Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information and Standards

Summary of Stakeholder Involvement - National Standards for Information Management in Health and Social Care

June 2024

Safer Better Care

About the Health Information and Quality Authority (HIQA)

The Health Information and Quality Authority (HIQA) is an independent statutory body established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.

- **Regulating social care services** — The Chief Inspector of Social Services within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.

- **Regulating health services** — Regulating medical exposure to ionising radiation.

- **Monitoring services** — Monitoring the safety and quality of permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social services.

- **Health technology assessment** — Evaluating the clinical and cost effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.

- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.

- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health and social care services, with the Department of Health and the HSE.

Overview of HIQA's health information function

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is, therefore, very important that information is managed in the most effective way possible in order to ensure a high-quality safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests — if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has an important role to play in healthcare planning decisions — where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under Section (8)(1)(k) of the Health Act 2007,(1) the Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under Section 8(1) (j), HIQA is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving its quality and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to promote quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Furthermore, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in health and social care services in Ireland is highly fragmented with major gaps and silos of information. This results in individuals being asked to provide the same information on multiple occasions.

In Ireland, information can be lost, documentation is poor, and there is an overreliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base our decisions.

As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice. A robust health information environment will allow all stakeholders — patients and people using services, health professionals, policy-makers and the general public — to make choices or decisions based on the best available information. This is a fundamental requirement for a highly reliable healthcare system.

Through its health information function, HIQA is addressing these issues and working to ensure that high-quality health information is available to support the delivery, planning and monitoring of services.

Contents

1 Introduction and background to the national standards

This report sets out a summary of the process and outcomes of the consultation undertaken to inform the development of National Standards for Information Management in Health and Social Care. Between October 2022 and April 2023, the Health Information and Quality Authority (HIQA) conducted a public consultation and targeted consultation to gather stakeholders' views on the *Draft National Standards for Information Management in Health and Social Care*.

For the remainder of this document:

Health information will be used to describe health and social care information.

The *National Standards for Information Management in Health and Social Care* were developed to contribute to safer better care by improving the management of health and social care information.

If collected, used and shared effectively with appropriate safeguards in place, good data and information can support effective decision-making and problem-solving; inform research and policy; enable an organisation to measure activity, performance and success; result in services that are more aligned with stakeholders' needs; and support better policies and strategies.(2)

In recent years, there have been a number of significant legislative changes that have had implications for organisations that process health and social care information. At a European-level, the enactment of the General Data Protection Regulation (GDPR) in 2018 introduced higher standards of data protection for individuals and imposed increased obligations on organisations.(3) There are likely to be further implications for organisations that process health and social care information over the coming years with the significant national legislative reform currently underway, including the publication of the Health Information Bill – General Scheme in May 2023. The forthcoming legislation emphasises the need to ensure that health information is protected by measures to safeguard the fundamental rights and interests of individuals which is key to the ongoing efforts to progress the European Health Data Space.(4)

1.1 Stages in the development of the standards

The *National Standards for Information Management in Health and Social Care* were developed in line with the methodology outlined in HIQA's Health Information and Standards Quality Assurance Framework. The following stages informed the development of these standards:

1

- Undertake an **evidence synthesis** of current structures and information management arrangements for national health and social care data collections in Ireland and internationally

2

- Convene an **advisory group** to provide feedback on the evidence review and draft standards

3

- Undertake a **public consultation** and **targeted consultation** on the draft standards

4

- Integrate feedback, seek approval from relevant stakeholders and groups, and **publish the standards** on HIQA's website

A more detailed overview of the stages which informed the development of these standards is presented in **Appendix 1**.

1.2 Aim of the report

The purpose of this report is to present the key findings of the public consultation and targeted consultation (stakeholder focus groups). These findings, alongside relevant international literature and examples of good practice, informed the development of the *National Standards for Information Management in Health and Social Care*.

2 Findings of the Public Consultation

This section provides a high-level overview and summary of the feedback received on the draft standards from respondents to the public consultation. All submissions were reviewed by the Project Team and subsequent changes to the draft standards agreed. While this report is not an exhaustive record of all comments received, it highlights some of the key items raised by people during public consultation.

The consultation comprised of one specific feedback question on each on the three principles in the Draft National Standards for Information Management for Health and Social Care. Respondents were asked to consider the following questions as part of their 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?

Respondents were asked to provide any additional comments or suggestions on the draft standards that were not included in the previous responses. Seven general feedback questions were also asked as part of the consultation. These questions covered the language, content and structure of the standards. Respondents were asked whether they have a better understanding of good information management practices having read the document and whether they intend to make any changes to their work practices, having read the draft standards. The aim of these general and specific feedback questions was to elicit public opinion on the draft standards.

2.1 Description of responses

Table 1: Summary of response to public consultation

Responses to public consultation		
	Number (N)	Percentage (%)
Emailed	39	76
Online	12	24
Total	51	100
Capacity in which you are responding		
	Number (N)	Percentage (%)
Organisation	35	69
Individual	16	31
Total	51	100

A total of 51 responses were submitted to HIQA, 39 (76%) were emailed and 12 (24%) were received via the online survey tool. 35 (69%) respondents represented an organisation while 16 (31%) responded in a personal capacity.

Of the 16 responses within a personal capacity, 11 of these responded as a professional. Examples of respondents' professional roles included; clinician, nurse, researcher and Information Management Professional. **Appendix 2** details further the types of organisations that made submissions to the public consultation.

2.2 Feedback on the standard statements and features set out under Principle : A rights-based approach

Respondents were asked to provide feedback on the standard statements and features set out under Principle on a rights-based approach.

Principle 1: A rights-based approach summary of feedback
84% (n=43) of respondents provided feedback on Principle 1: A rights-based approach. Overall, having a principle that focuses on human rights was welcomed by the vast majority of respondents.

The main concerns expressed by respondents under this principle was that; the structure of Ireland's health system will present challenges for ensuring that a human rights-based approach is upheld, that "data provenance" although very much needed would be costly and challenging to implement for an organisation; that there is an urgent need to implement an IHI; and further distinction required on the safeguards for personal data versus aggregate data.

Standard 1.1: People's rights relating to information

Nineteen responses were received and the majority of these reiterated that in order to deliver better outcomes for the public, this standard needs to highlight the best use of information, that information systems need to support the sharing of information (with appropriate controls in place) and organisations need to be transparent regarding the basis for the collection, use and sharing of data.

