



# Report on Early Stakeholder Engagement

## December 2020 – July 2021



## Advance Care Planning Programme Team

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# Introduction

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In September 2020, the Minister for Health approved the development of a health-related Advance Care Planning Policy for adults in Northern Ireland<sup>1</sup>. An Advance Care Planning Programme Team was established to develop the policy. Implementation of the Advance Care Planning policy will be supported by operational guidance, training and education and public messaging.

This report summarises the outcomes of the two phases of early stakeholder engagement undertaken which have informed the development of the Advance Care Planning policy. To ensure engagement with as wide a group of people as possible, an initial stakeholder mapping exercise was completed in November, which remains 'live'.

To date, there have been two stages of early engagements with stakeholders to inform the iterative development of the draft Advance Care Planning policy. These engagements have been conducted based on principles of inclusiveness and accessibility. Every effort has been made to reach out to, and maximise engagement with, a wide range of organisations and individuals including those representing and within Section 75<sup>2</sup> groups. The aim of the engagement was to support the active involvement of all stakeholders, primarily in shaping the policy development. These engagements have also informed the policy implementation plans.

Following Phase I and Phase II engagement, the policy is being revised, in preparation for a Public Consultation in autumn of 2021.

The Advance Care Planning Programme of work will include the development of operational guidance, training and education, public messaging and an outcome and evaluation framework, which will support the implementation of the final Advance Care Planning Policy. All of this work will include stakeholder involvement as appropriate to meet the given objectives as the work progresses, for example through task and finish groups or work with volunteer partners.

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<sup>1</sup> Following Phase I feedback, a submission outlining stakeholder recommendations to broaden the scope of the Policy to include wider aspects of Advance Care Planning was presented and subsequently approved by the Minister of Health in May 2021. The outcomes of a feasibility study into the planned adoption of the ReSPECT process (Recommended Summary Plan for Emergency Care and Treatment) were also presented and noted by the Minister at this time.

<sup>2</sup> Section 75 reference <https://www.health-ni.gov.uk/doh-equality>

# Stakeholder Mapping

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A stakeholder map was devised using three categories, as shown in the table below.

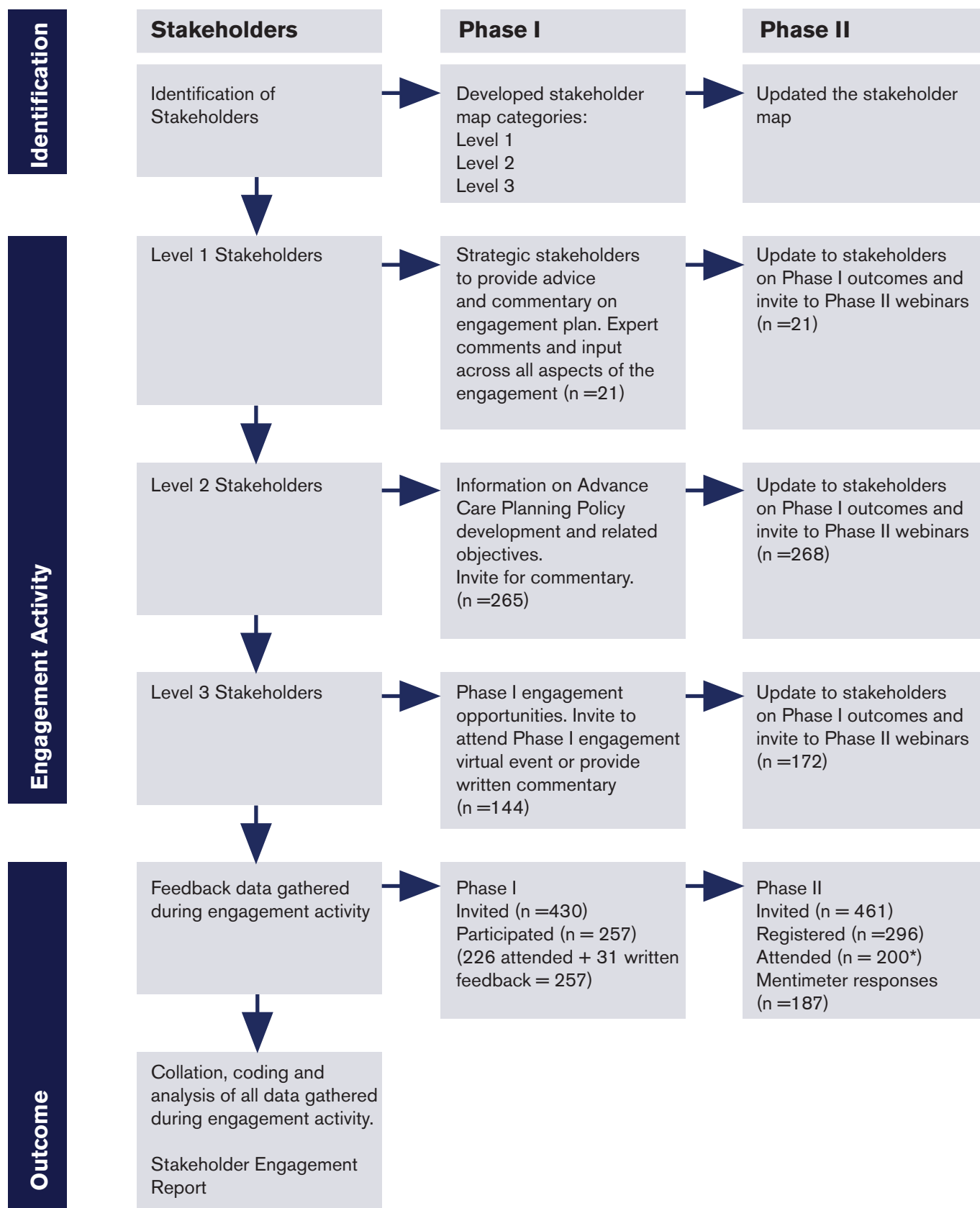
Early Stakeholder Engagement Level	
<b>Level 1</b>	Aim: Strategic stakeholders to provide advice and commentary on the engagement plan. Invitation to Phase II engagement opportunities.
<b>Level 2</b>	Aim: Information provided on the Advance Care Planning Policy development and related objectives. Invitation to Phase II engagement opportunities.
<b>Level 3</b>	Aim: Information provided on the Advance Care Planning Policy development and related objectives. Invitation to Phase I and Phase II engagement opportunities.

To maximise participation, the stakeholder map (see Appendix 1) has remained 'live', with additional stakeholders added as the engagement work progressed.

A list of those who had registered an interest to be informed about Department of Health public consultations was included and additional contacts were made.

The process of stakeholder identification, engagement activity and outcomes is illustrated in the PRISMA flow chart below.

## 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

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Phase I took place between December 2020 and February 2021. Letters of invitation were issued to the organisations and individuals identified in the stakeholder mapping. This included 424 letters of invitation issued via e-mail and 6 postal letters (430 in total). Further email communication and telephone calls were made to those who had not responded to the invitation letter in a bid to encourage participation.

Phase I engagement consisted of facilitated discussions and other opportunities<sup>3</sup> to give feedback on the draft policy. During this phase, the Programme Team held 40 engagement sessions involving 226 people and received an additional 31 written responses from a wide range of sectors, organisations and individuals. Therefore a total of 257 respondents participated.

## Methodology

The sessions were held virtually 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 five questions which would be used during the facilitated discussion. Each session was scheduled for 90 minutes and accessibility<sup>4</sup> arrangements were put in place as required (including for example, a longer session where this was appropriate and Sign Language interpretation).

Participants in these sessions were invited to make comment on the current draft of the policy document guided by five questions. (See Appendix 2)

1. What is your overall impression of/comment on 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?

Each session was recorded with consent from participants and transcribed for analysis.

During Phase I, 31 written responses to the engagement questions were also received. All the commentary was collated and themed for further analysis and coding.

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<sup>3</sup> By providing tracked changes/comments on the draft policy document and by returning completed feedback forms for consideration (see appendix 2)

<sup>4</sup> Inclusiveness and accessibility were central in planning and designing the engagement events; Royal National Institute for the Blind (RNIB) provided Inclusiveness and Accessibility advice and all Advance Care Planning Programme Team members completed Communication Access UK training and accreditation

# Phase I Outcomes and Policy Revision

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A total of 580 comments were noted for consideration as follows;

- 316 comments for consideration from the 40 engagement sessions
- 104 comments for consideration from feedback forms received
- 148 comments for consideration in tracked changes/comments on the draft policy document received
- 12 other comments for consideration/ comments received in e-mail correspondence

Key themes identified from the Phase I Early Stakeholder Engagement data included:

- The need to normalise Advance Care Planning Conversations
- Accessibility and inclusivity for all adults
- The need to ensure that the policy is implemented into practice

Overall, there was strong support for Advance Care Planning and the development and implementation of the policy, with commentary also provided in relation to operational elements.

Some quotations from the Phase I Early Stakeholder Engagements included;

***“[Advance Care Planning] probably the most important conversation you’ll ever have”***

***“[Advance Care Planning] long term benefits are considerable and should not be underplayed”***

***“I know that many older people would be comforted having a conversation about their future which for many would give them peace of mind”***

***“Great that the policy is so comprehensive, great that it recognises the need for public readiness”***

***“Great to see this happening, like it’s ambitious and aspirational”***

***“My hope is that families and wider society know (about ACP) and are able to make arrangements in a timely manner”***

The Advance Care Planning Programme Team analysed all Phase I Engagement feedback. The analysis identified a number of elements of the policy which needed to be clarified and/or strengthened, namely:

- Clear purpose of the policy and who the policy is for
- Ethics/Human Rights
- Behavioural change
- Inclusivity and accessibility
- Lasting and Enduring Power of Attorney
- Mental Capacity
- Donation of body to medical science
- Safeguards
- Values and principles
- Organ donation
- Glossary

A number of stakeholders also felt that the scope of the Advance Care Planning policy should be broadened beyond the focus on health and social care, to include other aspects such as making a will, financial aspects, spirituality and online accounts.

During the Phase I engagements, the ReSPECT process and documentation was raised by stakeholders as a potential alternative to a stand-alone do not attempt cardiopulmonary resuscitation (DNACPR) process and form. Subsequently, the Regional Advance Care Planning Policy Steering group approved a recommendation to seek further commentary on the ReSPECT process.

A feasibility study/survey was carried out with participation from relevant reference forums for the Advance Care Planning Programme. This included input from members of the Palliative Care in Partnership Programme (PCiP), The Regional Clinical Ethics Forum, HSC Resuscitation Committees and the British Medical Association (BMA).

In total, 19 responses were received to the feasibility study/survey indicating a firm agreement to the adoption of the ReSPECT process/form for Northern Ireland.

The extension of the scope of the policy was presented and subsequently approved and the proposed adoption of the ReSPECT process/form was noted by the Minister of Health, in May 2021.

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<sup>5</sup> Recommended Summary Plan for Emergency Care and Treatment



The commentary and feedback from Phase I engagement informed the revision of the draft Advance Care Planning policy document prior to further engagement in Phase II.

See the table below for details;

<b>Phase I - what the stakeholders said:</b>	<b>Actions taken in re-drafting the policy prior to Phase II:</b>
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.
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 Planning for Emergency Care including ReSPECT.
Provide more detail on how policy will be implemented	Feedback recorded for use in developing the operational documents.

# Phase II Engagement

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Between June and July 2021, a series of 5 Phase II stakeholder engagement events were held to gather feedback on the revised draft Advance Care Planning policy. These events took place online via Zoom webinar. Invitations to these events were circulated to stakeholders inviting them to register. Those who registered received a copy of the revised draft Advance Care Planning policy for consideration in advance of the event. To support the Phase II engagement, the revised draft policy was also made available in an accessible version format<sup>6</sup>. The letter of invitation included instructions for the use of Mentimeter and also included the themes that would be explored during the webinar session.

A total of 461 invitation letters were sent based on the 'live' stakeholder map. Some of the events were 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, along with the Community Development and Health Network (CDHN), provided additional promotion of the events. The Department of Health website also hosted information on the events.

## Methodology

The Phase II events followed a structured format with a series of short presentations on aspects of the 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.

Aspects of the policy for participants to consider in the Phase II webinars included;

- Overall Impression of the draft Advance Care Planning policy
- Accessibility and Inclusiveness
- Values and Principles of Advance Care Planning
- Normalising Advance Care Planning and Behaviour Change
- Advance Care Planning Components Model
- Planning for Emergency Care and Treatment
- Mental Capacity
- Advance Care Planning and You

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<sup>6</sup> As per guidance from Royal National Institute of Blind People in NI (RNIB Northern Ireland).

Each aspect was presented and followed by a series of related questions. Participants were invited to respond via Mentimeter. There were a total of 21 questions asked during each 90 minute session. A copy of the questions was available as a Word document for anyone wishing to respond in this way.

