

Health Information  
and Standards

Draft recommendations on a consent model  
for the collection, use and sharing of health  
information in Ireland

## **Public Consultation Feedback Form**

November 2021

## **Draft recommendations on a consent model for the collection, use and sharing of health information in Ireland**

The Health Information and Quality Authority (HIQA) is holding a public consultation to give people an opportunity to provide feedback on the draft recommendations on a consent model for the collection, use and sharing of health information in Ireland.

Your views are very important to us, and we will carefully assess all feedback received and use it to help develop the final recommendations which will be submitted to the Minister for Health for approval.

**Please note:** the focus for this consultation is the content and structure of the draft recommendations. The final wording, design and layout of the recommendations will be developed after the public consultation. We welcome responses to all questions, and there will be an opportunity at the end of the survey to provide any additional general comments.

**The closing date for the public consultation is  
Monday, 10 January 2022.**

## **Data Protection and Freedom of Information**

- HIQA will only collect personal information during this consultation for the purposes of verifying your feedback or where you have indicated that you would like to be contacted to partake in future stakeholder engagement.
- If you have any concerns regarding your data, please contact HIQA's Information Governance and Assurance Manager on [infogovernance@hiqa.ie](mailto:infogovernance@hiqa.ie).
- Please note that HIQA is subject to the Freedom of Information (FOI) Act and the statutory Code of Practice in relation to FOI. Following the consultation, we will publish a statement of outcomes document summarising the responses received, which will include the names and types of organisations that submitted feedback to us.
- For that reason, it would be helpful if you could explain to us if you regard the information you have provided us as being confidential or commercially sensitive. If we receive a request for disclosure of the information under FOI, we will take full account of your explanation, but we cannot give you an assurance that confidentiality can be maintained in all circumstances.

## Instructions for submitting feedback

- This public consultation is in relation to the draft recommendations for a consent model for the collection, use and sharing of health information in Ireland. You can find the draft recommendations, alongside the evidence synthesis paper that has informed these recommendations, on [www.hiqa.ie](http://www.hiqa.ie).
- There is also an option to complete a fully online survey, which you can find [here](#).
- If you are commenting in a personal capacity, there is no need to provide your name or any other personal information. However, if you would like to be contacted to take part in future stakeholder engagement, there is an option to provide your name and contact number.
- If you are commenting on behalf of an organisation, please combine all feedback from your organisation into one submission. In this case, we will request a name and contact number for a designated representative from your organisation in case we need to verify the authenticity of your contribution.
- Do not paste other tables into the boxes already provided — type directly into the box as the box expands.
- Please spell out any abbreviations that you use.

## 1. About you

### 1.1 In what capacity are you providing this feedback?

- As a member of the public
- In a professional capacity

### 1.2 If you are completing this in a professional capacity, please specify your current role:

### 1.3 Are you providing this feedback as an individual, or have you compiled it on behalf of an organisation?

- As an individual
- On behalf of an organisation

### 1.4 If you are providing this feedback on behalf of an organisation, please provide the organisation's name and contact details below.

### 1.5 If you would like to be contacted to participate in future stakeholder engagement in relation to this work, please provide your name and contact details below.

## 2. Your feedback on the draft recommendations

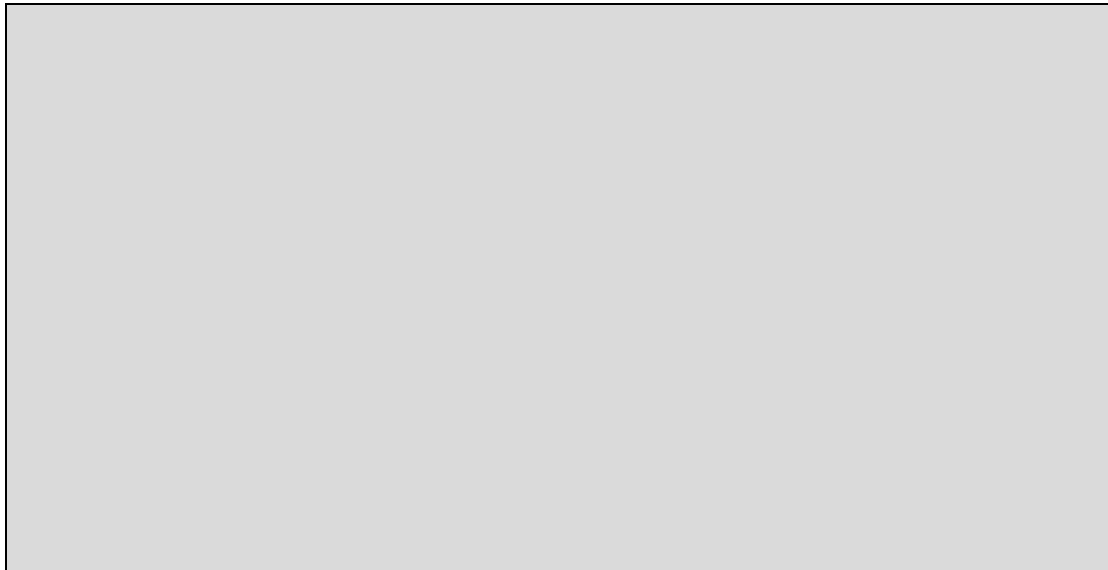
**In this section, we would like to find out what you think of the content of the draft recommendations for a consent model for the collection, use and sharing of health information in Ireland.**

