The ‘Let Me Decide’ Pilot Implementation project

The effect of simultaneous implementation of an advance care directive and a general palliative care educational programme on end-of-life care in a long-term care setting

Final Report

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Centre for Gerontology & Rehabilitation
UCC School of Medicine
St. Finbarr’s Hospital, Cork.
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# Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACD</td>
<td>Advance Care Directive</td>
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<tr>
<td>ACP</td>
<td>Advance Care Planning/Advance Care Plan</td>
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<tr>
<td>AIIHPC</td>
<td>All Ireland Institute of Hospice and Palliative Care</td>
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<tr>
<td>CGR</td>
<td>Centre for Gerontology and Rehabilitation</td>
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<tr>
<td>COLLAGE</td>
<td>Collaboration on Ageing (UCC/LAFCI)</td>
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<tr>
<td>CPR</td>
<td>Cardio-pulmonary resuscitation</td>
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<td>EIP on AHA</td>
<td>European Innovation Partnership on Active and Healthy Ageing</td>
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<tr>
<td>EOL</td>
<td>End-of-Life</td>
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<td>EOLCP</td>
<td>End-of-Life Care Plan</td>
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<td>EOLDCP</td>
<td>End-of-Life Decisions Care Plan for Person Lacking Capacity</td>
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<td>GSFCH</td>
<td>Gold Standards Framework in Care Homes</td>
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<td>HIQA</td>
<td>Health Information and Quality Authority</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<td>IAPC</td>
<td>Irish Association for Palliative Care</td>
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<td>IHF</td>
<td>Irish Hospice Foundation</td>
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<td>LMD</td>
<td>‘Let Me Decide’</td>
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<tr>
<td>LMD-ACD</td>
<td>‘Let Me Decide’ Advance Care Directive</td>
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<td>LMD-ACP</td>
<td>‘Let Me Decide’ Advance Care Planning</td>
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<td>LMD-PC</td>
<td>‘Let Me Decide’ Advance Care Planning &amp; Palliative Care Programme</td>
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<tr>
<td>LAFCI</td>
<td>Louth Age-Friendly County Initiative</td>
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<tr>
<td>LTC</td>
<td>Long-term care</td>
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<tr>
<td>NH</td>
<td>Nursing Home</td>
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<td>NHS</td>
<td>National Health Service (UK)</td>
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<td>PC</td>
<td>Palliative Care</td>
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<td>UCC</td>
<td>University College Cork</td>
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<tr>
<td>PCCF</td>
<td>Palliative Care Competence framework</td>
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<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
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<tr>
<td>SIACAD</td>
<td>Screening Instrument to Assess Competency to Complete an Advance Care Directive</td>
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<tr>
<td>SMMSE</td>
<td>Standardised Mini-Mental State Examination</td>
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<tr>
<td>SPELE</td>
<td>Staff Perception of End-of-Life Experience (SPELE) Tool</td>
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<td>QODD</td>
<td>Quality of Dying and Death questionnaire: last 7 day version</td>
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Executive Summary

This report document outlines the execution of a pilot study which involved the implementation of an advance care planning (ACP) programme using the ‘Let Me Decide’ (LMD) advance care directive (ACD), combined with a general palliative care (PC) educational programme in long-term care. The report is divided into three parts. Part 1 is the contextualisation of the project. This is where the literature is reviewed in relation to advance care directives, legal standing, palliative care interventions and relevant policy documents. Part 2 describes the content and process of implementation of the programme, along with findings from the evaluation of the implementation process, such as uptake of end of life care planning and challenges encountered. Part 3 presents the findings of the impact of the programme on the delivery of end-of-life care from both a qualitative and quantitative perspective. The report also outlines strategies for wider implementation of the programme and concludes with practice and policy recommendations.

The proposed activity outlined for this project, which was funded by a grant from the Irish Hospice Foundation, included:

- To refine an advance care planning program using the advance care directive ‘Let Me Decide’ for use in the Irish long term care setting. This includes refinement of the associated:
  - Policies
  - Training
  - Education material
- To implement the ‘Let Me Decide” program in LTC.
- To explore ways to communicate and make end-of-life care decisions for those with diminished capacity to make an advance care plan.
- To refine, develop and implement a clinical palliative care training program for use in the LTC setting
- To assess the effect of implementation of the program
- To assess the training and resources needed to initiate and maintain the operation and viability of this program.
- To provide information on how this program could be successfully disseminated nationally in a way that ensures its sustainability.

As with any project, issues and challenges arose. In most instances these were addressed without significantly affecting the scope of the project. However some issues such as the HSE South’s embargo on the use of the Liverpool Care Pathway (or adaptations of it) lead to some change to the original project remit.
The project was also adapted slightly so that it better complemented other initiatives in Palliative Care and Older persons in Ireland such as:

- The National Clinical Programme for Older People
- The National Clinical Programme for Palliative Care
- The Palliative Care Competence Framework, an AIHP, IAPC, HSE and IHF joint initiative.

In the first phase of this project, staff training was completed on advance care planning and palliative care in all of the participating nursing homes and community hospitals. Attention to staff feedback helped refine and adapt the programme for use in this setting.

Implementing an ACP programme into LTC settings presents many challenges for both management and nursing staff. Releasing staff for training is a considerable challenge both practically and financially for many LTC homes and for their staff. One of the main factors which staff felt would prevent them from attending training were: the location (they wanted it to be local), the time of the workshop (in particular if it was on their day off or interfered with commitments outside of work such as family life) and potential loss of pay.

This feedback received both verbally and from staff questionnaires triggered the development of an e-learning program to facilitate training in Palliative Care and separately in advance care planning using the “Let Me Decide” program.

The high prevalence of cognitive decline in the LTC population underlined the need to include the assessment of resident capacity as a key step in the completion of a valid ACD. Where residents lacked capacity to complete an ACD, families were encouraged to engage with healthcare staff in discussing end-of-life care (EOL) choices to help inform the completion of an EOL decisions care plan by the medical team for the incapacitated resident. Where possible, the resident was included in these discussions.

The program has been well received by both residents and their families. Following implementation, over 50% of residents had some form of end-of-life care plan in place (advance care directives; advance care plans; or end-of-life care plans for those with diminished capacity). Despite the high prevalence of cognitive impairment, at least 10% of residents had capacity to complete their own advance care directive. Of 70 residents who died during the study period, 84% had an end-of-life care plan in place (12% of these were advance care directives).

On the basis of challenges identified in this Implementation project, key recommendations for the effective implementation of ACP in LTC settings include:
Deliver a comprehensive ACP and palliative care education package to LTC staff

Implement a comprehensive policy on ACP, tailored to each nursing home’s individual requirements

Provide a structured ACP process for staff to follow

Clarify who is responsible for different aspects of the ACP process

Provide staff member(s) with specialist training to act as ACP facilitators and provide protected time for engagement in ACP

Provide appropriate educational material for residents and families (culturally-sensitive, appropriate literacy level, large print versions, bite-sized chunks)

Include education of GPs as part of programme implementation

Promote open communication between nursing staff, residents, families and doctors

Design systems within the nursing home so that ACD/ACP forms are accessible and all staff are aware of their existence and content

Provide information to out-of-hours doctors, emergency ambulance services, and local hospital emergency departments on the ACP programme

Promote communication and collaboration between LTC staff, GPs (including out-of-hours), emergency ambulance services and specialist Palliative Care doctors

Ensure ACD/ACP forms are easily interpretable by different groups of HCPs

Design systems for seamless transfer of ACP information between different healthcare settings

Implement quality assurance systems in place in the nursing home

Allow time for embedding.

Although it may be too late for many long-term care residents to complete their own ACD, the ‘Let Me Decide’ programme includes an option for structured end-of-life care planning for residents lacking capacity (to complete an ACD), which involves discussions with the resident, where possible, and the family. While end-of-life care planning was time-consuming to deliver, nursing staff were willing to overcome this and take ownership of the programme, once the benefits in terms of improved communication and enhanced peace of mind among all parties involved, became apparent in practice.

The program has been well received by staff. Results from focus groups indicate that all the homes have now embedded the programme as part of their care packages. In fact many have stated that the programme has transcended a number of care issues in the home and is much more than just a directive. Relationships with residents have deepened, there is a more open and honest environment with family, end of life care is now focused on symptom management, comfort and addressing spiritual care needs as opposed to crisis decision making and family
conflict. One director of nursing even stated that staff morale has improved as a result of the programme. It was unanimous that the programme should be rolled out to other care homes and all agreed that they would now not want to practice as healthcare professionals without it.

In terms of ensuring the sustainability and dissemination of the program to a national and potentially international level, various recommendations are made which include; education/training of staff on advance care planning and palliative care approach, MDT approach to end of life care, documentation of conversations with residents & family on wishes and preferences, providing external support to nursing homes, and introducing the concept of advance care planning on admission to long term care.

**Conclusion**
While delivering advance care planning to elderly LTC residents is both challenging and time consuming, this appears to be offset by the benefits in relation to promoting patient autonomy, bringing peace of mind to staff and families, improving communication between residents, their families and healthcare staff and increasing staff knowledge of palliative care approaches. The LMD-ACP programme offers a systematic approach to the implementation of ACP in combination with palliative care staff education in residential aged care settings, which has been demonstrated to enhance end of life care and maintain high standards of quality surrounding dying and death.
Part 1:

Contextualisation of the Project
Introduction

This Final Report outlines the execution of this Pilot Study which aimed to implement an advance care planning (ACP) programme using the ‘Let Me Decide’ (LMD) advance care directive (ACD), combined with a general palliative care (PC) educational programme.

ACP is a process of communication between an individual, their healthcare providers, and often those close to them about their values and preferences for their future treatment and care. The primary goal of ACP is to help people document their wishes in relation to what life-sustaining treatments they would or would not wish to receive in the future, in the event that they lose the capacity to make, or communicate, these decisions. One potential output of advance care planning is an advance care directive. This is a record (usually written) of an informed decision, made by a person with decision-making capacity, regarding the medical treatment they would wish to receive (or not receive) should they subsequently lose capacity. An ACD is only valid if it is made voluntarily, by a competent informed person and will only be used or acted upon if the person becomes incompetent to make medical decisions.

There are two types of ACD - instructional (living will) and proxy directives. The patient-designated healthcare representative, or proxy, is an adult nominated by the donor (person completing the directive) to act on his/her behalf. In an ACD, this proxy is nominated to make decisions about health or personal care on behalf of a person, in the event that the donor becomes incapable. This is termed a “proxy directive” and written evidence of this agreement must be present. It is essential that a discussion regarding wishes and preferences takes place between the proxy and the donor. An instructional directive (living will) is written by the donor and clearly states his/her wishes for certain treatments choices in the event of certain circumstances. The patient-designated healthcare representative/proxy may be asked to interpret the statement and potentially provide assurance of capacity at the time of decision making.

ACP in the LTC setting empowers residents to say how and where they wish to be cared for at the end of life. Studies have found that patients who had prepared ACDs received end-of-life (EoL) care that was strongly associated with their preferences (Silveira et al, 2010; Morrison et al, 2005). For patients, the perceived benefits of ACP include preparation for EoL care and death, the relief of anxiety, the avoidance of prolongation of dying, the strengthening of personal relationships, the relief of burdens placed on families, and the communication of future wishes (UK Dept. of Health, 2008). The process of ACP can also help family members prepare for the difficulties they may face in the future when their loved one dies (Caplan et al, 2006; Hertogh 2006; Vandervoort et al, 2014; Gillick et al, 1995).
ACP is a highly topical area given recent national publications of strategies and frameworks to improve end-of-life care (Health Service Executive and Irish Hospice Foundation, 2008; Hospice Friendly Hospitals, 2010; AllHPC 2013; Health Information and Quality Authority, 2010; McKeown et al, 2010), reports and recommendations on advance care directives and advance care planning (Law Reform Commission, 2009; Irish Council for Bioethics, 2007), and the anticipated legislation in the form of the General Scheme for Advance Healthcare Directives for Incorporating into the Assisted Decision-Making (Capacity) Bill 2013 (Irish Department of Health, 2013).

The National Clinical Programme for Palliative Care defines advance care planning as a:

"process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient’s condition with loss of capacity to make decisions and communicate these to others."

Since July 2009, the Health Information and Quality Authority (HIQA) have legal responsibility for the registration and inspection of all long term care centres for older people. Registration is a prerequisite for any home to provide care. Some of the recommended standards of care set out by HIQA in their ‘National Quality Standards for Residential Care Settings for Older People in Ireland’ (Health Information and Quality Authority, 2010) are highly pertinent to this project:

16.2 “The resident’s wishes and choices regarding end-of-life care are discussed and documented, and, in as far as possible, implemented and reviewed regularly with the resident. Where the resident can no longer make decisions on such matters, due to an absence of capacity, his/her representative is consulted”.

16.3 In accordance with the resident’s assessed needs, referrals are made to specialist palliative care services so that an integrated multi-disciplinary approach to end of life care is provided.

16.4 Staff are provided with training and guidance in end-of-life care as appropriate to their role

16.5 The residential care setting has facilities in place to support end of life care so that the resident is not unnecessarily transferred to an acute setting except for specific medical reasons, and in accordance with his/her wishes

The area of palliative care, end-of-life care, advance care planning and advance care directives is vast. This Pilot Implementation project deals with all of these areas. In light of this, there follows a brief summary of the scope of these areas as they relate to this project:

- Advance Care Directives (ACD) and Advance Care Planning (ACP)
- Legal standing of ACDs in Ireland
- Decision-making for the person with diminished capacity
- The ‘Let Me Decide’ advance care planning intervention
• Palliative care and end-of-life care in long term care settings
• The ‘Let Me Decide’ palliative care intervention in this Pilot Implementation project
• Potentially avoidable hospitalisation of LTC residents at the end of life
• Challenges in implementing ACP in long-term care settings
• Relevant publications
• Systematic review of ACD in long term care.

1.1 Advance Care Directives and Advance Care Planning

There have been many developments in end-of-life care over recent decades. Medical advances allow many diseases once fatal, to be cured. Life can be sustained, where death would once have been certain; however such prolongation of life is not always appropriate, in a patient’s best interests, or indeed what the patient would have wanted. Advance care directives evolved out of the fear of unwelcome treatment.

Paternalism in medicine has been replaced with a growing respect for patient autonomy. Patient involvement in medical decision making is encouraged, though not always possible e.g. through mental incapacity. We know that most Irish older people (94%) want to be consulted about end-of-life issues such as resuscitation and many (63%) want to be involved in medical decision making (Cotter et al, 2009; Wilkinson et al, 2008). ACDs and advance care planning have patient choice at their core. In the U.S., about 70% of those who die have an ACD (Teno et al, 2004). Irish knowledge of ACDs, and indeed many issues relating to end-of-life care, is poor (McCarthy et al, 2010a). In a recent nationwide survey, 71% had never heard of an ACD, and only 5% claimed to have drafted one (McCarthy et al, 2010a). ACDs are not yet part of our culture.

There is evidence that ACDs and advance care planning (ACP) can improve satisfaction with end-of-life care and reduce family anxiety, depression and stress. Two recent systematic reviews have found positive effects of ACP on the quality of EoL care (Houben et al, 2014; Brinkman-Stoppelenburg et al, 2014), including increased concordance between preferences for care and delivered care. In an Australian randomised controlled trial (RCT) carried out among elderly hospital inpatients, a systematic model of patient-centred ACP improved the care given at the end of life, improved patient and family satisfaction with hospital care, and reduced stress, anxiety and depression in surviving relatives (Detering et al, BMJ 2010). ACDs and advance care planning also improve compliance with patient’s wishes (Detering et al, BMJ 2010).

Implementing ACP in the LTC setting empowers residents to play an active role in their own personal health management and places them at the centre of the decision-making process. It proactively promotes their autonomy by enabling their wishes to be documented before potential loss of capacity to make decisions or to communicate their wishes. In long-term care, healthcare decisions are often made when a person has
become gravely unwell, at which time family may feel overwhelmed and emotionally distressed. Discussing end-of-life care in advance, in an informed way, may help to prevent healthcare decisions being made in such “crisis” situations and may prevent the initiation of unwanted treatment.

1.1.1 Common criticisms of Advance Care Planning and ethical considerations

While the evidence suggests that ACP has many positive effects, research has also identified a number of challenges that proponents of ACP need to address. Findings from some studies have challenged the accuracy of surrogate decision-making by proxies nominated in ACDs. An RCT conducted in the United States of America (USA) among 401 outpatients aged 65 years or older and their self-designated surrogates, found that having access to a patient’s instructional ACD did not significantly improve the accuracy of the surrogate’s predictions of the patient’s preferences for life-sustaining treatments in different illness scenarios - in short, the directive had little or no impact on the decisions made by surrogates (Ditto et al, 2001). Similarly, in a study of EoL decision-making involving African-American dialysis patients, it was found that the confidence that surrogates had that their decision-making was consistent with patients’ wishes, had little association with their actual understanding of patients’ values and goals (Song et al, 2012). This identified gaps between proxies’ knowledge of patients’ preferences and patients’ actual preferences, and suggests the need to develop strategies aimed at improving communication and understanding among the stakeholders involved in decision-making.

Another common criticism of ACP is that EoL treatment preferences can change over time as people may re-evaluate what they see as an acceptable quality of life. A recent systematic review of the evidence, with regard to the stability of EoL preferences, found that in 17 out of 24 studies, more than 70% of patients’ preferences for EoL care were stable over time (Auriemma et al, 2014). Patients who had engaged in ACP and those who were seriously ill, most commonly had stable preferences for future treatments. Preferences to forgo therapies were generally more stable over time than preferences to receive therapies. Although most patients had stable EoL preferences, this review indicates that a significant number (up to 30%), do change their minds; in particular, their choices about the treatment that they wish to receive may change over the course of their illness. This prompts the need for the regular re-evaluation of ACDs, in particular when patients experience a change in health status (Resnick & Andrews, 2002; Janssen et al, 2012).

Finally, in the absence of published evidence, there are particular concerns in relation to the effectiveness and impact of ACP in people with cognitive impairment and dementia (Dening et al, 2011). A 2012 systematic review of four studies found limited evidence for the effectiveness of ACP in people with cognitive impairment/dementia in terms of improving documentation of patient preferences for care, reduction in hospitalisation rates, and increased use of hospice services (Robinson et al, 2012). Three out of the four
studies reported the deployment of formal processes of capacity assessment which determined that only up to 36% of participants were judged to have capacity. This indicates that, if capacity is regarded as a pre-requisite for the discussion of ACP, it may be too late for many nursing home residents with dementia to engage fully in ACP. At the very least, it underlines the importance of ascertaining the wishes of dementia patients early in the disease, before their ability to consider their future care is compromised. In addition, it suggests the need to involve family members in the process, though caution is advised since the wishes and preferences of people with dementia and their loved ones may differ (Dening et al, 2013). However, family members may be uniquely positioned to relay the wishes of people with dementia, based on conversations that may have taken place prior to loss of capacity.

Factors identified as important in the completion of ACDs by individuals with dementia, include the stage of dementia, the degree of certainty of their wishes for EoL care, and the degree of contentment or distress experienced by the demented individual when engaging in the ACP process (Rempusheski et al, 2000). A fundamental ethical question that the completion of an ACD prompts, is whether or not a person with severe dementia should be bound by the decisions made by that person before they developed dementia. In short, it is not self-evident that the individual pre- and post-dementia are one and the same person. This uncertainty is intensified if the choices made by the individual while competent, conflict with what healthcare professionals believe is in the best interests of the now demented person (Dworkin et al, 1993).

However complex the challenges in introducing ACP to LTC residents with cognitive impairment, the stakes are, nevertheless, very high. For example, a prospective cohort study of hospital transfers among 323 nursing home residents with advanced dementia in the USA, concluded that the majority of their hospitalizations were due to infections and were therefore potentially avoidable. ACP in the form of a do-not-hospitalise (DNH) order was the only identified modifiable factor in that study associated with avoiding hospitalisation (Givens et al, 2012).

1.2 Legal standing of ACDs in Ireland

The first ‘living will’, a form of advance care directives, was drafted in 1967 by Luis Kutner, a US attorney. In 1976, the state of California enacted the first legislation for advance care directives in the U.S. All 50 states now have legislation. ACDs have a legal basis in the United Kingdom since 2009 when the Mental Capacity Act 2005 was enacted. Though Ireland currently lacks a legislative framework for ACDs, legislation is proposed under the General Scheme for Advance Healthcare Directives for Incorporating into the Assisted Decision-Making (Capacity) Bill 2013 (Irish Department of Health, 2013).
While the current lack of legislation makes the status of advance directives unclear, it is anticipated that the use of a valid ACD (i.e. completed voluntarily by an informed, capable adult) would not give rise to any substantial legal challenges. Dr. Deirdre Madden has stated:

“If created by a competent informed person, an ACD would be upheld as valid” (Madden, 2002).

This view is also supported by Dr. Simon Mills who has stated that an:

“Advance statement, properly made and containing no directives that were themselves unlawful, would be acceptable to Irish Law” (Mills, 2007).

In 2007 the Irish Council for Bioethics (ICB) published a detailed report on advance care directives following a consultation process which sought the views of the general public and key stakeholder groups. It stated that:

“it should be possible for an individual to make a legally binding advance directive, provided the decisions within the directive are themselves legal. The weight of legal opinion in the Republic of Ireland recognises the right of competent adults to decide on the nature of their medical treatment. Refusal of treatment by a competent individual to facilitate a natural death is permitted, but this right does not extend to allow euthanasia or assisted suicide.” (Irish Council for Bioethics, 2007)

In its report, the ICB supports the right of competent adults to prepare an advance care directive to govern future medical treatment, should they become incapacitated, in a way that reflects their personal values and beliefs. The need to develop a legal framework to facilitate the use and implementation of advance directives in Ireland was also underlined in the ICB’s report.

Overall, respondents to the ICB had positive views about the relevance and importance of advance care directives. Importantly in our own survey of 649 healthcare professionals in Ireland, though 84% knew about ACDs, only 38% had experience of them and only 35% had experience of patients with one. Overwhelmingly they felt positively about ACDs (92%), 75% would recommend people to complete one and the majority (79%) said they would feel comfortable following the wishes in an advance care directive if presented with one.

The ICB takes the view that:

“for the decisions outlined in an advance directive to be considered legally binding, the directive should state, in clear and unambiguous terms, both the specific treatments to which the directive relates and the situations to which these decisions are intended to apply. In other cases, individuals may wish to outline general preferences or a value statement regarding their future treatment and care in an advance directive that would be taken into account as opposed to being strictly legally binding. The ICB considers that such advance directives should also be accepted, but it recognises that such general statements may not be legally binding and may require more interpretation before they can be adhered to.”
Recently, the Irish government have proposed new legislation in relation to ACDs in the form of the ‘Draft General Scheme for Advance Healthcare Directives for Incorporating into the Assisted Decision-Making (Capacity) Bill 2013’. As part of a Public Consultation process on this proposed legislation, members of the ‘Let Me Decide’ research team submitted a response to the Department of Health on their views and suggestions in relation to the Draft General Scheme for Advance Healthcare Directives for Incorporating into the Assisted Decision-Making (Capacity) Bill 2013. This submission is shown in Appendix 1.

1.3 Decision making for the person with diminished capacity

Currently, the appointment of a proxy medical decision-maker, as part of an ACD, has no legal basis in Ireland. Ultimately, if an individual without an ACD (or advance care plan) loses the capacity to make healthcare decisions, the responsibility falls to their attending physician. However, even amongst doctors themselves there is some misunderstanding in this area. In our survey of 165 Irish doctors only 35% knew who legally had responsibility, the majority (58%) incorrectly felt it rested with the family. The Law Reform Commission states:

“The law on consent to medical treatment may need to be addressed because of the widespread false belief that family members and carers may make valid decisions on behalf of people who do not have legal capacity.” (Law Reform Commission, 2008)

In its ‘Guide to Professional Conduct and Ethics for Registered Medical Practitioners’ the Irish Medical Council advises that for patients lacking capacity (and who are not Wards of Court), the responsibility for medical decision-making falls to the attending physician, although consultation with the patient’s family is advised to determine what the patient would have wanted (Irish Medical Council, 2009).

In its recent report, the Irish Council for Bioethics proposes that the author of an advance healthcare directive:

“can nominate another person (the proxy) to be involved in the healthcare decision-making process on the author’s behalf should he/she become unable to express his/her wishes. The proxy can make a healthcare decision based solely on his or her judgment of what the author would want in that situation. Alternatively, the proxy could interpret for the members of the healthcare team the author’s wishes regarding healthcare in a given situation, as set out in the advance directive. This would enable the proxy to avail of the most up-to-date medical information and assess the wishes of the author of the directive in light of this new information.” (Irish Council for Bioethics, 2007)

The majority of residents in LTC settings in Ireland have cognitive impairment, but many no longer have the legal capacity to complete an ACD. Often decisions regarding
end of life care e.g. resuscitation preferences are not addressed until an individual becomes seriously unwell, when such decisions become urgent. This results in crisis decision-making. The healthcare staff who have to make such decisions are often meeting the critically ill patient for the first time. When families are consulted in these situations, they are often emotionally distressed and there is little time to clarify their understanding of prognosis or e.g. the likely success from resuscitation, or for them to reflect on what their relative would have wanted. One of the aims of this Pilot Implementation project was to assess whether it is possible to prevent crisis decision-making for LTC residents (without an ACD) who lack capacity by making decisions in advance.

While residents who lack decision-making capacity are ineligible to complete an ACD, their views on how they would like to be cared for at the end-of-life remain important and any views expressed are noted. Unfortunately for some residents their cognition may be so diminished as to preclude any expression of wishes relating to this area.

1.4 The ‘Let Me Decide’ Advance Care Planning Intervention

The ‘Let Me Decide’ Advance Care Planning programme (LMD-ACP) offers a structured approach to EoL care planning in the LTC setting for both residents with and without capacity to complete an advance care directive/plan. The programme was initially designed for use in Canada and was successfully implemented in LTC in several studies, including a large randomised controlled trial (Molloy et al, 2000). In this trial, Molloy and colleagues compared intervention LTC homes using ‘Let Me Decide’ with control homes. In the intervention homes, 49% of competent residents and 78% of families of incompetent residents completed a ‘Let Me Decide’ end-of-life care plan (EoLCPs). The rate of hospitalisation was lower in the intervention homes than in controls (0.27 vs 0.48, p=0.001), representing a statistically significant reduction in the cost of care with no significant difference in resident or family satisfaction with care. In Australia, a controlled study that utilised the LMD-ACP found that ACP, alongside implementation of a hospital-in-the-home scheme, can result in decreased hospital admission and mortality of nursing home residents (Caplan et al, 2006).

‘Let Me Decide’ has received enthusiastic support from a wide variety of people including doctors, nurses, patients, families, lawyers, clergy and advocates for the elderly. Publications relating to ‘Let Me Decide’ include over 30 peer-reviewed academic papers and a short book published in seven languages; an Irish edition of the book was published in 2011 (Molloy et al, 2011). In a recent review of published studies on ACP programmes in LTC homes, the LMD programme was classed as dementia-friendly based on a set of criteria in the Dementia Policy Lens Toolkit (Wickson-Griffiths, 2014).

Key elements of the LMD-ACP programme include education of residents about EoL care and a formal assessment of capacity to understand the implications of choices
made in completing a LMD-ACD. The assessment of capacity in clinical practice is a complex process since it relates to the ability to make specific decisions and may vary depending on the actual decision being made (Sampson & Burns, 2013). The LMD-ACP process uses a specially developed tool [Screening Instrument to Assess Competency to Complete an Advance Directive (SIACAD)] to assess capacity to complete an ACD (Molloy et al, 1996). While a resident who lacks capacity is ineligible to complete an ACD, any expressed views in relation to EoL care are documented. Families are invited to meet with healthcare staff to discuss EoL care for their relative, to help inform the completion of an ‘End-of-Life Decisions Care Plan for Person Lacking Capacity’ by the medical team.

The LMD-ACP is designed to enable the individual to define and document their healthcare wishes in a clear fashion. It includes a menu of healthcare options that the resident would choose in (i) their current state of health if they required treatment, and (ii) if their state of health/level of functioning became unacceptable to them and was irreversible. Competent residents are encouraged to include a close family member or friend in the ACP process. As part of the LMD programme, an individual may nominate a proxy decision-maker whom they would like to be consulted in the event that they lose capacity.

There are several important features of the LMD-ACP form which facilitate its interpretation by healthcare professionals (see Table 1). These include documented information on the cognition of the individual (their standardised mini mental state examination (SMMSE) result), and the capacity of the individual to complete the LMD-ACP, as assessed using the ‘Screening Instrument to Assess Competency to complete an Advance Directive’ (SIACAD), which is specific to LMD-ACP (Molloy et al, 1996). In addition, as part of the LMD process, the individual’s understanding of the wishes expressed in their ACD have been discussed with, assessed and witnessed by their doctor, and the program ensures that the ACD is made voluntarily and without undue coercion.

Table 1. Key features of the ‘Let Me Decide’ Programme for use in long-term care settings

<table>
<thead>
<tr>
<th>Feature</th>
<th>Description</th>
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<tbody>
<tr>
<td>The resident’s cognition is assessed using the SMMSE</td>
<td>(Molloy et al, 1991)</td>
</tr>
<tr>
<td>Includes structured education of residents and families about ACP</td>
<td>(end-of-life care planning)</td>
</tr>
<tr>
<td>The resident’s capacity to complete the LMD-ACP is assessed using the</td>
<td>SIACAD (Molloy et al, 1996)</td>
</tr>
</tbody>
</table>
| The LMD-ACP form includes a menu of healthcare options that the resident is asked to choose for two different situations: (i) in their current state of health, if they became seriously ill and required life-saving treatment and (ii) if their state of health/level of functioning had become unacceptable to them and was
irreversible, and they became seriously ill and required life-saving treatment

- When filling in the LMD-ACD form, a person can make a ‘Personal Statement’ indicating which irreversible states of health/levels of functioning would be unacceptable to them
- Healthcare choices relate to three different areas: (i) CPR or No CPR; (ii) Basic Feeding or Tube Feeding; and (iii) Level of treatment: Palliative-Comfort Care or Limited Care or Surgical Care or Intensive Care
- The individual’s understanding of the wishes expressed in the ACD have been discussed with, assessed and witnessed by their doctor.
- Residents are encouraged to include a close family member/friend in the ACP process
- The individual may nominate a surrogate decision-maker (healthcare proxy) whom they would like to be consulted in the event that they themselves lose capacity
- The LMD programme ensures that the ACD is made voluntarily without coercion or undue influence
- The form is witnessed by the senior nurse involved in the advance care planning process with the resident

For residents lacking capacity to engage in care planning, the LMD process has been modified to reflect the fact that healthcare decisions made by relatives or proxies currently have no legal basis in Ireland. The following process is followed:

- Their family are approached to see if they are interested in consenting to the care planning process for their relative.
- Their family is asked what they think the resident would have wanted.
- If the family do not know, they are asked what they think he/she would have wanted, based on their knowledge of the resident’s values and goals.
- The family are educated to ensure that their views are informed.
- This process offers the family time to come to terms with any issues they may have and to discuss and debate them.
- The views of the family are documented.
- The resident’s primary doctor is asked to make an end-of-life care plan relating to place of care and extent of care e.g. cardio-pulmonary resuscitation (CPR), taking into consideration the views of the resident (and their relatives), the resident’s medical condition and their prognosis.
- The resident’s family are made aware that this care plan is not legally binding and that ultimately, for a person lacking capacity to make decisions regarding healthcare, the responsibility for such decisions rests with the doctor treating them at the time.
- If the family request treatment incongruent with that which the doctor feels to be appropriate and in the resident’s best interest, a second opinion is offered.