A total of 296 registered to attend. The number of individuals who attended the events was approximately 200<sup>7</sup> and a total of 187 individuals responded to the questions using Mentimeter. A further 2 responses were received in document format and 1 response was through the Q&A functionality on Zoom. These responses were added to the dataset and included in the analysis.

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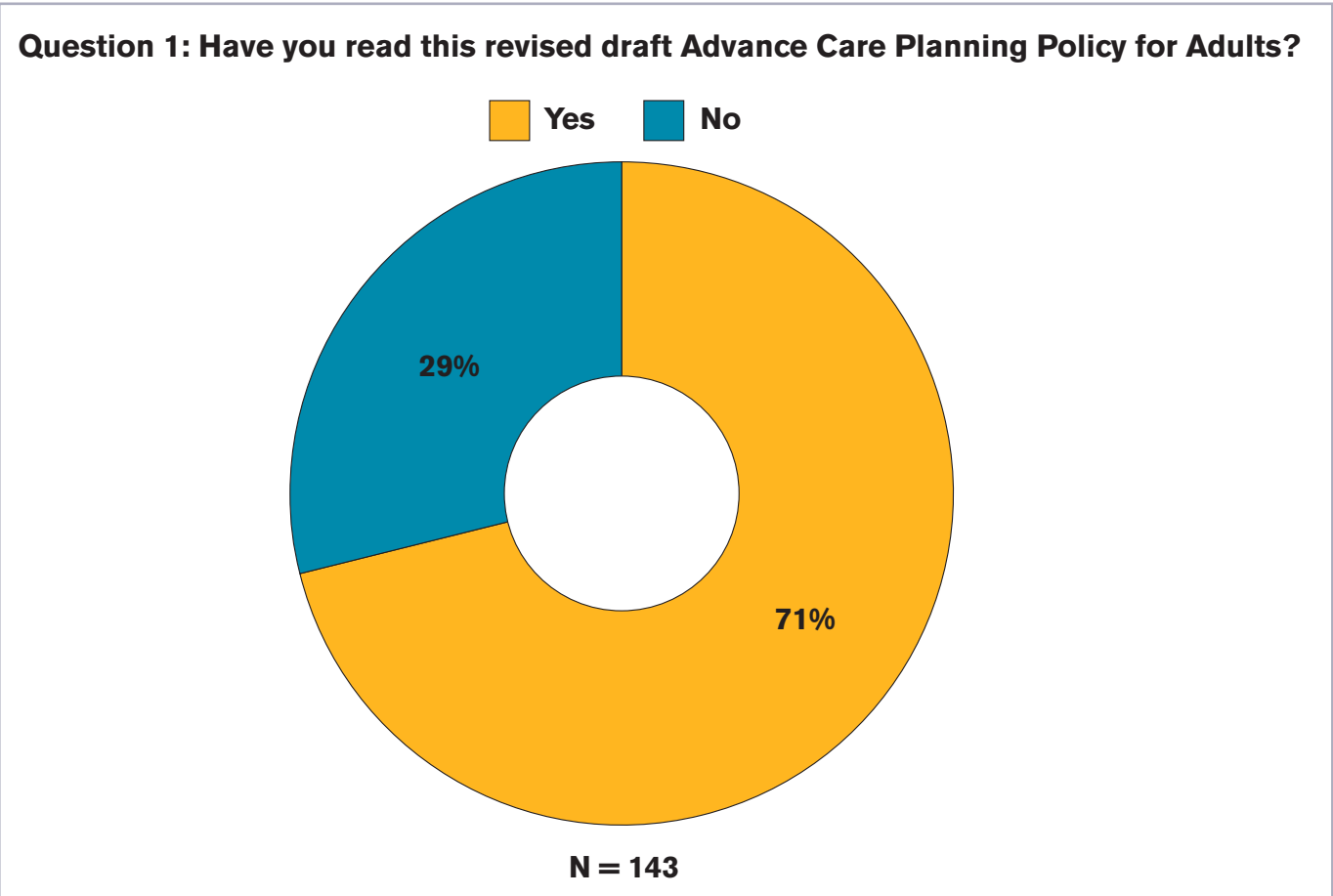
<sup>7</sup> This number is an estimate based upon attendance figures for those who registered but allowing for shared and late logins not recorded by the system.

# Phase II Outcomes

The following section provides an overview of the responses to the Phase II engagement questions across all 5 webinar engagement sessions. Further detail is provided in full data tables for each question in Appendix 3.

## Section 1: Overall Impression of the draft Advance Care Planning policy

The questions in this section asked webinar participants to give their overall impression of the revised draft Advance Care Planning policy and if they thought it would improve public understanding of what Advance Care Planning is. Responses indicated a very positive assessment where participants rated the draft policy as: comprehensive, clear, necessary and person-centred.



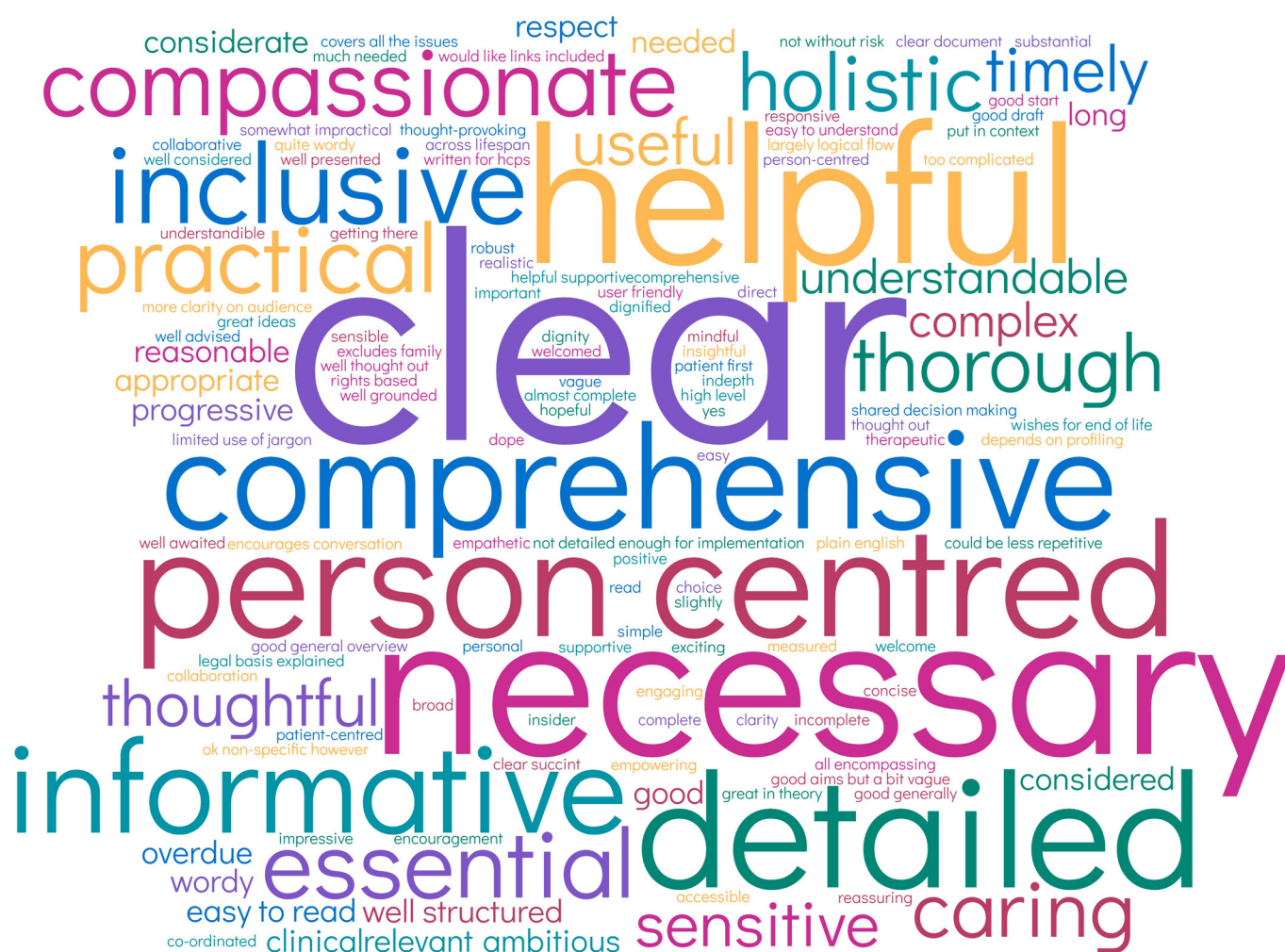
Of the 187 participants who responded to the Mentimeter questions, 143 responded to this question as follows: 102 (71%) indicated they had read the policy and 41 (29%) indicated that they had not.

A table of the full data relating to this question can be found in Appendix 3, Table I.

**Question 2: Please tell us briefly what your overall impression of the revised draft Advance Care Planning Policy is?**

This 'Word Cloud' question generated a total of 301 entries with 127 people responding at least once. The more often a word was used, the larger the font of the text. The Word Cloud can be seen below. This shows a very positive response in terms of participants' overall impression of the revised draft.

A full breakdown of entries/frequency for the Word Cloud is available in Appendix 3, Table II.



**Question 3: Based on this draft, do you think the policy will help improve public understanding of Advance Care Planning?**

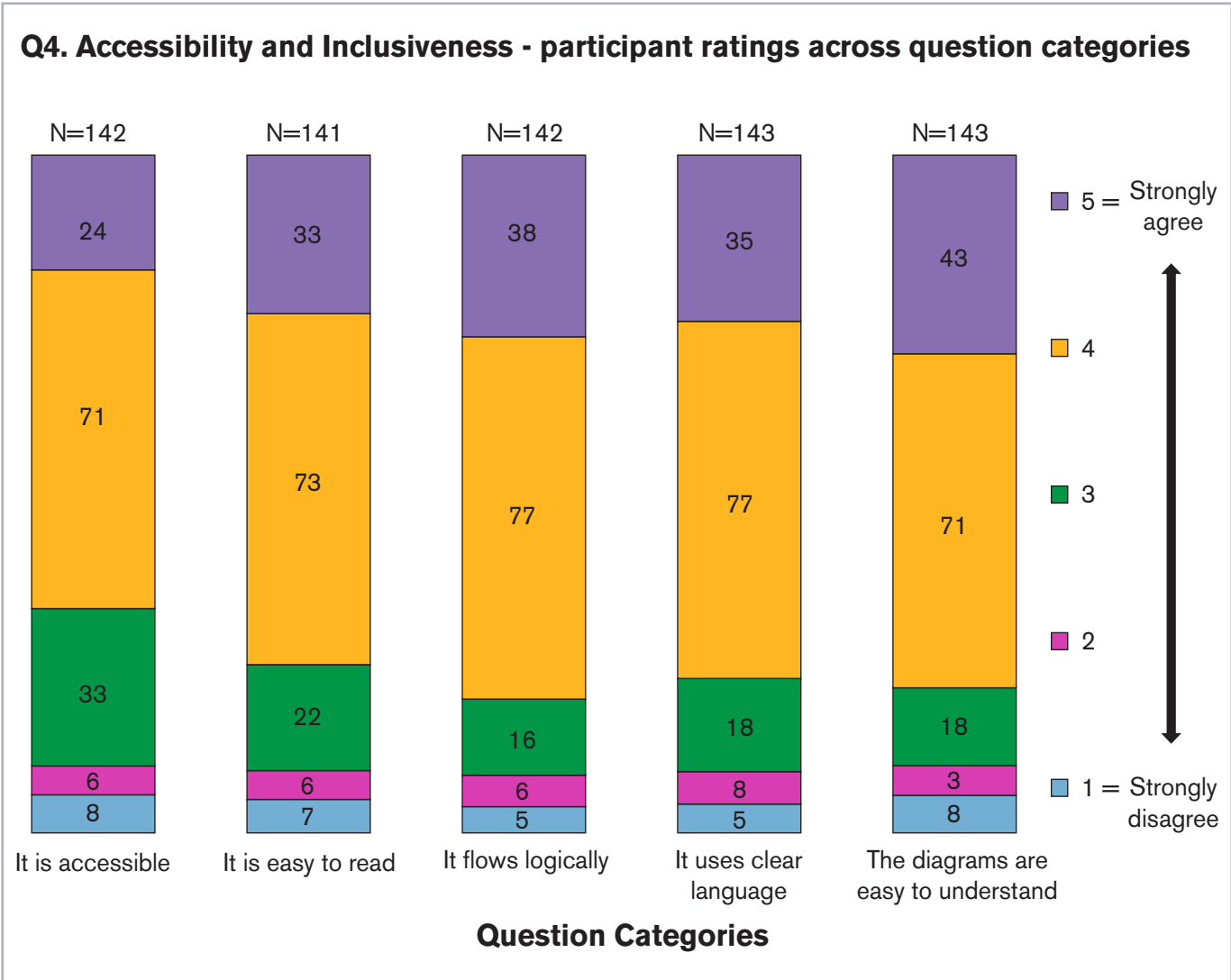
There was a generally positive response to this question. A total of 142 people responded, with 133 indicating a positive response. Only 3% of respondents did not agree that the policy would help improve public understanding.