Submissions also called for reference to the FREDA (Fairness, Respect, Equality, Dignity and Autonomy) principles within this standard in order to reflect the adoption of a human rights-based approach. Along with this, respondents highlighted that the standards need to ensure they are providing education with and guidance on rights. Individuals should also be supported "*to understand what their rights are and how to exercise their rights*." Furthermore, the accessibility requirements for individuals with different needs have to be considered.

Respondents also detailed the need for the inclusion of explicit reference to consent in this standard.

Standard 1.2: Privacy and confidentiality

Thirteen responses were received and a proportion of these underlined the need for guidance to develop a Data Protection Impact Assessment (DPIA) and ongoing support tools as DPIA is not a "*once off exercise*." In addition to this, respondants emphasised that the Privacy Statement should explicitly outline who the point of contact is. Education and training in this area was further highlighted by a number of respondents and that consideration be given to people with disabilities to gain access to their information through the assistance of others and the implications of this on an individual's privacy.

Standard 1.3: Person-centred

Fifteen respondents provided feedback on this standard and a clear message was that a '*design for all*' approach should underpin this standard, focussing on the needs and preferences of individuals. The inclusion of co-design in the standards was welcomed.

A number of responses explicitly stated that this feature needs to be reworded for clarity. It was also suggested that communication approach should also be referred to in this feature. Within 1.3.1, it was mentioned that the key stakeholders need to be engaged with "*in terms of design and development of the information system*" and that this should be explicitly referred to here.

2.3 Feedback on the standard statements and features set out under Principle: Accountability

Respondents were asked to provide feedback on the standard statements and features set out under the Principle on Accountability.

Principle 2: Accountability summary of feedback

78% of respondents (n=40) provided feedback on this principle of which 34 submissions provided general comments. The majority agreed this standard was well-written and covered relevant areas. However, some did describe this principle as being "*aspirational"* given the historical context of health information management and referred to the challenges posed by the current systems that are in place.

Most positively, it was noted that implementing these standards would strengthen governance arrangements and ensure that professionals have access to the data that they need: "*Furthermore we must not compromise the clear benefit of having data available as important clinical information in the right place and the right time when implementing data management policies and procedures. We feel this guidance strikes an appropriate balance in this regard and hope this will continue in practice*."

Some submissions cautioned that adequate resources need to be in place to implement this standard and there is a need for a national body with responsibility for overall accountability including strategy and performance.

Standard 2.1 Organisational governance, leadership and management

Eleven respondents commented on Standard 2.1: Organisational governance, leadership and management.

The alignment of these standards *"with relevant policies and legislation in this area*" was highlighted by many as being important to effective implementation. Several responses emphasised that organisations need to be mindful of the needs of individuals whose data is being shared and used, and those accessing these data. A suggestion was put forward that the feature on the statement of purpose should mention the need to be developed with input from the public.

Submissions also identified that some aspects of this standard are unclear and additional guidance will be required to implement this standard. Additionally, respondents were unsure if the governance requirements are aimed at an organisational or departmental level with some respondents expressing the need to appoint individuals with roles that are specific to information management within their organisation.

Standard 2.2 Strategy

Seven submissions commented on Standard 2.2: Strategy. The inclusion of strategy was welcomed within these standards although a number of suggestions were made with regard to the specific wording used.

It was also suggested that a strategy should take into account the size and resources of the organisation (proportionality) and that staff training within an organisation should be incorporated into this standard.

It was acknowledged that contingency and disaster recovery planning, though referred to under Principle 3: Responsiveness, should be also acknowledged in strategic plans. The strategy needs to take into account and be informed by the input of the public and patients. Again, it was suggested that accessibility needs to underpin the principle of accountability.

Standard 2.3 Performance assurance and risk management

Eight responses provided comment on Standard 2.3: Performance assurance and risk management.

A number of submissions highlighted the importance of the aspects included within this standard and the benefits of adopting the features. It was suggested that roles and responsibilities of committees, management and staff should be included within the performance assurance framework.

A few respondents requested clarity on a number of terms included in this standard, such as; performance assurance framework and whether Key Performance Indicators (KPIs) refer to indicators of information management or indicators of service performance.

Standard 2.4 Compliance with relevant legislation and codes

Four respondents commented on Standard 2.4: Compliance with relevant legislation and codes.

The majority of submissions highlighted the importance of identifying people who have responsibility for this standard as well as supporting ongoing training in this area.

2.4 Feedback on the standard statements and features set out under Principle: Responsiveness

Respondents were asked to provide feedback on the standard statements and features set out under Principle on Responsiveness

2.4.1 Feedback from public consultation

78% (n=40) respondents provided feedback on Principle 3: Responsiveness. The majority of respondents welcomed the inclusion of this principle.

Principle 3: Responsiveness summary of feedback

Thirty respondents provided feedback in relation to Principle 3: Responsiveness.

Responses included acknowledgement that the standards within this principle were '*clear*, *concise'* and that the features were '*sufficient*' and provided guidance for staff to support implementation. The standards were, for the most part, welcomed for their potential to support the implementation of large scale national projects with regard to health information. However, it was also mentioned that they would present challenges for the system and in terms of resourcing: "*A balance must be achieved between data security, protecting individual's personal information and accessing the data for reasons that are in the public's interest".* The structure of services could also present a specific challenge, for example, public, private and voluntary organisations.

Additional comments referred to: ensuring that patients have access to their data in addition to staff access; considering the burden implementation of these standards will place on smaller organisations; applying the learnings from the HSE cyber-attack; considering how organisations can determine the best approach to meaningful stakeholder engagement; and impact of forthcoming legislation and changes to the health information landscape

Standard 3.1: Alignment with national and international standards and best practice

Eleven respondents provided feedback on Standard 3.1: Alignment with national and international standards and best practice. Although responses agreed with the need for this standards, manysubmissions acknowledged the challenges to implementing this standard mainly that smaller organisations may not have relevant expertise in this area and that the adoption of new technologies and advancements required an initial testing period.

A number of submission endorsed incorporating examples "*It would be useful to provide examples of national/international standards, guidance and/or recommendations typically seen as best practice, for consideration.*"

Standard 3.2 Stakeholder engagement

Twelve respondents provided feedback on Standard 3.2: Stakeholder engagement.

