelled with names related to the findings. By displaying the various groups thus, this enables recognition and identification of themes and sub-themes in the analysed data. To create affinity diagrams originally, sticky notes of different colours were used and arranged manually on a wall or surface; they were paper based instead of a digital alternative (Holtzblatt et al 2004; Pruitt and Adlin 2010). The wall representation is very static, therefore for this study I created digital affinity diagramming to enable quick access and use in any surroundings.

The reasons behind choosing this way of analysing the interview data were 1) inductive processing of the data helps to illustrate significant factors to build the theory from bottom-up (Holtzblatt et al 2004; Martin and Hanington 2012), 2) the sorting, comparing, analysing and visualising of the data helps to identify the problematic aspects and to keep the focus on users’ needs and, 3) to recognize IT design and to extract the requirements to use in the designing and prototyping stage of UCD (Høiseth et al 2012) and 4) for developing personas in the prototyping phase (discussed in 4.2.3).
Design probes

Design probes were originally introduced as cultural probes by Gaver and colleagues (1999). In their original formulation, probes were a way to express the growing scepticism toward the rational(ist) method to collect design requirements, and to explore new tools that would trigger subjective and creative responses, rather than objective and universal ones. In order to design innovative technologies for the elderly, the original packs by Gaver et al (1999) offered a range of materials (postcards, map, disposable camera and photo album) to freely document the daily life of the elderly. Probes were intentionally designed to elicit ideas and inspiration in researchers, to facilitate the interaction between designers and users, and to motivate users to participate in the design process (Gaver et al 1999). In a similar vein, Crabtree and his colleagues (2002; 2004) adapted cultural probes to explore complex sensitive settings i.e. the life of the elderly and disabled people living in a hostel. The aim of the probes was “to explore care settings, to develop a design dialogue with participants” enabling “potential users to participate in the design process in a readily accessible way and reflexively trigger a design dialogue that is deeply attuned to their practical circumstances and needs” (Crabtree et al 2004, p 1-4). Mattelmäki (2006) who worked extensively on design probes from the tradition of participatory design pointed out that DPs “are an approach of user-centred design for understanding human phenomena and exploring design opportunities” (p 39). She emphasised three characteristics of DPs as an approach to UCD. DPs supported user participation by self-documentation (e.g. support PD) and a series of activities (physical objects and tasks) encouraging creative and subjective responses by the users that help with representing their own experience, daily lives, needs, and attitudes (Gaver et al 1999; Mattelmäki 2006). They focused the attention on the users as they examined their personal context and environment (e.g. users’ work places, homes, hostels, sensitive care settings, etc.). DP’s exploratory character supports creativity and interpretation by users and designers (Mattelmäki 2006; Tsvyatkova and Storni 2014b).

The first findings indicated the need for design/research activities for exploring sensitive domains that were less intrusive. Design probes seem to meet these requirements, moreover, this technique had been already adopted and used in several projects with children (Moser et al 2011; Iversen and Nielsen 2003; Wyeth and
Diercke 2006) even though it had not been explored with young participants with T1DM (see Section 3.4 and Section 3.5.2). As a result, this tool was selected and adapted for young individuals with T1DM and their parents with the hope to 1) increase participation and improve data collection by working with individuals at a distance, 2) complement the data gained from user interviews on everyday paediatric diabetes practices, 3) use as an alternative strategy of ethnographic study and 4) elicit and generate some design ideas about the design of educational IT. For the collection of produced materials Mattelmaki (2006) suggested that “A probing interview should get an idea of the user through probes, interpreting the material and looking for further design opportunities, not simply record facts” (p 86). Therefore, follow-up interviews and focus groups have been performed when the probe sets were being returned to the designers. The information extracted from the collated and analysed probe materials, along with the qualitative findings in intermediate step 2 supported my choice in selecting the collaborative storytelling technique for the design step 3 discussed below.

4.2.2 Designing: Collaborative Storytelling

Applying UCD, PD and CI, the design stage with participants and designers assists a discovery process in which the close partnership in elaborating and discussing different design ideas is supported by employing various techniques (Courage and Baxter 2005; Spinuzzi 2005). The information-generating instruments (i.e. tools and materials) needed to be designed in a way that facilitated inspiration, elaboration and articulation of concepts important for technology design (Benyon et al 2005; Rogers et al 2002). Their role was to improve the collaborative work, in supporting the selection process among numerous alternatives, by helping individuals to envision new designs and their functionality.

Storytelling and user narratives have been widely discussed in HCI, PD and CCI as a valuable approach in supporting children and adults in producing, sharing, developing, describing, illustrating daily activities, thoughts, experiences, etc. (Alborzi et al 2000; Martin and Hanington 2012; Muller and Druin 2009; Read and Markopoulos 2012; Spinuzzi 2005; Quesenbery and Brooks 2010). For example, Muller and Druin (2009) defined PD as a third space in HCI; it lies in a space providing hybrid experiences between the designers/researchers of new technology, and the end users. It is a space where they can negotiate successfully by defining
problems and solutions, for interactive by sharing of knowledge and strategies, for collective discovery and to jointly create a vision on technology design. One of the examples given in their paper illustrates the exploration of storytelling in various projects with children for “construction of third spaces and hybridity” (Muller and Druin 2009, p 25). They emphasised that “This work kept everyone learning from everyone else – children learning about technologies and the storyboarding environment, adults learning about children’s views and other adults’ expertise, and everyone negotiating the meaning of new technological and narrative ideas, as well as their implementations” (Muller and Druin 2009, p 26-27).

Through storytelling, children could discuss and share painful emotions they experienced, a situation that they found challenging or scary. For example, storytelling therapy is one of the options (i.e. drama therapy, visual art therapy, music therapy, etc.) for children’s effective treatment in Cognitive Behaviour Therapy (CBT). CBT is “a talking treatment that aims to change the way a person feels by altering how they think and behave in everyday situations” (Blenkiron 2011, p 6). Stories are described as “flexible tools” (Blenkiron 2011, p 260); they have a “message” that has a power “to shape everyday experience” (Bruner 2002, p 6-7). Using stories in CBT helps to “gain a new view or insight... to express the inexpressible that is linked to emotions...to stimulate creative thinking... to inspire and motivate... because they affect emotions as well as thinking” (Blenkiron 2011). Storytelling is also described as “a developmentally sensitive tool to elicit children's thoughts, identify their distortions, and help them to more accurately make sense of their world” (Friedberg 1994, p 209); they can “assist children in verbalizing their feelings safely”, providing “a rich creative experience” (Tanaka et al 2003, p 125). It is important to emphasise the similarity between designers and therapists in selecting appropriate tools (story) for communication with their participants (patients) according to its purpose, goals and objectives “To personalize and adapt stories, therapists need to be clear what the intended purpose is” (Blenkiron 2011, p 260), because the therapist and patient need “to work together and create a joint ‘story’” (Blenkiron 2011, p 18).

According to Quesenbery and Brooks (2010), telling stories “is one of the most natural ways to share information” - the story is “an active mechanism for communicating events, communicating contextual information, and for developing
connections between people” - their major benefit is in helping designers to “keep people at the center” of their work (p 2-35). They also could be applied “to any type of project” in developing technology “from understanding to evaluation” (Quesenbery and Brooks 2010, p 100). Telling stories could be used as a starting point for user-designer discussions, helping to understand individuals and their experience better, engaging the imagination to trigger new ideas, exploring or describing new design concepts and prototyping to create better products (Quesenbery and Brooks 2010). Stories can evolve through the design process, in combination with sketches, scenarios and storyboards; they can help to focus attention on the discovery process and to support an investigative function.

The choice behind using collaborative storytelling was strongly impacted by the data analysed in the intermediate step 2 (Graphic 2). Along with the initial set of requirements and characteristics used when suggesting concepts and joint creation of new ideas, the early findings indicated that the exploration of the topic with diabetic children would be a more complicated process as diabetes could elicit an emotional response in young participants (Section 5.2.1.3 and Section 5.2.1.4). The above discussion illustrates the use of storytelling as a therapy in CBT for supporting children to express and articulate thoughts and feelings (Blenkiron 2011; Burns 2004). Furthermore, Burns (2004) highlighted that storytelling was very effective for communication, because it is “interactive”, can “teach by attraction”, “bypass resistance”, “engage and nurture imagination”, “develop problem-solving skills”, “create outcome possibilities” and “invite independent decision making” (p 3-4).

When a child is invited to develop stories collaboratively, this process helps the young individual to become an active participant/creator of the narrative, where they can recognize the problems and present their solutions (Burns 2004); as I noted, this is one of the main purposes of this investigation. This was the reason behind the selection and use of the tool not only for the design process, but also to examine the narrative approach when prototyping the educational context of IT. Moreover, Read and Markopoulos (2012) outlined the exploration of stories and storytelling in the digital space with different types of technology as one of the challenges in the CCI community (Section 3.2) while Wyatt and Hauenstein (2008) highlighted the benefits of digital stories in eBooks for health education (Section 2.3.2). Additionally, children involved in the design process played the roles of design partners (i.e. on
elaboration) and informants (i.e. on dialogue) (Guha et al 2012; Hourcade 2007), therefore applying collaborative storytelling with both groups of participants has resulted in rich data for collating and analysing to reflect and illustrate their dissimilar contribution and input in design.

4.2.3 Prototyping: Collaborative Storytelling, Personas, Problem and Activity Scenarios and their Storyboards

According to Benyon et al (2005) a “prototype is a concrete but partial representation or implementation of a system design” (p 253). Applying a participatory approach in the prototyping stage, the equal stakeholders and designers use various supportive materials and tools to facilitate the prototyping process in producing artefacts (Benyon et al 2005; Courage and Baxter 2005). These activities enable the demonstration of various suggestions and concepts that usually are being evaluated in the fourth stage of UCD (Benyon et al 2005; Courage and Baxter 2005). For the first low fidelity prototypes of objects or basic versions of interactive systems, simple materials are used (such as paper, cardboard, etc.); these artefacts give an idea of the interface, content, navigational structure, key functionality and some basic features that are intended to be explored and tested.

For this study, the prototyping process was supported by a series of design interventions and various findings from data analysis to produce the first educational IT prototypes. As illustrated in Graphic 2, the intermediate steps 4 and 6 have been used to perform the prototyping process. The data analysed in step 4 helped a) to identify developed design ideas, b) to append and accumulate more IT requirements and c) to select and design the prototyping technique and materials (i.e. collaborative storytelling) supporting the work with children during the prototyping step 5. Then, to support my work as a designer in producing the initial prototypes, the artefacts developed by children were analysed in step 6, along with other IT requirements found in the intermediate step 2 and step 4 in order a) to select methods enabling the creation of the prototypes (i.e. personas, scenarios and storyboards) to adhere to the users’ needs and requirements, b) to perform the actual process of producing low-fidelity eBook artefacts (stories) and c) to select methods and materials to test and evaluate the prototypes with participants (i.e. layered elaboration). Therefore, collaborative storytelling, personas, scenarios and storyboards were all employed in the prototyping process.
Collaborative storytelling

The benefits of storytelling in design have emerged from the data analysis in step 4, particularly from the collaborative work with children with diabetes (Section 5.3.5), hence I decided to apply the same technique in the prototyping session with a different approach; each child was given materials to develop an individual story-prototype. As storytelling was discussed as a technique that may support the prototyping phase, (Druin 1999; Druin 2002; Muller and Druin 2009; Quesenbery and Brooks 2010) and based on the fact that “the same props can produce different stories” (Alborzi et al 2000, p 101), this strongly influenced my decision. As a result, some of the props designed and used during the design stage were reused as the support materials that facilitated individual prototyping were carefully considered and designed.

Personas, problem and activity scenarios and their storyboards

Personas, storyboards, problem and activity scenarios were considered as very helpful techniques by Årsand and Demiris (2008) when developing supportive technology for chronically ill people (Section 3.3). The examples used in supporting their statement did not include the exploration of these design activities with children with diabetes and their parents as design partners (i.e. only as testers). Hence, their advantages were not clear for developing educational IT applying PD and CI, and Markopoulos et al (2008b) highlighted that “child-specific methods for creating personas have not been fully explored in the field of child–computer interaction” (p 81).

In regard to personas, Mulder and Yaar (2004) argued that “there is no one right way to create personas”; it depends on who the users are, how the personas will be used in the design process and what time and resources will be invested into this activity (p 35). Personas help designers “become more user focused” (Pruitt and Adlin 2010, p 11); they provide summative information of a particular group of people, how they live, education, skills, age, etc. by creating “the most in depth character possible” (Scott 2014, p 409). As discussed, paediatric diabetes self-care management is a very complicated process in which many factors impact the proper treatment and care such as diabetes education, family support, local care, the national healthcare system, etc. (Section 2.2). Therefore, I needed tools that would support a deeper
understanding of paediatric diabetes self-care practices when translating developed ideas into the educational content of diabetes care, while adhering to the identified requirements and exemplifying how the users would interact with the educational tool by developing various scenarios and storyboards. Additionally, personas support the narrative approach by integrating them into problem and activity scenarios and storyboards. Scott (2014) stated; “Use these personas to explain user needs via scenarios. Communicate the value of these insights and the possibilities they hold for innovation.” (p 411). All these benefits of personas in UCD (Holtzblatt et al 2004; Pruitt and Adlin 2010; Scott 2014), as well as the complicated educational context of paediatric diabetes appeared as key factors in influencing my choice for their exploration in this study. I used the method to develop an educational IT that could satisfy the needs of a wide range of young users with T1DM, in addition, I further explored personas by placing/integrating them within the educational context of the eBook.

Personas as a tool was also adopted and adapted for children in various projects (Section 3.4 and Section 5.4.2) (Antle 2008; Moser et al 2011; Wärnestål et al 2014). As illustrated in Graphic 1 (Section 3.4), the tool child-personas falls in the intersecting zone of the UCD and PD because the developed users’ archetypes could play various roles in all stages of UCD (Pruitt and Adlin 2010). For this study, personas were developed for the prototyping process; the factoids used in affinity diagrams (intermediate Step 2, Section 4.2.1) did not provide any data on healthy children significant enough for developing child-learner personas, therefore this information was generated and collected in the design step 3 of UCD. This approach facilitated the accumulation of data to enrich the factoids used when developing child personas. To implement and build adults’ personas I used Pruitt and Adlin (2010)’s instructions and Antle’s framework (2008) for designing the child-learner archetype. Antle’s framework (2008) is composed of three dimensions i.e. childhood needs, developmental abilities and experiential goals that support the development of the child-archetype of young users (8-12 years of age); the first two dimensions are reusable, as they are well-founded in child development theories. The age of young patients with T1DM and their cognitive development emerged as key elements important 1) for the self-care practices and diabetes management (Section 2.2) and 2) in CCI when designing/adapting methods for children participation and design of IT.
(Section 3.2). For that reason, this strongly indicated that Antle’s framework (2008) may support the development of personas of young users with T1DM if aged between 8 and 12 years old, and the framework was explored by using the factoids along with some literary sources (Aziz 2013; Lange et al 2012; Hannan 2011; Silverstein 2005).

Scenarios and storyboards seem to be very helpful in design, prototyping and evaluation processes (Holtzblatt et al 2004; Rogers et al 2002; Rosson and Carroll 2011). In HCI, scenarios describe “human activities or tasks in a story that allows exploration and discussion of contexts, needs, and requirements” (Rogers et al 2002, p 223). As discussed, personas in scenarios illustrate in detail the current situation of users and how they are performing tasks to achieve their goals (i.e. Pruitt and Adlin 2010). Problem and activity scenarios respectively illustrate 1) the sequence outlining various realistic contexts with challenges and issues and 2) the narratives addressing the goals and strategies of the users/actors to solve the problems (Rosson and Carroll 2011). By using drawings, sketches, texts, etc. storyboards are a type of visual representation of scenarios; they show settings, dialogues, etc. or a simple user interface. They facilitate further discussion on described visions: provide a sequence of displayed information or manual steps offering interaction with the new system’s user interface for testing ideas (Holtzblatt et al 2004; Rosson and Carroll 2011). These characteristics of scenarios and storyboards perfectly suit the educational IT prototyping process - the narratives were used as an educational resource on paediatric diabetes care.

4.2.4 Evaluation Process: Layered Elaboration

As illustrated in Graphic 2, the evaluation is the last step (7) in the UCD process with which the first iteration of the UCD process ended; it was the last activity in this study for collecting empirical data with users. The intermediate step 6 was used to build prototypes and to select and design the evaluation techniques to perform the process with participants. Usually in the evaluation, users are invited to test and assess the initial design ideas – prototypes - (Courage and Baxter 2005) “to ensure that the result fits human desires, needs, and capabilities” (Norman 2013, p 208). Concerning the evaluation of patient-centric self-help tools, Årsand and Demiris (2008) highlighted that “Once design solutions have been produced, they need to be evaluated against the specified requirements. If a system prototype does not satisfy
these requirements, the process of understanding the context of use and the end user needs to be re-initiated” (p 166-167). From the reviewed techniques and tools developed to support design partners and evaluators in the evaluation process (Appendix A), the results indicated that most of these activities were explored with healthy children to measure the fun aspect and the child’s engagement with IT (i.e. Fun Toolkit (Read 2006)), to evaluate prototypes (i.e. This or That (Zaman and Abeele 2007)), or were used for usability evaluation (i.e. Co-Discovery (Kemp et al 1996; Van Kesteren et al 2003), Peer Tutoring (Hoysniemi et al 2002; Van Kesteren et al 2003), Thinking Aloud (Van Kesteren et al 2003), Active Intervention (Van Kesteren et al 2003), Retrospection (Van Kesteren et al 2003) and PIPC (Barendregt et al 2007)); none of these seemed suitable for this particular case for evaluating and reflecting on the educational context integrated into low fidelity artefacts with these two groups of participants of children (healthy and with T1DM) and their parents. Fails and her colleagues (2012) mentioned DisCo, Sticky notes, Fun toolkit, surveys, This or That, focus groups, large group discussions, but none of these satisfied the requirements of support within small-group evaluation sessions in complex settings. Therefore, looking for a technique that would meet certain requirements, I decided to apply Layered Elaboration (Walsh et al 2010).

The “Layered Elaboration is a useful technique as it enables co-design to take place asynchronously and does not require much space or many resources” (Walsh et al 2010, p 1237) (Section 3.4, Graphic 1). The technique was used to support idea elaboration with children (between 7 and 11 years old) for the development of two games, i.e. helping young users learn about history and develop a prototype about energy conservation. It was evolved as an asynchronous paper prototyping instrument in CCI to support the work of children as design partners. The materials in this technique are transparent sheets used to overlay on the original artefact (developed storyboards), and while children describe new ideas/suggestions, they use coloured markers to draw on the pages. The visualisation of all ideas can be accomplished when all produced pages by the different groups of children are overlapped. Five advantages of layered elaboration were highlighted: 1) the original prototypes are preserved after multiple uses with various participants, 2) the visualisation of all generated ideas provides valuable feedback for the work with different groups for comparison, 3) it is a portable tool, it needs little space to use by
children and designers, 4) the “iterative nature of the technique allows a number of
design partners to provide input and ideas in a short amount of time” and 5) it is
inexpensive (Walsh et al 2010, p 1240).

Layered elaboration was not suggested in the Årsand and Demiris (2008) framework
or explored in any of the maXi project (Glasmann et al 2010; Glasmann and
Kanstrup 2008) or SISOM system (Ruland et al 2008) (Section 2.3.2, Section 3.2 and
Section 3.5.2). Taking into consideration all the benefits of the technique, I selected
it for the assessment process for several reasons:

1) It had not been explored to support children with T1DM and their families as
design partners and healthy children as informants,
2) The transparent sheets allow for visibility of the prototypes’ content, hence
the evaluators can reflect on suggested ideas by adding drawings or text on
the layers while keeping the originals intact,
3) Simple to use by both parents and children,
4) Not heavy, easy to move and apply in various settings (i.e. pick up and
travel),
5) Supports quick visualisation and analysis (allows to see the similarity or
contrast) of various ideas produced.

Using this activity, the evaluation process step 7 was carried out with both groups of
participants. The generated data was analysed in order to juxtapose and reflect on the
specified requirement identified in step 2 (Graphic 2), as this helped to outline
whether the users’ participation influenced the quality of the educational IT and how
the selected activities supported the participatory approach with individuals.

4.3 People Involved in the Design Process: Ethical Approval and
Participants Recruitment

In this study, I worked with two groups of participants 1) parents/guardians and
adults who have experience with paediatric T1DM and children with diabetes, and 2)
healthy children. For this research, before having direct contact with children (i.e.
healthy and those with diabetes) and their parents, all ethical approvals to recruit and
work with volunteers were obtained from the Ethics Committee, University of
Limerick (Appendix B). Access to the members of the ‘Sweetpea Kidz Club’\(^{47}\) (set up by Diabetes Ireland (DI)) as well as permission to recruit children and their families through DI, was conditional on also obtaining ethical approval from DI. The second requirement was to work as a volunteer in DI, which allowed me to attend and participate in some of the activities organised by them. The approval required a Garda vetting\(^{48}\) process and this took a long time (about ten months) and as such my access to recruit potential participants for this study was delayed.

As noted, beginning the recruitment process for this research was problematic. When this study started, there were no parent support groups for children with T1DM in Limerick and the medical professionals in The Paediatric Diabetes Care Department, University Hospital Limerick did not show any interest in giving access and sharing information about this research with their cohort of patients diagnosed with type 1 diabetes. Consequently, targeting the recruitment of affected families who lived in different parts of Ireland, I started to advertise my work by using a wide variety of strategies: 1) I created and published a website ‘Design Technology Together’\(^{49}\), 2) I distributed flyers (i.e. to different Crèches & Kindergartens and General Practitioners’ (GPs) waiting rooms in Limerick), 3) I sent emails (i.e. to the primary schools in Limerick and to the university mailing list) and 4) I shared information through Facebook pages (i.e. Parents of Children & Teens with T1 Diabetes in Ireland, Diabetes Waterford and Diabetes Cork parents’ support group). I made several attempts in order to recruit the highest number of participants for this study. For example, I attended a variety of events organised by DI in Cork, Tralee, Dublin, Limerick, Ennis, etc. in which I talked about my research, and sent emails to healthcare providers in Galway, Dublin and Cork; I have met with some of them to discuss my work. Unfortunately, many of those attempts were not successful, as the members of these target groups usually have very busy agendas. The group of healthy children were recruited from the local non-profit voluntary group ‘Sunflowers’\(^{50}\). This group is organised by Russian-speaking parents for their children to partake in various fun activities i.e. music, dancing, drama, drawing and

\(^{47}\) As non-profit organisation, the club is focused particularly to support children with T1DM and their families by organising different activities for them. https://www.diabetes.ie/living-with-diabetes/child-diabetes/sweetpea-kidz-club/

\(^{48}\) http://www.volunteer.ie/who-we-help/organisations/garda-vetting

\(^{49}\) www.kidsindesign.com

\(^{50}\) https://www.facebook.com/Sunflowers-262826920521293/
Russian language lessons, etc., and in entertainment events i.e. theatre, trips, picnics, museums, etc. for the young members facilitated/lead by parents and teachers. These children are all born in Ireland and attend schools in Limerick. The main language used during the design sessions was English, and the children’s level of English is that of native speakers. At “Sunflowers”, children are divided into groups according to their age and choose which fun and learning activities they want to participate in. Usually, they are scheduled to meet every Saturday in their community centre. Both the person responsible for the running of the voluntary group and the parents were happy to support my research, so before I started planning a session with their children, I met with them to explain that the purpose of the workshop, tasks, materials, etc. was designed for use with young individuals, as well as to obtain permission (signed consent forms) to work with their children and set suitable dates and times to perform the activities. The sessions were carried out after the planned activities of the group were completed; some of the parents attended the workshops, but they were not involved in the co-design tasks. I acknowledge that my decision to work with children from this voluntary group could be seen as bias. For example, this means excluding other children whose participation may have been useful for this study. However, it was not possible to recruit young individuals from other schools, because when I contacted them, they were not interested in participating in this study.

A series of recruitment processes were carried out to find volunteers for all four stages of the UCD process (Table 3 and Table 4) applying PD, CI and ID; the number of participants for each phase is discussed in Section 5.2.1.1 (i.e. Interviews), Section 5.2.2.1 (i.e. DP), Section 5.3.1 (i.e. Design), Section 5.4.1.1 (i.e. Prototyping) and Section 5.5.1 (i.e. Evaluation). Twenty-six adults (i.e. four males and twenty-two females) and twenty children (i.e. five boys and fifteen girls) who have experience with T1DM (Table 3) have participated in this study. The ages of children with diabetes varied from 5 to 15 years. Only one child and her parent have participated in most of the activities organised for UCD (Parent8&T1DC8, Table 3). The newly diagnosed children with diabetes and their families involved in this research were Parent23&T1DC23 (three months) and Parent24&T1DC24 (four months) Parent26&T1DC26 (five months) and Parent27&T1DC27 (seven months). Playing the role of informants (i.e. ID), sixteen healthy children (i.e. thirteen girls and three
boys) between the ages of 8 and 12 years also contributed to the educational eBook design participating in the Design (Section 5.3.3 and Section 5.3.4) and Evaluation (Section 5.5.3) activities (Table 4).

Most of the young individuals with T1DM were girls; my attempt to involve more boys and newly diagnosed children in the study was unsuccessful. Soltesz et al (2007) reported that “The overall sex ratio is roughly equal in children” (p 9) while Patterson and his colleagues (2009) stated that “Girls showed faster rates of increase in incidence of type 1 diabetes in the 5–9 year age-group and slower rates in the 10–14 year age-group than did boys” (p 4). A National Register for Children and Teens with Type 1 Diabetes (ICDNR)\textsuperscript{51} in Ireland was launched in January 2008, unfortunately, reports illustrating the sex ratio of children with T1DM were not available.

To preserve confidentiality, all identifying information that could indirectly reveal the identity of participants has been removed. Splitting volunteers into five groups of adults, parents, healthcare providers, children with T1DM and healthy children, I have assigned different pseudonyms helping to maintain their anonymity: 1) Parent1, Parent2, Parent3, etc. for parents/guardians who have children with this chronic condition, 2) Participant12, Participant13, etc. for adult people who developed diabetes during childhood, 3) MP28 and MP29 as an abbreviation of Medical Professionals, 4) T1DC1, T1DC2, T1DC3, etc. as an abbreviation of Type 1 Diabetic Child and 5) HC1, HC2, HC3, etc. as an abbreviation of Healthy Child.

Before consent forms were signed by those individuals who agreed to participate, information sheets and verbal explanations were used to clearly inform the participants about the aim of this study, what materials and techniques would be applied and how the data generated during our collaborative work would be used. They were also assured of anonymity and confidentiality, and made aware that their participation was voluntary. At the beginning of each session, children and parents confirmed their agreement to participate by signing the consent forms. Children’s participation was not only based on their willingness to contribute in this research, but also on the permission given by their parents/guardians, dependent on their state of health and ability to participate.

\textsuperscript{51} http://medicine.tcd.ie/paediatrics/research/research-projects/epidemiology.php
### Table 3: Participants: children with T1DM and their families

<table>
<thead>
<tr>
<th>Participants</th>
<th>Semi-structured Interviews &amp; Focus groups</th>
<th>Design Probes</th>
<th>Workshop sessions</th>
<th>Age of individuals with T1DM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents and individuals having T1DM</td>
<td>Sick children</td>
<td>Interviews adults</td>
<td>Interviews children</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Parent1</td>
<td>Parent11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent2</td>
<td>Parent12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent3</td>
<td>Parent13</td>
<td>TIDC3</td>
<td>Parent3</td>
<td></td>
</tr>
<tr>
<td>Parent4</td>
<td>Parent14</td>
<td>TIDC4</td>
<td>Parent4</td>
<td></td>
</tr>
<tr>
<td>Parent5</td>
<td>Parent15</td>
<td>TIDC5</td>
<td>Parent5</td>
<td></td>
</tr>
<tr>
<td>Parent6</td>
<td>Parent16</td>
<td>TIDC6</td>
<td>Parent6</td>
<td></td>
</tr>
<tr>
<td>Parent7</td>
<td>Parent17</td>
<td>TIDC7</td>
<td>Parent7</td>
<td></td>
</tr>
<tr>
<td>Parent8</td>
<td>Parent18</td>
<td>TIDC8</td>
<td>Parent8</td>
<td></td>
</tr>
<tr>
<td>Parent9</td>
<td>Parent19</td>
<td>TIDC9</td>
<td>Parent9</td>
<td></td>
</tr>
<tr>
<td>Parent10</td>
<td>Parent20</td>
<td>TIDC10</td>
<td>Parent10</td>
<td></td>
</tr>
<tr>
<td>Parent11</td>
<td>Parent21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant12</td>
<td>Participant12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant13</td>
<td>Participant13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant14</td>
<td>Participant14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent15</td>
<td>Parent15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent16</td>
<td>Parent16</td>
<td>TIDC16</td>
<td>Parent16</td>
<td></td>
</tr>
<tr>
<td>Parent17</td>
<td>Parent17</td>
<td>TIDC17</td>
<td>Parent17</td>
<td></td>
</tr>
<tr>
<td>Parent18</td>
<td>Parent18</td>
<td>TIDC18</td>
<td>Parent18</td>
<td></td>
</tr>
<tr>
<td>Parent19</td>
<td>Parent19</td>
<td>TIDC19</td>
<td>Parent19</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TIDC20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>TIDC21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>TIDC22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent23</td>
<td>Parent23</td>
<td>TIDC23</td>
<td>Parent23</td>
<td></td>
</tr>
<tr>
<td>Parent24</td>
<td>Parent24</td>
<td>TIDC24</td>
<td>Parent24</td>
<td></td>
</tr>
<tr>
<td>Parent26</td>
<td>Parent26</td>
<td>TIDC26</td>
<td>Parent26</td>
<td></td>
</tr>
<tr>
<td>Parent27</td>
<td>Parent27</td>
<td>TIDC27</td>
<td>Parent27</td>
<td></td>
</tr>
<tr>
<td>MP28</td>
<td>MP28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MP29</td>
<td>MP29</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I travelled to meet and work with any individual who agreed to participate in this study. Quite often the interviews and sessions with parents and their chronically ill children were carried out in locations and places identified and selected by participants (Graphic 3), as this gave them some comfort and security, while the design and evaluation tasks organised for healthy children were held in the community centre in which they usually conducted planned activities with the voluntary group.

Graphic 3: A map illustrating the places where various activities with participants have been carried out
Table 4: Participants: healthy children

<table>
<thead>
<tr>
<th>Children</th>
<th>Age of children</th>
<th>Design Session 2</th>
<th>Design Session 3</th>
<th>Evaluation of the Prototypes</th>
</tr>
</thead>
<tbody>
<tr>
<td>HC1</td>
<td>11</td>
<td>HC1</td>
<td>HC1</td>
<td>Evaluation Session 7</td>
</tr>
<tr>
<td>HC2</td>
<td>11</td>
<td>HC2</td>
<td>HC2</td>
<td>Evaluation Session 8</td>
</tr>
<tr>
<td>HC3</td>
<td>11</td>
<td>HC3</td>
<td>HC3</td>
<td>Evaluation Session 9</td>
</tr>
<tr>
<td>HC4</td>
<td>11</td>
<td>HC4</td>
<td>HC4</td>
<td>Evaluation Session 10</td>
</tr>
<tr>
<td>HC5</td>
<td>11</td>
<td>HC5</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC6</td>
<td>12</td>
<td>HC6</td>
<td>HC6</td>
<td></td>
</tr>
<tr>
<td>HC7</td>
<td>12</td>
<td>HC7</td>
<td>HC7</td>
<td></td>
</tr>
<tr>
<td>HC8</td>
<td>12</td>
<td>HC8</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC9</td>
<td>8</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC10</td>
<td>10</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC11</td>
<td>12</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC12</td>
<td>8</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC13</td>
<td>8</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC14</td>
<td>9</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC15</td>
<td>10</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>HC16</td>
<td>8</td>
<td>–</td>
<td>–</td>
<td></td>
</tr>
</tbody>
</table>

Two different approaches were used in organising and conducting different activities with these two groups of children (i.e. healthy and those with diabetes) who participated in this study. Taking into consideration the treatment of people with diabetes, time-off necessary for taking medications, measuring blood glucose levels, eating snacks and breaks were planned in advanced. Young participants were informed that the workshop process could be stopped when needed and they could take a break if they were feeling tired and take a rest to manage their diabetes, performing tasks important for their health. At the beginning of each session with healthy participants, children had small healthy snacks and goodies to help create a friendly atmosphere before the planned activities started. At the end of each session children were given gifts and colourfully designed certificates as a token of appreciation for their participation.

Working with these two groups of individuals, I have conducted twenty-nine interviews, two focus groups, two iterations of applying DP (N=12), fourteen sessions i.e. three design sessions, one prototyping workshop and ten evaluation sessions (Section 4.3, Table 3 and 4) between the period of 2012-2015; the empirical process and results are described in the next Chapter 5.

119
Chapter 5: UCD and PD Approaches: Involving Participants in Design

5.1. Introduction

This chapter reports the empirical work applying UCD and PD approaches with a diverse group of participants (e.g. healthy, children with Type 1 Diabetes and their parents/guardians, diabetes educators, etc.) and presents an analysis on the empirical material. My main focus was on the design process and my approach of combining different methods and techniques with the aim to support the active participation of children with diabetes and their families in the design process. This account is not only about my work as a designer organising the whole design process, nor is it focused on the end results. Rather it is an account of 1) the complexity and difficulties of designing with young individuals, particularly children with diabetes, 2) the emergence of new roles and responsibilities during the co-design process, as an effect of selecting design tools and techniques to get access and explore children’s everyday practices and experiences, 3) the process of building a space for negotiation of values for dialogue and mutual learning, and 4) the development of strategies to deal with challenging emotional states experienced by participants with diabetes during collaborative activities. As mentioned in Chapter 1.1, my goal is twofold, with methodological concerns at the core of this work: 1) to improve the understanding of paediatric T1DM self-care practices and design an interactive technology that could resonate with the needs of the families, and 2) to reflect on the role of collaborative design tools, techniques, and methods that view affected families as equal design partners in developing a new piece of technology.

In performing UCD, PD, CI and ID, Table 5 illustrates the design methods, techniques and tools that have been explored to support the roles of “design partners” and “informants” in technology development, based on the participant's experience of having (or caring for a child with) T1DM and being a healthy young individual respectively. By examining a variety of co-design activities, this way of work also aimed to enhance the active participation and involvement of participants in the design process and to explore their different roles and input in the design of IT, particularly with these individuals: children who have diabetes, as they need to live
with this chronic condition, and their parents as they have a more holistic view in managing their child’s personal health.

Table 5: Methods, techniques and tool applying UCD

<table>
<thead>
<tr>
<th>UCD phases</th>
<th>Understand users</th>
<th>Design</th>
<th>Prototype</th>
<th>Test and evaluate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activities</strong></td>
<td>Literature review</td>
<td>Collaborative storytelling used in 3 design sessions</td>
<td>Collaborative storytelling in the prototyping session</td>
<td>Layered elaboration used in 10 evaluation sessions</td>
</tr>
<tr>
<td></td>
<td>Semi-structured interviews</td>
<td>1 design session with children with diabetes</td>
<td>Personas</td>
<td>6 evaluations with children with diabetes and their parents</td>
</tr>
<tr>
<td></td>
<td>Affinity diagrams</td>
<td>2 design sessions with healthy children</td>
<td>Scenarios</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Design Probes</td>
<td></td>
<td>Storyboards</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Follow-up interviews</td>
<td></td>
<td>Paper prototypes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Digital prototype</td>
<td></td>
</tr>
<tr>
<td><strong>Groups of participants and their roles in design process</strong></td>
<td><strong>Design partners</strong></td>
<td><strong>Design partners</strong></td>
<td><strong>Design partners</strong></td>
<td><strong>Design partners</strong></td>
</tr>
<tr>
<td></td>
<td>Families (i.e. children and parents) having experience with paediatric diabetes</td>
<td>Children with T1DM</td>
<td>Children with T1DM</td>
<td>Children with T1DM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parents/guardians</td>
<td>Parents/guardians</td>
<td>Parents/guardians</td>
</tr>
<tr>
<td></td>
<td><strong>Informants</strong></td>
<td><strong>Informants</strong></td>
<td><strong>Informants</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Medical professionals</td>
<td>Healthy children</td>
<td>Healthy children</td>
<td></td>
</tr>
</tbody>
</table>

The following four sections discuss the work completed for each stage of the UCD process (Graphic 3), i.e. 1) Understand users (red colour) - Section 5.2 explains the activities used to explore paediatric T1DM, users’ needs and the design space, 2) Design (blue colour) - Section 5.3 describes the collaborative process facilitating the elaboration of various design ideas, 3) Prototype (green colour) - Section 5.4 outlines the production of a wide range of design solutions by building the paper and digital prototypes of an interactive technology and 4) Evaluation (purple colour) - Section 5.5 shows the assessment process in which the suggested prototypes were tested and evaluated. Lastly, Section 5.6 summarises the main findings that emerged from the generated and collected empirical data.
Graphic 4: Work completed in an iteration of the UCD
5.2. Stage One: Exploring Paediatric Diabetes Everyday Care

This section aims to investigate the stage of UCD dealing with the exploration of the users’ needs to help identify technology requirements and an appropriate design solution (Section 4.2.1). Structured into two subsections, I explain my initial investigation and findings 1) in using qualitative semi-structured interviews with individuals who have experience with T1DM (shown in Section 5.2.1) and 2) in applying and performing two iterations of the Design Probes method with 12 families (illustrated in Section 5.2.2).

Below I report my findings from a study aiming to attain a better understanding of paediatric diabetes practices to help identify the needs of children with T1DM and their parents, and the role of interactive technology in supporting some of these practices (strongly related to my first sub-question shown in Chapter 1). A qualitative approach - the use of semi-structured interviews with participants, was applied. Through affinity diagrams analysis and a series of in-depth interviews, I have identified a number of key challenges in dealing with paediatric diabetes in everyday life that helped to shape the design of this study and identify opportunities for a design intervention (Section 4.2). As I will detail, two themes emerged clearly from the analysis: a) Theme 1 – the educational issues that suggested the need for further intervention and b) Theme 2 – the emotional state of young patients echoing strongly the main concern about the methods used in this study, focusing on how to design with/for children with T1DM.

I illustrated several reasons for choosing DPs (i.e. for collecting data unobtrusively, for gaining insights into everyday activities in sensitive settings and for increasing participation) (Section 4.2.1); the aim was to provoke self-expression of personality, explore the domestic environment, imagination and creativity of the parents and children, to inspire the designer. Moreover, even more imperative were the subjective and creative responses of the affected children that would lead to the development of a perspective, a language and an orientation for the technology design.

5.2.1 Qualitative Approach for Investigating Issues and Challenges in Paediatric Diabetes Practices Experienced in Domestic Environments

124
As discussed in Section 2.2, T1DM is the inability of the pancreas to produce insulin, causing chronically high levels of sugar in the blood. To manage their medical condition, individuals need to check their blood glucose regularly, take insulin, have a healthy low-carb diet and engage in physical activity (Ambler and Cameron 2010; Weinger and Carver 2009). For affected children and their parents, the complexity of diabetes management, the required adjustment to a completely new lifestyle, and the constant monitoring are extremely stressful (Smaldone and Ritholz 2011). It has been emphasised that the ability to make sense of their condition and understand diabetes to an appropriate level of detail is crucial for affected individuals (ibid.). This understanding is a crucial factor in dealing with the practicalities of everyday life, and has the potential to benefit both the physical health and emotional wellbeing of affected individuals (Mamykina et al 2006; Storni 2010; Storni 2013a; Weinger and Carver 2009). In this research, I began by exploring some of the challenges and issues in paediatric diabetes from the perspective of the affected children and their parents/guardians (Tsvyatkova and Storni 2014a). I have focused on everyday chronic care practices in domestic settings (home, schools, etc.) and the potential role of interactive technology as a tool for patient empowerment. I have seen the initial understanding and identification of the key issues and challenges in paediatric diabetes as central to understanding the extent of possible design interventions that are consistent with the UCD approach and that aim to address real users’ needs outside the attention of medical staff. In order to become familiar with the main issues affecting these children and their parents, I have conducted a series of in-depth interviews investigating the everyday practicalities, difficulties and intricacies of paediatric diabetes management, revealing that educational issues (especially related to newly diagnosed children) and potential emotional ramifications are key issues needing attention. Such findings help to identify key areas of further research and intervention and support an argument for the need of new educational tools that are mindful of the child’s feelings and how these may improve individual understanding (Tsvyatkova and Storni 2014a).

5.2.1.1 Sample and Data Analysis

The main selection criterion for allowing volunteers to participate in this qualitative investigation was to have direct (or personal) experience with paediatric diabetes management. In searching for more detailed and descriptive data on diabetes self-
care practices, twenty-nine volunteers with practical experience of paediatric T1DM were interviewed - eighteen parents/guardians who have children with diabetes (i.e. two males and sixteen females), three individuals who were diagnosed at a young age (i.e. two males and one female), six children (i.e. three boys and three girls) and two medical professionals (i.e. paediatric diabetes dietitian and educator working in the CHOICE programme (Section 2.2.3) (Table 6).

Table 6: Interviewed participants who have experience with T1DM

<table>
<thead>
<tr>
<th>Qualitative approach</th>
<th>Age of individuals with T1DM</th>
<th>Age at diagnosis</th>
<th>Age at interviews</th>
<th>Experience with the illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews adults</td>
<td>Interviews children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent1</td>
<td>—</td>
<td>8 Years old</td>
<td>23 Years old</td>
<td>15 Years</td>
</tr>
<tr>
<td>Parent2</td>
<td>—</td>
<td>10 Years old</td>
<td>17 Years old</td>
<td>7 Years</td>
</tr>
<tr>
<td>Parent3</td>
<td>—</td>
<td>21 Months</td>
<td>3 Years old</td>
<td>15 Months</td>
</tr>
<tr>
<td>Parent4</td>
<td>—</td>
<td>6 Years old</td>
<td>8 Years old</td>
<td>2 Years</td>
</tr>
<tr>
<td>Parent5</td>
<td>—</td>
<td>7 Years old</td>
<td>12 Years old</td>
<td>5 Years</td>
</tr>
<tr>
<td>Parent6</td>
<td>—</td>
<td>7 Years old</td>
<td>8 Years old</td>
<td>1 Year</td>
</tr>
<tr>
<td>Parent7</td>
<td>—</td>
<td>7 Years old</td>
<td>9 Years old</td>
<td>2 Years</td>
</tr>
<tr>
<td>Parent8</td>
<td>T1DC18</td>
<td>9 Years old</td>
<td>12 Years old</td>
<td>3 Years</td>
</tr>
<tr>
<td>Parent9</td>
<td>—</td>
<td>5 Years old</td>
<td>9 Years old</td>
<td>4 Years</td>
</tr>
<tr>
<td>Parent10</td>
<td>—</td>
<td>6 Years old</td>
<td>12 Years old</td>
<td>6 Years</td>
</tr>
<tr>
<td>Parent11</td>
<td>—</td>
<td>4 Years old</td>
<td>7 Years old</td>
<td>3 Years</td>
</tr>
<tr>
<td>Participant12</td>
<td>—</td>
<td>17 Years old</td>
<td>24 Years old</td>
<td>7 Years</td>
</tr>
<tr>
<td>Participant13</td>
<td>—</td>
<td>10 Years old</td>
<td>18 Years old</td>
<td>8 Years</td>
</tr>
<tr>
<td>Participant14</td>
<td>—</td>
<td>10 Years old</td>
<td>50 Years old</td>
<td>40 Years</td>
</tr>
<tr>
<td>Parent15</td>
<td>—</td>
<td>8 Years old</td>
<td>14 Years old</td>
<td>6 Years</td>
</tr>
<tr>
<td>Parent16</td>
<td>T1DC16</td>
<td>9 Years old</td>
<td>12 Years old</td>
<td>3 Years</td>
</tr>
<tr>
<td>Parent23</td>
<td>T1DC23</td>
<td>10 Years old</td>
<td>10 Years old</td>
<td>3 Months</td>
</tr>
<tr>
<td>Parent24</td>
<td>—</td>
<td>4 Years old</td>
<td>5 Years old</td>
<td>4 Months</td>
</tr>
<tr>
<td>Parent25</td>
<td>T1DC25</td>
<td>8 Years old</td>
<td>10 Years old</td>
<td>2 Years</td>
</tr>
<tr>
<td>Parent26</td>
<td>T1DC26</td>
<td>13 Years old</td>
<td>13 Years old</td>
<td>5 Months</td>
</tr>
<tr>
<td>Parent27</td>
<td>T1DC27</td>
<td>15 Years old</td>
<td>15 Years old</td>
<td>7 Months</td>
</tr>
<tr>
<td>MP28</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>MP29</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

As stated earlier (Section 4.3), to maintain the anonymity of the volunteers and the medical facilities in this study, I am using abbreviations for different groups of participants. Taking into consideration the model of care (Section 2.2.3) in which HSE services are intended to improve the care options and self-management skills in individuals with T1DM after young patients leave the hospital setting, this study aimed to explore paediatric diabetes care in domestic environments. It was difficult to conduct many interviews with children for two reasons: 1) their resistance to speaking about diabetes as the topic is very sensitive, and 2) the need for constant...
adult supervision which was required due to the age of the children. Most of the participants (N=18) in this qualitative investigation were parents of children with diabetes who live in different regions in Ireland. The children who agreed to participate had their interviews carried out under the close supervision of their parents.

The age at which the young individuals were diagnosed varied between 21 months and 17 years old. For some participants, diabetes was a very new experience: four of the children were recently diagnosed - they had T1DM for less than seven months (i.e. Parent23&T1DC23, Parent24&T1DC24, Parent26&T1DC26 and Parent27&T1DC27); other individuals had dealt with this chronic condition for more than five years (Parent1, Parent2, Parent5, Parent10, Participant12, Participant13, Participant14 and Parent15) (Table 6). The age of the interviewed children at the time of the diagnosis was 8 to 15. Having this diverse range of users’ experiences could be considered as an advantage in exploring paediatric diabetes self-care; this helped to define and compare some of problematic diabetes self-management practices experienced by the individuals and to identify the potential age group of the users, and the interactive technology that could support these practices. The response bias of twenty-nine semi-structured interviews in this study may not be representative of the entire Paediatric Diabetes community in Ireland, but it provides an overall picture of diabetes self-care for families living in different places. The fact that the participants live in different counties in Ireland has facilitated the exploration of the diverse access to quality diabetes care and the potential barriers to healthcare delivery in the areas these individuals live.

As diabetes education of newly diagnosed children and their families emerged as an issue, the need to explore the structured educational process and training available for children and parents appeared. As stated (Section 2.2.3), the limitations of such programmes that are specially developed to help affected families emerged after this project started (i.e. 2012). The CHOICE programme is new for Ireland (June 2013); it is a great option to provide education in paediatric diabetes centres across the country. Aiming to gain a clear understanding of current practices related to the education and materials used in the programme, I travelled to attend the original CHOICE programme in Northern Ireland in March 2014. I interviewed two medical professionals: the paediatric dietitian who works in one of diabetes centres in Ireland
who also became one of the educators in the CHOICE refresh programme in the same paediatric unit (MP28), and the specialist nurse delivering the child programme CHOICE in Northern Ireland (MP29). The dietitian has worked more than eight years in the field, while the nurse has experience in managing clinical trials and screens in diabetes with children for the last 20 years.

The in-depth, semi-structured interviews lasted between 20 minutes and 1.5 hours, their duration depended on the time that individuals could spend to participate. I developed several sets of interview questions that were used with the different groups of participants (Appendix C); some of the questions were open, while others were more basic and recurring in all interviews, enabling comparisons. More than 20 hours of audio have been recorded, transcribed and analysed using the MAXQDA software along with the affinity diagrams technique (Section 4.2.1). Widely used, this way of sorting data affords an insightful overview, and highlights problematic aspects that could inspire and guide the design process and activities that follow.

To analyse the rich collection of qualitative data, I have explained several reasons for applying the affinity diagrams (Section 4.2.1). The inductive approach of processing the data in a bottom-up fashion (Holtzblatt et al 2004; Martin and Hanington 2012) helped 1) to compare the similarities of individual problems and issues experienced by participants in daily diabetes care, 2) to focus on a variety of different approaches to a single problem used by the individuals, 3) to identify the significant elements in the generated and collected data indicating the selection of an interactive technology, and 4) to illustrate the system and user requirements that would correspond to the users’ needs, informing the design of the new technology. In addition, I used the affinity diagrams in the prototyping process to build personas and to understand the technology requirements and functionality (e.g. images, context, features, etc.) (Section 5.4.2).

After carefully reading the raw data extracted from the original source, the fragments of text suggesting important information were systematically sorted out by using the digital notes - factoids. I created my own template working with Illustrator (Figure 5); the factoids covering similar issues were arranged and labelled into clusters presented in different colours (can be read in Appendix D). They were then organised into meaningful themes, revealing and describing a holistic picture of day-
to-day life challenges in the diabetes management process. In the end, the data was clustered in 24 groups that contained essential and helpful information, which enabled the identification of the two - already mentioned - main themes explained below i.e. a) Theme 1: Diabetes Education composed of three sub-themes: Education at hospital, Education at home and Educators & CHOICE, describing the diabetes educational process from the perspective of parents, children and educators, and b) Theme 2: Child’s emotional state (referring to children with T1DM), the formation of feelings about the illness presented by parents in describing child’s attitudes and emotions towards the diabetes, personally explained by the interviewed children (Figure 5 and Figure 6).

For example, the first 19 groups in the affinity diagrams shows data linked to the diabetes educational process; this helped to identify and create Theme 1: Diabetes Education (Figure 5 and Figure 6). In this theme, the data in the first three clusters (e.g. Educating child: at hospital, Educating parents: at hospital and ‘Pete the Pancreas’) explain the educational sources and procedures used during the first education provided to newly diagnosed children and their families at the clinic after the initial diagnosis - the first sub-theme Education at hospital. The sub-theme 2 - Education at home - contains 15 groups; it emerged from the data describing the educational practices that have been carried out outside clinical settings. The factoids in the first eleven clusters from this sub-theme (e.g. Educating child: at home, Educating parents: at home, Carb counting, Sick days, Symptoms recognition, Emergency plan, Sharing responsibilities, Teachers/Schools, Parents-physician communication, Metaphors and Technology requirements) describe education as a continuous process in the domestic environment: the educational approach of parents.
in helping their children learn about diabetes, constant communication with medical professionals and teachers and extra information related to this process. The digital notes in the last four clusters that belong to the same second sub-theme (i.e. Daily care: child, Parent life, Daily care - parents and Emotions - parents) were included in this composition because 1) they describe the life of the individuals in managing diabetes, which requires sufficient knowledge obtained through education, but at the same time suggests continuous improvements in practical skills and diabetes knowledge by repeating the self-management tasks and 2) they show the emotions of fear and helplessness in parents provoked by some of the difficult scenarios in daily care. The last cluster in Theme 1 describes the need for regular follow-up structured education for families; this determined the sub-theme 3: Educators & CHOICE. Illustrating various issues provoking negative emotions in the children after diagnosis, the last 5 groups in affinity diagrams (e.g. Emotions - child, Other people, Child life, Diabetes care difficulties and Parities) enabled the recognition of Theme 2: The Child’s emotional state (Figure 5 and Figure 6).

5.2.1.2 Theme 1: Diabetes Education

My initial intention was to gain a deeper understanding of everyday practices and issues in paediatric diabetes self-management experienced by families in domestic settings. As said, educational issues emerged as a recurrent topic in the interviews. People involved in diabetes education practices are 1) the diagnosed child who needs to obtain specific knowledge and skills to manage his/her chronic condition (dependent on age), 2) the parents who also need to gain appropriate information and
ability to help their child with every-day diabetes practices for active, healthy lifestyles, 3) the relatives, teachers and other people who could offer different types of support and 4) the healthcare providers who assist affected families by providing education, information and treatment. Focusing on identifying common categories in the data, it was discovered that diabetes self-management education obtained in clinical settings and home environments is a long and dynamic process (Chaney 2012; Lange et al 2012; SWEET 2013), and a problematic experience for participants. As discussed in Section 5.2.1.1, the first two sub-themes (i.e. Diabetes education at the hospital and Diabetes education at home) describe the difficulties experienced by parents and children in gaining knowledge in these two different locations, while the third elaborates on the educational practices suggested to the families.

Sub-Theme 1: Diabetes education at hospital

The criterion for admission, stay and discharge from the hospital depends on the child's health; therefore, the child’s hospital stay can vary from three (a short admission) to ten days or even more (long admission). As the following extract confirms, these are the days when families and children are supposed to be trained and learn about diabetes care at home. “She probably was on the drip for 5 or 6 days. So we didn’t have practice on giving injections or anything like that in the first 5 days, just trying to get as much information [as possible].” (Parent15) Only those newly diagnosed children with T1DM who felt well got an outline of what diabetes is on the day of diagnosis in the hospital (see also Tsvyatkova and Storni 2014a).

“But we were told in the (name of the hospital) that from day one make sure that she takes her checks for herself and injects herself. So she was taught all that and we were shown the way how to do it, but we were strictly told that she had to do it herself from day one.” (Parent1)

“…they showed her what to do on the first day…” (Parent5)

Usually the first-day education is focused on the practical aspects of taking insulin injections and using different artefacts to measure glucose levels in which parents and some children were involved. Two ways of safe injection training were identified. In the first, the use of teddies or dolls to show how to inject is often used to transfer this knowledge “…we were injecting the teddy…” (Parent4), “…she
compared her to the doll and went through the areas and why she needed it…” (Parent7) and “…a rubber cushion and they injected that…” (Parent5), while in the second, children have been forced to practice on their own bodies using the most popular sites for injections such as stomach and legs.

When it came to understanding the nature of the disease, information was reported as being vague by the participants. Staff members were prone to talk to the parents instead of the children themselves, and the following extract confirms this: “…they didn’t really explain it to our daughter; they more explain it to us…” (Parent6) and “I wasn’t really told as much, it was only shown to me what to do with the injection.” (T1DC8). At that stage the young patients had many questions related with diabetes care, a normal reaction; “I wanted know what would put my sugars going up and down, what is one of the foods that has carbs and numbers” (T1DC23) or “…will I be able to eat normally…” (T1DC26), but unfortunately were not afforded the opportunity to ask.

Parents reported that these educational practices at the hospital were very traumatic, as many factors influenced the emotional state of their children. Some of parents noted their child’s fear of the illness: “she probably went through all the emotions, fear, everything else” (Parent6), while others experienced problems with needles or blood phobia presented by their children (Tsvyatkova and Storni 2014a). “She had a massive needle phobia, so it wasn’t a great time for your child to get a needle phobia so it was quite difficult at the start trying to teach her that” (Parent4). “It was extremely hard for her; she doesn’t like the needle at all… “What? I can't do it on myself, I don't want to”’” (Parent15). “I was so scared about telling her that she was going to have to get injections because she had flipped out at the doctor when he tried to take blood. She was uncontrollable” (Parent8).

Some children also shared these feelings, “I was so afraid, I wasn't even sure what it was all about” (T1DC8) and “I was horrified because I had a fear of needles. I have 6 injections every day.” (T1DC25) Two years since diagnosis, the boy (T1DC25) still has this fear - he uses an insulin pen that hides the needle completely and looks away to not focus on the poke.

For those children who were very young at the time of diagnosis (e.g. 4 or 21 months), the education was given to their parents, and they had to decide what their
children needed to know and at what age their child would learn about diabetes self-care practices (Tsvyatkova and Storni 2014a). “He hasn't asked yet (about diabetes), we have started to try to explain it to him. He doesn't obviously like getting his set changed (using insulin pump), because the needle hurts him. So I try and tell him “This will stop you are feeling sick, this needle will make you feel better.”” (Parent3, at the time of interview the child was 3-years-old).

Education for parents typically focused on how to manage the disease after they returned home i.e. injecting the child with insulin, understanding the relationship between insulin and carbohydrates, symptoms of hypo- and hyper-glycaemia (conditions of low or high blood glucose in diabetes), keeping a diary, etc.

“They explained it like you have just started school. They were brilliant; they will show you everything and telling you word by word what to do. Every time she was doing an injection, somebody has to show her. You can say to them "What I am supposed to be look in at?" And they will tell you. The nurses will tell you, then the diabetes team will come up every day to see you and train you for all the different things. I think that's why they kept her in for so long, because they wouldn't let me and let her go home until I was trained.” (Parent5)

“It took us about five days to get used to the idea of how the injections were to be used” (Parent7)

Many parents, however, thought that it was very difficult to learn all of this important information during their short stay at the hospital.

“I know it is easy now looking back but I think at the time it was very overwhelming... There is just so much, you are trying to take in about the insulin and carbohydrates. In exchanges, nurses say how many carbs this is worth, how many carbs that is worth. That was all new to me, I remember turning to my husband and saying “I can't imagine somebody who knew nothing about diabetes doing this. He was that, he knew nothing about diabetes and then he was relying a lot on me. That was really hard, I do everything good for the kids, they need something like that just to explain look what happens. I think that at the start, there is just so much, it is so overwhelming.” (Parent4)
Diagnosis can affect the parent's mood, presenting feelings of sadness, worry, stress, tension, etc. and “it was very difficult to take information in... You really need someone to talk with on the emotional level as well as the information” (Parent23).

One father explained that the information taken in the first days “was very much the mechanical use of the needles and taking measurements” but “they didn't really talk to us about food or how it impacts” (Parent6). In the first year, the honeymoon period (this is a period of months where the remaining beta cells in the pancreas are still producing small amounts of insulin) is very difficult as it wasn’t discussed a lot and the “lack of information at the very start which was kind of where you are left” (Parent2) and “they didn't explain in depth, this was on the piece of paper” (Parent15). A parent rated overall education “as poor” because there was no education “on how to deal with different scenarios, you're left at home to your own devices and when a scenario comes up you have to come back or call in” (Parent7), while others get only basic information: “if the blood sugar is that, do this. It is very easy to say what to do but in really applying that, when you see your child is unconscious it would be in a very scary situation.” (Parent15)(Tsvyatkova and Storni 2014a).

The age of the newly diagnosed child was found to be a major factor in access to proper education and pump treatment, therefore, “If the children are under 5 there is really big education on that. So we were lucky that she was so young, I know someone that her 10 year old child was diagnosed in August and she can't do anything. I know the government is prioritizing the fives...” (Parent24).

**Sub-Theme 2: Diabetes education at home**

This is the largest sub-theme in the affinity diagrams (Figure 5). As a result, with the aim to show the most important issues concerned with the education at home, the findings are distributed and discussed in four subsections below i.e. First day at home, Parents educate themselves alone, Parents educate their children and ‘Pete the Pancreas’.

**First days at home**

Leaving the hospital brings many doubts, fears and questions. Some of the parents lacked the confidence in dealing with diabetes back home (Tsvyatkova and Storni 2014a). “We were so scared. He didn't get a low in the hospital and they were kind of
hoping he would. He actually got sick a week after we got home. He caught a flu and was very low and we couldn't get him up. He didn't want to eat anything. I was trying everything to try keep him up but it was a scary time.” (Parent11)

Returning home presented a challenge for all of the parents; they needed to deal with their new circumstances alone. “After a week we were sent home and it was kind of a difficult thing because normally when you leave hospital you are fixed, so we had to change our habits. We had to take records, make our own observations and make decisions based on those observations. Although we were given a bit of knowledge, it was not enough…” (Parent6) “It's like bringing home a new child, you've to watch the diet, write down everything the child has been eating. The times you took the injections, what you took, what were their bloods two hours after. So you're constantly pricking her finger, constantly monitoring, reading labels on food.” (Parent8)

The lack of knowledge and experience required constant communication with the care services asking for professional support and information. “When we left the hospital I think we had a bit of a grasp on it, but there was a lot of ringing to the hospital for adjusting insulin because when we left we still didn't have how to adjust it ourselves.” (Parent15) Most of the parents did not feel prepared for this great responsibility; this ongoing learning process in coping with the diabetic management created some kind of dependency on the specialist paediatric diabetes team. “I think the education that we receive needs to be empowering rather than building dependence... So, I think people need to go beyond the medical establishment for their support.” (Parent9)

**Parents educate themselves alone**

A mother complained that the education at the hospital “is only medical” (Parent8) and “the human side of it, you don't really know till you come home and then there isn't really anyone to turn to” (Parent8). Other concerns were related to carb-counting education, “…we were never told about the carbs, well we were told that it's really only carbohydrates on the back on the wrapper that you need to look at. The Carb counting is only something new to us really because we're looking for the pump…” (Parent11), “…the different slow acting carbs, there is absolutely no education around that…” (Parent7), “…six months guessing not knowing how to
really count carbohydrates, how to do anything…” (Parent2), “…loads of people will be waiting to get on pumps and they’ll be asked: Can you carb count? And there’s nowhere for them to learn.” (Parent9) and “Diabetes is carbs in, insulin to meet it. So if you don’t know how much of your insulin should meet your carbs, how you will maintain any control of that all?” (Parent24) (Tsvyatкова and Storni 2014a).

Parents reported that they needed to educate themselves because of the shortage of structured education programmes or diabetes educators because they needed to help their children learn about diabetes. “…you have to educate yourself…after the diagnose honestly I don't think there is enough courses” (Parent15) “There was another woman who had a small kid, no carb counting and no awareness of the hypos because the dietician who was out sick for months. This is happening quite a lot at the moment as there are no replacements and the newly diagnosed people have nobody to help them with that.” (Parent2) “You can go in the CHOICE programme only if you want your child to get a pump, if you say “No, I don't want a pump” you can't have this option to go in the CHOICE.” (Parent24)

**Parents educate their children**

One-week long education in the hospital is not enough for children to understand how to deal with self-diabetes management at home. Parents try to educate their children about the carbs-insulin relationship and why the injections are part of the treatment (Tsvyatкова and Storni 2014a). “It was just one puppet had C for carbs and one puppet had I for insulin. So they were on a little seesaw…and I said "What happens when you eat?" and she goes "Your carbs go up", so she knows what happens when she eats, "What do you need to make your carbs not go up?" and she goes "The insulin", so when you give the insulin, you see the seesaw balance.” (Parent4)

Children struggle to recognize the symptoms of hypo- and hyper-glycaemia as all the symptoms are new for them. Their parent’s role as educator becomes critical; they used a different approach by asking about the children feelings "...tell mummy how you feel?" and she said "I am really, really hungry". "This is a hypo, you need to remember it” (Parent4) or by telling some facts “I told her that when she has high [levels] that is why she feels thirsty.” (Parent5), or by giving examples of some past experiences gained through traumatic events: "Did you see what happened to you
that day?" He had a headache and he was starving, that was because his blood sugar was low. So he had a good idea…” (Parent23). According to one girl, these symptoms had not been discussed with her in the hospital, “I don't remember nurses talk about this; I just learned this from my mom and reading books. Every night I have read through it a small bit.” (T1DC8). A ten-year old boy explained that he has read many diabetes books in order to acquire more knowledge about the disease, hence, “the most information I got really was from all the books that I have read. We have a pile of them and now I have so much more information.” (T1DC25), while another two children lost interest on the topic “we had an opposite effect to that, because he is a very curious boy and he loves information but on that he didn't want to know. He does actually understand it, but he didn't really actually want to know about the pancreas…” (Parent23) and “…she'll read books all the time but she will not pick up a book about Diabetes. She just feels that she doesn’t want to know about it…” (Parent10). Their denial could be explained by fear of negative and scary information about the possible diabetes long-term complications in the text. Diabetes complications were a very emotional theme for discussion. Some parents used examples from their daily routine to explain the implications of improper care.

“But I used to say to her, “Now you need to look after yourself.” and when I'd be putting on my night cream I'd say “see, mommy's looking after her skin.” So when I'm older, I'll look better than those who didn't bother looking after their skin. So if you look after your Diabetes, you won't incur problems later down the line that people might if they're careless now.” (Parent8)

“What I try to say to her "Look you will be fine, but if I am in the car and I am driving at 90m/hr in a 30 mile zone I’d actually probably kill myself. Likewise with your body if you do anything that's outside the limits you are risking serious harm.” That is very fully hard to say to them without making them feel a horrible pressure.” (Parent2)

Using ‘Pete the Pancreas’ book

‘Pete the Pancreas’, an illustrated children's booklet explaining T1DM, was identified by the parents as the only educational material provided to their children at the hospital, so “They only provided us with those set of books for ‘Pete the
Pancreas” (Parent6) and “I don't remember that there were really any materials to teach her except 'Pete the Pancreas'. “(Parent15) When mentioned, some parents did not see the book as good enough, pointing out the limitations of “deep medical detail about not only the insulin, the doses, carbohydrate counting, the biology and everything else” (Parent6) and “I want to see clear and accurate explanations of the disease but only up to a certain age and appropriate level. I don't want to see talk about amputations and stuff like that…I want to see role models…I want to see, what we say to care givers…” (Parent9)(Tsvyatкова and Storni 2014a). A few participants shared their opinion about the images used in the book - not all children liked the cartoons, because they “preferred to look at the natural images…” (T1DC8).

“Interestingly enough she wasn't too interested seeing what the cartoon 'Pete the Pancreas' is about, she wanted to go to Google Images and see what a real pancreas looks like. She wanted to physically see it, she wanted to know where it is located as opposed to a cartoon. Cartoons are good especially for kids but she wants to know physically what it looked like. And then she wanted to know how it could be fixed and why it was permanently broken.” (Parent6)

A newly diagnosed thirteen-year-old child shared her experience after reading ‘Pete that pancreas’, the only book provided in the hospital for her age.

“They were trying to explain it simply but they weren't explaining it simply. So when you were first diagnosed and you had this book, if this was your first reading on diabetes you can see that the complicated things have been explained easily, they're trying to introduce glucose to you and energy to you really quickly…but it doesn't appeal to me the way it's done, it's not it doesn't explain it well…” (T1DC26)

For example, it was suggested that having visual representations of some processes in the human body that the book does not support could increase learning and knowledge acquisition in children.

“I think, children especially at that age they do more things visually (education), they can keep it in their head and will stay for longer I think. If you are able to show, this is your body and this is what
happened then, show things about human organs with more fun, they can actually see in a real sense what is happening. I think when she was diagnosed she really wanted to see it. ‘Pete the Pancreas’ was OK in description but actually it still didn't really show in real time.” (Parent15).

The parent has used the book with other healthy children in the family and in the school. “I have the ‘Pete the Pancreas’ book. I used that for my daughter to explain to her what was happening.” (Parent3), “I actually love to show them some child friendly stuff, just to sit down with his brother and sister we go through the stuff in the book.” (Parent23) “At that time we only had the ‘Pete the Pancreas’ book so the teacher read it out to the class.” (Parent15).

One of the interviewed children thinks that the book provides very basic information because “It didn't tell you everything but it told you the basics, just told you what it was to have a balanced diet, exercise, telling friends and stuff like that.”, but it would be nice to have information on “the good things of having diabetes. Go in some detail about it, talks more about what it is like at home.” (T1DC16).

A mother shared that the book didn’t help her when she tried to explain the relationship between the carbs and insulin “…Pete (the book) doesn't work anymore…” (Parent4). Despite the use of engaging visual material, the book is too general and does not seem to speak the language of the user. It is medical in a way that might upset some children, but it is also not medical enough for those who want to know more. In reducing diabetes to its medical categories (glucose levels, insulin, cells) it also fails to ground the book into an everyday life context. In this sense, it is normative more than practical, and after a while it is not used any more. When a child is diagnosed with type 1 diabetes, their “carefree days to a certain extent” (Parent1) are over. “No day is ever the same though, no matter how hard you try, and it's one of the most disheartening things, because you're trying your best and it's a 24-hour job.” (Parent7) “Things change every day…” (Parent2). There is always something new to learn for diabetic children. Contrary to that, education is static and occurs in predefined moments (Tsvyatkova and Storni 2014a).

‘Pete the Pancreas’ is the first educational set given to newly diagnosed children and their families in the hospitals; it is a basic guide on how to live with and manage
T1DM (Figure 7). The authors of this booklet are health care professionals working in Our Lady's Children's Hospital (Crumlin), The Adelaide and Meath Hospital (Dublin) and Temple Street Children’s Hospital (Dublin). Consisting of medical educational content, the set is made up of four pieces: two booklets (one for the children and one for their parents), a diabetes diary and a tri-fold brochure. The child booklet contains a combination of selected age-appropriate information on diabetes with colourful cartoon illustrations of the pancreas, human cells, etc. along with some realistic images – a quick guide that explains the various successive steps of using the glucometer and insulin pen/syringe. Young patients can read about possible diabetes signs that children may experience before the initial diagnosis, they can find information on the primary care physicians in the hospital, why diabetes occurs, the functions of insulin and pancreas in the human body, hypo- and hyper-glycaemia and their symptoms, and the meaning of ketones in blood and urine. Additionally, a few pages in the booklet elaborate on sick days, school and sports, summarising all tasks related to diabetes self-care. Three pages in the book are dedicated to a word search puzzle asking children to find the medical terms related to diabetes and drawings of human organs, cells and sugar for children to colour. The last page proposes some FAQs (with answers). The small book for parents is similar to the booklet written and designed for children, but contains more text on the injection sites, ketoacidosis, low and high blood glucose treatment, and daily diabetes care. The small diary helps children and parents to keep records on the blood glucose test results, insulin brand and units taken for each day. The tri-fold brochure is an exploratory guide for parents/guardians of children with diabetes.
According to the booklet developed for children, the participants noted various limitations (affinity diagrams, cluster ‘Pete the Pancreas’) such as:

- Does not have real images of the pancreas and stomach;
- Does not explain the relationship between the carbohydrates and insulin and their balance;
- Does not mention role models of people who achieved their dreams despite having diabetes;
- Does not explain diabetes complications;
- Does not have clear and accurate explanation of the disease at an age appropriate level;
- Some of the illustrations supporting texts for diabetes symptoms, sick days, ketones, hypo- and hyper-glycaemia were presented with sad faces.

