Healthcare Decision-Making and the Older Person
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Definition of Terms

Advance Healthcare Directive:
An advance healthcare directive is an advance expression made by a competent adult relating to healthcare treatment decisions that may arise in respect of him or her at some point in the future should they be unable to subsequently express consent or dissent at that time.

Assisted Decision-Making (Capacity) Act 2015:
The Assisted Decision-Making (Capacity) Act 2015 (ADMC) was signed into law on the 30th December 2015. This piece of legislation is about supporting decision-making and maximising a person’s capacity to make decisions. Although the Act was signed into law, it has not yet been fully commenced.

Decision-Making Assistant:
A decision-making assistant is a person appointed under the ADMC Act to assist the appointer in making decisions on the appointer’s personal welfare or property and affairs, or both. This role is to be defined by the decision-making assistance agreement. More than one decision-making assistant may be appointed.

Decision-Making Representative:
The ADMC Act 2015 provides for court intervention where it is believed that a person lacks capacity to such an extent that they require decisions to be made on their behalf by another person. A decision-making representative is a person appointed pursuant to a decision-making representation order to make one or more than one decision specified in the order on behalf of the relevant person.

Designated Healthcare Representative:
In drafting an advance healthcare directive, a directive-maker may designate a named individual to exercise the relevant powers. The designated healthcare representative has the power to ensure that the terms of the advance healthcare directive are complied with. A directive-maker may confer one or both of the following powers on the designated healthcare representative:

(i) the power to advise and interpret what the directive-maker’s will and preferences are regarding treatment; and,
(ii) the power to consent to or refuse, up to and including life-sustaining treatment, based on the known will and preferences of the directive maker.

Functional Test for Capacity:
The functional test for capacity can be described as being time and issue specific. It was recognised in the case of Fitzpatrick v FK [2008] IEHC 104, and was included in the ADMC Act 2015. Under this approach to capacity, a person will lack capacity to make a decision if he or she is unable:

(a) to understand the information relevant to the decision;
(b) to retain that information long enough to make a voluntary choice;
(c) to use or weigh that information as part of the process of making the decision; or
(d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology).

**Informed Consent:**
Consent is to be given by a patient prior to any medical procedure being carried out on him/her. This process is intended to respect the patient’s autonomy and their right to self-determination. Consent should not be reduced to a signature on a form but requires communication between the healthcare professional and the patient. Ideally, the patient should understand the nature of the procedure and the fact that he/she is authorising it.

**Legal Capacity:**
Legal capacity refers to the capacity to hold rights and the power to act upon those rights. It ensures that a person is recognised before the law and can make decisions about their life. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides that countries ‘recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’.

**Mental Capacity:**
Mental capacity describes a person’s ability to perform specific cognitive functions and to exercise specific decision-making skills. It naturally varies among individuals and may be dependant on environmental factors.

**Power of Attorney / Enduring Power of Attorney:**
A power of attorney is a legal device which can be established by a person during their life at a time when they have sufficient capacity. It can be either specific or general. A specific power of attorney relates to a particular task or purpose, while the general power allows the attorney broad discretion to make decisions for the appointee.

An enduring power of attorney takes effect on the incapacity of the donor. It may give general or specific authority to the attorney. An enduring power of attorney may allow the attorney to make personal care decisions but this is distinct from health care decisions. A personal care decision may relate to matters such as: where and with whom the donor should live; whom the donor should have contact with; diet; housing, social welfare and other benefits. The potential scope of an enduring power of attorney is to be expanded under the Assisted Decision-Making (Capacity) Act 2015.

**Relevant Person:**
The term ‘relevant person’ is used in the Assisted Decision-Making (Capacity) Act 2015. It describes the following:

a) a person whose capacity is in question or may shortly be in question in respect of one or more than one matter,
b) a person who lacks capacity in respect of one or more than one matter, or
c) a person who falls within paragraphs (a) and (b) at the same time but in respect of different matters.
Executive Summary

Background
This report outlines the results of a collaborative research project undertaken by Dr John Lombard of the School of Law University of Limerick, and Age Action Ireland. The project explored healthcare decision-making and the older person, in particular, it examined the older person’s experience of autonomy and consent in healthcare, familiarity with decision-making practices, and awareness of forthcoming decision-making supports. The purpose of this empirical research was to gauge perceptions of autonomy, to identify aspects of healthcare decision-making which raise greatest concern for the older person, and to determine whether there is a lack of understanding surrounding aspects of the legal framework. The research project was therefore shaped by three core objectives:

1. To explore the older person’s understanding of autonomy in healthcare, familiarity with decision-making practices, and awareness of forthcoming decision-making supports.
2. To identify the priorities, concerns and needs of the older person around this topic.
3. To identify shortcomings between the legal framework and the subjective experience of research participants.

The experience and views of the older person were captured through quantitative research.

Study Design
A self-administered questionnaire was developed in association with Age Action. The questionnaire was composed of 25 questions which were set out across four sections. These sections addressed ‘demographic and social information’, ‘standard of health’, ‘consent to medical treatment’, and ‘advance care planning’. A majority of questions had fixed response options while a small number of open-ended questions were included. No specific identifying information was requested.

Respondents were primarily contacted through the Age Action Ageing Matters members magazine. This magazine is distributed in hard copy and digital formats. As such, the questionnaire was made available in both hard copy and digital formats. The survey was first distributed in July 2019 and data collection closed in September 2019. In total, 283 respondents completed the questionnaire. 206 people responded to the hard copy survey while 77 people completed the digital questionnaire.

Conclusions and Recommendations
1. The interaction between the healthcare professional and the older person can be strengthened and improved through more explicit engagement with the principles of informed consent.
   - Awareness of the HSE National Consent Policy should be further promoted among healthcare professionals.
Healthcare professionals should pay careful attention to the language used in communicating with the older person.

More explicit engagement with the principles of informed consent may also open opportunities for greater patient involvement and emphasise opportunities for meaningful patient input.

2. **Steps must be taken to promote the commencement and knowledge of the Assisted Decision-Making (Capacity) Act 2015**
   - The failure to fully commence the 2015 Act should be publicly highlighted and a national campaign should be implemented to push for commencement.
   - Knowledge dissemination events should be run in the lead-up to full commencement.

3. **The discussion of end-of-life care should be encouraged and supported**
   - The discussion of wishes for end-of-life care should be promoted. It should also be supported through the provision of guidance on the type of issues that might be considered and discussed.
   - Further research should be conducted in order to identify how best to support the GP in raising issues around end-of-life care.
   - Additional CPD events may be offered in the future which concentrate on legal issues facing the older person. These may serve to encourage and promote discussion among solicitors.

4. **The role and function of advance healthcare directives and power of attorney is the subject of much uncertainty and confusion**
   - Age Action should publish an explainer on advance healthcare directives and power of attorney. Additional information is required on both to bring some clarity to this area and avoid continued confusion.
   - Information on the creation of an advance healthcare directive and practical points to consider should be disseminated among members of Age Action.
Section 1: Introduction

1.1 Background

This research explored healthcare decision-making and the older person. The concept of healthcare decision-making raises a wide range of issues and challenges, with respect for a person’s autonomy a central concern. There were three core objectives which shaped this project:

1. To explore the older person’s understanding of autonomy in healthcare, familiarity with decision-making practices, and awareness of forthcoming decision-making supports.
2. To identify the priorities, concerns and needs of the older person around this topic.
3. To identify shortcomings between the legal framework and the subjective experience of research participants.