Involving families in care planning may help to avoid healthcare decision-making in a crisis situation and to increase the chances of the resident experiencing a “good” death, thereby positively impacting on the bereavement process. Previous studies have shown
that families of people who lack decision making capacity are willing to discuss these issues and consistently ask for low levels of intervention.

A copy of the ACD/"EOL Decisions Care Plan" accompanies any resident who is transferred out of the home (three copies are kept in the resident's notes), along with a letter explaining the study and the legal background to ACDs in Ireland.

1.5 Palliative care and end-of-life care in long-term care settings

Palliative care (PC) focuses on the total well-being of the person, embracing their physical, psychological, emotional, social, cultural and spiritual needs. It has a role in all life-limiting illnesses, not just cancer, and in all settings. Access to specialist palliative care should be based on need, not diagnosis. This is reflected in Irish policy documents and in changing practices (Health Service Executive and Irish Hospice Foundation, 2008; Health Information and Quality Authority, 2010; Department of Health & Children, 2001). The World Health Organisation (WHO) defines Palliative Care as:

> “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. Effective palliative care aims to:

- provide relief from pain and other distressing symptoms;
- affirm life and regards dying as a normal process;
- neither to hasten or postpone death;
- integrate the psychological and spiritual aspects of patient care;
- offer a support system to help patients live as actively as possible until death;
- offer a support system to help the family cope during the patients illness and in their own bereavement;
- use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- enhance quality of life, and help to positively influence the course of illness.

In the next 30 years, life expectancy is predicted to reach 86.5 years for men and 88.2 years for women. The population aged over 65 years will double to 1.4 million (5% of this group reside in LTC). Increases will be even more dramatic in those over 85 years, of whom 21% currently reside in LTC (Central Statistics Office, 2008). The ESRI estimates over the next 10
years, about 1000 extra LTC beds will be required each year to keep pace and accommodate the growing demand for LTC (Layte, 2009).

How we treat our dying is a reflection of our societal values, and yet there is evidence in many countries including Ireland, of suboptimal EOL care in the LTC setting including:

- Inappropriate transfers to acute hospitals of residents at or near the EOL
- Lack of resources, skills, confidence and knowledge to provide high quality end-of-life care (Seymour et al, 2011; Hall et al, 2011; Whittaker et al, 2006)
- Unmet palliative care needs in many dying in LTC (Reynolds et al, 2002; Torvik, 2009) and relatives’ dissatisfaction with care (Wetle et al, 2005)
- Varying degrees of awareness of LTC residents’ wishes with regard to care.

The location and face of death and dying has changed in Ireland. It has moved out of the home where it once most commonly occurred, to hospitals and long-term care (LTC). Whereas, in 1885, 85% of deaths in Ireland occurred at home, by 2005 this figure had reduced to 25% . Overall, 48% of deaths now occur in hospitals, 20% in LTC and 4% in Hospices (McKeown et al, 2010). Increasingly, LTC is where many of us will spend our last months and where we will die. The growth in the proportion of deaths occurring in LTC is a trend which has been seen in many other countries including the United States of America (USA) (Reynolds et al, 2002), the United Kingdom (UK) (Cartwright, 1991) and Australia (Hunt, 1997). Considering the rising life expectancy, increasing proportion of older adults, the growing number of people with dementia, and the underlying societal changes in Ireland, this trend is likely to continue over the coming decades.

Overall internationally, the quality of end of life care in Ireland is ranked highly (Economist Intelligence Unit, 2011). A recent audit of end-of-life care in acute and community hospitals in Ireland, found that although we compare favourably with hospitals in the US, UK and France, significant deficiencies still exist. Consequently, quality standards for end-of-life care in hospitals were published (Hospice friendly Hospitals, 2010; McKeown, 2010). They join other international strategies, frameworks and initiatives such as the Gold Standards Framework (GSFCH) and the Liverpool Care Pathway for the dying in the UK, in endeavouring to improve end-of-life care in the general palliative care setting (UK Department of Health, 2008; Ellershaw & Wilkinson, 2003). Many initiatives such as the GSFCH, contain a prompt for advance care planning, but don’t use ACDS, such as “Preferred Priorities for Care” (NHS National End of Life Care Programme, 2013), or “Respecting Patient Choices” (Respecting Patient Choices, 2013) or instructions as specific as in the “Let Me Decide” ACD (Molloy, 2011). Using a combined end-of-life care initiative and a specific ACD such as “Let Me Decide”, is relatively novel.

In Ireland, Palliative care services are structured in three ascending levels of specialisation: Level 1- Palliative Care Approach, Level 2- General Palliative Care and Level 3- Specialist Palliative Care. Primarily it is general practitioners, nursing staff and care workers, who deliver general palliative care and end-of-life care for most people dying in the community or
LTC. If more and more of us will die in LTC, then it is important that nursing homes are equipped and trained to provide high quality of end-of-life care consistent with a patient's wishes. There is evidence, however, that the resources, skills and knowledge to provide such end-of-life care to a high standard, is often lacking (Seymour et al, 2011; Hall et al, 2011; Whittaker et al, 2006). Many dying in LTC have unmet palliative care needs (Reynolds et al, 2002; Torvik, 2009) and bereaved carers are often dissatisfied with their relatives’ end-of-life care (Wetle, 2005).

1.6 The palliative care intervention in this Pilot Implementation project

In this Pilot Implementation project, the palliative care initiative aimed to improve the provision of general palliative care within LTC, and facilitate recognition of when an appropriate, timely referral to specialist palliative care would be of benefit. One objective of the intervention was to enable all staff to confidently and appropriately apply palliative care principles, in their approach to patients, and improve the ability of some to deliver general palliative care to patients at the end-of-life, through further training. Previous trials of the “Let Me Decide” ACD in LTC showed that the majority of residents completing the directive chose to remain in their nursing home at the end-of-life, to die cared for by the staff they trust and are familiar with (Molloy et al, 2000). They did not want to be transferred out to the local hospitals. Similar trends were noted in this project.

The Irish Medical Council (2009) states:

“Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible.”

The palliative care programme is predominantly educational; symptom based, at a general (non-specialist) palliative care level, and although focusing on communication and care as death draws near, is likely to also benefit patients earlier in the course of their illness. The programme consists of:

- an educational programme
  - The nature of palliative care
  - Loss, grief and bereavement
  - Communication skills
  - Ethical and legal issues
  - Symptom assessment and management
- minor organisational changes to ensure continuity of care
- creating clear pathways of access to external resources, when needed.

The aim of this programme was to facilitate and promote the provision of high quality, holistic, and patient-centred end-of-life care, through education and cyclical quality improvement measures. Implementing ACP in the LTC setting empowers residents to
make an informed choice as to where and how their end-of-life care needs would best be met. This palliative care intervention aims to improve the quality and efficiency of general palliative care for LTC residents by equipping staff to:

- Appropriately apply the palliative care approach
- Understand the emotional needs of the dying
- Understand potential legal and ethical issues surrounding death
- Communicate effectively with dying residents and their families
- Recognise and optimally manage symptoms to ensure patient comfort and dignity
- Be aware of specialist palliative care resources available and how to access them.
- Recognise when an appropriate, timely referral to specialist palliative care services would be of benefit.
- Provide support to those experiencing loss and grief.

1.7 Potentially avoidable hospitalisation of LTC residents at the end of life

The majority of older adults do not want interventions at the end of life, but are willing to accept interventions that will keep them comfortable (Resnick & Andrews, 2002; Silvester et al, 2013a). A National Audit Office Report in England suggested that about half of care home residents who died in hospital could have died in LTC or at home, and that the frail elderly were the most vulnerable to hospitalisation (UK National Audit Office Report, 2008). Several studies have found that ACP may help to prevent avoidable hospitalisation of nursing home residents (Molloy et al, 2000; Teno et al, 2007; Levy et al, 2008; Caplan et al, 2006).

A study of deaths in 2010 among LTC residents admitted to three public acute hospitals in Cork City (which provide the majority of acute hospital beds for the county) found a total of 59 deaths among 652 patients who were recorded as long-term care residents on admission to hospital (Martin et al, 2012). These numbers exclude residents attending the emergency departments not requiring admission. Taking the 3,447 LTC beds in the county of Cork, and extrapolating from national data, these figures crudely suggest that about 20% of all LTC residents in the county are admitted to hospital each year and approximately 10% of these subsequently die in hospital.

Of those LTC residents who died in hospital, almost 10% died within hours of arrival, some (5%) on trolleys in the emergency department and some in transit there. It was often not clear who initiated or requested transfer, and one resident was hospitalised against their treating doctor’s judgement as the family requested transfer. Most (61%) of the LTC residents who died in hospital were severely unwell on admission, most often with pneumonia (n=28), a further 20% had a diagnosis of sepsis (mainly
urosepsis). Patient charts were independently reviewed by three investigators and depending on the criteria used to judge “inappropriateness”, 14-37% of transfers (8 - 22 cases) may have been inappropriate or avoidable. Time from admission till death ranged from hours to 65 days (median time till death was 8 days). It is noteworthy that several patients may have had a missed opportunity to transfer back to the nursing home.

The use of ACDs evolved out of the fear of unwelcome treatment. Giving LTC residents the choice to avoid unnecessary or unwanted transfer to hospital may avoid futile treatment interventions at the end-of-life, thereby improving the quality of their end-of-life care while protecting their dignity and promoting their autonomy. Research indicates that healthcare professionals tend to treat patients who lack decision-making capacity more aggressively than they would a relative in similar circumstances, and would choose even less aggressive treatment for themselves (Coffey et al 2013; Darzins et al, 1993; Harrison et al, 1995). This highlights the importance of knowing a person’s wishes in relation to their future medical care.

1.8 Challenges in implementing ACP in long-term care settings

In addition to the standard criticisms of ACP, several barriers and challenges to its implementation in LTC settings have been identified. These include the lack of education and experience of staff; uncertainty about legal responsibilities and clinical roles; time constraints; the education of residents and their families; collaboration among health professionals; the use of standardized procedures and documentation; and the perceptions, understanding and concerns of residents/patients. These are discussed below in the context of the literature.

**Staff education and experience**

Healthcare workers cite a lack of knowledge and experience using ACDs as barriers to their implementation (Molloy et al,1997a). Many studies have identified education and practical experience as crucial to developing confidence among healthcare staff to engage in ACP discussions with patients (Stone et al, 2013; Markson et al, 1994; Lipson et al, 2004). In a study assessing implementation of the Gold Standards Framework for Care Homes (GSFCH), education and role-modelling of ACP were identified as important for staff to develop the knowledge, skills, and confidence necessary to engage in EoL discussions (Stone et al, 2013). Doctors also cite difficulties with communication as a barrier to delivering ACP, and anxiety on their part that ACP discussions might cause distress to patients, although the latter may be unfounded (Detering et al ,BMJ 2010). Perceived barriers to GP engagement in ACP with patients include a lack of skills to deal with vague requests, difficulties defining the right moment, the attitude that patients should initiate ACP, and fear of depriving patients of hope (De Vleminck et al, 2013).
**Legal responsibilities and clinical roles**

Staff from all disciplines need to be confident in following advance care plans (ACPs) and supported so they do not fear criticism if they follow one that requests that active treatment is not given (Sampson & Burns, 2013). Variations in legal frameworks for ACP across different countries may lead to uncertainty among staff about ‘what is legally binding’ and make staff wary of following ACPs, particularly when decisions have to be made in times of acute ill health and crisis (Robinson et al, 2013).

A qualitative study of professionals’ experiences of the implementation of ACP in dementia and palliative care, in the United Kingdom (UK), identified a lack of ‘ownership’ of the ACP process (Robinson et al, 2013). Findings indicated that ‘no single professional group considered assessment of capacity as their responsibility’, while participants viewed the assessment of capacity as a specialist role. This highlights a need for greater clarity regarding the roles and responsibilities of the different professional groups involved, and suggests that specialist skills and experience may be required to deliver the more complex aspects of ACP.

**Timing of initiation of ACP discussions**

Lack of time and lack of continuity are frequently cited as barriers to ACP by both doctors and nurses (Spoelhof & Elliott, 2012; Sulmasy 1996; Ryan et al, 2012). Difficulties in obtaining time for education of patients, and obtaining time from family members and doctors to discuss treatment decisions, were identified as two important barriers in implementing an ACP programme by community nurses in Canada (Molloy et al, 1997b). A focus-group study among 23 palliative care community nurses in England, identified one of the challenges to undertaking ACP as the timing of when to initiate such discussions (Seymour et al, 2010).

**Educating residents with cognitive impairment and supporting families**

The completion of an ACD is a complex process and educational materials need to be adapted to the literacy level of the target population (Sudore et al, 2007). Failure to grasp the concept of an ACD has been identified as a barrier to completion by Molloy et al (1997). Even in mild dementia, patients may find it difficult to project themselves into hypothetical future health states (a key part of the ACP process) and will frame their views according to their current situation (Dening et al, 2013).

Finally, there is a need for increased education and support for families around issues of EoL care decisions in advanced dementia (Reinhardt et al, 2014). In the UK, a qualitative study among people with mild to moderate dementia and their family carers, identified five main barriers to undertaking ACP. These were lack of knowledge and awareness, difficulty in finding the right time, a preference for informal plans over written documentation, constraints on choice around future care, and lack of support to make choices about future healthcare (Dickinson et al, 2013). The perception that dementia is
not a life-limiting illness may also present as a barrier to successful implementation of ACP in dementia care (Dempsey et al, 2013).

**Collaboration among healthcare practitioners**

Four requisites for successful implementation of ACP in residential aged care facilities were identified by an Australian case study. These include: the expert nurse, discussion, education, and involvement of a multidisciplinary team (Jeong et al, 2010). A qualitative study of the implementation of the GSFCH in nine care homes in the UK found that one of the perceived barriers was gaining the cooperation of general practitioners (Hall et al, 2011). In another British study, an evaluation of the impact of the GSFCH in 95 nursing homes found that only 33% of managers identified improved collaboration with primary care and specialist practitioners as one of the main outcomes (Badger et al, 2012). Challenges to collaboration included working with large numbers of general practitioners, out-of-hours services and access to specialist practitioners.

**The importance of standardised procedures and documentation**

One of the biggest challenges in delivering effective ACP is to develop systems to ensure that residents' ACDs/ACPs are easily retrievable, up-to-date, and easily transferable between different care settings (Billings, 2012) The use of standardised procedures and accessible standardised documentation will improve the quality of processes and outcomes of ACP in the LTC sector and increase professionals' confidence in adhering to ACPs (Silvester et al, 2013a; Detering et al, BMJ 2010). A recent study of the quality of ACP policy and practice in LTC facilities in Australia, concluded that a systematic approach to the implementation of ACP in LTC is required to ensure best practice is implemented and sustained (Silvester et al, 2013b). One example has been the successful use of a targeted electronic medical record intervention to increase completion of ACP discussion notes by the primary clinician in seriously ill nursing home patients (Lindner et al, 2007). One of the key targets for research identified by Billings (2012) was the development of more effective and standardised approaches to ACP discussions (Billings, 2012).

**Perceptions, understanding and concerns of residents/patients**

Barriers may differ depending on the healthcare setting and the patient population. An RCT of a patient educational intervention, aimed at increasing advance decision-making among elderly outpatients, found that patient procrastination, rather than lack of information or access to documents, appeared to account for the low completion rates in the intervention group (Sachs et al, 1992). Schickedanz et al (2009) found that the perception of ACP as irrelevant was the most commonly identified theme in a descriptive study of barriers to engaging in the ACP process, among older adults attending a general medicine clinic.

Although patient education and understanding of ACDs is important, and can result in more positive attitudes, it does not translate to completion of ACDs in all patients
People with dementia and their carers may benefit from talking about future healthcare wishes but may not want to commit these to paper (Robinson et al, 2013). A qualitative study of the views of dementia patients and family carers about future planning, identified a preference for informal plans over written documentation as a barrier to undertaking ACP (Dickinson et al, 2013).

The preference for having an ACD can be influenced by individual attitudes, cultural beliefs, health conditions, and trust in healthcare professionals (Jones et al, 2011; Beck et al, 2002). One study from the USA highlighted barriers to completing an ACD on the patient’s part, to include a lack of knowledge, a fear of burdening family, and a desire to have the doctor initiate the discussion (Spoelhof & Elliott, 2012). In Germany, where recent legal changes make non-compliance with ACDs a criminal offence, a critical review of studies on ACDs concluded that there remains low use, poor communication, fears about ACDs’ purpose and possible abuse, and some non-compliance, despite an increasing awareness of ACD’s (Evans et al, 2012).

Finally, qualitative interviews of 63 residents recruited from six care homes in the UK identified that, central to the older person’s ability to discuss EoL care is their acceptance of being in a care home, the involvement of family members in making decisions and the extent to which they believed they could influence decision making within their everyday lives (Mathie et al, 2012).

1.9 Relevant publications

Survey on Irish Attitudes to death, dying and bereavement

A survey of a nationally representative sample of 891 Irish adults on their attitudes towards dying, death and bereavement was recently commissioned by the Irish Hospice Foundation (Weafer, 2014). Findings indicate that only one third of the Irish adult population believe that discussion around death and dying is sufficient in Irish society, with almost six in ten adults saying that the level of discourse is not enough. A substantial number of respondents said they would be comfortable discussing death and dying, suggesting that Irish adults are at least open to the possibility of discussing death and dying more than is the case with the current level of public discourse. Three-quarters of respondents nominated their home as their preferred place of care if they were dying. The proportion of people saying they would like to be cared for in a hospice increased (and the proportion preferring homecare decreased) with respondents’ age, and when they were asked to consider their preferred place of care if their death was imminent. Only 6% of respondents wanted to be cared for in a hospital at the end of life.

When asked whether they had taken any action in relation to writing up an ‘advance care directive’ or appointing someone to consent to care and treatment on their behalf
in the event that you are unable to do so yourself, 27% of respondents indicated that they had, while 73% indicated that they had taken no action. A slightly higher number (35%) had seriously thought about, talked about, and/or recorded their preferences for care at the end of life. Older respondents were consistently more likely to have seriously considered or followed through on an end-of-life action than their younger counterparts.

**National Quality Standards for Residential Care Settings for Older People**

A report on ‘National Quality Standards for Residential Care Settings for Older People in Ireland’ was published in 2010 by the Health Information and Quality Authority (HIQA).

Some of the recommendations outlined in this report include:

- Where there is any doubt as to the resident’s capacity to decide on any medical treatment or intervention, his/ her capacity to make the decision in question is assessed by a suitably qualified professional using evidence-based best practice (3.8)
- Where the resident is deemed to lack the capacity to give or withhold consent, account is taken of his/her past and present wishes; the wishes of the family or representative; the resident’s needs and preferences, where they are ascertainable, and his/her general well-being and cultural and religious convictions (3.9)
- The arrangements to meet each resident’s assessed needs are set out in an individual care plan, developed and agreed with each resident, or in the case of a resident with cognitive impairment with his/her representative.
- The care plan reflects the assessment findings and sets out in detail the action to be taken by staff, to ensure that all aspects of the health, personal and social care needs of the resident are met. Residents, including those with dementia/ cognitive impairment, are actively encouraged to participate in this process (11.2)
- The care plan is discussed, agreed and drawn up with the involvement of the resident and/or his/her representative. If the resident is unable or unwilling to participate, this is documented (11.5)
- The resident’s wishes and choices regarding end-of-life care are discussed and documented, and, in as far as possible, implemented and reviewed regularly with the resident. This includes his/her preferred religious, spiritual and cultural practices and the extent to which his/her family are involved in the decision-making process. Where the resident can no longer make decisions on such matters, due to an absence of capacity, his/her representative is consulted (16.2)
- In accordance with the resident’s assessed needs, referrals are made to specialist palliative care services so that an integrated multi-disciplinary approach to end of life care is provided (16.3)
- Staff are provided with training and guidance in end-of-life care as appropriate to their role (16.4)
• The residential care setting has facilities in place to support end of life care so that the resident is not unnecessarily transferred to an acute setting except for specific medical reasons, and in accordance with his/her wishes (16.5)

• The quality of care and experience of the residents are monitored and developed on an on-going basis.

• Research, quality assurance and audit is carried out by the residential care setting in accordance with best practice and ethical principles (30.4).

National Audit of End-of-Life Care in Hospitals in Ireland

Hospice Friendly Hospitals (HfH) is a multi-centre intervention occupying a key place within IHF strategy since 2004, when a pilot scheme was initiated. The HFH programme was a five-year work-stream (2007-2012) designed to improve the quality of end-of-life care in acute and community hospitals in Ireland.

It was implemented across two ‘phases’: 2007-10; 2010-12. The programme was initiated by the IHF, in partnership with the Health Service Executive (HSE), and with a major grant from The Atlantic Philanthropies, as well as the support of the Dormant Accounts Fund and the Health Services National Partnership Forum. The goals of the programme were:

• To develop comprehensive standards for all hospitals in relation to dying, death and bereavement.

• To develop the capacity of acute and community hospitals to introduce and sustain these standards.

• To change the overall culture in hospitals and care settings in relation to dying, death and bereavement.

Its activities are focused around the four key themes of integrated care, communication, patient autonomy, and design and dignity. The HfH Programme published ‘The Manual’ which describes a system for a national audit of end-of-life care in Ireland, the first major initiative in an EU country to develop comprehensive standards for end-of-life care in the hospital setting (McKeown 2010; McKeown 2008). ‘The Manual’ acts as the protocol for implementing the audit system, and details a clear set of procedures to be applied consistently in all hospitals.

Ethical Framework for End-of-Life Care

The “Ethical Framework for End-of-Life Care” was developed for the HfH Programme of the Irish Hospice Foundation (IHF) (McCarthy, 2010b). This is a comprehensive, practical, clinical tool to enable healthcare professionals to be better informed, confident and collaborative in addressing ethical and legal challenges that arise in end-of-life care in Irish hospitals and healthcare settings. The overall aim of the Hospice Friendly Hospitals Programme is “to put hospice principles into hospital practice and to ensure that a systematic quality approach exists within the public health services to
facilitate ... a good death when it is expected, or can be predicted, and supportive systems when death occurs unexpectedly.”

**Palliative Care Competence Framework**

The Health Service Executive (HSE), in partnership with the All Ireland Institute for Hospice and Palliative Care (AIHPC), the Irish Association for Palliative Care (IAPC) and the IHF, has developed a Palliative Care Competency Framework (PCCF) to guide healthcare professionals working in various healthcare settings (Ryan et al, 2014). The framework provides for core competencies in palliative care whilst detailing individual competencies for each health and social care discipline. A national PCCF Development Steering Group was established involving representatives from the HSE, AIHPC, IHF and the IAPC. This framework will enhance the care of people with life limiting illness, fostering greater inter-professional and inter-organizational collaboration in palliative care provision.

The main domains of competence identified include:

- Principles of Palliative Care
- Communication
- Optimizing comfort and quality of life
- Care planning and collaborative practice
- Loss, grief and bereavement
- Professional and ethical practice in the context of palliative care.

**Dying in Hospital in Ireland: An Assessment of the Quality of Care**

This recent report into the quality of death & dying in Irish hospitals compared nurses, doctors and relatives’ perceptions of the quality of a patient’s dying experience (McKeown, 2010).

- Compared to nurses, relatives reported that patients had more frequent negative experiences of some physical and psychological symptoms such as being in pain, uncomfortable, anxious, or worried. The reported frequency of pain, for all or most of the time during the patient’s last week of life, varied significantly between relatives (34%), nurses (16%) and doctors (11%).
- The prevalence of ‘unacceptable’ deaths in hospitals as rated by relatives (21%), was found to be significantly higher compared to the rating by nurses (13%) or doctors (3%).
- The quality of care for patients who died appeared favourable, reflected in the finding that a substantial majority of relatives (78%) rated it as ‘good or very good’. The corresponding ratings by nurses (91%) and doctors (95%) indicated that relatives felt care was not as good as nurses and doctors believe it to be.

Overall, the quality of dying in Irish hospitals, as measured by the Quality of Dying and Death Instrument (QODD)(Patrick et al, 2001), was comparable to that found in other QODD-based studies of hospital deaths (Curtis et al, 2002; Hodde et al, 2004; Levy et al,
2005, Mularski et al, 2004; Mularski et al, 2005). The concept of ‘quality of care’ is not clear-cut, the perceptions of relatives, nurses and doctors are subjective, and their differing opinions are underlined by the fact that there was only 30% agreement between them. Relatives perceived the quality of care to be better when staff were responsive to requests, and when patients were free from pain and anxiety. The fact that communication with patients is consistently assessed by relatives, nurses and doctors as the weakest aspect of care presents a challenge.

Pilot end-of-life care audit and review system

The HfH Programme, in collaboration with the HSE Palliative Care Clinical Programme, has developed a pilot end-of-life care audit and review system (McLoughlin, 2013) which builds on the first National Audit of End-of-Life Care in Hospital in Ireland (2008/9) (McKeown, 2008). The system combines elements of audit, research and reflective practice, to support a process of continuous improvement in eight key domains of care for persons at the end of life:

- Staff training and support
- Care planning
- Pain and symptom management
- Preferred place of care
- Single room
- Team working
- Facilitating relatives
- Moment of death

According to the IHF strategic plan, the following three elements of HFH will be funded for 2012-2015: the Network of Hospice Friendly Hospitals; the new System of Audit and Review of End of Life Care to be used initially in acute hospitals; and the Final Journeys staff training programme.

1.10 Systematic Literature Review of RCTs of ACP implementation in older adults

A systematic review of the literature was conducted by the ‘Let Me Decide’ team to synthesise findings of prior randomized controlled trials that implemented ACP interventions among older adults. This was completed to inform this project and future up scaling of the programme.

Background

In terms of the evidence available for ACP interventions, several RCTs have been conducted to test the effects of such interventions on a range of different outcomes. Furthermore, a number of recently published systematic reviews have evaluated the effects of ACP. One by Lovell and Yates (2014) focused on the uptake of ACP in palliative care and found that influencing factors were complex and multi-faceted. Furthermore, it
was recommended that contextual factors including patient factors (e.g. demographic characteristics, diagnosis and health status, knowledge and attitudes), healthcare professional factors (e.g. uncertainty regarding timing of ACP and who should initiate ACP, discomfort with the process of ACP), and health service factors (legal status of ACPs, rights and responsibilities), are essential when designing ACP interventions. Brinkman-Stoppelenburg et al (2014) evaluated the effects of ACP on EOL care and reported benefits such as increased compliance with a person’s EOL wishes, a decrease in life-sustaining treatment, increased use of hospice care, and a decrease in unnecessary hospitalisation. Meanwhile, Houben et al (2014) conducted a systematic review and meta-analysis to identify the efficacy of ACP in different adult populations. They reported that ACP interventions increase the completion of ACDs, occurrence of ACP discussions, concordance between preferences for care and delivered care, and are likely to improve other outcomes for patients and their loved ones. Furthermore, they highlighted the need for research focused on the best way to implement structured ACP in standard care. Building on this prior work, a systematic review of ACP interventions implemented with older adults was conducted.

**Methods**

**Aim**
The aim was to review the findings of RCTs examining the impact of ACP interventions implemented with older adults, with a particular focus on those conducted in long-term care settings.

**Search Strategy and Selection Criteria**
Three electronic databases were searched: CINAHL, PubMed, and Cochrane database. The search was conducted in September 2014. Details of the CINAHL and PubMed search strategy are contained in Table 2. A search of the Cochrane database was also conducted to ensure that other important RCTs had not been omitted. Five systematic reviews were sourced that were relevant to ACP. Two of these were specific to EOL care for older adults. Of these two relevant reviews, one was a protocol and the other was a completed review which evaluated palliative care interventions. However, the interventions were not specific to ACP and thus were not excluded from the review.

Papers were identified for inclusion based on the following criteria:

(i) Reporting a randomized controlled trial,
(ii) Pertaining to an ACP intervention (i.e. a process of communication between individuals, their family, and healthcare professionals, to understand, reflect on, discuss and plan for future healthcare decisions, which may or may not result in the completion of a written ACD14),
(iii) Conducted with older adults (>65 years old),
(iv) Reported in English.
Of the 220 abstracts reviewed, the full-text paper was accessed for 30 of these. A final sample of nine papers was included in the review.

Results
The studies sourced were heterogeneous in terms of setting, types of interventions, methods and outcomes measured. The nine studies included a total of 3,646 individuals aged 65 years or older. Due to the heterogeneous nature of the studies included in the review, it was difficult to fully synthesise the findings and draw any clear conclusions from the review. Nonetheless, the findings demonstrated the feasibility of conducting RCTs, which evaluate the impact of ACP interventions, with older adults. Only one study implemented a standardised ACD (Molloy et al, 2000). Although an abundance of literature refers to the benefits of ACDs in terms of improving patient experience, and healthcare outcomes (Detering et al, 2010; Silveira et al, 2010), few RCTs have been conducted to rigorously evaluate these proposed effects.

In terms of study characteristics, the majority of studies were conducted in the USA and only one was conducted in Europe. Only two studies were conducted in nursing homes (Molloy et al, 2000; Morrison et al, 2005). With regard to the types of interventions included, most were informational with a view to increasing completion of ACDs and enhancing proxy-decision making. Only one study evaluated the effect on healthcare

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<tr>
<th>Table 2: Search strategy</th>
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<tr>
<td><strong>Search Details</strong></td>
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<tr>
<td>Search #1: “Advance directive” OR “Advance care directive” OR “Healthcare directive” OR “Health care directive” OR “Advance care planning”</td>
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<tr>
<td>Search #2: “Randomised Controlled Trial” OR “Randomized Controlled Trial”</td>
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<tr>
<td>Search #3: &quot;Long term care&quot; OR “long-term care” OR &quot;residential care&quot; OR &quot;nursing home&quot;</td>
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<tr>
<td>Search #4: “End of life” OR End-of-life OR Palliative</td>
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<td>#1 AND #2</td>
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<td>#1 AND #2 AND #3</td>
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<td>#1 AND #2 AND #4</td>
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<tr>
<td>Number of articles reviewed from combined searches</td>
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* = Limited by age (>65yrs)
utilisation (Molloy et al, 2000) and one study examined the effect on satisfaction with care (Detering et al, 2010). In these studies, ACP interventions were found to decrease hospitalisation and use of resources, and increase patient and family satisfaction with care. The outcomes measured across studies were categorised into ACP outcomes, and patient and family outcomes. In the first category, studies reported an increase in the documentation of EOL care preferences, and completion rates of a durable power of attorney or ACD. Patient and family outcomes also improved. For example, knowledge of ACP, concordance with EOL wishes, and understanding of EOL preferences were said to improve. Additionally, more discussions regarding EOL care took place as a consequence of ACP interventions. Hence, it can be concluded that ACP interventions have many benefits for patients, family, and healthcare staff. Yet, further RCTs, implementing complex ACP, should be conducted, to verify the impact on patient and healthcare outcomes (Brinkman-Stoppelenburg et al, 2014).