**The questions are not intended in any way to limit your feedback, and other comments relating to the draft recommendations are welcome.**

### **Recommendation 1: to define key concepts in legislation.**

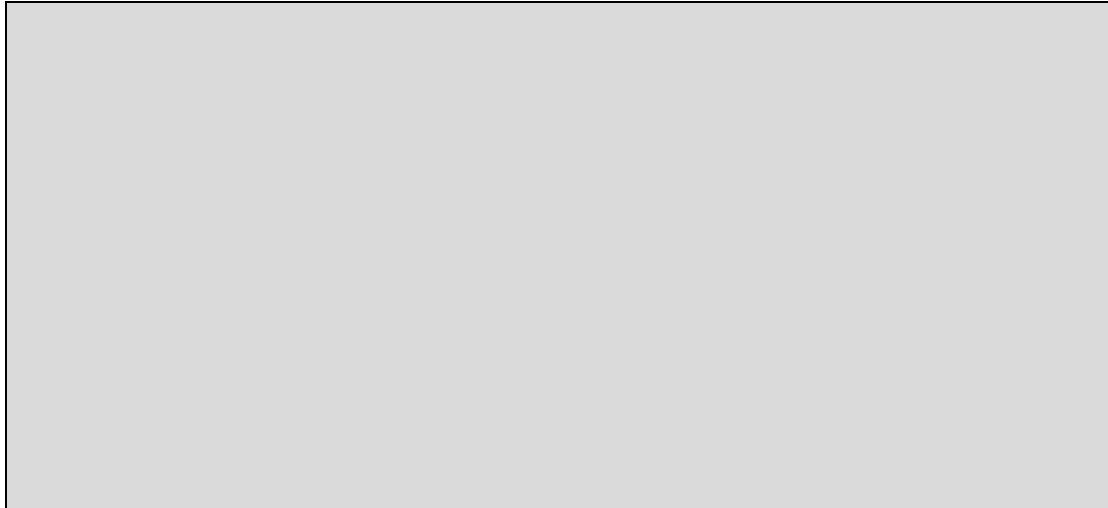
**2.1 Please provide your feedback on Recommendation 1: to define key concepts in legislation.**

*(Please provide specific feedback on the proposed definitions for health information; health information for direct care; and health information beyond direct care.)*