A table of the full data for this question can be found in Appendix 3, Table III.

**Section 2: Accessibility and Inclusiveness:**

The questions in this section asked participants to consider how accessible the revised draft policy was in terms of its general readability, clarity, the flow and structure of the document, and if it was relevant to all adults. Responses indicated that participants considered the draft policy to be both accessible and inclusive.

**Question 4: This question asked people to consider and rate this draft of the policy document in terms of a number of categories (as below) by entering a score out of 5 for each with 1 = strongly disagree through to 5 = strongly agree**

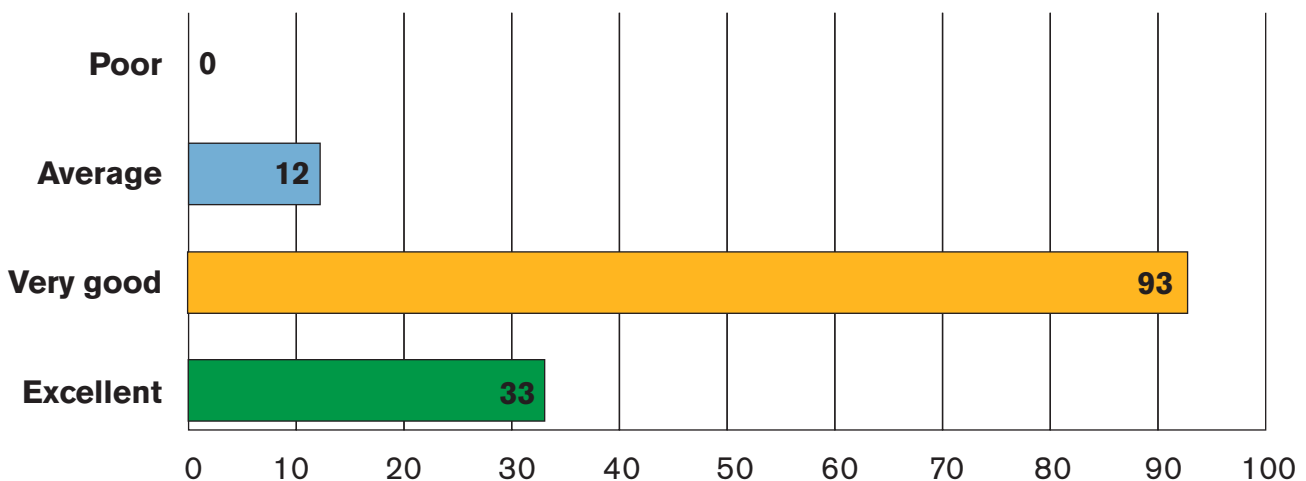


In response to this question, the majority of participants indicated positively, with 76% of participants selecting scores of 4 or 5 across the 5 categories (542 of 716 responses).

Of the 5 categories; 67% (95 of 142) scored 4 or 5 in the 'it is accessible' category, 75% (106 of 141) scored 4 or 5 in the 'it is easy to read' category, 81% (115 of 142) scored 4 or 5 in the 'it flows logically' category, 78% (112 of 143) scored 4 or 5 in the 'it uses clear language' category and 80% (114 of 143) scored 4 or 5 in the 'diagrams are easy to understand' category. A table of the full data relating to this question can be found in Appendix 3, Table IV.

**Question 5: How well does the policy set out the case that Advance Care planning is relevant to all adults?**

**N = 138**



The response to this question was positive with the majority of the 138 participants selecting either 'Excellent' (33 responses) or 'Very good' (93 responses). Only 12 participants selected 'Average' and no one selected 'Poor'.

A table of the full data relating to this question can be found in Appendix 3, Table V.

**Question 6: What would you suggest to improve accessibility and inclusiveness within the policy document?**

There were 200 individual responses to this open-ended free text question. A content analysis of the responses identified a number of themes. These were;

**Terminology/Glossary**

***“Some of the terminology may need to be explained more - e.g. ADRT”***

***“Maybe the references need to go at the beginning- I wasn't sure what ReSPECT meant”***

***“Include a glossary”***

**Summary document**

***“Summary version for general public”***

***“Short sharp summary - especially for hard-pressed medical professions”***

***“A short point based version - as a general introduction before moving on to full version”***

***“Summary booklets / leaflets / visual videos”***

***“Maybe a summary booklet illustrated”***

***“Summary with visuals”***

***“Include an executive summary”***

## **Promotion Platforms**

***“Use social media to promote”***

***“Major sustained education / messaging to public and Healthcare professionals”***

***“I think what has been proposed is excellent but definitely to reach younger people use social media ....‘normalise’ (the) conversation’***

***“Have a supporting website with patients and families from different backgrounds describing their experiences of ACP.”***

***“Visual /video/ audio made now might make it easier to engage***

***“Use of TV campaign”***

***“Easy online access”***

## **Engagement / Raising Awareness**

***“More engagement with all disciplines”***

***“Shared awareness by charities and voluntary sector organisations”***

***“Engage with as many people as possible”***

***“Introduce Health Literacy as a topic in school leavers’ essential education and introduce the Advanced Care Planning Policy to them there.”***

***“Some examples to show what a plan looks like when complete.”***

***“Genuine interest in people.. draw them in and make them a part of all plans”***



## Language

***“Continue to write the document from the users’ perspective”***

***“I think it is fine as is. It would be more about how this will be implemented or conveyed to different audience groups.”***

## Format/Diagrams

***“Different languages”***

***“Large print, electronic format for visual impaired with dark background /light writing.”***

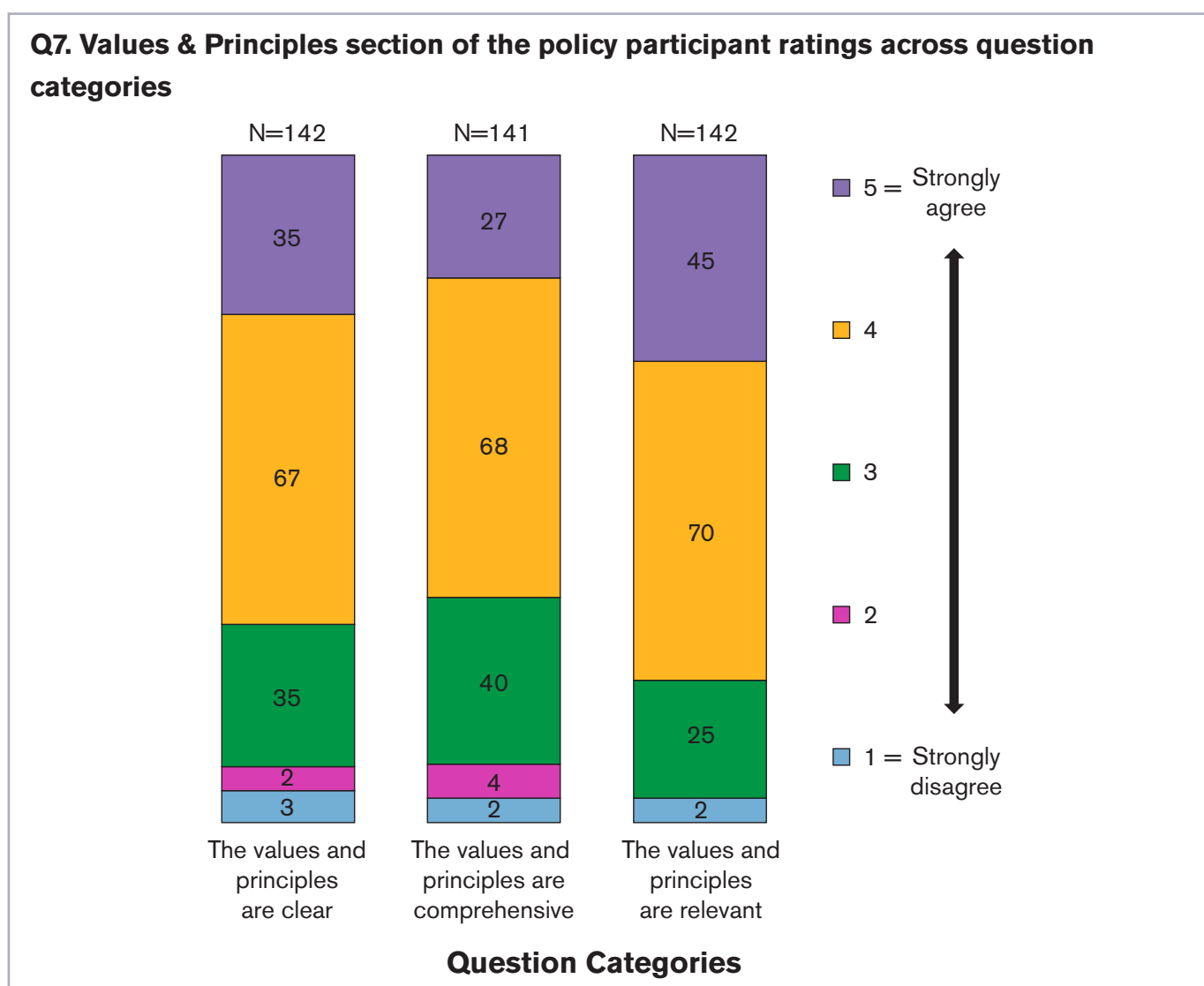
***“Shorter phrases, bullet points and possible use of flowchart to explain the process of completing Advanced Care Planning. Clearly identify who can complete, how details are documented”***

***“Some pages have a lot of text, can they be broken up with diagrams or bigger line spacing or paragraph spacing”***

### Section 3: Values and Principles of Advance Care Planning

The questions in this section asked participants to consider the Values and Principles that underpin the draft Advance Care Planning policy, and their relevance and appropriateness. Responses indicated that participants either agreed or strongly agreed that the draft policy values and principles are clear, comprehensive and relevant.

**Question 7: This question asked people to consider and rate their views on the “Values and Principles” section of the draft policy. Specifically, it asked if they thought the values and principles were clear, comprehensive and relevant by entering a score out of 5 for each, with 1 = strongly disagree through to 5 =strongly agree**



In response to this question, the majority of participants indicated positively with 71% of participants selecting scores of 4 or 5 across the 3 categories (302 of 425 responses). Across the 3 categories; 72% of respondents scored 4 or 5 in the 'clear' category (102 of 142), 60% scored 4 or 5 in the 'comprehensive' category (85 of 141) and 81% (115 of 142) scored 4 or 5 in the 'relevant' category.

A table of the full data relating to this question can be found in Appendix 3, Table VI.

