



Department of
Health

An Roinn Sláinte

Mánnystrie O Poustie

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Advance Care Planning Policy for Adults In Northern Ireland

Draft Equality Impact Assessment for Public Consultation

December 2021



Table of Contents

EXECUTIVE SUMMARY	4
INTRODUCTION	5
SUMMARY OF THE POLICY CONTENTS	6
CONSIDERATION OF AVAILABLE DATA.....	9
ENGAGEMENT WITH STAKEHOLDERS	9
<i>Stakeholder Engagement Process PRISMA Flowchart.....</i>	<i>10</i>
<i>Phase I Engagement (December 2020 – February 2021)</i>	<i>11</i>
<i>Revisions to Draft Policy Following Phase I Engagement.....</i>	<i>11</i>
<i>Table I: Phase I Early Stakeholder Engagement Outcomes</i>	<i>12</i>
<i>Phase II Engagement (June – July 2021).....</i>	<i>13</i>
<i>Table II.....</i>	<i>14</i>
<i>Phase II Early Stakeholder Engagement Outcomes.....</i>	<i>14</i>
<i>Personal & Public Involvement.....</i>	<i>14</i>
<i>Qualitative Insights from Engagements.....</i>	<i>15</i>
<i>Actions Taken to Support Accessibility</i>	<i>16</i>
RESEARCH	16
OTHER DATA.....	16
ASSESSMENT OF IMPACT.....	17
RELIGIOUS BELIEF	17
<i>Available Evidence.....</i>	<i>17</i>
<i>Assessment of Impact.....</i>	<i>17</i>
<i>Promoting Equality of Opportunity</i>	<i>18</i>
POLITICAL OPINION.....	18
<i>Available Evidence.....</i>	<i>18</i>
<i>Assessment of Impact.....</i>	<i>19</i>
<i>Promoting Equality of Opportunity</i>	<i>19</i>
RACIAL GROUP	19
<i>Available Evidence.....</i>	<i>19</i>
<i>Assessment of Impact.....</i>	<i>20</i>
<i>Promoting Equality of Opportunity</i>	<i>21</i>
AGE	21
<i>Available Evidence.....</i>	<i>21</i>
<i>Assessment of Impact.....</i>	<i>22</i>
<i>Mitigations/Alternative Policies.....</i>	<i>23</i>
<i>Promoting Equality of Opportunity</i>	<i>24</i>
MARITAL STATUS	24

<i>Available Evidence</i>	24
<i>Assessment of Impact</i>	24
<i>Promoting Equality of Opportunity</i>	24
SEXUAL ORIENTATION	25
<i>Available Evidence</i>	25
<i>Assessment of Impact</i>	25
<i>Promoting Equality of Opportunity</i>	26
GENDER	26
<i>Available Evidence</i>	26
<i>Assessment of Impact</i>	26
<i>Promoting Equality of Opportunity</i>	27
DISABILITY	27
<i>Available Evidence</i>	27
<i>Assessment of Impact</i>	28
<i>Promoting Equality of Opportunity</i>	29
DEPENDENTS	29
<i>Available Evidence</i>	29
<i>Assessment of Impact</i>	30
<i>Promoting Equality of Opportunity</i>	31
MULTIPLE IDENTITIES	31
<i>Available Evidence</i>	31
<i>Assessment of Impact</i>	31
<i>Promoting Equality of Opportunity</i>	31
HUMAN RIGHTS	32
GOOD RELATIONS	33
CONCLUSION	33
MONITORING AND REVIEW ARRANGEMENTS	34
<i>Proposed monitoring</i>	34
<i>Co-design/Co-production</i>	34
<i>Advance Care Planning Capabilities Framework</i>	34

Executive Summary

The Department of Health has developed a draft Advance Care Planning policy for adults (aged 18 years and over) in Northern Ireland.

Advance Care Planning is an umbrella term covering personal, clinical, legal, and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. Advance Care Planning is an on-going process of conversations between a person, those important to them¹ and those providing care, support or treatment². Advance Care Planning should be an important part of life for all adults.

This Advance Care Planning policy has been developed to support a person to have greater choice and control over decisions, including plans for their future care and treatment. This is very important if the person becomes unable to make the relevant decisions for themselves at any point.

Advance Care Planning provides the opportunity for adults who wish to do so to:

- Think about what matters to them;
- Then tell people who are important to them;
- Discuss it with those who provide care, support or treatment;
- Write it down and share it;
- Revisit the conversations and decisions, make any changes, and then share again.

This policy is underpinned by values and principles that respect and uphold the rights and dignity of the person and is inclusive of all adults aged 18 and over. It will provide an ethical, rights based approach to Advance Care Planning for adults in line with existing legislation, best practice and professional guidance and standards.

Traditionally, Advance Care Planning has been associated with end of life and palliative care or relevant only for older people. This policy aims to provide a framework for Advance Care Planning that extends to all adults aged 18 and over.

The rationale for the policy scope for those aged 18 years and over is based upon ethical principles of proportionality and consideration of legal aspects where provision is different for those under the age of 18 to that for those age 18 and over.

There are legal aspects underpinning this policy which are not applicable for those aged under 18 years. Furthermore, it is recognised that the needs of those aged under 18 years are significantly different and require a specifically tailored approach.

¹ Those important to the person: This may be family, carers or someone who knows, cares and has affection for the person. They may be connected through their personal, legal, cultural or emotional relationship.

² This includes people working within the community and voluntary sector, independent sector and other health and social care staff working in statutory services.

Alternative provisions for children and young people with palliative care needs are outlined in the Strategy “Providing High Quality Palliative Care for Our Children”³

Equality Impact screening did not identify any expected adverse impact for any of the section 75 categories and did not identify any significant adverse human rights impacts.

It is anticipated that the policy and its subsequent implementation will have a major positive impact in providing a framework to support a cohesive regional approach to Advance Care Planning for adults aged 18 years and over.

Introduction

Section 75 (1) of the Northern Ireland Act 1998 requires public authorities, in carrying out their functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity between specific identified individuals and groups, namely:

- between persons of different religious belief;
- between persons of different political opinion;
- between persons of different racial groups;
- between persons of different age;
- between persons of different marital status;
- between persons of different sexual orientation;
- between men and women generally;
- between persons with a disability and persons without; and
- between persons with dependants and persons without.

The legislation requires public authorities to conduct an equality impact assessment (EQIA⁴) where proposed legislation or policy is likely to have a significant or ‘major’ impact on equality of opportunity.

A ‘major’ impact may include:

- Where the policy is highly relevant to the promotion of the equality of opportunity;
- Where it affects large numbers of people;
- Where it affects fewer numbers of people but where its impact on them is likely to be significant; or
- Where it is a strategic policy or has a significant budget attached

Given that the remit of the policy will include all adults in Northern Ireland aged 18 years and over, on the grounds that it affects a large number of people, the Department has developed this Equality Impact Assessment (EQIA).

³ Department of Health, Providing High Quality Palliative Care for Our Children: A Strategy for Children’s Palliative and End of Life Care 2016 – 26

⁴ An EQIA is a thorough and systematic analysis of a policy to determine the extent of differential impact upon the relevant groups and in turn whether that impact is adverse.

The purpose of this EQIA is to assess any potential differential impact (negative or positive) that the Advance Care Planning Policy for Adults may have on section 75 groups and to detail the mitigations proposed where appropriate.

This EQIA provides an opportunity for comment, in the interests of identifying any unforeseen impacts and gathering further evidence.

The Equality Impact Assessment questions and details of how to respond can be found in Appendix I and II.

Summary of the Policy Contents

Advance Care Planning is an umbrella term covering personal, legal, clinical and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. Advance Care Planning is an on-going process of conversations between a person, those important to them and those providing care, support or treatment.

Advance Care Planning supports a person to have greater choice and control over decisions including plans for their future care and treatment. This is very important if the person becomes unable to make the relevant decisions for themselves at any point.