The above discussion along with affinity diagrams helped to identify and illustrate the design requirements that emerged below.

**Sub-Theme 3: Educators & CHOICE**

Critically discussed by the participants in this study, diabetes education emerged as an issue; therefore, I looked at the current state of structured education in Ireland to discover its pros and cons (Section 2.2.3). I learned that the CHOICE structured educational programme is the best that can be offered to support the families in Ireland and I decided to investigate it. In this sub-category, I describe the education provided to newly diagnosed children and their families through the eyes of the dietitian (MP28), then give details on the CHOICE programme discussed by the educator MP29 available in Northern Ireland and in some diabetes services in Ireland. This helped to shed light on the benefits of diabetes education, but at the same time to illustrate the shortage and need of various educational materials that may facilitate and enhance the process.

Diabetes education was described as an “ongoing” process that is vital for all diagnosed individuals; it helps to correct the bad habits in patients by replacing them with new healthier ones, which is an essential component for effective treatment (MP28). This procedure could start in “the first three months” of diagnosis - this period is very critical “for putting in place good habits and for trying to establish
good care. I suppose people are very motivated at the beginning and trying to optimize that time to make sure that they have the best education helping to establish good habits that will hopefully continue on throughout life.” (MP28)

After the initial diagnosis, many factors can impact the education delivered in the clinic settings which strongly suggests that reviewing and revising the information obtained during the hospitalization of the child is strongly required.

“For the first maybe week or two after diagnosis parents are often very overwhelmed and they feel they've so much to learn, they've so much to think about that sometimes they say retention of information isn't the best because so many things [are] going on in their mind that it can be hard to retain information. That is probably the idea that coming back to clinic they get a chance to go back over things again. Even people who have had diabetes for years can forget certain basic things; there is definitely an element of re-education at certain intervals throughout the child’s life really.” (MP28)

Materials and recommendations used for the healthy diet and diabetes self-management education are only in a written format “just written materials that's all”, and nothing specific for children except the ‘Pete the Pancreas’ book (MP28). “I think some of the companies might do a little book called ‘Pete the Pancreas’ which is a character that introduces children [to] the idea of diabetes. They use images like [a] cell door, and insulin is the key to open the cells, but when it comes to food I haven't been using any kind of child specific book about food.” (MP28)

The booklet has a lot of medical content; it was written by health care professionals and “for learning I would say a book is useful to have, but is it the best medium?” (MP28). When it comes to young patients, carb counting education is more complicated, because it depends on children’s knowledge of mathematics that they usually obtain later in their formal education at primary school (i.e. fifth and six classes). “To be able to do carb counting and to adjust the insulin it involves a lot of say calculations... maybe the level of maths for like eleven or twelve-year-olds. So obviously, younger children would rely on their parents to make the calculations.” (MP28).
Commonly, the carb counting education for parents does not start until after the diagnosis, “the beginning it's quite basic, but I think it's enough at the start and then we'll say over time parents can build on their knowledge and they become more familiar with foods and it progresses from there, and then we'll say for people that're really ahead I suppose doing more advanced carbohydrate counting.” (MP28). Generally, “the education provided wouldn't be tailored to them (children), it's very much directed at their parents... from my point of view the education I provide is very much based about providing with information and talking about things. I don't use any other like say, teaching aids, or anything like that... at some point if there were some kind of interactive teaching materials that were available I think that will be helpful.” (MP28)

Educating children on diabetes self-care is more complicated: “the hardest part of designing a programme for kids is that they don't want to give up too much time for school” (MP29), and because when you “train as a dietician you have no background in education per say, I mean you are not taught to be a teacher, so I guess it probably would be nice to maybe learn about teaching methods or how to be an effective teacher. “(MP28).

Based on a nutritional education with carbohydrate counting, CHOICE is a short diabetes educational programme consisting of sessions (lasting three hours each and delivered in four consecutive weeks) whose aim is to help children and their families to take control of their diabetes (Chaney et al 2013). It was developed a couple of years ago because “there was never more specifically designed for kids” (MP29) education. The educator (MP29) highlighted the positive benefits of this family-focused refresher training, for example, she explained that having “one hundred and sixty kids that have attended” (MP29) this child programme, the results indicated that the educational sessions helped to improve not only “the kid’s quality life but it is also shown the reduction 3% on Hb1C which is significant and (has) long term health benefits” (MP29). Additionally, she explained that the immaturity of children is a factor that impacts their responsibilities and active involvement in self-management practices, therefore, the parents are those who require more education as they need to supervise the daily self-care process of their children.
“I think that is the issue that children were encouraged in self-management from the age of 8, encourage them to do their own injections… yes, they can do that but they still need supervision and especially during teenage years. But it is very individual, some kids at 7 are quite happy to do their own injections with supervision. But I am always saying with supervision; never have the child by itself.” (MP29)

The CHOICE programme in Ireland was launched in June 2013, but “we only start the first program beginning of February (next year) and that is the first time there’s been CHOICE here in (town name)” (MP28). It could be run “about four times a year that would only be twenty-four children at the end. I think there had been nearly two hundred children attending this paediatric centre” (MP28), so it would be difficult for each young patient and his/her family to get an opportunity to attend the programme.

Unfortunately, most of the educational materials provided to the children during the CHOICE sessions are “almost adult type” (MP28) and “I think for children something interactive is wonderful and they definitely like the cartoon figures things that are bright” (MP28) (Figure 8). Further refinement of the programme should focus on the information available, and presented in multiple ways including visual materials that would facilitate children’s practical involvement, so while they play they could learn about the chronic illness.

“I think definitely they (children) like visual materials, I don't think this programme offer a lot of models and materials that kids can do more hands on. If you have for example the pancreas as a model they can see and ask what happens that will be better for them. They love the fit models and look at the fit bits; they are very interactive on that as well. Given leaflets and talking to them doesn't work, they need a mixture of materials and practical exercise.”(MP29)
Figure 8: CHOICE materials used in the programme: First image - posters explaining some of the processes in the human body, Second Image - plastic food models with right sized portion circle graph, Third image - how to count the carbs in a plate and Fourth image - the use of glucagon

The above discussion along with affinity diagrams helped to identify and illustrate the design requirements that emerged below.

**Important for the technology design**

‘Pete the Pancreas’ – disadvantages

- Does not have real images of the pancreas and stomach;
- Does not explain the relationship between the carbohydrates and insulin and their balance;
- Does not mention role models of people who achieved their dreams despite having diabetes;
- Does not explain diabetes complications;
- Does not have clear and accurate explanation of the disease at an age appropriate level;
- Some of the illustrations supporting texts for diabetes symptoms, sick days, ketones, hypo- and hyper-glycaemia were presented with sad faces.

Interactive technology could enable and support diabetes education particularly designed for newly diagnosed children, it could be used in both medical and home settings.

IT characteristics, context and features:

- Encourages diabetes self-management in children at age of 8
- Clear and accurate explanations of the disease
5.2.1.3 Theme 2: Child’s Emotional State

While explaining the variety of difficulties in everyday diabetes management, most of the parents shared their child’s emotional state. As shown in the next series of extracts, their feelings and emotions were very strong; they struggled to accept the diagnosis, they hated it, they were devastated, they asked why? “She struggled I think a lot with the diagnose, she hates it...she hates everything about diabetes...I don't think that in her heart she has fully accepted it...Every day with tears she'd say “I hate diabetes, I hate my life. Why did God give it to me?”(Parent4) “…would be more or less in a certain amount of denial about it, in that she doesn’t like to talk about it…” (Parent10) “I wish I didn't have this, you know that don't you? I wish I never got Diabetes.” (Parent8) “…she still has days with "I hate this" (Parent5) “…there was a lot of “why me?””, “Why did I get this?”, “I don’t want this.” (Parent7) “He goes and he lies on his bed and cries till he comes out of it.” (Parent9) “…she had trouble accepting this, yeah...You could see she was devastated.” (Parent1) “She just hates it, she hated it a lot...that has made her more sensitive emotionally, I think that has had emotional and psychological effects on her” (Parent15)

Most of the young individuals with diabetes sought help to overcome their anxiety caused by the illness. “I was going through a rough path myself for diabetes because I was having anxiety. So I was kind of knocked down by that. Then I went to a psychotherapist to get help for that.” (T1DC26) “She got very anxious. She suffers a lot from anxiety I think because her life was so structured, there was a plan, there
always had to be a plan so she became like that. I had to take her to a child psychologist” (Parent8).

For example, one of the children during the interview got upset, and this happened “because talking about it makes me go back to when it was scary. Because it is scary at the beginning.” (T1DC26) Irrelevant questions in relation to diabetes can really hurt the young individuals; this created feelings of sadness and helplessness when dealing with the bad behaviour of others. “You know the stupid questions... like "Why aren't you fat, do you eat too much sugar, why do you do that to yourself, what causes it, why do you have it, why are you eating different?"” (T1DC26) “There were a couple of people like teens like saying "I have a pancreas but you don't", there was a boy and a girl. I was really upset, I didn't try to talk with them.” (T1DC8)

Similar attitudes from some pupils in the school may create a bad experience for children by asking “If I touch your sharks’ box will I get diabetes? Is diabetes contagious?” (T1DC26) or “...she's said to me that people are starting to comment about it (i.e. diabetes) now and asking her questions she doesn't want to answer... everyone in the school knows she's type 1 diabetic and it's tough on her…” (Parent7) As a result, many of the children felt anxious going to school, “...she was afraid to go to school because of the people saying that she is diabetic because she eats too much...” (Parent5)

Quite often these young individuals are excluded from various activities organised in school e.g. school tour or camps; most of the children have not went to sleepovers in their friends’ homes and have not been invited to birthday parties. Thus this makes them very sensitive to the topic (i.e. diabetes), feel “fragile” and upset, and need a lot of attention and protection.

“There was one particular tour I did have an issue with, well, it was a choir on in Dublin the year before last and all the class were going and everything was fine, I assumed that she was going up with them on the bus but then I was told to ring up the teacher over the choir and she said that she preferred if (child’s name) didn't go up on the bus, that the SNAs wasn't going and that could I go up with her. It was the first time her diabetes ever became an issue.” (Parent10)
“Oh, I find them awful (i.e. birthdays). He's only started going to them this year, I didn't really trust him enough last year, he only went to one or two but every time he comes home extremely high [blood sugar]...He's fine until the stage where all the party stuff is up on the table. He doesn't eat as much as the other kids but he still eats too much for himself.” (Parent11)

All these issues made children with T1DM feel different from other children.

“She did feel she is very different. She did get upset several times especially early on and we just let her cry it out. We'd talk to her about it. Let those natural feelings flow through as opposed to tell her to stop asking questions. We didn't try to block, we just tried to let her flow as much as possible because it is tough being a child and being different. We try to let her come to terms with this difference as opposed to other kids pushing it on her.” (Parent6)

“Obviously, at his age and being a child, there's a big need to be normal and this is something that defines him as being not normal. And this is very difficult for him. We obviously understand his feelings about this but we've never experienced it ourselves.”(Parent9)

Hiding their feelings, as a reaction to these various challenges caused by the illness, the young individuals do not want other people to know that they have this illness, as it is difficult for them to talk about diabetes. “My daughter would be more or less in a certain amount of denial about it in that she doesn’t like to talk about it.” (Parent10) “She has seen a psychologist and she started art therapy last week so that seems to work. She doesn't like talking about it, she doesn't like people knowing that she has diabetes” (Parent4)

Loneliness or social isolation could be triggered by this chronic condition; it can occur because the child “didn't have any pairs to discuss [the] disease and she didn't want to” (Parent15) or because they stay at their homes and shun other people: “the girl who had diabetes (her friend) didn't really want to go to anything anymore so we haven't heard from them (the girl’s family) in ages because she just didn't go to anything” (T1DC16).
The discussed findings indicated several key factors, taken into consideration when I designed and organised the followed UCD activities with diabetic children (Section 4.2).

### Important for the co-design process

Children refuse to discuss their experience with diabetes; they are highly sensitive and emotionally vulnerable.

- Choose design activities that could be less obtrusive facilitating ethnography in sensitive settings and that could have therapeutic effect while co-designing with children
- Co-design tools that could reduce the stress, minimize the appearance of negative feelings and emotions
- Work with one child or small groups of participants because children are not very open to talk in front of others about diabetes
- Plan time for managing diabetes during the sessions
- Plan tactics to deal with the negative feelings (if they occur)
- Focus on the participants’ preferences in choosing time and place for co-design sessions

### 5.2.1.4 Discussion: Interviews

The initial qualitative investigation helped me to highlight a series of key issues around paediatric diabetes self-management that have informed my future research, as well as the exploration of the available design space for intervention. Together with potential users (parents and children), I have identified limitations in diabetes education for newly diagnosed children shown in Theme 1 and the sensitiveness of the topic illustrated in Theme 2. I discovered that education is an essential element in diabetes care, as it helps to ground new care practices into the daily routines of a family. Three sub-themes illustrated the education provided to the families 1) in hospital after the initial diagnosis, 2) in domestic settings later at home and 3) by dietitians and the CHOICE programme. I have learned that current education tends to be too general, normative and universal. The data analysis showed that current educational practices seem inadequate to ensure that parents and children are well equipped to manage the illness in a domestic environment. When they leave the hospital, families are left alone to deal with a series of difficulties they are not familiar with (e.g. the emotional state of their children). At home, a parent first must acquire detailed knowledge about diabetes management and then become an educator of diabetes self-management practices. Children need to know how to interpret bodily signals, the relation between insulin, carbs and physical activities,
and how to behave during sick days. Each child is a unique individual. Children’s needs and care standards change with their developmental stages of life, and they need to constantly acquire new self-management skills. The parents and educators have outlined the limitations of educational materials for children with T1DM, but also claim that written information combined with practical training and guidelines are imperative in preventing the risk of long-term complications. During the early stages of this research I realised that this direction of research was promising and needed to be explored further (Tsvyatkova and Storni 2014a). The following section reports on some of the most evident categories of data revolving around this key issue. These findings encouraged further investigation by examining valuable sources such as educational materials, books, brochures, educational programmes, paediatric services, model of care in Ireland, etc. (Section 2.2.3), as well as educational technology developed for children with T1DM (Section 2.3.2). Therefore, the formation of the concept of interactive technology design was triggered by the analysed qualitative data, but was also complemented by an additional study on the educational tools and materials/processes available for the families. As a result, I have decided to explore the role of new interactive media (such as digital storytelling, interactive eBooks) for newly diagnosed children with T1DM. Some research in the ambit has been done (Wyatt and Hauenstein 2008). “Digital stories have great potential for teaching health and management of chronic diseases” but “they have not been thoroughly explored as a delivery method for promoting health and well-being in children” (Wyatt and Hauenstein 2008).

Additionally, Theme 1 (Section 5.2.1.2) and Theme 2 (Section 5.2.1.3) helped to identify and outline respectively the content of the educational technology design, and the methods, techniques and tools for the following (i.e. design, prototype and test) activities in performing UCD (discussed in Section 4.2, Section 5.2.2, Section 5.3, Section 5.4 and Section 5.5). For example, Theme 1 helped 1) to recognize the age group of the users (i.e. newly diagnosed children between 8 and 12 years of age) as children at age 8 are encouraged to learn some of the self-care tasks related to the use of conventional insulin administration and blood testing and 2) to develop a list with some of the characteristics, functions and features that the eBook design may support, based on what participants did not find in the ‘Pete the Pancreas’ book (i.e. age appropriate context, visual representation of the human organs describing
diabetes, role models, healthy food, diabetes complications, symptoms recognition, etc.). Illustrating the children’s stress in coping with the illness, their struggles to accept the diagnosis, the accumulation of negative thoughts and feelings towards diabetes, and their reluctance to talk about diabetes, etc., Theme 2 clearly suggested that careful consideration of the co-design activities for involving children in design was crucial. To support users’ participation and their active role as equal stakeholders and to deal with these challenges, a series of creative interventions for IT design have been tailored, adapted and used with this group of young individuals and their parents. In Section 4.2, I discussed two reasons for selecting the design probes (Wyeth and Diercke 2006), collaborative storytelling (Alborzi et al 2000; Druin 2002; Fails et al 2012) and layered elaboration (Walsh et al 2010). The first reason was because some of these activities were pointed out in the Årsand and Demiris (2008) framework (Section 3.3 and Section 3.5) as being beneficial to the development of self-help tools for people with chronic illnesses, and the second was because 1) the design probes support a form of communication by generating and collecting data unobtrusively in sensitive settings (as showed by Crabtree et al 2004), 2) the collaborative storytelling method is quite often used in (CBT) with children facilitating self-expression - it is one of the traditional approaches in treating young individuals to help them explore difficult feelings through playful materials (Friedberg 1994; Friedberg and Wilt 2010; Handler 2012) - and 3) the layered elaboration technique is easy to use by participants of various ages; it suggests reflection on the prototypes through drawing and writing text on transparent sheets without destroying the original artefacts. Other considerations were focused particularly on organising the workplace for the meetings and sessions with the families, developing strategies to deal with some negative feelings if needed while working with diabetic children and planning time for breaks in which the young individuals could manage their chronic condition (i.e. having snacks, taking insulin, etc.).

As stated in Section 4.3, I experienced problems with recruiting participants for this study. Considering that parents are very busy with the constant care of their diabetic children, they have struggled to find time to be interviewed and the recruitment of the volunteers was a challenge for the researcher. The difficulties in interviewing the children were not only related to ethical reasons - constant adult supervision was
required - but also to their resistance to talk about diabetes, often seen as something that ‘makes them different’ (Tsvyatko and Storni 2014a).

This study helped me to gain a deeper understanding of the paediatric self-care process, to identify the potential role of interactive technology in supporting diabetes education and to fine-tune design tools facilitating collaborative work for technology development, enabling the collection of empirical data important for finding the answers to my second and third research sub-questions. The following sections describe the development of the eBook design with the participants through the implementation of the design activities discussed above.

### 5.2.2 Design Probes

I have used Design Probes as a communication tool supporting designers to collect self-documentation data from children and parents about their everyday tasks in chronic disease management (Section 4.2.1). As often discussed (Wallace et al 2013), the goal is not to establish facts about diabetes, but rather to develop an understanding of the individual’s perspective so that the design can better relate and resonate with the user’s actions, intentions, emotions and environment (Boehner et al 2007; Mattelmäki 2006; Tsvyatko and Storni 2014b). Moreover, this investigation aimed to explore the adaptation and design of appropriate probe activities that could better facilitate users’ engagement in using the provided materials, as well as to inform the design and development of an educational interactive eBook for newly diagnosed children and their families. This method has its benefits, particularly in gaining deep insights into the users’ lives and their needs with minimal intrusion early in the design process (Crabtree et al 2003). Diabetes management is, however, constant and ubiquitous (Storni 2013a); paediatric diabetes involves a series of actors (parents, child, nurses, doctors and their perspectives) and different sites (home, school, playground, hospital, and their practices, etc.). Gaining first-hand experience of an issue such as diabetes is very difficult: extensive ethnographic observations are difficult in domestic settings, especially in relation to such a sensitive topic; the interviews with parents were greatly informative, but children were reluctant to talk about their experience (parents were concerned that talking about diabetes was going to upset some of the children), therefore I decided to develop DPs (Tsvyatko and Storni 2014b).
Aiming to identify how to adapt and design probes (i.e. materials, activities, number of tasks, time, etc.) that could improve participants’ engagement to complete the probe kit by working with all suggested activities, the modified probes - for 8 to 12-year-old children who have diabetes and their parents - have been applied in two iterations. In the first cycle they have been used in the UCD for defining users’ requirements: the set contained eight probes distributed (i.e. seven for children and one for their caregiver) to seven families (Tsvyatkova and Storni 2014b). For the second iteration applied in the prototyping stage, the most favoured four of the eight activities used in the first round have been selected and used again by five new families. This section describes and discusses 1) the procedure of recruiting participants for both iterations of DPs (Section 5.2.2.1), 2) the strategies used to adapt the probe materials for young users with T1DM and their caregivers (Section 5.2.2.2), 3) the distribution and collection process and users’ responses (Section 5.2.3.3), 4) the collected and produced materials in the sets through the first and second cycle (Section 5.2.2.4 and Section 5.2.2.5) and 4) the results generated through the use of this method (Section 5.2.2.6).

**5.2.2.1 DP: Participants’ Recruitment**

Two successive stages of participants’ recruitment were carried out for both iterations in which the DP method was applied (Table 7). In the first, the recruitment of participants for probes was performed among the parents who had already been interviewed and who expressed their interest in continuing with this study. Seven volunteering families\(^{52}\) - the parents who have children with diabetes between 8-12 years of age - agreed to participate (Tsvyatkova and Storni 2014b). The second cycle was conducted in the prototyping stage after the session in Trabolgan had been completed (Section 5.4.1). Five of the children (aged 12) who articulated their willingness to work with the probe materials decided to take a set to use at home (Table 7). Therefore, the sets (e.g. eight probes) for the first iteration were distributed to the participants between 23 April to 10 May (2013), while the sets (e.g. four probes) for the second iteration were handed out to the young individuals on 29 March (2014).

---

\(^{52}\) As stated in Section 4.3, to keep confidentiality and anonymity of different groups of individuals who took part in this study they have been designated as Parent1, Parent2, etc. and T1DC1, T1DC2, etc (Table 5).
Table 7: Participants in first and second iterations

<table>
<thead>
<tr>
<th>First iteration</th>
<th>Second iteration</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants</strong></td>
<td><strong>Participants</strong></td>
</tr>
<tr>
<td>Parent4&amp;T1DC4</td>
<td>8 years old girl</td>
</tr>
<tr>
<td>Parent5&amp;T1DC5</td>
<td>12 years old girl</td>
</tr>
<tr>
<td>Parent6&amp;T1DC6</td>
<td>8 years old girl</td>
</tr>
<tr>
<td>Parent7&amp;T1DC7</td>
<td>9 years old girl</td>
</tr>
<tr>
<td>Parent8&amp;T1DC8</td>
<td>12 years old girl</td>
</tr>
<tr>
<td>Parent9&amp;T1DC9</td>
<td>9 years old boy</td>
</tr>
<tr>
<td>Parent10&amp;T1DC10</td>
<td>12 years old girl</td>
</tr>
</tbody>
</table>

5.2.2.2 Adapting Design Probe Materials for Children with Diabetes and their Parents

This part describes the fine-tuning stage in which the design probes package was designed to explore, familiarise and better understand young users’ needs, issues and perspectives regarding self-care practices in paediatric T1DM. During the interviews (Section 5.2.1), the parents discussed various challenges that emerged throughout the everyday self-care activities in dealing with diabetes, the difficult lives of their children, the complicated relationships with friends and relatives causing negative emotions, etc. This data also helped me to devise and select the activities in the set of probes. The box for the first iteration of the DPs implementation contained seven probes for children aged between 8 and 12 who have diabetes (Figure 10, Figure 11, Figure 12, Figure 13, Figure 14, Figure 15 and Figure 16), and one for their parents/guardians (Figure 17) while in the second rotation, the set included only the four activities (Figure 10, Figure 11, Figure 13 and Figure 15) which were favoured in the first cycle (Table 8).

All of the activities were open-ended to provoke children’s creativity and imagination, facilitating the production of rich and descriptive data. For each probe, a large colourful box was used for the materials, with labels and instructions (clear and expressed in child-appropriate language suitable for the age-group). All activities in the probe set were understandable to children used to having pre-structured materials. The aim was to encourage children’s creative thinking and to help them to express their unique interests and needs, to document their own self-care practices, feelings and experiences with diabetes. The boxes with the probes have been constructed in a way that allowed me to carry them easily, as I have travelled to meet each participant for the distribution and collection process. Below, I describe the
intended purpose of each probe material and how these have been adapted (Tsvyatкова and Stormi 2014b).

A pilot study with one healthy child was carried out to test the materials, activities and instructions in the probe kit; this helped to refine the probes before being distributed to the intended users. A problem with working the disposable cameras, especially for taking photographs indoors, was identified. Therefore, very clear instructions about the use of the ON/OFF flash activation button and rotation of the film advance wheel (Figure 9) were attached to the probe pack with the disposable camera.

![Instructions - Disposable camera](image)

**Figure 9: Instructions - Disposable camera**

1. **Disposable camera**

For this activity I had a disposable camera, a series of sticky labels with numbers (1 to 22) and a list with 22 picture requests (Appendix E) for the children (Figure 10). The purpose of this probe was to learn more about the children’s points of interests, how diabetes influenced different daily activities e.g. sports, visiting places, meeting with people, playing outside with friends, and things they liked or disliked, such as books, food, toys, etc.
2. Technology gadget design

All materials provided in this probe were to facilitate users’ inventive thinking, enabling children to expose their ideas by creating solid models of existing or imaginary objects, to display their concepts for user interfaces and to show the function attributes of novelty items designed by them. In this activity, children were asked to design a technological gadget that could help them in their daily life. Safe arts and crafts materials such as pipe cleaners (regular and short), buttons, beads, feathers and foam blocks (Figure 11) allowed children to use their creativity and imagination whilst developing solid objects. Number 21 in the pack (Appendix E) was added for taking pictures with a disposable camera, helping to gain information addressing the range of functions of their new gadget and its purpose.
3. Send a postcard

Taking into account the parents’ concerns about shared care responsibility in the family illustrated below, I have decided to use postcards as a tool to learn more about the children and their relationship with other family members, teachers, friends, relatives, etc.

“The only thing which bothers her was she never got to go to sleepovers...My mother lives in the north and she wants to stay there like sometimes in the summer and then maybe go on home. No problem but I can't leave her on her own, I didn't want to give my mum that responsibility.” (Parent5)

In the pack, I had seven illustrated postcards with stamped envelopes, glue, a pack full of decorative material and a list with ‘common’ people (your doctor, your granny, your teacher, your cousin, your classmate, Santa Claus and me) to send the postcard to (Figure 12).

![Sent a postcard](image)

Figure 12: Sent a postcard

4. Design collage/poster

This idea was taken from one parent who discussed how designing a poster for World Diabetes Day positively changed the attitude and life of her daughter.

“She became fascinated when she did the poster for the World Diabetes Day. She knows who discovered the insulin and how we discovered insulin and what he did. She gets very fascinated by that, the first boy who had insulin, she remembers his name now and
everything, she could tell his name, what age he was. From that point it is good for us as we tried to get her interested in that, because she shied away for so long. Then she started to love looking at famous people that have diabetes. And she would tell everybody such and such people had diabetes, stuff like that she was studying in Thomas Edison. Thomas Edison has type one or type two diabetes and she were telling everybody, excited.” (Parent4)

Trying to provoke children’s interest and curiosity with the topic (diabetes), this probe contained arts and crafts materials (Figure 13) that children use to develop their own collage/poster for an imaginary World Diabetes Day that they will present in class. Items included in this probe were an A1 white sheet paper, art materials (i.e. glue, scissors, water paint, coloured pencils and markers), sticky images and coloured paper that children could use to explore their idea. Also, children may use additional information such as images and text taken from magazines, the internet or other resources that may help participants to develop the design of their poster/collage.

![Design Collage/Poster](image)

**Figure 13: Design Collage/Poster**

5. Kid’s diary

Trying to escape the tedious and boring activity of diary writing (I found out that the traditional method of keeping a diary is not motivating enough (Wyeth and Diercke, 2006), I devised a graphical diary to provoke comments and reflections about self-monitoring and autonomy in children. I designed a template called “circle of activities” with five sectors. For each sector, I had a deck of images available for the
children to use to stick on the segment appropriate for their activity (Figure 14). The goal was to characterize diabetes related events (e.g. an accident) based on the five sectors: place where the event occurred, people who participated in that event, physical activity related to the event, used tools, and feelings. For example, they could use the image of a pump or of an insulin pen to describe the tool they used to inject insulin; they could use the image of a home or school to show the place where the insulin was taken. For participation or help, they were provided with the images of a teacher, parent, etc. I also used different images related to sports and physical activities linked with the event in question, and finally for the feelings segment, we gave them images representing hunger, dry skin, drowsiness, etc. A pack with small faces (ranging from sad to smiling) was also provided to help characterize the emotional state attached to that particular event. Children were also invited to decorate the diary and write supportive or other information they wished to share.

![Figure 14: Kids diary](image)

6. **Superhero and a story of his/her power**

Children were asked to use modelling clay to model a figurine of a Superhero who will help and support them in diabetes management. In order to help children develop the character and to write a story for the Superhero, I provided them with a series of questions (Figure 15) regarding the name of the hero, his/her work and power, and how the Superhero helps all children with diabetes. The aim of this activity was to get inspiration and hopefully develop one of the characters in the interactive educational eBook that was being planned.
7. Design your own Recipe Book

As reaffirmed in the exploratory interviews with parents, diet is one of the most difficult parts of diabetes management.

“The diet, I suppose…. She loved very sweet things…” (Parent1)

“The diet…She was so obsessed, too sugary, too fat.” (Parent4)

“I think it is the diet. She loves eating.” (Parent5)

Parents struggle with managing the child’s diet (especially avoiding sugar and balancing carbohydrate intake). Some of the parents use recipe books to help them with the ingredients and with counting carbohydrates (a key factor in a diabetes diet as carbohydrates are broken down into sugar by the body). With this probe I gave the children an opportunity to design their own recipe book, as the collected data would help to develop the interactive game elements in the eBook for healthy food. The book had four sections for breakfast, lunch, dinner and snacks, and a nice recipe template to fill (Figure 16).
8. My problem solving diary (parents)

Parents are very busy, working very hard to manage the activities of their family and constantly care for their diabetic child. I had only one activity for the parents and this was aimed at collecting stories about emerging problems and how they are dealt with. In the diary, each page has five sections where parents were asked to write their own concerns about diabetes care, feelings, emotional reactions, personal control of the situation, steps they take in solving identified problems, and lessons learned (Figure 17).

Figure 16: Design your own Recipe book

Figure 17: My problem solving diary
5.2.2.3 Distribution, Collection and Responses

As stated, seven sets were produced and distributed to seven families (Table 8). Individual meetings were organised with each parent to hand out the box and to explain the materials and activities placed in the kit and their instructions. Participants (i.e. parents and children) were asked to return the completed probes in a month’s time. A total of five probe sets were returned to the designer after the specified time (Parent4&T1DC4, Parent7&T1DC7, Parent8&T1DC8, Parent9&T1DC9 and Parent10&T1DC10, Table 7 and Table 8). A short follow-up interview with each volunteer during the collection process helped to gain more information in ascertaining the meanings of the newly produced artefacts and to articulate their ideas.

The most favourite activity for children was the Design Collage/Poster; all children produced their own poster for the imaginary World Diabetes Day (Table 8). Four young participants liked the Technology Gadget design, and the Superhero and a story of his/her power. Three of the children played with the probes requiring pictures by using the Disposable camera and Send postcards to their friends, relatives, etc. Less attention was paid to the materials facilitating the work of the Kids diary and Design of a personal Recipe book, having garnered only two and one response respectively.

<table>
<thead>
<tr>
<th></th>
<th>First iteration</th>
<th>Second iteration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity</td>
<td>Responses</td>
<td>Activity</td>
</tr>
<tr>
<td>Disposable camera</td>
<td>3</td>
<td>Disposable camera</td>
</tr>
<tr>
<td>Technology Gadget design</td>
<td>4</td>
<td>Technology Gadget Design</td>
</tr>
<tr>
<td>Send a Postcard</td>
<td>3</td>
<td>—</td>
</tr>
<tr>
<td>Design Collage/Poster</td>
<td>5</td>
<td>Design Collage/Poster</td>
</tr>
<tr>
<td>Kids diary</td>
<td>2</td>
<td>—</td>
</tr>
<tr>
<td>Superhero and a story of his/her power</td>
<td>4</td>
<td>Superhero and a story of his/her power</td>
</tr>
<tr>
<td>Design your own Recipe book</td>
<td>1</td>
<td>—</td>
</tr>
<tr>
<td>My problem solving diary</td>
<td>4</td>
<td>—</td>
</tr>
</tbody>
</table>

In the second iteration of applying DPs only four were used - the most favoured activities by the children: Disposable camera, Technology Gadget Design, Design Collage/Poster and Superhero and a story of his/her power (Table 8). After the prototyping session in Trabolgan had finished (Section 5.4.1), five sets were given to five children; the time for returning the sets was expanded to eight weeks with a hope
to increase the probes response rates. After two months four sets were collected (T1DC16, T1DC17, T1DC18 and T1DC19, Table 7). In the returned boxes, all four probe materials had been used by the young individuals. Two focus groups with the children and their parents lasting for 20 mins each (Parent17&T1DC17, Parent18&T1DC18 and Parent19&T1DC19) and one follow-up interview of around 10 mins (Parent16&T1DC16) were carried out to discuss the probes produced by the children. The focus groups and follow-up interviews for both iterations of applying DP were conducted in quiet places chosen by the adults.

### 5.2.2.4 First Iteration with Eight Activities: Collected Materials

The following is a discussion on the collected individual data produced by children and their parents using the kit with eight probes designed for the first iteration of the DP method. At the beginning, I started with the Design posters/collage activity as this probe provoked great interest in the children. Wyeth and Diercke (2006) also used a collage in their DP pack but they didn’t get any responses from the young users. Contrary to that experience, I have observed that designing a poster/collage for the World Diabetes Day was one of the favourite activities for the children who participated in this study (Table 8). This helped the children to articulate what they would like others to know about their diabetes; they sought out “positive role models” as an example of how they can achieve their dreams despite diabetes.

All children used their posters to explain technologies facilitating diabetes management (i.e. glucometers, insulin pen, and insulin pumps), to point out famous people with diabetes, to provide facts about this chronic condition, as well as to write down some of the feelings experienced by them prompted by the diagnosis and by living with the illness. For example, three children (T1DC4, T1DC9 and T1DC10) pointed out the names of footballers, actresses, rowers, scientists, singers, etc. who have diabetes (Figure 18, Figure 21 and Figure 22). Information on diabetes statistics was observed in two posters; “Type one or Juvenile diabetes affects 70 000 children under the age of 15 every year” (T1DC4) and “247 million people have diabetes” and “1 in 400 children have diabetes” (T1DC10). A lot of the drawings were used to describe diabetes self-management practices. These illustrations depicted the portable computerized devices for conventional insulin administration and for the control of blood glucose levels (T1DC11, T1DC12 and T1DC14), but only one child explained their functions – “The insulin pump is a device that gives you insulin
through a cannula which is much easier than injections, you simply key in your bloods and carbohydrates and it will calculate how much insulin you need to cover what you eat.”(Figure 20, T1DC8). A 9-year-old girl used smiley faces with different facial expression to rate the numbers of low, normal and high blood glucose levels in diabetes (Figure 19, T1DC7).

Figure 18: Poster, T1DC4 (8-Year-Old)

Figure 19: Poster, T1DC7 (9-Year-Old)
Wrong interpretations of type 1 diabetes were mentioned, mainly on what causes this disease. “Just because diabetes sounds like die, well it is spelled dia because people always say that but they don’t know anything about diabetes” (Figure 18, T1DC4) and “People say you get diabetes from sugar that is not true you get it any time” (Figure 18, T1DC4). Only one child mentioned the concept of a balanced diabetic diet in her poster; she gave some examples of fruit and vegetables that are “healthy for diabetes” (Figure 22, T1DC10). The other participant highlighted that even with having diabetes she “can still have sweets” (Figure 18, T1DC4).

Feelings after the diagnosis (i.e. "I was very scared when I was diagnosed as I did not understand at the time") and how diabetes changed her personality (i.e. “Diabetes has changed my life completely - it might be a pain but I wouldn’t be the person I am without it") was written on the poster made by a 12-year-old girl (Figure 20, T1DC8).
A less popular activity was the Technology gadget design probe - four young participants (T1DC4, T1DC7, T1DC8 and T1DC9) used materials to visualise their ideas of a design of a supportive device (Figure 23, Figure 24, Figure 25 and Figure 26). This activity was particularly appreciated and seen as fun. Children produced their own concepts explaining the gadget features, functionality and its practical use. The tangible objects that were developed are: a non-invasive glucometer-bracelet (Figure 23, T1DC8) and a combination of a glucometer and an insulin pump (Figure 24, Figure 25 and Figure 26). The glucometer takes data from the blood and sends it to the pump for the automatic adjustment of insulin in the body (Tsivyatkova and Storni 2014b).
Materials such as modelling clay encouraged children to think creatively in making their own choices for developing original ideas about the story character Superhero and to describe the vivid settings in which their protagonist would use his/her unique superpowers to help individuals with a chronic illness such as diabetes. The aim of this activity was to get inspiration and hopefully develop one of the characters in the interactive educational eBook that was being planned. Four children modelled a figurine of their Superhero and answered the questions. The produced results were extremely rich. One of the stories described “Hypo-Hyper Man” as a scientist (Figure 27, T1DC8). During the day he tries to find a cure for diabetes and by night he protects children having high or low blood glucose levels.

In other stories, the central characters of superheroes were Captain Baby (Figure 28), Helper D (Figure 29) and Michael (Figure 30); they all have powers to support other children managing their illness such as helping them “with pump sets, changing needles and carbs” (Figure 29, T1DC4) and “to do the right thing when there is a problem with their diabetes” (Figure 30, T1DC7). Modelling clay with different
colours gave great options to the users to add fine details of face, hair and clothes and other information instead of using more difficult expository and descriptive writing in illustrating the characteristics of a person, event, etc.

Less interest was shown by children in using the disposable camera probe suggested in the DP box; three young individuals took pictures using the pack with consecutive numbers and the list with picture requests (T1DC4, T1DC7 and T1DC8). From their photographs, I have learnt that participants with diabetes do not like: vegetables such as mushrooms (T1DC4) and green peppers (T1DC8), books ‘Dork Diaries: Pop Star’ (T1DC7) and ‘Artemis Fowl’ (SC8), sports such as soccer (T1DC8) and activities in outdoor playgrounds (T1DC4). It was found that they all had taken photographs of people that they love - family members such as their sister (T1DC4 and T1DC8) and father (T1DC7). It was possible to discern the favourite and least favourite toys from the images: a doll (Figure 31, first image) and a teddy bear (Figure 31, third image) respectively. The second image (Figure 31) is a picture of an animated/cartoon movie that participant T1DC7 enjoys watching. Unfortunately, many photographs were of poor quality because of the children’s inexperience with the use of disposable (not digital) cameras. For instance, even with the clear instructions, many had problems with activating the flash (key for taking pictures indoors), moving the advance wheel to wind forward to the next picture, and to determine the distance between the object and camera (disposable cameras have no screen) (Tsvyatkova and Storni 2014b).

![Figure 31: Disposable camera](image)

Participants decorated postcards conveying their messages to different imaginary and real recipients by adding nice drawings and images provided within the probe. Analysis shows that most of the postcards were addressed to children’s friends (Figure 32 and Figure 33) and only a few to their relatives (Figure 34). Diabetes requires control and can be frightening for people who don’t know how to deal with
T1DM in children. Sharing responsibility demands knowledge and practical skills in diabetes care in both children and adults who will care for them.

Figure 32: Postcard to friends, T1DC8

Figure 33: Postcard to the best friend, T1DC4
The kid’s diary was designed in order to gather information on the daily tasks performed by children and their parents managing the illness. It was not necessarily aimed at establishing any facts about their self-management, but to elicit comments about self-monitoring and their autonomy from children. For each day the child could have between 4 to 6 circles, depending on how often she/he has taken insulin or how actively she/he has written these events down in the journal. Unfortunately, only two participants used the materials for keeping their own diary (T1DC4 and T1DC8). One of the children (T1DC8) gave information about the hyperglycaemia detected at her breakfast (Figure 35). For problems, she glued the image of “extremely thirsty” that corresponded to her state perceived at that time.

![Figure 34: Postcard, T1DC7](image)

![Figure 35: Detecting hyperglycaemia, T1DC8](image)  ![Figure 36: Pain in the stomach, T1DC8](image)

Usually, these states are taken as warning signs of high blood glucose level. Additionally, using text she detailed that this condition was triggered by eating
sweets on her birthday. On the same day before her lunch, the girl had a pain in her stomach as she was very hungry. So, she illustrated her state by using a small yellow face (i.e. it was OK) that corresponded with her difficulties in dealing with high blood glucose levels (Figure 36).

![Figure 36: Diary, T1DC4](image)

The second child - an eight-year-old girl (T1DC4), used her diary in different settings. For example, she documented how at home before bed time, she watched TV, she adjusted the settings of her pump alone and she felt very drowsy, but this feeling did not change her mood (Figure 37, first image). At school during big break she got help from her teacher with the insulin pump settings and she was actively running with other children (Figure 37, second image). One day the child had fun with her friends in the swimming pool but only for one hour as she could not stay longer without wearing the insulin pump. As a result, the young individual had problems with her blood sugars and she felt very unhappy not being able to swim in the water with other kids (i.e. red colour of small faces) (Figure 37, third image).

Following the individual eating pattern, children are very sensitive to food (Section 5.2.1.2 and Section 5.2.2.2). Parents use different methods to motivate children to eat their healthy meals. The recipe book was designed to collect data on children’s preferences for healthy food for use in the design of mini-games integrated into the eBook story. The results had low responses (only one), which can be explained by children having traumatic experiences in relation to food intake (Figure 38). The child shared three recipes - tea and toast (first image, Figure 38), pancakes (second image, Figure 38) and fish in breadcrumbs (third image, Figure 38). This really reinforced the parents’ assertion about the problem with food in paediatric diabetes.
Figure 38: Recipes, T1DC8

The last activity in the set was designed for the parents/guardians. Diabetes is a chronic illness which requires constant care and every day is different (Section
5.2.1.2). Parents and children face different challenges, make multiple daily self-care decisions when it comes to managing paediatric diabetes every day. Each family has different lifestyles and daily routines based on their own personality styles. In the parent’s problem solving diary, each page has five sections with five questions asking people to tell about their experienced problems, how those have been solved and the lessons learned: What is the issue? How did you react? Did it work? Did you learn any lessons? Other comments? Parents could use the diary when they had an issue related to their child’s diabetes management, and were encouraged to write down their own concerns, feelings, emotional reactions, personal control of the situation, steps that they took in solving the problem and of course, the lessons learned.

The parent’s diary gave rich examples of the constant stress provoked by different issues related to the health of their children; struggles to make the right decision and lessons learned dealing with the problems (Figure 39). Most of the provided examples revolved around: sharing responsibilities with family members and institutions (schools and playschools) (Parent4, first image, Figure 39), holiday traveling and diabetes (Parent8, third image, Figure 39), GP appointments, pump settings (Parent7, third image, Figure 39), high or low blood glucose levels, helplessness and tiredness described by parents trying to control diabetes (Parent9, fourth image, Figure 39).
5.2.2.5 Second Iteration with Four Activities: Collected Materials

As stated, in this second iteration of exploring DP, only the most successful four probes in the set were given to the young individuals with diabetes. I have met with the children again, individually (T1DC16) and in a group (T1DC17, T1DC18 and T1DC19), to collect newly produced artefacts in the kits. This gave them the opportunity to explain their ideas for Superhero stories, to describe what text, pictures, drawings, etc. they had used in their posters/collages describing type 1 diabetes and to give details on the gadgets and their functions.

All children really liked to work with the arts and crafts materials in the activity that facilitated the development of the technology gadget; they all stated that this probe was their favourite in the designed pack. They spent time decorating their gadgets nicely by using feathers, many antennas and buttons helping to visibly display their functionality and appearance; all the devices suggested by participants aimed to facilitate users with type 1 diabetes. For example, T1DC19 suggested a new generation glucometer; she excitedly explained its features and functionality (Figure 40). “Here is the place for finger pricking. When you put your finger there it will take blood to measure your sugar (Figure 40, first image). And then if the blood is low 3.5
(Figure 40, second image) it dispenses sweets (Figure 40, third image). The technology also has built red and green light indicators, red will light up when the blood sugars are low while the green will indicate that the blood results are normal.” (Figure 40, fourth image).

Figure 40: Prick the finger (first image), Low results (second image), Sweet Dispenser (third image) and Light Indicators (fourth image), T1DC19

Figure 41 shows a gadget that would work together with the insulin pump. Connected wirelessly to the pump, the tool would monitor the blood glucose levels of the users. This device would warn the users by beeping when their blood sugar is very low then, being capable of speech, the technology would communicate some of the options to treat this condition, as well as supplying the appropriate amount of sweets (T1DC17).

Figure 41: Wireless gadget, T1DC17
An insulin pump that looks like a phone was suggested by T1DC18. One of the functions is to display high or low glucose levels of the users onscreen. There was a button that would correct these states automatically. A small handle attached to the pump was designed to carry the object comfortably; Menu and other buttons such as Up and Down, Take blood test, Yes and No were the suggested selection of various functions for continuous subcutaneous insulin infusion (Figure 42).

![Figure 42: Insulin pump similar to mobile phone, T1DC18](image)

Composed of two components, the magic tele-transportation machine is a gadget that would be designed especially for children with diabetes (Figure 43). With many spiral antennas made of pipe cleaners, the first module facilitates tele-transportation while the second piece is a teleporter that activates the whole process. When the child with T1DM has a day in which she/he really does not like dealing with diabetes or has some difficulties with the self-management activities, the user could press one of the buttons to trigger the journey to a different island (Figure 43, second image).

![Figure 43: Tele-transportation machine, T1DC16](image)
Children used different colours of plasticine to add many details to face characteristics, clothes, hair, etc. in developing their beautiful figurines. In the stories described by the children, Superhero is a female who has a magic power to help all children with T1DM. For their main character, different names were suggested i.e. Lightning girl (Figure 44, T1DC16), Debbie Diabetic (Figure 45, T1DC19), Ailish Ryan (Figure 46, T1DC18) and Information genie (Figure 47, T1DC17).

By having supernatural powers, they have the ability to fly (T1DC19), to be “super flexible and an amazing dancer” (T1DC18), to give “instant knowledge to everyone she touches” (T1DC17), and to “go anywhere in the world as quick as lightning” (T1DC16). In one of the stories Superhero helps “children with diabetes by going to their houses as fast as lightning and healing them to prevent fear of needles or set
changes, helping them if they have severe highs or lows that they can’t manage” (T1DC16). One child suggested that by touching young patients the Information genie gives diabetic children knowledge about the carbs in food and insulin, and also stops other healthy children asking silly questions (T1DC17). In other narratives, Debbie Diabetic helps newly diagnosed children understand diabetes (T1DC19), while Ailish Ryan shows how to use insulin pumps and glucometers (T1DC18).

Young participants also made nice and colourful posters/collages for the imaginary World Diabetes Day. Most of them described and showed the symptoms and the main causes of diabetes, the purpose of measuring the glucose in the blood (i.e. “Monitoring the amount of glucose in your blood is part of the daily care of your diabetes. It gives you information on how well you are controlling your diabetes” (T1DC19)), the functions of innovative devices such as glucometers and insulin pumps (medical technologies that are particularly developed to optimize treatment and improve diabetes self-management i.e. “Insulin pump therapy is an alternative to injecting insulin. An insulin pump is a small device that holds insulin” (T1DC17)), the effects of sports, hormones and pubertal growth spurt or excited or nervous moods on the blood glucose (i.e. “If you have a growth spurt you need more insulin because your blood sugars are high. As you grow up your body produces different hormones and these can also affect your blood glucose” (T1DC19)), their personal feelings (i.e. “Diabetes doesn’t mean that you are different from anyone else” (T1DC16)), images and names of famous people with diabetes and of course some facts (i.e. “The first pump was so big you had to carry it on your back” and “Frederick Banting invented insulin” (T1DC16)). Individuals used coloured paper for the text to describe a variety of themes related to diabetes (Figure 48 and Figure 49); some drew pictures of medical devices (Figure 50 and Figure 51), glued images of celebrities and technologies taken from magazines (Figure 50) and even pages from ‘Pete the Pancreas’ book explaining insulin administration and how diabetes will change the life of newly diagnosed individuals (Figure 48). Reading the text written on all the posters, it was identified that only one child mentioned a healthy and balanced diet - “Learn about what foods have less sugar, and eat regular meals and snacks every day” (T1DC17).
One of the children decided to write a poem about diabetes, she also drew images corresponding to the text (Figure 51, T1DC18).

This is an acrostic poem about
Young, juvenile or type 1 diabetes
Pay attention, if it was
Easy, everyone would have it
I dream of a cure
Diabetics could live without fear
Insulin pumps don’t magically appear
Always have hypo treatments near
Blood glucose is what we test
Endocrinologist visit we detest
Type 1 awesome
Every day a tightrope game
Sugar balance that our aim

Photographs taken with the disposable camera were primarily used to supplement and enrich the collection of data on children’s personal interests. Children used the disposable cameras very successfully. The quality of some photos, especially those that captured images displayed on tablets, TVs or computer screens, was poor.
Through photographs, I have found that all children depicted family members as people that they love using the label number 10 (Figure 52, Figure 53 and Figure 54).

Figure 52: Brother and parents, T1DC16  Figure 53: Mother and brother, T1DC18  Figure 54: Mother, T1DC18

Three children identified their favourite piece of technology as their personal tablets (T1DC16 and T1DC19) and a mobile phone (T1DC18); one individual took a picture of her insulin pump (T1DC17). The young participants had different food preferences: they liked milk with a biscuit (T1DC16), pasta (T1DC17), pineapple (T1DC18) and Pringles (T1DC19) but they hated pork sausages (T1DC18), tomatoes (T1DC17) and salmon (T1DC19). Two children loved the animated comedy ‘The Simpsons’ (T1DC16 and T1DC17). The number 9 was used in three pictures indicating the sport that the individuals hate i.e. football (T1DC16, T1DC17 and T1DC18). Trampoline (T1DC16), basketball (T1DC18) and catch (T1DC19) were the respective favourite sports, outdoor activities and games that the participants really enjoyed to play.

5.2.2.6 Discussion on Design Probes in Both Iterations

All playful materials enclosed in the box were used as media to generate and communicate rich information about the children’s perspectives and their experiences with diabetes. In the first iteration, the design of a poster/collage about an imaginary World Diabetes Day was the favourite activity in the box (Table 8). Using DPs, I have adapted objects and activities into sets for children who have type 1 diabetes to be appropriate for the children’s ages, to be focused on young users’ needs (e.g. design your own Recipe Book), shared care with close relatives (e.g. send a postcard), their individuality (e.g. disposable camera) and experiences in self-care management (e.g. kid’s diary, Superhero and a story of his/her power, technology gadget design and design collage/poster). The design of a Technological Gadget, the development of a Superhero and My problem solving diary were also pretty
successful and generated a lot of engagement. Children liked to work with materials to build their pieces with accurate features, but they had less interest in keeping diaries and designing their own recipe book. Similar low interest with the probe called My Journal was reported by Wyeth and Diercke (2006); only one child used this activity to record - using images and text - her/his ideas, thoughts and memories from school. This lack of enthusiasm in using these materials could be explained by the constant upkeep of a food journal and blood glucose log. Food restrictions related to diabetes, the scheduling of meals and children’s preferences cause parents constant concern about their children’s diet.

Unfortunately, unexpected challenges and limitations also emerged. For example, the collection of the probe materials was a problem; it took a few months to arrange a time to meet the parents (first iteration (June-August 2013) and second iteration (June-July 2014)). Two limitations were identified with 1) the amount of activities in the probe set and 2) the specified period of time given to the families for working with the materials to complete the probes. Eight activities for a month was a little ambitious, assuming that parents did not have the time to help and encourage children to use the materials (Tsvyatkova and Storni 2014b). Taking these issues into consideration, I decided to repeat the DPs process as my attempt was to improve young participants’ responses in using all the probes in the set. For that reason, the set was reduced to the four most appealing activities for the children and time for material submission was extended from four weeks to two months. This approach of applying the method showed promising results - children used all the activities provided in the box (Table 8). One problem that emerged with the use of the old fashioned film cameras was that disposable cameras were not suitable for taking photographs of images displayed on technologies such as PC monitors, TVs and tablets, as they have fixed-focus lenses causing low resolution images. Young individuals have experience in the use of digital cameras on their mobile phones; they can get immediate feedback of the object quality. The digital cameras could replace outdated single-use cameras in the set when designing DP for children.

The follow-up interviews and focus groups conducted during the collection process seemed to be very supportive for obtaining valuable data used for interpretation and analysis of the produced materials by the users. Therapeutic effects of using probes were observed and discussed by parents (Parent7 and Parent8), as well as the
cooperation of the family members (i.e. brother and aunt) in helping with the development of Superhero’s figurine (T1DC4 and T1DC8). The first example is related to one of the diabetic girls (T1DC7) who was admitted to the hospital. Her parent (Parent7) said that she found her daughter very enthusiastic to work with the probe materials especially when she designed her poster. She knows that her child hates diabetes and she was really surprised to see a big image of a yellow flower smiling on her poster (Figure 18). The child spent a lot of time on this activity that she really enjoyed; this engaged her, and she became calm and confident to explain her idea for a World Diabetes Day poster. After one week of treatment in the hospital, the probe-suggested activities focused her attention on something different and kept her from thinking about her health condition. At the same time, the child’s health status appeared as a reason to not play and use all the probes in the set (Parent7). The second example illustrated the help that two children got (T1DC4 and T1DC8) from some family members in sculpting their beautiful Superheroes from modelling clay - this kept them entertained and relaxed for hours (Parent8). The girl’s sibling (e.g. brother) checked the internet for the meanings of hypo- and hyper-glycaemia as it was hard for him to understand these two conditions described in the story and their treatment (i.e. Hypo-Hyper Man, Figure 26). The aunt of the second girl (SC4) helped her to create the Helper D figurine (Figure 28), as she wanted to make more colourful figures, with more details.

This study illustrated that the DP method suggests a promising way to collect data from children with chronic illnesses in private settings. The materials were considered as playful and intriguing by children; they were easy to use, helping to provoke a dialogue between the designer and the users. Having detailed descriptions and clear instructions, they supported the user’s involvement and participation in the design process. DPs helped to foster the children’s imagination and, in some cases, to increase their willingness to describe and discuss the world from their perspective, despite their negative feelings toward the illness (Tsvyatкова and Storni 2014b). My analysis of the DPs results highlighted the success of the idea of a Superhero, which shaped my focus to organise and conduct a series of design workshops for diabetic and healthy children entitled ‘Superhero is sick’, discussed below in Section 5.3.4. Here, children-generated scenarios were explored to fine-tune the language and narratives to be developed in my design. DPs further suggested the integration of
interactive elements, explaining the evolution of medical technology used in diabetes care, steps in using the glucometer, as well as the inclusion of references to real, famous people who have diabetes, therefore this data was used during the prototyping phase in Section 5.4.2.5.

Some of the design requirements collected throughout the two iterations of DP method are listed below.

**Design requirement collected:**

- e.g. “The hero has insulin guns to reduce the hypers and glucose guns to eradicate hypos. By being a scientist he spends the day looking for a cure for diabetes and by night he protects all children from hypos and hypers.” (T1DC8)
- e.g. “Diabetes is a condition where your pancreas stops working and you need to give yourself insulin instead of your body producing it”. (T1DC8)
- e.g. “Diabetes means too much sugar in the blood. Sugar comes from the food we eat. Insulin is a hormone that is made in the pancreas and works like a key to open the door. Insulin opens the door to the cell of your body allowing the sugar to go from the bloodstream into the cells where it is then used to make energy. What happens if your pancreas gets lazy? When you have T1DM you have to take insulin, because your body can’t make it anymore.” (T1DC16)
- e.g. “247 million people have diabetes, 1 in 400 children have diabetes” (T1DC10)
- e.g. “Frederick Banting invented insulin” (T1DC16)
- e.g. “eating healthy food” (T1DC16)
- e.g. “The first pump was so big you had to carry it on your back” (T1DC16) e.g. “The insulin pump is a device that gives you insulin through a cannula, which is much easier that injections, you simply key in your blood and carbohydrates and it will calculate how much insulin you need to cover what you eat.” (T1DC8)
- e.g. “The pump is a little device that delivers insulin to the body. Your type in the amount you need and it delivers it through a cannula to an injection site and in to your body. You need more insulin after eating carbohydrates.” (T1DC19)
- e.g. “There are a lot of things that can affect your blood glucose. For example, exercise brings your bloods down. If you have a growth spurt you need more insulin, because your blood sugars are high. As you grow up your body produces different hormones and these can also affect your blood glucose. Being nervous and excited can also change your blood glucose. Food is also something to look out for.” (T1DC19)
- e.g. “Sport activities will also change your bloods, but on a temporary basis, which will keep your bloods from dropping.” (T1DC8)
- e.g. emergency plan: hyper - “Measure blood sugar, if your bloods are near 10 you need to take extra insulin. The doctor will tell you what amount of insulin you can take in different cases.” hypo - “when sugars are under 4 -lucozade, dextrose tablets, glucagon injection” (T1DC8)
- e.g. “Fruit is healthy for diabetes, Vegetables are good for diabetes” (T1DC10)
- e.g. Gary Mabbutt, Halle Berry, Nick Jonas, etc. (T1DC4; T1DC9; T1DC10; T1DC16; T1DC19)
- e.g. Superhero could give “instant knowledge to everyone she touches” (T1DC17), in order to help newly diagnosed children understand diabetes.
- e.g. Superhero (role-playing)

### 5.3 Stage Two: Design
As stated (Section 1.1), the aim of the design of an interactive technology was twofold: 1) to use it as a tool that facilitates the exploration of the participatory approach by examining a series of different methods, techniques and tools in supporting active users participation in the design process and 2) to develop an application that may resonate better with the users’ needs identified in Section 5.2.1.2, with a focus on education. The initial investigation (Section 5.2) helped a) to detail the criteria used for choosing the design of an interactive eBook for newly diagnosed children and their families as a technology that may help to support some of these educational practices in home environments and b) to illustrate some of the ideas generated by children working with the probe Superhero and a story of his/her power identified and considered as helpful for their further elaboration during the design and prototyping step of UCD. Therefore, bearing in mind that this study is focused on design with/for children with T1DM and the educational eBook is for newly diagnosed children who would not be familiar with diabetes, there were two reasons behind the inclusion of healthy children in the design and evaluation stages (Section 4.2). Firstly, children will have specific knowledge and experiences accumulated during their childhood and their development within the school system, hence it was important to find out what healthy children think about the body and healthy food as this will likely be similar to what young patients know about these two issues immediately after their diagnosis. And secondly, to learn more about children’s language, creativity, communication skills, interaction with the environment, their cognitive abilities and problem solving skills (Tsvyatkova and Storni 2015a). To generate valuable data necessary for the design of the eBook, as seen in the methodology (Section 4.2 and Section 4.2.2), I have explored CI (Druin 2002), ID (Scaife et al 1997) and collaborative storytelling (Alborzi et al 2000; Fails et al 2012); these methods aim to support and facilitate the active participation of children who are healthy and those with diabetes. For example, CI and ID support two different “roles” of children’s involvement in the design i.e. as “design partners” and “informants” (Section 3.4), respectively qualified through their experiences of having diabetes and being a healthy child. Consequently, CI supported the involvement of young individuals with diabetes as design partners for “elaboration” in the technology development lifecycle, whereas in ID the contribution of healthy
children was as informants through “having a dialogue” - providing inputs at different phases of the design process (Section 3.5.1). In addition, I explored whether interactive storytelling is an appropriate technique for designing an educational eBook with young patients and healthy children to support their two different roles in design.

As a result, by playing the roles of “design partners” and “informants”, and applying collaborative storytelling in three different design workshops, the participants offered diverse contributions to the design. These three workshops were video and audio recorded, which produced a great deal of design material, including plasticine figures, drawings, diagrams, etc., all of which are valuable sources for: 1) analysing the role of the materials used to carry out CI and ID for interactive storytelling, 2) comparing the diverse contribution of the individuals in design, 3) examining the role of the designer in trying to balance and ensure equal participation of children during design activities and 4) observing how the materials produced by children were used to develop the first prototypes.

The five sections below provide more details on the work completed in performing the design stage of the UCD process. Section 5.3.1 explains the methods and materials used in the sessions, the participants’ recruitment, and the procedure used in the sessions. The next three parts show and describe the materials collected in the first (Section 5.3.2), second (i.e. ‘Traveling through the human body’) (Section 5.3.3) and third (i.e. ‘Superhero is sick’) (Section 5.3.4) co-design sessions with children. The last Session 5.3.5, discusses the findings extracted from the collected empirical data.

5.3.1 Design: Method, Materials, Participants’ Recruitment and Procedure

As outlined, CI, ID and collaborative storytelling were used to support children’s participation in the design process (Table 9). Along with the reasons discussed in Section 4.3 and Section 5.2.1.4 for selecting collaborative storytelling, the technique was described as “a powerful tool for communication, collaboration, and creativity support” that was used in the development of the StoryRoom for “immersive storytelling experiences for children” (Alborzi et al 2000, p 95), but had not been

53 These two roles have been discussed by Guha and her colleagues (2012) but only with healthy children
explored with diabetic children (Årsand and Demiris 2008). Therefore, the collaborative storytelling (Table 9) was deployed as an activity in all three design workshop sessions as an appropriate interactive communication tool that allowed us, together with the young participants, to define technology features and generate ideas about narratives, characters, plots etc., crucial to the development of educational stories that resonate with the child’s perspective and imagination. Knowing that discussions on diabetes with affected children may provoke negative emotional states (Section 5.2.1.3), it was important to explore how the interactive storytelling facilitated these individuals to collaborate actively in the organised design session by prompting the children’s willingness to express their experience with the illness, and to share ideas and feelings without harming young individuals emotionally. Also, to play the role of design partners, Guha and her colleagues (2012) highlighted that young healthy participants needed training (Section 3.5.2), but it was not clarified whether that chronically ill children - who would contribute to the design with their knowledge generated through their living with the illness acting as equal stakeholders - also needed some education on design activities before their active participation in activities.

Table 9: Design methods, participants, materials and place

<table>
<thead>
<tr>
<th>Session</th>
<th>Design method</th>
<th>Materials</th>
<th>Participants</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Cooperative Inquiry (CI)</td>
<td>A2 white paper, colouring pencils and printed images</td>
<td>One 12 year old diabetic child and her parent (Parent8&amp;T1DC8)</td>
<td>University Building</td>
</tr>
<tr>
<td>Two</td>
<td>Informant Design (ID)</td>
<td>A deck of cards, outline of the human body, pipe cleaners plasticine, buttons and feathers</td>
<td>Eight healthy children aged from 11 to 12 years old - HC1, HC2, HC3, HC4, HC5, HC6, HC7 and HC8</td>
<td>‘Sunflower’ community centre</td>
</tr>
<tr>
<td>Three</td>
<td>Informant Design (ID)</td>
<td>A deck of cards, A4 white paper, images, colouring pencils</td>
<td>Six healthy children aged from 11 to 12 years old - HC1, HC2, HC3, HC4, HC6 and HC7</td>
<td>‘Sunflower’ community centre</td>
</tr>
</tbody>
</table>

Focusing on the challenges described above and applying the collaborative storytelling approach, art and craft materials, along with two storytelling sets of cards (Figure 54) were provided as tools to inspire children’s imagination, creativity, and collaboration in fantasy plays in each workshop session (Table 9). For example, in the first workshop session, to promote creative choices of writing and drawing and to support participants in the elaboration process when shaping their own ideas, sheets of white A2 paper and art materials (colouring pencils), along with some selected
images were used. For the second and third sessions, two kits of storytelling cards for two different stories ‘Traveling through the human body’ and ‘Superhero is sick’ (second image, Figure 55) were developed, aiming to encourage the storytelling play with healthy children (Tsvyatkova and Storni 2015a). Their design was influenced by the collected and analysed data from the first session described in Section 5.3.2.

Figure 55: Two storytelling card decks: ‘Traveling through the human body’ and ‘Superhero is sick’

Figure 56: Design of the story starters and picture cards of ‘Traveling through the human body’

Figure 57: Design of the story starters and picture cards ‘Superhero is sick’
Colourfully illustrated and left intriguingly open-ended, the storytelling picture cards (second image, Figure 56 and Figure 57) were designed to engage young participants directly with the story, stimulating them to present their own concepts in a collaborative way. Together with the picture cards, the story starters were also designed to provide guidance and give hints in developing specific characters/objects, settings or dialogues for the story (first image, Figure 56 and Figure 57). Each set of cards had seven story starters (i.e. questions) respectively corresponding to one or two picture cards. In addition to the storytelling card decks, I also provided other materials to inspire a creative approach such as plasticine, a foam outline of the human body, pipe cleaners, buttons and feathers for the second session, while in the third session children were given A4 white paper, images, colouring pencils, dialogue boxes and glue to play with and expand their imagination (Table 9) (Tsvyatkova and Storni 2015a).

Young participants aged between 8-12 years who have T1DM were recruited through a series of strategies such as the use of the university mailing list, contacting the ‘Sweetpea club’, Diabetes Ireland association and different parents’ support groups for children with diabetes on Facebook, emails sent to primary schools, and flyers distributed in kindergartens and GP’s surgeries (Tsvyatkova and Storni 2015b). Some challenges in recruiting volunteers who agreed to partake in the intended design process activities were experienced (Section 4.3). Consequently, in the first session planned only for children who have diabetes, I worked with one 12-year-old diabetic child and her parent (Parent8&T1DC8); they were happy to share their personal experience and had already participated in the interviews process (Section 5.2.1.1) and DP activities (Section 5.2.2.1). Several factors in arranging and scheduling the session with participants (Section 5.2.1.3 and Section 5.2.1.4) were considered. For example, the design session had to be held at a time appropriate for the family in one of the meeting rooms in the University Building - the location was suggested by the individuals. Time for managing diabetes during the session was planned in advance to ensure the needs of the diabetic child were met. In the second and third design session, fourteen healthy children between 11 and 12 years of age (Table 9) were recruited from the voluntary group ‘Sunflowers’ (Section 4.3) and the workshop sessions were conducted in their community centre, where other activities organised by the group were usually hosted. The estimated duration to complete each
session was between 45 minutes and one hour (Tsvyatkova and Storni 2015a; Tsvyatkova and Storni 2015b).

At the beginning of each session, all young individuals were asked about their familiarity with interactive enhanced eBooks. Unfortunately, they had no experience with this new medium, for that reason two examples published on YouTube - *Alice's Adventures in Wonderland* 54 digitally remastered for the iPad and *Wild About Books for iPad* 55 - were shown to the children to grasp the idea of what interactive features are embedded in digital books aimed to improve the user’s enjoyment during reading. This also helped to show what makes them different from other paper or pdf (Kindle eReader) based books. In order to keep children’s attention on the design process and not on the technology itself, I did not show them a real eBook.

5.3.2 Design Workshop Session 1: Exploring Different Scenarios of Places and Activities Related to Diabetes Self-Management

In this session the child’s role was that of an expert, qualified by her experience formed through living with diabetes (Tsvyatkova and Storni 2015a; Tsvyatkova and Storni 2015b). Applying the collaborative storytelling approach, the goal of the first session was to gain some insights into the impact of diabetes on daily life. This session was undertaken to develop a set of scenarios to help explore the self-care practices that are usually carried out by young diabetics in clinical settings and in real-world environments (Tsvyatkova and Storni 2015a). By elaborating on various scenarios, I hoped to improve the discussion on paediatric diabetes and uncover some of the practicalities in insulin therapy, technology used in diabetes management, a balanced diet, physical activities, etc., and hence increase my understanding on how technology may support and expand the young user’s awareness of this chronic condition. Additionally, I wanted to gain a better overview of the educational process, and collect more requirements, particularly concerning how the content of the eBook may support this issue. Therefore, the materials supporting the collaborative storytelling technique were designed to make participants comfortable to tell and share their personal stories and to facilitate CI and participatory design approaches. A 12-year-old diabetic child and her parent participated as design partners. Together with the designer, they cooperatively built up a wide variety of

54 https://www.youtube.com/watch?v=gew68Qi5kxw&spfreload=10
55 https://www.youtube.com/watch?v=DXMFBXoyI7c
scenario stories taking place in different settings, e.g. at a hospital, at home, at the shop, at school, etc., trying to highlight how diabetes and its management impacted the daily life of the young individual and their family. In one of the scenarios, the young participant described her own feelings and problems experienced on the first day of diagnosis at the hospital, as well as what questions and emotions arose, her efforts to understand more about the disease and its treatment (Tsvyatкова and Storni 2015a). The child started with the scenario ‘Story into the human body’ by explaining the cause of diabetes, the work and functions of the pancreas in the digestive system, and the common symptoms of the illness (i.e. “tiredness, pain in the stomach, hungry, angry, drinking”, etc.). Then she created a short dialogue between the doctor and sick child in the hospital elaborating on the disease and treatment strategies. She wrote down three questions that she had at the time of diagnosis: “What is diabetes? What I need to do? How will I take the insulin?” The drawings were used to explain the educational process in which a newly diagnosed child is trained in the use of the glucometer (Figure 58, first image), the insulin injection procedure, the importance of knowing the appropriate body areas/sites for insulin injections illustrated with a simple diagram (Figure 59, first image) and the functions of an insulin pump (Figure 59, second image). Regarding the instructions for measuring the blood’s glucose levels, she specified that “You have to check your blood before you eat, if you are having a hypo and before any activity” (Figure 58, second image).
Then the participants explained the healthy food scenario by highlighting that all children with T1DM need to know nutrients such as Carbs, Fat and Proteins for matching bolus insulin (Figure 60, first figure). The girl sorted out the provided images of foodstuff into these three categories, articulating that all listed food in the first group have different amounts of carbs (Figure 60, second image). In the end, ice-cream, pizza and a bun were shown as food that is not particularly allowed because they contain fast acting carbs, and rapidly increase the blood glucose levels (Figure 60, fourth image).
Other interesting situations were discussed, such as how to buy healthy food in a shop, what is the honeymoon period for diabetes (Figure 61, first image), what may happen at school when the child presents with the different symptoms of hyper- or hypoglycaemia and the box for emergency situations (Figure 61, second image), and what is important for undertaking a journey (Figure 61, first image). She felt very confident when explaining that reading the food labels usually helps to find out the total carbohydrates in a pack, and that the honeymoon phase follows diagnosis as the pancreas still produces insulin, which decreases the insulin requirements. According to the child, all individuals with diabetes would need to have two plans for dealing with high and low blood glucose levels, and teachers and parents needed to be educated in that. The last scenario was the story of “Hypo-Hyper Man”, in which the Superhero is a scientist dedicated to his work of finding a cure for diabetes. The original version of the story was developed by the same child working with DP materials and during the workshop session the fairy tale was fully realised by her adding additional details (Section 5.2.2.4).
Later, all the collected materials generated in the workshop were analysed to identify features, images, text and contexts that could be implemented in the design of the educational eBook that may correspond/resonate/reflect with the needs of actual users. This exercise also helped to identify subject areas that are of an interest to the
child, e.g. to know more about the nature of diabetes, the digestive system and the relationship between food, insulin and physical activities. The next two design sessions were planned to cover these demands in collaboration with healthy children. For example, the generated data from the child–doctor dialogue on initial diagnosis in the hospital and ‘Story into the human body’ were used as ideas in designing activities for the second and third sessions discussed below.

