



Department of Health

An Roinn Sláinte

Máinystrie O Poustie

www.health-ni.gov.uk

Advance Care Planning Policy for Adults In Northern Ireland

Consultation Document

December 2021



Advance Care Planning Policy For Adults In Northern Ireland

Draft Policy For Public Consultation
December 2021



Advance Care Planning Policy For Adults In Northern Ireland

Draft Equality Impact Assessment for Public Consultation
December 2021



The Draft Advance Care planning Policy Consultation and Equality Impact Assessment (EQIA)

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How to Respond to the Draft Advance Care Planning Policy Consultation and Equality Impact Assessment (EQIA) Consultation

We are seeking your views as part of our consultations on;

- The draft Advance Care Planning policy
- Equality Impact Assessment

Please see questions in **Annex A**. You can choose to respond to both or either of the consultations. We invite responses from 17th December 2021 and the consultation closes at **5pm on 11th March 2022**.

When submitting your responses, it would be very useful if you could confirm whether you are replying as an individual or submitting a response on behalf of an organisation.

If you are replying on behalf of an organisation, please include:

- Your name;
- Name of your organisation;
- E-mail address.

There are **3 options** for accessing the relevant documents and responding to the Draft Advance Care Planning policy consultation and Equality Impact Assessment (EQIA) consultation. Choose from the 3 options below:

Option 1: Online

Complete the online questionnaires for the consultations online:

<https://consultations2.nidirect.gov.uk/doh-1/advancecareplanning-policy-adults-ni>

Option 2: Paper Copy

If you are unable to access the consultation online, you can request a paper copy of the consultation documents;

- By **telephoning** the dedicated Patient Client Council number **02895 368542**.
- Via **email** acpconsultation@health-ni.gov.uk.

A pre-paid envelope will be provided to return your completed responses.

Option 3: Telephone Support

Telephone number **02895 368542** can be used to speak directly to an operator (Monday - Friday, 9am-5pm).

The operator can:

- **Post a Consultation Pack** to you and provide a pre-paid envelope to return completed responses.
- **Answer any queries** you may have about submitting your response online using Citizen Space.
- **Complete the Advance Care Planning policy &/or EQIA consultations** by inputting your responses directly online to Citizen Space. You may request a copy of your response.
- **Put in place accessibility arrangements** such as interpreter service or sign language or any alternative format(s) for example braille.

Available Formats of Consultation Documents

The consultation documents will be available in the following formats on the dates listed below from <https://www.health-ni.gov.uk/consultations>;

Format	Available From
Arabic	17 th December 2021
Audio	15 th January 2022
Braille	17 th December 2021
British Sign Language	15 th January 2022
English	17 th December 2021
Irish Gaelic	17 th December 2021
Irish Sign Language	15 th January 2022
Large Print	17 th December 2021
Lithuanian	17 th December 2021
Mandarin	17 th December 2021
Polish	17 th December 2021
Portuguese	17 th December 2021
Romanian	17 th December 2021
Ulster Scots	17 th December 2021
Urdu	17 th December 2021
Video with subtitles	15 th January 2022

If you require the documents in any additional languages, please email acpconsultation@health-ni.gov.uk

Interpreting Services

Sign Language Interpreting Service

There is a free remote interpreting service available for those who wish to engage in the consultations in British Sign Language (BSL) and Irish Sign Language (ISL) in Northern

Ireland, via the SignVideo <https://signvideo.co.uk/hscni/> (previously InterpreterNow). The service is available;

- **On demand service**
BSL and ISL interpreters available between 9am – 5pm, Mon-Fri.
- **Pre-booked sessions**
Pre booked sessions will be available in January and February.

Spoken Language Interpreting Services

There is a free remote interpreting service available for those who wish to engage in the consultations in a language other than English. There are additional languages available in this service to those noted above. To access this service contact the dedicated Patient Client Council number **02895 368542** and they will arrange for an interpreter to join the call.

Option	Method	How
1	Access the consultation documents and respond online	https://consultations2.nidirect.gov.uk/doh-1/advancecareplanning-policy-adults-ni
2	Request a paper copy of the consultation documents	02895 368542 Or by e-mail at acpconsultation@health-ni.gov.uk
3	Telephone support to complete consultation response and/or make accessibility arrangements	02895 368542

Overview

Advance Care Planning is an umbrella term covering personal, legal, clinical, and financial planning. It enables a person to think about what is important to them and plan for their future. It is a voluntary process and helps a person to make known what their wishes, feelings, beliefs and values are, and to make choices that reflect these. A person's Advance Care Planning conversations, any recommendations and/or decisions will be used in the future should a person become unable to make the relevant decisions for themselves at any point. We would welcome your views on the draft Advance Care Planning policy for Adults (aged 18 years and over) in Northern Ireland.

