“National Strategy for Service User Involvement in the Irish Health Services: A Case Study Analysis of Policy Implementation”

Rachel Margaret McEvoy

PhD (Medicine – Primary Care)

University of Limerick

Supervisor: Professor Anne MacFarlane

Submitted to the University of Limerick

October 2014
List of Publications

This thesis is based on the following four research papers:


Abstract

National and international health policies recognise that communities should be centrally involved in shaping primary healthcare services. Using Normalisation Process Theory (NPT) this study is designed to critically explore the levers and barriers to implementing community participation in primary healthcare as a routine way of working in the Health Service Executive (HSE).

A qualitative systematic review of peer-reviewed literature using NPT was completed, as was a review of the ‘service user involvement’ academic literature in primary care following the principles of a critical interpretive synthesis. A qualitative case study methodology involving a review of documents, interviews and focus groups with key informants involved in the case of the Irish ‘Joint Community Participation in Primary Care Initiative’ was also carried out. All data were analysed using NPT constructs as the basis for thematic analysis. Findings were validated through data analysis clinics and feedback sessions with participants.

Researchers and practitioners alike continue to debate models, approaches, definitions and operational challenges of community participation in primary healthcare and as a policy ideal its enactment proves problematic. For many participants community participation in primary healthcare is considered to be a new and valuable way of working. Champions were seen as integral to this work, as is the need for all stakeholders involved to have a clear, shared understanding of the aims, objectives and benefits of this way of working. The need for strong partnerships was also reiterated, with some participants identifying the benefits of established relational interactions in sustaining this type of work.

This study shows that NPT, whilst a new theory, provides a generalisable framework that can be applied across contexts and potentially shape implementation journeys. Findings from this NPT analysis were further used to create a theoretically informed framework to support the implementation of community participation in primary healthcare in the HSE.
Declaration

The work is submitted to fulfil the requirements of the degree of Doctor of Philosophy at the University of Limerick. Three of the papers presented (i.e. Chapters 2-4) have been previously published in peer reviewed journals and the fourth paper (i.e. Chapter 5) is currently under review. The researcher’s contribution to the papers comprising the thesis is as follows:

<table>
<thead>
<tr>
<th>Paper</th>
<th>Title</th>
<th>Authors</th>
<th>Contribution of thesis author to the paper</th>
</tr>
</thead>
</table>
| 1     | Community participation in primary care in Ireland: the need for implementation research. | McEvoy R, & MacFarlane A.                   | • Paper conception and design (with supervisor AMacF)  
• Review of literature - lead  
• Drafting of manuscript – first author and lead  
• Critical revisions of manuscript (with supervisor AMacF)  
• Final preparation and editing of manuscript and submission to Journal. |
| 2     | A qualitative systematic review of studies using the normalization process theory to research implementation processes. | McEvoy, R., Ballini, L., O’Donnell, C., Mair, F., & MacFarlane, A. | • Paper conception and design (with supervisor AMacF & LB)  
• Review of literature - lead  
• Data analysis lead (with input from co-authors)  
• Drafting of manuscript first author and lead  
• Critical revisions of manuscript (with AMacF)  
• Final preparation and editing of manuscript and submission to Journal. |
| 3     | Service user involvement in primary care: a critical interpretive synthesis (CIS) of contemporary   | Tierney, E., McEvoy, R., O’Reilly De Brun, M., De Brun, T., Okonkwo, K., Rooney, M., Dowrick, M. | • Review of literature - lead  
• Data analysis collaborator  
• Drafting of manuscript (with supervisor AMacF & ET)  
• Critical revisions of manuscript (with AMacF & ET). |
<table>
<thead>
<tr>
<th></th>
<th>C., Rogers, A. &amp; MacFarlane, A.,</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>“Participation is integral”: Understanding the levers and barriers to the implementation of Community Participation in Primary Care as a routine way of working: A qualitative study using Normalization Process Theory.</td>
</tr>
<tr>
<td></td>
<td>McEvoy, R., Tierney, E. &amp; MacFarlane, A.</td>
</tr>
<tr>
<td></td>
<td>• Study conception and design (with supervisor AMacF)</td>
</tr>
<tr>
<td></td>
<td>• Review of literature - lead</td>
</tr>
<tr>
<td></td>
<td>• Data collection and analysis lead (with input from co-authors)</td>
</tr>
<tr>
<td></td>
<td>• Review of documentary data - lead</td>
</tr>
<tr>
<td></td>
<td>• Drafting of manuscript first author and lead</td>
</tr>
<tr>
<td></td>
<td>• Critical revisions of manuscript (with supervisor AMacF &amp; ET)</td>
</tr>
<tr>
<td></td>
<td>• Final preparation and editing of manuscript and submission to Journal.</td>
</tr>
</tbody>
</table>

Apart from due acknowledgements, this is entirely my own work.

Signed: __________________________  Date: ______________________

Rachel McEvoy
Acknowledgements

I wish to extend a warm and sincere thank you to my family, friends and HSE colleagues for their help and support during the conduct of this research and the writing of this thesis.

I am most thankful to Professor Anne MacFarlane for her guidance throughout this process. Also, I am grateful to Ms. Mary Culliton and Ms. Elaine Houlihan, whose words of encouragement were the final tipping point in committing to this journey.

I am most appreciative of the GEMS Primary Healthcare Research Group, whose support, encouragement and friendship made this process so much more insightful, inspiring and most importantly fun. Also, I benefitted from the knowledge and expertise of all my co-authors who provided much valuable input throughout this research.

To all those both in the HSE and our local communities and organisations who strive continuously for greater community participation in primary healthcare; I hope this study will help you in your work and does you justice.

Thank you to my parents, Peg and Gerry, my sisters and brother (RIP) and all my extended family and friends; you know who you are, and I am fortunate enough to say there are too many to name. Finally, to my husband Shane for always being there and most importantly for always just being himself.
Table of Contents
List of Publications ........................................................................................................... 2
Abstract ................................................................................................................................. 3
Declaration .............................................................................................................................. 4
Acknowledgements ............................................................................................................. 6
List of Appendices .............................................................................................................. 11
List of Boxes ......................................................................................................................... 12
List of Tables ......................................................................................................................... 13
List of Figures ......................................................................................................................... 14
Chapter 1  Introduction........................................................................................................... 15
  1.1 Papers Reviewed and Accepted for Publication ......................................................... 15
    1.1.1 Terminology .......................................................................................................... 15
    1.1.2 Paper 1: Rationale for implementation research .................................................. 17
    1.1.3 Paper 2: Theoretically informed analysis ............................................................. 18
    1.1.4 Paper 3: Exploring the literature on service user involvement ......................... 18
    1.1.5 Paper 4: Analysing community participation in primary care in practice ........ 18
  1.2 Key Literature Pertaining to this Thesis ...................................................................... 20
    1.2.1 Involving individuals and communities in health care ....................................... 20
    1.2.2 The Irish policy and political context ................................................................. 25
    1.2.3 Policy implementation research .......................................................................... 28
    1.2.4 The use of theory in implementation research ....................................................... 31
  1.3 The Overall Aim of this Research .............................................................................. 34
  1.4 Case Study Methodology ............................................................................................ 34
    1.4.1 Selection of the ‘Case’ and case context ............................................................... 36
  1.5 References .................................................................................................................... 41
Chapter 2: Paper 1 Community participation in primary care in Ireland: the need for
        implementation research ............................................................................................... 49
  2.1 Abstract ......................................................................................................................... 49
    2.1.1 Key Words .......................................................................................................... 50
  2.2 Community Participation in Primary Care ................................................................ 51
  2.3 Irish Health Policies for Primary Care and Community Participation ................. 54
  2.4 A Joint Community Participation in Primary Care Initiative .................................. 57
  2.4 Evaluation ..................................................................................................................... 60
  2.5 Project Activities across the Joint Initiative .............................................................. 61
  2.6 The Value, Learning and Outcomes of Community Participation .......................... 63
2.7 Impact of the Joint Initiative on Primary Care at HSE Level .........................64
2.8 Reflecting on the Sustainability of Community Participation in PCTs in Ireland .................................................................66
2.9 Progressing Community Participation in PCTs in Ireland - Implementation Research .........................................................................................70
2.10 Acknowledgements ......................................................................................72
2.11 References ....................................................................................................73

Chapter 3: Paper 2 A qualitative systematic review of studies using the Normalization Process Theory to research implementation processes ......................78

3.1 Abstract ........................................................................................................78
3.1.1 Background ..............................................................................................78
3.1.2 Methods ..................................................................................................78
3.1.3 Results ....................................................................................................79
3.1.4 Conclusions ............................................................................................79
3.1.5 Keywords ...............................................................................................79
3.2 Background ....................................................................................................80
3.3 From Normalization Process Model (NPM) to Normalization Process Theory (NPT) .................................................................................................81
3.4 Methods .......................................................................................................84
3.4.1 Search terms and strategy .......................................................................84
3.4.2 Inclusion and exclusion criteria ...............................................................85
3.4.3 Data abstraction and framework analysis .................................................86
3.5 Results .......................................................................................................87
3.5.1 Search results .......................................................................................87
3.6 Findings as per the Research Objectives ......................................................88
3.6.1 What interventions is NPT being used to analyse? .................................88
3.6.2 How is NPT being operationalised? .........................................................92
3.6.3 What are the reported benefits, if any, of using NPT? ..............................98
3.7 Discussion ..................................................................................................101
3.8 Limitations .................................................................................................104
3.9 Conclusions ...............................................................................................106
3.9.1 Abbreviations .......................................................................................106
3.9.2 Competing interests .............................................................................107
3.9.3 Authors’ contributions .........................................................................107
3.9.4 Acknowledgements .............................................................................107
3.9.5 Funding ...............................................................................................107
3.10 References ...............................................................................................108
Chapter 4: Paper 3 A critical analysis of the implementation of service user involvement in primary care research and health service development using Normalization Process Theory

4.1 Abstract
4.1.1 Background
4.1.2 Method
4.1.3 Findings
4.1.4 Conclusion
4.1.5 Keywords

4.2 Background

4.3 Methods

4.4 Findings
4.4.1 Definition
4.4.2 Enrolment
4.4.3 Enactment
4.4.4 Appraisal

4.5 Discussion
4.5.1 Methodological critique
4.5.2 Directions for future research and practice

4.6 Conclusion

4.7 References

Chapter 5: Paper 4 “Participation is integral”: Understanding the levers and barriers to the implementation of community participation in primary care as a routine way of working: a qualitative study using Normalization Process Theory. Under Review Health and Social Care in the Community

5.1 Abstract
5.1.1 Key Words
5.1.2 What is known about this topic
5.1.3 What this paper adds

5.2 Introduction

5.3 Methods
5.3.1 Study design
5.3.2 Ethical approval
5.3.3 Sampling and recruitment
5.3.4 Data generation and analysis
5.3.5 Quality and rigour ................................................................. 165
5.4 Findings .................................................................................. 165
5.4.1 Coherence ........................................................................... 168
5.4.2 Cognitive participation ...................................................... 170
5.4.3 Collective action ................................................................. 172
5.4.4 Reflexive monitoring ......................................................... 174
5.5 Discussion .............................................................................. 177
5.5.1 Summary of findings ......................................................... 177
5.5.2 Methodological critique .................................................... 178
5.5.3 Connections with existing literature .................................... 179
5.6 References ............................................................................. 181

Chapter 6 General Discussion ........................................................................... 185
6.1 Reflections on the Key Findings and Contributions ...................... 185
   6.1.1 The need for theoretical implementation research about involvement in primary healthcare ................................................................. 186
   6.1.2 Contested terminology .................................................... 187
   6.1.3 Involvement in enabling environments .............................. 189
   6.1.4 Participatory approaches ensuring meaningful involvement .. 190
   6.1.5 Developing an understanding of impact and outcome .......... 192
6.2 Identifying Ideal Conditions for Implementation and Recommendations of User Involvement in Primary Healthcare ................................................................. 193
6.3 Methodological Critique .......................................................... 196
   6.3.1 Reflexivity to enhance positionality .................................. 196
   6.3.2 A systematic approach to literature reviews ....................... 199
   6.3.3 Coding quality process .................................................... 201
   6.3.4 Using a variety of data generation methods ....................... 206
6.4 Implications and Recommendations Emerging from the Study ....... 208
   6.4.1 Implications for further research ...................................... 209
   6.4.2 Implications for primary care .......................................... 209
   6.4.3 Implications for healthcare policy ..................................... 211
6.5 Concluding Statement ................................................................ 212
6.6 References ............................................................................. 213
### List of Appendices

**Appendix 1**  
Rationale for Journal Selection .............................................................. 217

**Appendix 2**  
Memos of Self Reflection (Chapter 1: Section 1.4.1) ............................. 219

**Appendix 3**  
Copyright Permission ............................................................................. 222

**Appendix 4**  
PICO Table: A Qualitative Systematic Review of the Literature on Normalization Process Theory in use (Paper 2) ............................... 223

**Appendix 5**  
Electronic Search (Paper 2) ..................................................................... 251

**Appendix 6**  
Quality Appraisal Checklist & Quality Score Allocation (Paper 2) ...... 253

**Appendix 7**  
Completed PRISMA statement: A qualitative systematic review of studies using the Normalization Process Theory (Paper 2). A systematic qualitative review of the literature on Normalization Process Theory in use. .......................................................................................................................... 260

**Appendix 8**  
Author’s Contribution to Papers Comprising the Thesis ....................... 262

**Appendix 9**  
Sample Schedule of Empirical Data Analysis Clinics (Paper 4) ........... 263
List of Boxes

Box 1.1 National Strategy for Service User Involvement in the Irish Health Service (2008-2013) ................................................................. 17
Box 2.1 Overview of Project Activities in the Joint Initiative ..................... 62
Box 2.2 The Value of Engaging from Differing Perspectives ..................... 63
Box 3.1 NPT Theoretical Constructs ...................................................... 82
Box 4.1 Terminology: Service User Involvement .................................. 119
Box 5.1 The Joint Initiative .................................................................. 158
Box 5.2 Qualitative Study Details ........................................................ 160
Box 5.3 NPT Theoretical Constructs ...................................................... 161
Box 5.4 Data Coding Process ................................................................ 163
List of Tables

Table 1.1  Differences between Policy Implementation Research and Implementation Science .................................................................30
Table 1.2  Examples of Theoretical Approaches used in helping to think about Implementation Processes .........................................................32
Table 1.3  The Design and Overview of Four Peer Reviewed Papers .........................39
Table 3.1  Author, Country of Origin, Topic and Research Focus of Papers included in the Review .................................................................89
Table 3.2  The Operationalisation of NPT Across the Papers included in the Review ..................................................................................92
Table 4.1  Service User Involvement and Normalization Process Theory (NPT) 119
Table 4.2  Sample of 26 Papers included in the Critical Review Categorised by Six Sampling Parameters ............................................................122
Table 4.3  Our Working Definition of 1st, 2nd and 3rd Order Constructs ..................123
Table 4.4  Translation to Inform 1st Order, 2nd Order and 3rd Order Constructs and their Arrangement in Temporal Sequence ..............................125
Table 4.5  Description of 2nd Order Constructs - Partnership and Collaboration, Roles and Responsibilities, and Control and Power: Informing the 3rd Order Constructs ..............................................................................132
Table 5.1  An Overview of the Number of Participants and Data Generation Encounters ..................................................................................162
Table 5.2  Key Documents Analysed ......................................................................164
Table 5.3  Summary Table of activities in the Joint Initiative ................................. 166
Table 6.1  Ideal Conditions for Implementation and Recommendations of User Involvement in Primary Healthcare ..............................................194
List of Figures

**Figure 2.1** Joint Community Participation in Primary Care Initiative: Summary of project objectives, actions and learning across the 19 sites ……………59

**Figure 2.2** Joint Community Participation in Primary Care Initiative: Summary of project objectives, actions and learning across the six demonstration sites based in the Dublin region of Ireland…………………………………….60

**Figure 3.1** PRISMA Flow Diagram of Study Selection utilizing NPT/NPM .............85

**Figure 4.1** Sampling and Selection Process for Papers included in the Critical Review.................................................................121
Chapter 1  Introduction

This thesis “National Strategy for Service User Involvement in the Irish Health Services: A Case Study Analysis of Policy Implementation” is presented in a research paper based format. This first introductory chapter provides a brief overview of the four peer reviewed papers included in this thesis, and an introduction to the relevant literature pertaining to this research. This section also outlines the main aim of the research and the rationale behind selecting a case study approach to the empirical work conducted.

1.1  Papers Reviewed and Accepted for Publication

Three of the four of the papers, which are presented as chapters within this thesis, have been peer reviewed and accepted for publication. The fourth is under review at this time. Some formatting changes have been made in order to aid presentation and readability of the thesis. Figures and tables are presented in the chapters and numbered according to the papers and references presented in the chapters. The researcher’s rationale for the selection of Journals is presented in Appendix 1.

1.1.1  Terminology

In paper 1 the researcher talks about Primary Care Teams (PCTs) in particular but as the reader progresses through the papers they will note that the terminology changes from the specific reference to ‘PCTs’ to a more general and more compassing term ‘primary healthcare’. This change occurred for two main reasons; firstly, this work began with a focus on the 2008 National Strategy for Service User Involvement in the Irish Health Services (Department of Health and Children and HSE, 2008) and the ‘Joint Community Participation in Primary Care’ initiative (referred to as the Joint
Initiative throughout the remaining text) arising from Goal 5 of the National Strategy for Service User Involvement in the Irish Health Services (ibid) (see Box 1.1). Given the focus in the planned remit of the Joint Initiative on PCTs, at the beginning of this study the researcher employed that language and terminology. Secondly, during the review of user involvement in national and international academic primary care literature (paper 3) the focus of the studies reviewed was more than just on PCTs, but on the broader field of primary care as a whole. This was also the case in the work reported as paper 4 about the Joint Initiative in practice because, whilst the individual project leads might have initially looked to achieving community participation in PCTs, what actually happened was something different and broader. The community participation activities in the Joint Initiative spoke more to the social determinants of health (Whitehead, 1992) and the importance of primary healthcare.

Another important issue relates to terminology about involvement. The National Strategy for Service User Involvement in the Irish HSE (Department of Health and Children and HSE 2008) is couched in the term ‘service user involvement’, but the Goals outlined in this Strategy document relate to both individual and community activities. The Joint Initiative for example was developed as a means of ensuring community participation in primary healthcare (as per Goal 5 of the Strategy) which forms the basis and focus of papers 1 and 4. However in the review of the national and international literature (paper 3) it is noted by the researcher and co-authors that various terms are used to describe service user involvement, and subsequently for this chapter the term ‘involvement’ is used as a broad description of the field whilst still being faithful to other authors terminology as appropriate.
1.1.2 Paper 1: Rationale for implementation research

In this paper the 2008 National Strategy for Service User Involvement in the Irish HSE (Department of Health and Children and HSE 2008) is introduced and a description of the Joint Initiative arising from Goal 5 of the Strategy is provided (see Box 1.1). Whether this Joint Initiative can be replicated across all PCTs in the country and embedded as a core part of thinking and practice in everyday health care is questioned. In order to build knowledge about the ways in which innovations such as the Joint Initiative can be embedded into ongoing, routine healthcare practice the need for implementation research is highlighted, thus setting the scene for the overall PhD.

Box 1.1 National Strategy for Service User Involvement in the Irish Health Service (2008-2013) (ibid)

**Seven Goals:**

1. Commitment and leadership
2. A systematic approach to effective service user involvement
3. Patient involvement in their own care
4. A patients charter
5. Involvement of children, young people and socially excluded groups: *Joint Community Participation in Primary Care’ initiative*
6. Development of existing service user structures and
7. Performance and development.
1.1.3  **Paper 2: Theoretically informed analysis**

This article systematically reviews the literature on a contemporary social theory called Normalisation Process Theory (NPT). This is a theory which was developed to enhance understanding about factors that promote or inhibit the implementation of innovations or complex interventions in healthcare settings. The purpose of the review was to critically appraise the stability of the NPT constructs and its relevance and utility for health policy research and implementation. The paper shows NPT to be a useful practical and conceptual heuristic tool that could be employed to study health policy implementation. The findings of this review support the rationale for the application of the theoretically informed analysis utilising a framework such as NPT in this PhD.

1.1.4  **Paper 3: Exploring the literature on service user involvement**

This paper provides a critical analysis of the ‘service user involvement’ academic literature in primary care following the principles of a critical interpretive synthesis (CIS). The review examined; definitions, methods, reported outcomes of service user involvement, and the interrelationships and congruence, or lack of, between identified definitions, methods and outcomes; thus contributing to the researcher’s knowledge about the practice of service user involvement in primary care research and health service development.

1.1.5  **Paper 4: Analysing community participation in primary care in practice**

This paper reports on the results of an NPT analysis of empirical data about implementing community participation in primary healthcare. Drawing on data from 15 sites involved in the Joint Initiative on community participation in primary
healthcare, analysis focused on the findings in terms of NPT’s constructs. For example; (i) coherence (i.e. ensuring clarity as to the meaning of the work involved in terms of community participation and primary healthcare), (ii) cognitive participation (i.e. identifying not only champions for this way or working, but people with a specific mandate for this way of working), (iii) collective action (i.e. activities to enact community participation in real space and time whilst acknowledging the implications of task orientated activities versus process orientated activities), and (iv) reflexive monitoring (i.e. determining the value and impact of community participation in primary healthcare). This conceptual analysis, contributes to our understanding of the levers and barriers to implementation of community participation in primary healthcare within an Irish context.

**Paper 4** also incorporates data from a second qualitative study, FUSION (Towards a Framework for Implementation of **USer InvOlvemeNt** in Primary Care), deemed by the researcher to be a sister project. The FUSION project was a research collaboration formed in 2009 between the University of Limerick Graduate Entry Medical School (GEMS), the HSE National Advocacy Unit in the Directorate of Quality and Patient Safety (the researcher of this PhD study being one of the lead contributors from the National Advocacy Unit named on the proposal and work programme), with community partners from national settings, and academic partners from national and international settings. The research collaboration was funded by the Health Research Board Research Award 2010 HRA-HSP-2010-2. The purpose of the research collaboration was to learn what factors promoted or inhibited community participation activities in the sites involved in the HSE and Combat Poverty Joint Initiative (the Joint Initiative which is also the focus of this PhD study). The rationale for combining
data from these two projects was to ensure a multiperspectival approach incorporating high level policy makers, Joint Initiative project leads, and those working on the ground including GPs.

Table 1.3 below outlines the design of each paper and presents an overview of the results of each paper. The common threads throughout these papers are about building knowledge of the ways in which innovations to involve individuals and communities can be embedded into ongoing routine healthcare practice and providing a theoretically informed empirical analysis of the levers and barriers to the implementation of practices to promote involvement into routine primary healthcare practice.

1.2 Key Literature Pertaining to this Thesis

The relevant literature pertaining to this thesis is summarised and presented under four key headings:

- Involving individuals and communities in health care;
- The Irish policy and political context;
- Policy implementation research;
- The use of theory in implementation research.

1.2.1 Involving individuals and communities in health care

Since being proclaimed as ‘a right and a duty’ in the international Alma Ata Declaration (1978), there is increasing support for the concept of involving individuals and communities in health care services. It has become a key element of mission statements, policy documents and healthcare strategies around the world (Canada,
Given that individuals and communities are considered critical stakeholders in their healthcare and decision making (Titter, 2009; Health Information Quality Authority, 2012; Wiig et al., 2013), their involvement is increasingly recognised as having a major role in service planning and delivery, quality and patient safety, training and research (Parsons, Winterbottom et al., 2010; Brett, Staniszewska et al., 2010; Reader, Gillespie et al., 2014; Lewis, 2014).

At present, terms such as ‘patient and public involvement’ (PPI), ‘user involvement’, ‘citizen engagement’, and ‘community participation’ are commonplace in the literature and health policy circles (Brett, Staniszewska et al., 2010, Gallivan, Kovacs Burns et al., 2012). However, these terms are often used interchangeably, with little agreement about what they mean in the context in which they are used (Preston, Waugh et al., 2010). For example, Forbat and colleagues conclude that “a range of ways of conceptualizing involvement are used interchangeably in policy and practice without due recognition of the very different meanings of public consultation, patient/carer involvement in treatment decision-making, and patient/carer involvement in service design and development” (2009 p.2552). The challenge is to clarify who is involved (e.g. patient/user/citizen), in what (e.g. treatment decision making/service design and development/training/research) and to what degree (e.g. engagement/consultation/participation).
It has been argued (Brett, Staniszewska et al. 2010; Preston, Waugh et al. 2010; Gallivan, Kovacs Burns et al. 2012) that this current situation in the field contributes to the misunderstanding and misinterpretation of expectations, goals and outcomes by different groups of stakeholders, which poses barriers to achieving meaningful and successful outcomes in partnership work together.

In practice there are many examples of involvement across health care jurisdictions; in the UK, The Patient Advice and Liaison Service (PALS) helps patients and their carers address concerns in relation to their care and treatment and tries to sort out problems quickly by liaising with staff, managers, and other organisations. A study of quality improvement strategies in Europe also revealed that monitoring patients’ views by systematically conducting patient surveys was common practice in 64.5% of the 389 participating European hospitals but with widely disparate practice in different countries (Lombarts, Rupp et al., 2009). In India, which was one of the first countries to create a national community health worker scheme after the Alma Ata conference and subsequently saw the scheme disappear within 10 years, has now begun to revive the programme in the context of the National Rural Health Mission (Bhatia and Rifkin, 2010). In Australia, funding organisations such as the National Health and Medical Research Council (NHMRC) require grant applications to detail the process of involvement planned for funded programmes and expects project reports to include a discussion of how service user involvement was achieved (NHMRC, 2004).

Whilst there are undoubtedly many examples of involvement in practice across health care jurisdictions it is not without its challenges (Fudge, Wolfe et al., 2008; Attree, French et al., 2011; Lewis, 2014; Bath and Wakerman, 2013); for example these
challenges include resource issues (i.e. both in terms of time and cost); service user issues and organisational issues:

- **Resources**

  Adequate resources are needed to promote involvement programmes and ensure that individuals and communities are given an opportunity to contribute. Individuals and communities need to hear about the opportunity for involvement and be given adequate notice if they are to be involved (Ridley and Jones, 2002, Gregory, 2007).

  The view that ambition or rhetoric may outweigh economic realities is expressed in ‘The Empowerment of the European Patient’ report that “At the end of the day... There might be high policy ambitions but what is expressed “economic realities” often weigh more heavily” (Powerhouse, 2009 p.9).

- **Service user issues**

  In a review carried out by McCormack (2007) on community participation in health services, power differentials and dynamics between individuals and professionals in involvement activities were noted. These are historical and can be present at both organisational and individual levels.

  To be able to participate effectively at the policy level, individuals and communities need to develop a sound understanding of the health system and the issues it faces and they need to be able to talk about those issues. This can require extensive time in preparation, and significant support and training for their participation (Environmental Protection Agency, 2001, Horey and Hill, 2005), which in turn may result in time
delays (Brett, Staniszewska et al., 2010). For researchers and policy makers alike often working on short time scale this may cause difficulties and result in less than participatory modes of involvement.

If unfamiliar with the issues under discussion, the language used, the processes of meetings and policy development, or the people they are asked to work with, individuals and community representatives can face significant challenges (Oliver, Clarke-Jones et al.; 2004; Pivik, Rode et al., 2004; Horey and Hill, 2005). Anderson et al. (2006) report that the processes of meetings can be both tedious and daunting for individuals who need to survive an initially difficult period before they become familiar enough with the jargon and the processes to be able to contribute.

- **Organisational issues**

Organisational commitment and responsiveness have been identified as general factors that can inhibit user led service change and quality enhancement. This is because organisations may be unfamiliar with involvement practices, unfamiliar with working with individuals and/or community representatives, and may have negative attitudes towards their input. In addition, organisations may not have a clear idea of how to involve users actively and purposefully in the planning, development and delivery of services. Bramson (In Henton, Nguyen et al., 2001) identifies organisational barriers as involving a deficit in either will or skill: many managers lack the will to engage users because they feel it imposes enormous burdens without any benefit; at the same time, many have not developed the skills in facilitation, group processes and conflict resolution that are essential for user involvement.
In addition to the conceptual ambiguity and challenges in practice summarised above, Attree et al. (2010) also highlights that whilst there have been attempts to measure impact, largely in terms of user involvement in research, one of the difficulties is that there is an absence of widely recognised measurement criteria for judging the success or failure of such involvement. Fudge et al. (2008) also illustrate the difficulty of assessing effectiveness, especially when concepts are poorly defined.

Overall while the policy context is established and consistent, and there are examples of good practice in certain places at certain times, there are significant challenges sustaining practice and embedding policy rhetoric in healthcare settings. The next section of this chapter looks to the involvement of individuals and communities in primary healthcare in Ireland, with a focus on Irish policy and the political context.

1.2.2 The Irish policy and political context

In Ireland, policies about involvement date back over three decades, and can be traced to development of a social partnership approach to addressing a range of economic, social and industrial relations issues in the late 1980s. The National Economic and Social Council commenting on the development of social partnership ethos in the public policy area has stated that ‘it is now inconceivable that major policy initiatives would be taken without some consultation with, and/or involvement of, the social partners’.

In terms of the Irish health sector, The 2001 Health Strategy - Quality and Fairness: a Health Service for You (Department of Health and Children, 2001b) was one of

---

1The trade union pillar, the employer and business pillar, the farming organisation pillar and the community and voluntary pillar.
the most explicit Irish government strategies to use public consultation to inform its
development and to locate public consultation within a quality framework. A core
element of the Strategy’s vision is a health system that encourages the public to have
their say and ensures that views are taken into account (Department of Health and
Children 2001b, p.19). This is further echoed in other health planning documents
such as the HSE Corporate Plan 2005-08 (Objective 4) (Health Service Executive,
2005), and the National Intercultural Strategy (2007-2016) where “every child and
young person will have access to appropriate participation in local and national
decision making” (Health Service Executive, 2007 p.3).

To demonstrate its commitment to the HSE Corporate Plan, and to build on the
recommendations promoting involvement which were outlined in a position paper of
the National Primary Care Steering Group (Department of Health and Children, 2004),
the HSE specified the development and implementation of a framework for involving
service users and communities in service development as one of its thirteen
Transformation Programmes for 2007-20102 (Health Service Executive, 2007b). This
took the form of the National Strategy for Service User Involvement in the Irish Health
Service (Department of Health and Children and HSE 2008).

Compiled at the time by the HSE Office of Consumer Affairs3, and in partnership with
the Department of Health and Children (DoHC) and other key stakeholders (i.e. union
representatives, service users, statutory and voluntary organisations), the Strategy is
produced in the context of several key DoHC and HSE policy and strategy documents,

---

2 The HSE’s Transformation Programme 2007-2010 represents the organisation's ambition for the future. Specifically, this
Transformation Programme states the organisation's purpose 'To enable people live healthier and more fulfilled lives' and provides
a shared direction and focus in that 'Everybody will have easy access to high quality care and services that they have confidence
in and staff are proud to provide' Health Service Executive (2007b) Transformation Programme 2007-2010.(HSE 2007, p.9).

3 Renamed the National Advocacy Unit in 2010
which have previously demonstrated a commitment to service user involvement
namely the aforementioned Department of Health and Children’s Health Strategy
(Department of Health and Children, 2001b), as well as Primary Care – A New
Direction (Department of Health and Children, 2001a), and A Vision for Change
(Department of Health and Children, 2006).

This HSE strategy for service user involvement uses the term ‘service user’ to “take
account of the rich diversity of people in society whether defined by age, colour, race,
ethnicity or nationality, religion, disability, gender or sexual orientation, and may
have different needs and concerns” (Department of Health and Children and HSE
2008 p.6) and uses the term ‘involvement’ to refer to:

“A process by which people are enabled to become actively and genuinely
involved in designing the issues of concern to them, in making decisions about
factors that affect their lives, in formulating and implementing policies, in
planning, developing and delivering services and in taking action to achieve
change” (ibid)

The approach to the Strategy is based on three levels of involvement:

1. “Individual service users: involvement in their own care
2. Community: involvement in local service delivery and development
3. National: strategic policy informed through involvement of service user
   organisations in partnership with health care professionals” (ibid p.9).

The strategy document presents a strategic framework containing seven goals (see Box
1.1). In describing the necessary actions to be taken within each of these Goals, it also
identifies the specific areas of support and expected deliverables, such as the delivery
of the Joint Initiative under Goal 5.
However, despite these developments in strategic thinking and identified actions, there has been no analysis to date of the implementation of the National Strategy for Service User Involvement in the Irish Health Service (Department of Health and Children and HSE, 2008). The HSE National Advocacy Unit is charged with responsibility to ‘specify, enable and assure’ strategy implementation and, for this, considered it an opportune time to explore and analyse the dynamic processes at play in the implementation process and to establish if there is any evidence of practice change and integration in the HSE as a result of the 2008 service user involvement strategy. Most crucially, it was necessary to establish if new activities from the Joint Initiative had become sustained and embedded practices.

Given important developments with the reform of primary care in Ireland from 2001, specifically the policy imperative to develop PCTs across the country and to ensure community participation in these teams, the HSE National Advocacy Unit prioritised this research study to identify the levers and barriers to community participation in primary healthcare, with the Joint Initiative as the selected case.

Given the HSE National Advocacy Units responsibility to ‘specify, enable and assure’ strategy implementation, in the next two sections of this chapter we examine literature about policy implementation research, and the use of theory in implementation research.

1.2.3 Policy implementation research

There has been a proliferation of research about research-practice-policy links in recent decades (Nutley et al., 2010). ‘Policy implementation research’ which rose to
prominence in the 1970’s, emerged from the insight that political intentions seldom resulted in the planned changes, which encouraged researchers to investigate what occurred in the process and how it affected the results. With the emergence of evidence based medicine (EBM) and its wider application as evidence based practice in the 1990’s, ‘implementation science’, which is a related, more recent idea, has also contributed a substantial body of literature about these translational gaps.

However, whilst both fields of research deal with the challenges of translating intentions into desired changes, and both emphasise the importance of interdisciplinary research using a variety of research methodologies, there has been limited knowledge exchanged between both policy implementation research and implementation science (Nilsen et al., 2013).

Some authors, such as Nilsen et al. (2013), have teased out the differences between these two fields of research (see Table 1.1 below). However Peters et al. (2013), amongst others, present this area of interest more broadly as ‘implementation research’ defining it as:

“a type of health policy and systems research concerned with the study of clinical and public health policies, programmes and practices, with the basic intent being to understand not only what is and isn’t working, but how and why implementation is going right or wrong, and to test approaches to improve implementation. It is very often concerned with the problems arising when an initiative is rolled out or scaled up describes the scientific study of the processes used in the implementation of initiatives as well as the contextual factors that affect these processes” (Peters, Tran et al., 2013).

This definition echoes that of Werner (2005) who outlines ‘implementation research’ as a general term for research that focuses on the question ‘What is happening?’ in the design, implementation, administration, operation, services, and outcomes of social
programs; it also asks, ‘Is it what is expected or desired?’ and ‘Why is it happening as it is?’.

Implementation research expands the focus of traditional research from discovering what works to also discovering how the implementation of an intervention works in specific contexts. It requires the involvement of a wide range of stakeholders and draws on multiple disciplines in order to address complex implementation challenges. In doing so, properly conducted implementation research, with its all important focus on context can help implementers foresee and anticipate problems and/or explain processes retrospectively.

Table 1.1 Differences between Policy Implementation Research and Implementation Science (sourced from Nilsen, Stahl et al., 2013, and Peters, Tran et al., 2013).

<table>
<thead>
<tr>
<th>Policy Implementation Research</th>
<th>Implementation Science</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rose to prominence in the 1970’s. Core disciplines at origin include political science, public policy, public administration.</td>
<td>Origins traced to EBM/EBP in the 1990’s. Core disciplines include behaviour change (psychology, sociology, education, epidemiology).</td>
</tr>
<tr>
<td>Case study method is commonly employed to account for a large number of causal factors.</td>
<td>Although broadened it still features far more quantitative research than seen in implementation research. Case studies are not afforded the same status as in policy implementation research.</td>
</tr>
<tr>
<td>Faces problems in identifying what is being implemented because policies are complex phenomena.</td>
<td>The object in implementation science tends to be a more easily identifiable and delimited phenomenon.</td>
</tr>
<tr>
<td>Top down: central level policy makers and Bottom up: ‘Street level; programme implementers are the targets in policy implementation research.</td>
<td>Patients represent the targets in implementation science</td>
</tr>
<tr>
<td>Policy implementation studies concern naturally occurring circumstances, meaning that the investigator is not able to control or manipulate different</td>
<td>Implementation science studies draw strong influence from medical research. Involves testing the effectiveness of various strategies to achieved changes in</td>
</tr>
</tbody>
</table>
variables. clinical practice, preferably applying RCT study designs and systematic literature reviews to summarise the current knowledge of effective implementation interventions.