The majority of the studies sourced evaluated the effects of interventions on ACD completion rates, knowledge of ACDs, and proxy decision-making. These findings are important and provide some insight into the acceptability of ACDs amongst healthcare professionals, patients, and family members. However, with ACDs becoming more accepted among the general public, and in light of recent advancements in policy and legislation (American Academy of Nursing, 2013; Epstein et al, 2011; Sabatino, 2010) researchers need to consider other outcomes such as quality of EOL care, healthcare utilisation, quality of death and dying, patient satisfaction, and patient self-determination. Only one study included health care use and unit costs of services as outcomes (Molloy et al, 2000). Findings showed a decrease in hospitalizations and less resource use. However, this study did not carry out a full economic evaluation, taking account of both the costs and benefits of the programme. Future RCTs of ACP interventions should consider economic outcomes.

**Conclusion**

In summary, the findings help to elicit the current state of the science, in terms of ACP interventions and older adults, and highlight the gaps that need to be addressed. The majority of older adults would like an opportunity to discuss their EOL care, yet only a minority are given such opportunity (Sharp et al, 2013). Non-elicitation and lack of respect for a person’s wishes could be considered negligent practice. ACP interventions help to determine a person’s wishes for EOL care and ensure that those wishes are respected. Furthermore, some authors suggest that ACP interventions in nursing homes and long-term care settings can reduce unnecessary, and sometimes traumatic, hospitalisations of frail older adults (Brinkman-Stoppelenburg et al, 2014; Graverholt et al, 2014). However there is a need for further well-controlled studies to establish the effects of complex ACP interventions, especially in nursing home settings.
Part 2

Implementing the LMD-ACD and PC-education in LTC (Content and Process)
Introduction

The aim was to implement a structured advance care planning (ACP) and a palliative care educational programme into two nursing homes and one community hospital. The methods section describes the brief process of implementation. Results include key challenges identified during the ACP implementation process, and details of the uptake of ACP by residents and families.

The advance care planning (ACP) component of the ‘Let Me Decide’ (LMD) programme was originally developed in Canada and this Pilot Implementation project has evaluated its transferability to an Irish LTC setting. When compared with Canada, Ireland has significantly different legislation and culture surrounding ACDs and medical decision-making for the person lacking capacity. In addition, there are dissimilarities between the two countries in the demographics of the LTC population. These all had to be taken into consideration when adapting the ACP programme to the needs of the Irish long-term care population.

2.1 Aims and Objectives of LMD Advance Care Planning and Palliative Care Programme

The objectives of the LMD ACP and Palliative Care Programme were to:

1. Build the capacity of LTC staff to deliver both ACP and PC
2. Provide guidelines on ACP and palliative care to LTC providers
3. Equip healthcare staff with the necessary communication skills and knowledge to promote and facilitate ACP and to establish and respect residents’ healthcare wishes.
4. Provide appropriate educational material for LTC residents and their families to facilitate informed decision-making in relation to EOL care.
5. Offer LTC residents the opportunity to participate in advance care planning and to complete the ‘Let me Decide’ Advance Care Directive as part of the ACP process
6. Implement systems to proactively establish and document the expressed or perceived wishes of those residents who lack capacity and to plan their future care so as to avoid reactive decision-making in a crisis.
7. Educate and empower LTC residents (and their families) to be at the centre of the decision-making process with regard to end-of-life health care choices.
8. Increase the proportion of LTC residents completing an Advance Care Directive, Advance Care Plan or a care plan for end-of-life decisions.
9. Respect and document the wishes of LTC residents with regard to treatment they would like to receive at the end-of-life.
10. Prevent futile (and unwanted) medical interventions at the end-of-life
11. Educate healthcare staff on the general principles of palliative care to facilitate the development of skills of the core competencies framework
12. Promote a more holistic approach to end-of-life care, which encompasses not just the physical and medical needs of the patient, but also addresses their emotional, social, cultural and spiritual needs.
13. Reduce health inequalities by promoting access to an appropriate level of palliative care based on the needs of LTC residents, rather than on diagnosis or place of care.
14. Promote integrated, collaborative care between LTC providers, GPs, Specialist Palliative Care Services and Geriatricians.
15. Promote awareness amongst GPs and nurses, of appropriate prescribing practices as death approaches
16. To improve the quality of care and promote better use of scarce resources.
17. Assess the effects of implementing an ACP and PC educational programme on LTC residents and their families
18. Assess the economic and organisational effects of implementing an ACP and PC educational programme.
19. Assess changes in the patterns of healthcare utilisation through the use of ACP and PC education.

2.2 Programme Implementation

The process of implementing the ‘Let Me Decide’ advance care planning (ACP) programme combined with a general palliative care (PC) educational programme was evaluated by considering the following outcomes:

- Staff confidence in delivering advance care planning
- Uptake of end-of-life care planning by residents and their families
- Place of death and adherence to residents’ wishes recorded in their EoL care plans
- Estimated Costs Associated with Hospital Deaths
- Key challenges identified during the implementation process.

2.2.1 Methods

Recruitment of long-term care facilities
Three long-term care facilities who were interested in implementing the LMD-ACP programme were recruited from the Cork and Kerry region; these included two nursing homes and one community hospital, totalling approximately 290 beds. A sample policy on ACP was given to each of the participating homes for amendment to their requirements (see Appendix 2). All residents aged ≥ 65 years resident in participating nursing homes or community hospitals were eligible for inclusion in the programme.

Development of Policy & Procedures in the LTC Institutions
Because of the differences (particularly in legislation) between Canada and Ireland changes had to be made to the ‘Let Me Decide” program to ensure its transferability to the Irish long term care setting. Refinements to the program were informed through consultation with the legal profession, and representatives from the Health Service Executive and Health Information and Quality Authority. Policy, procedures and guidelines for use were tailored through extensive feedback from senior nursing staff, residents and their families. On-going monthly consensus-building workshops/review
meetings were held with senior nursing staff from all of the intervention homes, to discuss issues arising with the implementation of ACP. The educational material for residents and their families, including the LMD book, was adopted, edited and expanded, according to the observations, views and desires of the staff, residents and the residents’ families. The refinement phase was contributed to by staff representatives from all of the pilot homes.

**Ethical considerations**

Written consent was obtained from the relevant research ethics committee to conduct this Pilot Implementation project in each of the study sites. Each competent resident, who voluntarily decided to engage in the LMD-ACP process, was given a verbal and written explanation of the study. The information and assurances given to residents in relation to consent and confidentiality are listed in Table 3. They were asked to sign a consent form if they agreed to their medical records being reviewed, and were assured that any information collected would be treated as strictly confidential. They were also informed that they were free to withdraw their consent to participate at any time, and that they were under no obligation to complete an ACD. They were assured that their decision to engage in the ACP process would not affect the quality or amount of healthcare that they would receive, and that there would be no risks involved by their participation in the study. Those residents who completed an ACD were informed that they could change or withdraw their ACD at any time they wished.

Likewise, families of incompetent residents who voluntarily decided to engage in the LMD-ACP process were given a verbal and written explanation of the study. They were asked to sign a consent form if they agreed to their relative’s medical records being reviewed, and were given the same assurances, as for competent residents above, in relation to withdrawal of their consent, confidentiality, quality of their relative’s care, and the risks of participation in the study.

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<thead>
<tr>
<th>Table 3 Information and assurances given to residents voluntarily engaging in the ‘Let Me Decide’ process, regarding issues of consent and confidentiality</th>
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<tbody>
<tr>
<td>• You are <strong>not</strong> required to engage in the ‘Let Me Decide’ advance care planning (ACP) process, it is completely voluntary</td>
</tr>
<tr>
<td>• Your decision to engage in the ACP process will not affect the quality or amount of healthcare that you receive</td>
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<td>• There will be no risks involved by your participation</td>
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<tr>
<td>• You can decide at any stage that you no longer wish to proceed</td>
</tr>
<tr>
<td>• If you decide to proceed, you are under no obligation to complete an ACD form at the end of the ACP process; you may choose to document your wishes in a less formal way (like in the form of a ‘letter’)</td>
</tr>
<tr>
<td>• At any time, you can change your mind about any of the decisions you have made in your ACD, or you can withdraw your ACD completely</td>
</tr>
<tr>
<td>• Your ACD will only be used if, in the future, you are unable to make healthcare decisions or to communicate these to others; if you are still able to think straight and...</td>
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communicate your wishes, you will be asked about your treatment preferences at that time

- If you agree to your medical records being reviewed as part of this feasibility study, please sign the consent form after you are satisfied that you have enough relevant information
- Any information collected as part of this feasibility study will be treated as strictly confidential.

2.3 The Implementation process
A two-phased approach to implementation was taken: Phase 1 – Survey and education of healthcare staff on ACP and palliative care; Phase 2 – Delivery of structured ACP by staff to residents and families (See Timeline of Project in Appendix 3).

2.3.1 Phase 1 – Survey and education of healthcare staff

Pre- and Post-implementation Surveys of Nursing Home Staff on Attitudes to and perceived Barriers to Advance Care Planning, and Staff Learning Needs

As part of the pre-implementation phase of the study, 163 nursing and medical staff were asked to complete questionnaires on their attitudes to ACDs and ACP, perceived barriers to implementing ACP in their everyday work, and their palliative care learning needs. Results from the palliative care educational needs survey were used to fine tune the palliative care educational component of this intervention. A post-implementation survey of 279 Nursing Home Staff (nurses and healthcare assistants (HCA’s) across the three sites) was also conducted on attitudes, barriers and learning needs in relation to ACP and palliative care to determine areas for further education and development.

2.3.2 The Advance Care Planning Educational Intervention for staff

Over a 9 month period during Phase 1, approximately 40 senior nursing staff from participating homes completed two half-day workshops to gain a thorough understanding of the background, development and use of ACP and “Let Me Decide”, and of issues related to its implementation in LTC, including ethical and legal considerations. Through this training, staff were equipped to educate residents and families about ACP and to implement the ACP programme. Senior nursing staff were offered support in monthly feedback meetings to discuss issues arising during the implementation process.

2.3.3 The Palliative Care Educational Intervention

The main aim of the palliative care educational programme was to improve the provision of general palliative care within LTC, and facilitate recognition of when an appropriate, timely referral to specialist palliative care would be of benefit. One
objective was to enable all staff to confidently and appropriately apply palliative care principles, in their approach to patients, and improve the ability of some to deliver general palliative care to patients at the end-of-life, through further training. The palliative care educational initiative aimed to facilitate staff to provide holistic, patient-centred care, at a general palliative care level.

Evidence shows that for palliative care educational programmes to be effective “they must based on an assessment of the learning needs of the participants, to ensure that new knowledge and skills are built upon the learners’ experiences and existing knowledge and skills” (Whittaker et al, 2006). The syllabus and material for the palliative care educational program was developed and “fine-tuned” through information from a variety of sources including:

- Results of staff questionnaires on their palliative care learning needs and attitudes to end-of-life care for each pilot site
- The existing services relating to end-of-life care in each LTC residence
- Baseline data from chart reviews of residents who had died in each pilot site in the year prior to implementation of the program
- Baseline data from surveys of relatives of residents who had died in each pilot site in the year prior to implementation of the program
- The syllabus structure was influenced by the proposed core competence domains as proposed in the Palliative Care Competence Framework (draft version).

In each of the intervention homes there was a cohort of staff who had already undertaken further training in Palliative Care some up to diploma level.

Dr. Ciara McGlade, with input from Dr. Catherine Sweeney, developed the educational programme which takes the form of a series of workshops covering the following topics:

1. Principles of Palliative Care
2. Communication
3. Loss, Grief & Bereavement
4. Optimising comfort and quality of life including
   - Symptom assessment and management
   - Appropriate modes of drug delivery including use of the syringe driver
   - The “terminal” phase

Workshops 1, 2 and 3 are delivered to both healthcare assistants and nursing staff. Workshops 4 (duration equivalent to twice that of other workshops) and 5 are aimed at nursing staff only. The timing of the workshops is tailored to meet the needs of each pilot site: some homes preferred to do training over 2 half day sessions, others wanted to run training over a full day. Workshops were delivered to approximately 200 staff.
across three study sites (including nursing staff and healthcare assistants) as part of this Pilot Implementation project.

Within each home there was a cohort of nurses who had attended further training in palliative care, in most cases this was either a one-day or week long course (including “link-nurse” courses). In some instances further training was more extensive such as to diploma or masters level or having worked in hospice for a significant period. It is important to note that staff’s further training and experience is most useful when dissemination of the knowledge, skills and competencies developed is facilitated, encouraged and promoted by senior staff and management in LTC. A ‘train-the-trainer model’ similar to that of the link nurse courses has been explored in the pilot sites. Staff with established knowledge and competence in palliative care have engaged with this approach. This method increases the involvement of LTC nurses in the programme, while ensuring sustainability of the delivery of the educational component of this programme.

2.3.4 Phase 2 – Delivery of ACP by staff to residents and families
Over a 12 month period, a small number of senior nursing staff in each home delivered the LMD-ACP programme. These staff were supported by the research team on an ongoing and needs basis. Each of the study homes were given a detailed implementation manual which included a policy on completing ACDs/ACPs, decision aids for engaging residents, documentation templates, structured forms and educational resources for residents and families.

Refinement of educational material for residents
The program’s educational material for residents were developed and refined through feedback from senior nursing staff who were trained in using the ‘Let Me Decide” program and who were facilitating advance care planning discussions with residents. These staff found that the “let Me Decide’ book, although short, was too onerous for some residents to engage with. For many of their frailer residents their ability to concentrate even on a short book was diminished. A shorter synopsis of the most important material was produced and this has been well accepted. Other aids to the ACP process were also devised.

The first step in the LMD-ACP process assesses cognition, using the Standardised Mini-Mental State Examination (SMMSE) (Molloy et al, 1991) to measure whether a resident is likely to have sufficient capacity to engage with education on ACP. Residents who were deemed suitable (on the basis of their SMMSE score) were offered the opportunity to engage in the LMD-ACP process. The second step in the process was the delivery of education regarding ACP and LMD by senior nurses to individual residents and families. In addition, one-off evening and weekend information sessions for families and residents were delivered in the homes by senior members of the research team. Key
educational points for residents (and their families) engaging in the advance care planning (ACP) process are outlined in Appendix 4.

Following completion of the education, the resident’s capacity to complete the LMD-ACD was assessed using the SIACAD screening tool. The high prevalence of cognitive decline in the LTC population underlined the need to include the assessment of resident capacity as a key step in the completion of a valid ACD. A decision tree for the screening process to assess capacity to complete the LMD-ACD is shown in Appendix 5.

Where a resident lacked capacity to complete an ACD, the family was invited to engage with the medical team in discussing EoL choices for their relative to help inform the completion of an ‘End-of-Life Decisions Care Plan for Person Lacking Capacity’ by the doctor and senior nurse. Where possible and appropriate, the resident was included in these discussions. Table 4 lists key features of the LMD process for residents lacking capacity to complete their own LMD-ACD.

**Table 4  Key features of the ‘Let Me Decide’ process for residents lacking capacity**

**For a resident who lacks capacity to complete their own LMD-ACD:**
- Any expressed views in relation to their EoL care preferences are documented
- The family/next-of-kin is approached to see if they would like to engage with nursing and medical staff in discussing end-of-life care planning for their relative
- These discussions will help inform the completion of an ‘End-of-Life Decisions Care Plan for Person Lacking Capacity’ by the doctor and senior nurse
- As much as is possible and appropriate, the resident can be included in these discussions.

Guidelines for nurses commencing the advance care planning (ACP) process with residents with capacity are outlined in Appendix 6. The recommended steps for nursing staff to follow in helping a resident with capacity to accurately document their treatment preferences in an ACD are outlined in Appendix 7.
2.4 Results from evaluation of the implementation process

Results are presented below under the following headings as per outcomes:

- Pre- and post-implementation Survey of Nursing Home Staff (including staff confidence)
- Uptake of end-of-life care planning by residents and their families
- Place of death and adherence to residents’ wishes recorded in their EoL care plans
- Estimated costs associated with hospital deaths
- Key challenges identified during the implementation process

2.4.1 Pre-implementation Survey of Nursing Home Staff on Attitudes, Barriers and Learning Needs in relation to ACP and Palliative Care

As part of the pre-implementation phase of the study (before the LMD programme was implemented), 163 nursing and medical staff were asked to complete questionnaires on their attitudes to ACDs and ACP, perceived barriers to implementing ACP in their everyday work, and their palliative care learning needs. A total of 87 responses were received, yielding a response rate of 53%. The majority of respondents were nurses (87%), while 3 were doctors. A separate survey on barriers to implementing ACDs was completed by 25 nurses.

The survey in relation to palliative care skills identified diverse training needs and diverse levels of confidence among staff. Of those who responded, over 50% had no palliative care training. Several of the intervention homes had already completed “Train the Trainer” and Link Nurse Initiative courses in Palliative Care. Staff who undertake further training in Palliative Care (e.g. Diploma or Link Nurse courses) should be facilitated to use their training in the home.

Just over 40% of staff surveyed said that they would feel confident discussing end of life issues with a resident or their family, while just less than half said that they would feel confident dealing with bereavement issues with a resident’s family. Approximately 50% of those surveyed believed that “every competent person should be required to complete an ACD”.

For the majority of topics listed (32/36), 70% or more of staff felt that this was a learning need. The two most frequently chosen palliative care learning needs topics were “Pharmacological Management of Pain and opioids (e.g. morphine)” and “Non-Pharmacological Management of Pain (e.g. biofeedback)”, with 90% of respondents indicating that these educational topics were priorities for them. The next most cited topic was “Understanding the Emotional Needs of the Dying Person”.
All of the 25 nurses surveyed felt that barriers to implementing Advance Care Directives included lack of knowledge among the general public and families about advance care directives. The majority of respondents (90%) felt that finding sufficient time to educate residents/clients about advance care directives, and that hearing and other communication impairments among the elderly, were important barriers to implementation of ACP in this population.

Other reasons indicated as important barriers to implementation included lack of staff education about ACDs/ACPs, the lack of available education programmes about ACDs throughout the healthcare system, and a perception that residents and their families do not feel comfortable discussing ACP.

One respondent commented:

“The education alone won’t change the care – palliative care rooms must be allocated so that patients can die in peace and not with other dementia patients wandering around. All nurses need up-skilling on syringe drivers and people need to know palliative care isn’t just for cancer patients”.

2.4.2 Post-implementation Survey of Nursing Home Staff on Attitudes to and perceived Barriers to ACP, and Learning Needs in relation to ACP and Palliative Care

A post-implementation survey of Nursing Home Staff (nurses and healthcare assistants (HCA’s)) on attitudes, barriers and learning needs in relation to ACP and palliative care was undertaken across the three study sites. A total of 93 questionnaires were completed out of 279 issued, giving an overall response rate of 33%. The response rate was particularly poor among HCA’s, while the response rate among qualified nurses was higher, reaching almost 50%.

93 people completed the questionnaire from 3 of the long term care facilities involved in the study. 90% (n=84) of respondents were female. 67% (n=50) had not completed a similar questionnaire as part of the LMD programme in the past, it must be noted that in the intervening years they may have been high staff turnover. Over 50% (n=58) of those who completed the questionnaire were healthcare assistants, with 44% (n=40) registered nurses. The majority responded from a private nursing home (58%, n=49). Only 14% (n=12) responded that they had attended a palliative care workshop. However, 82% (n=14) indicated they found our palliative care training very useful. 68% had other palliative care training. 88% did not undertake the final journeys palliative care training. Very few (n=2, 2.4%) had worked in specialist palliative care.

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1 There appears to be more people responded to the question on whether they found the training useful, than those indicating if they attended, due to missing data the numbers do not correlate.
The majority (65%, n=60) strongly agree that every competent person can complete an ACD. There was agreement (96%) that ACDs are not a way of getting rid of older people. Only 1% agreed that they were and 3% were neutral.

Over 90% (n=83) believe that patients should become more involved in healthcare decision making and 86% (n=79) disagree that people would make the wrong decision. Over 80% (n=73) indicated that an ACD can contribute to a better patient/healthcare professional relationship, while very few (9.8%, n=9) believed that ACDs are a step on the road to euthanasia. For a full breakdown of responses to the attitudes questionnaire see appendix 8.

Participants were asked on the questionnaire to define palliative care, 69 responses were received. A wordle was created with the most common words displayed.

It was mostly defined as end of life care, that encompasses symptom relief, and an holistic approach that improves quality of life.

**Referral to specialist palliative care services**

Respondents were asked why they might refer a resident to specialist palliative care. Reasons included; advice & help on the management of symptoms (pain, agitation, nausea), control of pain medication, expertise needed and equipment, someone to talk to who’s already trained in pain control, proper assessment and treatment, help for the family and support for the person.

**Learning Needs**

Learning needs were measured across 37 topics (see appendix 9)

Top cited learning needs as indicated by over 85% of respondents included;

- Management of “death rattle” or respiratory secretions
Pharmacological Management of Pain and opioids (e.g. morphine)
Non-Pharmacological Management of Pain (e.g. biofeedback)
Pain and symptoms assessment
Understanding the Physiological Impact of Life-Threatening Illnesses
Stages of the Dying Process
Physical Changes as Death Approaches
Understanding Personal Autonomy
Advance Directives, Power of Attorney, and Living Wills
Culture and death
Ethical, religious and legal implications of dying
Management of grief and bereavement
Understanding the Emotional Needs of the Dying Person
Managing the Emotional Impact on Families as Death nears

Level of importance varied, those described as very important by over 70% were as follows;
1. Understanding the Emotional Needs of the Dying Person (79%)
2. Assessment and Management of Dehydration (74%)
3. Pharmacological Management of Pain and opioids (e.g. morphine) (73%)
4. Assessment and Management of Confusion and Agitation (71%)
5. Managing the Emotional Impact on Families as Death nears (70%)

Confidence around end of life care
Respondents were asked to answer 3 items on confidence around end of life care. Over 40% were confident discussing end of life issues and dealing with bereavement issues (see table 5).

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Neutral</th>
<th>Confident</th>
<th>Very Confident</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>How confident do you feel discussing end of life issues with a resident or their family?</td>
<td>11</td>
<td>22</td>
<td>22</td>
<td>35</td>
<td>9</td>
<td>33% not confident in discussing end of life issues</td>
</tr>
<tr>
<td>How confident do you feel dealing with bereavement issues with a resident’s family?</td>
<td>4</td>
<td>29</td>
<td>18</td>
<td>38</td>
<td>10</td>
<td>48% confident dealing with bereavement issues</td>
</tr>
<tr>
<td>How confident do you feel setting up and using a syringe driver to deliver medications to a person at the end of life?</td>
<td>39</td>
<td>12</td>
<td>15</td>
<td>28</td>
<td>5</td>
<td>39% not at all confident however over half of respondents were HCA and this is not part of their role,</td>
</tr>
</tbody>
</table>

Confidence around end of life care
Respondents were asked to answer 3 items on confidence around end of life care. Over 40% were confident discussing end of life issues and dealing with bereavement issues (see table 5).
Syringe driver
Respondents were asked when they use a syringe driver. A number of suggestions were proposed and these include; at end of life to provide medication for symptom management, end of life when swallowing difficulties are present, for comfort measures if pain is constant, if oral meds are no longer working. Participants were also asked if they think a syringe driver shortens or prolongs a person’s life. Fifty seven people provided qualitative comments. There were mixed views, with many believing that it depended on the person and their current condition. A number of people agreed that it neither shortened nor prolonged life, stating that its purpose is to provide comfort and give a better quality of dying experience.

Advance care directives
Participants were asked if they attended LetMeDecide ACP workshop, 40% (n=21) had. The majority of these found it very useful (65%, n=17). Nearly 20% had completed ACDs with patients. 65% felt either very confident or moderately confident going through the ACD process with residents who had capacity, while 31% were not at all confident about going through the process with someone who lacked capacity. When asked how useful they found the LetMeDecide process 86% stated that it was “quite useful” to “very useful”. On a scale of 1-5 (easy-difficult) participants were asked to rate how they found getting families involved when a resident had capacity, a mean score of 2.64 (SD 0.86) indicting that it was somewhat easy. A slightly higher mean score was achieved when asked how easy/difficult it was to engage a family when the resident lacked capacity (mean 2.8, SD 1.08). When asked how useful the LetMeDecide was to practice 77% stated that is was very useful.

Barriers’ to implementing advance care directives
Barriers’ to implementing advance care directives were measured using a 33 item questionnaire, most frequently cited barriers (those indicated as a barrier by over 80% of the sample are listed below (see also table 6)).

- Finding sufficient time to educate patients/residents/clients about advance care directives
- With elderly people with hearing or other communication impairments or who need more time
- The lack of education programs about advance care directives throughout the healthcare system
- Insufficient education for the general public about advance care directives
- Families who have not been previously educated about advance care directives
- Conflicting opinions among family members when filling out advance care directives.

### Table 6: Barriers to using ACDs

<table>
<thead>
<tr>
<th>In your work do you encounter any of the following potential barriers to the use of advance care directives?</th>
<th>N=No</th>
<th>Y=Yes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Differences in attitudes and values around life and death in different cultures?</td>
<td>N50</td>
<td>Y50</td>
<td></td>
</tr>
<tr>
<td>Differences in language or translating when completing advance care directives?</td>
<td>N58</td>
<td>Y42</td>
<td></td>
</tr>
<tr>
<td>Gender?</td>
<td>N84</td>
<td>Y16</td>
<td></td>
</tr>
<tr>
<td>Old age i.e. older people have more difficulty completing advance care directives?</td>
<td>N40</td>
<td>Y60</td>
<td></td>
</tr>
<tr>
<td>Low socio-economic status, i.e. poor people have more problems completing advance care directives?</td>
<td>N85</td>
<td>Y15</td>
<td></td>
</tr>
<tr>
<td>Lack of education, i.e. lower educated people have more problems completing advance care directives?</td>
<td>N56</td>
<td>Y44</td>
<td></td>
</tr>
<tr>
<td>A person’s youth, i.e. young people have more problems completing advance care directives?</td>
<td>N53</td>
<td>Y46</td>
<td></td>
</tr>
<tr>
<td>Finding sufficient time to educate patients/residents/clients about advance care directives have advance care planning discussions?</td>
<td>N17</td>
<td>Y83</td>
<td></td>
</tr>
<tr>
<td>With elderly people with hearing or other communication impairments or who need more time?</td>
<td>N9</td>
<td>Y91</td>
<td></td>
</tr>
<tr>
<td>Patient/Resident/Client's lack of education?</td>
<td>N28</td>
<td>Y72</td>
<td></td>
</tr>
<tr>
<td>Staff lack of education about the advance care directives/ advance care planning?</td>
<td>N26</td>
<td>Y74</td>
<td></td>
</tr>
<tr>
<td>The lack of educational aids, such as books and videos?</td>
<td>N38</td>
<td>Y62</td>
<td></td>
</tr>
<tr>
<td>Accommodating the different education needs of clients/residents/patients?</td>
<td>N23</td>
<td>Y76</td>
<td></td>
</tr>
<tr>
<td>People who do not want to learn about advance care directives?</td>
<td>N22</td>
<td>Y78</td>
<td></td>
</tr>
<tr>
<td>The lack of education about advance care directives in acute hospitals?</td>
<td>N33</td>
<td>Y68</td>
<td></td>
</tr>
<tr>
<td>The lack of education programs about advance care directives throughout the healthcare system?</td>
<td>N14</td>
<td>Y86</td>
<td></td>
</tr>
<tr>
<td>Insufficient education for the general public about advance care directives?</td>
<td>N20</td>
<td>Y80</td>
<td></td>
</tr>
<tr>
<td>Families who have not been previously educated about advance care directives?</td>
<td>N20</td>
<td>Y80</td>
<td></td>
</tr>
<tr>
<td>Too much conflicting education on advance care directives?</td>
<td>N55</td>
<td>Y45</td>
<td></td>
</tr>
<tr>
<td>Patients/Residents/ Clients being influenced too much by family members’ opinions when filling out advance care directives?</td>
<td>N28</td>
<td>Y72</td>
<td></td>
</tr>
<tr>
<td>Conflicting opinions among family members when filling out advance care directives?</td>
<td>N10</td>
<td>Y90</td>
<td></td>
</tr>
<tr>
<td>Patients/Residents/ Clients ignoring family members’ opinions when filling out advance care directives?</td>
<td>N50</td>
<td>Y50</td>
<td></td>
</tr>
<tr>
<td>Nurses who do not support advance care directives?</td>
<td>N65</td>
<td>Y35</td>
<td></td>
</tr>
<tr>
<td>Doctors who do not support advance care directives?</td>
<td>N64</td>
<td>Y36</td>
<td></td>
</tr>
<tr>
<td>Other staff, i.e. administrators, social workers, OT's Physiotherapists who do not support</td>
<td>N79</td>
<td>Y21</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>26</td>
<td>Poor communication with residents/patients and families about advance care directives?</td>
<td>N44</td>
<td>Y56</td>
</tr>
<tr>
<td>27</td>
<td>Finding a private area to discuss advance care planning?</td>
<td>N50</td>
<td>Y50</td>
</tr>
<tr>
<td>28</td>
<td>Because the area where directives are completed is too noisy?</td>
<td>N64</td>
<td>Y36</td>
</tr>
<tr>
<td>29</td>
<td>People who are not able to understand the concept of advance care directives?</td>
<td>N27</td>
<td>Y73</td>
</tr>
<tr>
<td>30</td>
<td>Assessing the patient/resident/clients competence to complete an advance care directive?</td>
<td>N33</td>
<td>Y68</td>
</tr>
<tr>
<td>31</td>
<td>Resident / their family don't feel comfortable to discuss advance care planning?</td>
<td>N21</td>
<td>Y79</td>
</tr>
<tr>
<td>32</td>
<td>Staff lack of comfort in discussing advance care planning?</td>
<td>N39</td>
<td>Y61</td>
</tr>
<tr>
<td>33</td>
<td>Staff lack of medical knowledge with regard to disease, prognosis, treatment options or end-of-life issues?</td>
<td>N56</td>
<td>Y44</td>
</tr>
</tbody>
</table>
2.4.3 Uptake of end-of-life care planning by residents and their families

The programme has been well received by both residents and their families. Following implementation, at least 50% of residents in each of the three study sites had some form of end-of-life care plan in place (advance care directives; advance care plans; or end-of-life care plans for those with diminished capacity). This ranged from 50%-60% across the 3 homes.

<table>
<thead>
<tr>
<th>Nursing Home</th>
<th>ACDs/EOL Care Plans completed (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 120 Beds</td>
<td>N = 68/120 (57%)</td>
</tr>
<tr>
<td>2. 97 Beds</td>
<td>N = 58/97 (60%)</td>
</tr>
<tr>
<td>3. 79 Beds</td>
<td>N = 39/79 (50%)</td>
</tr>
</tbody>
</table>

Despite the high prevalence of cognitive impairment, at least 10% of residents had capacity to complete their own ACD. The remaining EoLCPs were completed by the medical team for residents lacking such capacity, following discussions with the family and with the resident, where possible. From our audit of completed ACDs for patients with capacity, the majority choose (i) “No CPR”; (ii) “Basic feeding” (rather than “Tube feeding”); and (iii) either “Comfort/Palliative Care” or “Limited Care” (rather than “Surgical Care” or “Intensive Care”). Nursing staff reported that, in general, families were very keen to be involved in the EoL care planning process, and that families of residents who lacked the capacity to complete an ACD, consistently asked for low levels of intervention for their relative at the end of life.