A large proportion acknowledged the importance of stakeholder engagement and welcomed the references to educating and empowering individuals as well as encouraging accessibility. However, it was also reiterated that organisations need to consider all stakeholders beyond the public i.e. clinicians. Responses suggested that clarity is required in relation to the ways that organisations can ensure that their engagement is meaningful.

The inclusion of equity stratifiers in these standards was widely accepted although it was also noted that there needs to be "*further discussion of and work on equity stratifiers…*" and to also include disability as an example where the definition is provided. Respondents also agreed that training requirements need to be considered to implement this standard.

Standard 3.3 Use of information

Ten respondents provided feedback in relation to Standard 3.3: Use of information.

Many responses supported the key points within this standard but added technical requirements were a potential challenge: "*national IT infrastructure is a limiting factor and is not adequately referenced*."

One comment suggested that "*access to data should also include modern tools to analyse data rather than becoming a user of a dashboard of information*." Reference to the Five Safe Framework was welcomed.One respondent stated in their feedback that "*appropriate use of information should incorporate the prevention of discrimination within decision-making involving people with disabilities*."

The retention and storage of information as well as consent was called out by a number of submissions and that guidance was needed.

Standard 3.4 Data quality

Nine respondents provided feedback in relation to Standard 3.4: Data quality. Overall responses were positive welcoming this standard and its features.

Many respondents agreed that the feature on a data quality framework was beneficial but required some clarity whether it "*refers to the organisations overall data quality framework or for each specific data set or data collection within the organisation*."

Standard 3.5 Data security

Seven respondents provided feedback in relation to Standard 3.5: Data security.

The importance of this standard was supported by many submissions, "*data security is vital and the matters of accountability, risk assessment and policies are key safeguards..*."

Specific guidance on aspects of the features of this standard was called out by a number of respondents "*Users may need further guidance on risk assessment tools and their use and how it can assist in risk mitigation controls for the development of data quality systems and frameworks etc."*

Other significant comments included that clarity was needed around HIQA's monitoring approach in regards to these standards including how data breaches would be prevented, reported on and dealt with. Submissions further suggested the inclusion of an audit trail so an individual can see who has accessed their information.

2.5 Other comments or suggestions on the draft standards

Forty-three (86%) respondents provided further comments/suggestions on implementation, general understanding and content and structure of the standards findings are detailed in sections 2.6 and 2.7.

2.5.1 Feedback from public consultation

A number of responses welcomed the adoption of the principles within these standards and welcomed the standards generally: "*Very badly needed standards and if adopted, monitored and policed properly would make a huge difference to the health and social care climate in Ireland*". While they were welcomed it was also highlighted that it may be challenging to ensure that all sectors engage with the standards. Another mentioned that the reference to HIQA's experience of reviewing national data collections to date strengthens the standards. Some responses welcomed the change in scope of the standards but others recognised that smaller and community based organisations may find implementation more challenging. Clarity was also requested with regard to what is required by the standards and how compliance with the standards will be assessed.

Use of information and wider health information landscape

Many responses expressed optimism that these standards may promote better use of data and that appropriate consideration needs to be given to the purpose of the data collection and the use of the data. However, many also recognised the issue of fragmented data in the healthcare setting and questioned whether this should be specifically addressed within the standards.

Ensuring patients have access to their health information was highlighted as a positive. It was commented that the standards should be framed in a way that promotes the trust and confidence of the public: "*where possible, standards should be framed through this lens - i.e. providing information and facilitating involvement*." One comment was made about ensuring that systems are in place to support optimal use of information: "*… Systems should be designed to allow for extraction of data. Many healthcare systems cannot extract aggregate or individual level reports or struggle to do so*."

Health literacy was called out by a number of responses and that the enabling the public to understand their health records should be incorporated within the features.

Legislation

It was suggested that the standards need to make specific reference to legislation including the European Health Data Space regulations, as well as readiness to comply with this regulation. An amendment was suggested in relation to adding clarity on the Health Research Regulations. In addition, some responses suggested that the wording on HIQA's legislative remit needs to be stronger or it needs to be ensured that the application of these standards is covered in the forthcoming Health Information Bill and other forthcoming legislation within Ireland and Europe.

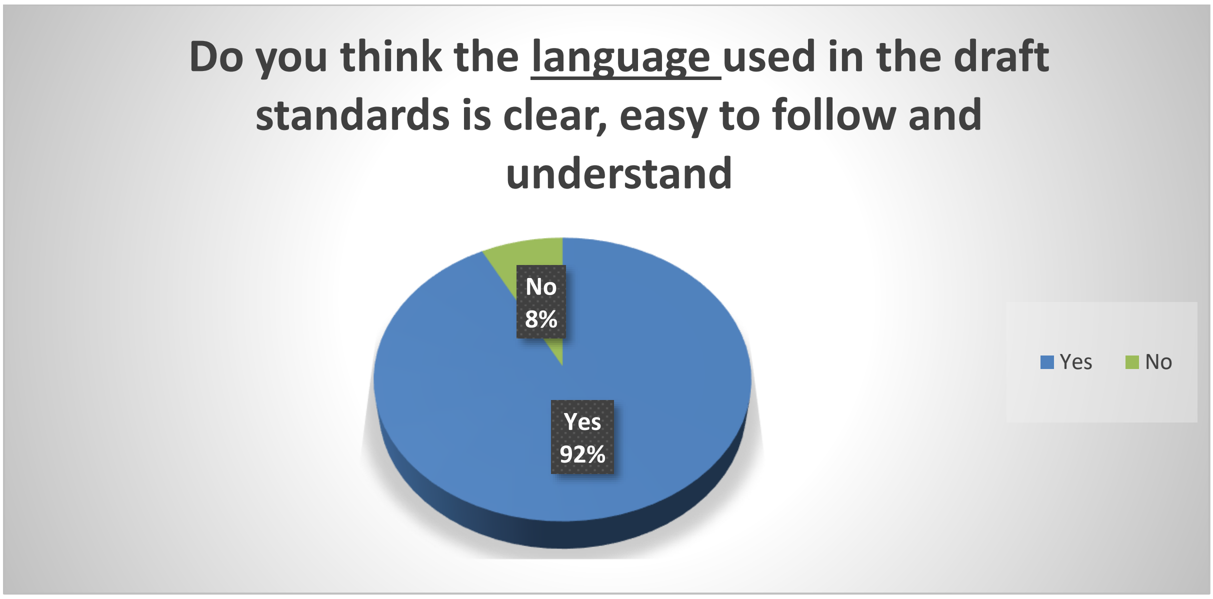
2.6 General feedback – language used, content and structure

Respondents were asked to provide feedback on the language used in the draft standards and if this was clear, easy to follow and easy to understand.