Whatever the field of research, there is however, common agreement and repeated calls amongst authors for the use of theory in ‘implementation research’ (Nilsen, Stahl et al., 2013; Peters, Tran et al., 2013; Damschroder, Arbor et al., 2013). For example, leading policy implementation researchers have argued that it is more fruitful to develop (and potentially test) different partial theories and hypotheses that address certain implementation aspects. Implementation science researchers have made a conscious effort to import and use various theories that can improve the understanding, explanations, and prediction of implementation endeavours, irrespective of the origins or source of these theories (Nilsen, Stahl et al., 2013). In the next section we will specify at the use of theory in implementation research.

1.2.4 The use of theory in implementation research

Eccles et al. (2009) have argued the need to see greater use of theoretical approaches in research focused on implementation, on the basis that this will offer (i) generalisable frameworks that can be applied across different settings and individuals, (ii) opportunity for the incremental accumulation of knowledge, and (iii) an explicit framework for analysis.

The use of theory enables the researcher to think creatively about the research, as it can improve understanding, explanation and prediction of implementation endeavours (Damschroder, Arbor et al., 2013, Nilsen, Stahl et al., 2013). It is therefore important
both to develop and test theories that are in use, to appraise their relevance and utility for the field of implementation research (Davies, Walker et al., 2010; Murray, Treweek et al., 2010; Morrison and Mair, 2012; Nilsen, Stahl et al., 2013).

Peters et al. (2013) also highlight that certain theoretical constructs are of value in helping to think about implementation processes, notable among them are theories of change that try to explain what is needed to achieve a long term goal such as improved health. A number of theories have been developed to promote the effective implementation of health interventions (see Table 1.2 Examples of Theoretical Approaches used in helping to think about Implementation Processes).

Table 1.2  Examples of Theoretical Approaches used in helping to think about Implementation Processes.

<table>
<thead>
<tr>
<th>Theory</th>
<th>Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theories of Planned Behaviour (Ajzen, 1991).</td>
<td>A theory about the link between beliefs and behaviour, and can explain the individuals social behaviour by considering the social norm as an important variable.</td>
</tr>
<tr>
<td>Diffusion of Innovations theory (Rogers, 1995).</td>
<td>Seeks to explain how, why, and at what rate new ideas and technology spread through cultures.</td>
</tr>
<tr>
<td>Reach, Efficacy, Adoption, Implementation and Maintenance Framework (RE-AIM) (Glasgow, Vogt et al., 1999).</td>
<td>Provides a practical approach to evaluating the effects of health interventions through changes in individual organisations and communities.</td>
</tr>
<tr>
<td>Contextual Interaction Theory (cited in O’Toole (2004).</td>
<td>A deductive, social process approach which posits that policy actors’ motivation, information needs, and level of power/collaboration are key variables influencing policy and program implementation.</td>
</tr>
<tr>
<td>Consolidated Framework for Implementation Research (CFIR) (Damschroder, Aron et al., 2009).</td>
<td>Developed as a way to consolidate the various theories and terms used to support further development of theory and testing on how to translate health interventions that have been shown to be effective.</td>
</tr>
<tr>
<td>Normalisation Process Theory (NPT) (May and Finch, 2009).</td>
<td>A middle range theory, NPT explains how material practices become routinely embedded in their social contexts as a result of people working, individually and collectively to enact them.</td>
</tr>
</tbody>
</table>

In light of the above literature, the use of theory to help understand the dynamics of implementing, embedding and integrating initiatives to involve individuals and communities in healthcare is considered key for good quality implementation research.

Whilst acknowledging the various theories outlined in Table 1.2, the theory of focus in this study is Normalisation Process Theory (NPT). According to the literature NPT has the capacity to elucidate the details of small scale implementation work but, also, to elucidate the ways in which macro, meso and micro levels of action and interaction shape that work (May and Finch, 2009). NPT was selected because one of its distinguishing features is that it is a theory of action, which means that it is concerned with explaining what people do rather than their attitudes and beliefs. It also extends beyond the initial introduction of innovation to investigate the processes by which innovation may become embedded and routinised in practice, so much so that it becomes regarded as a normal and taken-for-granted way of working.

NPT provides a comprehensive theoretical framework for a ‘whole system’ analysis of the factors that promote or inhibit the routine embedding of complex interventions in health care practice and the work involved, by individuals and groups, to implement change in healthcare settings (May and Finch, 2009). It has been used retrospectively in primary care settings (May, Mair et al., 2007; Gask, Rogers et al., 2008; Wilkes and Rubin, 2009; Franx,Oud et al., 2012), and is currently being used to prospectively
investigate implementation of Guidances and Training Initiatives (GTI) to improve communication between migrants and primary care providers (MacFarlane, O’Donnell et al., 2012).

Given its scope and application, the researcher is interested in its capacity to be used as a theoretical framework to investigate implementation of policies about involving individuals and communities in primary healthcare and identifying levers and barriers to practice, implementation and sustainability. In the next section the aim of the research and the case study approach is outlined.

1.3 The Overall Aim of this Research

In relation to the National Strategy for Service User Involvement in the Irish Health Service (2008-2013), the overall aim of this research is to:

- Explore the ideal conditions for policy implementation;
- Explore the process in implementing the Irish National Strategy for Service User Involvement in the Irish Health Services (Department of Health & Children and HSE 2008) with a particular focus on community participation in primary healthcare;
- Make recommendations to maximise opportunities for policy implementation of the aforementioned National Strategy for Service User Involvement.

1.4 Case Study Methodology

Methodology is defined as the strategy, plan of action, process or design lying behind the choice and use of particular methods and links the choice of methods to desired
outcomes (Crotty, 1998). The methodological framework chosen for this thesis was case study.

The process of defining case study methodology in the research literature has presented some problems (Bryar, 1999; Gomm, Hammersley et al., 2000; Stake, 2001), but a generically accepted definition is that it is:

“an intensive and systematic investigation of a single individual, group, community or some other unit, typically conducted under naturalistic conditions in which the investigator examines in-depth data related to background, current status, environmental characteristics and interactions” (Woods and Catanzaro, 1998 p.553).

A qualitative methodology, such as case study, based on principles of context, meaning and interpretation offers the most suitable framework to explore the levers and barriers to policy implementation. In order to understand and capture the complexities of the research questions (i.e. those outlined in section 1.3) it is vital to have the correct theoretical underpinning. In addition Yach (1992) has stressed the need for an increased application of qualitative approaches in community health research and demonstrate their value.

Case study methodology also encourages theoretical innovation (Orum, Feagin et al., 1991). According to Yin (2003), in case study research, the research design embodies a theory (i.e. NPT), a plan or a blue print of what is being studied and this serves the purpose of informing the research design and data generation and analysis processes.
1.4.1 Selection of the ‘Case’ and case context

In the present study, the ‘casing’ process (Ragin and Becker, 1992) involved identification of a single instrumental case (i.e. the Joint Initiative).

As a HSE employee within the Office of Consumer Affairs, the researcher was the appointed project co-ordinator for the Joint Initiative in the two years (2008-2010) prior to this current research. In addition, the researcher also led the development process and publication of the National Strategy for Service User Involvement in the Irish Health Services (Department of Health and Children and HSE, 2008). Therefore, there is some congruence between both the researcher and her HSE employee roles.

Creswell offers a cautionary note about studying one’s own organisation or workplace because to study one’s own workplace “for example raises questions about whether good data can be collected when the act of data collection may introduce a power imbalance between the researcher and the individuals being studied” (2007 p.122). It was considered that it may have been challenging for HSE staff, given the researchers position also as a HSE employee, to see or believe that their work around user involvement is not being judged in terms of its quality or impact, as opposed to determining the levers and barriers to such work.

However there were potential merits. Firstly, the researcher’s role as the Joint Initiative HSE project co-ordinator prior to this study afforded her access to the field of study and an established strong rapport with the research participants. Therefore the tensions that other researchers speak of when entering a social setting ‘cold’ were not an issue (Wellin and Fine, 2001 p.325). Secondly, the researcher’s immersion and involvement
in the case prior to the research, also required little further ‘soaking and poking’ which is often considered to be the first step in studying a case with which one is not already intimately familiar with (George and Bennett, 2005 p.89).

It is also worth acknowledging that according to Peters et al. (2013) implementation research cannot provide all the knowledge needed for successful implementation. Implementation know-how is also acquired through apprenticeship and experience involving observation and practice. This kind of know-how, sometimes referred to as ‘tacit knowledge’ is an important part of learning for individuals and organisations.

Overall, to maximise the merits of the situation, the methodological approach acknowledged the social world of the researcher and the fact that it may influence aspects of the research study. Rather than trying to eliminate the impact of that world the researcher chose to be ever mindful of her position and also sought to maximise the opportunities it presented in addressing the research question. A reflexive approach to the research design was also adopted, which involved reflection on self, process and representation, and critically examining power relations and politics in the research process, and researcher accountability in data collection and interpretation (Falconer Al-Hindi and Kawabata, 2002). In other words the constant awareness and assessment of a researcher’s own contribution and influence on research and consequent findings. This approach is congruent with the overall approach to this research study in that reflexivity is viewed as part of a paradigm shift: from a scientific to interpretive approach, from objectivist to relativist, and from value neutrality to normative interests (Scholte, 1972).
According to the literature, a more reflexive and flexible approach to fieldwork allows the researcher to be more open to any challenges to their theoretical position that fieldwork almost inevitably raises. Certainly a more reflexive approach, which the researcher adopted as part of this overall research process, requires careful consideration of the consequences of the interactions with those being studied.

Hammersley and Atkinson are strong proponents of a reflexive approach and refer to the use of analytic notes to record ‘promising theoretical ideas’ which arise while reading documents, making field-notes or transcribing tapes (1983 .p.164). Jean Briggs (1970) also argues that observing and thinking about her own feelings, assumptions, personality and actions have been invaluable sources of data. However, a reflexive approach is not just the practice of note keeping about findings and emerging theory. It is about ongoing interrogation of the knowledge acquired and the interests that this knowledge serves. Ongoing self reflection in memos and discussions with mentors and peers throughout the course of this research study were used by the researcher to help identify and account for the interference of any assumptions in the study and record issues which may have arisen and influence or biased the study in any way (See Appendix 2 for a sample of such memos).

The following chapters present the four peer reviewed papers included in this thesis as outlined in Table 1.3 below.
Table 1.3  The Design and Overview of 4 Peer Reviewed Papers.

(See Appendix 3 for Copyright Permission; and Appendix 8 for Authors contribution to the papers).

<table>
<thead>
<tr>
<th>Design</th>
<th>Paper 1 (Published)</th>
<th>Paper 2 (Published)</th>
<th>Paper 3 (Published)</th>
<th>Paper 4 (Under Review)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development</td>
<td>Development</td>
<td>Qualitative Review</td>
<td>Critical Interpretive Synthesis</td>
<td>Qualitative Analysis using NPT</td>
</tr>
<tr>
<td>Data Collection</td>
<td>Documentary</td>
<td>Literature Review</td>
<td>Literature Review</td>
<td>Interviews, documentary analysis and focus groups</td>
</tr>
<tr>
<td>Number of Participants</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Study 1 (n=32); Study 2 (n=39)</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>N/A</td>
<td>Deductive Framework analysis</td>
<td>Inductive and deductive thematic analysis</td>
<td>Inductive and deductive thematic analysis</td>
</tr>
<tr>
<td>Aim</td>
<td>To provide an overview of community participation in primary healthcare, establishing the policy context in which a recent ‘Joint Initiative on Community Participation in Primary Health Care’ was developed in Ireland. This Initiative was designed to support the involvement of disadvantaged communities and groups in the development of primary healthcare services at local level.</td>
<td>This review of NPT offers readers the opportunity to observe how, and in what areas, a particular theoretical approach to implementation is being used. In this article the authors review the literature on NPT in order to understand what interventions NPT is being used to analyse, how NPT is being operationalised, and the reported benefits, if any, of using NPT.</td>
<td>The aim of this review is to critically interrogate the conditions for the implementation of SUI in primary care research and health service development projects. The authors focus on a sample of published empirical work that is reported as SUI in the primary healthcare literature to advance knowledge about definition, enrolment, enactment and appraisal vis a vis each other and to make recommendations for SUI practice and implementation.</td>
<td>To explore the levers and barriers to the implementation of community participation in primary healthcare as a routine way of working in Ireland.</td>
</tr>
<tr>
<td><strong>Main Results</strong></td>
<td>This paper presents a summary of key findings from the evaluation of the Joint Initiative. It pays particular attention to the issue of sustaining community participation in newly developed Primary Care Teams (PCTs) and other primary care activities in the current and changing economic climate in Ireland, an issue considered crucial if the documented positive impacts of the Joint Initiative are to be maintained and the potential for health gains in the longer term are to be realised. It is argued that the Joint Initiative referred to in this paper clearly provides a strong prototype for community participation in PCTs and primary care in Ireland. The paper questions whether it can be replicated across all PCTs in the country and embedded as a core part of thinking and everyday health care. The authors highlight the need for research to build knowledge about the ways in which innovations such as this can be <em>embedded</em> into ongoing, routine healthcare practice. This research agenda will have relevance for policy makers, practitioners and evaluators in Ireland and other healthcare jurisdictions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>Twenty-nine articles met the inclusion criteria; in the main, NPT is being applied to qualitatively analyze a (Harris et al. 2012) diverse range of complex interventions, many beyond its original field of e-health and telehealth. The NPT (Elwyn et al. 2007) constructs have high stability across settings and, notwithstanding challenges in applying NPT in terms of (May et al. 2007a) managing overlaps between constructs, there is evidence that it is a beneficial heuristic device to explain and guide implementation processes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>From an initial sample of 289 papers, 26 were chosen as a purposeful sample of work that is reported as service user involvement (SUI) in the field of primary healthcare research and health service development. Few papers provided a clear working definition of involvement. The dominant rationale for involving service users was linked with policy imperatives for co-governance and emancipatory ideals. The majority of methodologies employed were standard health services research methods that in and of themselves do not qualify as research <em>with</em> service users. This indicates a lack of congruence between the stated aims and methods. Most studies only reported positive outcomes, raising questions about the balance or completeness of the published accounts.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>For many stakeholders, community participation in primary healthcare was a new way of working. Stakeholders did not always have a clear, shared understanding of the aims, objectives and benefits of this way of working. Drivers or champions were considered integral to its initiation and implementation, as were strong working partnerships between community and health service personnel. Participants emphasised the benefits of funding, organisational support, training and networking to enact relevant activities. Health promoting activities and healthcare consultation/information events were generally successful, but community representation on inter-disciplinary Primary Care Teams proved a particular challenge with little sustained progress reported. Overall, participants were broadly positive about the impacts of community participation, but were very concerned about the scope to sustain the work without the 'protected' space and resources of the national Initiative, and the economic recession.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.5 References


Research, 8.


Alliance for Regional Stewardship, Palo Alto, CA.


Chapter 2: Paper 1

Community participation in primary care in Ireland: the need for implementation research

2.1 Abstract

There are now several decades of history of community participation in health, with significant international evidence to suggest that there is much to be gained by primary health services and disadvantaged communities working in partnership.

In this paper we provide an overview of community participation in primary care, establishing the policy context in which a recent ‘Joint Initiative on Community Participation in Primary Health Care’ was developed in Ireland. This Initiative was designed to support the involvement of disadvantaged communities and groups in the development of primary health care services at local level.

An independent formative evaluation of the Joint Initiative took place between September 2009 and April 2010. We present a summary of key findings from this evaluation. We pay particular attention to the issue of sustaining community participation in newly developed Primary Care Teams (PCTs) in the current and changing economic climate, an issue considered crucial if the documented positive impacts of the Joint Initiative are to be maintained and the potential for health gains in the longer term are to be realised.
We then argue that the Joint Initiative referred to in this paper clearly provides a strong prototype for community participation in PCTs in Ireland. We also ask whether it can be replicated across all PCTs in the country and embedded as a core part of thinking and everyday health care. We highlight the need for research to build knowledge about the ways in which innovations such as this can be *embedded* into ongoing, routine healthcare practice. This research agenda will have relevance for policy makers, practitioners and evaluators in Ireland and other healthcare jurisdictions.

### 2.1.1 Key Words

Community; implementation research; participation; policy; primary healthcare

Received 9 August 2011; revised 6 December 2011; accepted 26 February 2012
2.2 Community Participation in Primary Care

‘Primary care brings promotion and prevention, cure and care together in a safe, effective and socially productive way between the population and health system’ (WHO, 2008 p.41). It aims to provide first-level contact that is accessible by self-referral and has a strong emphasis on working with communities and individuals to improve their health and social well-being (Department of Health and Children, 2001a). The attributes or functions of primary care have been summarised in the definition of the American Institute of Medicine referring to ‘the provision of integrated, accessible healthcare services by clinicians who are accountable for addressing a large majority of personal healthcare needs, developing a sustained partnership with patients and practicing in the context of family and community’ (Donaldson, Yordy et al., 1996 p.1).

In 1978, the Alma Ata Declaration emphasised the significance of community participation in the planning and delivery of primary health care, declaring that ‘health for all’ was achievable through primary health care by 2000 (WHO, 1975; 1978). However, Draper et al. draw our attention to the fact that many people are still coming to terms with the words and principles that followed this Declaration, and while there have been many attempts to define community participation, ‘a standard definition remains both elusive and contentious’ (2010 p.1103). We note that there are many concepts related to community participation in the literature, such as community involvement (Kahassay and Oakley, 1999), community development, community empowerment (Laverack and Wallerstein, 2001), community capacity, and
community competence (Goodman, Speers et al., 1998). For the purpose of this paper, however, we employ the following working definition of community participation:

‘a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (WHO, 2002 p.10).

There is evidence which indicates that building high levels of trust and group participation is critical to reducing mortality (Kawachi and Kennedy, 1997), while a lack of participation, control or self-esteem, along with poor social support structures, directly contributes to increased morbidity (Berkman, 1995). International literature also shows community participation to have a powerful impact on the outcomes of family and the intergenerational cycles, which have a cumulative effect of disadvantage across the life course on the social patterning of disease (Marmot, 2010). However, there are few rigorous studies that have definitively measured the effects of community participation in terms of health outcomes, wellbeing and quality of life (Crawford, Manley et al., 2002; Frankish, Kwan et al., 2002; Kearns and Neuwelt, 2009; Preston, Waugh et al., 2010).

There is however stronger evidence of community participation impacting positively on service improvement (Crawford, Manley et al., 2002; Kearns and Neuwelt, 2009; Preston, Waugh et al., 2010), and a collective understanding that the involvement of communities in primary health care results in more equitable and inclusive services, which are more responsive to the needs of the community (WHO 1978; 2002; 2008; Crowley, 2005; Draper, Hewitt et al., 2010; Houlihan, 2010). This is in line with contemporary social research ethics, which recognise the importance of active community participation in research processes (Alexander, 2010). Furthermore, it
reflects a shift away from ‘service-led systems, where people are fitted into the pattern of provision that has developed historically, to user-led or user-centred services’ (Beresford, 2010 p.438). Indeed, community participation is a central ideal found in almost all the contemporary major national and international declarations on health.

In this paper we provide an overview of community participation in primary care, and the policy context in which a recent national initiative was developed that resourced 19 projects to support and enable disadvantaged communities and groups to participate in local PCTs and Networks within the Health Service Executive (HSE). Each PCT in Ireland is designed to deliver health and personal social services to a local population of ~7000–10 000, and is the first point of contact for patients and clients in a local setting, ensuring continuation and co-ordination of services. A small number of PCTs are also connected to a Health and Social Care Network providing services for a population of 30 000 - 50 000 (Health Service Executive, 2011a).

We draw on findings from the formative evaluation of the *Joint Initiative on Community Participation in Primary Health Care* (hereafter referred to as the Joint Initiative: Pillinger, 2010), while paying particular attention to the issue of sustaining community participation in these PCTs in the current and changing economic climate; an issue considered crucial if the documented impacts of this Initiative are to be maintained and the potential for longer term health gains realised. Finally, we reflect on new areas for research, setting out important implementation research questions pertaining to the integration and embedding of community participation in primary
health care as a core part of thinking and everyday healthcare practice, which will have relevance for Ireland and other healthcare jurisdictions.

2.3 Irish Health Policies for Primary Care and Community Participation

The importance of primary care was recognised by the Irish government in its primary care strategy *Primary Care: A New Direction* (Department of Health and Children 2001a). The strategy acknowledged that Ireland’s primary care infrastructure was poorly developed and services were fragmented, with a focus on treatment at the expense of a more balanced emphasis on prevention, health promotion and well-being. This strategy set out for the first time in Irish policy, a plan for primary care as the central focus for the delivery of health and personal social services, with a commitment to the establishment of 500 PCTs around the country by 2011. This has been reiterated in recent years in a number of key policy documents, including the *National Development Plan 2007-2013* (NDP, 2007), the social partnership agreement *Towards 2016* (Department of the Taoiseach, 2006) and the *National Action Plan for Social Inclusion 2007-2016* (Government of Ireland, 2007).

A PCT is considered to be established where there are regular clinical team meetings between the HSE and general practice (GP) staff. In an environment of privately owned general practice, however, it is not always easy to establish such team meetings. A recent update on the HSE’s website indicates that there were 383 PCTs (76.6%) holding clinical team meetings at the end of June 2011. However, these figures have been contested by primary care providers and the newly appointed Minister for Health and Children. The Minister has further questioned the operational effectiveness of the Teams, and the lack of sufficiently developed indicators to enable
their assessment (Donnellan, 2011; Mudiwa, 2011); hence additional criteria are now being considered.

As outlined earlier, Irish health policy also recognises that communities should be centrally involved in shaping health services, including primary care services. Action 19 of the 2001 primary care strategy states that:

‘Community participation in primary care will be strengthened by encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services… at local level, primary care teams will be encouraged to ensure user participation in service planning and delivery… A greater input from the community and voluntary sector will enhance the advocacy of primary care teams in ensuring that local and national social environmental health issues, which influence health are identified and addressed’ (Department of Health and Children, 2001a p.39).

This recommendation is further reflected in the recent publication of the National Strategy for Service User Involvement in the Irish Health Service (Department of Health and Children and Health Service Executive, 2008). Compiled by the HSE Office of Consumer Affairs4, in partnership with the Department of Health and Children (DoHC) and other key stakeholders (ie, union representatives, service users, statutory and voluntary organisations), the strategy was produced in the context of several key DoHC and HSE policy and strategy documents which had previously demonstrated a commitment to service user involvement and the need to engage with communities in addressing their health needs (Department of Health and Children, 2001b, 2001c, 2006).

This strategy for service user involvement presents a strategic framework containing a range of goals (www.hse.ie/eng/services/ysys/Documentation/), but for the purposes

---

4 Renamed the National Advocacy Unit in 2010.
of this paper, we focus on Goal 5, which refers to the ‘participation of socially excluded groups and those whose voices are seldom heard’ in primary care (Department of Health and Children and Health Service Executive, 2008, Goal 5, Action 5.1 p.16). It is in this context, and building on the work of the Building Healthy Communities Programme (Houlihan, 2010), that in 2008 the Social Inclusion Division of the Department of Community, Equality and Gaeltacht Affairs (DCEGA) and the HSE National Advocacy Unit jointly developed the Joint Initiative.

The Joint Initiative was designed with three key purposes in mind. First and foremost, it was designed to help support disadvantaged communities and local health service interests to work together and plan for the participation of excluded communities and groups in local primary healthcare services and in the implementation of the primary care strategy. Community participation in project development, decision making and project delivery is frequently highlighted in the literature as crucial for collaborations that aim to make an impact in local communities (Pickin, Popay et al., 2002; WHO, 2002). Second, at a national level, recognising that a ‘one size fits all’ approach was not practical given the diverse and unique nature of each and every community and PCT (Krishna, Uphoff et al., 1997), it was envisioned that the Joint Initiative would result in a variety of demonstration projects and key learning that could subsequently be adopted by other PCTs across the HSE. Third, this Joint Initiative demonstrates a real attempt by the HSE to implement the 2001 policy ‘Primary Care: A New

---

5 The Building Health Communities programme was designed to support disadvantaged communities in Ireland in tackling poverty and health inequalities through strategies and innovative projects and programmes which were embedded in community development principles and practice.

6 The project was initiated by the former Combat Poverty Agency, which integrated with the Office for Social Inclusion to form the Social Inclusion Division, now part of the Department of Social Protection.
Direction’ (Department of Health and Children, 2001a) into practice by working in partnership with external stakeholders and across relevant departments and by providing resources and an infrastructure for its development in a range of settings.

2.4  A Joint Community Participation in Primary Care Initiative

In May 2008, the Joint Initiative funded and supported 19 demonstration projects; 17 of which were based in local (urban and rural) disadvantaged areas. The two remaining projects focused on specific target groups: travellers\(^7\) and minority ethnic communities (see Figures 2.1 and 2.2). Community partners included Community Development Projects (CDP), Community and Voluntary Forums, Local Development Companies, a Family Resource Centre (FRC) and a Local Regeneration Agency.

In many cases, the projects took a multi-sectoral approach by involving a wider network of statutory and non-statutory organisations and agencies that are tasked with tackling social exclusion and local regeneration. This Joint Initiative added to the many qualitative case study examples of actions by health systems in Europe to address poverty and social exclusion (WHO, 2010).

Key areas of activity supported under the Joint Initiative included:

- Developing and supporting community representative infrastructure to feed into PCTs/Networks.
- Developing joint plans between the HSE and community groups to support community participation in PCTs/Networks using participatory methodologies.

\(^7\) Travellers are an indigenous minority, documented as being part of Irish society for centuries. Travellers have a long shared history and value system which make them a distinct group. They have their own language, customs and traditions. http://www.paveepoint.ie/pav_culture_a.html
• Training and support for PCTs on community participation.

Once-off funding of between €10,000 and €15,000 was made available to each project based on their proposed work package. In addition to funding, and based on best practice (Beresford and Branfield, 2006), the 19 demonstration projects also benefitted from the following support and resources:

• Four national networking events took place, which brought together both community and HSE project partners to share and exchange project developments and link projects to national developments.

• Technical support and regional training was provided\(^8\), to increase the capacity of community and HSE representatives in areas such as participatory methodologies, establishing representative structures and the provision of support and facilitation to individual projects.

• An online forum was established through HSELanD (www.hseland.ie), which enabled all projects to share resources and learning and to network online. Monthly *Community Participation Information Bulletins* were also widely disseminated across the HSE and to community projects which can be accessed on www.hse.ie/eng/services/ysys/SUI/Library/participation/

• A National Working Group was established to oversee the Initiative, with representation from the Social Inclusion Division (DCEGA), the HSE, (including representatives from the National Advocacy Unit, primary care, population health and social inclusion), the DoHC, the Royal College of Surgeons (RCSI), the Irish College of General Practitioners (ICGP), the Institute of Public Health (IPH) and representatives from community organisations.

---

\(^8\) Provided by Community Action Network (CAN), an independent agency that works with disadvantaged communities using a human rights based approach.
Figure 2.1  Joint Community Participation in Primary Care Initiative: Summary of project objectives, actions and learning across the 19 sites
2.4 Evaluation

In early autumn 2009, the HSE and the former Combat Poverty Agency funded an independent formative evaluation of the Joint Initiative (see Pillinger, 2010). The aim of the formative evaluation was to develop and progress community participation in primary care by focusing on:

- The building of community infrastructure in the Initiative
- The project work plans, delivery and project outcomes
- The development of participatory methods and strategies
- The learning from the 19 projects across the Initiative
- The potential for the mainstreaming of learning for policy and service delivery.
The evaluation used a variety of qualitative methods and tools, which are outlined in full elsewhere (Pillinger, 2010). The methodology sought to provide for ongoing assessment and reflection, methods for building learning into the process, and the provision of regular feedback to all stakeholders. The evaluation process included the development of a set of principles and benchmarks for good practice, against which the project’s objectives, actions, outcomes and processes were monitored (Pillinger, 2010). Given its timeframe and design, the evaluation could not develop any baseline morbidity or mortality data or track changes in health outcomes over time. Therefore, reports on the health impact on the Joint Initiative are limited. This is consistent with Preston et al. (2010), who report that health improvements are not gained and demonstrated without an extended timeframe, adequate and sustained resources, and strong relationships.

For the purpose of this paper we draw briefly on the findings from the evaluation report in terms of project activities across the Joint Initiative, the value, learning and outcomes of community participation as perceived by community and HSE stakeholders, and its subsequent impact at HSE level.

2.5 Project Activities across the Joint Initiative

Through the formative evaluation process Pillinger (2010) documented a wide variety of activities across the 19 projects. The level of activity varied depending on the stage of PCT development within each site. Some of the demonstration projects, for example, were located within well established PCTs while others were working within PCTs that were not fully operating. While these activities have been reported
in detail previously (Pillinger, 2010), the most common activities that took place within the projects are summarised in Box 2.1.

**Box 2.1 Overview of Project Activities in the Joint Initiative**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Establishment of a Joint Community Participation Steering Group, which in some cases was made up of a wide network of local agencies. The Steering Groups managed and developed the strategic goals of the projects locally.</td>
</tr>
<tr>
<td>2.</td>
<td>Community consultations and mapping of community and PCT resources in the project area through public meetings, workshops or focus groups. These consultations often tapped into local knowledge and identified healthcare gaps and needs faced by the most disadvantaged communities.</td>
</tr>
<tr>
<td>3.</td>
<td>Joint training for community representatives and PCT representatives to develop skills for participatory research and community health needs assessments, or for establishing structures and terms of reference for community representation on PCTs.</td>
</tr>
<tr>
<td>4.</td>
<td>Training for PCT members to raise awareness of community participation processes and methods and the social determinants of health.</td>
</tr>
<tr>
<td>5.</td>
<td>Training for community representatives to build the capacity, knowledge and skills of local volunteers, to raise awareness of PCT services and to identify appropriate community participation methods and structures.</td>
</tr>
<tr>
<td>6.</td>
<td>Community needs analysis.</td>
</tr>
<tr>
<td>7.</td>
<td>Development of Community Health Forums. The projects presented various different models of how to establish a Forum. In several projects the Forum was established as part of the process of community consultation, while in others nominations were sought from groups in the local community. In most cases criteria were established from the outset in terms of representations from local geographic communities and target groups, with terms of reference setting out the role, scope and purpose of their local Forums.</td>
</tr>
<tr>
<td>8.</td>
<td>All projects have put in place a strategy to sustain community participation in the light of the ending of the funding from the Initiative. This included action plans and facilitated discussions between community and PCT representatives to identify priorities and future actions.</td>
</tr>
</tbody>
</table>

*Source: (Pillinger 2010: x)*

The activities outlined above are also reflective of those in the Health Action Zone Initiative in the United Kingdom (Bauld, Judge *et al.*, 2005), particularly in terms of a renewed focus on the broader determinants of health and the development of partnerships with local agencies to ensure that PCT services link into agencies that can impact on health outcomes. The activities, albeit in various combinations, are also
evident across projects presented in a recent review of empirical studies in the literature linking community participation and health outcomes (Preston, Waugh et al., 2010).

2.6 The Value, Learning and Outcomes of Community Participation

The Evaluation has captured the ‘perceptions of community, HSE and PCT representatives about the impacts and outcomes of community participation projects, providing some valuable qualitative evidence’ (Pillinger 2010 p.51). Pillinger reported on the community’s perspectives on working in partnership with the PCTs and vice versa, which revealed something about the ‘on the ground’ policy environment in terms of how the Initiative has worked in practice and what the differing perspectives are in relation to each others’ roles (see Box 2.2 The Value of Engaging from Differing Perspectives). The data demonstrated an appreciation of the value of working in partnership and the sharing of knowledge and experiences.

Box 2.2 The Value of Engaging from Differing Perspectives

<table>
<thead>
<tr>
<th>For community representatives the value of engaging with PCT members has led to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• An awareness of the role of health services and their links with community led services.</td>
</tr>
<tr>
<td>• Understanding of the scope of PCT activities.</td>
</tr>
<tr>
<td>• An appreciation of how the broader social context of health relates to PCTs.</td>
</tr>
<tr>
<td>• An opportunity to have a genuine engagement with and potential to influence health service delivery.</td>
</tr>
<tr>
<td>• Legitimacy for community participation, which has opened doors for local communities to engage in a sustainable process.</td>
</tr>
</tbody>
</table>

For PCTs the value of engaging in community participation can be summarised as leading to:

| • Successful and sometimes creative and inspiring outcomes. |
| • Mutual learning about and responding to different perspectives and ways of working. |
| • Possibilities to ‘think outside of the box’ and to recognise and realise the intrinsic value to them of community participation. |
| • New ways of approaching health and an evidence base for prevention-related
work with specific groups in the community.

- An understanding of the broader social context of health.

Adapted from Pillinger (2010: p.56-59)

Pillinger (2010) also reported that there was valuable learning across the projects with regard to the community participation process, including the importance of creating realisable goals and expectations, while building mutual learning and respect. Overall, the evaluation demonstrated that participation is a process that takes time and requires resources, and that different starting points require different methods of community participation. ‘Participation cannot be assumed but has to be systematically encouraged, and means have to be created to make it effective’ (Oakley, Bichmann et al., 1999 p. 117). However, in giving the process sufficient time and resources, initiatives such as this can help to break down barriers, promote dialogue between the community and the health service providers and subsequently identify and meet local community needs (WHO, 2002, 2008; Houlihan, 2010; Pillinger, 2010).

2.7 Impact of the Joint Initiative on Primary Care at HSE Level

The evaluation also demonstrated the impact of the Joint Initiative in relation to primary care, including:

- Community representation on the PCT and Local Implementation Group (LIG). In one project, for example:

‘The representation on the LIG group has proved very important. Because the LIG group plays a strategic role, it has provided an open door for the community to feed into the process at a strategic level’ (2010, p.140). In another, ‘Community representatives have played a very active role on the PCTs. This has been based on a huge amount of time and effort to gain respect, trust and support from HSE and PCT members. For example, the Lifford-Castlefinn PCT is chaired by the Community Coordinator from the
Lifford-Castlefinn Resource Centre and the community plays a very active role in leading community based developments’ (2010 p.130).

- PCT development is:

  ‘affected by the critical role of GPs in the process. In some projects there has been active participation of GPs who are supportive of community participation and have seen the benefits of it in practice, for example, in Lifford-Castlefinn. However, in some PCTs GPs have not been active in PCTs and this has impacted on the frequency of meetings. It is very evident that if the GPs are not active on PCTs the process of community participation has been more limited and less effective’ (2010 p.60).

- Understanding of the value of community participation and development of new models of community participation within the PCT, with a notable shift in the views of many key individuals in the primary care sector about the place of community involvement in the planning of primary health care at a local level.

- Joint approaches and working. For example, one project developed a joint action plan with priority themes identified on drug awareness for young people, production of a quarterly newsletter, a falls prevention programme, lower back pain clinics, obesity and exercise, joint emergency plan for local communities, engagement with the local GP out-of-hours service and community gardening.

- Improved capacity to identify community health needs and a shared understanding of the wider context of health. In one of the projects:

  ‘an important part of the consultations was to inform groups about primary care services. Sixteen target groups were consulted with through focus groups and interviews, which were facilitated by members of the working group. The consultations captured a broad range of perspectives on the needs of the area, with a specific focus on the determinants of health. The consultations highlighted a range of health issues, including the key problem of drug addiction in the area. This has resulted in an addiction counsellor joining the PCT’ (2010 p.134).

- Improved knowledge of PCT and community-led services, with several projects improving the availability of patient information sources within the local
community through the development of a Directory of Services and the ongoing delivery of information workshops.

- **Economic benefits.** One of projects commissioned a piece of research into *The Economic Impact on Health of the Community and Voluntary Sector in Donegal* (Garratt 2009, HSE West: Letterkenny), which has been critical to providing evidence of the benefits of community participation to saving resources in health care. According to the report, €26m/year is being invested by the community and voluntary sector in health-related work in County Donegal, over 60% of which comes from non-public sources.

If the observed positive impacts of the Joint Initiative outlined above are to lead to the health gains that the international literature identifies (Berkman, 1995; Kawachi and Kennedy, 1997; Marmot, 2010), then the issue of sustaining these projects and implementing community participation in primary care across the HSE is imperative. Interestingly, others have stressed that ‘*participation is not a product or a time-delimited project*’ (Morgan 2007 p.223), and that participation need to be ‘*continuous, sustained and locally grounded*’ (Krishna, Uphoff et al., 1997 p.5).

### 2.8 Reflecting on the Sustainability of Community Participation in PCTs in Ireland

What is the sustainability of the 19 projects that were established as part of the Joint Initiative specifically? And what is the scope for community participation in PCTs in Ireland in general? In their systematic review of innovation in service organisations, Greenhalgh *et al.* found evidence to be ‘*very sparse*’ with a ‘*near absence of studies focusing primarily on the sustainability of complex service innovations*’ (2004 p.581).

Furthermore, ‘*the question of sustainability is crucial if the gains ...from*
organisational innovations are to be maintained, rather than lost to what the NHS Institute has called the “improvement-evaporation” effect (Martin, Currie et al., 2011 p.1).

