



Health
Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Summary Report

Key considerations to inform policy for health information in Ireland

2022 ◀



About HIQA

The Health Information and Quality Authority (HIQA) is an independent organisation set up to drive high-quality and safe care for people using health and social care services in Ireland.

HIQA's role is to:

- Set standards for health and social care services
- Regulate social care services
- Regulate health services (medical exposure to ionising radiation)
- Monitor the safety and quality of health services and children's social services
- Conduct health technology assessments
- Drive improvements in health information
- Deliver the National Care Experience Programme.

Background

The Health Information and Quality Authority (HIQA) is an independent organisation working to improve health and social care services for the people of Ireland. We aim to ensure that high-quality health and social care information is available to support the delivery, planning and monitoring of health and social care services. As part of this work, we looked at best practice in other countries, and spoke with members of the public, health and social care professionals, policy-makers and relevant experts to understand what changes are needed to improve health and social care information in Ireland.

The use and sharing of health and social care information¹ is essential for providing high-quality health and social care. 'Sláintecare', the Government's plan to provide a single health service for all citizens, focuses on providing the right care in the right place at the right time. Sharing health information in a safe and secure manner is essential to reach this goal. Information is used to care for patients directly, as well as for other important purposes such as planning and managing services, public health and research.

Health information should be collected once and then re-used for different purposes. This would ensure health and social care professionals have access to the right information at the right time to provide care and support. It would also reduce the number of unnecessary tests being carried out and the need for you to repeat your information to different professionals. It also means the same information can be used to allow services to make better plans to support people's care needs, and for researchers to study how care and treatment can be improved.

However, this is not how health information is currently used in Ireland. Currently, health and social care services use different information systems – both electronic and paper-based systems. This means a professional treating you in one service cannot easily access your record from a different service, such as a hospital and a nursing home, and may not have access to all of the information about your health when important decisions are being made. Each organisation also has different ways of managing information such as storing information, which means information cannot be easily combined or compared to create a complete picture of your health.

Recent events, such as the COVID-19 pandemic and the cyber security breach within the Health Service Executive (HSE) in 2021, have shown there is a need to improve Ireland's health information systems and information sharing processes.

Irish citizens told us that they are ready for change and think health information

¹ For the remainder of this document, health information will be used to describe health and social care information.

should be collected, used and shared to improve their care and also for planning services, quality improvement and research. The vast majority of people who took part in a [national survey](#) believe that electronic health records are required to allow easier sharing of health information; to give a complete and up-to-date account of a person's health; and to make it easier for people to access their own information.

There are also a number of changes happening across Europe which will require progress in this area in Ireland. This includes advances to promote the re-use of information, better information sharing, and that citizens should have access to their electronic health records.

HIQA believes that advances are required in four areas to drive improvements in health information in Ireland. These are:

1. undertaking effective engagement with members of the public and professionals to guide changes that meet their needs;
2. developing a solid legislative framework to create clear rules for how health information should be collected, used and shared;
3. improving governance structures to support secure and effective use of health information;
4. and delivering technical and operational requirements to move towards the development of electronic health records and a citizen health portal.