The ambition of this policy and how it is put into practice is that:

- Advance Care Planning conversations become normalised;
- All adults in Northern Ireland have regular opportunities to express their wishes, feelings, beliefs and values in relation to Advance Care Planning; and that;
- These are reflected in the care, support or treatment they receive.

Policy Aim

A key aim of the Advance Care Planning policy will be to promote clear and consistent messages and practice for those providing care, support or treatment. The policy will also seek to increase public awareness and understanding of what Advance Care Planning is, encouraging adults at any age or stage of life to consider and plan ahead for their future. Advance Care Planning should be an important part of life for all adults.

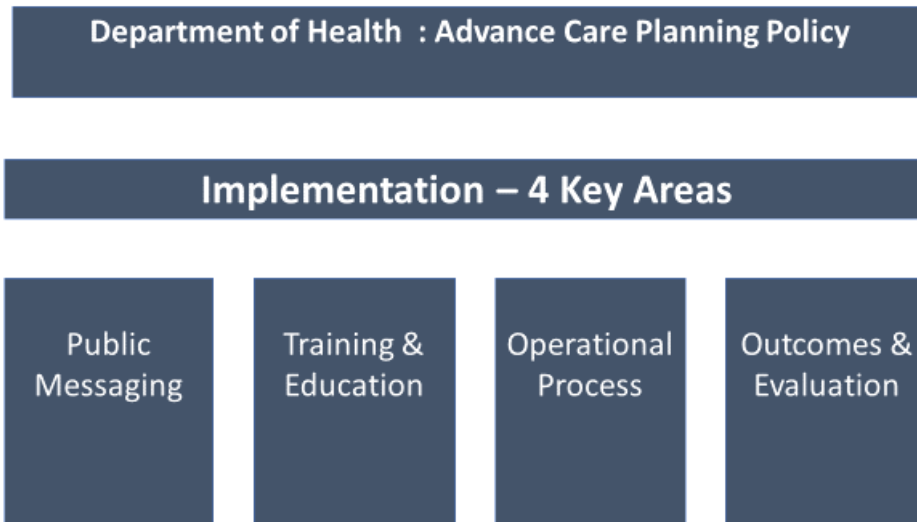
Specifics of the policy

The policy scope is to include all adults aged 18 years and over. Stakeholders include the general public, staff, service users, other public sector organisations, voluntary/community sector organisations and trade unions.

The policy will support a programme of work that includes:

- Public messaging
- Training and education,
- Operational process
- Outcomes and evaluation

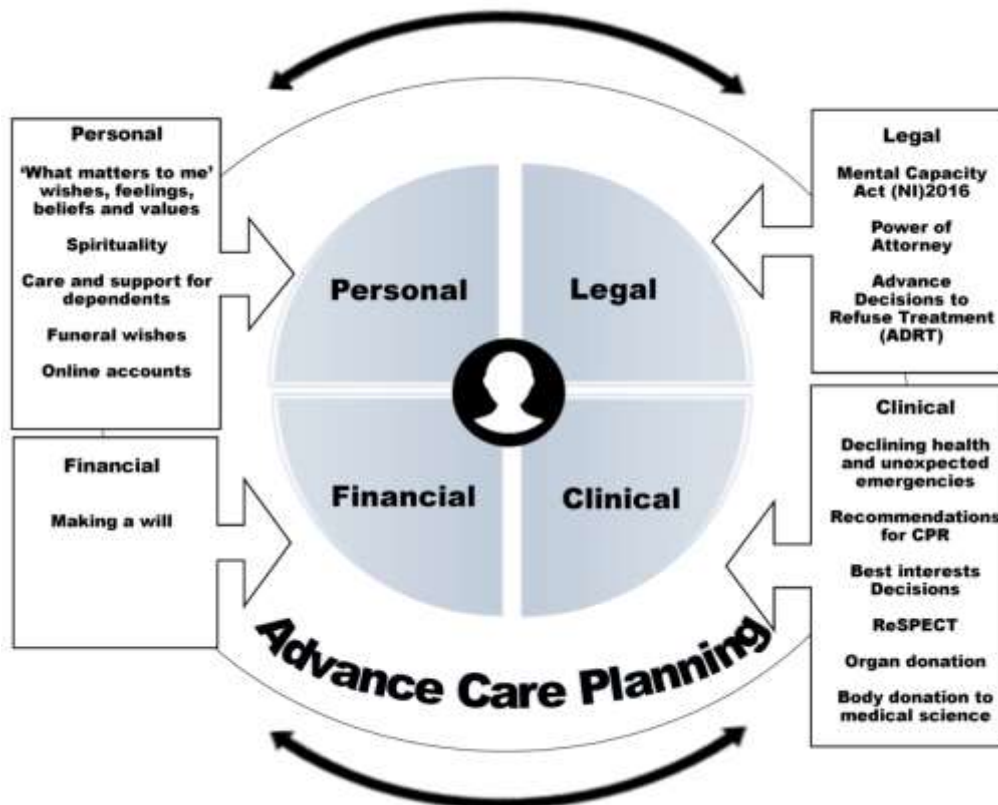
Figure I: Advance Care Planning Programme of work



Whilst the policy’s primary focus is on the health and social care aspects of Advance Care Planning, in response to feedback, the scope of the policy also includes a brief overview of wider aspects of Advance Care Planning, such as making a will, online accounts and funeral wishes.

The policy is underpinned by an Advance Care planning model that identifies four components of Advance Care Planning. They are Personal, Legal, Clinical and Financial. Each component contains one or more elements.

Figure II Advance Care Planning Components Model



The Policy includes sections on;

- The Policy Ambition
- What is Advance Care Planning?
- Advance Care Planning and Mental Capacity
- Values and Principles of Advance Care Planning
- Why is it important to have Advance Care Planning conversations?
- When and where should Advance Care Planning happen?
- Having Meaningful Advance Care Planning Conversations
 - The 'Six Ts' of Good Communication in Advance Care Planning Conversations
- Sharing Advance Care Planning Conversations, Recommendations and Decisions
- Reviewing Advance Care Planning Conversations, Recommendations and Decisions
- How Advance Care Planning Conversations Are Used
- Components of Advance Care Planning
 - Personal Component of Advance Care Planning
 - "What Matters To Me" - Wishes, Feelings, Beliefs and Value
 - Spirituality
 - Care and Support for Dependents
 - Funeral Wishes
 - Online Accounts
 - Legal Component to Advance Care Planning
 - Aspects To Consider Regarding Mental Capacity
 - Types of Power of Attorney
 - Enduring Power of Attorney
 - Lasting Power of Attorney
 - Advance Decisions to Refuse Treatment (ADRT)
 - Clinical Component of Advance Care Planning
 - Declining Health and Unexpected Emergencies
 - Clinical Recommendations for Cardiopulmonary Resuscitation
 - Best Interests Decisions
 - Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)
 - Organ Donation
 - Body Donation to Medical Science
 - Financial Component of Advance Care Planning
 - Making a Will

Consideration of available data

The Advance Care Planning Programme Team has collated and considered available information to assess any potential impact of this policy on Section 75 Groups. This includes publicly available data as well as data gathered and insights collected during engagements with people from a wide range of backgrounds including representation from public sector organisations, community and voluntary sector organisations, Health and Social Care professionals, carers, service users, interested members of the public, professional bodies and trade unions.

Engagement with Stakeholders

An early engagement process began in December 2020 and has been ongoing since then to inform the iterative development of the draft policy prior to public consultation. These engagements have been conducted based on principles of inclusiveness and accessibility. Every effort has been made to reach out to and engage with a wide range of people to support the active involvement of all stakeholders in shaping the policy development, including those from Section 75 groups.

At the outset of this process, a comprehensive stakeholder mapping exercise was conducted to identify and ensure representative participation across all Section 75 categories. The stakeholder map has been kept under constant review throughout the process to date and has developed accordingly.