The research gathered the experiences and views of older persons around the country through the use of a self-administered questionnaire. The questionnaire was made available in hard copy and digital formats to facilitate ease of participation.

The research was motivated by demographic changes in society as well as forthcoming changes in the legal framework for healthcare decision-making. Census 2016 indicated that the population of Ireland has continued to grow older since the 1980’s with 637,567 people over 65 years. This represents an increase of 19.1% since 2011 (CSO, 2016). A HSE document titled ‘Planning for Health: Trends and Priorities to Inform Health Service Planning 2017’ set out that adults 65 years and over will increase by up to 21% (131,000) by 2022. Moreover, it projected that there will be 16,100 additional people aged 85 years and over by 2022 (Smyth et al., 2017). While these figures represent a societal success in healthcare provision, it also raises challenges relating to the care of the older person.

The experience of healthcare can be daunting, and this is no less true for the older person. To improve the experience, healthcare services increasingly adopt a person-centred care approach. Key elements of this are service user involvement and health literacy which necessitates clear communication, informed consent, and respect for an individual’s autonomy. Autonomy can provide control and a sense of empowerment in healthcare. It has been held up in law and ethics as a response to the traditional paternalistic elements which framed healthcare decision-making in the past.

Autonomy has been recognised in the European Convention on Human Rights, the Irish Constitution, and in common law. More recently, the enactment of the Assisted Decision-Making (Capacity) Act 2015 marked a significant step forward in protecting autonomy and supporting service user involvement. However, much of the 2015 Act is yet to be commenced. Nonetheless, the legal framework for autonomy and healthcare decision-making has significantly evolved in Ireland over the last 25 years. These changes are reflected in case law, codes of professional conduct, and guidance documents. As such, a key element of this research
was to explore the points of convergence and departure between the subjective experience and the defined legal framework which governs the area.

1.2 Methodology

The research project was based on quantitative research methods. A self-administered questionnaire was developed in association with Age Action. The questionnaire was composed of 25 questions which were set out across four sections. These sections addressed ‘demographic and social information’, ‘standard of health’, ‘consent to medical treatment’, and ‘advance care planning’. Early sections were intended to provide additional nuance to subsequent data analysis. A majority of questions had fixed response options while a small number of open-ended questions were included. No specific identifying information was requested.

Respondents were primarily contacted through the Age Action Ageing Matters members magazine. This magazine is distributed in hard copy and digital formats. As such, the questionnaire was also made available in both hard copy and digital formats. An information letter, hard copy questionnaire, and a stamped addressed envelope were included with the hard copy magazine to facilitate research participation. A SurveyMonkey site was also established to collect any digital responses. The survey was first distributed in July 2019 and data collection closed in September 2019. In total, 283 respondents completed the questionnaire. 206 people responded to the hard copy survey while 77 people completed the digital questionnaire.

The findings provide an insight into the experience of healthcare decision-making for older people in Ireland. In particular, data was collected on the perceived involvement in healthcare decision-making, the last interaction with a healthcare professional, discussion of end-of-life care, and knowledge of advance care planning. Quantitative data was analysed using filter/compare rules in SurveyMonkey to produce descriptive and bivariate results. Thematic analysis was used to gain insight into patterns of meaning across open ended question responses (Braun and Clarke, 2012). Emerging themes were noted, reviewed, and supportive quotations were identified. These quotes are included in Section Three of this report.

1.2.1 Ethical Approval

The research proposal, including aims and methodology were submitted to the Research Ethics Committee (AHSS) in the University of Limerick. The research ethics application form indicated that this research involved working with persons over 65 years of age. It also set out that the research might involve adults under the protection of others in some form of care. For instance, some of the respondents may be living in a nursing home or receiving supports which required consideration.

The application addressed the protection of vulnerable research participants, and satisfied all other standards in relation to the period of data storage, confidentiality, and the right of withdrawal. Ethical approval was granted for this research project, 2019-04-20-AHSS.
1.3 Report Contents

The report is set out over four sections. Section Two provides a literature and policy review of the area. This section outlines the demographic changes in Ireland and the consequences of an ageing population for the health service. The section also addresses the legal framework in Ireland for healthcare decision-making. In this respect, the section sets out the role of human rights, capacity, and advance care planning. Section Three explores the data collected as part of the research project. The results from each section will be discussed and key themes emerging from open ended responses will be outlined. Conclusions and recommendations are set out in Section Four and are based on a review of the collected data.
Section 2: Literature and Policy Review

This section presents a literature and policy review of key issues and developments in healthcare decision-making for the older person in Ireland. It outlines the demographic changes in society and the related pressures facing healthcare provision. The section also engages with the legal framework as it describes the human rights instruments in this jurisdiction. It follows that this section will outline the right of autonomy and will set out the law on consent, capacity, and advance care planning.

2.1 Demographic Change in Ireland

The number of older people in the European Union is projected to peak at 149.2 million inhabitants in 2050, and their relative share of total population is expected to reach 28.5% in the same year (Eurostat 2019, p.8). Older people are defined as those aged 65 years or over by the Eurostat report (Eurostat 2019, p.9). World Population Prospects 2019 suggests that 1 in 6 people in the world will be over the age of 65 by 2050. The figure in 2019 is 1 in 11 (United Nations, 2019). These are dramatic changes and will place greater pressure on state finances, long-term care, and healthcare systems.

Ireland is also experiencing this demographic shift. Census 2016 indicated that the population of Ireland has continued to grow older since the 1980s with 637,567 people over 65 years. This represents an increase of 19.1% since Census 2011 (CSO, 2016). A population focused analysis of current and future needs was undertaken by the Health Service Executive and resulted in the publication of a report title ‘Planning for Health - Trends and Priorities to inform Health Service Planning 2017’. The HSE report set out that adults 65 years and over will increase by up to 21% (131,000) by 2022. Moreover, it included projections that there will 16,100 additional people aged 85 years and over by 2022 (Smyth et al., 2017). Further figures are provided by the Department of the Taoiseach in a report titled ‘National Risk Assessment 2019’. In this report it was stated that: ‘The share of population aged 65 and over is projected
to increase from one in eight to one in six by 2030, and the number of people aged 85 and over is projected to almost double.¹

Older persons tend to account for a greater number of interactions with healthcare professionals. It follows that an increase in older persons as a percentage of total population will result in increased pressure on health and social services in the State. In responding to these various challenges, it is important that the human rights of the older person be recognised and protected across policy, planning and practice.

![Projected population aged 65 years and over, 2016-2051](image)

### 2.2 Human Rights, Dignity, and the Older Person

Human rights have a fundamental role in shaping the care and treatment provided to people. In the context of healthcare, people may draw on rights such as the right to bodily integrity, protection from inhuman or degrading treatment, equality, and the right of autonomy and self-determination. This research places a particular emphasis on the latter.

Older persons are entitled to the same rights protection as anyone else in society. The legal framework does not discriminate against older persons and neither should policy or clinical practice. The legal framework for human rights protection in Ireland is composed of many different elements. For instance, it is shaped by the Irish Constitution, legislation, guidance documents, the European Convention on Human Rights, and treaties such as the International Covenant on Economic, Social and Cultural Rights. The Irish Constitution and the ECHR being particularly influential.

