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

An Roinn Sláinte
Department of Health

HSE

Responding to the National Public Engagement on Health Information

2020 - 2021

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About the National Public Engagement on Health Information

Background

The Health Information and Quality Authority (HIQA), in partnership with the Department of Health and the Health Service Executive (HSE), has conducted a National Public Engagement on Health Information to ask the public their views on how their health information should be collected, used and shared in Ireland. People were asked to share their views through a national survey and focus groups.

HIQA is an independent statutory authority which, under the Health Act 2007, has the legal remit to advise on the efficient and secure collection, use and sharing of health information; set national standards for health information systems; make recommendations and provide guidance to the Minister for Health to inform policy-making; and evaluate information resources and publish information on the delivery and performance of Ireland's health and social care services.

The Department of Health has overall responsibility for leadership and policy decision-making in the Irish health sector. The Research and Development and Health Analytics Division leads on health information policy, and currently focuses on the use of health information beyond direct care. The Sláintecare Programme Implementation Office is responsible for developing the eHealth Strategy; and setting priorities and facilitating the delivery of health information systems through managing resources and funding the delivery of health information system projects.

The HSE is tasked with providing Ireland's public health services in hospitals and communities nationally. The HSE is responsible for managing a number of key national data collections and implementing national health information systems not only within the HSE, but also for the wider health and social care systems. The Office of the Chief Information Officer (OCIO) is responsible for both the operational and strategic aspects of implementing national eHealth programmes.

Overall response to the findings

HIQA, the Department of Health and the HSE welcome the findings of the National Public Engagement which show that people welcome a move towards a more digital healthcare system, and understand the value of sharing health information to support an integrated model of care and to achieve additional personal and public benefits through sharing of information beyond direct care.

The need to place people at the centre of this process is acknowledged, alongside the need to develop an appropriate infrastructure that allows the transparency and control of personal health information that is desired. Ensuring people's rights to privacy and security in relation to health information are upheld will continue to 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 Public Engagement on Health Information. The findings provide useful insights into how members of the public recognise the importance of sharing health information for direct care, planning, quality improvement and research. It is also very positive that members of the public see the benefits of moving to electronic healthcare records and would like to see them implemented, provided their information is kept safe and secure. The findings will help inform national health information policy and the need for appropriate regulations and legislation.

The Department of Health's roles and responsibilities in relation to health information

The Department of Health leads on the development of policy and legislation and governance and organisational arrangements for health information in health and social care services in Ireland. The Sláintecare Programme Office, within the Department of Health, supports and drives the delivery of the vision outlined in the Sláintecare Report. The Sláintecare Implementation Strategy sets out the direction for the coming years and actions to be taken in the Sláintecare implementation process. Within this strategy there is a key focus on eHealth, as outlined in Strategic Action 10: "Put in place a modern eHealth infrastructure and improve data, research and evaluation capabilities."

The programme of work by HIQA planned for 2022 on patient portals, a consent model for the collection, use and sharing of personal health information and guidance on definitions for the use of health information will support the public's understanding of and implementation of eHealth initiatives in the immediate years ahead.

Sláintecare Implementation Strategy and Action Plan 2021 - 2023

Reform, if it is to be effective and to address expectations, will require solid evidence. However, at present health information is often fragmented and not harnessed sufficiently. The rollout of the individual health identifier and the opportunity to implement the eHealth strategy means it is now the right time to develop a new health information policy for Ireland that can connect the legislative requirements and governance and operational arrangements needed to exploit knowledge and information in a modern health service. In the future, a strong approach to data collection, analysis and management will underpin the delivery of our health and social care services.