2.4.4 Place of death and adherence to residents wishes regarding end-of-life care

Table 7 gives details of numbers of deaths in the post-implementation period, location of death, numbers of EOL care plans in place at time of death, and adherence to residents’ wishes as outlined in their EOL care plans.

Of those who died during the post-implementation period (n=70), 84% had an EoLCP in place (12% of these were ACDs completed by the residents); this ranged from 78% to 90% across the three sites. Of those who died in the nursing homes (n=62), 89% had an EoLCP in place, while 4 out of 8 (50%) of those who died following transfer to acute care had one in place. The wishes of those 3 residents who had an EOLCP in place indicating that they would prefer to stay in the nursing home if at all possible, but who had been transferred to hospital and subsequently died there, were only partially adhered to. The one other resident who had an EOLCP in place and who died in hospital following transfer had indicated that he wanted everything possible done to preserve his life;
therefore, transfer to hospital complied with his wishes. Table 7 gives details of the eight different residents who were transferred to acute care and who subsequently died there. Overall, among the 59 residents who had an EOLCP in place at the time of death, **wishes were fully adhered to in 95% of cases.**
TABLE 7: Numbers of deaths in the Post-Implementation period, location of death, numbers of advance care plans, and adherence to advance care plans

<table>
<thead>
<tr>
<th>TOTAL Deaths (N=70)</th>
<th>Died in the NH (N=62)</th>
<th>Died in Acute Hospital (N=8)</th>
<th>EOLCPlan Adhered to</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home A</strong></td>
<td><strong>Home A</strong></td>
<td><strong>Home A</strong></td>
<td><strong>Others</strong></td>
</tr>
<tr>
<td><strong>TOTAL Deaths: 16</strong></td>
<td>11 deaths in the NH (69%)</td>
<td>5 deaths in Acute Care (31%)</td>
<td>2 (40%) had an ACP; 1 was LMD ACD</td>
</tr>
</tbody>
</table>
| 13/16 (81%) had an ACP | 11/11 had an ACP; 8 were LMD ACPs | 2 (40%) had an ACP; 1 was LMD ACD | 1) Had LMD-ACD and WANTED to go to hospital for treatment; died in hospital 2 days later (had metastatic cancer)  
2) Had ACP (to remain in NH) but it was decided to transfer after consultation with family as they felt that the resident would get better with hospital treatment; died in hospital 2 days later (SMMSE: 9/30)  
3) Refused to engage in ACP process; No EOL care plan; WANTED to be transferred to hospital for treatment; died 2 weeks later  
4) No ACP but relative indicated "NO CPR" and wanted resident to be transferred to hospital if it meant they would be more comfortable; COPD exacerbation, died 7 days later (SMMSE: 17/27)  
5) No ACP in place; resident became ill suddenly (COPD exacerbation), was transferred to hospital (for respiratory failure); died in A&E one hour later. Family had asked for transfer. |
<p>| <strong>YES</strong> | Partially (no CPR or Tube feeding given) | N/A, resident's wishes were followed | N/A, family's wishes were followed |</p>
<table>
<thead>
<tr>
<th><strong>Home B</strong></th>
<th><strong>Home B</strong></th>
<th><strong>Home B</strong></th>
<th><strong>Home B</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Deaths:</strong> 31</td>
<td><strong>28 deaths in NH (90%)</strong></td>
<td><strong>3 deaths in Acute Care (10%)</strong></td>
<td><strong>1) Had EOLDCP form (wanted to remain in NH) - died 5 days after transfer to hospital for assessment (?bowel obstruction). CA of the stomach was diagnosed at the end-of-life.</strong></td>
</tr>
<tr>
<td>28/31 (90%) had ACP</td>
<td>26/28 (93%) had ACP; 6 were LMD ACPs, 20 were other ACPs</td>
<td>2/3 had ACP; 1 was EOLDCP</td>
<td>Partially</td>
</tr>
<tr>
<td><strong>Home C</strong></td>
<td><strong>Home C</strong></td>
<td><strong>Home C</strong></td>
<td><strong>Home C</strong></td>
</tr>
<tr>
<td><strong>Community Nursing Home</strong></td>
<td><strong>All 23 deaths in NH</strong></td>
<td><strong>0 deaths in Acute Care</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Total Deaths:</strong> 23</td>
<td>17/23 (74%) had LMD-ACPs, remainder had EOLC pathways commenced a few days before death</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>17/23 (74%) had LMD-ACPs, remainder had EOLC pathways commenced a few days before death</td>
<td></td>
<td>2) Had ACPlan (wanted to remain in NH) but was transferred to hospital with severe LRTI and died 5 days later (cause of death: CCF, Pulmonary Fibrosis, Pul. Oedema)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3) No ACP in place; resident suffered an stroke and was transferred to hospital (unconscious) and died one day later.</td>
</tr>
</tbody>
</table>
2.4.5 Estimated Costs Associated with Hospital Deaths

Often residents from aged care facilities such as nursing homes are frequently transferred to hospital for the management of acute deteriorations in health (Dwyer et al, 2014). From a systematic review of the literature, Dwyer et al (2014) indicates common reasons for in hospital admission amongst residents from facilities such as nursing homes are owing to respiratory conditions, fall related injuries, fractures and orthopaedic injuries, cardiovascular illness, infection, altered mental state or device related complications. Such hospitalisations result in consequences such as inpatient admissions, extensive use of resources, including emergency ambulances for transferring, in hospital complications, invasive interventions and mortality (Dwyer, Gabbe et al. 2014).

The results of the pilot project enabled us to estimate the burden associated with such consequences, inpatient admissions and ambulance transfers were quantified directly and invasive interventions indirectly, amongst those who had in hospital deaths.

The results revealed that eight of the deaths (11%) took place in an acute hospital. The primary diagnoses were congestive cardiac failure (25%), bowel obstruction (25%), respiratory arrest owing to COPD (25%), cerebrovascular accidents (13%) and pneumonia (13%). The direct costs associated with these from the HSE perspective are ambulance transfer costs, estimated at €97 per patient (as per Gannon et al, 2008) adjusted for inflation) and hospital costs. The average length of stay amongst those in the pilot project was 4.29 days (standard deviation 3.91). The average cost of treating this case mix in acute public hospitals ranges from €1,993 to €9,925 (average €4,081), (estimated using Diagnostic Related Group (DRG) costs. Source: Health Service Executive, 2013). Given the patient population and their stage of life it is unsurprising that the average length of stay (4.29) was less than the average length of stay associated with the case mix (8 days, standard deviation 5.13). Consequently, the DRG costs were apportioned so as to estimate daily cost per DRG. This daily estimate was applied to the length of stay from the pilot study. The resulting average hospital cost per patient is estimated at €2,067 (standard deviation €1,967), estimated using a probabilistic sensitivity analysis. Summing the ambulance and hospital costs estimates the average total direct costs as €2,164 per patient (standard deviation €1,967).

<table>
<thead>
<tr>
<th>Table 8 Results of Probabilistic Sensitivity Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of Stay</td>
</tr>
<tr>
<td>Average</td>
</tr>
<tr>
<td>Standard Deviation</td>
</tr>
<tr>
<td>95% Confidence Interval</td>
</tr>
</tbody>
</table>
From the above analysis it is clear from a cost perspective that hospitalisation at end of life should be avoided if possible. The figure below demonstrated that in two out of the three nursing homes there was a significant reduction in hospital transfers following the implementation of the programme, both those resulting in death and readmission to the nursing home.

Transfer to Hospital- before/after period (12 month average for before and after)

2.4.6 Key challenges identified during the implementation process

The key challenges identified during the implementation process are shown in Table 9.

Table 9. Key challenges identified in implementing advance care planning in long-term care

- Difficulties for management in releasing staff for training
- Reluctance of staff to take ownership of the ACP process, seeing it as a role for management
- Lack of staff confidence and experience with ACP and ACDs
- Lack of adequate time to deliver ACP to residents and their families
- Difficulties educating residents with cognitive, hearing and visual impairment
- Failure of other healthcare professionals to recognise completed ACD/ACP forms.
Difficulties in releasing staff for training

One of the most important issues with this Pilot Implementation project is determining how to make the educational component of these two programmes sustainable over the long-term. One difficulty encountered by the study homes was releasing staff for training while maintaining sufficient staff cover at ward level. On the financial level, there may be issues with the paid release of staff and training those staff who are off-duty. Another issue includes trying to fit as much educational material as possible into the short time staff could practically be released without compromising patient care. Repeating workshops to cover as many staff as possible raised issues of the availability and costs of manpower and the time and cost associated with travel.

Some Directors of Nursing indicated that it would be very difficult for them to release several staff at once for a whole day workshop, so training was delivered over two half-days. A repeat full-day workshop was offered at a later date for staff who had missed one or both of the earlier training sessions. Across the 3 study homes, approximately 30 senior nursing staff attended ACP workshops between 2012 and 2013, while approximately 200 nursing and care staff attended palliative care training sessions.

Development of e-learning resources

To address the difficulty in releasing staff for training, multidisciplinary e-learning modules on ACP and general palliative care have been developed to deliver training in a more efficient and flexible manner. The various professionals involved in caring for those nearing the end of life have differing educational needs, but there is considerable overlap especially in relation to core material. A collaborative group with representation from this project, the School of Medicine and the School of Nursing and Midwifery in University College Cork as well as from Specialist Palliative Care Services in Marymount Hospice was set up with the aim of developing core material on palliative care relevant to each of the disciplines which could be delivered online. The AIIHPC assisted with the transformation of the educational material into a format deliverable online, and the development of a central “hub” through which the palliative care educational material can be accessed online.

To view online e-resources on i) advance care planning and ii) palliative care education for staff. Please follow the link (http://learningplatform.thepalliativehub.com/) and use the instructions below to view both courses.
To view the programme on the Learning Platform, please follow the following steps:

- Open the Palliative Hub – Learning Platform site
- Register for the site (top of page)
- Click on ‘Other education providers’ courses and then click on ‘Palliative Care - Assessment and Management of Common Symptoms’
- You will be asked to enter the following enrolment key - Symptoms-2014 (capitalise the S of symptoms)
- You will then be able to access the programme

If you have any technical problems accessing the course, please contact Gareth Wescott: gwescott@aillhpc.org

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To view the programme on the Learning Platform, please follow the following steps:

- Open the Palliative Hub – Learning Platform site
- Register for the site (top of page)
- Click on ‘Other education providers’ courses and then click on ‘Introduction to Advanced Care Planning’
- You will be asked to enter the following enrolment key - ACP-2014
- You will then be able to access the programme
If you have any technical problems accessing the course, please contact Gareth Wescott: gwescott@aiihpc.org

Both courses were made available to staff of the 3 homes involved in the pilot project.

**Reluctance of staff to take ownership of ACP process and lack of staff confidence and experience**

Our pre-implementation survey in relation to palliative care skills among the 87 healthcare participants (85% of whom were nurses), identified diverse training needs and diverse levels of staff confidence. Less than 50% of respondents indicated that they had received palliative care training in the past, while only 40% said they would feel confident discussing EoL issues with a resident or family. Nursing staff considered important barriers to the implementation of ACP to include a lack of staff education about ACDs/ACPs, the lack of available education programmes about ACDs throughout the healthcare system, and a perception that residents and their families may not feel comfortable discussing ACP.

One Director of Nursing indicated that a small number of nursing staff, who had attended the ACP training workshops, demonstrated a reluctance to take ownership of delivering ACP to residents, seeing it as a role for management. To overcome this, we conducted live ACP demonstrations, with a sample of residents and families in front of small groups of nursing staff, in all three study sites.

Senior nursing staff indicated that they sometimes encountered difficulties in finding the appropriate time to introduce the subject of ACP to residents and their families. Routinely offering educational literature about the LMD programme to all new residents and their families on admission has helped to overcome this difficulty. Staff reported that the LMD programme has improved their ability to engage in difficult conversations around death and dying with both residents and family members. One Director of Nursing has reported that taking ownership of the programme has required a change in their whole approach to EoL care. Engaging in the ACP process, has brought benefits to residents, families and staff, in particular in relation to enhanced peace of mind regarding EoL care, with a reduction in crisis decision-making noted in all three homes.

**Lack of time to deliver ACP to residents and their families**

In the pre-implementation survey of nursing staff, the majority of respondents felt that finding sufficient time to educate residents about ACDs, and that lack of knowledge among the general public and families about ACDs, were important barriers to implementation of ACP in this population. Following implementation of the programme, feedback from staff indicated that a lack of time to deliver ACP was one of the biggest challenges they encountered, and that protected time would be needed to deliver ACP effectively. For residents lacking capacity to complete an ACD, the whole ACP process may be slowed down by family members having to consult with each other and achieve
consensus as to their understanding of what the resident might want (the question of which family member should be involved sometimes caused tension).

**Difficulties educating residents with cognitive impairment**

Hearing and other communication impairments in LTC residents present an important barrier to implementation of ACP, as rated by the majority of nurse respondents in our staff survey. For many frail residents, the ability to concentrate during the ACP education process was limited to short periods of time, necessitating the delivery of educational material in bite-sized chunks. Following feedback from staff, laminated education cue cards were developed which provided visual imagery to support the education process.

**Failure of other healthcare professionals to recognise completed ACD/ACP forms**

In this study, there have been isolated incidences of the failure of out-of-hours doctors, ambulance staff, and hospital A&E staff to recognise the validity of signed ACD/ACP forms, perhaps because of a lack of knowledge about these.

### 2.4.7 Discussion of challenges encountered in implementation

The effective delivery of ACP to residents and families may involve lengthy discussions of a sensitive nature and requires nursing staff to be knowledgeable about ACP and feel confident in their ability to deliver ACP in a sensitive, patient and supportive way. Providing comprehensive ACP education to LTC staff is key to promoting staff confidence. The development of a blended online learning programme in ACP and general palliative care (prompted by difficulties encountered in this study with releasing staff for training) will help to standardise the delivery of staff training and promote staff confidence. However, follow-up face-to-face workshops, which include simulation based training in completing ACDs/ACPs, is recommended. Other challenges reported by nursing staff, including lack of time and practical experience, could be minimised by the appointment of an ACP nurse facilitator with specialist training and skills. One Director of Nursing reported that staff were willing to overcome any challenges they encountered because they could see the benefits of the ACP programme in the longer-term.

LTC staff are ideally placed to appreciate the residents’ individual needs in the ACP process. Having a structured ACP programme in place in the LTC setting can be a powerful tool for staff in initiating difficult conversations about care at the end of life with residents and families, and can offer a framework for discussion. While it is useful for nurses to follow a structured ACP process, it is important that this does not become a “tick box” exercise. A person-centred approach more readily encourages residents’ meaningful participation (Jeong et al, 2010).

Communication is key to effective ACP; however, poor quality of communication about ACP may be common in practice, and patients often do not understand their decisions (Billings, 2012). The LMD-ACP programme includes education of residents about EoL care and a formal assessment of their capacity to understand the choices they are
making, which serves as a safeguard that the resident has been given enough information at a level and in a way that they can understand and that they have had time to reflect. Senior staff involved in this study have reported that the LMD-ACP programme has improved their ability to engage in difficult conversations in relation to death and dying with both residents and family members.

Over half of LTC residents have cognitive impairment that may be progressive (Molloy et al, 1996). In this study, educating elderly residents was found to be labour-intensive and presented as a bottleneck in the ACP process, prompting the simplification of educational materials and their presentation in smaller chunks. We have tailored the ACD/ACP forms and educational materials to the needs of this cognitively-challenged resident population, following an iterative feedback process with senior LTC nurses over a period of months. The use of educational materials aids patient involvement in the decision-making process by presenting the relevant information in a clear and understandable way. ACP should be introduced to residents at the earliest possible opportunity (ideally on admission, if appropriate) because of their high risk of decisional incapacity and high likelihood of facing choices about life-sustaining interventions in the near future.

Failure of out-of-hours doctors, ambulance staff, and hospital A&E staff to recognise the validity of signed ACD/ACP forms, perhaps because of lack of knowledge about their nature, was another challenge highlighted in this study. An out-of-hours doctor may decide to hospitalise a LTC resident who is deteriorating quickly, despite being presented with a signed form indicating ‘no transfer if at all possible’. In Ireland, the introduction of legislation for ACDs, which is pending, should help to overcome these barriers.

Healthcare professionals, in particular, those in the emergency services and those involved in caring for the elderly, need to be educated about ACDs/ACPs, and about the legal implications of failing to respect a patient’s recorded wishes with regard to refusal of particular treatments. There also needs to be clear procedures for staff to access advice from Specialist Palliative Care services outside of traditional hours (Irish Hospice Foundation, 2013).

Since many differences exist between countries with regard to the cultural aspects of discussing death, public and professional awareness of ACPs, and the legal framework in relation to ACDs, some of the findings above will not be applicable across all jurisdictions. Different challenges may be encountered in different LTC settings depending on the profile of the LTC population, the structure of LTC service provision, and how different healthcare professionals interact and cooperate within that structure.

Despite the challenges encountered, particularly with respect to lack of time to deliver ACP, in each of the three LTC facilities over 50% of residents had an EoLCP in place. The majority of residents (84%) who died during the post-implementation period had an EoLCP in place (12% of these were ACDs completed by the residents themselves), suggesting that staff may prioritise ACP for residents whose condition is deteriorating.
With the support of management, staff were willing to overcome challenges and take ownership of the programme, once the beneficial effects of their efforts became apparent in practice. Challenges appear to be offset by benefits in improving communication between staff, residents, and their families, promoting resident autonomy, and enhancing peace of mind of all involved.

**Conclusion from Implementation process**

The LMD-ACP programme offers a systematic approach to the implementation of structured ACP in LTC settings. Although many LTC residents lack capacity to complete their own ACD, the ‘Let Me Decide’ programme includes an option for structured EoL care planning for such residents, which involves discussions with the resident, where possible, and the family. Embedding the LMD-ACP programme in LTC requires time. Implementation is an iterative process, whereby changes are made, observed and then modified or tweaked to meet the needs of the LTC facility, staff and residents. While the ACP process can be challenging and laborious for LTC staff and families, it can promote communication between staff, residents, and their families, enhance peace of mind for all who engage, while at the same time increasing residents’ autonomy. Nursing staff were willing to overcome this and take ownership of the programme, once the benefits in terms of improved communication and enhanced peace of mind among all parties involved, became apparent in practice. In essence, the benefits far outweigh the challenges to implementation.
Part 3

Evaluating the impact of the LMD-ACP and Palliative Care programme on EoL care
Introduction

This section of the report outlines both the qualitative and quantitative evaluation of the programme, through the use of surveys, chart reviews and focus groups.

3.1 Aims and Objectives

This Pilot Study aimed to evaluate the effect of the implementation of an advance care planning (ACP) programme using the ‘Let Me Decide’ advance care directive (ACD)) combined with a general palliative care (PC) educational programme, on end-of-life (EOL) care in long-term care (LTC) settings.

The primary outcome evaluated was the intervention’s effect on the quality of death and dying using the ‘Quality of Dying and Death (QODD) questionnaire’ (last 7 day version) (Patrick et al, 2001) administered to relatives of deceased residents.

Secondary outcomes include:

- Quality of care and the care environment in the last week of life:
  - (i) from the perspective of healthcare staff (using the SPELE tool)
  - (ii) ascertained from review of charts of deceased residents
- Staff feedback on programme implementation and outcomes (focus groups).

3.2 Quality of Dying and Death in Long-term care

Deaths in the post-implementation period

There were 70 deaths in total across the three study homes in the post-implementation period (1st May/1st July 2013 – 30th June 2014) (see Table 10).

<table>
<thead>
<tr>
<th>Study site 1</th>
<th>Number of deaths</th>
<th>Time period</th>
</tr>
</thead>
<tbody>
<tr>
<td>(120 beds)</td>
<td>31</td>
<td>14 months</td>
</tr>
<tr>
<td>Study site 2</td>
<td>23</td>
<td>12 months</td>
</tr>
<tr>
<td>(97 beds)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study site 3</td>
<td>16</td>
<td>12 months</td>
</tr>
<tr>
<td>(79 beds)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>70 deaths</td>
<td></td>
</tr>
</tbody>
</table>
For these 70 deceased residents, data on end-of-life care/experience was collected from three separate sources:

(i) QODD survey (phonecall/postal) of bereaved next-of-kin (NOK)
(ii) Review of charts of deceased residents
(iii) ‘End of Life Experience (SPELE) Tool’ which was developed as part of this work (sub-sample of 15 deaths)

### 3.2.1 QODD survey (phonecall/postal) of bereaved Next-of-Kin

Data was collected from the next-of-kin (NOK) of residents who died in the year prior to implementation of the study intervention, using a questionnaire based on the Quality of Dying and Death questionnaire: last 7 day version (QODD) (Patrick et al, 2001). Likewise, the QODD survey was conducted among relatives of the 70 residents who died during the post-implementation period (12-14 months). Relatives of residents who died during the implementation period were not contacted as part of the QODD survey, to allow for a period of familiarisation of staff with the LMD programme and to allow for full implementation of Palliative Care programme. Below we report on findings from the QODD survey of bereaved

The following exclusion criteria are applied for use of the QODD:

- The resident who died was a ward of court or
- The resident had no known living relatives/friends or
- The family had not visited the resident in the last weeks of life.

The standard operating procedure for contacting bereaved relatives as part of this study is outlined in Appendix 10. When at least three months has passed after the death of a resident, a letter introducing the survey is sent to their relative by the Director of Nursing for the LTC institution. This is followed by a phone call to make contact with the relative and to get permission to do the survey either over the phone or by post. If contact by phone cannot be made, a letter is sent to the relative asking for permission to post the survey to them. Those who agreed to receive the questionnaire by post, but who did not return it within three weeks, were sent a reminder letter.

Following the implementation of programme the QODD Survey was completed by relatives of 51 deceased residents (see Table 11). A total of 53 completed questionnaires were returned (two questionnaires were returned for each of two deceased residents). It was not possible to include 9 out of 70 NOK in QODD survey for the following reasons:

- Two NOK had not seen their relative during the last week of life
- No valid contact details were available for six NOK (could not be contacted by phone and did not respond to the letter of invitation to take part)
- One NOK was deemed unsuitable by DoN for inclusion in the QODD survey.
Table 11  Response rates from Quality of Dying and Death (QODD) Survey for deaths in post-implementation period

<table>
<thead>
<tr>
<th></th>
<th>No. of deaths</th>
<th>No. Completed QODD</th>
<th>Response rate (%)</th>
<th>Adjusted Response rate (%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home 1</td>
<td>31</td>
<td>23</td>
<td>74</td>
<td></td>
</tr>
<tr>
<td>Home 2</td>
<td>23</td>
<td>15</td>
<td>65</td>
<td></td>
</tr>
<tr>
<td>Home 3</td>
<td>16</td>
<td>13</td>
<td>81</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>70</strong></td>
<td><strong>51 residents</strong></td>
<td><strong>73</strong></td>
<td><strong>84%</strong>*</td>
</tr>
</tbody>
</table>

*excluding 6 NOK who were not contactable by phone/post; 2 who were not with the resident in last week of life; and 1 NOK who was deemed unsuitable by Director of Nursing to take part in the survey.

The survey questionnaire used in this study is based on the Quality of Dying and Death questionnaire: last 7 day version (QODD) and includes questions relating to different aspects of the end-of-life experience (Patrick et al, 2001). Areas covered include:

- Environment where your relative/friend died
- Quality of your relative/friend’s life and activities of daily living
- Spending time with others
- Spiritual issues
- Satisfaction with care provided by staff
- Preparedness for death
- Overall quality of life during the last week
- Presence of common end-of-life symptoms
- Overall quality of death

Findings are presented below and follow the format of the questionnaire which contained 4 key sections; demographics, environment, quality of life and quality of dying, comments on care.
3.2.2 Section A – Demographics

This section focuses on the demographic background of participants. The results are summarised in Table 12 below. The majority of the respondents were female (n=35, 67.3%) and were reporting on the death of a parent (n=38, 71.7%). Only one respondent did not get to spend time with their relative during their last week of life. More than three quarters of respondents (n=39, 76.5%) were with their relative when they died.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (n=52)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17 (32.7)</td>
</tr>
<tr>
<td>Female</td>
<td>35 (67.3)</td>
</tr>
<tr>
<td>Relationship to person who died (n=53)</td>
<td></td>
</tr>
<tr>
<td>Husband or wife</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td>Child</td>
<td>38 (71.7)</td>
</tr>
<tr>
<td>Sister</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Other relative</td>
<td>6 (11.3)</td>
</tr>
<tr>
<td>Friend</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Age group (n=)</td>
<td>18 (8.3)</td>
</tr>
<tr>
<td>Did you get to spend time with your relative in their last week? (n=53)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>52 (98.1)</td>
</tr>
<tr>
<td>No</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Were you with your relative or friend when they died? (n=51)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>39 (76.5)</td>
</tr>
<tr>
<td>No</td>
<td>12 (23.5)</td>
</tr>
</tbody>
</table>

3.2.3 Section B – Environment where your relative or friend died

The second section pertained to the experience of where the person died. The first part of this section sought information on the room in which the person died (see Table 13). The majority (n=40, 76.9%) died in a single room and 80.4% (n=37) reported that their relative would have preferred to die in a single room. Meanwhile, there were mixed responses in terms of whether the type of room affected the quality of dying. Twenty five (48.1%) participants said it did not affect the quality of dying at all; in many of these cases, the dying resident was unaware of their surroundings. In contrast, 20 (38.5%) reported that it affected the quality of dying ‘a lot’ or ‘extremely’; this could be in a positive or negative way.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what kind of room did your relative or friend die? (n=52)</td>
<td></td>
</tr>
<tr>
<td>Single room</td>
<td>40 (76.9)</td>
</tr>
<tr>
<td>Shared room</td>
<td>12 (23.1)</td>
</tr>
</tbody>
</table>
In what kind of room do you think your relative or friend would have liked to have died? (n=46)

<table>
<thead>
<tr>
<th>Option</th>
<th>Count (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single room</td>
<td>37 (80.4)</td>
</tr>
<tr>
<td>Shared room</td>
<td>3 (6.5)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6 (13.0)</td>
</tr>
</tbody>
</table>

Did the type of room affect the quality of how he or she died? (n=52)

<table>
<thead>
<tr>
<th>Effect</th>
<th>Count (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>25 (48.1)</td>
</tr>
<tr>
<td>Mildly</td>
<td>3 (5.8)</td>
</tr>
<tr>
<td>Moderately</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>A lot</td>
<td>11 (21.2)</td>
</tr>
<tr>
<td>Extremely</td>
<td>9 (17.3)</td>
</tr>
</tbody>
</table>

Participants were then asked to rate the space and facilities provided for their relative during the last week of life (see Table 15). The majority of respondents regarded the private space provided as good or very good. Furthermore, most participants reported a very good opportunity to stay with their friend or relative for as long as they wanted them to. Finally, in terms of staff responses and the quality of care provided by staff, most participants rated this as good or very good.

### Table 15. Environment and Facilities

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The space where you could talk privately with staff (n=53)</strong></td>
<td></td>
</tr>
<tr>
<td>Very poor</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Poor</td>
<td>3 (5.7)</td>
</tr>
<tr>
<td>Average</td>
<td>4 (7.5)</td>
</tr>
<tr>
<td>Good</td>
<td>14 (26.4)</td>
</tr>
<tr>
<td>Very good</td>
<td>30 (56.6)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td><strong>The space where you could talk privately with your relative or friend (n=53)</strong></td>
<td></td>
</tr>
<tr>
<td>Very poor</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Poor</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Average</td>
<td>4 (7.5)</td>
</tr>
<tr>
<td>Good</td>
<td>8 (15.1)</td>
</tr>
<tr>
<td>Very good</td>
<td>39 (73.6)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>You could stay as long as your relative or friend wanted you to (n=53)</strong></td>
<td></td>
</tr>
<tr>
<td>Very poor</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Poor</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Average</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Good</td>
<td>4 (7.5)</td>
</tr>
<tr>
<td>Very good</td>
<td>47 (88.7)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>How did staff respond to your queries or requests (n=53)</strong></td>
<td></td>
</tr>
<tr>
<td>Very poor</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Poor</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Average</td>
<td>3 (5.7)</td>
</tr>
<tr>
<td>Good</td>
<td>12 (22.6)</td>
</tr>
<tr>
<td>Very good</td>
<td>37 (69.8)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
### What did you think of the quality of care provided by the staff (n=53)

<table>
<thead>
<tr>
<th>Quality of Care</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Poor</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Average</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Good</td>
<td>8 (15.1)</td>
</tr>
<tr>
<td>Very good</td>
<td>43 (81.1)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

### 3.2.4 Section C – Quality of life and quality of dying

This section asked respondents about the overall experience of their relative or friend, during the last week of life, including questions on the quality of life of the person and the quality of dying. Responses are summarised in Table 16 and have been assigned the following subcategories to ease interpretation: quality of life and activities of daily living; spending time with others; spiritual issues; financial and funeral plans; satisfaction with staff; preparedness for death; and overall quality.

#### Quality of life and activities of daily living

The majority of participants reported that their relative or friend had pain none of the time (n=16, 30.8%) while a further 55.8% (n=29) reported that their relative or friend had pain a little or some of the time. Most participants (n=46, 86.8%) reported their relative or friend to be unconscious or semi-conscious but unable to speak in the moment before they died. In terms of the ability to eat and drink, 23.5% (n=12) of respondents indicated that their relative/friend was unable to eat and drink, while 49.1% (n=25) indicated that their relative/friend could eat and drink only a little or some of the time. Over three quarters of participants (n=43, 82.7%) said their relative or friend was able to breathe comfortably a good bit of the time, most of the time, or all of the time. Over 80% of participants (n=42, 84.4%) reported that their relative or friend seemed comfortable or at ease a good bit of the time, most of the time, or all of the time. Meanwhile, only 2 participants (4%) reported that their relative or friend seemed anxious or afraid most or all of the time. Over half of participants (n=28, 58.0%) were reported as showing signs of enjoyment (e.g. smiling or laughing) during the last week of life none of the time or only a little of the time. Thirty eight (86.4%) participants said that their relative or friend seemed to have energy to do what they wanted to do none of the time or only a little of the time. In terms of bladder control, the majority had no control over this bodily function (n=38, 74.5%). Almost all participants (n=51, 98.1%) stated their relative or friend’s dignity and self-respect was maintained most of the time or all of the time. Only one participant reported that it was maintained some of the time.

#### Spending time with others

Almost all participants (n=47, 97.9%) reported that their relative or friend was able to spend time with their family in the way they wanted, most or all of the time. One participant said they didn’t know the answer to this question. The majority of participants (n=25, 71.5%) said that their relative or friend was able to spend time alone in the way they wanted to most or all of the time. Very few participants (n=2, 4%)
felt that their relative or friend seemed worried about causing strain to his or her loved ones most or all of the time. All participants (n=51, 100%) stated that their relative or friend had their loved ones around them in the last week of life and 90% (n=47) said that there was someone with their relative or friend at the moment of death.