The Irish Constitution, Bunreacht na hÉireann, recognises a number of fundamental rights. These rights are found in Articles 40-44 of the Constitution. Constitutional recognition of these rights underlines their status and protects from political interference. The Constitution contains both enumerated and unenumerated rights. Enumerated rights are rights expressly set out by the Constitution. In contrast, unenumerated rights are not expressly written in the Constitution but the courts have recognised these rights as they may be linked to an existing enumerated right, it may from the ‘Christian and democratic nature of the State, be grounded in natural law, or it may stem from another unenumerated right. The Constitution is at the top of the hierarchy.
for domestic sources of law. Other domestic sources of law therefore depend on the Constitution for their validity.

The European Convention on Human Rights was incorporated into Irish law by way of the European Convention on Human Rights Act 2003. This approach provided for the incorporation of the Convention at a sub-constitutional level thereby maintaining the supremacy of the Irish Constitution. The European Convention on Human Rights was drafted by the Council of Europe in 1950 and establishes a legal obligation on States to protect certain civil and political rights. Section 3 of the ECHR Act 2003 requires that ‘every organ of the State shall perform its functions in a manner compatible with the State’s obligations under the Convention provisions.’ Organs of State include bodies such as the Health Information and Quality Authority and the Health Service Executive. These bodies must therefore carry out their functions in a way which is compatible with the obligations placed on the State. Individuals who feel that their rights under the Convention have been violated by the State can ultimately bring a case to the European Court of Human Rights. However, domestic remedies must first be exhausted before applying to the ECtHR.

The infringement of human rights may not always be intentional but can come about due to weakness in service delivery, the poor provision of information, resource limitations, and inconsistencies in clinical practice (Sykes and Groom 2011). The manner in which care and treatment is structured can therefore have a considerable impact on the manner in which human rights are recognised, protected, and realised within a jurisdiction. In effect, the abstract nature of the rights contained in the legal framework come to be reflected and embedded in everyday practice and interactions between healthcare professionals and the older person. It follows, that the manner in which the older person experiences and participates in their medical care and treatment can draw out strengths and weaknesses in the relationship between clinical practice and the law, particularly in the context of healthcare decision-making.

2.3 Autonomy, Capacity, and Advance Care Planning

Autonomy is a fundamental concept for healthcare decision-making. The term ‘autonomy’ is derived from the Greek words ‘autos’ and ‘nomos’ meaning self-rule or law. The concept evolved over time to the point where it is now most closely linked to the will and preferences of an individual.

The practice of medicine was not traditionally shaped by patient autonomy but was grounded in ideas of beneficence and the sanctity of life. In effect, the healthcare professional was the arbiter of what was meant by doing good. The view of the doctor was therefore decisive in the care and treatment of the patient. Such an approach is reflected in the concept of paternalism (Lombard, 2020). The paternalistic culture which had dominated in healthcare began to shift from the 1960s. This was marked by the development of bioethics, scandals in medical research, and social movements underpinned by a desire for greater self-determination and self-realisation (Donnelly, 2014, p.13; Woods, 2007).

The framework for autonomy in a jurisdiction such as Ireland may be linked to a liberal understanding of autonomy. This interpretation is based on negative and positive rights. A
negative right is a right not to do something or can be described as a right to be let alone. In the context of medical care and treatment, the negative right arises when a patient refuses a form of treatment. A positive right is a right to receive a form of care or treatment. It is reflected in the principle of informed consent. Provided an individual has capacity, they are in a position to refuse any and all treatment, regardless of their reasons or lack thereof.

The right of autonomy in Ireland is recognised and protected under the common law, the Constitution, and the European Convention on Human Rights Act 2003. It is reflected in guidance documents such as the Health Service Executive National Consent Policy. Autonomy is also a core element in the Assisted Decision-Making (Capacity) Act 2015. The 2015 Act is expansive and detailed but not yet fully commenced.

The HSE National Consent Policy provides ‘one overarching HSE policy to guide staff’ (HSE, 2019). A person’s consent must be obtained before the provision of medical treatment. Several elements are required for valid consent, namely: voluntariness, capacity, and the disclosure of appropriate information. An absence of consent may result in trespass against the person, battery, or a breach of a patient’s rights. Informed consent is therefore a fundamental part of treatment, and, from a legal perspective, should not be neglected solely because the patient is vulnerable. Instead, patient involvement in decision-making may actually have therapeutic benefits (Dooley and McCarthy, 2012). The HSE National Consent Policy has been updated several times. It provides detailed guidance on the general principles of consent, consent for children and minors, consent in research, and DNAR orders.

The Assisted Decision-Making (Capacity) Act 2015 was signed into law by President Michael D Higgins on the 30 December 2015. The enactment of the legislation took a substantial amount of time from when it was first mooted. For instance, the genesis of the legislation can be traced back to the 2006 Law Reform Commission Report on Vulnerable Adults and the Law. The Report followed on from the Law Reform Commission Consultation Papers on Law and the Elderly, and Vulnerable Adults and the Law: Capacity. The UN Convention on the Rights of Persons with Disabilities also provided an impetus for the introduction of the 2015 Act. The Act was therefore necessary to support Ireland’s compliance with the obligations established under the UNCRPD, particularly Article 12 ‘Equal recognition before the law’.

The Assisted Decision-Making (Capacity) Act 2015 applies to persons whose decision-making capacity is called into question or may shortly be called into question. Key elements of the 2015 Act include recognition of the functional approach to capacity, the use of guiding principles in pace of best interests, the establishment of the Decision Support Service, the formalisation of decision-making supports, the abolition of the Ward of Court system, changes to enduring power of attorney, and the provision of a statutory framework for advance healthcare directives. Changes which will reshape the process for healthcare decisions in many respects.

The functional approach to capacity has come to be favoured and applied in this jurisdiction. It can be described as issue and time specific. Moreover, it is not a general or once-off assessment of cognitive ability. Under this model of capacity, a person may have adequate capacity to make certain decisions about their healthcare however there may be more complex healthcare decisions which are beyond the capacity of the individual at that time. This approach
to capacity has come to be reflected in case law, the Health Service Executive ‘National Consent Policy’, and as noted above it is an important component of the Assisted Decision-Making (Capacity) Act 2015.

A further feature of the 2015 Act is that the term ‘best interests’ is not used. Instead, ‘guiding principles’ are set out under Section 8 of the Assisted Decision-Making (Capacity) Act 2015. These principles are intended to apply before and during an intervention in respect of a relevant person. While the Section provides structure, the ‘intervener’ still has substantial discretion in applying these guiding principles.

The law on enduring powers of attorney were set out by the Powers of Attorney Act 1996. The powers provided under the 1996 Act did not extend to healthcare decisions. This has been addressed by the 2015 Act. Section 59 of the Assisted Decision-Making (Capacity) Act 2015 describes an enduring power of attorney as an arrangement whereby a donor may appoint another person on whom he or she confers general authority to act on the donor’s behalf in relation to all or a specified part of the donor’s property and affairs, and/or authority to do specified things on the donor’s behalf in relation to the donor’s personal welfare or property and affairs. An enduring power of attorney does not enter into force until such time as the donor lacks capacity in relation to one or more of the relevant decisions which are the subject of the power, and the instrument creating the enduring power of attorney has been registered in accordance with Section 69 of the Act. An enduring power of attorney is not synonymous with an advance healthcare directive.

2.3.1 Recognition of Advance Healthcare Directives

The Assisted Decision-Making (Capacity) Act 2015 defines an advance healthcare directive as ‘an advance expression made by the person, … of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lack capacity’. The concept of an advance healthcare directive was first proposed by Luis Kutner in 1969. However, legal recognition of advance healthcare directives was to occur much later in this jurisdiction.