Investment in ICT, eHealth and health information systems has the potential to be the biggest and most effective driver of change and improvement for better patient

outcomes across the health system. In the future, a coherent suite of eHealth solutions will underpin and support our overall vision for integrated, patient-centred care, population health planning and more effective and safe delivery of health services. Patients and health professionals will have ready access to clinical records and administrative information, which will enable better decisions to be made. Our priorities are to:

- Implement the electronic health record (EHR) in the acute and community health sectors.
- Design and rollout solutions to connect data across the system and, over time, make data available to patients as well as clinicians and other healthcare providers via an online portal.
- Design and rollout a range of primary and community-based ICT services that will improve the lives of patients, including ePrescribing, summary care records and commence implementing telehealth solutions to support care in the community.
- Develop new ICT systems and invest in infrastructure to support the health workforce and the delivery of integrated care.

Project 6 of the Sláintecare Implementation Strategy and Action Plan outlines the actions required to implement the eHealth Programme. The eHealth Programme is a critical enabler of the Sláintecare Reform Programmes, and significant investment in eHealth capital and staffing will be available for implementation over the course of the Sláintecare Strategic Action Plan. Key critical eHealth and technology actions that will support integration, keep people well in their community or at home, and support better acute demand management include:

- National COVID-19 Vaccination IT System
- National Waiting List Management System
- Decision support pathways
- ePharmacy / ePrescribing
- Residential Care and Home Support Management Systems
- Video Conferencing / Remote Consultation
- Electronic Discharge System
- Health Performance and Visualisation Platform
- Integrated Information Services Supporting Recovery
- Summary and Shared Care Record
- Community Patient Management System.

Health Service Executive (HSE) response to the findings

HSE's roles and responsibilities in relation to health information

The HSE provides public health and social care services to everyone living in Ireland. The management of health information is an integral part of the healthcare system and is essential to support the delivery of high-quality, effective health and social care. eHealth solutions will enable patient information to be shared across healthcare settings to optimise the efficiency of health staff and improve the patient experience. The delivery of high-quality, evidence-based, safe, effective and person-centred care, is a key objective for the HSE

The Office of the Chief Information Office

The Office of the Chief Information Officer (OoCIO) is the HSE office responsible for the delivery of technology to support and improve healthcare in Ireland. It is committed to realising the eHealth Ireland Strategy by ensuring that information and technology support healthcare efficiently and effectively throughout the whole health service.

Other key national policies and strategies include:

- Sláintecare 2018 report presented a 10-year vision to transform Ireland's health service with investment for system changing measures, which includes the implementation of an eHealth strategy. This commitment recognises the critical role eHealth will play for the HSE to provide this transformation of the Irish healthcare system.
- HSE Corporate Plan 2021-2024 is informed by Sláintecare's vision with a focus on prioritising eHealth, data and information quality and safety.
- National Service Plan 2021 will be delivered within the strategic framework of the HSE Corporate Plan 2021 – 2024. With the accompanying eHealth and ICT Capital Plan, there is a commitment to the delivery of eHealth solutions as set out in the Sláintecare report. This will enable a major health reform initiative with patient health information central to its delivery.
- As of Quarter 3 2021, the OoCIO has deployed and upgraded many aspects of the ICT infrastructure that patient data resides in. This provides a greater level of security that protects and defends the HSE against cyber security attacks and is in line with the highest international security standards.

Overall findings

The overall findings from this public engagement have been very positive. The HSE welcomes the results provided from the survey and focus groups, specifically where

people understand and value the importance of health information to support safe and efficient health and social care. Furthermore, the HSE welcomes the public's understanding of the need for continued development of safe dissemination of health information to the appropriate stakeholders. Some of the key findings arising from this public engagement are relevant to current policies and can be aligned to HSE's healthcare vision.

How the public view the importance of using health information for direct care and secondary purposes, beyond direct care and views on digital health records

- The public have high levels of trust in healthcare professionals to keep their information safe and secure, and this increases their willingness to share information for their direct care.
- The findings show that most people think it is important that healthcare professionals have access to their health information to inform appropriate and timely direct patient care, and to contribute to a more efficient health service for all patients.
- The survey and focus groups showed there is an appetite for the public to have greater access to their information so that they can be more involved in their own care.
- Overall, most people have no concerns with health information being used for purposes beyond the direct care of the patient and have high levels of trust that health information will be kept safe and secure.
- Most people want to be informed about how their information is shared for purposes beyond their direct care.
- Most people have no concerns about their health information being accessed electronically.
- The public want to see what information is available on their digital record and to know who views their digital record and their reason for accessing the information.

