Health
Information
and Quality
Authority
An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health

RESPONSE TO THE FINDINGS:
NATIONAL ENGAGEMENT ON Digital Health & Social Care

2024

Contents

About the National Engagement on Digital Health and Social Care

Background

The Health Information and Quality Authority (HIQA), in partnership with the Department of Health and the Health Service Executive (HSE), conducted a National Engagement on Digital Health and Social Care. The National Engagement on Digital Health and Social Care was undertaken to build on findings from the National Public Engagement on Health Information and in the context of the evolving digital health landscape including EU targets and the Health Information Bill 2024, which pave the way for people having access to and control over their health records digitally in Ireland. In addition, under the Sláintecare health reform programme, the Government has goals around using digital technologies in health and social care resulting in increased investment in this area.

The aim of this engagement was to ask the Irish public and professionals for their views in relation to the digitalisation of health and social care services. Both the public and professionals were asked to share their views through surveys and focus groups. The findings of this engagement provide evidence to inform the development and provision of digital health systems and services in Ireland.

The Department of Health has overall responsibility for leadership and policy decision-making in the Irish health sector. The eHealth and Information Systems unit is responsible for the development of Digital Health policy and the national Digital Health agenda with specific focus on enabling delivery of integrated care under the Sláintecare reform agenda. The Health Information Policy Unit is responsible for leading on the regulation of health information in Ireland, and related policy, strategy, and implementation.

The HSE is tasked with providing Ireland’s public health service in hospitals and communities nationally. The HSE is responsible for implementing national health information systems not only within the HSE, but also for the wider health and social care systems. Technology and Transformation is the HSE division responsible for the delivery of technology to support healthcare across the Irish health service.

HIQA has a statutory remit to set standards, evaluate and make recommendations about deficiencies in health information as outlined under section (8)(1)(k) of the Health Act 2007. HIQA, through its health information and standards setting function, has a responsibility to promote health information for people using services across public and private settings. HIQA does this by using best available evidence to develop recommendations, standards, and guidance to support the Irish eHealth and health information landscape.

Overall response to the findings

HIQA, the Department of Health and the HSE welcome the findings from the National Engagement on Digital Health and Social Care. The findings demonstrate that the public are ready for the digitalisation of health and social care services and can see the benefits of an online health record to empower them on their health care journey. While professionals can see the benefits for the public of online health records and digital care, they are also aware of the potential barriers to implementation and areas where improvements in infrastructure and further support will be required.

The need to ensure care remains person centred and that people's needs and preferences are considered in the move to digitalise health and social care services is acknowledged. Preventing digital exclusion and ensuring that supports are in place, including education on digital literacy, will be an important part of how these findings are used in future policy and practice.

Department of Health response to the findings

The Department of Health welcomes the publication of the findings of the National Engagement on Digital Health and Social Care. The report provides valuable new information about the opinions and attitudes of the Irish public and professionals in relation to the digitalisation of health and social care services. The finding identify specific supports that could improve participants' willingness to engage with digital health and social care. The responses gathered from both a public and professional perspective, represent a broad evidence base to inform national policy going forward.

The publication of the findings will inform developments in digital health and how best to provide patients with access to their own digital health record and related health information. The findings also provide valuable insights into the views of healthcare professionals, which will be crucial as we invest in the modernisation and reform of health service delivery using digital technology.

The European Health Data Space (EHDS) Regulation which will be in force in EU Member States from autumn 2024 and the Health Information Bill 2024 will introduce a robust legislative basis to support digitisation of health and social care in Ireland. Strong engagement with the public is vitally important for empowering individuals to access and control their own health data as envisaged by the legislation.

The report highlights concerns around the patient's literacy levels including the ability to speak and understand information in English and whether they will have the necessary digital skills to be able to access health information. The Department of Health recognises the importance of Health Literacy and Digital Literacy and is supporting the whole-of-Government *Adult Literacy for Life (ALL) Strategy*.

The role of Literacy, Digital Literacy and Health Literacy in improving health outcomes for patients is acknowledged in several Department of Health strategies and policies including the *Healthy Ireland Framework*, the *Sláintecare Implementation Strategy and Action Plan*, and the *Digital for Care – A Digital Health Framework for Ireland*.

The Department of Health has established a Health Literacy Liaison Group to provide a focus for health literacy-related work within the Department. It includes representatives from external patient groups. Current projects include developing a Health Literacy Policy Toolkit for use within the Department, publication of the Health Literacy Survey, awareness raising on Health Literacy matters within the Department and Digital Health Literacy.

