

Department of Health

By email only: acpconsultation@health-ni.gov.uk

11 March 2022

Dear Sir/Madam,

Re: Public Consultation - Advance Care Planning Policy for Adults in Northern Ireland

1. The Information Commissioner is pleased to respond to the Department of Health (DoH) in Northern Ireland, regarding its public consultation on 'Advance Care Planning Policy for Adults'.
2. The Commissioner has responsibility for promoting and enforcing the UK General Data Protection Regulation (UK GDPR), the UK Data Protection Act 2018 (DPA 2018) and additional information rights legislation.
3. The Commissioner is independent of government and upholds information rights in the public interest, promoting openness by public bodies and data privacy for individuals. The Commissioner does this by providing guidance to individuals and organisations, solving problems where he can, and taking appropriate action where the law is broken.
4. Integrating Advance Care Planning (ACP) into society is intended to help normalise additional support and offer greater choice and control over an individual's plans for their future care and treatment. A person's ACP conversations, recommendations and decisions is understood to be beneficial should they become unable to make relevant decisions for themselves.
5. We welcome the opportunity to respond to the above consultation and it is acknowledged that the document sets out non-statutory draft guidance concerning the voluntary advance care planning for adults.
6. It is acknowledged that third party controllers will be required to process personal data for the purposes of executing the proposed policy, and consequently they will be required to consider the application of the data protection legislation. Our response to the consultation will predominately relate to the provision of guidance

which the DoH may wish to communicate to those executing the policy.

General observations

7. It would be useful to make explicit reference to the application of the data protection regime in the guidance produced by DoH. We recommend that any questions about data protection legislation should be raised with the organisations Data Protection Officer (DPO). Part of the DPO's role under the UK GDPR is to advise and inform their organisation of their obligations under the relevant data protection laws. The DPO must be involved from the outset in relation to any and all issues relating to data protection.

Data protection by design and default

8. DoH will need to comply with [data protection by design and default](#) under Article 25 of the UK GDPR during the drafting and implementation of the ACP Policy. Implementing technical and organisational measures at the initial phases of the design process and operation could lead to the safeguarding of privacy and data protection principles from the onset of the policy.

DPIA

9. Organisations having to implement the ACP Policy should consider carrying out a Data Protection Impact Assessment (DPIA) on how they plan to do so. There is [guidance](#) available on our website about conducting a DPIA.
10. Article 35(1) of the UK GDPR requires controllers to carry out a DPIA prior to conducting processing that are likely to result in a high risk to the rights and freedoms of individuals. It is for the controller to determine whether the threshold of requiring a DPIA is reached, but our guidance expands on what factors organisations should consider.
11. One of the criteria for needing a DPIA relates to data concerning [vulnerable data subjects](#). Whilst there may be a number of reasons as to why an individual or sections of society may be considered vulnerable, one of the reasons may be due to an imbalance of power in their relationship with a controller which can cause vulnerability for data protection purposes if they believe that they will be disadvantaged if the processing does not go ahead. The ICO

therefore recognises a participant may be subjected to an imbalance (or perceived imbalance) of power when receiving medical or social care or guidance, and as such a DPIA is likely be required.

12. A DPIA will assist with identifying any potential risks associated with proposed personal data processing. As part of this, organisations should consider areas such as human error data breaches, inappropriate access to sensitive information, staff training, data storage and data transfer mechanisms. Article 25 of the UK GDPR mandates that, at the time of the determination of the means of processing and at the time of the processing itself, appropriate technical and organisational measures should be in place to implement data protection and to integrate the necessary safeguards into the processing.