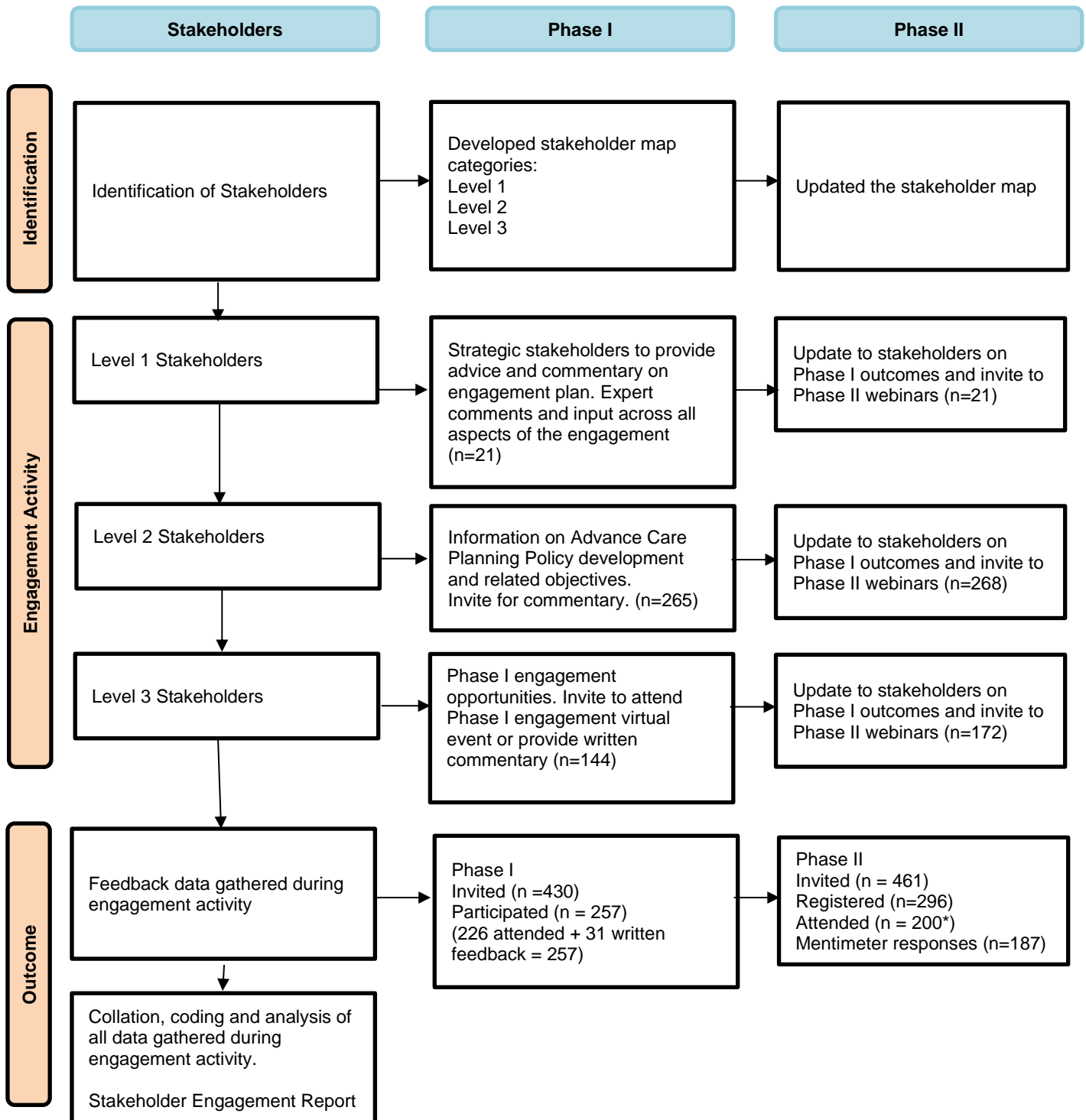
The table below shows a breakdown of organisations included in the stakeholder map across the Section 75 categories where the remit of the organisation aligns with a specific equality group or groups⁵.

Section 75 Specified Equality Group	Number of organisations included in stakeholder map
Gender	28
Religious Belief	46
Political Opinion	19
Racial Group	41
Age	56
Marital status	26
Sexual Orientation	20
Disability (those with a disability and those without)	77
Dependants (those with dependants and those without)	49
TOTAL	362

⁵ At the time of writing, a further 99 organisations are included in the stakeholder map who do not have a specific or obvious alignment to any particular Section 75 equality group.

To date, there have been two phases of early engagements with stakeholders. The flow chart below outlines the Stakeholder Engagement activity.

Stakeholder Engagement Process PRISMA Flowchart



* This number is an estimate based upon attendance figures for those who registered but allowing for shared and late logins, not recorded by the system.

Phase I Engagement (December 2020 – February 2021)

During Phase I, the Advance Care Planning Programme team held 40 engagement sessions involving 226 people including representatives from a wide range of sectors and organisations as well as interested individuals. In addition, 31 written responses were received, bringing the number of participants for phase I, to a total of 257.

Participants in these sessions were invited to make comment on an initial draft of the policy document guided by five questions:

1. What is your overall impression/comment of the draft?
2. What are you pleased to see in the document and what do you feel is missing?
3. What are your best hopes for Advance Care Planning and/or this policy?
4. What are your fears/concerns about Advance Care Planning and/ or this Advance Care Planning Policy?
5. Any other comments?

Due to COVID -19 restrictions, the sessions were virtual using the Zoom platform, with a small number of participants invited to each session. Before each session, the participants were provided with a briefing pack which included: an agenda, the current draft of the Advance Care Planning policy at that time, and the five questions which would be used during the facilitated discussion.

Each session was scheduled to run for 90 minutes. Accessibility arrangements were put in place as required, including for example, a longer session where this was appropriate and BSL/ISL interpretation where necessary. All sessions were recorded with consent from participants, with comments and feedback noted, to be subsequently themed for analysis. The gender breakdown of participants in Phase I was approximately 25% male and 75% female.

Revisions to Draft Policy Following Phase I Engagement

Following the Phase I engagements, all feedback was analysed and considered to inform a second, revised draft of the policy document. Based upon the feedback received, the initial draft Advance Care Planning policy document was revised across a number of areas prior to further engagement in Phase II. See Table I below for details.

During Phase I, a number of stakeholders had suggested the addition of “Values” within the existing “Principles” section. This section outlines the ethical standards and ideals which underpin the policy including: considerations for Human Rights, equality, person centred individual choice, dignity, consent, confidentiality, accessibility, sensitivity and compassion.

In addition, following feedback from Phase I engagements and the subsequent completion of a feasibility study, it was agreed that the draft policy will include the use of the ReSPECT⁶

⁶ <https://www.resus.org.uk/respect>

form (*Recommended Summary Plan for Emergency Care and Treatment*) to record personalised recommendations for a person’s future care and treatment - The ReSPECT form will guide and inform those providing care, support or treatment at a time when a person is unable to make decisions or communicate what their wishes, feelings beliefs and values are.

The ReSPECT form will be the regional form for recording all recommendations about emergency care and treatment, including cardiopulmonary resuscitation, and do not attempt cardiopulmonary resuscitation (DNACPR) forms will no longer be used. The ReSPECT form will be held by the person themselves.

Table I: Phase I Early Stakeholder Engagement Outcomes

Phase I - what the stakeholders said:	Actions taken in re-drafting the policy prior to Phase II:
Clarify the purpose of the policy	Purpose of the policy strengthened in the introduction.
Increase accessibility and inclusiveness	Accessibility and Inclusiveness added as two separate values and will be reflected in all aspects of this work.
Revise the language to make more inclusive	Revision of the language used in the initial draft policy document from “irrespective of” to “inclusive of” in relation to Section 75 categories.
Need to support “normalising” Advance Care Planning	Normalising Advance Care Planning added as an “ambition.”
Need to include a section on behaviour change	Added a section on “behaviour change.”
Include a “Values” section	Added “Values” to the “Principles” section of the policy document.
Emphasise the Human Rights and Ethics aspect of Advance Care Planning	Specified the Human Rights and ethical based approach of Advance Care Planning.
Broaden scope beyond health related aspects of Advance Care Planning	Included additional elements beyond health related aspects e.g. making a Will, funeral wishes, online accounts, donation of body to medical science etc.
More detail regarding mental capacity and Power of Attorney	Added greater detail regarding mental capacity and how it links to Advance Care Planning.
More clarity on decisions regarding resuscitation	Added section on declining health and unexpected emergencies including ReSPECT. ⁵
Provide more detail on how policy will be implemented	Feedback recorded for use in developing the operational documents.
Use diagrams to illustrate	Advance Care Planning components model diagram developed and tables used to present information where appropriate.