While funding through the Joint Initiative ceased in May 2010, the evaluation indicated that all projects put in place a strategy to sustain their work plans. This included action plans and facilitated discussions between community and PCT representatives to identify priorities and future actions. However, as highlighted by Morgan, ‘Participation can be sustainable only as long as the relevant actors remain committed, and the sociopolitical and economic environments remain conducive, to the process’ (2001 p.223).

Although there is no further financial support for the projects involved in the Joint Initiative, dissemination of the learning and benefits that emerged through the Joint Initiative, and utilisation of the networks that developed throughout the process, are ongoing. The HSE National Advocacy Unit, for example, continues to work with the HSE National Primary Care Office to consolidate policy and practical lessons emerging from the Initiative and to link relevant stakeholders (i.e. social inclusion, health promotion, community development, performance and development) at a national level to drive the agenda of community participation and primary care forward. This should be a lever to sustainability and should avoid the aforementioned ‘improvement-evaporation’ effect (Health Service Executive, 2011a).

A major development is that, working through the HSE’s National Advocacy Unit, a key performance indicator (PI) is now written into the National HSE Service Plan to
monitor the ‘percentage of primary care Local Implementation Groups with at least two community representatives in each Local Health Office’ (Health Service Executive, 2011b p.12)

This PI is collated on a quarterly basis, and within the HSE reporting matrix the PI is further defined and stipulates:

‘The number and percentage of Local Implementation Groups in each LHO, acting on the recommendations of the Community Participation and Primary Care Joint Funding Initiative, who have at least two community representatives in place in each LHO. A Local Implementation Group is a local management structure for primary care teams in each local health office area.

‘Community representatives are individuals, who are ‘representing’, representative, and/or ‘consultative’ of one or more populations or affinity groups. They can be stakeholders, opinion leaders, organisers and advocates. They serve as a platform and channel for information and voices of community, communicating ideas and concepts between community and health and social services and who hold people and processes accountable’ (Health Service Executive, 2011c, p.10).

Notwithstanding the documented challenges involved in working towards representation (Green, 2007) and the different types of representation (Frankish, Kwan et al., 2002; Green, 2007), nationally this is an important milestone, helping to raise the ‘profile’ of and increase the momentum for the participation of communities in the design, development and delivery of primary health services (Pillinger, 2010). Further discussion to establish how existing and new performance indicators on community participation in primary care can be delivered and built into the performance indicators of health promotion, social work and social inclusion is ongoing. This is particularly important as staff in these areas are well placed to provide strategic and operational support under the key result area on community participation.
Another significant development, at a broader level, is the renewed focus in the *New Programme for Government* (Department of the Taoiseach, 2011) on service users in public service organisations (by giving them a ‘Choice and Voice’), and on patient safety with the establishment of a Patient Safety Authority, incorporating the Health Information Quality Authority (HIQA). It remains to be seen whether, or how, this high-level policy rhetoric, and indeed the other levers outlined here, will impact on routine practice ‘on the ground’.

Certainly, there are factors that may diminish the capacity of communities and PCTs to continue the activities that they have initiated. The current economic crisis in Ireland and cuts to public sector budgets, for example, have seen funding for community development projects cut and consequently two of the 19 projects no longer exist. The *New Programme for Government’s* (Department of the Taoiseach, 2011) proposed restructuring of the HSE could also impact on the proposed radical reform of primary care, which in turn could impact on the issue of community participation in primary care. In order to effectively engage in the HSE Change Process (Health Service Executive, 2008), which acknowledges that service users and the local community are integral to HSE service, the government, practitioners and the health system must recognise and accept that community participation is a *‘process requiring a long-term and consistent investment, with health system reform process and restructures managed so that they do not impact negatively on the processes’* (Preston, Waugh *et al.*, 2010 p.14).
2.9 Progressing Community Participation in PCTs in Ireland - Implementation Research

Reflecting on the Joint Initiative, we are reminded of Taylor et al. who stated that those who set out to drive programmes of change are confronted with two enormous tasks: ‘The first is to develop prototypes. The second involves large scale replication. One without the other is insufficient’ (1999 p.322). Clearly, the Joint Initiative referred to in this paper provides a strong prototype for community participation in PCTs but can it be replicated across all PCTs in the country? This is about building knowledge of the ways in which innovations can be embedded into ongoing, routine healthcare practice. This is a key issue for further research and practice development which falls within the field of ‘implementation research’. This is a general term for research that focuses on the question, ‘What is happening?’ in the design, implementation, administration, operation, services, and outcomes of social programmes. It also asks, ‘is it what is expected or desired?’ and ‘why is it happening as it is?’ (Werner, 2005).

Eccles et al. (2009) have argued that we need to see greater use of theoretical approaches in research focused on implementation, on the basis that this will offer (i) generalisable frameworks that can be applied across different settings and individuals, (ii) opportunity for the incremental accumulation of knowledge and (iii) an explicit framework for analysis. Similarly Nutbeam (2004) outlines the need to invest in research that improves our understanding of how effective interventions should be implemented.
Undoubtedly, given the national and international policy imperatives outlined above, it is apposite to conduct implementation research in Ireland to support the replication of the Joint Initiative prototype across the HSE. An extensive, theoretically informed, empirical analysis of the implementation work that has taken and is taking place to embed the Joint Initiative into routine practice is required. Its findings would inform HSE activities around the specific issue of community participation in PCTs. Moreover, there is scope for such a theoretically informed analysis to generate insights and transferrable lessons for the implementation, integration and embedding of service user involvement in other HSE settings and contexts (May, Finch et al., 2007; Eccles, Armstrong et al., 2009).

A recently developed social theory, that provides a comprehensive theoretical framework to investigate, assess and support implementation of innovation in routine day-to-day healthcare settings is Normalisation Process Theory (NPT) (May and Finch, 2009; May, Mair et al., 2009). It has been applied in several areas of health services research to aid understanding of the implementation of complex interventions including the work processes entailed in implementing treatment regimes into patients’ routines, the development and application of decision support tools and the redesign of primary care mental health services and self-management training packages (May, Finch et al., 2011). The authors envisage that as NPT is developed from qualitative empirical studies and is used to generate qualitative data that capture the complexity of innovation, it will help to make the layers of activity and work inherent in the Joint Initiative visible.
The application of a theoretically informed analysis utilising a framework such as NPT is important because, whilst the Joint Initiative is anchored in Ireland, Nutbeam in his editorial on ‘Getting evidence into policy and practice to address health inequalities’ affirms that this is ‘a challenge recognised in countries all over the world’ (2004 p.137). Hence the issues we have discussed in this paper in relation to engaging with disadvantaged communities, promoting community participation and, most importantly, the sustainability of organisational innovations are relevant to the challenges facing not only Ireland but also other nations, regardless of the structure of the health system itself.

2.10 Acknowledgements

The project was initiated by the former Combat Poverty Agency, which integrated with the Office for Social Inclusion to form the Social Inclusion Division, now part of the Department of Social Protection and the HSE. With financial support from both partners the Initiative was independently evaluated by Dr. Jane Pillinger. We wish to acknowledge the work of all those involved in the Joint Initiative. We also extend appreciation to Professor Catherine O’Donnell for her helpful insights and comments, and for those provided by the anonymous reviewers on an earlier draft of this paper.
2.11 References


Department of Health and Children (2001c) Primary Care a New Direction. Dublin, Stationary Office.


Donnellan, E. (2011) Minister 'does not accept' HSE Claims on Number of Primary Care Teams. Irish Times. Dublin.


Goodman, R.M., Speers, M.A., McLeroy, K., Fawcett, S., Parker, E. and Smith, S.R. (1998) Identifying and defining the dimensions of community capacity to provide a basis for
measurement. *Health Education and Behavior, 25*: 258-278.


Pickin, C., Popay, J., Stanley, K., Bruce, N. and Jones, C. (2002) Developing a model to enhance the capacity of statutory organisations to engage with lay community. *Journal of Health Services and Policy, 7*: 34-42.


Chapter 3: Paper 2

A qualitative systematic review of studies using the Normalization Process Theory to research implementation processes

3.1 Abstract

3.1.1 Background

There is a well-recognized need for greater use of theory to address research translational gaps. Normalization Process Theory (NPT) provides a set of sociological tools to understand and explain the social processes through which new or modified practices of thinking, enacting, and organizing work are implemented, embedded, and integrated in healthcare and other organizational settings. This review of NPT offers readers the opportunity to observe how, and in what areas, a particular theoretical approach to implementation is being used. In this article we review the literature on NPT in order to understand what interventions NPT is being used to analyse, how NPT is being operationalised, and the reported benefits, if any, of using NPT.

3.1.2 Methods

Using a framework analysis approach, we conducted a qualitative systematic review of peer-reviewed literature using NPT. We searched 12 electronic databases and all citations linked to six key NPT development papers. Grey literature/unpublished studies were not sought. Limitations of English language, healthcare setting and year of publication 2006 to June 2012 were set.
3.1.3 Results

Twenty-nine articles met the inclusion criteria; in the main, NPT is being applied to qualitatively analyse a diverse range of complex interventions, many beyond its original field of e-health and telehealth. The NPT constructs have high stability across settings and, notwithstanding challenges in applying NPT in terms of managing overlaps between constructs, there is evidence that it is a beneficial heuristic device to explain and guide implementation processes.

3.1.4 Conclusions

NPT offers a generalisable framework that can be applied across contexts with opportunities for incremental knowledge gain over time and an explicit framework for analysis, which can explain and potentially shape implementation processes. This is the first review of NPT in use and it generates an impetus for further and extended use of NPT. We recommend that in future NPT research, authors should explicate their rationale for choosing NPT as their theoretical framework and, where possible, involve multiple stakeholders including service users to enable analysis of implementation from a range of perspectives.

3.1.5 Keywords

Implementation, Policy, Normalization process theory, Theory, Translational gaps

Received 13 May 2013; accepted 3 December 2013; published 2 January 2014
3.2 Background

There has been a proliferation of research about research-practice-policy links in recent decades (Nutley, Morton et al., 2010). In spite of the growth in literature, there remains a well-recognized and significant translational gap between these domains. This gap has captured the attention of policy makers and researchers alike, with repeated calls for the greater use of explicit theory in research that explores implementation processes (Greenhalgh, Robert et al., 2004; Woolf, 2008; Eccles, Armstrong et al., 2009). The proposed benefits are that theory can offer us generalisable frameworks that can apply across differing settings and individuals; the opportunity for incremental accumulation of knowledge; and an explicit framework for analysis (Eccles, Armstrong et al., 2009; Forster, Newton et al., 2011). Also, using theory may enhance our understanding of barriers to implementation, but more than that, it may enhance our ability to design interventions and explore mediating pathways to shape and improve implementation processes (Helfrich, Damschroder et al., 2010; MacFarlane, O'Donnell et al., 2012). It is thus important both to develop and test new theories that are in use, to appraise their relevance and utility for the field of implementation research (Davies, Walker et al., 2010; Murray, Treweek et al., 2010; Morrison and Mair, 2012).

One such new theory presented in the literature is the Normalization Process Theory (NPT). NPT is a sociological theory that has been widely promoted as a means to understand implementation, embedding and integration of innovation in healthcare settings, and has been advocated as a means of bridging the translational gap (Murray, Treweek et al., 2010; Morrison and Mair, 2012). It has potential utility as a conceptual framework to explore the gap between health research evidence, policy, and practice because epistemologically, it emphasizes the fluid, dynamic and interactive processes between context, actors and objects.
that is congruent with interactive and social models of research use (Nutley, Walter et al., 2007); it is derived from studies seeking to understand the implementation of innovation and complex interventions in healthcare settings so it is highly attuned to the specifics of this organizational setting; and it encourages the recommended whole-system perspective on implementation research (Greenhalgh, Robert et al., 2004). In the next section, we provide an overview of NPT before going on to describe our research objectives and the methods of our review.

3.3 From Normalization Process Model (NPM) to Normalization Process Theory (NPT)

The NPM was initially developed as an applied theoretical model to assist clinicians and researchers to understand and evaluate the factors that inhibit and promote the routine incorporation of complex healthcare interventions in practice (May 2006; May and Finch 2009; May, Mair et al., 2009). Much of the early work was related to implementation of e-health applications.

The further empirical applications of the NPM showed that while it could explain factors that promote and inhibit ‘collective action’ (i.e., the distribution of work required among stakeholders and the resources to support that), it did not address how participants understood and came to engage and support a new practice and how they reflected on and evaluated it. Through the development of further constructs (see NPT theoretical constructs from Finch, Mair, et al. (Finch, Mair et al., 2012)), accounting for how people understand and make sense of a practice (i.e. Coherence), engage and participate with it (i.e. Cognitive Participation), and reflect or appraise its effects (i.e. Reflexive Monitoring), the model became a theory, i.e. NPT. For the most part, the term NPT is used throughout this paper, unless otherwise stated.
Box 3.1 NPT Theoretical Constructs (from Finch, Mair et al. 2012)

1. **Coherence**: the process and work of sense-making and understanding that individuals and organisations have to go through in order to promote or inhibit the routine embedding of a practice.

2. **Cognitive Participation**: the process and work that individuals and organisations have to go through in order to enrol individuals to engage with the new practice.

3. **Collective Action**: the work that individuals and organisations have to do to enact the new practice. (“Collective Action” was initially referred to as NPM, and consisted of four subcomponents (i.e. Contextual Integration (CI), Relational Integration (RI), Interactional Workability (IW), and Skill Set Workability (SSW)). For a more detailed description of NPM see May (May, 2006)).

4. **Reflexive Monitoring**: the work inherent in the informal and formal appraisal of a new practice once it is in use, in order to assess its advantages and disadvantages, and which develops users’ comprehension of the effects of a practice.

Since then, the theory’s development has focused on building a middle-range theory that explains how material practices (the things that people do when they implement complex healthcare interventions) become routinely embedded in their social contexts as the result of people working, individually and collectively, to enact them (May and Finch, 2009; May, Mair et al., 2009).

Given its sociological origins, NPT is not focused on the relationship between individual attitudes and intentions and behavioral outcomes, which is the concern of psychological theories such as the Theory of Planned Behavior (Ajzen, 1991). Like the sociological theory
of Communities of Practice (Wenger, 1998), NPT does pay attention to how knowledge is held, transferred, and created within and across professional groups, but it also seeks to understand the work that actors (clinicians, implementers, and patients alike) have to engage in to implement new knowledge in practice (Gallacher, May et al., 2011; Murray, Burns et al., 2011). Similar to theories of actor networks and diffusion of innovation (Rogers, 1995; Latour, 2005), NPT pays attention to the legitimacy of the intervention and the role of opinion leaders; it is concerned with understanding trust and interpersonal relationships within social networks as they impact on the introduction of innovation (Doumit, Wright et al., 2011; Harris, Provan et al., 2012). However, NPT extends beyond the initial introduction of innovation to investigate the processes by which innovation may become embedded and routinised in practice, so much so that it becomes regarded as a normal and taken-for-granted way of working. Among NPT’s distinctive features is the attention to all stakeholders’ involvement in implementation processes, the work that they have to do individually and collectively, and the subtle and gradual processes from embedding and integrating to normalization (May and Finch, 2009). The theory is centred on understanding social phenomena defined by four theoretical constructs, which characterize mechanisms that are energized by investments made by individuals and organizations (see Box 3.1 NPT Theoretical Constructs).

The development of NPT (May, Mair et al., 2009) focused on addressing two key criteria for theory to be ‘useful’: that it must offer adequate description and be fit for purpose. Thus, as outlined by Finch, Mair et al. (2012), the theory has been developed to offer transparent and transferable explanations for the phenomena of interest (i.e. processes of embedding new practice and ways of working) revealed by empirical investigation.
There is a growing community of researchers who have made an *a priori* choice to use NPT in their research. Given the aforementioned calls to investigate new theories, we consider it timely to review how this particular new theory is being operationalised and, importantly, explore what benefits, if any, are seen to derive from its utilization. This review of NPT contributes to a body of knowledge about how theory may benefit implementation research, and if so what should the research agenda now be for NPT and other relevant theories in the field. Therefore, in this article our research objectives are to review the literature on NPT (see Appendix 4: PICO Table) in order to understand what interventions NPT is being used to analyse, how NPT is being operationalised and the reported benefits, if any, of using NPT.

3.4 Methods

We conducted a qualitative descriptive review of peer-reviewed NPT literature in the English language published from 2006 up to June 1st 2012.

3.4.1 Search terms and strategy

Utilizing the interface engine EBSCO host, the first author (RM) completed an advanced search incorporating the following electronic bibliographic databases: Academic Search Complete; AMED—The Allied and Complementary Medicine Database; Biomedical Reference Collection: Expanded; CINAHL Plus with Full Text; MEDLINE; OmniFile Full Text Mega (H.W.Wilson); PsycARTICLES; PsycINFO; Social Sciences Full Text (H.W. Wilson); UK and Ireland Reference Center (see Appendix 5). A search of both Embase and Pubmed was also carried out. In the search process, the terms ‘Normalization Process Theory’ or ‘Normalization Process Model’ were used. The first author (RM) also screened all citations linked to six key concept papers that were specific to the development of the theory/model (May, 2006; Elwyn, Taubert *et al.*, 2007; May, Finch *et al.*, 2007; May and...
Finch, 2009; May, Mair et al., 2009; Murray, Treweek et al., 2010). Citations were also solicited from academics involved in the development of NPT. Google Scholar alerts were further activated during the search process, which commenced in February 2012 and ended on June 1st 2012. The final list of articles was then circulated to a number of experts in the field of NPT for review and no additional papers were noted. The issue of discrepancies did not arise.

Figure 3.1 PRISMA Flow Diagram of Study Selection utilizing NPT/NPM

3.4.2 Inclusion and exclusion criteria

Papers on the subject of ‘Normalization Process Theory’ or ‘Normalization Process Model’ in a health-related field that met all the following criteria were included: Published peer-reviewed empirical papers or papers that may be in press or accepted for publication; and an explicit reference to NPT or NPM in the article heading, abstract or keywords. Given the decision to review the application of NPT in completed empirical work, study protocols,
editorials, discussion/briefing papers, conference papers, or core concept papers that describe
the theory and its development were not included (e.g. May and Finch, 2009).

3.4.3 Data abstraction and framework analysis

Citations were downloaded into EndNote reference manager software, and full documents
were imported into NVivo 10 software for analysis.

Given our interest in identifying a priori themes (i.e. the four NPT constructs), we adopted a
framework analysis approach (Richie and Spencer, 1994). We also sought out emergent
issues (e.g. country of origin, research focus, stakeholder involvement) that were considered
relevant to the objectives of our review.

This framework analysis approach incorporated the following five key stages: familiarization,
identifying a thematic framework, indexing, charting, and mapping and interpretation. For
indexing and charting, the first author extracted material from any part of the paper that was
relevant to an a priori or emergent theme. For the a priori themes, only data that were
explicitly connected to NPT by the authors of the identified papers were coded.

The final stage of mapping and interpretation focused primarily on our a priori themes and
had two objectives. First, to examine stability of the constructs across studies, we explored
how NPT was being operationalised across settings. For this we analysed whether data coded
explicitly by authors as a particular construct had resonance with our understanding of that
construct as per the core NPT papers. We also compared authors’ accounts of each construct
as applied to their study setting and any relevant corresponding data. Given the subjectivity
involved in interpretive analysis processes, our aim was to see if we could understand
authors’ coding decisions rather than judging them to be ‘correct’ or ‘incorrect’ \textit{per se}.

Second, to determine whether there were any benefits to using NPT we focused on the authors’ reflections, usually located in the discussion section of the papers.

The mapping and interpretation of the data, and recommendations, were discussed with all co-authors and refined until consensus was reached.

3.5 Results

3.5.1 Search results

From the 383 records screened, 354 were excluded and 29 full-text articles that met the inclusion criteria were retrieved (see Figure 3.1) (see Appendix 4: PICO Table). Due to the qualitative nature of the literature being reviewed, PICO as a search strategy did not neatly fit with our research questions, so we adapted the PICO Table to include the following criteria: participants, study design and collection approach, interventions, analysis, aims/discussion, and outcomes.

Drawing on Hawker \textit{et al.} (2002) (see Appendix 6: Quality Appraisal Checklist & Quality Scoring), each of the 29 papers was subjected to a quality appraisal process undertaken by three of the authors (RM, AMacF and LB). This process enabled us to make an informed decision about the quality of the reported research. All 29 papers were included, with scores ranging from 18 to 36 (maximum score being 36) and a mean score of 29.06. Study-specific appraisal results are included in Appendix 6. Overall, these were good quality studies.
To ensure consistency during the data abstraction and framework analysis phase of work, one-fifth of the articles were double-coded independently. Coding agreement was close to 100%.

3.6 Findings as per the Research Objectives

3.6.1 What interventions is NPT being used to analyse?

Of the 29 articles appraised, 21 originated in the UK (the country of origin for NPT), five in Australia, and one each in Ireland, South Africa, and The Netherlands (see Table 3.1). NPT is mainly being used in qualitative research to study the implementation of complex interventions that introduce a new way of working in healthcare settings (see Table 3.1). This includes eight studies (Murray, May et al., 2010; Bouamrane, Osbourne et al., 2011; Godden and King, 2011; May, Finch et al., 2011; May, Finch et al., 2011; Murray, Burns et al., 2011; Finch, Mair et al., 2012; Mair, May et al., 2012) in the field of e-health and telehealthcare and the remaining 21 studies (May, Mair et al., 2007; Elwyn, Legare et al., 2008; Gask, Rogers et al., 2008; Mair, Hiscock et al., 2008; Morriss, 2008; Wilkes and Rubin 2009; Gask, Bower et al., 2010; Gunn, Palmer et al., 2010; Kennedy, Chew-Graham et al., 2010; Atkins, Lewin et al., 2011; Forster, Newton et al., 2011; Furler, Spitzer et al., 2011; Gallacher, May et al., 2011; James, 2011; MacFarlane and O’Reilly-de Brún, 2011; Sanders, Foster et al., 2011; Spangaro, Poulos et al., 2011; Watson, Parr et al., 2011; Blakeman, Protheroe et al., 2012; Ehrlich, Kendall et al., 2012; Franx, Oud et al., 2012) in several other healthcare fields, for example chronic health care, maternity care, and language interpretation services. Three of the papers reported the use of NPT to inform the development of tools that support implementation work (Murray, May et al., 2010; May, Finch et al., 2011; Finch, Mair et al., 2012).
<table>
<thead>
<tr>
<th>Author</th>
<th>Country of Origin</th>
<th>Topic</th>
<th>Research Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blakeman et al. (2012)</td>
<td>UK</td>
<td>Chronic kidney disease in primary care.</td>
<td>Qualitative interview study in general practices participating in a chronic kidney disease (CKD) collaborative, that aims to explore processes underpinning the implementation of CKD management in primary care.</td>
</tr>
<tr>
<td>Franx et al. (2012)</td>
<td>The Netherlands</td>
<td>Primary care: Stepped-care treatment.</td>
<td>An intervention study using a controlled before and after design. Part of the study was a process evaluation utilizing semi-structured group interviews to provide insight into the perceptions of the participating clinicians of the implementation of stepped cared for depression into their daily routines.</td>
</tr>
<tr>
<td>Ehrlich et al. (2012)</td>
<td>Australia</td>
<td>Registered nurses in general practice.</td>
<td>A qualitative focus group study designed to develop understanding about how a registered nurse-provided care coordination model can ‘fit’ within organizational processes and professional relationships in general practice.</td>
</tr>
<tr>
<td>Finch et al. (2012)</td>
<td>UK</td>
<td>E-health.</td>
<td>This paper describes the process and outcome of a project to develop a theory-based instrument for measuring implementation processes relating to e-health interventions, and identifies key issues and methodological challenges for advancing work in this field. A 30-item instrument (Technology Adoption Readiness Scale (TARS)) for measuring normalization processes in the context of e-health service interventions was developed and pre-tested in two professional samples.</td>
</tr>
<tr>
<td>Gallacher et al. (2011)</td>
<td>UK</td>
<td>Chronic heart failure.</td>
<td>A secondary analysis of qualitative interview data to assess the burden associated with treatment among patients living with chronic heart failure.</td>
</tr>
<tr>
<td>Watson et al. (2011)</td>
<td>UK</td>
<td>Transitional care for young people.</td>
<td>Scoping review of the evidence to identify successful models of transitional care for young people with complex healthcare needs. Three conditions were used as exemplars: cerebral palsy, autism spectrum disorders, and diabetes.</td>
</tr>
<tr>
<td>Forster et al. (2011)</td>
<td>Australia</td>
<td>Maternity care.</td>
<td>Authors use two case studies where new models of maternity care were implemented and evaluated via randomized controlled trials (RCTs) to discuss how (or whether) the use of theory might inform implementation and sustainability strategies.</td>
</tr>
<tr>
<td>Authors</td>
<td>Location</td>
<td>Topic</td>
<td>Description</td>
</tr>
<tr>
<td>------------------</td>
<td>-----------</td>
<td>------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Atkins et al. (2011)</td>
<td>South Africa</td>
<td>TB treatment.</td>
<td>A qualitative interview and focus group study documenting providers’ experiences of the implementation of a new tuberculosis treatment programme.</td>
</tr>
<tr>
<td>Godden and King (2011)</td>
<td>UK</td>
<td>Telehealth in respiratory medicine.</td>
<td>To determine the potential for applying telehealth in a region of the UK by exploring the distribution of patients and examining attitudes to implementation of telehealth.</td>
</tr>
<tr>
<td>James (2011)</td>
<td>UK</td>
<td>Speech and language therapy.</td>
<td>A review and data synthesis of qualitative research data on a speech and language intervention.</td>
</tr>
<tr>
<td>MacFarlane and O’Reilly-de Brún (2011)</td>
<td>Ireland</td>
<td>Language interpretation services.</td>
<td>A reflexive account of the authors’ experience of using a theory-driven conceptual framework, in a qualitative evaluation of general practitioners’ uptake of a free pilot language interpreting service. Authors conducted an inductive thematic analysis using the constant comparative method.</td>
</tr>
<tr>
<td>Murray et al. (2011)</td>
<td>UK</td>
<td>E-health initiatives.</td>
<td>A qualitative semi-structured interview study, using a case study methodology. Three case studies were selected to provide a range of healthcare contexts to assess factors that promote or inhibit the successful implementation, embedding, and integration of e-health initiatives.</td>
</tr>
<tr>
<td>Sanders et al. (2011)</td>
<td>UK</td>
<td>Back pain.</td>
<td>A qualitative interview study of the perceptions of general practitioners towards the use of a new system for treating back pain.</td>
</tr>
<tr>
<td>May et al. (2011)</td>
<td>UK</td>
<td>Telecare for chronic disease management in the community.</td>
<td>Large-scale comparative study employing qualitative data collection techniques, including semi-structured interviews.</td>
</tr>
<tr>
<td>May et al. (2011)</td>
<td>UK</td>
<td>Development of a simplified approach and web-enabled toolkit.</td>
<td>A description of processes by which the authors developed a simplified approach of NPT for use by clinicians, managers, and policy makers, and which could be embedded in a web-enabled toolkit and online users manual.</td>
</tr>
<tr>
<td>Furler et al. (2011)</td>
<td>Australia</td>
<td>Diabetes.</td>
<td>A qualitative interview study exploring the use of insulin in general practice with a focus on barriers and enablers for timely initiation.</td>
</tr>
<tr>
<td>Bouamrane et al. (2011)</td>
<td>UK</td>
<td>Remote and telehealth services.</td>
<td>The authors outline a theoretical model of processes of intervention within the health services, and describe issues with the continued sustainability of existing models of care – and the potential opportunities for new technologies in addressing these challenges.</td>
</tr>
<tr>
<td>Spangaro et al. (2011)</td>
<td>Australia</td>
<td>Screening for intimate partner violence (IPV) in Australian antenatal, mental health, and substance abuse services.</td>
<td>Explores providers’ perceptions about the relevance of IPV to their role, the extent to which screening is routine, the existing challenges, the impact on clinical work or patient care, and the suggested changes to the policy.</td>
</tr>
<tr>
<td>Authors</td>
<td>Country</td>
<td>Topic</td>
<td>Study Details</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------</td>
<td>----------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Kennedy et al. (2010)</td>
<td>UK</td>
<td>Delivering the WISE (Whole Systems Informing Self-Management Engagement) training package in primary care.</td>
<td>Learning from formative evaluation, the purpose being to ensure that the WISE training package was robust and likely to be effective enough to be tested in an RCT.</td>
</tr>
<tr>
<td>Gunn et al. (2010)</td>
<td>Australia</td>
<td>Embedding effective depression care: Using theory for primary care organizational and systems change.</td>
<td>Authors used a method informed by the principles of participatory action research (PAR) and utilized a mix of quantitative and qualitative methods to gather data about routine depression care in a range of primary care settings via: audit of electronic health records; observation of routine clinical care; and structured, facilitated whole-of-organization meetings.</td>
</tr>
<tr>
<td>Gask et al. (2010)</td>
<td>UK</td>
<td>Collaborative care for depression?</td>
<td>Qualitative data collected in both focus groups and one-to-one interviews before and after an exploratory RCT of a collaborative model of care for depression.</td>
</tr>
<tr>
<td>Murray et al. (2010)</td>
<td>UK</td>
<td>E-health.</td>
<td>Reports on the development and formative evaluation of an e-Health Implementation Toolkit (e-HIT), which aims to summarize and synthesize new and existing research on implementation of e-health initiatives.</td>
</tr>
<tr>
<td>Wilkes and Rubin (2009)</td>
<td>UK</td>
<td>Infertility management and primary care.</td>
<td>A process evaluation of open access hysterosalpingography (HSG) utilizing the results of two qualitative studies (a focus group study and an in-depth interview study) and two quantitative studies (a pilot survey and a pragmatic cluster RCT).</td>
</tr>
<tr>
<td>Gask et al. (2008)</td>
<td>UK</td>
<td>Mental health in primary care.</td>
<td>A longitudinal qualitative multiple case study approach in a purposive sample of 12 organizations, chosen to reflect a maximum variety of organizational contexts for mental health care provision.</td>
</tr>
<tr>
<td>Elwyn et al. (2008)</td>
<td>UK</td>
<td>Decision support technologies (DST).</td>
<td>A conceptual analysis of the outcomes of previous primary research and reviews to highlight implementation problems for DSTs in routine settings. Using a virtual working environment to examine: the ‘workability’ of DSTs in professional-patient interactions; how DSTs affect knowledge relations between their users; how DSTs impact on users' skills and performance; and the impact of DSTs on the allocation of organizational resources.</td>
</tr>
<tr>
<td>Mair et al. (2008)</td>
<td>UK</td>
<td>Utilization of telecare in chronic lung disease</td>
<td>A process evaluation of a RCT of home telecare for the management of acute exacerbations of chronic obstructive pulmonary disease (COPD).</td>
</tr>
<tr>
<td>Morriss (2008)</td>
<td>UK</td>
<td>Clinical guidelines for bipolar disorder.</td>
<td>To critically review the evidence concerning the implementation of clinical guidelines for bipolar disorder.</td>
</tr>
</tbody>
</table>
3.6.2 How is NPT being operationalised?

NPT, and its four related constructs, were utilized in over one-third of the papers reviewed (n = 11) (Finch, Mair et al. 2012; Gallacher, May et al., 2011; Mair, May et al., 2012; Bouamrane, Osbourne et al., 2011; Blakeman, Protheroe et al., 2012, Franx, Oud et al., 2012; Watson, Parr et al., 2011; May, Finch et al. 2011; May, Finch et al. 2011; Kennedy, Chew-Graham et al., 2010; Gunn, Palmer et al., 2010). One paper (Sanders, Foster et al. 2011) focused solely on the construct of Coherence. The remaining papers (n = 17) (Forster, Newton et al., 2011; Murray, Burns et al., 2011; Godden and King, 2011; Murray, May et al., 2010; Ehrlich, Kendall et al., 2012; Atkins, Lewin et al., 2011; James, 2011; MacFarlane and O’Reilly de Brun, 2011; Furler, Spitzer et al., 2011; Spangaro, Poulos et al., 2011; Gask, Bower et al., 2010; Wilkes and Rubin, 2009; Gask, Rogers et al., 2008; Elwyn, Legare et al., 2008; Mair, Hiscock et al., 2008; Morriss, 2008; May, Mair et al., 2007) focused solely on the construct of Collective Action, or NPM as it was earlier known (see Table 3.2, column 2).

<table>
<thead>
<tr>
<th>Author</th>
<th>Level of Use Model/Theory</th>
<th>Application of NPM/NPT</th>
<th>Study Participants in Empirical Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>May et al. (2007)</td>
<td>NPT</td>
<td>A retrospective analysis of the implementation of two different complex trials: (i) the delivery of problem-solving therapies for psychosocial distress, and (ii) the delivery of nurse-led clinics for heart failure treatment in primary care.</td>
<td>UK Process evaluation for complex interventions in primary care.</td>
</tr>
<tr>
<td>Blakeman et al. (2012)</td>
<td>NPT</td>
<td>NPT provided a framework for generation and analysis of the data.</td>
<td>GPs and practice nurses.</td>
</tr>
</tbody>
</table>

Table 3.2 The Operationalisation of NPT Across the Papers included in the Review
<table>
<thead>
<tr>
<th>Authors</th>
<th>Framework</th>
<th>Description</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Franx et al. (2012)</td>
<td>NPT</td>
<td>Related findings to NPT constructs.</td>
<td>Professionals (clinicians, healthcare staff including manager and team co-ordinator).</td>
</tr>
<tr>
<td>Ehrlich et al. (2012)</td>
<td>NPT</td>
<td>Although NPT was the overarching theoretical framework used for the broader series of studies in this project, NPM was used specifically to aid data interpretation and the discussion in this study.</td>
<td>Professionals (nurses).</td>
</tr>
<tr>
<td>Finch et al. (2012)</td>
<td>NPT</td>
<td>A 30-item instrument (Technology Adoption Readiness Scale (TARS)) for measuring normalization processes in the context of e-health service interventions was developed on the basis of NPT.</td>
<td>Professionals (First phase authors of published reviews of e-health; second phase nurses, call handlers, health info advisors, nurse advisors and others).</td>
</tr>
<tr>
<td>Gallacher et al. (2011)</td>
<td>NPT</td>
<td>A secondary analysis of qualitative interview data, using framework analysis, informed by NPT.</td>
<td>Patient.</td>
</tr>
<tr>
<td>Watson et al. (2011)</td>
<td>NPT</td>
<td>All papers were coded using a framework analysis which evaluated the data in two ways using the 10 transition categories and four elements of Normalization Process Theory that are important for successful implementation and integration of healthcare interventions.</td>
<td>N/A</td>
</tr>
<tr>
<td>Forster et al. (2011)</td>
<td>NPM</td>
<td>Survey and interview questions specific to the project were designed to reflect the four constructs of NPM in the implementation of the new model of care.</td>
<td>Professionals and patients (midwives and women).</td>
</tr>
<tr>
<td>Atkins et al. (2011)</td>
<td>NPM</td>
<td>Data were analyzed initially using qualitative content analysis. The resulting categories were then organized under the constructs of the NPM.</td>
<td>Professionals and lay workers.</td>
</tr>
<tr>
<td>Godden and King (2011)</td>
<td>NPM</td>
<td>Analysis was supported by NPM. The principles of NPM were used to explore how successful implementation of proposed new technologies could be achieved.</td>
<td>Professionals (GPs, consultants, nurses, and others involved in respiratory care)</td>
</tr>
<tr>
<td>James (2011)</td>
<td>NPT</td>
<td>Created coding categories that were then examined under headings according to the NPM.</td>
<td>Practitioners and parents</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Framework/Methodology</td>
<td>Description</td>
<td>Participants</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>MacFarlane and O’Reilly-de Brún (2011)</td>
<td>NPM</td>
<td>The authors describe their actual use of NPM to inform research questions, sampling, coding and data analysis.</td>
<td>Professionals and patients (GPs and patients).</td>
</tr>
<tr>
<td>Murray et al. (2011)</td>
<td>NPT Collective Action and its four subcomponents</td>
<td>Data were analyzed using the framework method according to four components of the Collective Action construct of NPT.</td>
<td>Professionals (staff with responsibility for planning and/or executing an e-health initiative—‘implementers’ were defined as any person charged with assisting with the implementation of an e-health system.</td>
</tr>
<tr>
<td>Sanders et al. (2011)</td>
<td>NPT Specific focus on coherence</td>
<td>Semi-structured interviews were organized around the four dimensions of the NPT. The analysis of the second stage interviews identified seven emergent themes, which were mapped onto the ‘Coherence’ construct within the NPT.</td>
<td>Professionals (GPs).</td>
</tr>
<tr>
<td>May et al. (2011)</td>
<td>NPT</td>
<td>Framework analysis of qualitative data informed by NPT.</td>
<td>Professionals and patients (health professionals, managers, patient, carers, social care professionals and managers, and service suppliers and manufacturers).</td>
</tr>
<tr>
<td>May et al. (2011)</td>
<td>NPT</td>
<td>Presented NPT to potential and actual users for review.</td>
<td>Professionals.</td>
</tr>
<tr>
<td>Furler et al. (2011)</td>
<td>NPM</td>
<td>Data analysis drew on the NPM in developing initial coding categories.</td>
<td>Professionals and patients (GPs, nurse educators and patients)</td>
</tr>
<tr>
<td>Bouamrane et al. (2011)</td>
<td>NPT</td>
<td>Review of NPT and use in three e-health supporting case studies.</td>
<td>Professionals and patients (case study one: nurses, doctors, patient advocates, administrators, technologists, researchers).</td>
</tr>
<tr>
<td>Spangaro et al. (2011)</td>
<td>NPT Collective Action and its four constructs</td>
<td>NPT was applied to the findings.</td>
<td>Professionals (staff and management).</td>
</tr>
<tr>
<td>Kennedy et al. (2010)</td>
<td>NPT</td>
<td>NPT provided a framework for development of the intervention. NPT was used to give a focus to discussions and analysis, and reading of the interviews was undertaken in the context of the training observations and from the perspective of NPT.</td>
<td>Professionals (GPs, nurses, practice managers, clerical and reception staff).</td>
</tr>
<tr>
<td>Authors</td>
<td>Framework</td>
<td>Description</td>
<td>Participants</td>
</tr>
<tr>
<td>------------------</td>
<td>-----------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gunn et al. (2010)</td>
<td>NPT</td>
<td>NPT identified as an analytical theory to guide the conceptual framework for implementing best practice depression care. Transcripts coded using interpretive framework of NPT.</td>
<td>Professionals (healthcare professionals, including receptionists, practice nurses, dieticians, nurse educators, psychologists and social workers).</td>
</tr>
<tr>
<td>Gask et al. (2010)</td>
<td>NPM</td>
<td>The authors describe their actual use of NPM to inform research questions, coding, data analysis and interpretation.</td>
<td>Professionals and patients.</td>
</tr>
<tr>
<td>Murray et al. (2010)</td>
<td>NPM</td>
<td>The content of the e-HIT was derived by combining a theoretical framework with a literature review and new empirical data.</td>
<td>E-health experts and implementers.</td>
</tr>
<tr>
<td>Wilkes and Rubin (2009)</td>
<td>NPM</td>
<td>The results of two qualitative studies and two quantitative studies are interpreted by mapping the results to the NPM.</td>
<td>Professionals and patients.</td>
</tr>
<tr>
<td>Gask et al. (2008)</td>
<td>NPM (SSW and CI)</td>
<td>Framework analysis based on NPM. To examine the extent to which clinical governance of mental health care has been normalized within NHS primary care.</td>
<td>Professional – lay informant (clinical governance leads, managers, audit leads and mental health leads; chief executive, and a lay informant).</td>
</tr>
<tr>
<td>Elwyn et al. (2008)</td>
<td>NPM</td>
<td>NPM was used as the basis of conceptual analysis to examine the ‘workability’ of decision support technologies in professional-patient interactions. The authors sought to develop and refine the NPM through a concept analysis approach.</td>
<td>Physicians, patients and managers</td>
</tr>
<tr>
<td>Mair et al. (2008)</td>
<td>NPM</td>
<td>A framework approach to data analysis was used.</td>
<td>Professionals (nurses) and patients.</td>
</tr>
<tr>
<td>Morriss (2008)</td>
<td>NPM</td>
<td>NPM was applied to analyze the NICE guideline recommendations for bipolar disorder.</td>
<td>N/A</td>
</tr>
<tr>
<td>May et al. (2007)</td>
<td>NPM</td>
<td>Applied the NPM retrospectively to analyze trials of complex interventions in mental health and heart disease.</td>
<td>Professionals and patients.</td>
</tr>
</tbody>
</table>

Our analysis of the application of the constructs across settings indicates that authors attributed meanings to each construct that, in general, resonated with our understanding of the
constructs and had veracity in terms of their reported analysis and interpretation of data from their specific study setting.