2.6.1 Feedback from public consultation

Thirty-nine respondents answered both questions; 'Do you think the *language used* in the draft standards is clear, easy to follow and easy to understand?' and 'Do you think the *content and structure* of the draft standards is clear, easy to follow and easy to understand?

Figure 1: Responses to the language used in the draft standards



92% (n=36) agreed yes to both questions and 8% (n=3) disagreed with no to both questions.

Respondents were also asked to provide any additional comments on the language, content and structure of the draft standards: Twenty-six respondents provided comments on these questions. Feedback referred to the, content, structure, language, scope and accessibility of the document. A number of helpful comments were received relating to the general formatting and specific suggestions were made with regard to updating the wording throughout document which were considered. The comments are summarised below.

Structure:

The majority of respondents commented positively on the layout and structure of the document, they agreed it was clear and easy to follow however may benefit from being professionally graphic designed. The grouping of themes into principles, standards and features provides clearer guidance to both health and social care organisations and individuals than the previously used themes.

Content:

While responses were generally positive about the content of the standards, a number of suggestions were made for improvements. Many respondents also requested that examples and further information is provided regarding what is expected to achieve compliance.

Language:

A large proportion of responses stated that the standards and features were clear and easy to follow with key terminology that is adequately explained in the opening section of the draft standards document "*Well-structured ensuring a consistency in flow of the document".* However, some respondents highlighted that the accountability section was hard to read with long sentences and technical Jargon. Using stronger wording within the standards and features suggested as well as ensuring the document was accessible to its audience in terms of its content, readability and format.

2.7 General feedback – understanding, intention to change practice, and supporting implementation

In this section the summary of feedback from respondents on their understanding of what good information management practice looks like, their intention to change their practice and on what is needed to support their implementation of the standards will be presented.

2.7.1 Feedback from public consultation

Understanding of what good information management looks like for organisations that process health and social care information

Fourth-two responses were received in relation to the understanding of "What good information management looks like for organisations that process health and social care information". Of these, 86% (*n=36*) indicated yes they did, of which nine further clarified their response with comments.

In general, many agreed that these standards help to understand what good information management looks like, although some acknowledged that the challenge would be to implement this in practice: "*Yes, this is a comprehensive document which takes account of the activities required for effective information management within an organisation*." And that *"a strong national governance structure is needed to make the standards work for the individual and organisations"*

Some acknowledged that the principles approach facilitated their understanding of what good information management involves: *"[The Principles] … highlight the obligations of an effective and person centred organisation to provide a service that addresses quality, inclusiveness, accessibility, engagement, and safe and reliable information management for the provision of care to its key stakeholders, who are the service users."*

Others commented that although the standards make sense from an internal point of view, that good information management requires all organisations to enhance and standardise practice, particularly in terms of coding and interoperable systems: *"… It is important that national and international coding systems are used consistently to allow for extraction of records in line with data protection…"*

Those that provided a "no" response stated that they already work in information management and were familiar with the information within the standards.

Intention to change practice

Thirty-two responded to this question, of which 78% (n=25) agreed that they intended to make changes to their work practices, having read the draft standards. The majority of responses stipulated that they need to ensure that the policies, procedures and strategies of their organisation are aligned with the standards and the need to engage with individuals and the public. Furthermore, some respondents detailed that they intend to form information governance committees to ensure good information management practices and monitor progress with regard to achieving what is set out under the standards.

Only 7 respondents indicated that they would not change/adapt their work practises with in light of the standards, mainly because their organisation falls outside the scope of these standards but they did see the value of the standardsto support quality improvement.

Supporting implementation

Over half of the respondents (61%) detailed what supports are needed in the implementation of the standards within their organisation. Many of the responses called for increased training, more resources and better systems. There was a very strong finding on the need for support, through examples, templates and communities of practice. In particular, responses noted the following to support the implementation of these standards:

- National frameworks, strategies and plans to support implementation.
- Guidance, resources and tools to support implementation and prevent duplication of work at a local level in various types of organisation and the types of data processed by organisations
- Make standards mandatory requirement for all organisations
- Ensuring appropriate expertise of those implementing the standards
- Mechanisms to support the involvement of all stakeholders including the public
- Support with regard to quality improvement
- Increased awareness of the standards.

3 Findings of focus group discussions and interviews

The Project Team analysed all of the feedback received from the focus groups and interviews using HIQA's principles for standards development as a framework: A Human Rights-based Approach, Responsiveness, Safety and Wellbeing and Accountability. Additional broader themes was also used including health information policy considerations and implementation support. The framework method(5) was used to analyse of the focus group data (see **Appendix 3-5**).

Feedback was also received on the content, structure and language of the standards. Participants welcomed the inclusion of what an individual can expect of their service provider. In general, the standards were described as being "*user-friendly*" and "*easy to read and interpret*".

3.1 Theme 1: Safety and wellbeing

Participants across focus groups acknowledged that it should be possible to use information to promote the safety and wellbeing of individuals and of the population.

Healthcare professionals need to have access to all information required to make decisions that ensure the safety and wellbeing of the individual concerned. "*On the clinical side, there are issues with sharing even within a hospital…Clinicians should not have to look through multiple sources for vital information".*

Many discussed the risks to patient safety. "*This is a risk and we want to keep patients safe. There are lots of different systems in place and they all have their uses but sometimes information gets lost if in one place and not in another, and this can be a risk to the patient at the transition of care*."

Others discussed the need to use information effectively to drive improvements in outcomes. For example, organisations need to take control of their information in order for the full benefits for population health to be realised: "*We don't have the data about different cohorts in many instances so we don't know if they are having different outcomes. Having that data to identify different outcomes is going to become a requirement*."

Further to this, there was much discussion about the need for strong national leadership in the area of national health information strategy to ensure that information flows with the patient and across care settings to ensure that those providing care are able to make informed decisions.