Prior to the Assisted Decision-Making (Capacity) Act 2015, there was a tenuous recognition of advance healthcare directives in the comments of O’Flaherty J in Re a Ward of Court. In this case, O’Flaherty J stated:

I find it impossible to adapt the idea of the ‘substituted judgment’ to the circumstances of this case and, it may be, that it is only appropriate where the person has had the foresight to provide for future eventualities. That must be unusual (if it ever happens) at the present time: with increased publicity in regard to these types of cases it may get more common. ([1996] 2 IR 79)

The willingness to recognise advance healthcare directives was further supported by the obiter comments of Laffoy J in Fitzpatrick v FK. Greater legal clarity came from the case of Governor of X Prison v PMcD ([2015] IEHC 259) in which Baker J stated: ‘I consider that as a matter of law … that a person may make a freely stated wish in regard to their future care and that this
ought to be, and can in an appropriate case be, respected by those with care of that person.’ Nonetheless, many of the procedural elements remained to be addressed by the Assisted Decision-Making (Capacity) Act 2015.

Advance healthcare directives are provided for by Part 8 of the Assisted Decision-Making (Capacity) Act 2015. Among other issues it addresses the making of advance healthcare directives, issues of validity and applicability, the role of a designated healthcare representative, and the role of courts. Section 84 of the 2015 Act describes the requirements for making a valid advance healthcare directive and sets out conditions in which a refusal of treatment would be complied with. As such, a person should have attained the age of 18 years and should have the requisite mental capacity. A refusal of treatment would be complied with in situations where the directive-maker lacks capacity, the treatment to be refused is clearly identified in the directive, and the circumstances in which the refusal of treatment is intended to apply are clearly identified. Section 84(3) provides that a request for treatment may be set out although it is not legally binding. The Act provides much needed clarity and legal certainty on the position of advance healthcare directives. It is therefore disappointing that this Part of the Act remains to be commenced. Nevertheless, it is clear from the preceding discussion that advance healthcare directives occupy an unusual position in Irish law. While accepted in judicial decisions we await more robust legal architecture to address and clarify the issues of validity and applicability.
Section 3: Healthcare Decision-Making

There was a total of 283 respondents to the questionnaire. 206 completed the questionnaire in hard copy, while 77 completed the questionnaire online. Information was collected under four main headings, namely, demographic and social information, standard of health, consent to medical treatment, and advance care planning. This section will outline this data and will begin to draw out connections and points of divergence in the results. Themes emerging from open ended question responses will also be set out and discussed over the course of Section Three.

3.1 Demographic and Social Information

Under the heading of ‘demographic and social information’, information was gathered on age, gender, education, employment status, and living arrangement. A majority of respondents, 38.30%, were in the 80+ age category. 21.28% of respondents were in the 75-79 category, while 20.92% of respondents were aged between 70-74 years.

67.02% of respondents indicated that they are female, while 32.62% are male. The questionnaire included options for ‘transgender’, ‘other’, and ‘rather not say’. Only one respondent selected the ‘other’ option. No one selected transgender or ‘rather not say’.

Question Three asked ‘What is the highest level of schooling that you have completed?’ The purpose of this question was to get a clearer image of the respondent group but also to subsequently ascertain whether levels of education had any connection to issues such as consent to medical treatment, and advance care planning. 49.47% of respondents indicated that they had completed some form of third level education. Secondary school was the highest level of education for 40.21% of respondents. National school was the highest for 9.61% of respondents. Only two respondents (0.71%) had not completed any level of schooling. Respondents were generally well educated and this is apparent when we consider wider population data. Census 2016 shows that 18.9% of those aged 65 and over possess a third level
qualification. The census data also demonstrated that 39.7% of those aged 65 plus were educated to primary level only.

Question Four asked about the respondent’s employment status. The vast majority of respondents, 92.17%, are retired. 4.98% are employed and just 1.07% are not employed but are looking for work. CSO data on labour force participation by those aged 65 and over indicates that 11% of this group are in employment. It should be noted that in this study, a large number of respondents were in the 80+ age category and are 99.07% of this cohort are retired. In contrast, 5% of respondents in the 65-69 age category are in employment.
The final question in this section sought information on living arrangement. Response options included: living alone, living with partner / spouse, living with family member, living in long-term residential care, and other. The ‘other’ option allowed respondents to provide further detail on their living arrangement if they wished to do so. Responses to Question Five are set out in the chart below.

There were two predominant responses. 53.71% of respondents indicated that they live alone, while 37.46% live with a partner or spouse. 5.30% are living with a family member, and 1.06% are living in long-term residential care. Seven respondents selected the ‘other’ option and this included responses such as living with tenants, living in a religious community, and living with a caregiver.

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>30.43%</td>
<td>65.08%</td>
</tr>
<tr>
<td>Living with partner/spouse</td>
<td>63.04%</td>
<td>25.40%</td>
</tr>
<tr>
<td>Living with family member</td>
<td>3.26%</td>
<td>6.35%</td>
</tr>
</tbody>
</table>

The box above illustrates the difference in living arrangements between male and female respondents. Female respondents were more likely to be living alone whereas male respondents were more likely to be living with a partner or spouse. Census 2016 also recognised that there
were more elderly women living alone than men; women accounted for 62.3% of all older persons living alone.

In addition to informing subsequent bivariate analysis, this section provides a snapshot of respondents. The respondent group is primarily an older cohort, highly educated, and responses to living arrangement suggest a good level of independence. Such points are to be borne in mind for later sections and discussion.

3.2 Standard of Health

The second section in the questionnaire addressed the individual’s standard of health. Questions were posed about engagement with healthcare professionals, attendance at hospital, treatment for chronic health problems, and self-reported standard of health.

Question Six asked ‘Have you visited a GP / Consultant / Health & Social Care Professional for a health problem in the past 12 months?’ The vast majority of respondents, 94.7%, had visited a GP etc. at some point in the last year. 4.95% of respondents did not visit with any healthcare professional over the period, while only 1 respondent was ‘not sure’. People living alone were more likely to have visited a GP etc in comparison with respondents living with a partner or spouse, 97.37% and 91.51% respectively. A high level of engagement with healthcare professionals is to be expected as figures indicate that a person aged 65 years and over attends a GP practice an average of seven times a year (Smyth, 2017, p.19). In response to question seven, 28.21% of respondents indicated that they had been in hospital in the last 12 months. 71.07% of respondents had not been in hospital during this period.

Question Eight asked, ‘Are you being treated for a chronic health problem?’ A chronic health problem was described as ‘a long-term condition that requires ongoing management but is usually incurable, e.g. diabetes, arthritis, asthma, COPD’.

Q8 Are you being treated for a chronic health problem? (A chronic health problem is a long-term condition that requires ongoing management but is usually incurable. e.g. diabetes, arthritis, asthma, COPD)
51.09% of respondents indicated that they are being treated for a chronic health problem. 2.55% of respondents were not sure, however 46.35% answered ‘No’. The ‘No’ response is particularly high when compared with broader population data and suggests that this data set represents a very healthy population. For instance, a study of multimorbidity and prevalent disease combinations in older Irish adults set out that only 9.08% of the population do not have any of the 31 diseases examined for the study (Hernández, Reilly, and Kenny, 2019).