For Coherence, there was a clear emphasis on understanding and conceptualization of interventions and their work (n = 8) (Gunn, Palmer et al., 2010; Bouamrane, Osbourne et al., 2011; Gallacher, May et al., 2011; Sanders, Foster et al., 2011; Watson, Parr et al., 2011; Blakeman, Protheroe et al., 2012; Finch, Mair et al., 2012; Franx, Oud et al., 2012). For Cognitive Participation, the emphasis was on notions of legitimation and buy-in, both in terms of the individuals involved and involving others (n = 8) (Finch, Mair et al., 2012; Gallacher, May et al., 2011; Mair, May et al., 2012; Bouamrane, Osbourne et al., 2011; Blakeman, Protheroe et al., 2012, Franx, Oud et al., 2012; Watson, Parr et al., 2011; Gunn, Palmer et al., 2010).

For Collective Action, the emphasis was on organizational resources, training and divisions of labour, confidence and expertise as well as the workability of the intervention in clinical interactions (n = 25) (Forster, Newton et al., 2011; Finch, Mair et al., 2012; Murray, Burns et al., 2011; Gallacher, May et al., 2011; Mair, May et al., 2012; Godden and King, 2011; Bouamrane, Osbourne et al., 2011; Murray, May et al., 2010; Blakeman, Protheroe et al., 2012; Franx, Oud et al., 2012; Ehrlich, Kendall et al., 2012; Watson, Parr et al., 2011; Atkins, Lewin et al., 2011; James, 2011; MacFarlane and O’Reilly de Brun, 2011; Furler, Spitzer et al., 2011; Spangaro, Poulos et al., 2011; Gunn, Bower et al., 2010; Gask, Bower et al., 2010; Wilkes and Rubin, 2009; Gask, Rogers et al., 2008; Elwyn, Legare et al., 2008; Mair, Hiscock et al., 2008; Morriss, 2008; May, Mair et al., 2007).
For Reflexive Monitoring, the emphasis across studies was on appraising and monitoring implementation work (n = 9) (May, Mair et al., 2007; Gask, Rogers et al., 2008; Kennedy, Chew-Graham et al., 2010; Bouamrane, Osbourne et al., 2011; Gallacher, May et al., 2011; Blakeman, Protheroe et al., 2012; Ehrlich, Kendall et al., 2012; Finch, Mair et al., 2012; Mair, May et al., 2012).

There were, however, exceptions to this general finding, which typically related to the overlap between constructs. For example, in Gunn et al.’s (2010) paper we considered that data about the doubts practice nurses and receptionists had regarding their role in delivering depression care could fit with Cognitive Participation’s subcomponent legitimation, and could also fit with Collective Action’s subcomponent skill set workability, which relates to the division of labour and the allocation of tasks. Sanders et al. (2011) also reported all their data about a new system for treating back pain under Coherence, although for us much of the data appeared to relate to Collective Action (because the data were based on data generated with study participants based on their experiences of doing implementation work). However, the main point is that irrespective of whether the issue fitted best in one construct or another, the framework helped to raise important issues.

In almost all cases NPT was used as an organizing framework for analyses and reporting findings. It was also used to inform study/intervention design (Gask, Bower et al., 2010; Kennedy, Chew-Graham et al., 2010; Forster, Newton et al., 2011; MacFarlane and O’Reilly-de Brún, 2011; Sanders, Foster et al., 2011), to generate research questions for fieldwork (Gunn, Palmer et al., 2010; James, 2011; Sanders, Foster et al., 2011), and to create tools for investigating and supporting implementation (TARS and eHIT) (May, Finch et al., 2011; Finch, Mair et al., 2012) (see Table 3.2, column 3).
As presented within Table 3.2, column 4, while almost half of the studies (n = 13) (May, Mair et al., 2007; Elwyn, Legare et al., 2008; Gask, Rogers et al., 2008; Mair, Hiscock et al., 2008; Wilkes and Rubin 2009; Gask, Bower et al., 2010; Atkins, Lewin et al., 2011; Bouamrane, Osbourne et al., 2011; Forster, Newton et al., 2011; Furler, Spitzer et al., 2011; James 2011; MacFarlane and O’Reilly-de Brún 2011; May, Finch et al., 2011) were multi-perspectival with involvement of professionals and service users, 12 of the remaining studies (Gunn, Palmer et al., 2010; Kennedy, Chew-Graham et al., 2010; Murray, May et al., 2010; Godden and King, 2011; May, Finch et al., 2011; Murray, Burns et al., 2011; Sanders, Foster et al., 2011; Spangaro, Poulos et al., 2011; Blakeman, Protheroe et al., 2012; Ehrlich, Kendall et al., 2012; Finch, Mair et al., 2012; Franx, Oud et al., 2012) focused on the perspectives of healthcare professionals only. However, it is evident that within the latter studies, different perspectives were often sought from within the healthcare profession (i.e., GPs, nurses, allied health professionals, senior management).

It is interesting to note that Gallacher et al.’s study (2011) is the only one to focus solely on the patient’s perspective. While not multi-perspectival, it does reinforce the message that the implementation of complex health interventions owes as much to the work of patients as it does to service providers and other personnel in health and social care agencies (May, Finch et al., 2011).

3.6.3 What are the reported benefits, if any, of using NPT?

The majority of papers reviewed (May et al., 2007; Elwyn et al., 2008; Mair et al., 2008; Morriss, 2008; Wilkes and Rubin, 2009; Gask et al., 2010; Gunn et al., 2010; Atkins et al., 2011; Forster et al., 2011; Gallacher et al., 2011; James, 2011; MacFarlane and O’Reilly-de
Brún, 2011; May et al., 2011; Murray et al., 2011; Spangaro et al., 2011; Watson et al., 2011; Blakeman et al., 2012; Finch et al., 2012; Franx et al., 2012; Mair et al., 2012) provided data about their experiences of using NPT, and the various challenges and benefits in using it.

MacFarlane and O’Reilly-de Brún (2011) reflected on the challenge, for example, of overcoming tensions around using a predetermined conceptual framework and not wishing to ‘force data into predetermined codes or categories.’ They also described their concerns about understanding the constructs and ‘getting it right,’ stating that ‘it was sometimes difficult to know exactly what CI was about in this specific setting, and how it differed from SSW, and so on. The concern was that if the authors misunderstood the intended conceptual meaning of the constructs, their analysis would not be congruent with the NPM, and this would reduce the benefits of using the theory in the first place. Atkins et al. (2011) and Franx et al. (2012) shared similar views in that the application of the NPT constructs was problematic due to the aforementioned overlap and difficulty of discerning the differences between the constructs.

Gunn et al. (2010) remarked on the efforts required in developing each of the constructs within the complexity of current organizational practice.

Some authors commented on data falling outside of the NPT/NPM coding frame (Mair, Hiscock et al., 2008; Gallacher, May et al., 2011; Mair, May et al., 2012). Mair, May et al. (2012) noted that:

‘only 6% of issues fell outside of their coding framework, either because they were strictly technical and attitudinal or because they were so generic and vague, with accompanying contextual data, that it was not possible to determine whether the concept really lay outside the model or was simply too general to be coded.’

Gallacher et al. (2011) commented on the fact that while very few data fell outside the NPT coding frame, those that did consisted of emotional work. Mair, Hiscock et al. (2008) reflected on ‘attitudes’ and comment that this particular theme did not map onto the
constructs of NPM. However, they acknowledged that unlike other theories such as the Theory of Planned Behavior, NPM relates to the work being done in interactions rather than focusing on how attitudes or intentions will affect work.

Overall, there was strong endorsement from researchers for the theory across a range of disciplines. Of the 20 papers that provided data about their experiences of using NPT, 15 papers (May, Mair et al., 2007; Elwyn, Legare et al., 2008; Mair, Hiscock et al., 2008; Morriss, 2008; Wilkes and Rubin, 2009; Gask, Bower et al., 2010; Atkins, Lewin et al., 2011; Forster, Newton et al., 2011; Gallacher, May et al., 2011; James, 2011; Murray, Burns et al., 2011; Spangaro, Poulos et al., 2011; Watson, Parr et al., 2011; Franx, Oud et al., 2012; Mair, May et al., 2012) commented that NPT was beneficial because it provided an explanatory theoretical framework for helping to identify factors that promote and inhibit implementation of complex interventions:

‘Our findings suggest that NPT provides a useful framework for understanding the processes that affect the implementation, embedding, and integration of new technologies into healthcare systems’ (Murray, Burns et al. 2011).

‘The findings suggest that NPT is a theoretical framework that facilitates understanding of experiences of health care work at the individual, as well as the organizational, level’ (Gallacher, May et al. 2011).

It was also emphasized that NPT had assisted in making clear recommendations for future implementation (n = 11) (Elwyn, Legare et al., 2008; Morriss, 2008; Wilkes and Rubin, 2009; Gask, Bower et al., 2010; Gunn, Palmer et al., 2010; Atkins, Lewin et al., 2011; Forster, Newton et al., 2011; James, 2011; Murray, Burns et al., 2011; Franx, Oud et al., 2012; Mair, May et al., 2012):

‘The model also assists in making clear recommendations for future implementation. This was important as this program was a pilot with a view to inform service decisions on whether and how to scale up the program across the province. We anticipated that the model could provide insights regarding the factors that would lead to normalization of the program’ (Atkins, Lewin et al., 2011).
Finally, some authors discussed the positive impact of NPT on trial design and development of an intervention (n = 3) (May, Mair et al., 2007; Gask, Bower et al., 2010; Forster, Newton et al., 2011), for example:

‘The NPM provides a useful structure for both guiding and analysing the process by which an intervention is optimized for testing in a larger scale trial or for subsequent wide-scale implementation’ (Gask, Bower et al., 2010).

At the same time, authors suggest further development of NPT (Finch, Mair et al., 2012, Murray, Burns et al., 2011, Atkins, Lewin et al., 2011, Mair, Hiscock et al., 2008) relating to: the determination of its value to guide the development of interventions for use in routine healthcare (Murray, Burns et al., 2011); the need for study-specific measure/application of NPT (Finch, Mair et al., 2012); the development of tools and methods to assist in the use of the NPM (Atkins, Lewin et al., 2011); its potential to be used as a tool to assess the likelihood of future normalization of a complex intervention (Mair, Hiscock et al., 2008).

3.7 Discussion

Across the 29 NPT papers included in this review, most of which were from the UK, there is evidence of a growing interest in the application of the NPT beyond its original field of e-health and telehealth. It is mainly being used to qualitatively analyse the implementation of complex interventions in a diverse range of healthcare settings.

Our analysis of the application of the NPT constructs across settings indicates that, overall, authors attributed meanings to each construct that resonated with our understanding of the construct and that had veracity in terms of their reported data from their specific study setting. We did have some queries about authors’ coding decisions; these related to potential overlaps between constructs, and also the issue of what stage in the implementation journey data related to. Indeed, some authors reported challenges of this nature when discussing their
use of NPT. They described the difficulties experienced in assigning data, which can often be so closely interrelated, to a single category within the theory (Atkins, Lewin et al., 2011).

While it is valuable to note that the NPT constructs are not in competition with each other but are intended to work together to explain causal mechanisms, we do recognize the challenge of such coding decisions, which is inherent in all qualitative analyses (Gibbs, 2007). Our own experience of NPT coding is that if data are based on planning the implementation of an intervention they are most likely to relate to Coherence and Cognitive Participation, and if they are based on actual experiences of enacting a new intervention they are most likely to relate to Collective Action and Reflexive Monitoring. At the same time, NPT has been developed with attention to the dynamic nature of implementation work (e.g., sense making may be influenced by enactment). Therefore, we also acknowledge that the fluidity and flexibility inherent in NPT is important to take into account during coding, based on the specific context of each piece of data.

Overall, there was strong endorsement from several authors that it was beneficial to use NPT as a conceptual framework to analyse implementation processes and inform recommendations to guide implementation work (Forster, Newton et al., 2011; MacFarlane and O’Reilly-de Brún, 2011). This is an extremely important finding, suggesting that NPT is a new theory that does provide a generalisable framework that can be applied across contexts, with opportunities for incremental knowledge gain over time and an explicit framework for analysis that can explain and potentially shape implementation journeys. This finding about the benefit of using NPT is similar to Helfrich et al.’s (2010) finding about the benefit of using the ‘Promoting Action on Research Implementation in Health Services’ framework,
and thus we can see an expanding evidence base about the use of theory in studies about translational gaps.

A number of authors reported that some of their findings were outside the NPT conceptual framework. This is not a problem *per se* because the NPT, like any middle-range theory, cannot and does not claim to be a theory of everything. This finding indicates that authors are thinking critically about the relevance of NPT constructs to their data and are using it as a heuristic device rather than as a ‘conceptual straitjacket.’ Such critical and flexible use of NPT is recommended by its developers (May, Finch *et al.*, 2011) and advocates of using theory in social science research more generally (Layder, 1998).

In terms of recommendations for future use of NPT, we note that authors rarely explained why they had selected NPT as opposed to other theories and rarely contrasted findings to previous studies. This may in part be a function of the current development of the implementation science literature, and the natural evolution of standards and expectations about what details researchers most need to report (Helfrich, Damschroder *et al.*, 2010). However, for future use it would be valuable to have this detail in the write-up of NPT or any theory. We therefore recommend that authors explicate their rationale for choosing NPT as their theoretical framework, particularly given that implementation science, like other closely related fields (*e.g.*, health services research, health technology assessment, and improvement science), needs comprehensive, robust, and rigorous theories that explain the social processes that lead from inception to practice (May, 2013). In detailing their use of theory, authors will be making a contribution to implementation theory.
Also, even though NPT has highlighted the need to provide a whole-system analysis, many papers in this review only included single-stakeholder perspectives and there was an emphasis on service providers rather than service users. The limitations of such an approach to inform implementation processes should be considered during the analysis process (May, Finch et al., 2011) and acknowledged by researchers as they develop recommendations for future research or practice.

Finally, to fully explore the scope of NPT to shape implementation journeys, we need more studies that use the theory in a prospective manner. In this review there was only one such study (Atkins, Lewin et al., 2011), but others are underway and will provide valuable findings in the future (MacFarlane, O'Donnell et al., 2012). As suggested by Grol et al. (2007) and Murray et al. (2010), there is scope for NPT to be used during the planning stages of implementation projects to explore the real-world context in which the work will take place. Such approaches may provide important data to re-direct or stop planning if the likelihood of normalization is low.

### 3.8 Limitations

First, this review did not include non-English language papers and therefore we cannot comment on the use and perceived value of NPT in non-English speaking settings. However, it would be valuable to do so in future reviews and to explore its use and stability across cultural settings, given that our search identified a number of foreign language papers using NPT from countries such as Sweden and Italy and the use of NPT in three European-wide research projects: REsearch into implementation SStrategies to support patients of different ORigins (RESTORE) (MacFarlane, O'Donnell et al., 2012), Self-care Support for People
with Long Term Conditions, Diabetes and Heart Disease: A Whole System Approach (EU-Wise) and INnovative, Midlife INtervention for Dementia Deterrence (In-MINDD).

Second, reviews are one step removed from the primary data, and therefore we rely on the authors’ reports of benefits and limitations of NPT usage, which could be limited or sanitized versions of their experience. No attempts were made to contact authors for additional information.

In terms of gaps in the information provided by the studies, we noted that in the quality appraisal process the lowest scoring domain tended to be in terms of ethics and bias, primarily because there was very limited discussion of either of these issues within the papers. As an example, while authors reported whether they had ethical approval or not, they did not elaborate on ethical issues in the research process. This limited reporting about ethics and bias is likely to be a function of the word count restrictions in journal articles.

To enhance quality and rigor, we took several steps to increase the transparency and reliability of our review. First, given that some of the authors (LB, COD, FSM and AMacF) have been involved in the development of NPT, we decided at the outset of the review that we would focus on explicit accounts of NPT in use and explicit reflections by authors on its merits/demerits (i.e., to allow the authors of the NPT papers to speak for themselves as much as possible). We favoured this approach on the basis that it would heighten the authenticity of our conclusions given our involvement in the development of NPT. Second, all steps of the review were led by the lead author who has had no prior involvement in the development of the theory. Third, during the coding process we employed double independent coding during indexing and charting of the data, and discussions with all authors to reach consensus during
the mapping and interpretation phases. These three steps heightened our critical thinking
during the analysis process and the authenticity of our conclusions.

As this was a qualitative review of predominantly qualitative empirical studies, some aspects
of the PRISMA (2009) statement were not applicable (see Appendix 7).

3.9 Conclusions

In conclusion, NPT has served as a useful and beneficial conceptual heuristic for many
researchers and practitioners from different communities in terms of framing and enhancing
analysis of implementation processes and informing recommendations for improving
implementation.

NPT has potential to help understand the translational gap, providing us with a generalisable
framework that can apply across differing settings and individuals, the opportunity for
incremental accumulation of knowledge, and an explicit framework for analysis. Whether
NPT can serve as a tool to shape implementation processes in ways that will promote
integration and embedding of complex interventions remains unclear and merits
investigation.

3.9.1 Abbreviations

CI: Contextual integration; CKD: Chronic kidney disease; COPD: Chronic obstructive
pulmonary disease; DST: Decision support technologies; HSG: Hysterosalpingography; In-
MINDD: INnovative, midlife INtervention for dementia deterrence; IPV: Intimate partner
violence; IW: Interactional workability; NPM: Normalization process model; NPT:
Normalization process theory; PAR: Participatory action research; RESTORE: REsearch into
implementation STRategies to support patients of different ORigins; RCT: Randomized controlled trial; RI: Relational integration; SSW: Skill set workability; TARS: Technology adoption readiness scale.

3.9.2 Competing interests
LB, FM, AMacF, and COD have been part of an international group of academics who have contributed to the development of NPT. LB is a member of the Advisory Board of Implementation Science. Editorial decisions regarding publication of this manuscript were made independently by another editor.

3.9.3 Authors’ contributions
RM and AMacF were responsible for overall coordination; RM, LB and AMacF conceived of the study; all authors (RM, AMacF, LB, SM, FSM, COD) participated in the study design, coding of data, analysis and drafting of the manuscript; while RM and AMacF undertook the independent quality appraisal process. All authors read and approved the final manuscript.

3.9.4 Acknowledgements
We would like to acknowledge the contributions of Carl May and Tracy Finch to earlier drafts of the manuscript.

3.9.5 Funding
Funders: Research 4i, GEMS, University of Limerick; in respect of journal publication costs.
3.10 References


implementation: does the Normalisation Process Model explain why it's so difficult to embed decision support technologies for patients in routine clinical practice? Implementation Science, 3.


Godden, D.J. and King, G. (2011) Rational development of telehealth to support primary care


In-MINDD. (2012). INnovative, Midlife INtervention for Dementia Deterrence (In-MINDD) http://www.inmindd.eu/


package in primary care: learning from formative evaluation. *Implementation Science, 5.*


MacFarlane, A., O'Donnell, C., Mair, F., et al. (2012) REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings (RESTORE): study protocol. *Implementation Science, 7.*


May, C., Finch, T., Ballini, L., MacFarlane, A., Mair, F., et al. (2011a) Evaluating complex


Chapter 4: Paper 3

A critical analysis of the implementation of service user involvement in primary care research and health service development using Normalization Process Theory

4.1 Abstract

4.1.1 Background

There have been recent important advances in conceptualising and operationalising involvement in health research and healthcare service development. However, problems persist in the field that impact on the scope for meaningful involvement to become a routine – normalised – way of working in primary care. In this review, we focus on current practice to critically interrogate factors known to be relevant for normalization – definition, enrolment, enactment and appraisal.

4.1.2 Method

Ours was a multidisciplinary, interagency team, with community representation. We searched EBSCO host for papers from 2007-2011 and engaged in an iterative, reflexive approach to sampling, appraising and analysing the literature following the principles of a critical interpretive synthesis approach and using Normalization Process Theory.

4.1.3 Findings

Twenty-six papers were chosen from 289 papers, as a purposeful sample of work that is reported as service user involvement in the field. Few papers provided a clear working definition of service user involvement. The dominant identified rationale for enrolling service
users in primary care projects was linked with policy imperatives for co-governance and emancipatory ideals. The majority of methodologies employed were standard health services research methods that do not qualify as research with service users. This indicates a lack of congruence between the stated aims and methods. Most studies only reported positive outcomes, raising questions about the balance or completeness of the published appraisals.

4.1.4 Conclusion

To improve normalisation of meaningful involvement in primary care, it is necessary to encourage explicit reporting of definitions, methodological innovation to enhance co-governance and dissemination of research processes and findings.

4.1.5 Keywords

Service User Involvement; Critical Interpretive Synthesis; Primary Healthcare; Patient Participation; Normalization Process Theory.

Article first published online: 24 Jul 2014


4.2 Background

The idea of involving patients and the public in healthcare has grown significantly in recent decades and is now enshrined in health policy across a range of international settings (Charles and DeMaio, 1993; Department of Health, 1999; Canada Health, 2000; Department of Health, 2001; Neuwelt, 2012).

Therefore, patient and public involvement (PPI) has increasingly become the focus of attention in health services research and health services development. Thompson et al. (2012) argue that these are overlapping categories whereby data generated by such research can inform and improve healthcare services. There are a number of models or frameworks that aim to conceptualise PPI. Gibson et al.’s (2012) recent work on conceptualisation of PPI provides a valuable overview of models and frameworks in the field, and provides new theoretical directions (that were previously absent) for an emancipatory concept of PPI in health services development. A systematic review by Brett et al. (2010) focused on the conceptualisation, measurement and impact of outcomes of PPI in health and social care research.

However, conceptualisation and theorisation of PPI is not common in studies of PPI (Brett, Staniszewska et al., 2010). Furthermore, there have been recent important developments in the operationalisation of public and patient involvement in health research and health service development. Earlier literature in the field proposed that involvement could be captured through the use of conventional health service research methods such as surveys, in-depth interviews and general consultation (Arnstein, 1969). It is now accepted that these methods, by themselves, do not facilitate meaningful involvement unless service users have contributed to research design. This emphasis on more extensive involvement is captured in the
INVOLVE definition of involvement in health research and health service development as research ‘with’ or ‘by’ service users, rather than ‘to’, ‘about’ or ‘for’ service users (see www.invo.org.uk).

There have been examples of concerted efforts to develop infrastructure and capacity to support meaningful collaborations and partnerships between academia, healthcare providers and patients in North America (see http://pram.mcgill.ca/) and the United Kingdom (see http://piiaf.org.uk/).

However, problems persist in the field. Firstly, there is a problem of definition. There is still a wide range of terms used in the field, including patient involvement, patient engagement, patient participation, service user involvement, citizen engagement, community participation, community engagement, and public involvement (Buckland, 2007). Gallivan et al. (2012) argue that this can contribute to misunderstanding and misinterpretation of expectations, goals and outcomes by different groups of stakeholders, which poses barriers to achieving meaningful and successful outcomes in partnership work together. We clarify our terminology in Box 4.1.

**Box 4.1 Terminology: Service User Involvement**

In this paper we employ the term Service User Involvement (SUI) because this is the terminology employed by the Health Service Executive (HSE) in Ireland in its Strategy for Service User Involvement 2008 (Department of Health and Children and HSE, 2008), and the research reported here is designed to inform our national policy context as well as informing international debates. In the Irish context, the term SUI refers to ‘a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (Department of Health 2001, Department of Health and Children and HSE, 2008;). The term SUI was chosen from a variety of options (e.g., engagement, public participation and community participation) (Canada, 2000; McEvoy, Keenaghan et al., 2008; Neuwelt, 2012) as a workable rather than ‘perfect’ definition.
Secondly, there are many reasons why service users and health professionals get involved with SUI projects. This presents the problem of enrolment in the field (WHO, 1978; Brophy, 2006; Department of Health and Children and HSE, 2008; Flynn 2009). We do not know what factors motivate health professionals or service users to enrol in specific projects: Is it a question of personal motivation or is it a response (voluntary or involuntary) to policy directives? Are service users and health professionals enrolling with shared or differential motivations and definitions of involvement?

Thirdly, there is the problem of enactment. As above, standard conventional research methods can be mistakenly conflated with SUI (Morrison and Dearden, 2013). It is important to know why a specific method is selected for a project and whether the selected methods are congruent or not with an intended level of involvement and working definitions of SUI in health research and/or health service development.

National and international literature reviews of the field have highlighted that it is very possible for healthcare professionals to be ‘engaged’ in numerous purported involvement activities with service users without genuinely involving people (particularly if the professionals continue to set and drive the agenda and make decisions about services and treatments without involving service users in a meaningful way) (McEvoy, Keenaghan et al., 2008; Jagosh, Macaulay et al., 2012). This has implications for understanding the outcomes of SUI, which is the fourth problem – appraisal of SUI. While negative effects of SUI on research processes and subsequent health service outcomes have been reported (Bryant and Beckett 2006; Boote, Baird et al., 2010; Brett, Staniszewska et al., 2010), there is growing evidence that participatory approaches to research that involve service users in a meaningful and sustained way can have positive impacts in terms of setting the research agenda,
programme sustainability and advancement, the generation of systemic change (Faulkner 2006; Abma and Broerse, 2010; Faulkner, 2010; Jagosh, Macaulay et al., 2012), and on service users themselves (Macaulay, 1999; Beresford, 2002; Rhodes, 2002; Cotterell, Harlow et al., 2011). Therefore, we have to seriously and critically analyse any claims about outcomes based on SUI where, in fact, SUI did not occur or was so poorly enacted that it ought not to be claimed as genuine SUI.

Overall, our observation is that the four problems outlined above are problematic in and of themselves, but they are also barriers to the implementation of meaningful SUI as a routine way of working in healthcare research and healthcare service settings (i.e., as a normalised practice). The problems are about the definition, enrolment, enactment and appraisal of SUI, and these resonate with the four constructs of Normalization Process Theory (NPT) (May and Finch, 2009) (see Table 4.1). This is a contemporary social theory that can be used to understand and investigate the normalisation of innovation in healthcare (McEvoy, Ballini et al., 2014).

Table 4.1  Service User Involvement and Normalization Process Theory (NPT) (May and Finch, 2009)

<table>
<thead>
<tr>
<th>Question re SUI</th>
<th>Problems in the practice of SUI</th>
<th>NPT construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is service user involvement defined?</td>
<td>Definition</td>
<td>Coherence</td>
</tr>
<tr>
<td>Why do stakeholders get involved?</td>
<td>Enrolment</td>
<td>Cognitive Participation</td>
</tr>
<tr>
<td>What methods are used?</td>
<td>Enactment</td>
<td>Collective Action</td>
</tr>
<tr>
<td>What are the outcomes?</td>
<td>Appraisal</td>
<td>Reflexive Monitoring</td>
</tr>
</tbody>
</table>
The aim of this review is to critically interrogate the conditions for the implementation of SUI in both primary care research and health service development projects in order to make recommendations that will enhance chances of its normalisation. We focus on a sample of original published empirical work that is reported as SUI in the primary care literature to rigorously examine the way definition, enrolment, enactment and appraisal are reported vis-à-vis each other.

4.3 Methods

The methodological approach for conducting this review followed the broad precepts of a critical interpretive synthesis (CIS) (Dixon-Woods, Cavers et al., 2006). We employed an inductive and iterative approach using the research question as a compass during the review process. We sought a purposeful sample of papers, integrated quantitative and qualitative data, and aimed for a more fundamental critique of literature (rather than a summary). While we adopted an inductive approach at the outset of the review process, given our interest in implementation and normalisation, we used NPT as a heuristic device to synthesise emergent findings and draw out key recommendations.

The research team constituted academics, health authority personnel, clinicians and community organisation representatives, all of whom have experience of using participatory research approaches. We searched EBSCO host for original primary care papers about research and health service development projects that were identified by relevant search terms between 2007 and 2011 (see Figure 4.1 Sampling and Selection Process for Papers included in the Critical Review).
The first stages of the review involved an iterative reflexive approach to searching and sampling the literature using a series of identification, sampling and appraisal steps as per the CIS methodology. Each of these stages of the review was led by the first author with substantial input, independent reviewing of abstracts and development of sampling parameters by the second and last author, and consultation with the other authors. The thematic analysis and subsequent synthesis of findings was led by the first and last author in consultation with all other authors, using a combination of data analysis clinics, project meetings and email correspondence.

We identified 289 abstracts at the outset, which resulted in 234 abstracts after duplicates were removed. From this, 78 empirical abstracts were identified, and using iteratively developed
sampling parameters, we excluded conventional qualitative research studies and selected a final purposive sample of 26 papers for inclusion in the review (see Table 4.2).

Table 4.2 Sample of 26 Papers included in the Critical Review Categorised by Six Sampling Parameters

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Number of Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=8 - SUI studies explicitly reporting experience of ‘doing’ SUI and/or studies that demonstrate high-level involvement using participatory methodologies.</td>
<td>8</td>
</tr>
<tr>
<td>n=3 - Qualitative and quantitative health services research (HSR) studies that focus on the perspective or experiences of service users, with more of an emphasis than other HSR studies on reporting outcomes or actions taken as a result of their input.</td>
<td>3</td>
</tr>
<tr>
<td>n=5 - Qualitative and quantitative health services research studies on the theme of SUI and/or patient participation.</td>
<td>5</td>
</tr>
<tr>
<td>n=2 - Studies with a focus on shared decision-making, including studies that analyse patient/practitioner consultations in which there is shared decision-making.</td>
<td>2</td>
</tr>
<tr>
<td>n=4 - Randomised controlled trials where the intervention component has some evidence of patient involvement (e.g., learning skills for self-management, participation in mentoring or coaching).</td>
<td>4</td>
</tr>
<tr>
<td>n=4 - Irish papers (including grey literature) focusing on user involvement in primary care in the Irish context, as recommended by our research team to ensure our review (a) had relevance to the national policy context and (b) was inclusive of studies with participatory methodologies, which were under-represented at one point in the sampling process.</td>
<td>4</td>
</tr>
</tbody>
</table>

Not all papers included in the review involved service users in a meaningful way as per the definition espoused by INVOLVE, but we included them on the basis that they were identified in the literature as SUI. Our search terms therefore represented ‘current practice’ reported in peer-reviewed published literature. They were included because they contained at least some data about definition or enrolment or enactment or appraisal of SUI. For example, the work was presented as SUI in the introduction section against the policy background of SUI, or the work reported revealed proximity between data generation and healthcare service outcomes, which we considered relevant to understanding the impact and appraisal of SUI.

Table 4.2 provides an overview of the final set of sampling parameters and the numbers of papers reviewed per parameter. Following Dixon Woods et al. (2006), and using checklists developed by others (Jadad, Moore et al., 1996, Hawker, Payne et al., 2002) we conducted a
quality appraisal exercise on these 26 papers with an emphasis on the relevance of the paper to our review. All were deemed appropriate for inclusion in the review.

For the data extraction process we used a modified version of the Critical Appraisal Tool (CAT) (Wright, Foster et al., 2010). Our process and working definitions for the synthesis are shown in Table 4.3. First order constructs were drawn from the information extracted during the critical appraisal process, and were informed by the items on the amended CAT (Wright, Foster et al., 2010) (see Table 4.4, Column 1). All papers, qualitative and quantitative, were appraised by the same method.

Table 4.3  Our Working Definition of 1st, 2nd and 3rd Order Constructs (drawing on work of Noblit and Hare, 1988; Britten, Campbell et al., 2002; Malpass, Shaw et al., 2009).

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Description</th>
<th>Interpretations of what the literature tells us about SUI in primary care research and health service development.</th>
</tr>
</thead>
<tbody>
<tr>
<td>First order constructs</td>
<td>Information extracted during the critical appraisal process of reviewing the evidence in the literature for service user involvement in primary care research and health service development.</td>
<td>Interpretations of what the literature tells us about SUI in primary care research and health service development.</td>
</tr>
<tr>
<td>Second order constructs</td>
<td>Interpretation and collation of themes from 1st order constructs.</td>
<td>Interpretations of interpretations of what the literature tells us about SUI in primary care research and health service development.</td>
</tr>
<tr>
<td>Third order constructs</td>
<td>The views and interpretation of the synthesis team expressed in terms of themes and key concepts and mapped onto four NPT constructs.</td>
<td>Interpretations of interpretations of what the literature tells us about SUI in primary care research and health service development.</td>
</tr>
</tbody>
</table>
These first order constructs informed the development of our second order constructs through interpretation and collation of themes from first order constructs (see Table 4.4, Columns 3 and 4).