The draft Advance Care Planning policy provides a framework for Advance Care Planning for adults (aged 18 years and over) in Northern Ireland, focusing on the health and social care aspects. The policy provides an overview of Advance Care Planning, and the values and principles that underpin it. It sets out why Advance Care Planning is important and how it can help people make timely, realistic and practical plans for their future. It encourages these plans to be made in conversation with those who are important to them and/or someone providing care, support or treatment (this includes people working within the community and voluntary sector, independent sector and other health and social care staff working in statutory services).

The draft Advance Care Planning policy aims to support a person to have greater choice and control over decisions, including plans for their future care and treatment. The ambition of the policy is that Advance Care Planning conversations become normalised; all adults in Northern Ireland (NI) have regular opportunities to express their wishes, feelings, beliefs and values in relation to Advance Care Planning; and these are then reflected in the care, support or treatment they receive.

To provide strategic advice and oversee the development of the Advance Care Planning policy, a Steering Group was established comprising policy leads from the Department of Health, Health and Social Care Board and Public Health Agency, as well as the Chair of the Regional Clinical Ethics Forum and an interested member of the public and a carer representative. A Programme Team was established to develop the Advance Care Planning

policy and its supporting Advance Care Planning implementation programme, to include operational guidance, education and training and public messaging.

Why Your Views Matter

The draft policy has been developed using a co-production approach with extensive stakeholder engagement and input. Stakeholders included service users, carers, interested members of the public, and those from community and voluntary organisations, research/academia, health and social care professionals and their representative bodies.

(For more information on this please see the supporting document: [Early Stakeholder Engagement Report published as part of this consultation](#)).

The next phase of engagement is to complete a public consultation to seek further views on the draft Advance Care Planning policy and Equality Impact Assessment.

Impact Assessments

A number of impact assessment screenings have been completed and are noted in **Annex B** of this document. A full Equality Impact Assessment (EQIA) has been completed and will be launched in parallel with the draft Advance Care Planning policy for a 12 week public consultation.

The full screening documents are also available as part of the suite of consultation documents.

What Happens Next

A number of virtual information sessions will be held to let you know how you can respond to the consultations.

Thursday 20th January 2022 at 10am

Wednesday 2nd February 2022 at 2:30pm (BSL Session)

Tuesday 8th February 2022 at 2:30pm (ISL Session)

Thursday 10th February 2022 at 2pm

Tuesday 15th February 2022 at 6:30pm

You can register for these events via: <https://pcc-ni.net/get-involved/advance-care-planning/>

Following the close of the consultation on **11th March 2022 at 5pm**, all responses and feedback will be collated for review by the Department of Health, and a consultation report will be produced.

The consultation report will be published alongside the final Advance Care Planning policy and EQIA report.

Privacy, Confidentiality and Access to Consultation Responses

We will publish a summary of the consultation responses and, in some cases, the responses themselves but these will not contain any personal data. We will not publish the names or contact details of respondents, but will include the names of organisations responding.

Your response, and all other responses to this consultation, may also be disclosed on request in accordance with the Freedom of Information Act 2000 (FOIA) and the Environmental Information Regulations 2004 (EIR); however all disclosures will be in line with the requirements of the Data Protection Act 2018 (DPA) and the UK General Data Protection Regulation (UK GDPR).

If you want the information that you provide to be treated as confidential it would be helpful if you could explain to us why you regard the information you have provided as confidential, so

that this may be considered if the Department should receive a request for the information under the FOIA or EIR.

For further information on how we will process data and your rights, see the Advance Care Planning Policy Consultation Privacy Notice at **Annex C**.

Annex A: Consultation Response Form

Personal details	
Name	
Email address	
Please select the option that best describes your interest in the Advance Care Planning Policy for Adults in Northern Ireland	<p>I am a Carer</p> <p>I am a Health & Social Care Professional</p> <p>I am a Service User</p> <p>I am an Interested Individual</p> <p>I am representing an Organisation</p> <p>Other</p>
Organisation <i>(if applicable)</i>	

Draft Advance Care Planning Policy Consultation Questions

Number	Section Title in Policy	Question	
1	<p>Ambition of Advance Care Planning</p> <p>(page 6)</p>	Do you agree with the ambition of the Advance Care Planning policy? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	
2	<p>What is Advance Care Planning?</p> <p>(page 6)</p>	Does the policy clearly explain what Advance Care Planning is? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	

3	Values & Principles of Advance Care Planning (page 7 and page 8)	Are the Values and Principles stated in the policy clear, comprehensive and relevant? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	
4	Why is it important to have Advance Care Planning Conversations? (page 8 and page 9)	Does the policy clearly explain the benefits of Advance Care Planning? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	

5	When should Advance Care Planning happen? (page 10)	Do you agree that Advance Care Planning is important for any adult at any stage of life? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	
6	How Advance Care Planning Conversation(s) are used (page 15 and page16)	Do you understand how Advance Care Planning conversations are used? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	

7	Components of Advance Care Planning (page 16)	Does the components model help explain the different elements of Advance Care Planning? (Please Tick)	Yes
			No
		Please provide any further information you wish to share on your answer.	
8	Legal Component of Advance Care Planning 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
			No
		Please provide any further information you wish to share on your answer.	