The next question sought information on the self-reported standard of health. A majority of respondents, 53.19%, described their current standard of health as ‘good’.

![Pie chart showing health standards](chart.png)

1.06% described their health as ‘very poor’. Other responses were: poor 7.09%, fair 20.92%, and excellent 17.73%. 60% of respondent who live with a partner or spouse described their health as ‘good’ whereas the figure for persons living alone was 47.37%.

The key takeaway from this section relates to the health of the respondents. The data suggests that 46.35% of respondents are not receiving treatment for a chronic health problem. It must be acknowledged that this question is not the exact same as asking whether the respondent has a chronic health problem. Nonetheless, if a person does have a chronic health problem then it is likely that they would be in receipt of some form of treatment. Consequently, the standard of health remains high when this is considered.

### 3.3 Consent to Medical Treatment

Section Three of the questionnaire inquired about consent to medical treatment. Under this heading, respondents were asked about their involvement in medical treatment, and multiple questions were posed about the respondent’s last interaction with a healthcare professional.
Q10 Do you feel involved in making decisions about your medical treatment?

The above bar chart suggests a relatively positive experience for respondents. 74.91% of respondents felt they were involved in making decisions about their medical treatment. 22.91% were of the opinion that they were somewhat involved. Only 2.18% did not feel involved at all in making decisions about their medical treatment.

77.7% of respondents who had completed some form of third level education felt involved in making decisions about their medical treatment. In contrast to this, 65.38% of respondents whose highest level of schooling was national school felt involved. A difference in response was also discernible when living arrangement was considered.

<table>
<thead>
<tr>
<th></th>
<th>Living alone</th>
<th>Living with partner / spouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involved</td>
<td>71.14%</td>
<td>79.41%</td>
</tr>
<tr>
<td>Somewhat involved</td>
<td>26.85%</td>
<td>17.65%</td>
</tr>
<tr>
<td>Not involved at all</td>
<td>2.01%</td>
<td>2.94%</td>
</tr>
</tbody>
</table>

Subsequent questions enquired about discussion of end-of-life care and advance care planning. While these will be discussed in more detail later on, it can be noted that 82.54% of respondents who discussed their wishes for end of life care considered themselves to be involved in decision-making, while 16.67% are somewhat involved. In a similar vein, 88.14% of persons who completed an advance care directive feel involved in making decisions about their medical treatment.

Question 11 asked persons who did not feel involved in decision-making, to consider what the reason for their lack of involvement might be. Respondents could select as many options as appropriate. Options included: ‘perceived not to have capacity by others’, ‘not provided with
the opportunity’, ‘do not wish to participate’, ‘communication difficulties’, ‘family resistance’, and an ‘other’ option which allowed further information to be provided.

Q11 If you do not feel involved, what do you think is the reason for your lack of involvement?
(Please tick as many as appropriate)

As the chart above illustrates, the question was not applicable for a majority of respondents. The most common barrier to involvement for those to whom the question applied was that the respondent was not provided with the opportunity; this was an issue for 8.92% of respondents. 1.88% were perceived not to have capacity by others. 1.41% did not wish to participate, and 4.23% identified communication difficulties as the barrier to their involvement. 3.76% of respondents indicated another reason for their lack of involvement. From these responses, issues of timing, communication, and a sense of paternalism in healthcare emerged. A selection of responses are set out below with some reflecting multiple themes.

“Not given sufficient time for in-depth discussion”

“Some health grades dictate that no one question their decisions.”

“Doctors are non-communicative and always need to be questioned about results.”

“Have to ask questions as GP is not very informative”

“Medical team knows what should be done – when lying in a bed with others listening there is no time to ask questions and probably not as alert due to worry.”

Question 12 was a multi-part question which asked respondents to reflect on their last interaction with a healthcare professional regarding a medical treatment. Questions and responses are set out below. Response options were limited to ‘Yes’, ‘No’, and ‘No Sure’.
<table>
<thead>
<tr>
<th>In your last interaction with a healthcare professional regarding a medical treatment (e.g. GP / Consultant / Health and Social Care Professional etc):</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you explicitly asked to consent to treatment?</td>
<td>64.03%</td>
<td>29.64%</td>
<td>6.32%</td>
</tr>
<tr>
<td>Did you have an opportunity to ask questions about the proposed treatment?</td>
<td>87.95%</td>
<td>8.84%</td>
<td>3.21%</td>
</tr>
<tr>
<td>Did you feel that your views were listened to?</td>
<td>81.67%</td>
<td>8.76%</td>
<td>9.56%</td>
</tr>
<tr>
<td>Were you given enough information when making a decision?</td>
<td>77.73%</td>
<td>12.15%</td>
<td>10.12%</td>
</tr>
<tr>
<td>Was the information provided in an adequate time for you to fully consider it?</td>
<td>80.32%</td>
<td>12.05%</td>
<td>7.63%</td>
</tr>
<tr>
<td>Was the information provided in clear and concise language?</td>
<td>84.62%</td>
<td>11.34%</td>
<td>4.05%</td>
</tr>
<tr>
<td>Were you asked if you needed any support or help to make the decision-making easier? (e.g. having a relative, partner, friend, or carer present)</td>
<td>23.48%</td>
<td>73.28%</td>
<td>3.24%</td>
</tr>
</tbody>
</table>

These questions were shaped by the HSE National Consent Policy. This is an overarching HSE policy intended to guide staff on issues of valid consent. The policy covers a wide range of issues including general principles, consent for children and minors, and principles of consent for research. For the purposes of this research, the focus was placed on the provision of information when engaging with a service user. As such, these questions sought to draw out the various aspects of the patient – healthcare professional interaction such as listening to the patient, providing sufficient information, and allowing sufficient time to consider and process the information provided.
The responses are largely positive, although 8-12% of respondents appear to have had a less than optimal experience. The first question asked whether the respondent was explicitly asked to consent to the medical treatment. It is essential that consent be obtained in advance of commencing treatment or a medical investigation. A failure to secure appropriate consent may result in civil or criminal proceedings against the healthcare professional. It is good practice to secure explicit consent, although implicit consent may be relied on in many instances. 64.03% of respondents were explicitly asked to consent to medical treatment. 29.64% answered ‘No’, and 6.32% were not sure if they had been asked for consent.

87.95% of respondents had an opportunity to ask questions about the proposed treatment. 81.76% felt that their views were listened to. The provision of enough information appeared to be an issue for some respondents. 12.15% of respondents were of the opinion that they had not received enough information and 10.12% were not sure. In relation to the timing of information, 80.32% indicated that it had been provided in adequate time. However, 12.05% did not receive the information in adequate time, and 7.63% were not sure.

The issue of language and understanding was a recurring theme in the open-ended responses later in this questionnaire. Yet for this question, 84.62% respondents felt that information was provided in clear and concise language. Nonetheless, 11.34% of respondents stated that the information was not clear and concise, while a smaller cohort, 4.05%, were not sure.

The final element in this multi-part question asked whether the respondent was asked if they needed any help or support to make the decision-making easier. 23.48% of respondents indicated that this offer had been made. The response tended to vary depending on whether the respondent was male or female. 16.97% of female respondents were offered support in contrast to 37.5% of male respondents.

### 3.4 Advance Care Planning

The fourth section in the questionnaire explored the topic of advance care planning. It sought to gauge awareness of the Assisted Decision-Making (Capacity) Act 2015, the nature of discussions about end-of-life care, the knowledge of advance care directives, and the respondent’s intentions for advance care planning. Please see the Literature and Policy Review for an outline of the Assisted Decision-Making (Capacity) Act 2015, including discussion of supported decision-making procedures and the legal status of advance healthcare directives.