HSE recommendations

All the findings will be used to inform the delivery of fundamental elements of Sláintecare vision. The HSE Corporate Plan for 2021-2024 outlines that a more transparent picture is needed in the approach related to how data and information is collected, stored, shared and accessed across the health service. It will give an

understanding of the importance of the use of information in decision-making, process improvement and public health.

The findings of this survey and focus groups show that people feel it is important that health information is used for purposes beyond the direct care of the patient, such as quality improvement, service planning, and health-related research, as long as it provides personal or public benefit. These findings will inform the HSE's Corporate Plan commitment around patient data and information which includes:

- Enabling the availability of people's health and care information.
- Identifying and agreeing appropriate information and data sources and address key gaps.
- Ensuring patient health information is being handled appropriately, safely, securely and in an approved and controlled way.
- The implementation of an Integrated Information Service which will consolidate information and provide insights to inform decision-making.
- The implementation of a Health Performance Visualisation Platform to support our clinicians, managers and policy-makers to have appropriate access to timely, accurate data.
- The adoption of appropriate technologies, building capacity for modelling and predictive analytics, standardising reporting and automating where appropriate, to better understand demand and support population health planning.

The survey results show trust in healthcare professionals having access to people's health information, but people also think that digital records would make it easier to access their own health information. The findings of this survey and focus groups can also inform the HSE's Corporate Plan commitment to implementing technology and eHealth solutions which includes:

- Implementation of eHealth and technology solutions that will enable patients to access care closer to home (for example, Remote Consultation and the Patient Portal).
- Implementation of digitally connected clinical systems, and eHealth solutions across acute and community care to support integrated care delivery.
- Implementation of a shared care record that enables clinical staff to work collaboratively to care for patients and service users regardless of the setting.

- Implementation of technology that allows accurate and integrated data collection to support data-driven decision-making across the organisation.
- Commitment to invest in the infrastructure and security to ensure that our eHealth and technology solutions can deliver patient outcomes while robustly protecting their information.

A key finding shows the public would prefer to be more informed about the different uses of their health information. This will feed into one of the key enablers of the HSE Corporate Plan which will be centred on communications and engagement:

- The HSE will communicate openly and effectively to build confidence in the health service.
- We will develop digital communications and invest in designing and delivering patient focused digital health communication platforms.
- We will develop the necessary structures to effectively involve and engage staff, patients, service users, families and the general public in the planning, design and improvement of our services.
- The HSE will identify innovative ways and work with partners in order to provide information and engage with those who are unable or do not prefer to use digital channels.
- We will provide appropriate training to health service professionals to ensure that all communication is easily understood and accessible to the public.
- The HSE will build capacity and skills within our health service leaders to manage risk and crisis communication.

HIQA response to the findings

HIQA's roles and responsibilities in relation to health information

HIQA has a legislative remit under the Health Act 2007 to drive improvements in health information in Ireland. Through this health information function, HIQA works to support health and social care organisations in improving the quality of their data to better support the delivery, planning and monitoring of health and social care services. HIQA does this by using best available evidence to develop recommendations, standards and guidance to support the Irish eHealth and health information landscape. HIQA also assesses compliance with standards to further drive improvements in this area.

Overall, the findings from the first national public engagement have been positive. It is evident that people understand and value the importance of using and sharing health information to support safe and efficient health and social care, but they want to be better informed of how their health information is used, and they want the systems in place to be secure and fit for purpose.

Some of the key findings arising from this public engagement are very relevant to the work that HIQA undertakes in relation to health information. For example:

1. People want to be assured that safeguards are in place to keep their personal health information secure and that their right to privacy will be protected.
2. People think it is important for health information to be collected, used and shared by healthcare professionals who are providing them with care. However, they would like to be more informed about who will use it and for what purpose.
3. People think it is important for health information to be shared for purposes beyond their direct care, but they are more comfortable if identifiable information, such as their name and address, has been removed.
4. People want to be able to access their own health information. They want to be actively involved in their own care and decisions that are made about their health information.
5. People are comfortable with their health information being stored and shared electronically, and see the benefits of moving towards a more integrated digital healthcare system, once safeguards are in place to protect their privacy.