**Question 8: Is there anything you would change or add to the Values and Principles outlined in the draft policy?**

There were 128 individual responses to this open-ended free text question. Within the 128 responses, 62 people (48%) indicated that they were content with this section of the revised draft stating that no further revision was necessary. Examples of comments include:

***“Very comprehensive, no further additions required”***

***“Values/principles outlined - very thorough and relevant.”***

***“I think you have covered many of the areas I would say are important for values and principles”***

***“Inclusive and sensitive”***

***“Perspectives on values and principles would need to take account of cultural and diverse beliefs.”***

***“Could be reordered. Perhaps, values/principles relating to the interaction with the individual followed by general principles.”***

***“The implementation of the values and principles - how to measure their effectiveness”***

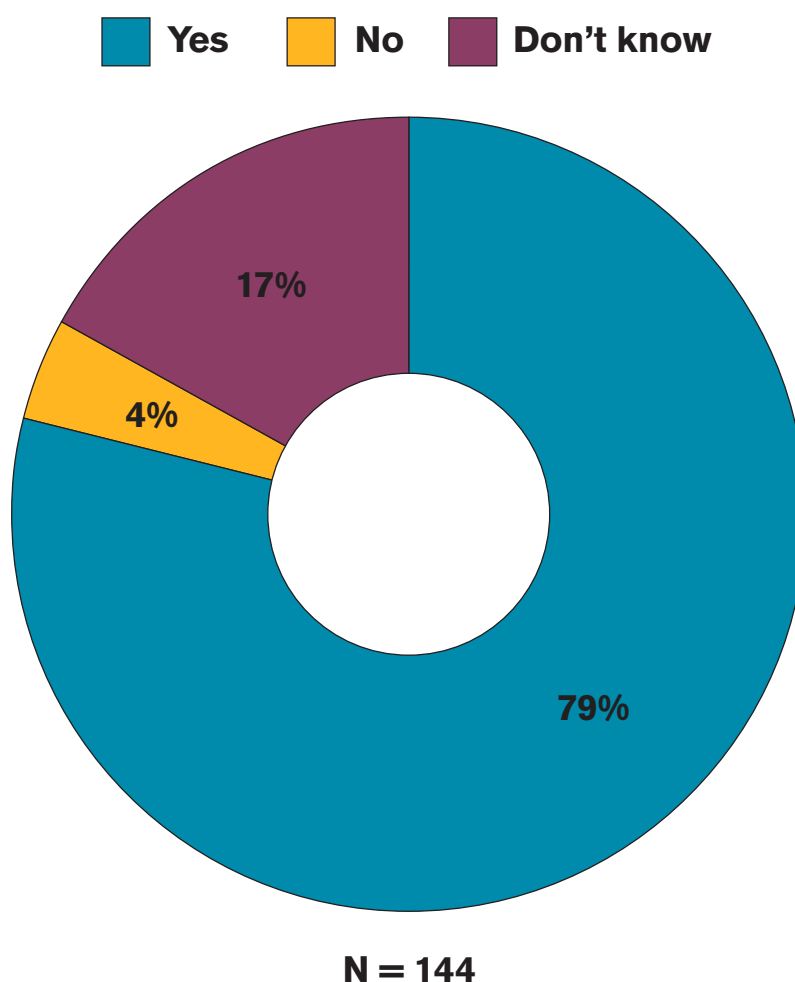
***“Could be condensed but then you don’t want to lose detail”***

## Section 4: Normalising Advance Care Planning and Behaviour Change

The questions in this section sought participants' views on whether the draft policy would help to normalise Advance Care Planning conversations and the behaviour change that might be needed to achieve the policy's ambition that these conversations would become normalised. Responses indicated that the draft policy would help "normalise" Advance Care Planning conversations through raising awareness, and encouraging people to engage in such conversations.

Some valuable suggestions were offered in the free text around supporting the necessary behaviour change to engage in Advance Care Planning. These included, for example, training and education across sectors and at all levels.

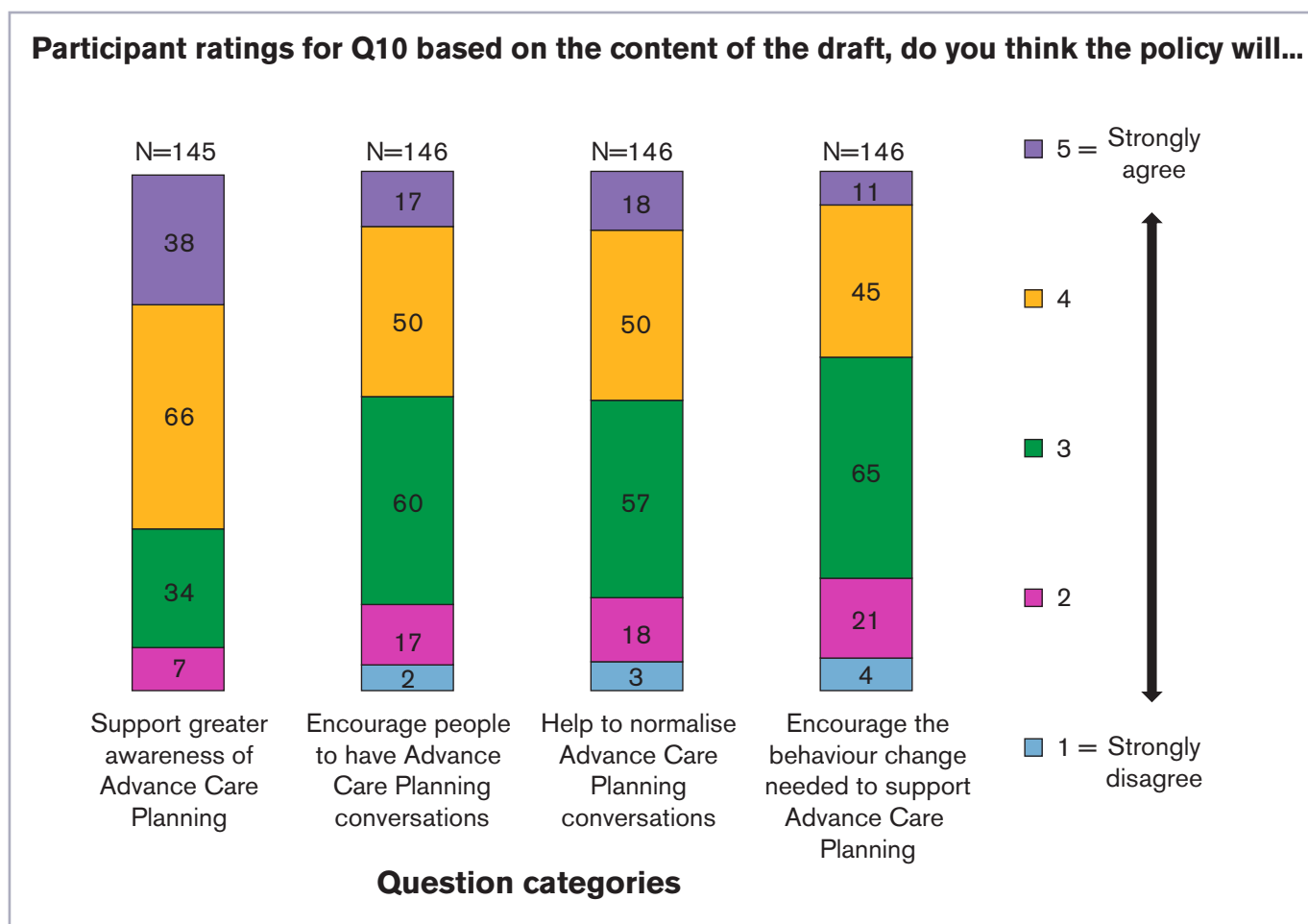
### Question 9: One of the policy ambitions is to normalise Advance Care planning conversations. Do you think the draft policy encourages this?



Overall the results for this question were positive with 79% (114 of 144) of participants indicating that they thought the draft policy encourages the policy ambition of normalising Advance Care Planning conversations. 17% (25 of 144) indicated 'don't know' and only 4% (5 of 144) indicated 'no'.

A table of the full data relating to this question can be found in Appendix 3, Table VII.

**Question 10: This question asked people to consider and rate their views on whether the policy would help support awareness of and normalise Advance Care Planning conversations and support the behaviour change needed for this by entering a score out of 5 for each of the question categories, with 1 = strongly disagree through to 5 = strongly agree.**



In response to this question, just over half (50.5%) of participants selected scores of 4 or 5 across the 4 categories (295 of 584 responses). A further 31% indicated a mid-range score of 3 (216 of 584).

72% (104 of 145) scored 4 or 5 in the 'support greater awareness of Advance Care Planning' category and a further 23% gave a score of 3 (34 of 145). 46% (67 of 146) scored 4 or 5 in the 'encourage people to have Advance Care Planning conversations' category and a further 41% (60 of 146) gave a score of 3. 47% (68 of 146) scored 4 or 5 in the 'help to normalise Advance Care Planning conversations' category and a further 39% (57 of 146) gave a score of 3.

38% (56 of 146) scored 4 or 5 in the 'encourage the behaviour change needed to support Advance Care Planning' and a further 45% (65 of 146) gave a score of 3.

A table of the full data relating to this question can be found in Appendix 3, Table VIII.

## **Question 11: What could help support the behaviour change needed to normalise Advance Care Planning conversations?**

There were 254 individual responses to this open-ended free text question. A content analysis of the responses identified a number of themes. These were:

### **Raising awareness/Communications**

***“Need to be able to direct the public how to get more information, start the process, support them in the conversations etc.”***

***“Community level campaign , i.e. focus groups, health promotion departments and primary care, Community pharmacy working with community. Continuation of this work and resources for community to do this”***

***“Local Community Networks need to be involved”***

***“Highlight positive experiences based on real life examples where people reflect well on their experiences with Advance Care Planning”***

***“Awareness campaign using media, social media, GPs, workplaces etc.”***

***“Advertising campaign, development of online register, application that can be accessed via smart phone, laptop, etc.”***

### **Training & Education**

***“Patient representative bodies and the charitable sector should educate patients and families in relation to advance care planning and advocate for health care organisations and professionals to take the lead in introducing it to patients.”***

***“Incorporate into healthcare student curriculum”***

***“Professionals need to take the initiative, so they need appropriate training and support.”***

***“Train staff to be comfortable having these conversations early in their careers”***

### **Behavioural change**

***“This should be a sociocultural approach and not left to health professionals only”***

***“Start early and often! School kids, older kids, medical, nursing and other health and social care students; undergraduate, solicitors, mortgage lenders, bank staff. If exposure is made available, it will become as normal as writing a will”***

***“This is much larger than a singular policy. Rather you have outlined a cultural shift that will need to happen. Therefore attacked from many angles. Schools, education. To get a mortgage need a will etc. Wider policy. Support teams.”***

***“Focus groups in every town encouraging and welcoming all to participate.”***

***“Find ways of having those conversations regularly through GPs and other regular services people access. Publicity in surgery and banks etc. too might help and not just focussed on older or sick people.”***

***“Fact it’s still voluntary will make behaviour change difficult. Also hard to measure because of this”***

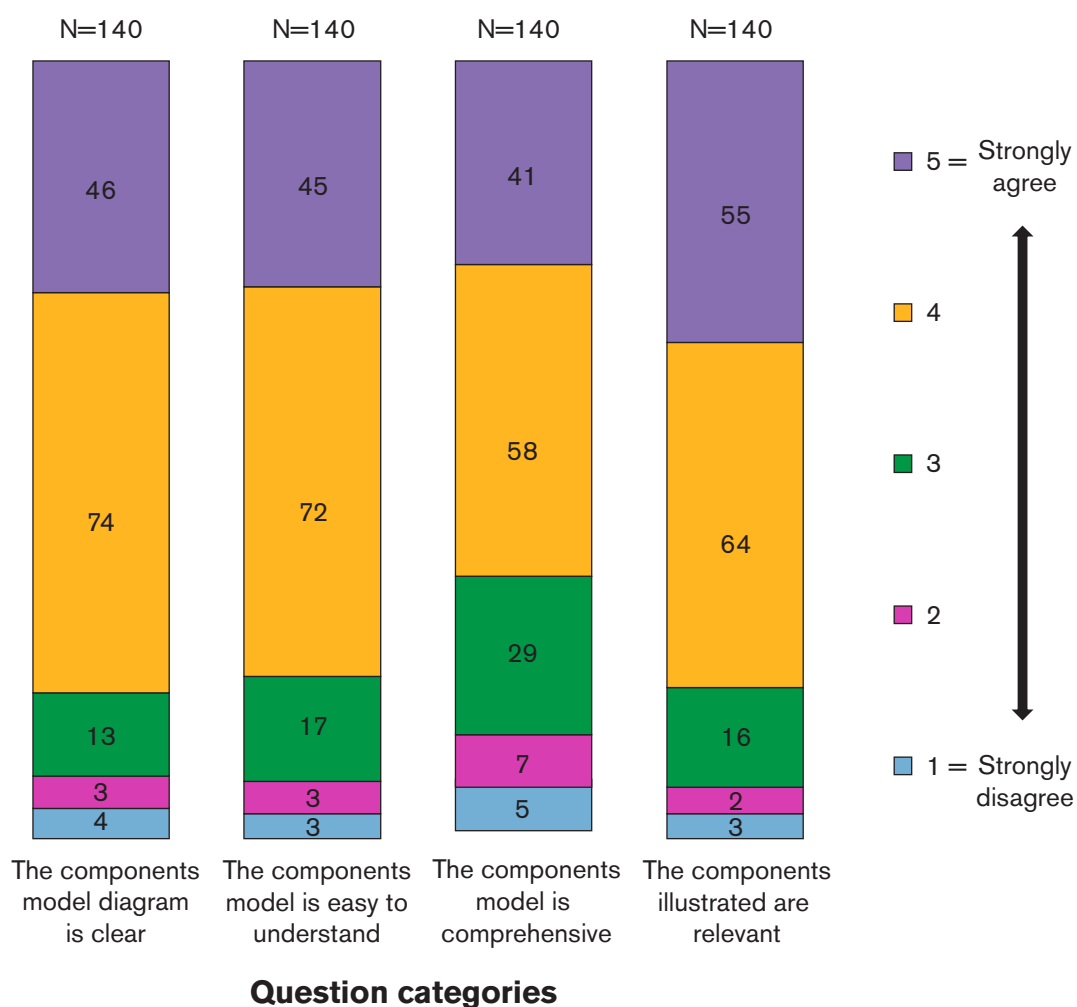
***“A policy alone won’t change behaviour it needs to be backed up with a promotional/publicity campaign with funding and resources behind it”***

## Section 5: Advance Care Planning Components Model

The questions in this section asked participants to provide feedback on the clarity and relevance of the Advance Care Planning component model and to identify any gaps in the elements noted within the components. Responses indicated that participants welcomed the components diagrams which they described as, for example, “clear”, “easy to read”, and “comprehensive”. Participants identified one or two gaps that could be included within the components such as “spirituality”, “caring for dependents”, and “caring for pets”.