**Spiritual issues**

In terms of having meaning and purpose in life, most participants (n=21, 43.8%) said their relative did have meaning and purpose in life, while 14 participants (n=29.2%) said no, and 13 (27.1%) said they didn't know. The majority of participants (n=46, 86.8%) reported that their relative or friend had a visit from a religious or spiritual advisor and one person reported that their friend or relative did not want to receive such a visit.

**Financial and funeral plans**

Six participants (11.8%) reported that their relative or friend did have money worries (e.g. cost of care) prior to death and one person didn't know whether their relative or friend had such worries. The majority of participants (n=30, 56.6%) reported that their relative or friend had not made funeral plans.

**Satisfaction with staff**

On a scale of 1-10 (1=very poorly, 10=excellent), the majority of participants (n=39, 75.0%) reported that staff communicated excellently (9-10) with their relative or friend. Similarly, most participants (n=38, 77.6%) scored 9-10 when asked whether the end-of-life care provided, respected their relative or friend’s wishes. In terms of advance care planning, only nine (17.3%) participants reported that their relative or friend discussed how they wanted to be cared for at the end of life, with their doctor or other staff. For the majority of the remaining cases, these discussions could not have taken place due to the resident’s lack of capacity to discuss their end-of-life care preferences. However, 76.1% (n=35) of survey participants said that the doctor or other staff did ask what type of end-of-life care the resident would have wanted.

**Preparedness for death**

Over three quarters of participants (n=40, 75.5%), said that they were expecting their relative or friend’s death and almost three quarters of participants (n=38, 73.1%) reported feeling prepared for their relative or friend’s death. Almost half of participants said that their relative or friend said goodbye to their loved ones (n=24, 47.1%). The majority of participants (n=39, 75.0%) said that they had enough information on what to expect as someone is dying or what to do afterwards.

**Overall quality**

Participants were asked to rate the quality of life during the last week, and the quality of death, of their relative or friend on a scale of one to ten (1=terrible, 10=almost perfect). Half of participants (n=26) rated their relative or friend’s quality of life between seven and ten, while 27% of participants (n=14) rated it between one and four. With regard to quality of death, almost 90% of participants (n=45, 86.6%) rated it between seven and ten.
<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Table 16. Experience of Death and Dying</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Quality of life and activities of daily living</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Did your relative or friend have physical pain? (n=52)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>16 (30.8)</td>
</tr>
<tr>
<td>A little of the time</td>
<td>13 (25.0)</td>
</tr>
<tr>
<td>Some of the time</td>
<td>16 (30.8)</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>All of the time</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td><strong>In the moment before your relative or friend died, were they? (n=53)</strong></td>
<td></td>
</tr>
<tr>
<td>Alert</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Semi-conscious but able to speak</td>
<td>8 (15.1)</td>
</tr>
<tr>
<td>Unconscious</td>
<td>38 (71.7)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td><strong>Was your relative or friend able to eat or drink? (n=51)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>12 (23.5)</td>
</tr>
<tr>
<td>A little of the time</td>
<td>19 (37.3)</td>
</tr>
<tr>
<td>Some of the time</td>
<td>6 (11.8)</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>3 (5.9)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>6 (11.8)</td>
</tr>
<tr>
<td>All of the time</td>
<td>5 (9.8)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Was your relative or friend able to breathe comfortably? (n=52)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>0 (0)</td>
</tr>
<tr>
<td>A little of the time</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>Some of the time</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>17 (32.7)</td>
</tr>
<tr>
<td>All of the time</td>
<td>24 (46.2)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td><strong>Did your relative or friend seem comfortable and at ease? (n=51)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>0 (0)</td>
</tr>
<tr>
<td>A little of the time</td>
<td>2 (3.9)</td>
</tr>
<tr>
<td>Some of the time</td>
<td>6 (11.8)</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>6 (11.8)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>23 (45.1)</td>
</tr>
<tr>
<td>All of the time</td>
<td>14 (27.5)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Did your relative or friend seem anxious or afraid? (n=49)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>20 (40.8)</td>
</tr>
<tr>
<td>A little of the time</td>
<td>11 (22.4)</td>
</tr>
<tr>
<td>Some of the time</td>
<td>10 (20.4)</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>4 (8.2)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>All of the time</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2 (4.1)</td>
</tr>
<tr>
<td><strong>Did your relative or friend smile, laugh or show signs of enjoyment in their last week? (n=51)</strong></td>
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</tr>
<tr>
<td>None of the time</td>
<td>14 (27.5)</td>
</tr>
<tr>
<td>Question</td>
<td>Frequency</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-----------</td>
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<tr>
<td>A little of the time</td>
<td>14</td>
</tr>
<tr>
<td>Some of the time</td>
<td>14</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>3</td>
</tr>
<tr>
<td>Most of the time</td>
<td>5</td>
</tr>
<tr>
<td>All of the time</td>
<td>0</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td><strong>Did your relative or friend seem to have the energy to do most of the</strong></td>
<td></td>
</tr>
<tr>
<td><strong>things that they wanted to do? (n=44)</strong></td>
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<tr>
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<td>33</td>
</tr>
<tr>
<td>A little of the time</td>
<td>5</td>
</tr>
<tr>
<td>Some of the time</td>
<td>4</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>0</td>
</tr>
<tr>
<td>Most of the time</td>
<td>2</td>
</tr>
<tr>
<td>All of the time</td>
<td>0</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0</td>
</tr>
<tr>
<td><strong>Was your relative or friend able to physically control when they went</strong></td>
<td></td>
</tr>
<tr>
<td><strong>to the toilet? (n=51)</strong></td>
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<tr>
<td>None of the time</td>
<td>38</td>
</tr>
<tr>
<td>A little of the time</td>
<td>1</td>
</tr>
<tr>
<td>Some of the time</td>
<td>4</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>2</td>
</tr>
<tr>
<td>Most of the time</td>
<td>4</td>
</tr>
<tr>
<td>All of the time</td>
<td>0</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
</tr>
<tr>
<td><strong>Was your relative or friend’s dignity and self-respect maintained?</strong></td>
<td></td>
</tr>
<tr>
<td>(n=52)</td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>0</td>
</tr>
<tr>
<td>A little of the time</td>
<td>0</td>
</tr>
<tr>
<td>Some of the time</td>
<td>1</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>0</td>
</tr>
<tr>
<td>Most of the time</td>
<td>13</td>
</tr>
<tr>
<td>All of the time</td>
<td>38</td>
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<tr>
<td>Don’t know</td>
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<tr>
<td><strong>Spending time with others</strong></td>
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<tr>
<td><strong>Was your relative or friend helped to spend time with their family in</strong></td>
<td></td>
</tr>
<tr>
<td><strong>the way they wanted to? (n=48)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>0</td>
</tr>
<tr>
<td>A little of the time</td>
<td>0</td>
</tr>
<tr>
<td>Some of the time</td>
<td>0</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>0</td>
</tr>
<tr>
<td>Most of the time</td>
<td>6</td>
</tr>
<tr>
<td>All of the time</td>
<td>41</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td><strong>Was your relative or friend helped to spend time alone in the way they</strong></td>
<td></td>
</tr>
<tr>
<td><strong>wanted to? (n=35)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>0</td>
</tr>
<tr>
<td>A little of the time</td>
<td>2</td>
</tr>
<tr>
<td>Some of the time</td>
<td>1</td>
</tr>
<tr>
<td>A good bit of the time</td>
<td>0</td>
</tr>
<tr>
<td>Most of the time</td>
<td>8</td>
</tr>
<tr>
<td>All of the time</td>
<td>17</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7</td>
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<tr>
<td><strong>Did your relative or friend seem worried about causing strain to his or</strong></td>
<td></td>
</tr>
<tr>
<td><strong>her loved ones? (n=51)</strong></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td>28 (54.9)</td>
</tr>
<tr>
<td>A little of the time</td>
<td>10 (19.6)</td>
</tr>
<tr>
<td>Some of the time</td>
<td>7 (13.7)</td>
</tr>
<tr>
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<td>1 (2.0)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>All of the time</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3 (5.9)</td>
</tr>
</tbody>
</table>

**Did your relative or friend have his or her loved ones around them in the last week of life? (n=51)**

| Yes | 51 (100) |
| No | 0 (0) |
| Don’t know | 0 (0) |

**Was anyone there at the moment of your relative or friend’s death? (n=52)**

| Yes | 47 (90.4) |
| No | 3 (5.8) |
| Don’t know | 2 (3.8) |

**Spiritual issues**

**Did your relative or friend seem to have meaning and purpose in their life? (n=48)**

| Yes | 21 (43.8) |
| No | 14 (29.2) |
| Don’t know | 13 (27.1) |

**Did your relative or friend have one or more visits from a religious or spiritual advisor such as a priest? (n=53)**

| Yes | 46 (86.8) |
| No | 3 (5.7) |
| Didn’t want these visits | 1 (1.9) |
| Don’t know | 3 (5.7) |

**Financial and funeral plans**

**Did your relative or friend have any money worries, such as the cost of care? (n=51)**

| Yes | 6 (11.8) |
| No | 44 (86.3) |
| Don’t know | 1 (2.0) |

**Had your relative or friend made funeral plans? (n=53)**

| Yes | 22 (41.5) |
| No | 30 (56.6) |
| Don’t know | 1 (1.9) |

**Satisfaction with staff**

**How well did staff (doctors and nurses) communicate with your relative or friends about their illness? (n=50)**

<p>| (1) Very poorly | 0 (0) |
| (2) | 0 (0) |
| (3) | 1 (2.0) |
| (4) | 0 (0) |
| (5) | 1 (2.0) |
| (6) | 1 (2.0) |
| (7) | 1 (2.0) |
| (8) | 8 (16.0) |
| (9) | 6 (12.0) |
| (10) Excellent | 19 (38.0) |
| Don’t know | 13 (26.0) |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well did staff communicate with your relative or friend’s family about his or her illness and death? (n=52)</td>
<td>(1) Very poorly</td>
<td>1 (1.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(2)</td>
<td>0 (0)</td>
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</tr>
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<td>(3)</td>
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<tr>
<td></td>
<td>(8)</td>
<td>4 (7.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(9)</td>
<td>9 (17.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(10) Excellent</td>
<td>30 (57.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>How well did staff provide end of life care that respected your relative or friends wishes? (n=49)</td>
<td>(1) Very poorly</td>
<td>1 (2.0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(2)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(3)</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>(4)</td>
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</tr>
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<td></td>
<td>(5)</td>
<td>1 (2.0)</td>
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<tr>
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<td>(8)</td>
<td>3 (6.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(9)</td>
<td>9 (18.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(10) Excellent</td>
<td>29 (59.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>4 (8.2)</td>
<td></td>
</tr>
<tr>
<td>Did your relative or friend discuss with their doctor or other staff how they wanted to be cared for at the end of life? (n=52)</td>
<td>Yes</td>
<td>9 (17.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>36 (69.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>7 (13.5)</td>
<td></td>
</tr>
<tr>
<td>If no, did the doctor or staff looking after your relative or friend ask what care at the end of life your relative or friend would have wanted? (n=46)</td>
<td>Yes</td>
<td>35 (76.1)</td>
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</tr>
<tr>
<td></td>
<td>No</td>
<td>10 (21.7)</td>
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</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>1 (2.2)</td>
<td></td>
</tr>
<tr>
<td>Preparedness for death</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Were you expecting your relative or friend’s death? (n=53)</td>
<td>Yes</td>
<td>40 (75.5)</td>
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</tr>
<tr>
<td></td>
<td>No</td>
<td>13 (24.5)</td>
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<td></td>
<td>Don’t know</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Did you feel prepared for your relative or friend’s death? (n=52)</td>
<td>Yes</td>
<td>38 (73.1)</td>
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</tr>
<tr>
<td></td>
<td>No</td>
<td>13 (25.0)</td>
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</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>1 (1.9)</td>
<td></td>
</tr>
<tr>
<td>Did your relative or friend say goodbye to their loved ones? (n=51)</td>
<td>Yes</td>
<td>24 (47.1)</td>
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<tr>
<td></td>
<td>No</td>
<td>23 (45.1)</td>
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</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>4 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Would you have liked more information on what to expect as someone is dying or what to do afterwards? (n=52)</td>
<td>Yes</td>
<td>11 (21.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>39 (75.0)</td>
<td></td>
</tr>
</tbody>
</table>
3.2.5 Section D – Comments on care

This section asked participants to comment on the care their relative or friend received. The following three questions were asked:

- What went well in the care of your relative or friend during their last week of life?
- What did not go so well in the care of your relative or friend during their last week of life?
- Are there any other comments you would like to add?

A number of comments were extracted from the data to provide insight into the overall consensus on the LMD programme. Not all of the comments were included as some were repetitive. These comments and quotations are graphically presented below. It is important to note that the majority of feedback was of a positive nature with only a few negative comments and these related to experiences that were not reflective of a situation that could not have been changed, as opposed to substandard care provided.

### Overall quality

<table>
<thead>
<tr>
<th>Overall how would you rate relative or friend’s quality of life during their last week? (n=52)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Terrible</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>(2)</td>
<td>3 (5.8)</td>
</tr>
<tr>
<td>(3)</td>
<td>3 (5.8)</td>
</tr>
<tr>
<td>(4)</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>(5)</td>
<td>3 (5.8)</td>
</tr>
<tr>
<td>(6)</td>
<td>3 (5.8)</td>
</tr>
<tr>
<td>(7)</td>
<td>7 (13.5)</td>
</tr>
<tr>
<td>(8)</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>(9)</td>
<td>8 (15.4)</td>
</tr>
<tr>
<td>(10) Almost perfect</td>
<td>7 (13.5)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>6 (11.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall how would you rate the quality of your relative or friend’s death? (n=52)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Terrible</td>
<td>0 (0)</td>
</tr>
<tr>
<td>(2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>(3)</td>
<td>2 (3.8)</td>
</tr>
<tr>
<td>(4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>(5)</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>(6)</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>(7)</td>
<td>3 (5.8)</td>
</tr>
<tr>
<td>(8)</td>
<td>4 (7.7)</td>
</tr>
<tr>
<td>(9)</td>
<td>13 (25.0)</td>
</tr>
<tr>
<td>(10) Almost perfect</td>
<td>25 (48.1)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3 (5.8)</td>
</tr>
</tbody>
</table>
What went well?

“The love she was surrounded by at the end of life. She was loved by the staff”.

“Every effort was made to keep my mother comfortable and pain-free. The family were helped in every way, allowed to make tea etc. An apartment was given to me so that I could stay close by for the week. Fr. X at Nursing Home X had become a good friend to my mother and he called often. The only negative thing leading up to her death was her own sense of imminent death – this would have been the case wherever she was.”

“I have only positive things to say about the care”.

“My dad was sedated during the last week of his life, which lessened his agitation. Staff always rang if there was a problem and called us the night he died so we were with him at the end”.

“She was happy and content, had plenty visitors and her routine was the same as other weeks. This was important to her. She came home for her granddaughter’s birthday, spent time with the family which she hadn’t done for some time. So this worked out perfectly. We have photos and videos of the occasion”.

“She was in a single room. We had space where we could talk privately to her. We could stay as long as we wanted to and all staff were more than helpful at all times”.

“We were kept very well informed throughout. Privacy and support were ensured. Every kindness was shown. She was kept as comfortable as possible with meds”.
What did not go so well?

“Like all family it was difficult to fully accept she was so close to death but nursing staff continued to emphasise it was close. Her care did not change however”.

“Possible delay in transfer to hospital, this was out of respect to her wishes not to be transferred but with no improvement in her condition, transfer was necessary. We are left with questioning whether we should have asked for earlier transfer and maybe outcome would have been different”.

“Because of the circumstances i.e. being estranged from her cousins (her closest family members) it was an awkward situation...that was not the fault of the staff....”

“Her own sense of imminent death – this would have been the case wherever she was”.

“The only thing was the four bedded room – it was a bit shabby in my opinion and could have done with refurbishment. The curtain was shabby and the wardrobe was old. At 92 when she went in, it didn’t matter to her where she was, but she might have noticed that her surroundings were shabby. It’s a small thing, but I do feel it’s’ worth mentioning”.

“We felt a bit isolated in the single room – it would have been nice if a priest had visited, but we were able to pray ourselves. The staff came in with a candle after my mother died and they were very good at listening. She died at 4am”.

“The pain management was poor and the doctor attending declined to avail of services available from [the] hospice”.

“Because of the circumstances i.e. being estranged from her cousins (her closest family members) it was an awkward situation...that was not the fault of the staff....”
"A booklet should be available...to explain the way in which dying was managed and the choices available to families. In [long-term care site], an ill resident could be moved to the relative’s room which would be more suitable. A ribbon should be on the door of a room where someone is very ill to alert staff and other visitors.”

"Any other comments?"

"I completed the advance care directive on mum’s behalf which I am sure helped doctors and nurses to decide on appropriate care”.

"My husband died in [long-term care site] in 2005...and my father died there in 2009. I can see that they are definitely doing things better now when it comes to residents approaching the end of life...”

"I was delighted we attended the talk Prof W. Molloy gave about choices and that she spoke about and told staff her wishes because her death was sudden, so her end of life wishes were carried out”.

"I, and my family, will never forget the kindness shown to my mother in her final days. Staff were loving and caring and my mother mentioned many times how good they were to her. Obviously the staff have seen many deaths but we were made to feel as if we were the only people that mattered. Cups of tea and a hand on the shoulder mean an awful lot at a time like this. I was also touched when staff came to the funeral.”

"All the staff without exception took an interest in mum. They always treated her with great professionalism and anything she took interest in was followed up and encouraged by the staff. Also, anything the family requested was granted. She could not have been more comfortable and the degree of care was superb. Her physical, mental, emotional and spiritual needs were all taken care of”.
3.3 Review of charts of deceased residents in the post-implementation period

There were 70 deaths in total across the three study homes in the 12-14 month post-implementation period (see Table 17). All charts of deceased residents (N=70) were reviewed to obtain information in relation to resident characteristics, documented symptoms in the last week of life, medications charted and administered, and end-of-life care given.

Of the 62 residents who died in the nursing homes, 63% were female and 27% were male. The mean age at death was 85.9 years. For the 51 residents for whom data was available, the mean MTS score (out of 10) was 3.3. The mean number of co-morbidities recorded in the residents’ charts was 4.1, while the mean number of GP visits they had in the last three months of life was 10.2.

With regard to scale of decline, in the majority of cases this was gradual (68%), while it was “slow” for 14% and “quick” for 18% of cases. Death had been expected in the majority of cases (87%). In 85% of cases it was recognised in advance that the resident was dying, and this occurred on average eight days before the death (median figure was 3 days). Of the 62 residents, 89% had a Do-Not-Resuscitate (DNR) order in place.

The mean number of symptoms documented in the resident’s chart in the last week of life was 3.9. The most frequently documented symptoms were ‘pain’ and ‘fatigue’, with these each affecting two-thirds (65%) of residents (see Table 13). This is consistent with results from the QODD Survey, in which 65.3% of bereaved NOK reported that their relative/friend had pain at least some of the time during their last week, while 31% (n=16) reported that their relative or friend had pain none of the time.

The next most commonly documented symptoms were ‘Anxiety/Agitation/Restlessness’, and ‘secretions’, with each of these affecting almost half (48%) of all dying residents. In 45% of cases, it was documented that the resident had shortness of breath. This figure is consistent with results from the QODD Survey, in which 52% of bereaved NOK reported that their relative/friend was not able to breathe comfortably at least some of the time in their last week of life.

The majority of the 70 residents (87%) were described in the medical/nursing notes as “comfortable” during the last week of life; this was not specifically documented for the remaining cases (some of these were sudden deaths). A quarter of residents were reviewed by the Specialist Palliative Care Team, while 19% had a syringe driver in place for administration of medications leading up to the time of death. A number of the remaining cases had sub-cutaneous morphine/midazolam/hyoscine etc. charted for use in the period leading up to death. In 25% of cases, IV/SC fluids were administered in the last week of life. In one of the nursing homes where all 23 deaths in the post-
implementation period occurred in the home itself, 16 residents (70%) were placed on an EoL care pathway; most (69%) were commenced on this pathway during their last week of life.

Table 17  Presence of Symptom documented in resident charts in the last week of life

<table>
<thead>
<tr>
<th>For residents who died in the Nursing home (N=62)</th>
<th>Presence of Symptom documented in last week of life</th>
<th>%</th>
<th>Symptom documented in chart as NOT being present or not documented at all</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>40</td>
<td>65%</td>
<td>22</td>
<td>35%</td>
</tr>
<tr>
<td>Fatigue/weakness</td>
<td>40</td>
<td>65%</td>
<td>22</td>
<td>35%</td>
</tr>
<tr>
<td>Anxiety/Agitation/Restlessness</td>
<td>30</td>
<td>48%</td>
<td>32</td>
<td>52%</td>
</tr>
<tr>
<td>Secretions</td>
<td>30</td>
<td>48%</td>
<td>32</td>
<td>52%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>28</td>
<td>45%</td>
<td>34</td>
<td>55%</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>21</td>
<td>34%</td>
<td>41</td>
<td>66%</td>
</tr>
<tr>
<td>Cough</td>
<td>18</td>
<td>29%</td>
<td>44</td>
<td>71%</td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
<td>15</td>
<td>24%</td>
<td>47</td>
<td>76%</td>
</tr>
<tr>
<td>Constipation/diarrhoea</td>
<td>10</td>
<td>16%</td>
<td>52</td>
<td>84%</td>
</tr>
<tr>
<td>Seizure</td>
<td>7</td>
<td>11%</td>
<td>55</td>
<td>89%</td>
</tr>
<tr>
<td>Hallucination/nightmare</td>
<td>1</td>
<td>2%</td>
<td>61</td>
<td>98%</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>10</td>
<td>16%</td>
<td>52</td>
<td>84%</td>
</tr>
<tr>
<td>Mean number of documented symptoms</td>
<td></td>
<td></td>
<td></td>
<td>4.0</td>
</tr>
</tbody>
</table>

For a small number of cases (n=6, 10%), notes documented in the resident’s chart indicated that the resident was aware they were dying (see Table 18). In contrast, in 90% of cases, the family was aware that the resident was dying, while 77% (n=47) of dying residents had their family with them at the moment of death. In the QODD Survey of bereaved NOK, 90% (N=47) of respondents indicated that their relative/friend had someone present with them at the time of death.

In almost a quarter of cases (24%), it was documented in the notes that the family was provided with a quiet room and facilities. Results from the QODD survey of bereaved relatives indicate that, following the death of a resident, the care given to families and friends was very good. Finally, for 82% of residents, it was documented in the notes that the resident received the Sacrament of the Sick or had a pastoral care visit at the end of life.
Table 18  Data from review of charts of those residents who died in the nursing home (N=62)

<table>
<thead>
<tr>
<th></th>
<th>Male:</th>
<th>Female:</th>
<th>Mean age at death</th>
<th>Mean MTS Score (/10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>27% (N=17)</td>
<td>63% (N=45)</td>
<td>85.9 years (N=61)</td>
<td>3.3 (N=51)</td>
</tr>
<tr>
<td>Mean no. of co-morbidities</td>
<td>4.1 (N=62)</td>
<td>Mean No. of GP visits in the last 3 months</td>
<td>10.2 (N=62)</td>
<td></td>
</tr>
<tr>
<td>Scale of decline (N=57)</td>
<td>Slow 14% (N=8)</td>
<td>Gradual 68% (N=39)</td>
<td>Quick 18% (N=10)</td>
<td></td>
</tr>
<tr>
<td>Was death expected? (N=59)</td>
<td>YES 52 (87%)</td>
<td>No 7 (12%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was it recognised that the resident was dying? (N=60)</td>
<td>YES 51 (85%)</td>
<td>NO 1 (2%)</td>
<td>Not documented 8 (13%)</td>
<td></td>
</tr>
<tr>
<td>WHEN was it recognised that the resident was dying? (N=50)</td>
<td>Mean 8 days</td>
<td>Median 3 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was resident described as comfortable? (N=59)</td>
<td>YES 52 (87%)</td>
<td>NO 1 (2%)</td>
<td>Not documented 7 (12%)</td>
<td></td>
</tr>
<tr>
<td>Was the resident reviewed by the Specialist Palliative Care Team? (N=60)</td>
<td>YES 15 (25%)</td>
<td>NO 42 (70%)</td>
<td>Not documented 3 (5%)</td>
<td></td>
</tr>
<tr>
<td>Were IV/SC fluids administered? (N=61)</td>
<td>YES 15 (25%)</td>
<td>NO 46 (75%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was a syringe</td>
<td>YES</td>
<td>NO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>YES</td>
<td>NO</td>
<td>Not documented</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----</td>
<td>-----</td>
<td>----------------</td>
<td></td>
</tr>
<tr>
<td>driver used to administer medications? (N=61)</td>
<td>12 (19%)</td>
<td>49 (79%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was resident aware they were dying? (N=60)</td>
<td>6 (10%)</td>
<td>10 (17%)</td>
<td>44 (73%)</td>
<td></td>
</tr>
<tr>
<td>Was Family aware of impending death? (N=62)</td>
<td>56 (90%)</td>
<td>3 (5%)</td>
<td>3 (5%)</td>
<td></td>
</tr>
<tr>
<td>Were the family present at the time of death? (N=61)</td>
<td>47 (77%)</td>
<td>12 (20%)</td>
<td>2 (3%)</td>
<td></td>
</tr>
<tr>
<td>Were family provided with quiet room &amp; facilities? (N=58)</td>
<td>14 (24%)</td>
<td>1 (2%)</td>
<td>43 (74%)</td>
<td></td>
</tr>
<tr>
<td>Did resident receive Sacrament of the Sick or have a visit from a priest/vicar? (N=62)</td>
<td>41 (82%)</td>
<td>9 (18%)</td>
<td>12 (5%)</td>
<td></td>
</tr>
</tbody>
</table>
3.4 Measuring Staff Perception of End-of-Life Experience of Older Adults in Long Term Care; Post implementation

During the two year-long study, we received continuous informal feedback from staff on the deaths occurring in the home, in relation to symptom management, adherence to patients’ wishes and communication issues with family and the broader healthcare provider community. It was evident that perceptions of quality of care at end of life needed to be measured in a more structured way, to facilitate reflection and learning from each death in each home, and to correlate these with chart data and family perceptions of care. Against this background a multi-dimensional questionnaire was designed.

Consequently, this section describes the initial development and pilot testing of the Staff Perception of End-of-Life Experience questionnaire (SPELE) to measure the end-of-life experience in older adults, in LTC, from the perspective of healthcare professionals caring for them.

METHOD

A two-phase approach was taken; phase 1 focused on the development of the questionnaire and phase 2 was a pilot study evaluating the inter-rater reliability of the instrument in a sample of 15 healthcare professional dyads.

Procedure

**Phase 1: Instrument development.** Item generation and refinement, measurement format and content validity are fundamental stages in questionnaire design and development (DeVellis, 2003).

*Item generation and refinement.* Three main sources were used for item generation; literature, the Hospice Friendly Hospice/Health Service Executive of Ireland National End of Life Audit (McKeown et al, 2010) and focus groups discussions with healthcare staff working in long-term care, geriatricians and senior nursing management. The questionnaire measures if individual preferences and advance care directives were complete and includes global perception scores on the quality of care provided. It also captures information on the physical aspects of end-of-life care through the domain of pain and symptom management. The presence of common symptoms at end-of-life is measured, as well as the perceived management of symptoms and staff perception of the amount of distress caused by each symptom. Global rating of care is also measured. In total 7 subscales make up the SPELE questionnaire.

*Content Validity.* An essential component of questionnaire development is content validity; this is most commonly achieved through the use of an expert panel of judges (Rattray & Jones, 2007). The panel was composed of three nurses with PhDs in the area of pain management, spirituality and symptom burden, two specialist geriatricians, one director of nursing in LTC and one non-healthcare professional (lay expert).

*Structure.* Following this initial validation process, the questionnaire brought forward to the pilot study contained eight sections. Section 1 has nine demographic
questions. **Section 2** contains six questions on person and setting. **Section 3** measures pain and symptom experience in one scale (13 symptoms; pain, nausea, shortness of breath, cough, seizure, hallucination, constipation, diarrhea, agitation/restlessness, dry mouth, secretions, fatigue, and decreased appetite) and one global question. **Section 4** has two questions (1 scale -11 items, 1 global rating scale) on personal acceptance, insight and control. **Section 5** measures resident’s preferences across three questions and includes two items measuring perceived level of control, and desire for control. **Section 6** relates to communication and contains three questions. **Section 7** has 4 questions measuring distress and satisfaction. Finally, **section 8** contains two questions on global ratings of care.

**Phase 2: Pilot design.** The aim of this phase was to evaluate the inter-rater reliability of the subscales. Between December 2013 and June 2014 each LTC site participating in the larger end-of-life research programme was asked to notify the research team of any deaths. Two staff involved in the care during the last week of life were identified by the Nurse Manager, and invited to complete separate SPELE questionnaires on the same death independently, (i.e., without consulting each other). The questionnaire was required to be completed within one month of the death occurring. Inclusion criteria dictated that only nurses and healthcare assistants that cared for a resident, during the last week of life, were eligible to participate. An information leaflet was provided and written consent was gained prior to data collection. Completed questionnaires were placed in a sealed envelope and collected by the research team during periodic site visits.

**RESULTS**

**Demographic Profile**

The questionnaire was piloted on 15 deaths that occurred over a 6 month period using dyads of healthcare assistants (n=15) and registered general nurses (n=15). Level of education ranged from FETAC level 5 course for healthcare assistants (n=14) (The Further Education and Training Awards Council- short course for carers up to 50 hours in duration) to Masters (n=1). Over half (n=18, 60%) were between the age of 31-50 years. The gender spread across healthcare facilities was typical, with the majority female (n=28, 93.3%). The predominant nationality was Irish (n=26, 86.7%) and consequently most were Roman Catholic (n=26, 96.7%). Over 55% (n=15) indicated that they received education in palliative care, while 25.9% (n=7) had attended training on advance care planning.

**Person and Physical Environment**

Most of the deaths reviewed occurred in a single room (n=12) and staff were invited to comment if this had an impact on the dying experience. Thirteen participants responded with only one person noting the importance of the environment at the time of death, and the role of the ‘single room’ in promoting dignity and privacy; ‘It makes the patients last moments more dignified and provides more privacy to family’ In all, only 33% of nurses and 40% of healthcare assistants felt that the type of setting made a difference to the care provided.

The family were present at the time of death in 64.3% (n=9) of the cases. The rate of the persons overall decline was measured using the following scale; Slow, Gradual, Quick,
Sudden. Over 78% of healthcare assistants described the death as slow or gradual, compared to 60% of nurses. Over 85% of the deaths were considered expected.

