

# Advance Care Planning for Adults Policy

Response from the Commissioner for Older People for Northern Ireland

March 2022

Annex A: Consultation Response Form

<b>Personal details</b>	
Name	The Commissioner for Older Persons Northern Ireland
Email address	info@copni.org
Please select the option that best describes your interest in the Advance Care Planning Policy for Adults in Northern Ireland	Representing an Organisation.
Organisation <i>(if applicable)</i>	The Office of the Commissioner for Older Person Equality House, 7-9 Shaftesbury Square, Belfast, BT2 7DP

Draft Advance Care Planning Policy Consultation Questions

Number	Section Title in Policy	Question	
1	Ambition of Advance	Do you agree with the ambition of the Advance Care Planning policy? (Please Tick)	Yes

	<p><b>Care Planning</b>  (page 6)</p>	<p>Advance Care Planning, and discussions around the subject are very important for all members of society and have particular importance for older person’s and their carers. COPNI agrees with the ambition of the policy but also acknowledges that it is no doubt an ambitious one and it will be challenging to achieve its goals.</p> <p>ACP discussions can require sensitive approaches and preparation for both clinicians, patients loved ones and carers especially if they are to provide patients with real choices. Older people, especially those with cognitive impairment, are particularly vulnerable in this context.</p> <p>Any further discussion or improvements around this can only to ease the burden around ACP discussions.</p>	
<p>2</p>	<p><b>What is Advance Care Planning?</b>  (page 6)</p>	<p>Does the policy clearly explain what Advance Care Planning is? (Please Tick)</p>	<p>Yes</p>
		<p>On reviewing the policy, COPNI believes that it does clearly explain Advance Care Planning (ACP) and its importance.</p> <p>For future guidance on best practice for clinicians and guidance for patients, their relatives, and carers it may be worth considering giving greater focus to dealing with the issue of nominated individuals, such as those with Power of Attorney and the fact that unlike in other UK regions they are unable to make decisions on medical treatment and how this issue might be navigated by those affected.</p> <p>Within what is described as the financial component of ACP there is no reference to making plans regarding the cost of care and planning for future situations were persons may have to enter residential care. The potential future cost of future residential care and related aspects should be considered in any ACP policies or related guidance.</p>	
<p>3</p>	<p><b>Values &amp; Principles of Advance</b></p>	<p>Are the Values and Principles stated in the policy clear, comprehensive and relevant?</p>	<p>Yes</p>

	<p><b>Care Planning</b></p> <p>(page 7 and page 8)</p>	(Please Tick)	
		<p>On reviewing the document, the Values and Principles are stated in a clear and comprehensive manner. However, it is important that people are clear on the difference between decisions regarding financial matters and issues of treatment.</p> <p>It is also important that those in involved in ACP know what legal instruments are available to them to make ACP discussions legally binding where appropriate, and that they know what the limitations of these frameworks and instruments are. For example, that individuals in Northern Ireland cannot currently make decisions on treatment on behalf of someone else.</p>	
4	<p><b>Why is it important to have Advance Care Planning Conversations?</b></p> <p>(page 8 and page 9)</p>	<p>Does the policy clearly explain the benefits of Advance Care Planning? (Please Tick)</p>	<p>Yes</p>
		<p>The policy explains the benefits of ACP for all age groups. However, more detail is required on how to achieve greater engagement with the subject and the barriers to such discussions about ACP and related subjects such as wills.</p> <p>Recent research has indicated that over 80% of people in Northern Ireland have not made a Will<sup>1</sup>.</p> <p>1. <a href="https://www.nihospice.org/news/2021/february/northern-ireland-hospice-launches-annual-make-a-will-month-campaign">https://www.nihospice.org/news/2021/february/northern-ireland-hospice-launches-annual-make-a-will-month-campaign</a></p>	
5	<p><b>When should Advance Care Planning happen?</b></p> <p>(page 10)</p>	<p>Do you agree that Advance Care Planning is important for any adult at any stage of life? (Please Tick)</p>	<p>Yes</p>
		<p>COPNI agrees that this ACP is important at any age. Having younger people engaged in the subject will help to mitigate the issue</p>	