**Question 12: This question asked people to consider and rate their views on the Advance Care Planning Components model by entering a score out of 5 for a number of aspects (as below) with 1 = strongly disagree through to 5 =strongly agree.**

### Q12. Views on the Advance Care Planning Components Model





In response to this question, the majority of participants indicated positively with 86% selecting scores of 4 or 5 across the 4 categories (455 of 560 total responses).

Across the categories: 86% gave a score of 4 or 5 in the 'components model is clear' category (120 of 140); 84% gave a score of 4 or 5 in the 'components model is easy to understand' category (117 of 140); 71% (99 of 140) gave a score of 4 or 5 in the 'components model is comprehensive' category; and 85% (119 of 140) gave a score of 4 or 5 in the 'components illustrated are relevant' category.

A table of the full data relating to this question can be found in Appendix 3, Table IX.

### **Question 13: Advance Care Planning Components - is there anything you would add?**

There were 149 individual responses to this open-ended free text question. 41 of these responses indicated that respondents were content with the components section of the revised draft.

***“Looks good, easy to understand & content very clear”***

***“Very thorough/comprehensive”***

***“Seems very clear on components covered. These components cover important issues. “***

***“Really like the diagrams”***

A content analysis of the remaining responses identified a number of themes. These were;

#### **Spiritual**

***“Within the personal section, would a mention of faith / spirituality be appropriate?”***

***“Fairly comprehensive maybe something about faith”***

***“Do we need to make a reference to people’s spiritual needs?”***

#### **Legal**

***“More clarity on Power of Attorney and Lasting Power of Attorney coming in once Mental Capacity Act NI fully implemented”***

***“Do you need to clarify if it is a legal document or not?”***

***“I would differentiate between best interests in clinical and MCA (NI) in legal”***

## Financial and Funeral

***“More information under financial, e.g. funeral plans etc.”***

***“Would there be anything about last wishes/ funeral arrangements/ choice?”***

***“Financial - A reminder to contact the Bereavement Service, to report death and check benefits”***

***“Estate planning in financial section. This could be an early prompt for further engagement in other sections”***

## Dependents

***“Other caring responsibilities pets, children or adults with disabilities/ caring responsibilities”***

***“For older carers with disabled adult children there’s a genuine concern about what will happen to their children if something happens to them - I’m not sure if that falls into legal or personal”***

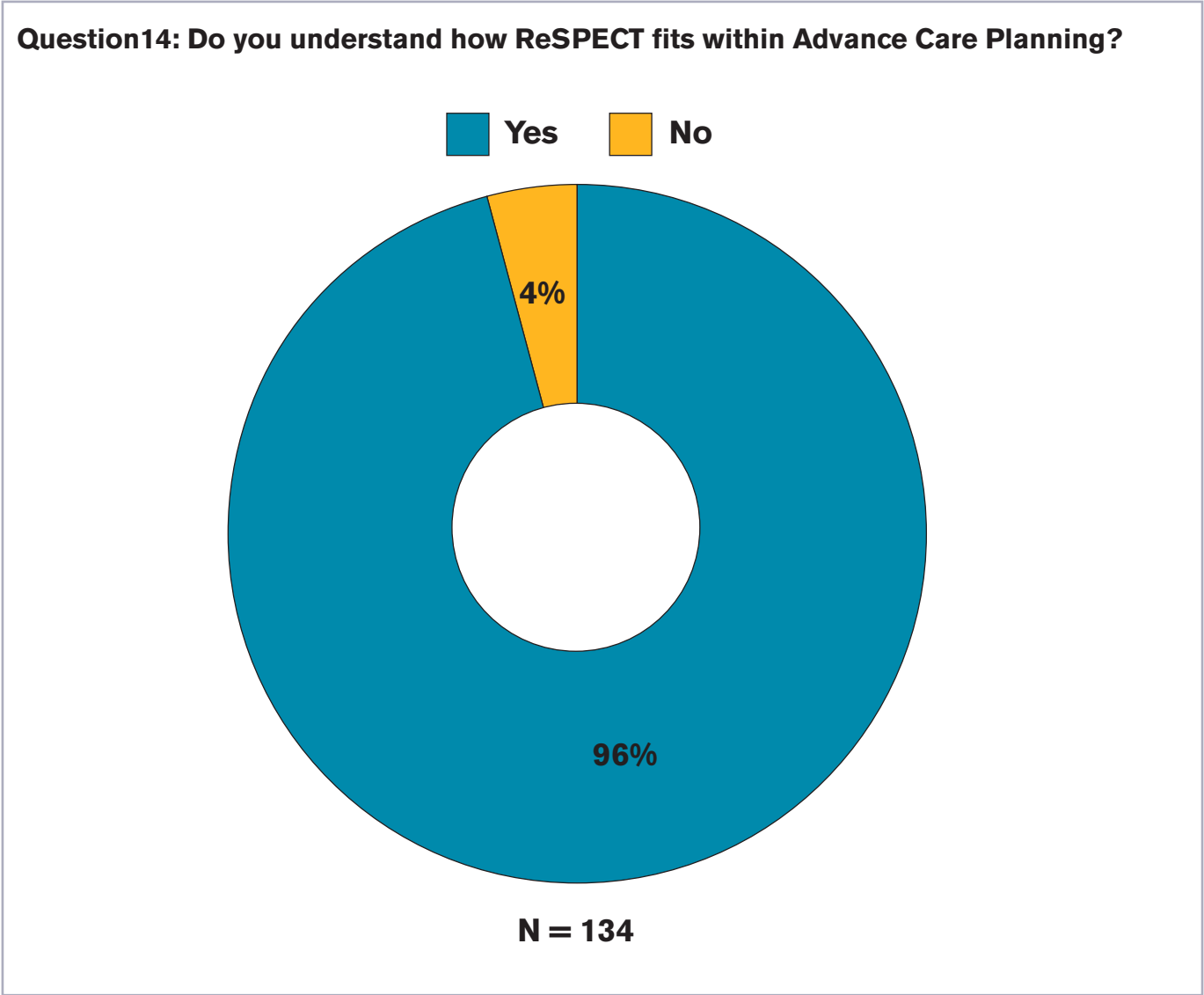
***“Who matters to me (including pets)”***

***“Planning for those who are left behind”***

***“Example of ‘care of children’ or even pets would perhaps encourage people to look closer”***

**Section 6: Planning for Emergency Care and Treatment**

The questions in this section sought participants’ views on the use of ReSPECT to support planning for emergency care and treatment and asked if the draft policy was clear on the link between ReSPECT and Advance Care Planning. Responses indicated a clear understanding of how ReSPECT fits within Advance Care Planning.



A majority of respondents, 96% (129 of 134) indicated that they understood how ReSPECT fits within Advance Care Planning.

A table of the full data relating to this question can be found in Appendix 3, Table X.

**Question 15: If not, what would help to make this link clearer?**

There were 186 individual responses to this open-ended free text question. Suggestions on how to make the link clearer included training and education, operational consideration and raising public awareness.

***“Get the (ReSPECT) acronym out into public discourse - the public at large does not know about this - only become aware of this type of discussion when they are in an emergency or situation of very serious illness; frail relative etc.”***

***“Information sessions at local level.”***

***“Some of the language and topics could be scary to many vulnerable people”***

***“Wider discussion in all professional fields.”***

## **Operational**

***“Needs workshops going through ReSPECT when / if implemented”***

***“It needs to sit in a context of shared decision-making about all care”***

***“Healthcare Professionals need training”***

***“Maybe some information about who completes it and when. Is it online or paper? Who holds it and how is it transferred across sites?”***

***“Documentation needs to be regionalised for consistency especially in emergency care”***

***“Support and facilitation to implement.”***

## **Clarity**

***“Clarify the removal of DNACPR process across NI to avoid any future confusion.”***

***“Examples would be really useful to help people think around the type of events that this may relate to”***

***“Include a sample ReSPECT form in the document that has been filled out with detail”***

## **Case Studies**

***“Use of a few brief vignettes demonstrating how ACP delivers better outcomes in particular and typical cases and common presentations”***

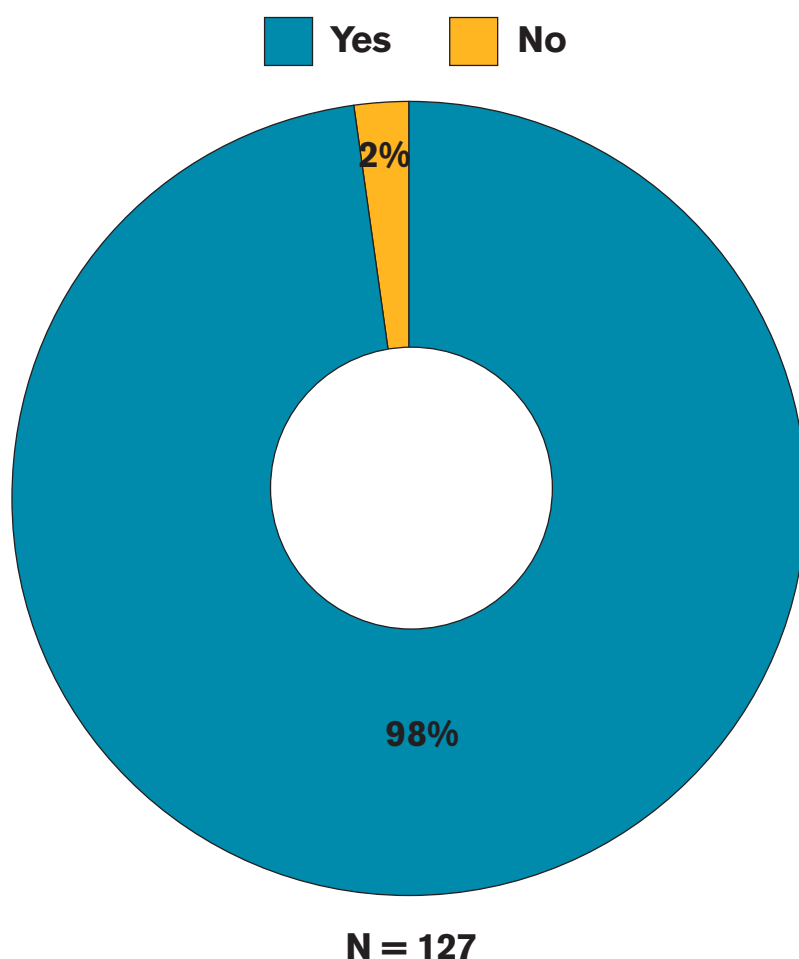
***“Examples would be really useful to help people think around the type of events that this may relate to”***

***“Case examples of ReSPECT in practice”***

## Section 7: Mental Capacity

The questions in this section asked participants to consider if the revised draft Advance Care Planning policy demonstrated the link between mental capacity and Advance Care Planning and explained the relevant legal aspects of the Mental Capacity Act (NI) 2016. Respondents indicated that they understood how mental capacity links to Advance Care Planning.

### Question 16: Do you understand how mental capacity links to Advance Care Planning?



A majority of respondents, 98% (124 of 127) indicated that they understood how mental capacity fits within Advance Care Planning.

A table of the full data relating to this question can be found in Appendix 3, Table XI.

### Question 17: If not, what would help to make this link clearer?

There were 103 individual responses to this open-ended free text question. A number of responses suggested the need for training and education, in relation to mental capacity.