5.3.3 Design Workshop Session 2: ‘Traveling through the human body’

In the design sessions two and three (Section 5.3.4), the child’s role was as an expert in “being a healthy child” (Tsvyatkova and Storni 2015b). In this session, my work with healthy children aimed to collect data on 1) children’s awareness and knowledge about the human body, 2) story narrative, particularly explaining the digestive system through the eyes of the young individuals and 3) developing some of the characters important for the eBook design (Section 5.3). I hoped that having a combination of a card set and other supportive materials (Table 9) to create a friendlier environment may facilitate individuals spontaneously to participate in the process of telling the story, to build a space that would encourage communication and collaboration between children and the designer. As a creative tool, the story starters - having more concrete questions - were designed to guide the participants through the creative process by giving them some hints for idea generations, while the role of modelling clay was to generate fun while making figurines to support creative thinking and imagination (Tsvyatkova and Storni 2015a).

My participants - informants (e.g. ID) - were eight healthy children who played with the card set that was designed to develop the story ‘Traveling through the human body’. As discussed in Section 5.3.1, a set of 15 cards, together with other provided materials (Table 9 and Figure 55), helped the children explain the key story elements by gradually adding details through working with images and questions. The story is about two children who decide to make a journey into the human body. Traveling in a miniature technology, they are able to explore the inside of the human body and its functions. For example, the first two storytelling cards (Figure 62) helped children to develop and describe physical characteristics, age and the relationship of the two main characters in the narrative.
Having constructed the dialogue, it was decided that the protagonists are ten- and nine-year-old siblings called Liam and Abbie (Figure 63), then the children made their figurines adhering to the earlier proposed suggestions (Figure 64) (Tsvyatkova and Storni 2015a; Tsvyatkova and Storni 2015b).

Participants were given the option between five images (Figure 65) to choose which technology to use for the magic trip, so they built a small pink submarine decorated with pipe cleaners, buttons and feathers (Figure 66). Everyone worked in making different parts of the submarine, which the children then assembled to make the technology. Playing with the modelled objects and performing the dialogue between characters, the children suggested that the journey into the human body should start from the mouth; one of the children drew the mouth, nose and eyes outlining the face of the body in detail (Figure 71).
Next, cards encouraged young individuals to describe the functions of some human organs such as the lungs, heart, stomach and pancreas that Liam and Abbie could see through their submarine porthole during the journey. In the interviews (Section 5.2.1.2), some of the children with T1DM preferred to see the realistic images of the pancreas and stomach rather than the cartoons in the small book ‘Pete the Pancreas’ (Parent6 and T1DC8). The storytelling cards were designed to show a selection of both realistic and cartoon images of these internal human organs, so children had the option to decide what picture they would use to create their plasticine figurines (Figure 67).
All figures were nicely decorated; they had hands, legs, eyes, mouth, etc. similar to the original funny cartoons shown in the cards (Figure 68, Figure 69 and Figure 70).

When asked about some facts related to these internal human organs and about their functions in the human body, children gave some examples of how the heart and the lungs work by imitating a heartbeat sound, what happens when the food reaches the stomach (i.e. explaining digestion as forming bubbles because of the stomach acid),
but none of them knew about the pancreas position or function in the human body. The purpose of the foam outline of the human body was to help children explore different possibilities in the fantasy play and to rearrange the figurines of human organs, trying to find their appropriate place in the frame (Figure 71).

At the beginning, children made different parts of one object and then they joined them together to make the figurine; this method was very time consuming. I decided to split the children up into small groups wherein each group created one object. Role playing the dialogue between the main character Liam and Abbie made the work environment more friendly and relaxed. Each child was asked to read the questions written on one story starter and elaborate on the answers, and then other children were free to express divergent views or their own ideas. This tactic was used to stimulate other individuals who were less active by giving them the opportunity to prompt and improve their involvement in the activities.

5.3.4 Design Workshop Session 3: ‘Superhero is Sick’

The goal of this session was similar to session two (Section 5.3.3) - here the second set of storytelling cards ‘Superhero is sick’, together with art and craft materials were designed to explore children’s language while elaborating on a doctor-patient dialogue, to show their understanding of healthy food, to identify what they know about the health benefits of physical activities in children, etc. In addition, I also expected to gain some insights into children's lives, based on their meaningful socio-cultural practices of living as a healthy child, with the hope that this could help to create a plausible image of potential users at a particular age group that would not have information on diabetes, but would have some awareness and knowledge of the issues described above. Moreover, along with the data produced in the second session (Section 5.3.3), the identification of a starting point for the educational context of the eBook could be established.

In session six, children were asked to develop a story “Superhero is sick”, in which a Superhero meets a doctor seeking effective treatment. The treatment included taking medication on time, having a healthy diet and being physically active. Children were asked to elaborate, describe and draw two main characters - the Superhero and the doctor - using the provided art materials (Table 9) along with the second storytelling card set (Figure 72) (Tsvyatkova and Storni 2015a; Tsvyatkova and Storni 2015b).
Similar to the second session, children first generated suggestions on the character traits of the main protagonists, settings, their physical appearance including gender, clothing, etc. and then they drew the developed ideas. Named Anastasia by the children, the imagined Superhero was a 14-year-old superwoman that could fly (Figure 74). She lived in a fancy apartment located in the city centre (Figure 73).
Doctor Jenny was a very smart and popular doctor who cared for patients in the hospital (Figure 75 and Figure 76) (Tsvyatkoa and Storni 2015a).

Through playing out the patient-doctor dialogue, Superwoman was advised to take her medication on time, to have a healthy diet and to partake in regular physical activities (Figure 77, third image). Most of the children wrote down their own questions/dialogue (Figure 77, first image), drew different images to illustrate the procedure and settings of the GP or doctor’s office (Figure 77 second image).

Children were asked to explain healthy eating to Anastasia and give examples of healthy grocery shopping (Figure 78).

Selecting food items from the provided images, they created two categories of food i.e. ‘bad for you’ and ‘good for you’ (Figure 79). Healthy individuals found it difficult to describe the criteria used for their classification; they gave a few answers like “Sweets and cakes are not healthy for you because they have a lot of sugar”, “Fruit and vegetables are good for you because it grows from the ground” and “Milk and cheese is good for your bones” (Figure 79).
Young participants were encouraged to choose a device that would remind Superwoman to take her medication on time. The technologies proposed by the children were a smart belt that had an alarm, a note and a Wi-Fi enabled connection with other Superheroes (Figure 80). Finally, children were asked to motivate Anastasia to do exercise and some of the suggestions were to play a sport with friends, as physical activities would help her to be healthy and then she could fly to save people’s lives.

I have observed that some children felt very shy sharing their ideas. I have tried to involve them in the collaboration of ideas by asking gently to use the art materials as a medium to show their personal concepts. This was the reason behind the generation of many suggestions for the Doctor-Superhero dialogue.

5.3.5 Discussion of the Three Workshops

In the attempt to tailor an educational technology to the appropriate age group (8-12 years), children’s capabilities, specific language and natural skills, I organised three workshop sessions applying CI (Guha et al 2012), ID (Guha et al 2012; Scaife et al 1997) and collaborative storytelling technique to facilitate children’s participation in the design, (Alborzi et al 2000; Fails et al 2012) in which children played different roles as “equal design partners” and as “informants”. This approach was successful for collecting and combining ideas and experiences from healthy children and those with diabetes which would inform the design of the future educational technology.

I have discussed the sensitiveness of the topic in this research and how this influenced the emotional state and further recruitment of children with T1DM in the next, more design-oriented stages. Also, these phases were significantly affected by the appropriate selection of methods and materials that would encourage children...
with diabetes to participate in the design process that was less emotional and stressful for them. Building personal stories using the collaborative storytelling method, the child was asked to elaborate on scenarios using art materials, explaining her experience with diabetes at the time of diagnosis and afterwards at home. The young participant felt confident in giving clear details on using the insulin pump, reading the numbers on the glucometer, food categories and on symptoms recognition in regards to hyper- or hypo-glycaemia. A problem that arose in practice was the appearance of some feelings of sadness. The role of the designer was to notice the early signs of those states and react accordingly, giving small breaks or changing the topic for a while to help the child to overcome the emotions. Checking blood sugar levels and having snacks during the workshop were planned in advance - this helped to observe the use of the glucometer, work with the insulin pump and gain some experience. During the co-design workshops, the need to train the child in design activities to share feelings, skills, experience and thoughts was not experienced. It is important to highlight that the partnership between young participants and researchers was essential to identify the main features and content that the eBook needs to support. The first design workshop session - in which the participant was an expert in living with diabetes - was crucial in discerning what information and knowledge the eBook needed to provide to help children and their parents learn about diabetes after diagnosis, and support them in diabetes self-care management when they return home. For example, children would like to know about the pancreas, insulin and their functions in the digestive system, and presenting this in a more playful manner may reduce the level of stress and anxiety associated with hospital stays. Having funny, yet sophisticated stories related to diabetes could help children to regulate their emotions and to reduce the pressure that they may experience in accepting the diagnosis and the treatment. The integration of videos/animations in the eBook showing - in detail - some of the diabetes self-management tasks, games related to food and carbohydrate counting, and a small thesaurus with images and animations could help children to gradually learn about the terminology and diabetes treatment, starting at the clinic and continuing in a domestic environment. Therefore, the idea was used in the prototyping stage by developing a series of narratives with different scenarios on diabetes care illustrated in Section 5.4.2.5, which were then integrated by building numerous initial prototypes. Having only one young participant (at a time) could be seen as an
advantage for successful user-designer communication and dealing with emerging situations during the design session.

In an attempt to learn about children’s language, their awareness about the digestive system and healthy food, their communication skills and cognitive abilities, as well as to generate more valuable data for the eBook design, I also worked with healthy children as “informants”. The art and craft materials for each workshop session were carefully chosen to work in a constructive way to prompt creative direction for collaborative fantasy storytelling, introducing the basic story concepts in a fun and kid-friendly way. Storytelling cards, in combination with other materials used in the design process, have been found to be a wonderful technique that afforded a lot of fun, inspiring children to develop their own stories, and to use art materials when they were building their ideas. Having concrete questions revolving around the particular personas I developed (as opposed to generic and abstract questions) helped to spur the young participants’ imagination and creativity, generating focused ideas from the children. Using the outline of the human body and mock-ups of human organs made by children in the second workshop helped young participants - in a playful way - to show and test their story, and to generate data important for designers. The contribution of healthy children as informants in the second and third session was significant for the IT development. For example, healthy children know little about the pancreas and its function in the digestive system, but they were very confident about the heart and lungs. This definitely confirms the usefulness of a fairy tale about the human body and digestive system that includes the role of insulin and the process of converting food into energy. In the third session, children were inspired to elaborate on the dialogue between doctor and patient, asking the questions that each child may have when they are sick. They were confident in dividing food into healthy and un-healthy groups, but struggled with identifying the reasons behind the food categorisation. The second collaborative storytelling kit ‘Superhero is sick’ was used again in the prototyping session with children with T1DM described below in Section 5.4.1, helping them to build a series of low-tech paper prototypes for the eBook story. Also, the valuable information collected from the healthy children was used to build three children archetypes called personas – one representing the group of newly diagnosed users and two of the child siblings in Section 5.4.2.3. Their purpose was to support the work of the designer, by improving the understanding of
potential users and to develop scenarios and storyboards during the prototyping process to test some ideas. During my work with the participants, I have noticed that some children are more open and confident in sharing their ideas. The role of the designer was to encourage each child to freely participate through reading the questions and forming small groups of two children to develop one object using the modelling clay, or to draw a character.

Due to the emotional load that children associate with their illness, the first workshop session was limited by the small number of participants. To deal with these constraints, the design probes method was applied earlier (Section 5.2.2). Also, several issues were detected while engaging children in the design process. Limiting the number of activities and questions offered more time for the children to engage with the contents and to lead the discussion. Using modelling clay to make figurines and adding details was a time-consuming process and this problem was overcome by forming small groups of children to develop one object. Through observation, the duration of workshop sessions should be no more than 45 min as the children get tired and lose interest.

Below I illustrate the final comments based on the data collected.

<table>
<thead>
<tr>
<th>Design partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>- No education needed on design to play the role of design partner</td>
</tr>
<tr>
<td>- Child was confident in explaining personal experience with T1DM</td>
</tr>
<tr>
<td>- Partnership was essential to identify the eBook main features and content</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Collaborative storytelling</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Personal stories were identified as an effective approach to discuss sensitive topic</td>
</tr>
<tr>
<td>- Helped to articulate personal experience with diabetes care</td>
</tr>
<tr>
<td>- Indicated the key role of supported materials</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Sensitive, may provoke negative emotions</td>
</tr>
<tr>
<td>- Working in pairs, one parent and one child, may better facilitate sharing experiences on health</td>
</tr>
<tr>
<td>- Tactic to deal with emotions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scheduling/organising session</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Break to manage the illness during session</td>
</tr>
<tr>
<td>- Break to deal with negative feelings</td>
</tr>
<tr>
<td>- Parent supervision</td>
</tr>
<tr>
<td>- Certificates and gifts</td>
</tr>
</tbody>
</table>

| Collected data – eBook content |
• Should provide information on initial diagnosis and what diabetes is
• Should include questions/answers on diabetes and its care
• Should provide instruction/information on the use of the glucometer, insulin injection/pen and insulin pump
• Should provide information on buying/eating healthy food, carbohydrate counting
• Should include discussion on the emergency plan - hyper- or hypoglycaemia
• Should include scenarios on diabetes care and travelling
• Should include scenarios of diabetes care at school
• Should include scenarios of diabetes and honeymoon period
• Should include support for diabetes education geared toward family members, teachers, etc.
• Should provide meanings of different medical terms
• Should include fictional character e.g. Superhero

Informants

• Need concrete guides/questions/ hints revolving around the particular experience
• Informants helped to create plausible image of potential users i.e. newly diagnosed child

Collaborative storytelling

• The set of cards were identified as an effective tool for collaborative storytelling
• Less questions i.e. story starter may improve the engagement with the contents
• Indicated the key role of supported materials for fun and active involvement
• Work in groups
• Tactic to improve active and equal participation

Scheduling/organising session

• Time for snack before session
• Certificates and gifts
• Duration 45 min
• Need time for making plasticine figurines and drawings

Collected data – eBook content

• Helped to enable the identification of a starting point to build educational context
• Children do not know pancreas as human organ nor its function
• Children are able to recognize healthy and un-healthy food
• Should have a a story about the human body and digestive system
• Should include similar settings and characters as ‘Superhero is sick’

The next section (5.4) illustrates the use of the generated and collected rich empirical data by applying interviews (Section 5.2), design probes (Section 5.2.2) and collaborative storytelling (Section 5.3) in the prototyping process.

5.4 Stage Three: Produce Design Solutions

Split into two fragments, this Section explains all activities that were carried out to develop a series of initial prototypes. Section 5.4.1 discusses the prototyping session in which seven children with diabetes developed individual prototypes of the story ‘Superhero is sick’ by using the collaborative storytelling technique (Alborzi et al
Section 5.4.2 shows the process 1) of building personas, scenarios and storyboards facilitating the work of the designer in developing the educational narratives for the eBook and 2) of the two stories 'Superhero in sick' and 'What is type 1 diabetes' prototyping.

5.4.1 Prototyping Workshop Session 4: Developing Prototypes of the Story 'Superhero is Sick'

Observing the benefits of the collaborative storytelling technique (Alborzi et al 2000) in the design process (Section 5.3.5), the focus of this Section is 1) to examine how the same tool (i.e. collaborative storytelling) supports the young children with T1DM as “design partners” (CI) (Druin 2002) during the prototyping activities of the story ‘Superhero is sick’, 2) to actively involve the young individuals in the prototyping process to help them share their experience with the current issue – diabetes - and 3) to produce and generate data important for the design of the eBook prototypes.

The collaborative activities have been designed particularly to facilitate the creative thinking in individuals for elaboration and generation of ideas - a series of narratives for developing many paper prototypes. Based on the empirical results, some children were not very open to sharing their experience with the illness (Section 5.2.1.3) therefore, this may create some difficulties in collaborative partnerships between children and designer when developing only one prototype. Hence, in trying to overcome these barriers, children have been asked to develop individual stories-prototypes. This approach was used as a strategy aiming to facilitate individuals to explore their personal ideas by using non-verbal forms, i.e. through images and text to help them communicate their personal concepts. Consequently, Section 5.4.1.1 details the participants’ recruitment and settings in which the session was conducted and explains the materials and procedure applied for the prototyping session. Section 5.4.1.2 shows children’s ideas and input in implementing narratives for the eBook. Collected data is analysed and discussed in Section 5.4.1.3.

5.4.1.1 Prototyping: Materials, Participants’ Recruitment, Settings and Procedure

The storytelling card set for developing the story ‘Superhero is sick’ (Section 5.3.1, Figure 55, second image) has shown promising results in supporting healthy children as informants in developing the story and in collecting data based on their personal experience (Section 5.3.4). For that reason, the same deck of cards was used in the
session together with other materials facilitating the prototyping process i.e. A4 white pages with printed wireframes simulating the screens of a tablet, and were joined with ties, acting as a spine, and given to each child who participated in the session. Additional resources provided for producing prototypes were coloured pencils and markers, different cut-out illustrations of food, sports, etc., stickers, glue and dialogue boxes, which were placed in the middle of the table to be accessible to all children. Also, two sets of questions were developed and used during the prototyping process 1) to help participants to think about the eBook story content and 2) as creative prompts to inspire and engage young children’s thinking while developing their own stories (Figure 81).

**eBook content**

- What do you want to read (see) in this interactive book about diabetes? What would you like to have in the story?
- Is there a topic that you would like to learn more about?
- What is the beginning of the story? The middle? The end?
- How should information be made available from your point of view?

**Questions for prototyping story ‘Superhero is sick’**

- Create your own Superhero (he/she).
- Draw an image of your Superhero.
- What is the name of your Superhero?
- Describe the Superhero’s home.
- Describe the Superhero and his/her power.
- What does the hero do?
- What kind of power does the Superhero have?
- Superhero is sick and he/she needs to go to the doctor. Create your own doctor (he/she)
- Superhero will have an appointment with the doctor. What questions will Superhero ask the doctor?
- What did the doctor tell to Superhero?
- What is healthy food?
- What technology will help superhero to take medication on time?
- What is your favourite activity? Why? Could you ask Superhero to join you when you go to do it?

**Figure 81: Questions used in the prototyping session**

Each year Diabetes Ireland ‘Sweetpea Kidz Club’ organise a 3 days Easter camp for families who have children with diabetes and their siblings. These camps aim to share information about daily diabetes care (i.e. daily administration of insulin, blood tests, diet, emotional support for the family, etc.) by organising workshops for parents and children, as well as offering a lot of indoor and outdoor springtime fun
activities for children and their siblings. Working as a volunteer in the club, I have participated in a wide variety of games, competitions, and educational sessions during these days that have offered creative and enjoyable experiences to the children. Participants for my workshop were recruited from the people who attended the camp in 2014 (28-30 March) through 1) letters sent out by DI informing parents and children about the scheduled activities for each day, 2) giving a short presentation of this project at the beginning of the parents’ workshops and 3) using flyers during the first day in the camp. The prototyping session was carried out after the planned entertainment for the second day had finished in one of the holiday houses used by the volunteer committee members - ideal planned settings that could be considered as safe and ethical. Seven 12-year-old girls with T1DM participated in this workshop (Table 10).

Table 10: Participants in the prototyping session

<table>
<thead>
<tr>
<th>Participants</th>
<th>Prototyping</th>
<th>Design Probes</th>
<th>Evaluation Process</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1DC16</td>
<td>T1DC16</td>
<td>T1DC16</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>T1DC17</td>
<td>T1DC17</td>
<td>T1DC17</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>T1DC18</td>
<td>T1DC18</td>
<td>T1DC18</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>T1DC19</td>
<td>T1DC19</td>
<td>-</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>T1DC20</td>
<td>T1DC20</td>
<td>-</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>T1DC21</td>
<td>-</td>
<td>-</td>
<td>12 years</td>
<td></td>
</tr>
<tr>
<td>T1DC22</td>
<td>-</td>
<td>-</td>
<td>12 years</td>
<td></td>
</tr>
</tbody>
</table>

Five of these children (T1DC16, T1DC17, T1DC18, T1DC19 and T1DC20) also took part in the second iteration of the Design Probes and three in the Evaluation process (T1DC16, T1DC17 and T1DC18) (Table 15). Some boys with T1DM came to the building but they felt uncomfortable sitting down and working with a group of girls. We all had limited days of staying in the camp, so it was impossible to arrange another session with only boys. The session lasted about 1 hour.

Having children with diabetes as participants, my role as designer and facilitator in the session was 1) to encourage individuals to use the described tools and materials designed to trigger individuals’ creative ideas and 2) to create a nice and friendly ambience for active involvement and participation in prototyping individual stories. Moreover, as a designer, I needed a specific approach, strategy and tactic in case if the discussions on diabetes provoked negative emotional states in the children as,
observed in the episodes described in Section 5.2.1.3 and Section 5.3.2. Additionally, time for taking medications or snacks had been planned in advance, in case some of the children needed to measure their blood glucose levels, take insulin or food (adhering to the requirements discussed in Section 5.2.1.4).

5.4.1.2 Individual Prototyping of the Story ‘Superhero is Sick’

The goal of this session was to explore the collaborative technique in supporting the prototyping stage with children with T1DM, particularly in producing a series of artefacts facilitating the users’ active involvement in the design of the eBook. I hoped that this technique would enable the collection of data based on the child’s individual experience at the time of diagnosis, by illustrating the settings and dialogue with the doctor, the language used when describing the balanced diet and the need for physical activities, and their ideas about technology that may support young, newly diagnosed patients in taking medication on time (the regimental way of taking food and insulin was described by parents during the interviews, Section 5.2.1.2). In addition, as a relaxation strategy to promote fun, participants were asked to give some ideas about the interactive features such as music, animations, trigger and response effects, etc. for their stories.

During the prototyping session, seven individual stories – prototypes of ‘Superhero is sick’ - were produced by the children (Figure 82). Below, I discuss the children’s work and the prototyping process in building these narratives. Also, I draw attention to several short, not very productive discussions as a result of low children responses.
to the questions that have been asked mainly to engage participants with the storyline and to prompt their creative thinking process.

The first question used in the session was to identify whether children were familiar with some existing enhanced interactive eBooks accessible to a wider audience. Only one young participant explained that the eBooks were stories that can be opened and read on computers; they have integrated games, animations and music (T1DC18). Two videos - the examples explained in Section 5.3.1 - were shown to the children for them to understand the eBook design, structure and user interface. It was then explained that the users of this interactive narrative would be newly diagnosed children with T1DM and the individuals were asked questions to identify their opinions about the eBook story content. Some of the recommendations given were to explain what is diabetes (T1DC19), how do people get type 1 diabetes (T1DC17) and how to use the glucometer (T1DC17). Unfortunately, their first reaction indicated that they were not very eager to further discuss these suggestions. Taking into consideration the emotional sensitiveness of some young individuals with T1DM (Section 5.2.1.1 and 5.3.2), I decided to move to the next step and ask children to use the prepared materials to facilitate their work on the prototypes creation. I hoped that by engaging the children with materials and completing tasks in a positive and friendly work environment, this would help them to overcome some of these feelings and make them more collaborative. At the end of the session children were asked again about the content of the eBook: one child highlighted that it would be nice for other children to know that “diabetes doesn't make you different from others” (T1DC19) and “don't think that you will have this (i.e. diabetes) forever” (T1DC19).

The prototyping process was started by asking each participant to develop an individual story - a paper prototype by using all the materials that were placed on the table, together with the deck of storytelling cards. As a facilitator, I read the text questions in consecutive order, then the story starters and picture cards were given to children in order to be used if needed. Additionally, the second set of the questions shown in Figure 81 (page 208) were asked, to inspire creative thinking in the children and group discussions. They also helped to stimulate participants’ imagination and personal interpretations of the story questions while working on their prototypes.
Similar to the workshop session three (Section 5.3.4), children first identified the central characters in the fairy-tales, described their primary personality traits and then elaborated on the dialogue between the two main protagonists. Developing their stories individually, children first drew the image of Superhero in their small “paper books” and then added more details such as name, gender, power and personal characteristics (Figure 83, Figure 84 and Figure 85).

Figure 83: Lizzie, T1DC20

Figure 84: Katie Cat, T1DC17
Portraying their own Superheros, participants spent 15 min adding many details such as hair (Figure 83 and Figure 86) and facial expressions (i.e. happiness (Figure 83 and Figure 84) and sadness (Figure 85)), clothes and body posture. Aged between 9 and 15 years, children created two boys called Sky Master and Donal and five girls named Zoom girl, Katie Cat, Bella Bendy and Lizzie. Individuals came up with their own ideas about the magic or superpowers that their characters could have in the narrative; some examples of abilities were to zoom anywhere as quickly as lightning (T1DC16), to turn into a cat (T1DC17), to bend (T1DC18), to mind read (T1DC19), to fly (T1DC21) etc. Only one child (T1DC18) proposed settings; she made a line-drawn house illustrating that her Bella Bendy (Figure 86) lives in Ireland (Figure 87). For outer and inner characteristics of the Superhero, two suggestions were given i.e. “cheerful, fun and mischief maker” (T1DC20), “brown hair and green eyes” (T1DC22).
In dealing with the next question, the second character for the story - the doctor - was developed, i.e. three males and four females. Only three of the children gave the doctors names – Dr. Smith (Figure 89, T1DC17), Dr. Amy (T1DC18) and Dr. Doctorpus (Figure 90, T1DC20). Some participants gave details of the portrayal of the medical professional; for example they described the doctor’s clothes (i.e. navy uniform (T1DC21) and white lab coat (T1DC22)), hair (i.e. black hair (T1DC17 and T1DC21), grey hair (T1DC22)), their individual facial features (i.e. bushy eyebrows (T1DC22)), a medical device (stethoscope (T1DC22)), supportive objects such as a clipboard paper holder (Figure 88, T1DC16 and Figure 89, T1DC17) and a place of work (i.e. in the children ward (T1DC20), in the Diabetes Department (T1DC17 and T1DC18)).
With both characters ready, children were asked to develop the dialogue between Superhero and Doctor, elaborating on the symptoms, diagnosis and treatment with the help of the cards in Figure 91 and Figure 92. Also, I tried to provoke participants’ imagination for generating various ideas and their active participation with a little discussion on the issue.
I decided to play the role of the Doctor by asking children what their friend Superhero would explain to the doctor about his/her medical condition (i.e. symptoms) and what questions he/she would ask about the treatment of the illness, as I had not specifically spoken about diabetes. A few ideas were expressed: “he would say like “Doctor I am very sick”” (T1DC19), “what is my illness” (T1DC17), “will this medication help me” (T1DC22) “will I have this forever” (T1DC22) and “why do I have this” (T1DC17). I observed that the young participants were not very active in expressing verbally their ideas about the Superhero – Doctor meeting, but they all wrote down the conversations using questions and answers that were strongly related to type 1 diabetes and self-care management practices, which was one of the main aims of this question in the study. Reasons for their reluctance to comment on this subject could be their similar personal experience after the diagnosis, or the fact that their focus was on the prototyping activities and not on the discussion.

After analysing the data, I discovered that the young participants used two different ways of illustrating the dialogue. In the first way, (Figure 93, Figure 94 and Figure 99) they wrote all the questions that their Superhero would ask and then all the
answers given by the Doctor. In the second way (Figure 95, Figure 96, Figure 97 and Figure 98) the individuals created a small conversation. In the dialogue, a few children gave a short explanation of some common symptoms in diabetes such as “I’ve had to go to the toilet a lot. I’ve also been really thirsty” (Figure 95), “very thirsty, and really tired” (Figure 96) and “I am feeling tired and I am more thirsty than usual” (Figure 98), while others described diabetes self-care tasks such as taking medication, measuring blood glucose levels, balanced diet, hypoglycaemia and hyperglycaemia, etc. (Figure 93, Figure 94, Figure 96 and Figure 99). Two questions were found in the dialogues which were particularly concerned with what causes diabetes type 1 (i.e. What is diabetes? (Figure 98 and Figure 99), but the participants did not go further in formulating the doctor’s answers. One of the dialogues really grabbed my attention; the young individual expressed very strong negative feelings in the conversation between the main story characters, which could be seen as a reaction to their own traumatic experiences at diagnosis (Figure 99).

Some of the questions and answers described by children have been integrated into the digital prototype in two scenes: 1) Superhero explains his symptoms (page 8) and 2) the dialogue between main characters in which the Doctor gives details on diagnosis and treatment (page 10, Section 5.4.2.5, Appendix H).

![Figure 93: Dialogue, T1DC16](image)

**Superhero:**
- Will I have diabetes forever?
- Will I have to check my bloods?
- Can I have a treat?
- Can I still do all the activities I used to do?

**Doctor:**
- You need to check your blood regularly, take medications, keep active and stay healthy.
- You can still have small treats sometimes.
- You can still do everything you used to.
Superhero:
• How can I keep my blood sugars normal?
• What do I do if my bloods go high?
• How often do I need to check my bloods?
• Why do I have diabetes? Did I do something wrong?
• Can I still do everything I did before?
Doctor:
• Your life will be different but it does not make you not normal
• You will need to take insulin and check your blood regularly
• Just like everyone you need to eat healthy and exercise.
• Every 3 months we will need to meet up to talk about your diabetes.

Doctor: Hello Bella
Bella: Hello Dr Amy
Doctor: Now you haven’t been feeling well lady
Bella: No. I’ve had to go to the toilet a lot. I’ve also been really thirsty.
Doctor: I think you have diabetes, Bella. This means you need to go to the hospital.
Bella: Oh, no. But I don’t like the Hospital!
Doctor: Don’t worry. All the doctors are very nice.
Bella: But won’t I pass it onto one of my friends?
Doctor: Ha Ha…, no Diabetes isn’t contagious; you can’t give it to anyone. It’s like not sharing. You aren’t sharing diabetes.

Donal: I have been very thirsty, and really tired.
Doctor: You might have diabetes.
Donal: I know you would say that, I can read minds.
Doctor: You will have to take insulin every day, every few hours. You also have to make sure, you eat a balanced diet.
Donal: Is there a cure?
Doctor: No, but as long as you take care of it take your insulin and eat healthy, it will be fine.
Donal: Will it be scary?
Doctor: At first, but you will learn how to use it and it will stop being so scary. Doctor explains about high blood sugars, low blood sugars, carbs, insulin and other technologies.
Doctor: I would like to do a blood test
Superhero: No Never! Never, never, never!
Doctor: Now!
Superhero: Mmm…quickly, Oww, I’m dying, the pain is horrible.
Doctor: You need to go
Superhero: Where to?
Doctor: Hospital

Doctor: How are you today?
Sky master: I am feeling tired and I am more thirsty than usual.
Doctor: Ahh, I think you might have diabetes.
Sky master: What is diabetes?
Doctor: I’m glad you asked. Diabetes is…

Doctor: You have diabetes.
Superhero:
• What is diabetes?
• What medicine do I need to take and how often? How?
• How do I take a blood glucose test?
• What is a hypo/hyperglycaemia?
Doctor:
• Diabetes is…
• You will need to take insulin.
• You will need to take it before meals and bedtime.
• You take insulin in a small injection.
• To take a blood glucose test you…
Other controversial topics in the prototyping stage provoking collaborative discussions were the questions related to taking medication on time, eating healthy food and partaking in physical activities. Here, children highlighted that setting a daily alarm on a mobile phone or on the insulin pumps could help Superhero to not miss any dose of his/her medication. Quite often they use the alarm on their own insulin pumps; it was an option to set a repeating alarm every 2 or 3 hours, reminding them to measure their blood glucose levels. Two children drew images of a watch, alarm clock and mobile phone (Figure 100 and Figure 101).

![Figure 100: A watch, alarm clock and mobile phone, T1DC17](image1)

![Figure 101: Alarm clock and mobile phone, T1DC22](image2)

It was identified that food is one of the hardest parts in diabetes management and children avoided commenting on this topic (Section 5.2.1.2 and 5.2.2.4). So, in the discussion about healthy food, I decided to play the role of the Superhero who would like to find out what is healthy and un-healthy food, what he/she could have for breakfast, lunch and dinner. Stimulating informal constructive discussion for lengthy responses, I used easy questions that children would usually ask. My attempt here was to boost young users’ involvement in the conversation that would inspire them to generate more suggestions in their prototypes. This time, more participants took part in the dialogue and their answers were clear and concise, but again they did not support for further discussion (Figure 102). Even with my effort to continue to talk about the issue, it was meaningless to keep the conversation going because there seemed to be little interest in the topic. The children lost focus on the subject and became less engaged in the ongoing discussion.

Q: What is healthy food?
A: You could have vegetables and fruit such as tomatoes and potatoes, because these products contain carbohydrates (T1DC22).
Q: How many times per day do I need to eat vegetables?
A: Three times per day (T1DC22).
Q: What do I need to have for breakfast?
A: Cereal and toast (T1DC17).
Q: Can I have jam for example?
A: Yes, you can (T1DC22).
Q: What about orange juice?
A: Yes (T1DC22).
Q: Or some eggs?
A: Yes (T1DC22).
Q: If I am hungry, what can I eat between breakfast and lunch, like a snack?
A: Something small like a biscuit (T1DC18).
A: Or something that contains a small amount of carbohydrates, it could be an apple (T1DC22).
Q: What do I need to have for lunch?
A: Sandwich (T1DC18).
Q: What about on Saturdays and Sundays when you do not go to school?
A: Casserole (T1DC18).
Q: What is your favourite food?
A: Sausages (T1DC20).
A: Salmon (T1DC17).
Q: What about vegetables?
A: Broccoli (T1DC19).
Q: Is ice-cream healthy to eat?
A: In small amounts, yes. You can have it after dinner (T1DC18).

Figure 102: Example of healthy food discussion

As a result, only two individuals who took part in the dialogue gave some examples about the food in their prototypes, the first child listed food into two categories i.e. healthy and not healthy (Figure 103, T1DC17), while the second participant drew images (Figure 104, T1DC22).

For physical activities, children were asked to explain the benefits of regular exercise, to mention their favourite sports and motivation goals that could encourage their Superhero to start his/her participation in various fun outdoor games. Only two
individuals wrote answers; participant T1DC22 stated that sport helps “to keep their sugars down” (Figure 106) and T1DC22 suggested that if the Superhero started to learn different types of sports, it could motivate him to be more active (Figure 105). To support her idea, she glued pictures of various sports such as soccer, tennis, cycling, etc.

To help children become more relaxed and keep them in a good mood, a strategy - aiming to deal with some emotions and particularly to change the topic for a while - was implemented between the questions, discussions and individual drawing sessions wherein participants were asked to think about the interactive elements that they would add to make their story interesting, entertaining and funny. For example, when they finished their drawings or writing text linked to a specific question (e.g. develop character or dialogue), they were asked to add interactive elements to their developed ideas and then to explain it.

This approach resulted in a positive attitude and engagement with the task. They described the touch and response interaction (i.e. play music, stretching, dancing,
disappearing, etc.), animations of how the doctor gives an injection (Figure 107), the use of a glucometer and changing the facial expressions of Superhero - sad turned into happy (T1DC19), read-aloud narration of the questions and answers (T1DC22) and one image of a happy face that could constantly move across the screen (Figure 108).

5.4.1.3 Discussion: Interactive Storytelling Technique in the Prototyping Stage

While performing various steps in developing seven stories-prototypes, my effort to encourage children to play a more active role in the discussions did not achieve significant success; however, the storytelling cards and other supportive materials have facilitated young participants to develop their individual stories on the Superhero who gets diabetes, based on their personal experience with the illness. Children have experienced difficulties in engaging in discussions on healthy food, physical activities and technology. They were not emotionally comfortable in sharing their opinions in informal conversations, rather they preferred to express their knowledge on paper by using the materials provided for making prototypes. As a result, my role as facilitator was difficult in two ways: 1) I was limited to asking questions that would not evoke a negative emotional state, as children were very sensitive to diabetes – related topic and 2) to steer their imagination and inspiration to include subjects such as Superhero-Doctor dialogue and healthy diet, that are strongly connected with the illness and were an important part of the storyline. As discussed, changing the topic for a while by asking children to suggest interactive features on each scene/page of their story was observed to be a supportive strategy that helped to create a balance between the questions facilitating the development of the narratives, the short discussions on particular topics, and the elaboration of individual ideas for the prototypes. This approach gently guided the gradual development of the story by using a friendly language and a positive attitude. Actually, individuals were very quiet, disciplined and more mature for their age; they were focused on the activities as responsible designers and suggested many concepts using visual communication through pictures and text; they developed characters, dialogues and other important components of the adventure story. Many children did not complete their stories; some spent more time than others on adding many details such, as facial expressions, clothes, etc., trying to create nice drawings of their
protagonist and the time allocated for the session (about 60 mins) was insufficient to fully develop their ideas.

Incorporating the collaborative storytelling technique into the prototyping stage was a method to engage children in the creation of individual stories - paper prototypes - developing eBook narratives for children with diabetes. The storytelling cards were used as a tool to facilitate children to progressively develop and create the story and to draw participants’ attention to those specific elements that needed to be included in the narrative content. Suggesting simple but meaningful questions and options of various images, the deck of cards presented itself as an important vehicle for developing the narrative, facilitating children’s active involvement in the prototyping process. The young individuals had difficulties articulating their feelings verbally in the discussions, when the second set of questions was used (Figure 81), but they actively narrated the educational and emotional elements, having the means of expressing themselves through drawings and text in the prototyping practices, similar to creative therapies. Developing an individual story was a non-verbal and less intrusive way of communicating difficult thoughts and feelings. The technique showed positive results; through these planned art activities for storytelling, the children got the chances to express themselves without the use of words. This way of prototyping provided a more viable solution - a non-verbal form that was particularly suited for emotional expression. In this age-appropriate art and creative play session, children with diabetes used symbolic language for developing main characters in the story. Drawing on the pages sparked children’s creativity and imagination in describing the Superhero and his/her magical powers, in elaborating on the meeting with the doctor and in writing down the dialogues. This way of prototyping fostered children’s inspiration, allowing them to describe and share their personal experiences with T1DM through the stories they developed.

Using this particular approach of collaborative storytelling, by asking each child to design and create individual prototypes, enabled the generation of rich data that was used to develop and build the initial prototypes of the eBook story. For example, they all had diverse experiences before and during the time of diagnosis, which could trigger various reactions to diagnosis and questions about their illness and the treatment. Therefore, the Doctor-Superhero dialogues described by them have suggested very rich and valuable information, based on their experiences illustrating
the questions that newly diagnosed patients may have. These results could not have been achieved if the participants were asked to design only one story, as many of them might not have felt confident to share their experience with other individuals attending the session. Co-design with children can be challenging when children have to talk with unfamiliar adults, which may create some barriers to playing the role of design partners and informants during the design (Marti and Bannon 2009). Based on the data collected during this study, it was critical to have time to create an appropriate connection with the participants, communication that can be built only by direct contact. This may help to establish a degree of trust and respect, facilitating the power of creative expression in children and their active involvement in the process. Furthermore, designers need to think about alternative pathways, methods and tools that could be enjoyable for children to help foster their creative possibilities, to trigger appropriate self-expression in participants and to regulate their emotions and impulses, and - in this particular case - the narrative approach indicated promising results. The different materials used (i.e. the storytelling cards and other art and craft materials) facilitated the exploratory process, enabling children to reach their full potential; it motivated them to become involved with the planned activities. Our goal as designers is to help young individuals interact productively with materials that will effectively engage their attention, boost their creativity and spur children's imaginations.

Below I outline some of the key points found in the data collected.

**Design partner**
- No education needed on prototyping to play the role of design partner
- Child felt confident in describing his/her personal experience with T1DM using symbolic language
- Partnership was essential to generate data for the eBook content and main features
- Direct contact with the participants to establish a degree of trust and respect may increase children’s active participation and creative expression

**Collaborative storytelling**
- The set of cards and other materials effectively facilitated the prototyping process
- The technique observed was similar to creative therapies
- Individual approach in developing personal story enables generation of rich data
- Non-verbal form of drawings and text suited for emotional expressions

**Topic**
- Sensitive to discuss, may provoke negative emotions
- Individual approach in developing personal story facilitated less intrusive way of communicating difficult thoughts and feelings
- Changing the topic by asking for eBook interactive features helped to balance between questions, short discussions and individual ideas elaboration and to increase
engagement with the task

**Scheduling/organising session**
- Break to manage the illness during session
- Break to deal with negative feelings
- Parents supervision
- Certificates and gifts

**Collected data – eBook content**
- Should include information on initial diagnosis in clinical settings
- Should include dialogue between protagonists 1) Superhero explains his symptoms and 2) the dialogue between main characters in which the Doctor gives details on diagnosis and treatment
- Should include “diabetes doesn't make you different from others”
- Should describe some common symptoms of diabetes
- Should explain what diabetes is
- Should describe diabetes self-care tasks such as taking medication, measuring blood glucose levels, balanced diet, hypo- and hyper-glycaemia
- Should show and describe the use of the glucometer
- Should show and discuss the food into two categories i.e. healthy and not healthy
- Should discuss sport in diabetes, it helps “to keep their sugars down”
- Should suggest touch and response interaction i.e. play music, stretching, dancing, disappearing, etc.
- Should include animations on how the doctor is giving an injection
- Should show image of happy face that could move across the screen suggests options
- Should show the facial expressions of Superhero turning from sad into happy
- Should provide a feature for read-aloud narration of the questions and answers used in the narratives

The children’s participation in this prototyping stage was fundamental to further work on the interactive technology development. The next section (5.4.2) describes the designer work, i.e. the process in which the eBook prototypes were further developed and built with the use of personas, scenarios and storyboards, as these helped to keep the focus on users and their activities, to develop various concepts and to reflect upon and test their feasibility.

**5.4.2 Personas, Scenarios and Storyboards**

“Users are complicated and varied. It takes great effort to understand their needs, desires, preferences, and behaviors” (Pruitt and Adlin 2010, p 6). Personas are described as a very powerful tool that may support the user centeredness in design by helping to clearly define the end users, to summarise their characteristics and to build their archetype (Pruitt and Adlin 2010). Quite often, personas are generated through qualitative data by applying interviews, focus groups or contextual inquiries at the beginning of the design process (Pruitt and Adlin 2010; Antle 2008). There are a variety of examples describing different approaches to creating adult and children personas. For instance, Moser *et al* (2011) created children-personas of healthy
children for games based on developed, produced and used cultural probe materials by the children involved in their study. The child-persona method has already been explored by Wärnestål et al (2014); they organised a set of design workshops in which children who had been treated for cancer were asked to design personas, and later these archetypes were integrated into digital peer support services for children. LeRouge et al (2010) investigated how the user profiles and personas as methodological tools could inform the design of an effective Consumer Health Technology (CHT) capturing the needs of the elder population dealing with self-management of chronic diabetes. They highlighted the personas success in being “leveraged to ensure successful implementation and diffusion of CHTs among aging patient groups” and suggested a conceptual user model (guidelines) helping toward successful personas creation (LeRouge et al 2010, p e263).

In Section 4.2.3, I discussed four reasons that influenced the selection and application of personas, scenarios and storyboards:

1) The development of archetypes of newly diagnosed children with diabetes and his/her family members have not received much attention in CCI and HCI (Årsand and Demiris 2008), therefore further investigation is required.

2) To gain a holistic understanding of real users’ problems, settings and everyday activities related to diabetes care by exploring a series of methods, techniques and tools for bridging the gaps in translating primary data translation into users’ requirements and design.

3) To illustrate how the real users will interact with the system by using personas in problem and activity scenarios.

4) To build the educational story ‘Superhero learns about diabetes’ involving scenarios and storyboards, in which the personas developed were integrated as believable main characters into the eBook narratives.

This Section starts with the exploration of the personas technique to build adults’ and children’s archetypes and then illustrate their integration into a series of scenarios and storyboards that helped to elaborate and test some ideas showcasing how the technology may support the users in the educational process. Therefore, Section 5.4.2.1 describes the methods and empirical data used to develop personas and the preliminary procedure that helped to identify the final number needed for this study.
Section 5.4.2.2 and Section 5.4.2.3 illustrate the actual process of building four adults and three children personas and Section 5.4.2.4 shows the use of the personas in problem and activity scenarios and their storyboards. The last two sections, Section 5.4.2.5 and Section 5.4.2.6 respectively, explain the process during which the prototypes of the two stories were designed and built, and detail the findings that emerged.

5.4.2.1 Methods and Empirical Data Used to Identify Various Group of Users Facilitating the Development of Adults’ and Children’s Personas

This study examines different tactics in building personas - firstly, the personas development process for this project occurred at the early stages of the prototyping phase supporting the designer’s work in developing two prototypes, and secondly, the primary data sources used for building personas include all data generated throughout the various UCD activities with participants (Section 4.2.3, Graphic 2) that helped to identify users’ needs (Section 5.2.1 and Section 5.2.2), to elaborate on some design ideas (Section 5.3) and to build a series of initial paper prototypes (Section 5.4.1). Two different approaches have been used to develop these two archetypes of adults and young individuals: Cooper’s personas process (Pruitt and Adlin 2006) and Antle’s framework (2008) for child-personas. For example, following the Cooper personas process explained by Pruitt and Adlin (2006), several successive steps were aimed at recognizing the target group of users, their roles, needs and goals, at identifying the primary users and at generating their persona skeletons for both personas. This process facilitated the identification of the user groups with high priority, and then the design of the adults and children personas. The child-personas are not based on users’ goals; they required more attention and time to develop than the adult personas because they are highly impacted by the children’s needs defined by their various cognitive developmental stages (Antle 2008). Antle (2008) highlighted that the “lack of access to children as design partners or informants” for the CBC4Kids.ca project was the reason behind modifying Cooper’s personas technique (Cooper and Reimann 2003) and suggesting the framework for “creating abstractions of child-users” aged 8 to 12 (p 155). Three reasons, discussed in Section 4.2.3, impacted the choice of selecting Antle’s framework to develop the child personas of a newly diagnosed child and his/her siblings:
1) To explore whether this child-persona framework (Antle 2008) supports the design of user-learner archetypes of newly diagnosed children with diabetes between the ages of 8 and 12 and his/her siblings.

2) The modifications suggested by Antle (2008) are based on children’s developmental needs defined by their various cognitive developmental stages rather than based on their goals. Similar approaches were found in some articles discussing diabetes education for children (Lange et al 2012; Hannan 2011; Silverstein 2005), and in interviews when the parents shared the diverse educational practices used at home with the child with diabetes and his/her siblings to explain the illness (Section 5.2.1.2); this indicated that the educational process depends on the child’s needs and age.

3) To adhere to the requirements given for age appropriate interaction with tablets when designing the eBook interface (Aziz 2013).

To build personas, first I will discuss how the empirical data was used for this preliminary procedure to help recognize the various groups of users and the final number of personas. Then in the following two parts, I show how the data was used in the process while creating four adult and three child personas.

Having emerged from the analysis of the qualitative data, Theme 1: Diabetes education (Figure 6) (Section 5.2.1.2) offered information on three issues:

1) The identification of two target groups of users i.e. the newly diagnosed children with T1DM and their families.

2) The limitations of the diabetes education provided from the perspective of the participants, demonstrating what the families (e.g. parents and diabetic children) learned (or didn’t) after the diagnosis. This helped to recognize the personas’ goals. Additionally, this enabled the design of the eBook.

3) Illustrated the pros and cons in using the booklet ‘Pete the Pancreas’ along with other methods, metaphors and materials used by the parents to educate their children about diabetes and other people, such as teachers, siblings, relatives, etc. This suggested valuable information for the educational context of the interactive technology, its functionality and features.

Usually, personas need to map the physical and mental characteristics of the various users by explaining their settings, daily and professional activities, perceived
challenges, demographic, economic and behavioural variables. Having qualitative
data mainly on families who have experience with diabetes for creating personas of
children before diagnosis, required additional data sources indicating the healthy
children’s awareness and knowledge of the human body and healthy food. Children
have different cognitive development and learning abilities - the meaningful learning
may occur when the child studies about the human body and food in science; they
construct their understanding gained through their personal experiences or doing
scientific investigations in school environments with the help of their teachers. Some
children can require more time to become aware of and understand the main
functions of the stomach or why some food and drink that contain sugar are not
healthy. Developing a new educational product for children requires not only the
gradual increase of awareness and understanding of the theme, but also the
identification of a starting point at which the knowledge will be constructed. These
demands were obtained during the co-design with healthy children (Section 5.5.2 and
Sections 5.5.3); collected additional data was used to fill the finer gaps in the
knowledge about these young individuals while building the child personas.
Moreover, it helped to explore the needs of newly diagnosed patients in particular -
my target user audience. This was actually one of the reasons to apply personas in
the prototyping stage of the UCD. Another reason was the need to enrich the data by
doing further investigation on educational practices at the initial diagnosis from the
perspective of diagnosed children, to learn more about diabetes management at
various scenarios, to learn of the first reactions to diagnosis and questions that the
young patients may have at that time. This was achieved by the use of subsequent
activities such as design probes (Section 5.2.2), design and prototyping sessions
(Section 5.3 and Section 5.4.1) with participants. Furthermore, this approach helped
to elaborate on some design ideas and scenarios for the eBook narratives i.e.
characters, settings, dialogues, animations, etc.

With the exception of the two groups of main users described above (i.e. the child
with T1DM and their parents), the affinity diagrams (Appendix D) helped to
illustrate other actors that may take part in paediatric diabetes self-care practices
hence, they could also be identified as users of the eBook. For example, constant
communication of the parents with physicians (e.g. parent-physician communication
cluster) and teachers (e.g. teacher/schools cluster), and the need to share
responsibilities in diabetes management (e.g. sharing responsibilities cluster) with family members, siblings, relatives, neighbours, etc. suggest that there are other groups of people who may have various levels of engagement with the affected families. As a result, seven groups of users emerged: the diabetic child, parents/guardians, siblings, medical professionals, primary school teachers, family members (e.g. uncle, aunt, grandparents, etc.) and friends, classmates and neighbours. Therefore, their different levels of priority needed to be identified because this helped to uncover the number of personas to develop. To do this, the colour coded Table 11 was built to list these seven groups of potential users (first column), to describe their roles (second column) and goals (third column), and to illustrate some of the facts called factoids (fourth column). For example: 1) Users are those direct end users or individuals who potentially will use the new technology - the eBook - in paediatric diabetes education: for each group of users a different colour was applied in Table 11, i.e. blue colour for newly diagnosed children, orange for parents/guardians, purple for siblings, green for medical professional, brown for primary school teachers, yellow for family members and red for friends, classmates, etc., 2) Roles describe users’ activities in terms of their responsibilities, job descriptions, education, task, etc., 3) Goals illustrate what individuals would like to achieve in relation to paediatric diabetes care and education, and 4) Factoids are facts and key data points derived from numerous data sources, i.e. affinity diagrams, design probes, design and prototyping sessions. The information in Table 11 was used to develop seven persona skeletons - one for each group of users, facilitating the recognition of their key attributes and priority levels of each group. Usually, a persona skeleton gives a short explanation listed in bullets for the users group; it outlines their current roles and goals. When the skeletons were ready, each category of users was carefully considered to determine which of the three different levels of priority applied to them, i.e. high, medium or low. The process described below indicated that in this particular case, the user groups are the following seven: the child with T1DM and his/her mother and father, the child siblings (brother and sister), the medical professional and teacher.
Table 11: Users, users' roles, goals and factoids

<table>
<thead>
<tr>
<th>Users</th>
<th>Role</th>
<th>Goals</th>
<th>Factoids</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetic child</td>
<td>• The child as a technology user</td>
<td>• Have fun/be entertained</td>
<td>• Know little about the digestive system, mainly of stomach</td>
</tr>
<tr>
<td>(female or male) (high priority)</td>
<td>• The child as a learner/student</td>
<td>• Learn about diabetes self-care</td>
<td>• Have some awareness of healthy and un-healthy food</td>
</tr>
<tr>
<td></td>
<td>• The child as a newly diagnosed with type 1 diabetes</td>
<td>• Get relaxed</td>
<td>• Have some basic skills in maths</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Have access to education at any time and place</td>
<td>• No information on the functions of pancreas</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Find answers on questions related to the illness</td>
<td>• No or little information on carbohydrates, proteins and fats</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Get confidence in self-care of his/her illness</td>
<td>• Search for famous people with diabetes and insulin using internet</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Search for illustrations of pancreas, pictures of pancreas location</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Limitations of educational materials such as books, video games, websites, etc.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Using dolls or diagrams to show the areas for injections</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Using cushions, teddy bears or their body for injection practice</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Education at hospital:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- education on the first day after diagnosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- injection practices</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- use glucometer</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- none or small explanation on diabetes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- none or very small information about healthy food</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- no information on honeymoon period</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- use diagrams to show body sites for injections</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- limitations of educational materials (only ’Pete the pancreas’ booklet)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Education at home from parents-educators:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- long duration</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- how the digestive system works</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- diabetes and insulin</td>
</tr>
</tbody>
</table>
- carbs and insulin (Supernanny’s episode-seesaw)
- exercise and diet
- how to correctly set up his/her insulin pen
- complication
- why hypo- and hyper-glycaemia occur and their treatment
- learn to recognize the symptoms
- emergency plan
- carb counting
- keeping diary

- No sleepovers
- Cope with the illness alone-autonomy
- Play with video game consoles
- Use tablets, computers, mobile phones
- Child asks a lot of questions
  - What is diabetes?
  - Why do I have diabetes? Did I do something wrong?
  - Is there a cure?
  - Will I have diabetes forever?
  - But won’t I pass it onto one of my friends?
  - Will I have to check my bloods?
  - How often do I need to check my bloods?
  - Can I have a treat?
  - Can I still do all the activities I used to do?
  - How can I keep my blood sugars normal?
  - What do I do if my bloods go high?
  - Can I still do everything I did before?
  - Will it be scary?

- Child looked for scientific answer
- Include child in decision making process
- Reading books with parents
- Child afraid to learn about complications
- Negative feelings
- “Fragile” and delicate
- Difficulties to accept the illness
- Difficulties looking at others eating sweets
- Bad days
- Hate to talk about diabetes
- Hate other people knowing that he/she has diabetes
- Feel different
- Strong connection with the parents
- Less stable relationships with relatives
- Feels socially isolated from others
- Excluded from school trips
- Tasks in diabetes management:
  - some may count the carbs
  - eat healthy food
  - measure blood (results) at day and night
  - some can operate with the insulin pump
  - some may give themselves insulin by injection or insulin pen,
  - keep diary
  - measure ketones
  - detect symptoms of hypo and hyperglycaemia
  - deal with hypos
  - hate diabetes
  - some may have regimental eating routine
| Parents/guardians (fathers and mothers) (high priority) | • The parents as guardian/monitor  
• The parents as a technology users  
• The parents as educator  
• The parents as having a newly diagnosed child with diabetes | • Have a tool helping in diabetes education child/teacher/family  
• Help child learn about diabetes and self-care  
• Have educational materials helping to answer questions asked by children at home  
• Support relaxed atmosphere  
• Have access to education at any time and place  
• Get confidence in the self-care of his/her child illness | • Education at hospital:  
- injection practices  
- use glucometer  
- know about carbs using scales  
- hypo and hyper-glycaemia symptoms and treatment  
- emergency plan  
- little or no information on honeymoon period  
- diagrams to show the areas for injections  
- limited information on the sick days  
• No carb counting education, only reading the food labels  
• No information on slow and fast acting carbs  
• Emergency plan- need better education on using Glucagon  
• The formation sought was not provided on time  
• Pump education only in Dublin  
• Provide the set ‘Pete the pancreas’ as educational materials, leaflets, prints, etc.  
• It takes time to learn about diabetes and its care  
• Education is very overwhelming  
• Education needs to empower rather than build dependence  
• Difficulties to understand eating pattern and carbs  
• No information on how to deal with different scenarios  
• Education at home:  
  - learn carb counting  
  - read books, magazines, articles on diabetes, search the internet  
  - a lot of effort spent on what the parents need to know  
  - read user manuals on pump, insulin pens, glucometers  
  - search appropriate materials explaining diabetes for children and use them when educating the child |
- Parents educate the child with T1DM at home:
  - long duration
  - how the digestive system works
  - diabetes and insulin
  - carbs and insulin (Supernanny’s episode-seesaw)
  - exercise and diet
  - how to correctly set up his/her insulin pen
  - complication
  - why hypo- and hyper-glycaemia occur and their treatment
  - learn to recognize the symptoms
  - emergency plan
  - carb counting
  - keeping diary

- Parents educate the healthy children at home:
  - what is type 1 diabetes
  - why take insulin
  - why eat healthy food
  - how to manage diabetes

- Parents educate teachers at school:
  - healthy eating
  - taking insulin
  - keeping diary
  - using glucometers
  - emergency plan
  - sick days
  - how to recognise low and high blood glucose levels and their treatment

- Parents educate other family relatives:
- healthy eating
- taking insulin
- keeping diary
- using glucometers
- emergency plan
- how to recognise low and high blood glucose levels and their treatment
- Meet with other parents of children with diabetes
- Support groups
- Left to their own devices
- Constant parents-teacher communication
- Constant patients-physicians communication
- One of the parents staying at home to take care of their diabetic child
- Use metaphors to explain diabetes complications
- Difficulties to share responsibilities with other family members
- 24 hours work
- Worried
- Hate diabetes
- Dedicated to their child with T1DM
- Reorganise the life in the family, new roles, new responsibilities
- Tasks in diabetes management:
  - cooking healthy food
  - counting carbs
  - check/measure blood (results) at day and night
  - work with the insulin pump and change the pump settings
  - give injections
  - collect child from school
<table>
<thead>
<tr>
<th><strong>Primary school teachers (high priority)</strong></th>
<th><strong>Have a tool helping in diabetes education</strong></th>
<th><strong>Learn about diabetes care:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Have access to education at any time and place</strong></td>
<td><strong>- how to recognise low and high blood glucose levels and their treatment</strong></td>
<td><strong>- measure blood glucose</strong></td>
</tr>
<tr>
<td><strong>Have a tool to find out the answers of some questions asked about diabetes</strong></td>
<td><strong>- keep diary</strong></td>
<td><strong>- keep diary</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Medical professionals (doctors, nurses and dieticians) (high priority)</strong></th>
<th><strong>Have a tool helping in diabetes education</strong></th>
<th><strong>- measure ketones</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support family</strong></td>
<td><strong>- observe child behaviour as result of diabetes</strong></td>
<td><strong>- deal with hypos</strong></td>
</tr>
<tr>
<td><strong>Have access to education at any time and place</strong></td>
<td><strong>- manage diabetes of her/his child trying to achieve high standards</strong></td>
<td><strong>- manage diabetes of her/his child trying to achieve high standards</strong></td>
</tr>
<tr>
<td><strong>Have a tool to find out the answers of some questions asked about diabetes</strong></td>
<td><strong>- Know that their brother/sister has diabetes</strong></td>
<td><strong>- Know that their brother/sister has diabetes</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Siblings (sisters and brothers) (high priority)</strong></th>
<th><strong>Have a tool helping in diabetes education</strong></th>
<th><strong>- Parents teach children what is diabetes and about its treatment using ‘Pete the pancreas’</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The sibling as technology users</strong></td>
<td><strong>- Learn about healthy food</strong></td>
<td><strong>- Learn about healthy food</strong></td>
</tr>
<tr>
<td><strong>The sibling as learners</strong></td>
<td><strong>- Have a tool to find out the answers of some questions asked about diabetes</strong></td>
<td><strong>- Have a tool to find out the answers of some questions asked about diabetes</strong></td>
</tr>
<tr>
<td><strong>The siblings as children who have a brother or sister newly diagnosed with diabetes</strong></td>
<td><strong>- Know that their brother/sister has diabetes</strong></td>
<td><strong>- Know that their brother/sister has diabetes</strong></td>
</tr>
<tr>
<td><strong>Have fun/be entertained</strong></td>
<td><strong>- Parents teach children what is diabetes and about its treatment using ‘Pete the pancreas’</strong></td>
<td><strong>- Parents teach children what is diabetes and about its treatment using ‘Pete the pancreas’</strong></td>
</tr>
<tr>
<td><strong>Have a tool to find out the answers of some questions asked about diabetes</strong></td>
<td><strong>- Learn about healthy food</strong></td>
<td><strong>- Learn about healthy food</strong></td>
</tr>
<tr>
<td><strong>Know that their brother/sister has diabetes</strong></td>
<td><strong>- Have a tool to find out the answers of some questions asked about diabetes</strong></td>
<td><strong>- Have a tool to find out the answers of some questions asked about diabetes</strong></td>
</tr>
<tr>
<td><strong>Parents teach children what is diabetes and about its treatment using ‘Pete the pancreas’</strong></td>
<td><strong>- Help parents with diabetes care; oldest son could mind the child with T1DM (sister/brother)</strong></td>
<td><strong>- Help parents with diabetes care; oldest son could mind the child with T1DM (sister/brother)</strong></td>
</tr>
<tr>
<td>Family members (e.g. uncle, aunt, grandparents, etc.) (medium priority)</td>
<td>The family members as assistants if parents can trust them • The family members as learners • The family members as technology users</td>
<td>Have a tool helping in diabetes education • Have access to education at any time and place • Have a tool to find out the answers of some questions asked about diabetes</td>
</tr>
<tr>
<td>Family members (e.g. uncle, aunt, grandparents, etc.) (medium priority)</td>
<td>The family members as assistants if parents can trust them • The family members as learners • The family members as technology users</td>
<td>Have a tool helping in diabetes education • Have access to education at any time and place • Have a tool to find out the answers of some questions asked about diabetes</td>
</tr>
<tr>
<td>Friends, classmates and neighbours (low priority)</td>
<td>As knowing someone who have type 1 diabetes • As learners • As technology users</td>
<td>Have a tool helping in diabetes education • Have access to education at any time and place • Have a tool to find out the answers of some questions asked about diabetes</td>
</tr>
</tbody>
</table>
Diabetes demands great care and personal responsibility that usually lays with the parents, therefore this category of users is discussed first. After their child has been diagnosed, the family dynamic was significantly impacted (Section 5.2.1.2). Families reorganised household tasks by adding and renegotiating new roles and duties that emerged from diabetes daily care. Analysing the affinity diagrams and interviews data in Section 5.2.1.2, it was found that most of the caregivers in the household i.e. parents/guardians tried to share diabetes responsibilities in the home to help their child with diabetes management\textsuperscript{56}. These categories of users have high priority; the two archetypes of this group are mothers and fathers. Usually, families in Ireland are large, having the highest number of children in the EU\textsuperscript{57}. Most of the families who participated in this study have three or more children. These young family members also have their roles in diabetes education and care, which alludes to their high level of priority (Table 11). As discussed in Section 5.2.1.2, participants (i.e. parents) in this study highlighted that they spent time talking about diabetes with their own healthy children (Parent3, Parent6 and Parent23); quite often they used the same small, childish book ‘Pete the Pancreas’ to support their conversations. For this reason, siblings were placed in the category of main users. This suggested the need for three different children’s personas: one persona representing newly diagnosed children with T1DM, and two personas describing the user group of brothers and sisters. In the qualitative data, the parents and the children pointed out the different roles of each health care practitioner in relation to diabetes care. For instance, diabetes nurses were identified as the main educators in the hospital. Their work and support was highlighted as significant because they deal with the outpatient services, maintain nursing records, offer information and advice through the telephone advice services, etc. Dietitians would help to develop personalised meal plans and show carbohydrate counting, but it was also noted that some parents had to wait a long time to meet them (Parent2 and Parent10). Participants felt that the paediatric endocrinologists’ work was more concerned with the initial diagnosis, treatment and regular screening. Some parents found that the doctor-parent communication was problematic (Section 5.2.1.2). Acknowledging the greater involvement of nurses in diabetes education and care, the group of nurses took preference over the others (dietitians and paediatric endocrinologists), indicating the need for a higher priority

\textsuperscript{56} Only one mother shared that she divorced after her child was diagnosed with diabetes (Parent7)

\textsuperscript{57} http://www.dcyia.gov.ie/viewdoc.asp?DocID=2614
to build their persona. School teachers’ role in child diabetes management was also discussed in the interviews and design probes; parents explained that teachers need education on diabetes, because during the day they partake in the responsibilities of measuring glucose levels, insulin, dealing with hypo- or hyper-glycaemia, keeping a diary and communicating information to the parents. Some of the family members, such as grandparents, relatives, friends, neighbours and classmates are represented in two different groups of users (Table 11) that could help if they had enough knowledge and skills, and if parents could trust them. Unfortunately, the findings in the interviews and design probes (Section 5.2.1 and 5.2.2) indicated that most of the parents were afraid to give responsibilities to these people, consequently, these two groups of users respectively got medium and low priority ratings.

In summary, only five groups of users - children with diabetes, together with their siblings and parents, diabetes nurses, and teachers - received high priority. Developing these personas helped to understand their diverse roles and needs better in diabetes education and care. Moreover, teachers, siblings and medical professionals\(^{58}\) did not participate in the design and prototyping activities and their requirements for diabetes educational materials were not collected. This approach helped to identify and envision how the design of the eBook may support the educational process of these individuals as well. Integrating and using personas in numerous scenarios facilitated the exploration of multiple perspectives to enable the justification of the effective features and educational content of the eBook narratives. Therefore, each archetype was given a name (Table 12), and then the actual process of personas development, explained in Section 5.4.2.2 and Section 5.4.2.3, was carried out. All the names given to personas are fictional; only the name Liam was suggested by children in the design workshop session two (Session 5.3.4).

<table>
<thead>
<tr>
<th>Adults</th>
<th>Personas’ names</th>
<th>Children</th>
<th>Personas’ names</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td>Mother Anna</td>
<td>Diabetic child</td>
<td>Boy Daniel</td>
</tr>
<tr>
<td></td>
<td>Father Jonathan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>Nurse Hazel</td>
<td>Siblings</td>
<td>Brother Liam</td>
</tr>
<tr>
<td>professionals</td>
<td></td>
<td></td>
<td>Sister Sarah</td>
</tr>
<tr>
<td>Teachers</td>
<td>Teacher Mary</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

\(^{58}\) Participation of medical professionals in interviews helped to explore the limitations of educational materials and sources, but they did not describe their context, requiems and features.
5.4.2.2 Building Personas: Adults

With personas, I tried to capture and present an understanding of various problems that may occur when a child in a family is diagnosed with diabetes, as well as to define some of the challenges during the educational process, to uncover the emotions and feelings presented by the real people, and illustrate the essential skills and knowledge necessary for proper diabetes management. Trying to build rich and unique personas, the foundation of their characteristics, roles, goals, fears, activities, environments and behaviours were derived from the factoids (Table 11). This information was also used to describe a personal profile, outlining age, occupation, family, work place, technology experience and interests/activities.

The most important attributes explaining the personality traits in developing personas of parents, children and teachers were derived by comparing and distinguishing among these two groups of people: 1) healthy families describing their lack of any experience in diabetes care before diagnosis and 2) diagnosed children and their families who explained their personal knowledge acquisition process, training, and understanding of diabetes management obtained after the initial diagnosis.

As illustrated in Table 12, the first two personas of the mother and father are called Anna and Jonathan (Figure 109, Appendix F). Quite often, one of the partners has a greater level of responsibility for routine care in the family - this was influenced by the family structures and dynamics determining different duties among partners. It was identified that the roles were largely gender-stereotypical - most of the mothers were staying at home taking care of children, while one of the fathers’ main responsibilities was to ensure the household income. Most of the parents who took part in this study highlighted that after diagnosis, the working mothers left their jobs to stay at home, because caring for a child with diabetes is dedicated, 24-hour work. Fathers had less time to attend the educational lectures at the clinic because of their work, and they had a lower degree (in comparison to the mothers) of sharing care in diabetes management.
The next two personas of the adult users group are those of the teachers and medical professionals. Not all schools have Special Needs Assistants (SNAs); it is a matter for the individual school authority to appoint SNAs to their pupils who have special care needs or disabilities. As a result, the majority of parents felt that they get more support in diabetes from the teachers of their children. Quite often the shortage of diabetic nurses (Section 2.2.3) was the reason for parents to become educators at the schools where their chronically ill children were attending. They could spend days to build appropriate parent–teacher communication important for the health of their children. For instance, aiming to increase the quality of daily management tasks, the parents used books, booklets, manuals, etc. to facilitate the educational process and understanding in diabetes care - they discussed the emergency plan, the use of a glucometer, insulin pen, pumps and other issues related to the illness. In the primary schools in Ireland, the class teachers teach all subjects to their class. As per educational policy, every year or second year teachers swap classes with other teachers in the school. Of course, this can create some problems as every year (or every second year), parents have to educate a new teacher. All this valuable data was used to develop the persona of a primary school teacher called Mary (Figure 110,
Appendix F). The work of diabetes nurses is very intense; one of their responsibilities is to provide education about diabetes management to newly diagnosed children and their families. The persona called Hazel summarised nurses’ characteristics that were identified earlier and articulated by parents and children during interviews (Figure 110).