		experienced as they get older and are more likely to need to avail of the benefits of having such plans in place.	
6	<p><b>How Advance Care Planning Conversation(s) are used</b></p> <p>(page 15 and page16)</p>	Do you understand how Advance Care Planning conversations are used? (Please Tick)	Yes
		<p>Under current legislation in respect to medical treatment ACP plans can only be used to inform and guide healthcare providers to guide and inform 'best interests' decisions. Although such plans are also important in terms of other matters such as financial matters and funeral arrangements.</p> <p>More clarity is needed on what members of the public should have these conversations with. In the case of a person losing capacity or becoming chronically ill it is important that guidelines are in place for members of the public and healthcare providers as to who would be the best person(s) to engage in such conversations. There may be many different situations where there are conflicting opinions about what is best for the person affected. For example, for an older person, discussions around care could involve spouses, children, partners, carers, or other direct relatives.</p> <p>There are also common misconceptions around common law partnerships. Couples who live together, also called co-habitants, do not hold the same rights as married couples or civil partners. Recent research carried out in 2019 in England and Wales showed that 50% of people mistakenly believe that unmarried couples who live together have a common law marriage and enjoy the same rights as couples that are legally married<sup>1</sup>.</p> <p>Any further work undertaken to employ these policies would need to take consideration of such factors and provide clear guidance on who can be consulted in the event of the need for ACP and who is person(s) best to have such conversations with.</p> <p>This issue is of relevance for healthcare providers and loved ones regarding the proposal to adopt, Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms.</p> <p>1. <a href="http://socialsciences.exeter.ac.uk/law/newsandevents/news/articles/almosthalfofusmistakenlybe.php">http://socialsciences.exeter.ac.uk/law/newsandevents/news/articles/almosthalfofusmistakenlybe.php</a></p>	

7	<b>Components of Advance Care Planning</b>  (page 16)	Does the components model help explain the different elements of Advance Care Planning? (Please Tick)	Yes
		<p>The differing components of ACP are well explained including the differing aspects of legal and clinical.</p> <p>It would be helpful for future documentation or guides for stakeholders to clearly explain which ACP decisions can be made and by whom, and when there may be a need to employ legal instruments such as the different forms of Power of Attorney.</p> <p>For example, under the ‘Personal’ section of the four components of ACP, it includes online accounts. As the integration between smartphones, social media accounts and financial services grows it may be important to ensure that people consider this aspect when discussing ACP.</p>	
8	<b>Legal Component of Advance Care Planning</b>  Mental Capacity Act (NI) 2016  (page 19 to page 22)	Is the policy clear on how mental capacity relates to Advance Care Planning? (Please Tick)	Yes
		<p>Given that legislative matters and the interpretation of legal text can be sometimes difficult for lay persons, COPNI believes that the draft document is clear on how mental capacity and the Mental Capacity Act (NI) 2016 and how it applies to ACP.</p> <p>As with all the topics covered in the strategy, further consideration will be needed to ensure there is a wider understanding of the implications of mental capacity and attendant legislation. In addition, there will be a need to ensure that this information is both widely available and accessible to all persons engaging in discussion around ACP and those most likely to be affected by mental capacity issues.</p>	
9	<b>Clinical Component of Advance Care Planning</b>	Is the policy clear on:	Yes
		(a) How the ReSPECT recommendations form part of Advance Care Planning? (Please Tick)	

	Declining Health and Unexpected Emergencies		
	(pages 26 to page 29)	The policy is clear on ReSPECT recommendations as these are not yet common practice in Northern Ireland, there will be a need to ensure adequate training for healthcare providers, including the provision of accessible and easy to use sources of information for health services users, carers, family members and relevant stakeholders.	
	Is the policy clear on:		Yes
	(b) How resuscitation recommendations will be recorded on the ReSPECT form, and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms will no longer be used? (Please Tick)		
	This aspect is explained well within the document. Again, as with all aspects of the ACP process proposed within the policy it is important that adequate training and sources of information are available to explain the process and the implications for those involved in the process.		