The Assisted Decision-Making (Capacity) Act 2015 provides for substantial changes to the legal framework for healthcare decision-making in Ireland. At the time of writing (December 2019), much of the Act remains to be commenced. Nonetheless, information about the Act has been communicated through seminars, newspaper reports, and other forms of media. Question 13 asked whether the respondent was aware of the Assisted Decision-Making (Capacity) Act 2015. 73.68% of respondents were not aware of the Act with 7.52% of respondents selecting ‘Not Sure’. It follows that 18.8% of respondents are aware of the 2015 Act.
Awareness of the Act varied based on the highest level of schooling completed. For example, 27.41% of persons who completed some form of third level qualification were aware of the Act. The figure was much lower for persons who completed secondary school at 8.82%, while awareness among persons who had completed national school was at 14.81%. This would suggest that the well-educated cohort in this survey have raised the levels of awareness beyond what might be expected in a broader sample. In effect, this data might present a more positive picture than what might be seen in a more extensive survey.

Question 14 asked whether the respondent had discussed their wishes for end-of-life care with someone. Respondents could select as many options as appropriate. There was also an option to specify a person not included in the set response options.
As the bar chart illustrates, the majority of respondents, 54.78%, had not discussed their wishes with anyone. This lack of discussion can create problems for future healthcare decisions and may lead to a second-guessing of a person’s thoughts and desires.

People who have discussed their wishes for end of life care most commonly engaged with a family member 39.34%, a solicitor 18.01%, and/or their general practitioner 4.41%. 6.99% indicated that they had spoken with someone not listed on the response options. On this point, responses included friends, a consultant, an executor, an undertaker, and members of a religious community. Some respondents also referenced specific family members such as son or wife, despite ‘family member’ being included on the list of options.

The level of discussion with solicitors is particularly high and suggests some confusion surrounding the discussion of wishes for end-of-life care. Several respondents indicated that they had spoken with their solicitor about drafting a will. Although estate planning is undoubtedly important, the focus on this issue may be indicative of some uncertainty about what a discussion about end-of-life care might entail. A general point made by respondents to this question was that when a discussion had taken place, these tended to be brief and had not explored their end-of-life wishes in detail.

A notable difference in response arose between people who live alone and people who live with a partner or spouse. 50% of people living alone have not discussed their wishes with anyone. In contrast 65.35% of people living with a partner or spouse have not discussed their wishes with anyone.

3.4.1 Advance Healthcare Directives

An advance healthcare directive can be described as ‘a statement made by a competent adult relating to the type and extent of medical treatments he or she would or would not want to undergo in the future should he/she be unable to express consent or dissent at that time.’ (Irish Council for Bioethics 2007). Question 15 asked respondents if they knew what an advance healthcare directive is. The term ‘advance healthcare directive’ is used by the Health Service Executive, the Irish Hospice Foundation, and is found in the Assisted Decision-Making (Capacity) Act 2015.

<table>
<thead>
<tr>
<th>Q15 Do you know what an 'advance healthcare directive' is?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
60.53% of respondents did not know what an advance healthcare directive is, and 17.29% were not sure. It follows that 22.18% of respondents indicated that they know what an advance healthcare directive is. However, based on other responses to the questionnaire it would seem that some respondents are confusing advance healthcare directives with power of attorney. Moreover, this figure may also reflect the fact that this is a relatively well-educated cohort. For instance, 28.15% of those with third level education indicated a knowledge of advance healthcare directives while the figure was 15.38% for those with national school education alone.

Knowledge of advance healthcare directives was particularly high, 33.33%, among respondents who had discussed their wishes for end-of-life care with someone. The figure for respondents who had not discussed their wishes was much lower at 12.16%.

The subsequent question asked respondents if they had completed an advance healthcare directive.

Q16 Have you completed an advance healthcare directive?

![Pie Chart]

The above pie chart illustrates that 88.15% of respondents had not completed an advance healthcare directive. 3.17% were not sure and 8.15% had completed an advance healthcare directive. Yet, the above proviso continues to apply and it would appear that several of these respondents may have completed a power of attorney and not an advance healthcare directive. As such, it would seem that people require much more information and this is a recurring theme in the open-ended responses.

Question 17 asked respondents whether they intend on completing an advance healthcare directive at some point in the future. For persons who answered ‘Yes’ to Question 15, 78.26% intend on completing an advance healthcare directive, 21.74% do not know, and no respondent answered ‘No’. In looking at all respondent data, 55.47% did not know whether they intended to complete an advance healthcare directive. It is to be remembered that in Question 15, 60.53% of respondents stated that they did not know what an advance healthcare directive is.
Presumably it is this lack of knowledge which contributed to the high ‘Not Sure’ response in Question 17.

Question 18 asked respondents, ‘Should your General Practitioner raise the issue of advance care planning with you?’ In a previous question, 4.41% of respondents had discussed their wishes for end-of-life care with their General Practitioner. Yet, the majority of respondents wanted their GP to raise the issue of advance care planning with them.

Q18 Should your General Practitioner raise the issue of advance care planning with you?

52.45% of respondents replied ‘Yes’. The ‘No’ response was much lower at 12.08%, while 35.47% of respondents did not know whether their GP should raise the issue with them. Persons who have discussed their wishes for end-of-life care with someone are far more likely to want their GP to raise the issue of advance care planning with them in contrast to persons who have not had such discussions as the chart below demonstrates.

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have not discussed my wishes with anyone</td>
<td>25.85%</td>
<td>6.12%</td>
<td>68.03%</td>
</tr>
<tr>
<td>Discussed wishes with someone</td>
<td>55.05%</td>
<td>7.34%</td>
<td>37.61%</td>
</tr>
</tbody>
</table>

This chart also reveals a particularly high response, 68.03%, for ‘not sure’ among those who have not discussed their wishes for end-of-life care with anyone. Again, it may be that more information might assist in clarifying a person’s views and thoughts on the issue.
Is there anything you would like to add on the issue of healthcare decision making?
The final question was open-ended as it asked respondents whether there was anything they would like to add on the issue of healthcare decision-making. There was a total of 112 responses to this section. Thematic analysis was used to identify key themes emerging from these comments. The most common themes being advance healthcare directives, information, and support. Less frequent themes included: ageism, planning, and waiting times.

Advance Healthcare Directives
The legal status of advance healthcare directives was outlined in Section 2 of this report. Several cases have demonstrated judicial acceptance of advance healthcare directives however it is the Assisted Decision-Making (Capacity) Act 2015 which provides for the clearest statement of validity and enforceability. Unfortunately, the relevant section in the 2015 Act is yet to be commenced. Comments on advance healthcare directives included concerns about effectiveness, practical steps, and the relationship to the enduring power of attorney.

One of the respondents raised the issue of effectiveness and applicability. The respondent felt that an advocate was essential in ensuring the effectiveness of an advance healthcare directive.

“Later down it is very difficult to know if your opinions will be carried through if you are not able to stand up for yourself. Advance care directive depends on who is looking after your affairs and has an interest in seeing that you are cared for properly.”

This concern may, in part, be addressed by the appointment of a designated healthcare representative which is provided for under Section 87 of the Assisted Decision-Making (Capacity) Act 2015. Closely linked to this comment is a concern about how to alert healthcare professionals to the presence of an advance healthcare directive.