**Pain and symptom experience at end-of-life**

For the two groups of raters (i.e. nurses and healthcare assistants), a Kappa score was calculated on each of the 13 symptoms to determine the level of agreement regarding the presence of each symptom during the last week of the resident’s life. It was not possible to calculate scores for the distress this symptom caused, or the management of the symptom, as there was a large amount of missing data, coupled with the small sample size from inception. Table 19 shows the raters agreement for each item. Kappa values show that in all cases there was varying degrees of agreement among raters, with scores ranging from 0.28-0.84. A score of > 0.41 indicates moderate agreement, while 0.61-0.99 represents substantial agreement [40]. Lack of agreement on some of the symptom domains confirms the discrete nature of the disciplines and their interpretations of symptoms. Compared to nurses, healthcare assistants, appear to have observed the presence of significantly more symptoms such as pain (71.4% V 28.6%, p=0.13), nausea (40% V 10%, p=0.20), dry mouth (57.1% V 35.7%, p=0.20), during the last week of life. The majority of these symptoms are usually observed during moments of direct personal care e.g. dry mouth. Substantial agreement regarding the presence of symptoms was found in the reporting of agitation (0.77, 95% CI 0.35-1.00), decreased appetite (0.84, 95% CI 0.53-1.00) and SOB (0.63, 95% CI 0.17-1.00). The association between staff nurses and healthcare assistant rating for these symptoms was statistically significant.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Staff Nurse (n=15)</th>
<th>Healthcare assistant (n=15)</th>
<th>Kappa value (95% CI)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>28.6%</td>
<td>71.4%</td>
<td>.28 (.03-.58)</td>
<td>.13</td>
</tr>
<tr>
<td>Nausea</td>
<td>10.0%</td>
<td>40.0%</td>
<td>.29 (-.19-.76)</td>
<td>.20</td>
</tr>
<tr>
<td>SOB</td>
<td>45.5%</td>
<td>45.5%</td>
<td>.63 (.17-1.00)</td>
<td>.04</td>
</tr>
<tr>
<td>Cough</td>
<td>16.7%</td>
<td>33.3%</td>
<td>.57 (.08-1.00)</td>
<td>.03</td>
</tr>
<tr>
<td>Seizure¹</td>
<td>-</td>
<td>-</td>
<td>Seizure present constant</td>
<td>-</td>
</tr>
<tr>
<td>Hallucination</td>
<td>9.1%</td>
<td>0.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td>0.0%</td>
<td>16.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>40.0%</td>
<td>40.0%</td>
<td>.58 (.07-1.00)</td>
<td>.07</td>
</tr>
<tr>
<td>Agitation</td>
<td>33.3%</td>
<td>44.4%</td>
<td>.77 (.35-1.00)</td>
<td>.02</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>35.7%</td>
<td>57.1%</td>
<td>.31 (-.13-.76)</td>
<td>.20</td>
</tr>
<tr>
<td>Secretions</td>
<td>50.0%</td>
<td>40.0%</td>
<td>.40 (.16-.96)</td>
<td>.20</td>
</tr>
<tr>
<td>Fatigue</td>
<td>46.2%</td>
<td>53.8%</td>
<td>.54 (.09-.99)</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Decreased Appetite</td>
<td>64.3%</td>
<td>71.4%</td>
<td>.84 (.53-1.00)</td>
<td>.001</td>
</tr>
</tbody>
</table>

Table 19 Inter-rater reliability of the pain and symptom experience at end of life scale

¹ none of the patients experienced seizure symptoms

**Global Pain and Symptom Experience at End-Of-Life**
Despite the disparity of agreement on the presence of pain and other symptoms, evaluation of the global rating of pain and symptom management during the last week of life, indicated a high degree of agreement between raters (τ = .45, p = .04; Nurse M=4.40 Healthcare assistant M=4.43, see Table 20).

<table>
<thead>
<tr>
<th>Sub Scale</th>
<th>Staff Nurse (n = 15)</th>
<th>Healthcare Assistant (n = 15)</th>
<th>Kendall's tau-b, p-value</th>
<th>Wilcoxon signed ranks test p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Global Pain and Symptom Experience at End-Of-Life</strong></td>
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<tr>
<td>Global pain and symptom management</td>
<td>4.40±.63</td>
<td>4.43±.76</td>
<td>τ = .45, p = .04</td>
<td>p = 1.00</td>
</tr>
<tr>
<td><strong>Personal Acceptance, Insight and Control</strong></td>
<td></td>
<td></td>
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<tr>
<td>Acceptance</td>
<td>3.50±1.60</td>
<td>3.50±1.64</td>
<td>τ = -.82, p &lt; .001</td>
<td>p = .29</td>
</tr>
<tr>
<td>Insight</td>
<td>2.44±1.42</td>
<td>2.86±1.46</td>
<td>τ = .00, p = 1.00</td>
<td>p = .71</td>
</tr>
<tr>
<td>Control</td>
<td>2.56±1.24</td>
<td>3.00±1.67</td>
<td>τ = -.53, p = .17</td>
<td>p = .28</td>
</tr>
<tr>
<td><strong>Decision Making Control and Preferences</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Level of Control in Decision Making</td>
<td>4.00±1.55</td>
<td>2.92±1.56</td>
<td>τ = .59, p = .01</td>
<td>p = .18</td>
</tr>
<tr>
<td>Control wanted in Decision Making Process</td>
<td>4.40±.55</td>
<td>2.92±1.62</td>
<td>τ = .78, p = .08</td>
<td>p = .32</td>
</tr>
<tr>
<td>Meeting Wishes</td>
<td>4.92±.28</td>
<td>4.62±.87</td>
<td>τ = -.17, p = .32</td>
<td>p = .26</td>
</tr>
<tr>
<td>Meeting Spiritual Needs</td>
<td>4.93±.26</td>
<td>4.67±.82</td>
<td>τ = -.13, p = .33</td>
<td>p = .26</td>
</tr>
<tr>
<td>Meeting Religious Needs</td>
<td>4.80±.41</td>
<td>4.73±.80</td>
<td>τ = -.19, p = .18</td>
<td>p = 1.00</td>
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<tr>
<td><strong>Communication</strong></td>
<td></td>
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</tr>
<tr>
<td>Communication between Healthcare professional and Family</td>
<td>4.69±.63</td>
<td>4.71±.83</td>
<td>τ = .37, p = .38</td>
<td>p = 1.00</td>
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<tr>
<td>Communication between Resident and Family</td>
<td>4.29±1.14</td>
<td>4.71±.83</td>
<td>τ = .54, p &gt; .05</td>
<td>p = .13</td>
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<tr>
<td>Communication between resident and Healthcare professional</td>
<td>4.80±.78</td>
<td>4.73±.80</td>
<td>τ = .62, p = .27</td>
<td>p = .66</td>
</tr>
<tr>
<td><strong>Family Distress, Satisfaction and Level of Support</strong></td>
<td></td>
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<tr>
<td>Family Distress</td>
<td>4.20±1.08</td>
<td>3.50±1.00</td>
<td>τ = .33, p = .28</td>
<td>p = .03</td>
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<tr>
<td>Family Satisfaction</td>
<td>4.93±.26</td>
<td>4.73±.59</td>
<td>τ = -.13, p = .33</td>
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<tr>
<td>Level of Support</td>
<td>4.87±.52</td>
<td>4.87±.52</td>
<td>τ = -.07, p = .45</td>
<td>p = 1.00</td>
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<tr>
<td><strong>Global Ratings of Care</strong></td>
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<td></td>
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</tr>
<tr>
<td>Acceptable Level of Care</td>
<td>1.27±.46</td>
<td>1.13±.35</td>
<td>τ = .21, p = .50</td>
<td>p = .32</td>
</tr>
<tr>
<td>Global Quality of Death and Dying</td>
<td>4.53±.83</td>
<td>4.80±.41</td>
<td>τ = .00, p = 1.00</td>
<td>p = .21</td>
</tr>
</tbody>
</table>

Table 20 Comparing ratings for management of different aspects of care at end of life.

Note: Nurse and Healthcare Assistant values are reported as Mean ± Standard Deviation

**Personal Acceptance Insight and Control**

Overall personal acceptance, insight and control were measured using three 5-point scales from poor=1 to excellent=5. Means scores on the acceptance scale were 3.5 (nurses) and 3.5 (healthcare assistants), indicating that the residents had poor acceptance of death as perceived by healthcare professionals. Wilcoxon signed rank test shows no significant difference exists between the numerical values of rating (pair) provided by nurses and healthcare assistant. Comparable findings were noted on both the insight and control scales.

**Decision Making Control and Preference**

Of the deaths surveyed, 93% had an ACD/ACP in place. Pooled results from both nurses and healthcare assistants indicate that 100% of the active ACDs, from the 15 cases, were adhered to at end-of-life. Nurses and healthcare assistants scored the level of control they perceived a resident had over decision making. There was a statistically significant association, with both groups of raters likely to indicate that the resident had moderate - good control (mean scores ranged from 2.92- 4.0). Similarly, when asked how
much control they perceived the resident wanted over their decision making, nurses projected that residents would want almost full control (M=4.40) compared to healthcare assistants who indicated lesser perceived desire for control (M=2.92). The raters were also asked to score how well residents wishes, spiritual needs and religious beliefs were met. Responses were measured on a scale ranging from 1 (not at all) to 5 (fully met). Wilcoxon signed rank test shows high level of agreement between rater groups, on all three items (p>0.05). Mean values of over 4.62, in all categories, show that both nurses and healthcare assistants perceived that the resident's needs were almost always met.

**Communication**

Three communication networks were measured; resident and staff, resident and family, staff and family. Nurses and healthcare assistants were asked to rate the level of communication between these groups on a scale of 1-5 (Poor-Excellent). Mean scores of over 4.29, for both raters, suggest very positive communication links. There was no statistical difference in the mean scores between the rater groups, suggesting good inter-rater reliability.

**Family Distress & Satisfaction with Care**

Family/relative distress, satisfaction with care, and level of support, were measured using a 5-point scale (1=negative end point, 5=positive end point). Mean scores on the distress scale ranged from 4.20 for nurse to 3.50 for healthcare assistants. A significant difference was observed between raters, indicating that nurse’s perceived less family distress than healthcare assistance. Perceived levels of family satisfaction with care did not differ significantly (p=0.26). Overall, nurses and healthcare assistants perceived low levels of distress among bereaved relatives, high levels of satisfaction with care, and excellent levels of support given to families during the last week of life.

**Global Ratings of Care**

Mean scores on the global rating of care scale demonstrated that nurses (M=1.29) and healthcare assistants (M=1.13) perceived the care delivered to be totally acceptable (1=totally acceptable 5= totally unacceptable). When asked to rate the quality of dying and death experience from 1-5 (poor - excellent), there was little disparity among raters with mean scores in excess of 4.53.

**Summary**

Kendall’s tau-b and Wilcoxon signed ranks test evaluated the differences and associations between two groups of raters (nurses and healthcare assistants) on all scales across the six domains. There were few significant difference observed (family distress), and only 2 statistically significant associations demonstrating high level of agreement (global pain and symptom management, level of control in decision making). These findings, although preliminary, are indicative of good inter-rater reliability of the subscales. In contrast, the scoring of presence of pain and symptoms scale, varied significantly between groups. The implications of these findings, and others, are discussed.

**DISCUSSION**
This section describes the development, and preliminary validation, of a questionnaire – the SPELE, that measures both the quality of care provided and the quality of the dying and death experience from the healthcare provider’s perspective. Findings demonstrated that the SPELE is a useful questionnaire to capture the various facets of the dying experience. The majority of subscales demonstrated good group inter-rater reliability, with no statistical differences observed across the domains. One significant exception was the pain and symptom experience scale, where Kappa values, for all 13 symptoms, demonstrated only slight-moderate agreement between nurses and healthcare assistants, on the presence of 8 out of 13 symptoms, during the last week of life. The healthcare assistants were more likely to indicate the presence of certain symptoms, such as dry mouth, nausea and pain, than their nursing colleagues. These findings suggest that healthcare assistants are more involved in these aspects of care, and are sensitised to symptoms that the nurse may not be detecting, due to a largely administrative and clinical management role e.g. medication administration. Yeatts & Cready\textsuperscript{41} contend that healthcare assistants often have a more intimate professional relationship with the residents in LTC, compared to nurses or doctors, and are best positioned to detect changes in condition including burdensome symptoms at end-of-life. Unfortunately, the role of healthcare assistants is often underrated, and their skills underutilized\textsuperscript{31}. Research is recommended on the role of healthcare assistants in symptom assessment, reporting and management at end-of-life in LTC. Education of healthcare assistants needs to empower symptom reporting, owing to their adjacent care proximity.

Findings from this pilot show that both nurses and healthcare assistants perceived all 15 cases to be positive experiences or ‘good deaths’. In addition, the quality of the care provided, and the context in which it occurred, was also satisfactory. There was little disparity on this.

**CONCLUSION TO SPELE SECTION**

The SPELE is a useful questionnaire with a dual purpose of capturing both the quality of care at end-of-life, and the quality of dying and death experience from the perspective of key informants, i.e. nurses and healthcare assistants. While preliminary testing is positive, further research and refinement is recommended before it is established and recommended for use. This section highlighted the unique and understated role of healthcare assistants, who need to be empowered to report symptoms. Educating and empowering healthcare assistants in LTC could lead to improvements in resident’s symptom management and overall quality of life and death.
3.5 Evaluating the programme for a user’s perspective: focus groups with staff

The aim of this section is to report on the evaluation of the systematic implementation of the ‘LetMeDecide’ advance care directive and palliative care education programme from the users perspective i.e. nurse working in the long term care sites.

**Methods:** Qualitative descriptive approach was used. Focus groups were conducted with staff working in 3 of the long term care sites where the programme was rolled out. A semi-structured topic guide was used to direct the questions posed to the focus group. Questions addressed the implementation process, challenges implementing advance care planning, advantages/disadvantages and recommendations for the future. Written consent was gained prior to conducting the focus groups. Focus groups were tape recorded. Data from the interviews were first transcribed to a Word document. Subsequently the data were analysed using manifest content analysis (Graneheim and Lundman, 2004 p. 106), whereby the ‘visible, obvious components’ of the text were highlighted using coloured markers and grouped according to the predetermined categories of the interview guide. These sections of text or statements were subsequently labelled ‘meaning units’. The meaning units were then reread and the key words extracted to form ‘condensed meaning units’. These data were then presented in table format for ease of interpretation and further commonalities were assembled. Codes were then developed to reflect the meaning of frequently occurring statements within each category. Common emerging codes were grouped to form subcategories.

**Sample:** The sample consisted of 15 Clinical Nurse Managers and two Directors of Nursing.

**Results:** The majority of respondents were between the age of 41-60. Two had a qualification in Gerontological nursing and the average length of time working in care of the older adult was 14.5 years. Eleven people had attended education sessions delivered as part of the ‘LetMeDecide’ programme. The length of the focus groups varied from 51 minutes to 1 hour 12 minutes. Each focus group began with everyone introducing themselves and providing one word to describe the LetMeDecide programme. Words used included: Positive, Painless, Convenient, way forward, supportive, essential, completeness, forward planning, advance care, wonderful and work, peace of mind, clarity, control. A wordle was created to reflect this. See figure below
There were five key categories presented, with 16 corresponding subcategories. These subcategories emerged as a result of 37 codes. See table 12 below.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Codes</th>
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</thead>
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<tr>
<td>Implementing advance care planning</td>
<td>Directing care</td>
<td>Essential for practice</td>
</tr>
<tr>
<td></td>
<td>Implementation of the programme</td>
<td>Care planning for the future</td>
</tr>
<tr>
<td></td>
<td>Emotive process</td>
<td>Fear of unknown</td>
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<td></td>
<td></td>
<td>Support from research team</td>
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<td></td>
<td></td>
<td>User friendly resources</td>
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<tr>
<td>Benefits</td>
<td>Enhancing communication</td>
<td>Pathway for difficult conversations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Normalising death</td>
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<td></td>
<td>Changing care culture</td>
<td>Building relationships</td>
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<td></td>
<td></td>
<td>Composed care environment</td>
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<tr>
<td></td>
<td>Avoiding crisis decision making</td>
<td>Promoting multi-disciplinary awareness</td>
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<td></td>
<td></td>
<td>Enhancing practice and profession</td>
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<td></td>
<td>Preference-based care</td>
<td>Reducing emotional distress</td>
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<td></td>
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<td>Family preparedness</td>
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<td></td>
<td>Reduce end of life hospital transfer</td>
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<tr>
<td>Challenges</td>
<td>Establishing capacity</td>
<td>Persons lacking capacity</td>
</tr>
<tr>
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<td>Capacity assessment</td>
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<td>Borderline capacity</td>
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<tr>
<td></td>
<td>Enactment of ACP</td>
<td>Ensuring compliance</td>
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<td>GP involvement</td>
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<td>Legal aspects</td>
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<tr>
<td></td>
<td>Indecision</td>
<td>Gaining consensus</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Misperceptions of purpose</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not for everybody</td>
</tr>
<tr>
<td>Disadvantages</td>
<td>Resource Intensive</td>
<td>Time and Effort</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reviewing and updating</td>
</tr>
<tr>
<td>Recommendations</td>
<td>Education/training</td>
<td>Train the trainer model</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Blended approach and simulations</td>
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<tr>
<td></td>
<td>MDT approach</td>
<td>Role of senior nurse and managers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Getting everyone involved</td>
</tr>
<tr>
<td></td>
<td>Documentation</td>
<td>Capturing conversations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sticker alerts on charts</td>
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<tr>
<td></td>
<td>External support</td>
<td>Link facilitator</td>
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<tr>
<td></td>
<td></td>
<td>Freely available ACP tool kits</td>
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<tr>
<td></td>
<td>Introduce concept around admission</td>
<td>Introduce concept around admission</td>
</tr>
</tbody>
</table>
**Category 1: Implementing advance care planning**

This category relates to the initial reaction to the programme when first introduced and reflections on the process of implementation. Subcategories include ‘directing care’, implementation of the programme and the ‘emotive process’. Within the subcategory of directing care two codes identified; essential for practice and care planning for the future.

An exemplar quote demonstrates the significance of the programme in practice

‘we are just negligent to look after people without finding out what their wishes are and I think we have no right to look after people without asking them-give them the opportunity’.

The second subcategory was ‘implementation of the programme’. There were three codes identified; fear of the unknown, support from research team, user friendly resources. For many the process included both positive and negative aspects and some stating that they initially feared getting involved in advance care planning. However support from the research team ensured successful engagement with the programme. The user-friendliness and convenience of the resources, such as patient packs, laminated visual education aids etc made the process of implementation more seamless. Examples of quotes from participants highlight this:

“There was very good support from the research team, without them being intrusive. There were clear lines of communication and we were always informed in advance about when the research team were coming on site and what their visit would involve. It has been a pleasure to work with them in implementing this programme.”

“The other thing is the packs, I love the packs. It’s just so handy to grab the packs. I like the yellow sheet where you list the number of conversations because it shows the evidence of the talks”

The final subcategory in this section was ‘emotive process’. Participants felt that dealing with families and the residents themselves was a very emotional process. Many conversations and discussion brought up sensitive issues and some were relieved to have these conversations while others found it difficult to talk about death and dying.

“I have had daughters crying at meetings you know. Because they never knew what their parent wanted and they were reluctant to bring it up with them I think”.

**Category 2: Benefits**

Within this category participants spoke about the benefits the programme had brought to their practice, care setting and those they cared for. Four subcategories were identified: enhancing communication, changing care culture, avoiding crisis decision making, preference-based care. Overall the focus group discussions were dominated by the benefits of using the programme.

For enhancing communication three codes emerged from the text, these were focused around ‘pathways for difficult conversations’, ‘normalising death’ and ‘building
relationships’. These were seen as key benefits of implementing the programme. One comment from a CMN2 shows how conversations were started as a result of the programme. LetMeDecide created a pathway for difficult conversations.

“In this forum it helped to ease everybody into this conversation, whereas I think without this tool I think we would never have had this conversation between those two parties [family & resident].”

The topic of death was normalised as a result of the advance care planning process and participants were also surprised how the relationships with the resident and their family has developed and strengthened.

“I think it makes a good relationship with the nurse and everybody. You have talked at those levels, painful levels with family members and the residents, they see you as maybe someone who is closer to them you know.”

“It requires engagement on a deeper level particularly with family members and it means getting involved in discussions that heretofore may have been avoided or deferred so as not to upset people.”

Not only was communication enhanced so too was the care culture. For most, they experienced a significant change whereby there was a more composed and calm care environment (composed care environment)

“The payoff is when the patient comes to that stage and that is the pay off the convenience of it at their end of life whether it is weeks or days, it so calm in comparison to before”

Further codes in this category include promoting multi-disciplinary awareness and enhancing practice and profession. Nurses felt that the programme had promoted multi-disciplinary awareness of advance care directives and preference-based care. Healthcare assistance, Physiotherapist, GPs, Emergency Medical Technicians and Occupational Therapist were all aware of the programme and as it became imbedded into practice people were actively seeking the residents advance care directive before making a decision regarding their care.

“Our G.Ps were delighted with it anyway and they keep saying when people are in we have this and we have Advanced Care Directives and everything here in this home and they would be sort of boasting about it that we have it and it is great. They all think it is great.”

Participants in the focus groups spoke about the many ways the programme has enhanced their practice, how it gave a person centered, structured approach to advance care planning and palliative care.

“I think staff were willing to overcome any difficulties they encountered because they could see the importance of the programme in the longer-term. When they started seeing the benefits of having been through the advance care planning process with residents and
families, how it made such a big difference when the resident came to the end-of-life, the staff could see that it was worth all the effort involved."

“The staff have received education on the technical aspects of symptom control and management and this has enhanced their competencies in this area”

“I think it has made end of life care in general smarter since we started it. I think we have examined critically our end of life care”

The third subcategory within the benefits section was the ability of the programme to assist in ‘avoiding crisis decision making’. This was composed of codes such as ‘reducing emotional distress’, ‘family preparedness’ and ‘reducing end of life hospital transfer’. Throughout the interviews participants continually highlighted how crisis decision making was no longer the norm and that family, staff were not under pressure to make last minute decisions.

“And the family are aware of it. The uncertainty and how we are going to deal with the family and they are all going in different directions it is all done, there is no anxiety, there is no arguing between families it is all done.”

“The programme has demonstrated that in fact advance care planning actually relieves emotional distress.”

Families are more prepared at end of life. Respondents felt that families were happy that difficult issues were dealt with in advance. One exemplar demonstrates this:

“I have received very positive feedback from relatives after their loved one has passed away and some of the feedback directly relates to the level of preparedness of the family and next of kin as a result of LMD. Being prepared and understanding what to expect at this difficult time has helped family members deal with the loss of their loved one.”

A similar study in Canada using the LetMeDecide programme showed that hospital transfer were reduced as residents end of life wishes were to remain in the nursing home. This project has also demonstrated these trends. There was congruence among participants of the focus groups, that the number of transfers to hospital resulting in death, had reduced significantly;

“we have had a reduction in the number of transfers to acute hospital at the end of life, the staff are happier that they are not seeing dying residents transferred out of their home to a busy A/E Department.”

The final subcategory in this section is the benefit of being able to provide preference-based care to residents of the homes involved in the project. Staff felt that were now in a position to provide care that was based largely on the wishes of residents. For many this created a sense of ‘knowing how to care’.
“I think what we were doing before is we were talking about it. When the resident had a turn or became unwell, whereas now we are doing it from you know more or less when they come through the door.”

“What’s not the norm now is to wonder about what to do with somebody that gets ill that is not the norm now.”

Some of the nurses stated that feedback from residents was overwhelming, with many thanking the nurses for giving them the dignity and opportunity to make end of life treatment decisions.

“I know in a nursing home it is kind of like maybe you relinquish all control of your life and you are running off somebody else’s agenda it is task orientated. Whereas you are giving them the dignity of making that decision.”

It is evident that there are multiple benefits to systematically implementing advance care planning using the LetMeDecide programme. One Director of Nursing was quoted as saying:

“There is nothing about the programme that I think should be changed. From my perspective, as Director of Nursing, I have not identified any disadvantages to using the LMD programme, only benefits resulting from its implementation”

Category 3: Challenges
There were lengthy discussions about the challenges of implementation and while there were some that were repeated across focus groups, there was a reassurance from all that although challenges exited, the benefits far outweighed the barriers. Some challenges in particular focused on ‘establishing capacity’ ‘enacting the ACP’ and ‘indecision’ among family and residents.

Establishing capacity was often seen as difficult. This subcategory was made up of codes such as ‘person’s lacking capacity’ ‘capacity assessment’ and ‘borderline capacity’. Staff found it very challenging when a resident was able to clearly articulate certain wishes such as no CPR but lack capacity to make decisions around assisted feeding or palliative care versus intensive care.

“I think there should be a patient’s page for those lacking full capacity to complete and ACD but are clear on some wishes”

Others found the SIACAD (Screening Instrument to Assess Competency to Complete an Advance Directive) difficult to use initially. While they acknowledged the importance of using a tool to measure understanding on decisions made some found the terminology problematic for some residents. Also there appeared to be a repetitive nature to some of the questions.
“I think the SIACAD is a bit clinical a bit too long you know you are losing their attention.”

Based on feedback throughout the lifetime of the project, the research team modified the SIACAD, these modifications appeared to make it more user-friendly;

“Definitely improvements have happened with the SIACAD since we started in the sense that you know we can do a section at a time and they can have the sheet in front of them and they can refer to it. That is a big improvement.”

Enactment of ACP also proved challenging in certain cases. Examples were given by staff where an ACP would be in place, however if the resident was transferred to hospital, medical staff there were reluctant to adhere to the document, choosing instead to complete a hospital based form which would involve discussing the same issues with family again. This was seen as needless by staff and many wished there could be better cohesion between acute and long-term care.

“That has happened to one of my residents as well that I sent up with an Advanced Care Directive and it was ignored”

Other barriers to carrying out an ACP included lack of GP involvement or legal aspects such as no national framework for ACDs.

A final challenge voiced was issues around indecision. Common codes were ‘gaining consensus’, ‘misperceptions of purpose’ and ACDs ‘not being for everybody’.

Gaining consensus included the sometimes frustrating process of bringing family together and reaching agreement on the course of action. This was not easy at times as the following quote demonstrates;

“And then you would have family members that don’t talk and one member wants this and the other members want that so you have to bring them all together. In a circle where the patient isn’t compos mentis and you have to make sure that the whole lot of them are on the same wavelength otherwise you could forget about it.”

There were a number of residents and family who misinterpreted or had misperceptions about the motive for conducting ACP. Some felt that it was a way to avoiding hospital treatment, while others felt GOD would make the decision for them and were averse to the idea of discussing such issues. According to the nurses there was also a cohort of residents that felt there must be bad news coming if the topic of end of life care was being broached. One nurse described the reaction she received from one resident when she introduced the programme.

“I approached a resident one day about it and he said to me no I don’t want to have anything to do with that now at all he said because I know well what is going on here. They just don’t want the likes of me turning up in hospital he said.”
Nonetheless there was consensus among the focus groups that ACP was not for everyone, however there were challenges inherent in this when a resident would suddenly deteriorate. Providing care to those without ACPs was much more complex and shrouded in uncertainty.

**Category 4: Disadvantages**

Very few disadvantages to using the programme emerged during the interviews. Those that did related to ‘time and effort’ and ‘reviewing and updating’. Staff expressed their concern about the process of reviewing on an annual basis and were unsure of the level of detail that should be discussed at review, some feared that residents would become frustrated when it was brought up again and they believed it was complete and a closed subject. Everyone agreed that although a huge amount of time and effort goes into completing the entire process with a resident and their family, it was worth it in the end.

“I think that once staff began to see the benefits of their hard work delivering ACP to residents and families, they felt that it was worth putting in the effort, even in the face of time constraints”.

Completion of a full ACD took from two hours to six hours over a number of meetings/weeks, depending on the resident’s capacity level, availability of family, and ward environment.

“You need quite a few meetings actually, you have to introduce it, introduce the literature and then try and get the relatives and give them the literature and explain it all to them and then go back and well of course you have to do the SMMSE first you know so it starts there really. I suppose it does need that amount of consideration it is a very big decision.”

**Category 5: Recommendations**

A number of recommendations were suggested by the participants of the focus groups. There ranged from methods of providing education and training to timely of introducing ACP to residents and their family. Within this category there were 5 subcategories; education/training, MDT approach, documentation, external support, and introducing the concept around admission.

Recommendations around education and training were focused on the type of delivery. There was consensus among the groups that the face to face sessions were excellent as they facilitated meaningful discussions around this difficult topic. While they agreed that some components of online education would be favourable, as this would alleviate the pressure of trying to attend sessions, they recommended a blended approach, i.e. online and face to face.

“I thought the face-to-face educational sessions were extremely useful for the staff – to be able to be discuss these EOL issues openly with the support and understanding of your work colleagues – this brings a richness to the educational experience. I would worry about how
staff would engage with an online educational programme – it would not offer the same incentives or richness as the group training sessions.”

Simulations or demo type sessions were also suggested, whereby the whole process was complete using role modelling and case scenarios. For a larger scale roll out the nurses felt that a train the trainer model or approach would be most beneficial. Nurses also recommended a multi-disciplinary approach from the start of the process. This encompassed getting everyone involved including, healthcare assistants, GP etc.

“Because a lot of times when you go around you find that the residents will talk more with the health carers, the person washing the floor they will talk more with than they talk to the person coming into care for them and wash them.”

It was apparent from the regular visits to the nursing homes that the role of completing and ACD was undertaken primarily by senior staff (Clinical Nurse Managers). During the focus groups session this observation was confirmed. Most felt that it was such an important aspect of the person care planning that the core aspects of it needed to be led by senior staff. One Director of Nursing clearly articulates the rationale for including it as part of a senior nursing role;

“I would see the delivery of advance care planning as a role for senior nursing staff/ward managers – at this point in time anyway, at least until the process is established and clinical staff have the required competencies to engage in the process. The senior nursing staff are usually the people that the family come to anyway. They have the status and the families have trust in them. It is a highly difficult and sensitive area and you need to be competent and very confident to have these discussions with residents and families.”

Documentation of conversations was also recommended and these were described as learning tools for that staff reflected on when trying to improve their communication skills around the care planning process.

“I found taking notes worked really well and when I look back on the early ones now I cringe because just the wording you are almost leading them whereas I now I have a much better approach into it. What I say to everybody is you know would you like to talk about what you like to do if you became sick.”

Once conversations were captured and the ACP process complete staff recommended placing sticker alerts on the charts so that everyone was aware and could easily access the content of the plan in the case of an emergency situation.

“We put a sticker on the outside of the charts so even at a glance before you can pull everything off the shelf you see the sticker and you know that there is an ACD.”
The final two recommendations related to external support i.e. having a link facilitator to liaise with if problems arose and having freely available tool kits, introducing the concept around time of admission. This appeared to be the most opportune time to talk about the available of this care option in the nursing home.

Overall, it is evident from the focus groups that the programme was evaluated in a very positive light. All the homes have now embedded the programme as part of their care packages. In fact many have stated that the programme has transcended a number of care issues in the home and is much more than just a directive. Relationships with residents have deepened, there is a more open and honest environment with family, end of life care is now focused on symptom management, comfort and addressing spiritual care needs as opposed to crisis decision making and family conflict. One director of nurses even stated that staff morale has improved as a result of the programme. It was unanimous that the programme should be rolled out to other care homes and all agreed that they would now not practice as healthcare professionals without it.

**Widening the Implementation of the LMD-PC Programme**

UCC, in collaboration with Louth Age-Friendly County Initiative (LAFCI), has become a designated Reference Site of the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA). The LMD programme is one the key action areas of the COLLAGE (UCC/LAFCI ‘Collaboration on Ageing’) initiative.