6. People consider certain types of information to be more sensitive than others and are more concerned about this information being shared without their consent.

HIQA is currently developing a new corporate plan for 2022-2024. Aligned to our core objectives in relation to health information, HIQA will continue to support Ireland's health information and eHealth landscape by:

1. providing evidence to inform national policy and legislation in the form of recommendations on a model for the collection, use and sharing of health information in Ireland.
2. developing guidance for the public, for healthcare professionals, and for the wider health system.

1. Recommendations and other contributions to inform national health information policy and implementation of policy

In Ireland, there is no clear legislative framework in place for the use of health information. The current legislative landscape is complex and draws on a number of discrete pieces of legislation, making it difficult to understand and navigate. Examining international practice, it is evident that having clear legislation and guidance on the rules for processing health information provides professionals with the knowledge and confidence to share confidential health information in the best interest of patients and the public.

Recommendations on a model for the collection, use and sharing of personal health information in Ireland

All of the findings from the public engagement will be used to inform a set of recommendations that is currently being developed by HIQA on a model for the collection, use and sharing of personal health information in Ireland. The recommendations will be published and sent to the Minister for Health in early 2022.

The recommendations on a model for the collection, use and sharing of personal health information in Ireland will be informed by a public consultation, and the final recommendations will be published on www.hiqa.ie. As part of this work, HIQA will:

- recommend definitions for key terms, such as health and social care information, use of health information for direct care, and uses of health information beyond direct care
- recommend a model for the collection, use and sharing of health information for direct care and beyond direct care, including where exemptions for explicit

consent may be warranted to support population health and the effective functioning of health and social care services

- recommend the governance structures necessary to provide public assurance of the appropriate use of health information
- recommend a process for ongoing engagement with the public and health and social care professionals to ensure their views and experiences shape the model for the collection, use and sharing of health information.

Recommendations on a national portal for health and social care

The findings from the public engagement clearly show that there is a need to enable individuals to access their own health information. It is clear that people want access to their own health information and that they believe the current system does not enable this sufficiently. The majority would like to be able to access their information via an online national portal.

To address this, HIQA will commence the development of recommendations on a national portal for health and social care in 2022. As part of this work, HIQA will:

- conduct a review of countries that have introduced national patient and citizens' portals internationally
- engage with key stakeholders across the Irish health and social care system to better understand the barriers and enablers to introducing a national portal
- engage with patients and the public to better understand their views in relation to the introduction of a national portal using a public engagement model
- develop recommendations, based on the best available evidence, to inform the introduction of a national portal that will be acceptable to the public and suitable for the Irish healthcare system.

2. Guidance for the public and the health system in relation to health information

Guidance on the uses of health information and people's rights in relation to health information

The findings clearly show that the public would like to be more informed about the different uses of health information and that they feel it is important to be able to access their own health information.

To address this, HIQA will develop guidance to explain the uses of health information and people's rights in relation to health information in 2022. As part of this work, HIQA will:

- develop an easy-to-read guidance booklet for the public that clearly explains:
    - relevant terms, such as 'health information', 'use of health information beyond direct care' and 'non-identifiable information'
    - what, why and how health information is currently shared in Ireland
    - people's rights in relation to health information
- provide information on the roles and responsibilities of health and social care professionals as gatekeepers of health information
- develop an animation for the public describing the different uses of health information and people's rights in relation to health information.

Publication of findings: National Public Engagement on Health Information

The findings of the National Public Engagement on Health Information were published in September 2021. The related documents published include:

- Findings from the National Public Engagement on Health Information
- Technical Report for the National Public Engagement on Health Information
- Responding to the National Public Engagement on Health Information
- The anonymised survey data file[1].

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

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

National Public Engagement on Health Information

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