## **Recommendation 2: a rights-based approach.**

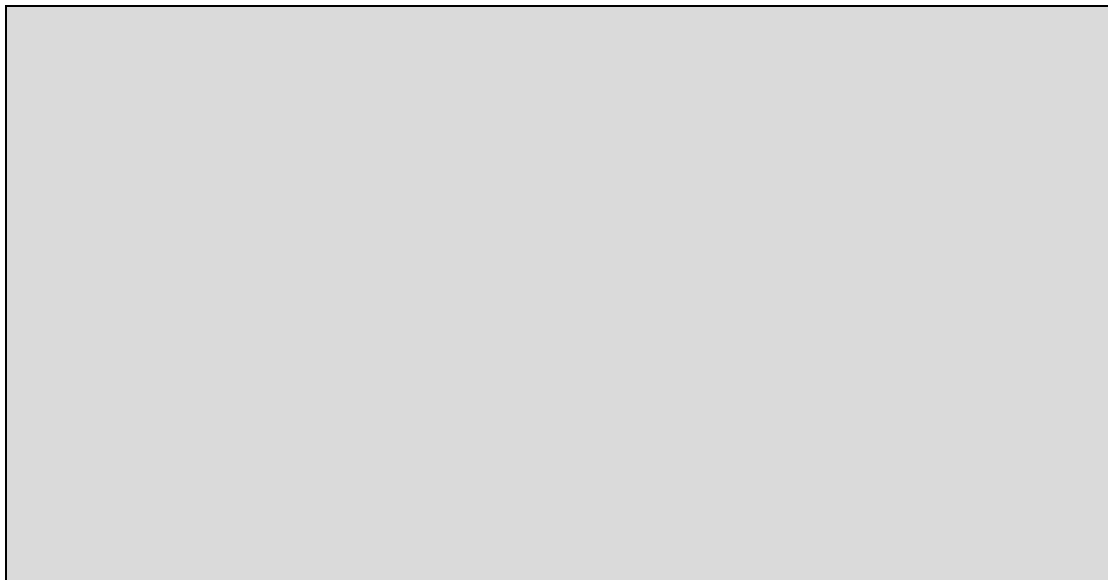
**2.2 Please provide your feedback on Recommendation 2: to follow a rights-based approach when implementing a consent model for health information.**



## **Recommendation 3: to define the consent model and exemptions in legislation**

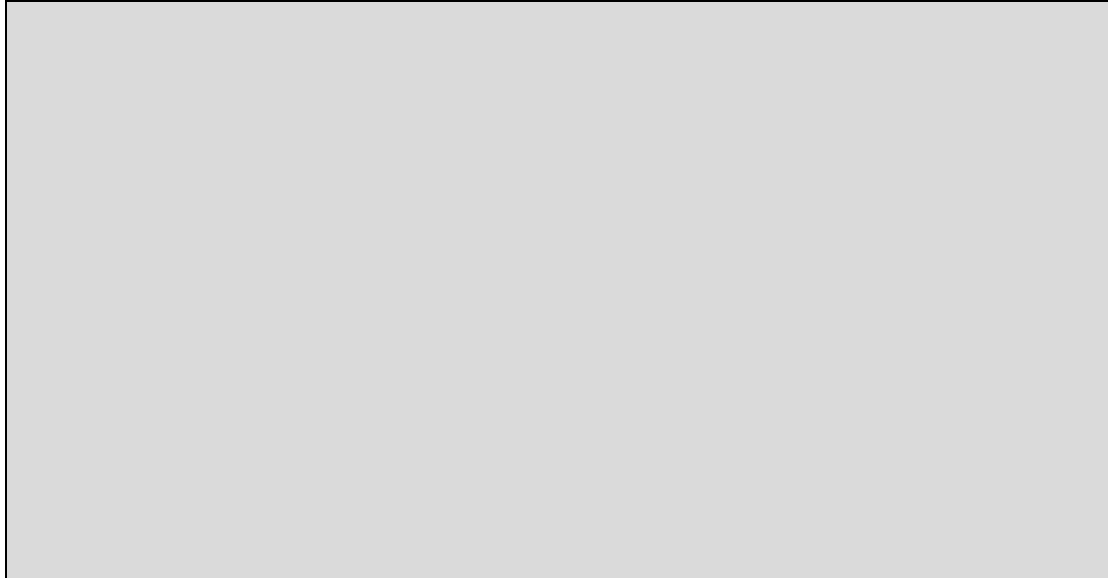
**2.3 Please provide your feedback on Recommendation 3: the proposed consent model.**

*(Please comment specifically on the four categories in the proposed consent model, as well as the proposed exemptions.)*