### Teacher Mary

**Teacher:** Harris School Teacher  
**Age:** 26  
**Occupation:** Primary school teacher  
**Workplace:** Harris School  
**Technology experience:** Good computer skills, sending email, surfing the internet, using DHR, downloading and printing educational materials  
**Interests/Activities:** Likes to read novels, music, history, cycling.

Mary is a primary school teacher qualified to teach a range of primary school subjects to children aged 5-13. As a class teacher in Harris School, her primary responsibilities are to support the progress of all the pupils in the educational program, teach, and plan the curriculum. She feels that her role is particularly challenging because of the broad range of subject areas that she needs to cover. In a long conversation, Mary shared her views on the importance of diabetes education in schools and the role of primary school teachers in teaching children about diabetes.

### Nurse Hazel

**Nurse:** Harris (the diabetes nurse)  
**Age:** 32  
**Occupation:** Diabetes nurse  
**Workplace:** Paediatric Diabetes Care Department, University Hospital Linneck  
**Technology experience:** Good computer skills, sending email, surfing the internet, using Word and PowerPoint, downloading, and print different articles  
**Interests/Activities:** Reading the latest medical research on diabetes, reading books, watching television.

Hazel is a 32-year-old diabetes nurse working in the Paediatric Diabetes Care Department of the University Hospital Linneck. She works on the ward and in the clinic, assessing and managing children with diabetes and their families.

### 5.4.2.3 Building Personas: Children

This section discusses the development of three child personas applying Antle’s framework (2008). The age of each child persona was chosen so that it meets the criteria of representing the stages of cognitive development identified by Piaget (1970): for example, a nine-year-old newly diagnosed child named Daniel enters in the concrete operational stage (7–11 years), his sister Sarah at age 12 falls into the formal operational stage (11-16 years), and his brother Liam at age 5 belongs to the pre-operational stage (2-7 years). As discussed, Antle’s framework (2008) was particularly developed to support the creation of child-personas of young users aged between 8 and 12 - the target user group of our educational eBook. She illustrated three main dimensions of childhood needs, developmental abilities and experiential goals that were considered in developing the child-archetype (Antle 2008). The first
two dimensions are reusable; they are grounded “on theoretical understandings and empirical findings taken from children’s developmental psychology”, whereas the third dimension is related particularly to the project and “explores experiential product goals” (Antle 2008, p 156). Therefore, the first two framework dimensions for the development of the Daniel and Sarah personas could be reused as they fall in the same age group.

Taking into consideration that the three child-personas in this study need to represent user-learners at different ages, using the assumptions based on the primary data and some literary sources (Aziz 2013; Hannan 2011; Silverstein 2005), Antle’s three dimensional frameworks (Antle 2008) was explored by generating Table 13. The first and second columns in the table show these three dimensions along with their themes pointed out by Antle (2008), while the third, fourth and fifth columns illustrate the corresponding attributes used for each theme and for each child. For the first dimension (e.g. childhood needs), Antle outlined four themes of 1) love, security and independence, 2) positive social interactions, 3) mastery in learning and 4) control and responsibility. For example, the factoids identified in the interviews were used to illustrate the first two themes (i.e. the love, security and independence, and positive social interactions (Table 11)). The factoids taken from the workshop sessions with the healthy children (Section 5.3.3 and Section 5.3.4), together with the teaching activities on the human body and food taken from the Irish Primary School Curriculum in Science have been used for the third theme (i.e. mastery in learning) (Table 13). The information describing the children’s autonomy and diabetes education according to their cognitive development was extracted from a book and an article (Hannan 2011; Silverstein 2005) and used for the last theme - explaining the control and responsibilities. The second dimension in the table explores the developmental abilities and limitations by suggesting what interactive elements could be appropriate to integrate into the design of the new product - they have to correspond to the age of the young users. With the knowledge that the technology is an interactive eBook, two sources were used. The first explains children’s ability and motor, social and cognitive development by Bruckman and Bandlow (2003), as it was also used by Antle (2008), and the second describes the gesture interaction with tablet applications by Aziz (2013). The third and final dimension listed the different needs of each child according to their roles and goals as users taken from Table 11.
In Table 13, differences between children at 9 and 12 obviously appeared, as children entered in the same users’ age group (8-12) will have different knowledge and understandings about the human body and food that are strongly influenced by the educational curriculum. This assumption is crucial for the children newly diagnosed with T1DM, because the eBook needs features that will enhance the learning experience in young users with diverse knowledge bases. Also, children’s cognitive development at 12 years of age is similar to adults, whereas the cognitive development for children at 9 is only near to the adults’ cognitive ability. This influences the autonomy, control and daily responsibilities of children in diabetes management. Concerning the gesture interaction, they have the same needs and abilities, although children between 10 and 12 want more fun and challenges when playing with apps. Therefore, by exploring the framework suggested by Antle (2008) in developing the child-learner personas of a newly diagnosed patient with T1DM, the results above indicated that in this particular case, the first and second dimensions for Daniel (at 9) and Sarah (at 12) are different, hence the reuse is not possible. The benefits of applying this framework cannot be denied, because it offers a way to classify data to help identify and show how the needs of children at different ages varied according to the educational curriculum, maturation and different degrees of responsibilities.

When the identification of characteristics for each age group of young users was successfully accomplished, with their various experiential goals, needs and cognitive development (Table 13) taken into consideration, the three personas of Daniel, Liam and Sarah have been built (Figure 111 and Appendix F). Having completed the process of personas development, the next Section 5.4.2.4 illustrates the use of these archetypes in problem and activity scenarios, helping to demonstrate the current situation and to envision how the eBook will be used by the users.
Table 13: Antle’s framework for developing child personas of Liam, Daniel and Sarah

<table>
<thead>
<tr>
<th>Antle’s three dimensions</th>
<th>Liam, 5 years</th>
<th>Daniel, 9 years</th>
<th>Sarah, 12 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>First dimension</td>
<td>Theme 1. Love, security and independence</td>
<td>Theme 2. Positive social interactions</td>
<td>Theme 3. Mastery in learning</td>
</tr>
<tr>
<td></td>
<td>• Children love their parents and siblings</td>
<td>• They have normal relationships with family members</td>
<td>Children’s knowledge about the human body is different, it is based on the Irish Primary School Curriculum on Science(^{59})</td>
</tr>
<tr>
<td></td>
<td>• Small children need greater attention</td>
<td>• After diagnosis less stable relationships with relatives</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Theme 2. Positive social interactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• They have normal relationships with family members</td>
<td>• Children in 3(^{rd}) and 4(^{th}) class should become aware of some of body’s major external and internal organs, physical changes in male and female during maturation process (p 61)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Children in 5(^{th}) and 6(^{th}) class “should be enabled to develop a simple understanding of the structure of some of the body’s major internal and external organs(^{60}) as well as food and nutrition and reproductive system (p 83)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Children don’t know the functions and position of the pancreas and different food categories.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Theme 3. Mastery in learning</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Children’s knowledge about the human body is different, it is based on the Irish Primary School Curriculum on Science(^{59})</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Theme 4. Control and responsibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Less autonomy</td>
<td>• Encouraging autonomy</td>
<td>• Medium to high level of autonomy</td>
</tr>
<tr>
<td></td>
<td>• Strict-intensity of adult control</td>
<td>• Moderate-intensity of adult control</td>
<td>• Moderate-intensity levels of adult</td>
</tr>
</tbody>
</table>


\(^{60}\) http://www.ncca.ie/uploadedfiles/Curriculum/Science_Curr.pdf

247
<table>
<thead>
<tr>
<th>Second dimension</th>
<th>Motor, social and cognitive development</th>
<th>Second dimension</th>
<th>Gesture interaction with tablet applications</th>
<th>Third dimension</th>
<th>Different experiential goals</th>
</tr>
</thead>
</table>
| Bruckman and Bandlow 2003 | Short attention span  
Difficulty with abstractions  
Pre-literate stage  
Select target with mouse  
Avoid the use of keyboards | Silverstein 2005 | Moderate level of dependence  
Depends on personal development and maturation | Aziz 2013 | Behaviour and feelings could change  
Empathy and understanding  
Some simple questions about the illness  
Have fun with his brother |
| | Cognitive maturation near to adult cognitive abilities  
Difficulties to formulate hypothesis and abstract concepts  
Looking for a playful approach in the apps  
Fine motor skills to use simple keyboards and mouse | | | | Behaviour of newly diagnosed children usually changes after diagnosis  
New thoughts and feelings related to the illness  
Many questions about the diabetes and its treatment |
| | Cognitive development similar to adults | | Are able to use all seven gestures  
Think of easiest way to learn how to do drag and drop if faced difficulties  
Less easy to drag a 2D objects than 3D objects  
They can use a lot of gestures on one interface | | Behaviour and feelings could change  
Empathy and understanding  
Have fun with her brothers and be entertained  
Feel independent  
Some questions about the diabetes and its treatment |
<table>
<thead>
<tr>
<th>New responsibilities</th>
<th>Diabetes self-management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have fun with his siblings, schoolmates, neighbours</td>
<td></td>
</tr>
<tr>
<td>Feel independent</td>
<td></td>
</tr>
<tr>
<td>Learn diabetes self-care</td>
<td></td>
</tr>
<tr>
<td>long duration</td>
<td></td>
</tr>
<tr>
<td>carb counting</td>
<td></td>
</tr>
<tr>
<td>how the digestive system works</td>
<td></td>
</tr>
<tr>
<td>what is diabetes</td>
<td></td>
</tr>
<tr>
<td>carbs and insulin</td>
<td></td>
</tr>
<tr>
<td>exercise and diet</td>
<td></td>
</tr>
<tr>
<td>how to correctly set up his/her insulin pen</td>
<td></td>
</tr>
<tr>
<td>take appropriate amount of insulin</td>
<td></td>
</tr>
<tr>
<td>use glucometer</td>
<td></td>
</tr>
<tr>
<td>injection practices</td>
<td></td>
</tr>
<tr>
<td>complications</td>
<td></td>
</tr>
<tr>
<td>why hypo- and hyper-glycaemia occur and their treatment</td>
<td></td>
</tr>
<tr>
<td>learn to recognize the symptoms of hypo- and hyper-glycaemia</td>
<td></td>
</tr>
<tr>
<td>emergency plan</td>
<td></td>
</tr>
<tr>
<td>keeping diary</td>
<td></td>
</tr>
<tr>
<td>find appropriate educational materials</td>
<td></td>
</tr>
<tr>
<td>manage diabetes effectively at home and at school</td>
<td></td>
</tr>
<tr>
<td>Learn about diabetes</td>
<td></td>
</tr>
<tr>
<td>Learn about healthy food</td>
<td></td>
</tr>
<tr>
<td>Find appropriate educational materials for her brother</td>
<td></td>
</tr>
<tr>
<td>Try to help and support her parents and brother</td>
<td></td>
</tr>
<tr>
<td>Try to help her brother with diabetes management</td>
<td></td>
</tr>
<tr>
<td>Could mind her brother with diabetes</td>
<td></td>
</tr>
</tbody>
</table>
Figure 111: Personas Liam, Daniel and Sarah

Brother Liam

Has a brother diagnosed with type 1 diabetes

**Goals:**
- Reduce blood glucose levels
- Learn to manage diabetes
- Stay healthy

**Features:**
- Requires insulin injections twice daily
- Uses a glucometer to check blood glucose levels
- Uses an insulin pump
- Follows a strict diet

**Technology use at home:**
- Computer
- Smartphone
- Tablet
- Insulin pump

**Technology use at school:**
- Smartphone
- Tablet
- Computer
- Insulin pump

**Technology use at clinic:**
- Computer
- Telephone
- Tablet
- Insulin pump

**Technology use at home:**
- Smartphone
- Tablet
- Computer
- Insulin pump

**Technology use at school:**
- Smartphone
- Tablet
- Computer
- Insulin pump

**Technology use at clinic:**
- Computer
- Telephone
- Tablet
- Insulin pump

Sister Sarah

Has a brother diagnosed with type 1 diabetes

**Goals:**
- Reduce blood glucose levels
- Learn to manage diabetes
- Stay healthy

**Features:**
- Requires insulin injections twice daily
- Uses a glucometer to check blood glucose levels
- Uses an insulin pump
- Follows a strict diet

**Technology use at home:**
- Computer
- Smartphone
- Tablet
- Insulin pump

**Technology use at school:**
- Smartphone
- Tablet
- Computer
- Insulin pump

**Technology use at clinic:**
- Computer
- Telephone
- Tablet
- Insulin pump

**Technology use at home:**
- Smartphone
- Tablet
- Computer
- Insulin pump

**Technology use at school:**
- Smartphone
- Tablet
- Computer
- Insulin pump

**Technology use at clinic:**
- Computer
- Telephone
- Tablet
- Insulin pump

250
5.4.2.4 Problem and Activity Scenarios and Associated Storyboards

As noted (Section 4.2.3 and Section 5.4.2), one of the aims of building personas was to use them in many scenarios, storyboards and in the eBook educational narratives. For example, the problem and activity scenarios were specially designed:

1) to describe the key aspects of the current situation for each persona, their reactions, individual choices and behaviours and,

2) to illustrate a sequence of actions, responses and events while personas interacted with the educational eBook designed to help them accomplish their goals.

Scenarios in design are simple stories that usually have basic components inherent to the narratives such as settings, plot, characters, objectives, dialogues, challenges, social relationships, etc.; they can be descriptive and vivid enough to illustrate and reveal personal desires, attitude, feelings, fears, actions, etc. (Section 4.2.3). In order to communicate design ideas for action and reflection, they are flexible, easy to extend or change by adding new settings, actors, events and problem-solving challenges (Rosson and Carroll 2011). Having great explanatory power, they help designers to focus on the barriers and problems for specific users by suggesting some imagined situations on how the new designs may facilitate users to overcome these obstacles in order to achieve their targets (Holtzblatt et al 2004; Rogers et al 2002; Rosson and Carroll 2011). While exploring various design alternatives, the personas enriched my scenario-based design by making the envisioned possibilities more tangible, drawing attention particularly to the educational features and context that needed to be integrated in the eBook. Then, by sketching the scenes in storyboards, capturing the storylines vividly, I illustrated how people performed different complex activities to make progress in pursuing their goals. This visual interpretation offered a rich realistic view of the possible concepts, by helping me to reflect on the design ideas, indicating critical elements and possible alternatives.

Problem Scenarios

Discussed by Rosson and Carroll (2011), problem scenarios are narratives explaining the current practices; they describe the context of people’s problems, activities, settings, etc., all to help reveal the problem domain; the factoids column (Table 11) helped me to identify them. For most personas (not applicable to the diabetes nurse
 persona), the diagnosis is a new, very serious experience that usually starts with the presence of some emotions, quite often associated with negative feelings: frustration, fear, etc. For example, they spent a lot of time thinking about the disease, they need knowledge necessary to live with diabetes, about new responsibilities, and specific tasks and activities that would be required to manage the illness. Similar to the findings in the interviews (Section 5.2.1.4), the problem scenarios demonstrate the problematic aspects of diabetes education, starting on the first day when the family is informed that their child has diabetes, and then their education at home; the narratives summarised the experiences of parents and their children using the assumptions made for each persona (Figure 112).

<table>
<thead>
<tr>
<th>Diabetic child Daniel</th>
<th>Mother Anna</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the last week Daniel had been very tired, thirsty and he had pain in his tummy. His mother Anna took him to the hospital, she was very worried about Daniel's health. Daniel was diagnosed with type 1 diabetes and hospitalised for a week in the Children's Ac unit, University Hospital Limerick. There he met Hazel, the diabetes nurse that helps newly diagnosed children and their parents get education on diabetes management. She was very kind to him, Hazel gave Daniel the early available book for newly diagnosed children with diabetes ‘Pete the Pancreez’ that he can read and learn about what causes diabetes and its treatment. She also brought him a new glucometer that Daniel can use at the hospital and later at home to measure his blood glucose levels. During his stay in the hospital Daniel was encouraged by Hazel to practice using the glucometer and to take insulin by practicing with a teddy bear. When he was alone in his bed he started to read the book trying to understand why he needs to have this type of treatment and why he needs to have injections rather than insulin in the form of tablets. Despite reading the book he was not able to see where the pancreas is located in the human body and why they has to take the shot of insulin whenever he eats. He also wanted to know what happens to the food when he eats it. The nurse told him that he must only eat healthy food and to have a balanced diet. He tried to find in the book where it mentioned the balanced diet, but he could not find it. Hazel used many words in diabetes management like carbohydrates, HbA1c, etc. and he found it difficult to understand their meaning as they were not explained in the book. He also wanted to know if there are famous people that have diabetes and if so how they live with this illness. He found that the book is not very helpful to him as it did not answer his questions. Now Daniel is at home, he needs help from his mum in diabetes self-care education. His mum Anna really tried to find children's books explaining diabetes and other interactive materials that could help both Daniel and her learning process. She knows that Daniel likes to use different technology, having same tools for children with all the information about diabetes may really help in the learning process.</td>
<td></td>
</tr>
<tr>
<td>It was very difficult for Anna and Jonathan to learn that their son Daniel has diabetes. Daniel was admitted into the hospital for a week. During that time Anna and Jonathan had been educated on how to manage the illness at home. Anna attended all the classes trying to learn as much as possible. She received practical training on how to read the food labels, count the carbs using the kitchen scales, how to use the glucometer, how to give insulin injections to her son and what are hypo- and hyperglycaemia, their symptoms and treatment. Jonathan is a farmer and he is very busy; he was only available to attend the first lesson in the clinic. During the educational activities, Anna was not fully focused on the material presented. Feelings of sadness affected her ability to concentrate on the tasks and information that are important for diabetes management. She felt overwhelmed; first she needed time to accept Daniel's diagnosis and then try to help him. The nurse was very good to her and Daniel, she gave them a small children's book about diabetes ‘Pete the Pancreez’ that they can both read at home. When Daniel was discharged from the hospital she still had many questions. These questions were related to insulin and carbs in the food, blood tests results, honeymoon period and sick days. Anna felt that she needed more educational materials for her son and more education on diabetes self-care. Unfortunately, there is no structured education provided for parents outside the clinic environment. She also found that the education was too medically focused; the human side of it was not discussed and she was not informed on how to deal with different scenarios. Anna found herself alone at home with her own devices and when a scenario came up she would need to go to the clinic or call them. Her son Daniel started to ask questions related to diabetes and the small book was not very helpful. Her new role as educator was very difficult, she struggled to find educational sources of nice interactive adventure stories, games or apps that they can both use together. Even ones that she can use with her other children Sarah and Liam. A mixture of materials such as videos explaining how to perform self-care tasks, or count the carbs could improve her ability and confidence in diabetes care.</td>
<td></td>
</tr>
</tbody>
</table>

Figure 112: Problem scenarios: Daniel and Anna

252
Activity Scenarios

Most of the personas have a similar goal: the need for appropriate and accessible educational materials in different settings that could help them learn, know or teach about diabetes self-care and treatment was identified (Section 5.2.1.4). As discussed in Theme 1 (Section 5.2.1.2), for parents and the diagnosed child, acquisition of personal knowledge and training on paediatric diabetes is a long-term continuous process with two phases: at hospital and in domestic settings.

![Figure 113: Problem and activity scenarios: examples](image)

The activity scenarios (Figure 113) enabled and prompted discussions addressing the question of how the eBook may facilitate the teaching and learning process when the users exploit this technology in these two environments, and what content,
interactive features and details may successfully support the knowledge exchange while the children are engaged with the interactive stories. Furthermore, they helped to reflect on how to introduce rigorous learning materials in an appropriate way, finding the delicate balance using the child-friendly text and fun elements to display background on diabetes that suit appropriate learning outcomes and to make stories for the eBook interesting, designed to grab children’s attention.

5.4.2.5 Building the Prototypes

Above, I illustrated the preliminary activities that have been carried out to facilitate the designer work, whose objective was to build numerous prototypes by exploring various methods and techniques in supporting this process. Additionally, I explained the criteria used to make the choice for design – an educational eBook for newly diagnosed children with T1DM (Section 5.2.1.4) - and now I move on to the tasks performed to build the technology prototypes. The development of a series of prototypes was a process in which different components of the technology were designed and built; the data collected with/from participants helped to identify the product content, functional specifications and requirements. The prototyping process began with the analysis of the users’ requirements for educational materials on paediatric diabetes. I will discuss 1) the reasons for building the mock-up and digital prototypes, 2) the use of personas in the eBook story and the narrative writing process and 3) the prototyping procedure for the two stories ‘Superhero is sick’ and ‘What is type 1 diabetes?’.

‘Users’ requirements

In order to develop the design of the educational eBook, I used all the requirements collected applying UCD, PD, CI and ID with participants; they are shown in Table 14, first column. The second column lists the types of different activities used to collect these requirements, e.g. The state of the art, Interviews, DP, Design workshop 1, Design workshop 2 and Design workshop 3 and Prototyping workshop 4. The state of the art represents ideas for the design of the interactive elements (e.g. balance, visualisation, animations, games, etc.) aiming at improving diabetes educational content in the eBook; they are taken from the review of 21 educational technologies (Section 2.3.1, Table 1, p 33). In addition, analysing the text and images in the children’s booklet ‘Pete the Pancreas’, I discerned a lack of information on healthy
eating guidelines such as diet, healthy food, the food pyramid, reading food labels and carb counting. There was no information on the honeymoon period, why children need to take insulin injections, insulin pumps, travelling abroad or emergency situations, which were all discussed in the first design session with the child with T1DM (Section 5.3.2). Therefore, all these gaps found in the booklet along with the emergent requirements helped to identify the content, features, illustrations and interactive elements that needed to be integrated into the storylines of the eBook during the prototyping process.

Table 14: User requirements and the state of the art

<table>
<thead>
<tr>
<th>Requirements</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. “…children were encouraged in self-management from the age of 8…” (MP29)</td>
<td>Interviews</td>
</tr>
<tr>
<td>e.g. Parents educate their children on diabetes</td>
<td>Interviews ‘Pete the Pancreas’</td>
</tr>
<tr>
<td>e.g. “I actually love to show them some child friendly stuff, just to sit down with his brother and sister we go through the stuff in the book.” (Parent23)</td>
<td></td>
</tr>
<tr>
<td>e.g. “a wall chart of the human body” (Parent11)</td>
<td></td>
</tr>
<tr>
<td>e.g. “it was a talk about the mechanics of the digestive system when we eat food and then it is converted to energy” (Parent6)</td>
<td></td>
</tr>
<tr>
<td>e.g. The use of puppets I and C (Parent8)</td>
<td></td>
</tr>
<tr>
<td>e.g. Treat and care for a bear with T1DM (Parent15)</td>
<td></td>
</tr>
<tr>
<td>e.g. The use of examples of “high achievers or people who have lived normal, but full life” (Parent9)</td>
<td>Design workshop 1</td>
</tr>
<tr>
<td>e.g. “At that time we only had the ‘Pete the Pancreas’ book so the teacher read it out to the class.” (Parent15).</td>
<td>Interviews The state of the art</td>
</tr>
<tr>
<td>e.g. Develop scenario stories describing diabetes care in different settings e.g. at a hospital, at home, at the shop, at school, etc.</td>
<td>Design workshop 1</td>
</tr>
<tr>
<td>e.g. “She got very anxious. She suffers a lot from anxiety I think, because her life was so structured, there was a plan, there always had to be a plan so she became like that. I had to take her to a child psychologist” (Parent8)</td>
<td>Interviews The state of the art</td>
</tr>
<tr>
<td>e.g. “She did get upset several times especially early on and we just let her cry it out.” (Parent6)</td>
<td></td>
</tr>
<tr>
<td>e.g. “There was a lot of crying and disbelief that she had this…this experience was so much for us” (Parent7)</td>
<td></td>
</tr>
<tr>
<td>e.g. “I want to see clear and accurate explanations of the disease, but only up to a certain age and appropriate level. I don't want to see talk about amputations and stuff like that… I want to see role models… I want to see, what we say to care givers…” (Parent9)</td>
<td>Interviews Prototyping workshop 4 ‘Pete the Pancreas’</td>
</tr>
<tr>
<td>e.g. dialogue between Doctor and Superhero</td>
<td></td>
</tr>
<tr>
<td>e.g. “The hero has insulin guns to reduce the hypers and glucose guns to eradicate hypos. By being a scientist he spends the day looking for a cure for diabetes and by night he protects all children from hypos and hypers.” (T1DC8)</td>
<td>Design Probes Design workshop 1 Design workshop 2 Design workshop 3 Prototyping workshop 4 The state of the art</td>
</tr>
<tr>
<td>e.g. The setting may include a particular scenario elaborating on diabetes self-care task i.e. travelling “injection, insulin, set change for pump, glucagon injection, medical card, extra supplies, meter, cooling pack for insulin, etc.” (T1DC8)</td>
<td>Interviews Design workshop 1 The state of the art ‘Pete the Pancreas’</td>
</tr>
</tbody>
</table>
e.g. Doctor- Sky master dialogue
Sky master: I am feeling tired and I am more thirsty that usual.
Doctor: Ahh, I think you might have diabetes.
Sky master: What is diabetes?
Doctor: I’m glad you asked. Diabetes is…” (T1DC21)

Design workshop 1
Prototyping workshop 4

Design workshop 1
Prototyping workshop 4

Interviews
Design Probes
Design workshop 1
Prototyping workshop 4

Interviews
Design workshop 1
Design workshop 2

Interviews
Design workshop 1
Prototyping workshop 4

Design workshops
Design Probes

Design Probes

Design Probes

Design Probes

Design workshop 1
Prototyping workshop 4

Design workshop 1
<table>
<thead>
<tr>
<th>Topic</th>
<th>Example</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing Blood Glucose</td>
<td>e.g. Why children need to eat healthy food: foodstuff into two categories&lt;br&gt;&lt;br&gt;e.g. “healthy and not healthy.”&lt;br&gt;&lt;br&gt;e.g. “Fruit is healthy for diabetes, Vegetables are good for diabetes” (T1DC10)</td>
<td>Interviews, Design Probes, Design workshop 1, Design workshop 3, Prototyping workshop 4, Design workshop 1, Prototyping workshop 4</td>
</tr>
<tr>
<td>Emergency Plan</td>
<td>e.g. emergency plan: hyper - “Measure blood sugar, if your bloods are near 10 you need to take extra insulin. The doctor will tell you what amount of insulin you can take in different cases.”&lt;br&gt;&lt;br&gt;hypo - “when sugars are under 4 - lucozade, dextrose tablets, glucagon injection” (T1DC8)</td>
<td>Interviews, Design workshop 1, Prototyping workshop 4</td>
</tr>
<tr>
<td>Exercise and Sport Activities</td>
<td>e.g. Sport activities will also change your blood sugars, but on a temporary basis, which will keep your bloods from dropping.” (T1DC8)</td>
<td>Interviews, Design workshop 1, Design workshop 3, Prototyping workshop 4</td>
</tr>
<tr>
<td>How to Buy Healthy Food and Carbohydrate Counting</td>
<td>e.g. “they didn’t really talk to us about food or how it impacts” (Parent6)&lt;br&gt;&lt;br&gt;e.g. “…six months guessing not knowing how to really count carbohydrates, how to do anything…” (Parent2)</td>
<td>Interviews, Design workshop 1</td>
</tr>
<tr>
<td>The Role of Sport in Diabetes Care</td>
<td>e.g. The role of sport in diabetes care&lt;br&gt;&lt;br&gt;e.g. It helps “to keep their sugars down” (T1DC22)&lt;br&gt;&lt;br&gt;e.g. “bring your sugar down” (T1DC8)</td>
<td>Design Probes, Design workshop 1, Prototyping workshop 4</td>
</tr>
<tr>
<td>The Honeymoon Period Age</td>
<td>e.g. The honeymoon period amongst children with T1DM&lt;br&gt;&lt;br&gt;e.g. “lack of information at the very start, which was kind of where you are left” (Parent2)&lt;br&gt;&lt;br&gt;e.g. “Honeymoon period usually happens after being diagnosed. In that time you need to measure your blood sugar, take insulin and have loads of activities. Your bloods may go up and down that is, because the pancreas used to produce so little insulin and now with the injection it gives you a lot.” (T1DC8)</td>
<td>Interviews, Design workshop 1</td>
</tr>
<tr>
<td>Medical Terms in Diabetes</td>
<td>e.g. Medical terms in diabetes as insulin, carbohydrates, ketones, etc.</td>
<td>Interviews, ‘Pete the Pancreas’, Design workshop 1</td>
</tr>
<tr>
<td>Role Models Discussed by Parents and Children</td>
<td>e.g. Role models discussed by parents and children&lt;br&gt;&lt;br&gt;e.g. Gary Mabbutt, Halle Berry, Nick Jonas, etc. (T1DC4; T1DC9; T1DC10; T1DC16; T1DC19)</td>
<td>Interviews, Design Probes</td>
</tr>
<tr>
<td>Superheroes</td>
<td>e.g. Superhero (role-playing)</td>
<td>Design Probes, Design workshop 2, Design workshop 3, Prototyping workshop 4, The state of the art</td>
</tr>
<tr>
<td>Relationship Between Insulin Doses and Carbohydrates, Simulation</td>
<td>e.g. The relationship between insulin doses and carbohydrates – simulation seesaw&lt;br&gt;&lt;br&gt;e.g. “It was just one puppet had C for carbs and one puppet had I for insulin. So they were on a little seesaw...and I said &quot;What happens when you eat?&quot; and she goes &quot;Your carbs go up&quot;, so she knows what happens when she eats, &quot;What do you need to make your carbs not go up?&quot; and she goes &quot;The insulin&quot;, so when you give the insulin, you see the seesaw balance.” (Parent4)</td>
<td>Interviews, The state of the art (balance, simulation - visualisation)</td>
</tr>
</tbody>
</table>
In this research, one of the main questions was how to involve participants effectively in design. Effective involvement in the evaluation stage means that children clearly understand the meaning of the prototypes used during the assessment process, the combination of its content (i.e. animations, text, buttons, etc.) and the functionality of the product (i.e. facilitate education on paediatric diabetes). Paper and digital prototypes convey different forms of information about the interactive technology, but they also afford different forms of interaction and interaction styles and therefore provide different types of feedback. The mock-up contained sketches illustrating the concept, screen layout and design direction by suggesting an open design space in which the evaluator may reflect, while the digital prototype responds to the user input, allowing testers to interact with the user interface by representing the behaviour of the eventual product. These dissimilarities in behaviour of the artefacts may impact children’s understanding on the prototype functions, hence their
active involvement and feedback in the evaluation process. As this research is concerned with the methodology, particularly to explore some of participatory methods and techniques with/for children and their parents, the main reason to develop the paper mock-up and the digital prototypes for the evaluation process was to examine 1) which of these two prototypes will involve children actively in the test and evaluation phase, illustrating the impact of the prototype fidelity on the users’ reflection (if any) and 2) how the layered elaboration technique (Walsh et al 2010) would support participants to examine both prototypes during the assessment activities, communicating their opinions and new suggestions (Section 4.2.4).

I embraced the ideas suggested and developed in the first co-design workshop (Section 5.3.2) in which, together with the child who has T1DM, we elaborated on diabetes management in different settings starting from the first day of diagnosis. So, for the eBook design, while mapping the characteristics of personas developed earlier in Section 5.4.2.2 and Section 5.4.2.3, the sequence of stories was written so that within each narrative the main character - a newly diagnosed child - has to deal with different scenarios, such as a particular aspect or event related to diabetes in everyday life, exploring a certain mood, settings, challenges, etc. The stories were tailored for children aged 8-12, and only the first two narratives ‘Superhero is sick’ and ‘What is type 1 diabetes?’ were built as prototypes and described below. Taking into consideration that the protagonist in the original story of Superhero is a man (e.g. Superman or Superhero), as well as Daniel’s persona, the main character in the educational narrative is a boy called Superhero. The name was chosen because most of the parents think that their children are little heroes. The personas of Daniel’s family (i.e. mother, father and his siblings) were also integrated into the story and their names were not changed. Only one new character was added to the narrative – Dr. Jenny; her name and gender was suggested during the third co-design session (Section 5.3.4). First, the stories were written, and then their storyboards were created to test the initial ideas. The visual representations of the narratives were used as a guide while building the paper and digital artefacts (Figure 114).
**First story - ‘Superhero is sick’**

With 14 pages (Figure 115), the first story describes Superhero as a happy boy who lived with his family and had many friends (page 3). Suddenly, Superhero lost his powers to fly (page 4). Trying to find out what caused this problem (page 5), he went to the hospital along with his mother where he met Dr. Jenny (page 6 and page 7). After Superhero explained his symptoms (page 8), Dr. Jenny used the glucometer to measure his blood glucose and explained the appropriate sequence of using this supportive technology (page 9). The boy was diagnosed with diabetes; he had many
questions about the illness and Dr. Jenny was very kind to answer them all (page 10). He was able to learn some facts about different technologies developed for diabetes management such as insulin pumps and glucometers (page 11). Looking at Dr. Jenny’s album, he discovered that some celebrities also have T1DM, but even then they achieved their dreams (page 12). Finally, he understood that the main everyday tasks related to diabetes treatment and care includes the taking of insulin, measuring blood glucose level, eating healthy food and sports (page 13).
The digital version of the story has been built to simulate real interactions; this was an option to help children to get an idea of the final product. Together with the educational context, the artefact contained animations based on touch-and-response interactions, sounds, text and of course nice and colourful illustrations. I used Adobe Illustrator CS6 to create the illustrations for each page, Photoshop CS6 to develop some animations and Axure RP Pro 7.0 to design and build the prototype. Then the digital version was generated and exported as a HTML prototype, saved in a folder together with the sounds files and playable with Mozilla Firefox on a computer or tablet.

While interacting with the prototype, a series of tests were performed; they helped to detect problems that may occur during the real time evaluation process. Several improvements were made: for example shadows were added to the objects that could
be moved around the screen, flashing arrows for giving hints for interactions or to activate animations, for explaining visual consistency, and guidance through the sequence when the objects could be moved.

**Second Story ‘What is type 1 diabetes’**

The second story discusses Superhero’s adventure during his hospital stay; it has 18 pages (Figure 116). Superhero wanted to see the objects inside Dr. Jenny’s cabinet again, so he decided to go to her office alone (page 3). There he saw something that caught his attention (page 4), but suddenly Dr. Jenny came into the room and he felt embarrassed (page 5). In the room, he found a magic submarine (page 6) and together with Dr. Jenny they decided to take a small trip explaining diabetes, (page 7) relocating to Superhero’s kitchen (page 8). The small submarine was hidden in the glass of water sitting on the kitchen table (page 8). After Superhero’s brother Liam drank the water (page 9), the journey into the body started. They were able to see how the digestive system works (page 10) and the functions of the pancreas (page 11). The story tried to give simple explanations on what caused diabetes by playing with the human cells and small keys of insulin (page 11). When the pancreas stops producing insulin, caused by the high blood sugar, some warning signs and symptoms occur (page 12 and page 13). Superhero played with the seesaw simulation helping him to understand about the recommended balance between the carbs and insulin, answering the question of why children need to take insulin for each food they eat (page 14). When their journey was over (page 15), they returned back to the hospital and kept the adventure as their little secret (page 16). Superhero happily slept in his bed in the children’s ward holding a small submarine; the next day he was not sure whether the journey was true or just a dream (page 17).
Figure 116: Mock-up prototype
Similar to the digital prototyping, I have used scenarios and their storyboards to build the mock-up prototype for the second story, ‘What is type 1 diabetes’. Like pop-up books, this paper prototype included text, illustrations and a variety of other moving parts with tabs that suggested low levels of interaction where the users play with the images, move them simultaneously in different directions helping to represent simulations of animations, changes to the shapes (shrink, enlarge), flying, bouncing, etc. (Figure 116). All of the components were made of paper; only the 10.1-inch Android tablet outlines were built with the help of a 3D printer from black ABS (acrylonitrile butadiene styrene) plastics.

5.4.2.6 Discussion: Prototyping Process

The prototyping of the mock-up and digital narratives was a long process and the tools such as personas, scenarios and storyboards have facilitated these activities successfully. These tools seem to be very supportive when developing educational technology for children with T1DM, resulting in three clear benefits. Firstly, building personas in the prototyping stage by using all the data collected in performing UCD enables a deeper understanding of various groups of users (i.e. to highlight more potential users of the educational eBook), their diverse roles in paediatric diabetes care (i.e. have diabetes, care for a child with T1DM and educate newly diagnosed children and their families), similar goals (i.e. have educational materials helping to know and learn more about the chronic condition) and various difficulties experienced in the diabetes management process. For example, the identification of different groups of users and their levels of priority facilitated the recognition of the teachers, nurses and siblings as potential users of the eBook, therefore, the development of their archetypes, numerous scenarios and storyboards illustrating the use of technology have enriched the design of the eBook story by exploring users, settings, purposes, features, etc. - they helped to reflect on the narratives design while developing the educational content of the interactive story. Secondly, Antle’s framework (2008) for developing child-learner personas was identified as a helpful approach, because it demonstrates that children at 9 and 12 years of age may have different knowledge and awareness about the location of some human organs and their functions in the body, and about food selection for a balanced diet or healthy eating. The reasons for this dissimilarity can be explained by the child's intellectual growth, the knowledge obtained in school (i.e. Primary School Curriculum) and
personal experiences/observations of the world or of similar issues. The exploration of the framework (Antle 2008) by using sources to illustrate the levels of autonomy, adult control and dependence in diabetes care (Hannan 2011; Silverstein et al 2005), various cognitive development in children (Bruckman and Bandlow 2003) along with the factoids (Table 11), assisted in enriching the details of healthy children at 5, 9 and 12 years of age, describing their characteristics and peculiarities before initial diagnosis. Consequently, this process particularly facilitated the building of the persona of a newly diagnosed child. Additionally, using Antle’s framework, the results pinpointed that the second and third dimensions for Daniel and Sarah are different, hence, it was not possible to reuse them when developing personas of a child-learner as a newly diagnosed young patient with T1DM. Thirdly, they showed the benefits of integrating and mapping some of these archetypes were integrated and mapped with the characters in the story while building the prototypes, as this helped to map users’ experiences with the storyline to enable the transfer, build and portrayal of reality into a more reliable narration. Personas helped to guide my decisions to eliminate many improper choices in the eBook content when the writing for the series of scenarios started. Furthermore, they helped to keep the focus on the target users - newly diagnosed children with diabetes and their families.

After exploring the assistance and benefits of personas, scenarios and storyboards in this final step of the prototyping stage, two well-illustrated stories were produced and prepared for the test and evaluation activities. The next Section 5.5 explains the whole process carried out with children and parents.

5.5 Stage Four: Test and Evaluation of the Prototypes

Similar to Section 5.3, two groups of participants participated in the evaluation process: children with T1DM and their families as “equal stakeholders”, and healthy young individuals as “informants”. Applying layered elaboration (Walsh et al 2010), the designed educational entertainment content of the digital and mock-up prototypes - ‘Superhero has diabetes’ and ‘What is type 1 diabetes?’ - were assessed by the individuals to explore: 1) the layered elaboration as a technique supporting participants to articulate their opinions and ideas in the test and evaluation activities of the mock-up and digital prototypes, 2) whether the fidelity of the prototype impacts young participants’ active involvement in the assessment process, 3) the role and input of children with T1DM of different age groups during the evaluation
sessions, 4) whether the prototypes helped healthy children learn about diabetes and what the complicated parts and challenges were to the specific context.

The layered elaboration (Walsh et al 2010) is a paper-based prototyping technique supporting asynchronous co-design with many participants for idea elaboration (Section 3.4). As noted in Section 4.2.4, the tool was selected for the assessment process because the overlying transparent material allows for visualisation of the mock up and digital stories context and reflection on ideas without destroying the original artefacts (i.e. draw image, write text, add button, etc.), it is simple and easy to use, small in volume (i.e. easy to pick up and travel), and facilitates quick visual representation of similarities and differences for each page of the prototypes, helping to further improvements to the design.

Section 5.5.1 describes the materials used for the evaluations; it gives information on the participant recruitment process and discusses the settings in which the sessions were held. The applied procedure in ten sessions with design partners and informants during the evaluation process, along with the users’ reflection on the initial prototypes are shown respectively in Section 5.5.2 and Section 5.5.3. The last Section 5.5.4 illustrates the findings that emerged in the produced data, with special attention paid to the layered elaboration technique, the impact of the artefacts’ fidelity on users’ involvement and the participants’ age diversity, as they are strongly related to the questions of this research.

5.5.1 Evaluation: Materials, Recruitment Process, Settings and Designer’s Role

In order to apply the layered elaboration technique (Walsh et al 2010), various materials were given to participants: A4 clear transparency film sheets that children could use to draw images/characters or write text on to improve each scene, permanent coloured markers, stickers with coloured circles i.e. red, yellow, green and blue, and self-adhesive white labels for writing information or ideas (Figure 117, second image). Each coloured circle corresponded to a different interactive feature that the eBook could support: for example, the red dot represented the features of moving, zooming, appearing, etc., the yellow was for game elements e.g. puzzle, drag & drop placing/arranging, etc., the green for sounds, while the blue was for video or animation. To assist users’ action while evaluating the prototypes, they have been provided with a single-page printed instructions sheet (Figure 117, first image).
Along with these materials, two different sets of questions were prepared in advance for each group of participants and used in all sessions; they are discussed in the Section 5.5.2.1 (Figure 118) and Section 5.5.3.1 (Figure 140).

The evaluation studies started with further recruitment of children (healthy and those with diabetes) and their parents, organizing a venue, allocating time, etc. for running a series of new sessions with participants living in different regions. Multiple recruiting strategies to inform and invite participants were used. For example, participants falling in the first group (e.g. diabetic children and their parents) were recruited 1) through the Facebook page Parents of Children & Teens with T1 Diabetes in Ireland, 2) from the members of Sweetpea Kidz Club who attended the Easter camp 2015 (17-19 April) in Trabolgan via printed flyers announcing the evaluation sessions, and 3) sending emails to those families who have already participated in the past activities conducted for the study. The second group of participants - healthy children - were recruited from the same voluntary group ‘Sunflowers’. The criteria for participation in the sessions were based on 1) the children’s age (8-12 years old) and 2) those individuals who had not taken part in the previous activities organised for this research.

Six evaluation sessions with fourteen young individuals with diabetes and their parents (e.g. six girls, three boys and five parents, N=14) and four sessions with nine healthy children (e.g. six girls and three boys) were organised between April 2015 and July 2015 (Table 15). The abbreviations discussed in Section 4.3 were used to keep the anonymity of all participants in the evaluation study. As noted, participants had different roles in the evaluation process, therefore for each group of individuals their characteristics such as age, number of children in the session, diagnosis, etc. and sessions settings are discussed separately below.
Table 15: Participants in the evaluation process

<table>
<thead>
<tr>
<th>Evaluation Sessions</th>
<th>Participants</th>
<th>Child Age</th>
<th>Diagnosed</th>
<th>Place &amp; Time</th>
<th>Evaluation Sessions</th>
<th>Participants</th>
<th>Child age</th>
<th>Place &amp; Time</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Previously participated</td>
<td>New</td>
<td></td>
<td></td>
<td></td>
<td>Previously participated</td>
<td>New</td>
<td></td>
</tr>
<tr>
<td>Evaluation Session 1</td>
<td>T1DC16</td>
<td>-</td>
<td>13</td>
<td>9</td>
<td>Trabolgan 1.32 hours</td>
<td>HC2</td>
<td>-</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>T1DC17</td>
<td>-</td>
<td>13</td>
<td>3</td>
<td></td>
<td>-</td>
<td>HC9</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>T1DC18</td>
<td>-</td>
<td>13</td>
<td>8</td>
<td></td>
<td>-</td>
<td>HC10</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-</td>
<td>HC11</td>
<td>12</td>
</tr>
<tr>
<td>Evaluation Session 2</td>
<td>-</td>
<td>T1DC3&amp; Parent3</td>
<td>6</td>
<td>At 21 months</td>
<td>Dublin 1.27 hours</td>
<td>-</td>
<td>HC12</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-</td>
<td>HC13</td>
<td>8</td>
</tr>
<tr>
<td>Evaluation Session 3</td>
<td>-</td>
<td>T1DC24&amp; Parent24 A healthy boy</td>
<td>5</td>
<td>4 months ago</td>
<td>Limerick 1.38 hours</td>
<td>-</td>
<td>HC14</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-</td>
<td>HC9</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-</td>
<td>HC15</td>
<td>10</td>
</tr>
<tr>
<td>Evaluation Session 4</td>
<td>-</td>
<td>T1DC25&amp; Parent25</td>
<td>10</td>
<td>8</td>
<td>Ballinasloe 1.37 hours</td>
<td>-</td>
<td>HC16</td>
<td>8</td>
</tr>
<tr>
<td>Evaluation Session 5</td>
<td>-</td>
<td>T1DC26 &amp; Parent26</td>
<td>13</td>
<td>5 months ago</td>
<td>Nenagh 1.40 hours</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Evaluation Session 6</td>
<td>T1DC8&amp; Parent8</td>
<td>-</td>
<td>15</td>
<td>9</td>
<td>Limerick 1.03 hours</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

270
First group: children with T1DM and their families

The first six sessions (Table 15) with diabetic children and their parents were carried out in small groups of 2 or 3 people. Some of the parents and children (Evaluation Sessions 1, 2 and 6) had already been involved in some activities, such as interviews (Section 5.2.1), Design Probes (Section 5.2.2), and design and prototyping sessions (Section 5.3.1; Section 5.4.1). For example, the young girls (i.e. T1DC16, T1DC17 and T1DC18) felt very excited and intrigued to play with the stories, particularly to see how the images, characters, dialogue, etc. suggested by them during our collaborative work had been integrated into the prototypes. Parent3 (i.e. Evaluation Session 2) was interviewed (Section 5.2.1) at the beginning of this research, but her child only took part in the assessment process. Participants in the Evaluation Session 3, 4 and 5 – four children and their parents - participated for the first time in this study. A seven-year-old healthy boy – brother of the young child with diabetes - participated in the Evaluation Session 3.

One of the identified challenges during the UCD was related to the regulation (or principle) of young users’ participation in the design practices grounded in the child developmental stages according to their different ages (i.e. if developed IT is for children aged 8 to 12, then the individuals who are involved in the participatory approach should be within this age group). Therefore, the cognitive, perceptual and motor ability (discussed in Section 3.2) of the young individuals influenced how the IT for the children should be developed and designed. Usually, similar research projects to this would have a duration of four years and naturally, children grow up during that time. In this research, when the design process started, some of the participants were aged between 11 and 12 years, so the main question was whether they could/couldn’t continue their participation in all four phases of the UCD process, even if they no longer fell within the age group 8-12 years. This question was also discussed in Section 2.3.2 and Section 3.5.3 and it was highlighted as one of the gaps in developing IT with young individuals and in CCI. To explore whether their participation could enhance/diminish the design practices, as well as how to involve individuals in design better, the age diversity of the young participants was important for this research. Therefore, children’s ages vary, including participants who already had made contributions to the eBook design, from the eldest young
individual who was 15-years-old to the new families where the youngest child was 5 (Table 15).

In the Evaluation Sessions 3 and 5, children (i.e. T1DC24 and T1DC26) had been diagnosed four and five months ago respectively, so these young individuals had knowledge and experiences similar to the potential users of the eBook. They both have a family history of T1DM: the grandfather and the mother (diagnosed at age 13) of the young kid had this chronic condition for a long time (Evaluation Session 3). The 13-year-old girl has an elder brother (now student) who was diagnosed with type 1 diabetes two years ago. The boy in the Evaluation Session 4 was diagnosed two years ago; his grandmother has this illness as well. Other children involved in this evaluation process have had this chronic condition for more than four years (Evaluation Session 1 and 6) despite no family history of it, therefore, it could be assumed that some of these participants (i.e. T1DC16, T1DC17, T1DC18 and T1DC8) may have more experience and knowledge on diabetes self-management compared to those who had been diagnosed in the previous months - this may influence their criteria when evaluating the prototypes.

All sessions were carried out in quiet places in which the participants felt comfortable, outside the University building. Usually, these places were cafés or hotel reception areas suggested by the families, close to where they live, as this made them feel more comfortable. Only the Evaluation Session 1 and 5 were carried out in one of the holiday homes (at the Trabolgan Holiday Village) used by the volunteers of the ‘Sweetpea Kidz Club’ and in the home of one of the participants (Nenagh). The time for the sessions was scheduled based on participant preferences, with an average length of between 1 and 2 hours. Time-off necessary for taking medication, measuring blood glucose levels, eating snacks and breaks was planned in advance. Most of the young individuals, especially in those sessions where the children were very young (5 and 6 years old), had a few breaks for taking food and for blood testing.

**Second group: healthy children**

Healthy children were allocated into four groups with a size of four, three, two and one participant in each session. Corresponding to the target age group of users for which the interactive eBook was designed, the girls were between 8 and 12 years of age.
The age of the boys was 8 and 9. The second criterion for participation was not completed in all cases: for example, the girl HC2 (12 years of age) had participated in the Design workshop sessions two and three (Section 5.3.3 and Section 5.3.4); she liked the design activities organised for this research, and as a result, she wanted to participate in the evaluation stage as well. The girl HC9 (8 years of age) took part in the Evaluation Sessions 7 and 9 because during the Evaluation Session 7, children assessed only the paper prototypes working with the pages 1-9 (they had not tested the whole story), and the girl wanted to continue her participation in evaluating both stories, therefore she also took part in the Evaluation Session 9 (Section 5.5.3.2). Other children involved in the evaluation process participated for the first time in this study. The Evaluation Sessions 7, 8 and 9 were held in the same premises where the ‘Sunflowers’ voluntary group usually runs different events for children; they were carried out after the planned entertainment for the day was completed. Their duration was between 60 and 80 min. The last Session 10 was carried out in the university building at a time appropriate for the participant; it was divided in two sessions held on two consecutive days lasting 80 and 20 minutes respectively.

As a researcher I had to play numerous roles during the evaluation process:

1) to explain the purpose of the prototypes in design, their levels of fidelity and the use of materials facilitating the layered elaboration technique (Figure 117),

2) to convey design ideas, by making the planned concepts clear for each scene (page) in the mock-up story, as the illustrations and text were static and they presented the storyline as a normal printed book: they did not support the simulation of various planned features such as touch and response, animation, sound, etc.,

3) to observe how the children manipulate the paper narrative or interact with the digital artefact, their understanding of the prototypes’ meaning and stories and if needed, to give additional information about their functionality and context,

4) to motivate all children take an active role in the evaluation process by asking questions, as this may help young participants to explain their personal standpoints, to trigger idea generation and rich feedback, interpretations and
thoughts for the eBook stories, to encourage them to suggest approaches to the overall problem, to prompt critical and creative thinking, hence the use of the layered elaboration technique and

5) to explain, with simple appropriate words and images, the problematic elements (if any) in the stories, trying to provoke discussions for enhancing children’s understanding of the narratives, particularly when working with the healthy children.

5.5.2. Evaluation Process with Children with T1DM and their Parents

This segment outlines the procedure used in the first six evaluation sessions (Section 5.5.2.1) and discusses the findings generated through assessing and applying the layered elaboration (Section 5.5.2.2).

5.5.2.1 Procedure: Design Partners

During the sessions, various questions were used, and as illustrated in the first set (first image, Figure 118) these questions helped to

1) find out about the participants’ experience with T1DM (discussed in Section 5.5.1),
2) understand their familiarity with tablets and interactive stories,
3) help evaluators to reflect on the eBook’s educational context by asking them what they like or dislike and why, and what may improve the narratives to increase the general knowledge of diabetes in children playing with the interactive eBook and
4) identify what the users’ opinion of the prototypes as tools that may support the educational process of diabetes self-care management.

The other set of questions related to the booklet ‘Pete the Pancreas’ (second image, Figure 118) aimed to understand users’ opinions about the available educational material, to distinguish different reasons for the likes/dislikes by pointing out specific parts of the book. Both prototypes were tested and evaluated; usually the process started with the assessment of the mock-up prototype (i.e. ‘What is type 1 diabetes?’) and then continued with the digital variation (i.e. ‘Superhero has diabetes’). The paper story provides a static display - children (users) “can see what the product is supposed to do, but the prototype may not respond to user input” (Rudd et al 1996, p 78). As a result, some young individuals may have found difficulties in
understanding its purpose, particularly when they played with the simulated interactive elements, which may reflect on their active involvement and feedback, which is one of the main issues to be explored, i.e. the relation (if any) between the level of fidelity of the prototypes and the participants’ active involvement. In Sessions 2 and 3, participants started by assessing the digital story first and then the mock-up, as I hoped that this might help them get a better idea of the eBook functionalities when evaluating the low-fidelity artefact. Additionally, this decision was driven by the age of children, their short attention spans and the time we had to accomplish this process with the families, usually in accordance with the preferences of the parents. As the young child in Session 3 exhibited signs of tiredness, this hindered our work of evaluating the mock-up with the participants, so they worked only with the digital one.

5.5.2.2 A Series of Evaluation Sessions with Children with T1DM and their Parents: Analysing Data and Findings Discussion

The assessment of both prototypes, along with the application of the layered elaboration technique aimed to identify the technique’s benefits in supporting participants to reflect on the suggested ideas, by giving their opinions on the educational context, the impact of the prototypes’ fidelity (if any) on the active involvement of the participants, and the potential of the technology to be marketed as an educational product.

Figures 118: Questions used in the evaluation sessions with children with T1DM and their parents

- Questions for the prototypes
  - How long have you had diabetes?
  - Did you ever read an eBook? What do you expect from the eBook?
  - Do you use a tablet at home and if yes how often?
  - Can you tell me what you are thinking about the story?
  - What parts do you like best?
  - What new features can be added?
  - What do you like less?
  - What was too boring?
  - What would you change/add in the story?
  - What parts of the story are confusing? How would you change them?
  - Do you have any additional comments or thoughts?
  - Can children learn helped by the technology so it can be marketed as an educational product?
  - Do you have any additional comments or thoughts?

- Questions for the book ‘Pete the Pancreas’
  - Did you read the book ‘Pete the Pancreas’?
  - What did you expect from the book?
  - Can you tell me what you are thinking about the book?
  - What parts do you like the best in the book?
  - What do you like the less?
  - What was too boring?
  - What would you change/add in the book?
  - What parts of the book are confusing? How would you change them?
  - Do you have any additional comments or thoughts?

Examples of the eBook stories were shown to all participants.
involvement of children in the process, and the role and input of diabetic children in the evaluation process according to their different age groups (Section 5.5). Therefore, to deal with these issues, the analysed data of all six evaluation sessions was organised into four parts discussing 1) participants’ comments/feedback on the eBook educational narratives, 2) how the tool was employed (e.g. transparent sheets, coloured dots and self-adhesive white labels) in supporting children and parents to reflect on the developed artefacts, 3) children’s age as a factor for active involvement in the evaluation process and 4) participants’ opinions on the book ‘Pete the Pancreas’ and the eBook story ‘Superhero learns about diabetes’ as educational resources in paediatric diabetes care.

**Children and parents’ reflection on the mock-up and digital prototypes applying layered elaboration**

As the eBook was designed to help and support newly diagnosed children in their educational process on the illness and its treatment, in the evaluation process - along with the discussions of the complete stories - I hoped 1) to prompt feedback, particularly on those educational elements integrated into the eBook that had been identified, discussed and offered by the participants in the preceding phase of UCD, as this helped 2) to find the answer to the research question investigating how the user’s participation influenced the quality of technology that may resonate with their self-care practices better (Section 1.4); therefore, this part mostly discusses the findings regarding those pages/scenes containing their designs. In the mock-up story, these elements were integrated into the content explaining the digestive system (page 10 and 11) and what causes diabetes (page 12), diabetes treatment (page 13) and the carbs and insulin relationship (page 14), while in the digital story there were illustrations, text and interactive elements describing the early signs and symptoms of diabetes (page 8), steps of using the glucometer (page 9) the dialogue between the main characters during initial diagnosis (page 10), supportive technology used in diabetes care (i.e. glucometer and insulin pump) (page 11) and famous people with T1DM (page 12) (see Section 5.4.2.5 and Appendix H). In the assessment process, participants were asked to read the stories and play/interact with the artefacts, and then discuss what they liked/disliked about the narratives, and how the educational content could be improved. Additionally, I described the planned interactive features in the mock-up, as this helped participants to get a better idea of how the elements
such as touch and response, animation, sound, etc. were designed to support the educational context. The purpose and use of the transparent sheet was also explained, along with other supportive materials (i.e. dots, white labels, etc.) when reflecting on the text, illustrations, interactivity, etc. in the prototypes.

After identifying users’ experience with diabetes (explained in Section 5.5.1) and interactive eBooks (Figure 118), the same very short videos used in the previous sessions (described in Section 5.3.1) were shown to the parents and children. All participants had some practical skills in using tablets, but they were not familiar with the diverse content, design and functionality of the enhanced interactive eBooks; even those who had been involved earlier in the design and prototyping stages (T1DC16, T1DC17, T1DC18 and Parent8&T1DC8, Table 15) failed to recall having discussed this type of IT and having watched some examples of published interactive stories. One of the boys (T1DC25) shared that he loves to play video games, but never read interactive stories on his tablet.

Table 16 illustrates the ideas generated in these six sessions - the first column (blue) and the second column (red) respectively show suggestions for the mock-up artefact and for the digital story. Individuals are identified within the text (i.e. abbreviations for keeping anonymity), the number of the story pages that the suggestions were made for (discussed in Section 5.4.2.5) and the number of the session. The data in Table 16 and the other following tables were extracted from a table illustrating all data collected and analysed in the evaluation process and presented in the Appendix G.
### Table 16: Participant's reflection on both prototypes

<table>
<thead>
<tr>
<th>Suggestions for ‘What is type 1 diabetes?’ - paper prototype 18 Pages</th>
<th>Suggestions for ‘Superhero has diabetes’ - Digital prototype 14 pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Steps sounds (page 3)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>1. Make the interactive elements flash or use arrows to suggest interaction (page 3)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
</tr>
<tr>
<td>2. Submarine makes sound when going out the window (page 7)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>2. Add animation and sounds to the toys (page 5)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
</tr>
<tr>
<td>3. Change images of human organs once they are in the right place to more realistic ones (page 10)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>3. The receptionist clicking on the keyboard and answering the phone. (page 7)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
</tr>
<tr>
<td>4. When they (cubes of sugars) are walking play music, when the cell opens (insulin is a key) play the sound of door opening (page 11)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>4. Add the image of glucometer. It is lighter, smaller, and quicker (page 11)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
</tr>
<tr>
<td>5. Try drag sugar out of liver bring them to the cells, then a question comes up (game)(page 12)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>5. Scientist having T1DM (page 12)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
</tr>
<tr>
<td>6. More diabetic symptoms: faint, vomiting, loss of concentration (page 12)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>6. Add diary as image (page 13)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
</tr>
<tr>
<td>7. Maybe the spaceship moves around (page 13)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>7. Constant toy/image that can be interactive (page 6)(T1DC3&amp;Parent3)(Session 2)</td>
</tr>
<tr>
<td>8. Maybe change “palate” to another simple word to understand “tickling in his throat” (page 15)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>8. Pick which door to enter. Something to involve the child in the waiting room-play with toys, sounds? (page 7)(Parent3&amp;T1DC3)(Session 2)</td>
</tr>
<tr>
<td>9. Drag him to his bed, add snoring sound (page 17)(T1DC16, T1DC17 and T1DC18)(Session 1)</td>
<td>9. Q: Scary? A: Special needles to make it as easy as possible. Medicines can change as you grow, but you need same medicine through the day. Q: Can I eat sugar/sweets? A: Need to reduce the sugar but managed treats are ok. Healthy food is good for everyone. (page 10)(Parent3&amp;T1DC3)(Session 2)</td>
</tr>
<tr>
<td>10. Maybe if the text appeared in different stages so there’s not so much text in one go (page 3)(Parent3&amp;T1DC3)(Session 2)</td>
<td>10. Maybe put first pump near or beside backpack, maybe be able to slide it into backpack (page 11)(Parent3&amp;T1DC3)(Session 2)</td>
</tr>
<tr>
<td>11. Control or manage (replace the word)(page 11)(Parent3&amp;T1DC3)(Session 2)</td>
<td>11. An arrow by each topic to show what needs to be done –press line (page 1)(Parent24&amp;T1DC24&amp;)(Session 3)</td>
</tr>
<tr>
<td>12. If balance is up or down then Superhero looks sad, happy if balanced (page 14)(Parent3&amp;T1DC3)(Session 2)</td>
<td>12. Under/over each arrow write next page or previous page on back arrow (page 2)(Parent24&amp;T1DC24&amp;)(Session 3)</td>
</tr>
<tr>
<td>13. The dialogue box about the Superhero thoughts related with the things that he saw in Dr. Jenny's cabinet (page 3)(Parent25&amp;T1DC25)(Session 4)</td>
<td>13. Maybe when describing superhero, just describe him not his home life. This play … is more for very young children but the later pages are more for older children (page 3)(Parent24&amp;T1DC24&amp;)(Session 3)</td>
</tr>
<tr>
<td>14. Door opening, floor board creaking. Tap the green dot (page 5)(Parent25&amp;T1DC25)(Session 4)</td>
<td></td>
</tr>
</tbody>
</table>
16. Tap on the food to find the submarine (page 8)(Parent25&T1DC25)(Session 4)
17. Press a button to see a real organ, give facts on each organ (page 10)(Parent25 &T1DC25)(Session 4)
18. Make sound when opening the cell (page 11)(Parent25&T1DC25)(Session 4)
19. Show superhero asking questions in the submarine (page 13)(Parent25&T1DC25)(Session 4)
20. Which food needs insulin? (page 14)(Parent25&T1DC25)(Session 4)
21. Tap on Liam to make him sneeze (page 15)(Parent25&T1DC25)(Session 4)
22. Screen will go all white to show that he is dreaming (page 17)(Parent25&T1DC25)(Session 4)
23. Most kids would not know what intrigued means; change it to interested. The door creaking (page 3)(Parent26&T1DC26)(Session 5)
24. Sound steps (page 4)(Parent26&T1DC26)(Session 5)
25. If/when Dr. Jenny comes in, Superhero jumps from fright. Like he was just about to take off the cover (page 5)(Parent26&T1DC26)(Session 5)
26. Shrinking sound, touch blanket to take it off (page 6)(Parent26&T1DC26)(Session 5)
27. Shrinking sound (page 7)(Parent26&T1DC26)(Session 5)
28. Plop sound (page 8)(Parent26&T1DC26)(Session 5)
29. Just mention that the insulin is the key (page 11)(Parent26&T1DC26)(Session 5)
30. Diabetes cannot make insulin. Make unhappy face of the cells. Add symptoms such as bathroom a lot, thirsty (page 12)(Parent26&T1DC26)(Session 5)
31. Add images of an unhappy cell –having diabetes, in a normal cell sugar and key (insulin) holding hands (page 13)(Parent26&T1DC26)(Session 5)
32. Claps and says “Well done” (page 14)(Parent26&T1DC26)(Session 5)
33. A big sneeze (page 15)(Parent26&T1DC26)(Session 5)
34. Superhero and Dr. Jenny pinkie promising/or she winks (page 16)(Parent26&T1DC26)(Session 5)
35. Leave it as a mystery (page 17)(Parent26&T1DC26)(Session 5)
36. Would 8-year-old know what intrigued means (page 3)(Parent8&T1DC8)(Session 6)
14. Q: Why don’t I feel right? Now I can’t help other people. Q: I am too tired to fly …thirsty to run (page 4)(Parent24&T1DC24)(Session 3)
15. Maybe split the trip between a visit to the GP who the child knows. After next page he goes to the hospital to be diagnosed by the special doctor (page 5)(Parent24&T1DC24)(Session 3)
16. Dr. Jenny introduces herself as a doctor who specialises in diabetes (page 6)(Parent24&T1DC24)(Session 3)
17. (A new name of the brand) wipes are not alcohol wipes. 1: wash hands, 2: take out glucometer 3: insert glucometer strip, 4: lancet 5: Place blood on strip (page 9)(Parent24&T1DC24)(Session 3)
18. At that stage it gets complicated for the young children. Maybe meet regularly with their doctor. The nurse is the main point of contact (page 10)(Parent24&T1DC24)(Session 3)
19. Add name Ryan Reed - NASCAR Driver – to list of different stars with diabetes (page 12)(Parent24&T1DC24)(Session 3)
20. Instead/add to sport Activity/exercise: Trampoline/ dancing ballet shoes  (page 13)(Parent24&T1DC24)(Session 3)
21. Choice for parent: topic name boy/girl (Parent26&T1DC26)(Session 5)
22. Image of pancreas waving hand for “Hello” (page 2)(Parent26&T1DC26)(Session 5)
23. Superhero you have type 1 diabetes (page 10)(Parent8&T1DC8)(Session 6)
As noted (Section 5.5.2.1), in most of the sessions the paper and digital prototypes were assessed starting with the mock-up artefact and then evaluating the digital narrative. In the Evaluation Session 3 the participants (e.g. T1DC24&Parent24 and a healthy boy) only tested the digital story. All participants interacted with the user interface components of text, drawn backgrounds and movable hand-cut paper images, touch and response components, etc. developed for each page/scene of the initial prototypes. They were free to give their opinion about the developed stories. For example, while playing with the mock-up most of the children wanted to have images and text in the narratives that wouldn’t make the eBook story too childish (T1DC16, T1DC17, T1DC18, T1DC25 and T1DC26). The boy (T1DC25) thought that the cartoon images used for some human organs (that are part of the digestive system) in page 10 were not appropriate for children between 8 and 12 years of age. These images were used for an educational mini-game to help children learn about their position in the human body as a result of the findings from the design session two (i.e. healthy participants did not know the position and function of the pancreas, Section 5.3.3). He recommended and drew a button on the transparent sheet that would allow the images be changed between natural pictures and cartoons, depending on the user’s preferences. Additionally, when these objects were dragged and dropped into their appropriate places within the outline of human body, the young users could have the option to read some interesting facts for these human organs (Figure 119). Similarly, the children in the Evaluation Session 1 (T1DC16, T1DC17 and T1DC18) wanted to change the cartoons into realistic ones when these images had been arranged properly by the young users playing the game. They stuck the red (for dragging) and blue (for animation) dots to illustrate their suggestion (Figure 120). While explaining the balance between the food and insulin by using a scales, images of various food and insulin bottles in page 14, the boy found out that eating fish (proteins) did not raise the blood glucose levels and having a game with the question “which food needs insulin?” will help children learn about this. The use of the seesaw idea was described as a tactic for carb and insulin education during interviews (Parent4, Section 5.2.1.2).

62 The choice made by healthy children during the workshop session two, Section 5.3.3.
For the same page (14), Parent3 proposed one animation illustrating that the facial expression of the Superhero could change according to the user’s answer - she added a blue dot to the transparent layer to illustrate her idea (Figure 122).

The 13-year-old girl (T1DC26) examined how to make the images in the story friendlier for the potential users. Overlapping the original page with the transparent layer, she added happy/unhappy faces for the human cells depending on the insulin presence/shortage in the human body (page 13). This page explains diabetes i.e. what happens with the cells because of the lack of insulin (Figure 121).

In assessing the digital prototype, two parents (Parent3 and Parent24) with young children raised some criticism related to the story (Table 15, second column). They were really concerned with the narrative text, its structure and with some of the integrated interactive features in pages 8, 9 and 10 supporting the visualisation of some of the warning signs of diabetes, the description of dialogue between the
characters when discussing diabetes and illustrating the steps of using the glucometer (all discussed in the design and prototyping sessions with participants, Section 5.3.1 and 5.4.1.1). For example, Parent24 highlighted that the digital story did not truly resonate with her family situation (her family is very untraditional); the story shows a traditional family structure that may not correspond to children who are not living in similar settings or with both parents (Evaluation Session 3, Figure 123). To overcome this problem, she suggested describing only the main character Superhero, his friends, neighbours, etc. but not his family (it was identified that the family support in diabetes management is crucial and was used in page 3, introducing Superhero and his family (Section 5.2.1.2)). Her young five-year-old girl could not see herself within the story because the narrative did not reflect the true facets of her personal experience with the illness i.e. the sequence of events showing the meeting with the GP, and then being admitted to hospital (different for each newly diagnosed child, Section 5.2.1.2). She shared that at the beginning, the story text and the interactive elements are more appropriate for young children, but at page 10, featuring the Superhero and Dr. Jenny dialogue after the initial diagnosis, the narrative becomes more complicated. Therefore, splitting the story into two parts, directed at users of different age groups, could solve this issue, as they may select the level of difficulty on the first page of the eBook. Page 10 shows the discussion on diabetes that was taken from the individual story prototyping session with diabetic children (Session 5.4.1.1). On the same page, the mother (Parent3) in the Evaluation Session 2 looked carefully at the questions, assessing the written answers, and how they corresponded to her general vision and personal viewpoint on the theme. As a result, she suggested two questions along with their answers to be added to the dialogue (i.e. Q: Scary? A: Special needles to make it as easy as possible. Medicines can change as you grow, but you need same medicine through the day. Q: Can I eat sugar/sweets? A: Need to reduce the sugar but managed treats are ok. Healthy food is good for everyone.), as well as to have one constant image/toy on each page that the child could interact with; this may help to hold his/her attention when listening to the story (Figure 124).
While interacting with the digital prototype, it was observed that children (T1DC25 and T1DC26) in the Evaluation Sessions 4 and 5 were happy how the story introduced type 1 diabetes, while the young participants in Session 1 (T1DC16, T1DC17 and T1DC18) proposed to have more objects i.e. supportive technologies, in Dr. Jenny’s cabinet that the user could play and interact with when reading page 11 (Figure 125). They used some drawings on the transparent sheet to support their ideas. To explain the functions of technologies such as the insulin pump and glucometer that were discussed in the prototyping session (Section 5.4.1.2), both new and previous versions of these technologies was shown in the scene.