Whilst we were reviewing our second order constructs and the data contained therein, we were exploring the evidence from across all studies in the review to integrate this data into a synthesising argument. Given our noted link between the practice of SUI and NPT’s constructs, we developed a synthesising argument around the theory’s four constructs of Coherence, Cognitive Participation Collective Action and Reflexive Monitoring (Table 4.4 shows how the data from each paper informed this final synthesis).
<table>
<thead>
<tr>
<th>First order constructs informed by CAT (Wright et al. 2010).</th>
<th>Studies</th>
<th>Second order constructs – emergent inductive themes.</th>
<th>Studies</th>
<th>Third order constructs following NPT (May and Finch, 2009).</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Level of SUI</td>
<td>3. Ethical Practice</td>
<td>3. Enactment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>---------------------</td>
<td>--------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Theme 1 Socio-political context or drivers</td>
<td>Theme 2 Definition</td>
<td>Theme 3 Level of SUI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-------------------</td>
<td>---------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Ethics

6. Roles and Responsibilities
| 8. **Other** | (Emmett, Murphy *et al.* 2007; Box 2009; Frank, Asp *et al.* 2011; Goodrich, Buis *et al.* 2011) |
9. Impact of SUI

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
By mapping our first and second order constructs onto these synthesising NPT constructs in a sequential manner, we were representing the network of synthetic constructs and explaining the relationships between them with the aim of providing a more insightful formalised and generalisable way of understanding a phenomenon (Dixon-Woods, Cavers et al. 2006) - in this case the phenomenon of SUI in primary care research and health service development. Therefore, the synthesising constructs of NPT were informed by data from across the second order constructs (which were developed from thematic analysis and interpretation of first order constructs).

In the main, the second order constructs which most informed the final stage of our synthesis and conclusions were partnership and collaboration, roles and responsibilities, and control and power (See Table 4.5 Description of 2nd Order Constructs).

Table 4.5 Description of 2nd Order Constructs - Partnership and Collaboration, Roles and Responsibilities, and Control and Power: Informing the 3rd Order Constructs.

<table>
<thead>
<tr>
<th>Theme Name</th>
<th>Theme Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partnership and</td>
<td>The data in this theme relate to partnerships and collaborations for research and healthcare projects. Data refer to the working relationship and style of working involved in partnerships and collaborations. Data also refer to working in a specialised way or with specialised roles within partnerships and collaborations.</td>
</tr>
<tr>
<td>Collaboration Subthemes</td>
<td>The data in this theme relate to where collaboration has happened and there is evidence of what happens when collaboration and partnership is in place. Data that describe partnership with service providers, partnership between systems (socio-political systems, health systems), communities and individuals were also included here. Data were included if they describe system-level changes that are required for partnership and collaboration to occur.</td>
</tr>
<tr>
<td>Roles and</td>
<td>The data in this theme refer to particular roles or responsibilities that were defined and described in the research paper. The focus is on actions and responsibilities.</td>
</tr>
<tr>
<td>Responsibilities</td>
<td></td>
</tr>
<tr>
<td>Control and</td>
<td></td>
</tr>
<tr>
<td>Power: Informing the 3rd</td>
<td></td>
</tr>
</tbody>
</table>
The other themes generally described standard information about the conduct of the research typically contained in an academic write-up of a peer-reviewed paper, but they did not reveal anything specific about the topic of SUI itself. For example, all accounts of ethical practice referred to standard procedures of applying and receiving ethical approval. There were no data about specific ethical considerations that had to be taken into account to support/enhance the SUI dimension, for example, the development of training or mentoring to enhance service users’ capacity for co-working and co-governance. Our findings are reported under the headings of definition, enrolment, enactment and appraisal below.

### 4.4 Findings

The majority of papers were from the UK (n=11). Four were from Ireland, three from the US, two from Australia and one each from Brazil, Canada, Finland, Germany, Sweden and The Netherlands.
4.4.1 Definition

Only six papers included a definition of SUI (Loh, Leonhart et al., 2007; Box, 2009; Alexander, 2010; Radermacher, Sonn et al., 2010; Frank, Asp et al., 2011; McEvoy and MacFarlane, 2012). All six definitions focused on the notion of SUI as involving partnership, collaboration, and notions of ownership and empowerment for service users. Thus, we inferred that in each case the researchers were indicating strong aspirations for meaningful SUI. In the other papers, while authors didn’t provide an explicit definition, many stated that their project had been designed in response to policy imperatives to re-balance control and power between those planning or delivering health services, and those who use the health services.

There were no data in any paper about whether definitions within or across stakeholder groups differed, so we could not determine if the definitions were shared or not by those involved in the work.

4.4.2 Enrolment

Several papers reported that the rationale for creating partnerships and collaborations was specifically to reform aspects of healthcare delivery by drawing on the experiences and perspectives of service users in research projects (O’Reilly, Reaper et al., 2005; de Brun and Du Vivier, 2008; Hodges, Butcher et al., 2009; Iliffe, Kharicha et al., 2010; Koelewijn-van Loon, van der Weijden et al., 2010; Heidemann and Almeida, 2011). O’Reilly et al.’s (2005) aim was to gather drug users’ perspectives on how they are treated by services, and to assess drug users’ views of health services in order to change services. There were examples of collaborations that were initiated to improve clinical consultations, specifically, studies about shared decision-making
which aimed to improve adherence, satisfaction with treatment, and clinical outcomes (Emmett, Murphy et al., 2007). Other studies enrolled patients in SDM for depression treatment (Loh, Leonhart et al., 2007), and for the treatment of depression in patients with cancer (Hodges, Butcher et al., 2009), and for cardiovascular risk management (Koelewijn-van Loon, van der Weijden et al., 2010). Other partnerships and collaborations were initiated for the purposes of iterative testing and refinement of clinical tools with providers and patients (Goodrich, Buis et al., 2011). For example, Goodrich et al. (2011) sought patient input into the development of an Internet-mediated walking programme to develop and evaluate an online interface and to monitor participant progress in the programme.

Partnership in healthcare service development was addressed by Peconi et al. (2008) in scoping activities that brought together key players and stakeholders in emergency and unscheduled care, strengthening commitment to the proposed research and development network. This was reported to be the first time in Wales that these groups were brought together across the emergency care system, to focus on research issues in this way.

Across studies overall, the key reported rationale for enrolment in research and health service developments was to bring the service user perspective to the work in hand. This is consistent with a vision of primary healthcare as one that stretches the boundaries of relationships beyond formal agencies and professionals, to include community representatives as collaborators to influence healthcare delivery, healthcare decisions and research (Beard and Redmond, 1979). However, what is missing are data on who initiated the collaborations, and data about what strategies, if
any, were employed to facilitate meaningful collaboration, as well as critical reflections on the nature of the partnerships or collaborations.

4.4.3 Enactment

Service users reportedly held a diverse set of roles and responsibilities across the studies reviewed. The most common one was being asked to comment on study materials/proposed interventions, and often there is evidence of some changes to the projects as a result of their input. However, as reported above, despite the fact that most papers’ explicit or implicit definitions indicated strong aspirations for meaningful SUI, standard methodologies such as interviews and focus groups were generally employed (Kuosmanen, Jakobsson et al., 2010; Lowes, Robling et al.; Emmett, Murphy et al., 2007; Lindenmeyer, Hearnshaw et al., 2007; Peconi, Snooks et al., 2008; Shipman, Hotopf et al., 2008; Iliffe, Kharicha et al., 2010; Linnell and James, 2010; Frank, Asp et al., 2011; Lowes, Robling et al., 2011).

There were some examples of innovative methods that enabled more meaningful involvement and these were studies that were designed at the outset as participatory health research projects (O'Reilly, Reaper et al., 2005; Lindenmeyer, Hearnshaw et al., 2007; de Brún and Du Vivier, 2008; MacFarlane, Dzebisova et al., 2009; Alexander, 2010; Heidemann and Almeida, 2011; Lowes, Robling et al., 2011). Here, there was evidence of stronger congruence between the aims of sharing power and control and practicing emancipatory principles, and the methods employed. For example, de Brún and Du Vivier (2008) conducted a participatory learning and action (PLA) research study with homeless men to design an intervention using PLA timelines (designed to elicit accounts of life journeys and stories of personal
breakthroughs). A visual representation of the meta-analysis of their experiences was presented in a PLA matrix chart. Interestingly, participants and researchers generated data together on the topic of interest, shared each others’ experiences and perspectives, and completed a co-analysis together. In the Alexander study (2010), emancipatory actions during the research process supported ethnically diverse women to regain control of their healthcare and maintain equality over the course of five successive focus group meetings and in their subsequent interactions with primary care clinicians.

Furthermore, in several of these participatory studies it was evident that service users had sustained involvement in the project, with changing roles as per the project progression. Lindenmeyer et al. (2007) reported that service users shaped the direction of their work at the outset, and also assisted with recruitment, the development of questionnaires, analysis and dissemination activities. However, even where such efforts were made, an explanation of how a participatory research process can lead to empowerment or other similar positive health service outcomes was lacking, which begs the following questions: What actually happens in the research process that leads to these outcomes, and in what ways can researchers elucidate or report these processes?

Finally, it was interesting to note that in the majority of papers reviewed participants are referred to as ‘patients’, which perhaps reflects notions of the ‘expert patient’ (i.e. that patients have expertise by virtue of their experience of a particular condition or illness or health service utilisation). In other cases, rather than using the term ‘patient’, the authors used terminology that emphasised the individual’s or group’s
socio-demographic identity (e.g. men (Linnell and James, 2010), women (Alexander, 2010), or older people (Iliffe, Kharicha et al., 2010)). Whether this difference in terminology is indicative of researchers’ attitudes toward the service user, which in turn may be reflective of power differentials within research or service development initiatives, is hard to say, but it may be worthy of further examination.

4.4.4 Appraisal

Authors’ appraisals of their work were mostly positive. The most consistent claim made was that service users offered a unique and practical expertise that added credibility to the work with positive impacts on service delivery of research. Many authors reported that SUI added real-world connection to their research (Peconi, Snooks et al., 2008; Iliffe, Kharicha et al., 2010; Linnell and James, 2010; Lowes, Robling et al., 2011), and changed the mind-sets of researchers (Lindenmeyer, Hearnshaw et al., 2007).

There were reported benefits for service users. For example, confidence and self-knowledge increased (Alexander, 2010), confidence in making healthcare decisions increased (Slade, Molloy et al., 2009; Alexander, 2010), a sense of power increased (Slade, Molloy et al., 2009; Alexander, 2010), and participants learned how to speak up and talk back (Slade, Molloy et al., 2009; Alexander, 2010). Equality in the research process led to positive interactions (Alexander, 2010) and equality of interaction (Lindenmeyer, Hearnshaw et al., 2007). Interestingly, only one paper (O'Reilly, Reaper et al., 2005) provided data from service users directly to support these claims.
In contrast, negative outcomes were rarely reported, for example whether there had
been frustrations, power struggles or disengagement by either the service users or
healthcare workers/researchers. Few studies explored the problems or challenges of
participation, including passive consumer roles and tokenism. A notable exception
was Radermacher et al. (2010) who provided a critical analysis of the powerlessness
of people with disabilities in the face of organisational structures and culture.

4.5 Discussion

In this review, we focussed on documented problems in the field of involvement in
primary healthcare research and healthcare service development projects – problems
of definition, enrolment, enactment and appraisal. We have critically interrogated
conditions for implementation of meaningful involvement in primary care in primary
healthcare research and health services development projects.

Our findings confirm rather than resolve the problem of definition. Only six papers in
our sample provided an explicit definition to convey the meaning of the work they
were doing. The definitions provided were typically in the introduction section, with
references to existing literature. There were no empirical data about how different
stakeholder groups involved in the project defined involvement. This limited the
scope for our intended analysis of issues of definition vis-à-vis enrolment, enactment
and appraisal within individual projects, and diminishes the scope for strong
coherence in the field.

In terms of enrolment, based on these available data we see an emphasis on policy
imperatives to involve service users in primary care in order to share power and
control. There is a sense that those involved in research and healthcare delivery projects believe it is right that they engage with stakeholders in order to follow policy imperatives, but less evidence that they believe it is worthwhile and valuable as a way of working. It was interesting to contrast the rhetoric about sharing power and control with the apparent gravitation to high ideals about meaningful involvement with the enactment of SUI. Much of what is reported reflects standard practice in health service research and health service development projects rather than evidence of a body of specialised practice that is committed to realising such high ideals.

Notwithstanding the fact that there are ethical practices and scientific principles that are important across all kinds of research designs, we would argue that it is reasonable to expect to see additional and/or creative activities in this particular field. The purpose of such activities would be to enable service users to undertake roles and responsibilities that go beyond ‘having an input’. Service users would be enabled to create and participate in meaningful and ongoing partnerships and collaborations, which in turn would enhance the scope for sharing power and control. In this review there were papers that claimed to have these aims but did not employ suitable methodologies to achieve those goals. For example, most papers reported involvement at only one point in time, echoing findings reported elsewhere by Brett et al. (2010) who found that user-led or collaborative studies with users were more likely to demonstrate sustained involvement.

There are valuable examples in our data set of the specific considerations that some researchers reported in their efforts to enact more meaningful participatory approaches. Alexander (2010) describes her investigator role as providing a forum
where analysis, reformulation and recognition of emancipatory interests could be supported and encouraged, and she outlines the use of a participatory group methodology to create such a context for women in the research process to experience empowerment. De Brún and Du Vivier (2008) describe their decision to generate data and share their life stories and turning points with the homeless men with whom they were engaged.

Our finding about enactment echoes previous work but we emphasise that a major finding from this review is that the balance of work in the field appears to be consultative rather than participatory (Faulkner, 2010). Moreover, there are significant gaps in the field that make it challenging to progress the realisation of emancipatory ideals in this field (Gibson, Britten et al., 2012). For example, the gap in knowledge about whether stakeholders have shared or differential understandings of the work in hand is problematic. Such ambiguities can cause frustrations and misunderstandings which become barriers to meaningful involvement (Gallivan, Kovacs et al., 2012). Worse, we know that repeated disappointments with research involvement among specific communities can accumulate, leading to research fatigue and resistance to partnerships and collaborations with university or health service personnel (Feldman, Frese et al., 2002; Johnson, 2006; Kennedy, deBrun et al., 2010). This in turn affects the appraisal and reported outcomes of SUI for research and health service development projects.

Therefore, to advance our understanding and practice it is important that issues of definition and expectations are made explicit so that appraisals of outcomes can be fair and meaningful. A recent review of the benefits of participatory research (Jagosh,
Macaulay et al., 2012) carefully identified and explicated key characteristics of participatory practice, which enabled compelling conclusions to be drawn about the positive impact of such research approaches. This kind of attention to framing the specifics of practice in the field is important for expanding its evidence base. In time it would be good to see an evidence base about different levels of involvement and their outcomes. Like Brett et al., we argue that poor reporting of impact acts ‘as a fog obscuring the real impact of PPI’ (2010 p.15).

Another key finding from this review is the observed emphasis in the papers on positive appraisal and impact. The exception in our review was Radermacher et al. ’s (2010) critical analysis of the powerlessness of people with disabilities in the face of organisational structures and culture. It is interesting to note that the analysis of barriers to participation was not incidental or secondary to their research, but was in fact their stated objective. This explicit attention to problems is unusual in our sample of literature, where the emphasis is on ideals and notions of only good practice because of/during SUI initiatives. Arguably, this more critical stance is as real and warrants further scrutiny, particularly given recent findings from the PIRICOM Review (Brett, Staniszewska et al., 2010) which reported negative impacts in terms of personal impact, skill levels and knowledge levels and users feeling overburdened, not listened to and marginalised.

4.5.1 Methodological critique

This review was based on a search of one platform database only. Arguably, we could have included other platforms. However, EBSCO offers a suite of more than 300 full-text and secondary research databases, and our intention was not to conduct a
comprehensive review of all published literature but to generate a purposeful sample that represented the range of practice in this field. Our iterative development of sampling parameters during the search phase was crucial for this.

Our critique of the literature is limited to single accounts of the studies in our review, which in turn are limited by the strict criteria for style and word count of academic journals. This may, of course, influence the nature of what is reported and may explain the emphasis on positive findings. We did not engage in chain referencing to identify additional papers about the studies in our sample, and this may have augmented or modified our analysis. However, we did note that during our search there were no obvious examples of related papers; had there been, we would have included them. We only included grey literature from an Irish context and not from an international setting, and we do accept that there are additional and extended accounts of SUI in practice in reports and other documentation that may have provided detail missing from academic journal articles. However, we had a specific interest in reviewing literature that had been through peer review and had therefore been accepted by our peers as a form of SUI and representative of work in the field. Our review is influenced by our background as participatory researchers and our national contexts. We have endeavoured to be open and reflexive about that throughout the work and in this article.

Finally, this review is limited to papers published up to 2011. We acknowledge that there are relevant recent additions to the literature that have further enhanced our knowledge about co-productions of knowledge with expert laity (Gillard, Simons et al., 2012), experiential expertise (Thompson, Bissell et al., 2012) and positive
contributions to research (e.g., acquisition of new skills, knowledge and experience) (Gillard, Simons et al., 2012). The GRIPP checklist for reporting the practice of PPI (Staniszewska, Brett et al., 2011) is another valuable addition and, indeed, there are similar findings across our two studies. However, the additional contribution this review makes is its focus on analysing current practice to understand implementation of SUI in health research and health services development, and to make recommendations that will improve practice and the chances of normalisation. Our use of NPT was appropriate for these aims. It helped us to ‘think through’ complex data and inter-related macro, meso and micro level issues because we could organise them conceptually under NPT’s four constructs which enhances understanding (McEvoy, Ballini et al., 2014).

4.5.2 Directions for future research and practice

It would be valuable to seek answers to the questions of definition, enrolment, enactment and appraisal by prospectively conducting multi-perspectival fieldwork with stakeholders about their work together in specific projects. This would be a very effective way to explore shared and differential perspectives. We also recommend that primary care researchers publish an explicit account of their working definition of SUI, the process by which that was determined (i.e., whether it was in consultation with other stakeholders or not), and an explanation of their choice of methods in relation to that definition. Effectively, this practice should become part of the repertoire of practice and reporting procedures by researchers engaged in the field of SUI to augment the evidence base, encourage more methodological innovation and enable robust appraisals of work that is undertaken (Beard and Redmond, 1979; Staniszewska, Brett et al., 2011).
4.6 Conclusion

Following NPT, the likelihood that SUI becomes a routine and normalised way of working in healthcare settings relies on the four problems of definition, enrolment, enactment and appraisal being resolved. It is necessary to encourage explicit reporting of definitions employed, methodological innovation to enhance co-governance, and dissemination of research processes as well as findings. This will augment the evidence base about current practice and improve normalisation of meaningful involvement.
4.7 References


Brophy, S. (2006) "Personal excellence" as a value for health professionals: a patient's


Involving Service Users in Forensic Mental Health Research, National Programme on Forensic Mental Health R&D. Department of Health, London.


O'Reilly, F., Reaper, E. and Redmond, T. (2005) "We're People too". Views of Drugs Users on Health Services. UISCE, Mountjoy Street Family Practice, Participation and Practice of Rights Project, Dublin.


Chapter 5: Paper 4

“Participation is integral”: Understanding the levers and barriers to the implementation of community participation in primary care as a routine way of working: a qualitative study using Normalization Process Theory. Under Review Health and Social Care in the Community.

5.1 Abstract

A number of international health policies recognise the WHO (2008) vision that communities should be involved in shaping primary health care services. However, researchers continue to debate definitions, models, and operational challenges to community participation. Using Normalization Process Theory (NPT) this qualitative study is designed to critically explore the levers and barriers to the implementation of community participation in primary care as a routine way of working in the Health Service Executive (HSE) Ireland. We conducted two complementary qualitative studies based on a national initiative designed to support community participation in primary care. We had a combined multi-stakeholder purposeful sample (n=72), and utilised documentary evidence (study 1), semi-structured interviews (studies 1 and 2) and focus groups (study 2). Data generation and analysis were informed by Participatory Research and Normalization Process Theory. For many stakeholders, community participation in primary care was a new way of working. Stakeholders did not always have a clear, shared understanding of the aims, objectives and benefits of this way of working. Drivers or champions were considered integral to its initiation and implementation, as were strong working partnerships between community and health service personnel. Participants emphasised the benefits of funding,
organisational support, training and networking to enact relevant activities. Health promoting activities and healthcare consultation/information events were generally successful, but community representation on inter-disciplinary Primary Care Teams (PCT) proved a particular challenge with little sustained progress reported. Overall, participants were broadly positive about the impacts of community participation, but were very concerned about the scope to sustain the work without the 'protected' space and resources of the national initiative, and the economic recession. In the current climate, the likelihood of community participation in primary care as a routine way of working in Ireland is low.

5.1.1 Key Words
Community Participation; Primary Care; Normalization Process Theory

5.1.2 What is known about this topic
- Community participation is the founding principle of primary health care, with cited benefits such as improved health outcomes, service access, equity, quality and responsiveness.
- Despite considerable debate and research surrounding community participation and primary care, evidence of the tangible impact of community participation is questionable.

5.1.3 What this paper adds
- Empirical data about levers and barriers to implementation of community participation in primary care.
• Evidence of specific challenges that community participation is difficult to implement in primary care because it is a relatively diffuse way of working that relies on relationships which cannot be ‘mandated’.

• Use of a social theory to enhance the generalisability of emergent themes for other healthcare jurisdictions.
5.2 Introduction

A number of international health policies recognise the WHO (2008) vision that communities should be involved in shaping primary health care services (Tierney et al., 2014). In Australia and South Africa, for example, there is evidence of community participation impacting positively on health service improvement (Preston et al., 2010; Meier et al., 2012; Kenny et al., 2013; Bath and Wakerman, 2013), and a collective growing understanding across jurisdictions that the involvement of communities in primary healthcare results in more equitable and inclusive services which are more responsive to the needs of the community (WHO, 2002; 2008; Kenny et al., 2013; Draper et al., 201; Houlihan, 2010; Henderson et al., 2014). As highlighted by Bhatia and Rifkin (2010) in their debate, India, which was one of the first countries to create a national community health worker scheme after the Alma Ata conference and subsequently saw the scheme disappear within 10 years, has now begun to revive the program in the context of the National Rural Health Mission.

This reflects a shift away from: ‘service-led systems, where people are fitted into the pattern of provision that has developed historically, to user-led or user-centred services’ (Beresford, 2010 p.438). However, researchers continue to debate definitions, models, and operational challenges to community participation (see Kenny et al., 2013). As a policy ideal, its implementation has proved problematic (Draper et al., 2010; Meier et al., 2012). These challenges resonate with the broader field of knowledge translation. According to Taylor et al. (1999), those who set out to drive programmes of social change are confronted with two enormous tasks: ‘The first is to develop prototypes. The second involves large scale replication. One without the other is insufficient’ (p.322). Nutbeam (2004) outlined the need to invest in research
that improves our understanding of how effective health interventions should be implemented. Eccles et al. (2009) have further argued that we need to see greater use of theoretical approaches in research focused on implementation, on the basis that this will offer (i) generalisable frameworks that can be applied across different settings and individuals, (ii) an opportunity for the incremental accumulation of knowledge, and (iii) an explicit framework for analysis.

The Irish Health Service Executive (HSE) and Combat Poverty Agency Joint Community Participation in Primary Care Initiative (the Joint Initiative: see supporting material Box 5.1) provides a strong prototype for community participation in primary care, but the question remains about whether it can be replicated across the country of Ireland. Drawing on the documented challenges with the implementation of community participation, and international recommendations for implementation research outlined above, the aim of this study is to conduct a theoretically informed (McEvoy et al., 2014) empirical analysis of the levers and barriers to the implementation of the Joint Initiative into routine primary care practice.

Box 5.1 The Joint Initiative

The Community Participation in Primary Care Initiative (the Joint Initiative) was designed to support disadvantaged communities and local health service providers to work together and plan for the participation of excluded communities and groups in primary care including their participation in local newly established Primary Care Teams (PCTs) and networks. The initiative was developed to support implementation of elements of the 2001 Irish National Primary Care Strategy: A New Direction.

The Joint Initiative funded and supported 19 demonstration projects in rural or urban areas...
of disadvantage across Ireland. Two of the 19 projects focussed on specific target groups (Travellers’ and the minority ethnic community). Each project site was managed by two principal applicants, one being a community representative, usually from a non-govermental organisation, and the other a HSE representative. The 19 projects were supported by two project co-ordinators who reported quarterly to the National Joint Initiative Steering Group.

In many cases the projects took a multi-sectoral approach by involving a wider network of statutory and non-statutory organisations and agencies that are tasked with tackling social exclusion and local regeneration.

A formative evaluation of the Joint Initiative took place between September 2009 and April 2010, with a view to drawing out the learning from the 19 projects, and to make policy recommendations for the further development of community participation in primary care.

### 5.3 Methods

#### 5.3.1 Study design

This research is based on a case study of the Irish Joint Initiative (see supporting material Box 5.1: The Joint Initiative). The case was selected on the basis that it was at the ‘leading edge’ of change (Schofield, 2000), and could be deemed the precursor of changes that are taking place within primary care in Ireland (Department of Health and Children, 2008).

This research consists of two complementary, theoretically informed qualitative studies (see supporting material Box 5.2: Qualitative Study Details). While each

---

9 The name “Travellers” refers to a nomadic Irish ethnic group. Irish Travellers are a people with a separate identity, culture and history, although they are as fully Irish as the majority population. The definition of Irish Travellers in Irish law is given in the Equal Status Acts as:

“Traveller community” means the community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions including, historically, a nomadic way of life on the island of Ireland.
study had some unique objectives and focused on particular groups of stakeholders, each study shared a similar core theme of exploring community participation in primary care in Ireland within the context of the Joint Initiative. Taken together, they provide a comprehensive data set about levers and barriers to its implementation.

**Box 5.2 Qualitative Study Details**

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification of the ideal conditions for policy implementation of the Irish National Strategy for User Involvement (Department of Health and Children &amp; HSE 2008)</td>
<td>Exploration of what definitions of community participation were being used across sites?</td>
</tr>
<tr>
<td>Exploration of the process of implementing the Strategy, with a focus on the drivers/champions of the Joint Initiative</td>
<td>How and why did stakeholders get involved in community participation projects?</td>
</tr>
<tr>
<td>Make recommendations about how to maximise opportunities for policy implementation.</td>
<td>What methods were used to enact community participation in primary care?</td>
</tr>
<tr>
<td></td>
<td>How do stakeholders evaluate the impact of community participation projects?</td>
</tr>
</tbody>
</table>

Both studies were informed by Normalization Process Theory (NPT) (May and Finch, 2009; May et al., 2009). NPT consists of four constructs (see supporting material Box 5.3: NPT Theoretical Constructs) designed to explain how participants understand and make sense of a practice (coherence), and how participants come to engage and support a new practice (cognitive participation). It also explains the factors that promote and inhibit the routine incorporation of complex health care interventions in practice (collective action), and how participants reflect on and evaluate it after a period of time (reflexive monitoring). The theory is novel because it offers a conceptual framework about implementation processes that is derived from empirical generalisations developed within studies of implementation and integration processes,
rather than being derived from plausibly useful constructs embedded in other theories (MacFarlane and O’Reilly-de Brún, 2011). It has proved useful as a heuristic device to enhance understanding of implementation journeys of a variety of interventions and innovations in healthcare settings. Therefore, we employed it as our conceptual framework to inform the development of topic guides and to analyse levers and barriers to the implementation of the Joint Initiative into routine primary care practice.

**Box 5.3  NPT theoretical constructs (from Finch, Mair, et al. (2012))**

1. **Coherence**: the process and work of sense-making and understanding that individuals and organisations have to go through in order to promote or inhibit the routine embedding of a practice.

2. **Cognitive Participation**: the process and work that individuals and organisations have to go through in order to enrol individuals to engage with the new practice.

3. **Collective Action**: the work that individuals and organisations have to do to enact the new practice.

4. **Reflexive Monitoring**: the work inherent in the informal and formal appraisal of a new practice once it is in use, in order to assess its advantages and disadvantages, and which develops users’ comprehension of the effects of a practice.

5.3.2 *Ethical approval*

The Irish College of General Practitioners (ICGP) provided ethical approval for both studies.

5.3.3 *Sampling and recruitment*

Following the principles of purposeful sampling (Patton, 1990): Study 1 (n=33) involved Principal Applicants (PAs) to the Joint Initiative from both the HSE (n=11) and community organisations (n=14) from across 15 of the 19 project sites. Seven of the 18 members of the national Joint Initiative steering group participated, as did the independent evaluation officer (n=1).
Study 2 (n=39) involved community representatives, paid and unpaid (n=26); HSE service providers working in PCTs (n=6); HSE service planners and policy makers who oversee the development of PCTS (n=4); and General Practitioners (n=3) (see Table 5.1 An Overview of the Number of Participants and Data Generation Encounters). Four HSE (PAs) and four community representatives (PAs) also participated in study 1.

Table 5.1 An Overview of the Number of Participants and Data Generation Encounters

<table>
<thead>
<tr>
<th>Study 1 (n=33)</th>
<th>Status</th>
<th>Data Generation</th>
<th>Study 2 (n=39)</th>
<th>Status</th>
<th>Data Generation</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSE Principal Applicants (PA)</td>
<td>Paid</td>
<td>n=11</td>
<td>One to one interview</td>
<td>Community Representatives</td>
<td>Paid</td>
</tr>
<tr>
<td>Community PA’s</td>
<td>Paid</td>
<td>n=14</td>
<td>One to one interview</td>
<td>Community Representatives</td>
<td>Unpaid</td>
</tr>
<tr>
<td>National Steering Group, HSE</td>
<td>Paid</td>
<td>n=4</td>
<td>One to one interview</td>
<td>Community Representative</td>
<td>Unknown</td>
</tr>
<tr>
<td>National Steering Group, Community</td>
<td>Paid</td>
<td>n=3</td>
<td>One to one interview</td>
<td>HSE personnel</td>
<td>Paid</td>
</tr>
<tr>
<td>Evaluator</td>
<td>Paid</td>
<td>n=1</td>
<td>One to one interview</td>
<td>HSE policy personnel</td>
<td>Paid</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Paid (as GPs but not in capacity to support CP in PC)</td>
</tr>
</tbody>
</table>

In study 1, 12 of the PAs were either uncontactable, had since retired, and/or were no longer in the same role or post, and hence declined to participate in the study.
Similarly, a number of national steering group members had since retired or moved into new roles and felt they were not best placed to contribute to the aims and objectives of the study.

To ensure confidentiality, coding based on pseudonyms and/or case site numbers were used throughout the data coding process (see supporting material Box 5.4 Data Coding Process).

**Box 5.4 Data Coding Process**

The code (S1, HSE, Steering Group, 76) indicates the participant was from study 1 (S1), was employed by the HSE, and was a member of the National Joint Steering Group Committee. 76 was their assigned participant coding number.

(S1, PA, Community, 4) indicates the participant was from study 1 (S1), was a Principle Applicant (PA) to the Joint Initiative from the community sector, and 4 was their assigned participant coding number.

(S2/CS2, Community paid, Shell) indicates the participant was from study 2 (S2), case study site 2 (CS2), and was a paid community worker. Wherein study 1 the researcher gave participants a numerical coding number, participants in study 2 selected their own pseudonyms, which in this case was Shell.

### 5.3.4 Data generation and analysis

As shown in Tables 5.1 and 5.2, data was generated by utilising documentary evidence (study 1), semi-structured interviews (studies 1 and 2) and focus groups (study 2).

The documentary analysis included the collation of all key documents written or produced about the Joint Initiative (Simons, 2009) (see Table 5.2 Key Documents Analysed). These documentary sources were analysed according to the principles of
framework analysis using NPT to build a more integrated understanding of events, processes and interactions in the case (Miles and Huberman, 1994; Gale et al., 2013).

Table 5.2  Key Documents Analysed

<table>
<thead>
<tr>
<th>Documents</th>
<th>Sets of Minutes</th>
<th>Number of Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Joint Initiative Oversight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Committee meetings (NJI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. 31st March 2009</td>
<td>● 3</td>
<td></td>
</tr>
<tr>
<td>2. 23rd June 2009</td>
<td>● 4</td>
<td></td>
</tr>
<tr>
<td>3. 7th Oct 2009</td>
<td>● 4</td>
<td></td>
</tr>
<tr>
<td>4. 18th Jan 2010</td>
<td>● 6</td>
<td></td>
</tr>
<tr>
<td>5. 31st March 2010</td>
<td>● 6</td>
<td></td>
</tr>
<tr>
<td>6. 29th Sept. 2010</td>
<td>● 9</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>32</td>
</tr>
<tr>
<td>Joint Initiative Networking Event meetings (JIN)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. 4th Dec 2008</td>
<td>● 10</td>
<td></td>
</tr>
<tr>
<td>2. 25th March 2009</td>
<td>● 11</td>
<td></td>
</tr>
<tr>
<td>3. 22nd Sept 2009</td>
<td>● 10</td>
<td></td>
</tr>
<tr>
<td>4. 20th Jan 2010</td>
<td>● 8</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
<td>39</td>
</tr>
<tr>
<td>Joint Initiative Evaluation Information Bulletins (JIE)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Sept 2009</td>
<td>● 2</td>
<td></td>
</tr>
<tr>
<td>2. Oct 2009</td>
<td>● 2</td>
<td></td>
</tr>
<tr>
<td>3. Nov 2009</td>
<td>● 2</td>
<td></td>
</tr>
<tr>
<td>4. Jan 2010</td>
<td>● 2</td>
<td></td>
</tr>
<tr>
<td>5. March 2010</td>
<td>● 2</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Formative Evaluation of the Joint Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation in Primary Care Initiative Executive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary (FES)</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>National Strategy for Service User Involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2008-2013 (NSSUI)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>20</td>
</tr>
</tbody>
</table>

In both the interviews and focus groups sessions, participatory interactive techniques were used to stimulate data generation (O’Reilly-de Brún and de Brún, 2011). NVivo 10 software was used to facilitate data handling and the sharing of data across the research teams.
5.3.5 Quality and rigour

Several steps were taken to increase the transparency and reliability of our results including the recording of reflective fieldworks, data analysis clinics for NPT analysis and member checking (MacFarlane and O’Reilly-de Brún, 2011, Layder, 1998).

5.4 Findings

The structure of the results is framed around the study’s conceptual framework (NPT) (i.e. coherence, cognitive participation, collective action and reflexive monitoring).

The range of community participation activities that participants described is also presented. Such activities ranged from basic health promoting interventions (e.g. drug and alcohol awareness programmes, suicide prevention programmes), to community needs assessments and representation on primary care teams (PCTs). Overall, our data speak to the full range of projects activities as highlighted in the formative evaluation of the Joint Initiative (see Table 5.3 Summary Table of Activities in the Joint Initiative (Pillinger, 2010)).
Table 5.3  Summary Table of Activities in the Joint Initiative (Source: Pillinger 2010)

<table>
<thead>
<tr>
<th>Lead Community Partner</th>
<th>Community Participation Steering Group</th>
<th>Community Consultations</th>
<th>Community Needs Analysis</th>
<th>Joint Training</th>
<th>CP training for PCT Members</th>
<th>Training for Community Reps</th>
<th>Community Health Forum</th>
<th>Sustainability built into Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSE West</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Roscommon</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mayo</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leitrim</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belmullet</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limerick</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donegal</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HSE South</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bantry</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wexford*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waterford</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clonmel</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HSE DML</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Westmeath</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tallaght</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatima</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offaly</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HSE DNE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blanchardstown*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blanchardstown*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monaghan*</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finglas</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pavee Point</td>
<td>*</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Lead community partner denoted with an asterisk did not participate in the study.
5.4.1 Coherence

There were shared perceptions as to the primary aim of community participation in primary care across all participants. Participants generally described community participation in primary care as being about developing partnerships, collaborating with all relevant inter-agency stakeholders, building trust between the community and the HSE, and ensuring that the voice of the local community was heard and involved in the design and development of local health services:

*But with community participation it’s an equal partnership so people are coming together to see how they can maximise health outcomes in an area by working together.* (S2/CSI, HSE Personnel paid, Digitalis)

*Yeah to start a dialogue I suppose between community and between the statutory services and also then GPs so that the services would be delivered in a way that would be better to people who needed them the most....* (SI, Interagency Partner Steering Group, 77)

However, at the same time it was clear that there was considerable confusion about what exactly was involved in this way of working. This was often a function of the range of disciplines, language and terminology involved across agencies and settings. For example, according to analysis of meeting minutes and interview data, there was continuous debate as to the precise meaning of community participation versus service user involvement and evidence of confusion when terms with different meanings were used interchangeably (NJI/31032209; JIN/04122008; JIE/092009):

*...Some people think it’s (community participation) about lobbying, some people think it’s about developing services. Some people think it’s about developing employment initiatives. Some people think it’s about something else ...and the community people are coming from one perspective, individuals come from another perspective. The primary care staff coming from a different perspective.* (S2/CS2; HSE Primary Care Development Officer, Paddy)

*I think community, obviously it comes down to you, a lot of it as well in terms of even language, that language that is used in the community development*
sector, and the language that is used within the HSE, the same word can mean
different things to different people and that can create sometimes some
unnecessary stuff. (S1, PA, Community, 4)

Interestingly, for community stakeholders the difficulty was often in clarifying what is
meant by primary care – this was not a familiar term to the ‘average’ lay person from
the community.

Overall, this confusion about the meaning of community participation meant that it
was hard to engage stakeholders from their wider networks in the Joint Initiative:

        Understanding what community participation involves: Yeah, on all sides I
        think it was very difficult to sell to people what it involved...our challenge
        going forward is to continuously look at ways to see how people could have a
        better understanding of that.... (S1, PA, Community, 4).