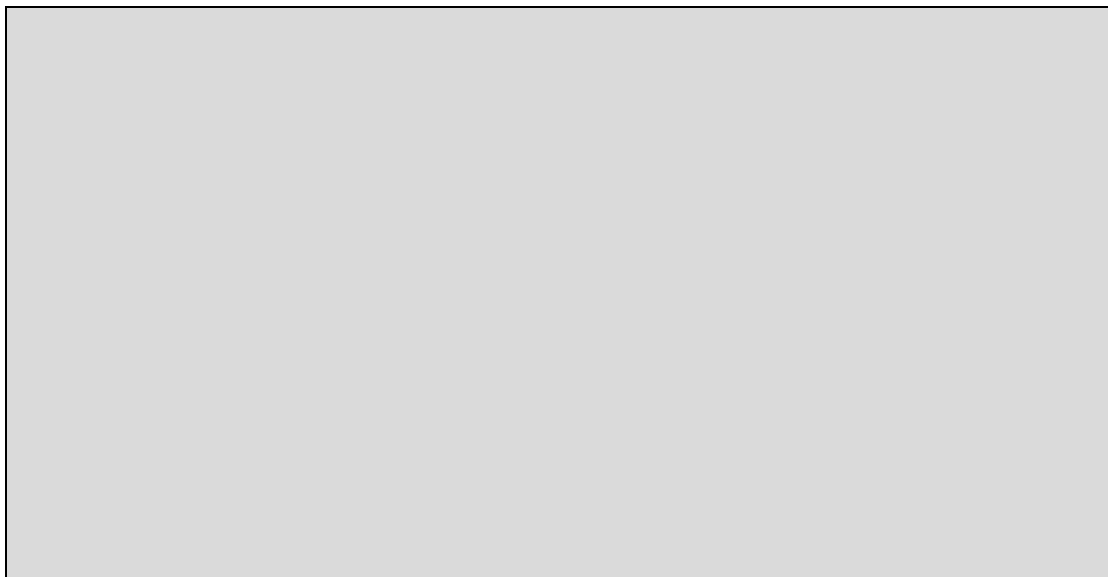
## **Recommendations 4 and 5: Legislation**

**2.4 Please provide your feedback on Recommendations 4 and 5: to develop specific legislation for uses of health information.**



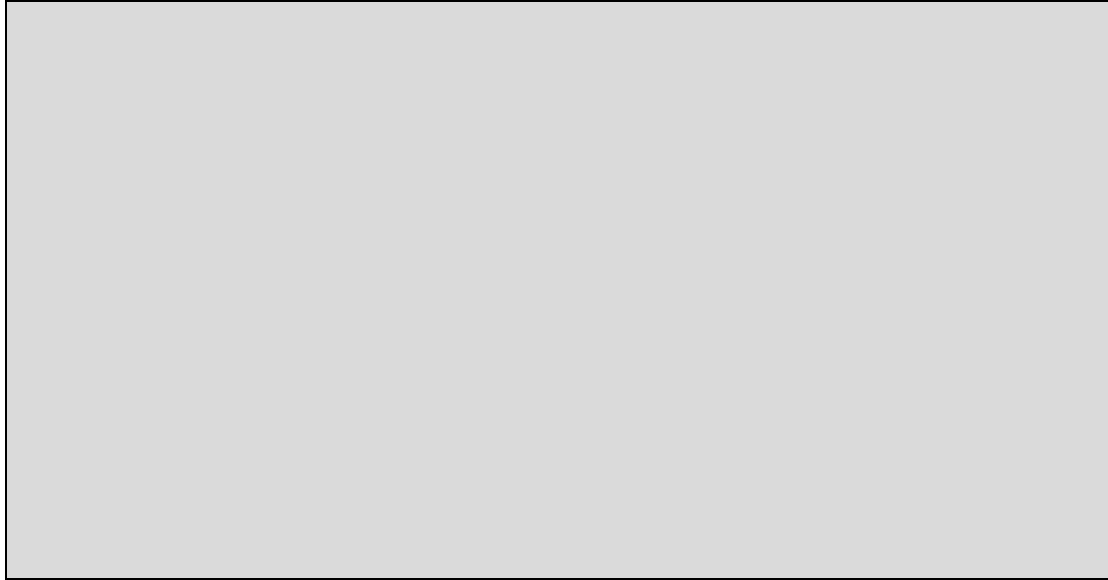
## **Recommendation 6: Governance structures**