9	Clinical Component of Advance Care Planning Declining Health and Unexpected Emergencies (pages 26 to page 29)	Is the policy clear on:	Yes
		(a) How the ReSPECT recommendations form part of Advance Care Planning? (Please Tick)	No
		Please provide any further information you wish to share on your answer.	
		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)	No
		Please provide any further information you wish to share on your answer.	

10	Further comments	Further comments relating to the Advance Care Planning Policy can be noted below.

Annex B: Impact Screening Outcomes

Impact assessment screening documents are available on request 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:

<p>Question 1: 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)</p>	Yes	
	No	
<p><i>If yes, please state the group(s) and provide comment on how these adverse impacts could be reduced or alleviated in the proposals:</i></p>		

Question 2: 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)	Yes	
	No	
<i>If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact:</i>		
Question 3: Is there an opportunity to better promote equality of opportunity or good relations? (Please Tick)	Yes	
	No	
<i>If yes, please give details as to how:</i>		

<p>Question 4: Are there any aspects of the Advance Care Planning policy where potential human rights violations may occur? (Please Tick)</p>	Yes	
	No	
<p><i>If yes, please give details as to how:</i></p>		

Annex C: Advance Care Planning Policy Privacy Notice

Data Controller Name: Department of Health (DoH)

Email: acpconsultation@health-ni.gov.uk

Telephone: 02890520241

Data Protection Officer Name: Charlene McQuillan

Telephone: 02890522353

Email: DPO@health-ni.gov.uk

Being transparent and providing accessible information to individuals about how we may use personal data is a key element of the [Data Protection Act \(DPA\)](#) and the UK General Data Protection Regulation (UK GDPR). The Department of Health (DoH) is committed to building trust and confidence in our ability to process your personal information and protect your privacy.

Purpose for processing

The Department of Health has developed an Advance Care Planning Policy for adults (aged 18 year and over) in Northern Ireland which is published for public consultation. We are encouraging organisations and institutions to respond but also interested members of the public, service users and carers. We will process personal data provided in response to consultations for the purpose of informing the policy. We will publish a summary of the consultation responses and, in some cases, the responses themselves but these will not contain any personal data. We will not publish the names or contact details of respondents, but will include the names of organisations responding.

Lawful basis for processing

The lawful basis we are relying on to process your personal data is Article 6(1) (e) of the UK GDPR, which allows us to process personal data when this is necessary for the performance of our public tasks in our capacity as a Government Department.

We will only process any special category personal data you provide, which reveals racial or ethnic origin, political opinions, religious belief, health or sexual life/orientation when it is necessary for reasons of substantial public interest under Article 9(2)(g) of the UK GDPR, in the exercise of the function of the Department, and to monitor equality.

How will your information be used and shared?

We will process the information for the above stated purpose. The information will be shared with the Advance Care Planning Programme Team comprised of representatives from the Department of Health, the Health and Social Care Board, the Public Health Agency and Patient and Client Council to enable consultation responses to inform the policy development. Where information is provided by a consultation respondent in an alternative format, we will share this information with an approved translation service in line with information governance requirements. Where a consultation respondent uses the consultation support service to enable their response to the consultation to be made, by doing so the respondent is agreeing to sharing their information with that service for that purpose. We don't intend to share your personal data with any other third party. Any specific requests from a third party for us to share your personal data with them will be dealt with in accordance the provisions of the data protection laws.

How long will we keep your information?

We will retain consultation response information until our work on the subject matter of the consultation is complete, and in line with the Department's approved Retention and Disposal Schedule [Good Management, Good Records](#) (GMGR).

What are your rights?

- You have the right to obtain confirmation that your data is being [processed, and access to your personal data](#)
- You are entitled to have personal data [rectified if it is inaccurate or incomplete](#)
- You have a right to have personal data [erased and to prevent processing](#), in specific circumstances
- You have the right [to 'block' or suppress processing](#) of personal data, in specific circumstances
- You have the right to [data portability](#), in specific circumstances
- You have the right to [object to the processing](#), in specific circumstances
- You have rights in relation to [automated decision making and profiling](#).

How to complain if you are not happy with how we process your personal information

If you wish to request access, object or raise a complaint about how we have handled your data, you can contact our Data Protection Officer using the details above.

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF
casework@ico.org.uk