Indeed some participants, particularly those new to enacting this way of working,
openly admitted that initially they did not know the type of work that would be
involved. However, they recognised the potential opportunity to work with others
who they thought had that vision, knowledge and support to drive this way of working
forward:

        I didn’t have that vision, when (HSE rep) came to me, it wasn’t my vision. I
        didn’t understand it the way HSE rep understood it. You know and then even
        applying for the BHC funding, like (name) very much supported us doing that
        because you, you know, you need a certain amount of vision at that stage with
        something very, very new to you, and it was very, very new to me as a
        community worker in the area. (S1, PA, Community, 6)

Overall, participants were keen to highlight that it was not wise to ever assume a
shared understanding of this way of working amongst all stakeholders.
5.4.2 Cognitive participation

The main drivers or champions were the PAs within the Joint Initiative. They led the development of project steering groups to get the work started in each local setting (JIE/092009; FES). As illustrated in the previous quote, they were crucial in influencing stakeholders to become involved and to stay involved in the Joint Initiative.

In addition, community and HSE personnel ‘on the ground’ had a key role in developing strong working partnerships between community and health service personnel:

> Just thinking participation is integral...you need the community support and that’s the catalyst for anything to change, if you haven’t got the community backing you up and supporting things you are attempting to do you can all the great ideas on earth but they won’t work unless they are integral to the life of the community and wanted and needed and researched valued.... (S2/CS6; Community Representative, Laura)

The policy context was also important: HSE participants felt it was legitimate for them to be involved in the Joint Initiative because this work formed part of the overall national primary healthcare strategy which was launched in 2001 (Department of Health and Children, 2001a). The Joint Initiative was viewed by the participants as an opportunity to organise themselves to collectively contribute to the work involved in implementing community participation in primary care:

> ... I wanted to see more of a role for primary care itself in the general scheme of things, because for so long we’ve talked about primary care as being the kind of corner stone and so, and yet in practice it hasn’t always been the case.... (S1, HSE, Steering Group, 78)

Even so some participants explained that it was difficult to enrol other colleagues in the HSE to get involved in the work as it developed, particularly those with a clinical
role, who did not always consider community participation in primary care to be part of their day job: 

I think people were quite polite sometimes, maybe they didn’t say what they actually thought, you know, that this wasn’t, they didn’t see this as part of their work you know. (S1, PA HSE, 14)

One of the biggest issues for us was staff feeling that it wasn’t their day job to engage in the Joint Initiative with the ... our clinicians are saying well my job is to see people ... and the facilitators have been having meetings with heads of services about you know getting heads of services agreements that this is part of their work and creating that space for clinicians that they feel ok doing it so that’s going on at the moment. (S1, PA HSE, 6)

Another challenge with enrolment was that HSE stakeholders, in particular, were often cynical as to the community representative’s actual ‘representativeness’. They were concerned that community representatives would only present their individual and personal views and or/issues. Most community representatives interviewed, however, did in fact understand the importance of representing the wider community rather than their own personal interests when engaging in community participation in primary care:

…. and even though I knew it wouldn't be just representing mental health I felt I could be a voice for them as well on the team. I suppose that was my expertise, I could give my experience from working in the mental health area and I suppose I do push that a bit. But at the same time you are still very aware that you are, it’s not just mental health issues that we discuss. (S2/CS1; Community unpaid, Tess)

These community representatives emphasised that they believed that it was right for them to be involved in community participation in primary care, either because of their training, role, responsibilities and/or their personal backgrounds. Moreover, they felt they had a significant contribution to make:

...I grew through it, I came in as a community development worker and it was regeneration. And I live locally; I don’t live in [place name]. I live in [place name] so the whole area for me is very important how it develops. So I’m
passionate from that point of view as well, it’s my area, do you know what I mean... (S2/CSI, Community paid, Roisin)

5.4.3 Collective action

It was clear that the resources provided by the Joint Initiative were pivotal to supporting the drivers and champions in the enactment of this way of working. As well as having resources to establish the aforementioned steering groups, projects in the Joint Initiative were provided with nationally co-ordinated networking events, community development training, and training in facilitation skills, enabling both participants and stakeholders to perform the tasks required. With regard to training, it was striking that participants emphasised the need for training both community and health professionals together. In practice, this was rare.

Participants from both the HSE and the community were very clear that macro level organisational policy and managerial support were also crucial resources for enactment:

...and from a national point of view we’re trying to keep our heads above water trying to sustain services, trying to look at community participation, trying to do it, it’s never been sexy, it’s not one of the things that will gather their attention, at the end of the day you won’t be in front of the PSE because you didn’t have community participation. (S1, HSE Steering Group, 75)

I think it needs to be on the national agenda and shouldn’t be having to be reminded, that you have to remind somebody you know and to push all the time to get the Key Performance Indicator in, like there has to be a time when it’s just part of the strategy part of it like everything else, part of the implementation you know it’s on the same par as whatever getting the (primary care) teams set up getting ICT in place, getting the buildings organised getting needs assessments done you know whatever. (S1, PA HSE, 6)

At the same time, participants described meso and micro level influences. Differences in working styles as per individual professional training and socialisation meant that interactions were problematic: there were clashes between GP’s norms
around short, task-oriented meetings and community development workers’ norms around long, process-centred workshop events:

...they’re all coming from a different perspective, you have the private view that the fact the GPs they don’t they really are anti any kind of long meetings or training so that’s all militating against you know.... (S1, PA HSE, 6)

...not everybody liked it though, because I also remember like one of the Public Health Nurses saying she hated it...And I know that’s because, some people that, community is very process orientated, it’s very talk orientated, sometimes probably way too much! I don’t know, I suppose I feel people in the HSE services are very task orientated.... (S1, PA Community, 13)

Overall, the most successful types of projects were those that tended to be specific, time-bound activities that resulted in a positive outcome in a relatively short period of time, for example, a health fair day, development of a directory of local community services, a one-off information/community consultation event. Some of the HSE PAs were of the view that the shorter time frame, with a clear start and finish date, was something that health professionals, particularly those with a clinical role, could and would commit to.

In contrast, activities that required ongoing support were more challenging, particularly if there was no-one in a paid ring-fenced role to lead the work, including, for example, project steering groups, community health forums and particularly involving community representatives in newly established PCT meetings.

Sites that did report successful community health forums and community representation on inter-disciplinary PCTs tended to be ones where there was a strong history and experience of community participation in primary care prior to the Joint Initiative. These sites had strong consistent drivers, and had invested the necessary
resources over time to nourish relationships and skill sets amongst all stakeholders involved:

...I would say like with the people we’re used to working with [in the community]... that it’s very easy to work with them. But that’s taken time....

(S1, PA HSE, 11)

... if I had to say what was the one most important thing that actually moved this on, that actually led to a good infrastructure in terms of the community and the HSE and particularly around primary care and the primary care teams and stuff, I would say it was that long-term working relationship. (S1, PA Community, 6)

Finally, all participants from HSE and community sectors spoke time and time again of the importance of the aforementioned paid ‘ring-fenced’ role dedicated to initiating and sustaining the work of community participation in primary care. It was not considered sufficient that it be driven by people’s good will. Participants were also adamant that it was not simply just about having a named person with a ring-fenced role, it was about having a named person who is clear about the meaning of community participation and primary care, who possesses the right skill set and interpersonal qualities; “capacity, energy and...enthusiasm” (S1, E, 81) are considered key.

5.4.4 Reflexive monitoring

Broadly speaking, most participants reflected positively about the impacts of this way of working during the lifetime of the Joint Initiative. Drawing primarily on their own informal appraisals, participants spoke of skills development as a result of training, improved networking and information sharing between community and HSE settings, and new and improved working relationships between the HSE and the community.
Participants were able to support their positive informal appraisals with several concrete examples of outcomes from their work addressing real life local issues, including successful community health fair days, a useful information directory of community and health services, and improved signage to local health services. Interestingly, another positive outcome was that, for some, getting involved in a specific community participation project enhanced understanding of the work and its relevance.

In terms of more formal appraisals, through the documentary analysis (FES), we determined that all projects initially put in place a strategy to sustain community participation in primary care in the light of the ending of the funding from the Joint Initiative. Certainly there were examples from the interviews with participants of work that was sustained and further developed over time:

Well I think an ongoing thing that’s impressed me is that the joint meetings between the Community Health Forum and the Primary Health Care Team are ongoing... like you're not getting enormous numbers but there is still, that channel of communication still exists. (S1, PA Community, 11)

... the other thing was that it was evaluated as being, coming out really well that it should keep going so it has kept going, like the sessions lunch time, hourly health related information sessions are still there, they’re still being run, they’re still, people are still coming together.... (S1, PA HSE, 13)

However, it is important to note that a couple of participants, particularly from the community sector, were somewhat critical of the degree of progress made during the Initiative. One key barrier to sustainability was poor coherence – not having shared aims and objectives and expectations:

I don’t think we’ve managed to reach out and quite achieve everything that we thought we were going to achieve and wanted to achieve. I think that the very nature of the fact that we are a group of migrants means people come and go. And it made the group hard to gel and hard to move. (S2/CS2, Community unpaid, Ella)
Another key barrier was the inter-linked challenges of political commitment and resources which are increasingly under strain due to the economic recession. In particular, participants remarked on the continuous ‘shifting sands’ regarding organisational priorities, and appointed roles and responsibilities, both in the HSE and in the community development sector. They also reflected on public apathy and the ad hoc development, resourcing and functioning of PCTs and the loss of personnel in protected paid roles.

Most participants reflected on their diminishing resources and highlighted the modifications and concessions made to their work to ensure that this way of working can continue. For some projects such modifications have been: “to pick a more specific piece of work to do…to have a standard sort of approach for every PCT…a basic step” (S1, PA HSE, 14); “amalgamation of the steering group with the group of participants” (S1, PA Community, 5); “for the Health Forum, I suppose, to take a bit more responsibility” (S1, PA Community, 3); and “trying to be more proactive around, you know, giving information, sharing information rather than waiting for issues to arise” (S1, PA HSE, 11).

Finally a few participants remarked that it is too early in the process to determine the specific impacts of the Joint Initiative:

I think as well because it was a short initiative …then they were just starting to get something from the statutory side and from the GPs to say, well actually there is benefits in this, you know, but there wasn’t long enough for those impacts really to be demonstrated, you know, people were grappling with doing
it and working together and all the rest of it, but we hadn’t really gotten to the stage of impacts and outcomes. (SI, Interagency Partner, Steering Group, 80)

5.5 Discussion

5.5.1 Summary of findings

Despite the ability of all participants to describe the idea of community participation in primary care, it is clear that its meaning in terms of the work involved is not entirely clear or stable within or across HSE and community settings. This low coherence is a function of the diversity of terminology and practice, which are, in turn, a function of the diversity of disciplines and contexts involved. Low coherence influences enrolment work, and enactment work, and attempts to appraise the impact of the work. In spite of this, the financial resources and organisational supports provided by the Joint Initiative certainly enabled individuals in healthcare and community settings, who have a clear vision for community participation and primary care, to drive a range of activities forward in partnership with each other.

Organisational commitment, interpersonal qualities and relational strengths were core to the work. An over-reliance on informal inter-personal relationships and partnerships, however, is a less than ideal scenario, because relationships can falter due to changes and turnover of stakeholders involved. This can also result in inconsistent services across geographical areas, depending on the nature of the personal relationship between stakeholders in different organisations.

At the final analysis, and in the midst of a recession which is putting a continuous strain on community and healthcare sectors, all participants are clear that this way of
working is at risk, and they are asking the key question: how can the work be sustained?

5.5.2 Methodological critique

The strength of our study is that it draws on multiple data sources and multiple stakeholder perspectives. We acknowledge the retrospective nature of the data and the fact that some participants explained that their memory of specific events was limited. However, the scope to compare and contrast data was valuable in this regard.

The first author (RM) was employed by the HSE, and had a key role in co-ordinating the Joint Initiative. While we could sometimes draw on RM’s ‘insider’ knowledge to enhance our understanding of the study context, we did not compromise our responsibility to understand participants’ accounts as their realities (Layder, 1998). Our use of regular data analysis clinics was key in this regard.

Our qualitative case study analysis, using contemporary social theory, provided thick description (Geertz, 1973), and is in line with international recommendations for implementation research (Eccles et al., 2009). The theoretical basis of our work enhances the generalisability of emergent themes for other healthcare jurisdictions (Eccles et al., 2009). Overall, this analysis has improved understanding of levers and barriers to sustainability of community participation in primary care. It provides an important addition to the field, which is characterised by descriptive empirical reports about pilot studies and initiatives at a particular point in time, and some ‘analysis paralysis’ rather than action to tackle the issue (Nutbeam, 2004).
5.5.3 Connections with existing literature

Community participation in primary care is surrounded by confusion and debate among stakeholders involved about what this ‘thing’ is exactly. This reflects confusion and debate in the field more broadly (Kenny et al., 2013). An obvious recommendation, and in line with Gallivan et al. (2012) and Tierney et al. (2014) is that stakeholders should take time to share perspectives at the start of community development projects, in order to identify shared and differential perspectives.

At the same time, we highlight an important finding that sense-making or coherence can be enhanced by experience and practice. This means that positive experiences of being involved in community participation projects can enhance coherence and become a lever to implementation work. The challenge is to maximise the opportunities for positive experiences. One of the most complex aspects of community participation in primary care relates to the tension between enactment of short term, task-oriented activities versus long term, process-orientated activities the outcomes of which are less tangible and harder to quantify. Both can certainly constitute community development, but the latter requires much more acceptance of a community development style of working, which means that the process is the work and is, in and of itself, a marker of success (Kahssay and Oakley, 1999, Rifkin et al., 2000). Stakeholders whose professional background and organisational culture is developed around tasks, indicators and outcomes (Classen and Kilbridge, 2002), find it hard to justify continuous involvement with no apparent value for the investment of time and effort.
Inter-agency training could be adopted as one strategy in overcoming these. However, Buckley (2002) states that training can only have this positive impact if it is underpinned by a commitment at senior level and a shared responsibility and ownership of the work. This highlights the potential to adopt participatory approaches, which are core to community development ways of working (Chambers, 1994) and advocated to improve implementation (Greenhalgh, Robert et al., 2004), to address the observed professional and disciplinary differences.

In conclusion, community participation is difficult to implement in primary care because it is a relatively diffuse way of working that relies on relationships which cannot be ‘mandated’. It requires significant resources and an acceptance of process-orientated work that clashes with the professionalisation and organisational context of many stakeholders and which is challenging to appraise. Further progress will require inter-sectoral partnerships between the community, health service and academia to engage together in participatory, action-oriented training and development projects to maximise levers and minimise barriers.
5.6 References


Methodology 12.


MacFarlane, A. and O’Reilly-de Brún, M. (2011) A reflexive account of using a


Chapter 6  General Discussion

In this study, a “National Strategy for Service User Involvement in the Irish Health Services: A Case study Analysis of Policy Implementation” the researcher sought to:

- Explore the ideal conditions for policy implementation;
- Explore the process in implementing the Irish National Strategy for Service User Involvement in the Irish Health Services (Department of Health and Children and HSE, 2008) with a particular focus on community participation in primary healthcare;
- Make recommendations to maximise opportunities for policy implementation.

This final chapter is presented in four key parts:

- Part 1 presents the researchers reflections on the key findings and contributions;
- Part 2 presents the ideal conditions for implementation and recommendations of user involvement in primary healthcare;
- Part 3 addresses the methodological quality of the overall body of work;
- Part 4 presents the implications and recommendations emerging from the overall thesis.

6.1  Reflections on the Key Findings and Contributions

The researcher has previously outlined a summary of the results per paper (1-4) in Table 1.3, Chapter 1. Here the focus is on summarising findings under five over-arching, inter-related themes and highlighting the key contributions of this thesis:
The need for theoretical implementation research about involvement in primary healthcare;

Contested terminology;

Involvement in enabling environments

Participatory approaches to ensure meaningful involvement

Developing an understanding of impact and outcomes.

6.1.1 The need for theoretical implementation research about involvement in primary healthcare

In paper 1 the researcher highlighted the need for research to build knowledge about the ways in which innovations such as the ‘Joint Initiative’ can be embedded into ongoing, routine healthcare practice thus setting the scene for the overall PhD study. The researcher also explicated the importance of using theory in implementation research with a view to highlighting that a greater understanding of the complexities of implementation is needed to inform health policy and funding (Willis et al., 2012).

In highlighting the need for an extensive, theoretically informed, empirical analysis of the implementation work (paper 1), a literature review of the proposed conceptual framework (i.e. NPT) was carried out (paper 2). The review process enabled the researcher to explore how others had used NPT (i.e. in almost all cases NPT was used as an organising framework for analysis and reporting findings), their understanding of its theoretical constructs, and whether or not it would prove a useful heuristic tool that the researcher could then apply to this particular study.
In completing this process the researcher was assured of the value and merit of using NPT as a conceptual framework to analyse implementation processes and as a means of creating tools for investigating implementation (Forster, Newton et al., 2011; MacFarlane and O’Reilly-de Brún, 2011). This is an extremely important finding, suggesting that NPT is a new theory that does provide a generalisable framework that can be applied across contexts, with opportunities for incremental knowledge gained over time and an explicit framework for analysis that can explain and potentially shape implementation journeys. The researcher also identified a potential gap in the literature in that whilst NPT had been successfully used in primary healthcare settings (e.g. Blakeman, Protheroe et al., 2012, Franx, Oud et al., 2012) it had not yet been applied to the field of community participation in primary healthcare. Thus, the use of NPT to analyse implementation of community participation in primary healthcare is a novel contribution to the literature.

6.1.2 Contested terminology

The NPT review (paper 2) revealed that many of the NPT papers published to date were based on its predecessor NPM (n=17/29). Thus one of the findings of the review of NPT in use was the lack of studies that had used ‘coherence’ as an analytical element within their research. Indeed only one paper (Sanders et al., 2011) focused solely on this particular construct.

However, when undertaking the CIS review of the user involvement literature (paper 3), and in using coherence as an analytical element, there was clear evidence of conceptual ambiguity about what ‘service user involvement’ is. In fact only six of the papers reviewed (Alexander, 2010, Loh, Leonhart et al., 2007, Box, 2009,
Radermacher, Sonn et al., 2010, Frank, Asp et al., 2011, McEvoy and MacFarlane, 2012) provided an explicit definition to convey the meaning of the work they were doing. This issue also emerged strongly during the fieldwork phase of the PhD study (paper 4), where participants reported the considerable confusion among stakeholders from different agencies and settings about what exactly was involved in this way of working (i.e. community participation in primary healthcare).

Hence coherence, which the researcher identified was particularly under researched within the NPT literature, is in fact one of the key reasons why practice and implementation of community participation is suffering in primary healthcare. In this way, the analytic benefits of this NPT construct in this body of work provides an important contribution to literature about the use of coherence as an analytical concept in implementation research.

In terms of findings reported in paper 4 about coherence, it was key for the analysis of implementation to understand that despite the ability of all participants to describe the idea of community participation in primary healthcare, the researcher and co-authors found that its meaning in terms of the work involved is not entirely clear or stable within or across HSE and community settings. This low coherence is a function of the diversity of terminology and practice, which are, in turn, a function of the diversity of disciplines and contexts involved. More importantly, this reflects confusion and debate in the field more broadly (Kenny, Hyett et al., 2013). Low coherence influences enrolment work, and enactment work, and attempts to appraise the impact of the work.
The researcher and co-authors (paper 4) highlight however an important finding that sense-making or coherence can be enhanced by experience and practice. This means that positive experiences of being involved in community participation projects can enhance coherence and become a lever to implementation work. The challenge is to maximise the opportunities for positive experiences.

6.1.3 Involvement in enabling environments

As highlighted by the WHO (2010), and presented through this study’s empirical data (paper 4), community support for health has unique advantages in its close connections with communities, its ability to mobilise the many resources that community members and organisations can bring to the processes of policy and decision making and to service delivery. However these partnerships and collaborations between users, communities and health service professionals do not occur easily. In this study’s empirical data for example it was emphasised that these relationships often evolve due to informal relationships developed through other networks and contexts as opposed to high coherence (i.e. any true appreciation, value or understanding of this way or working).

However, what does assist the development of such collaborations, and the implementation of community participation in primary healthcare, is the creation of enabling environments and advocacy (WHO, 2010) wherein the work is fostered and promoted at a national level. Through the Joint Initiative for example a national mandate for community participation in primary healthcare was given (paper 4), which according to the research participants gave all project stakeholders a sense of legitimation in being involved in this type of work. To state that the work was part of
a national initiative was also perceived by the participants to lend weight to the significance and value of this way of working, something which they considered to be somewhat lacking in the past.

An over-reliance on senior champions and informal inter-personal relationships and partnerships, however, is a less than ideal scenario, because relationships can falter due to changes and turnover of stakeholders involved. For example (paper 4), when the national committee for the Joint Initiative came to an end, and several of the senior champions for user involvement moved to different roles within and/or outside of the HSE, the creation of an enabling environment for community participation in primary healthcare also began to dissolve. Participants interviewed by the researcher believed this was justified by management by saying that community participation was only one of many important issues that needed attention. Without a national mandate, local Joint Initiative projects struggled in legitimising their involvement in community participation in primary healthcare particularly given the time and resources required to foster and nurture partnerships and collaborations.

6.1.4 Participatory approaches ensuring meaningful involvement

International literature (Preskill and Jones, 2009) would suggest that recommendations that result from a participatory process are more likely to be accepted by a broader constituency and implemented more fully and with less resistance. In addition, as reported by participants in paper 4, when stakeholders had opportunities to meet one another as part of the overall participatory process (e.g. networking events; training; project working groups), they were able to share their interests, experiences and program and content knowledge.
The researcher also identified that engaging in participatory approaches may result in stronger networks of those working on similar health and social programs/goals. As highlighted in the international literature, these connections may be important in terms of implementation of future initiatives, and/or future research, as participants find synergies and possible collaboration opportunities (Preskill and Jones, 2009). As demonstrated in paper 4, if projects are given the mandate, support, knowledge, time and resources to develop and engage in participatory approaches, whilst not without its challenges, it is possible to implement this way of working. Without ring-fenced time and resources, stakeholders whose professional background and organisational culture is developed around tasks, indicators and outcomes (Classen and Kilbridge, 2002) may find participatory approaches particularly challenging and find it hard to justify continuous involvement with no apparent value for the investment of time and effort.

In paper 3 the researcher, and co authors, are also quite critical of current practice, wherein the majority of methodologies employed across the papers were found to be standard health services research methods (e.g. focus groups, surveys, interviews) as opposed to more participatory approaches to data generation and analysis that are designed to share power and control with individuals and communities (McMenamin, Tierney and MacFarlane, forthcoming). Similarly, Riley, MacDonald et al. (2008) amongst others (Jagosh, Pluye et al., 2011) also comment on the failures of community health intervention programs to either describe or take into account community involvement in the design stages of an intervention.
Unless service users have contributed to the research design, the researcher and co-authors found that these methods by themselves (i.e. surveys, focus groups, interviews) do not facilitate meaningful involvement. This distinction is critical if further repeated disappointments with research involvement and subsequent research fatigue among communities and community representatives are to be avoided (Preskill and Jones, 2009, Brett, Staniszewska et al., 2010).

6.1.5 Developing an understanding of impact and outcome

As highlighted in Chapter 1 and above, the lack of conceptual thinking in terms of community participation in primary healthcare has implications not only in terms of coherence, and collective action, but also in terms of developing an understanding of impact and outcomes.

For the most part it would appear that researchers tend to report the benefits of this way of working, albeit often very briefly, and limit the reporting of negative outcomes. In the CIS review (paper 3) for example it is noted that very few papers explored the problems or challenges of participation. This insufficient reporting subsequently prevents the systematic study of processes contributing to health outcomes across studies and in turn the development and implementation of evidence based guidelines (Riley, MacDonald et al., 2008).

In paper 4 it is also evident that whilst a lot of the projects were using participatory approaches (i.e. working in partnership, engaging in community development forums, engaging in joint training etc.) and positive appraisals and outcomes were reported by the research participants; the connection between the two was not always clearly
described and quantified. This finding which resonates with that of the international literature (Preston, Waugh et al., 2010, Brett, Staniszewska et al., 2010, Riley MacDonald et al., 2008). For some project participants this participatory way of working was considered to be a process or a journey *per se*, as opposed to a specifically defined event. Hence, it is none too surprising that they considered it somewhat difficult to determine at this stage of their journey whether or not they considered their projects successful in terms of health impact and outcomes.

In many ways the state of the evidence base as to the impact and outcomes of community participation in primary healthcare (papers 1, 3 & 4) is reflective of its developing nature, in an area where little guidance on reporting impact and outcome has existed, and no agreed robust ways of capturing or measuring impact have been utilised beyond short descriptions (Brett, Staniszewska et al., 2010). However as Riley et al. (2008) noted more emphasis on reporting implementation process in both successful and unsuccessful interventions will improve capacity to deliver effective healthcare.

6.2 Identifying Ideal Conditions for Implementation and Recommendations of User Involvement in Primary Healthcare

From the body of work presented it is possible to formulate ideal conditions for implementation of community participation in primary healthcare and recommendations to achieve those ideals. These are currently being prepared as a Framework for Community Participation in Primary Healthcare Document (see MacFarlane, Tierney and McEvoy 2014), with a summary presented below in Table 6.1.
This Framework for Community Participation in Primary Healthcare is designed for use by all stakeholders who are involved in community participation in primary healthcare. The researcher and co-authors focus on the network of stakeholders that could or should work together on a project which may be focused on a one-off event such as a community health fair day or a longer process such as supporting a community garden, drug and alcohol awareness programmes, stress management programmes or community representatives to work with PCTs.

The Framework for Community Participation in Primary Healthcare is underpinned by an awareness that not all stakeholders have the same power as each other and that it is too easy, and all too common, to involve community members in a tokenistic rather than a meaningful way (paper 3). Therefore, the Framework for Community Participation in Primary Healthcare includes a series of NPT informed interactive exercises that are designed to stimulate thinking among and across all stakeholders about the influences on community participation and to encourage stakeholders to share their knowledge and expertise with each other and to learn from each other.

The development of the Framework is a critical step because it is indicative of the researcher’s tacit knowledge of the importance of translating an academic piece of work, as conveyed through papers 1-4, into an accessible usable guidance document for all stakeholders who are involved in the work of community participation in primary healthcare.

It is acknowledged that this Framework for Community Participation in Primary
Healthcare was developed in a particular context (i.e. based on findings from two studies which explored community participation in state funded projects within the context of the Joint Initiative). However the recommendations outlined in this Framework Document, because they are based on NPT, have a transferability and relevance across a variety of contexts for many activities and projects which have involvement in primary healthcare as their core objective. If utilised the researcher has every confidence that the Framework Document will have strong potential to impact in a very significant way on the future approach to involvement in health care services.

Table 6.1  Ideal Conditions for Implementation and Recommendations of User Involvement in Primary Healthcare (Adapted from the Framework for Community Participation in Primary Healthcare (see MacFarlane, Tierney and McEvoy 2014)).

<table>
<thead>
<tr>
<th>Ideal</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense making</td>
<td>All stakeholders clarify their own understanding of community participation in primary healthcare and, through dialogue with each other, arrive at a shared understanding of community participation in primary healthcare with other stakeholders at the start of a community participation project. Stakeholders’ understanding of community participation can change over time based on their experiences so it is valuable to return to this point occasionally as a group to ensure that there is still a shared understanding.</td>
</tr>
<tr>
<td>Engagement</td>
<td>Stakeholders work together to clarify who needs to be involved and agree to work together to drive the implementation of community participation in primary healthcare forward</td>
</tr>
<tr>
<td>Enactment</td>
<td>Stakeholders have appropriate resources, skills and training, trust and confidence in each other’s work and the ability to perform all tasks</td>
</tr>
</tbody>
</table>
in primary healthcare activities and processes take place involved in order to make an activity or process take place. Community participation in primary healthcare relies on resources. It cannot and should not rely on the good will of, or ad hoc arrangements between, HSE or community personnel.

<table>
<thead>
<tr>
<th>Appraisal</th>
<th>Stakeholders use formal and informal methods to learn about what is working well and what can be modified to maximise the positive impacts of community participation in primary healthcare. People working in community and healthcare settings are often tired of evaluations. However, understanding the impact of community participation in primary healthcare is really crucial because knowing about impact means that stakeholders can:</th>
</tr>
</thead>
<tbody>
<tr>
<td>all stakeholders have clear information to determine the impacts of community participation in primary healthcare</td>
<td>• See whether their efforts are worthwhile • Make informed decisions about their involvement in this work • Develop appropriate mechanisms to demonstrate outcomes from community participation in primary healthcare.</td>
</tr>
</tbody>
</table>

6.3 Methodological Critique

When studying one's own organisation or workplace, Creswell (2007) recommends the use of multiple strategies to enhance the quality and rigour of the work. With this in mind the following accepted strategies were applied:

- Reflexivity to enhance positionality;
- A systematic approach to literature reviews;
- Quality of coding process;
- Using variety of data generation methods resulting in ‘rich thick’ description.

6.3.1 Reflexivity to enhance positionality

Framing the research question; forming the research proposal by engaging with various stakeholders and working alongside an experienced principle investigator (PI) challenged the researcher to critically reflect on the issue of positionality and on ‘what is relevant and important about the researcher and her contribution to the research which might impact the research and consequent findings.
As mentioned in Chapter 1 the roles played by the researcher prior to this study brought with them certain strengths and challenges, and equally reflect the shifting nature of the researchers ‘position’ (Herr and Anderson, 2005). The researcher has taken the opportunity to reflect in terms of how she has presented herself throughout the research process. A summary of the strengths and challenges are outlined below.

- **Strengths**

The various roles held by the researcher prior to initiating the research ensured a high level of access to the field of study and the development of a strong rapport with the research participants for the empirical work (paper 4). Subsequently the researcher did not experience the tensions that other researchers speak of when entering a social setting ‘cold’ (Wellin and Fine, 2001 p.325). Whereas researchers ‘who enter the field as strangers or outsiders discover that informants may play games in order to conceal apparently trivial aspects of everyday life’ (Mewett, 1989 p.82). In addition, positioning herself firmly within these relationships that were developed with the research participants helped the researcher to better understand them and hopefully to better represent their views (Chesney, 2000).

The researcher is also of the view that this existing relationship contributed strongly to the research participants willingness to meet with the researcher and to be interviewed in a time where travel was strongly curtailed within the HSE, resources limited and the commitment to community participation perceived to be somewhat clouded at a national level.
The researcher’s previous role as HSE project co-ordinator of the Joint Initiative also meant that when initiating this study the researcher shared a ‘stock of knowledge’ with the participants. According to Ashworth ‘where the members share in a stock of knowledge, communication is easy and participation can occur. Where they do not, communication and participation are flawed’ (1995 p.374). At the same time, the researcher was ever mindful of documenting the specifics of her experiences about this stock of knowledge as empirical data. Therefore, the researcher took care to encourage participants to explicate their meanings and experiences during interviews even when both the researcher and participant knew that the researcher already had some of that knowledge. On these occasions, the researcher simply asked the participants to think of the researcher as someone with absolutely no prior knowledge and therefore to describe their journey in as much detail as possible.

- **Challenges**

Given the time spent as project co-ordinator prior to this study, some of the relationships with the participants had developed into friendships. Hence the researcher had to be ever mindful to what extent the exchanges within the context of that friendship becomes data. However, similar to Savage (1995), the researcher was determined to accept information as data from the participants only when directly related to the study, but not that provided during social occasions away from the office or at networking events outside of the case study context. Any arising tensions because of this were discussed and debated during data analysis clinics.

Initially, the researcher had some concerns that the research participants might still perceive the researcher to hold a certain degree of influence at a national level which
may have been held during the time of initiating and co-ordinating the Joint Initiative. However, with rapid changes in the ranks of the HSE and within voluntary organisations, this degree of influence as it may have been had somewhat diminished over time. However it transpired that the fifteen months between the end of the Joint Initiative project in 2010 and commencing this study provided a sufficient ‘cooling off’ period, as contact during this time was minimal with the majority of participants.

6.3.2 A systematic approach to literature reviews

Paper 1 is a research development discussion paper and is not guided by a specific review methodology per se. However, the paper has been peer reviewed and reviewers were in agreement with the selection and discussion of the literature presented. In developing this paper the researcher was mindful of the case study evaluation criteria as outlined by Creswell (2007) outlining the need for a clear identification and description of the case in the study. Hence this paper ensured:

- Familiarity with key literature and background theory to inform the researchers thinking, as well as evidence from other sources such as expert advice;
- A strong descriptive account of the policy context in which the study was embedded;
- Critical thinking about the topic of community participation in light of the existing literature and evidence about implementation research;
- The rationale for the proposed research was clearly argued and key points outlined.

The researcher’s skills for systematic critical analysis of literature were developed during work for papers 2 and 3. One review method was a systematic qualitative
review (paper 2) and the other a critical interpretive synthesis (CIS) (paper 3).

Reviews of research are a better basis for informing policy than a single study or expert opinion (Sheldon, 2005).

Paper 2 is the first qualitative review of NPT in use, and contributes to a body of knowledge about how theory may benefit implementation research. According to Mays and Pope (2000) one of the main criteria for judging the quality of qualitative research is the researcher’s efforts to make explicit the theoretical framework used. This review contributed substantially to the researchers efforts in this regard.

CIS (paper 3) draws on traditional systematic review methodology whilst incorporating a qualitative tradition of enquiry (Flemming, 2009). According to Dixon-Woods, Cavers et al. (2006), using CIS to synthesize a diverse body of evidence enables the generation of theory with strong explanatory power. What distinguishes CIS from meta ethnography and other approaches is its emphasis on theory generation, its rejection of a ‘stage’ approach to review work, and its promotion of a more flexible, iterative, dynamic, critical and reflexive approach to synthesis (Dixon-Woods, Cavers et al. 2006). Albeit on this particular occasion, whilst the researcher and co-authors were not seeking to generate new theory *per se* because of our interest in using NPT as a conceptual framework to analyse findings, there was an interest in applying a dynamic, critical and reflexive approach to synthesis.

Using a quality checklist developed by Hawker, Payne et al. (2002), all papers included in both reviews were quality appraised by members of the research team (2
within the NPT team; and 3 in the CIS team). For randomised controlled trials (paper 3) this checklist was used in combination with that developed by Jadad and Moore (1996). All papers appraised were considered to be of high quality.

In paper 2, the full text articles that met the inclusion criteria were also appraised utilising the PICO criteria as per the publishing Journals requirements. The term PICO (patient, intervention, control and outcome) is frequently used in evidence based practice literature to describe the structure a clinical question requires (Mayer, 2004). Due to the qualitative nature of the literature being reviewed, PICO as a search strategy did not fit neatly with our research questions which was challenging. However, the PICO Table was adapted to include the following criteria: participants, study design and collection approach, interventions, analysis, aims/ discussion, and outcomes. The final list of articles was also circulated to a number of experts in the field of NPT for review and no additional papers were noted.

6.3.3 Coding quality process

Different approaches to coding were used for different aspects of the research thus extending the researcher’s skill-set for qualitative coding. In paper 2 given the researcher and co-authors interest in identifying a priori themes (i.e. the four NPT constructs), only data that were explicitly connected to NPT by the authors of the identified papers were coded. To ensure consistency during the data abstraction and framework analysis phase of work, one-fifth of the articles were double-coded independently. Coding agreement was close to 100%.
In papers 3&4 data analysis was carried out using a two stage analysis approach. The first stage of coding was carried out via an inductive method (Thomas, 2006) using the constant comparative technique to generate themes in the raw data.

As recommended with all qualitative research (Silverman, 2013), the research team worked in a group, comparing coding, discussing thoughts, refining (again and again) the coding frame (see appendix 9 for schedule of data analysis clinics). Analysis reported in paper 4, for example, was the product of several data analysis clinics. There were three specific data analysis clinics organised to develop inductive code descriptors and coding of data were interrogated by all of the authors. The researcher and co-authors independently coded three anonymised interview transcripts using the emergent coding descriptors for the inductive themes. Utilising NVivo, an inter-rater reliability test on all three interviews was carried out and an average 40% agreement in the coding was reported. The researcher and co-authors then reviewed the relevant three transcripts in more detail and discussed where the coding of the data had differed. On the basis of these discussions, the code descriptors were once again refined and all coded data were again reviewed by the researcher over a five day period (21st-24th and 26th Jan 2013) to ensure that they were true to the coding descriptors as discussed and agreed by the co-authors research team.

The second stage of deductive coding began thereafter (Feb 2013), with the coded data being mapped onto the four constructs of NPT. By relating the findings to the NPT constructs, the researcher was able to provide another layer to the organisation of emergent findings. The constructs provided sensitising concepts that could lead to a better understanding of the findings of this study as well as guide additional
recommendations on how to conduct implementation projects in primary healthcare. Throughout this process the researcher and the lead researcher on the FUSION project, who was engaged in a similar NPT coding process, swopped samples of their coding with recorded memos as a means of monitoring understanding and the use of NPT in the coding process. This was considered crucial by both researchers given the volume of data being analysed and the potential threat of engaging in mindless coding.