HIQA’s programme of work, advising on the efficient and secure collection and sharing of health information and standards setting will play a fundamental part in the successful implementation of digital health and social care.

Health Service Executive (HSE) response to the findings

Overall findings

The Health Service Executive (HSE) is pleased to acknowledge the publication of the findings from its partnership project with HIQA and the Department of Health; the National Engagement on Digital Health and Social Care.

These findings offer critical insights into the public's readiness and desire to engage with digital health and social care services. It is particularly encouraging to note that the public recognises the benefits of online records in facilitating their healthcare journeys, supporting practical tasks, and fostering active participation and autonomy in healthcare decision-making. Additionally, the HSE appreciates the public's heightened awareness of the importance of data privacy and security. The report underscores the value of collaborative partnerships between service users and providers, aimed at enhancing the design, delivery, and accessibility of digital health and social care services.

While the public may feel prepared to engage with digital health and social care services, it is important to acknowledge that it is the opinion of the professionals that additional supports maybe required to enable this transformation. The findings offer valuable insights into the need for additional technical and policy-driven educational aids, to enhance digital health and social care services. It is encouraging that professionals recognise the benefits of a national strategy to facilitate information sharing between health and social care services, as well as the importance of a collaborative approach between service users and providers in the delivery of these services. Additionally, it is noteworthy that professionals see the empowerment potential of online health records in enabling individuals to take greater control of their own health.

The key findings from this public and professional engagement align closely with current policies and can further advance the HSE’s healthcare vision.

HSE Digital for Care – the HSE’s Digital Health Roadmap

The Department of Health (the Department) recently launched the *Digital for Care – A Digital Health Framework for Ireland 2024-2030* which sets out the aims to digitally transform health services and improve access for patients. In collaboration with the Department, the HSE have published the ambition for the role digital will play in the future of health in Ireland through the *Digital Health Strategic Implementation Roadmap* (the Roadmap).

The HSE Roadmap reflects the results of the public survey in the following ways:

- The Roadmap aligns with the public's readiness for digital health, focusing on modernising the delivery of health and social care.
- Patient needs and preferences are central to the Roadmap's patient-centred care approach.
- Patients are empowered with control and autonomy over their online health records.
- Security and data privacy are foundational principles of the Roadmap.
- Digital inclusivity is a commitment to ensure equal access for all.
- Patient safety is prioritised through data integration and analytics.
- The Roadmap includes initiatives for Electronic Health Records (EHRs) to enhance patient health management.
- Digital systems integration will allow practical use of online health records.

Additionally, the Roadmap reflects the results of the professional survey in the following ways:

- The Roadmap addresses professionals' concerns about public digital readiness by emphasising patient-centred care and providing accessible digital tools.
- It aligns with the desire for person-centred digital delivery by incorporating patient input into health data.
- The Roadmap recognises the need for equal access to digital health and includes measures to educate and empower all users.
- It acknowledges the necessity for technical support and training to build a digitally skilled healthcare workforce.
- It supports a national strategy for information sharing by aiming to integrate health and social care services.
- Online records are seen as a way to empower patients, giving them more control over their health.

The findings of this engagement will be used to inform the delivery of key elements of the HSE *Digital Health Strategic Implementation Roadmap* and Sláintecare vision. The Digital for Care Framework and the Roadmap set out the vision to digitally transform health services and improve access for patients. This includes:

- **The patient app** which will enable patients to manage their health identity, personal information, care coordination, and service access in one secure, user-friendly platform.
- **Patient feedback platform** which will allow patients to provide feedback on their experience with the health and social care system, allowing care providers to understand user experiences and make improvements to services
- **Public facing engagement and digital health literacy development programmes** which aims to empower patients and service users to effectively use digital health and social care services. The goal is to ensure that people can independently, confidently, and thoughtfully engage with digital health environments, thereby promoting digital health literacy and inclusion.
- **Digital health capability building** offering a variety of learning opportunities, such as workshops, webinars, online courses, and mentorship programmes, to enable the workforce to gain new digital competencies and stay updated on emerging technologies and leading practices.
- **Improve employee experience** offering a range of digital applications and tools aimed at enhancing the work environment for health and social care workers, regardless of their location or situation.
- **Electronic Health Record** with the vision to have a single, comprehensive EHR for every individual, which should be accessible to healthcare professionals and the patient.