While reading the dialogue on page 10 and the text in page 12 i.e. Dr. Jenny’s album on celebrities with diabetes (emerged as one of the requirements identified in the interviews data, Section 5.2.1.2), the girl (T1DC26) identified that she had the same questions when she was diagnosed. For example, the first thing that she wanted to
know was “who else except her has type 1 diabetes” (Evaluation Session 5). Some of these questions were not discussed in the booklet ‘Pete the Pancreas’. Parent24 liked the idea of the album, so she suggested adding the name of Ryan Reed – a NASCAR Driver.

**Exploring layered elaboration technique**

Upon reflection on the prototypes, it is important to describe the role of the tool - the layered elaboration technique - in facilitating the evaluation process. The ideas generated throughout all evaluation sessions numbered 36 for the paper story, and 23 for the digital narrative (Table 16). As discussed above, children as evaluators have focused considerable attention onto the context along with the interactive elements in both prototypes; therefore, this approach influenced the use of the provided materials. As a result, two different ways of applying the technique from children (first column) and parents (second column) have been identified, shown in Table 17. For instance, the boy (T1DC25) in Session 4 used all the materials when evaluating the paper story, while the girls in the evaluation session 1 and 5 (T1DC16, T1DC17, T1DC18 and T1DC26) used all the materials assessing both prototypes. All young participants placed different coloured dots dependent on the type of interactivity that they had suggested, drew new images on the transparent overlying sheets or added small details on the existing pictures, and stuck the white labels to write and explain their concepts. Parent3 and Parent24 and the family in the Session 6 (T1DC8&Parent8) deployed mostly the self-adhesive sticky labels to write down their own ideas, focusing on the storyline content and the eBook’s interface (i.e. they did not use any drawings or coloured dots to illustrate their ideas or interactive elements that could suggest more fun); Parent3 used the blue dot only once when testing the mock-up story (Session 2, Figure 121). This indicated that children apart from assessing the educational text were also concerned with the fun and entertainment aspect of the eBook.

<table>
<thead>
<tr>
<th>Materials used by the children</th>
<th>Materials used by the parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Two children simultaneously drew their ideas using markers with different colours assessing the digital prototype (T1DC16, T1DC17 and T1DC18) (Session 1)</td>
<td>1. The parent (and child) used the white sticky labels to write suggestions (Parent3&amp;T1DC3) (Parent24&amp;T1DC24)(Parent8&amp;T1DC8) (Session 2)(Session 3)(Session 6)</td>
</tr>
</tbody>
</table>
2. When the children drew on the transparent sheet, which covers the digital prototype scene/page, they activated some animations or interactive elements. (T1DC16, T1DC17 and T1DC18) (Session 1)

3. When writing notes for the digital prototype, the transparent material was moved onto the table (T1DC16, T1DC17 and T1DC18) (Session 1)

4. When writing notes for the mock-up prototype, the transparent material lay on top of the page/scene (T1DC16, T1DC17 and T1DC18) (Parent25&T1DC25) (Parent26&T1DC26) (Session 1) (Session 4) (Session 5)

5. The child/children used suggested sources in the stories i.e. images, text, interactivity, etc. for further idea elaboration (T1DC16, T1DC17 and T1DC18) (Parent25&T1DC25) (Parent26&T1DC26) (Session 1) (Session 4) (Session 5)

6. The child/children wrote their ideas alone using the white labels (T1DC16, T1DC17 and T1DC18) (Parent25&T1DC25) (Parent26&T1DC26) (Session 1) (Session 4) (Session 5)

7. The child/children used the dots to represent interaction with images (T1DC16, T1DC17 and T1DC18) (Parent25&T1DC25) (Parent26&T1DC26) (Session 1) (Session 4) (Session 5)

8. The child/children used the transparent sheets to draw some images, dialogue bubbles, buttons on the place where they should be for the paper story (Parent25&T1DC25) (Parent26&T1DC26) (Session 4) (Session 5)

9. The child/children used the transparent sheets to draw some images for the digital story (T1DC16, T1DC17 and T1DC18) (Parent26&T1DC26) (Session 1) (Session 5)

10. The mother helped to formulate some of the text ideas (Parent25&T1DC25) (Session 4)

11. Children asked which coloured dot is appropriate for specific interaction (T1DC16, T1DC17 and T1DC18) (Session 1)

12. Used the instructions provided for the coloured dots (T1DC16, T1DC17 and T1DC18) (Parent25&T1DC25) (Parent26&T1DC26) (Session 1) (Session 4) (Session 5)

13. Confident to use all materials supporting the technique (Parent25&T1DC25) (Parent26&T1DC26) (Session 4) (Session 5)

2. The coloured dots were not used to suggest various interactions (Parent24&T1DC24) (Parent8&T1DC8) (Session 3) (Session 6)

3. Blue dot used to illustrate animation (T1DC3&Parent3) (Session 2)

4. The mother suggested sources i.e. images, text, interactivity, etc. for further idea elaboration by writing different ideas on the white labels (Parent3&T1DC3) (Parent24&T1DC24) (Parent8&T1DC8) (Session 2) (Session 3) (Session 6)

5. The child wrote the numbers of the pages on the transparent material, mother suggested the new ideas (Parent3&T1DC3) (Session 2)

6. The boy helped his parent sticking the white self-address labels on the transparent sheets (Parent24&T1DC24) (Session 3)

7. The child drew a picture as a present for the designer on the transparent sheet using the coloured markers and dots (Parent3&T1DC3) (Session 2)

8. The parent preferred to look at each page by adding notes for the digital prototype, the transparent material was placed on the table while the child/children interacted with the digital prototype (Parent3&T1DC3) (Parent24&T1DC24) (Session 2) (Session 3)

9. No drawings on the transparent materials, only notes (Parent3&T1DC3) (Parent24&T1DC24) (Parent8&T1DC8) (Session 2) (Session 3) (Session 6)

10. The mother (and child SC8) explained the hints that could improve the visibility in interaction (Parent3&T1DC3) (Parent24&T1DC24) (Parent8&T1DC8) (Session 2) (Session 3) (Session 6)

11. The sibling (a boy) asked how to use the coloured dots, but he did not use them (Parent24&T1DC24) (Session 2)

12. Kept the instructions near on how to use the additional materials such as dots and white labels (Parent3&T1DC3) (Parent24&T1DC24) (Session 2) (Session 3)
Also, it was identified that the layer of transparent material was used in different places/positions - in most of the sessions the clear sheets overlapped the original paper mock-up slides, facilitating the writing/drawing of users’ ideas reflecting on the story design (Evaluation Sessions 1, 2, 4, 5 and 6) or they were placed on the table near to the PC screen while children and parents wrote their suggestions for the digital version (Evaluation Sessions 2, 3, 5 and 6). It was only in the Evaluation Session 1 that children added their own recommendations on the transparent sheets placed directly over both original prototypes (i.e. paper and digital) (Figure 126, Figure 127 and Figure 128). When they played with the digital story, they simultaneously drew their suggestions for improving the visibility of interactive and playful features (Figure 129), but with the paper prototype they worked individually (Figure 130).

In using the materials, it was observed that the adults and young children in the Evaluation Sessions 2 and 3 had different roles - while the young children (T1DC3 and T1DC24) played with the interactive user interface and flipped pages through the eBook, the parents discussed and wrote their suggestions (Figure 129). In the third
session, the healthy boy helped his mother by sticking the labels on the transparent sheets (Figure 130).

In Sessions 4 and 5, the boy (T1DC25) and girl (T1DC26) came up with more ideas on the mock-up story than on the digital prototype (Figure 131, Figure 132 and Figure 133) and their parents had very passive roles. All the ideas were suggested by the boy (Figure 131). The mother did not discuss the text or images alone or with him; however, she helped him to rephrase the text of some of his ideas (Session 4). The adult in session 5 only suggested the option for personalization of the eBook and her child wrote down the idea on the sheet (Figure 133).

The layered elaboration seems to be a very portable; it is not heavy and bulky. This evaluation tool could be carried out and applied at different settings chosen by participants, easy and simple to use for both parents and children. It helped individuals to explore the narrative structures and visual work through the transparent overlying sheets while developing their concepts about design by adding multiple ideas such as drawings or rough sketches on one page. Moreover, it facilitated fast analysis of the developed ideas for each page for further improvement on the initial designs. Only one problem has emerged when applying this tool. When the transparent sheet overlays the tablet display, drawing images on the layer may trigger or select some interactive elements, animations or change the size of the scene displayed on the screen (Figure 126 and Figure 127). Of course, this did not destroy the original artefact, but it took time to correct the errors on the display, interrupting the process of describing and generating ideas on the sheet. This influenced the participants’ work - they used the digital prototype more carefully by moving the layer sheets to the table while interacting with the user interface and writing ideas. However, they covered the tablet screen with the transparent layer when they drew images, as this helped to add and find a place for their drawings.
Children’s age as a factor for active involvement in the assessment process

Bearing in mind that the young participants involved in these activities were at various ages (e.g. from 5 to 15) and had different experiences with diabetes (from 4 months to more than four years) (Section 5.5.1), they had dissimilar knowledge on diabetes treatment, different cognitive and motor development and awareness/experiences with interactive technology. These differences may have impacted their interaction with and understanding of the prototypes, and their active involvement in the process. Interacting with both prototypes (except in the evaluation Session 3), the data pinpointed relevant information to deal with the second and third questions posed to explore in the assessment process (Section 5.5) - they investigate the fidelity effect on the users’ active participation in the evaluations and their roles and feedback influenced by their age.

In the data, the age of the young evaluators emerged as a crucial factor for understanding their involvement in the assessment process, and consequently their interaction with the artefacts and reflection on the narratives. Testing the digital story in the Evaluation Sessions 2 and 3, the very young girl and boy (e.g. respectively 5 and 6 years of age) played with the images while their parents read them the story. The dialogue between the characters in the narrative were used as questions by the mothers to ask their children, and then while reading the answers they added some feedback based on their personal opinions or clarified some details. Interacting with the page explaining the steps of blood glucose measuring, one of the new questions asked by the parent was “What is the glucometer for?” and the child’s answer was “It is for pricking the finger and know what your bloods are” (Parent24 and T1DC24, Session 3). Also, children liked to interact with the images that played sounds after being pressed, dragged and moved; they continued to interact with them or returned to the pages that they found entertaining. Their actions gave the impression that they are playing with a final product rather than with a prototype. The 5-year-old girl (Session 3) was very eager to interact with the story alone without getting any help from her brother. She looked at the page depicting Superhero and his family several times for any option available to reactivate (reload) the same animation; she played with the arrows to flip the pages and return to that scene showing the animation of how Superhero appeared in the story. The child tried to use the drag and drop function in an attempt to move the static test strip image to the glucometer to help
Superhero check his blood glucose (Figure 134). This actually helped to identify how to improve the scenes by adding the option to reload some of the interactive elements and a new animation for playing with the glucometer. Asssessing the mock-up in the evaluation session 2, the six-year-old boy (T1DC3) was very happy to play with the arrows and all the movable parts while his mother was reading the story aloud. He even started to play the roles of Dr. Jenny and Superhero, moving their images and saying “yes” excitedly as an answer to the question related to the journey with the magical submarine (Figure 135). He tried to find out the appropriate place for the human organs by looking for the help of his mother, but again he did not grasp the idea of what interaction this could suggest in a digital format, or that he was interacting with a prototype. In that part of the story the child was very active, he listened carefully to the text explaining diabetes and then asked “What is pancreas?” (T1DC3).

Figure 134: Child trying to insert the test strip into the glucometer (Session 3)  
Figure 135: 6-year-old boy playing with the images of Superhero and Dr. Jenny (Session 2)

Even with the young age of the children in Sessions 2 and 3, their participation helped to identify 1) that they did not grasp the purpose of the prototypes nor their different functions in the assessment process, and 2) that they have some knowledge on diabetes despite their young age and short experience with the illness, particularly for the girl (e.g. only four months of diagnosis). In the same way, through interacting with the digital prototype, the girl was able to show her preferences when playing with the images. Her way of suggesting ideas was not through words but rather with actions that the paper prototype was not able to support. It also helped to create a more realistic picture on how the final product of the eBook may be used by both parents and children, supporting the parents’ role of educator in home settings. This indicated the importance of the young children and their parents in the evaluation
process, assessing the educational technology at the early stages of its development (Sessions 2 and 3).

In contrast, the children between 10 and 13 years of age (e.g. Evaluation Sessions 1, 4 and 5) did not experience any difficulties in understanding the purpose of the prototypes. Their participation showcased other factors influencing their active involvement in the process such as 1) the number of participants in the session 2) the fresh experience with the diagnosis and 3) the experience with similar interactive technology. The results indicated that in these sessions, the young evaluators utilised a completely different approach when they assessed the prototypes. It was observed that having more than two participants in the session created difficulties in having every child physically play with each page of the suggested paper story (Session 1). When children were asked to rearrange the pictures of the human internal organs to try and place them appropriately into the outline of the human body (scene 10 in paper prototype) - simulating how a mini-game could work - each child took a piece and waited for their turn to play with the page (Figure 136). This left children feeling shy; they were afraid to give any suggestion in case it could be wrong for the prototype, or the other children would not like it. It was difficult to arrange and elaborate one single idea together, even by prompting with questions to arouse suggestions, active discussions, and synthesize and express ideas. Unlike the approach that follows, the boy (T1DC25) and girl (T1DC26) in the Evaluation Sessions 4 and 5 needed fewer stimuli to spark comments; they were very active in generating feedback for almost every sheetscene of the mock-up story. As a result, a good number of different ideas for the paper artefact was generated during these sessions (Table 15, first column). For instance, the 13-year-old girl (T1DC26) had a very fresh experience of the diagnosis; hence, she looked for specific information linked to her needs at the time of when she was in the hospital. This helped her envision how her cousins (9-10 years of age) could play with this narrative or how the younger users could interact with images while their parents read them the story. Her recent diagnosis sparked her curiosity; this resulted in her analysing and looking for simple but accurate explanations in the text about diabetes as a disease using the eBook. The young participants (T1DC25 and T1DC26) played with the small movable parts to simulate interaction; they imitated sounds effects of steps, the submarine changing shape, water splash sounds, clapping hands and sneezing, as
well as the replacement of some of the images to make the book more child friendly (Figure 137 and Figure 138). The boy’s (T1DC25) experience of playing video games helped him in suggesting many ideas.

This indicated that a small number of participants could increase users’ involvement in the evaluation process and may help to break the shyness barrier in sharing thoughts about the content and functions. Users having recent experiences with the issue (e.g. diagnosis) and with similar interactive products increased the children’s reflection during the evaluation.

‘Pete the Pancreas’ and ‘Superhero learns about diabetes’ as tools helping children get awareness about diabetes care

In order to identify what book participants preferred more and why, in this part, I discuss users’ opinions on ‘Pete the Pancreas’ and ‘Superhero learns about diabetes’ as educational materials helping young participants understand diabetes care. As noted in Section 5.5.2.1 (Figure 118), the second set of questions helped to identify what participants liked and disliked in the small book ‘Pete the Pancreas’. The results indicated that both parents and children knew the booklet very well but they had different opinions concerning the educational material supplied (Table 18). For example, most of the young participants described the book as being very childish and easy to read. It also gives newly diagnosed children valuable but very basic information on diabetes (T1DC16, T1DC17, T1DC18, T1DC25 and T1DC26) (Table 18). The boy (T1DC25) in Session 4 believed that the book needed to contain more details on diabetes, because “I could look over and over again when I need it”, but he was also “horrified” after reading that the insulin is taken solely by injections (i.e. referring to the needle phobia that the boy still has).

More critical feedback was given by a 13-year-old newly diagnosed girl: she stated that the booklet did not provide appropriate educational material for her age - the set
(Section 5.4.2.5) was given to her and her family at the hospital to learn about T1DM (Parent26&T1DC26). This clearly indicated that during the time of this research (started in 2012), new educational materials for diabetic children were not developed and used by the medical professionals and diabetes educators in the primary care settings. She pointed out that she does not like the questions and answers given in page 30 (Figure 139) “Because what I remember reading this "Would you grow out of diabetes?" No, you will always have diabetes. It didn't say "Well for now you'll definitely have diabetes." You know it gave you the sense of...this is a life sentence; you know there's no cure." (T1DC26). The girl wanted to read more on diabetes and sports such as tennis and basketball because these activities dropped her bloods quickly; unfortunately, the book does not provide simple information on different anaerobic and aerobic sports.

Figure 139: ‘Pete the Pancreas’, page 30
<table>
<thead>
<tr>
<th>Booklet ‘Pete the Pancreas’</th>
<th>Like</th>
<th>Dislike</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. I read the book when I was younger (T1DC16, T1DC17 and T1DC18) (Session 1)</td>
<td>1. It is a bit childish (T1DC16, T1DC17 and T1DC18) (Session 1)</td>
</tr>
<tr>
<td></td>
<td>2. Quite basic (T1DC16, T1DC17 and T1DC18) (Session 1)</td>
<td>2. It was better when I was younger (T1DC16, T1DC17 and T1DC18) (Session 1)</td>
</tr>
<tr>
<td></td>
<td>3. Read the book with parents (T1DC16, T1DC17 and T1DC18) (Session 1)</td>
<td>3. The pages have lots and lots of writing. Difficult to keep child attention when reading the book “turn the page, turn the page” (Parent3&amp;T1DC3) (Session 2)</td>
</tr>
<tr>
<td></td>
<td>4. Gives children simple information on diabetes (Parent3&amp;T1DC3) (Session 2)</td>
<td>4. It would be better to have more pictures that parents can use when explaining diabetes (Parent3&amp;T1DC3) (Session 2)</td>
</tr>
<tr>
<td></td>
<td>5. Used to explain functions of the pancreas (Parent3&amp;T1DC3&amp;) (Session 2)</td>
<td>5. To provide a fun resource that children can reference to enhance their understanding of diabetes (Parent3&amp;T1DC3) (Session 2)</td>
</tr>
<tr>
<td></td>
<td>6. Appropriate for children (Parent3&amp;T1DC3) (Session 2)</td>
<td>6. Some bits at the beginning did not explain diabetes well, so I just skipped those pages (Parent3&amp;T1DC3) (Session 2)</td>
</tr>
<tr>
<td></td>
<td>7. Used to explain the relationship between blood sugars levels and food (Parent3&amp;T1DC3) (Session 2)</td>
<td>7. It would be nice to add some games to keep children engaged (e.g. providing activities on every three pages) (Parent3&amp;T1DC3) (Session 2)</td>
</tr>
<tr>
<td></td>
<td>8. Used at school to explain to other children about diabetes (Parent3&amp;T1DC3) (Session 2)</td>
<td>8. Have something in the car that is different from the book that the child could play with (Parent3&amp;T1DC3) (Session 2)</td>
</tr>
<tr>
<td></td>
<td>9. Does not have scary images (Parent3&amp;T1DC3) (Session 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10. Very helpful, it was used by class teachers, SNAs and family members (Parent24&amp;T1DC24) (Session 3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11. The child “likes the fact that Pete is a character, it was not this pancreas in your body as organ...Pete has a face” (Parent24&amp;T1DC24) (Session 3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12. Easy to read (Parent25&amp;T1DC25) (Session 4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13. Valuable information on how the pancreas works and the functions of the hormone insulin (Parent25&amp;T1DC25) (Session 4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14. Provides simple explanation on diabetes (Parent26&amp;T1DC26) (Parent8&amp;T1DC8) (Session 5) (Session 6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>
| 9. | Not specific to this booklet, but most books written on this theme present the child with diabetes alone having no friends with diabetes (Parent24&T1DC24)(Session 3)  
10. | Could provide more fun activities (Parent24&T1DC24)(Session 3)  
11. | Need to add a lot of details on that, “I could look over and over again when I need it” (Parent25&T1DC25) (Session 4)  
12. | “Horrified reading that I need to inject insulin” (Parent25&T1DC25)(Session 4)  
13. | The book is very childish for her age (Parent26&T1DC26)(Session 5)  
14. | Does not give a lot of information on sports and diabetes (Parent26&T1DC26)(Session 5)  
15. | Do not like the questions and answers in page 30 (Parent26&T1DC26)(Session 5)  
16. | It was long time ago (Parent8&T1DC8)(Session 6) |

### Superhero learns about diabetes

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 1. | The eBook was described as being more fun than ‘Pete the Pancreas’ (T1DC16, T1DC17 and T1DC18)(Session 1)  
2. | The question was not discussed (T1DC3&Parent3)(Parent24&T1DC24)(Parent8&T1DC8)(Session 2)(Session 3)(Session 6)  
3. | The eBook is better for children my age (Parent25&T1DC25)(Session 4)  
4. | The eBook provides more information about diabetes (Parent25&T1DC25)(Session 4)  
5. | ‘Pete the Pancreas’ is appropriate for younger children (Parent25&T1DC25)(Session 4)  
6. | The eBook explains type 1 diabetes better than the book ‘Pete the pancreas’ (Parent26&T1DC26)(Session 5)  
7. | You are doing what the pancreas does, not only colouring the images (Parent26&T1DC26)(Session 5)  
8. | The eBook contains questions and answers that are not discussed in the ‘Pete the Pancreas’ (Parent26&T1DC26)(Session 5)  
9. | My cousins would be able to understand the eBook story (Parent26&T1DC26)(Session 5)  
10. | The images, objects in the eBook are very nice, they are not scary (Parent26&T1DC26)(Session 5) |
Parent3 and Parent24, whose children were very young, found the small book very helpful - it was given to the child’s school and was used by other family members (i.e. civil partner and oldest child in the family) to read and learn about diabetes. The book was read to their children with diabetes, used to explain the functions of the pancreas (Parent24) and the relationship between the blood sugars and food (Parent3). From the parents’ perspective, the booklet is appropriate for children, does not contain any scary images (Parent3), and the child “likes the fact that Pete is a character, it was not this pancreas in your body as an organ...Pete has a face” (Parent24). At the same time, Parent24 highlighted that in most of the stories written on this theme (not specifically in this book), the main character is a child with diabetes that “is always on their own, they never have another diabetic friend” (Parent24). This made the child believe that “no one else has diabetes”. This poses problems, making the child feel that she is the only child in the world with this chronic condition (Parent24). Parent2 shared that the book contains a lot of writing which bored her six-year-old boy who asked her to “turn the page, turn the page” looking for games, illustrations, or other elements that could be fun. Therefore, this created difficulties in engaging him in the topic. Additionally, it was highlighted that she (Parent24) did not like the text in the first pages, as they did not present and explain the chronic condition well. Usually, she skips those pages. She suggested that having more images or games every two or three pages could improve the booklet. The parent mentioned that she would like to have something in the car that is different from the book that the child could play/use alone while they are travelling to their home when returning from the school.

At the end of the sessions, some of the participants were also asked which book they preferred\(^{63}\): the eBook describing a story about Superhero and his experience in learning diabetes or the pamphlet ‘Pete the Pancreas’. The children highlighted that they liked the interactive story more because having games, animations, sounds, etc. could provide the users with a more relaxing and enjoyable experience than the booklet (Session 1), and because the story contains more information helping children learn about diabetes (Session 4 and Session 5)(Table 18). The young individuals in the sessions 1, 4 and 5 all agreed that the eBook is appropriate for

\(^{63}\) Not in Evaluation Sessions 2 and 3 as there was a shortage of time and the children still struggled with reading alone.

295
children: by interacting and playing with pictures of cells, sugar (cubs) and insulin (key), the newly diagnosed child could visualise and understand how the pancreas functions. In contrast, the booklet only provides a small number of colouring activities (T1DC26, Sessions 5).

In conclusion, the assumptions based on the analysed collected data (i.e. video and produced materials in Table 16, Table 17 and Table 18) indicated that:

1) The layered elaboration appeared as a very supportive tool facilitating all participants in reflecting on the stories during the evaluation process. It was applied by the individuals in two different styles: the children used all the materials to suggest their concepts for the stories’ text and interactive features while the parents focused on the educational context by writing down their ideas on the transparent sheets. Therefore, their diverse contribution indicated that the participation of both parents and children was significant for the evaluation of the eBook stories.

2) The digital prototype provoked various discussions between participants in the sessions (between parent and child or between children) (Sessions 1, 4, 5 and 6), i.e. on the layout, illustrations, objects’ position, interactivity, visibility, text, etc. but the number of suggested ideas (N=23) for the story was less than the number of ideas generated for the paper prototype (N=36). These results could be explained by the static interface and layout of the mock-up, and many suggestions elaborated on the interactivity of the story (i.e. sound, animations, games, etc.).

3) The number of participants during the evaluation sessions was detected as an essential factor when working with children with diabetes. Individual sessions may improve the user’s interaction with the prototypes and idea generation – and hence the assessment process - for the following the following reasons i.e. children may more openly share their knowledge and diabetes practices with a designer because of the personal attention, and because of their reluctance to discuss and communicate their experiences about diabetes in front of their peers.

4) The age of the children with T1DM emerged as a critical element for the evaluation: the young children between 5 and 6 years of age may not grasp the concept of the prototypes or elaborating ideas, but observing how they play with the artefacts - particularly those that suggest some levels of interactivity (i.e. digital) - may propose valuable data for further refinement of the design. Children between 10 and 13 were found to be very supportive in the assessment process; they demonstrated an understanding of the activities and their roles as evaluators, the attitude of the 15 year-old girl towards the work was observed as similar to adults.

5) The benefit of the newly recruited participants in the study was identified as important; their involvement, related experiences and suggested criteria for the educational materials helped to enrich the feedback on the initial designs (Sessions 3, 4 and 5). The input of the newly diagnosed children in the assessment process suggested valuable data based on their fresh experiences with diabetes management i.e. the educational process and materials.

6) By including embedded media and various features that suggest interactions, the eBook story contains more information about paediatric Type 1 Diabetes because this helps users to visualise the process of digestion and what cause diabetes. The discussion on various issues such as the relationship between carbs and insulin, supportive technologies (pumps and glucometers), celebrities with this chronic condition, etc. were all identified by children as helpful. In the narratives, children recognised their own questions triggered by their initial diagnosis, questions not discussed in the small booklet ‘Pete the Pancreas’.
5.5.3 Evaluation Process with Healthy Children

With only healthy children as evaluators in the assessment process, this fragment 1) describes the procedure used for the exploration of the layered elaboration tool during four sessions in which the paper and digital stories were tested and evaluated (Section 5.5.3.1), and 2) discusses the results found from the analysed and collected data (Section 5.5.3.2).

5.5.3.1 Procedure: Informants

To avoid confusion with the session titles discussed in 5.5.2, in this segment the evaluation sessions continue the numerical sequence, named 7, 8, 9 and 10 respectively (Table 14). To support my work with children-informants, together with the materials facilitating the layered elaboration technique (Section 5.5.1, Figure 117), two sets of questions were developed and used. To identify children’s experience and knowledge with eBooks, tablets and diabetes, the questions in the first set (first image, Figure 140) were asked at the beginning of each session. Carefully crafted, the questions in the second set (second image, Figure 140) aimed 1) to provoke discussion on the narratives and 2) to identify difficult and problematic parts in the context and generate some ideas for their improvement and 3) to discern whether the participants grasped the educational information after reading the eBook stories and how the narratives helped them become aware of diabetes.

**Before reading the story**
- Do you know what Type 1 diabetes is?
- Do you have a friend with type 1 diabetes? Some relatives?
- Do you use a tablet at home and if yes how often?
- Have you read any interactive eBooks? If so, please provide some examples.

**Questions for assessing the eBook prototypes**
- Do you think you understand the story? Is there anything difficult to understand? Is everything clear in the story?
- Can you tell me what you think the story is about?
- What is type 1 diabetes?
- What parts of the story are confusing, difficult to understand? How would you change it?
- What parts do you like the best?
- What new features such as video, sound, animations, etc. can be added?
- What do you like the least?
- What was too boring?
- What would you change/add in the story? (content and interactivity)
- Do you have any additional comments or thoughts?

Figure 140: Questions used for the evaluation sessions with healthy children
In examining the layered elaboration technique during the assessment process, two different tactics of evaluating the prototypes were carried out:

1) After reading the text suggested for each page/slide, the children were asked to share their understanding of the narrative, dialogue and illustrations and to point out any words, text segments that they found difficult to understand. They were also asked to give their personal opinions on how these problematic parts could be improved by using the layered elaboration technique (Evaluation Session 7).

2) First the stories were read and discussed with a young evaluator, and then they were asked to use the layered elaboration tool to explain their concepts, elaborating on the challenging images and text that they found ambiguous (Evaluation Session 9 and 10).

The second tactic was influenced by the collected and analysed data throughout the Evaluation Session 7. In assessing the mock-up story, it was identified that the children spent more time sharing and developing their own concepts instead of focusing on the educational context by discussing what they found difficult/problematic in the narrative. Most of the proposed ideas did not link with the story narrative and the suggestions given by children were only on the first 9 pages explaining how Superhero’s adventure at the hospital had begun. Reading the educational content on pages 10-11 - particularly designed to provide young readers with information on the digestive system, pancreas, diabetes, etc. - the participants felt puzzled because they were not able to give suggestions on how to improve the parts they found problematic. Therefore, in the Evaluation Sessions 9 and 10, children first read each story with my help, and then we discussed the context to detect what words, sentences and images participants found ambiguous and to suggest improvements. The layered elaboration technique was not used in Session 8; the time allocated to conduct the session was used only for reading and discussing the digital story because the children had read the text very slowly, got tired quickly, and lost focus on the theme.

Both prototypes were analysed in Evaluation Sessions 9 and 10. I used the contrastive strategy to examine whether the levels of fidelity impacted/influenced the active involvement of the young healthy evaluators. In Session 9 (HC9, HC14 and
HC15), the evaluation started with the mock-up and then continued with the digital prototypes, while in Session 10 (HC16) the process began with the digital version and concluded with the low-fidelity paper prototype. In the Evaluation Sessions 7 and 8, only one prototype was tested. Four participants (HC2, HC9, HC10 and HC11) worked with the paper story ‘What is type 1 diabetes?’ and two boys (HC12 and HC13) assessed the digital story ‘Superhero has diabetes’ (Table 15).

5.5.3.2 A Series of Evaluation Sessions with Healthy Children: Analysing Data and Findings Discussion

I had three reasons to involve healthy child informants as evaluators in this study:

1) While playing with the prototypes and assessing the narratives with children, I wanted to trigger various questions and discussions on those sections in the stories explaining diabetes and self-management practices. It was important to identify what the problematic parts in the educational content were for the young individuals not familiar with T1DM (similar to newly diagnosed children) and how to improve them,

2) To identify what aspects of the stories aided or hindered children’s understanding of diabetes, and

3) To generate some ideas that may help to increase the quality of the content on the eBook.

In Section 5.4, I outlined four aims to explore when assessing the produced educational artefacts and applying the layered elaboration technique. Therefore, in this section, my work with healthy children and the findings that emerged in the collected data are discussed in five small pieces:

1) The proposed suggestions by children generated in the assessment process for both prototypes using the transparent layers and supportive materials (Figure 117),

2) How the layered elaboration facilitated healthy children to evaluate the initial prototypes,

3) Children’s engagement with the paper and digital stories,

4) Children’s age, personal experience and working with each child individually emerged as factors in the assessment process,
5) The use of metaphors and children’s understanding of diabetes after reading the narratives.

**Healthy children’s reflection on the mock-up and digital prototypes applying the layered elaboration**

In this section, I show the contrast between the children’s reflection on the paper and digital prototypes when the two different tactics for applying the layered elaboration technique were utilized i.e. at the beginning and at the end of the assessment process (discussed previously in Section 5.5.3.1).

To make sure that the children understood their contribution and involvement in this process as informants, I explained the functions of the prototypes and their application in design, as well as the activities planned for the evaluations. Similar to the evaluation sessions with the participants with diabetes, these sessions started with questions (first image, Figure 141, page 298) to identify healthy participants’ familiarity with T1DM and their experiences with tablets and eBooks. Children explained that they had no friends or relatives with diabetes. Most of these young individuals had tablets at home but they never played/read interactive eBooks. To inform the participants and make them aware what and how the images, sounds, animations, games, etc. would behave when the final product is ready, the two movies shown in previous sessions were used. Additionally, I explained the purpose of the transparent layers, dots and white labels in the evaluation process and the role of the movable cut-out images in the paper story. I also indicated what games, animations and interactions they supported on each page. The second set of questions (Figure 140) was used to facilitate the discussion of both stories.

The transparent layers and other supportive materials for the assessment process were used in Sessions 7, 9 and 10; the ideas generated for the mock-up (first column) and digital artefacts (second column) were extracted from the table in Appendix G and shown in Table 19. The content presented in this table is as provided by the children in the evaluation sessions and contains no modifications.
### Table 19: Suggestions made by healthy children for both prototypes

<table>
<thead>
<tr>
<th>Suggestions for ‘Superhero has diabetes’- paper prototype 18 Pages</th>
<th>Suggestion for ‘Superhero has diabetes’ - Digital prototype 14 pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) He can have a pet bird. He opened the window and let the bird out to solve a problem (HC9, 8 years old, page 3)(Session 7)</td>
<td>1) Can I at least have 1 treat? (HC16)(page 10)(Session 10)</td>
</tr>
<tr>
<td>2) To add in a doctor or other objects (HC2, 12 years old, page 3)(Session 7)</td>
<td>2) When he (Superhero) asked the question she (Dr. Jenny) will write it down (HC16)(page 10)(Session 10)</td>
</tr>
<tr>
<td>3) A puzzle to play with the spaceship (HC11, 12 years old, page 3)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>4) Click on word that child does not know and see the meaning (dictionary). He moved the cover and his bird was there (HC9, 8 years old, page 4)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>5) Quiz with 3 questions, when he gives the right answer he went to the next room (HC10, 10 years old, page 4)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>6) We could put air bubbles and they can say things (HC9, 8 years old, page 5)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>7) You could write down what these small things are and what they do - expand and talk about the object (HC2, 12 years old, page 5)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>8) The magic submarine could change into people (HC9, 8 years old, page 6)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>9) You could add particles around the submarine (HC2, 12 years old, page 6)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>10) Sounds on how the ship shrinks and gets bigger or how the door opens. Tap on the ship to shrink or get bigger (HC11, 12 years old, page 6)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>11) It (submarine) can change as a tiny dot like this (HC9, 8 years old, page 7)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>12) You could tap on the ship until it reaches the right size (HC2, 12 years old, page 7)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>13) Change size ship yourself by tapping on the ship (HC11, 12 years old, page 7)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>14) It can fall in the sink and fall under the ground (HC9, 8 years old, page 8)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>15) When he finds the submarine it gets bigger (HC2, 12 years old, page 8)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>16) The ship gets stuck in glass of water and shrinks even more (HC11, 12 years old, page 8)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>17) Liam gets sick and gets to the hospital and the submarine gets out (HC9, 8 years old, page 9)(Session 7)</td>
<td></td>
</tr>
<tr>
<td>18) If Liam sees the ship in water he will not drink it, he maybe leaves it. If in the glass was milk Liam will drink it because he will</td>
<td></td>
</tr>
</tbody>
</table>
In Session 7, the layered elaboration methods were used at the beginning of the session: each slide/page was read and discussed with the children and then they suggested ideas to improve the content. This approach encouraged the children to focus on how to use the materials by producing plenty (if impractical) of ideas that were later detected as not relevant enough to implement. Most of these formulated concepts were on page 1-9, and they were basically for adding new characters or objects in the story (Table 19). For example, the text in page 3 describes Superhero, who was diagnosed with type 1 diabetes, and was admitted as a patient to the hospital. He wanted to see the objects (i.e. insulin pumps and glucometer) in Dr. Jenny’s cabinet that help people manage their diabetes again. So, he decided to go into Dr. Jenny’s office without anyone seeing him. By using the transparent layers, children drew, wrote and explained their suggestions: “He can have a pet bird. He opened the window and let the bird out to solve a problem” (HC9, Figure 141) and “To add in a doctor or other objects” (HC2, Figure 142).

Similar results were found for page 9 - in this scene, the submarine is in the Superhero’s kitchen. Being very small in size, it has sunk into the glass of water left on the table. After his breakfast, Liam (Superhero’s brother) drank the water and the magical journey into the human body started. Some of children’s ideas were, “Liam gets sick and gets to the hospital and the submarine gets out” (HC9, Figure 143) and

<table>
<thead>
<tr>
<th>not see it (HC11, 12 years old, page 9)(Session 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>19) When the submarine goes down the throat, the milk would change into water and children easily could see and interact with other organs (HC2, 12 years old, page 9)(Session 7)</td>
</tr>
</tbody>
</table>
“If Liam sees the ship in water he will not drink it, he maybe leaves it. If in the glass was milk, Liam will drink it because he will not see it” (HC11, Figure 144).

Of course, there were also some valuable recommendations to improve the interactive features: for instance, to use the dialogue bubbles (HC9, Figure 145), to expand over the objects displayed in Dr. Jenny’s cabinet and to give information about them (HC2, Figure 146), and to tap on the ship until reaches the appropriate size (HC11, Figure 147).
Children struggled to understand the text presented on pages 10 and 11 that explained the functions of the digestive system and pancreas; therefore, it was meaningless to try to garner more ideas. I tried to refocus their attention on the narrative and to discuss these problematic words, images, processes, etc. Unfortunately, the amount of time set for the session was over and we failed to discuss the whole story. Hence, this was the reason for applying the layered elaboration after the stories were read and discussed. Using this approach in assessing the paper story, the young participants in Sessions 9 and 10 (HC9, HC14, HC15 and HC16) highlighted that the pages (e.g. 11, 12, 13 and 14), whose educational context gave information on cells, what causes diabetes and explained the balance between insulin and carbohydrates were difficult for them to grasp. I played the role of an educator and together with the children we read, moved and interacted with the text and images provided for each scene. This helped to raise and improve the children’s understanding of the topic. When the discussion on the whole story was completed and the young evaluators started to show some awareness of the text and the supporting illustrations, they were asked to suggest ideas that could help to improve these problematic portions by using the layered elaboration technique. Only the boy (HC14) in Session 9 articulated that the story is very long, but he did not use the materials to write his opinion.

Similarly, in evaluating the digital story, together with the children we read, played and discussed the scenes that the children identified as problematic. Only two suggestions were proposed. The boy (HC14) in Session 9 thought that having the story read-aloud (narration) would help children to read the story faster; again, he did not use the materials supporting the layered elaboration. The girl (HC16) in Session 10 (Figure 148) proposed a question for page 10 asked by Superhero “Can I at least have 1 treat?”, and an animation showing Dr. Jenny writing down the question in her
records (Figure 148). These results indicated that children need time to discuss and understand the educational context before starting to generate ideas.

![Figure 148: Add question, page 10, Session 10, 8 years old child](image)

**Exploring layered elaboration technique with healthy children**

While exploring the layered elaboration, the results indicated that not all children used the suggested materials to illustrate their ideas. However, the young individuals in Session 7 drew images, wrote information on the white self-addressed labels related to their suggestions and stuck on the coloured dots to explain the proposed interactive elements. They did not find any difficulty in working with the materials facilitating users to illustrate and show their own concepts. In order to improve access to the original page/slide used for discussion and idea elaboration, it was placed in the middle of the table. To increase collaboration between children, participants were split into two groups at the beginning (Figure 149), however, they started to articulate individual ideas using the materials alone. Each child wanted to develop and explain their own idea; this was observed as a time consuming process, therefore, they evaluated pages 1-9 only. Additionally, the children focused on suggesting plenty of images and features to improve the prototype; this hindered their attention from the narrative.
In Session 9, the materials were not employed. In Session 10, the girl (HC16) provided little but meaningful ideas; she illustrated her suggestions by sticking the blue dot to represent animation and wrote down her opinion on the white labels (Figure 150).

**Healthy children’s engagement with the prototypes**

Through analysing the children’s actions - particularly how they played, read and interacted with the stories - it was indicated that all the children were aware of the meaning of these artefacts and understood their role as evaluators in the study. The young healthy individuals engaged with the prototypes differently; some were very intrigued to interact with the digital story (Sessions 8 and 9) while others found the paper artefact more interesting to play with (Session 10). For example, the digital prototype provoked children to play with the images without reading the text - their attention was focused on figuring out how the interactive features on the eBook worked (e.g. pressing the images to play animations - Sessions 8 and 9) (Figure 151 and Figure 152). In contrast, while assessing the paper story, the children were only active on the pages that provided some games or animations. When the children were asked in Session 9 to place the small images of human organs into the outline of the human body (working with page 10), and to play with the glucose cubes, insulin and cell images to visualise the work of the pancreas (page 11), all the children wanted to take part in these activities (Figure 153). It was noticed that the 8-year-old girl (HC9) used the images in page 12 to explain what causes diabetes to other children after we discussed the issue (Figure 154).
In Session 10, the child (HC16) really enjoyed playing with the mock-up prototype as opposed to the digital story (the evaluation started with the digital prototype). She was so excited to read the text, to move all the small parts simulating the interaction with the real product i.e. playing with the main characters Superhero and Dr. Jenny, to figure out where the submarine was hidden on page 8 (Figure 155), and to interact with the images of Liam drinking the water on page 9 (Figure 156), etc. The young evaluator also produced whistling sounds in conjunction with the submarine’s flight and to imitate its size changing - she was really fascinated with the prototype elements. The child did not face any difficulties in arranging the human organs correctly (except the pancreas because she knew nothing about it) (Figure 157, page 10) or to identify healthy and non-healthy food.
Children’s age, personal experience and individual approach emerged as factors for the assessment process

As discussed, the young healthy evaluators were of various ages. They could have had different knowledge of the human body, healthy food and cognitive and motor development; together these may have influenced their understanding of the narratives and their active participation in the assessments. It is important to highlight that all the participants were honest in their answers describing what they knew and what they found difficult to understand. Interacting with the prototypes, 1) the age of participants, 2) their personal experiences and 3) individual approach (i.e. working with the children in small groups of two or one) have emerged as factors for testing the educational context of the prototypes. Participants who were 8-9 years of age (Sessions 8, 9 and 10) needed more time to read the stories, and also required help with some words, especially with those that were linked to diabetes treatment and self-care practices. The evaluators who were at age 8 (HC9, HC12, HC13 and HC16) were really supportive - for example, the boys in Session 8 (HC12 and HC13) were very active in explaining what they saw on the slide and what they understood (or did not understand) in the text. While playing with the scene illustrating Superhero in the hospital waiting room (page 7), one of the boys explained the receptionist's role - “it is a girl and if someone rings and wants an appointment they just ring. She picks up the phone, types down on the computer what time they did the appointment for the doctor and she knows that source”. Similarly, the girl (HC9) was so energetic and cooperative when explaining the meaning of the word active (as one of the components in diabetes management), she moved from her place to perform (act out) body movements of walking, running and jumping. The child (HC16) in Session 10 was active in asking questions and giving answers about the story.
The personal experiences of the children regarding some health issues indicated various benefits in evaluating the educational stories. The new words found in the digital narrative such as glucometer, lancet, strips, insulin, etc. (in pages 9 and 10) were pointed out by children as challenging; they raised questions that helped to generate valuable information. Some of the children already had experience with the blood test. One of the boys (HC13) was very confident in explaining the functions of the lancet - “prick the finger for a sample to take blood” (HP13) - because he gave blood samples at the clinic twice. The doctor used something similar to the lancet which the boy called a “cylinder”. The girl (HC16) commented on her own experience at the hospital with a similar test but with the use of cream to reduce the pain because the blood was taken from her vein. Both children struggled to understand what information the glucometer gives in relation to blood. After reading page 10 in which Superhero learns that part of his treatment includes a healthy diet, the girl (HC16) highlighted that he could not eat sweets and chips or buy food from McDonalds as they are not healthy (Session 10). She knows about this from the food pyramid poster displayed in school that she studied, and un-healthy products such as crisps, chocolates and fizzy drinks are shown at the top of the pyramid. Also, her knowledge on human organs was obtained during Teddy bear hospital activities at school, as well as playing one game on her Nintendo DS.

Finally, the evaluation sessions carried out with a small number of children were found to be more productive (Sessions 8 and 10) that the other sessions because individuals understood that all attention was focused on them. As a result they were more supportive and responsive in completing the evaluation tasks.

The use of metaphors and children’s understanding of diabetes after reading the stories

Assessing the simplicity of the stories was important during the evaluation process. All participants faced difficulties in grasping the functions of the glucometer and insulin pump; the digestive system and pancreas; understand what glucose and insulin were and their function in the human body; why diabetes occurs and the balance between food intake and insulin. As noted, I supported their explanation by discussing these issues with simple words and images built in the prototypes. The use of metaphors in the narrative i.e. stomach works as a mixer, insulin works as a key,
etc. was observed as a very successful strategy for explaining the educational materials, and the children used them as well in their answers by adding a new one when they explained the human organ pancreas i.e. the pancreas looks like a banana (HC14, Session 9). The children in Session 9 highlighted that taking injections with each meal in order to achieve the balance (page 14, paper prototype) will be very difficult for Superhero. The girl (HC16) in Session 10 was confused about the word glucose used instead of sugar: this was a reaction from linking the word with its real meaning - sugar – and that it was not healthy for the body. In the end, she was able to explain that Superhero needs to take his medication by injections; he needs to maintain a healthy diet, and understand the function of insulin in the human body. With relation to diabetes cure, the young evaluator stated that when Superhero gets better “his power will be how it was” (HC12, Session 8).

In conclusion, the emerged findings indicate that:

1) Applying the layered elaboration technique at the beginning of the evaluation process was observed as a distracting activity, the children’s focus was diverted from assessing the educational context to elaborate ideas that most were found to be infeasible. Using the tool at the end, when the stories were read and discussed, the technique was found to support the users’ reflection on the prototypes, producing less but more meaningful suggestions.

2) The results show that both prototypes triggered various discussions in the evaluation sessions, particularly on the pages where content is more medically oriented, discussing diabetes. Suggesting real interaction with the story, the digital prototype provoked curiosity in children to play with each page/scene by looking for the various elements integrated to offer fun and entertainment, while the mock-up artefact attracted the evaluators with the moving parts simulating games or animations.

3) In both prototypes the pages/scenes elaborating on the illness diagnosis and treatment were identified as difficult to read and understand by the children; they needed help to pronounce the medical terms and further information on their meanings.

4) Good explanations by using simple words, metaphors, examples of images and illustrations may help children to grasp the story, explaining Superhero’s experience with diabetes and its treatment.

5) The participants who were at 8 years of age seem to be very supportive in communicating their opinion, knowledge and understanding of the educational context.

6) Knowledge accumulated through personal experience i.e. being sick, school curriculum, playing games, etc., as well as the individual approach - i.e. working with one or two individuals at a time - may improve user’s active involvement in the evaluation process and influence the collection and generation of valuable data.

5.5.4 Discussion of Ten Evaluation Sessions
Table 20: Findings evaluating the prototypes with design partners and informants

<table>
<thead>
<tr>
<th>Findings</th>
<th>Children with T1DM and their parents as “design partners”</th>
<th>Healthy children as “informants”</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Layered elaboration</strong></td>
<td>Very supportive tool facilitating all participants to reflect on the stories during the evaluation process</td>
<td>Advantages vs disadvantages</td>
</tr>
<tr>
<td></td>
<td>- Children used all the materials to describe their concepts, they critically evaluated both the educational context and interactive elements</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Parents used the tool mostly to write their suggestions, they critically assessed the educational context</td>
<td>- At the beginning of the evaluation process it emerged as a distracting tool, shifting the focus from assessing the educational context - greatest number of ideas but most were inapplicable</td>
</tr>
<tr>
<td></td>
<td><strong>Advantages vs disadvantages</strong></td>
<td>- At the end, after the discussing the stories, it supported participants to show their ideas – less number of ideas, but more meaningful</td>
</tr>
<tr>
<td><strong>2. Fidelity effect</strong></td>
<td>Both prototypes triggered various discussions on the medically oriented context and interactivity as:</td>
<td>Both prototypes triggered various discussions on the medically oriented context as:</td>
</tr>
<tr>
<td><strong>Both prototypes evaluated in each session:</strong></td>
<td>- The digital prototype produced less number of ideas (N=1364), provoked various discussions on the layout, illustrations, objects position, interactivity, visibility, text, etc.</td>
<td>- The digital prototype produced greatest number of ideas (N=2), provoked interest in children to play with the interactive objects offering fun, curiosity and entertainment</td>
</tr>
<tr>
<td></td>
<td>- The mock-up story generated greatest number of ideas (N=36), most of them describe interactive features such as sound, animations, games, etc.</td>
<td>- No ideas65 suggested for the mock-up artefact. The evaluators were focused on plying with the moving parts simulating games or animations</td>
</tr>
<tr>
<td><strong>3. Age</strong></td>
<td>- 5 and 6-year-old children may not grasp the idea of the prototypes or elaborate ideas, while interacting with the artefacts supporting some levels of interactivity (i.e. digital) may offer valuable data for further refinement of</td>
<td>- 8-year-old children seem to be very supportive in communicating their opinion, knowledge and understanding of the educational context</td>
</tr>
</tbody>
</table>

64 In Session 3, 11 ideas were suggested for the digital prototype, but the participants did not work with the paper prototype

65 In Session 7, 19 ideas were suggested for the paper artefact, but the children did not work with the digital prototype
the design
- Children between 10 and 13 were found to be very supportive in the assessment process
- The 15–year-old individual may behave similar to adults

| 4. Educational context | - eBook stories supply more information about diabetes than the book ‘Pete the Pancreas’
- eBook provides more fun and entertaining activities than the book ‘Pete the Pancreas’
- eBook presents visualisations of the process explaining diabetes
- eBook explains T1DM better than the book ‘Pete the Pancreas’ | - In both prototypes, the pages/scenes discussing diagnosis and treatment i.e. medical terms, processes and words, were identified as difficult to understand, further clarification required
- Using simple words, metaphors, examples of images and illustrations may help users grasp the educational story |

| 5. Individual approaches | Individual approach i.e. working with one or two individuals at a time may improve:
- User’s interaction with the prototypes
- Idea generation - all attention will be focused on the young participant
- Sharing their knowledge and experience on diabetes self-care practices only with designer
- The reluctance to discuss and communicate personal experience about diabetes with others | Individual approach i.e. working with one or two individuals at a time may improve:
- User’s interaction with the prototypes
- Idea generation - all attention will be focused on the young participant |

| 6. Experience | - The newly recruited participants in the study helped to enrich the feedback on the initial designs
- The newly diagnosed children offered fresh experience of diabetes management, educational materials and processes | - Knowledge accumulated through personal experience i.e. being sick, school curriculum, playing games, etc. helped children reflect on the educational narratives |
The findings of all ten evaluation sessions are illustrated in Table 20. The first column shows six categories of layered elaboration, prototypes, age, educational context, individual approaches and experience. The first four categories are linked with the questions asked in Section 5.5 aiming to explore the layered elaboration technique in the evaluation process; fidelity effect on user’s active involvement, children’s age, and educational context. The last two - i.e. individual approach and experience - emerged from the analysed data. The second and third columns outline the diverse results when having two groups of participants as evaluators playing the roles of “design partners” (second column) and “informants” (third column), identified by their experience of having/caring (for) T1DM and being a healthy child. All these categories, along with their findings, are discussed in sequential order below.

The contrasting results indicate the advantages and disadvantages of applying the layered elaboration technique, particularly when assessing the prototypes with healthy children. For example, having young individuals with T1DM and their parents for evaluators, the tool provided promising results in supporting their reflection on both stories. Two different styles to using the suggested materials were identified, influenced by the participants’ approach of assessing the educational content. For example, adults quite often used the white labels to write down and explain their comments on text (Sessions 2, 3 and 6), while diabetic children played with all materials by using drawings, dialogue bubbles and sticking coloured dots according to the instructions, illustrating their ideas for improving the text, user interface and interactivity (Sessions 1, 4 and 5). With healthy children as the evaluators, the layered elaboration technique was applied in two different modes i.e. during and after the educational stories were read, explained and discussed (Section 5.5.3.2). The results indicated that when using the first tactic, healthy evaluators lost their focus on assessing the text and the supporting illustrations, and preferred to develop many, albeit impractical, ideas (Session 7); however, with the second tactic, they suggested less, but more meaningful recommendations (Session 10). In the first tactic, the technique was identified as a distracting activity that grabbed children’s attention for creative thinking, neglecting their primary goal as evaluators (i.e. to assess the educational content in the developed eBook narratives). Keeping the
participant’s attention only on the story by discussing and asking children questions related to the narrative helped the evaluators to focus and identify the sections, words and illustrations that they found difficult and problematic, indicating specific information important for the further refinement of the prototypes. Therefore, the layered elaboration technique successfully supported the young participants with T1DM and their families at the beginning of the prototypes assessments, while for healthy children the technique showed to be beneficial when applied at the end, after the process of reading and discussing the stories was accomplished. The transparent sheets and other materials were easy to use for all participants in different settings and allowing them to write, draw and explain their creative thinking and ideas, keeping the original artefacts from being damaged. Easy to store and analyse, the transparent sheets could be used again with the same or different participants to reflect on the earlier suggested ideas. One problem was detected when applying the technique for digital story assessment. When participants draw images/sketches on the transparent sheets overlaying the screen of the Tablet, they sometimes activated or selected the interactive elements, animations, etc. built for the scene/page. This appeared to interrupt the creative process - correcting the error took time in which the children had to stop their reflection on the narrative.

Children become aware of their different roles as evaluators at the beginning of the sessions through explaining the meaning of the prototypes in the design process, and showing examples of enhanced interactive eBooks. The analysed data illustrated that all children between 8 and 15 years of age understood the purpose of the paper and digital prototypes in the evaluation process. In exploring the fidelity effect on users’ active involvement in the evaluation process, it was observed that all young participants liked to interact with both prototypes, and as a result they provoked various discussions and suggestions. For example, analysing the data collected on the transparent sheets from only the Evaluation Sessions (i.e. 1, 2, 4, 5, 6, 9 and 10) in which both prototypes have been evaluated, the results indicated that children with diabetes and their parents (Sessions 1, 2, 4, 5 and 6) made more recommendations for the mock-up story (N=36) than the digital narrative (N=13) (Table 16). Most of the suggestions given for the paper story described various features such as animations, sounds, games, etc. In contrast, healthy children (Sessions 9 and 10) proposed the
greater number of ideas for the digital artefact (N=2), and no suggestions were made for the paper prototype (Appendix I).

It was also identified that a visually rich digital story designed to offer a more interactive way of exploring the graphic elements provoked more discussions between the participants and designer (Evaluation Sessions 1, 2, 6, 8 and 9), emphasizing the eBook functionality and layout of iconic visual language (i.e. images suggesting playful engagements), dialogue between the characters, the album with celebrities with T1DM, etc. Not all of the discussed ideas were written on the transparent sheets, but they supported the collaborative dialogue between the designer and evaluators by involving participants actively in the process. Some of the children really liked to play with the paper prototype (Sessions 4, 5 and 10). They moved the paper pieces according to the narrative by simulating some of the interactive features or animations, imitated some sounds to support the touch and response interaction, etc. As the digital story was evaluated as a second prototype, it can be assumed that the children were tired, and less focused to take note of their ideas. Therefore, it is difficult to identify which of the prototypes facilitated the children’s involvement better based on the produced recommendations, but in both artefacts the elements suggesting various levels of interaction (i.e. rearrange images to simulate games, move cut-out images, activate animations, move objects to produce sounds, touch and response interaction, etc.) were observed to provoke the user’s curiosity and willingness to play with the stories. Children’s personalities were observed as a factor impacting active involvement in the process; some of evaluators demonstrated forms of shyness when asked to share and express their point of views in front of others (i.e. children and designer)(Session 1 and Session 9), so they needed time to analyse the friendly atmosphere and people to overcome these feelings. To decrease these emotions, meeting young participants on a regular basis could create a good relationship between designer and children to work together.

The age of the children appeared as a key factor for their active involvement in evaluation activities. As discussed in Section 5.5.2.2, the 6-year-old boy and 5-year-old girl played with the paper and digital prototypes, demonstrating that they understood the text of the stories read by their mothers, but they did not grasp that by touching and playing with the images/parts of the stories artefacts, they were actually
evaluating the prototypes (Session 2 and 3). For instance, their attempt to find more interactive elements that were fun and the manner in which they moved the objects helped the designer to come up with some ideas for improving the user interface of the eBook; this was observed particularly when they played with the digital prototype. They did not give any suggestions for the text or images because of their young age, but they showed some basic knowledge of diabetes as a result of education at home with their parents. In assessing the narrative structure of the story in the mock-up prototype and its visual representations using illustrations and movable images, the girl who was 15-years-old (Session 6) was less active compared to other evaluators. Her approach in assessing the stories was similar to adults (parents); together with her mother, they communicated various ideas provoked by discussions on the stories, text and images, but only a few of them were illustrated on the transparent layers. All healthy children who were at age 8 were very supportive and approachable during the evaluation (Evaluation Sessions 7, 8, 9 and 10) - they freely discussed what they knew about the human body and healthy food, about their personal experience in the hospital, problematic words, illustrations, performed acting, etc.

Friendly and open for collaborative work in detecting and resolving issues, the healthy children showed great enthusiasm while evaluating both prototypes. When a new topic such as diabetes was discussed, their most typical response was to ask questions, hence as a designer playing the role of educator I provided as much details as possible to help explain the subject. It was important for the evaluators to create their own understanding of the new material and reflect on the suggested information, so my competence in that area/discipline was essential. Also, the acquisition of new information and its successful recall may vary for children, even if they are at the same age. This influences how quickly they can grasp the educational material and give the correct answers to the questions related to the topic. Diabetes health care education is an ongoing process that usually starts after the initial diagnosis and this could be taken into account when evaluating educational technology. The knowledge is constructed and accumulated not only from the educational materials along with the help of educators, but also from the personal experience gained through living with the chronic condition. For children, this
process also depends on their age and maturation (Session 5.2.1.2). It would be naïve to think that by only reading and explaining the text to healthy children that they will learn/grasp everything about diabetes discussed in the stories, because the practical activities - i.e. the daily regimental tasks that are also part of diabetes education - were missing. It was observed that children were very honest in indicating their difficulties in story comprehension. Even after the discussions and details given for the story, they would point out what they still did not understand. In both stories, the pages containing information on diabetes were identified by children as complex because the content contained new terminology, processes and technologies. To deal with this problem, children replaced and explained the meanings in their answers by using metaphors that they found in the text, or they created their own which clearly suggests that they understood the narratives. They were aware and able to explain what is healthy and un-healthy food, physical activities, blood samples, injections, and even how the cells in the human body work (HC9). Children did not understand about the control needed for the blood glucose levels (i.e. insulin and food) and the value of the work done by medical devices used in diabetes management such as the insulin pumps and glucometers. In contrast, children with diabetes did not face any difficulties with the narrative, words, technology, and processes; they found the stories educating by using visualisations of some of the processes explaining diabetes, and offering more fun and information on diabetes than the book ‘Pete the Pancreas’.

Additional contributions indicated the benefits from 1) the individual approach – having small groups of one or two children, 2) newly recruited individuals for both groups of participants and 3) knowledge accumulated through personal experience and 4) more time for work with children by having some breaks for snacks and to relax. The evaluation sessions carried out with small numbers of children were more productive (Evaluation Sessions 2, 3, 4, 5, 8 and 10); the young individuals understood that all attention was focused on them so they were more supportive and responsible in completing the evaluation tasks. Moreover, the reluctance to share experience with diabetes emerged during Session 1, similar to Workshop Session 4 (5.4.1.3) in the prototyping process. Most of the participants (Session 3, 4, 5, 8, 9 and 10) were not involved in the previous activities organised in performing UCD -
recruiting new participants for the evaluation sessions indicated positive results for generating rich data based on their dissimilar experiences i.e. having (caring for) diabetes, newly diagnosed and being a healthy child. Fresh experience with the illness in newly diagnosed young individuals, as well as experience based on some health problems, healthy food, etc. in healthy children indicated various benefits when assessing the educational prototypes. Finally, healthy children between 8 and 9 needed more time to read the whole story or both narratives - they got tired quickly and lost focus on the activities (Session 8), hence the reason for performing the evaluation process over two consecutive days (Session 10). Therefore, planning and allocating time for evaluation of educational prototypes with this group of children, as well as the number of activities become factors that could be considered.

Participation of both groups was essential for the evaluation process. For instance, the results indicated that the involvement of parents and their diabetic children as equal design partners was important for the study because they had different assessment approaches in reflecting on the educational stories. The parents as educators of their young children with T1DM have created their own criteria for appropriate context that could resonate better with the educational needs of their children; this guided their feedback and personal reactions to the developed text, backgrounds and images in the eBook (Sessions 2 and 3). They paid more attention to the narrative than on the interactive features; they wanted to draw children's interest in diabetes education by having more realistic storylines and mapping some scenarios in which children may recognise themselves when dealing with diabetes everyday self-care tasks. Their different points of view were prompted by their rich experience with the illness; therefore, their contribution facilitated the quality and design of the educational technology. Some of the parents (Session 4 and 5) had a more passive role, relying on the opinion of their children as they were experts in managing their health conditions. These young participants were at an age (10 and 13) where they could read alone, explain their experience with the illness, and communicate thoughts and ideas. The young participants in Sessions 1, 4 and 5 evaluated the prototypes carefully looking for child-appropriate language (not childish), images that support the narratives, characters, dialogues, etc. emphasising aspects that, in combination with the educational context, could provide fun and
entertainment. This different approach that was observed has its benefits, accumulating the rich data necessary for the enhancement of the design of the eBook at the early stages of its implementation. Playing the role of informants, the evaluation activities in Sessions 7, 8, 9 and 10 with the healthy children were primarily focused on investigating the educational perspective – how the knowledge about diabetes was conveyed by the stories to help children to become aware of the chronic condition and its treatment. The theme diabetes was new for all healthy children - their feedback helped to identify that the use of metaphors for explaining the processes of the stomach and human cells may improve the knowledge acquisition in the potential users and their awareness of diabetes. Living in meaningful socio-cultural practices as experts in their everyday lives (Iversen and Brodersen 2008), they were very honest in sharing their diverse opinions and understanding of the narratives while discussing the healthy diet, the use of the glucometer and insulin, the digestive system, etc. This actually pinpointed that the experience gained through various activities and diabetes self-management appeared as one of the main factors for healthy young participants and those with diabetes respectively in the testing process. Working with the informants, the results indicated that these healthy participants already had some personal experience with taking blood samples, healthy food, the position and functions of some human organs, etc. therefore, this influenced their feedback and idea generation during the evaluations (Section 5.5.3.2). Similarly, using the various experiences gained through living with diabetes, affected children contributed to the educational context in the narratives by adding more details/corrections that could increase the quality of the eBook. Also, having recent experiences with the educational issues at the hospital and at home, a newly diagnosed child (T1DC26) appeared as a key element in illustrating the need of this group of participants in the study. The girl in Session 5 was very active during the assessment - even though she did not fall within the age group of the users as she was 13 at that time – and being diagnosed only five months previously, she was able to recall small details of her experience with the education provided in the hospital, the questions and information that she looked for and needed at that time, and what was important for her to know about diabetes. Other children who participated in the Evaluation Sessions 1 (age 13) and Session 4 (age 10) who have diabetes for a long time contributed with their extensive knowledge on the illness obtained by managing
their chronic condition by elaborating on the details related to the questions used in the text, by explaining the balance between insulin and food with the scales, etc. The boy’s experience with games helped him to easily suggest plenty of ideas related to images and their interactive functions.
Chapter 6: Reflection and Discussion

6.1 Introduction

As stated in Chapter 1, this thesis examines the role of the children with T1DM and their parents in the design of IT that may resonate with their perspectives and the practicalities in their everyday life. This chapter reviews the emergent findings from the empirical work in order 1) to answer the research questions and 2) to outline the contributions made in PD, CI and ID while developing an educational interactive eBook by exploring methods, technics and tools that actively involve participants in the UCD process. The chapter includes three sections outlining those results which answer each sub-question posed in this study. Section 6.2 considers the findings for the first sub-question through 1) using the inductive qualitative data analysis to explain and identify the problems in paediatric diabetes care outside the secure clinical settings and 2) performing further investigation in the literature to explore the model of care in Ireland, paediatric diabetes services and educational materials and practices, as both examinations helped to identify the role of IT in paediatric diabetes care. Section 6.3 refers to the answers to the second sub-question that examines the role of the participants in the design and their contribution to the quality of the eBook design. Section 6.4 discusses the findings in regard to the third sub-question, collected by exploring various design interventions, applying UCD and a participatory approach to enable and facilitate the creative process with children (i.e. healthy and those with diabetes) and their parents in designing an educational IT - eBook.

6.2 Practicalities of Affected Individuals in Everyday Life: Exploring Paediatric Diabetes Care in Ireland

RQ 1: What are the problems, issues and practicalities experienced in paediatric diabetes self-care? What are the current limitations in the care provided for families who have children with T1DM? What is the role of IT in supporting paediatric diabetes care practices?

With respect to my first sub-question, i.e. to generate an explicit understanding of users, this section is divided into two segments discussing respectively 1) the practicalities of everyday life in the affected families, identified through the use of
semi-structured interviews (Section 6.2.1) and 2) the current limitations in paediatric diabetes education (Section 6.2.2).

6.2.1 Paediatric Diabetes in Everyday Life: Issues, Difficulties and Practicalities

It was highlighted in the Årsand and Demiris (2008) framework (modified UCD discussed in Section 3.3) that at the start of the UCD process the users’ involvement is required, to help to acquire information and a deeper understanding of their everyday healthcare practices in order to design technology that may better correspond to their needs. Some of the discussed methods supporting these early activities are interviews and field studies. Adhering to these guidelines, I used the qualitative semi-structured interviews with parents and their children with T1DM, aimed at improving my understanding of paediatric diabetes management by exploring their daily self-care practices and decision-making processes in the domestic environment e.g. at home, in school and other. The analysis presented in Section 5.2.1 helped to identify two themes, illustrating paediatric diabetes challenges from the perspective of the participants: 1) the major limitation in diabetes education i.e. the shortage of educational materials and structured education provided for newly diagnosed children and their families (Section 5.2.1.2) and 2) the formation of negative emotions in children towards diabetes (Section 5.2.1.3). For example, many of the diagnosed children did not have a family history of diabetes. For these young patients and their parents, their education in hospital was their first step toward an understanding of what causes the chronic illness and its treatment. Most of the young patients were encouraged to start their practical education (i.e. use of the glucometers and insulin injections) from the first day after being admitted in the hospital (Section 5.2.1.2). This approach brought large amounts of stress, rejection, questions, negative feelings, etc. triggering the formation of the first experience with diabetes described in the sub-theme 1: Diabetes education at hospital. Both children and parents needed time to overcome these first emotions (often connected to the fear of the unknown), adjust to their new lifestyle with drastic changes in the family dynamics for effective diabetes management and facing a shortage of knowledge and skills of self-care practices. Unfortunately, training was limited to “the needles and taking measurements” (Parent6). Most of the families
involved in the study also required “someone to talk to on the emotional level” (Parent23), “how to deal with different scenarios” (Parent7), in “scare situation” (Parent15), “the human side of it” (Parent4), “how to adjust ourselves on that” (Parent15), etc. because “No day is ever the same though, no matter how hard you try” (Parent7). Parents and children needed to gain practical skills and knowledge to cope with an unexpected life-threatening condition in a diverse environment to successfully manage the chronic illness. The families, dietitian and diabetes educator highlighted that paediatric self-management education is a lifelong process in which the knowledge is obtained through personal experience dealing with different scenarios, by using available educational sources and materials, by meeting other parents in support groups, by constant communication with paediatric services and available educational programmes. This long process of education opened up a new role for the parents; they become educators of their children, of teachers or other family members who may share diabetes management. Of course, this new position demands certain knowledge on the various self-management tasks (i.e. administrating insulin injections, blood glucose measurements, appropriate response to hypo- and hyperglycaemia, etc.) that they first have to obtain. They needed to find educational tools and teaching resources to support their learning and teaching process because the provided set ‘Pete the Pancreas’ did not cover all educational needs in newly diagnosed children and their families (Section 5.2.1.2). As a result, the parents spent time discussing diabetes, those serious and complex matters as emergency plans for hypo- and hyper-glycaemia treatment, diabetes complications, good nutrition and healthy balanced diet, etc. The results indicated that diabetic children had dissimilar attitudes towards individual education, influenced by their own views and feelings; some read books and other educational sources to know more about the illness while others felt terrified of the described outcomes of improper treatment, that could sound scary “…she will not pick up a book about Diabetes. She just feels that she doesn’t want to know about it” (Parent10). This indicated the need for tailored educational materials that address diabetes self-management in children, designed in a way to meet and increase the optimal delivery of information based on individual preferences for learning.
The young individuals with diabetes needed to become more disciplined by accepting to play a greater role in their care “the doctor said to her, she couldn’t believe what he said, “grow up quickly move back from the table” (Parent1). Unfortunately, the young patients displayed different levels of coping with the various demands of diabetes, based on their age, experience with the illness, maturity and personality. As described by the parents, the constant stress and the difficulties experienced in managing the illness caused the formation of emotional responses creating negative thoughts and feelings in young individuals towards the illness, “…she hates everything about diabetes…” (Parent4), “…she doesn’t like to talk about it…” (Parent10), “…cries till he comes out of it…” (Parent9) and “…she was devastated” (Parent1) (Section 5.2.1.3, Theme 2: The Child’s Emotional State). Many of these young patients keep it secret that they have diabetes because they feel that they are “treated differently from the other children” (Parent7), and they show avoidance to discuss this topic with people or even share personal experience with other diabetic children. Anxiety, depression, negative emotional states, sadness, social isolation, reluctance or unwillingness to meet and communicate with others are very common for children with T1DM.