## **Training & Education**

***“Workshops/information sessions/webinars with a speaker to explain the link and requirements where the person does not have the capacity to make their own decisions.”***

***“More training and awareness linking in with more mental health organisations and clarity of legal aspect of proxies in this process.”***

***“Education will be very important as well as public and professional awareness”***

***“Issue in that the Mental Capacity Act (NI) 2016 provision is not yet in situ. Should the Policy be reflective of the current situation with updates as required?”***

***“Situation about legal position on mental capacity in NI still very complex, needs expert legal input to get it clear”***

***“Don’t use jargon - put yourself in the position of the person needing ACP and use language they use and understand”***

***“This section especially the footnotes has a bit more jargon for unfamiliar public audience - e.g. the footnote about LPAs could be clarified.”***

## **Case Studies**

***“Case studies re fluctuating capacity”***

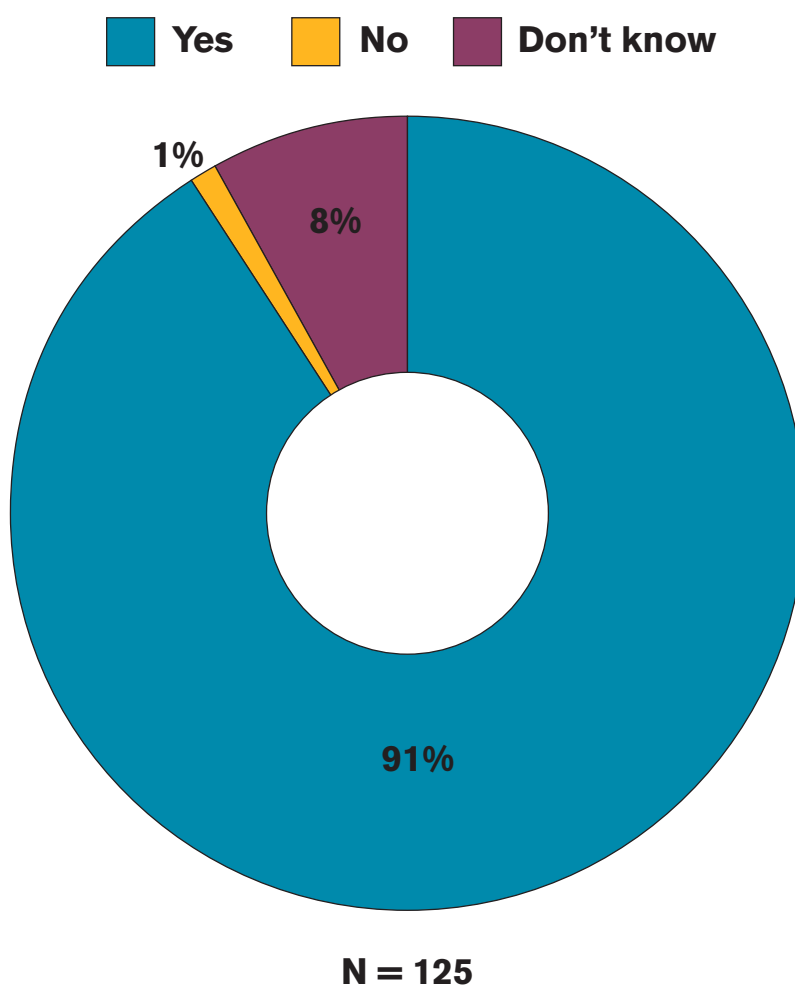
***“Possibly examples of problems when person does not have a Power of Attorney made”***

***“Use of some vignettes of typical cases which illustrate some of the challenges involving MH /ACP and how that can be successfully addressed”***

## Section 8: Advance Care Planning and You

The questions in this section asked participants to think about how they and/or their organisation had a role in Advance Care Planning and how they could be supported in this role. Responses indicated that the majority of respondents recognised their own role or that of their organisation in Advance Care Planning. Responses further suggested that training, raising awareness and improved communication would support them in their role.

### Question18: Do you feel there is a role for you personally or your organisation in Advance Care Planning?



A majority of respondents, 91% (114 of 125) indicated 'yes' that they felt there was a role for them personally or their organisation in Advance Care Planning, with a further 8% (10 of 125) indicating 'maybe'. Less than 1% (1 of 125) responded with 'no'.

A table of the full data relating to this question can be found in Appendix 3, Table XII.

## **Question 19: What would support you in that role?**

There were 191 individual responses to this open-ended free text question. A content analysis of the responses identified a number of themes. These were:

### **Raising awareness & Communications**

***“Having access to awareness sessions for people at grassroots level, campaigning, training, resources”***

***“Public awareness, talking on TV/radio shows, social media influencers etc e.g. it’s not just for old people”***

***“Much wider conversation needs to happen to affect that cultural shift to make it acceptable practice and normal”***

***“Joint campaigns to raise the breadth of those involved and available to support”***

***“Materials which could be used consistently to communicate. Spokespeople who are fully au fait with all of the detail who could conduct workshops with, e.g. GPs,”***

### **Information**

***“Much better information on legal issues, incorporation in a leaflet”,***

***“Clear guidance for professionals, including how to support families or where to signpost”***

***“Information about the extent to which people’s rights e.g. UNCRPD are being respected in practice in the implementation of the policy.”***

***“Information to share across the organisation...Signposting colleagues to information and learning opportunities, training and education”***

***“Similar webpage as those for the Mental Capacity Act”***

***“Booklet which I can give to people. Having these booklets prominent in public places e.g. pharmacies, hospitals, libraries”***

### **Support**

***“A truly holistic approach and involvement between statutory and voluntary groups in the process”***



***“Member led organisation support”***

***“Funding for organisations”***

***“Clear point of contact for questions and queries”***

***“ACP champions in organisations to facilitate and support.”***

***“Partnerships”***

***“Support to roll this out- it requires preparation and delivery time within the working day”***

***“Protected time”***

## **Training & Education**

***“Clear and specific inclusion of Advance Care Planning in the professional curricula.”***

***“Clarity in role, training in how to deal with this and reactions”***

***“Training, mentoring, peer support”***

***“Consider making ACP part of CPD for clinicians”***

***“Workshops at local level i.e. healthy living centres”***

***“I don’t know what “personal” questions to ask friends and family about what is important to them. Guidance on this would be helpful”***

***“Education, clear competencies, support and debriefing following conversations”***

***“Awareness raising within organisations and to public and carers....Having support from senior management regarding this...Staff training”***

***“Training in characteristics needed for health and social care staff is the most important first point. Awareness on unconscious bias for staff in doing what they think is best as opposed to what are wishes from person.”***

## **Operational**

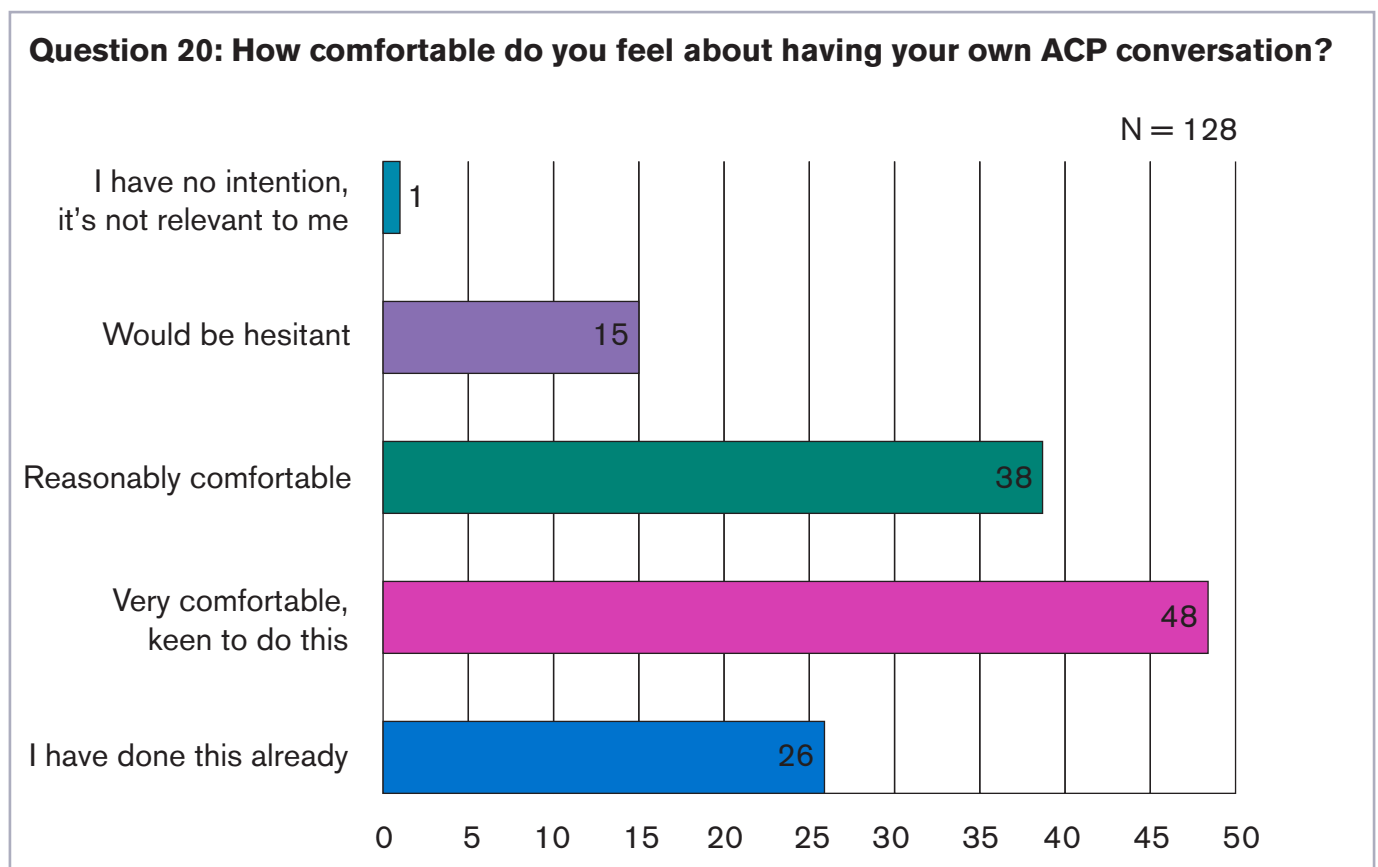
***“Operational guidance, Training Packs, Standardised documentation, Outreach to public voluntary groups”***

***“Expectations of professionals- does it become part of the workload- workforce planning required”***

***“Who to go to when care planning is to be initiated - who is the responsible and best trained?”***

***“Collaboration between multidisciplinary teams and training between non-traditional groups”***

***“Clear communication between communities, GPs, hospitals etc ...clear process ...clear such as where to find information, who holds this information, responsibilities etc ...engagement with all multi professional teams... funding and resources”***



Responses to this question indicated that the majority of participants were positive about having their own Advance Care Planning conversation: with 20% (26 of 128) indicating 'I have done this already'; 37% (48 of 128) indicating 'I'm very comfortable/keen to do this'; and 30% (38 of 128) indicating they were 'reasonably comfortable'.

12% (15 of 128) of participants indicated they 'would be hesitant' and only one person indicated they 'have no intention/it's not for me'.

A table of the full data relating to this question can be found in Appendix 3, Table XIII.

**Question 21: WORD CLOUD:** Please enter a word or two on your overall view of this engagement event.

This 'Word Cloud' question generated a total of 283 entries with 108 people responding at least once. The more often a word was used, the larger the font of the text. Responses indicated that participants rated the engagement session very highly, using words such as inclusive, engaging, informative and well-organised.

The Word Cloud can be seen below and a full breakdown of entries/frequency for the Word Cloud is available in Appendix 3, Table XV.



The commentary and feedback from Phase II engagement informed the revision of the draft Advance Care Planning policy document which will be published for public consultation.

See the table below for details.

<b>Phase II - what the stakeholders said:</b>	<b>Actions taken in re-drafting the policy prior to Public Consultation:</b>
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

# Conclusion

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Strong support for Advance Care Planning, and the development and implementation of the policy has been indicated by stakeholders across both Phase I and Phase II of stakeholder engagements.

Themes identified in Phase I of engagements as needing further clarification or strengthening were addressed in the re-drafting of the policy prior to Phase II. These, changes to the first draft, together with the extension of the scope of the policy and the proposed adoption of the ReSPECT process/form were welcomed by stakeholders, in Phase II engagement.

The overall impression of the revised draft Advance Care Planning Policy was positive, and indicated that people thought it would improve public understanding of Advance Care Planning.

The majority of respondents considered the revised draft to be accessible and inclusive and agreed that it set out the case that Advance Care Planning is relevant to all adults. Suggestions put forward to improve the accessibility and inclusiveness of the policy in Phases I & II have been welcomed and noted by the Programme team, with many already in place or under consideration as important factors in supporting the implementation of the policy.

Based on feedback from the Phase I engagements, a 'Values & Principles' section was added to the revised draft policy. The addition of this section was very well received by participants in the Phase II engagements with almost half of respondents indicating that they would make no changes. The majority agreed that the Values and Principles were clear, comprehensive and relevant.

Responses to questions in Phase II about normalising Advance Care Planning and behaviour change indicated that most respondents felt that the policy would have a positive impact in terms of normalising Advance Care Planning and bringing about behavioural change in the long term. Respondents' suggestions to help bring about the necessary behavioural change, emphasised the need for: training and education, cultural change and a focussed campaign to raise public awareness about the policy.

Phase I engagements had highlighted the need for visual illustrations to support people's understanding of the various elements of Advance Care Planning. In response, a components model was developed and included in the redrafted policy. The components model diagram was received very positively by participants in Phase II. Almost one-third indicated that no further changes to the components model were necessary. Suggestions for further additions to the components have been addressed in revision of the policy prior to public consultation.