In addition, organisations need to take ownership in defining who is responsible for ensuring information is best used to promote the safety and quality of care. Others noted that data collected needs to be outcomes focussed and that the uses need to be communicated to individuals so that they are aware that their information is being used to ensure better safety and wellbeing.

3.2 Theme 2: A human rights-based approach

Participants agreed with the importance of a human rights-based approach to data: "*A rights-based approach makes inherent sense, at its core - the patient's data about their care is their data*." Participants discussed the challenges surrounding accessing information, ensuring that the privacy and confidentiality of individual's data is protected at all times and the importance of including consent in these standards.

Participants also provided examples of instances where it was challenging to ensure a person-centred approach is adopted with regard to an individual's health and social care data. This was reflected in comments about ensuring that the most relevant data is collected and that it is used appropriately. This point was made both in relation to direct care of an individual and secondary use of information such as for service planning in the case of national data collections.

From a human-rights perspective, it is important that information is communicated to the individual in a way that is appropriate for that individual. It should also be transparent to individuals how they can request access to the data that is held about them. For example, "*It is difficult to know if parents, carers, children etc. know of rights as it is not recorded properly if this was discussed. There are some excellent examples in place but practice varies*." The need for staff training on how to uphold the rights of individuals was also discussed.

With regard to the content of the standards, participants mentioned that specific consideration needs to be given to accessibility of information for individuals and professionals (role-based access) and the need to include a feature stating that organisations have a clear point of contact for individuals when they have a query about information held about them.

3.3 Theme 3: Accountability

Participants discussed issues relating to complying with relevant legislation and codes of practice. Legislation such as GDPR is having a direct impact on how information is managed in health and social care settings and in the absence of appropriate infrastructure, it can be a barrier to making the best use of information and to sharing information.

With regard to organisational governance, leadership and management, a number of participants referred to the implications of this for health and social care settings. The need for organisations to have staff with specific roles relating to information management and who are trained in this area was highlighted.

It was also noted that having specific systems in use will not solve the challenges surrounding information management in the health and social care setting: "*Yes, the infrastructure does need to be in place to find and share information and this is a massive piece of work but you also need to have people with the expertise and qualifications in place in each setting*."

At a senior-level, there needs to be a focus on and understanding of the importance of information management within organisations that collect, use and share health information. The roles of staff pertaining to information management need to be clearly outlined in contracts of employment. People and systems need to be in place to ensure these standards can be applied within services. This will require consideration from both a clinical and administrative perspective. This focus and training has to extend across 'all levels' within an organisation: "*Everyone has to be aware. It's training across all levels. There is that fear in people and they hide and say it's not my responsibility but again training and education across the services will be important*."

It was mentioned that many services and organisations are aware of the challenges posed by management of information and have developed guidance and policies to address these. There is a growing requirement is that organisations need to have policies and procedures in place to reduce the risk of information loss when multiple systems are in place. It is also important that organisations manage access to information: "*It might be important to call out how organisations manage accessibility to information; access depends on the role a person has in a hospital to protect privacy and confidentiality; it needs to be appropriate to what information a person needs*."

Organisations need to ensure that '*buy-in*' is present in organisations so that the new standards will be adopted. In particular, there is a need to ensure that smaller organisations with less resources can see themselves reflected in the current standards.

3.4 Theme 4: Responsiveness

The importance of responsiveness was highlighted by participants in discussions about ensuring information is managed in a coordinated way that meets the needs of the individual and also that the data contributes to informed decisions that benefit the public.

In order to address issues surrounding information governance in the health system, participants agreed there is a need for strong leadership in the form of a national approach. As well as engaging with staff at all levels to ensure they understand the importance of good information management practices. Participants also mentioned that consideration has to be given to achieving the balance between sharing information as required and the preferences of the individuals to whom the data pertains: "*Another challenge that we face is the provider achieving balance between information sharing and privacy*." Participants highlighted that some providers may struggle to align with national and international best practices and standards based on the resources available to them and therefore guidance, support and dedicated resoruces will be important.

Infrastructure needs to be in place to facilitate best use of the data such as for linkage and for completing complex analyses. Not having a fully implemented individual health identifier (IHI) also poses a challenge to data quality and making best use of available data. It was also reported that practice varies in terms of recording information. The standards may address this variation in practice. While standardisation brings benefits, there is also a need to be cognisant of increased burden for those who work in health and social care.

Specific challenges surrounding data quality were also referred to including ensuring data and information is accurate, current and not duplicated. Some organisations have developed their own approaches to managing data quality issues. Thus there may be potential to create an area where learning can be shared across organisations. Data security was also highlighted by participants across focus groups as an area that needs to be considered and as something the standards should make explicit reference to.

3.5 Theme 5: Broader health information policy considerations

Across focus groups participants referred to the broad areas where progress is needed to promote better information management practices.

National infrastructure to support data sharing

Participants described some of the challenges which apply to the overall systems in place for the collection, use and sharing of health information: "*I think everyone would agree that sharing information such as between GP, hospital and community without a national system for information is definitely an issue (such as EHRs or portal)*." There needs to be national level of investment to support the technical and operational requirements to support the health information system and to develop a central spine. GDPR can present a barrier to data sharing and the absence of appropriate infrastructure and unique identifier presents a barrier to data sharing and linkage.

An over-reliance on people and manual processes was mentioned as a major obstacle and it was suggested that increased automation will facilitate better use of data. The system must deal with different levels of ICT maturity and varied levels of expertise.

Specific challenges are the levels of resources available to individual organisations and the requirement to share information across services and multiple systems. Technical challenges to this include when "*platforms or systems don't talk to each other*." Furthermore, the division between public, private and voluntary providers presents challenges. Across the health and social care system, there is no 'one' centralised system which results in siloed information. Where change is introduced, training needs to be made available. There is a need to "*break down siloes*" within this area. While work is underway to develop digital solutions, this work needs to be progressed.

The need for coordination across systems was highlighted: "*Where can it all be joined up? There are lots of groups looking at different things. Lots of potential overlap but nobody is looking at them all and seeing where they can join up*." There was also an opposing view raised that in practice it is difficult to achieve full interoperability. It was mentioned in a focus group that international jurisdictions have struggled to achieve this: "*I don't agree in trying to join them all up as there are so many systems in place and trying to join them all up will be too difficult*."