⁶ <https://www.resus.org.uk/respect>

Phase II Engagement (June – July 2021)

The revised draft of the policy document was subjected to further scrutiny by stakeholders in Phase II of stakeholder engagements. In this phase, a series of five engagement events were held online via Zoom webinar. Invitations to these events were circulated to all those listed on the stakeholder map, inviting them to register. Those who registered received a copy of the revised draft Advance Care Planning policy, including an accessible format version for consideration in advance of the event. The letter of invitation also included the themes that would be explored during the webinar session and instructions on how to participate.

A total of 461 invitation letters were sent based on the 'live' stakeholder map. Three of the events were held in partnership with other organisations namely: the Northern Ireland Council for Voluntary Action (NICVA), the Healthy Living Centre Alliance (HLC Alliance) and the Northern Ireland Health Care Leaders Forum. These organisations, together with the Community Development and Health Network (CDHN) provided additional promotion to wider audiences, for all five events. The Department of Health website also hosted information on how to register for the events.

The webinar events followed a structured format with a series of short presentations on aspects of the revised draft Advance Care Planning policy interspersed with questions. Beginning with an overview of the process to date, the presentations went on to outline specific areas where the original draft policy had been revised based on feedback from the Phase I Stakeholder engagements. Each presentation was followed by a series of questions and attendees were invited to respond via Mentimeter. There were a total of 21 questions asked during each 90 minute session. To ensure accessibility, a copy of the questions was also available as a word document for anyone wishing to respond this way.

A total of 296 registered to attend across the five dates. The actual number of individuals who attended the events was approximately 200⁷ and 187 individuals responded to the questions using Mentimeter. A further two responses were received in document format and one response was through the Q&A functionality on zoom. These were added to the dataset and included in the analysis.

The gender breakdown of participants in Phase II was approximately 25% male and 75% female.⁸

Following the Phase II engagements, all feedback was analysed and considered. Based upon the feedback received, the draft Advance Care Planning policy was then revised further across a number of areas prior to public consultation. See Table II below for details.

⁷ This number is an estimate based upon attendance figures for those who registered but allowing for shared and late logins, not recorded by the system.

⁸ Based upon Christian names of those registered who attended the webinar

Table II**Phase II Early Stakeholder Engagement Outcomes**

Phase II - what the stakeholders said:	Actions taken in re-drafting the policy prior to Public Consultation:
Be clearer on who the policy is for	Greater clarity provided within the policy introduction
Clarify terminology used	Ensured consistency in language use and added a glossary to explain terminology
Include the role of spirituality	New section on spirituality included
Acknowledge cultural influences	Referenced cultural influences in 'Values' section
Expand 'What matters to me' e.g. Dependents, pets	New section 'Care and support for dependents'
Clarify purpose of Advance Care Planning	Greater clarity provided, including section 'How Advance Care Planning Conversations Are Used'
Illustration with case studies	Case studies will be developed for both operational guidance and public messaging
Separate and clarify Values and Principles section	Reviewed section and further clarified Values and updated Principles to 'Principles of Practice'
Further clarity on legal elements	Provided more clarity regarding legal elements such as mental capacity
More detail on Best Interests decisions	Further developed and expanded Best Interests section
Include further information on behavioural change	Revised behavioural change section including behavioural change diagram
Add detail to components diagram to illustrate interconnectedness	Amended components diagram to better illustrate interconnections between all four elements
Financial matters	To be considered as part of implementation

A full report on the Early Stakeholder Engagement activity was published in October 2021.⁹

Personal & Public Involvement

In July 2021, in partnership with the Patient and Client Council, a pool of 74 volunteer partners, comprising service users, carers and interested members of the public was recruited. This group will be drawn upon to support co-production/co-design at various stages of the Advance Care Planning Programme of work.

Upon registering an interest, volunteer partners were invited to participate in an induction session and asked to complete a questionnaire for the purposes of assessing representation across Section 75 categories.

⁹ [doh-advance-care-plan-policy-adults-report_0.pdf \(health-ni.gov.uk\)](#)

There were 41 responses to this questionnaire with results as outlined in the table below:

Composition of Volunteer Partners Group

- **Gender:** 9 male, 32 female.
- **Age:** 20 – 29 (1 member), 30 – 39 (2 members), 40 – 49 (5 members), 50+ (32 members), Prefer not to say (1 member).
- **Marital Status:** Married (25 members), Living with partner (1 member), Single (8 members), Separated/Divorced (2 members), Widowed (4 members), Prefer not to say (1 member).
- **Dependents:** those with (17 members), those without (23 members), Prefer not to say (1 member).
- **Disability:** those with (7 members), those without (30 members), Prefer not to say (3 members).
- **Sexuality:** Heterosexual (39 members), Lesbian/Gay (1 member), Bisexual (1 member).
- **Religion:** Protestant (19 members), Catholic (15 members), Other (3 members), Prefer not to say (4 members).
- **Racial Group:** White (40 members), Black and Minority Ethnic groups (1 member).

Qualitative Insights from Engagements

Additional qualitative insights reflecting the specific needs of a number of Section 75 groups have come to light throughout the early stakeholder engagements. These have helped to inform appropriate approaches to the engagement activities as well as contributing to the policy development and implementation. Some examples of these insights are noted below.

“I find that language is challenging not just here, more widely ...we talk about irrespective of gender etc instead of saying inclusive of all those identities ... we almost say we don’t care about those things...we should be saying this is an important part and acknowledging that. There is a mindset that surrounds this... people say I don’t see colour, I don’t care about those things but we should care about them ..acknowledge it’s someone’s lived experience.”

“Making an Advance Care Plan relies on being able to write or speak... how do we make it accessible to people with other communication needs, i.e. those with dementia or learning disability...”

“Communications support is really important .. deaf individuals have different needs ..”

“I like the front loaded engagements with community and voluntary sector, it’s the right type of partnership approach.”

“What stood out for me were the principles....good to see the principles up front ... usually you see the underpinning values at the end of a document .. these are

important when thinking about Advance Care Planning .. I think these could maybe be extended a bit more to include dignity of people in Advance Care Planning some of the more values based language could be beneficial for people looking at this policy and professionals engaging with people making their Advance Care Plan.”

Actions Taken to Support Accessibility

- The completion of Communication Access UK training & accreditation by all Advance Care Planning Programme Team members.
- Inclusiveness & Accessibility Advice & Support provided by RNIB.
- Additional support provided to meet needs identified by the deaf community.
- The need for all information to be provided in accessible formats is recognised. In addition, the need for multilingual and health literacy support has been identified.

Research

The development of the policy has been informed by a commissioned research report from Ulster University “Where are we now?”¹⁰ A total of 28.5 per cent of respondents had heard of the term ‘Advance Care Planning’ but only 7 per cent had ever engaged in a conversation about it. Despite this, four fifths of respondents (82.2 per cent) felt that it would be comforting to know that they had left guidance about their wishes for their family.

The research was based on a representative sample of adults from the NI population aged 18 years and over.