For the CIS reported in Paper 3 we conducted data analysis clinics with stakeholders to enhance the multiperspectival element of the analysis and discuss emerging findings. These were held with HSE personnel, academics, service users and community organisation representatives. Bringing a range of stakeholders to the table however was not without its challenges both logistically and in terms of trying to ensure that the selection of data presented was reflective of the perspectives, experiences and insights of the stakeholders at the table. There were however considerable benefits including their extensive knowledge of the Irish context and ability to critically comment on the emerging sample of papers. For example, following one of the early data analysis clinics the research team acknowledged the need to enhance the sampling for the CIS by including papers from the Irish context to take account of the cultural environment. The key objective here was primarily to ensure the relevance of the review for the national context as the work was being conducted in partnership with the HSE but, also, to consider the way in which examples from Ireland may inform the field more broadly.
Focusing on the use of NPT in the analyses, the use of NPT in both review processes (papers 2 & 3) provided the researcher with a firm rationale and confidence in utilising NPT as a framework for both data collection and analysis during the fieldwork phase of the research (paper 4), whilst also bringing to light the cautionary notes of other authors experiences in that the “application of the NPT constructs was problematic due to the aforementioned overlap and difficulty of discerning the differences between the constructs”. The researcher gave particular consideration to these words of caution, as is highlighted in the study’s overarching methodological issues.

In practice, when NPT was used in the analysis of data across papers 3 & 4 the experience was at times considered all consuming and quite intensive, particularly given the time and attention also given to the prior inductive thematic analysis. However, similar to MacFarlane and O’Reilly-de Brun (2011), engaging in such a two stage process benefitted the researcher in terms of enhanced critical thinking and understanding, and subsequently the data proved more insightful and advanced.

In thoroughly exploring the data, and questioning the data as it applied to the constructs and subcomponents of NPT, there was, as outlined above, a greater sense of veracity in terms of the overall data analysis process. For example in paper 4, data about ‘communication and information’ when reviewed through the lens of NPT became nuanced under three distinct NPT constructs:

1. Participants commented on issues around communicating what this way of working is about and the confusion that is particularly evident amongst HSE
stakeholders (relevant to coherence); which if not addressed first and foremost has potential negative consequences in terms of collective action.

2. There was also the question of who is communicating the message of the value and importance of this way or working (relevant to cognitive participation). The ad hoc nature of information being communicated from senior management to front line staff was also considered to be a significant barrier to enrolment and engagement.

3. Communication and information were considered key when implementing community participation in primary healthcare (relevant to collective action). Ensuring that all stakeholders were knowledgeable as to who was who within both the HSE and the local community was identified as an important goal and led to the development of various information based activities. For some of the project groups this resulted in the organisation of information nights in partnership with a key local community organisation, for others it was through the development of an information directory of services, and/or community health fair days.

The constructs and subcomponents offered by NPT were applicable to the vast majority of the data analysed in the papers (2, 3 & 4). In paper 4, the issue of non-coding, as reported in some of the NPT papers reviewed (paper 2), was less of an issue, it was more the issue of ‘double coding’ that warranted further discussion amongst the research team. For example attached to the following quote is an annotation made by the researcher as to her justification for double coding:

“One of the biggest issues for us was staff feeling that it wasn’t their day job to engage in the Joint Initiative with the community for example a carers initiative
or a walking group or like OTs that would be their bread and butter or even newsletters you know information out to the public about the PCTs you know the community reps are big into all of that stuff because they are all big into doing things all the time but our clinicians are saying well my job is to see people you know my job is to so at the moment they are negotiating, J and the facilitators have been having meetings with heads of services about you know getting heads of services agreements that this is part of their work and creating that space for clinicians that they feel ok doing it so that’s going on at the moment”

**Research Authors annotation for NPT rationale:** I could be tempted to code this as collective action, however given our conversations on 20032013 and distinguishing between ‘doing the doing’ and what needs to be done prior to doing. Hence in order to make CP and PCT happen this HSE participant & Project lead is highlighting issues in relation to low coherence/communal specification (i.e. it wasn't their day job to engage in the JI/not on the same page). It also speaks to legitimation in terms "of creating a space for clinicians that they feel ok doing it". Double coded.

Through these three phases of the research study (i.e. NPT review *(paper 2)*, CIS review *(paper 3)* and fieldwork data collection and analysis *(paper 4)*) the researcher has shown that using theory in implementation research is a positive thing; enhancing “the interpretation of data constituting thick description” (Geertz, 1973) and adding “conceptual density to the analysis” (Strauss and Corbin, 1998). As highlighted by Creswell (2007), using a theoretical framework (such as NPT) also ensures that the case study findings are analytically generalisable. Therefore given that the study has shown NPT to be a useful analytical tool, as presented in *paper 2, 3 & 4*, other researchers can take NPT and study other forms of involvement in healthcare thus helping to bridge the evidence to practice gap.

6.3.4 Using a variety of data generation methods

Consistent with a case study approach (Yin, 2009), a combination of data methods were employed to generate the empirical data (i.e. documentary analysis, semi-
structured interviews and focus groups (paper 4); thus ensuring a broader perspective on the overall issue of community participation in primary healthcare.

Observation, another data collection method common to the case study, was:

‘discounted on the grounds that the phenomenon in question would be difficult to define operationally and sufficiently inclusively for the purposes of an observation schedule...Further the inferences made from observed behaviour may have subjectivity bias in an area given to different interpretations’ (Bergen and While, 2000 p.932).

Interviews on the other hand, allowed the participants to speak within his/her own conceptualisation of the phenomenon, and to make this explicit (Bergen and While 2000).

Simons (2009) defines a document as anything written or produced about the context or the site. This can include documents that formally represent the organisation (such as prospectuses, annual reports, audit reports, rules and regulations) and also informal documents (such as newspapers, bulletins, memos). All of these may contain clues as to how the organisation perceives itself or how the programme has evolved (Tellis, 1997; Simons, 2009; McDonnell, Jones et al., 2000). Furthermore, policy documents may be necessary to help understand the background and rationale for certain practices (Simons, 2009).

The careful compilation and review of relevant key documents using NPT as an analytical framework was carried out in order to (i) detail the policy context in which the national strategy for service user involvement (Department of Health and Children and HSE, 2008) was developed and is currently being implemented in Irish health services; (ii) to help uncover issues that may be useful to explore in the case and (iii)
to provide a context for the interpretation of interview data (Attree, Morriss et al., 2010, Simons, 2009). Whilst no document can be regarded as a completely accurate representation of the phenomenon of interest, within limitations and taking the social context and process of construction into account they can be valuable sources of data about society and the interrelation of events (Bowling, 2002).

The researcher considered triangulation not only in terms of data generation methods, but also in terms of ensuring a multi-stakeholder purposeful sample during the fieldwork phase of the study (i.e. HSE service providers working in PCTs; HSE service planners and policy makers; and community representatives (see Table 1: paper 4). This multi stakeholder approach was considered key given that one of NPT’s distinctive features is the attention to all stakeholders’ involvement in implementation processes.

Utilising a variety of data generation methods resulted in rich thick description (papers 1 & 4), which according to Creswell (2007) enables readers to transfer information to other settings. The digital recording and transcription of the interviews were also critical to the development of this rich description indicating “the trivial but often crucial pauses and overlaps” (ibid).

6.4 Implications and Recommendations Emerging from the Study

Implications and recommendations for research, primary care and healthcare policy are based on the findings emerging from this study:

207
6.4.1 Implications for further research

In providing a theoretically comprehensive analysis of implementation issues this research has contributed to an improved understanding of the levers (e.g. participatory processes; resources; national mandates) and barriers (e.g. contested terminology; diminished resources) to the normalisation of community participation in primary healthcare.

This is an important addition to the field which is characterised by descriptive empirical reports about pilot studies and initiatives which do not provide a comprehensive analysis of implementation issues. Further research is required to monitor and support community and health researchers and practitioners working together to understand and recognise the levers and barriers to community participation in primary healthcare, and to engage more fully with each other in the community participation in primary care process to maximise levers and minimise barriers as contained in the Framework for Community Participation in Primary Healthcare (MacFarlane, Tierney and McEvoy 2014).

6.4.2 Implications for primary care

Whilst the definition of ‘Primary Care’ in Ireland, as outlined in Primary Care: A New Direction (Department of Health and Children, 2001a), was broader than the term ‘Primary Medical Care’, it was still not as inclusive as the WHO ‘Primary Health Care’ definition; a conceptualisation based on community involvement and cannot operate without it (WHO, 1975). Primary Health Care incorporates an understanding of the social determinants of health. As such, in this study of the Joint
Initiative the community were very much involved in Primary Health Care using a community development approach.

In order to practice in a manner that reflects the best available evidence the there is need for senior management to legitimise this focus on primary healthcare and the use of community development approaches as way of working in the HSE. It is necessary to have a commitment in the HSE to the following:

- An agreed strategy for community participation in primary healthcare *vis a vis* the Framework for Community Participation in Primary Healthcare developed through this research process (MacFarlane, Tierney & McEvoy 2014);
- Ring fenced funding for community participation in primary healthcare;
- Nominated lead personnel and champions;
- Resources (e.g. time, training, support and guidance);
- The development of participatory processes.

Ring fenced funding is required in each Integrated Social Area for community participation in primary healthcare projects. This funding should be sufficient to ensure that all PCTs have access to a budget to support community participation. This should also include financial support to sustain existing projects as well as those that are starting their work.

Measures should also be put in place to ensure that existing staff from community participation projects can act as ‘champions’, ‘advocates’ or ‘experts’, sharing learning and expertise for new projects and initiatives. This could be supported and
encouraged through the development of excellence awards and publicity, as is currently being demonstrated for patient involvement in the acute sector in Ireland.

Resources for training, technical support, external facilitation and other networking supports are also recommended. Buckley (2002) states that training can only have this positive impact if it is underpinned by agreed strategies, commitment at senior level and a shared responsibility and ownership of the work.

This study suggests that participatory approaches which are core to community development ways of working and advocated to improve implementation are good for inter-stakeholder working on community participation and primary care. This is reflected within several of the activities outlined in the Framework for Community Participation in Primary Healthcare (Tierney, MacFarlane and McEvoy 2014).

6.4.3 Implications for healthcare policy

- Implement a strengthened policy for community participation in primary healthcare meaning *vis a vis* the Framework for Community Participation in Primary Healthcare developed through this research process (MacFarlane, Tierney & McEvoy 2014).
- Develop a renewed strategic policy commitment from the Department of Health and Children to community participation in primary healthcare with strengthened and reorganised Key Results Areas and Performance Indicators in future HSE Service Plans.
6.5 Concluding Statement

The researcher through an extensive review of the literature and empirically generated data proposes that this PhD has:

- Explicated the need for research about implementation of community participation in primary healthcare (paper 1);
- Identified major challenges and weaknesses in the practice of ‘involvement’ in academic primary healthcare (paper 3);
- Generated evidence about the value of NPT as a theoretical framework for implementation studies (paper 2);
- Provided a sophisticated NPT analysis of levers and barriers to the implementation of community participation in primary healthcare in the Irish setting (paper 4), and
- Contributed to the development of generalisable ideals and recommendations for improving the implementation of community participation in primary healthcare which have relevance for Ireland and abroad (paper 4 and Framework for Community Participation in Primary Healthcare).

In a field currently characterised by descriptive empirical reports about pilot studies and initiatives at a particular point in time, and some ‘analysis paralysis’ rather than action to tackle the issue (Nutbeam, 2004); this theoretically informed study is a novel and key contribution to the field of implementation research.
6.6 References


Appendix 1  Rationale for Journal Selection

Careful consideration was given to the type of Journal that would best resonate with the aims, objectives, content and intended target audience of each of the four research papers. Hence the four Journals selected were based on their attention to implementation research and or the primary healthcare context and user involvement.

The first journal “Primary Health Care Research & Development” was selected given its focus on primary healthcare research and its target audience of researchers, academics and practitioners (i.e. nurses, GPs, health service managers, local groups in community health), thus bridging the gap between the two areas. This Journal and its call for research and development papers in primary healthcare also provided a platform wherein the researcher could build a clear identification and description of the case in the study, (Creswell 2007) and present the overall rationale for building knowledge about the ways in which innovations such as the case outlined can be embeded into ongoing, routine healthcare practice.

The second paper was submitted to Implementation Science with a view to it being an open access online Journal that promotes the uptake of research findings into routine healthcare practice. Since its publication in the Journal the paper has been marked as especially “highly accessed”.

The submission of the CIS review paper (paper 3) to Health Expectations was based on the Journals focus on informed debate about all aspects of public participation in healthcare and health policy, including papers which clarify concepts, develop
theories and critically analyse and evaluate specific policies and practices, which resonated with the overall aim of the CIS paper.

The final paper (Paper 4) was submitted to *Primary Health and Social Care in the Community* with the intention of ensuring that the findings of the fieldwork study would reach an audience not just of academics *per se*, but also practitioners and community stakeholders. Thus bringing the research cycle full circle and bridging the aforementioned evidence to practice gap.
Appendix 2 Memos of Self Reflection (Chapter 1: Section 1.4.1)

Comments and observations in relation to the researchers meeting with a community joint initiative principal applicant:

Morale would definitely seem to be at a low, although the participant has reiterated that I might have just have caught her on a bad day.

What struck the researcher really in this meeting, and other meetings, is the fact that the projects have not continued to network or liaise with each other, in the last fifteen, eighteen months since the end of the Joint Initiative. And yet they are very eager to know what the other projects are doing, asking me whether they are experiencing similar issues or have they cracked the nut in terms of community representation on PCT’s.

In terms of the researchers notes, the participant makes specific reference to her HSE Joint Initiative partner at the time and her commitment to the process of community participation in primary care, and in a sense how lost this participant has felt since her partner moved to a new role within the HSE. And while it is evident that the participant does not want to diminish the role or the work of her new HSE contact, it is clear that it is not the same relationship. And from what the researcher is hearing the Joint Initiative in one sense helped to cement that partnership between the participant and her HSE colleague.
It makes the researcher wonder how important that actually is, that process of partnership working and relationship building. The participant queries how to sustain it (i.e. community participation) and is worried about the sense of raising expectations within the community. And almost selling a story that maybe doesn’t have the same national profile that it once had, but again reflects on very much the changing environment that we’re now working in as opposed to 2008 when the Joint Initiative first commenced.

The participant is also conscious of her own community and that there is also a certain level of attrition, and not only within the PCT. She questions, about really progressing this work and chasing it. She would like to see a tangible end to the work. She questions what value does it really demonstrate in terms of making a difference to the health of the people.

The participant reflected on and talked about the different initiatives that took place within the Joint Initiative. The researcher and participant spoke briefly about maybe a projects based approach might be a way to go if the participant has doubts about the valid process of a community representative being involved in the primary care business teams meetings. She talks about the fact that the PCT only meet for four times a year for forty five minutes and the environment of those meetings doesn’t really reflect a community participation process. She’s very, very honest in saying she just doesn’t know where this is going and in good conscience she states ‘can I continue to be the cheerleader’. It would seem to the researcher that the participant is willing to give her time to it (i.e. community participation in primary healthcare) but questions if there an end to it?
In terms of the eighteen months that the participants went through the Joint Initiative process, she felt that they had gone a long way in terms of developing relationships and that it was a very successful relationship and valued that working together and gaining that commitment. The participant talks about strengthening capacity of the PCT and wonders is her time is better spent elsewhere especially if the PCT is constantly changing and evolving. In the researchers own mind she wonders for participants is there always that reverting back to stage one of building relationships and is that worth it and can we ask or expect people to continuously do that.

The participant does talk a little bit around community people going to the PCT business meetings. She reflects on the process as something that’s very strange. It was meant to be chaired by a HSE chairperson but in reality it is chaired by the GP. She mentioned that she went to this particular meeting as she had made a point of not going to meetings beforehand. She felt it should be a community representative and not her in her role as a community coordinator but on feedback that she was getting from the community representative she decided to go along to one of the meetings alongside the community representative. She had submitted issues to be on the agenda but they weren’t on the agenda and were actually addressed in terms of AOB, which she felt was sending out a very mixed message.
Appendix 3  Copyright Permission

**Paper 1:** Email received from Ms. Linda Nicol, Permissions Manager Oct. 2\textsuperscript{nd} 2014 10.00, granting permission to include the journal article in the researcher’s forthcoming thesis, stating “we just ask that you give full copyright acknowledgement to the original source”.

**Paper 2:** Email received from Implementation Science: 1\textsuperscript{st} Oct 2014 02.55 confirming that “all authors retain copyright of their manuscripts and can therefore use any part of it again as long as the original article is properly cited”.

**Paper 3:** Email received from RightsLink/John Wiley and Sons Transaction: 4\textsuperscript{th} Oct 2014 1e.22: License Number 3481910532690
Appendix 4  PICO Table: A Qualitative Systematic Review of the Literature on Normalization Process Theory in use (Paper 2)


<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Participants</th>
<th>Study Design &amp; Collection Approach</th>
<th>Interventions</th>
<th>Analysis</th>
<th>Aim/Discussion</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atkins, S. Lewin, S. Ringsberg K. and Thorson A.</td>
<td>Provider experiences of the implementation of a new tuberculosis treatment programme: A qualitative study using the normalisation process model.</td>
<td>All nurses (n=6) and adherence counsellors (n=6) working on the programme were asked to participate in interviews. All treatment supporters (approximately 85) were invited through adherence counsellors to participate in focus group discussions (FGDs).</td>
<td>A qualitative approach was used. Interviews and focus group discussions.</td>
<td>Using the NPM as an analytic framework, this study aims to explore staff perceptions of a new TB treatment programme modelled on the ART treatment programme.</td>
<td>Data were analysed initially using qualitative content analysis. The resulting categories were then organised under the constructs of the NPM.</td>
<td>Aims to explore staff perceptions of a new TB treatment programme modelled on the ART treatment programme.</td>
<td>The NPM assisted in categorising the challenges experienced during implementation of the TB Treatment Programme. The results suggest that issues remain that need to be resolved before the programme is implemented more widely. Considerable work is needed in order to embed the TB Treatment Programme in routine clinic practice.</td>
</tr>
<tr>
<td>Blakeman, T., Protheroe, J., Chew-Graham, C., Rogers, A. and Kennedy, A.</td>
<td>Understanding the management of early stage chronic kidney disease in primary care.</td>
<td>In total, 21 out of the 28 health professionals (75%) invited agreed to participate. The final sample was spread across 11 practices and comprised 11 GPs (six male, five female; median age 45 years</td>
<td>A qualitative study using semi structured interviews.</td>
<td>Using NPT as a framework, the study constructs an understanding of how early-stage CKD is encountered and dealt with in general practice.</td>
<td>NPT was used to sensitise the analysis to the work being carried out in primary care. Initial coding of the data was undertaken</td>
<td>To explore processes underpinning the implementation of CKD management in primary care.</td>
<td>The study builds on previous findings concerning the disclosure of CKD in primary care. This study sought to understand the work undertaken by GPs and practice nurses in implementing a relatively new phenomenon into general practice. The findings highlight</td>
</tr>
</tbody>
</table>
and 10 nurses (all female; median age 47.5 years [range 39–60 years]). Eighteen out of the 21 participants were directly involved in the CLAHRC CKD collaborative independently by three of the authors and categories were identified by comparing these codes. Using the coding framework to help operationalise the theory, these constructs were applied to the sets of practices outlined above, concerning the management of CKD in primary care. The coding framework assisted comparative analysis of data from each individual account, matched interviews, and across the dataset out in primary care.

Tensions experienced by professionals surrounding the management of individuals with early-stage CKD. These tensions need to be considered when developing interventions to improve the delivery of care for people with mild and moderately ‘low kidney function’, vascular conditions, or multimorbidity.

NPT provided a framework to explore in greater detail the interactional work that occurs in clinical encounters and within an organisation.

| Bouamrane, M, Osbourne, J, Mair, F. | Understanding the implementation and integration of | Case study 1: 68 interviews with: consultant dermatologists (19), Review of NPT and supporting case studies. | Case study 1: Qualitative approach | Review of NPT and supporting case studies: Case study 1: The authors review the application of NPT to three | The authors begin by describing issues with the continued sustainability of existing models of care – tensions experienced by professionals surrounding the management of individuals with early-stage CKD. These tensions need to be considered when developing interventions to improve the delivery of care for people with mild and moderately ‘low kidney function’, vascular conditions, or multimorbidity. NPT provided a framework to explore in greater detail the interactional work that occurs in clinical encounters and within an organisation. | Case studies that have normalisation of e-health services were successful when certain facilitating factors as per |
remote and telehealth services…an overview of NPT.

| Ehrlich, C. Kendall, E., Winsome S.J. | How does care coordination provided by registered nurses ‘fit’ within the organisational processes and professional relationships in the general practice context? | Eleven general practices, who were members of a single division of general practice in South-East Queensland, Australia, were invited to participate. Six general practices met the selection criteria (that is, an experienced RN was involved, general practice managers supported the | A qualitative interpretive research design, which used focus group interviews with nurses using a semi-structured interview protocol. To explore how registered nurse (RN)-provided care coordination could move beyond implementation to become embedded and integrated within the organisational processes and professional | Interpretive analysis of interview data was conducted using NPT, particularly NPM, to structure data analysis and interpretation. The aim of this study was to develop understanding about how a registered nurse-provided care coordination model can ‘fit’ within organisational processes and professional relationships in general practice. | Within teams of health care providers, interventions need to be workable and able to be integrated if they are to ‘fit’ within the context and become part of routine practice. Interventions such as RN-provided care coordination, which was piloted in this study, are more likely to become part of routine practice if they: (a) confer an interactional advantage, (b) equal or improve relational integration through |
intervention, general practice management systems were organised and maintained, RNs had access to necessary resources, and the general practice could demonstrate capacity to meet the demands of the project. One general practice withdrew prior to commencement of the intervention. A total of nine RNs from five general practices participated in the study. Six participants were general practice RNs (one general practice was represented by two RNs), and three were RN GPLOs who provided pivotal support to general practice RNs.

relationships of the general practice context.

accountability and confidence within networks, (c) improve skill-set workability by calibrating to an agreed skill-set at a recognizable location in the division of labour, and (d) support contextual integration by conferring an advantage on an organisation in flexibly executing and realizing work (May, 2006).
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elwyn, G., Legare, F. et al. [49]</td>
<td>Ardous implementation: Does the Normalisation Process Model explain why it's so difficult to embed decision support technologies for patients in routine clinical practice?</td>
<td>Physicians, patients and managers.</td>
<td>The NPM was used as the basis of conceptual analysis of the outcomes of previous primary research and reviews. Using a virtual working environment, the authors applied the model and its main concepts to examine: the 'workability' of DSTs in professional-patient interactions; how DSTs affect knowledge relations between their users; how DSTs impact on users' skills and performance; and the impact of DSTs on the allocation of organizational resources. Through a conceptual analysis of the outcomes of previous primary research and reviews, authors aimed to decide whether the NPM was of value in understanding the difficulties encountered in getting DSTs embedded into practice. NPM was used as the basis of conceptual analysis To test the conceptual adequacy of the model in understanding the difficulties encountered in getting DSTs embedded into practice. One of the main insights gained by applying the NPM was the need to consider its propositions from the perspective of different actors, particularly when DSTs is an inherent component of interactions between the actors.</td>
</tr>
<tr>
<td>Finch, T., Mair, F., O Donnell, C., Murray, E. and May, C.</td>
<td>From theory to 'measurement' in complex interventions: Methodological lessons from the development of an e-health normalisation instrument</td>
<td><strong>Phase 1:</strong> A total of 63 participants completed the expert survey out of 252 invitations (24% response) that were presumed to be received (subtracting invitations returned as 'undeliverable'). <strong>Research background:</strong> Medical 32; Social science 24; Informatics 21; The instrument was pre-tested in two health care settings in which e-health (electronic facilitation of healthcare decision-making and practice) was used by health care professionals.</td>
<td>A 30-item instrument (Technology Adoption Readiness Scale (TARS)) for measuring normalisation processes in the context of e-health service interventions was developed. This paper aimed to (1) describe the process and outcome of a project to develop a theory-based instrument for measuring implementation processes relating to e-health interventions; and (2) identify key issues and methodological challenges for advancing work in this field. The practical output of this study was the development of the TARS instrument, which was intended to enable researchers and practitioners to quantify a range of processes proposed by the NPT to contribute to the successful normalisation of e-health, either as a ‘diagnostic’ tool or for evaluation purposes.</td>
</tr>
</tbody>
</table>
| Nursing 11; Economics 2; Health Services Research 5; Non-specific 6. **Gender:** Male 59 and Female 41. **Location of residence:** USA 37; UK 27; Canada 13; Europe (excluding Scandinavia) 10; Australia/New Zealand 8; Scandinavia 6. **Phase 2:** At Site 1, 46/243 participants completed the survey (19% response rate). 100% female. **At Site 2,** 231/1351 (17% response rate) completed the survey sufficiently for inclusion in the analysis. **Gender:** 86% female & 14% male. | on the basis on Normalization Process Theory (NPT). NPT focuses on how new practices become routinely embedded within social contexts. | Forster, D., Newton, M., McLachlan, H., Willis, K. | Exploring implementation and sustainability of models of care: can theory help? | **Case study 1:** One thousand women were recruited to the team midwifery trial between February 1996 and November 1997. Eight midwives were recruited from volunteers among the existing midwifery staff in the hospital, and team midwifery | The authors use two case studies where new models of maternity care were implemented and evaluated via RCTs to discuss how (or whether) the use of theory might inform implementation and sustainability strategies | The authors demonstrate how the NPM was applied in planning of the evaluation phases of the RCT as a means of exploring the implementation of the caseload model of care. The authors argue that a theoretical understanding of issues related to implementation and sustainability is crucial. | The Normalisation Process Model has provided a framework within the COSMOS trial to examine some of these issues prospectively, both through the evaluation research design (relating to the implementation of the model of care into practice) and analysis of findings. Organisations may use the evidence from the trial findings to guide implementation strategies.
Care was provided following the same clinical protocols and guidelines as standard care. **Case study 2:** Recruitment of 2314 women to the trial took place from September 2007 to June 2010, with the last birth in December 2010 (primary outcomes reported elsewhere). Midwives already employed at the Women’s were offered first preference to work in the caseload model, then external advertising was used to fill further vacancies (to a total of approximately 12 full time equivalent positions).

<p>| Franx, G. Oud, M., de Lange, J. Wensing, M. and Gro, R. | Implementing a stepped-care approach in primary care: results of a qualitative study | Participants for the study were selected from thirteen multidisciplinary primary care teams participating in the depression Quality Improvement Collaborative (QIC). These thirteen QIC teams had been | An intervention study using a controlled before and after design was performed. Part of the study was a process evaluation utilizing a semi structured group interviews, to provide insight into the perceptions of the participating clinicians | Since 2004, ‘stepped-care models’ have been adopted in several international evidence-based clinical guidelines to guide clinicians in the treatment of depression. | Analysis was supported by NPT, with reference to Gnu’s NPT framework on depression. | The qualitative process analysis presented here aims to add to the quantitative findings as it documents the way in which the intervention was received and implemented by clinicians, and identifies the factors associated with reception and implementation. | By relating the findings to the NPT constructs, the authors were able to provide another layer to the findings. The constructs provide the authors with sensitizing concepts that could lead to a better understanding of the findings of this process evaluation, as well as guide additional recommendations on how to conduct implementation strategies, ensuring that constructs that have been identified as important for the model’s sustainability are encompassed in implementation strategies. In addition, future trials of models of care may benefit from using the NPT not only to understand implementation, but to guide trial design and development of the intervention. |
| recruited throughout the country by a national QIC project team on the basis of the following criteria: the team had a multidisciplinary structure, there was sufficient motivation and time for all members to participate, and a local team coordinator was available. Although team members sometimes had worked together in another context, most of them had not worked together as a depression team prior to the QIC. At the start of the QIC, all teams were asked to participate in the intervention study and the process evaluation, alongside their implementation work. Five teams did not wish to spend extra time on research activities and declined. Eight teams consented, consisting of PCPs, primary care | on the implementation of stepped care for depression into their daily routines. | organisation of depression care. To enhance the adoption of this new treatment approach, a Quality Improvement Collaborative (QIC) was initiated in the Netherlands. Alongside the QIC, an intervention study using a controlled before-and-after design was performed. Part of the study was a process evaluation, utilizing semi-structured group interviews, to provide insight into the perceptions of the participating clinicians on the implementation of stepped care for depression into their daily routines. | projects in depression care. |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Participants</th>
<th>Methodology</th>
<th>Data analysis</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Furler, J., Spitzer, O., Young, D. and Best, J.</td>
<td>Insulin in general practice: Barriers and enablers for timely initiation.</td>
<td>Ten general practitioners, four diabetes nurse educators and 12 patients were interviewed.</td>
<td>A qualitative study using semi-structured, in-depth interviews.</td>
<td>Insulin in general practice drew on the NPM in developing initial coding categories.</td>
<td>This study explores barriers and enablers to insulin initiation in general practice.</td>
</tr>
<tr>
<td>Gallacher, K., May, C. et al.</td>
<td>Understanding Patient's Experiences of Treatment Burden in Chronic Heart Failure Using Normalization Process Theory.</td>
<td>Participants were 47 patients with chronic heart failure managed in primary care in the United Kingdom who had participated in an earlier qualitative study about living with this condition.</td>
<td>Secondary analysis of qualitative interview data.</td>
<td>To assess the burden associated with treatment among patients living with chronic heart failure and to determine whether NPT is a useful framework to help describe the components of treatment burden in these patients.</td>
<td>To use NPT to identify, describe, and understand the components of treatment burden experienced by patients with chronic heart failure.</td>
</tr>
</tbody>
</table>

Normalisation process theory provides a framework for analysis of the findings through focusing on how the ‘work’ of diabetes care is understood, given meaning, undertaken and supported.
What work has to be done to implement collaborative care for depression? Process evaluation of a trial utilizing the NPM.

A convenience sample of stakeholders was recruited from primary care organizations (PCOs) in the north of the UK. Primary Care Physicians (PCPs) and practice nurses were recruited from practices in PCOs that had agreed to participate in the trial. Other participants were recruited from teams and specialist care providers that provided primary and secondary mental healthcare to the PCOs. Patients were recruited by four participating PCPs who each mailed a letter to 20 of their patients who were receiving treatment for depression in primary care. No participants had had any experience of this method of organizing care and none been involved in the trial design. The authors interviewed 49 participants. All 38 professionals who were asked to participate in

Application of the NPM to qualitative data collected in both focus groups and one to one interviews before and after an exploratory randomised controlled trial of a collaborative model of care for depression.

This study utilises the Normalisation Process Model (NPM) to inform the process of implementation of collaborative care in both a future full-scale trial, and the wider health economy.

Framework analysis, based on the NPM.

Aim to apply the NPM to the process data in order to consider what can be learnt about the additional or ‘hidden’ work (i.e., that which is not immediately apparent at conception of the project or not usually included in publication of results of a trial) that needs to be done to make a collaborative care intervention for depression in primary care both workable and integrated into routine practice in both our forthcoming full-scale trial of collaborative care for depression in the UK and the wider healthcare settings following the trial. In initiating this task, the authors were particularly interested in the value of application of the NPM to process data in order to aid in the further development and evaluation of this intervention in the UK.

The NPM provided a neat and conceptually rich framework to guide analysis and our thinking about a range of key issues in the implementation of collaborative care for depression in both research trials and routine practice. It provided a novel way of evaluating and interpreting process data that added value to the analysis. Using the model, it was possible to observe that certain predictions about work that would need to be done that could be made from analysis of the pre-trial data relating to the four different factors of the NPM were borne out in the post-trial data.
the study agreed to do so: 12 PCPs, four psychiatrists, four clinical psychologists, four practice nurses and 14 mental health workers (seven mental health nurses, two counsellors, three graduate mental health workers, one social worker, and one unqualified support worker). Most interviews were conducted individually apart from two focus groups with 11 of the 14 mental health staff. From the 80 letters posted to patients, 17 consented to participate of which 11 were interviewed, five subsequently declined or could not be contacted, and one became so distressed that the interview was abandoned on ethical grounds and the patient was encouraged to contact the PCP.
| Gask, L. Rogers, A. et al. | **Beyond the limits of clinical governance? The case of mental health in English primary care.** | Interviews with clinical governance leads and managers (12 interviews carried out with 17 informants), audit leads (3 interviews) and mental health leads (11 interviews with 18 informants- one site could not identify a lead) to explore how implementation of clinical governance had progressed. Additionally the authors interviewed informants identified as by PCT informants as 'primary care' leads at the local Mental Health provider trust. For three of the sites, as the Trust was an integrated provider of primary care and mental health, there was no need to conduct a further interview. A further site arranged a single group interview with four representatives from both primary care and mental health. Four interim interviews with | A longitudinal qualitative multiple case-study approach in a purpose sample of 12 PCTs. | To explore the quality of primary care for people with mental health problems through the new institutional processes of 'clinical governance'. | Framework analysis, based on the NPM. | To examine the extent to which clinical governance of mental health care has been normalised within NHS primary care. | The NPM predicts that in order to become normalised, new working practices such as clinical governance activities have to satisfy four (sets of) conditions. The contested nature and status of 'mental health' within primary medical care makes it particularly difficult to change clinical working practices and the ways in which patients and professionals themselves interact, i.e. to satisfy the interactional workability and relational integration, insofar as they apply to clinical governance activities. It also compounds the (more substantial) skill-set and contextual problems and uncertainties faced by those who seek to 'improve the quality of primary mental health care'. The data show a lack of clear conceptualisation about what primary mental health care is or ought to be, under defined roles and wide professional discretion, especially for GPs. They also suggest that clinical governance and the mental health NSF only weakly satisfy the NPM's contextual integration conditions. This is not for want of willingness on senior managers' or clinicians' parts but more due to lack of knowledge |
mental health leads in both PCTs and mental health trusts were carried out at two sites during 2001, selected on the basis of the case study profiles because they might provide contrasting views of the development of primary care. These sites were unchanged from the previous year, however by 2003–4 the PCT mental health leads had changed in all but 3 of the 11 sites for which they could identify a lead person. A total of 41 interviews carried out with 49 informants form the main empirical material for the analysis.

A total of 41 interviews carried out with 49 informants form the main empirical material for the analysis.

Godden, D. and King, G.  
Rational development of telehealth to support primary care respiratory medicine: patient distribution and organisational factors.

Semi-structured interviews (n=20) were conducted with health professionals and managers likely to be involved in implementation of telehealth. These key informants – including GPs, consultants, nurses, and others.

Qualitative interviews with health professionals (n=20) focussing on the potential for telehealth in respiratory medicine were analysed using the NPM.

The potential for telehealth in respiratory medicine.

Analysis was supported by NPM.

The study examined the potential for applying telehealth in a region of the UK by exploring the distribution of patients and examining attitudes to implementation of telehealth.

The main perceived barriers to implementation in the study were in skill set workability – mainly training issues – and contextual integration – mainly about costs. Interestingly, realisation – an element of contextual integration which refers to moving responsibilities between professional groups – was not a prominent concern.
involved in respiratory care – had responsibilities across the region (including urban, rural and remote areas) and they were recruited purposively.

perhaps reflecting the extent to which this is already happening in rural communities as, for example, nurses and paramedics take on roles previously delivered by doctors. However there is evidence that actual implementation of telecare services can face major problems of interactional workability where nurses lack confidence in the technological approach adopted.


Seven eligible primary care organisations were identified. Each had from two up to ten or more GPs working within them plus other professionals (receptionists, practice nurses, dieticians, diabetic nurse educators, psychologists, and social workers). Five organisations were privately owned by principal GPs, one was a corporate owned health centre, and one was a publicly funded community health centre.

Authors used a mixed method, observational approach to gather data about routine depression care in a range of primary care settings via: audit of electronic health records; observation of routine clinical care; and structured, facilitated whole of organisation meetings.

To identify the components of an effective model of depression care. NPT identified as an analytical theory to guide the conceptual framework development.

To identify the components of an effective model of depression care. Work is presented as a conceptual framework to guide how to implement organisational and systems change in mental health care reform in primary care.

Identifies NPT as suitable for the task of providing an analytical theory to develop a conceptual framework to guide the implementation of an effective model and system of depression care.
| James, D.M. | The Applicability of Normalisation Process Theory to Speech and Language Therapy: A review of qualitative research on a speech and language intervention. | There were five papers that presented data on the parents’ or therapists’ views. Three of these papers used semi-structured interviews or focus groups to elicit participants’ views on the intervention. Two of the papers presented data from questionnaires that were used to elicit parental views of speech and language therapy. These studies were included because they explored parental views on direct (traditional) versus indirect (such as the HPP) approaches with children and families. **Girolametto, Tannock and Siegel** (1993); Mothers who had taken part in a HPP N = 32. **Glogowska and Campbell** (2000) Parents who had taken part in a RCT to evaluate traditional SLT intervention in pre-school children N = 16 selected. | Secondary analysis of qualitative interview data. | Speech and Language Therapy. | Framework analysis, informed by NPT. | The primary aim of this study was to test the applicability of the propositions on the role of collaborative work laid out in the NPM and NPT to the context of speech and language therapy so that, if found to be applicable, the NPT could be used to inform the design of new intervention research in the field. | The analysis based on the NPM uncovered interpersonal processes between the practitioners and parents that were likely to have given rise to successful implementation of the intervention. In previous qualitative research on this intervention where the Medical Research Council’s guidance on developing a design for a complex intervention had been used as a framework, the interpersonal work within the intervention had emerged as a barrier to implementation of the intervention. It is suggested that the design of services for children and families needs to extend beyond the consideration of benefits and barriers to embrace the social processes that appear to afford success in embedding innovation in healthcare. |
respondents according to the logic of maximum variation. 

