



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

Health Information  
and Standards

Draft National Standards for Information  
Management in Health and Social Care  
**Public Consultation Feedback Form**  
**October 2022**

*Safer Better Care*

The Health Information and Quality Authority (HIQA) is holding a public consultation to give people an opportunity to provide feedback on the Draft National Standards for Information Management in Health and Social Care (referred to in this document as the draft standards).

Your views are very important to us, and we will carefully assess all feedback received and use it to help develop the final standards 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 standards. The final design and layout of the standards 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 feedback from your consultation form will be used to develop the Draft National Standards for Information Management in Health and Social Care, for research purposes and to inform further reports. Any information you provide will be held securely and will not be published, subject to legal requirements under Freedom of Information (FOI) legislation or where you are responding on behalf of an organisation, in which case the name and type of organisation will be published in Summary of Stakeholder Involvement Report.

**The closing date for the public consultation is:**

**5pm, 19th December 2022.**

## Instructions for submitting feedback

- The draft standards document is available at [www.hiqa.ie](http://www.hiqa.ie).
- 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.
- When referring to a specific section of the standards document, please include the section and page number that you are commenting on.
- 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.

**You can email or post a completed form to us. You can also complete and submit your feedback on [www.hiqa.ie](http://www.hiqa.ie).**

## 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 are 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 stakeholder involvement report 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 to 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.



## 1.2 Are you commenting:

**In a professional capacity**

*(Please use the box below to specify your role in the organisation you currently work for.)*

Director of Digital Health and Transformation.  
St Patrick's Mental Health Services.

**As a member of the public / user of health and social care services**

*(If you would like to provide any additional details, please share in the box below.)*

[Click here to enter text.](#)

## 2. Your feedback on the draft standards

In this section, we would like to find out what you think of the content of the Draft National Standards for Information Management in Health and Social Care. This section focuses on the three principles, standard statements and features presented in the draft standards. Taken together, the principles, standard statements, and the features provide a common language to describe what good information management practices in health and social care should look like.

### **The draft national standards are underpinned by three principles:**

- A rights-based approach
- Accountability
- Responsiveness.

The questions in this section are not intended in any way to limit your feedback, and other comments relating to the draft national standards are welcome.

### **Please consider the following questions as part of your review of the draft standards:**

1. Do you think all important areas have been covered in each standard statement or are there any areas that should be included or excluded?
2. Are the features listed sufficient to assist staff working in organisations that process health and social care information?

## **2.1 Please provide your feedback on the standard statements and features set out under Principle 1: A rights-based approach**

SPMHS welcomes the inclusion of a 'rights-based approach' as an explicit principle in the Draft National Standards for Information Management in Health and Social Care Services. We believe that these organisations have a critical responsibility in respecting the information rights of those who seek help, treatment and care from health and social care services, often at times in their lives when they are vulnerable or have difficulty speaking up for themselves.

Specifically on Page 17 in relation to the Standard 1.1 'People's rights relating to information', SPMHS suggest that the 'Right to restriction' be added under section 1.1.1 to the list of features associated with this standard.

In relation to Standard 1.2 'Privacy and Confidentiality', SPMHS suggest the inclusion of a privacy by design and by default approach be included as a feature of this standard. In addition, whilst there is some reference to the retention of a record of processing activities (ROPA) on page 36 and 44, SPMHS suggest a ROPA should also be included as a feature of this standard including data flows detailing the data lifecycle for all processing activities.

Standard 1.3 'Person-Centred' is an important standard in how health information should be managed. SPMHS support the explicit listing of the associated person-centred features of this health information management standard, including a focus on a person's needs and preferences, diversity, accessible and timely access, co-design and feedback.

With regard to the feature of 'timely access to health information', SPMHS believes there is an opportunity to reference within this standard how dynamic sharing of healthcare information with service users, during care delivery, can contribute to service user empowerment as well as improving the quality of health information across the five dimensions of data quality; relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; accessibility and clarity. Dynamic sharing of information, during care delivery, respects service users' rights, and recognises the important role they have in contributing to their own high-quality information that will improve the safety and quality of their care.

## **2.2 Please provide your feedback on the standard statements and features set out under Principle 2: Accountability**

SPMHS welcomes the inclusion of Accountability as an explicit principle of how health information needs to be managed and the associated standards of organisational governance, leadership and management; strategy; performance assurance and risk management; and compliance with legislation and codes of practices. SPMHS believes these standards will provide organisations with an important auditable framework which assures service users and other primary stakeholders that their information is managed in a transparent, ethical and robust manner.

## **2.3 Please provide your feedback on the standard statements and features set out under Principle 3: Responsiveness**

SPMHS welcomes the inclusion of the Principle of Responsiveness and the associated standards for managing health information.

In light of recent cyberattacks on health organisations in recent years including the 2021 HSE cyber-attack and the 2022 Australian Medibank Health Insurer cyberattack, the Data Security Standards is of particular relevance in what is becoming a digitally enabled and connected health and social care environment. In relation to Data Security, Section 3.5 of the document states a key feature of Data Security should be 'strong accountability and governance arrangements are in place to support robust data protection and data security structures. SPMHS believe a "standards-based" approach to data security should explicitly reference published and available standards. For example, explicit reference to ISO 27001 and related standards, or to one or more of the EU Network and Information Security Directive / relevant Irish Statute / NCSC Guidelines for Operators of Essential Services. The following details could be included in the "References" section of the final version of the National Standards for Health Information Management:

1. EU NIS Directive: <https://www.enisa.europa.eu/topics/cybersecurity-policy/nis-directive-new>
  - a. The NIS Directive (EU 2016/1148)
  - b. Note: Updated legislation is on the way (NIS2), but for now, this is current.
2. Statutory Instrument, S.I. No. 360/2018 - European Union (Measures for a High Common Level of Security of Network and Information Systems) Regulations 2018:



- a. <https://www.irishstatutebook.ie/eli/2018/si/360/made/en>
- b. Irish Statute giving effect to EU NIS Directive (EU 2016/1148)
3. NIS Compliance Security Guidelines for OES (published by the NCSC):
  - a. <https://www.ncsc.gov.ie/pdfs/NIS%20Compliance%20Security%20Guidelines%20for%20OES.pdf>
  - b. Executive summary calls out healthcare as “Operators of Essential Services” on page 1.
  - c. Appendix B of this document refers to the standards and frameworks which Healthcare providers can refer to, including CIS, COBIT, ISO, NIST, etc

## **2.4 Are there any other comments or suggestions on the draft standards that you would like to make?**

Recognising the public sector focus of the Draft National Standards for Information Management in Health and Social Care, the language used in the document is clear, easy to follow and easy to understand. The draft standards appear to be comprehensive and the structure and content is clear and easy to follow and understand.

We welcome the format of how these Draft National Standards are written where each standard is described from the perspective of a) What the individual should expect and b) What the organisation should do to achieve the standard. This respects the primacy of the service user experience in determining if the standards relating to how their own health information is managed, has been met by the organisation.

### **3. General Feedback**

#### **3.1 Do you think the language used in the draft standards is clear, easy to follow and easy to understand?**

- Yes**
- No**

#### **3.2 Do you think the content and structure of the draft standards is clear, easy to follow and easy to understand?**

- Yes**
- No**

#### **3.3 Please provide any additional comments on the language, content and structure of the draft standards.**

SPMHS supports all aspects of the Draft National Standards for Health Information and whilst these standards are focused on public sector health and social services, we believe they provide a timely and comprehensive framework for any and all health and social care organisations who manage health information.

As described in our previous submission on a Draft Model for Health Information, SPMHS recommends that the implementation process should be carried out with reference to the National Digital Health Strategy.

As referenced in our previous submission, on the draft recommendations on the standards development process, the draft national standards for health information management do not reference a National Data Model and Dictionary which SPMHS believe is essential to underpin effective and efficient health information sharing.

In addition, on Page 15 of the Draft National Health Information Management Standards, under the Section titled 'What is Information management', it states that "Information should be collected once and used many times". SPMHS suggest this should clarify that health information should only be used for the purpose in which it was collected (purpose limitation under GDPR).

Under the Section relating to the 'Relevant Legislative developments' of the draft standards document, on page 17, it states that 'As part of this amendment, the Health Research Regulations 2018 were enacted, which make 'explicit consent' the lawful basis for using a patient's personal data in research, unless a consent exemption is sought, and subsequently the Health Research Consent Declaration Committee (HRCDC) was established as an independent statutory body to assess applications for consent declarations'. SPMHS is of the view that explicit consent is not technically the lawful basis for using a patient's personal data under the Health Research Regulations (HRR). The requirement to obtain explicit consent under the Health Research Regulations, we believe, is generally interpreted as an additional safeguard to a data controller's obligation to rely on a legal basis to process personal data under Article 6 GDPR or Article 9 GDPR, with respect to special category data, which may also be consent based.

Finally, the document does not address "purpose limitation" and "storage limitation" as is described under the GDPR principles. This is particularly pertinent in ensuring that service users' data is not used or stored beyond the purpose or retention period for which it was originally obtained without explicit consent.

**3.4 Having read the draft standards, do you have a better understanding of what good information management looks like for organisations that process health and social care information?**

- Yes**
- No**

***Comments:***

Click here to enter text.

**3.5 If you work in an organisation that processes health and social care information, having read the draft standards, do you intend to make changes to your work practices?**

- Yes**
- No**

**Can you describe what these changes may be?**

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

SPMHS has a comprehensive governance approach to health information management including an information governance framework, committee and suite of policies which guide the organisation in how it manages its health information. We will strengthen this framework with the addition of a policy that specifically addresses Data Quality standards and features.

### **3.6 What is needed to support the implementation of these standards in the organisation that you work in?**

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

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### **3.7 Are there any other comments that you would like to make about these draft standards?**

SPMHS welcomes the publication of HIQA's draft national standards for health information management. We believe that these standards will assist organisations in improving the management of the health information they are responsible for in a manner that respects the rights of service users and which demonstrates accountability and responsiveness.

The passing of the enabling Health Information legislation is a critical first step in progressing the implementation of these standards.

We note the absence of any independent mental health service on the health information advisory and would welcome the opportunity to contribute in a meaningful manner to the development of National Health Information standards.

*Thank you for taking the time to give us your views on the Draft National Standards for Information Management in Health and Social Care.*

**Please return your form to us by email or post.**

You can **download** a consultation feedback form at [www.hiqa.ie](http://www.hiqa.ie) and then **email** the completed form to: [healthinformation@hiqa.ie](mailto:healthinformation@hiqa.ie)

**or**

Print the consultation feedback form and **post** the completed form to:

Health Information Quality Team,  
Health Information and Quality Authority,  
Unit 1301,  
City Gate,  
Mahon,  
Cork  
T12 Y2XT

You can also complete an **online consultation form** at [www.hiqa.ie](http://www.hiqa.ie)

If you have any questions on this document, you can contact the HIQA Health Information Quality Team by:

**Phone:** 021 240 9300 or **Email:** [healthinformation@hiqa.ie](mailto:healthinformation@hiqa.ie)

Please ensure that you return your form to us by **5pm on 19 December 2022.**