Other Data

In addition to the research outlined above, the following sources of quantitative evidence/information have been considered;

- Information from the 2011 Census in Northern Ireland, published by the Northern Ireland Statistics and Research Agency (NISRA);
- Statistics for sexual identity in the UK by sex, region and age group, sourced from the Annual Population Survey published by the Office for National Statistics;
- Information from the 2019 HSC Staff Survey conducted by NISRA;
- The 2020 NI Health & Social Care Workforce Census published by the Department of Health, Information Analysis Directorate.
- The NISRA 2020 Mid-Year Population estimates

¹⁰ Northern Ireland Life and Times Survey (NILT) is a constituent part of ARK (Access, Knowledge, Research) which aims to support policy development and debate in Northern Ireland through providing information and critical analysis. The report can be accessed online; www.ulster.ac.uk/_data/assets/pdf_file/0012/819678/Where-are-we-now-Examining-public-knowledge-and-attitudes-towards-palliative-care-and-advance-care-planning-in-NI.pdf

Assessment of Impact

Religious Belief

Available Evidence - Religious Belief

It is not possible to get a specific breakdown of the religious belief held by service users, or for all health and social care staff. However, we do know the breakdown across the adult population as per the 2011 Census¹¹.

The population of Northern Ireland at the time of the 2011 census was 1,810,863, with religious belief broken down as follows:

- Catholic – 40.8 per cent
- Protestant – 41.6 per cent
- Other – 0.8 per cent
- No religion or Religion not stated – 16.9 per cent

In 2019, NISRA conducted the HSC Staff Survey¹², which collected some demographic data from respondents. It is important to note that, of the 77,781 staff employed at the time of the survey, only 19,094 completed a response.

Of those who responded, community background religion was broken down as follows:

- Protestant Community – 42 per cent
- Roman Catholic Community – 45 per cent
- Neither Protestant nor Roman Catholic community – 13 per cent

In addition, religious belief was broken down as follows:

- Christian – 77 per cent
- None – 18 per cent
- Other religion – 5 per cent

Assessment of Impact - Religious Belief

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is not expected to have any differential impact based on religious belief.

The data pertaining to religious belief in Northern Ireland as outlined above indicates the predominance of Christian faiths. It is anticipated that this policy may have a positive impact on good relations between persons of different religious beliefs. Advance Care Planning will

¹¹ <https://www.nisra.gov.uk/statistics/census/2011-census>

¹² [HSC Staff Survey 2019 Regional Benchmark Report](#)

enable wishes feelings, beliefs and values to be discussed, documented and shared to inform future planning, including care, support or treatment.

Promoting Equality of Opportunity – Religious Belief

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of all religious beliefs in terms of implementing this Advance Care Planning policy. Proactive measures will include the promotion of the policy to church/belief groups through relatable messaging as part of the public messaging and promotion of the policy.

An Advance Care Planning Capabilities Framework has been developed to support training and education for those who provide care, support and treatment. This aims to enable those supporting Advance Care Planning, to practice in a person centred manner which upholds the person's right to make choices and decisions even where they differ from those of the person providing care and support.

Political Opinion

Available Evidence – Political opinion

There is limited data available on political opinion. However, data on the first preference votes per party in NI Assembly Elections 2017¹³ shown below can be used as proxy information:

- DUP: 225,413 (28.1 per cent)
- Sinn Féin: 224,245 (27.9 per cent)
- UUP: 103,314 (12.9 per cent)
- SDLP: 95,958 (11.9 per cent)
- Alliance Party: 72,717 (9.1 per cent)
- TUV: 20,523 (2.6 per cent)
- Green: 18,527 (2.3 per cent)
- Independents: 14,407 (1.8 per cent)
- People Before Profit Alliance: 14,100 (1.8 per cent)
- PUP: 5,590 (0.7 per cent)
- Conservative: 2,399 (0.3 per cent)
- Others: 6,122 (0.8 per cent)

¹³ Table 5.1 in [Election Report: Northern Ireland Assembly Election, 2 March 2017 NIAR 20-17](#)

NI Assembly members have demonstrated cross party support for the development of the Advance Care Planning Policy. This is evidenced in the Committee for Health Inquiry Report on the impact of COVID-19 in Care Homes (NIA 59/17 -22) Published 1st February 2021 and in Plenary debate on the 27th April 2021 (Hansard Vol 138, No 6).

Assessment of Impact – Political opinion

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is not expected to have any differential impact based on political opinion.

Promoting Equality of Opportunity – Political opinion

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of all political beliefs in terms of implementing this Advance Care Planning policy. Proactive measures will include the promotion of the policy across all communities through relatable messaging as part of the public messaging and promotion of the policy.

An Advance Care Planning Capabilities Framework will be developed to support training and education for those who provide care, support and treatment. This aims to enable those who are supporting people in their Advance Care Planning to practice in a person centred manner which upholds the person's right to make choices and decisions even where they differ from those of the person providing care and support.

Racial Group

Available Evidence – Racial group

The population of Northern Ireland at the time of the 2011 census was 1,810,863, and 1.8 per cent (32,596) of the usual resident population belonged to minority ethnic groups. The overall population breakdown was as follows:

- White – 98.21 per cent (1,778,449)
- Chinese – 0.35 per cent (6,338)
- Irish Traveller – 0.07 per cent (1,268)
- Indian – 0.34 per cent (6,157)
- Pakistani – 0.06 per cent (1,087)
- Bangladeshi – 0.03 per cent (543)
- Other Asian – 0.28 per cent (5,070)
- Black Caribbean – 0.02 per cent (362)
- Black African – 0.13 per cent (2354)
- Black Other – 0.05 per cent (905)

- Mixed – 0.33 per cent (5976)
- Other – 0.13 per cent (2354)

Of the population (aged 3 and over) 3.14 per cent considered a language other than English as their main language. It should also be noted that of the 98 per cent of people usually resident in Northern Ireland on Census Day 2011 who identified their ethnicity as White, almost 10 per cent (179,000) were born outside of Northern Ireland. This includes; 19,300 individuals from Poland, 7,250 from Lithuania, 4,000 from America, 3,800 from Germany and 1,650 from South Africa.

The largest minority ethnic sub-groups in 2011 were Chinese (6,300 people; up from 4,100 in 2001), Indian (6,200; up from 1,600), and Other Asian (5,000; up from 200), each accounting for around 0.3 per cent of the usually resident population (Table DC2248NI). Including the 1,300 Irish Travellers, 1.8 per cent (32,400) of usual residents belonged to Minority Ethnic groups in 2011, more than double the proportion in 2001 (0.8 per cent).

It can be expected that the number of people born outside of the Northern Ireland has increased significantly since the 2011 census.

The 2011 Census results indicate a difference in the age profile of the Irish Traveller community in relation to the white population. While 78 per cent of Travellers are aged under 45, (compared to 61 per cent of White ethnicity), only 6.4 per cent (83 persons) are aged 65 or over, compared with 15 per cent of those who are of White ethnicity.

The small number and proportion of older Travellers is a reflection of their much lower life expectancy. The All Ireland Traveller Health Study (2010)¹⁴ found that male Travellers in Ireland (including Northern Ireland) had a life expectancy at birth of 61.7 years, equivalent to that of the general population in the 1940s. For female Travellers, life expectancy was 70.1 years, similar to that of the general population in the 1960s¹⁵.

Assessment of Impact – Racial Group

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is not expected to have any differential impact based on racial group.

¹⁴ DHSSPS (2010) All Ireland Traveller Health Study. University College Dublin. Available at: <http://www.dhsspsni.gov.uk/aiths.pdf>

¹⁵ It is also worth noting that while Census 2011 enumerated a total of 1,301 Travellers in Northern Ireland, the All Ireland Traveller Health Study (UCD / DHSSPS, 2010) found a total of 1,562 Traveller families living in Northern Ireland, with an estimated Traveller population of 3,905

Advance Care Planning could provide the opportunity for persons of different racial groups to have conversations with those who provide care, support or treatment which may include sharing information about their ethnic and cultural beliefs and traditions. This has the potential to promote greater understanding between persons of different racial groups as well as helping to ensure that different ethnic/cultural beliefs and traditions, when important to the person are reflected accordingly in the care, support or treatment that a person receives.

It may also be expected that the policy will impact positively on racial groups with lower life expectancy, as it will create opportunities for the expression of choice in care, support or treatment that may not have been available before the introduction of the Advance Care Planning policy.