Effective engagement

Effective engagement with the public is required to understand the needs and requirements regarding the management of their information: "*We need to keep the public on side*". There needs to be a programme of education and communication with individuals to inform them of what rights they have with respect to their information. This approach also needs to incorporate effective engagement with all relevant stakeholders including healthcare professionalsIt was suggested within a number of focus group that a phased implementation of these standards should support their adoption within the system: "*This phased approach is really important. You need to be really aware of people on the ground and what they have been through*."

Legislative framework

There was some discussion surrounding the uncertainties posed by the gaps in legislative framework currently in place with regard to health information. Focus group participants expressed awareness that new legislation is forthcoming and that this will have implications for the new standards. New legislation was welcomed, with one participant saying: "*There is going to an explosion of data in future – legislation in this area is needed that specifically addresses these issues. Storage comes with a cost so need to think of this when making decisions in this area*."

Others welcomed further clarity regarding legal basis for sharing for different purposes to improve flow of data across public, voluntary and private organisations.

Participants also highlighted the need for the standards to reflect existing legislation and guidelines such as the Medical Council Guidelines.

Governance structures

The need for organisations to provide clarity regarding arrangements for governance structures was raised. There was in-depth discussions around the governance and leadership structures within the HSE and determining who has overall responsibility for safety and wellbeing. There was a strong agreement that the governance structures should actively drive improvements to health information: "*A focus on information governance doesn't happen by itself. My thought is that the [organisational] governance element is key*."

Others highlighted the need for appropriate leadership and that this has proved difficult nationally and internationally. At a national level, there is a need for national strategy, national governance structures for health information, as well as significant investment in infrastructure for systems.

In order to support the implementation of new systems, business intelligence solutions and education and training initiatives to support staff are required. As one participant mentioned: "*Systems will evolve. But we need governance. We need to be clear on who is leading on this, both national responsibility and local responsibility".*

3.6 Theme 6: Implementation support

All groups were asked for their thoughts on how to support implementation of the standards. Most participants agreed that having templates and examples available to organisations as methods to assist organisations in adopting these standards would be important. Many expressed concern about the resources required to comply with the standards. It was suggested that implementation should be supported by the embedding of good information management practices within organisations: "*There is a need to focus on implementation and then embedding – people need to understand that these practices need to be embedded*."

Participants also highlighted that burden in relation to information management can exist for all staff and also those with specific responsibilities for information management. Managing data and information in healthcare is highly resource intensive and it is important to remain cognisant of this when implementing the standards: "*Every clinician will have felt the extra burden of collecting data where you feel data will not impact the delivery of care at that moment in time e.g. in a clinical trial. Sometimes people will feel that standards, even if they get the overall concept, they may not want the extra burden, e.g. extra clicks, extra questions may not be wanted*."

There is also a need for guidance regarding the implications of the new legislation on practice and the specific roles and responsibilities required at different levels. Continued education of those using the standards is needed to facilitate use of data in the most optimal way and to foster confidence in those collecting, using and sharing health information. Having templates for policies and procedures and checklists outlining what is needed in order to meet the standards would support their implementation. Others suggested holding webinars and making presentations available at the time of the launch as a means to promote the standards and get their message across to stakeholders. In addition, some suggested the benefit of sharing examples of best practice and developing 'communities of practice' where organisations can share experiences and learn from each other.

4 HIQA's response

The Health Information team analysed all public consultation focus group and targeted consultation data and made a number of revisions to the final standards document. Most notably, an additional principle was included on 'Safety and Wellbeing'. The final version of the standards now comprising of four principles including; a human rights based approach; safety and wellbeing; responsiveness; and accountability.

Principle 1: A human rights-based approach

The majority of respondents supported the inclusion of principle that focuses on human rights. Although, there was a collective agreement that the structure of Ireland's health system presented a number of challenges to ensure that a human rights-based approach is upheld.

Firstly, the value of FREDA as an internationally recognised framework through which human rights can be considered under five principles which are: Fairness, Respect, Equality, Dignity and Autonomy was outlined in the introduction section.

As being person-centred is synonymous with taking a right's based approach, Standard 1.3 was merged into *Standard 1.1: Uphold people's rights relating to information.*. Standard 1.1 was then further expanded to include guidance on equity, rights and informed consent to encourage organisations to have effective arrangements in place to ensure individual rights are upheld and to promote an equitable approach to information management.

Additional detail was added to *Standard 1.2.2: Protect privacy and confidentiality* specifically to recoginise that a Data Protection Impact Assessment (DPIA) is an ongoing process and to identify a contact point for feedback in the publication of Privacy Statement or Notice

A clear message from stakeholder feedback was that a 'design for all" approach should underpin this standard, focussing on the needs and preferences of individuals. Whilst this term was not included specifically in Principle 1, there is a strong focus on co-design and ensuring that all stakeholders, as identified in Standard 2.2.1, are involved in the co-design of new health information initiatives or systems

Principle 2: Safety and wellbeing

This principle was not included in the initial public consultation of the standards. However, a strong message from survey and focus group data was that the safety and wellbeing of individuals should underpin quality health information management.

Having access to timely, accurate and relevant information is the foundation to high quality and safe service provision therefore leading to better health outcomes of all individuals. Therefore, the standards related to the effective use of information and engagement with stakeholders, which were initially included under the principle of Reponisveness, now have been included under the principle of Safety and Wellbeing. A strong focus on appropriate access to information, including personal access to one's own information to drive safer better care, is included in *Standard 2.1 – Optimise the accessibility, use and value of information.* Feedback on the need for an equitable approach to information manangement and consent (which related to content which was in the standard on stakeholder engagement) now feature in Standard 1.1 - Upholding people's rights relating to information.

Principle 3: Responsiveness

A large number of submissions acknowledged the challenges to implementing this standard mostly involved resourcing. Smaller organisations may not have relevant expertise in this area and that the adoption of new technologies and advancements required an initial testing period. To address this *Standard 3.4 Develop staff capability and capacity for information management* was included within this principle to promote ongoing training and education for to all staff to assist them in meeting their information management responsibilities.

Also reiterated throughout the public consultation feedback was the call to include 'examples' to highlight the application of the standards within the system. After careful consideration incorporating 'examples' within final revision of the standards would result in the standards going out-of-date very quickly as developments occur in this area. Therefore, to ensure the standards remain relevant in the future, it was decided to include specific examples in guidance and support tools to accompany the standards which can be updated on a regular basis.