Following the Phase I engagements, a further section on Planning for Emergency Care and Treatment was added to the policy. The majority of participants in Phase II welcomed the inclusion of ReSPECT and understood how it linked to Advance Care Planning. Respondents cited that training and education, and case studies would help to make the link clearer. These suggestions will be followed up to support the implementation of the Advance Care Planning policy.

The addition of a section on mental capacity was also well received. The majority of respondents in Phase II indicated that they understood how mental capacity links to Advance Care Planning. Suggestions for how this could be clarified further were factored into the revision of the policy prior to public consultation and will be considered in supporting its implementation.

The majority of participants in Phase II responded positively to the proposition that there was a role for them in Advance Care Planning, either personally or for their organisation, with only 1% indicating a negative response.

Overall, public messaging, training and education, with operational guidance were cited as key to supporting the implementation of this policy.

## Next Steps

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### **Public Consultation**

Responses and feedback from the Phase II engagements have informed the further revision of the draft policy. The revised draft of the Advance Care Planning Policy will be subject to public consultation in autumn 2021.

An Implementation structure is currently being progressed, which aligns with key themes raised during Phase I and Phase II engagements.

# APPENDIX 1: Stakeholder Map

## Advance Care Planning Programme Engagement Stakeholders

### Stakeholders

#### Advance Care Planning Programme Reference Groups

HSC Regional Clinical Ethics Forum

Palliative Care in Partnership Programme (see link - <https://pcip.hscni.net/>)

#### Strategic Organisations

Chief Allied Health Professions Officer, Department of Health

Chief Dental Officer, Department of Health

Chief Medical Officer, Department of Health

Chief Nursing Officer, Department of Health

Chief Pharmaceutical Officer, Department of Health

Chief Social Work Officer, Department of Health

Commissioner for Older People NI

Equality Commission for NI

Equality Unit, Department of Health

Interim Mental Health Chief Champion for NI

NI Human Rights Commission

Patient Client Council

Regional Personal Public Involvement Lead, Public Health Agency (PHA)

#### Health & Social Care Trusts

Chief Executive, Belfast HSC Trust (BHSCT)

Chief Executive, Northern HSC Trust (NHSCT)

Chief Executive, South Eastern HSC Trust (SEHSCT)

Chief Executive, Southern HSC Trust (SHSCT)

Chief Executive, Western HSC Trust (WHSCT)

Northern Ireland Ambulance Service

#### Health & Social Care Board Network Managers Forum

Cancer Network

Cancer Trials Network

Cardiology Network

Child Health Partnership

Clinical Research Network

Critical Care Network  
Diabetes Network  
Eye Care Network  
Forensic Network Manager  
Frailty Network  
Major Trauma Network  
Modernising Radiology Clinical Network  
Neonatal Network  
Paediatric Network  
Pathology Network  
Physical and Sensory Disability  
Regional Trauma Network  
Stroke Network

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### **Regulators**

General Dental Council  
General Medical Council  
Health and Care Professions Council  
Northern Ireland Health Care Chaplains Association & UK Board of Health Care Chaplains  
Northern Ireland Social Care Council  
Nursing & Midwifery Council  
Pharmaceutical Society NI  
Regulation and Quality Improvement Authority

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### **Trade Unions / Professional Bodies**

Allied Health Professions Federation NI  
British Medical Association  
College of Paramedics  
GMB  
Irish College of General Practitioners  
Irish Congress Of Trade Unions NI  
Northern Ireland Public Service Alliance  
Royal College of General Practitioners NI  
Royal College of Midwives NI  
Royal College of Nursing NI  
Royal College of Obstetrics & Gynaecologists  
Royal College of Physicians of Edinburgh  
Royal College of Psychiatrists in NI  
UNISON  
Unite the Union

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### **Training & Education**

Head of HSC Clinical Education Centre  
Northern Ireland Medical & Dental Training Agency  
Project Echo NI



## **Academics / Researchers**

Global Brain Health Institute, Trinity College Dublin  
NI Division of Clinical Psychology Northern HSC Trust  
Research Development, Public Health Agency  
School of Applied Social and Policy Sciences, Ulster University  
School of Health, Wellbeing & Social Care, Open University  
School of History, Anthropology, Philosophy and Politics, Queens University Belfast  
School of Law, Queens University Belfast  
School of Medicine, Dentistry and Biomedical Sciences, Queens University Belfast  
School of Nursing and Midwifery, Queens University Belfast  
School of Nursing, Ulster University  
School of Pharmacy, Queens University Belfast  
School of Psychology, Queens University Belfast  
School of Social Sciences, Education and Social Work, Queens University Belfast

## **Care Homes**

Care Home Lead Independent Health and Care Provider  
Care Home Leads Belfast Locality  
Care Home Leads Northern Locality  
Care Home Leads South Eastern Locality  
Care Home Leads Southern Locality  
Care Home Leads Western Locality  
Care Home Manager Lead (SHSCT)  
Care Home Transformation (PHA)  
Care Homes Clinical Care Network

## **Carer Policy / Services**

Carers Co Coordinator, (SHSCT)  
Elderly and Community Care, Department of Health  
Integrated Care Team, (SHSCT)

## **Interested Parties & Section 75 Groups**

Abbeyfield  
Accord NI  
Action Cancer  
Action for Children  
Action Mental Health  
Action MS  
Action on Elder Abuse  
Action on Hearing Loss  
Addiction NI  
Advice NI  
Afro-Asian Residents Group  
Age NI

Al-Anon  
Alcohol Awareness for Youth  
Alzheimer's Society NI  
Alzheimer's Society NI (User Group)  
Amnesty International  
Amplify NI  
Archbishop of Armagh  
Arthritis Care  
Association for Real Change  
Association of Independent Advice Centres  
Asthma UK  
Autism Initiatives  
Autism Network NI  
Autism NI  
Aware Defeat Depression  
Ballymena Congregational Church  
Barnardo's  
Belfast Butterfly Club  
Belfast Healthy Cities  
Belfast HSC Trust Resus Chair  
Belfast HSC Trust Resuscitation Officer  
Belfast Islamic Association  
Belfast Jewish Community  
Belfast Pride  
Bereavement Network  
Brain Injury Matters  
British Association Of Dental Nurses  
British Deaf Association Belfast  
British Dental Association  
British Fluoridation Society  
British Geriatric Society  
British Geriatrics Society NI Group  
British Heart Foundation NI  
British Psychological Society, David Keir Building NI Sch of Psychology  
British Red Cross  
Brook  
Bryson Care  
Business Services Organisation  
Cancer Focus  
Carers NI  
Centre for Independent living NI  
Chartered Society of Physiotherapy  
Child Accident Prevention Trust

Children in NI  
Children's Law Centre  
Chinese Resource Centre  
Chinese Welfare Association  
Co Operation Ireland (All Island Peace Building organisation)  
Coastal Core  
College of Occupational Therapists  
Committee on the Administration of Justice  
Community Development (BHSCT)  
Community Development Health Network  
Community Evaluation NI  
Community Foundation NI  
Community Pharmacy NI  
Compassion in Dying  
Confederation of Community Groups  
Conservation Volunteers (NI)  
Coroners Service for Northern Ireland  
Corporate Services, (HSCB)  
Council For Catholic Maintained Schools  
Council for Homelessness NI  
Council for Social Witness  
Council for the Homeless  
Council on Social Responsibility Methodist Church in Ireland  
Craic NI (Cultivate Respect, Appreciate Inclusion in Communities NI)  
Cruse Bereavement Care  
Dementia Service Improvement Lead (NHSCT)  
Dementia NI  
Dementia UK  
Department for Infrastructure  
Department for the Economy  
Department of Agriculture Environment and Rural Affairs  
Department of Education Equality Team  
Department of Finance Equality Branch  
Department of Justice Equality  
Derry Well Woman  
Diabetes UK  
Dialogue for Diversity  
Digital Health & Nursing (PHA)  
Diocese of Connor & Down & Dromore (Church of Ireland)  
Disability Action  
Disability Equality Group – NI  
Downs Syndrome Association  
Dunlewey Substance Advice Centre

Dysphagia Coordinator & Project Lead (SHSCT)

Early Years

East Belfast Community Development Agency

Education Authority

eHealth (PHA)

Equality Coalition

Every Day Harmony

Extern

Extra Care

Faith Forum

Faith Groups NI

Falls Community Council

Families Involved NI

Family Care Adoption Services

FOCUS The Identity Trust

Fostering Network

Four Seasons Healthcare

Foyle Down Syndrome Trust

Foyle Newpin NI

Foyle Women's Aid

Gender Identity Panel

General Consumer Council for NI

Guide Dogs NI

Hands That Talk

Harmony Community Trust

Health Care Infection Society

Health Improvement, (PHA)

Healthy Living Centres

HERE NI

Home Start

HSC Trust Resuscitation Committee Chairs

HSC Trust Resuscitation Officers

Huntington Disease NI

IHRD - Inquiry into Hypothermia Related Deaths

Include Youth

Independent Health Care Providers

Independent Living Fund Scotland

Indian Community Centre Belfast

Information Commissioners Office

INSPIRE

Institute of Directors

Institute of Public Health in Ireland

Inter Ethnic Forum

Irish Hospice Foundation  
Irish Traveller Movement (ITM)  
Japan Society of NI  
Jark Downpatrick  
Kidney Research NI  
L'Arche Belfast  
Law Centre NI  
Leonard Cheshire  
LGBT Consortium  
Lifestart Foundation  
Macmillan  
Marie Curie  
Mediation NI  
Mencap  
Mensaid (NI)  
Mental Health and Older People Service (NHSCT)  
Microphthalmia, Anophthalmia & Coloboma Support (MACS)  
Mid & East Antrim Agewell Partnership (MEAAP)  
Migrant and Minority Ethnic Council  
Migrant Centre NI  
MindWise  
MobiriseCooltura - Polish Community Centre  
Motor Neurone Disease Association NI  
Multiple Sclerosis Society  
National Association of Funeral Directors  
National Autistic Society  
National Children's Bureau  
National Deaf Children's Society  
National Middle School Cadet Corps (NMSCC)  
National Society for the Prevention of Cruelty to Children (NSPCC)  
Newtownabbey Senior Citizens Forum  
Nexus  
NI Assembly  
NI Association of Social Workers - BASW-NI  
NI Cancer Registry  
NI Chest Heart & Stroke  
NI Child Minding Association (NICMA)  
NI Community Relations Council (NICRC)  
NI Council for Racial Equality (NICRE)  
NI Federation of Private Members  
NI Fire & Rescue Service  
NI Hospice  
NI Humanists

NI Local Government Association (NILGA)  
NI Pakistani Cultural Association  
NICS LGBT Staff Network  
North West Community Network  
North West Forum of People with Disabilities  
Northern HSC Trust Resuscitation Chair  
Northern HSC Trust Resuscitation Officers  
Northern Ireland Association for the Care and Resettlement of Offenders (NIACRO)  
Northern Ireland Blood Transfusion Service (NIBTS)  
Northern Ireland Commissioner for Children & Young People (NICCY)  
Northern Ireland Confederation for Health and Social Care (NICON)  
Northern Ireland Council for Voluntary Action (NICVA)  
Northern Ireland Federation of Housing Associations (NIFHA)  
Northern Ireland Guardian ad Litem Agency  
Northern Ireland Practice and Education Council for Nursing (NIPEC)  
Northern Ireland Youth Forum  
Now Group  
Oaklee Care and Support Services / Choice Housing  
Oasis Caring in Action  
Omagh Ethnic Support Group  
Organ Donation Consultation Team, Department of Health  
Ormeau Park Surgery  
Parenting NI  
Parkinson's NI  
Participation & Practice Of Rights (PPR)  
Pharmaceutical Society of Northern Ireland  
Playboard NI  
Positive Futures  
Positive Life  
Praxis Care  
Press for Change  
Quaker Service  
Rare Disease Partnership  
RCN Care Home Manager Network/Independent Sector Nurse Managers Network  
Red Cross  
Registered Nursing Home Association  
Relate NI  
Resuscitation Council UK  
Royal British Legion  
Royal College of Anaesthetists (RCOA)  
Royal College of Occupational Therapists  
Royal College of Speech and Language Therapists (RCSLT)  
Royal National Institute of Blind People (RNIB)