<p>10</p>	<p>Further comments</p>	<p>Further comments relating to the Advance Care Planning Policy can be noted below.</p> <p>COPNI welcomes the formation of an ACP policy. The complexity of the issue, and the current lack of engagement on ACP aspects such as wills will mean that achieving the goals of the policy will be challenging. Greater consideration is needed on the funding of later life care and the cost of residential care.</p> <p>Further work will be required to ensure both increased public engagement and the provision of accessible and clear information to support this.</p> <p>In summary COPNI would make the following recommendations:</p> <ul style="list-style-type: none"> <li>• COPNI agrees with the ambition of the policy but also acknowledges that it is no doubt an ambitious one and it will be challenging to achieve its goals.</li> <li>• For future guidance on best practice for clinicians and guidance for patients, their relatives, and carers it may be worth considering giving greater focus to dealing with the issue of nominated individuals, such as those with Power of Attorney unlike in other UK regions, where they are unable to make decisions on medical treatment - and how this issue might be navigated by those affected.</li> <li>• It is also important that those involved in ACP know what legal instruments are available to them to make ACP discussions legally binding where appropriate. Additionally, they need to be aware what the limitations of these frameworks and instruments are.</li> <li>• Consideration is needed on the potential future cost of residential care, and the related aspects in relation to ACP policies and guidance.</li> <li>• More detail is required on how to achieve greater engagement about ACP and the barriers to such discussions, for instance on greater utilisation of wills.</li> <li>• Any further work undertaken to employ these policies would need to provide clear guidance on who can be consulted in ACP and who best to have such conversations with.</li> </ul>
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		<ul style="list-style-type: none"> <li>• Future documentation or guidance for stakeholders clearly needs to explain which ACP decisions can be made and by whom and when there may be a need to employ legal instruments such as the different forms of Power of Attorney. For example, under the ‘Personal’ section of the four elements of ACP it includes online accounts. As the integration between smartphone and social media accounts and financial services grows it may be important to ensure that people consider this aspect when discussing ACP.</li> <li>• Mental Capacity - As with all the topics covered in the strategy further consideration will be needed to ensure there is a wider understanding of the implications of mental capacity and attendant legislation. In addition, there will be a need that this information is both widely available and accessible to all persons engaging in discussion around ACP and those most likely to be affected by mental capacity issues.</li> <li>• ReSPECT- There will be a need to ensure adequate training for healthcare providers and provision of accessible and easy to use sources of information for health services users, carers, family members and relevant stakeholders.</li> </ul>
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## Annex B: Impact Screening Outcomes

Impact assessment screening documents are available on request [acpconsultation@health-ni.gov.uk](mailto:acpconsultation@health-ni.gov.uk).

A summary of the outcome of each is provided in the table below:

Impact Assessment Screening	Outcome
Equality/Human Rights	Full Equality Impact Assessment has been undertaken and will be consulted on
Regulatory	

	No significant impact identified – full impact assessment not required
Rural	No significant impact identified – full impact assessment not required

## Equality and Human Rights

Section 75 of the [NI Act 1998](#) requires departments in carrying out their functions relating to NI to have due regard to the need to promote equality of opportunity:

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

## Equality Impact Assessment Questions:

<b>Question 1:</b> Are the proposals set out in the draft Advance Care Planning policy likely to have any potential adverse impact on any of the nine equality groups identified under Section 75 of the 1998 Act? (Please Tick)	Yes	
<p>Without appropriate accessible and comprehensive information on changes to current ACP provisions such as the new ReSPECT process and clarity on the legal aspects of ACP for service users, loved ones and carers there is a risk that confusion surrounding these issues could add to the stress of already challenging events in people’s lives. Older persons are more likely to encounter situations were elements such as lasting power of attorney or ReSPECT forms become matters for consideration. Conversations around ACP will have benefit, but it is not clear how these will be recorded or verified, especially in the case of disputes between relatives or carers of persons impacted by a loss of capacity when formal instruments such as ReSPECT forms have not been completed. While current and proposed policy and legislation does allow for input from next of kin and carers to input to “Best Interest” decisions by clinicians. Clarity is needed around who people that are considering ACP in the event of future illness or loss of capacity should have these conversations with and how they can ensure that their wishes are enacted in the event of a loss of capacity or serious illness. Further work in this area should seek to provide clarity to help eliminate the potential of disputes in relation to care on behalf of those who face a loss of capacity or terminal illness.</p>		

<p><b>Question 2:</b> Are you aware of any indication or evidence – qualitative or quantitative – that the Advance Care Planning policy may potentially have an adverse impact on equality of opportunity or on good relations? (Please Tick)</p>	Yes	
<p>If ACP policies, procedures and sources of information do not adequately take account of issues relating to protected characteristics such as age, religion and disability there is a risk that this may impact adverse impact on equality of opportunity or on good relations.</p> <p>For example, those living with cognitive impairment may require information to be provisioned in differing formats or those with specific religious beliefs whose beliefs may conflict with best interest decisions and the current situation in Northern Ireland whereby third parties are legally unable to make decisions on treatment even when granted lasting power of attorney.</p> <p>A 2017 report by the NHS: “Involving people in their own health and care Equality and health inequalities”<sup>1</sup> found that there was risk of inequalities in end-of-life treatment for those with protected characteristics. The report found that discrimination in relation to age may arise, where assumptions are made in relation to someone’s capability to exercise choice and control over their health, care and wellbeing. In the case of older people, they may face discrimination due to assumptions made around their mental capacity, or because of digital exclusion where key resources are only available online.</p> <p>In relation to disability, the report found that discrimination may arise where disabled people are prevented or not enabled to be equal partners in the decisions about their health, care and wellbeing. Barriers linked to digital exclusion may include inaccessible websites and electronic publications which may leave disabled people unable to access documents and information relating to their care. The report recommended that consideration should be given to the need for information in alternative formats such as braille, audio or ‘Easy Read’.</p> <p>1. <a href="https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-individual-involvement-equalities-analysis.pdf">https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-individual-involvement-equalities-analysis.pdf</a></p>		
<p><b>Question 3:</b> Is there an opportunity to better promote equality of opportunity or good relations? (Please Tick)</p>	Yes	