“I worry where is the best place to keep my advance healthcare directive. In cases of sudden illness/ambulance/hospitalisation/GP it is not consulted. Should older people be encouraged to keep a list of current medications or a copy of their AHD by their front door? … AHDs are not only for older people – serious illness can strike at any age!”
The above quote also illustrates the need for more information to be made available so these type of concerns can be addressed. Greater information may encourage more discussion of end-of-life care and, significantly, it could reduce some of the confusion surrounding enduring power of attorney. This confusion was a recurring theme as demonstrated by two of the comments set out below.

“I would certainly consider completing such a directive but would need a lot more information in order to reach an informed decision.”

“It would be helpful if a practitioner discussed the above. Also, I am confused about Enduring Power of Attorney.”

“Have to be continuously pro-active in my own health care. If advanced healthcare directive is enduring power of attorney - yes I have done that.”

The Assisted Decision-Making (Capacity) Act 2015 may ultimately bring greater clarity to this area but it currently occupies a grey-zone. We are aware that changes are to be introduced and know the general form of many of these changes. Yet, the failure to fully commence the Act leaves us with a poorer framework for healthcare decision-making.

“Too much delay in the commencement of the ADMC Act. Enduring Power of Attorney is expensive to put in place and does not reflect decision making act – costly to update.”

**Information**
The theme of information arose at several points in the open-ended responses. In addition to a desire for greater information on the subject of advance healthcare directives, respondents also desired more information about the Assisted Decision-Making (Capacity) Act 2015 as the comments below illustrate.

“I’d like more information in the public domain about Assisted Decision-Making (Capacity) Act 2015. … I would like to attend a public talk on the subject.”

“Information and explanation need to be highlighted and made more easily accessible to older people. More awareness in general of Assisted Decision-Making (Capacity) Act 2015.”

Several respondents indicated a desire for more open communication with healthcare professionals. This included the provision of all relevant information as well as opportunities to ask questions about information provided.

“I think if your doctor knows the information they should discuss when it being obvious that a patient needs it.”

“I have had very good and very poor experiences of health care provision. Many were excellent. The answers to questions 12-18 relate to the most recent experience,
when I was asked to sign a consent form and doctor seemed to get annoyed when I asked questions.”

A further point highlighted in the responses was that the information should be provided in a way which is clear and understandable. In effect, the information should not be communicated using clinical terms but should be in terms which can be readily understood by the older person.

“Should be all in plain English, not a series of medical jargon.”

“Make sure information provided is clear, understandable to even the least educated. Make sure the client is totally au fait with what’s available and where it can be sourced.”

“Information needs to be in plain English i.e. K.I.S.S (Keep it Short and Simple). As sometimes hospitals and GP's speak in medical terms known only to medics.”

The availability of information for the next of kin was also an issue identified by respondents.

“As next of kin to someone recently in hospital, I felt that decisions were not fully explained and doctors were not accessible enough.”

While next of kin may want information, it is important to remember that next of kin cannot give or refuse consent on behalf of an adult patient unless they have specific legal authority to do so. Despite this, the status of next of kin is often confused. Greater healthcare planning may take place if more people were made aware of this and knew that next of kin would have a limited role in shaping any future healthcare decisions.

Support
Support and the lack thereof arose in several responses. These comments underlined the various forms that support may take and the challenges that are experienced when support is lacking. Several respondents drew attention to a lack of family or social supports and the pressures this places on them.

“Don't have any relatives to help. Hospital staff find this incredible and get annoyed when I can't give them a "next of kin" for their forms. Have a good GP and private health insurance but not sure how long I can avoid going into a nursing home. … My solicitor will look after my funeral etc and my 'living will' but not entitled to any support from District Nurse or clinic as I do not have medical card.”

“Feel have to be so proactive in my own health care and get satisfactory results. Not easy when on your own, and in pain and consequently unable to drive.”

Time pressures were set out by respondents who felt their experience with healthcare professionals was dictated by timing.
“When I go to the GP I feel as though I am on a conveyor belt that she does not have time to listen, and therefore does not have a comprehensive view of the presenting problems.”

“More time with professional would be great, when making decisions. I don't like asking questions as I feel the consultants time is too valuable plus I feel silly not knowing the answers.”

The manner in which support and information is provided is also an important consideration. Availability and ease of access must be kept in mind. Many respondents referred to the availability of information in hard copy while no respondent asked for additional material to be made available online.

“As we're nearly all living longer help should be offered re health and aging Everything now seems to be 'online' forgetting those who can't cope online - even after "getting started" courses.”

**Involvement**

The final theme to address is ‘involvement’. Question 10 set out that 74.91% of respondents felt that they were involved in making decisions about their medical treatment. It was clear in the open-ended responses that involvement was seen as being especially important and that people should not be distanced from their care.

“The subject should always be listened to and their wishes taken seriously, not discounted, ignored or overridden.”

“Patients should be fully involved in their healthcare decision making for best outcomes. I’m looking to future and I’m certain that for best patient outcomes, as much care as possible should be available in the patient's home, cheaper and far better.”

“Patients should have choices of care if they wish.”

**3.5 Section Summary**

The respondents in this research project represented an older, highly educated, and relatively healthy cohort. For instance, 49.47% had completed some form of third level education. As a result, certain responses were more positive than a survey of the general population might indicate. Nonetheless, this may serve to emphasise particularly intransigent challenges surrounding healthcare decision-making. Across fixed and open-ended responses certain key concerns emerged, namely, knowledge of advance healthcare directives, provision of information, multiple supports, and a desire for involvement in decision-making.

A majority of the respondents, 74.91%, felt they were involved in making decisions about their medical treatment. This high response may have been shaped in part by personal expectations
and desires about their level of involvement. Nevertheless, timing, communication and a sense of medical paternalism were all mentioned in relation to a lack of involvement.

A key takeaway from this Section is the high number of respondents who have not discussed their wishes for end-of-life care. 54.78% of respondents had not discussed their wishes. For persons who had discussed their wishes, people most commonly engaged with a family member 39.34%, a solicitor 18.01%, and/or their general practitioner 4.41%. The level of interaction with solicitors is particularly high and it was suggested that this might hint at some confusion surrounding the nature of end-of-life care discussions. In any case, respondents suggested that when a discussion had taken place, these tended to be brief and had not been especially detailed.

A failure to grasp the nettle of healthcare planning was again illustrated by responses to questions on advance healthcare directives. 22.18% of all respondents know what an advance healthcare directive is. 8.15% indicated that they had made an advance healthcare directive. Yet, there was uncertainty about the distinction between advance healthcare directives and enduring power of attorney. As such, the recurring issue is the need for greater and clearer information. This may be information relating to the Assisted Decision-Making (Capacity) Act 2015, the distinction between various legal documents, and clarity on the role of the next of kin. This information may encourage more discussions and improved planning for challenging healthcare decisions.
Section 4: Conclusions and Recommendations

At the outset it was noted that there were three core objectives which shaped this research project:

1. To explore the older person’s understanding of autonomy in healthcare, familiarity with decision-making practices, and awareness of forthcoming decision-making supports.
2. To identify the priorities, concerns and needs of the older person around this topic.
3. To identify shortcomings between the legal framework and the subjective experience of research participants.