The diverse ages of the participants at the time of their diagnosis (i.e. between 21 months and 17 years old) combined with their parents’ perspective and recollection enabled the gathering of great detail on their paediatric diabetes care. For instance, the parents’ participation was crucial in identifying problematic aspects in diabetes management, providing comprehensive information not only on their personal experience with the illness but also on the challenging issues related to their children. Usually, the treatment should be discussed with the parents/guardians; some children, diagnosed at a very young age, cannot remember many details (Section 5.2.1.2), others provided valuable insight on their feelings, emotions and educational practices obtained initially at the clinic and later at home individually. This demonstrates that the participation of both parents and their diabetic children in the first stage of UCD was essential 1) to generate and collect systematic information on users and their environment and 2) to explore concepts and arguments facilitating justifications for a design choice.
6.2.2 Current Limitations in Provided Care for the Families and the Role of Technology in Supporting Paediatric Diabetes Care

In order to learn more about these educational practices, the findings suggested further research in a broad subject area focusing on the model of care in Ireland, on educational practices and paediatric diabetes services available and accessible to diagnosed children and their families, discussed in Section 2.3.2. Furthermore, I met and conducted interviews with a dietitian and diabetes educator, to discuss the educational programme CHOICE and to get authoritative information on the nutritional education necessary for effective paediatric diabetes management (Section 5.2.1.2). In 2012, paediatric diabetes education was available only after diagnosis in clinic settings; there was no refresher education (i.e. structured educational programmes) available for the families. Investigating diabetes care in the Republic of Ireland, the first national audit in 2013 identified many problems and challenges such as shortage of well-qualified staff, limited access to psychosocial services, etc., indicating the need for a new structure that may support better the patients’ need for proper treatment (Hawkes and Murphy 2014). For that reason, in 2015 the first model of care for Continuous Subcutaneous Insulin Infusion (CSII) suggested by O’Riordan and Ms. Turner in 2012, was updated with the ‘Model of care for all children and young people with Type 1 diabetes - November 2015’ (O’Riordan and Turner 2012; O’Riordan et al 2015). Described by O’Riordan et al (2015), this new model (Porter and Thomas 2013) will be built on integrated practice units (IPUs). An IPU will consist of “one centre of reference and a number of additional units” as each centre “will have between 150 and 300 patients” (O’Riordan et al 2015, p 23). Education was described as a key element for the success of diabetes paediatric care; the model recommends the development of national educational programmes for young diabetic patients and their families that “should be available to the child, their family and ideally staff members from the child’s school” (O’Riordan et al 2015, p 24). Additionally, it was stated that “All education programmes delivered to children and young people, and their families, needs to be quality assured, and their delivery also needs to be independently quality assured, e.g. the Quality Institute for Self-Management Education (QISMET)” (O’Riordan et al 2015, p 24). This illustrates that during these four years (2012-
2016) of working on this project, some improvements in paediatric diabetes care have been made, but there is still much to be done to achieve the desired result.

The qualitative investigation helped to identify that the CHOICE structured educational programme (Chaney et al 2010) for children and adolescents with T1DM has started to run in four week sessions in one of the diabetes centres in Ireland with “nearly two hundred children attending”, this paediatric unit (MP28), but would only have places for “twenty four children at the end” of each year (MP28). A parent (Parent24) highlighted that the programme is accessible mainly for those families who would like to use CSII with insulin pumps (Section 5.2.1.2). Consequently, families with children older than 5 years of age who have not decided whether an insulin pump will match their child’s needs could not get access to revised knowledge on paediatric diabetes care. In addition, the only identified educational materials for young patients were the ‘Pete the Pancreas’ booklet along with some “written materials” (MP28) that were defined as “almost adult type” (MP28). The current educational practices are “very much directed at their parents”, they have not been “tailored” accordingly to the needs of the young patients (MP28), and this could be seen as a reason for the lack of educational resources for children with T1DM. Moreover, the results indicated a shortage of such resources in three different contexts (Section 5.2.1.2), they are 1) explained by the families - these materials have to support children and parents in use at various settings, 2) discussed by the dietitian - these resources need to facilitate the nutritional education for children and 3) described for the CHOICE programme - the need of more child-friendly visual materials and models “that kids can do more hands on” (MP29).

The study was more concerned with the problems experienced by the affected families instead of the challenges observed by the medical professionals providing care. The findings enabled the exploration of the role of technology in supporting diabetes education for newly diagnosed children and their families (Section 5.2.1.4). Later, the need for new tools supporting these educational practices was confirmed in the evaluation of the eBook prototypes (Session 5, May 2015), indicating that the choice made of the design direction was correct. The same childish book ‘Pete the Pancreas’ was given to a 13 year old newly diagnosed child (T1DC26) for her education in the hospital (Section 5.5.2.2). This could be taken as evidence that since
the start of this project, nothing has changed with respect to education; new educational materials for young patients with T1DM have not been developed and used to facilitate this process.

All the findings discussed in Section 2.2.3 and Section 5.2.1 helped 1) to display the limitations in care provided for families and the current rationale in paediatric management practices, 2) to identify the role of technology in supporting paediatric diabetes education, and 3) to describe product functionality and features. However, in the context of this research, the eBook should be considered to be an instrument to explore a series of design activities applying participatory approach with children with T1DM and their parents (Section 1.4).

6.3 Design Intervention Supporting Everyday Life of Children with T1DM and their Parents

This piece suggests some of the evidence that emerged in the empirical data facilitating the answer of the second sub-question posed in the study.

RQ 2: How to design an intervention that would better resonate with their perspective and the practicalities of their everyday life?

The findings 1) outline the roles of healthy children and those with diabetes in design when developing educational interactive technology for newly diagnosed children (Section 6.3.1) and 2) illustrate how participant’s input (i.e. young individuals with T1DM and their parents) in performing the UCD impacted the quality of produced eBook prototypes (Section 6.3.2).

6.3.1 Roles of Participants in Design

As stated, by applying the UCD to design an educational IT in this study two groups of participants have been involved 1) diabetic children and their parents/guardians as “design partners” and 2) healthy children as “informants”. The children were classified as experts, having a certain level of expertise obtained by “living with diabetes” (applying CI) and as experts on “being a healthy child” (using ID) (Druin 2002; Scaife et al 1997; Tsvyatkova and Storni 2015a; Tsvyatkova and Storni 2015b). The need to involve healthy children in this research came from the design of the eBook i.e. to help newly diagnosed children with T1DM become aware and be
informed about this chronic condition (Section 5.3 and Section 5.5). Similarly to the healthy children, the new patients may not have information about the causes of the illness along with its self-management practices. As shown in Section 3.5.1, ID supports children’s participation to inform the designer about their knowledge in some particular field (Druin, 2002; Guha et al 2012; Scaife et al 1997), for example to learn more about their language, their experience of the world or current technologies. Bringing children into the design process for “having a dialogue” to “provide feedback to adults” (Guha et al 2012, p 16), they were involved in the design and evaluation steps of UCD. The generated data throughout the design stage (Section 5.3.2 and Section 5.3.4) was used for developing child-personas (Section 5.4.2.3) and a starting point from which the educational context of the eBook narratives/prototypes have been constructed and built (Section 5.4.2.4 and Section 5.4.2.5). In the evaluation (Section 5.5.3), the healthy individuals helped discern whether the complexity of the eBook’s content, when integrated into an interactive story, would be at an appropriate comprehension level for the children. Playing the role of design partners, the contribution of children with diabetes was on “elaboration” (Druin, 2002; Guha et al 2012); their participation and input in each phase of the UCD was significant for the IT design for two reasons. Firstly, they described some of the challenges experienced in managing T1DM that helped 1) to recognize the context of technology intervention – an educational eBook and 2) to carefully consider and select design activities to support participants’ involvement in the technology development (Section 5.2.1.4). Secondly, their subsequent participation in UCD further explored paediatric diabetes care by providing more insight on various issues facilitating the development of the eBook educational content, i.e. to identify in detail the education in hospital and diabetes management in different settings (Section 5.2 and Section 5.3.2), to illustrate feelings and questions experienced during initial diagnosis (Section 5.4.1.2) and to reflect on suggested prototypes considering the diverse opinions of parents and children with T1DM about the educational stories (Section 5.5.2.2).

I’m using some examples taken from the empirical data to show the contribution of these two groups based on their dissimilar roles in the eBook design by illustrating the need for their involvement and participation. As discussed in Section 3.5, healthy
children helped to design system SISOM for young patients (7–12 years) with cancer (Ruland et al 2008). The authors reported that these healthy individuals experienced difficulties to “grasp the context in full” and act as real users, because the “personal experience may be an important factor for valuable design contributions” (Ruland et al 2008, p 634). These results raised doubts concerning their participation in participatory design as “proxies”, because for children it was difficult to “conceptualize” the idea of being sick with a serious illness as cancer, hence not all “of the children’s ideas were therefore, feasible” (Ruland et al 2008, p 634). This statement partly corresponds to the findings emerging from the data working with healthy children and those with diabetes, it is crucial to emphasise that the healthy individuals participated as “informants” not trying to “serve as proxies in participatory design and evaluations” (Ruland et al 2008, p 634). As a result, in the design phase they helped the designer to identify their experience of “being a healthy child”, their involvement clarified what children know (or don’t) about the digestive system and human internal organs, healthy food, questions when meeting a doctor, etc. defining attributes that will be similar to newly diagnosed children (Tsvyatkova and Storni 2015a; Tsvyatkova and Storni 2015b). In evaluating the eBook stories, their feedback was primarily pointing out the text and images that they found difficult to understand, indicating the parts in the narratives that would also be difficult for newly diagnosed children. Children were honest in showing their comprehension of educational context; they gave some suggestions for its improvement. For example, based on his personal experience with giving blood in the hospital (not related with diabetes) one of the participants in the Evaluation Session 8 used a metaphor describing the lancet as a “cylinder” (Section 5.5.3.2). The boy (HC13) was very confident in explaining the lancet functions in using the glucometer - “prick the finger for sample and take blood“. In all sessions, the children developed an idea related to the topic diabetes (i.e. “Can I at least have 1 treat?” (HC16, Evaluation Session 10). This would be added to the dialogue between the protagonists when they discuss diabetes treatment (Section 5.6.3.3). In assessing the paper prototype, the collected data in Evaluation Session 7 shows that not all ideas suggested improving the narrative (Section 5.5.3.2) were practical and fitted for the educational context of the story. This confirms that having knowledge and experience based on their life as a “healthy child”, their participation as informants
could only be on this expertise; they cannot replace diabetic children by taking their role in the design process. In contrast, the young participants with diabetes felt very confident explaining their individual experience accumulated through dealing with daily demands and various challenges triggered by the condition. When they developed individual stories for the eBook educational content i.e. characters, dialogue, settings, challenges, etc., they actually communicated their expertise influenced by living with diabetes. These various contributions in design reaffirmed the need, of both groups of young individuals, for developing the eBook for newly diagnosed children with T1DM.

When discussing the BRIDGE method (Section 3.5.1), Iversen and Brodersen (2008) stated that young participants gain knowledge and experience by living with meaningful socio-cultural practices, they become experts in their everyday lives, hence these practices “can and should” be considered as a starting point in design (p 86). This enables individuals to act as “design partners” and to make important decisions in the design process by facilitating their equality with any other stakeholders. Consequently, in this study developing technology for young patients with T1DM, only diabetic children could be taken as “design partners”, because they are living with different meaningful socio-cultural practices (having an illness) and their contribution to design was based on these practices (caring for diabetes). Therefore, their participation was as “authentic stakeholders” and their practices were taken as a starting point when selecting the purpose of IT and design activities that acknowledged their contribution. The selected design interventions assisted the communication of values between designer and children, enabled the legitimate access to their practices supporting mutual learning and understanding. In the same way, the aim of technology is to support newly diagnosed children that may not have experience with diabetes. Before diagnosis these children have lived with socio-cultural practices similar to the healthy participants involved in this study, and this also could be considered as a starting point for the design. Consequently, this raises a new question whether the participation of healthy children based on their experience, which is similar to the newly diagnosed children with diabetes, was not as an “authentic stakeholders”. Can we say that in this particular study, both groups of participants (i.e. healthy and with diabetes) have participated in the design process as
“design partners” based on their everyday lives by living with different meaningful socio-cultural practices, so as expert their decisions taken will be on these practices? This strongly indicates the need of rethinking the roles of involved children in design based on the purpose of IT when developing products (supportive tools) for newly diagnosed young patients with chronic diseases. With the above statement, particularly for supporting both groups of children as “design partners”, careful consideration in selecting a design intervention is strongly required, because this could enable children to articulate and express these different practices.

6.3.2 Quality of the eBook Prototypes

Following the basic four steps in UCD i.e. understanding users’ needs, design, prototyping and evaluation throughout the entire development process, as well as incorporating PD, CI and ID for involving participants in design, this approach enabled me to obtain information directly from the potential users. My role as a designer was to facilitate the process by involving affected families in the design to explore the complex design space and then, based on the findings, to suggest numerous initial ideas by developing different fidelity prototypes. Participants’ input in the entire UCD process was crucial for the development of the eBook; the ideas generated were analysed, synthesised and integrated into the storyline content, trying to build an interactive technology that could better correspond to the users’ criteria of educational technology design.

The initial findings discussed in Section 6.2.1 and Section 6.2.2, i.e. the shortage of educational resources and the sensitivity of children about their diabetes after the diagnosis, influenced the choice of technology – an interactive eBook. This tool is not yet fully explored in supporting paediatric diabetes education (Section 2.3.2). Moreover, the technology needs to suggest interactive activities with a pleasant context that tries to relax users, to create a positive and joyful experience, to spark curiosity and encourage exploration of the topic, and to motivate users to interact with the product. In addition, supported by a combination of images, animations, texts, etc., the content of the eBook story was broken down into a series of smaller narratives, helping to explain diabetes self-management in different scenarios by proposing valuable information on the subject to the young users.
Chapter 5 discusses the whole process of the IT design, here I will not talk about each phase of the UCD, but rather show the results emerged from the evaluation as they illustrate a reflection on the quality of the eBook prototypes. The analysis in Section 5.5.2.2 indicated that participatory approach suggested promising results in developing educational technologies that correspond to the users’ needs and criteria. Most diabetic children and their parents who assessed both eBook stories (i.e. paper and digital) found the proposed ideas as nice and child-friendly, designed to evoke a positive experience in young users. The narratives were found to be funny, beautifully illustrated, providing important information on T1DM; they kept the interest levels high by giving some details on medical technology used in diabetes, by portraying a fantasy adventure - travelling into the human body, describing the achievements of celebrities with diabetes, etc. The children expressed their positive opinion on the prototypes; they believed that the new interactive stories in the eBook explained better type 1 diabetes, and the use of similar materials at the time of their diagnosis could have greatly helped their training. The questions and answers shown in the dialogue between the main characters in the story discussing diabetes treatment (described by the participants in the prototyping stage, Section 5.4.1.2) have been recognized by the young evaluators as their own questions that had arisen after finding out that they had diabetes, which had not been discussed by educators in the hospital and those questions were not covered in ‘Pete the Pancreas’. It was highlighted that this medium (i.e. the interactive eBook) supports education with some features inherent to digital technologies as animations, sounds, games, etc. They could support users to better grasp diabetes and its treatment because of the interaction, fun and visualisation of some processes, instead of the normal book that offers only colouring pages, pictures and text. In relation to this issue, Iversen and Dindler (2013) highlighted that technology developed to support the intellectually disabled children will be seen as successful only if participants (i.e. children, parents, caregivers, etc.) “are able to recognise their newfound values in their everyday life” (p 27). Of course, the evaluated eBook was only a prototype, during these assessment activities many new recommendations have been made, facilitating the design of next level of fidelity artefacts, but again this exemplifies the important role of children with T1DM and their parents in design and their future participation in
repeating the UCD process. This indicates the fundamental role of participants in the design process when developing IT to support paediatric diabetes practices.

Discussing the types of contributions made involving young participants in design, Yarosh and her colleagues (2011) examined various long papers in IDC between 2002 and 2010. They suggested that designers could work “more closely” with parents and teachers when developing technology for children because this could “customize a given technology to better meet a child’s needs” (Yarosh et al 2011, p 142-144). The design of eBook was a result of close work with parents, children and medical professionals. The outcomes indicated that the participation of both parents and their children with diabetes was important for technology development and design. Caregivers and individuals who have diabetes have different experience with paediatric diabetes care that complement each other, thus making contributions to the quality of design. For instance, the analysed data illustrated that children and parents had dissimilar training and education on T1DM (in the hospital and later in their homes), questions about diabetes management, expectations for proper education based on their different responsibilities in performing self-care tasks and the immaturity of the young individuals i.e. being children. Additionally in the evaluations (Section 5.5.2.2), the parents and children assessed the prototypes based on their different standards for educational context. Playing the roles of educators, caregivers and parents, the adults’ requirements were prompted by their needs for appropriate educational materials; hence this approach facilitated the design of technology having high standards. Their involvement and participation was imperative for this study, for building a holistic investigation and exploration of paediatric diabetes self-management in domestic settings which influenced the research process in terms of choosing design activities and tools for enriching the data for design.

By including new participants in different steps of the UCD it assisted the generation of rich data important for the quality of the IT. In the prototyping phase (i.e. T1DC16, T1DC17, T1DC18, T1DC19, T1DC20, T1DC21 and T1DC22) newly recruited children produced seven different prototypes, their ideas were essential to reach a design with high educational standards (Section 5.4.1). Each story was carefully analysed, the collected ideas were integrated in the digital narrative.
prototype. In the evaluation stage the newly recruited parents and children (i.e. Parent24&T1DC24, Parent25&T1DC25 and Parent26&T1DC26) assessed the initial prototypes having no input in the design and prototyping phases (Section 5.6.2). For instance, when testing the digital story Parent24 was very critical as the storyline shows traditional family structure (i.e. mother, father, siblings, etc.). She believed that this would not be relevant to those children living in different settings. The sequence illustrating the process of initial diagnosis, i.e. visit the GP and then the hospitalization was also detected by her as a limitation, because it does not explain the nuances of a patient’s journey in the initial diagnosis; the young users may not recognize themselves in the story (Section 5.5.2.2). Moreover, it was found that parents were strongly focused on the text whilst the children were seeking the fun element as an addition (Section 5.5.2.2). Such factors reflect new directions and targets in the design of technology, and perhaps most importantly, getting valuable feedback regarding all functionality of proposed early designed products. Consequently, to enhance the success and quality of educational IT for newly diagnosed children, the participatory approach with young patients with T1DM and their parents is highly required.

6.4 Practicalities of Designer in Exploring Participatory Approach with Children and Parents

The following five sections discuss different aspects linking with the last third sub-question addressed in this study.

RQ 3: How to design an interactive technology for/with children with diabetes and their parents? What are the issues experienced by designers working with this group of users? What combination of methodological strategies should be employed to overcome/avoid these issues when designing solutions for self-care practice of chronic paediatric conditions? Are co-design/participatory approaches adequate for this challenge? What combination of design principles and guidelines should be employed when developing interactive technologies that aim to facilitate diabetes education in newly diagnosed children with T1DM and their families?

Concerned with the actual design process WITH participants, the first section illustrates the results of applying UCD and participatory approaches by reflecting on the methods, techniques and tools explored in the study along with other issues that emerged during the process (Section 6.4.1). Regarding the FOR in the main question,
the second part suggests a series of requirements and an abstract model for developing educational IT by involving children with T1DM and their parents/guardians in the design process (Section 6.4.2).

6.4.1 Exploring Participatory Approach WITH Children and Parents in Developing an Educational IT

This part shows the issues and challenges experienced in organising UCD process (Section 6.4.1.1), it illustrates the results of applying DP, collaborative storytelling and layered elaboration (Section 6.4.1.2), details the formation of new roles in dealing with the group dynamics (Section 6.4.1.3), clarifies the obstacles and problems that were not solved (Section 6.4.1.4), and formulates other contributions in exploring methods of affinity diagrams, personas, scenarios and storyboards supporting the design work in building the prototypes (Section 6.4.1.5). Finally based on all discussed findings, Section 6.4.1.6 shows the benefits of participatory approach with children with T1DM and their parents when developing IT aiming to support paediatric diabetes practices.

6.4.1.1 Issues Experienced by Working with this Group of Users

This segment is divided into two pieces showing 1) the numerous challenges experienced in the recruiting process and 2) the variety of obstacles and complications that emerged as a result of scheduling and conducting various design activities with participants in settings outside university lab/building.

Recruiting process

Restricted access to the national organizations and groups supporting individuals with diabetes i.e. Diabetes Ireland, Facebook parent support groups, etc. (Section 4.6) challenged the recruitment of participants, I discuss three examples to illustrate my personal experience with the issue. Example one shows the long process of ethical approval for getting access to the members (i.e. parents and children) in Diabetes Ireland, which also requires applying as a volunteer to the organization, a process that proved to be quite lengthy (almost a year). This challenged research project work plan, which motivated me to look for and try various recruitment interventions (i.e. sending emails to the university mailing list, using flyers, publishing a website for my research, etc. (Section 4.6) in order to find participants
outside of these organizations. My efforts were successful; during these eleven months of waiting to get access to DI members, this approach helped conduct 14 interviews, perform the first iteration of DPs (Section 5.2.2) and the first storytelling session by applying the CI (Section 5.3.2). Diabetes Ireland was helpful in conducting this research however due to the Child Care (Special Care) Regulations 2004\textsuperscript{66}, it requires that all volunteers working with children obtain a Garda vetting statement – a process extending over ten months. Nonetheless, these difficulties should not be seen as a barrier to the involvement of children with T1DM in IT design.

The second example illustrates my inability to get access to the newly-formed parent support group T1 Diabetes – Parents Get-Together. Unfortunately, my attempts to attend these informal meetings were unsuccessful, this group was closed to non-diabetics or those without relatives with T1DM (Figure 158). My presence was considered “intrusive”, impeding the free discussions on various issues and problems experienced by families, causing potential barriers for the arrangement of new meetings. In fact, the organiser of these meetings was very supportive, and she and her child have participated in most of the activities organised in developing the eBook. Her emails (Figure 158) were not prompted by the reluctance to help, but rather to avoid future problems with the formation of the group.

\texttt{From: (name)}
\texttt{Sent: Monday, February 25, 2013 9:14 AM}
\texttt{To: Damyanka.Tsvyatkova}
\texttt{Subject: RE: T1 Diabetes Parents Get-Together}

Good morning Damyanka,

The get-together I am proposing for March 20\textsuperscript{th} is really just for parents at the moment as we have no support group in (name of the town) and I am trying to get something up and running so I am not involving the Diabetes Federation either at the moment. It’ll just be a very informal cup of tea and a chat. If you want to give me details of what you are doing I can give to parents on the night and if I can help you out myself, my daughter has type 1 diabetes 3 years now. I am working here on campus.

Regards

\texttt{From: (name)}
\texttt{Sent: Tuesday, May 21, 2013 2:30 PM}
\texttt{To: Damyanka.Tsvyatkova}
\texttt{Subject: RE: T1 Diabetes Parents Get-Together}

Hi Damyanka,

The get-together itself is really only for parents Damyanka and going on our first meeting I got the impression that’s the way parents wanted it but I will certainly remind them of your project and the work you are doing, is that ok with you? I trust you understand where I’m coming from. Likewise, if I can be of any other assistance to you, please let me know.

(name)

Therefore, the ethical obligations and limited access to specific groups of individuals falling under the category of “vulnerable participants” was a difficult approach. Trying other options did not always guarantee success, but they should be considered at the start of the research, particularly from those researchers/scientists who are planning to include children with chronic illnesses and their families in their studies.

The last example is focused on the trust and mutual understanding that has been built solely on the personal experience with the illness. The main question when meeting people and talking about this research was: “Why have you decided to work with diabetic children if you don’t have a child with diabetes?” Having no relevant experience with my child could create complications to “step into the parent’s shoes” when trying to explore and understand the issues and problems around paediatric diabetes self-care management in “real-life” settings. Similar findings can be found where parents claimed that doctors cannot understand their needs because they have no personal experience with diabetes. Difficulties to build trust between designer and parents have been qualified likewise to the patient-doctor relationship described by Lowes et al (2015) “Many children, adolescents and carers believed that, if health professionals did not live with T1D, they could not possibly understand what it is like” (p 58).

**Scheduling events process**

Very little is known about how to design, conduct and run design activities with children with type 1 diabetes and their families in an environment different from a University Building (or design lab). Some challenges have emerged from scheduling and organising various meetings and workshops with the participants. As discussed (Section 5.2.1.1 and Section 5.4.2.2), most of the interviewed participants described that parental responsibilities were divided up. Mothers are usually those who are
caring for the children and household while their husbands/spouses are responsible for family income “my husband isn't around much because he's farming and I'd be the one who'd end up weighing it” (Parent10) and “I know all parents have to work but I have no family around, I have nobody else who could be there with her... supporting the family I am at home as a carer” (Parent2). The unpredictable nature of the illness, responsibilities and complex daily regimen impact the everyday life of the family, many parents struggled to find time to meet. As a result, there were several occasions in which participants cancelled our meetings for interviews and evaluation sessions as their children got sick (Figure 159), this created some constraints in conducting the planned activities. Rescheduling the meetings is not an option because the treatment of the sick child may take longer, may influence the emotional state and the willingness to participate.

From: (name)
Sent: Sunday, December 02, 2012 8:37 PM
To: Damyanka.Tsvyatкова
Subject: Re: meeting tomorrow

Damyanka,

I am so sorry I cannot come to Dublin tomorrow my little boy (child’s name) is really sick. We are only home from hospital with him. He had a severe temp and passed out with it. Frightened the life out of me I thought he stopped breathing. He is fine though just a bad infection. I cannot leave him with anyone I need to be home with him. I’m so sorry I only remembered you when I got the email. Really sorry and if you are up again I promise I can meet you.

Name of the parent

Figure 159: Cancelling interview

In this study, the workshop sessions and meetings with participants living in different counties were carried out in different venues creating additional difficulties. To feel more secure and relaxed, the parents chose the place and time for our interviews/sessions. I had two reasons to use this approach i.e. 1) to support individuals to focus only on our work (i.e. the distractions at home settings) and 2) to help to bridge the distance by creating feelings of informal meetings by sharing thoughts, feelings, ideas, etc. This analysis promised results; it increased the number of participants in the study and collection of empirical data for the eBook design. Unfortunately, this manner of work also had its weaknesses because I had to deal with various issues that needed to be considered for organising, managing and
conducting an effective investigation in the field. In these new settings, the limitations in using camera stands, appropriate light and more free spaces created difficulties in using technologies such as video/audio recorders and digital cameras at the interviews/sessions. Carrying many bags with DP sets, various materials for planned activities, gifts for children, etc. have created some discomfort travelling to work with parents and children. Using the public transport services and timetables did not always fit my schedule and destinations which increased the cost of travel. Travelling was very time consuming, usually took a day to meet and work with one individual or family. Limited access to the Internet brought careful consideration when I developed the digital prototype for the evaluation process (Section 5.4.2.5).

As discussed in Section 3.5.2, some designers preferred to use less critical settings that could be considered as ethical e.g. the two-weeks summer camp in Germany - maXi research (Glasemann and Kanstrup 2008; Glasemann et al 2010; Glasemann and Kanstrup 2011). Similarly, having 2 years at my disposal with those Easter camps in Trabolgan, if I were to solely rely on them it would be impossible to do a full iteration of UCD with participants. Each camp lasted 3 days, once a year and I was only able to do 1 session per camp. Equally, this may create some constraints for the partaking of other volunteers who did not attend these activities organised by DI. Other issues and problems also appeared when I organised the entire UCD process which emerged during the collection of empirical data, applying different methods, techniques and tools that are discussed in Section 6.4.2 below.

6.4.1.2 Combination of Methodological Strategies Employed to Overcome/Avoid Challenges When Designing Solutions for Self-Care Practice of Chronic Paediatric Conditions

Seeking information about paediatric diabetes care from the perspective of parents and children by using the semi-structured interviews provoked emotional difficulties in participants (Section 5.2.1.2 and Section 5.2.1.3). Talking about diabetes created a level of discomfort in individuals, they felt sad, vocally expressed their emotion, varying speech tones, tearful eyes. For example one of the interviewed children (T1DC26) got very upset; her eyes were filled with tears when she was describing her stay in the hospital. She was very scared at the time of her diagnosis and talking about those first days provoked negative feelings. Many parents also experienced
sadness when they described various tough moments/challenges in dealing with diabetes.

“She had this fear of the hospitals and remembers her asking "Am I going to die?" This was her first fear and then ...(crying) trying to explain her that like...(crying) I remember her asking me “Am I gonna have this to the rest of my life mummy?”...(crying) it was very hard to answer because...(crying) sorry.” (Parent4)

“(crying) Every day was hard. You would be worried about her because she was never in the hospital before. In her whole life she was never in the hospital. It was horrible to see my child being sick all the time. (crying)” (Parent5)

As a result, this affected 1) the selection of co-design activities supporting participants’ involvement in the eBook design (Chapter 4), 2) the low number of diabetic children willing to participate (Section 5.3.1) and 3) the creation of new roles and tactics to deal with negative emotions if needed (Section 5.3.5 and Section 5.4.1.3).

My first important role as a designer was to figure out how to organise the whole design process in a way to actively involve participants in the design. I primarily focused on identifying and selecting design activities that are suitable for applying in a complex and sensitive context facilitating participation in the whole UCD; this was an essential strategy to increase users’ participation. These design interventions needed 1) to be appropriate for children by having clear and understandable instructions to use and 2) to be able to adapt and facilitate the work with young patients with T1DM. In addition, as powerful tools they have to trigger discussions, provoke ideas elaboration, support communication and active participation, be appealing, motivating and engaging. As I had to travel to engage with the participants these activities had to be portable and easy to use in different settings. Therefore, in trying to implement a safe and supportive process, all these issues described above, along with the challenges discussed in Section 6.4.1 created extra levels of difficulties working with participants as design partners.
DP (Moser et al 2011; Iversen and Nielsen 2003; Wyeth and Diercke 2006) (Section 5.2.2), collaborative storytelling (Alborzi et al 2000; Muller and Druin 2009; Quesenbery and Brooks 2010) (Section 5.3 and Section 5.4.1) and layered elaboration (Walsh et al 2010) (Section 5.5) were selected as activities to explore the eBook development. Both techniques are discussed below illustrating their benefits in supporting both groups of children – healthy and with diabetes together with their guardians in design.

**Design Probes**

Aiming to adapt probe activities that could improve young users’ engagement in completing all suggested materials in the box, DPs were applied in two iterations (Section 5.2.2). Other reasons to use this method were 1) to avoid and minimize ethical challenges in working with children (parental supervision is required), 2) to collect data unobtrusively by applying ethnography in sensitive settings (home, school, etc.) and 3) to deal with negative emotions generated by the illness (Tsvyatkova and Storni 2014b). Based on self-documentation practices DP method was adjusted to collect concrete data about daily paediatric diabetes management getting access to sensitive domains as domestic environments. Carefully adapted, the probes have facilitated communication enabling dialogue between users and the designer in helping to gather contextual knowledge and to build deeper understanding of problems and issues experienced by children and their caregivers. The playful activities in the set have been used as data collecting instruments by suggesting the production and modification of artefacts that made feelings, thoughts, knowledge, etc. visible to the designer. Comparing the results from this study with the results discussed by Wyeth and Diercke (2006) (i.e. applying DP with healthy children in educational context), some similarities and differences have been identified. For example, Wyeth and Diercke (2006) had similar activities in their set as Technology Collage (i.e. creating a collage by using images of “technology that looks fun”), Gadget Design (i.e. designing gadgets to support the learning process at school), Science Toy (i.e. designing a toy that will help children understand science) and My Journal (i.e. for recordings of users’ ideas and thoughts from school). Based on eight collected sets, the authors highlighted that the Gadget Design had the highest responses (N=7), less popular were the Science Toy (N=2) and My Journal
(N=1), no interest was observed with the Technology Collage (N=0). In this study, the analysed data of the returned five sets in the first iteration DPs illustrated that the favourite activities for children with T1DM were Design Collage/Poster (N=5), Technology Gadget design (N=4) and Superhero and a story of his/her power (N=4), less popular were a Disposable camera (N=3) and Send a Postcard (N=3). Low interest was shown by the children with diabetes to play with the materials for the Kids diary (N=2) and Design your own Recipe book (N=1). This demonstrates the contrast of children’s interest in probes i.e. Design Collage/Poster (N=5) and Technology Collage (N=0), as well as a Superhero and the story of his/her power (N=4) and Science Toy (N=2). The children with diabetes liked to develop their Collage/Poster for the imaginary World Diabetes Day and write a story about superhero and his powers. In contrast healthy children did not present an interest in making their Technology Collage. Comparable results were found for the materials supporting Gadget Design (N=7), and Technology Gadget design (N=4), My Journal (N=1) and Kids diary (N=2), they indicate that young individuals liked to design their own technologies but did not express willingness to keep a diary.

The authors did not specify the materials used to design their probes, but they highlighted that “children became more engaged in activities which required them to be creative and constructive” (Wyeth and Diercke 2006, p 386). The results from this study partly confirmed that statement, a wide variety of arts and craft materials (Section 5.2.2.2) have been used for the design of the probes (i.e. modelling clay, foam blocks, pipe cleaners, A1 white sheets of paper, glue, scissors, water paint, colouring pencils, nice diary templates called “circle of activities”, beautiful illustrated recipe book templates etc.) suggesting that young users have fun whilst using the objects. Nevertheless, they showed less interest on working with the probes Kids diary and Design your own Recipe book. This could be explained with the constant journaling of insulin, portions and carbs important for diabetes care along with the diabetic dietary restrictions imposed on them. It highlights that it is not related to the probe materials but rather with the personal experience with the illness.

Additionally, Wyeth and Diercke (2006) discussed the number of probes in the set i.e. “cultural probe pack which includes five or six self contained activities” (p 388). Similarly, the results based on the second iteration of DP indicated that a small
number of activities in the box (between 3 and 5) and having a longer period for using the probes (about two months) may increase children’s involvement and engagement in completing the probes materials (Section 5.2.2.6). Children with T1DM need more time to play with probes as they have other very important responsibilities i.e. to manage their chronic condition. Unfortunately, the health status of the child could also be a factor in working with the materials; two different cases (e.g. gastroenteritis and thyroid gland) support this statement. A mother (Parent7&T1DC7) informed me of the reason of low response (Figure 160). At the time of our meeting, one of the parents (Parent10) felt very concerned; she shared that the medical professionals did not take into consideration the complaints and health status of her daughter caused by the thyroid gland (more common in people with diabetes). She had written a complaint to the Medical Council for the clinical negligence. The young individual (T1DC10) felt very tired, and therefore she only designed her poster (Section 5.2.2.4).

From: (name)
Sent: Monday, 10, 2013 9:29 AM
To: Damyanka.Tsvyatkova
Subject: Re: Design Probes

Hi Damyanka,

Thank you for getting in touch. Unfortunately (child name) hasn't been very well since her hospital visit. She picked up a bad stomach bug and is still just recovering. She has done some work on the project which I will return to you hopefully tomorrow or Wednesday. We are back in hospital next week in Dublin so I feel she will probably not get much more done. I hope this is alright. I will let you know when I have all the items together and we can meet up then.

Thanks a lot
Parent7

Figure 160: Returning DP

The disposable camera probe was identified as an old fashioned technology for taking pictures, it could be replaced with a digital one, because it provides fewer restrictions on the number of photos and children often use the digital cameras on their mobile phones. Regarding the use of digital cameras and Dictaphones integrated into the mobile phones, Iversen and Nielsen (2003) discovered that these digital cultural probes “motivated spontaneous use by the children because mobile phones are key artifacts in the children’s lives and thus well-known and easily” and “this spontaneous use of the probes is highly beneficial to design because it provides
us with insight in children’s informal practice, which combined with in-depth interviews offer a rich collection of cultural material” (p 1).

The follow-up interviews and focus groups used to collect the DP sets helped to understand children’s ideas and parents’ point of view when using the probes. A therapeutic effect while working with these materials was observed and reported by parents, hence this increased the need of similar tools that are not potentially harmful but rather help in reducing the stress, improving mood, enhancing communication and sharing of ideas. Arranging time to collect produced DP materials was problematic due the intricacies of caring for a child with diabetes. Described above, benefits indicated that the DP method had been successfully used as an alternative solution facilitating users to take an active role even with their busy lives, provoked their inspirational responses and fostered participants’ creativity to inspire the design of the eBook.

Collaborative Storytelling

Storytelling is one of the techniques used in the tailored UCD framework. It is suggested by Årsand and Demiris (2008) but it was not explored with children with T1DM (Section 3.5). Muller and Druin (2009) discussed “story-collecting” and “story-telling” as a key element for building the third spaces and for hybridity in PD, because they “require a kind of third space in which to occur” (p 27). In design, the stories have four main characteristics, they may 1) activate conversations and feedback, 2) support the user to describe his/her experience, explore opportunities for design and technology specification and services, 3) facilitate researcher and user for presenting concepts and technology functionality and 4) use “as proxies for real user” (Muller and Druin 2009, p 25). Storytelling is also used in CBT, showing promising results in helping young individuals with post-traumatic stress disorder, generalized anxiety disorder, etc. (Section 4.3). Burns (2004) highlighted that the stories are most effective when they are “developed collaboratively with a child they have more therapeutic impact than if they are seen to be imposed by the therapist, because the child is an active participant in the creation of the story, the resolution of the problem, and the attainment of the outcome” (Burns 2004, p 42). Collaborative storytelling is widely used in CCI (Section 3.3, Section 3.4 and Section
4.3). Druin (1999; 2002) has explained its benefits when children play the role of design partners in CI. The benefits discussed above highly influenced my choice in applying a narrative approach to diabetes education by building stories in the eBook and using it as a communication tool in the design (Section 5.3) and prototyping stages (Section 5.4.1) of UCD with both groups of participants. Taking into consideration that ‘idea elaboration’ is the main objective in the design process (Alborzi et al 2000; Druin, 2002; Guha et al 2012), the first sessions was carried out with a family who have experience with diabetes (Section 5.3.2). Starting from the first day of the diagnosis, the discussion with participants revolved around paediatric diabetes management. Playing the role of design partners by applying PD and CI at which stage the collaborative storytelling served as a springboard 1) to new ideas detailing some of the scenarios in which diabetes management occurs, 2) to envision the educational context of design and 3) to develop materials facilitating exploration of those context in the next two design sessions with healthy children. Having this particular approach i.e. letting participants develop their own stories related to their experience has had several benefits. The storytelling has created this third space for sharing ideas for negotiation, it has increased communication effectively by generating valuable information on self-management practices, it has improved the dialogue and understanding on the chronic nature of diabetes, and it has furthered the education needed for the decision-making process in dealing with everyday challenges (Section 5.3.2). The drawings included during the collaborative storytelling helped to convey the meanings of the narrative. Through the process of developing scenarios and storyboards the engagement of the storyteller increased, they suggested visualisation of participants’ ideas, were enabled to describe insights, situations and environments, and thereby helped define the functionality and content of the eBook which resonates with the users’ needs. The small fragments of story assisted the child to identify and articulate the main issues and goals in daily diabetes management and to evolve the narrative through the design process. Therefore, the collaborative storytelling in the first design session has been extremely helpful for the design of the eBook and the following co-design activities with healthy children.

The participants, healthy informants, needed direction facilitating the storytelling process during the second and third sessions. Involving children (ages 7-11 years of
age) as design partners (i.e. CI) in ‘StoryRooms’ research, Alborzi et al. (2000) emphasised that the tools used in “storytelling can also be a critical part”, they developed an “authoring tool” - a “story-starter method” with “story props” helping children to start create their own narratives (p 59-101). Considering this statement, the collaborative storytelling process in this study was supported by two sets of storytelling cards and other helpful materials such as modelling clay, an outline of the human body, A4 white paper, colouring pencils, etc. It enabled healthy participants to develop two stories ‘Traveling through the human body’ and ‘Superhero is sick’ and to explore the tool in ID (Section 5.3.2 and 5.3.3).

During the second session (i.e. ‘Traveling through the human body’), in developing the main characters, dialogues, settings, etc. it was identified that children had no information on the pancreas and its functions in the human body. They knew what healthy food is but they had difficulties explaining why it is healthy. Producing figurines and developing figures for the story, the plasticine as a material suggested fun experiences for participants, increased the collective work between children and the sharing of concepts. For example, when children were asked to generate ideas to describe the characters in the story, some of the young participants felt shy to share their concepts, but when they started to develop the figurines each child wanted to participate by making different parts of an object and then to assemble them into a figure. Handing out the parts and other materials as buttons, feathers, etc. to decorate the figures by adding details had engaged children with the process and improved dialogue in discussing different options for the modelling object. Additionally, by arranging the human organs into the outline of the human body the participants explored many variations when trying to find the position of the pancreas, revealing the shortage of knowledge on the subject. Other arts and crafts materials used for evolving and building the second narrative (i.e. ‘Superhero is sick’) also supported informants’ imagination and storytelling process. It was observed that describing the questions and answers between the main characters superwoman Anastasia and Dr. Jenny most of the children suggested dialogue based on their experience with different health issues that did not link to diabetes. The arts and crafts materials supported children’s inspiration; they created colourful pictures of the main characters in detailed settings. Playing and sorting the images of different foodstuffs
facilitated the discussion on healthy and un-healthy categories of food. The storytelling card sets, in combination with other materials, were identified as helpful tools for developing stories with children-informants; they triggered creativity, increased communication and engagement with designed activities. As discussed, the aim to navigate participants to develop the storylines, the questions in the story starters were concrete instead of abstract. It was indicated that the participants needed more time to work with the supportive materials. Seven story starters (i.e. questions) for one hour was difficult to elaborate on, less questions/prompts could allow more time for various discussions while building the narratives.

The collaborative storytelling could also be applied in the prototyping process (Druin 1999; Druin 2002; Muller and Druin 2009; Quesenbery and Brooks 2010) and the same story props can be used to develop and produce different story structures (Alborzi et al 2000). Considering the benefits of the storytelling cards in the design stage, the second set of cards (i.e. ‘Superhero is sick’) was reused for the prototyping process. The supported materials (i.e. A4 white pages with printed wireframes, colouring pencils, markers, dialogue boxes, etc. (Section 5.4.1.2)) were selected in a way to assist young individuals with T1DM as equal stakeholders while developing individual paper prototypes. During the session as a facilitator, I asked additional questions to stimulate and foster profound informal conversations on the dialogue between the main characters in the story, discussing the benefits of healthy eating, describing the guidelines in taking medication, etc. and prompting a creative response when children told their stories. Unfortunately, most of the young individuals displayed difficulties in partaking in discussions but each child created its own story based on the personal experience obtained during their initial diagnosis. The collaborative storytelling happens to have a therapeutic effect while the process of building prototypes occurs; the tool along with other materials facilitated children to non-verbally communicate their perspectives, the described ideas were extracted from their personal understanding and knowledge on the chronic condition. In the prototyping stage, the collaborative storytelling achieved similar results as in the design phase. Having an individual approach (some children do not like to talk about diabetes (Section 5.2.1.3)) by letting participants prototype personal stories seems to have a number of benefits. Firstly, it was observed as an explanatory style supporting
emotional expressions on a sensitive theme like diabetes by sharing difficult thoughts and feelings with texts and drawings making participants less distressed. Secondly, it enabled participants’ involvement by motivating them to get engaged with the activity which supported the generation and production of dialogue between protagonists by letting them add lots of details. Many of the questions and answers described by children in the dialogue were integrated in the digital prototype (Section 5.4.2.5) and as discussed in Section 6.3.2, during the evaluations they are recognized as valuable pieces of information suggested for the real user. This statement from the young evaluators with diabetes strongly confirmed the benefits of collaborative storytelling as a prototyping activity. Therefore, the results show that collaborative storytelling supports the design and prototyping process with informants and design partners effectively.

**Layered Elaboration**

As discussed in Section 3.4, the transparent sheets and markers in the layered elaboration were used to enable co-design asynchronously through an iterative process having for child participants aged between 7 and 11 years old (Guha et al 2012, Walsh et al 2010). Aiming to extend the existing concepts by adding new ideas from children “to design both a game about history and a prototype of an instructional game about energy conservation”, is a technique that evolved through the CI design process (Walsh et al 2010, p 1237). The transparent sheets cover the top of the original storyboards and participants can draw without destroying the original artefact. Overlaying the transparent sheets, designers could visualise, see and discuss the modifications suggested by different groups of children. The layered elaboration was not explored for the evaluation process nor suggested in the Årsand and Demiris (2008) framework. This technique was chosen for the evaluation stage, because it suggests portability (small size), easy use by children and parents, it is inexpensive, supports visibility of the text and images on the mock-up and digital version slides of the eBook and individuals can reflect on them without destroying the originals. Furthermore, it provides a quick visual representation of the suggestions made (Section 5.5.4). Additional materials such as stickers with dots in different colours and self-adhesive white labels together with the sets of questions have assisted the conversations to delve more deeply into the topic. By applying the
technique as a tool to support the assessment activities, two benefits were identified; it helped 1) to test both the mock-up and digital prototypes and 2) to produce visual feedback of various new ideas developed by the evaluators for each slide/page of the assessed artefacts. The layered elaboration technique supported both groups of participants (i.e. the young individuals with T1DM and their parents in PD and CI, and the healthy children in ID). However, the analysed data (from the evaluation with healthy children) had indicated contrary results. For instance, the parents and children felt free to write and draw their new suggestions and recommendations on the transparent layers reflecting on both prototypes. Through analysing the collected data it was found that the materials were used by the participants according to their own criterion i.e. children assessed the text and interactive features (by drawings, coloured dot stickers and written suggestions) as individuals who have diabetes while parents were more critical about the educational context (mostly by writing down ideas) being influenced by their roles as educators, carers and parents. However, playing the role of “informants” during the Evaluation Session, 7 healthy young individuals felt distracted from the technique. They were less focused on the evaluation of the prototypes, which was the main goal of their participation, instead using the materials to elaborate on various ideas (i.e. suggesting new images and features), then finding many to be unfeasible (Section 5.5.3.2). As stated (Section 5.5.3.1), these findings influenced the use of the technique when the reading and discussion of the stories with participants was finished. As a result, child-informants proposed fewer ideas, but were still meaningful. One limitation to the technique was discussed particularly when working with the digital prototype (Section 5.5.4) i.e. drawing or writing text on the transparent paper that overlies the tablet screen may activate some of the interactive features while children proposed their concepts. Fixing the errors may interrupt the creative process for a while.

Summary

From the above discussion, the results indicated that the applied Design Probes, collaborative storytelling and layered elaboration seem to be very helpful in supporting children with T1DM and their parents as “design partners”. The work of Årsand and Demiris (2008) could benefit by adding these tools to their UCD framework for designing patient-centric self-help technologies. The collaborative
storytelling indicated similar results because the design stage facilitated the involvement of healthy young individuals as “informants”. The layered elaboration also supported “informants”, after the educational context was clearly discussed and clarified by the children and designer. It is important to highlight that choosing design activities, that activate and stimulate appropriate self-expression in children with diabetes, helping them to regulate their feelings and emotions, could be seen as a key factor for co-design with these participants. The two-card sets designed, aiming to give a boost to the collaborative storytelling process, along with other helpful materials, supported children in a fun experience while developing and generating ideas, were also significant. As stated, some results have shown that the DPs and collaborative storytelling have therapeutic effects, helping children to successfully communicate their concepts and knowledge of diabetes non-verbally. These results confirmed Iversen and Dindler’s (2013) statement that PD with children is a dynamically divergent process in which the selection and use of appropriate tools in design is crucial, because they facilitate the negotiation and development of value building participatory epistemology.

Some final remarks; a question about children’s participation in the evaluation process based on their age emerged in the Section 5.5.1. Yarosh et al (2011) stated that involving children at different age groups would “expand the body of IDC work and provide avenues for new insight and innovation“(p 143). This was the reason to include individuals with T1DM between the ages of 5 to 15 in the evaluations, who are not belonging to the target age group of the users i.e. 8-12 years old. The youngest participants, a 6-year-old boy and a 5-year-old girl, participated together with their parents. During the assessments, they did not elaborate ideas because they did not fully grasp the meaning of the prototypes. While their parents were reading the stories, the children played with the artefacts, particularly interacting with the digital prototype. This generated valuable information that prompted new ideas regarding improvement the user interface. Therefore, I am arguing to apply the criteria and to involve only those children, in the design, who are entering the age group for which the IT is being designed because their input could benefit the quality of the product. The parents’ participation was desirable as they know the personality of their very young children. Children aged (10 and 13) were more active than their
parents in the sessions, whilst the 15 year old girl was more passive. Healthy children between 8 and 9 years of age were very supportive in the evaluation (Section 5.5.3.2), even with having slow reading speed, they had read the text, shared personal experience with some issues i.e. giving blood samples in the hospitals, displayed awareness of healthy food and the human body, etc. Consequently, age could be a factor suggesting very different degrees of engagement during the co-design.

6.4.1.3 The Dynamic Nature of Conducting Sessions

New designer roles have appeared to balance participation 1) to deal with some negative emotions (Section 5.3.2 and Section 5.4.1.2) if needed and 2) to stimulate active and equal involvement of all individuals (Section 5.3.3 and Section 5.3.4). The results indicated that designing with both groups of children (e.g. healthy and with diabetes) had some peculiarities related to their active involvement in the process. The facilitator/designer must be sensitive to the group dynamic while performing planned activates in the sessions. For example, the initial findings indicated (Section 5.2.1.2, Section 5.2.1.3 and Section 6.4.2) the delicateness of the topic, hence, during the design and prototyping activities with diabetic children, it was crucial to observe and detect participants’ feelings (if any) and their emotional state (if they become upset). My role as a designer was to detect the early signs of emotional upset such as facial expressions, voice changes, etc. and change the subject of discussion or take a break. While discussing the initial diagnosis in the first design session (Section 5.3.2), a child became sad, so I changed the topic by asking the participant to take a break, as an emotional regulation strategy. Additionally, having only one child during the session was observed as beneficial in dealing with emotions. In the prototyping session working with seven girls (Section 5.4.1.2) with T1DM, I needed to find another approach to deal with this issue by 1) asking children to prototype individual stories and 2) using the balance between the planned tasks. As discussed (Section 6.4.2.3), the symbolic language of drawings and text – non-verbal forms of generating and communicating ideas enabled the young children with diabetes to develop their individual story prototypes. The balance was achieved by exploring three different tasks related to the prototyping process: 1) reading and clarifying the questions used to build the story gradually, 2) the informal and friendly discussions of topics linked to the questions and 3) idea elaboration on the interactive elements.
(i.e. dragging, animations, sounds, etc.) that they could add for each scene/page. Choosing ethically secure settings for work with participants and constant adult supervision are required. Scheduling time for taking medication or snacks during the sessions is important for the health of the young participants. In contrast, when I worked with healthy children my role was to keep the balance of participation by managing participant’s attention to the tasks and by dealing with children’s shyness and timidity, whilst trying to actively involve all of the children in the process (Section 5.3.3, Section 5.3.4 and Section 5.5.3.2 Evaluation). The formation of small groups of two children who worked together on one question, character or object helped to redress the balance and to increase their participation. Time for snacks before each session assisted the creation of a positive working environment.

As noted in Section 3.5, Guha and her colleagues (2012) discussed the training process of children in design before they play the role of design partners in the CI method. During my work with diabetic children, the need of this education was not observed but the individuals needed clarification (i.e. show and describe by using video examples) on the eBook’s features and purpose as most of them had never used/played with this IT. In relation to diabetes, they spontaneously shared ideas and opinions based on their personal self-management routines integrated in their life.

Additionally, the number of participants in the workshop session was observed as a factor for good collaboration, communication and idea generation. Working in pairs with one parent and one child with T1DM as “design partners” was very productive in contrast to working with multiple participants in a session; these results were found in performing design and evaluation activities (Section 5.3.2 and Section 5.5.2.2). The child feels the special attention given by the designer; he/she felt more engaged and confident to share thoughts and experiences when other children with T1DM did not attend or listen to their challenges with diabetes and point of view on the subject (Section 5.2.1.3). An individual approach also suggested an equal degree of participation; some children are very dominating over those who are shy or passive. Similar results were found when involving healthy young individuals as “informants” during the evaluations (Section 5.5.3.2), but the group work was highly recommended for the design process (Section 5.3.3 and Section 5.3.4).
6.4.1.4 What Did Not Work

In Section 4.6, I have discussed issues and challenges experienced 1) in getting support from the Paediatric Diabetes Care Department, UL hospital and 2) in recruiting participants. Unfortunately, I was only able to work with two specialists; a paediatric dietitian who works in one of diabetes centres in Ireland and a nurse delivering the child programme CHOICE in Northern Ireland. Both specialists have diverse opinions about diabetes education as educators. As discussed in Section 4.1, no interest in this study was shown by medical professionals, (paediatric endocrinologists and diabetes nurses), working in the Regional Hospital and in other paediatric centres (i.e. Galway, Dublin and Cork) as a result of their busy agendas. Hence, I did not have the option to elaborate on the specialists’ work to newly diagnosed children and their families. It was also not possible to conduct observations on the type of education currently being provided in clinical settings. The exploration of the first diabetes education at clinics will suggest information on some issues as to how the small booklet ‘Pete the Pancreas’ was used by educators, i.e. what approach was applied in explaining diabetes complications, the practice of safe injection, the use of glucometers, and tactics that were used to deal with negatives feelings in families, etc. Despite applying multiple recruitment strategies (Section 4.1 and Section 6.4.1) my attempt was not successful in recruiting more children at different ages with T1DM that would like to partake in the design stage of the UCD and young individuals who are newly diagnosed. I was able to organise a design session with one family which is one of the reasons I applied the DP method, as this helped to generate more data from children to inspire the design.

Most of the young individuals with diabetes who participated in this study were girls between 8 and 12 years of age i.e. DP (Section 5.2.2.1), design (Section 5.3.1) and prototyping stages (Section 5.4.1.1). For example, the prototyping (Section 5.4.1.1) and evaluation sessions (Section 5.6.2) were conducted during the Easter camp in Trabolgan. Some boys came to the building were the activities were carried out, but they felt some discomfort sitting with girls and working together with them. Therefore, it would have been interesting to explore the design and prototyping steps with boys and newly diagnosed participants of different ages; this will help to demonstrate the contrast and similarity in applying the same design intervention and
then to compare the generated data and see how the story content of the eBook would be different.

The DP is a great option to support both participants and designer in developing IT, but becomes expensive to buy materials for designing the probes in the sets. Additionally, travelling to distribute and collect the completed sets further increased the cost for applying this method.

6.4.1.5 Additional Contribution in Exploring Other Methods to Facilitate Designer Work in Developing the Interactive eBook

Personas and scenarios were also indicated as helpful techniques in Årsand and Demiris’ (2008) framework (Section 3.3 and Section 3.5.1). Their benefits were not explored with young participants with T1DM as design partners; the first case study in their paper illustrates participation of diabetic children only as test users (Årsand and Demiris 2008). This suggested an area for a further exploration of these tools; hence, this piece discusses the affinity diagrams, personas, scenarios and storyboards explored to facilitate the work of a designer in performing the design process.

Affinity diagrams (Appendix C) have been used in two steps of the UCD; 1) to analyse the qualitative data because the diagrams are “built from the bottom up… grouping the data into key issues under labels” (Holtzblatt et al 2004, p 159-160) and 2) to develop personas in the prototyping phase and eBook prototypes because “affinity diagramming does open the door to misrepresentations of your data… to validate your personas after you have created them” (Pruitt and Adlin 2006, p 195). The digital variations of affinity diagrams had been built (Section 5.2.1.1) instead of the use of index cards or sticky notes placed on a wall/whiteboard to create online accessibility. The collection of many segments organised into two themes helped to visualise the data and to identify the key elements important for design, thus adhering to the user’s requirements. The affinity diagrams, combined with MAXQDA qualitative analysis tools, facilitated successful distillation and filtration of the rich transcribed semi-structured interviews, and supported the search of patterns and creation of categories that emerged from the data by applying an inductive approach. For building personas, the affinity diagrams enabled to identify a number of archetypes recognized by their levels of priority, were used as factoids.
(Table 11) to show personas’ characteristics and their different roles and goals in diabetes care (Section 5.4.2.1).

The developed personas in this study were used 1) to increase understanding on different roles in diabetes self-care management, different needs and design requirements by creating archetypes of the main users of eBook and 2) to integrate some of the created personas as characters in the stories and to build a series of scenarios, storyboards and prototypes. Usually the personas need to map physical and mental characteristics of the various users, daily and professional activities, settings, perceived challenges and other variables. Consequently, knowing that “The stories you tell about personas are a natural way of understanding people and events.” (Quesenbery and Brooks 2010, p 179), adult personas (i.e. mother, father, teacher and diabetes nurse) were built using the guidelines explained by Pruitt and Adlin (2010). Antle’s framework (2008) supporting the development of child-users personas aged 8-12 was explored to produce a user-learner archetype of a newly diagnosed child and his/her siblings - Liam (at 5), Daniel (at 9) and Sarah (at 12). The framework (Antle 2008) is composed by three dimensions (i.e. childhood needs, developmental abilities and experiential goals); the first two are reusable as they are grounded on the children’s developmental psychology and only the third dimension deals with the product goals. Assuming that all personas are archetypes of healthy children before initial diagnosis, only the third dimension of the framework for Daniel and Sarah personas will be different because their age meets 8-12 age range. Leading the instructions, different sources were used to explore the framework (Table 13, Section 5.5.2.3). The first dimension used the factoids in Table 11 (Section 5.4.2.1), the teaching activities at different ages described in the Irish Primary School Curriculum on Science and the control and responsibilities in diabetes care based on children’s cognitive development (Hannan 2011; Silverstein 2005). The second dimension explored literature on children’s ability and motor, social and cognitive development (Bruckman and Bandlow 2003) along with gesture interaction with tablet applications (Aziz 2013). The third dimension illustrated different roles and goals of these three children. By using the described above sources, the results indicated that in this particular case - developing child-learner personas, the first and second dimensions in the framework for Daniel and Sarah
archetypes were different (Table 15, Section 5.5.2) because 1) the children between 8 and 12 will have dissimilar awareness and understanding on the human body and healthy food based on the educational curriculum, and 2) the cognitive development is different i.e. at 9 years of age is near to adults while at 12 is similar to adults and 3) gesture abilities are the same but young individuals aged 10-12 want apps suggesting more fun and challenges. These findings were crucial for developing narratives for the eBook prototypes aiming to facilitate knowledge building on diabetes management, while also providing an entertaining experience through playing with the artefacts.

Using the personas, the problem and activity scenarios along with their storyboards were developed. This enabled the exploration of the personas’ current situations and how the eBook assisted them to achieve their goals. Performing these activities conveyed deeper understanding on the users’ practices, obstacles and demands supporting the prototype building process. Aiming to meet the identified requirements for educational technology, I mapped the personas with the main characters in the stories, integrated fantasy elements and curious facts to produce reliable narratives with age-appropriate content for the eBook prototypes. Hence, affinity diagrams, personas, scenarios and storyboards have shown promising results in supporting designers’ work when developing educational technology prototypes.

6.4.1.6 Participatory Design for/with Children with Diabetes and their Parents in Developing IT

From the findings discussed above in relation to the questions of this thesis (Section 1.4), the results illustrate various benefits of the applied participatory approach in developing IT for children with T1DM. In most of the sections in this chapter, I demonstrate:

1) The need of participants’ involvement in technology design based on their role, input and contribution while performing UCD i.e. exploring paediatric diabetes care in domestic settings, designing, prototyping and evaluating the educational context and features of the interactive technology.

2) The approach in selecting methods, techniques and tools used to facilitate their active involvement and participation applying UCD, PD, CI and ID along with challenges experienced in collecting empirical data.
Therefore, the findings reaffirm the statement made by Glasemann and Kanstrup (2008) that diabetic children can and should be involved when developing technology supporting their self-management practices. I argue that parents’ contribution in the design process is significant; hence their participation is required.

This long journey in the designing of the IT was neither easy nor smooth. Some of the challenges experienced in co-designing with participants are linked to the exploration of this sensitive and complex topic, the recruitment process, the difficult access to children with T1DM and their parents, problems in building trust with participants and the shortage of parents’ free time to participate in the design. Organising and conducting UCD and participatory approach with the young individuals with diabetes triggered diverse issues. For example, choosing places and settings for working with the participants, selecting materials and activities that could facilitate better participation and collaborative work, developing new practices aiming to deal with negative feelings during the sessions and expecting inability to participate as a result of current health status in children. Selection of design interventions is a dynamic process; the designer needs to be aware of what and how the materials will support parents and children to play the role of equal stakeholder in the creative process enabling collaborative work. As stated by Iversen and Dindler (2013), each case is very specific, requires special attention and individual tactics when designing with children. The participatory approach was hard to apply but not impossible. Even though the group of users with this illness had specific emotional and health requirements, they should not be undermined and be given the right to voice their opinions in the designing of the IT. Designers and participants need to work together when developing products whose purpose is to resonate better with the individual’s needs.

6.4.2 Designing an Educational IT FOR Children with T1DM and their Parents: A Set of Requirements and an Abstract Model

In this section, I focus on the design of the educational eBook. I highlight the contributions that resulted from investigating the FOR part of my main research questions. Similar to discussing the design process (Sections 6.4.1) the contributions presented in this section are grounded on children and parents’ experiences in paediatric diabetes education and perspectives on the role of new interactive
technology for newly diagnosed young individuals with T1DM and their families. The elaboration of an abstract model to design FOR affected children emerged from the empirical data gathered during the UCD and PD process. The model was built based on four main categories that arose as sets of requirements for the technology design, namely requirements about Users, Educational Contents, Language used and provided Interactivity with content. In the following two sections, 1) I discuss a series of dimensions that emerged from the data that helped me to identify a series of suggested transitions to design an educational tool FOR children with type 1 diabetes (Section 6.4.2.1) and 2) I suggest a series of dimensions for the development and design of educational IT to be used by newly diagnosed children with chronic diseases and their families (Section 6.4.2.2).

6.4.2.1 A Set of Design Requirements at the level of Users, Educational Content, Language and Interactivity

The analysed empirical data helped to specify a set of requirements not only for how to work and design WITH children with type 1 diabetes, but also for what to design when we design technology FOR them to use, especially in relation to interactive technology and in the context of an educational design intervention. As discussed in the thesis (Chapter 5), these requirements were considered and used to inform the design choices and the development of the educational eBook. These requirements fall into the four general categories of Users, Educational Content, Language and Interactivity shown in the first column of Table 21. The ‘Users’ category specifies what type of users the educational eBook should be designed for; they could be newly diagnosed children with chronic illness and their families, teachers, friends, etc. Educational Content refers to the type and format of actual information that the eBook should provide/express/deliver (its characteristics) and how it should be presented to the target audience (e.g. through using text, images, videos, etc.). Language refers to the actual linguistic categories and wording used in the eBook (e.g. visual symbols, expressions, metaphors, etc.). Interactivity refers to the direct interaction with the eBook interface in order to improve the quality of the educational experience offered to the users (e.g. images, animations, sounds, etc.). A general outline of these four categories is offered in Table 1 and is organised as follows.
### Table 21: Requirements at the level of Users, Educational content, Language and Interactivity

<table>
<thead>
<tr>
<th>Levels</th>
<th>General requirements</th>
<th>Particular findings</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users</td>
<td>The users of educational IT designed for newly diagnosed children with chronic condition should be between the age of 8 and 12 (based on the medical professionals perspective)</td>
<td>e.g. “…children were encouraged in self-management from the age of 8…” (MP29)</td>
<td>Interviews</td>
</tr>
<tr>
<td></td>
<td>The educational IT should be designed for affected children and their families (i.e. parents and siblings)</td>
<td>e.g. Parents educate their children on diabetes</td>
<td>Interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. “I actually love to show them some child friendly stuff, just to sit down with his brother and sister we go through the stuff in the book.” (Parent23)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. “a wall chart of the human body” (Parent11)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. “it was a talk about the mechanics of the digestive system when we eat food and then it is converted to energy” (Parent6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. The use of puppets I and C (Parent8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. Treat and care for a bear with T1DM (Parent15)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. The use of examples of “high achievers or people who have lived normal, but full life” (Parent9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The educational IT should be used by different people (i.e. teachers, relatives, etc.) in various settings (e.g. home, hospital, school, etc.)</td>
<td>e.g. “At that time we only had the ‘Pete the Pancreas’ book so the teacher read it out to the class.” (Parent15).</td>
<td>Interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. Develop scenario stories describing diabetes care in different settings</td>
<td>Design workshop 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. at a hospital, at home, at the shop, at school, etc.</td>
<td></td>
</tr>
<tr>
<td>Educational Content</td>
<td>The content should be compelling and enjoyable, it should employ fun features to entertain children and their family (helping to reduce the stress from diagnosis)</td>
<td>e.g. “She got very anxious. She suffers a lot from anxiety I think, because her life was so structured, there was a plan, there always had to be a plan so she became like that. I had to take her to a child psychologist” (Parent8)</td>
<td>Interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. “She did get upset several times especially early on and we just let her cry it out.” (Parent6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>e.g. “There was a lot of crying and disbelief that she had this...this experience was so much for us” (Parent7)</td>
<td>The state of the art</td>
</tr>
<tr>
<td>The educational content and language should reflect the perspective of the children and their parents, it should be age-appropriate and child-friendly</td>
<td>e.g. “I want to see clear and accurate explanations of the disease, but only up to a certain age and appropriate level. I don't want to see talk about amputations and stuff like that…I want to see role models…I want to see, what we say to care givers…” (Parent9)</td>
<td>Interviews Prototyping workshop 4</td>
<td></td>
</tr>
<tr>
<td>Should use narratives (fantasy adventure short stories) for building educational content</td>
<td>e.g. “The hero has insulin guns to reduce the hypers and glucose guns to eradicate hyps. By being a scientist he spends the day looking for a cure for diabetes and by night he protects all children from hypos and hypers.” (T1DC8)</td>
<td>Design Probes Design workshop 1 Design workshop 2 Design workshop 3 Prototyping workshop 4 The state of the art</td>
<td></td>
</tr>
<tr>
<td>The narratives should have a combination of multiple settings and characters</td>
<td>e.g. The setting may include a particular scenario elaborating on diabetes self-care task i.e. travelling “injection, insulin, set change for pump, glucagon injection, medical card, extra supplies, meter, cooling pack for insulin, etc.” (T1DC8)</td>
<td>Interviews Design workshop 1 The state of the art</td>
<td></td>
</tr>
<tr>
<td>Should include information/story on initial diagnosis at clinic/GP settings</td>
<td>e.g. Doctor-Sky master dialogue  e.g. “Doctor: How are you today? Sky master: I am feeling tired and I am more thirsty that usual. Doctor: Ahh, I think you might have diabetes. Sky master: What is diabetes? Doctor: I’m glad you asked. Diabetes is…” (T1DC21)</td>
<td>Design workshop 1 Prototyping workshop 4</td>
<td></td>
</tr>
<tr>
<td>Should describe some common symptoms of the chronic condition</td>
<td>e.g. “tiredness, drinking, toilet, pain in stomach, weight loss, hungry, angry “ (T1DC8), e.g. “I’ve had to go to the toilet a lot. I’ve also been really thirsty.” (T1DC18)</td>
<td>Design workshop 1 Prototyping workshop 4</td>
<td></td>
</tr>
</tbody>
</table>
| Should explain to the extent possible how people are diagnosed with the chronic illness | e.g. “Diabetes is a condition where your pancreas stops working and you need to give yourself insulin instead of your body producing it”. (T1DC8)  
  e.g. “Diabetes means too much sugar in the blood. Sugar comes from the food we eat. Insulin is a hormone that is made in the pancreas and works like a key to open the door. Insulin opens the door to the cell of your body allowing the sugar to go from the bloodstream into the cells where it is then used to make energy. What happens if your pancreas gets lazy? When you have T1DM you have to take insulin, because your body can’t make it anymore.” (T1DC16) | Interviews  
  Design Probes  
  Design workshop 1  
  Prototyping workshop 4 |
| Should show some facts about the chronic condition (i.e. frequently diagnosed people, treatment options, medications, etc.) | e.g. “247 million people have diabetes, 1 in 400 children have diabetes” (T1DC10)  
  e.g. “Frederick Banting invented insulin” (T1DC16) | Design Probes |
| Should include a story of the human body (i.e. explaining systems and organs and their functions) that may help to describe the chronic condition | e.g. “If you are able to show, this is your body and this is what happened then, show things about human organs with more fun, they can actually see in a real sense what is happening.” (Parent15)  
  e.g. Healthy children do not know the position and function of the pancreas in the human body. | Interviews  
  Design workshop 1  
  Design workshop 2 |
| Should include questions and answers on the disease and its care | e.g. Dialogue between doctor and child, dialogue between protagonists 1) Superhero explains his symptoms and 2) Doctor gives details on diagnosis and treatment  
  e.g. Children wanted to learn that “diabetes doesn't make you different from others” (T1DC19) | Interviews  
  Design workshop 1  
  Prototyping workshop 4 |
| Should describe the good aspects of having chronic illness | e.g. “eating healthy food” (T1DC16) | Interviews  
  Design Probes |
| Should explain self-care management tasks, steps of using supportive technology and medication treatment | e.g. Glucometer and insulin administration by injection/insulin pen “With diabetes you have to check your bloods between 4-6 times a day. This means you have to prick your finger and give blood to a device called a meter, which will tell you what your sugars are.” (T1DC8)  
  e.g. “You can get reusable or disposable pens. With a pen you can have 2-6 injections a day. Some people prefer the pen to the pump, because they don’t want something hanging off them.” (T1DC16) | Interviews  
  ‘Pete the Pancreas’  
  Design Probes  
  Design workshop 1 |
<table>
<thead>
<tr>
<th>Design Probes</th>
<th>Design workshop 1</th>
<th>Prototyping workshop 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. Provide images of insulin pump and glucometer used in self-care management and explain their evolution</td>
<td>Design Probes</td>
<td>Design workshop 1</td>
</tr>
<tr>
<td>e.g. “The first pump was so big you had to carry it on your back” (T1DC16)</td>
<td>Prototyping workshop 4</td>
<td></td>
</tr>
<tr>
<td>e.g. “The insulin pump is a device that gives you insulin through a cannula, which is much easier that injections, you simply key in your bloods and carbohydrates and it will calculate how much insulin you need to cover what you eat.” (T1DC8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. “The pump is a little device that delivers insulin to the body. Your type in the amount you need and it delivers it thorough a cannula to an injection site and in to your body. You need more insulin after eating carbohydrates.” (T1DC19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Hypo- and hyper-glycaemia and their treatment, ketones and emergency care plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. “There are a lot of things that can affect your blood glucose. For example, exercise brings your bloods down. If you have a growth spurt you need more insulin, because your blood sugars are high. As you grow up your body produces different hormones and these can also affect your blood glucose. Being nervous and excited can also change your blood glucose. Food is also something to look out for.” (T1DC19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. “Sport activities will also change your bloods, but on a temporary basis, which will keep your bloods from dropping.” (T1DC8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. emergency plan: hyper - “Measure blood sugar, if your bloods are near 10 you need to take extra insulin. The doctor will tell you what amount of insulin you can take in different cases.” hypo - “when sugars are under 4 - lucozade, dextrose tablets, glucagon injection” (T1DC8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Why children need to eat healthy food: foodstuff into two categories</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. “healthy and not healthy”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. “Fruit is healthy for diabetes, Vegetables are good for diabetes” (T1DC10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. How to buy healthy food and carbohydrate counting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interviews</td>
<td>Design Probes</td>
<td>Design workshop 1</td>
</tr>
<tr>
<td></td>
<td>Design workshop 3</td>
<td>Prototyping workshop 4</td>
</tr>
</tbody>
</table>

362
<table>
<thead>
<tr>
<th>Language</th>
<th>Should use fictional characters based on real children (e.g. personality traits, needs, goals, etc.)</th>
<th>e.g. Superhero (role-playing)</th>
<th>Design Probes Design workshop 2 Design workshop 3 Prototyping workshop 4 The state of the art</th>
</tr>
</thead>
<tbody>
<tr>
<td>Should include references to real, famous people who have the same chronic condition</td>
<td>e.g. Role models discussed by parents and children e.g. Gary Mabbutt, Halle Berry, Nick Jonas, etc. (T1DC4; T1DC9; T1DC10; T1DC16; T1DC19)</td>
<td>Should provide meanings of different medical terms e.g. Medical terms in diabetes as insulin, carbohydrates, ketones, etc.</td>
<td>Interviews ‘Pete the Pancreas’ Design workshop 1 Design Probes</td>
</tr>
<tr>
<td>Should provide meanings of different medical terms</td>
<td>e.g. “they didn’t really talk to us about food or how it impacts” (Parent6) e.g. “…six months guessing not knowing how to really count carbohydrates, how to do anything…” (Parent2)</td>
<td>e.g. The role of sport in diabetes care e.g. It helps “to keep their sugars down” (T1DC22) e.g. “bring your sugar down” (T1DC8)</td>
<td>Design workshop 1 Design Probes Design workshop 1 Prototyping workshop 4</td>
</tr>
<tr>
<td>e.g. The honeymoon period amongst children with T1DM e.g. “lack of information at the very start, which was kind of where you are left” (Parent2) e.g. “Honeymoon period usually happens after being diagnosed. In that time you need to measure your blood sugar, take insulin and have loads of activities. Your bloods may go up and down that is, because the pancreas used to produce so little insulin and now with the injection it gives you a lot.” (T1DC8)</td>
<td>Design workshop 2 Design workshop 3 Prototyping workshop 4 The state of the art</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Should use metaphors to explain the complication that may trigger the chronic condition</td>
<td>e.g. “Now you need to look after yourself.” and when I'd be putting on my night cream I'd say “see, mommy’s looking after her skin.” So when I'm older, I'll look better than those who didn't bother looking after their skin. So if you look after your Diabetes, you won’t incur problems later down the line that people might if they’re careless now.” (Parent8)</td>
<td>Interviews</td>
<td>The state of the art</td>
</tr>
<tr>
<td>Should explain some process emphasising on the balance in the human body that is important for managing the chronic illness via visualisation/simulation</td>
<td>e.g. The relationship between insulin doses and carbohydrates – simulation seesaw e.g. “It was just one puppet had C for carbs and one puppet had I for insulin. So they were on a little seesaw...and I said &quot;What happens when you eat?&quot; and she goes &quot;Your carbs go up&quot;, so she knows what happens when she eats, &quot;What do you need to make your carbs not go up?&quot; and she goes &quot;The insulin&quot;, so when you give the insulin, you see the seesaw balance.” (Parent4)</td>
<td>Interviews</td>
<td>The state of the art (balance, simulation - visualisation)</td>
</tr>
<tr>
<td>Should suggest comparisons</td>
<td>e.g. Information about glucose, insulin and pancreas function in a healthy person and those with diabetes along with their visual representation</td>
<td>Interviews</td>
<td>Design workshop 1 Design workshop 2 ‘Pete the Pancreas’ The state of the art (simulation – visualisation)</td>
</tr>
<tr>
<td>Should provide natural and cartoon images of internal human organs linking to the chronic condition</td>
<td>e.g. Pancreas, stomach, liver and heart e.g. “she wanted to go to Google Images and see what a real pancreas looks like” (Parent6)</td>
<td>Interviews</td>
<td>Design workshop 2</td>
</tr>
<tr>
<td>Interactivity</td>
<td>Educational IT should suggest rich interactions (e.g. drag and drop, touch-and-response interaction, read the text aloud feature, animations, sound, etc.)</td>
<td>e.g. How the doctor is giving an injection (T1DC21) (animation) e.g. Questions and answers between the main characters in the story (T1DC22) (narration) e.g. Mini-games e.g. Should include images that are not part of educational context, but they suggest some interaction</td>
<td>Prototyping workshop 4 Prototyping workshop 4 The state of the art</td>
</tr>
<tr>
<td>Each scene/page should include one constant image</td>
<td>e.g. Image of happy face that could move across the screen (T1DC19)</td>
<td>Prototyping workshop 4</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>The main fictional character should have various characteristics and abilities</td>
<td>e.g. When pressing the Superhero it can play music, stretch, dance, disappear, etc.</td>
<td>Prototyping workshop 4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e.g. The facial expressions of Superhero should turned from sad into happy (T1DC19)</td>
<td>Prototyping workshop 4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e.g. Superhero could have abilities to zoom anywhere as quickly as lightning (T1DC16), to turn into a cat (T1DC17), to bend (T1DC18), to read your mind (T1DC19), to fly (T1DC21), etc.</td>
<td>The state of the art</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e.g. Superhero could give “instant knowledge to everyone she touches” (T1DC17), in order to help newly diagnosed children understand diabetes.</td>
<td>Design Probes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e.g. Outer and inner characteristics of Superhero i.e. “cheerful, fun and mischief maker” (T1DC20), “brown hair and green eyes” (T1DC22).</td>
<td>Prototyping workshop 4</td>
<td></td>
</tr>
</tbody>
</table>
Along with the four categories in the first column, general definitions based on particular findings are listed respectively in the second and third columns. The fourth column gives information on the type of sources in terms of the techniques that have elicited those requirements, e.g. The State of the Art\textsuperscript{67}, Interviews, Design Probes, Design workshop 1, Design workshop 2, Design workshop 3 and Prototyping workshop 4. From analysing and comparing this set of requirements for educational technology with the current practices and educational material in Irish paediatric diabetes care available to newly diagnosed young patients and their families, four oppositions emerged. The oppositions are discussed below.