The HSE welcome this National Engagement on Digital Health and Social Care findings report and is committed to leveraging these insights to guide the Digital for Care programme, ensuring that the needs of the patients and professionals alike are met with innovative, secure and inclusive solutions that empower everyone to take an active role in their healthcare journey.

HIQA response to findings

Overall, the findings from the national engagement demonstrate the public's readiness for the digitalisation of health and social care services. The findings show that people want to be more in control of their health, they want to have access to their online health record and to use it for practical tasks to manage their health care journey. Professionals see the benefits of online health records and digital care for empowering people on their health care journey, however, professionals are aware of the barriers to implementation and foresee areas where support and improvements in infrastructure will be required.

Outlined below are key findings arising from this engagement that are relevant to the programme of work that HIQA undertakes in relation to health information:

1. People want to be actively involved, and their needs and preferences to be considered, in decision-making around the format and delivery of digital care.
2. People are happy to share information in their online health record, however, they want full control over their record. People want to know who is accessing their record, how often, and for what purpose.
3. People want to be assured that their information will be kept confidential and secure before they feel comfortable with their data being shared in an online format.
4. People are happy to share their personal information, including name and date of birth or mobile number to identify them when accessing services. A lower proportion were comfortable providing their Personal Public Services Number (PPSN) or MyGovID.
5. Professionals want decisions around digital care delivery to be person-centred and informed by the healthcare need and patient's choice. Professionals do not want anyone to be excluded in the move to online health and digital care.
6. Professionals want protocols in place to know when it is appropriate to provide services or information digitally. In particular, professionals noted that they would like policy direction and standards developed for clinical note-taking.
7. Professionals want a national strategy that will inform and facilitate the sharing of information between health and social care services.
8. Professionals want up to date digital systems with awareness of the measures in place to keep services and information private and secure from cyber-attacks.

9. Professionals require technical support and training in digital tools prior to feeling comfortable interacting digitally with the public.

There are a number of key programmes of work underway within HIQA's Health Information function that will contribute to ensuring findings from the national engagement are addressed in current and future digital health developments in Ireland. These include:

1. Supporting the promotion and implementation of the *National Standards for Information Management in Health and Social Care*.
2. Informing the health information standards programme of work.
3. Dissemination, training and support to progress goals under HealthData@IE.

1. Supporting the promotion and implementation of the National Standards for Information Management in Health and Social Care

In June 2024, HIQA published *National Standards for Information Management in Health and Social Care* which aim to improve how information is managed across all levels of the health and social care system. These standards aim to provide a roadmap for organisations and services to improve their information management practices and to optimise both primary and secondary uses of information. The national standards acknowledge the importance of adequate infrastructure in ensuring that information is available when, and where, it is required.

Findings from the national engagement demonstrate how important confidentiality and security of data are for both the public and professionals. They also highlight the importance of a person-centred approach to digital healthcare and information management and the importance of technical support and training in digital tools for professionals. These findings are addressed through the national standards which are underpinned by four person-centred principles: A human rights-based approach; responsiveness; safety and wellbeing; and accountability. The standards and their associated features cover key areas of information management, for example, upholding people's rights; protecting privacy and confidentiality and aligning with best practice with regards to the use of standards and definitions.

Through the following programmes of work to promote the standards and support their implementation, HIQA will contribute to ensuring that the relevant findings from the national engagement are addressed:

- To support organisations and services to meet these national standards, HIQA has published three guidance documents including an Assessment Judgment Framework as well as a Guide to the Assessment Judgment Framework; and a

Self-Assessment Tool (SAT). HIQA will promote and support the implementation of the national standards through a series of presentations and webinars, as well as a social media campaign and other publications. HIQA will continue to engage with the sector to identify priorities with regard to guidance and tools to support the implementation of the national standards across all levels of the health and social care system.

- HIQA will use the national standards to review information management practices in national data collections[*] and eHealth services[†] that fall within its remit. This will build on previous reports published by HIQA regarding information management practices including reviews and recommendations. HIQA will also use the national standards to review information management practices at a national level within the HSE and Tusla. HIQA will work closely with organisations to support them to achieve compliance and will develop a revised review programme to assess compliance against the standards.