**Glogowska, Campbell, Peters, Roulstone and Enderby** (2001); 
Parents who had taken part in a RCT to evaluate traditional SLT intervention in pre-school children. N = 89. 

**Baxendale, Frankham and Hesketh** (2001); 
Parents who had taken part in a controlled study to compare HPP with traditional clinic-based SLT N = 37 in total. 

**Pennington and Thomson** (2007) SLTs who deliver the HPP in the UK N = 16.

| Author(s) | Delivering the WISE Training Package in Primary Care: Learning from formative evaluation. | Practices with more than two GPs were identified within a Primary Care Trust (PCT). The practices who agreed to take part in the study were asked to select two training dates where all staff (GPs, nurses, practice managers, and clerical and reception staff) | Observation, audio recordings, and face to face semi structured interviews were conducted. | Using the NPM as an analytic framework, this study aims to learn from the formative evaluation of the Whole System Informing Self-management Engagement (WISE) | Framework analysis informed by NPT. | Aimed to refine the patient, practitioner, and patient level components of the WISE approach and translate the principles of WISE into an operational intervention deliverable through NHS training methods. | The formative evaluation approach and attention to normalisation process theory allowed the training team to make adjustments to content and delivery and ensure appropriate staff attended each session. |

Kennedy, A. Chew-Graham, C. et al.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Participants</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>MacFarlane, A. and O’Reilly De Brun, M.</td>
<td>A reflexive account of using a theory-driven conceptual framework in qualitative health research.</td>
<td>18 General practitioners; 4 General practice administrators; 2 Independent interpreters; 2 Service user representatives; 14 Service user representatives; 1 Company manager.</td>
<td>The emphasis for sampling and recruitment was on identifying information-rich cases, participants who were understood to have knowledge and experiences relevant to the phenomenon under investigation (Patton, 1990). The funders of the study had a particular interest in the experiences and views of general practitioners, and the</td>
<td>The authors present a reflective paper on their decisions about whether or not to use the NPM, and describe their actual use of it to inform research questions, sampling, coding, and data analysis.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>approach which encompasses creating, finding, and implementing appropriate self-care support for people with long-term conditions.</td>
<td>A reflexive account of using a theory-driven conceptual framework in qualitative health research.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>NPM was used as the basis of conceptual analysis.</td>
<td>The authors provide a reflexive account of their experience of using a theory-driven conceptual framework, the NPM, in a qualitative evaluation of general practitioners’ uptake of a free, pilot, language interpreting service in the Republic of Ireland.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The added value of the NPM analysis was that the authors’ understanding of individual themes became more insightful and advanced, and the interpretation of themes was enhanced. The NPM offered an organizing principle to “think with our data” in a very specific way; i.e., to think about the layered meanings of individual themes in relation to prespecified macro- and micro-level issues, and the mediating relations between these, and thus to be more alert to the complex processes of implementation and conditions for normalization. In a sense, it provided an element of the researcher analyst role in that it offered an outline of analytic and theoretical categories to advance the descriptive analysis (Gibbs, 2007).</td>
<td></td>
</tr>
</tbody>
</table>
original study remit included general practitioners as the sole participant group. However, the authors encouraged inclusion of a broader group of participants so that experiences and views of implementation and normalization could be examined across stakeholder groups. This was prompted by our experience of using a multiperspectival approach in qualitative research.

| Mair, F., Hiscock, J. and Beaton, S. | Understanding factors that inhibit or promote the utilization of telecare in chronic lung disease. | Patients (n=9) and specialist respiratory nurses (n=11) providing the telecare service in chronic lung disease. | Participant observation of activities involved in the implementation and delivery of the home telecare service. Semi-structured interviews were carried out with patients (n = 9) and nurses (n = 11) participating in a RCT. | A process evaluation of a randomized controlled trial (RCT) of home telecare for the management of acute exacerbations of chronic obstructive pulmonary disease (COPD), using the NPM as an explanatory framework. | A framework approach to data analysis was used. | The telecare service did not provide an interactional advantage for the nurses providing this service and did not fit with the nurses’ views of the most appropriate or preferred use of their skills. The telecare service seemed unlikely to become normalized as part of routine healthcare delivery, because the nursing team lacked confidence that it was a safe way to provide healthcare in this context and it was not perceived as improving efficiency. The telecare intervention failed | The NPM effectively mapped onto the study findings and explained those factors that inhibited the routine delivery of COPD services by telecare. |
Mair, F., May, C., O’Donnell, C., Finch, T., Sullivan, F. and Murray, E.

A systematic review of reviews of e-health implementation studies, focusing on implementation processes rather than outcomes.

From 8206 unique citations screened, the authors excluded 7973 on the basis of the title or abstract and retrieved 233 full-text articles. Of these, 37 met the inclusion criteria. Of note, 20 of these reviews were published between 1995 and 2007 and 17 were published in the following two years.

An explanatory systematic review.

A systematic review of reviews of e-health implementation studies, focusing on implementation processes rather than outcomes.

The authors have interpreted the results in the light of an explanatory framework – NPT, that specifies mechanisms of importance in implementation processes.

This review not only collates and summarizes data but also analyses it and interprets it within a theoretical framework, NPT. The authors approach has allowed them to explore the factors that facilitate and hinder implementation, identify gaps in the literature and highlight directions for future research. In particular, this work highlights a continued focus on organizational issues, which, despite their importance, are only one among a range of factors that need to be considered when implementing e-health systems.

Content analysis of the 37 reviews identified 801 attributive statements about implementation processes that could be interpreted using NPT as an explanatory framework.

May, C. Finch, T. et. al.

Integrating telecare for chronic disease management in the community: What needs to be done?

Drawn from telecare services in community and domestic settings in England and Scotland, 221 participants were included, consisting of health professionals.

Large scale comparative study employing qualitative data collection techniques: semi-structured interviews with key informants, task-groups, and.

To identify factors inhibiting the implementation and integration of telecare systems for chronic disease.

Framework analysis informed by NPT.

To identify the policy and practice factors that affect the routine incorporation of telecare into everyday practice, and to explore the ways that these factors promoted or inhibited the implementation and.

The study revealed the ways that multiple cycles of uncertainty run through implementation processes, and inhibit the embedding and integration of new ways of delivering care. The authors present a model of the analysed data that shows how.
| May, C. Finch, T., Ballini, L., MacFarlane, A., Mair, F. Murray, E. Treweek, S. and Rapley, T. | Evaluating complex interventions and health technologies using NPT: development of a simplified approach and web enabled toolkit. | Multiple potential users, researchers and practitioners, of NPT (n=60). | Presented NPT to potential and actual users. (ii) created a simplified set of statement and explanations expressing core constructs of the theory (iii) circulated statements of a criterion sample of 60 researchers, clinicians and others to collect qualitative data about their criticisms of the statements (iv) reconstructed statements and explanations to meet users criticisms. | Development of a simplified version of NPT for use by clinicians, managers, and policy makers, and which could be embedded in a web-enabled toolkit and online users manual. | The authors treated the comments about the value and limits of the NPT toolkit as attributive statements and analysed them using a simple and descriptive thematic analysis. | The paper describes the processes by which the authors developed a simplified version of NPT for use by clinicians, managers and policy makers and which could be embedded in a web enabled toolkit and online users manual. | Provides a user friendly version of NPT that can be embedded in a web enabled toolkit and used as a heuristic device to think through implementation and integration problems. |
| May, C. Mair, F. Dowrick, C. and Finch, T. | Process evaluation for complex interventions in primary care: Understanding trials using the NPM. | Not specified. | NPM is applied to two complex trials: the delivery of problem solving therapies for psychosocial distress and the delivery of nurse-led clinics for health failure treatment in primary care. | Case studies of randomized controlled trials of complex interventions in primary care form useful opportunities to explore at a general level how the NPM might be applied. In this study the authors draw on two such examples: the delivery of problem solving therapies for psychosocial distress and the delivery of nurse-led clinics for health failure treatment in primary care. | Explores its application to two bodies of research around the effectiveness and implementation of complex interventions – problem solving therapies for people with depression and nurse-led heart failure clinics in primary care. | The Normalization Process Model (NPM) is an evaluation model that asks what people do to make a complex intervention workable, and to integrate it in practice. The paper develops this by first discussing the development of the theoretical model, and then applies it to two case studies of complex trials that combine both treatment and organizational interventions in primary care. | Application of the NPM shows how process evaluations need to focus on more than the immediate contexts in which trial outcomes are generated. Problems relating to intervention workability and integration also need to be understood. NPM may be used effectively to explain the implementation process in trials of complex interventions. |
| Morriss, R. | Implementing clinical guidelines for bipolar disorder | Not applicable | A Medline search was made of the literature on the implementation of guidelines in bipolar disorder and mental health. The implementation of nonpharmacological treatments from the 2006 NICE Guideline | To critically review the evidence concerning the implementation of clinical guidelines for bipolar disorder. | NPM of complex interventions was applied to the NICE guideline recommendation for bipolar disorder. | To critically review the evidence concerning the implementation of clinical guidelines for bipolar disorder. May’s normalization process model can be used to predict how easily a guideline recommendation will be to implement, so that it | Application of the NPM shows how process evaluations need to focus on more than the immediate contexts in which trial outcomes are generated. Problems relating to intervention workability and integration also need to be understood. NPM may be used effectively to explain the implementation process in trials of complex interventions. |
| Murray, E., May, C and Mair, F. | Development and formative evaluation of the e-Health Implementation Toolkit (e-HIT). | In the first stage of the evaluation, those interviewed included senior clinicians, managers and academics each of whom had extensive experience of e-health implementations within the NHS (N = 13). In the second stage of the formative evaluation, the revised toolkit was circulated by e-mail to the implementers who had been interviewed in the qualitative study (N = 23). | A two stage formative evaluation of the e-HIT was undertaken. For the first stage, the prototype e-HIT was circulated to a group of e-Health experts. These experts were asked to complete the e-HIT for an e-Health initiative they had personal experience of, and on the basis of this experience, to comment critically on the e-HIT. In the second stage of the formative evaluation, the revised toolkit was circulated by e-mail to the implementers who had been interviewed in the qualitative study (n = 23). Participants were asked to comment on the likely usefulness of the e-HIT, make suggestions for | The development and formative evaluation of an e-Health Implementation Toolkit (e-HIT) which aims to summarise and synthesise new and existing research on implementation of e-Health initiatives, and present this evidence in a format that could be easily digested and used by staff considering or planning an e-Health implementation. The aim of this paper is to describe the process of development and formative evaluation of e-HIT, and describe the final toolkit, in line with recent calls for more detailed descriptions of the processes and content of complex interventions. | The e-HIT shows potential as a tool for enhancing future e-Health implementations. Further work is needed to make it fully web-enabled, and to determine its predictive potential for future implementations. |

Data derived from interviews were summarised, synthesised and combined with the constructs from the NPM. The aim of the e-HIT was to summarise and synthesise research evidence on factors that impede or facilitate implementation of e-Health initiatives and present this evidence in a format that could be easily digested and used by staff considering or planning an e-Health implementation. The aim of this paper is to describe the process of development and formative evaluation of e-HIT, and describe the final toolkit, in line with recent calls for more detailed descriptions of the processes and content of complex interventions. | The e-HIT shows potential as a tool for enhancing future e-Health implementations. Further work is needed to make it fully web-enabled, and to determine its predictive potential for future implementations. |
| Murray, E. Burns, J. et al. | Why is it difficult to implement e-health initiatives? A qualitative study | The authors purposively recruited a maximum variety sample, aiming to include senior Department of Health or Connecting for Health staff with responsibility for a number of e-health projects across multiple organizations, senior staff from within the Trust or Health Board with lead responsibility for implementing a number of e-health systems within their organization (such as chief executive officers), and middle management with day-to-day responsibility for the implementation under study. Recruitment within each case study continued until the | Qualitative data collection: semi-structured interviews. Three case studies selected to provide a range of healthcare contexts. | To explore and understand the experiences of implementers and their assessment of factors which promote or inhibit the successful implementation, embedding, and integration of e-health initiatives, as per the constructs outlined in NPT. | Data were analyzed using the framework method proposed by Ritchie and Spencer, according to four components of the collective action construct of NPT (May 2006): Data were coded to the four constructs and overall degree of normalization. | To explore and understand the experience of implementers and their assessment of factors that promote or inhibit successful implementation, embedding and integration of e-health initiatives. | NPT with its emphasis on collective action provided a good explanation for the observed variability in normalisation of three contrasting technologies in different contexts. |
The authors reached saturation, (i.e., until no new data were emerging from subsequent interviews. Based on previous experience, the authors estimated that up to ten interviews per case study would be needed. Twenty-three interviews were undertaken: ten for Case Study 1, five for Case Study 2, and eight for Case Study 3.

Sanders, T., Foster, N. and Bie Nio Ong

Perceptions of general practitioners towards the use of a new system for treating back pain: a qualitative interview study.

General practitioners (GPs) before (n = 32) and after (n = 9) the introduction of a subgrouping for targeted treatment system.

A qualitative interview survey. The GP interviews were embedded within a prospective, population-based, quality improvement study comprising three phases: (a) assessment of GPs’ and physiotherapists’ attitudes and behaviours regarding low back pain, (b) a quality improvement intervention comprising educational courses, regular feedback sessions, and the

The interviews were nested within a larger study (the IMPaCT Back (‘IMplementatio n study to improve PAatient Care through Targeted treatment for Back pain’) study), which aimed to evaluate the improvement in quality of care for back pain patients.

Data analysed using constant comparison drawing upon insights and development connections between themes. Adopted the NPT to explain the uptake of the new system and to examine the relevance of coherence for the implementation of innovations in organisations.

The key obstacle to implementation of the new subgrouping for targeted treatment system for low back pain in primary care was an initial failure to achieve ‘coherence’ of the desired practice change with GPs. Despite this, GPs used the tool to different degrees, though this signified a general commitment to participating in the study rather than a deeper attitude change towards the new system.

The task of integrating new ways of working in healthcare settings can be challenging [28]. According to the NPT the implementation of a new approach is operationalised through four mechanisms: The GPs in this study did not progress beyond the first stage of implementation, or coherence, the main focus of this paper. In summary, low back pain was generally perceived as an ‘uninteresting’ and clinically unchallenging health problem by GPs, which may partly explain their lack of engagement with it. In working from NPT, the adoption of a new way of
installation of computerised and paper-based systems for subgrouping for targeted treatment system, and (c) assessment of GPs’ and physiotherapists’ attitudes and behaviours regarding low back pain and the subgrouping for targeted treatment system.

following implementation of a subgrouping for targeted treatment system.

working by GPs was partly determined by the meaning that they ascribed to it (i.e. Coherence), and any perceived change to the stability and continuity of routine medical work could be met with resistance. Therefore, an appreciation of such routines is the first step towards understanding the perceived acceptance of innovations. The second is a familiarity with how a new way of working may affect work patterns; and, the third is the impact that it may have on interpersonal relationships with peers. Failure to adequately understand all three dimensions may result in largely unsuccessful attempts at integrating new ways of working in the NHS.
Spangaro, J., Poulos, R., and Zwi, A.  

Pandora Doesn’t Live Here Anymore: Normalization of Screening for Intimate Partner Violence in Australian Antenatal, Mental Health, and Substance Abuse Services  

Ten focus groups were conducted with 59 participating health workers: 5 were conducted in antenatal clinics (29 participants); 4 were held at substance abuse services (23 participants); and 1 was conducted at a mental health service (7 participants). Six male and 53 female participants had been screening for an average of 4.4 years. Despite the policy requiring staff training, only 48 participants (81%) had been trained. The remainder had commenced in their roles subsequent to the instigation of the policy and had not been included in repeat training.  

A qualitative study using focus groups.  

This study used focus groups with health care providers undertaking screening in an established program to understand challenges, and enablers of screening apply this to a model of how health policies become routinized in practice.  

The analysis employed an inductive approach involving immersion in the data to derive patterns and interrelationship s, confirmation of relationships, and synthesis of key findings (Patton, 2002). Normalization process theory, developed to explain how complex health interventions become embedded in practice, was also applied to the findings.  

Normalization of Screening for Intimate Partner Violence in Australian Antenatal, Mental Health, and Substance Abuse Services.  

Both the sustained screening rate reported by these services and the responses of the workers in this study point to a policy that has become the normalized practice. The authors suggest that it is not solely the static presence of these four elements described by May (2006) that has led to the normalization of this policy, but an interactional effect, over time. In their application of May’s schema, it appears that training and referral pathways were initially important and remain so for maintenance. However, it appears that “normalization” was most strongly brought about through familiarity acting as a mechanism from the use of brief, scripted, visible questions, further reinforced by women’s favourable reactions.

Watson, R, Parr, J., Joyce, C., May, C. and Le Couteur, A.S.  

Models of transitional care for young people with complex health needs: a scoping review  

The database searches and expert recommendations yielded 350 papers. Using the study inclusion and exclusion criteria, 19 papers (reporting 18 service Scoping review: using search terms concerning transitional care, four databases were systematically searched for papers published in English between 1980 and April 2010.  

To identify successful models of transitional care for young people with CHNs. Three conditions were used as All papers were coded using a framework analysis which evaluated the data in two ways using the 10 transition  

To identify models of transitional care from child to adult health services for CP, ASD and diabetes, using a broad range of literature including peer reviewed publications (1980–April 2010); To seek evidence to  

The scoping review identified no models of transitional care for young people with ASDs, either from electronic database searches or from UK professionals working in the field. Services lacked evaluation, with only a minority
models) met the study criteria. These included 14 diabetes service models from Australia, USA, Canada, UK, Italy, Spain and Denmark; four service models for young people with CP from the USA and UK. All of the CP models included young people with a range of physical disabilities and CHNs (including CP). The excluded papers included reviews of services provision rather than descriptions of specific services, papers focussing on other conditions and service recommendations. No models of transitional care for young people with ASD were identified from database searches or expert recommendations. Additional informal search methods included recommendations from colleagues working with young people with each of the three conditions and making contact with clinical and research teams with expertise in transitional care. Inclusion and exclusion criteria were applied to define the papers selected for review. A separate review of policy documents, adolescent health and transition literature was also undertaken; 10 common summary categories for the components of high quality services were identified. Nineteen papers were selected for review. exemplars: cerebral palsy, autism spectrum disorders and diabetes. categories and four elements of Normalization Process Theory that are important for successful implementation and integration of healthcare interventions. inform ‘best practice’ about transitional care for children with CHNs; To investigate whether the identified models of transitional care have been evaluated; To use Normalization Process Theory to evaluate whether aspects of service sustainability had been considered. reporting consideration of sustainability of the service. NPT provided a structure to assess key elements required for successful implementation and integration of new practice into everyday healthcare.
| Wilkes, S. and Rubin, G. | **Process evaluation of infertility management in primary care: has open access HSG been normalised?** | **Four empirical studies:** (i) **Pilot Study:** Using hospital clinical records, the authors tracked the outcome of all infertile couples from the six pilot practices over a nine-month period. (ii) **Focus group study:** The authors purposively selected three focus groups to provide a range of GPs’ views. In total, 13 practitioners participated: 11 GPs, one GP registrar and one Nurse practitioner. (iii) **Pragmatic cluster-randomized controlled trial:** 670 infertile couples presented to 33 intervention practices and 25 control practices. **In-depth interview study:** 39 interviewees: 12 GPs, 5 fertility specialists and 13 infertile couples (9 interviewed with their partner). | **The results of two qualitative studies and two quantitative studies evaluating open access HSG are interpreted by mapping the results to the NPM.** | **Process evaluation of infertility management in primary care.** | **The results of four empirical studies evaluating open access HSG in the initial management of infertility in general practice were mapped to the NPM constructs.** | **To map the results of four empirical quantitative studies to the NPM to explain why open access hysterosalpingography (HSG) for the initial management of infertile couples has or has not normalized in primary care.** | **The NPM has given an explanation why open access HSG has been adopted but not normalized into everyday general practice. The challenge, now, is to define and address the constructs within the model that are limiting normalization and propose methods to address these barriers. Modelling a complex intervention and mapping the barriers is currently a process seldom undertaken in complex intervention trials (Bosch et al., 2007). The NPM has been a useful tool to describe the likely normalization of open access HSG for the initial management of infertility in primary care.** |
Appendix 5  Electronic Search (Paper 2)


**Interface** - EBSCOhost

**Search Screen** - Advanced Search

**Database** - Academic Search Complete; AMED - The Allied and Complementary Medicine Database; Biomedical Reference Collection: Expanded; CINAHL Plus with Full Text; MEDLINE; OmniFile Full Text Mega (H.W. Wilson); PsycARTICLES; PsycINFO; Social Sciences Full Text (H.W. Wilson); UK & Ireland Reference Centre

<table>
<thead>
<tr>
<th></th>
<th>Query</th>
<th>Limiters/Expanders</th>
<th>Last Run Via</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>S2</td>
<td>&quot;Normalization Process Theory&quot; OR &quot;Normalization Process Model&quot;</td>
<td>Limiters - Scholarly (Peer Reviewed) Journals Search modes - Boolean/Phrase</td>
<td>Interface - EBSCOhost Search Screen - Advanced Search Database - Academic Search Complete; AMED - The Allied and Complementary Medicine Database; Biomedical Reference Collection: Expanded; CINAHL Plus with Full Text; MEDLINE; OmniFile Full Text Mega (H.W. Wilson); PsycARTICLES; PsycINFO; Social Sciences Full Text (H.W. Wilson); UK &amp; Ireland Reference Centre</td>
<td>28</td>
</tr>
<tr>
<td>S1</td>
<td>&quot;Normalization Process Theory&quot; OR &quot;Normalization Process Model&quot;</td>
<td>Search modes - Boolean/Phrase</td>
<td>Interface - EBSCOhost Search Screen - Advanced Search Database - Academic Search Complete; AMED - The Allied and Complementary Medicine</td>
<td>46</td>
</tr>
<tr>
<td>Database; Biomedical Reference Collection: Expanded; CINAHL Plus with Full Text; MEDLINE; OmniFile Full Text Mega (H.W. Wilson); PsycARTICLES; PsycINFO; Social Sciences Full Text (H.W. Wilson); UK &amp; Ireland Reference Centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 6  Quality Appraisal Checklist & Quality Score Allocation (Paper 2)


This checklist is from Hawker, S., Payne, S. et al. (2002) Appraising the Evidence: Reviewing Disparate Data Systematically. Qualitative Health Research 12(9): 1284-1299.

Reviewers were asked to assess each paper on the following criteria.

For scoring please refer to notes below.

Good=4
Fair=3
Poor=2
Very poor=1
Lower scores =poor quality
Notes for appraising the quality of each paper:

1. **Abstract and title:**
   - Did they provide a clear description of the study?
     - Good: Structured abstract with full information and clear title.
     - Fair: Abstract with most of the information.
     - Poor: Inadequate abstract.
     - Very Poor: No abstract.

2. **Introduction and aims:**
   - Was there a good background and clear statement of the aims of the research?
     - Good: Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.
     - Fair: Some background and literature review. Research questions outlined.
     - Poor: Some background but no aim/objectives/questions, OR Aims/objectives/questions but inadequate background.
     - Very Poor: No mention of aims/objectives. No background or literature review.

3. **Method and data:**
   - Is the method appropriate and clearly explained?
     - Good: Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
     - Fair: Method appropriate, description could be better. Data described.
     - Poor: Questionable whether method is appropriate. Method described inadequately. Little description of data.
     - Very Poor: No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. **Sampling:**
   - Was the sampling strategy appropriate to address the aims?
     - Good: Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
     - Fair: Sample size justified. Most information given, but some missing.
     - Poor: Sampling mentioned but few descriptive details.
     - Very Poor: No details of sample.

5. **Data analysis:**
   - Was the description of the data analysis sufficiently rigorous?
     - Good: Clear description of how analysis was done. Qualitative studies: Description of how themes derived/respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed.
     - Fair: Qualitative: Descriptive discussion of analysis. Quantitative.
     - Poor: Minimal details about analysis.
     - Very Poor: No discussion of analysis.

6. **Ethics and bias:**
   - Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?
Good Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair Lip service was paid to above (i.e., these issues were acknowledged).
Poor Brief mention of issues.
Very Poor No mention of issues.

7. Results:
Is there a clear statement of the findings?
Good Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor Findings not mentioned or do not relate to aims.

8. Transferability or generalizability:
Are the findings of this study transferable (generalizable) to a wider population?
Good Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4. Poor Minimal description of context/setting.
Very Poor No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?
Good Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair Two of the above (state what is missing in comments).
Poor Only one of the above.
Very Poor None of the above.
Results based on the Quality Scoring above:

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Journal</th>
<th>Year</th>
<th>Quality Approved Total score allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atkins, S. Lewin, S. Ringsberg K. and Thorson A.</td>
<td>Provider experiences of the implementation of a new tuberculosis treatment programme: A qualitative study using the normalisation process model</td>
<td>BMC Health Services Research</td>
<td>2011</td>
<td>31</td>
</tr>
<tr>
<td>Bouamrane, M, Osbourne, J., Mair, F.S.</td>
<td>Understanding the implementation and integration of remote and telehealth services...an overview of NPT</td>
<td>Pervasive Computing Technologies for Healthcare</td>
<td>2011</td>
<td>31</td>
</tr>
<tr>
<td>Elwyn, G., Legare, F. et. al.</td>
<td>Arduous implementation: Does the Normalisation Process Model explain why it's so difficult to embed decision support technologies for patients in routine clinical practice?</td>
<td>Implementation Science</td>
<td>2008</td>
<td>25</td>
</tr>
<tr>
<td>Gask, L. Bower, P. Lovell, K. Escott, D., Archer, J., Gilbody, S. Lankshear, A. Simpson, A., Richards, D.</td>
<td>What work has to be done to implement collaborative care for depression? Process evaluation of a trial utilizing the NPM</td>
<td>Implementation Science</td>
<td>2010</td>
<td>29</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Journal</td>
<td>Year</td>
<td>Page</td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
<td>---------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Godden, D. and King, G.</td>
<td>Rational development of telehealth to support primary care respiratory medicine: patient distribution and organisational factors</td>
<td>Primary Care Respiratory Journal</td>
<td>2011</td>
<td>18</td>
</tr>
<tr>
<td>James, D.M.</td>
<td>The Applicability of Normalisation Process Theory to Speech and Language Therapy: A review of qualitative research on a speech and language intervention</td>
<td>Implementation Science</td>
<td>2011</td>
<td>23</td>
</tr>
<tr>
<td>Kennedy, A. Chew-Graham, C. et al.</td>
<td>Delivering the WISE Training Package in Primary Care: Learning from formative evaluation.</td>
<td>Implementation Science</td>
<td>2010</td>
<td>32</td>
</tr>
<tr>
<td>MacFarlane, A. and Oreilly De Brun, M.</td>
<td>A Reflexive Account of Using a Theory-Driven Conceptual Framework in Qualitative Health Research</td>
<td>Qualitative Health Research</td>
<td>2011</td>
<td>35</td>
</tr>
<tr>
<td>Mair, F., Hiscock, J. and Beaton, S.</td>
<td>Understanding factors that inhibit or promote the utilization of telecare in chronic lung disease</td>
<td>Chronic Illness</td>
<td>2008</td>
<td>30</td>
</tr>
<tr>
<td>May, C. Finch, T. et al.</td>
<td>Integrating telecare for chronic disease management in the community: What needs to be done?</td>
<td>BMC Health Services Research</td>
<td>2011</td>
<td>34</td>
</tr>
<tr>
<td>May, C. Mair, F. Dowrick, C. and Finch, T.</td>
<td>Process evaluation for complex interventions in primary care: Understanding trials using the NPM.</td>
<td>BioMed Central</td>
<td>2007</td>
<td>31</td>
</tr>
<tr>
<td>Name(s)</td>
<td>Title</td>
<td>Journal/Conference</td>
<td>Year</td>
<td>Volume</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------------------------------------------------------------------</td>
<td>---------------------------------------------------------------</td>
<td>------</td>
<td>--------</td>
</tr>
<tr>
<td>Morriss, R.</td>
<td>Implementing clinical guidelines for bipolar disorder</td>
<td>Psychology and Psychotherapy: Theory, Research and Practice</td>
<td>2008</td>
<td>26</td>
</tr>
<tr>
<td>Murray, E., May, C and Mair, F.</td>
<td>Development and formative evaluation of the e-Health Implementation Toolkit (e-HIT)</td>
<td>BMC Medical Informatics and Decision Making</td>
<td>2010</td>
<td>33</td>
</tr>
<tr>
<td>Murray, E. Burns, J. et al.</td>
<td>Why is it difficult to implement e-health initiatives? A qualitative study</td>
<td>Implementation Science</td>
<td>2011</td>
<td>33</td>
</tr>
<tr>
<td>Sanders, T., Foster, N., Bie Nio Ong</td>
<td>Perceptions of general practitioners towards the use of a new system for treating back pain: a qualitative interview study</td>
<td>BMC Medicine</td>
<td>2011</td>
<td>33</td>
</tr>
<tr>
<td>Finch, T., Mair, O Donnell, Murray and May</td>
<td>From theory to 'measurement' in complex interventions: Methodological lessons from the development of an e-health normalisation instrument</td>
<td>BMC Medical Research Methodology</td>
<td>2012</td>
<td>34</td>
</tr>
<tr>
<td>Ehrlich, C. Kendall, E., Winsome S.J.</td>
<td>How does care coordination provided by registered nurses ‘fit’ within the organisational processes and professional relationships in the general practice context?</td>
<td>Collegian (2012)</td>
<td>2012</td>
<td>32</td>
</tr>
<tr>
<td>Furler, J., Spitzer, O., Young, D. and Best, J.</td>
<td>Insulin in general practice Barriers and enablers for timely initiation</td>
<td>Reprinted from Australian Family Physician</td>
<td>2012</td>
<td>33</td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Journal</td>
<td>Year</td>
<td>Page</td>
</tr>
<tr>
<td>---------</td>
<td>-------</td>
<td>---------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Blakeman, T., Protheroe, J., Chew-Graham, C., Rogers, A. and Kennedy, A.</td>
<td>Understanding the management of early stage chronic kidney disease in primary care.</td>
<td>BMJ of General Practice</td>
<td>2012</td>
<td>33</td>
</tr>
<tr>
<td>Spangaro J, Poulos GR, Zwi BA:</td>
<td>Pandora doesn’t live here anymore: normalization of screening for intimate partner violence in Australian antenatal, mental health, and substance abuse services.</td>
<td>Violence and Victims</td>
<td>2011</td>
<td>31</td>
</tr>
</tbody>
</table>
Appendix 7  Completed PRISMA statement: A qualitative systematic review of studies using the Normalization Process Theory (Paper 2).


<table>
<thead>
<tr>
<th>Section/Topic</th>
<th>#</th>
<th>Description</th>
<th>Page No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td>1</td>
<td>A systematic qualitative review of the literature on Normalization Process Theory in use.</td>
<td>1</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>3</td>
<td></td>
<td>5-6</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Additional file 2: PICO Table</td>
<td></td>
</tr>
<tr>
<td>METHODS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol &amp; registration</td>
<td>5</td>
<td>No Protocol registered</td>
<td>N/A</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td></td>
<td>8-9</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Figure 2: PRISMA Flow Chart</td>
<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>9</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Data collection process</td>
<td>10</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Data items</td>
<td>11</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Risk of bias in individual studies</td>
<td>12</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Summary measures</td>
<td>13</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>14</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>15</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>----------------------------</td>
<td>----</td>
<td>-----</td>
<td></td>
</tr>
<tr>
<td>Additional analyses</td>
<td>16</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

**RESULTS**

<table>
<thead>
<tr>
<th>Study selection</th>
<th>17</th>
<th>Flow diagram developed (see Figure 2)</th>
<th>8</th>
<th>See Figure 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study characteristics</td>
<td>18</td>
<td>See Tables 1 &amp; 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk of bias within studies</td>
<td>19</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>Additional File 2 PICO Table</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional analysis</td>
<td>23</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**DISCUSSION**

<table>
<thead>
<tr>
<th>Summary of evidence</th>
<th>24</th>
<th>Tables 2 &amp; 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limitations</td>
<td>25</td>
<td>17</td>
</tr>
<tr>
<td>Conclusions</td>
<td>26</td>
<td>17-18</td>
</tr>
</tbody>
</table>

**FUNDING**

| Funding                    | 27 | 20                                 |
## Appendix 8  Author’s Contribution to Papers Comprising the Thesis

<table>
<thead>
<tr>
<th>Paper</th>
<th>Title</th>
<th>Authors</th>
<th>Contribution of thesis author to the paper</th>
</tr>
</thead>
</table>
| 1     | Community participation in primary care in Ireland: the need for implementation research | McEvoy R, & MacFarlane A.                                              | - Paper conception and design (with supervisor AMacF)  
- Review of literature - lead  
- Drafting of manuscript – first author and lead  
- Critical revisions of manuscript with supervisor AMacF  
- Final preparation and editing of manuscript and submission to Journal |
| 2     | A qualitative systematic review of studies using the normalization process theory to research implementation processes | McEvoy, R., Ballini, L., O’Donnell, C., Mair, F., & MacFarlane, A.    | - Paper conception and design with supervisor AMacF & LB  
- Review of literature - lead  
- Data analysis lead with input from co-authors  
- Drafting of manuscript first author and lead  
- Critical revisions of manuscript with AMacF  
- Final preparation and editing of manuscript and submission to  
Journal |
- Data analysis collaborator  
- Drafting of manuscript with supervisor AMacF & ET  
- Critical revisions of manuscript with AMacF & ET |
| 4     | “Participation is integral”: Understanding the levers and barriers to the implementation of Community Participation in Primary Care as a routine way of working: A qualitative study using Normalization Process Theory. | McEvoy, R., Tierney, E. & MacFarlane, A                                  | - Study conception and design (with supervisor AMacF)  
- Review of literature - lead  
- Data collection and analysis lead with input from co-authors  
- Review of documentary data - lead  
- Drafting of manuscript first author and lead  
- Critical revisions of manuscript (with supervisor AMacF & ET)  
- Final preparation and editing of manuscript and submission to Journal |
Appendix 9  Sample Schedule of Empirical Data Analysis Clinics (Paper 4)


Understanding the levers and barriers to the implementation of Community Participation in Primary Care as a routine way of working: A qualitative study using Normalization Process Theory. Under Review Health and Social Care in the Community.

<table>
<thead>
<tr>
<th>PhD Data Analysis Clinics (AMF &amp; RM)¹⁰</th>
<th>Collective Data Analysis Clinics (AMF/ET/RM)</th>
<th>Joint Data Analysis Clinics (RM &amp; ET)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TC ¹¹ 20th March 2012</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TC 25th May 2012</td>
<td>27th June</td>
<td></td>
</tr>
<tr>
<td>TC October 8th 2012</td>
<td>TC January 18th 2013 UL (Final PhD TC data analysis clinic F2F)</td>
<td></td>
</tr>
<tr>
<td>March 1st 2013 (AM, RM &amp; MO’S: NPT discussion) Aim: Select a small portion of data and start reading the data looking for resonance with the four constructs.</td>
<td>March 22nd 2013 (Table Development)</td>
<td></td>
</tr>
<tr>
<td>March 22nd 2013 (11.00 – 1.00)</td>
<td>April 12th (TC 10-12)</td>
<td></td>
</tr>
<tr>
<td>March 29th (9.30-11.00)</td>
<td>April 15th (TC 2-4)</td>
<td>March 21st (Ideal Table Conditions F2F)</td>
</tr>
<tr>
<td>April 12th (9-10)</td>
<td>April 19th (TC 10-12)</td>
<td>April 22nd (venn Diagram visual representation F2F)</td>
</tr>
<tr>
<td>April 15th (1-2)</td>
<td>May 7th (TC 10-12.00)</td>
<td>April 29th (TC further dev &amp; discussion re. Venn Diagram)</td>
</tr>
<tr>
<td>April 19th (12-1)</td>
<td>May 20th (TC 11.30 – 1.00)</td>
<td>May 20th (TC 10.30 – 11.30)</td>
</tr>
<tr>
<td></td>
<td>June 13th (TC F2F)</td>
<td></td>
</tr>
</tbody>
</table>

¹⁰ Memos developed for each meeting
¹¹ TC : Thematic Coding