Looking at the users of such educational technology, the emerging requirements highlight an opposition between the traditional individual approach to learning and the collective approach (in this case family-based) learning (Figure 161).

![Figure 161: Formal Learning/Alone vs Informal Learning/Together](image)

A traditional approach to learning sees children as the recipients of the educational content, which is typically offered in a formal, top-down fashion, during the time of diagnosis in the clinical environment. What was noticed in the investigation is that, once back home, the whole family is often left alone wondering about self-management best practices and how to deal with the myriad of practical difficulties outside the clinic. I found that learning should not be limited to particular moments (the diagnosis) and subject (the diagnosed children), but rather should be informal, distributed in time and addressed to the whole family and/or guardians. Despite the presence of the word ‘self’ in self-management, paediatric diabetes care is a family/collective effort; therefore the entire family should be involved and considered. Looking at moments when the family learn together, it was not difficult

\textsuperscript{67} Some features/ideas taken form Table 1 (Section 2.3.1) fourth column used in the design of reviewed 21 educational technologies
to identify already existing practices within the family that could be leveraged to sustain a design intervention that aim to educate the whole family. The well-established tradition of parents reading books to children represents one of these moments when parents and children come together and enjoy some type of content. Mindful of these moments, I saw the development of the eBook as a way to stage informal occasions to learn together, away from the tensions of the hospital and the top-down, prescriptive way of passing information typical of the clinical environment (and of the more traditional educational materials made available to newly diagnosed children and their families). For instance, most of the parents described how they spend time discussing Type 1 diabetes with all members of the family including those children who are not affected by diabetes (e.g. “sit down with his brother and sister we go through the stuff in the book” (Parent23)). Therefore, in order to support family education in a positive way, for these informal discussions in a domestic environment, parents used a mixture of different child-friendly materials/resources (e.g. “a wall chart of the human body” (Parent11)) and talks (e.g. “it was a talk about the mechanics of the digestive system when we eat food and then it is converted to energy” (Parent6)), that helped to increase awareness of the chronic condition and its treatment. Based on the child’s capacity and readiness, and for effective sharing information and communication, the parents also needed appropriate strategies. These approaches quite often included positive themes for helping individuals become personally involved in the process. During this educational process, the parents and children sometimes play with I and C puppets (Parent4), treat and care for a bear with T1DM (Parent15) or read together books describing “high achievers or people [with diabetes] who have lived normal, but full life” (Parent9). During the design process of the eBook, all of these examples have been taken into account. These requirements are linked to the educational content, language and interactivity of the eBook; hence, they are discussed in these three categories below.

At the level of the “Educational Content”, another meaningful opposition that guided the development of the educational eBook emerged. Medical education tends to reflect a medical perspective and medical knowledge that is typically universal, quantitative, based on scientific experiments and their validation. This might clash
with the patient perspective that is - on the contrary – personal, idiosyncratic, qualitative and based on the personal, subjective and practical experience of the disease (Figure 162).

Figure 162: Medical perspective vs Patient perspective

Such opposition results on a top-down vs bottom up approach to teaching, where there is a fine line between disciplining (training people to obey rules whether the rules are understood or not) and educating (training people in understanding basic rules so that they adapt their behaviour as a form of self-efficacy). The former reinforces the dependency of those in need of education on those educating; the latter reinforces a sense of autonomy and self-determination. The UCD design was definitely useful to unpack more personal, experiential and patient-centric concerns that helped me to reflect the patient perspective in the eBook design. For instance, the initial diagnosis provoked feelings in both the affected child and his/her family (e.g. “She got very anxious” (Parent8), “we just let her cry it out” (Parent6), “There was a lot of crying and disbelief that she [daughter] had this” (Parent7), etc.); as a result, the need of educational resources that promotes a relaxed atmosphere while learning about diabetes may help to relieve the stress of diagnosis. As discussed (Section 2.4. and Section 6.2.2), these findings partly influenced the choice of selecting an interactive eBook as the interactive technology to design; the eBook aimed to facilitate diabetes education of newly diagnosed young patients and their families. As educators of their children, parents deemed the booklet ‘Pete the Pancreas’ not very successful as a learning resource. They wanted materials that have particular educational context, based on their personal experience of the chronic illness as parents, carers and educators. These materials needed to be child-friendly, to “show things about human organs with more fun, so they [children] can actually see in a real sense what is happening” (Parent15), to suggest “clear and accurate explanations of the disease” (Parent9) and to include “role models” (Parent9) for
encouraging the child in positive ways. In a similar vein, to increase their knowledge on the topic, children preferred to read educational and fictional adventure stories rather than medical books with facts about diabetes. These narratives allow empathy without identification (learn about Superhero’s diabetes as opposed to learning about own diabetes) and offer descriptions of the chronic condition that are contextualized in real life (in-the-wild vs in-a-vacuum), that use simple and understandable language, and that reflect the perspective of the children and their parents (e.g. “What happens if your pancreas gets lazy? When you have T1DM you have to take insulin, because your body can’t make it anymore.” (T1DC16)). In my case, stories included diabetes care contextualized in multiple settings (e.g. initial diagnosis, traveling, at the shop, at the school, etc.) integrating different characters (e.g. Superhero, doctor, brother, etc.) with magical powers of varying kinds (e.g. Superhero can fly (T1DC21)) or magical journeys (with miniaturized submarine). Additionally, the content must suggest information on diabetes self-care management tasks (e.g. “Fruit is healthy for diabetes” (T1DC10), “you have to check your bloods between 4-6 times a day” (T1DC8), “With a pen you can have 2-6 injections a day.” (T1DC16)), as well as technologies developed/used to support diabetics in their daily routine e.g. “The pump is a little device that delivers insulin to the body.” (T1DC19). Also, by using language and illustrations that could spawn learning and curiosity in children, the stories could 1) show the evolution of technologies used to manage chronic illness, such as the first insulin pump (e.g. “The first pump was so big you had to carry it on your back” (T1DC16)), 2) give information on the digestive system (e.g. “she wanted to go to Google Images and see what a real pancreas looks like” (Parent6)), 3) provide details on who discovered the medicine (e.g. “Frederick Banting invented insulin” (T1DC16)), 4) reveal some general facts about the chronic condition (e.g. “247 million people have diabetes, 1 in 400 children have diabetes” (T1DC10)), and 5) list and describe celebrities with diabetes (e.g. Gary Mabbutt, Halle Berry, Thomas Edison, Nick Jonas, etc. (T1DC4; T1DC9; T1DC10; T1DC16; T1DC19). Finally, children wanted to read about the positive aspects (if any) of having this chronic illness (e.g. “eating healthy food” (T1DC16)) and even having diabetes this “doesn’t make” them “different from others” (T1DC19). All these requirements for educational materials on diabetes care indicated the need for a new content grounded on patient experience. Therefore, the eBook design needed to be
more patient-centred (e.g. children with T1DM and their families) rather than medical-based. These requirements do not exclude the medical recommendations and management guidelines; however, they should be explained through the lens of children and parents’ perspectives and perceptions e.g. “There are a lot of things that can affect your blood glucose. For example, exercise brings your bloods down. If you have a growth spurt you need more insulin, because your blood sugars are high. As you grow up your body produces different hormones and these can also affect your blood glucose. Being nervous and excited can also change your blood glucose. Food is also something to look out for.” (T1DC19).

From the medical perspective, objective knowledge influenced the way information is presented and used prescriptive language and styles. In this direction another meaningful opposition emerged, i.e. language (Figure 163).

![Figure 163: Prescription vs Narrative](image)

Reflecting on the opposition between the medical and patient perspective, as well as the one between formal (top-down, asymmetrical) and informal (bottom-up, among peers), the language used in the existing educational material is key and also offers another interesting opposition. Since medical knowledge is normative and based on rules, it affords being provided in the form of prescriptions (usually taking the form of imperatives from the expert: *do this, do not do this*). Prescription is indeed a common term in medical science referring to the instructions that the doctor gives authoritatively to the patients. It links with the notion of compliance, which is also a medically oriented term referring to whether the patient follows the orders of the doctors or not. As often acknowledged in the literature about chronic care (Conrad 1985; Storni 2013), self-care is often not so much about following the orders of the doctor, but rather experiencing a complex lifestyle with demanding and challenging aspects. When interrogated about this experience, the patients rarely come up with rules to be followed, but rather come up with narratives about their experiences.
During the design process, the strength of a narrative approach asking participants to develop stories about diabetes turned out to be very generative and a strong vehicle for sharing information. The use of narrative (from recalling anecdotes to coming up with stories about diabetes) was highly recurrent in all the research activities that led to the development of the eBook. It was noted that narratives in the third person were also less problematic than narratives in the first person. The former allowed affected individuals and their families to express their knowledge (or lack of) without necessarily referring to their own situation. On the contrary, the latter were reminders of the difficult situation one is in and therefore more problematic for the children who, I saw, became emotionally distressed when discussing their situation.

Based on this, I uncovered an opposition between a language that is based on prescriptions (direct do and do not, typically in the second person) and a language that employs a narrative approach for the provision of information (typically in the third person – ‘Superhero is sick’ – than in the first/second person – I/am You/are sick). For example, children developed different stories about Superhero and his/her power by using probe materials when applying the DP method. Playing the role of the fictional character by putting themselves in the shoes of Superhero, children could see themselves in the stories by helping other young individuals in managing their diabetes or accomplishing different tasks related to their own chronic condition. Stories play a central part in children’s life and their diabetes is not an exception; every newly diagnosed patient has his/her own story on the early symptoms of diabetes, on the initial diagnosis, and on the experienced problems and the challenges. These personal stories have been identified during the prototyping session, and a series of paper prototypes – the narrative ‘Superhero is sick’ (Section 5.4.1) - have been developed. Describing particular narrative settings (e.g. clinic settings) and certain real-life situations (e.g. diabetes symptoms), the character of Superhero experienced similar feelings and behaviour (e.g. curiosity, fear, blood and needle phobia, etc.) like the child with diabetes (e.g. role playing). Children can recognise themselves in various situations portrayed in the narratives (e.g. initial diagnosis), the questions they had (e.g. dialogue between Superhero and doctor) and the information they needed (e.g. looking for facts, technologies, etc.). In addition, with a realistic portrayal of a child who deals with diabetes, stories can help
readers cope with many feelings and problems. Stories can inform readers about the potential solutions to different challenges. Focusing on particular aspects of learning, the narratives could help young readers discover a specific perspective, and also promote awareness of their needs and goals.

In the narratives, to make the story educational, the language may include different forms, i.e. metaphors, comparisons, visualisations and illustrations. These forms could help to describe more serious issues in diabetes care or to provide more valuable/realistic information on some processes in the human body connected to the chronic disease. For instance, comparing the digestive system of a healthy child with that of those who have diabetes may help the young users see and understand the need for insulin treatment and a healthy diet. Other examples indicated that the use of metaphors and visualisations/simulations of taking insulin and the food process emphasising that balance is important for controlling the blood glucose levels (e.g. the use of two puppets - C for carbs and I for insulin - and the seesaw). Many parents described various metaphors for explaining complications that may occur as a result of improper diabetes treatment and they could be successfully integrated into the stories (e.g. “see, mommy's looking after her skin.” So when I'm older, I'll look better than those who didn't bother looking after their skin. So if you look after your Diabetes, you won't incur problems later down the line that people might if they're careless now.”(Parent8)). Illustrations also convey meanings in the stories depicting details that are important for the educational narratives as a whole. Therefore, they help to describe settings (e.g. at home, at waiting room), facial expressions (e.g. happy, sad, etc.) and body language (e.g. shyness, fear, etc.) of the main characters, emphasising certain elements of the story (e.g. steps in using glucometers), extra details such as providing realistic images (e.g. natural images of the pancreas and the stomach), etc. Additionally, the stories need to be colourful, attractive, child-friendly, clear and simple. All these described characteristics of the narratives make them preferable for children and parents, because of their more informal and descriptive language.

Finally, at the level of “Interactivity”, an opposition between static information (in relation to printed material) vs. interactive information (in relation to interactive eBooks) was identified (Figure 164).
Content presented on paper e.g. ‘Pete the Pancreas’, leaflets, printed materials, books, etc. is static; this content (e.g. text, images, illustrations, etc.) does not require much interaction from the young reader. Reading alone was described quite often by children as being a boring and tedious activity. As discussed from the medical perspective, these materials are very prescriptive and their content includes text and simple illustrations or photos. Search puzzles of words used in diabetes (e.g. ketones, insulin, hypo, etc.) or colouring pages (e.g. boy, sugar, key, etc.), such as those provided in the booklet ‘Pete the Pancreas’, were described by the children as dull or childish. In contrast, the digital stories, particularly those developed for enhanced interactive eBooks, could provide rich visualisations of the narratives through illustrations, animations, sounds, interactive games, images, etc. The eBook stories provoke interaction with the touch-screen interface, because they may include interactive features such as narration, video, audio, animations, illustrations, text, mini-games, etc. They allow users to perform certain tasks (e.g. moving images, drag and drop, touch and respond interaction, etc.) and observe the results of their actions. Interactive stories could be seen as a very powerful teaching tool, as they could make the experience of reading the narratives interesting and attractive. These stories can communicate messages, which could make the learning process enjoyable and easy for children and families. Even more, having the stories in digital format as an enhanced interactive eBook may improve the dialogue between children and parents; thus making learning fun for young readers, helping children pay attention to the topic, and stay active. These stories make the teaching process more effective; all members in the family could read, play or interact with the stories provided on the eBook. For the design of the eBook stories, participants in the study suggested various interactive features. For example, as opposed to providing primary text base stories, it could be useful to also supply a ‘real aloud’ narration feature. Other images that are not normally associated with educational content should provide some levels
of interaction to enhance the experience of the users, e.g. each scene/page should have (display) one constant image of a happy face moving across the screen (T1DC19). Additionally, to make the story more interesting, Superhero could have different abilities e.g. to zoom (T1DC16), to turn into a cat (T1DC17), to bend (T1DC18), to read minds (T1DC19), to fly (T1DC21), etc. Some of the suggested interactive elements aimed to improve the educational content; they include the integration of visualizations, simulations, animations, videos, mini-games etc. that in practice are not possible to apply in normal printed educational materials.

6.4.2.2 An Abstract Model of the Educational Process Based on Current Practices and Users’ Requirements

Placing these four categories (dimensions) described above into one graph helped me identify the required transition toward the design (educational) tools FOR children with Type 1 Diabetes. The horizontal x-axis represents a merger of the last three categories - Educational Content, Language and Interactivity - because they all refer to qualities in the educational materials, i.e. those that are currently used by the newly diagnosed children and their families (‘Pete the Pancreas’) and those that the individuals needed and developed during this study (the eBook ‘Superhero learns about diabetes’). The vertical y-axis illustrates the ‘Users’ category by showing the opposition of individual/formal and collective/informal learning approaches that these two educational sources support (Figure 165).
The proposed arrangement suggests a much needed shift from the top left quadrant to the bottom right one. The ‘Pete the Pancreas’ reaffirms a medically oriented, formal, normative and static education devised for individual learning. In contrast, ‘Superhero learns about diabetes’ fosters a more informal, interactive and narrative-based approach to learning devised around the idea that learning should reflect everyday experience, the perspective of the affected ones, and be inclusive so that the whole family could be engaged (Figure 166).
The following examples helped me to outline the opposition that emerged between these two educational sources shown in Figure 6. In several sections of this thesis, I described the disadvantages of the booklet’s content; they are based on the children and parents’ experiences with the existing educational resources (Section 5.2.1.2) and on the empirical data analysis (Section 5.4.2.5) used in the prototyping process of the eBook stories. Having a small size (A5), ‘Pete the Pancreas’ contains 33 pages that provide basic limited information on paediatric diabetes care. The content is medical and formative; for example, bullet points list the key information on diabetes (Figure 169 and Figure 170) and all the images, colouring pages, and the word search puzzle are strictly linked to the topic (Figure 167, Figure 168, Figure 169, Figure 170, Figure 171 and Figure 172). The only options that were considered fun for the young readers were the colouring pages and the word search puzzle (Figure 167 and Figure 168). Both of these activities facilitate individual activities as opposed to group interactions (e.g. placing the book on the table and the use of colouring pencils or sharpies).
On ‘Pete the Pancreas’, most of the text is prescriptive rather than descriptive e.g. on healthy eating and diet “Watching what you eat – you must eat regular meals and snacks every day” (p 26), on treatment “Take insulin injections/use an insulin pump” (Figure 169, p 13), “Drink plenty of water/fluids” (p 21), etc.

Cartoon characters of pancreas, cells, insulin and glucose are used as illustrations, to explain diabetes (e.g. “Without the insulin key, glucose from your food can’t get into your cells. Your cells feel sad, because they have no energy”, Figure 171). Natural images illustrate the steps of using the glucometer (Figure 172). Little information is given about the treatment with the insulin - the use of insulin pump and pen (e.g. “Your insulin may come in: a syringe, a pen device, or in a pump, which you leave in all the time”, Figure 170). Some questions on diabetes as a chronic condition and its treatment along with their answers are enclosed in page 30 of the booklet. One of these questions covers the treatment of T1DM with insulin tablets instead of insulin injections (many children wanted to know if there was any other option for receiving insulin different from injections) “Is there a tablet available to treat type 1 diabetes?” and the given answer is “No not yet...”.

Comparing what participants needed (gleaned from my Interviews, Design Probes, Design workshop 1 and Prototyping workshop 4) and what the book provides as an educational source, it was identified that ‘Pete the Pancreas’ does not include important information on the honeymoon period, traveling, different scenarios in diabetes management and complications. Additionally, distinctions between healthy and unhealthy food, carb counting and label reading are not discussed.
The interactive eBook for newly diagnosed children with diabetes (ages 8-12) and their families called ‘Superhero learns about diabetes’ is a collection of different stories describing diabetes care in various scenarios and settings. Using the requirements (Table 21, third column), two stories for the eBook were developed: the digital prototype of ‘Superhero is sick’ and the paper mock-up of ‘What is type 1 diabetes?’ (Section 5.4.2.5 and Appendix H). Having fictional characters and natural scenes, the educational content was integrated into both narratives. The first story introduces a setting illustrating the initial diagnosis of a nine year old boy called Superhero (Figure 173 and Figure 174). In the second narrative, the main character goes on a small adventure (travelling through the human body) with a magic submarine; this helps him in understanding the function of the pancreas and insulin treatment (Figure 175 and Figure 176).
The text is simple, descriptive and informal, and developed based on participants’ experience with the chronic illness (Figure 177).

“Superhero, you have diabetes,” said Dr. Jenny.
“Will I have diabetes forever?” he looked at her.
“For now yes, but many scientists are working now to find a way to cure diabetes and I believe that it will happen very soon.”

Apart from the illustrations corresponding to diabetes, both stories include images allowing various interactions that are not associated with the educational content.
(e.g. sounds, moving a car, open a door, animation of Superhero’s dream, shrink/enlarge submarine, finding objects, etc.) (Figure 173, Figure 174, Figure 175 and Figure 176). Their purpose is to maintain the child’s attention (those who have diabetes and their siblings, friends, etc.) on the stories and allow them to have fun while reading alone or with their families.

In order to enable rich interactions with the storyline and to convey information about the topic, I have used different games, visualisations, images, etc. For example, in the hospital, after Superhero explained his symptoms (here children can interact with three objects to see the symptoms), he was advised by the doctor to do a blood test. In selecting appropriate images by playing with the integrated game, the users learn about the medical equipment (e.g. glucometer, test strips, lancets, etc.) and the steps used when measuring the blood glucose levels - as opposed to having only photos and instructions in bullet points (Figure 172). For example, the ‘Superhero is sick’ story presents information as follows: Step 1: “First we need to clean your finger. Look at the table. What should you use to clean your finger?”, Step 2: “Very good. You need to clean your finger with soap & water or a cleaning pad like these.”, Step 3: “Very good. Do you see this gadget that can measure the sugar in your blood? This is a glucometer, and this is a small test strip that works together with the glucometer. We need to take a strip from the container and then put it in the glucometer.” (Figure 178).

Similarly, in the same story, playing with the images of the insulin pump and glucometer, children can read about the former versions of these technologies developed years ago (e.g. “This is the first glucometer called Ames Reflectance Meter; it was invented by Anton Clemens and weighed 1.2 kg. It was only available
for doctor’s offices and hospital emergency departments. Now we have many modern glucometers so that diabetic children like you can use them at home or at school.”

(Figure 179). One of the requirements for the content was to integrate role models in the narratives. This was achieved with the doctor’s photo album: users can select an image of a celebrity who has diabetes and read about his/her story (e.g. “Gary Mabbutt is an English former professional footballer, who won 16 caps for the England national team. He was diagnosed with type 1 diabetes at 17 years of age and now he is 53.” p 12, Appendix H). The second story aims to describe diabetes and self-care practices to the users. The educational process starts with a magic trip into the human body, helping to describe, and show, the functions of the stomach and pancreas. In order to explain difficult content in a comprehensible manner, metaphors, games, and illustrations were used (e.g. “the stomach works as a mixer breaking the food into smaller pieces”, Figure 180). Playing with one of the mini-games, the learners need to rearrange the placement of different organs in the human body.

Similar to ‘Pete the Pancreas’ (Figure 168), images of sugar cubes and keys to explain how the pancreas functions were used in the eBook. However, children have more freedom to move and interact with these images, which could help them to understand and visualise the process (Figure 181 and Figure 182). Additionally, the text in the second narrative provides more details on diabetes e.g. “For people who have diabetes, their pancreas stops making insulin and then the glucose cannot get into the cells normally, so the blood sugar levels get too high. As a result of not having fuel they may feel tired, thirsty, have blurred vision, visit the toilet often and
have mood changes. Lots of sugar in the blood makes people sick if they do not get treatment – insulin” (Figure 181) and insulin treatment e.g. “Insulin is really important for the body and you can get it only through injections. The insulin tablets are broken down in the stomach before they can be absorbed and they are not able to replace the injections.” (Figure 182). For explaining the balance needed when taking insulin and food, a seesaw game could provide a simple visualisation/simulation, illustrating what food contains carbohydrates and requires insulin (Figure 183).

During the evaluation process with children and parents, the images in the eBook stories were considered nice, colourful and child friendly. In contrast, the cartoons presented in the booklet (e.g. ‘Pete the Pancreas’) were described as boring and childish (Section 5.5.2). The interactivity inherent to the interactive eBook appeared to be an important element for reading the stories with family members; while parents read the text, children could play with the interactive elements, thus improving the parent-child communication and discussing diabetes. Unfortunately, this cannot be achieved with ‘Pete the Pancreas’, because colouring images or word puzzles are considered as individual activities by the readers of this book.

With the discussed examples, I showed that while these two educational materials, ‘Pete the Pancreas’ and the eBook story ‘Superhero learns about diabetes’, are both designed to support paediatric diabetes education for newly diagnosed children with T1DM, they have diametrically opposed perspectives in their content and learning approach. I suggested an abstract model, recommending that the design of such educational interactive technologies could create a more patient-oriented approach,
involving all members in the family learning together. The educational content of these technologies could be informal, based on the patients’ perspective and personal experience with the chronic condition. Using a narrative approach, the rich interaction with the content could be used as a powerful teaching tool for enhancing the learning experience, making the process fun and interesting. The early involvement of participants in the design process could facilitate the gathering of design requirements in order to develop the design of an informal interactive educational resource that may better resonate with the users’ needs. Applying UCD, PD, CI and ID could support the co-design activities and the participation of children and parents during the development and design of the interactive educational technology.

Finally, this section discusses the findings presented in the thesis with relation to the research questions I proposed in Chapter 1. This study 1) provides critical reflection on the design process WITH this particular group of individuals and 2) suggests design requirements and a model for designing educational interactive technology FOR newly diagnosed children and their families. Here, the focus is on unpacking some of the limitations and problems, which emerged in HCI, PD and CCI, contributing to the growing discourse on parents’ and children’s participation in developing technologies supporting self-care practices. I highlighted the benefits of their participation, as well as some of the challenges and obstacles that may arise during the collaborative work. The guidelines that emerged, (i.e. a set of requirements and an abstract model) indicated the need for educational interactive resources that have informal content, are based on the users’ experience with the chronic condition and are facilitating a group learning approach. Therefore, the empirical data generated in this study successfully assisted in answering the initial questions.
Chapter 7: Limitations, Further Work and Conclusion

This chapter consists of three sections: Section 7.1 summarizes the work completed during this investigation, Section 7.2 outlines a number of practical contributions along with some opportunities to further investigate design process activities in producing and publishing the educational eBook, and Section 7.3 illustrates how the evaluation of technology - particularly in healthcare settings - may trigger a series of challenges impacting the design process.

7.1 Summary

The main question - described in the introduction of this thesis - guided the overall investigation of this study to help explore design practices for/with children with Type 1 Diabetes Mellitus (T1DM) and their parents/guardians. To support my work, I suggested a set of three sub-questions that have been addressed within this investigation:

**RQ 1:** What are the problems, issues and practicalities experienced in paediatric diabetes self-care? What are the current limitations in the care provided for families who have children with T1DM? What is the role of IT in supporting paediatric diabetes care practices?

**RQ 2:** How to design an intervention that would better resonate with their perspective and the practicalities of their everyday life?

**RQ 3:** How to design an IT for/with children with diabetes and their parents? What are the issues experienced by designers working with this group of users? What combination of methodological strategies should be employed to overcome/avoid these issues when designing solutions for self-care practice of chronic paediatric conditions? Are co-design/participatory approaches adequate for this challenge? What combination of design principles and guidelines should be employed when developing interactive technologies that aim to facilitate diabetes education in newly diagnosed children with T1DM and their families?

In Chapter 2 and Chapter 3, I reviewed the current literature specifically addressing the areas of paediatric diabetes care and type 1 diabetes management, along with publications and resources in HCI examining UCD and participatory approach with adults and children in developing interactive technologies. In Chapter 2, I demonstrated the increasing prevalence of non-communicable diseases amongst the
young population; the ubiquitous nature of paediatric diabetes care; some of the challenges and issues in self-care practices and long-term health problems that may occur as a result of living with this chronic condition. The treatment of type 1 diabetes, paediatric services and model of care in Ireland supporting young patients with diabetes and their families were also discussed as this helped to pinpoint several limitations in the provided care. Among others, the shortage of educational materials and processes emerged as a limitation of current systems, especially from the perspective of newly diagnosed children and their families. Additionally, an extensive review of different educational IT designed for children with T1DM showed two limitations i.e. a shortage of details in explaining the design process and how to support/foster young users’ involvement in IT design. In Chapter 3, I looked over the academic articles, books and other sources describing HCI, UCD, PD and CCI practices with a focus on design approaches that were aimed at, and supported, the involvement of children with chronic illnesses (such as diabetes) and their parents. Approaches to collaborative and participatory design such as ID (Scaife et al 1997), CI (Druin 2002; Hourcade 2007; Guha et al 2012) and BRIDGE (Iversen and Brodersen 2008) were critically discussed. A visualisation displaying a selection of methods, techniques and tools in CCI that are currently used to support children playing different roles in the design process was developed and discussed. Particular attention was paid to the lack of analysis concerning the suitability and usefulness of many of these design interventions - particularly with diabetic children and their guardians as design partners - when exploring sensitive issues such as chronic diseases. In addition, and perhaps more importantly, the chapter outlined and justified the needs and reasons for pursuing further research in the study field.

In Chapter 4, I defined the methodological approach applied to collect and generate empirical data to help find the answers to the research questions posed in Chapter 1. In order to outline and derive methods for involving children with chronic diseases, I have shown that the modified UCD by Årsand and Demiris (2008) - that was suggested when designing for patient-centric self-help tools in particular - had not been explored with design partners such as children with diabetes and their parents by involving them in the whole design process. In addition, I described in detail what criterion was used when the methods, techniques and tools were selected to facilitate
and enable the user’s participation and performance of UCD. Furthermore, affinity diagrams, design probes, collaborative storytelling, personas, scenarios, storyboards and the layered elaboration technique have not been explored with children with T1DM and their caregivers applying CI and PD. Furthermore, I outlined the need for healthy children to be involved in the eBook design as role *informants*. The chapter concludes with a section describing how participants were recruited, along with the challenges experienced in this process.

In Chapter 5, I described UCD in detail, starting with the semi-structured interviews used to explore paediatric diabetes self-care practices from the perspective of young patients and their families. Then, I illustrated how the analysed data helped to identify the design of the eBook, as well as describing which design activities were adapted to enable and support the participation of individuals in the study. The context and characteristics of the educational interactive technology were defined with the help of the children (e.g. healthy and those with T1DM) and their parents. Data was gathered through organising and conducting a series of design and prototyping sessions by applying different co-design activities, including a mixture of tools and materials. Furthermore, I demonstrated the mock-up and digital prototypes’ development and their evaluation processes with both groups of participants: I discussed the participants’ various contributions and roles in the assessment procedure.

The findings reported in Chapter 6 revealed how the exploration of paediatric diabetes care practices enabled the identification of the participants’ needs and requirements. The empirical data generated was used as a catalyst for the design decisions i.e. to select and design an educational eBook. This chapter also provided information on the multiple strategies used for recruiting participants, as a necessary step considering the difficulty in accessing organizations supporting families who have children with diabetes. I discussed the different roles and inputs of parents and children into the design of interactive technologies, their contribution to the educational context and the quality of the technology, outlining the importance of their participation in the technology’s development. The findings indicated 1) that the examined methods, techniques and tools could be used as valid and reliable instruments facilitating UCD, PD, CI and ID with participants, and 2) the list of
requirements and the model developed could help researchers in developing educational tools to deal with chronic diseases in general, or with type 1 diabetes in particular, particularly for those newly diagnosed. Some results exposed the complexities and challenges faced in organising design activities in numerous settings; the sensitivity presented by the children with T1DM when their health issues were discussed to explore diabetes care in complex real-life settings, and other issues that impacted the accomplishment of scheduled meetings and sessions. Over time, I altered my role as designer in response to the group dynamic that took place at the workshops. I responded to how the participants used the tools and materials in performing design, prototype and evaluation activities, to achieve balanced participation at the design sessions. Even though the discussed constraints and obstacles did appear in involving diabetic children and their parents as design partners, the results pinpointed the need for active participation of this group of vulnerable users in design when developing IT aiming to support some of their paediatric self-care practices. Hence, this participatory approach may effectively facilitate their involvement.

7.2 Contribution and Limitations of the Study

As illustrated in Chapter 6, the exploration of UCD and the participatory approach for designing an educational technology with/for children with diabetes and their parents facilitated the construction of knowledge based on the empirical data. This data was then used to address the research questions in this study. With this thesis, I have demonstrated and confirmed Glasemann and Kanstrup’s statement (2008) that children with T1DM and their parents can and should be involved in participatory design when developing an educational tool to help young individuals to learn about diabetes. The information used for the development of the eBook was generated by people who participated in this study and then translated into a design; I argue for the importance of children with T1DM and parents’ involvement as design partners. In this case, I have confirmed that UCD, PD and CI supported their participation in the design process. Having different roles and involvement in paediatric diabetes management (i.e. the child who manages their diabetes and the parent who is the educator and caregiver), the individuals have created various visions on the educational process - criteria based on their diverse experience. As a result of their
complementary roles as participants and their diverse input, this approach helped to generate rich data for the educational content of the eBook, facilitating the quality of the technology design and I have illustrated all of these benefits. As discussed, designing with these participants was not easy to achieve - it needed careful planning of all activities supporting co-design to help build a holistic understanding of their daily life with diabetes and enabling their participation from the first steps of the design process. Moreover, this assisted in identifying the sensitive nature of the topic when discussed, as well as the fact that the health status of children could be a key factor affecting their participation in planned activities. These issues created some barriers that were experienced and discussed during this study: they impacted 1) the recruitment of young individuals to participate in the study and the access to the various groups supporting patients with chronic diseases, 2) the scheduling and organising of a series of events to meet and work with the participants and 3) the organization and implementation of the UCD process, particularly in selecting design interventions supporting active participation. In order to cope with these problems, I explored multiple recruitment strategies, places to conduct the meetings and sessions, and a series of methods, techniques and tools to involve participants in the design process. In addition, I justified the selection of mixed methods and materials to support the participatory approach and demonstrated how they were adapted for children (i.e. healthy and those diagnosed with diabetes) and their parents 1) to support the eBook design and 2) to explore and reflect on the effects of UCD, PD, CI, interviews, design probes, affinity diagrams, collaborative storytelling, personas, storyboards, scenarios and layered elaboration methods in a sensitive manner for developing educational technology for/with children with chronic diseases. Moreover, the discussing the sensitive topic individually and the implementation of the new roles of the designer to deal with the negative emotions presented during the collaborative process have emerged as important factors when designing with children. This helped to outline the need for a relationship based on trust between the designer and the young individuals with T1DM and an empathetic understanding of their struggles to share their personal challenges in managing diabetes. In addition, I reflected on the whole design process by discussing the participation of both healthy and chronically ill children in the design. I showed the involvement of these two groups of participants who played the roles of design partners (i.e. children with
diabetes and their parents) and of informants (i.e. healthy young individuals) based on their experience of living with different, meaningful socio-cultural practices i.e. of having diabetes and being a healthy child. As a result, I described how the selected activities facilitated the design process with each group, as well as their input and contribution to the eBook design. Additionally, I suggested a set of requirements for educational IT design based on four categories: Users, Educational Content, Language and Interactivity. This helped me to critically discuss the current educational practices in comparison to the educational requirements that participants (e.g. children and parents) have. The results were represented in a model illustrating the differences between the already existing educational material and the one put forward in this study. In the first, the content is medical, formal, static, based on rules and designed to support individual learning. In the second, the design uses narratives and is interactive; the design is based on the patients’ experience, language, and facilitates group (family) learning. Such valuable information could benefit and guide researchers/designers in their work when developing educational IT for children with chronic diseases and their families.

I discussed the various contributions of this study, but some limitations have also been identified. Described below, these issues fall outside the scope of this study - they were not taken into account during this research and remain to be addressed. Hence, they could be specified as limitations and may be used as a springboard for future investigation of IT design with this group of users. Four main limitations along with their outcomes should be considered and investigated further:

1) The explored methods, techniques and tools in this research have only addressed the first iteration of UCD of the interactive technology with children (i.e. both healthy and with T1DM) and their parents/guardians up to medium fidelity prototyping. Therefore, the suitability of other methods that may support the development of high-fidelity prototypes or the final product of the eBook educational stories (i.e. to perform the following iterations) has yet to be explored.

2) As the role of educational technology is to support newly diagnosed children in different settings i.e. at the home and within healthcare contexts, the methods examined within this design process, particularly the evaluation
activities, were applied in various locations but not in clinical or in school settings. These activities required medium or high level fidelity prototypes, consequently their application in these environments requires more UCD iterations and further research. The future investigation needs to consider how these assessment activities when applied in a wider range of environments may support the involvement of different evaluators such as a) newly diagnosed children, healthcare educators and parents at the clinic and home, and b) teachers in schools. The following activities will require new ethical approvals to enable the design work, including new actors and settings. Taking into consideration the busy agendas of medical professionals, educators and teachers, these methods, techniques and tools need to support the evaluation process with less distraction from the normal work and treatment process.

3) The educational aspect of technology, which the design process was focused on, suggests that the research only reported the involvement of participants in the development of the eBook. Therefore, the findings are linked to this specific context. For example, if the users need other kinds of healthcare technology, other design activities could encourage better participation and contribution in designs.

This thesis illustrated that the involvement of children with T1DM and their parents in the design of educational interactive technology can be achieved with the use of interviews, design probes, collaborative storytelling and layered elaboration in environments outside the university building and design lab. However the usefulness and applicability of these design activities within hospitals and school settings has not been established. Additionally, the participation of medical professionals and teachers in the design of an educational eBook has not been fully explored in this study. Therefore, it remains an open question as what valuable information they could provide in the design process. To promote UCD and participatory approach and to enhance the participation of the vulnerable group of young individuals with diabetes in developing IT, the thesis findings provide a point of reflection on the explored design activities for researchers working in similar areas and participants.
7.3 Future Work

In the previous section, three limitations have emerged that could be considered a reasonable opportunity for further investigation. Generally, UCD is a long design process involving various users affected by technology. For that reason, this thesis shows only the first iteration of the large and long UCD process needed for the IT design; therefore, the assumptions about the effectiveness of applied methods, techniques and tools were made solely within the given context. For improving the quality of the technology before the final design of the product, a number of consecutive iterations are highly recommended. In performing each of these iterations, new challenges and issues may arise, particularly when testing the functionality of the eBook in clinical and school environments with various evaluators such as diabetes nurses, dietitians, newly diagnosed young patients and teachers. Similar studies have already reported various problems when designing in healthcare settings (Baggott et al 2015; Ruland et al 2008). For example, to work with these individuals, obstacles and barriers addressing ethical and recruitment processes may trigger various questions. One of them could be with the ethical constraints for research in healthcare settings, i.e. if some paediatric diabetes centres do not show any interest in the research and deny access to the medical centre and their group of patients diagnosed with type 1 diabetes, how will the designers overcome these barriers? In the case that they do get support from the clinic, what design activities would be appropriate to apply in busy and demanding settings? Where and how will the meetings and workshops be organised to support the participation of various participants? The design process could be started by gaining a clear understanding of a typical children's ward at a hospital and a overview of the facility as this may help to organise activities in a time and place that do not infringe upon patient diagnostic and treatment processes. Thus, adaption of the user-centred design process and other methods, techniques and tools to hospitals and other healthcare environments may be required to facilitate participatory design with medical professionals, diabetic children and their parents. Other questions that could be addressed include how the educators might integrate the technology into their diabetes educational practices in order to test the prototypes, and what design activities could help measure the educational success and satisfaction as a result of
using the eBook as an educational tool. Firstly, the educational aspect of the eBook must be quality assured by the national authority (e.g. the Quality Institute for Self-Management Education (QISMET)\(^68\)) before the testing of the prototype as part of the educational process. Secondly, the educators have to be familiar with the eBook itself to be able to use it as part of diabetes education to help answer questions on the topic. To successfully measure the effectiveness of interactive stories, the integration of quizzes with rewards to open mini-games or questionnaires (Baggott et al 2015) before they get access to the next narrative could be implemented as part of the eBook design. This could enable the collection of data unobtrusively, helping to analyse the progress made as a result of playing and using the product. These results could inform and facilitate further change to the educational context and design.

### 7.4 Conclusion

This dissertation work demonstrates and argues that children with T1DM, their parents and HCI researchers/designers can work together as design partners when developing interactive technologies to support some of the paediatric diabetes practices. This point was illustrated through the examination of carefully selected and adapted methods described in the PD and CCI collections to support the participation of young individuals with diabetes and their families in communicating and articulating information related to their experiences with the chronic condition to inform the design process. Moreover, the thesis shows that the work with healthy children as informants offers valuable contributions in developing educational technology for newly diagnosed children with diabetes. The design of this technology was based on an extensive investigation of paediatric diabetes practices in a domestic environment and of the methods used to support the collaborative work between children and designers. Working closely with the participants also helped to suggest an abstract model along with a set of requirements that could benefit future researchers when developing educational IT for newly diagnosed children with chronic diseases and their families. Therefore, by examining these methods’ effectiveness in a challenging field and working in an emotionally demanding

environment, this thesis could be strongly beneficial to future designers when undertaking similar design focus areas.

The future research should try to continue to enhance the knowledge obtained in the field by addressing the involvement of more actors and exploring various settings in which the design process may be undertaken. This can be supported by exploring the suitability of other existing tools and techniques suggested in the PD and CCI or develop/adapt new ones to ensure that these design interventions successfully aid various groups of participants by generating and offering valuable guidelines for further technology design and investigations within the field.
References


Diabetes Action (2011) 'Proposal for Improved Child and Adolescent Diabetes Services May-August 2011', [online], available: http://www.diabetesaction.ie/PDFs/PaedsCampaign.10.05.05.11.pdf [accessed 12 March 12].


401


404


Webber, D., Guo, Z. and Mann, S. (2013)'Self-care in health: we can define it, but should we also measure it?', SelfCare Journal, 4(5), 101-106.


## Appendix (A) Colour coded Table illustrating a selection of method, techniques and tools

<table>
<thead>
<tr>
<th>Area</th>
<th>Methods</th>
<th>Techniques</th>
<th>Tools</th>
<th>Purpose &amp; Design stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCD area</td>
<td><strong>User eXperience</strong></td>
<td><strong>Contextual Laddering</strong></td>
<td><em>This or That</em></td>
<td>Evaluation of prototypes</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Zaman and Abeele 2010</em></td>
<td><strong>Zaman and Abeele 2007</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Fun Toolkit</strong></td>
<td><em>Read 2006</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>To measure the child’s engagement with interactive products</td>
</tr>
<tr>
<td></td>
<td><strong>Usability evaluation</strong></td>
<td><strong>Co-Discovery</strong></td>
<td></td>
<td>Usability Evaluation</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Kemp et al 1996</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Van Kesteren et al 2003</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Peer Tutoring</strong></td>
<td><strong>Hoysniemi at al 2002</strong></td>
<td></td>
<td>Usability Evaluation</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Van Kesteren et al 2003</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Thinking Aloud</strong></td>
<td><strong>Van Kesteren et al 2003</strong></td>
<td></td>
<td>Usability Evaluation</td>
</tr>
<tr>
<td></td>
<td><strong>Active Intervention</strong></td>
<td><strong>Van Kesteren et al 2003</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Retrospection</strong></td>
<td><strong>Van Kesteren et al 2003</strong></td>
<td></td>
<td>Usability Evaluation</td>
</tr>
<tr>
<td></td>
<td><strong>PIPC</strong></td>
<td><strong>Barendregt et al 2007</strong></td>
<td></td>
<td>Usability Evaluation to identify levels of engagement and problems in games</td>
</tr>
</tbody>
</table>


| UCD and PD intersection zone | Informant Design  
Scaife et al 1997 | May apply in various design stages e.g. identify problems, design, prototype and evaluation |
|---|---|---|
| Bonded Design  
Large et al 2006 | | At all stages of design process, mainly used in school settings for a short period of time |
| Bluebells  
Kelly et al 2006 | Before play: researchers | Only for designers/researchers |
| | During Play: Children | |
| | I-Spy | To collect contextual information by observing children while they explore the context and environment |
| | Hide and Seek | To collect information about product/application content |
| | Tig | To gather information concerning how children navigate, interact, and control user interfaces |
| | Blind Man’s Bluff | To produce initial prototypes using the data from ‘During Play’ stage |
| | | |
| | After Play: researchers | Only for designers/researchers |
| MESS  
Horton et al 2012  
Read et al 2006 | Obstructed Theatre  
Read et al 2010 | In the design process for identifying specification of devices |
| Cultural probes (CP)  
Gaver et al 1999  
Mattelmäki 2005 | Educational  
Wyeth and Diercke 2006 | At the early stage of the design process, to discover children’s personal interests and their ideas within an educational context |
| | Digital  
Iversen and Nielsen 2003 | At the early stage of the design process, to gain basic knowledge of children’s learning process outside the typical school environment |
<table>
<thead>
<tr>
<th>LCD and PD</th>
<th>Design methodology</th>
<th>Use</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interception zone</strong></td>
<td><strong>Curriculum-focused design</strong>&lt;br&gt; Rode et al 2003</td>
<td>To understand the type of users and create child personas</td>
<td>To generate scenarios exploring bullying issues in a classroom and to evaluate storyboards with users to gather feedback</td>
</tr>
<tr>
<td></td>
<td><strong>Comicboarding</strong>&lt;br&gt; Moraveji et al 2007</td>
<td>To generate scenarios exploring bullying issues in a classroom and to evaluate storyboards with users to gather feedback</td>
<td>Work with children in the brainstorming sessions to generate ideas gradually</td>
</tr>
<tr>
<td></td>
<td><strong>Magicboarding</strong>&lt;br&gt; Moraveji et al 2007</td>
<td>Work with children in the brainstorming sessions to communicate children’s ideas</td>
<td>Work with children in the brainstorming sessions to communicate children’s ideas</td>
</tr>
<tr>
<td></td>
<td><strong>Emotional</strong>&lt;br&gt; Chung and Gerber 2010</td>
<td>Encouraging children to express their feelings and to generate meaningful content</td>
<td>Encouraging children to express their feelings and to generate meaningful content</td>
</tr>
<tr>
<td><strong>Child personas</strong>&lt;br&gt; Antle 2008</td>
<td></td>
<td>Can be used to guide design in scenarios, to test prototypes, and develop persona-centric usability studies. Used to overcome the lack of access and work with children as design partners or informants</td>
<td>Can be used to guide design in scenarios, to test prototypes, and develop persona-centric usability studies. Used to overcome the lack of access and work with children as design partners or informants</td>
</tr>
<tr>
<td><strong>PD zone</strong></td>
<td><strong>CI</strong>&lt;br&gt; Druin 1999&lt;br&gt; Druin 2002</td>
<td>Suggest ideas or build prototypes</td>
<td>Suggest ideas or build prototypes</td>
</tr>
<tr>
<td></td>
<td><strong>Bags of Stuff</strong>&lt;br&gt; Guha et al 2012</td>
<td></td>
<td>Suggest ideas or build prototypes</td>
</tr>
<tr>
<td></td>
<td><strong>Technology immersion</strong>&lt;br&gt; Druin 2002&lt;br&gt; Nesset and Large 2004</td>
<td></td>
<td>Observing children’s interaction with various technologies to identify roles and patterns at the beginning of the project</td>
</tr>
<tr>
<td>Method</td>
<td>Description</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mixing of ideas</strong>&lt;br&gt;Guha et al 2004</td>
<td>To design innovative new technology and engage children in a collaborative design process</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sticky noting</strong>&lt;br&gt;Guha et al 2012</td>
<td>For design requirements</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Layered elaboration</strong>&lt;br&gt;Guha et al 2012</td>
<td>Paper-based prototyping technique enabling to add and to expand ideas asynchronously without destroying the original resource</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Telling stories</strong>&lt;br&gt;Alborzi et al 2000&lt;br&gt;Druin 2002</td>
<td>Collaborative storytelling with children in the brainstorming sessions</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pictorial flowcharts</strong>&lt;br&gt;Druin 2002</td>
<td>A note-taking technique that can be used by children while observing other children</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Journals</strong>&lt;br&gt;Fails et al 2012</td>
<td>To keep writing down individual ideas related with the design</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BRIDGE</strong>&lt;br&gt;Iversen and Brodersen 2008</td>
<td><strong>DisCo</strong>&lt;br&gt;Walsh et al 2012 To enable asynchronous and intergenerational co-design with children</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Video Prototyping</strong>&lt;br&gt;Mackay et al 2000, Ylirisku 2004</td>
<td>To explore the potential of mobile phones in educational contexts</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Probing practice</strong>&lt;br&gt;Boltman et al 1998&lt;br&gt;Druin 2002</td>
<td>To collect data on 1) a specific experience in context and 2) how children interact with certain types of technology</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fictional Inquiry &amp; Mission from Mars</strong>&lt;br&gt;Muller and Druin 2003&lt;br&gt;Dindler et al 2005</td>
<td>To collect data on children’s present practices and everyday life through role-playing. This data is then used to generate user requirements</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DESIGN WORKSHOPS</strong></td>
<td><strong>Group composition</strong></td>
<td>Ideal group size for the session is between four to six participants with children aged 7 to 10 years old.</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Geographical location and scheduling</strong></td>
<td>Location should be familiar to the children</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Creating the right environment</strong></td>
<td>Create a comfortable atmosphere for children e.g. appropriate room layout, lights, temperature, etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Moderator</strong></td>
<td>The moderator usually prepares the questions to be discussed during the focus group. Personal traits: have a positive attitude and personality; have a good understanding of the dynamics of the group and have the skills to engage kids in the group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Introducing the group</strong></td>
<td>Provide clear explanation about children’s role, rights (consent form and information sheet), work activities and tasks planned for the session.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Conducting and recording the discussion</strong></td>
<td>Plan in advance open-ended questions and activities. Organise audio/video recording or to have an assistant moderator who can take notes during the session. Sessions last between 45-90 minutes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Rewards and recognition</strong></td>
<td>A small gift or certificate as rewards for children’s participation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix (B) Information Sheet & Consent Form

**INTERVIEWS ADULTS/PARENTS - INFORMATION SHEET**

**Project Title:** “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

**What is the aim of the study?**

Parents of children with diabetes experience a series of unique problems in taking care of their children and managing their disease outside the attention of the medical staff. The purpose of this study is to gain knowledge about these everyday practicalities and issues; shed light on the difficulties that parents and children experience in monitoring blood glucose and act accordingly (such activities include taking medications, monitoring glycaemic index, following specific diet, doing physical exercise and so on).

**What are amount of time involved for participant?**

Each volunteer will be invited to take part in a semi-structured interview investigating current care practices in relation to their diabetes. The interview will last for about 1 hour.

**Where the research will take place- will participant have any say in this?**

At a location convenient for the volunteer.

**What are the risks or benefits?**

Minimal risk related to data protection and information confidentiality. This research will benefit participant by allowing them to reflect on their problems and become more aware of the technological solutions that might be available to them. This data will inform the design of a solution that can bring further benefit to their everyday care practices.

**How confidentially and data will be protected?**

The interview will be audio recorded using a digital recorder and if the volunteer feels uncomfortable with being recorded at any time, he/she can request that all the recording equipment will be switched off. All gathered information will be transcribed into text. It will be kept confidential and all data will be anonymized. The data will be stored in a secure facility in the Interaction Design Centre, University of Limerick, room CS2-032 using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. Upon completion of this project, all data will be stored for 7 years after the collection and after that time will be destroyed.

**What if you do not won’t to take a part in this research?**

Participation in this study is entirely voluntary and the participant may choose not to answer questions or withdraw from any activity related to this study at any time without giving reason.

**Contact information:** Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvaytkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
INTERVIEWS CHIDLREN - INFORMATION SHEET

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

What is the aim of the study?
Children with diabetes experience a series of unique problems in managing their disease outside the attention of the medical staff. The purpose of this study is to gain knowledge about these everyday practicalities and issues and shed light on the difficulties that the children experience in monitoring blood glucose and act accordingly. Such activities include, but are not limited to, taking medications, monitoring glycaemic index, following specific diet, doing physical exercise and so on. Your parents/guardians have already given their consent for your participation, but you will decide whether or not to take part in this interview.

What are amount of time involved for participant?
Each volunteer will be invited to take part in a semi-structured interview investigating current care practices in relation to their diabetes. The interview will last for about 1 hour.

Where the research will take place- will participant have any say in this?
At a location convenient for the volunteer.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participant by allowing them to reflect on their problems and become more aware of the technological solutions that might be available to them. This data will inform the design of a solution that can bring further benefit to their everyday care practices.

How confidentially and data will be protected?
The interview will be audio recorded using a digital recorder and if the volunteer feels uncomfortable with being recorded at any time, he/she can request that all the recording equipment will be switched off. All gathered information will be transcribed into text. It will be kept confidential and all data will be anonymized. The data will be stored in a secure facility in the Interaction Design Centre, University of Limerick, room CS2-032 using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. Upon completion of this project, all data will be stored for 7 years after the collection and after that time will be destroyed.

What if you do not won't to take a part in this research?
Participation in this study is entirely voluntary and the participant may choose not to answer questions or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

What is the aim of the study?
You are being invited to take part in this research because of your experience and knowledge as a diabetes nurse/diabetes dietician. The focus of this project is to investigate everyday practicalities and difficulties of managing paediatric diabetes. The aim is to better understand current educational practices and to explore the role of interactive technology in supporting newly diagnosed children (8-12 years old) and their parents in learning about diabetes, making sense of it and improving self-management practices.

What are amount of time involved for participant?
The interview will last for about 45 minutes.

Where the research will take place- will participant have any say in this?
At a location convenient for the volunteer.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality.

How confidentially and data will be protected?
The interview will be audio recorded using a digital recorder and if the volunteer feels uncomfortable with being recorded at any time, he/she can request that all the recording equipment will be switched off. All gathered information will be transcribed into text. It will be kept confidential and all data will be anonymized. The data will be stored in a secure facility in the Interaction Design Centre, University of Limerick, room CS2-032 using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. Upon completion of this project, all data will be stored for 7 years after the collection and after that time will be destroyed.

What if you do not won’t to take a part in this research?
Participation in this study is entirely voluntary and the participant may choose not to answer questions or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
**DESIGN PROBES - INFORMATION SHEET (FIRST ITERATION)**

**Project Title:** “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

**What is the aim of the study?**

You are invited to take part in a research project. This project aims to explore the role of design and new Interactive Technology (IT) in helping and supporting children with type 1 diabetes and their parents in the everyday management of diabetes. If you agree to take part, you and your child (8 – 12 years old) will participate through self-documentation using a set of probes especially designed for this project. These probes contain purposefully selected tools and detailed instructions for their use. Your tasks will include sending postcards, taking photographs using the disposable camera, designing a gadget, designing a collage/poster, completing a kid’s diary, modelling a clay Superhero, designing your own recipe book and completing a problem solving diary. All the needed materials are provided and ready for use over a period of four weeks and then the materials will be collected and analysed. The purpose of the probes is to gain in-context information about living with diabetes and to capture a better understanding of your experiences.

**What are amount of time involved for participant?**

Each volunteer will be given a kit of materials for four weeks.

**Where the research will take place—will participant have any say in this?**

The volunteer will use the set at her/his home.

**What are the risks or benefits?**

Minimal risk related to data protection and information confidentiality. This research will benefit participant by allowing them to reflect about their problems with everyday care practices.

**How confidentially and data will be protected?**

However, all materials and photographs generated from the probes will be confidential and the only people who will work with this information will be myself, my supervisor Dr. Cristiano Storni and my examiners, who will be checking my work. No-one will be named in the report, privacy and confidentiality will be kept. No pictures revealing identity will be used in any published documentation. All materials and photographs generated from the probes will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

**What if you do not won’t to take a part in this research?**

Participation in this study is entirely voluntary and the participant may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

**Contact information:** Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvaytkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

What is the aim of the study?
You are invited to take part in a research project. This project aims to explore the role of design and new Interactive Technology (IT) in helping and supporting children with type 1 diabetes and their parents in the everyday management of diabetes. If you agree to take part, you and your child (8 – 12 years old) will participate through self-documentation using a set of probes especially designed for this project. These probes contain purposefully selected tools and detailed instructions for their use. Your tasks will include taking photographs using the disposable camera, designing a gadget, designing a collage/poster and modelling a clay Superhero. All the needed materials are provided and ready for use over a period of eight weeks and then the materials will be collected and analysed. The purpose of the probes is to gain in-context information about living with diabetes and to capture a better understanding of your experiences.

What are amount of time involved for participant?
Each volunteer will be given a kit of materials for four weeks.

Where the research will take place will participant have any say in this?
The volunteer will use the set at her/his home.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participant by allowing them to reflect about their problems with everyday care practices.

How confidentially and data will be protected?
However, all materials and photographs generated from the probes will be confidential and the only people who will work with this information will be myself, my supervisor Dr. Cristiano Storni and my examiners, who will be checking my work. No-one will be named in the report, privacy and confidentiality will be kept. No pictures revealing identity will be used in any published documentation. All materials and photographs generated from the probes will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this research?
Participation in this study is entirely voluntary and the participant may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Workshop session one: Developing an idea for an interactive eBook for children with type 1 diabetes

What is the aim of the study?

You are invited to take part in a workshop session. Children with diabetes have experience in solving different issues in taking care of type 1 diabetes and its treatment. The purpose of this workshop session is to develop an idea of interactive eBook specifically designed for children with type 1 diabetes in Ireland. Your knowledge and experience with diabetes will help us to identify features, content, and other important characteristics of the technology that will help children learn more about the nature of diabetes and self-care practices. In this session, we will use a big sheet of paper and art materials (paper, glue, images, colouring pencils, etc.), as well as sticky notes to create images and drawings while generating some ideas. We will use collaborative storytelling to stimulate your creative minds.

Your parents/guardians have already given their consent for your participation, but you will decide whether or not to take part in this workshop session.

What amount of time is involved for participants?

The session is planned to be for one hour and 30 minutes in length.

Where the workshop session will take place?

The session will take place at the ‘Interaction Design Centre’ at the ‘University of Limerick’.

What are the risks or benefits?

Minimal risk related to data protection and information confidentiality. This research will benefit participants by allowing them to reflect on their problems. It will help them become more aware of the technological solutions that might be available for them. It will also help to inform future design phases to help develop solutions that can bring further benefit to their everyday care practices.

How confidentially and data will be protected?

The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?

Participation in this workshop session is entirely voluntary. You may choose not to take part in this workshop session or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
DESIGN WORKSHOP 1 - PARENT/CARER INFORMATION SHEET

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Design workshop session one: Developing an idea for an interactive eBook for children with type 1 diabetes

What is the aim of the study?

We would like to invite you and your child (ages 8-12) to participate in our workshop session 1. The purpose of this workshop session is to develop an idea for an interactive eBook specifically designed for children with type 1 diabetes in Ireland. In this session, we will use a big sheet of paper and art materials (paper, glue, images, colouring pencils, etc.), as well as sticky notes to create images and drawings while generating some ideas. The use of collaborative storytelling will stimulate your child’s creative minds to generate some ideas. These materials will help develop each child's unique perspective and individual style of creative expression and imaginative output. We would really appreciate your assistance with our research, and especially you allowing your child to participate in this workshop session.

What amount of time is involved for participants?

The session is planned to be for one hour and 30 minutes in length.

Where the workshop session will take place?

The session will take place at the ‘Interaction Design Centre’ at the ‘University of Limerick’.

What are the risks or benefits?

Minimal risk related to data protection and information confidentiality. This research will benefit participants by helping them become more aware of design process in action and different types of interactive applications for children.

How confidentially and data will be protected?

The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-034 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?

Participation in this study is entirely voluntary and the participant (your son/daughter) may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 061 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
DESIGN WORKSHOP 2 - CHILD INFORMATION SHEET

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Design workshop session two “Traveling through the human body”: Developing an idea for an interactive eBook for children with type 1 diabetes

What is the aim of the study?
You are invited to take part in a collaborative storytelling workshop session. The purpose of this workshop session is to develop an idea for an interactive eBook specifically designed for children with type 1 diabetes in Ireland. In this session, we will use storytelling cards, modeling clay kit to create figurines and foam cross-section human body model. The use of collaborative storytelling will stimulate your creative minds to generate some ideas. These materials will help develop your unique perspective and individual style of creative expression and imaginative output. Your parents/guardians have already given their consent for your participation, but you will decide whether or not to take part in this workshop session.

What amount of time is involved for participants?
The session is planned to be for one hour in length.

Where the workshop session will take place?
The session will take place at the Russian school “Sunflower”, Diocesan Pastoral Centre, Limerick.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participants by helping them become more aware of design process in action and different types of interactive applications for children.

How confidentially and data will be protected?
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-034 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?
Participation in this workshop session is entirely voluntary. You may choose not to take part in this workshop session or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvaytkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
**DESIGN WORKSHOP 2 - PARENT/CARER INFORMATION SHEET**

**Project Title:** “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

**Design workshop session two “Traveling through the human Body”:** Developing an idea for an interactive eBook for children with type 1 diabetes

**What is the aim of the study?**
We would like to invite you and your child (ages 8-12) to participate in our design workshop session 2. The purpose of this workshop session is to develop an idea for an interactive eBook specifically designed for children with type 1 diabetes in Ireland. In this session, we will use storytelling cards, modeling clay kit to create figurines and foam cross-section human body model that have the potential to stimulate open-ended activities contributing to our design work. The use of collaborative storytelling will stimulate your child’s creative minds to generate some ideas. These materials will help develop each child's unique perspective and individual style of creative expression and imaginative output. We would really appreciate your assistance with our research, and especially you allowing your child to participate in this workshop session.

**What amount of time is involved for participants?**
The session is planned to be for one hour in length.

**Where the workshop session will take place?**
The session will take place at the Russian school “Sunflower”, Diocesan Pastoral Centre, Limerick.

**What are the risks or benefits?**
Minimal risk related to data protection and information confidentiality. This research will benefit participants by helping them become more aware of design process in action and different types of interactive applications for children.

**How confidentially and data will be protected?**
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-034 for 7 years after the collection and after that time will be destroyed.

**What if you do not want to take a part in this workshop session?**
Participation in this study is entirely voluntary and the participant (your son/daughter) may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

**Contact information:** Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie,
Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
DESIGN WORKSHOP 3 - CHILD INFORMATION SHEET

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Design workshop session three “Superhero is sick”: Developing an idea for an interactive eBook for children with type 1 diabetes

What is the aim of the study?
You are invited to take part in a collaborative storytelling workshop session. The purpose of this design session is to develop an idea for a novel learning technology specifically designed for children with type 1 diabetes in Ireland. In this session, we will use storytelling cards, as well as a big sheet of paper and art materials (paper, glue, images, colouring pencils, etc.) to create images and drawings while generating some ideas. The use of collaborative storytelling will stimulate your creative minds to generate some ideas. These materials will help develop your unique perspective and individual style of creative expression and imaginative output. Your parents/guardians have already given their consent for your participation, but you will decide whether or not to take part in this workshop session.

What amount of time is involved for participants?
The session is planned to be for one hour in length.

Where the workshop session will take place?
The session will take place at the Saint Michael's Church, Limerick.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participants by helping them become more aware of design process in action and different types of interactive applications for children.

How confidentially and data will be protected?
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-034 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?
Participation in this workshop session is entirely voluntary. You may choose not to take part in this workshop session or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Design workshop session three “Superhero is sick”: Developing an idea for an interactive eBook for children with type 1 diabetes

What is the aim of the study?
We would like to invite you and your child (ages 8-12) to participate in our design workshop session 3. The purpose of this workshop session is to develop an idea for a novel learning technology specifically designed for children with type 1 diabetes in Ireland. In this session, we will use storytelling cards, as well as a big sheet of paper and art materials (paper, glue, images, colouring pencils, etc.) to create images and drawings while generating some ideas. The use of collaborative storytelling will stimulate your child’s creative minds to generate some ideas. These materials will help develop each child's unique perspective and individual style of creative expression and imaginative output. We would really appreciate your assistance with our research, and especially you allowing your child to participate in this workshop session.

What amount of time is involved for participants?
The session is planned to be for one hour in length.

Where the workshop session will take place?
The session will take place at the Russian school “Sunflower”, Diocesan Pastoral Centre, Limerick.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participants by helping them become more aware of design process in action and different types of interactive applications for children.