Prof. Molloy, Dr. Ciara McGlade and Dr. Nicola Cornally have presented numerous information seminars on the LMD-PC programme to a variety of different stakeholders within and outside the Cork Region, including HSE managers, doctors and other healthcare workers (both hospital and community based), families of LTC residents and members of the public. This is an effective method of promoting awareness and interest in the programme. For example, Prof. Molloy presented on the IT aspects of “Implementing Advance Care Directives and Palliative Care into Irish nursing homes” at the e-Health Week Conference in Dublin in May 2013. In addition, the LMD programme was promoted at COLLAGE’s publicity stand during this three-day conference.

The LMD-PC programme team have been approached by a number of LTC institutions and community dwelling associations in the Cork and Kerry area who are keen to adopt the programme. The engagement of LTC institutions in this programme will facilitate them to fulfil their Good Clinical Practice obligations in relation to ACP and the provision of end-of-life care to residents; this should enhance uptake in the wider dissemination of the programme.

One of the study sites recently had a HIQA inspection on end-of-life care practices. The findings in the HIQA report indicate that the nursing home is fulfilling all of its requirements in relation to end-of-life care practices. An excerpt from the HIQA report is included below:
“The inspector reviewed the centre’s policy on end-of-life care. Information to guide staff in providing holistic care at the end of life stage was documented. The inspector reviewed a sample of residents’ care plans with regards to end-of-life care and noted that they comprehensively recorded residents’ preferences at this time. All information was accessible to staff and staff indicated that relevant information was shared at report handover time. Residents with whom the inspector spoke were positive about the care available in the centre. Most residents stated that in the event that their needs changed in the future they would prefer to be cared for in the centre. They expressed confidence in the care given by the GP (general practitioner) and were aware of the advanced care planning process. One resident told the inspector that she did not want to go back to the general hospital. This information was recorded in the end-of-life care plan in the resident’s file. Relatives with whom the inspector spoke were welcoming of the advanced care planning and said that this was sensitively approached by the person in charge and her team.

Staff training records indicated that staff had attended training on palliative care issues including spiritual care, psychological support, pain management and communicating with the bereaved relatives. Training was facilitated internally and externally. Staff, with whom the inspector spoke, had received training on the use of a syringe driver and were knowledgeable in the administration of subcutaneous fluids, if these were required. The person in charge stated that the centre was well supported by the specialist team from the local hospice. Records which the inspector viewed indicated that the palliative team were responsive to the GP and the staff in providing specialist advice in pain relief and symptom management. There was evidence that relatives were appropriately involved and informed of residents evolving medical conditions.

Religious and cultural practices were facilitated. Residents had the opportunity to attend religious services held in the centre and had access to ministers from a range of religious denominations. Residents were provided with the sacrament of the sick on a monthly basis. There was an oratory in the centre and this was available for reflection. The priest who visits twice a week, said that he felt that residents in the centre were content with their lives and that he was available at all times for support.

There was evidence in residents’ care plans that they would be facilitated in their choice as to the place of death if a request was made including the option to go home. The majority of bedroom accommodation in the centre was of single occupancy bedrooms but a single room was available if required for those in the two-bedded rooms. Sitting rooms were available for family and friends to use as an overnight facility at this time. Facilities were provided for relatives to have refreshments and snacks. Open visiting was facilitated. The inspector reviewed a sample of care plans of deceased residents and noted that residents were regularly reviewed by the GP and specialist services. There was evidence that medication management was regularly
reviewed and closely monitored by the GP. It was evident that residents received care at end of life which met their physical, emotional, social and spiritual needs.

Following the death of a resident the staff met to evaluate the care given, and an audit of the practice of caring for those at end of life was regularly undertaken. The person in charge showed the inspector documentation which supported this practice. There was evidence that learning occurred if any area for improvement was identified. The inspector viewed next of kin questionnaires which had been returned to the Authority prior to the inspection. These contained very positive comments about the care that the residents and relatives had experienced at this time and statements such as "excellent care", "pain free" and "staff kindness and friendliness" were used to convey the experience in Haven Bay.

The centre used a recognised end-of-life care symbol to support the administration of dignified and respectful care for the dying person. A remembrance service was held annually and relatives and residents were invited to attend. The person in charge stated that upon the death of a resident, his/her family or representatives were offered information, both verbally and in leaflet form, on what to do following the death of their relative. Staff were supported and residents could attend the services and removal if they wished. Staff and relatives confirmed this with the inspector stating that they would form a 'guard of honour' at the door of the centre for the removal.

As a result of the HIQA themed inspections there has been a growing interest in the programme from a number of nursing homes. The team recently received funding from the Health Research Board to conduct a randomised control trial using the LMD programme in a further six sites. Talks are also underway to roll out the programme in select European countries.

**Overall Conclusion & Key Recommendations**

The ACP process can be a highly personal journey for older LTC residents and must be delivered with understanding, care, patience and support. The familiarity LTC staff have with residents, means they are the ones best placed to effectively deliver and appreciate the residents’ differing needs in the ACP process. They are also the providers of their care at end of life.

Using a combined end-of-life care initiative with palliative care education and a specific ACD such as “Let Me Decide”, is relatively novel. The rationale for this approach was based on feedback from a similar study conducted in Canada, whereby only advance care planning was introduced into the study homes. As the study progressed it was apparent that the majority of residents wished to remain in the home at end of life and receive palliative care, however many of the care staff and nurses were not educated in this approach and thus quality of care at end of life and adherence to patients wishes could
not be guaranteed. A key recommendation from the study was to ensure that palliative care education was provided in combination with advance care planning. This dual approach ensures that a programme of this nature, delivered in a systematic way, can build capacity among staff to deliver both advance care planning and palliative care. Numerous studies have shown that given the option people will opt for palliative care if they are faced with an irreversible and self-perceived unacceptable condition it is therefore prudent that staff can provide care that is consistent with their patient’s wishes. This negates the need for a person to be transferred to acute care for symptom management and has the potential to reduce the burden on specialist palliative care services.

The palliative care education sessions were delivered to staff of the nursing home by Dr. Ciara McGlade and Prof. Molloy, sessions included education on communication and facilitating conversations around advance care planning. This equipped staff with the necessary knowledge and skills to promote and conduct advance care planning. An additional benefit of upskilling staff in palliative care was the reduction of health inequality. In essence residents now had access to an appropriate level of palliative care based on their needs, rather than on diagnosis or place of care. There was a clear increase in staff confidence in delivering palliative care, particularly in the area of symptom management, as a result of implementing this programme.

As part of the programme LTC providers were given implementation manuals with policies on advance care planning and copies of all palliative care education session, thus ensuring sustainability of the programme in the home. To complement this, an online programme was developed and details regarding access to this were given to LTC providers. Tailored education materials were given to both residents and their family and numerous information evenings were held in the nursing homes. This ensured that LTC residents and their families were making informed decisions in relation to EOL care.

A further objective of this programme was to offer residents of LTC the opportunity to participate in advance care planning. This was achieved in all homes and completion rates of care plans went from zero in some homes to 50% completion rate. Some residents opted out of completing a plan; however it was important that they were given the opportunity to make this decision. Others were unable to make complex decisions regarding their end of life care, in these cases family members were empowered to advocate for their loved one and assist the GP and nursing staff in preparing a care plan consistent with perceived wishes and best medical advice.

The accurate documentation of resident’s wishes was central to this programme and this helped to ensure better adherence to care plans. The study showed that of the residents that died, their wishes were honoured in 95% of cases. In addition to this, futile and unwanted medical interventions at end of life were reduced significantly over the life time of the programme.
Promoting integration and collaboration among LTC providers and other healthcare professionals was also an objective of this programme. This was achieved through one-to-one sessions with key staff and servicing GPs, regular site visits, and structured Q&A meetings. Written information was also provided to feeder hospital sites and local GP practices regarding the programme. Towards the end of the 2 year implementation process feedback from staff indicated that regular and out of hours GPs and acute care staff were actively seeking details of residents advance care plans prior to prescribing treatment pathways.

The programme has ensured that end of life care is now focused on symptom management, comfort and addressing spiritual care needs as opposed to crisis decision making and family conflict. Staff feedback indicated that the programme should be rolled out to other care homes and all agreed that advance care planning is an essential part of their practice.

Key recommendations for the effective implementation of ACP in LTC settings include:

- Deliver a comprehensive ACP education package to LTC staff to include palliative care education, appropriate to care context. This should be in line with the Palliative Care Competency Framework (PCCF) and include topics such as those outlined on page 43.
- Palliative care education should follow an assessment of staff learning needs and be tailored to meet such needs.
- Due to the large amount of material that needs to be covered in relation to palliative care it is recommended that staff first access online theory based material and this should be followed by face to face sessions- a blended approach was described as desirable by staff in this study. Problem based case scenarios were favoured by staff as this facilitated open discussions and peer learning. Skills based sessions which included role play between staff or ‘live demos’ with actual residents completing an advance care directive in front of a training audience were seen as valuable education tools.
- Implement a comprehensive policy on ACP, tailored to each nursing home’s individual requirements and consistent with current legislation.
- Provide a structured ACP process for staff to follow to ensure consistency and quality.
- Clarify who is responsible for different aspects of the ACP process.
- Provide staff member(s) with specialist training to act as ACP facilitators and provide protected time for engagement in ACP.
- Provide appropriate educational material for residents and families (culturally-sensitive, appropriate literacy level, large print versions, bite-sized chunks).
- Include education of GPs as part of programme implementation.
- Promote open communication between nursing staff, residents, families and doctors.
- Design systems within the nursing home so that ACD/ACP forms are accessible and all staff are aware of their existence and content
- Provide information to out-of-hours doctors, emergency ambulance services, and local hospital emergency departments on the ACP programme
- Promote communication and collaboration between LTC staff, GPs (including out-of-hours), emergency ambulance services and specialist Palliative Care doctors
- Ensure ACD/ACP forms are easily interpretable by different groups of HCPs
- Design systems for seamless transfer of ACP information between different healthcare settings
- Implement quality assurance systems in place in the nursing home
- Allow time for embedding
- Ensure that completed ACDs fulfil the legal requirements for validity (see Appendix 11).
Dissemination
Presentations and Publications


**Published Papers**


Coffey, Alice; McCarthy, Geraldine; Weathers, Elizabeth; Friedman, M. Isabel; Gallo, Kathy; Ehrenfeld, Mally; Itzhaki, Michal; Chan, Sophia; Li, William; Poletti, Piera; Zanotti, Renzo; Molloy, D. William; McGlade, Ciara; Fitzpatrick, Joyce. "Nurses' preferred end-of-life treatment choices in five countries." *International nursing review* 60, no. 3 (2013): 313-319.


**Papers submitted for publication**

Nicola Cornally, Alice Coffey, Elizabeth Weathers, Ciara McGlade, Rónán O’Caoimh, Edel Daly, Anton Svendrovske, Kathleen McLoughlin, D. William Molloy. Measuring Staff Perception of End-of-Life Experience of Older Adults in Long Term Care. *Applied Nursing Research.*

Edel Daly, Ciara McGlade, Nicola Cornally, Elizabeth Weathers, Ronan O’Caoimh, D. William Molloy. Challenges in implementing an advance care planning programme in long-term care. *Nursing Ethics.*


**Abstracts**

Coveney, S., Cornally, N., Daly, E., McGlade, C., Molloy, W. (2014). *Too Much, Too Late: Polypharmacy at End-of-Life.* IRISH JOURNAL OF MEDICAL SCIENCE, SPRINGER LONDON LTD 236 GRAYS INN RD, 6TH FLOOR, LONDON WC1X 8HL, ENGLAND.

Cronin, U. Cornally, N., Daly, E., McGlade, C., Molloy, W (2014). *Capturing the Quality of Death and Dying in Long Term Care (LTC) Facilities: Family Perspectives.* IRISH JOURNAL OF MEDICAL SCIENCE, SPRINGER LONDON LTD 236 GRAYS INN RD, 6TH FLOOR, LONDON WC1X 8HL, ENGLAND.


**Poster/Oral Presentations**


**Cornally, N.** Critical Care Nurses Annual Conference. Conducting advance care planning with Older Adults. September 2014. Galway

**McGlade, C., Daly, E., Cornally, N. Molloy, W.** ‘Let Me Decide’ Advance Care Planning Programme. Palliative Care Needs of People with Dementia - Building Capacity 26th March, University of Limerick.


**Submission to the DoH in relation to Draft General Scheme for Advance Healthcare Directives**


A website showcasing “Let Me Decide” is up and running and can be used as an information source for interested relatives/friends: [www.letmedecide.ie](http://www.letmedecide.ie). Educational videos have been uploaded onto [YouTube](https), and take the form of brief explanations (delivered by Dr. Tony O’Brien and Prof. Will Molloy) of the following topics:

- What is Palliative Care?
- When is Palliative Care recommended?
- What distinguishes Palliative Care?
- What is a Hospice?
- When should someone go to a hospice?
- Prescribing morphine: What are the challenges?
- Managing Pain: What is the biggest challenge?
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Appendices


Appendix 2  Sample policy on advance care planning for LTC facilities

Appendix 3  Timeline

Appendix 4  Key educational points for residents (and their families) engaging in the advance care planning (ACP) process

Appendix 5  Decision tree showing the screening process to assess capacity to complete ‘Let Me Decide’

Appendix 6  Guidelines for nurses doing advance care planning with residents with capacity

Appendix 7  Recommended steps for nursing staff to follow in helping a resident with capacity to accurately document their treatment preferences in an advance care directive (ACD)

Appendix 8  Attitudes results

Appendix 9  Learning needs results

Appendix 10 Standard Operating Procedure for Contacting Relatives regarding completion of QODD Survey Questionnaire

Appendix 11 List of requirements for a valid ACD

Appendix 12 Project costings (will be sent separately by UCC Finance Office-Jan)
Appendix 1

Public Consultation:


This submission is made by the ‘LetMeDecide’ advance healthcare directives (AHDs) research team at the Centre for Gerontology and Rehabilitation, University College Cork http://www.collage-ireland.eu/initiatives/specific-action-group-members/let-me-decide/

The programme is co-led by Professor William Molloy and Dr. Nicola Cornally. Professor Molloy has worked in the area of AHDs for the past 20 years (see publications at the end of this document). This document was compiled by Professor William Molloy, Dr. Nicola Cornally, Dr. Edel Daly, Una Cronin, Dr. Eileen O’Herlihy, Dr. Alice Coffey, Dr. Ciara McGlade and Dr. Ronan O’Caoimh. We are currently completing a two year study of the systematic implementation of the ‘LetMeDecide’ advance healthcare directive programme in three nursing homes in Ireland, funded by the Irish Hospice Foundation and Atlantic Philanthropies. We have applied to the Health Research Board and Horizons 2020 to conduct a larger randomised controlled trial (RCT) in Ireland, and a multi-centre European RCT.

What are your views on requiring an individual to obtain professional advice (clinical/legal) before preparing an advance directive?

According to the draft general scheme (subheading 2 page 7) it is ‘important that the individual understands what s/he is refusing and the implications of the decision’. Healthcare professionals have been tasked with this responsibility in the past, as patient education is rooted in their code of practice. However it is noted, in the draft, that a person will not be required to provide evidence of any discussion or consultation with a healthcare professional regarding his/her decision (subheading 2 page 7). It is suggested, in the draft, that people can access information from the internet etc. The accuracy of the information sourced is unknown and serious and complex decisions may be made based on misinformation.
Important healthcare, often life or death decisions, are made through advance healthcare directives. It is essential that people have current, evidence-based information available to them, to make comprehensive informed decisions. The only way to ensure that this has transpired in the documentation is to include a healthcare professional in the process. This will also ensure that there is no ambiguity that a person understood the implications of their decisions, as explained by a registered healthcare professional, providing confidence in the validity of the AHD if and when the person presents for care. This prevents the situation where decisions are made on isolated anecdotal evidence, or media influence, which is often not accurate or evidence based.

On the one hand, one requires that AHDs are made accessible and that few obstacles inhibit the public from using them. By minimising the requirements to complete an AHD, they are made as accessible as possible. In the current process, anyone can write what they want and two people merely witness the signature, testifying that this is the person who signed it. They are not in any way testifying that the person knew what they meant or were capable at the time of completion. This approach certainly makes AHDs more accessible.

There are potential problems with this approach.

1) People may not understand what they are saying in AHD.
2) They may be misinformed, and essentially incapable.
3) They may be delusional, intoxicated, depressed, suicidal or otherwise of “unsound mind”.
4) If the document is not dated- it may be very old and completed before the person was 18 years of age.
5) It may be written in terms that contradict each other.
6) It may be very unclear and essentially impossible for healthcare professionals to interpret.

Now let’s consider the Healthcare professional who must interpret the document. These are new in Ireland. They represent a significant shift in the law. They require a huge shift and adjustment in practice. Healthcare professionals may be dealing with a number of very confusing, complex and fatally dangerous statements. How will they react? Will they follow documents and instructions just because they are ‘legal’? Are they ‘legal’ if the person was depressed, suicidal, delusional, or of “unsound mind” when it was completed? What would a healthcare professional do in an emergency department if presented with a suicide note belonging to a person who is a coma from an overdose of drugs, stating that s/he wants to die? This person has written an AHD, refusing CPR, or any intervention
that could potentially be life-saving. This could be signed by two friends (witnesses - who may have also lacked capacity at the time of signing).

There are arguments for and against both approaches to the legislation. There is tension between the public who want a simple process that is unencumbered; however we run the risk that healthcare decisions will be badly informed. On the flip side, healthcare professionals want safeguards. We need to strike a balance and develop a system that is agreeable to both parties.

So how does the government proceed? Do the legislators open the doors to all types of AHDs? Or do you introduce the new approach, carefully, one step at a time and relax the restrictions as you go, testing the waters? We would suggest the latter. The idea is so new to people in Ireland. It is such a potential sea change to practice and healthcare professionals have to adjust to AHDs. We would suggest a more careful cautious approach. By taking an unstructured, relaxed approach you run the risk of discrediting AHDs entirely. There is tension between the public’s desire to make AHDs as simple and accessible as possible and healthcare professionals who would request safeguards to try to preserve the quality of these documents. Given the importance of these documents, there novelty and potential life and death nature of the decision – we would suggest that people who want to complete AHD should show that their choice represents their competent status, so healthcare professionals can follow them with some certainty, and peace of mind.

**Is it necessary for the provision to designate a specific, mandatory time period within which AHDs are reviewed?**

It is our opinion that AHDs should be reviewed in the long-term care setting on a regular basis. We recommend annual review. This is a measure of quality assurance and provides evidence that the information contained in the directive is current and valid. We also recommend that directives be reviewed following an acute medical episode, death of a family member, recent diagnosis, deterioration in condition or whenever the person sees fit to do so. Within the public domain we would recommend the legislation encourage the public to review their AHD annually or the very least or every few years depending on age and health status. Evidence of annual review does not need to be mandatory. However it may provide the impetus for people to discuss advances/developments in healthcare with their healthcare practitioner that may impact on their decisions. This is proposed as good practice. They are/become part of an on-going discussion about one’s healthcare.
**Should a standard format be developed?**

It is our recommendation that a standard format could be used to ensure that vital information is documented. This adds to the validity and credibility of the directive. It will also help healthcare professionals in the acute sector to interpret peoples wishes and ensure that time is spent on adhering to the wishes, rather than filtering through an unstandardized form that may contain superfluous, unfocused even contradictory directions. From feedback we received to date, people have welcomed the standardised format as this allows them to include relevant information and signposts them to consider issues that they may have otherwise overlooked. A standardised format also simplifies implementation, education of public and healthcare professionals. Consensus from key stakeholders should be sought if this standardised approach is used. A standardised approach could be offered, even recommended but others could be used as well. It does not have to be exclusive to a single approach.

**Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed?**

Funded initiatives in the area of advance care planning by the Irish Hospice Foundation include ‘Think Ahead’ and the ‘LetMeDecide’ programme. While national interest exists, there is no method of tracking the number of active AHDs, and the impact of public campaigns and other initiatives remain unquantified. There is no way of knowing how many directives have been completed, or what impact these AHDs will have on services. The development of a model/process for recording AHDs is the next logical step in this process. Numerous countries use AHD registries. Registries increases citizen engagement and empowerment in healthcare decision for end-of-life care.

A national electronic registry would enable quick access to information for healthcare professionals, if and when, a person is admitted to hospital. According to a report by Maryland State Advisory Council in 2006, “An advance directive that is unknown at the time of crucial treatment decisions, is useless, and a well-functioning registry reduces the risk of this outcome.” We acknowledge that people’s preference may lie with a paper copy and this must be respected. However if an AHD is completed in conjunction with a healthcare professional, we can see the merit of recording the content of the directive electronically. Of course this is dependent on systems that will allow secure storage of data and accessibility of this information on demand, at point of care sites. The HSE could easily do this. We recommend the person keeps a paper copy and
that the standard form would include information on a nationally agreed storage site, in the persons home e.g. under the mattress in their bedroom, behind the front door, on the fridge. We also recommend that the GP has a copy in the patients’ medical records (electronic or paper).

What additional measures could be included to ensure that their existence is known about and they can be readily accessible?

The number of completed AHDs are growing in Ireland and will continue to grow. Based on international figures we can expect that over 40% of the population in Ireland will have an AHD in the coming years. The routine screening by healthcare professionals for AHDs on admission to hospital is essential. We recommend that this become common practice. A question such as ‘do you have an AHD’ could be included in all hospital admission forms. This needs to be as routine as asking if the person has any known allergies. We suggest that GPs also integrate a section on their patient’s profiles to include this information.

The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?

Tell people clearly that AHDs cannot be used to demand treatment. They can request it e.g. if necessary ICU and/or tube feeding. If my kidneys fail, I would agree to/want dialysis, if medically indicted. This is where a standardised form, with a standardised education package is invaluable. Education of the general public will be essential to the process.

What do you think the role of the patient-designated healthcare representative should be? Should the representative’s role be limited to that of interpreting the individual’s advance healthcare directive? Should the representative have a broader role to advise as to what the individual’s will and preferences regarding treatment are likely to be?

There are two types of AHD- instructional (living will) and proxy directives. The patient-designated healthcare representative, or proxy, is an adult nominated by the donor (person completing the directive) to act on his/her behalf. In an AHD, this proxy is nominated to make decisions about health or personal care on behalf of a person, in the event that the donor becomes incapable. This is termed a “proxy directive” and written evidence
of this agreement must be present. It is essential that a discussion regarding wishes and preferences takes place between the proxy and the donor. An instructional directive (living will) is written by the donor and clearly states his/her wishes for certain treatments choices in the event of certain circumstances, e.g. if I was in a persistent vegetative state, I would not want tube feeding, CRP in the event of a cardiac arrest or antibiotics for pneumonia. The patient-designated healthcare representative/proxy may be asked to interpret the statement and potentially provide assurance of capacity at the time of decision making. We believe this to be the extent and limit of the role. The proxy is a conduit to advise the healthcare professional what the person (donor) wishes are, nothing more, nothing less.

What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

We recommend that a healthcare professional co-signs the document and thus ensures that the donor had some measure of capacity when s/he completed the directive. It avoids undue influence and abuse. It is a quality assurance provision that may avoid, or at the very least minimise, potential abuse of the process.

Any other additional issues?

(i) Capacity assessment

The draft scheme states that a person must have capacity at the time of completing the directive (Head 5 page 14). While a capacity assessment is not mandatory, we strongly feel that a healthcare professional should co-sign the ACD and thus provide a level of assurance that capacity to understand the information and the consequences of the decisions made, was present at the time of completion. We recommend that the following sentence at the very minimum be included in a standard form and signed by a healthcare professional ‘I believe that the person completing the ACD is capable of understanding or giving these instructions’. 
(ii) Minimum information

The date of completion needs to be included in the minimum information data set.

(iii) Label of ‘Patient-designated healthcare representative’ to describe a nominated proxy requires revisions

The term ‘Patient-designated healthcare representative’ is too long. We would suggest the term ‘health proxy’. Proxy refers to a person authorized to act on behalf of someone else and is an acceptable term used internationally within the context of advance care directives. By using universal terminology, one reduces confusion for people when they will inevitably explore this topic on the internet. It also aids researchers when publishing or presenting their work internationally, as terms do not have to be explained and there is a common language. Finally, the use of the words ‘healthcare representative’ are misleading and could be interpreted that that designated person must be a representative of the healthcare profession. Proxy is much simpler and is in common usage, by simplifying it you are making it more accessible.

(iv) Two witness are to sign the AHD

How useful is it to have two witness signatures? What if they are not contactable? Can they attest to the person’s capacity? Who can attest that they had capacity? What is the purpose of this? What does it achieve? Does this mean that healthcare professionals should try to contact the witness when they are using an AHD?

To conclude, with rights come responsibility and in drafting this legislation the government must consider its duty of care to the citizens completing directives and the healthcare professionals that are tasked with interpreting and adhering to his/her wishes and preference.

We are happy to meet to discuss any of the issues raised above at your convenience. We are leading a European Consortium application in this area and have extensive experience working with AHDs both nationally and internationally.

Professor W. Molloy & Dr. Nicola Cornally. Email: n.cornally@ucc.ie
‘Let Me Decide’ Publications


Appendix 2: Sample Policy on Advance Care Planning

INTRODUCTION:
Nursing Home X is committed to providing residents with choice and options. Advance Care Directives (or “Advance Healthcare Decisions” as they are called in the proposed Advance Healthcare Decisions Bill 2012) provide people an opportunity to document their choices about the type of care they wish to receive in the event of incapacity. They also allow a person to designate another individual to be consulted or to be involved in decisions regarding care on their behalf.

Incapacity to make an advance healthcare directive is defined in the Advance Healthcare Decisions Bill 2012 Section 4 (draft June 2012) as follows:

...... a person shall lack the capacity to make an advance healthcare decision or any decision in respect of treatment if at the material time, he or she is unable—
   i. to understand the information relevant to the decision,
   ii. to retain that information,
   iii. to use or weigh that information as part of the process of making the decision, or
   iv. to communicate his or her decision (whether by talking, using sign language or any other means) or, if the decision requires the act of a third party to be implemented, to communicate by any means with that third party.

POLICY:
An Advance Care Directive will be offered to all residents and families. The completion of an Advance Care Directive is voluntary.

PURPOSE:
1. For a resident who has the capacity to make healthcare decisions:
   a. To determine and record the wishes of the resident with regard to their future healthcare so that their wishes are known, should they become unable to make healthcare decisions in the future.
   b. To support the resident in designating a person to be consulted, if in the future, the resident becomes unable to make their own healthcare decisions and such decisions have to be made. Under the proposed Advance Healthcare Decisions Bill 2012 and its proposed extension of the Powers of Attorney Act 1996, this designated person could furthermore be appointed as an attorney with the power to make certain specified healthcare decisions on the resident’s behalf.

2. For a resident who has lost the capacity to make healthcare decisions:
   a. To support families to record any wishes or views their relative may have expressed in relation to future healthcare at a time, in the past, when they still had decision-making capacity.
   b. To facilitate families through consultation with a healthcare professional, to determine and record what they think their relative would have wanted in relation to future healthcare, and should this not be possible, to record what the family’s wishes are.

PROCEDURE:

On admission, the CNM 1 will determine if the resident has completed an Advance Care Directive (or Advance Healthcare Decision, both are referred to as ACD).
A. For residents who have completed an ACD prior to admission to Nursing Home X which is not a “Let me decide” (LMD) directive

1. The CNM 1 will arrange a meeting with the doctor, the resident and any other relevant people e.g. family members.
2. The doctor will assess whether the resident understands the ACD they completed.
   a) Provided the resident understood the ACD and has the capacity to do so, any changes desired may be made to the existing ACD at this stage.
   b) The resident will be offered the opportunity to complete an LMD directive instead. If they wish to do this, the procedure in section B will be followed.
   c) For residents who no longer understand the ACD they previously completed, and no longer have the capacity to make healthcare decisions, no changes will be made to the ACD unless there is a compelling legal reason to do so.
3. The doctor will document the meeting, its outcome and any care plan agreed upon in the resident’s medical notes.
4. The CNM1 will document the discussion and outcome in the multidisciplinary notes.
5. The current and valid ACD will be filed in the front of the Care file with 2 copies attached.

B. For residents who have not completed an ACD prior to admission to Nursing Home X

The CNM1 will provide information to the resident and/or their family about advance care planning and ACDs and for the purposes of education will make the “Let Me Decide” booklet available to them.

1. For residents who are not interested in advance care planning or completing an ACD, this will be documented in the front of the Care Plan by the CNM1.
   a) They will be offered the opportunity to complete an ACD again on an annual basis, after a serious illness or transfer to hospital unless they state otherwise.
2. For residents who are interested in advance care planning and/or completing an ACD using “Let MeDecide” (LMD), the CNM1 will arrange to meet with the resident (and/or their family according to the resident’s wishes).
   a) The CNM1 will do a cognitive screen using the Standardised Mini Mental State Exam (sMMSE) which will be filed in the resident’s medical care file.
      i. Residents who score <10 on the sMMSE will be deemed to lack capacity to complete LMD unless there are reasons to suspect otherwise e.g. they have speech disturbance making it difficult for them to express themselves.
      ii. Residents who score 10 to 20 on the sMMSE will be interviewed further by the CNM 1 prior to education on advance care planning to assess whether they are likely to understand what is involved.
      iii. Residents who score >20 will be educated on LMD.
   b) After education, all residents who wish to complete the LMD directive will need to have their capacity assessed using the SIACAD questionnaire which will be filed in the resident’s care file.
      i. Residents with SIACAD scores < 10 will be deemed to lack capacity to complete the LMD directive
      ii. Residents with SIACAD scores of 10-15 will be re-educated on LMD. The SIACAD will be re-administered. If their score is ≤15, they will be assessed by their doctor prior to completing the LMD directive.
      iii. Residents with SIACAD scores > 15 will be deemed capable of completing the LMD directive.
   c) The CNM 1 will arrange a meeting with the doctor, the resident and any other relevant people e.g. family members, to discuss the advance care plan and ACD and to answer any questions or clarify any issues for them.
d) The doctor will assess whether the resident understands the ACD they wish to complete.

e) The doctor will document the meeting, its outcome and any care plan agreed upon in the resident’s medical notes.

f) The CNM1 will document the discussion and outcome in the multidisciplinary notes.

g) The ACD will be filed in the front of the Care plan with 3 copies attached. The original will always remain in the care file.

h) The resident will be offered a copy of their ACD.

3. For residents who have not completed an ACD and are deemed to lack capacity to complete one. Any care decisions will be discussed with the next-of-kin/significant other.
   a) Once it has been confirmed by the doctor that the resident lacks capacity to make care decisions, the CNM 1 will provide information on care planning on end-of-life issues to the family/“next-of-kin”.
   b) If it is felt that the resident would be able to express their own views on end-of-life care, these should be explored and documented, even if the resident lack capacity to make care decisions. Any expressed views should be taken into account when making decisions on the resident’s behalf.
   c) If they are interested in providing input into the resident’s end of life care plan, they will be given a copy of the “Let Me Decide” booklet and a meeting will be arranged with the CNM 1 and any other relevant person such as the doctor. A discussion will take place to ascertain:
      i. if the resident ever expressed wishes with regard to end-of-life care
      ii. if not, what they think the resident would want were they still able to decide for themselves
      iii. if they can’t answer i) or ii) what the family’s wishes are in relation to care
   d) This discussion will be documented in the resident’s care file by the CNM 1.
   e) If the doctor was not at this meeting, the information from this meeting will be provided to him/her so that together a “care plan for end-of-life decisions for people lacking decision making capacity” (EOL decisions care plan) can be completed.
   f) If an EOL decisions care plan is completed, this will be filed at the front of the resident’s care file with 3 copies attached. The original will always remain in the care file.