A number of public consultations submissions requested more clarity in regards to what is required by the standards and how compliance with the standards will be assessed. As already mentioned above, detailed guidance and support tools on implementation will be addressed in supporting documentation.

Principle 4: Accountability

Accountability was strongly welcomed as a standard overall. However, some feedback suggested that having good quality data through strong information management practices would support this principlenotingthat implementing the standards would strengthen governance arrangements and ensure that clinicians have access to the data that they need to inform personal decision making.

Therefore, a stronger focus on effective engagement to support accountability and accessibility was incorporated into *Standard 2.2 Undertake effective stakeholder engagement* and more clarity included within *Standard 4.1: Develop strong organisational governance, leadership and management* to include information on good governance and transparency regarding strategy. Further detail was also included to define level at which KPIs should be applied and to outline what is required in terms of reviewing an organisation's performance relating to information management in 4.3.2 and by clearly identifying roles and responsibilities of committees including reporting arrangements to senior management. The need to consider proportionality is addressed in the introduction section 1.2 Scope of the national standards.

5 Conclusion and next steps

A summary of the feedback and subsequent changes was presented to the Advisory Group in April 2023. After the Advisory Group, further changes were made to the standards based on feedback from members. The final National Standards then underwent internal approval within HIQA by the HIQA Executive Management Team and subsequently by the HIQA Board. Once approved, the National Standards will be submitted to the Minister for Health, in consultation with the Minister for Children, Equality, Disability, Integration and Youth.

HIQA would like to thank all of those who contributed to the development of these standards through the Advisory Group, public consultation, focus groups, as well as individual stakeholder meetings.

Glossary of Abbreviations

Abbreviation	Explanation
EHR	Electronic Health Record
EU	European Union
FOI	Freedom of Information
GDPR	General Data Protection Regulation
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICT	Information Communication Technology
KPI	Key Performance Indicator
NCCP	National Cancer Control Programme
SIRT	Standards Information Resource and Technology
DPIA	Data Protection Impact Assessments
GP	General practitioner
IHI	Individual Health Identifier

6 References

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4. Health Information and Quality Authority. *Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland*. Dublin: 2022. Available from: https://www.hiqa.ie/sites/default/files/2022-08/Key-policy-considerations-for-health-information.pdf. Accessed on: 4 October 2022.

5. Nicola K. Gale, Gemma Heath, Elaine Cameron, Sabina Rashid, Sabi Redwood. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 2013; 13(1):[117 p.]. Available from: https://doi.org/10.1186/1471-2288-13-117. Accessed on: 20 February 2023.

6. Health Information and Quality Authority. *Evidence synthesis of international evidence on governance structures and information management arrangements in place for national health and social care data collections*. Dublin: 2022. Accessed.

Appendix 1 – Stages in the development of the standards

Stage 1: Evidence synthesis - An evidence synthesis of international evidence on governance structures and information management arrangements in place for national health and social care data collections was conducted in 2022 which includes an 'as-is' analysis of the current situation in Ireland. This paper was used to inform the draft national standards and ensures that they are evidence-based and fit for purpose in an Irish context.(6)

Stage 2: Advisory group - At the beginning of the process, an advisory group was established to provide expert advice (see **Appendix 6** for list of members). The Advisory Group is made up of a diverse range of interested and informed parties. At each stage of the process, members of the Advisory Group had an opportunity to input into the development of the standards. This included informing the scope of the project, providing feedback on the draft standards prior to public consultation, submitting a response to the public consultation, and providing further feedback on the standards following the public consultation process.

Stage 3: Public consultation and targeted consultation - An eight-week public consultation ran from 24 October 2022 to 19 December 2022 to gather feedback on the content and structure of the draft standards. The draft standards document was made publicly available to download on www.hiqa.ie and a consultation feedback form was developed to assist people to make submissions (**Appendix 7**). Submissions could be made using an online survey tool, emailed to a dedicated email address, or posted to HIQA.

At the start of the public consultation, the Project Team notified members of the Advisory Group that the public consultation had commenced and asked that they inform the organisations and groups they represent of this. The Project Team also contacted relevant health and social care professionals, policy-makers, advocacy groups and interested stakeholders by email to inform them of the process and request that they share information about the public consultation and encourage their colleagues and members of the public connected to their services to participate in the process. In order to reach as wide a range of stakeholders as possible, the public consultation was advertised in HIQA's newsletter and on its website. In addition, a press release about the public consultation was issued, and the consultation was advertised periodically via HIQA's social media channels, including Twitter, Facebook, LinkedIn and Instagram. See **Appendix 2** for a list of the organisations that responded to the public consultation.

During the public consultation process, the Project Team held five focus groups with 47 individuals to discuss the draft standards. The groups were representatives from health and social care workforce (n = 23 across two focus groups), HIQA inspectors (n = 8) and representatives of national data collections (n = 8) and Private hospitals (n=8). For each focus group, a copy of the draft standards, the link to the consultation webpage, and a briefing document on the aims and process of the focus group were sent to participants. All focus groups were conducted online. A schedule of questions used in the focus group discussions can be found in **Appendix 5**.

Individual meetings were also held with targeted stakeholders to discuss specific details of the draft standards based on their particular expertise. Five individual meetings were held and a list of the organisations represented is available in **Appendix 3**.

Stage 4: Publication of standards – All responses from the public and targeted consultation, including responses to the public consultation, focus group and interview notes, were reviewed and used to inform the development of the standards. The standards will be presented to the Advisory Group for its consideration in April 2023. Following analysis and review of the additional feedback, the standards will be completed and sent for approval to the HIQA Executive Management Team, before approval by the HIQA Standards Information Research and Technology (SIRT) committee, a sub-committee of its Board, and then the HIQA Board. After the HIQA Board approved the standards, they will be submitted to the Minister for Health and published on the HIQA website.