2. Informing the health information standards programme of work.

Standardising health information is fundamental to the transition of digital health records, as a precursor to the development of interoperability standards and overall supports an integrated health information system. Significant progress in the area of standardising health information is required given the imminent policy changes occurring at both European and national level. At a European level, the European Health Data Space (EHDS) promotes cross-border health data exchange, necessitating harmonised standards to ensure data consistency. At a national level, the Department of Health's *Digital for Care - A Digital Health Framework for Ireland 2024-2030* sets out a strategic vision for integrating digital technologies into healthcare, requiring standardised health information to streamline processes and improve patient outcomes. The Health Information Bill 2024 puts forward a legal framework for the collection, use and sharing of health information. Collectively, these developments underline the critical role of health information standards in achieving a cohesive, efficient and secure digital health ecosystem in Ireland.

The findings from the survey show that professionals' view the development of standards as important in order to provide information or services digitally. Professionals, for example, identified clinical note taking as an area where they need guidance and standards to inform the minimum required for a clinical note.

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[*] National data collections are national repositories of routinely collected health and social care data.

[†] eHealth services are the technology, people and processes which facilitates the sharing of electronic patient-specific information between health and social care services across organisations and/or care settings.

Professionals also rated that having protocols in place would increase their comfort sharing information and providing services digitally.

In the context of the evolving health information landscape, HIQA is undertaking a programme of work including the development, updating or adoption of health information standards in order to reduce fragmentation, duplication and ensure a more consistent approach to documenting health information. HIQA will contribute to ensuring that the relevant findings from the national engagement are addressed. As part of this work HIQA will:

- Undertake research on international developments in relation to the standardisation of health information to identify areas of best practice.
- Develop and implement a prioritisation process that will help to identify the areas of highest potential impact for developing new and updated standards, to reduce variation and improve safety and quality.
- Collaborate with stakeholders and engage with the public and service users to developing national health information standards that are operational, fit-for-purpose and improve experience of people using services.
- Develop tools to support the implementation of the standards into practice.

3. Dissemination, training and support to progress goals under HealthData@IE

The European Health Data Space (EHDS)[‡] is a major health information development in all EU countries. One of its aims is to develop health data access bodies (HDABs) in each country to facilitate access to good quality health data for secondary use.[§] Under an EU co-funded grant, HIQA is partnering with the Department of Health and the Health Research Board (HRB) to advance this HealthData@IE project.[**] Under the HealthData@IE project, HIQA is responsible for three programmes of work:

- Dissemination, training and support

[‡] The EHDS is an initiative that will enable people to access their electronic health data nationally and across borders.

[§] Secondary use involves the collection, use and sharing of health information for reasons beyond direct care such as planning and management of health services, policy-making, public health and research.

[**] The HealthData@IE project is co-funded by the European Union through EU4Health 2021-2027 under grant agreement number EU4H-2023-JA-3-IBA-10. The grant related to the HDAB project is from October 2023 to October 2027. gov - HealthData@IE– National Project Implementing EHDS (www.gov.ie)

- National health data catalogue
- Data quality enhancement.

The National Engagement on Digital Health and Social Care provides further evidence of the need to engage effectively with the public and professionals on changes to how health information is collected, used and shared. Failure to engage with the public and professionals as part of the establishment of a HDAB may result in negative attitudes towards its functions and responsibilities which could impact its success. Based on the findings of the national engagement, where a majority of the public and professionals are positive about digital developments in health and social care, this is an opportune time for HIQA to engage meaningfully with the public and professionals through this change.

HIQA will use the findings from the national engagement as a tool to inform, consult, involve, collaborate with and empower the public and health and social care professionals in terms of the governance and operation of the HDAB. As part of this work HIQA will:

- establish a Public and Patient Involvement (PPI) panel to bring the perspective of the public to the project
- convene a working group of professionals to bring the perspective of professionals to the project
- develop a dissemination, training and education plan, a training needs analysis and a training portal to support the governance and operation of the HDAB.

Publication of findings: National Engagement on Digital Health and Social Care

The findings from the National Engagement on Digital Health and Social Care were published in September 2024. The related documents published include:

- Findings from the National Engagement on Digital Health and Social Care
- Technical Report for the National Engagement on Digital Health and Social Care
- Responding to the National Engagement on Digital Health and Social Care
- The anonymised survey data files[††]

All published reports and outputs can be downloaded from www.hiqa.ie

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[††] Certain variables were redacted from the anonymised data files to protect the identities of participants. Further details are provided in the data files.

Published by the Health Information and Quality Authority (HIQA).

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