Lawfulness

13. As controllers, it is a requirement to comply with the data protection principles of the UK GDPR. Principle A of the UK GDPR states that personal data should be processed lawfully, fairly and in a transparent manner.
14. To comply with the lawfulness strand of principle A, organisations implementing the ACP Policy will need to consider their lawful basis for their processing under Article 6 of the UK GDPR. Where processing relates to special category data, an additional basis will also be required under Article 9 of the UK GDPR, and where appropriate, a schedule 1 condition for processing under the DPA 2018. The relevant basis for processing should be identified before the implementation of the ACP policy.
15. Consent is one of the lawful basis available under Article 6, but it is one of a wider six options and is not always the most appropriate basis for processing personal data. Caution should be exercised when referring to consent in any guidance as there is a distinction between consent under UK GDPR as opposed to clinical consent, or consenting to the ACP initiative as a whole.
16. We therefore believe the wording in lines 1-4 under the section titled "Principles of Practice", line 15 under "Why is it important to have Advance Care Planning conversations?", as well as the definition of consent under Appendix 1, should be amended to clarify whether participants are consenting under the UK GDPR or

another process. Given the high standard of consent required under the UK GDPR, controllers implementing the ACP Policy will likely find it difficult to rely on consent as a lawful basis given the imbalance of power between the organisation and the individual subject to the ACP. For this reason, the guidance will need to make it clear which type of consent is being referred to. Our guidance on consent as a lawful basis can be found [here](#).

Fairness and Transparency

17. To comply with the fairness and transparency strands of principle A, controllers must be transparent about how they will use and process the personal information, and individuals have a right to be informed by controllers about what will happen to their data. It may therefore be beneficial for the Department to remind those executing the ACP policy of this fundamental right, and signpost them to our guidance on the [right to be informed](#).

Accuracy

18. When a controller has implemented the ACP policy, it is important that appropriate thought is given to the accuracy principle under Article 5(1)(D) of the UK GDPR. This principle stipulates that personal data shall be accurate, and where necessary, kept up to date.
19. As the sections "Reviewing Advance Care Planning Conversations, Recommendations and Decisions" explains that the ACP can be revised at any time, participating Trusts and other controllers must ensure that they are reviewing advance care plans to ensure that the record reflects the current views, beliefs and decisions of the individual. Consideration should also be given to whether past conversations which do not mirror the present position of the ACP should be removed or retained.

Retention

20. Controllers should also consider appropriate retention schedules relating to plans under the ACP policy.

Data Sharing

21. The consultation document references participants consenting to the sharing of information among third parties in order to facilitate an adult care plan. Whilst we understand the importance of sharing information from an individual's plan with relevant third parties, we would like to remind controllers that it is important to give careful consideration to data protection legislation when doing so. Data shared with external parties must be done so in a lawful, fair and accurate manner and in keeping with the UK GDPR principles.
22. Organisations involved in data sharing should also consider the implementation of data sharing agreements which should:
- set out the purposes of the data sharing;
 - cover what happens to the data at each stage; and
 - set standards and help all the parties involved in sharing to be clear about their roles and responsibilities.
23. Data sharing agreements should also deal with any practical problems that may arise when sharing personal data. This should ensure that all organisations involved in the sharing have detailed advice about what personal data regarding an individual's care plan can be shared and with who. This should assist with the prevention of irrelevant or excessive information being disclosed. Such agreements will also assist with ensuring that organisations have common technical and organisational security arrangements in place and address any operational differences which may exist with respect to retention or deletion periods. Further guidance on this matter has been published in our [Data Sharing Code of Practice](#).

Security

24. Given the sensitive nature of the personal information which will be processed to facilitate an individual's care plan and considering that the policy is highly likely to affect vulnerable groups in society, specific and detailed consideration should be given to ensuring appropriate security measures are implemented so that personal information is not compromised.

Mental Capacity

25. In terms of the legal components of Advance Care Planning, DoH may wish to refer to the ICO's guidance on 'Can an individual make a request on behalf of someone?', specifically our section on

Mental capacity, and Powers of Attorney (PoA) and what this means for DP rights. More guidance can be found [here](#).

We hope you find the above comments helpful as you move forward with your proposals. Should you wish to discuss any of the above further, please do not hesitate to contact our office at ni@ico.org.uk.

Yours sincerely,

Ceri Hall
Senior Policy Officer – Northern Ireland
Information Commissioner's Office