<p>To promote equality of opportunity and good relations, in respect to older persons COPNI would recommend the following:</p> <ul style="list-style-type: none"> <li>• Consider how to help healthcare providers identify and address the needs of those who experience hidden discrimination, to ensure that they can be involved meaningfully in ACP.</li> <li>• When drafting and planning educational and informational resources that relevant authorities use, a flexible range of methods are required to ensure involvement from potentially excluded groups, including those who may be digitally excluded or have cognitive issues that require alternative formats.</li> <li>• COPNI welcomes the existing research undertaken by the DoH with the University of Ulster on engagement with ACP. COPNI would also recommend further research and reviewing existing research to understand, how people with protected characteristics such as age or disability feel about planning their own care, and their opinions on information sources and processes relating to ACP as these are being developed.</li> </ul>		
<p><b>Question 4:</b> Are there any aspects of the Advance Care Planning policy where potential human rights violations may occur? (Please Tick)</p>	<p>Yes</p>	
<p>If ACP policies are not appropriately delivered, and if healthcare users, carers and loved ones are not fully aware of their rights or in cases where there is no ACP in place there is a risk that human rights violations may occur. Some examples of this are:</p> <p><b>Do not attempt cardiopulmonary resuscitation’ (DNACPR)</b> - In April 2021 the Care Quality Commission (CQC) in England published “Protect, respect, connect – decisions about living and dying well during COVID-19”<sup>1</sup> a review of ‘do not attempt cardiopulmonary resuscitation’ decisions during the coronavirus (COVID-19) pandemic. The review found from that start of the pandemic, there have been concerns that ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions were being applied to groups of people rather than considering each person’s individual circumstances.</p> <p>The review found that some users experienced compassionate, person-centred care and were fully involved in conversations, and their rights upheld. However, there were occasions when this did not happen which was distressing for families and carers and that</p>		

conversations took place at short notice with people did not fully understanding what was happening or what a DNACPR was.

**Home Care** - The Equality and Human Rights Commission (ECHR) for Great Britain first published an inquiry in 2011: “Close to home, an inquiry into older people and human rights in home care”. The inquiry found that most of the older people using home care had little or no understanding of how the home care process works or what they were entitled to, what they had a right to expect, or the different options for managing their care. Some found the system too complex and difficult to understand. The ECHR published a further statement in 2021 on the inquiry<sup>2</sup> reiterating the issues with home care and its implications on human rights and the continued need for reform.

**Care Homes**- In 2018, COPNI published its “Home Truths” report an investigation into issues at the Dunmurry care home. In relation to findings regarding safeguarding and human rights, the investigation found many examples of issues where residents rights were breached and their wishes were not sought or adhered to.

The report made 59 recommendations with 7 specific recommendations in relation to Safeguarding and Human Rights.

Of these 7 recommendations there were a number that related to the planning of care and involvement of relatives and carers and are relevant to ACP. These were:

- All staff in care settings, commissioners of care, social care workers, and regulators must receive training on the implications of human rights for their work
- Practitioners must be trained to report concerns about care and treatment in a human rights context.
- Policies and procedures relating to the care of older people should identify how they meet the duty to be compatible with the European Convention on Human Rights.

In relation to care planning and involvement of family the report also made the following recommendation:

- There should be meaningful family involvement in care and treatment plans and decision making at all key milestones. Electronic or written care plans should be available to families on request, including nutritional information.

1. <https://www.cqc.org.uk/publications/themed-work/dnacpr-conclusion>

<ol style="list-style-type: none"><li>2. <a href="https://www.equalityhumanrights.com/en/inquiries-and-investigations/inquiry-home-care-older-people/background-home-care-inquiry">https://www.equalityhumanrights.com/en/inquiries-and-investigations/inquiry-home-care-older-people/background-home-care-inquiry</a></li><li>3. <a href="https://www.copni.org/media/1444/copni-home-truths-summary-report-web.pdf">https://www.copni.org/media/1444/copni-home-truths-summary-report-web.pdf</a></li></ol>		
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Commissioner for **Older People**  
for Northern Ireland