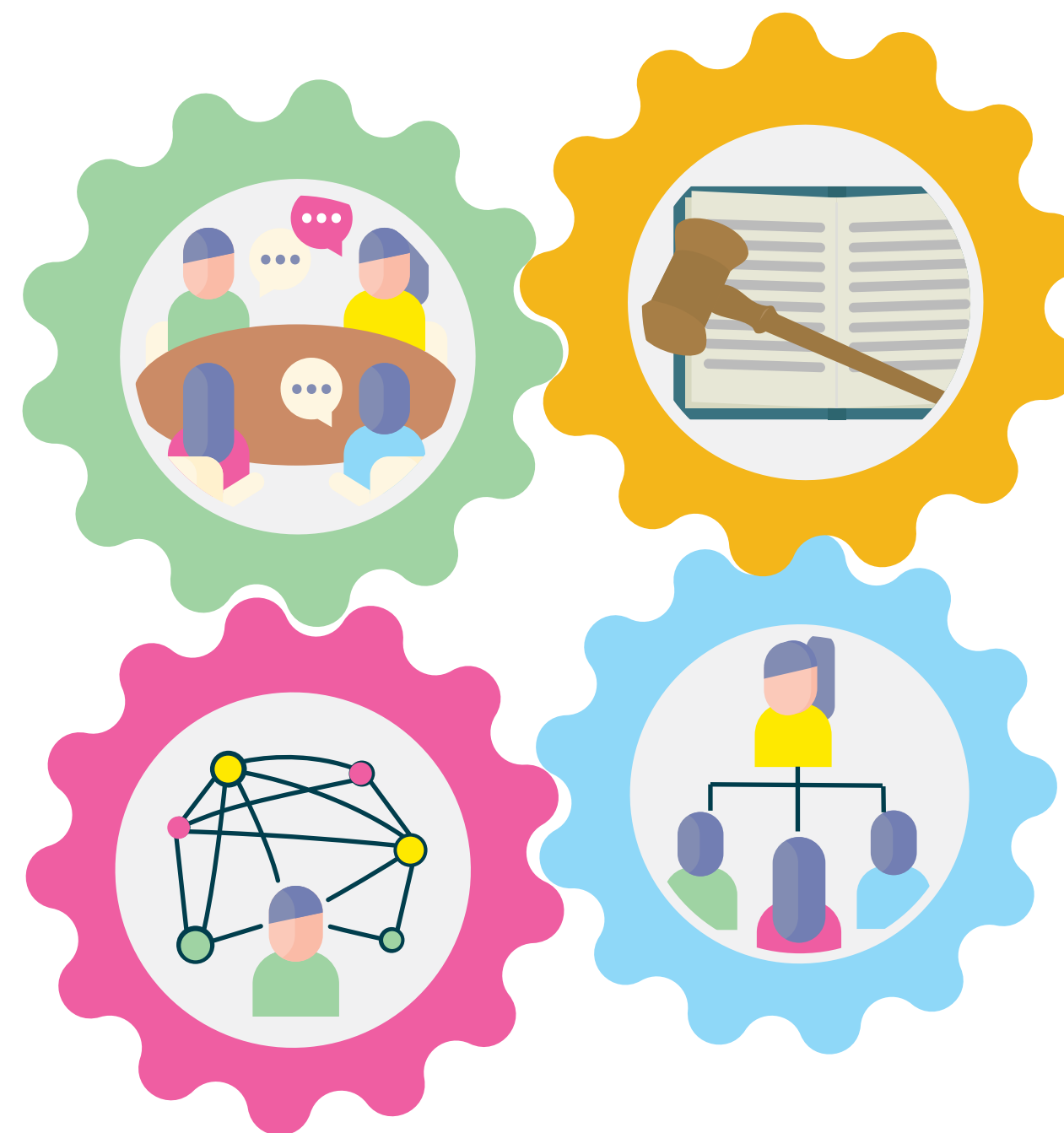
Progress in all four areas is needed to improve health and social care information in Ireland. In this document, we explain what changes are needed in each area in more detail.

Key considerations to inform policy

COLLECTION, USE and SHARING of health and social care information

Effective engagement

Coordinated and ongoing public and professional engagement is essential to build trust and ensure success of new initiatives. This requires strategic leadership and a clear strategy and implementation plan.



Legislative framework

New legislation should address the health information landscape in a holistic way and act as a catalyst for a more integrated health and social care sector. Regulations, guidelines, codes of practice and policy should be developed to support implementation.

Technical & operational requirements

Infrastructure to support data use is needed, including a citizen health portal and data sharing service. These must be underpinned by technical, security and data quality standards. Appropriate resources must be allocated for implementation.

Governance structures

Governance structures for the collection, use and sharing of health information, including a national strategic entity and relevant oversight committees, are critical. They must be underpinned by expertise at a local level, and supported by a standards-based data governance framework.



Effective engagement

People should be involved in important decisions about their health information. HIQA is recommending that there should be a national conversation where we openly talk about people's rights in relation to health information and how the information is collected, used and shared.

Engagement is a two-way process of listening to and working with people about particular changes or issues to take on board their views and understand their needs. Engagement can involve making sure people are properly informed of how health information is collected, used and shared. It can also involve asking people their opinions in surveys or focus groups. It can also involve asking people to take part in workshops, citizen assemblies, or advisory panels where they spend time talking with different experts on specific issues and people can then give their views on these issues after hearing all of the facts.

Engagement must be the first step in the process when making changes to how health information is collected, used and shared to make sure that people's needs are addressed. As systems and practices change, ongoing engagement is also necessary to monitor the public's and professionals' views and opinions in this area.

Before changes are made, it is essential that those responsible for planning changes in the area of health information engage with both the public and health and social care professionals. This will help to build and maintain trust on how health information is collected, used and shared. Effective engagement will also ensure that new digital health technologies, such as electronic health records, are designed and managed in a way that is acceptable to the public and professionals.

HIQA recommends that a national health information engagement strategy and action plan is developed to make sure there is a clear approach to engagement in Ireland. Citizens and health and social care professionals must be involved at all stages of developing and monitoring this strategy. Involving professionals and the public will help to make changes that are successful and lead to improvements in the collection, use and sharing of health information in Ireland. The Department of Health is responsible for making policy decisions for health information in Ireland.



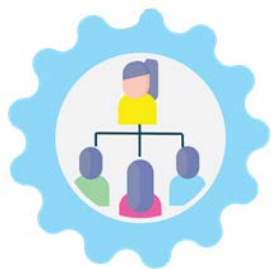
Legislative framework

There are many changes happening in Europe in relation to health information. New European laws are coming into place that will focus on the re-use of information and encourage better information sharing across sectors. There is also a target for all European Union citizens to have electronic access to their health information by 2030. We believe that progress is needed in Ireland to keep up with the developments happening in other European countries.