**2.5 Please provide your feedback on Recommendation 6: governance structures.**



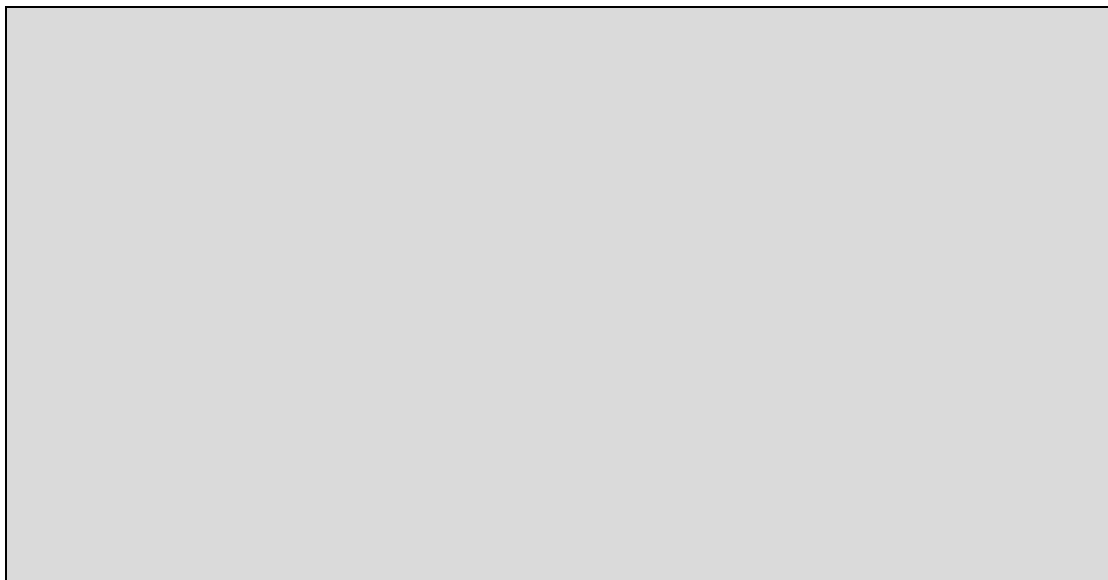
## **Recommendations 7 and 8: Technical and operational requirements**

**2.6 Please provide your feedback on Recommendations 7 and 8: the technical and operational considerations.**



## **Recommendations 9 and 10: Public engagement**

**2.7 Please provide your feedback on Recommendations 9 and 10: Public engagement.**





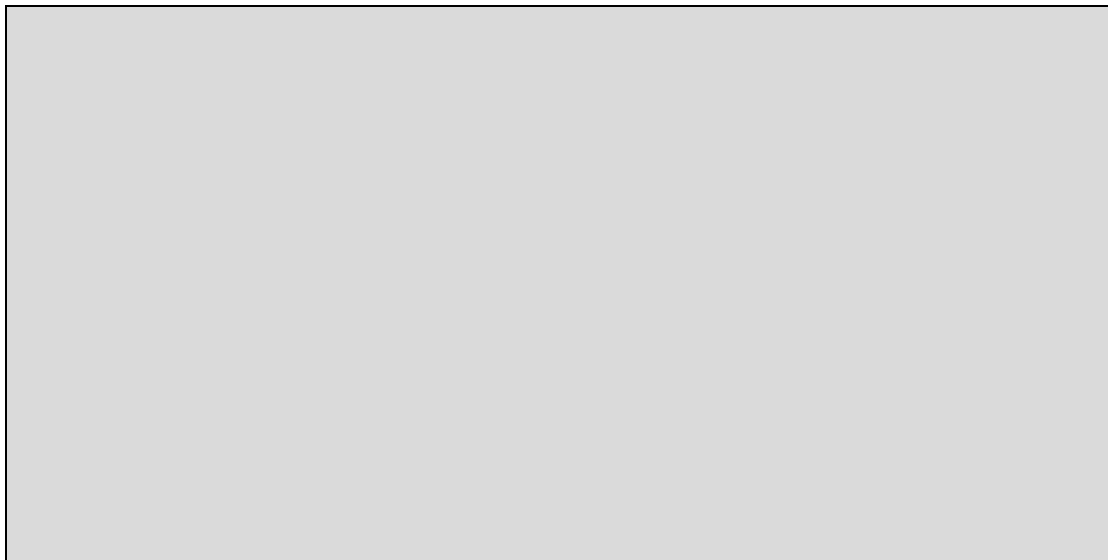
### 3. General feedback

**3.1 In your opinion, are there any aspects not covered in these draft recommendations? If so, please describe them here.**