Promoting Equality of Opportunity – Racial Group

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of all racial groups in terms of implementing this Advance Care Planning policy. The need for multilingual support has been identified. There are indications that some ethnic groups are less likely to access services. This is a factor that will be considered when implementing the policy to ensure that any existing barriers are mitigated to support equitable access. Proactive measures will include the promotion of the policy to all racial groups through relatable messaging as part of the public messaging and promotion of the policy.

An Advance Care Planning Capabilities Framework will be developed to support training and education for those who provide care, support and treatment. This aims to enable those who are supporting people in their Advance Care Planning to practice in a person centred manner which upholds the person's right to make choices and decisions even where they differ from those of the person providing care and support.

Age

Available Evidence - Age

Northern Ireland's average age increased from 34 years to 37 years between the 2001 and 2011 Censuses. Over the same period, the share of the population represented by children aged under 16 years fell from 24 per cent to 21 per cent, while the proportion of people aged 65 years and over rose from 13 per cent to 15 per cent.

Compared with the 2001 Census, the number of people aged 65 years and over living in NI increased by 18 per cent (40,400) to 263,700 on Census Day 2011.

Between 2002 and 2012, the number of people aged 60-84 rose by 20 per cent, while those aged 85+ rose by 38 per cent. This indicates an ageing population demographic.

The 2020 Mid Year Population estimates¹⁶ indicate the current population of Northern Ireland is estimated as 1,895,510 with 441,108 (23 per cent) of those aged under 18 and 1,454,402 (77 per cent) aged over 18.

Research conducted by iReach on behalf of the All Ireland Institute of Hospice and Palliative Care (AIHPC)¹⁷ indicated that 73 per cent of NI respondents agree (agree or strongly agree) that they would like to be supported to discuss and write down their wishes and preferences for care at the end of life. There was no marked variation across the age bands surveyed with results as follows;

- 73 per cent of those aged 18 -34 expressed this preference,
- 71 per cent of those aged 35 – 55 expressed this preference and
- 78 per cent of those aged 55+ expressed this preference

In February 2007, the Alzheimer's Society published a major study on the social and economic impact of dementia in the UK. The research¹⁸, commissioned through King's College London and the London School of Economics provides a detailed and robust picture of prevalence and economic impact of dementia in the UK. This report estimates that one in 14 people over 65 years of age and one in six people over 80 years of age have a form of dementia. A further report published by Alzheimer's Society: 'Dementia 2013: The hidden voice of loneliness'¹⁹ indicated that 18,862 people in NI had dementia.

Assessment of Impact - Age

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact for all adults aged 18 years and over

Traditionally, Advance Care Planning has been associated with end of life and palliative care or thought to be relevant only for older people. This policy aims to provide a framework for Advance Care Planning that extends to all adults aged 18 years and over. This approach is aimed at encouraging adults of all ages and stages of life to think about and plan for their future needs.

In Northern Ireland, persons under the age of 18 are in the minority, currently estimated to be less than a quarter of the population (23 per cent).

This policy does not include children and young people under the age of 18 directly. The rationale for the policy scope, for those aged 18 years and over, is based upon ethical

¹⁶ <https://www.nisra.gov.uk/publications/2020-mid-year-population-estimates-northern-ireland>.

¹⁷ <https://aiihpc.org/wp-content/uploads/2020/10/Palliative-Care-Study-NI-July-2020-V1.2.pdf>

¹⁸ LSE, King's College London, Alzheimer's Society. Dementia UK: The Full Report, 2007 [alzheimers_16425](#)

¹⁹ [Dementia 2013: The hidden voice of loneliness \(alzheimers.org.uk\)](#)

principles of proportionality and consideration of legal aspects where provision is different for those under the age of 18 to that of those over the age of 18.

This decision has been informed by legal and practical considerations as outlined below:

It is recognised that the needs of children and young people in the under 18 age group are significantly different and would require a specifically tailored approach. The Children (NI) Order 1995²⁰ recognises that children should be given a voice in what happens to them and opportunities for working in partnership with children should be given, as far as their age and development allows. The Children (NI) Order 1995 requires the child's²¹ welfare to be given paramount consideration.

Furthermore, existing legislation and practice frameworks that underpin this policy do not align with provision for under 18s. The Age of Majority (NI) Act 1969²² requires a person to have reached the age of 18 before they can make certain contractual decisions. Likewise, the law generally does not allow anyone under the age of 18 to make a statutory will.

The policy includes Advance Decisions to Refuse Treatment (ADRT). Where this is a person's choice, to be valid, the person must be 18 or over and have the capacity to make the decision.

The inclusion of those aged 16 – 17 for parts of the Mental Capacity Act (2016) legislation is acknowledged, however, the policy scope being for those aged 18 years and over is based upon ethical principles of proportionality.

There is a potential indirect positive impact for those aged under 18 in that the policy includes a provision for considering dependents in Advance Care Planning. It is anticipated that will offer potential benefits for children and young people as well as vulnerable adults, should a parent or carer with Advance Care Planning in place become ill or lose capacity.

All Section 75 categories of the adult population (aged over 18) are expected to benefit from this policy. A core aim of the policy is to extend the practice of Advance Care Planning beyond palliative and end of life care, to normalise Advance Care Planning Conversations and, ideally, to help ensure that such conversations happen before any crisis such as the diagnosis of a serious illness.

Mitigations/Alternative Policies - Age

As outlined above, the rationale for the policy scope for those aged 18 years and over, is based upon ethical principles of proportionality and consideration of legal aspects where provision is different for those under the age of 18 to that for those aged 18 and over.

²⁰ [The Children \(Northern Ireland\) Order 1995 \(legislation.gov.uk\)](#)

²¹ *a person under the age of 18 is defined a "child" under the Children (NI) Order 1995 and under international law.*

²² [Age of Majority Act \(Northern Ireland\) 1969 \(legislation.gov.uk\)](#)

Alternative provisions for children and young people with palliative care needs are outlined in the Strategy “Providing High Quality Palliative Care for Our Children”²³

which states;

“Care and support will be planned, taking account of the wishes and needs of the child and their family, and will focus on the best interests of the child and their quality of life.”

Promoting Equality of Opportunity - Age

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of all age groups in terms of implementing this Advance Care Planning policy. Proactive measures will include the promotion of the policy to different age groups through relatable messaging as part of the public messaging and promotion of the policy.

Marital status

Available Evidence – Marital Status

The 2011 Census data provides information on marital status. It showed that almost half (48 per cent) of people aged 16 years and over were married, and over a third (36 per cent) were single. Just over 1,200 people (0.1 per cent) were in registered same-sex civil partnerships in March 2011. A further 9.4 per cent of usual residents were either separated, divorced or formerly in a same sex civil partnership, while the remaining 6.8 per cent were either widowed or a surviving partner.

Assessment of Impact – Marital Status

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is not expected to have any differential impact based on marital status.

Promoting Equality of Opportunity – Marital Status

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of different marital status in terms of implementing this Advance Care Planning policy. Proactive measures will include the promotion of the policy to persons of different marital status through relatable messaging as part of the public messaging/promotion of the policy.

Should evidence of any potential impacts become apparent, these will be explored to identify appropriate mitigations.

²³ Department of Health, Providing High Quality Palliative Care for Our Children: A Strategy for Children’s Palliative and End of Life Care 2016 – 26

Sexual Orientation

Available Evidence – Sexual Orientation

It is acknowledged that accurate figures are not available for sexual orientation of the general population, and many estimates vary. NISRA, alongside other UK census offices, have proposals in place to address this in the 2021 census.

The 2012 Life and Times Survey²⁴ interviewed 1204 adults to establish their sexual orientation.

- 98 per cent of respondents identified themselves as Heterosexual/Straight,
- 1 per cent as Gay/Lesbian, and
- 1 per cent provided No answer/Refusal.