Appendix 2 – Organisations that responded to the public Consultation

The following organisations submitted a response to HIQA's public consultation on the draft national standards for information management in health and social care:

- Tusla
- Mental Health Commission
- HSE Health Intelligence Unit
- HSE eHealth & Disruptive Technologies
- HSE Healthcare Pricing Office
- HSE Business Intelligence Unit Community
- Health Protection Surveillance Centre
- National Screening Service
- HIQA – Standards Team
- HIQA – National Care Experience Programme
- St. James's Hospital
- St. Luke's General Hospital, Carlow-Kilkenny
- St Patrick's Mental Health Services
- Public Health Area B
- Community Healthcare Organisation 9
- Health Research Consent Declaration Committee
- Health Research Board
- National Cancer Control Programme
- National Office of Clinical Audit
- National Cancer Registry Ireland
- Cystic Fibrosis Registry of Ireland
- Coronary Heart Attack Ireland Register (CHAIR)
- Trinity St James's Biobank Network
- State Claims Agency
- Avista CLG
- Nursing Homes Ireland
- Irish Platform for Patient Organisations, Science & Industry (IPPOSI)
- Irish Medical Organisation
- Pharmaceutical Society of Ireland (PSI) - The Pharmacy Regulator
- Association of Occupational Therapists of Ireland
- National Disability Authority
- National Council for the Blind of Ireland (NCBI)
- Irish College of General Practitioners
- HaloCare Group
- National Clinical Programme for Trauma and Orthopaedic Surgery

Appendix 3 – Focus groups and individual meetings

Focus groups were held with:

- Health and social care professionals (n = 23 across two focus groups)
- HIQA inspectors (n = 8)
- Representatives of national data collections (n = 8)
- Private hospital association representatives (n=8).

Individual meetings with representatives from the following organisations:

- Mental Health Commission
- Saolta Hospital Group
- National Cancer Control Programme (NCCP)
- HIQA Healthcare senior management
- HIQA Regulation senior management.
- Department of Health
- Department of Children, Equality, Disability, Integration and Youth

Appendix 4 – Coding Framework

- A Human Rights-based Approach
- Responsiveness
- Safety and Wellbeing
- Accountability
- Broader health information policy considerations
    - Effective engagement
    - Technical and operational requirements
    - Legislative framework
    - Governance structures
- Implementation support

Appendix 5 – Focus group and interview topic guide

Opening questions:

- From your experience working in [area worked in], what are the major issues with information management currently?
- Do you think the draft standards address these?
- Can you foresee any challenges or opportunities for implementing these standards?
    - Can you identify any implementation support tools that are needed to support you to implement these standards / any examples of tools already in use?

Questions on the standard statements and features:

Principle 1: A rights-based approach

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

Principle 2: Accountability

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

Principle 3: Responsiveness

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

Additional questions:

- Do you have any general comments on the language, content and structure of the draft standards?
- Do you have any thoughts on the decision to extend the scope of the standards to all services and organisations that process health and social care information?
    - Do you think this will have any implications (positive or negative) for the health system?
- Are there any other comments that you would like to make about these draft standards?

Appendix 6 – Membership of the Advisory Group

Name	**Organisation** - ***Title***
Azul O' Flaherty	Department of Health - *Assistant Principal, Health Information Policy Unit*
Cliona O Donovan	National Office for Clinical Audit - *Quality Assurance and Operations Manager*
Colin White	HSE National Patient Representative Panel - *Member*
David Stratton	Primary Care Reimbursement Service, HSE - *Business Manager, PCRS*
Deirdre Murray	National Cancer Registry Ireland - *Director*
Derek McCormack	Operational Performance and Integration, HSE - *General Manager, Acute Business Information Unit*
Eve Robinson	Health Protection Surveillance Centre, HSE - *Specialist in Public Health Medicine*
Fiona Boland	Royal College of Surgeons in Ireland - *Lecturer, Data Science Centre, School of Population Health*
Fiona Kearney	Tusla - *Records Management Lead*
Jacqui Curley	Healthcare Pricing Office - *Coding Manager*
Jennifer Martin	Quality and Safety Directorate, HSE - *Clinical Lead, Quality and Patient Safety Intelligence*
Johnny Sweeney	Irish College of General Practitioners - *Project Manager, National General Practice IT Project*
Ken Moore	Central Statistics Office - *Senior Statistician, Quality Management Support and Assurance Division*
Laura Heavey	National Screening Service, HSE - *Specialist in Public Health Medicine*
Mark Conroy	Tusla - *ICT Data and Analytics Manager*
Margaret Hynds O'Flanaghan**	CORU- *Head of Recognition*
Maurice Farnan**	HSE-*interim National Director Community Operations*
Michael Courtney	Department of Health - *Statistician*
Michael Power	HSE National Patient and Service User Forum - *Member*
Pawel Stepala**	Mental Health Commission- *Head of Regulatory Practice and Standards*
Sandra Ryan	Office of the Chief Information Officer, HSE - *Technical Standards Lead*
Sarah Craig	Health Research Board - *Head of National Health Information Systems*
Selina Ryan	Health Informatics Society of Ireland (HISI) - *Nurse Lead for Informatics, St James Hospital*
Simon Woodworth	University College Cork - *Director, Health Information Systems Research Centre*
Theresa Barry	HSE- *Clinical Terminology Architecture Lead*
Tibbs Pereira	Patients for Patients Safety Ireland - *Member*
Tom Foley**	HSE- *Consultant Psychiatrist*
Tracy Kelleher	NCRI -*Data Integration Supervisor*
Trevor Duffy	Royal College of Physicians in Ireland - *Director of Healthcare Leadership*

Trish King**	HSE- *General Manager, Scheduled Care, Acute Operations*

** Additional members invited to join the advisory group to broaden representation.

Appendix 7 – Public consultation feedback form

Draft National Standards for Information Management in Health and Social 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.
- 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.

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.
- 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.

About you

Are you providing feedback as:

☐ **an individual**

(If you would like to be contacted to participate in future stakeholder engagement, please provide your name and contact number below. Otherwise, please move on to the next question.)

Click here to enter text.

☐ **on behalf of an organisation**

(If you are responding on behalf of an organisation, please provide your organisation's name and contact details below for verification purposes.)

Click here to enter text.

Are you commenting:

☐ **In a professional capacity**
(Please use the box below to specify your role in the organisation you currently work for.)

Click here to enter text.

☐ **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.

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?

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

Click here to enter text.

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

Click here to enter text.

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

Click here to enter text.

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

Click here to enter text.

General Feedback

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

☐ **Yes**

☐ **No**

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

☐ **Yes**

☐ **No**

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

Click here to enter text.

Having read the draft standard, 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.

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.)*

Click here to enter text.

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.)

Click here to enter text.

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

Click here to enter text.

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