4. For residents who are Wards of Court the CNM 1 will contact the appropriate office to determine if the designated decision-maker will make a plan with regard to end-of-life care on the resident’s behalf.

5. If the resident has an ACD or an EOL decisions care plan, a white circular sticker will be attached to the spine of the residents care file.

6. If the resident is transferred to hospital:
   a) Send a copy of the ACD or EOL decisions care plan attached to the Transfer Letter and make a note of it on the Transfer sheet
   b) Photocopy the ACD or EOL decisions care plan and replace the one which was sent with the resident to the hospital.

7. If the resident is discharged to another facility or home, send the original ACD or EOL decisions care plan with the resident. The copies of the ACD or EOL decisions care plan will be retained in the resident’s file.

8. All directives will be reviewed and updated:
   a) Annually
b) After a significant change in health or after a serious illness

c) Anytime the resident (with capacity) wishes.

For families who were initially not interested in being involved in advance care planning for the resident, they will be offered the opportunity again as outlined in 8.a) and 8.b)
## Appendix 3: Timeline

### Pilot Study Timeline

**MAY 2015**

<table>
<thead>
<tr>
<th>DATES</th>
<th>SETTING UP STUDY</th>
<th>PRE-IMPLEMENTATION</th>
<th>IMPLEMENTATION</th>
<th>POST-IMPLEMENTATION &amp; ANALYSIS &amp; WRITE-UP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>3 months</strong></td>
<td>Recruitment of LTC institutions (LTCs)</td>
<td><strong>BEFORE</strong> Period</td>
<td>Transition Period</td>
<td><strong>AFTER</strong> Period</td>
</tr>
<tr>
<td><strong>Aug 2011 – Aug 2012</strong></td>
<td>1. Make contact with LTCs</td>
<td>Retrospective collection of data on deaths in the period before Implementation of the “Let Me Decide” and Palliative Care Programmes</td>
<td><strong>JULY 2013 – Oct 2014</strong></td>
<td>Collection of data on deaths and palliative care interventions for transition/quality assurance</td>
</tr>
<tr>
<td><strong>Sep 2012 – Nov 2012</strong></td>
<td>2. Arrange meeting with Director or sundial to explain study protocol</td>
<td>3. Give presentation to Board</td>
<td><strong>Nov 15 – June 2014</strong></td>
<td><strong>Analysis &amp; Write-up</strong></td>
</tr>
<tr>
<td><strong>Dec 2012 – June 2013</strong></td>
<td>4. Obtain approval from relevant managers</td>
<td>5. Collect profile data on LTCs (questionnaire)</td>
<td><strong>July 14 – Oct 2014</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Refine policy on ACP

- **Before** Period (approx. 12 months)
  - Refine policy on ACP to suit the needs of the LTC
- **Transition Period** (10 months)
  - Transition Period
- **After** Period (12 months)
  - **Analysis & Write-up**

### Collection of data from Chart Review

- **Before** period: Commercial Retrospective Chart Review of all deaths in the “Before” period
- **After** period: Complete Chart Review of all deaths in the “After” period

### Collection of 40000 data from Bereaved Relatives

- **Before** period: Commercial collection of 4000 data from relatives (deceased or surviving) for deaths occurring in the “Before” period
- **After** period: Complete collection of 4000 data from relatives for deaths occurring in the “After” period

### Collecting data on Staff Attitudes to ACP and staff Palliative Care Training Needs

- **Before** period: Commercial questionnaire to staff and colleagues on:
  - Attitudes to ACP and ACC
  - Barriers to ACP and ACC
  - Staff’s Palliative Care Training Needs
- **Transition Period**: Review data on staff Institute Training Needs to inform the development of the Palliative Care Educational Programme
- **After** period: Complete staff training in delivering PC Care (April 2014)

### Education on Advance Care Planning and “Let Me Decide”

- **Before** period: “Let Me Decide” Education:
  - ACP Facilitators
  - Other nursing staff
  - Admin staff
  - Staff involved in emergency departments
- **Transition Period**: Set up “Let Me Decide” Educational Programmes
  - “Let Me Decide” Educational Programmes
  - “Let Me Decide” Educational Programmes
  - Further discussion feedback sessions with nursing staff in study sites
- **After** period: Maintain support to nursing home staff and responding to their feedback

### Palliative Care Education

- **Before** period: Palliative care education
  - ACP Facilitators
  - Other nursing staff
  - Healthcare assistants

### Implement Palliative Care Programmes

- **Before** period: Ongoing implementation of Palliative Care Programmes

### Systematically offer ACP to all residents’ families

- **Before** period: Promote and advertise ACP in the LTCs (use seminars, posters, brochures)
- **Transition Period**: Begin systematically offering ACP to all residents/families
- **After** period: Continue systematically offering ACP to residents/families and to all incoming residents

---

**Dates**

- **Aug 2011 – Aug 2012**
- **Sep 2012 – Nov 2012**
- **Dec 2012 – June 2013**
- **JULY 2013 – Oct 2014**
- **Nov 15 – June 2014**
- **July 14 – Oct 2014**

**Time Period**

- **3 months**
- **7 months**
- **4 months**
- **8 months**
- **4 months**
<table>
<thead>
<tr>
<th>Period of Study</th>
<th>“Before” Period (approx. 12 months)</th>
<th>Transition Period (18 months)</th>
<th>“After” Period (15 months)</th>
<th>Analysis &amp; Write-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steering Committee</td>
<td>First meeting of Steering Committee held in Mar 2013</td>
<td>Steering Committee Meetings scheduled for June 2013, October 2013, March 2014, and June 2014</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DATABASE of Resident ACPS/ACPs EOL Care Plans</td>
<td></td>
<td>Develop and update Study DATABASE of Resident ACPS/ACPs EOL Care Plans</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring and Feedback from LTCs</td>
<td></td>
<td>Obtain FEEDBACK from LTCs and use this to inform implementation programme.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Development of SPELE Tool for use by staff in Reviewing deaths</td>
<td></td>
<td>Development of Staff Perception of End-of-Life Experience (SPELE) Tool</td>
<td>Jan-Jun 2014</td>
<td>Numeracy Home staff to use SPELE Tool on sample of recent deaths</td>
</tr>
<tr>
<td>Assess compliance with the programme</td>
<td></td>
<td>Assess compliance with the programme among residents with and without cognitive impairment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Develop online resources for education</td>
<td></td>
<td>Continue to develop “Lifelong Learning” Adult E-Learning Module with UCC/AHPC.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liaise/Synthesise with other ACPS/EOL Care initiatives</td>
<td></td>
<td>Liaise/Synthesise with other ACPS/EOL Care initiatives currently being promoted by HPS NI/AHPC e.g. RapidAudit tool on Quality of EOL Care for ongoing quality assurance in the homes after completion of this Pilot Study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collecting COST data &amp; Chart Reviews</td>
<td></td>
<td>Chart review to collect data on use of hospital resources etc. to analyse cost savings associated with the Programme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assess resources needed for sustainability</td>
<td></td>
<td>1. Assess the training and resources needed to maintain operation and sustain SUSTAINABILITY of the programme.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prepare &amp; submit papers for publication</td>
<td></td>
<td>Start drafting papers for publication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of data and Analysis</td>
<td></td>
<td>Review of data and Analysis</td>
<td>Review of data and Analysis</td>
<td>Submit Final Report to Health Research Foundation Oct 2014</td>
</tr>
</tbody>
</table>
Appendix 4  Key educational points for residents (and their families) engaging in the advance care planning (ACP) process

Key educational points for residents (and their families) engaging in the advance care planning (ACP) process

- ‘Let Me Decide’ helps you to state your healthcare wishes so they are known should a time ever come when you can no longer communicate or decide for yourself. It allows you to outline your wishes in writing in the form of an Advance Care Directive (ACD) in a way easily understood by healthcare workers.
- You are not required to engage in the advance care planning (ACP) process, it is completely voluntary; and you can decide at any stage that you no longer wish to proceed.
- If you wish, in your ACD you can nominate/appoint a Healthcare Proxy (also called a “Substitute Decision-Maker”) to make future health care decisions on your behalf should you ever become unable to communicate or make those decisions yourself.
- If you nominate a substitute decision-maker (healthcare proxy), it is important to choose a person who understands your healthcare wishes as outlined in your ACD; this person does not have to be a member of your family, but instead can be a trusted friend or confidante.
- While a person has a legal right to refuse any medical treatment even if this refusal leads to their death, a person cannot demand any particular medical treatment.
- An ACD is a statement of your wishes/preferences with regard to your future healthcare; where you have indicated that you would like to receive a particular treatment, it will be up to the doctor treating you to decide if your preferred treatment option is appropriate and in your best interests.
- Your ACD will only be used if, in the future, you are unable to make healthcare decisions and communicate these to others; if you are still able to think straight and communicate your wishes then you will be asked about your treatment preferences.
- When filling in the ‘Let Me Decide’ ACD, a person can make a ‘Personal Statement’ indicating which irreversible states of health would be unacceptable to them personally.
- “Irreversible” or “incurable” means that a person is not going to get better, even with treatment
- Unacceptable & irreversible state of health: an irreversible state of health that a person would consider to be intolerable or that would make their quality of life unacceptable to them.
- You can change your mind at any time about any of the decisions you have made in your ACD.
- You are not required to complete an ACD form at the end of the ACP process; instead you may choose to document your wishes in a less formal way (like in the form of a ‘letter’).
Appendix 5: Decision Tree for Implementing “Let Me Decide” (Pilot Study)

Nurse approaches Resident regarding ‘Let Me Decide’

Resident Interested in Let Me Decide  No interest in LMD

**STEP 1 – Use sMMSE to assess Cognition**

- sMMSE Score 10-20
  - Explore/ Interview further
  - **Resident lacks capacity to complete Let Me Decide**
  - **Competent**

- sMMSE Score >20-30
  - **Explain Study & Obtain CONSENT from**
  - **STEP 2 – EDUCATE Resident regarding LMD**
  - **STEP 3 – Use SIACAD to assess CAPACITY**

- sMMSE Score <10
  - **Doctor decides whether resident has capacity to complete Let Me Decide**

**SIACAD Score >15**

- Resident HAS capacity to complete Let Me Decide ACD
- **Score >15**
  - **Competent Resident completes Let Me Decide ACD**

**SIACAD Score 10-15**

- **RE-educate resident regarding**
- **SIACAD is RE-administered**
- **Score 10-15**
  - **Ask Next-Of-Kin for CONSENT to participate in Study**

**SIACAD Score <10**

- **Resident LACKS capacity to complete**
- **Score <10**
  - **Discuss End-of-Life care with next-of-kin /Resident**
  - ‘End-Of-Life Decisions Care Plan for Person Lacking Capacity’ is drawn up and signed off by Doctor
Appendix 6  Guidelines for nurses doing advance care planning (ACP) with long-term care residents with capacity

- Where appropriate, offer ACP information leaflets/booklets to new residents (and their families) on/after admission and inform them it is part of routine policy and procedure.
- A LTC facility should have appropriately trained nursing staff to act as ACP facilitators, and all attending GPs should also receive training in how to deliver ACP to this population.
- If the resident is considered to be a suitable candidate for ACP (on the basis of routine cognitive tests), broach the subject again after an appropriate settling-in period and ascertain the resident’s willingness to learn more about the ACP process.
- If the resident is willing, arrange a set time to start introductory educational session about ACP.
- Encourage the resident to involve a family member(s)/close friend in the ACP process from the outset, and help the resident to identify a suitable person(s); this person should be nominated as a substitute decision-maker (healthcare proxy) on a completed ACD if the resident wishes.
- Choose a time of day when the resident is unlikely to be tired; choose a quiet draught-free place away from distractions and interruptions.
- If possible, seize on periods of lucidity to engage in ACP discussions.
- Where appropriate, ensure the resident has functioning hearing aid(s) and clean reading glasses.
- Educate the resident (and family) about the various components of ACDs (including their limitations); deliver any information in 'bite-sized' chunks to avoid overwhelming the resident.
- Provide information tailored to the resident’s readiness for engagement in the ACP process, taking the cue from the resident (Ramsaroop et al, 2007; Fried et al, 2010)
- Encourage the resident (and family) to ask questions and answer questions using clear simple language, carefully explaining any terminology.
- Keep positive, succinct, and don’t be morbid.
- Acknowledge/respect any particular cultural or religious traditions/beliefs/rituals relating to end-of-life that may be important to the resident.
- Carefully document any outcomes from discussion and set a time for the next session if a resident is willing to proceed further.
- Involve the resident’s GP at the appropriate stage of the ACP process and at any stage requested by the resident (or family), and where any issues/conflict arises.
- It may take several indepth discussion/educational sessions, over several weeks (or even months) to cover all aspects of the ACP process.
- The resident should be allowed to proceed at his/her own pace; residents (and their families) should be given enough time in between sessions to reflect on what was discussed, and to request more information on any particular topic.
- Before the completion of a formal ACD, the resident’s capacity to understand the decisions they are making should be assessed.
- Ensure that there is consistency over time in the resident’s responses when asked the same questions at different points in the ACP process; ensure internal consistency in responses to related/similar questions.
- A resident should only complete an ACD after they have carefully considered their goals of care and have communicated these to their loved ones (where applicable) and to the
healthcare professionals caring for them.

- The ACD (and several copies) should be stored at the front of the resident’s chart; a copy should always accompany the resident if they are transferred to hospital.
- An ACD should be kept up-to-date; it is recommended that ACDs are reviewed at least annually and after a change in health, an admission to hospital, or whenever requested by the resident.
- Where appropriate, residents should be encouraged to re-evaluate the preferences documented in their ACD following any change in their clinical or personal circumstances.
- The ACP process does not necessarily have to result in the completion of a structured ACD form; a resident’s wishes can be documented in an unstructured format, but should be stored at the front of the notes as for a formal ACD.
Appendix 7  Recommended steps for nursing staff to follow in helping a resident with capacity to accurately document their treatment preferences in an advance care directive (ACD)

Table FF  Steps in helping the resident to accurately document their treatment preferences in an advance care directive (ACD)

- During discussions, encourage the resident to consider what are their values and goals of care (including end-of-life care), and encourage them to verbalise these as if they were writing a 'letter'.
- Start with structured discussion formats that first address the resident's values and goals of treatment rather than particular life-sustaining procedures.
- Present the resident with a range of future clinical scenarios that are relevant to their current condition and outline specific treatment options that might present for each scenario.
- Help the resident to decide how far they would like treatment to go (i.e. palliative care, “limited” care, surgical care, or intensive care) and which treatment options they would wish to receive for each of the particular clinical scenarios.
- For each of the treatment options considered, provide appropriate education to the resident (and family) using photos and visual aids with large print where possible.
- Explain common life-sustaining treatments e.g. CPR, mechanical ventilation, and tube feeding, including side-effects and complications; describe common conditions that often require such treatments.
- Help the resident to reflect upon and establish what states of health/levels of functioning they personally would find unacceptable if these were irreversible/incurable; offer a menu of such health states with appropriate descriptions (e.g. inability to communicate; inability to recognise my family; inability to walk; inability to wash, dress or feed myself; in a permanent state of confusion).
- Help the resident to decide how far they would like treatment to go (i.e. palliative care, “limited” care, surgical care, or intensive care) and which treatment options they would wish to receive if they were in an irreversible/incurable state of health that was unacceptable to them.
- Ask the resident about any particular wanted/unwanted treatments.
- Encourage the resident to also formulate a statement of general treatment goals e.g. 'If at all possible, I would like to remain here in (Name) Nursing Home and to be kept comfortable and pain free.'
- If the resident does not wish to involve a family member/friend in the ACP process, they should be encouraged to make their advance care directive (ACD) as detailed as possible.
### Appendix 8: Advance care planning and advance care directives attitudes

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Disagreed</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every competent person has the right to accept or refuse medical treatment</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>27</td>
<td>69</td>
<td>Majority strongly agree that people have the right to refuse treatment (69%, n=64)</td>
</tr>
<tr>
<td>Every competent person can complete an advance care directive</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>31</td>
<td>65</td>
<td>The majority (65%, n=60) strongly agree that every competent person can complete an ACD</td>
</tr>
<tr>
<td>Advance care directives are a way of getting rid of old people</td>
<td>76</td>
<td>20</td>
<td>3</td>
<td>1</td>
<td>-</td>
<td>87 (96%) disagreed that ACDs are a way of getting rid of old people</td>
</tr>
<tr>
<td>Healthcare professionals are the best people to make health decisions for patients</td>
<td>9</td>
<td>36</td>
<td>27</td>
<td>16</td>
<td>12</td>
<td>Only 28% (n=26) agree that HCP are best placed to make decisions for patients</td>
</tr>
<tr>
<td>A patients family are the best people to make health care decisions when a patient no longer can and has no ACD</td>
<td>7</td>
<td>34</td>
<td>27</td>
<td>23</td>
<td>10</td>
<td>Over 40% (n=3) did not agree that that family were the best decision makers</td>
</tr>
<tr>
<td>There is a need for patients to become more involved in their health care decisions</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>42</td>
<td>48</td>
<td>Over 90% (n=83) believe that patients should become more involved in healthcare decision making</td>
</tr>
<tr>
<td>If people are allowed to make their own health care decisions, they will usually make the wrong decision</td>
<td>32</td>
<td>54</td>
<td>11</td>
<td>3</td>
<td>-</td>
<td>86% (n=79) disagree that people will make the wrong decision</td>
</tr>
<tr>
<td>People who complete advance directives should be allowed to leave instructions which others may feel are not in the persons own best interest</td>
<td>4</td>
<td>18</td>
<td>13</td>
<td>45</td>
<td>20</td>
<td>65% (n=59) agree that people should be allowed to leave instructions that others may disagree with</td>
</tr>
<tr>
<td>Advance care directives can make the decision-making process for healthcare professionals easier by letting them know the patients and family’s wishes</td>
<td>-</td>
<td>3</td>
<td>1</td>
<td>47</td>
<td>48</td>
<td>Just under half strongly agree that ACDs can make the decision making process easier for HCP</td>
</tr>
<tr>
<td>Every competent person should be required to complete an advance care directive</td>
<td>2</td>
<td>11</td>
<td>19</td>
<td>34</td>
<td>34</td>
<td>68% (n=62) believe that every competent person should have an ACD</td>
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<tr>
<td>Advance care directives can contribute to a better patient/healthcare professional relationship</td>
<td>-</td>
<td>3</td>
<td>17</td>
<td>41</td>
<td>40</td>
<td>Over 80% (n=73) indicated that an ACD can contribute to a better patient/healthcare professional relationship</td>
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<tr>
<td>Advance care directives are a step on the road to legalised euthanasia</td>
<td>38</td>
<td>32</td>
<td>21</td>
<td>8</td>
<td>2</td>
<td>Very few (9.8%, n=9) believed that ACDs are a step on the road to euthanasia</td>
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<tr>
<td>The elderly should be allowed to request intensive care treatment</td>
<td>1</td>
<td>5</td>
<td>12</td>
<td>50</td>
<td>32</td>
<td>Over 82% agree/strongly agree that the elderly can request ICU care</td>
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<tr>
<td>ACDs are a positive step towards greater patient autonomy</td>
<td>-</td>
<td>-</td>
<td>14</td>
<td>56</td>
<td>30</td>
<td>86% (n=78) believe ACDs promote patient autonomy</td>
</tr>
<tr>
<td>Healthcare providers should be required to follow advance care directives</td>
<td>-</td>
<td>3</td>
<td>9</td>
<td>43</td>
<td>45</td>
<td>88% (n=80) agree or strongly agree that HCP should follow ACDs</td>
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</table>
### Appendix 9: Learning needs analysis

<table>
<thead>
<tr>
<th>Topic</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Very Important (%)</th>
<th>Important (%)</th>
<th>Less Important (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Advance Directives, Power of Attorney, and Living Wills</td>
<td>87</td>
<td>13</td>
<td>57</td>
<td>38</td>
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<tr>
<td>2. Determining a person’s mental Competency</td>
<td>82</td>
<td>18</td>
<td>67</td>
<td>31</td>
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<td>3. Understanding Personal Autonomy</td>
<td>86</td>
<td>14</td>
<td>61</td>
<td>35</td>
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<td>4. Primary Roles of the Palliative Care Team</td>
<td>84</td>
<td>16</td>
<td>61</td>
<td>36</td>
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<tr>
<td>5. Understanding the Physiological Impact of Life-Threatening Illnesses</td>
<td>88</td>
<td>12</td>
<td>62</td>
<td>37</td>
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<tr>
<td>7. Physical Changes as Death Approaches</td>
<td>88</td>
<td>13</td>
<td>65</td>
<td>27</td>
<td>8</td>
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<tr>
<td>8. Diagnosing Dying</td>
<td>79</td>
<td>21</td>
<td>57</td>
<td>41</td>
<td>2</td>
</tr>
<tr>
<td>9. Pain and Symptoms Assessment</td>
<td>86</td>
<td>14</td>
<td>73</td>
<td>25</td>
<td>2</td>
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<tr>
<td>10. Assessment and Management of Nausea</td>
<td>81</td>
<td>19</td>
<td>56</td>
<td>38</td>
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<tr>
<td>11. Assessment and Management of Incontinence</td>
<td>70</td>
<td>30</td>
<td>44</td>
<td>49</td>
<td>7</td>
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<tr>
<td>12. Assessment and Management of Loss of Appetite/Weight/Taste</td>
<td>81</td>
<td>19</td>
<td>55</td>
<td>42</td>
<td>3</td>
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<tr>
<td>13. Assessment and Management of Dyspnoea</td>
<td>80</td>
<td>20</td>
<td>60</td>
<td>37</td>
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<td>14. Assessment and Management of Impaired Swallowing</td>
<td>83</td>
<td>17</td>
<td>61</td>
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<td>2</td>
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<tr>
<td>15. Assessment and Management of Confusion and Agitation</td>
<td>86</td>
<td>14</td>
<td>71</td>
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<td>2</td>
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<tr>
<td>16. Assessment and Management of Dehydration</td>
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<td>13</td>
<td>74</td>
<td>24</td>
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<td>17. Management of Fatigue</td>
<td>84</td>
<td>16</td>
<td>48</td>
<td>43</td>
<td>9</td>
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<td>18. Management of “death rattle” or respiratory secretions</td>
<td>90</td>
<td>10</td>
<td>62</td>
<td>36</td>
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<td>19. Pharmacological Management of Pain and opioids (e.g. morphine)</td>
<td>90</td>
<td>10</td>
<td>73</td>
<td>27</td>
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<tr>
<td>20. Non-Pharmacological Management of Pain (e.g. biofeedback)</td>
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<td>12</td>
<td>59</td>
<td>38</td>
<td>3</td>
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<tr>
<td></td>
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<tr>
<td>21</td>
<td>Assessment and Management of Sleep Disorders</td>
<td>74</td>
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<td></td>
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<tr>
<td>22</td>
<td>Maintaining Mobility/Preventing Complications of Immobility</td>
<td>80</td>
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<tr>
<td>23</td>
<td>Maintaining Self-Care Activities (e.g. mouth care)</td>
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<tr>
<td>24</td>
<td>Management of the Nutrition as Death Approaches</td>
<td>82</td>
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<tr>
<td>25</td>
<td>Understanding the Emotional Needs of the Dying Person</td>
<td>90</td>
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<tr>
<td>26</td>
<td>Managing the Emotional Impact on Families as Death nears</td>
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<td></td>
<td></td>
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<tr>
<td>27</td>
<td>Stress Management for the Individual and Family</td>
<td>85</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Crisis Management for the Individual and Family</td>
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<td></td>
<td></td>
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<tr>
<td>29</td>
<td>Management of Grief and Bereavement</td>
<td>87</td>
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<tr>
<td>30</td>
<td>Spiritual Needs of the Individual and Family</td>
<td>83</td>
<td></td>
<td></td>
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<tr>
<td>31</td>
<td>Ethical, Religious, and Legal Implications of Dying</td>
<td>87</td>
<td></td>
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<tr>
<td>32</td>
<td>Culture and Death</td>
<td>87</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Counselling the Family</td>
<td>81</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Stress Management for Staff</td>
<td>84</td>
<td></td>
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<tr>
<td>35</td>
<td>Developing Communication and History-Taking Skills</td>
<td>84</td>
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<td></td>
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<tr>
<td>36</td>
<td>Support Services for the Family and the Individual</td>
<td>82</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Other: Respondents had other learning needs and these related to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>after support for family, feedback from both families and staff on</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>what was good, what needs improvement, staff support</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Appendix 10  

Standard Operating Procedure for Contacting Relatives regarding completion of QODD Survey Questionnaire

(The following is carried out by UCC researchers conducting the ‘Let Me Decide’ Pilot Implementation project)

Standard Operating Procedure for Contacting Relatives regarding completion of QODD Survey Questionnaire

1. For each of the residents who die during the study period in question, the Director of Nursing will provide contact details to the researcher for the resident’s Relative/Friend (if they visited the resident in the last weeks of life).

2. After 3 months has passed since the resident’s death, the researcher drafts a letter of invitation from the Director of Nursing to the Relative/Friend (details in letter changed as relevant to the resident’s sex, relationship with Next-of-Kin, name of residential home etc.).

3. The Letter of Invitation is given by the UCC researcher to the Director of Nursing for signing and for sending out to the Relative/Friend i.e. the first point of contact with the Relative/Friend introducing the Study comes from the Nursing Home.

3. This letter of invitation asks if the Relative/Friend would be willing to take part in a Survey of Bereaved Relatives and Friends. The letter states that one of the UCC researchers will phone the Relative/Friend “in the next week or so” to discuss if they would be willing to take part in the survey.

4. After one or two weeks has passed, the researcher phones the Relative/Friend to follow up on the letter sent by the Director of Nursing. See Standard Operating Procedure (Appendix X) for making a phonecall to a study participant.

5. When phoning the Relative/Friend, the researcher:
   - Introduces herself/himself
   - States that she/he is a researcher at UCC
   - States that she/he is ringing to follow-up “on a letter you might have received in the last week from XXX (name of Director of Nursing) about a survey we are doing”
   - Asks if the Relative/Friend has had time to think about whether or not they would be willing to take part in the survey
   - (Offers condolences to the Relative/Friend on the resident’s death and says that they know this might be a difficult time for the Relative/Friend)
   - If the Relative/Friend indicates that they are interested in doing the survey, the researcher explains that the survey can be done in either of two ways: (i) over the phone which would take about 10 minutes or (ii) the survey can be posted out to the Relative/Friend and they can complete it on their own.
• Explains that if the Relative/Friend is willing to complete the survey over the phone, it can be done now if that suits the Relative/Friend or else the researcher can phone back at another more convenient time.
• States that she/he does not work for XXXX (name of nursing home) so that the Relative/Friend “can say whatever they like in the survey as it will be completely confidential”
• States that while information from the survey will be fed back to XXXX (name of nursing home), the Relative/Friend will not be identifiable.

If the Relative/Friend wishes to be sent the survey in the post:
• Explains that there is a contact telephone number and an email address written at the bottom of the letter in case the Relative/Friend has any queries in relation to completing the questionnaire.
• Checks details of the Relative/Friend’s postal address with them.
• Thanks the Relative/Friend for taking the phonecall and for their time.

If the Relative/Friend wishes to complete the survey there and then over the phone the researcher:
• Adapts the wording of the survey questions to make them more personal e.g. “When John died…” or “Did you feel that your mother’s death…”
• Thanks the Relative/Friend for taking the phonecall and for their time.
• Sends a letter of thanks to the Relative/Friend in the post.

If the Relative/Friend wishes to be sent the survey in the post rather than to complete it over the phone:
• The QODD questionnaire is posted to the Relative/Friend along with a covering letter.
• A prepaid addressed envelope is enclosed for their convenience.

When the completed QODD questionnaire is returned to the research team by the Relative/Friend
• A letter of thanks is sent to the Relative/Friend.

If after 3 weeks the QODD questionnaire (completed or uncompleted) has not been returned by the Relative/Friend:
• A reminder letter is sent to the Relative/Friend
• This letter asks if they would like to be sent another copy of the questionnaire, or if they would like to complete the questionnaire over the phone (they are given a phone number to call to arrange a time)
• This letter asks the Relative/Friend to inform the researcher by post/phone/text/email if they do NOT wish to complete the questionnaire.
• A prepaid addressed envelope is enclosed for their convenience.

If the Relative/Friend is not contactable by phone:
• A letter is posted to the Relative/Friend asking for their consent to send the QODD questionnaire to them in the post.
- They are asked to return the letter/slip to indicate whether or not they are willing to receive the questionnaire in the post or if they would be willing to complete the questionnaire over the phone.
- A prepaid addressed envelope is enclosed for their convenience.
Appendix 11  Requirements for a valid ACD

Requirements for a valid advance care directive (ACD)

- An ACD should be only completed by a person who has capacity to understand the choices they are making; this includes being able to understand the information presented to them, to retain that information, to use it to weigh up the different options available, and to understand the consequences of their choices.
- The result of any assessment of the resident’s capacity should be clearly documented on the front of the ACD.
- The result of any assessment of the resident’s cognitive function should be clearly documented on the front of the ACD (e.g. SMMSE result).
- An ACD should be clear and easy to understand, and be specific enough to guide healthcare professionals involved in treating the subject; vague statements should be avoided.
- Choices documented in an ACD should be internally consistent.
- An ACD should be completed voluntarily by a resident without coercion or undue influence by the doctors, nurses or the family.
- An ACD should accurately state the resident’s wishes.
- An ACD should be signed by the resident’s GP as a safeguard that the resident has understood the choices outlined in their ACD and that the person was of sound mind when completing it; the GP’s name, address and telephone number(s) should also be included so that they can be called upon to verify the contents of the ACD.
- Ideally, an ACD should be witnessed (signed) by a suitable person as a safeguard that the ACD was completed voluntarily without coercion/undue influence; the witness’s name, address and telephone number(s) should also be included so that they can be called upon to verify the contents of the ACD.
- A witness should not be related to the resident nor should they be a named beneficiary in the resident’s will; the healthcare professional who has guided the resident through the ACP process is normally the most suitable person to act as an independent witness.
- The ACD should include the signature, name, address and contact telephone number(s) of any healthcare proxy decision-maker(s) nominated by the resident.
- An ACD should be kept up-to-date; it is recommended that ACDs are reviewed at least annually and after a change in health, after an admission to hospital, or whenever requested by the resident.
- An ACD should only be invoked where the patient no longer has the capacity to make or communicate their own healthcare decisions.
- An ACD should only be applied where the treatment options/refusals specified in it are applicable to the clinical situation at hand, and all circumstances outlined are present.
- The ACD (and several copies) should be stored at the front of the resident’s chart; a copy should always accompany the resident if they are transferred to hospital.
- An ACD must be easily accessible and readily available to the attending healthcare team involved in treating the resident.
- There should be systems in place for the seamless transfer of resident ACD information across different healthcare settings.