Figures published by the Office of National Statistics in 2010 recorded that 0.9 per cent of the UK population identified themselves as gay or lesbian, while a further 0.5 per cent identified themselves as bisexual (Measuring Sexual Identity: An Evaluation Report²⁵). It is likely that the true figures are significantly higher.

Phase I and II stakeholder engagement has included feedback from groups representing persons who identify as LGBTQ+. Specific points relating to the experiences of LGBTQ+ persons have helped to inform revisions of the draft policy. These include: recognition that the traditional family structure does not always apply; concerns that LGBTQ+ relationships are not always acknowledged in care settings and suggestions that language should reflect inclusivity.

“looked at it with LGBT lens ... and in terms of barriers for LGBT people.. issues around family members and decision making and their visibility, their capacity to come out within care environments and the safety and barriers around that”

“for me thinking about the LGBT+ person, often the barrier is that people don’t ask about sexual orientation or gender identity... people are not asked ... the responsibility is on the client to out themselves to be fully recognised as who they are as their whole selves.”

Assessment of Impact – Sexual Orientation

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care

²⁴ [Northern Ireland Life and Times Survey 2012 \(ark.ac.uk\)](http://ark.ac.uk)

²⁵ <https://data.gov.uk/dataset/e6033627-3106-47a9-a3fb-4bcaa34c1bcb/measuring-sexual-identity-evaluation-report>

Planning is likely to have an overall positive impact and is expected that this policy may have a positive impact for persons of different sexual orientation.

Advance Care Planning will enable wishes feelings, beliefs and values to be discussed, documented and shared to inform future planning, care, support or treatment. This may, if the person wishes, include matters relating to their sexual orientation and relationships. Therefore, Advance Care Planning could provide the opportunity for persons of different sexual orientations to have conversations with those who provide care, support or treatment. This may include sharing information about their sexual orientation. This has the potential to promote greater understanding between persons of different sexual orientations as well as helping to ensure that what matters to the person is reflected accordingly in the care, support or treatment they receive.

It may also be expected that the policy will impact positively on persons who identify as LGBTQ+ who may have non-traditional family structures, as it will create greater opportunity for the expression of choice in their care, support or treatment. The policy purposely uses the phrase “those important to the person” to be inclusive and reflect non-traditional family structures.

Promoting Equality of Opportunity – Sexual Orientation

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of all sexual orientations in terms of implementing this Advance Care Planning policy. Proactive measures will include the promotion of the policy to persons of different sexual orientation through relatable messaging as part of the public messaging and promotion of the policy.

An Advance Care Planning Capabilities Framework will be developed to support training and education. This aims to enable those who are supporting people in their Advance Care Planning to practice in a person centred manner which upholds the person’s right to make choices and decisions even where they differ from those of the person providing care and support.

Gender

Available Evidence - Gender

The 2011 Census data showed that 49 per cent of all usual residents in Northern Ireland are male, with 51 per cent of the population female. In addition, a small number identify as neither male or female or both.

Assessment of Impact - Gender

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and

control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is not expected to have any differential impact based on gender.

It is anticipated that this policy may have a positive impact for persons of different gender identities. Advance Care Planning will enable wishes feelings, beliefs and values to be discussed, documented and shared to inform future planning, care, support or treatment. This may, if the person wishes, include matters relating to their gender identity.

Advance Care Planning could provide the opportunity for persons of different gender identities to have conversations with those who provide care, support or treatment. This has the potential to promote greater understanding between persons of different gender identity

Promoting Equality of Opportunity - Gender

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward persons of all gender identities in terms of implementing this Advance Care Planning policy. Proactive measures will include the promotion of the policy to persons of different genders through relatable messaging as part of the public messaging and promotion of the policy.

An Advance Care Planning Capabilities Framework will be developed to support training and education. This aims to enable those who are supporting people in their Advance Care Planning to practice in a person centred manner which upholds the person's right to make choices and decisions even where they differ from those of the person providing care and support.

Disability

Available Evidence - Disability

In 2011, Census data showed that just over one in five of the usually resident population (21 per cent) had a long-term health problem or disability which limited their day-to-day activities. The most common long-term conditions among the usually resident population were:

- a mobility or dexterity problem (11 per cent);
- long-term pain or discomfort (10 per cent);
- shortness of breath or difficulty breathing (8.7 per cent);
- chronic illness (6.5 per cent); and
- an emotional, psychological or mental health condition (5.8 per cent).

Early stakeholder engagement included consultation with the Chief Equality Commissioner and staff from the Equality Commission for Northern Ireland. The importance of the United Nations Convention on the Rights of Persons with Disabilities UNCRPD was noted with specific reference made to Article 12 (Equal recognition before the law) and Article 25

(Health), as well as General Comment No.1 of the UN Committee on the Rights of Persons with Disabilities which elaborates on the requirements of Article 12²⁶.

It is recognised that people with a disability are not a homogenous group. Specific points relating to differing needs of persons with different disabilities were noted during stakeholder engagements.

One example is how different communication support is required for those in the deaf community

“Often the first assumption is that the person will be a sign language user and require an interpreter, however this is not the case for the majority of deaf people who lip read. It is important to recognise both communication preferences.”

“what is most Important is information needs to be in BSL and ISL format ... to make it accessible on a website in both formats ... Advocacy support will be important too... use scenarios ... to explain”

Also during the stakeholder engagements, differences in the levels of awareness of the concept of Advance Care Planning between different disability groups has come to light;

Those with learning disability and those important to the person with a learning disability had experience of planning future care “Person centred planning is not new to the Learning Disability world .. this is what we do everyday”

This was in contrast to some members of the deaf community who commented that;

“Meaningful person centred planning for all. – is a new concept for the Deaf community”

Assessment of Impact - Disability

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is expected that the Advance Care Planning policy may have a positive impact for persons with a disability.

Advance Care Planning will enable wishes, feelings, beliefs and values to be discussed, documented and shared to inform future planning, care, support or treatment. This may, if the person wishes, include matters relating to their disability. Therefore, Advance Care

²⁶ <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

Planning could provide the opportunity for persons with a disability to share information with those who provide care, support or treatment.

This has the potential to promote greater understanding of the needs of persons with a disability as well as helping to ensure they have greater opportunity for choice and control in their care, support or treatment. It may be expected that the policy will help ensure the persons beliefs and values are respected and this is reflected accordingly in the care, support or treatment they receive.

It may also be expected that the policy will impact positively on persons with a disability with lower life expectancy, as it will create greater opportunity for the expression of choice in care and treatment.

Promoting Equality of Opportunity - Disability

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward the specific needs of persons with a disability in terms of implementing this Advance Care Planning policy. (eg: communications needs, reasonable adjustments). Where the specific needs of persons with different disabilities arise, these will be explored to identify appropriate mitigations, as was the case during the stakeholder engagements.

Proactive measures will include the promotion of the policy to persons with disabilities through relatable messaging as part of the public messaging/promotion of the policy. There will be ongoing work with people with disabilities to ensure that the policy is presented in accessible formats and meets the multiplicity of needs in implementation.

An Advance Care Planning Capabilities Framework will be developed to support training and education. This aims to enable those who are supporting people in their Advance Care Planning to practice in a person centred manner which upholds the person's right to make choices and decisions even where they differ from those of the person providing care and support.

Dependents

Available Evidence - Dependents

In 2011, one-third (34 per cent) of households in Northern Ireland contained dependent children, down from 36 per cent in 2001. Two-fifths (40 per cent) of households contained at least one person with a long-term health problem or disability; made up of those households with dependent children (9.2 per cent) and those with no dependent children (31 per cent). In March 2011, 5.8 per cent of households contained dependent children and no adults in employment.

In the 2011 census, 214,000 people in Northern Ireland were providing some form of unpaid care, equating to approximately one in eight residents in Northern Ireland (12 per cent). This compares with 185,066 in 2001, an increase of 16 per cent.

Figures show that: over half of unpaid carers (122,000, 57 per cent) were providing care for between 1–19 hours per week, while 35,000 (17 per cent) were engaged for 20–49 hours per week. Just over a quarter (56,000, 26 per cent) had caring responsibilities for 50 or more hours per week.