How confidentially and data will be protected?
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-034 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?
Participation in this study is entirely voluntary and the participant (your son/daughter) may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvytakova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
PROTOTYPING WORKSHOP - CHILD INFORMATION SHEET

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Prototyping workshop session four “Superhero is sick”: Build paper prototypes of an educational eBook for children with type 1 diabetes

What is the aim of the study?
You are invited to take part in a prototyping workshop session. Children with diabetes have experience in solving different issues in taking care of type 1 diabetes and its treatment. The purpose of this session is to build ideas for an educational eBook that will support newly diagnosed children and their families. Your knowledge and experience with diabetes will help us to identify features, content, and other important characteristics of technology that will help children learn more about the nature of diabetes and self-care practices. In this session, we will use storytelling cards, paper and art materials (paper, glue, images, colouring pencils, etc.), as well as sticky notes to create images and drawings while building prototypes. We will use collaborative storytelling to stimulate your creative minds. Your parents/guardians have already given their consent for your participation, but you will decide whether or not to take part in this workshop session.

What amount of time is involved for participants?
The session is planned to be for one hour in length.

Where the workshop session will take place?
The session will take place at the Easter camp, Trabolgan.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participants by allowing them to reflect on their problems. It will help them become more aware of the technological solutions that might be available for them. It will also help to inform future design phases to help develop solutions that can bring further benefit to their everyday care practices.

How confidentially and data will be protected?
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?
Participation in this workshop session is entirely voluntary. You may choose not to take part in this workshop session or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Prototyping workshop session four “Superhero is sick”: Build paper prototypes of an educational eBook for children with type 1 diabetes

What is the aim of the study?

We would like to invite you and your child (ages 8-12) to participate in our prototyping session. Children with type 1 diabetes (and their parents) have experience in solving different issues in taking care of diabetes and its treatment. The purpose of this session is to build ideas for an educational eBook that will support newly diagnosed children and their families. Your knowledge and experience with type 1 diabetes will help us to identify features, content and other important characteristics of technology that will help children learn more about the nature of diabetes and self-care practices. In this session, we will use storytelling cards, paper and art materials (paper, glue, images, colouring pencils, etc.), as well as sticky notes to create images and drawings while building prototypes. We will use collaborative storytelling to stimulate your children’s creative minds. We would really appreciate your assistance with our research, and especially you allowing your child to participate in this workshop session.

What amount of time is involved for participants?
The session is planned to be for one hour in length.

Where the workshop session will take place?
The session will take place at the Easter camp, Trabolgan.

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participants by allowing them to reflect on their problems. It will help them become more aware of the technological solutions that might be available for them. It will also help to inform future design phases to help develop solutions that can bring further benefit to their everyday care practices.

How confidentially and data will be protected?
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design different technology prototypes. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this workshop session?
Participation in this study is entirely voluntary and the participant (your son/daughter) may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
**Project Title:** “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

**Evaluation session:** Test and evaluate the eBook prototypes

**What is the aim of the study?**
You are invited to take part in the eBook evaluation session. In our design sessions, we developed an idea for the design of an educational eBook for newly diagnosed children with type 1 diabetes helping them to learn about diabetes and the self-care practices. The aim of the prototyping workshop session was to generate feedback by building paper based prototypes together with children and their parents. This helped us modify and improve our design concept. Then we developed a series of stories which will be a part of the interactive eBook. This workshop session is organised to test and evaluate some of the ideas that we have developed. Together with you and your parent we will read and play with the story prototypes in order to elicit your comments to improve our designs. All the feedback collected during the sessions will be used to build more complete prototypes. Your parents/guardians have already given their consent for your participation, but you will decide whether or not to take part in this workshop session.

**What amount of time is involved for participants?**
The session is planned of 90 minutes in length.

**Where the workshop session will take place?**
At a location convenient for the volunteer (or at the Russian school “Sunflower”, Diocesan Pastoral Centre, Limerick).

**What are the risks or benefits?**
Minimal risk related to data protection and information confidentiality. This research will benefit participants by allowing them to reflect on their problems. It will help them become more aware of the technological solutions that might be available for them. It will also help to inform future design phases to help develop solutions that can bring further benefit to their everyday care practices.

**How confidentially and data will be protected?**
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design our medium fidelity prototype. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

**What if you do not want to take a part in this workshop session?**
Participation in this workshop session is entirely voluntary. You may choose not to take part in this workshop session or withdraw from any activity related to this study at any time without giving reason.

**Contact information:** Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvaytkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
EVALUATION SESSION - PARENT/CARER INFORMATION SHEET

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Evaluation session: Test and evaluate the eBook prototypes

What is the aim of the study?
We would like to invite you and your child (ages 8-12) to participate in the eBook evaluation session. In our design sessions, we developed an idea for the design of an educational eBook for newly diagnosed children with type 1 diabetes helping them to learn about diabetes and the self-care practices. The aim of the prototyping session was to generate feedback by building paper based prototypes together with children and their parents. This helped us modify and improve our design concept. Then we developed a series of stories which will be a part of the interactive eBook. This evaluation session is organised to test and evaluate some of the ideas that we have developed. Together with you and your child we will read and play with the story prototypes in order to elicit your comments to improve our designs. All the feedback collected during the sessions will be used to build more complete prototypes. We would really appreciate your assistance with our research, and especially you allowing your child to participate in this workshop session.

What amount of time is involved for participants?
The session is planned of 90 minutes in length.

Where the workshop session will take place?
At a location convenient for the volunteer (or at the Russian school “Sunflower”, Diocesan Pastoral Centre, Limerick).

What are the risks or benefits?
Minimal risk related to data protection and information confidentiality. This research will benefit participants by allowing them to reflect on their problems. It will help them become more aware of the technological solutions that might be available for them. It will also help to inform future design phases to help develop solutions that can bring further benefit to their everyday care practices.

How confidentially and data will be protected?
The workshop session will be video recorded. If you feel uncomfortable with being recorded at any time, you can request that all the recording equipment be switched off. We will take pictures of all the materials generated in the workshop session. All gathered information (materials, pictures and video recordings) will be used to design our medium fidelity prototype. It will be kept confidential and all materials will be anonymized. No pictures revealing identity will be used in any published documentation. The video recordings will be kept and stored in a secure facility in the ‘Interaction Design Centre’ at the University of Limerick using password protected computers. Only I and my faculty supervisor Dr. Cristiano Storni will have access to this information. All materials and pictures will be kept in a locked cabinet, room CS2-032 for 7 years after the collection and after that time will be destroyed.

What if you do not want to take a part in this research?
Participation in this study is entirely voluntary and the participant (your son/daughter) may choose not to partake or withdraw from any activity related to this study at any time without giving reason.

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
CHILD WORKSHOP CONSENT FORM

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Participant's Agreement:

- I understand the intent and purpose of this workshop session. I declare that I have been fully briefed on the nature of this study and my role in it and have been given the opportunity to ask questions before agreeing to participate.

- I understand that my role in this study is as an informant and that this is not an evaluation/judgement of my ability, knowledge or intelligence.

- The researcher has reviewed the individual and social benefits and risks of this workshop session with me.

- I am aware of how the data, materials and video recordings will be used in this project. I have the right to review, comment on, and/or withdraw information, materials and photographs prior to the project’s submission.

- I also understand that my participation in this study may be recorded by a video recorder and pictures may be taken of the materials produced in the workshop session and I agree with this. However, should I feel uncomfortable with being recorded at any time, I can request that all recording equipment be switched off. I am entitled to copies of all recordings and pictures made during the session if I wish to have them.

- Anonymity regarding the materials, pictures and video recordings gathered in this study will be strictly maintained unless I specify otherwise. No pictures and video recordings revealing my identity will be used in any published documentation.

- I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in this workshop session. I am aware that my participation in this workshop session is voluntary.

- I am making a decision to participate. My signature indicates that I have read the information provided above and have decided to participate.

I ___________________ agree to participate in this study.

Volunteer signature_________________________ Date____________________

Researcher signature______________________ Date______________________

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkov@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
PARENT/CARER CONSENT FORM - INTERVIEWS, DESIGN, PROTOTYPING AND EVALUATION SESSIONS

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Participant’s Agreement:

- I understand the intent and purpose of this interview/workshop session. I declare that I have been fully briefed on the nature of this study, mine and my son’s/daughter’s role in it and have been given the opportunity to ask questions before agreeing participation in this workshop session.
- I understand that mine and my son’s/daughter’s role in this study is as an informant and that this is not an evaluation/judgement of my ability, knowledge or intelligence.
- The researcher has reviewed the individual and social benefits and risks for me and my son/daughter in this project.
- I am aware of how the data, materials and video recordings will be used in this project. I have the right to review, comment on, and/or withdraw information, materials and photographs prior to the project's submission.
- I also understand that mine and my son’s/daughter’s participation in this study may be recorded by a video recorder and pictures may be taken of the materials produced in the workshop session and I agree to this. However, should I feel uncomfortable with being recorded, my child and I at any time can request that all recording equipment be switched off. I am entitled to copies of all the recordings and pictures made during the session if I wish to have them.
- The data gathered in this study are confidential with respect to me and my son/daughter personal identity unless I specify otherwise. I also understand that no video recordings and pictures revealing identity of me and my child will be used in any published documentation.
- I have read the above form and, with the understanding that I can withdraw mine and my son/daughter’s participation at any time and for whatever reason. I am aware that mine and my child’s participation in this project is voluntary.
- I am happy to let my son/daughter take part in this project. My signature indicates that I have read the information provided above and have decided I and my son/daughter will participate.

I __________________ agree to participate in this study.
Volunteer signature_______________________ Date_________________

Researcher signature__________________ Date_________________

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvaytkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
CONSENT FORM - ADULTS

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Participant's Agreement:

- I understand the intent and purpose of this research. I declare that I have been fully briefed on the nature of this study and my role in it and have been given the opportunity to ask questions before agreeing to participate.
- I understand that my role in this study is as an informant and that this is not an evaluation/judgement of my ability, knowledge or intelligence.
- The researcher has reviewed the individual and social benefits and risks of this project with me.
- I am aware of how the data will be used in this project. I have the right to review, comment on, and/or withdraw information prior to the project's submission.
- The data gathered in this study are confidential with respect to my personal identity unless I specify otherwise.
- I also understand that my participation in this study may be recorded by AV means, as well as in the form of notes taken by observers and I agree to this. However, should I feel uncomfortable with being recorded at any time, I can request that all recording equipment be switched off. I am entitled to copies of all recordings made during the session if I wish to have them.
- I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in interview.
- I am aware that my participation in this project is voluntary.
- I am making a decision to participate. My signature indicates that I have read the information provided above and have decided to participate.

I __________________ agree to participate in this study.

Volunteer signature_________________________ Date_________________

Researcher signature________________________ Date_________________

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
CONSENT FORM - MEDICAL PROFFESIONALS

Project Title: “Designing Interactive Technology (IT) for/with Children with T1DM: Exploring Methods, Techniques and Tools Facilitating Participatory Approach”

Participant’s Agreement:

- I understand the intent and purpose of this research. I declare that I have been fully briefed on the nature of this study and my role in it and have been given the opportunity to ask questions before agreeing to participate.
- I understand that my role in this study is as an informant and that this is not an evaluation/judgement of my ability, knowledge or intelligence.
- The researcher has reviewed the individual and social benefits and risks of this project with me.
- I am aware of how the data will be used in this project. I have the right to review, comment on, and/or withdraw information prior to the project's submission.
- The data gathered in this study are confidential with respect to my personal identity unless I specify otherwise.
- I also understand that my participation in this study may be recorded by AV means, as well as in the form of notes taken by observers and I agree to this. However, should I feel uncomfortable with being recorded at any time, I can request that all recording equipment be switched off. I am entitled to copies of all recordings made during the session if I wish to have them.
- I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in interview.
- I am aware that my participation in this project is voluntary.
- I am making a decision to participate. My signature indicates that I have read the information provided above and have decided to participate.

I ___________________agree to participate in this study.

Volunteer signature_______________________ Date_________________

Researcher signature_____________________ Date_________________

Contact information: Researcher: Damyanka Tsvaytkova Email: Damyanka.Tsvyatkova@ul.ie, Supervisor: Dr. Cristiano Storni Email: Cristiano.Storni@ul.ie Tel: 61 202632. If you have any concerns about this study and wish to contact someone independent you may contact the Chair, Faculty of Science and Engineering Research Ethics Committee, University of Limerick, Limerick. Tel: 061 202802.
Appendix (C) Four sets of interview questions

INTERVIEW QUESTIONS - PARENTS/GUARDIANS

Discovering about diabetes

1. When did you first learn that your child had developed diabetes?
2. Did you know about diabetes before? What did you have to learn?
3. How did it impact on your everyday life? What did you change first?
4. What does it mean to be a parent of a diabetic child?

Incorporating diabetes into daily life and the parent-child relationship

1. Can you describe a typical day with your child?
2. How has having type 1 diabetes changed your child's life?
3. What are the practicalities that you are experiencing on a daily basis?
4. How has your communication with your child changed? Do you find it difficult to talk about it? Do you find it difficult to describe issues and problems? Do you find it difficult to understand your child’s problems and issues?
5. How has your daily life as a family been rearranged around diabetes (e.g. have you rescheduled or re-organised things in your house or your daily routines)?
6. How is your child communicating with you about his/her difficulties? And with School teachers? And with friends?
7. What would you like other parents/friends/teachers at school to know about this disease? Why?

Protecting the child, support self-management and self-care practices

1. Can you describe any issues related to the diet? What sort of issues did you experience and how did you deal with them?
2. Can you describe any issues related to physical exercise? What sort of issues did you experience and how did you deal with them?
3. Can you describe any issues related to self-monitoring and self-medication? What sort of issues did you experience and how did you deal with them?
4. What level of autonomy is your child displaying in these three key activities (diet, physical exercise and self-monitoring (Journaling and medication))?
5. How do you cooperate on this? Who is doing what? Does your child want you to do something (e.g. testing blood, journaling values, inject insulin)?
6. Which one of the following is more difficult to monitor: insulin injections, blood testing, diet, physical activities, dealing with Hypos?
Relationship with the medical Staff

1. Have you received any medical training to deal with your child’s diabetes? What specifically? Was that enough? Did you have to learn other things on your own? What and how?
2. Describe your relationship with the medical staff. How often do you meet a professional and what do you discuss/ask/learn?
3. Do you find it difficult to communicate with them? Can you give me an example?
4. Do you find it difficult to comply with their advice? Can you give me an example?
5. What is your child’s relationship with the medical staff?
6. What is your child’s reaction to medical consultations, hospitalizations and medical exams?
7. Does your child lack confidence in his abilities? Has your child got low self-esteem?
8. If this is the case, what have you tried to overcome the problem?

Using technology

1. Do you use any specific technology to journal your child’s values (web, mobile applications, paper diary)?
2. What technology supports your care practices (self-monitoring, self-medication)?
3. Do you use any specific technology to improve your child’s diet?
4. Do you use any specific technology to improve your child’s physical exercise?
5. Do you have any issues using any of the technology you mentioned?
6. Do you use the Internet to deal with some of your problems? How do you use it (what for?)
7. Do you use any social media technology to deal with some of the issues? (e.g. find out people in similar situations, asking for advice, asking for confirmation).
8. If this is the case, in what sense are these communications different to the one with the medical staff (the doctors, the specialist, the nurse or the pharmacist)?

Being like everyone else.

1. What would you like to change about the current situation?
2. What do you hope is going to change in the near future?
3. What do you hope is going to change in the far future?
4. What would you need to improve your ability to deal with your child’s diabetes?
INTERVIEW QUESTIONS - DIABETIC NURSES/DIETITION

**CHOICE Educator**

1. Tell me about yourself and how you came to enter the CHOICE programme?
2. What does an educator do? What are their key tasks?
3. Can you give an example of a case in which you had to explain a medical issue to someone who didn’t understand medical terms?
4. How many children with diabetes, on average, would you educate per year?
5. Can you tell me about your experiences on caring for children with diabetes?
6. How do you deal with a child having fear of needles or blood?
7. How do you motivate your young patient or her/his parents/caretakers?
8. Can you recall any particularly positive experience you had educating a child with diabetes?
9. Can you recall any negative experience you had educating a child with diabetes?
10. What is the most difficult aspect of caring for a child with diabetes?
11. What recent changes have you noticed within the health service and what is your opinion of these changes?
12. What information do children ask for? What information do you think patients need?
13. Why is education so important in diabetes management?
14. What are the benefits/advantages of diabetes education classes?
15. What makes a child give up on controlling their diabetes?
16. What is the appropriate age for children to start learning how to manage their diabetes?
17. What teaching methods have been most effective for children with diabetes in measuring blood sugar, insulin injections and diet?
18. How do you teach a child to use a glucometer? And insulin injection or pump? What about healthy diet?
19. Toys can help teach children basic skills and can be a great tool in the education process. From your experience, what toys, books or technology may help children learn more about diabetes?
20. How exactly do educators and parents help children develop their self-monitoring and self-care practices?
21. Where are the best sources of information on taking medicine, testing blood sugar, etc. for a child with diabetes?
22. In your experience, what makes someone want to control his or her disease?
23. Does personality affect diabetes management? If yes to what extent?

24. Do you have any suggestions (doctor, the hospital, the health department, or wellness centres) for better helping people control their diabetes?

25. What advice would you give people who are just diagnosed with diabetes type 1?

**Dietitian**

1. What does a diabetes dietician do?
2. How many children with diabetes, on average, would you care for daily?
3. What are the main hurdles you face during this initial first meeting?
4. What kind of materials do you use and education do you provide to newly diagnosed children and parents in relation to diet?
5. What teaching methods have been most effective for children in relation to diet?
6. From your experience what obstacles do children find especially difficult regarding diet?
7. What information do children ask about diet?
8. What is the appropriate age for children to start learning about how to manage their diet?
9. How do you teach nutrition to children with diabetes, food label reading skills, ability to determine carbohydrate?
10. Toys can help teach children basic skills and can be a great tool in the education process. From your experience, what toys, books or technology may help children learn more about diet?
11. Where are the best sources of information on diet and other lifestyle changes important for diabetes self-care practices?
12. What makes a child give up on controlling their diet?
13. How do you motivate your young patient or her/his parents/caretakers?
14. What information do parents ask about the diet? What information do you think patients need to have?
15. What teaching methods have been most effective for parents to learn carb counting?
16. Give an example of a situation where your work was criticised by the parents?
17. Do you feel the information and education provided is satisfactory?
18. Do you have any suggestions for better helping people control their diet?
19. What helpful services are available in this county? What about in nearby counties?
20. What do you think about the CHOICE programme?
INTERVIEW QUESTIONS – CHILDREN

1. Can you tell us your story?
2. When did you first learn that you had diabetes? Did you know about diabetes before? What did you have to learn?
3. How did type 1 diabetes change your life? What habits did you change first?
4. Can you describe how having diabetes affected your day to day activities?
5. How was your communication regarding diabetes different between your parents? School teachers and friends?
6. Do you find it difficult to talk about your condition? Do you find it difficult to describe issues and problems that you have?
7. How has your families’ daily life been rearranged around diabetes (e.g. how have you rescheduled or re-organised things in your household or your daily routine)?
8. What did you prefer other children/friends/teachers at school to know about your disease? Why?
9. Can you describe any issues you had related to your diet as a child? What sort of issues did you experience and describe how you dealt with them?
10. Can you describe any issues you had related to self-monitoring and self-medication as a child? Can you give an example?
11. What level of autonomy do you have in these three key activities (diet, physical exercise and self-monitoring (journaling and medication))? Can you give any examples?
12. Do you prefer to do some things privately e.g. testing blood, journaling values, inject insulin?
13. Are any of the following particularly difficult to monitor: insulin injections, blood testing, diet, physical activities, and dealing with Hypos? Can you explain why?
14. Have you received any medical training to deal with your diabetes? At what age?
15. How is your relationship with the medical staff?
16. Do you find it difficult to communicate with the medical staff? Can you give any examples?
17. Do you find it difficult to comply with their advice?
18. What was your reaction to medical consultations, hospitalizations and exams when you were a child?
19. As a child, do you have lack confidence or have low self-esteem? Can you give an example?
20. If this is the case, what have you done to overcome this problem?
21. What technology supports your care practices (self-monitoring, self-medication)?
22. Do you have to use any specific technology to document your values (web, mobile applications, paper diary)?
23. Do you use any specific technology to help improve your diet?
24. Do you use the Internet to deal with some of your problems? How did you use it (what for?)
25. Do you use any social media technology to deal with any issues? (e.g. find out people in similar situations, asking for advices, asking for confirmations).
26. What improvements are needed to help children manage their diabetes?
Appendix (D) Affinity diagrams
Child’s emotional state

Other people
- How other people treated him is a huge factor
- Hates telling people having diabetes
- Diabetic is not the big myth that, they can eat like little sweets, they can have their treats, they can do everything anyone else can do.
- People say to her that she got diabetes because she ate too many sweets
- Afraid to go to school because of the people saying that she is diabetic because she eats too much
- Well she used to eat an awful lot of sweets didn’t she, and she’s a skinny little thing! Because they associate Diabetes with Obesity and they’re probably thinking I was feeding her a load of crap. That, as a mother, would make me very defensive about what it was and I’d always say she’s a type 1 Diabetic I’d never just say “Diabetic”
- People are starting to comment about diabetes self-care tasks now and asking her questions she doesn’t want to answer now

Child’s life
- It changes his life in the way that you couldn’t expect in that
- She never got to go to sleepovers
- They have to grow very quickly
- No travelling abroad alone
- She is a bit more fragile, she needs protection
- No sleepworn I couldn’t put that responsibility on another mother
- The child can’t be excluded from any activity, it might mean more planning but we will do that
- Have bad days
- He is gonna grow up with diabetes
- A lot more attention from parents
- Need to get rid of their stresses
- Getting more independent and stronger
- No interest in talking about diabetes with other kids with diabetes
- Can’t live in the same way other children at the similar age live
- No caregivers, the most devastating part of diagnosis
- Abused trust of the parents, eat sweets secretly
- Miss the school tour because of diabetes

Diabetes care: difficulties
- Hates the blood tests
- The diet
- Injections
- The amount of snack to cover sports
- Not eating sweets
- Gap between the meals
- Trying to have regular meals at regular times
- Looking at other children eating sweets at any time
- Putting the sensor for continuous glucose monitoring
- Had treats only at the weekends

Parties
- Make my own treats and bring them in
- Give him/her a slice of cake
- Sugary cereals at Christmas time
- Want more sweets on Halloween
- Have a bit of candy
- No sweets
- A Diabetic bar of chocolate
- And I kind of say for sweets “can you just put them away for a while, you are here visiting us” and a lot of people get a bit cross
<table>
<thead>
<tr>
<th>Take some photographs of your day.</th>
<th>Use the number</th>
<th>Check boxes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Take 1 to 2 photographs of your favourite food using the label with number 1.</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2. Take 1 photograph of food you don't like, using the label with number 2.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3. Take 1 photograph of your favourite book, using the label with number 3.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4. Take 1 photograph of a book you do not like, using the label with number 4.</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. Take 1 photograph of an animated/cartoon movie that you enjoy watching, using the label with number 5.</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>6. Take 1 photograph of your favourite toy, using the label with number 6.</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>7. Take 1 photograph of a toy you do not like, using the label with number 7.</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>8. Take 1 photograph of your favourite sport, using the label with number 8.</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>9. Take 1 photograph of sport that you do not like, using the label with number 9.</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>10. Take from 1 to 2 photographs of people that you love, using the label with number 10.</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>11. Take 1 photograph of your favourite piece of technology, using the label with number 11.</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>12. Take 1 photograph of your favourite game, using the label with number 12.</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>13. Take 1 photograph of your favourite Video Game, using the label with number 13.</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>14. Take 1 photograph of the place that you like going, to using the label with number 14.</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>15. Take 1 photograph of a place that you do not like going to, using the label with number 15.</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>16. Take 1 photograph of activity and game you enjoy outdoors with other kids, using the label with number 16.</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>17. Take 1 photograph of something funny, using the label with number 17.</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>18. Take 1 photograph of something sad, using the label with number 18.</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>19. Take 1 photograph of something interesting, using the label with number 19.</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>20. Take 1 photograph of something boring, using the label with number 20.</td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>
# Appendix (F) Personas

## Mother Anna

**Has a newly diagnosed child with type 1 diabetes**

*"The main focus in my life at the moment is my sick child. I have not found one book that didn’t have an objectionable comment."*

<table>
<thead>
<tr>
<th>Mother:</th>
<th>Anna</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>39</td>
</tr>
<tr>
<td>Family:</td>
<td>Married for Jonathan. Three children: Daniel, Sarah and Liam</td>
</tr>
<tr>
<td>Occupation:</td>
<td>Seals manager</td>
</tr>
<tr>
<td>Work place:</td>
<td>Home</td>
</tr>
<tr>
<td>Technology experience:</td>
<td>Basic computer skills: sending emails, surfing the internet, uploading photos, has a facebook account</td>
</tr>
<tr>
<td>Interest/Activities:</td>
<td>Likes to read books, cook, Facebook, watch television, talk on the phone with friends</td>
</tr>
</tbody>
</table>

Anna is a lovely mother; she has three children Liam (5), Daniel (9) and Sarah (12). Her husband Jonathan is very busy and she is responsible for the care of the children and for the housework. Anna decided to quit her job and to take care of Daniel, because he was diagnosed with type 1 diabetes two weeks ago. Daniel was hospitalised for a week. During that time she had three hours per day training, the nurse helped her to read food labels to identify the total amount of carbohydrates per serving, to use the glucometer and to inject Daniel with insulin safely. Also, the nurse gave her different leaflets and printed materials that Anna can read at home.

When Daniel was discharged from the hospital she still had many questions related to the insulin and carbohydrates in the food, blood tests results, honeymoon period and sick days. She felt that she needed more information and education about diabetes self-care. Unfortunately, there was no structured paediatric diabetes education provided outside the clinic. Now, Anna tries to help Daniel by looking for educational resources designed to improve the learning process that they can both use together. Also, Daniel needs assistance and supervision in school, this is another challenge for her to ask his teacher for help and support.

**Technology use at clinic:**
- Personal technology as: Tablet or PSP, Smart phone
- Technology use at home:
  - Shares computer
  - Tablet
  - Video game console
  - Have access to the internet

**Goals:**
- Build my kids’ self-esteem.
- Make good choices for my kids.
- Learn how to use the glucometer, inject insulin, count carbs in the food, to help the child have physical activities.
- Find appropriate educational materials to use at home.
- Find appropriate educational materials for Daniel that she can use if he has questions.
- Manage her son’s diabetes effectively at home and at school.

**Fears:**
- How will diabetes change Daniel’s life? How will she manage the diabetes of her child?
- What does she need to know and learn about diabetes? What educational materials can she and Daniel use?
- Who will help her if she has questions related to the illness?
- How will Daniel manage diabetes at school?
- With whom can she share diabetes care at home?
**Father Jonathan**

**Has a newly diagnosed child with type 1 diabetes**

"I think the education that we receive needs to be empowering rather than building dependence. They were very slow to give us that information even though we constantly looked for it."

<table>
<thead>
<tr>
<th>Father:</th>
<th>Jonathan (the father of newly diagnosed child with diabetes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>43</td>
</tr>
<tr>
<td>Family:</td>
<td>Married for Anna. Three children: Daniel, Sarah and Liam</td>
</tr>
<tr>
<td>Occupation:</td>
<td>Farmer</td>
</tr>
<tr>
<td>Work place:</td>
<td>Farm</td>
</tr>
<tr>
<td>Technology experience:</td>
<td>Basic computer skills: sending emails, surfing the internet, uploading photos, has a facebook account</td>
</tr>
<tr>
<td>Interest/Activities:</td>
<td>Likes to play video games with children, watch television, play sports</td>
</tr>
</tbody>
</table>

Jonathan is a 43 year old farmer married to Anna, he has three children Liam, Daniel and Sarah. A few weeks ago, all of his family were shocked when Daniel was admitted in the hospital and diagnosed with diabetes. Unfortunately, he did not have time to help Anna with Daniel's care in the hospital and even when he had returned home. Farm-work is constant, heavy, tightly scheduled and filled with tasks for production to maintain farm progress. He only attended the first lesson for diabetes education provided for parents in the clinic as there was nobody who could substitute him in his workplace. He felt that he left all of the responsibilities of Daniel's diabetes management to his wife Anna.

Jonathan wanted to have more options for diabetes education, not only in the clinic or at any specific time. He found that diabetes education is important, he needs to know how to help Daniel if something happens and his wife is not available at that time. Reading books and other printed materials take time. He needs something that he can use anywhere, have different visual materials appropriate for Daniel and for other members of the family.

**Technology use at clinic:**
- Tablet or PSP
- Smart phone

**Technology use at home:**
- Personal computer
- Tablet
- Video game console
- Have access to the internet

**Goals:**
- Build my kids' self-esteem.
- Make good choices for my kids.
- Learn how to use the glucometer, inject insulin, count carbs in the food, to help Daniel find physical activities that he likes.
- Find appropriate educational materials to use at home.
- Manage his son's diabetes effectively at home and at school.
- Try to share care and responsibility in diabetes management.

**Fears:**
- He will not be able to help his wife during the daytime.
- How will Anna manage Daniel's diabetes alone?
- What does he need to know and learn about diabetes? What materials can he use?
- Who will help them if they have questions related to the illness?
- How will their sick child manage diabetes at school?
- How do teachers and SNAs help their son Daniel at school?
Teacher Mary

Has a newly diagnosed student with type 1 diabetes

"Caring for students with diabetes is a big responsibility, good parent-teacher communication and education are required."

Teacher: Mary
Age: 39
Family: Married
Occupation: Primary school teacher
Workplace: Limerick School Project
Technology experience: Good computer skills: sending emails, surfing the internet, using Office, downloading and printing educational materials
Interest/Activities: Likes to read books, music, history, cycle

Mary is a primary school teacher qualified to teach a range of primary school subjects to children aged from 4 to 12 years old. As a class teacher in Limerick School Project, her primary responsibilities are to support the progress of all the pupils in the educational program. Each year she is given a different class to teach and currently she is teaching children in fourth class. A few days ago Daniel’s mother Anna came to the school to talk to the principal and other teachers because Daniel was diagnosed with type 1 diabetes, he requires assistance with diabetes management. Mary and other teachers did not have any experience with this chronic condition; Daniel is the first child with type 1 diabetes in this school. Usually, the hospital nurses go to school to help teachers and Special Needs Assistants (SNAs) with useful advice about healthy food, testing of blood sugars and insulin administration. Due to the lack of staff in the main paediatric diabetes centre, Daniel’s mother came along to give these instructions. The hardest part was to establish teachers’ responsibility and parent-teacher communication if Daniel is unwell at school and how to deal with hypo- and hyperglycaemia.

Mary felt that having a student with diabetes was very demanding work that needs constant supervision. She was afraid that she needs more time to learn about diabetes every day care, about symptoms of hypo- and hyperglycaemia and their treatment. Anna gave her some readings about the illness but she needs visual educational materials in the practical tasks of measuring blood sugar levels, injecting insulin, and calculating nutrients that she can use at home.

Technology use at school:
- Shares computer
- Smart phone
- Have access to the internet

Technology use at home:
- Shares computer
- Tablet
- Video game console
- Have access to the internet

Goals:
- Build good knowledge in diabetes management.
- Learn how to use the glucometer, inject insulin, count carbs in the food and provide alternative options for unplanned vigorous physical activity.
- Find appropriate educational materials to use at home.
- Build an emergency plan for emergency situations.
- Help Daniel manage diabetes at school.

Fears:
- How will she help Daniel to manage diabetes at school?
- What does she need to know and learn about diabetes? What materials can she use?
- Who will help her if she has questions related to the illness?
- What does she need to know about the emergency plan? What does she have to do in an emergency situation?
- How to maintain effective communication with Daniel’s parents?
Nurse Hazel

Works with diabetic children and their families

“Children love to fit models and look at the fit bits, giving leaflets and talking with them doesn’t work, they need a mixture of materials and practical exercise.”

<table>
<thead>
<tr>
<th>Nurse:</th>
<th>Hazel (the paediatric diabetic nurse)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>35</td>
</tr>
<tr>
<td>Family:</td>
<td>Married</td>
</tr>
<tr>
<td>Occupation:</td>
<td>Diabetes nurse</td>
</tr>
<tr>
<td>Workplace:</td>
<td>Paediatric Diabetes Care Department, University Hospital Limerick</td>
</tr>
<tr>
<td>Technology experience:</td>
<td>Good computer skills: sending emails, surfing the internet, using Word and PowerPoint, downloading and print different articles</td>
</tr>
<tr>
<td>Interest/Activities:</td>
<td>Reading the latest medical research on diabetes, reading books, watching television</td>
</tr>
</tbody>
</table>

Hazel is a 35 year old diabetic nurse working in the Paediatric Diabetes Care Department, Regional University hospital in Limerick. She received her BS and MS in Nursing from the Dublin City University and now she is a team member providing paediatric diabetes education to children with type 1 diabetes and their families, coordinating care with a multidisciplinary team and consultations in the hospital. Working as a paediatric diabetic nurse in the hospital, some of her responsibilities are to teach children and their parents about diabetes, to conduct exams and tests in order to monitor the patient’s progress, to help patients develop a treatment plan, to maintain the clinic appointments and to anticipate signs and symptoms of new health problems. Every day she has to answer phone calls from parents who have questions or need help in relation to the health of their diabetic children.

If a young patient is diagnosed with type 1 diabetes in the Children’s ark unit, her work is to assist this child and his/her parents in diabetes management, to help them understand and learn about diabetes self-care practices. Working with the child she uses different educational materials such as the book ‘Pete the Pancreas’, objects as teddy bears or oranges for practicing how to give injections, diagrams to show the insulin injection areas and the food pyramid poster. She found that diabetes education is a long process for which parents and children need a mixture of materials to continue their education when they return home.

<table>
<thead>
<tr>
<th>Technology use at clinic:</th>
<th>Goals:</th>
<th>Fears:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Shares computer</td>
<td>• Feelings of competence and self-worth.</td>
<td>• She has professional concerns regarding the quality and safety of the patient’s care.</td>
</tr>
<tr>
<td>• Smartphone</td>
<td>• Capture daily nursing tasks and activities to improve the work in the clinic.</td>
<td>• What do parents and children need to know about diabetes?</td>
</tr>
<tr>
<td>• Glucometer</td>
<td>• Empathy and emotion working with patients.</td>
<td>• What materials and methods will help to improve education in paediatric diabetes management?</td>
</tr>
<tr>
<td>• Insulin pump</td>
<td>• Provide a tailored patient educational intervention.</td>
<td>• How to avoid making mistakes at work?</td>
</tr>
<tr>
<td>• Have access to the internet</td>
<td>• Nurse-patient communication.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Technology use at home:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Personal computer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Smartphone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Have access to the internet</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Brother Liam

Has a brother diagnosed with type 1 diabetes

“My mom gives more attention to my brother because he has diabetes.”

Brother: Liam (the brother of newly diagnosed child with diabetes)
Age: 5
Family: Mother Anna, father Jonathan, brother Daniel and sister Sarah
Student: Junior infants, primary school
School: Limerick School Project
Technology experience: Play simple video games, watch TV, Nintendo DS, Xbox 360, PSP Tablet
Interest/Activities: Likes to play video games with his brother Daniel, play football, cycling, playing in the backyard and watching television

Liam is a small boy who just started junior infants in Limerick School Project. He cannot read or write, he only knows a few letters from the alphabet. He likes to play different games appropriate for his age on the Nintendo DS and Xbox 360 with or without his father or brother. During the last few weeks, Liam felt sad because his brother Daniel was diagnosed with diabetes and they could not play video games as usual. Daniel looked very upset, he needed to be very careful with his health. Before they play football, Daniel needs to have a small snack and to measure his blood glucose levels. Liam was so scared when he saw how Daniel pricked his finger for the first time to take a small drop of blood and when he injected himself with insulin. He still hides when his brother needs to do it. He was also very confused when his mom told him that his brother will have his treats only during the weekends and he is not to share any sweets with Daniel.

Liam is very young and for him it is difficult to understand diabetes. Together with his mom and Daniel they read a small book about it, but he did not grasp why Daniel cannot eat too many sweets.
Daniel
Newly diagnosed with type 1 diabetes

"Am I gonna have this to the rest of my life mummy?"

<table>
<thead>
<tr>
<th>Boy:</th>
<th>Daniel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>9</td>
</tr>
<tr>
<td>Family:</td>
<td>Mother Anna, father Jonathan, sister Sarah and brother Liam</td>
</tr>
<tr>
<td>Student:</td>
<td>Fourth class, primary school</td>
</tr>
<tr>
<td>School:</td>
<td>Limerick School Project</td>
</tr>
<tr>
<td>Technology experience:</td>
<td>Basic computer skills, surfing the internet, video games, Nintendo DS, Xbox 360, Tablet, mobile phone</td>
</tr>
<tr>
<td>Interest/Activities:</td>
<td>Likes to play video games, read books, play football, cycle, swim, play in the backyard, watch television</td>
</tr>
</tbody>
</table>

Daniel is 9 years old, he is in fourth class in Limerick School Project. Two weeks ago he was diagnosed with type 1 diabetes. At home, he uses different technology for fun and entertainment, but he doesn’t know about those technologies designed to help diabetic people. During his hospital stay, he was encouraged to learn how to use the glucometer and practice on the teddy bear how to inject insulin. The nurse told him that diabetes education is very important and she gave him the only available for newly diagnosed children ‘Pete the Pancreas’ booklet. Daniel had many questions related to diabetes and its management, he was not able to find all the answers in this booklet.

Now Daniel is at home and he needs to continue his diabetes education with the help of his parents because there is no education provided for children and parents outside the clinic environment. He also requires various educational sources to help him understand the proper treatment of diabetes.

Technology use at clinic:
- Personal technology as:
  - Nintendo DS
  - Tablet or PSP
  - Smart phone

Technology use at home:
- Shares computer
- Tablet
- PSP
- Xbox 360
- Have access to the internet

Goals:
- Have fun/be entertained.
- Feel independent.
- Learn how to use the glucometer, inject insulin, count carbs in the food and have regular physical activities.
- Find appropriate educational materials.
- Manage diabetes effectively at home and at school.

Fears:
- Concerned with his health.
- What does he need to know about diabetes and its care?
- What does he need to learn to manage the illness?
- What educational materials will help him?
- How will he live with diabetes?
- How will diabetes change his life?
Sister Sarah

Has a brother diagnosed with type 1 diabetes

“I am worried to not get diabetes because I have a blood phobia.”

<table>
<thead>
<tr>
<th>Sister:</th>
<th>Sarah</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td>12</td>
</tr>
<tr>
<td>Family:</td>
<td>Mother Anna, father Jonathan, brothers Daniel and Liam</td>
</tr>
<tr>
<td>Student:</td>
<td>Six class, primary school</td>
</tr>
<tr>
<td>School:</td>
<td>Limerick School Project</td>
</tr>
<tr>
<td>Technology experience:</td>
<td>Basic computer skills, surf the internet, play video games, Nintendo DS, Xbox 360, Tablet, mobile phone</td>
</tr>
<tr>
<td>Interest/Activities:</td>
<td>Likes to play games with her brothers, read books, dance and swim, talk on the phone with friends, watch television</td>
</tr>
</tbody>
</table>

Sarah is 12 and she is in sixth class in Limerick School Project. She has two brothers Daniel (9) and Liam (5). She was very upset when Daniel was diagnosed with diabetes. No one in their family has ever been diagnosed with this chronic disease. Sarah did not know anything about this illness, its transmission, symptoms and treatment. Seeking different sources about this disease made her feel anxious and sad. Sarah found that there are so many important things that her parents and Daniel need to learn about diabetes care but what bothered her most were some horrible pictures showing the results of improper treatment. This made her worry about Daniel. She decided to not tell her mom about these pictures, only ask her about Daniel’s treatment.

When Daniel returned home, she understood that he has only one small book explaining diabetes - ’Pete the Pancreas’. So she wants to find other educational books and materials about diabetes that they can both use together and are written for his age.
### Appendix (G) Collected data-Evaluation Sessions 1, 2, 3, 4, 5, and 6

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Session 1 T1DC16, T1DC17 and T1DC18</th>
<th>Session 2 Parent3&amp;T1DC3</th>
<th>Session 3 Parent24&amp;T1DC24</th>
<th>Session 4 Parent25&amp;T1DC25</th>
<th>Session 5 Parent26&amp;T1DC26</th>
<th>Session 6 Parent8&amp;T1DC8</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Steps sounds (page 3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>submarine makes sound when going out the window (page 7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>change images of human organs once they are in the right place to more realistic ones (page 10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>when they (cubes of sugars) are walking play music, when the cell opens (insulin is a key) play the sound of door opening (page 11)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>try drag sugar out of liver bring them to the cells, then a question comes up (game)(page 12)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>more diabetic symptoms: faint, vomiting loss of concentration (page 12)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>maybe the spaceship moves around (page</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>maybe if the text appeared in different stages so there’s not so much text in one go (page 3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>control or mange (replace the word)(page 11)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>if balance is up or down then superhero looks sad, happy if balanced (page 14)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>the dialogue box about the Superhero thoughts related with the things that he saw in Dr. Jenny’s cabinet (page 3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>door opening floor board creaking. Tap the green dot (page 5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>tap on the window to open (page 7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>tap on the food to find the submarine (page 8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>press a button to see a real organ, give facts on each organ (page 10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>make sound when opening the cell (page 11)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>show superhero asking questions in the submarine. (page 13)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>which food needs insulin? (page 14)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>tap on Liam to make him sneeze (page 15)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>most kids would not know what intrigued means; change it to interested. The door creaking. (page 3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>sound steps (page 4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>if when Dr. Jenny comes in Superhero jumps from fright. Like he was just about to take off the cover (page 5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>shrinking sound, touch blanket to take it off (page 6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>shrinking sound (page 7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>plop sound (page 8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>just mention that the insulin is the key (page 11)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>diabetes cannot make insulin. Make unhappy face of the cells. Add symptoms such as bathroom a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>would 8 year old know what intrigued means (page 3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 13) | • Maybe change “palate” to another simple word to understand “tickling in his throat” (page 15)  
• Drag him to his bed, add snoring sound (page 17) |  |  
• Screen will go all white to show that he is dreaming (page 17)  
• Add images of an unhappy cell – having diabetes, in a normal cell sugar and key (insulin) holding hands. (page 13)  
• Claps and says “Well done” (page 14)  
• A big sneeze (page 15)  
• Superhero and Dr. Jenny pinkie promising/or she winks (page 16)  
• Leave it as a mystery (page 17) |
| Test and evaluate ‘Superhero has diabetes’ - Digital prototype (14 pages) | • Make the interactive elements flash or use arrows to suggest interaction (page 3)  
• Add animation and sounds to the toys (page 5)  
• The receptionist clicking on the keyboard and answering the phone. (page 7)  
• Add the image of glucometer. It is lighter, smaller, quicker (page 11)  
• Scientist having T1DM | • Constant toy/image that can be interactive (page 6)  
• Pick which door to enter. Something to involve the child in the waiting room-play with toy, sounds? (page 7)  
• Q: Scary? A: Special needles to make it as easy as possible. Medicines can change as you grow, but you need same medicine through the day. Q: Can I eat sugar/sweets? A: Need to reduce the  
• An arrow by each topic to show what needs to be done – press line (page 1)  
• Under/over each arrow write next page or previous page on back arrow (page 2)  
• Maybe when describing superhero just describe him not his home life. This play is more for very young children but the later pages are more for older children (page 3)  
• Q: Why don’t I feel | • Choice for parent: topic name boy/girl  
Image of pancreas waving hand for “Hello” (page 2)  
• Superhero you have type 1 diabetes (page 10) |
Add diary as image (page 13)

Sugar but manage treats are ok. Healthy food is good for everyone. (page 10)

Maybe put first pump near or beside backpack maybe be able to slide it into back pack (page 11)

right? Now I can’t help other people Q: I am too tired to fly …thirsty to run (page 4)

Maybe split the trip between a visits to the GP who the child knows. After next page he goes to the hospital to be diagnosed by the special doctor (page 5)

Dr. Jenny introduces herself as a doctor who specialises in diabetes. (page 6)

(name of the brand) wipes are not alcohol wipes. 1: wash hands, 2: take out glucometer 3: insert glucometer strip, 4: lancet 5: Place blood on strip (page 9)

At that stage it gets complicated for the young children. Maybe meet regularly with their doctor. The nurse is the main point of contact (page 10)

Add name Ryan Reed - NASCAR Driver – to list of different stars with diabetes (page 12)

Instead/add to sport Activity/exercise
<p>| Playing with the mock-up prototype | Trampoline/dancing ballet shoes (page 13) | NO | | | |
|---|---|---|---|---|
| • Read the text silently | • Read the text out loud | • Started reading the text silently and then out loud | • Read the text out loud | |
| • Simulated interaction with the arrows showing how they are supposed to work | • The child played with the arrows simulating a page-turning type of interaction | • Played and moved the small parts to visualise animation and interaction (page 7) | • Played and moved the small parts to visualise animation and interaction (page 7) | |
| • Asked for further clarification on different types of interaction | • The child liked to play with the movable parts of paper while his mother read the text | • Simulated interaction with the arrows showing how they are supposed to work | • Simulated interaction with the arrows showing how they are supposed to work | |
| • Rearranged images to simulate interaction of the human body (page 10) | • The child interacted with the moving parts of Dr. Jenny and Superhero paper accordingly as the dialogue between these two characters (which his mother read) playing the roles and saying “Yes” (to have a journey) on (page 5) | • Grasped the idea of the meaning of the paper prototype | • Grasped the idea of the meaning of the paper prototype | |
| • Simulated interaction on how the cell needs insulin and sugar (page 12) | • The child liked to play with all movable parts | • Rearranged images to simulate interaction of the human body (page 10) | • Rearranged images to simulate interaction of the human body (page 10) | |
|  | • The child rearranged the images of the human body (page 10) asking the question “where is the position of the liver?” | • Simulated interaction on how the cell needs insulin and sugar (page 12) | • Simulated interaction on how the cell needs insulin and sugar (page 12) | |
|  | • Parent looked critically at the text – appropriate to children (page 11) |  |  | |
|  | • While reading the text |  |  | |
|  | • Grasped the idea about the meaning of the paper prototype. |  |  | |
|  | • Understood how different elements could be expected to behave |  |  | |
|  | • Suggested improvement of the images that could provide fun (happy faces of the human cells) |  |  | |
|  | • Added new images explaining the symptoms of diabetes |  |  | |
|  | • Read the text out loud |  |  | |
|  | • Parent focused more on the text and less on the interactive elements |  |  | |
|  | • Did not play or move the small pieces simulating interaction |  |  | |</p>
<table>
<thead>
<tr>
<th>Interacting with the digital prototype</th>
<th>Excited to interact with the interactive technology</th>
<th>The child interacted with the images while his mother read the text</th>
<th>The mother asked the children to help her play and read the story</th>
<th>The eBook suggested better visibility of the integrated animations and games than the paper prototype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Omitted objects to play with: car and dog (page 3), car and airplane (page 5) – improve visibility</td>
<td>Child easily navigated between the pages</td>
<td>Mother read the text and children played with integrated interactive images</td>
<td>Omitted objects to play with: car and dog (page 3), car and airplane (page 5) – improve visibility. More focused on the text and illustrations and did not notice other interactive elements</td>
<td>Omitted objects to play with: car and dog (page 3), car and airplane (page 5) – improve visibility. More focused on the text and illustrations and did not notice other interactive elements</td>
</tr>
<tr>
<td>Suggested better visibility of the text by using the dialogue bubbles</td>
<td>Used the Play again arrow to read the second story</td>
<td>Questions in the text were used to ask the child’s opinion and then mother explained the answer</td>
<td>The eBook suggested better visibility of the integrated animations and games than the paper prototype</td>
<td>Omitted objects to play with: car and dog (page 3), car and airplane (page 5) – improve visibility. More focused on the text and illustrations and did not notice other interactive elements</td>
</tr>
<tr>
<td>Presenting interactive elements clearly</td>
<td>The child tried to move images looking for those that could suggest interaction (animation, sound, drag and drop, etc.)</td>
<td>Looked critically on the visual layout mode suggesting navigation between the pages</td>
<td>The child interacted with the images while his mother read the text</td>
<td>The child interacted with the images while his mother read the text</td>
</tr>
<tr>
<td>Suggesting better representation of features and how they fit together</td>
<td>Mother asked the child what he would like to see on the picture (page 7)</td>
<td>Looked for the visual cues</td>
<td>The child interacted with the images while his mother read the text</td>
<td>The child interacted with the images while his mother read the text</td>
</tr>
<tr>
<td></td>
<td>The child liked to play with those objects producing sounds when they are touched</td>
<td>Critically looked at the text suggesting new ideas while interacting with each page</td>
<td>The child interacted with the images while his mother read the text</td>
<td>The child interacted with the images while his mother read the text</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The young child asked how to activate some animations that have been played already</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

About diabetes, the child asked his mother what a pancreas is. Did not grasp the idea about the meaning of the paper prototype.
| Layered Elaboration technique | The child tried to activate all images at once (i.e. question marks in page 8)  
| Provoked discussion on each page and what needed to be added and improved | The young child wanted to play alone with the images  
| The parent discussed each page giving suggestions on how to improve the text  
| Adapted technology to support young users at different ages having few difficulties  
| Parent wanted to have a story that creates a perfect representation of reality (meet GP then doctor in the A & E department, nurse gives education)  
| The young child was looking for more images to interact with (i.e. if I touch the plant it will grow) |

| | Two children simultaneously drew their ideas using different coloured markers  
| The children used suggested sources in the stories i.e. images, text, interactivity, etc. for further idea elaboration  
| Blue dots used to illustrate animation  
| The mother used suggested sources in the stories i.e. images, text, interactivity, etc. for further idea elaboration by writing different ideas on the white labels  
| The child wrote the | Parent used the white sticky labels to write suggestions  
| The coloured dots were not used to suggest various interactions  
| The mother and child used suggested sources in the stories i.e. images, text, interactivity, etc. for further idea elaboration by writing different ideas on the white |

| | Discussed visual cues on page 3  
| Spent more time interacting with the digital prototype than with the mock-up prototype  
| Elaborated options for creating two levels of the story that will correspond on the child age (8-10) and (10-12)  
| Elaborated options for creating two levels of the story that will correspond on the child age (8-10) and (10-12)  
| The coloured dots were not used to suggest various interactions  
<p>| The mother and child used suggested sources in the stories i.e. images, text, interactivity, etc. for further idea elaboration by writing different ideas on the white |</p>
<table>
<thead>
<tr>
<th>Activity</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>When the children drew on the transparent sheets which covers the digital prototype scene/page</td>
<td>They activated some animations or interactive elements.</td>
</tr>
<tr>
<td>When writing notes for the digital prototype the transparent material was moved onto the table.</td>
<td></td>
</tr>
<tr>
<td>When writing notes for the mock-up prototype the transparent material lay on the top of the page/scene</td>
<td></td>
</tr>
<tr>
<td>The children wrote their ideas alone using the white labels.</td>
<td></td>
</tr>
<tr>
<td>The children used the dots to represent interaction with images.</td>
<td></td>
</tr>
<tr>
<td>The children used the transparent sheets to draw some images for the digital story.</td>
<td></td>
</tr>
<tr>
<td>Children asked which of the coloured dots are appropriate for specific interactions.</td>
<td></td>
</tr>
<tr>
<td>Used the instructions provided for the elaboration by writing different ideas on the white labels.</td>
<td></td>
</tr>
<tr>
<td>The child a picture as a present for the designer on the transparent sheet using the colouring marker dots.</td>
<td></td>
</tr>
<tr>
<td>The parent preferred to look at each page by adding notes for the digital prototype, the transparent material was placed on the table while the child/children interacted with the digital prototype.</td>
<td></td>
</tr>
<tr>
<td>No drawings on the transparent materials, only notes.</td>
<td></td>
</tr>
<tr>
<td>The mother explained the hints that could improve the visibility in interaction.</td>
<td></td>
</tr>
<tr>
<td>Keep the instructions on how to use the additional materials as dots and white labels nearby.</td>
<td></td>
</tr>
<tr>
<td>The boy helped his parent sticking the white self-address labels on the transparent sheets.</td>
<td></td>
</tr>
<tr>
<td>The parent preferred to look at each page by adding notes for the digital prototype, the transparent material was placed on the table while the child/children interacted with the digital prototype.</td>
<td></td>
</tr>
<tr>
<td>No drawings on the transparent materials, only notes.</td>
<td></td>
</tr>
<tr>
<td>The mother explained the hints that could improve the visibility in interaction.</td>
<td></td>
</tr>
<tr>
<td>The sibling (a boy) asked question how to use the coloured dots, but he did not use them.</td>
<td></td>
</tr>
<tr>
<td>Used the instructions provided for the coloured dots.</td>
<td></td>
</tr>
<tr>
<td>Confident to use all of the materials supporting the technique.</td>
<td></td>
</tr>
<tr>
<td>The children wrote their ideas alone using the white labels.</td>
<td></td>
</tr>
<tr>
<td>The child used the dots to represent interaction with images.</td>
<td></td>
</tr>
<tr>
<td>The child used the transparent sheets to draw some images, dialogues bubbles, buttons on the place where they should be for the paper story.</td>
<td></td>
</tr>
<tr>
<td>The mother helped to formulate some of the text by suggesting idea.</td>
<td></td>
</tr>
<tr>
<td>Used the instructions provided for the coloured dots.</td>
<td></td>
</tr>
<tr>
<td>Confident to use all of the materials supporting the technique.</td>
<td></td>
</tr>
<tr>
<td>The child wrote their ideas alone using the white labels.</td>
<td></td>
</tr>
<tr>
<td>The child used the dots to represent interaction with images.</td>
<td></td>
</tr>
<tr>
<td>The child used the transparent sheets to draw some images, dialogues bubbles, buttons on the place where they should be for the paper story.</td>
<td></td>
</tr>
<tr>
<td>The mother and child explained the hints that could improve the visibility in interaction.</td>
<td></td>
</tr>
<tr>
<td>Parent and child used the white sticky labels to write their suggestions.</td>
<td></td>
</tr>
<tr>
<td>The child wrote their ideas alone using the white labels.</td>
<td></td>
</tr>
<tr>
<td>The child used the dots to represent interaction with images.</td>
<td></td>
</tr>
<tr>
<td>The child used the transparent sheets to draw some images, dialogues bubbles, buttons on the place where they should be for the paper story.</td>
<td></td>
</tr>
<tr>
<td>The mother helped to formulate some of the text by suggesting idea.</td>
<td></td>
</tr>
<tr>
<td>Used the instructions provided for the coloured dots.</td>
<td></td>
</tr>
<tr>
<td>Confident to use all of the materials supporting the technique.</td>
<td></td>
</tr>
<tr>
<td>No drawings on the transparent materials, only notes.</td>
<td></td>
</tr>
<tr>
<td>The mother and child explained the hints that could improve the visibility in interaction.</td>
<td></td>
</tr>
<tr>
<td>Parent and child used the white sticky labels to write their suggestions.</td>
<td></td>
</tr>
</tbody>
</table>

465
<table>
<thead>
<tr>
<th><strong>Book ‘Pete the Pancreas’</strong></th>
<th><strong>colour dots</strong></th>
<th><strong>I read the book when I was younger</strong></th>
<th><strong>Gives children simple information on diabetes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>Quite basic</strong></td>
<td><strong>Used to explain functions of the pancreas</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Read the book with parents</strong></td>
<td><strong>Appropriate for children</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Used to explain the relationship between the blood sugars and food</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Used at school to explain to other children about diabetes</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Does not have scary images</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Very helpful, it was used by the class teacher, SNA and family members</strong></td>
<td><strong>Easy to read</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Valuable information on how the pancreas works and the functions of the hormone insulin</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>The child “likes the fact that Pete is a character, it was not this pancreas in your body as organ...Pete has a face”</strong></td>
<td><strong>Simple explanation of diabetes</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Used to explain the relationship between the blood sugars and food</strong></td>
<td><strong>Simple explanation of diabetes</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>It was a long time ago</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Book ‘Pete the Pancreas’</strong></th>
<th><strong>dislike</strong></th>
<th><strong>It is a bit childish</strong></th>
<th><strong>The pages have lots and lots of writing. Difficult to keep the child’s attention when reading the book “turn the page, turn the page”</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>It was better when I was younger</strong></td>
<td><strong>It will be better to have more pictures that parents can use when explaining diabetes</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>To have some fun that</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Not for this booklet specifically but most books written on this theme present the child with diabetes alone having no friends with diabetes</strong></td>
<td><strong>It is a childish book</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Need to add a lot of details on that, “I could look over and over again when I need it”</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>“Horrified reading that I need to inject insulin”</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>The book is very childish for her age</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Doesn’t give a lot information on sports and diabetes</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Does not like the questions and answers on page 30</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>It was a long time ago</strong></td>
</tr>
<tr>
<td>Which book was preferred: the paper book 'Pete the Pancreas' or the eBook 'Superhero learns about diabetes'?</td>
<td>The eBook suggests better fun</td>
<td>The question was not discussed</td>
<td>The question was not discussed as the participants did not interact with the second story</td>
</tr>
</tbody>
</table>
Appendix (H) Educational sections: Digital Story (P 8, 9, 10, 11 and 12) & Mock-up Story (P 10, 11, 12, 13 and 14)

“What are your complaints?” Dr. Jenny asked gently.
“I don’t know, Dr. Jenny. I am here because I lost my power to fly.” He looked at her helplessly.
“OK”, she smiled. “Tell me more about yourself. How are you feeling?”
Images of Thirsty, Hungry and Tired
I think we need to do a blood test and see what the results are,” said Dr. Jenny.
“Does it hurt a lot?” asked Superhero and looked at Dr. Jenny suspiciously.
I don’t think it does. Don’t worry, I will show you.

Step 1: “First we need to clean your finger. Look at the table. What should you use to clean your finger?”
Step 2: “Very good. You need to clean your finger with soap & water or a cleaning pad like these.”
Step 3: “Very good. Do you see this gadget that can measure the sugar in your blood? This is a glucometer, and this is a small test strip that works together with the glucometer. We need to take a strip from the container and then put it in the glucometer.”
Step 4: “Excellent. I will use this lancet to poke a tiny hole in your finger to get a small drop of blood...
Step 5: “...which we apply to the test strip so we can see the results.”
Dr. Jenny - “The glucometer displays 12.5, which is high.”
“Superhero, you have diabetes,” said Dr. Jenny. 
“Will I have diabetes forever?” he looked at her. 
“For now yes, but many scientists are working now to find a way to cure diabetes and I believe that it will happen very soon.” 
“Can I still do all the activities I used to do?” asked Superhero. 
“Of course you can. All the people who have diabetes can live long and healthy lives,” said Dr. Jenny and she rubbed his head. 
“What medicine do I need to take and how often?” was the next question that Superhero had. 
“You will need to take insulin before meals and bedtime. You will take insulin in a small injection. Also, you need to check your blood regularly and write down the results using a diary. Just like everyone, you need to eat healthy and exercise. Every 3 months we will meet to talk about your diabetes.” 
“Will it be scary?” continued Superhero. 
“At first, but you will learn how to use it and it will stop being so scary,” said Dr. Jenny. 

She moves to her cabinet and tells Superhero “Come here, I would like to show you something. Do you see this very big box?” She points at a big black box behind the glass window. 
“Dr. Arnold Kadish is the inventor of the first wearable pump, device that is attached to the body to deliver insulin.” 
“This is the first glucometer called Ames Reflectance Meter; it was invented by Anton Clemens and weighed 1.2 kg. It was only available for doctor’s offices and hospital emergency departments. Now we have many modern glucometers so that diabetic children like you can use them at home or at school.” 
“This is the next-generation device - a small portable insulin pump that deliver adjustable doses of insulin as required. You can see that many new technologies have been developed to help people manage their diabetes.”
“Diabetes does not mean that you are different from anyone else, Superhero.” continued Dr. Jenny. “Do you want to see my photo album with famous people who have diabetes?” Superhero nodded his head approvingly. "Yes, I do."
“Gary Mabbutt is an English former professional footballer, who won 16 caps for the England national team. He was diagnosed with type 1 diabetes at 17 years of age and now he is 53.”
“Melanie Stephenson is a young British sprinter, diagnosed at 13 years old. She was nominated and invited to carry the Olympic torch through Cardiff and past Cardiff Castle.”
“Thomas Edison invented the electric light bulb and the motion picture camera. He was diagnosed with type 2 diabetes.”
“Nick Jonas is an American singer-songwriter, a multi-instrumentalist musician and actor. Nick was diagnosed with Type 1 diabetes at the age of 13.”

“Our body is made up of many cells that need energy to function.” said Dr. Jenny. “Yes” continued Superhero, “we are making this energy by eating food.”
“Excellent, the digestive system is made up of organs that work together to break down the food and turn it into energy. That helps the body to grow and work. When the food has been eaten it goes into the stomach.” “Then the stomach works as a mixer breaking the food into smaller pieces... is that right Dr. Jenny?” He waited impatiently for her answer.
“Yes, the food particles began to mix with the stomach’s acid and enzymes turning it into glucose or simply called sugar. The glucose travels to all your fat cells and muscles in the body, through the bloodstream. The cells use the sugar as fuel to provide energy for the body. Hiding behind the stomach there is an organ called the pancreas. This produces insulin which helps all of the cells in the body to use glucose and regulate the concentration of sugar in the bloodstream.”

“For people who have diabetes, their pancreas stops making insulin and then the glucose cannot get into the cells normally, so the blood sugar levels get too high. As a result of not having fuel they may feel tired, thirsty, have blurred vision, visit the toilet often and have mood changes. Lots of sugar in the blood makes people sick if they do not get treatment - insulin.”

Some symptoms
Hungry
Tired
Losing weight
Sugar in urine
Blurred vision
“And how can diabetic people get insulin?” asked Superhero.

“Insulin is really important for the body and you can get it only through injections. The insulin tablets are broken down in the stomach before they can be absorbed and they are not able to replace the injections. Each time before your meals, you need to measure your blood glucose and take your insulin injection. Also you need to eat healthy food and stay very active. I will help you with a diet and a medication plan so that your blood sugar is regulated. Diabetes doesn’t make you different from other children.”

Balance in getting insulin and food
## Appendix (I) Collected data-Evaluation Session 7, 8, 9 and 10

### Tasks

#### Session 7
- HC2, HC9, HC10&HC11

- **He can have a pet bird. He opened the window and let the bird out to solve a problem** (HC9, 8 years old, page 3)
- **To add in a doctor or other objects** (HC2, 12 years old, page 3)
- **A puzzle to play with the spaceship** (HC11, 12 years old, page 3)
- **Click on word that child does not know and see the meaning** (dictionary). He moved the cover and his bird was there (HC9, 8 years old, page 4)
- **Quiz with 3 questions, when he gives the right answer he went to the next room** (HC10, 10 years old, page 4)
- **We could put air bubbles and they can say things** (HC9, 8 years old, page 5)
- **You could write down what these small things are and what they do - expand and talk about the object** (HC2, 12 years old, page 5)

#### Session 8
- HC12&HC13

- **NO**

#### Session 9
- HC9, HC14&HC15

- **NO**

#### Session 10
- HC16

- **NO**

---

**Test and evaluate ‘Superhero has diabetes’- paper prototype 18 Pages**
• The magic submarine could change into people (HC9, 8 years old, page 6)
• You could add particles around the submarine (HC2, 12 years old, page 6)
• Sounds on how the ship shrinks and gets bigger or how the door opens. Tap on the ship to shrink or get bigger (HC11, 12 years old, page 6)
• It (submarine) can change as a tiny dot like this (HC9, 8 years old, page 7)
• You could tap on the ship until it reaches the right size (HC2, 12 years old, page 7)
• Change size ship yourself by tapping on the ship (HC11, 12 years old, page 7)
• It can fall in the sink and fall under the ground (HC9, 8 years old, page 8)
• When he finds the submarine it gets bigger (HC2, 12 years old, page 8)
• The ship gets stuck in glass of water and shrinks even more (HC11, 12 years old, page 8)
• Liam gets sick and gets to the hospital and the submarine gets out (HC9, 8 years old, page 9)
• If Liam sees the ship in water he will not drink it, he maybe leaves
it. If in the glass was milk Liam will drink it because he will not see it (HC11, 12 years old, page 9)
- When the submarine goes down the throat, the milk would change into water and children easily could see and interact with other organs (HC2, 12 years old, page 9)

Test and evaluate ‘What is type 1 diabetes?’ - Digital prototype 14 Pages

| • Can I at least have 1 treat? (page 10) |
| • When he (Superhero) asked the question she (Dr. Jenny) will write it down (page 10). |

Playing with the mock-up prototype

| • Read the text out loud |
| • Children took turns to read the text |
| • Read and analyse only pages 1-9 |
| • Children at different age had different reading speed |
| • The child HC9 played with the cut out image of a submarine to simulate its movement (page 9) |
| • Difficulties understanding pages 10 and 11 of the digestive system |

| • Read the text out loud |
| • Only a boy read the text |
| • Used arrows to turn the pages |
| • Difficulties in understanding the medical text explaining the digestive system, glucose, diabetes, functions of the pancreas, insulin and balance of carbohydrates and insulin (pages 10, 11, 12, 13 and 14) |
| • Difficulties understanding the meaning of the word bloodstream |
| • The story is very long, too many pages (boy’s opinion) |

| • Read the text out loud |
| • Used arrows to turn the pages |
| • Really enjoyed to read and play with the movable cut out images presenting interaction in the prototype |
| • Moving the cut out images of objects and characters according to the text while reading all of the pages |
| • Produced sounds (whistling) imitating the submarine travel |
| • Difficulties in understanding the meaning of the words intrigued, pallet (pages 3 and 15) |
| • Playing with images simulating how Liam drinks water (page 9) |
| • Rearranged the images of the human body but she was not |
| Interacting with the digital prototype | NO | • Read the text out loud • Children took turns to read the text • Used arrows to turn the pages • Omitted objects to play with: car and dog (page 3), car and airplane (page 5) – improve visibility • Children needed help from an adult to read and explain the medical part by giving details and using simple words • Trying to move the arrow which pointed at the interactive image and not the image (page 4) • Children had difficulties understanding the use of the glucometer (page 9) • Simultaneously played with the images trying to find out the appropriate steps of using the glucometer (page 9) • Read the text out loud • Only the 8 years old girl read the text • Used arrows to turn the pages • Omitted objects to play with: car and dog (page 3), car and airplane (page 5) – improve visibility • The child needed help from the adult to read and explain the medical part by giving details and using simple words • Difficulties in understanding the purpose of the glucometer and its steps of appropriate use • Needed further clarification for the insulin, injections, insulin pump, diagnosed, glucometer and strips (pages 9, 10 and 11) • Simultaneously playing with page 9 • Read the text out loud • Used arrows to turn the pages • Interacted with objects: car and dog (page 3), car and airplane (page 5) – improve visibility • Liked the mystery elements finding Superhero (page 3) • The child needed help from the adult to read and explain the medical part by giving details and using simple words • Asked questions about the meaning of words related to diabetes treatment such as contagious, insulin, injections, insulin pump, diagnosed, glucometer and strips (pages 9, 10 and 11) • Difficulties to understand the purpose of the glucometer and its steps of appropriate use | familiar with the pancreas (page 10) • Difficulties understanding the medical text explaining diabetes, glucose, functions of the pancreas, insulin and balance of carbohydrates and insulin (pages 11, 12, 13 and 14) |
| Layered Elaboration | The text on pages 10, 11 and 12 were difficult to read alone  
Difficulties to understand the questions and answers on page 10 – dialogue between Superhero and Dr. Jenny  
They did not know the meaning of the word contagious (page 10)  
The words related to diabetes were new for them: contagious, injections, insulin, glucometer, lancet, strips and insulin pump (pages 9, 10 and 11)  
Children were very enthusiastic with the text on the first pages, medical part of the story decrease their interest of the narrative | The original artefact was moved between children to see the text and images again  
Sometimes the transparent sheets overlaid the original paper slide or was placed on the table  
Children used instruction for the dots  
Children drew images  
Used the dots to explain the interactive elements  
Used white labels to write their ideas  
Drew a red dot instead of using the red dot sticker (8 years old girl)  
Asked for clarification on the | The child alone wrote the ideas using the white labels  
Used the instructions provided for the coloured dots  
Transparent material placed on the table to write the ideas | Needed further clarification for the insulin, injections, insulin pump, diagnosed, glucometer and strips (pages 9, 10 and 11)  
She did not know the meaning of the words: contagious and scientists (page 10)  
The text on pages 10, 11 and 12 were difficult for her to read alone  
Difficulties to understand the questions and answers on page 10 – dialogue between Superhero and Dr. Jenny  
NO | NO | NO |
<table>
<thead>
<tr>
<th>Reading comprehension of the story</th>
<th>Content grasped by children</th>
<th>Content grasped by children</th>
<th>Content grasped by children</th>
<th>Content grasped by children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper prototype:</td>
<td>Only pages 1-9</td>
<td>Children understand the steps in the use of a glucometer (page 9)</td>
<td>Children understand the steps in the use of a glucometer (page 9)</td>
<td>The child understands the steps to use the glucometer (page 9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>They grasp diabetes treatment i.e. injections, healthy food and physical activities (page 13)</td>
<td>They grasp diabetes treatment i.e. injections, healthy food and physical activities (page 10)</td>
<td>She grasps diabetes treatment i.e. injections, healthy food and physical activities (page 10)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Understand the text about celebrities having type 1 diabetes</td>
<td>Understand the text about celebrities having type 1 diabetes</td>
<td>Understands the text about celebrities who have type 1 diabetes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paper prototype:</td>
<td>Paper prototype:</td>
<td>Paper prototype:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Understanding the functions of the stomach, pancreas and human cell</td>
<td>Understanding the functions of the stomach, pancreas and human cell</td>
<td>Understanding the function of the stomach, pancreas and human cells</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Taking medication (insulin), having healthy food and physical activities</td>
<td>Taking medication (insulin), having healthy food and physical activities</td>
<td>Taking medication (insulin), having healthy food and physical activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participant HC9 understands what causes diabetes</td>
<td>Participant HC9 understands what causes diabetes</td>
<td>Participant HC9 understands what causes diabetes</td>
</tr>
</tbody>
</table>