The conclusions and recommendations advanced in this Section are closely linked to these objectives. Moreover, the conclusions and recommendations are defined by a respect for the human rights and inherent dignity of the older person. Particular attention is paid to concepts of autonomy and self-determination.

It is also worth repeating that the respondent group is an older cohort, highly educated, relatively healthy, and has a high level of independence. Nonetheless, the conclusions and recommendations are widely applicable and serve to underline issues in need of action.

The interaction between the healthcare professional and the older person can be strengthened and improved through more explicit engagement with the principles of informed consent.

Recommendation: Awareness of the HSE National Consent Policy should be further promoted among healthcare professionals.

Recommendation: Healthcare professionals should pay careful attention to the language used in communicating with the older person. Language difficulties was a recurring theme in the open-ended responses in the questionnaire. Moreover, 11.34% of respondents stated that information provided by a healthcare professional was not clear and concise while 4.05% were not sure.

Recommendation: More explicit engagement with the principles of informed consent may also open opportunities for greater patient involvement and emphasise opportunities for meaningful patient input. It can be noted that the most common barrier to involvement in healthcare decision-making was a failure to provide the respondent with the opportunity.

Steps must be taken to promote the commencement and knowledge of the Assisted Decision-Making (Capacity) Act 2015

Recommendation: The Assisted Decision-Making (Capacity) Act 2015 was signed into law by President Michael D Higgins on the 30 December 2015. The failure to fully commence this legislation should be publicly highlighted and a national campaign should be implemented to push for commencement.

Recommendation: Once steps towards full commencement begin, it is recommended that a series of seminars aimed at the general public be offered. These seminars should provide
information on discrete sections of the Act. These knowledge dissemination events are necessary to ensure people can take full advantage of the supports provided by way of the Assisted Decision-Making (Capacity) Act 2015.

The discussion of end-of-life care should be encouraged and supported

Recommendation: The discussion of wishes for end-of-life care should be promoted. It should also be supported through the provision of guidance on the type of issues that might be considered and discussed. A majority of respondents failed to discuss their wishes for end-of-life care with anyone. Where these conversations had taken place, these tended to be brief and had not discussed the matter in detail. Guidance may serve to structure these conversations and provide a framework for navigating difficult personal issues.

Recommendation: A majority of respondents wanted their GP to raise the issue of advance care planning with them. Further research should be conducted which can identify appropriate times for this subject to be raised, the content of such a discussion, and what additional supports should be made available to support all parties.

Recommendation: 18.01% of respondents spoke with a solicitor about their wishes for end-of-life care. Many of these discussions may have related to estate planning but this also presents an opportunity for further discussion. Additional CPD events may be offered in the future which concentrate on the legal issues facing the older person. These may serve to encourage and promote discussion among solicitors.

The role and function of advance healthcare directives and power of attorney is the subject of much uncertainty and confusion

Recommendation: Age Action should publish an explainer on advance healthcare directives and power of attorney. Additional information is required on both to bring some clarity to this area and avoid continued confusion.

Recommendation: Information on the creation of an advance healthcare directive and practical points to consider should be disseminated among members of Age Action. Greater awareness and clarity is likely to lead to increased planning and will stimulate more discussions about end-of-life care.
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Healthcare Decision-Making and the Older Person

This research is supported by the Irish Research Council New Foundations funding scheme. It is a collaborative project between Dr John Lombard and Age Action. Responses will be processed by the Principal Investigator, Dr John Lombard, and all answers will be treated as confidential. An online version of this survey can be accessed at: https://www.surveymonkey.com/r/52PG2LP

Please read the Information Letter in advance of completing the questionnaire. Return the completed questionnaire using the prepaid addressed envelope by 20 September 2019. Thank you for taking the time to assist with this research.

**DEMOGRAPHIC AND SOCIAL INFORMATION**

1. **Age Group:**
   - 64 or younger □  65-69 yrs □  70-74 yrs □  75-79 yrs □  80+ yrs □

2. **Gender:**
   - Female □  Male □  Transgender □  Other □  Rather not say □

3. **What is the highest level of schooling that you have completed?**
   - National school □  Secondary school □  Third level *(University/College)* □  None of the above □

4. **Which of the following categories best describes your employment status?**
   - Employed □
   - Not employed but looking for work □
   - Not employed and not looking for work □
   - Retired □

5. **What is your living arrangement?**
   - Living alone □
   - Living with partner / spouse □
   - Living with family member □
   - Living in long-term residential care □
   - Other, please specify ________________

**STANDARD OF HEALTH**

6. **Have you visited a GP / Consultant / Health & Social Care Professional for a health problem in the past 12 months?**
   - Yes □  No □  Not sure □

7. **Have you been in hospital in the last 12 months?**
   - Yes □  No □  Not sure □
8. **Are you being treated for a chronic health problem?** (A chronic health problem is a long-term condition that requires ongoing management but is usually incurable. e.g. diabetes, arthritis, asthma, COPD)
   
   Yes ☐  No ☐  Not sure ☐

9. **How would you describe your current standard of health?**
   
   Very Poor ☐  Poor ☐  Fair ☐  Good ☐  Excellent ☐

**CONSENT TO MEDICAL TREATMENT**

10. **Do you feel involved in making decisions about your medical treatment?**
    
    Involved ☐  Somewhat involved ☐  Not involved at all ☐

11. **If you do not feel involved, what do you think is the reason for your lack of involvement?** (Please tick as many as appropriate)
    
    Perceived not to have capacity by others ☐  
    Not provided with the opportunity ☐  
    Do not wish to participate ☐  
    Communication difficulties ☐  
    Family resistance ☐  
    Other, please specify ___________ ___________  
    Question not applicable (I do feel involved) ☐

<table>
<thead>
<tr>
<th>In your last interaction with a healthcare professional regarding a medical treatment <em>(e.g. GP / Consultant / Health and Social Care Professional etc)</em>:</th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
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<tr>
<td>12. Were you expressly asked to consent to treatment?</td>
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<td>13. Did you have an opportunity to ask questions about the proposed treatment?</td>
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<td>14. Did you feel that your views were listened to?</td>
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<td>15. Were you given enough information when making a decision?</td>
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<td>16. Was the information provided in an adequate time for you to fully consider it?</td>
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<tr>
<td>17. Was the information provided in clear and concise language?</td>
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<td>18. Were you asked if you needed any support or help to make the decision-making easier? <em>(e.g. having a relative, partner, friend, or carer present)</em></td>
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</table>
ADVANCE CARE PLANNING

19. Are you aware of the Assisted Decision-Making (Capacity) Act 2015?
   Yes ☐  No ☐  Not Sure ☐

20. Have you discussed your wishes for end-of-life care with any of the following?
    (Please tick as many as appropriate)
    Family member(s) ☐
    General Practitioner ☐
    Public Health Nurse ☐
    Solicitor ☐
    Priest / Rabbi / Imam etc ☐
    Home Care/Help Provider ☐
    Other, please specify ______________
    I have not discussed my wishes with anyone ☐

21. Do you know what an ‘advance healthcare directive’ is?
    Yes ☐  No ☐  Not Sure ☐

22. Have you completed an advance healthcare directive?
    Yes ☐  No ☐  Not Sure ☐

23. Do you intend on completing an advance healthcare directive at some point in the future?
    Yes ☐  No ☐  Don’t know ☐

24. Should your General Practitioner raise the issue of advance care planning with you?
    Yes ☐  No ☐  Don’t know ☐

25. Is there anything you would like to add on the issue of healthcare decision making?

THANK YOU