Using the 2017 mid-year population estimates, which show a three per cent increase in population since 2011, there are likely to be around 220,000 people in Northern Ireland with some form of caring role ²⁷.

A recent report published by Carers UK on October 2020²⁸ cited that there were 212,000 unpaid carers in Northern Ireland and has estimated that the COVID-19 pandemic has resulted in an additional 98,000 people new to caring in Northern Ireland. Based upon population projections, Carers UK suggest there are currently as many as 310,000 unpaid carers in Northern Ireland²⁹.

The inclusion of provision for dependents in Advance Care Planning was raised in a number of Stakeholder Engagements. This was a particular concern for the parents of vulnerable adults who cited that the care of their children was their main reason for engaging in Advance Care Planning.

“There are two different pieces of work .. for each one of us our own Advance Care Planning conversationand then, what about this other adult whom I have responsibility for whom I love and whom I want the right things for?”

This issue was acknowledged and the revised policy draft outlines a components model for Advance Care Planning that includes an element within the ‘Personal’ component for considering dependents in a person’s Advance Care Planning.

Assessment of Impact - Dependents

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact.

The policy may potentially impact positively on those with dependents as it will enable Advance Care Planning Conversations to include the person’s wishes, feelings, beliefs and

²⁷ [Carers in Northern Ireland: Some key statistics - Research Matters \(assemblyresearchmatters.org\)](https://assemblyresearchmatters.org)

²⁸ Caring behind closed doors: six months on The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers, Carers UK October 2020 [Caring_behind_closed_doors_Oct20.pdf \(carersuk.org\)](https://carersuk.org)

²⁹ Carers Week (2020) Carers Week Research Report [CW_2020_Research_Report_WEB.pdf \(carersuk.org\)](https://carersuk.org)

values in relation to their dependents. It is not anticipated that this will be a disadvantage to those without dependents.

Promoting Equality of Opportunity - Dependents

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward the specific needs of persons with caring responsibilities in terms of implementing the Advance Care Planning policy. (eg; reasonable adjustments). Proactive measures will include the promotion of the policy to persons with caring responsibilities through relatable messaging as part of the public messaging and promotion of the policy. Training and Education measures for staff introduced as a result of policy implementation will accommodate the needs of those with caring responsibilities.

Multiple Identities

Available Evidence – Multiple Identities

It is difficult to determine the full extent of impacts for persons of multiple identities until implementation planning of the policy with detailed actions.

Assessment of Impact – Multiple Identities

Advance Care Planning ensures people have the opportunity to have realistic and practical conversations about what matters to them, and to consider and record their wishes, feelings, beliefs and values, if they choose to do so. It supports a person to have greater choice and control over decisions, including plans for their future care and treatment. Advance Care Planning is likely to have an overall positive impact and is not expected to have any differential impact based on the grounds of multiple identity. Given the person-centred nature of the approach to Advance Care Planning the policy will support, it is expected that there will be significant positive impacts for persons in this category.

Promoting Equality of Opportunity – Multiple Identities

In the interests of promoting equality of opportunity, due regard will be given to ensure sensitivity and respect toward the specific needs of persons of Multiple identity in terms of implementing this Advance Care Planning policy. Should evidence of any potential impacts become apparent, these will be explored to identify appropriate mitigations.

Human rights

ARTICLE (ECHR/ HRA 1998)	POSITIVE IMPACT	NEGATIVE IMPACT = human right interfered with or restricted	NEUTRAL IMPACT
Article 2 – Right to life	<input checked="" type="checkbox"/>		
Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment	<input checked="" type="checkbox"/>		
Article 4 – Right to freedom from slavery, servitude & forced or compulsory labour			<input checked="" type="checkbox"/>
Article 5 – Right to liberty & security of person			<input checked="" type="checkbox"/>
Article 6 – Right to a fair & public trial within a reasonable time			<input checked="" type="checkbox"/>
Article 7 – Right to freedom from retrospective criminal law & no punishment without law.			<input checked="" type="checkbox"/>
Article 8 – Right to respect for private & family life, home and correspondence.	<input checked="" type="checkbox"/>		
Article 9 – Right to freedom of thought, conscience & religion	<input checked="" type="checkbox"/>		
Article 10 – Right to freedom of expression	<input checked="" type="checkbox"/>		
Article 11 – Right to freedom of assembly & association			<input checked="" type="checkbox"/>
Article 12 – Right to marry & start a family			<input checked="" type="checkbox"/>
Article 14 – Prohibition of discrimination in the enjoyment of the convention rights	<input checked="" type="checkbox"/>		
1st protocol Article 1 – Right to a peaceful enjoyment of possessions & protection of property	<input checked="" type="checkbox"/>		
1st protocol Article 2 – Right of access to education			<input checked="" type="checkbox"/>
ARTICLE - UNCRPD	POSITIVE IMPACT	NEGATIVE IMPACT = human right interfered with or restricted	NEUTRAL IMPACT
Article 12 (Equal recognition before the law)	<input checked="" type="checkbox"/>		
Article 25 (Health) of the United Nations Convention on the Rights of Persons with Disabilities	<input checked="" type="checkbox"/>		

Good Relations

'Good Relations' is defined by the Equality Commission as; "The growth of relationships and structures for Northern Ireland that acknowledge the religious, political and racial context of this society, and that seek to promote respect, equity and trust, and embrace diversity in all its forms."³⁰

The Advance Care Planning policy may have an indirect positive impact on good relations between persons with differing religious beliefs, persons with differing political opinions or between persons from different racial groups. Advance Care Planning will enable wishes, feelings, beliefs and values to be discussed, documented and shared. This may provide the opportunity for persons of different opinions, beliefs and cultural backgrounds to have conversations. This has the potential to promote greater understanding.

The policy is supported by a Capabilities Framework for those providing care, support or treatment. Training will enable those who are supporting a person's Advance Care Planning to practice in a person centred manner which upholds the person's right to make choices and decisions even where they differ from those of the person providing care and support.

Conclusion

This EQIA has used available evidence to consider all 9 Equality groupings. It is evident that, overall, the Advance Care Planning policy is expected to have a positive impact for all adults aged 18 and over. Alternative provisions for children and young people with palliative care needs are outlined in the Strategy "Providing High Quality Palliative Care for Our Children"³¹

³⁰ www.equalityni.org/ECNI/media/ECNI/Publications/Employers%20and%20Service%20Providers/Public%20Authorities/Good_Relations_Public-Authorities-Summary_Guide.pdf

³¹ Department of Health, Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End of Life Care 2016 – 26

Monitoring and review arrangements

Proposed monitoring

A new outcomes framework will be developed to measure outcomes of the policy. Any potential impacts of the policy, projects or service developments undertaken to meet the implementation of the policy will be dealt with, as appropriate, at the individual policy, project or service development level.

Co-design/Co-production

The pool of volunteer partners recruited in partnership with the Patient and Client Council will be drawn upon to support co-production/co-design activities at various stages of the Advance Care Planning Programme of work. As the policy development and implementation progresses, these volunteer partners will be offered the opportunity to contribute in the following areas:

- Shaping how Advance Care Planning will be put into practice, to ensure everyone has the opportunity to have Advance Care Planning conversations.
- Shaping the training and education for individuals and professional groups who provide care and support.
- Helping to develop messages for the public - to ensure that everyone knows what Advance Care Planning is and understands why it is an important thing that all adults, at any stage of life should consider.
- Reviewing the Advance Care Planning Programme of work and the difference it has made to people by developing and agreeing ways of measuring the outcomes and impact of the policy and its implementation.

The initial focus will be to develop public messages about the Advance Care Planning policy to support the launch of the public consultation.

Advance Care Planning Capabilities Framework

An Advance Care Planning Capabilities Framework will be developed in partnership with Educators to support training and education for those who provide care, support or treatment. The agreed Capabilities Framework will underpin the programme of training and education to be developed to support the implementation of the Advance Care Planning policy.