The Department of Health is developing a new law around health information in Ireland. HIQA believes that this is a chance to rethink how health information is collected, used and shared in Ireland, as good health information systems will help to create better health and social care services. In particular, HIQA is recommending that this new law should focus on how to promote better information sharing, while also making sure that information is shared in a safe and secure manner. It is important that the law ensures that all organisations collect information in a similar way so that it can be used to improve services for all.

When developing the new law, it will be important to consider the variety of organisations that collect health information and the different ways that health information is used. For example, there should be clear rules for sharing health information across the range of health and social care services that we use — such as public and private hospitals, general practices (doctors' offices), pharmacies, and nursing homes.

The new law should make sure that people's rights are a central focus and that there is clarity about what choices we have in relation to our health information. HIQA recommends that guidance documents and policies are developed to make sure that the rules for the collection, use and sharing of health information are clear for everyone. These will also give professionals the knowledge and confidence to safely and securely share information in the best interest of patients and members of the public.



Governance structures

HIQA is recommending that a national organisation is set up with responsibility for overseeing and managing health information across public, private and voluntary health and social care services. This is similar to what was recommended in a previous Government plan, called 'eHealth strategy for Ireland', which said a national organisation should be set up with responsibility for health information.

Putting these national structures in place will help to ensure there is appropriate coordination and responsibility for the collection, use and sharing of health information. This will help to build people's trust and confidence by making sure the right controls are in place for the safe sharing of health information. Citizens, representatives from all health and social care sectors, and other organisations involved in the collection, use and sharing of health and social care information in Ireland must be involved in developing and managing this organisation.

A national organisation for health information should have responsibility for:

- Developing a strategic plan and managing the actions that need to be put in place to make sure the future vision for health information in Ireland is achieved.
- Developing clear rules for sharing information across all health and social care organisations and making sure that organisations are following these rules.
- Coordinating national datasets[†] to help make sure they follow the same practices, improving the quality of the information that is being shared. In other countries, these national datasets are coordinated by a central organisation, but this is not the case in Ireland.
- Coordinating a national linkage service — where information is collected from different sources and linked together — to ensure information is kept secure and private in a controlled way. All personal information, such as your name and address, is removed so that the information can be used in a safe way to help plan and manage services and to answer specific questions to improve care.

[†] These national datasets store health and social care information that is usually collected as part of a person's care. They are important for planning and managing services, developing policy and for research.



Technical & operational requirements

In order to improve how health information is collected, used and shared, it is important that the right technology and systems are in place.

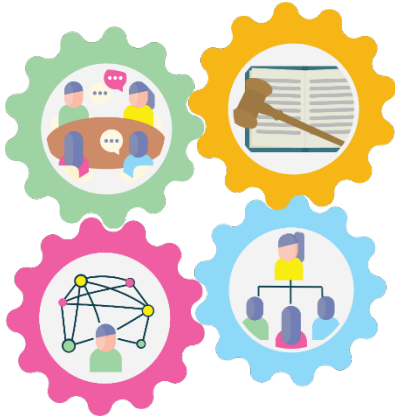
Electronic health records are essential to support high-quality and safe health and social care services. They provide a complete electronic record of a patient's care journey across different services. They hold information that is recorded by health and social care professionals from when they treat a patient, such as past illnesses and operations, test results and vaccinations.

Currently, people in Ireland do not have access to electronic records of their health information. This differs to the experience of people in many other European countries. Other European countries have signed up to the 'Path to the Digital Decade' Policy Programme which aims for all citizens to have access to their electronic health records by 2030. HIQA recommends that a citizen health portal is created to allow Irish people to access their information about their health and social care online, through an app or using a website.

HIQA is also recommending that appropriate infrastructure is put in place to support a national service for linking and sharing health information. This should include 'trusted third party' and 'safe haven' services. A trusted third party service removes information that would identify you and links this information in a secure way. A safe haven is a service which can be a physical location or an online space, where information is held securely and can be shared with people responsible for planning and managing services, policy-makers and researchers under controlled conditions.

It is important that a new citizen health portal and information linking service are developed in line with international best practice. Information standards are needed to ensure that each organisation uses the same method to collect and save information so it can be easily combined or compared. Compared to other countries, Ireland has no coordinated approach to developing standards for health information. This is an important step in the development of new systems, and to promote better health and social care services.

Adequate investment and leadership are crucial to guide the change. HIQA is recommending that work begins now to put in place the key elements necessary for success.



Next steps

We have sent our key considerations to the Minister for Health so that the Department of Health can use the information to guide future decisions in the area of health information and to develop the new legislation on health information.

We will continue to speak with the Department of Health, the Health Service Executive and other health and social care organisations to share our learning in this area to help drive much needed change in health information in Ireland. We will also continue to review how health information is managed in other countries and to identify best practice to guide where further changes are needed.



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