Royal Society for the Prevention of Accidents (ROSPA)  
Rural Action  
Rural Community Network  
Rural Support  
Samaritans  
Sense NI  
Shelter NI  
Shine  
Simon Community  
Society of St Vincent de Paul  
South West Age Partnership (SWAP)  
St John's Ambulance  
Step NI  
Stronger Together  
The Baptist Centre  
The British Diabetic Association  
The Cedar Foundation  
The Executive Office Equality and Human Rights  
The Rainbow Project  
The Royal Institution of Chartered Surveyors  
The Society of Radiographers  
The Stroke Association  
Threshold  
Tiny Life  
Twins and Multiple Births Association (TAMBA)  
Ulster Chemists Association  
United Kingdom Home Care Association (UKHCA)  
University of the Third Age  
Versus Arthritis NI  
View Digital  
Voice Of Young People In Care (VOYPIC)  
Volunteer Now  
Welcome Organisation  
Western HSC Trust Resus Chair  
Women's Aid  
Women's Forum Northern Ireland

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### **Northern Ireland Councils**

Antrim and Newtownabbey Borough Council  
Ards and North Down Borough Council  
Armagh City, Banbridge and Craigavon Borough Council  
Belfast City Council  
Causeway Coast and Glens Borough Council

Derry City and Strabane District Council  
Fermanagh and Omagh District Council  
Lisburn and Castlereagh City Council  
Mid and East Antrim Borough Council  
Mid Ulster District Council  
Newry Mourne and Down District Council

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### **NI Political Parties**

Alliance Party for NI  
Democratic Unionist Party  
Progressive Unionist Party  
Sinn Féin  
Social Democratic & Labour Party  
The Green Party  
Traditional Unionist Voice  
Ulster Unionist Party

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### **Other Participants**

Participant 1 - Carer  
Participant 2 – Interested Member of the public  
Participant 3 – Interested Member of the public  
Participant 4 – Interested Member of the public  
Participant 5 – Interested Member of the public  
Carers (SHSCT)  
Carers (SHSCT)  
Carers (SHSCT)  
Carers (SHSCT)  
Carers (SHSCT)

**This is a live Stakeholder Map which is updated by Advance Care Planning Programme Team and continues to be open to the public, interested individuals and organisations. Some organisations may fall under more than one category.**



# APPENDIX 2: Phase I Engagement Feedback Form

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Department of  
**Health**

An Roinn Sláinte

Mánnystrie O Poustie

[www.health-ni.gov.uk](http://www.health-ni.gov.uk)

## **DEVELOPMENT OF A DEPARTMENT OF HEALTH HEALTH RELATED ADVANCE CARE PLANNING POLICY FOR NORTHERN IRELAND (FOR ADULTS)**

### **EARLY STAKEHOLDER ENGAGEMENT SESSION BRIEFING**

Thank you very much for your time and interest to be part of the early stakeholder engagement for this policy development. We are keen to seek your views on the draft Advance Care Planning policy, through discussion of the following 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

Thank you for your time. We look forward to seeking and hearing your views, which will be very valuable to inform this work.

## APPENDIX 3: Phase II Engagement Data Tables

**Table I - Responses to Question 1: Have you read this revised draft Advance Care Planning Policy for Adults?**

Answer choices	Count of all	Count of responses	% of who responded
Yes	102	102	71%
No	41	41	29%
No response	44		
<b>Totals</b>	<b>187</b>	<b>143</b>	

**Table II - Responses to Question 2 Word Cloud: Please tell us briefly what your overall impression of the revised draft Advance Care Planning Policy is?**

This 'Word Cloud' question generated a total of 301 entries with 127 people responding at least once (the more often a word was used, the larger the font of the text).

The results are as follows;

Comprehensive (31 entries), Clear (16 entries), Helpful (13 entries), Necessary (13 entries), Detailed (10 entries), Person Centred (10 entries), Informative (8 entries), Inclusive (7 entries), Compassionate (6 entries), Essential (6 entries), Practical (6 entries), Caring (5 entries), Holistic (5 entries), Thorough (5 entries), Considered (4 entries), Sensitive (4 entries), thoughtful (4 entries), Timely (4 entries), Understandable (4 entries), Useful (4 entries), Complex (3 entries), Patient centred (3 entries).

The following words each received 2 entries; Ambitious, Appropriate, Clinical, Collaborative, Easy to read, Good, Long, Needed, OK, Overdue, Progressive, Reasonable, Relevant, Respect, Supportive, Welcome, Well structured, Wordy,

The remaining words/phrases received one entry each; Accessible, Across lifespan, All encompassing, Almost complete, Broad, Choice, Clarity, Complete, Concise, Easy to read, Coordinated, Could be less repetitive, Covers all the issues, Depends on profiling, Dignified, Dignity, Direct, Easy to understand, Empathetic, Empowering, Encouragement, Encourages conversation, Engaging, Exciting, Excludes family, Getting there, Good aims but a bit vague,

Good draft, Good general overview, Good generally, Good start, Great ideas, Great in theory, High level, Hopeful, Important, Impressive, Incomplete, In depth, Insider, Insightful, Largely logic flow, Legal basis explained, Limited use of jargon, Measured, Mindful, More clarity on audience, Much needed, Non-specific however, not detailed enough for implementation, Not without risk, Personal, Plain English, Positive, Put in context, Quite wordy, Realistic, Responsive, Reassuring, Rights based, Robust, Sensible, Shared decision making, Simple, Slightly Vague, Somewhat impractical, Substantial, Succinct, Therapeutic, Thought out, Thought-provoking, Too complicated, User Friendly, Well advised, Well awaited, Well considered, Well grounded, Well presented, Well thought out, Wishes for end of life, Would like links included, Written for HCPs, Yes, Yes no.

**Table III - Responses for Question 3: Based on the revised draft, do you think the policy will help improve public understanding of Advance Care Planning?**

Answer choices	Count of all	Count of responses	% of who responded
Yes	84	84	59%
No	5	5	3%
Maybe	49	49	35%
Don't know	4	4	3%
No response	44		
<b>Totals</b>	<b>186</b>	<b>142</b>	

**Table IV - Responses for Question 4: Please rate this draft of the policy document in terms of the categories below by entering a score out of 5 after each one; 1 = strongly disagree, through to, 5= strongly agree**

Accessibility and Inclusiveness - please rate this draft of the policy document in terms of the categories below...	No of respondents per score (1-5)					Total respondents	No of respondents giving score $\geq 3$ out of 5		No of respondents giving score $\geq 4$ out of 5	
	1	2	3	4	5					
It is accessible	8	6	33	71	24	142	128	90%	95	67%
It is easy to read	7	6	22	73	33	141	128	91%	106	75%
It flows logically	5	6	16	77	38	142	131	92%	115	81%
It uses clear language	5	8	18	77	35	143	130	91%	112	78%
The diagrams are easy to understand	8	3	18	71	43	143	132	92%	114	80%

**Table V - Responses for Question 5: How well does the policy set out the case that Advance Care Planning is relevant to all adults?**

Answer choices	Count of all	Count of responses	% of who responded
Excellent	33	33	23%
Very good	93	93	68%
Average	12	12	9%
Poor	0	0	0%
No response	50		
<b>Totals</b>	<b>188</b>	<b>138</b>	

**Table VI - Responses for Question 7: Your views on the “Values and Principles” section of the draft policy; please rate the “Values and Principles section of the policy in terms of the categories below by entering a score entering a score out of 5 after each one; 1 = strongly disagree, through to, 5= strongly agree**

Your views of the Values & Principles section; The values and Principles are.....	No of respondents per score (1-5)					Total respondents	No of respondents giving score >3		No of respondents giving score >4	
	1	2	3	4	5					
Clear	3	2	35	67	35	142	137	96%	102	72%
Comprehensive	2	4	40	68	27	141	135	96%	95	67%
Relevant	2	0	25	70	45	142	140	98%	115	81%

**Table VII - Responses for Question 9: One of the policy ambitions is to normalise Advance Care Planning conversations, do you think the draft policy encourages this?**

Answer choices	Count of all	Count of responses	% of who responded
Yes	114	114	79%
No	5	5	4%
Don't know	25	25	17%
No response	44		
<b>Totals</b>	<b>188</b>	<b>144</b>	

**Table VIII - Responses for Question 10: Based on the content of the draft, do you think the policy will...**

**Please enter a score out of 5 after each one; 1 = strongly disagree, through to, 5= strongly agree**

Based on the content of the draft, do you think the policy will...	No of respondents per score (1-5)					Total responses	No of respondents giving score >3	No of respondents giving score >4
	1	2	3	4	5			
Support greater awareness of Advance Care Planning	0	7	34	66	38	145	138	104
Encourage people to have Advance Care Planning conversations	2	17	60	50	17	146	127	67
Help to normalise Advance Care Planning conversations	3	18	57	50	18	146	125	68
Encourage the behaviour change needed to support Advance Care Planning	4	21	65	45	11	146	121	56

**Table IX -Responses for Question 12: Your views on the Advance Care Planning Components model; Please enter a score out of 5 after each of the categories below; 1 = strongly disagree, through to 5= strongly agree)**

Your views on the Advance Care Planning Components model...	No of respondents per score (1-5)					Total responses	No of respondents giving score >3	No of respondents giving score >4
	1	2	3	4	5			
The Components model diagram is clear	4	3	13	74	46	140	133	120
The components model is easy to understand	3	3	17	72	45	140	134	117
The components model is comprehensive	5	7	29	58	41	140	128	99
The components illustrated are relevant	3	2	16	64	55	140	135	119

**Table X - Responses for Question 14: Do you understand how ReSPECT fits within Advance Care Planning?**

Answer choices	Count of all	Count of responses	% of who responded
Yes	129	129	96%
No	5	5	4%
No response	52		
<b>Totals</b>	<b>184</b>	<b>135</b>	

**Table XI - Responses for Question 16: Do you understand how Mental Capacity links to Advance Care Planning?**

Answer choices	Count of all	Count of responses	% of who responded
Yes	124	124	98%
No	3	3	2%
No response	60		
<b>Totals</b>	<b>187</b>	<b>127</b>	

**Table XII - Responses for Question 18: Do you feel there is a role for you personally or your organisation in Advance Care Planning?**

Answer choices	Count of all	Count of responses	% of who responded
Yes	114	114	91%
No	1	1	1%
Maybe	10	10	8%
No response	63		
<b>Totals</b>	<b>188</b>	<b>125</b>	

**Table XIII - Responses for Question 20: How comfortable do you feel about having your own ACP conversation?**

Answer Choices	Count of all	Count of responses	% of who responded
I have done this already	26	26	20%
Very comfortable, keen to do this	48	48	37%
Reasonably comfortable	38	38	30%
Would be hesitant	15	15	12%
Have no intention, it's not relevant for me	1	1	1%
<b>No response</b>	<b>60</b>		
<b>Total responses</b>	<b>188</b>	<b>128</b>	

**Table XIV - Responses to Question 21 Word Cloud; Please enter a word or two on your overall view of this engagement event...**

This 'Word Cloud' question generated a total of 283 entries with 108 people responding at least once (the more often a word was used, the larger the font of the text).

The results are as follows;

Engaging (27 entries), Informative (26 entries), Interactive (13 entries), Inclusive (12 entries), Excellent (11 entries), Well organised (10 entries), Interesting (9 entries), Useful (8 entries), Helpful (7 entries), Positive (6 entries), Clear (5 entries), Encouraging (5 entries), Good (5 entries), Comprehensive (4 entries), Masterclass (4 entries), Thought provoking (4 entries), Easy (3 entries), Important (3 entries), Supportive (3 entries), Well structured (3 entries).

The following words/phrases each received two entries; Brilliant, Concise, Co-production, Different, Enjoyable, Forward thinking, Great, Stimulating, Very good, Well paced, Well presented, Worthwhile.

The following words/phrases were entered once; A bit multiple choice, Accessible, Active participation, Adaptable document, All sectors here, Anticipative, Be flexible, Collaborative, Compassion, Controlled, Done, Easy to follow, Easy to participate, Effective, Empowering, Enjoyed, Enlightening, Essential, Eurovision here you go, Fabulous, Fantastic, Faultless, Felt listened to, Genuine, Genuinely engaging, Glorious, Good format, Good general overview, Good to balance speakers, Good to get started, Great



participation, Great to be able to input, Great to be involved, Hard to sustain attention, Informal, Informed, Innovative, Insightful, Intelligent, Keep going with momentum, Local, Logical progression, Loved Mentimeter, Meaningful, Measured, Menti Meter, Menti works well, Missed verbal interaction, Motivating, Necessary, Need digital literacy, Needed, Non-conversational, One of the best webinars, Paced, Pandemic proofed, Panel open to feedback, Partnership, Perceptive, Perhaps a little shorter, Practical, Pre reading essential, Proactive, Productive, Professional, Progressive, Questions, Quiet, Realistic, Really interesting, Session flowed, Slow, Thank you - great session, The best ever, Thinking, Thorough, Use the feedback, Valued, Very engaging, Very helpful, Very interesting, Very useful, Very well presented, Welcoming, Well done to all involved, Well done to all speakers, Well thought-out, Well timed, Well-led, Wonderful, You have listened.



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