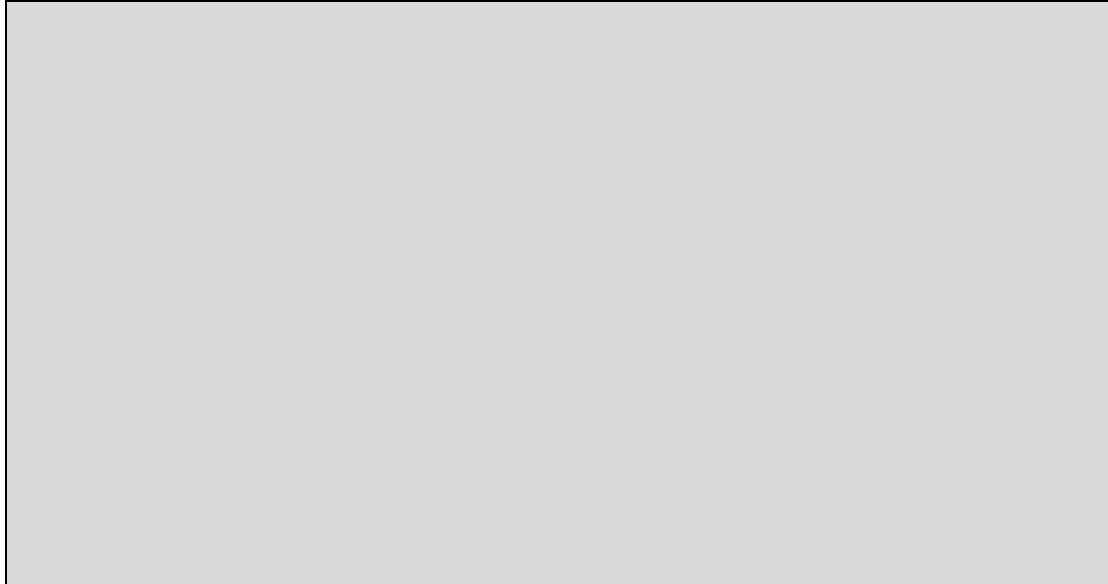


**3.2 What are the greatest challenges that you currently face in collecting, using and sharing health information?**

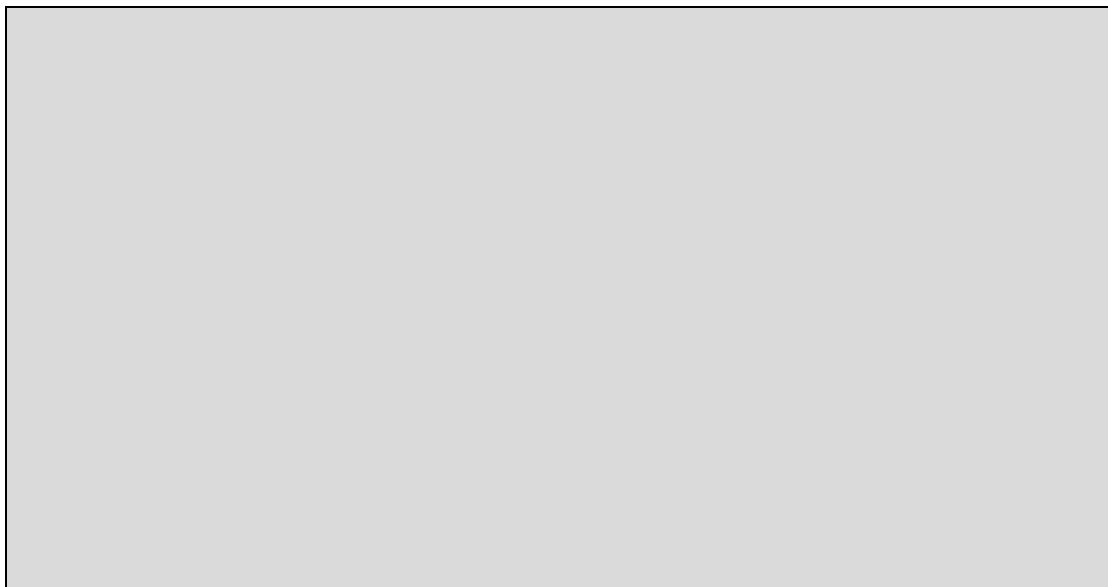
*(If this question is not relevant to you, please move on to the next question.)*



**3.3 Having read the draft recommendations and associated evidence synthesis paper, do you have any thoughts on a proposed 'opt-out' consent approach for using health information and how this might work in Ireland?**



**3.4 Are there any other comments that you would like to make about these draft recommendations?**



**Thank you for taking the time to give us your views on the draft recommendations on a consent model for the collection, use and sharing of health information in Ireland.**

Please return your form to us by email or post before:  
**5pm, 10 January 2022.**

**Email:**

[healthinformation@hiqa.ie](mailto:healthinformation@hiqa.ie)

**Post:**

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Health Information Quality Team,  
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City Gate,  
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For further information on this work, please visit [www.hiqa.ie](http://www.hiqa.ie) or email [healthinformation@hiqa.ie](mailto:healthinformation@hiqa.ie).



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