



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# **THE NEED TO REFORM IRELAND'S NATIONAL HEALTH INFORMATION SYSTEM** to support the delivery of health and social care services

**Frequently Asked Questions**

**October 2021**

## About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority 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.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. 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 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 health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these 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 services, in conjunction with the Department of Health and the HSE.

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## **1. What is the Health Information and Quality Authority (HIQA)?**

The Health Information and Quality Authority (HIQA) is an independent body set up to promote safety and quality in 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, Equality and Youth, HIQA has responsibility for:

- setting standards for health and social care services
- regulating social care services nursing homes, care centres for people with disabilities and special care units for children
- regulating medical exposure to ionising radiation (for example, X-rays, CT scans, mammograms, radiotherapy)
- monitoring services
- evaluating and providing advice on health technologies
- the National Care Experience Programme.

## **2. What is HIQA's role in health information?**

Through its legal remit, HIQA works collaboratively with people using services and service providers, using best available evidence, to develop national recommendations, standards and guidance on health information. HIQA provides leadership in areas set out as important in national health policy such as electronic prescribing, summary care records, patient portals and models for sharing and using information.

In addition, through our review programmes, we review governance arrangements and assess compliance of national data collections and eHealth services against national standards. The review programmes identify good practice and make recommendation on where services need to improve.

We:

- provide leadership to define the health information landscape in Ireland by using best available evidence and engagement with stakeholders
- develop standards and guidance for health information using robust methodologies

- assess compliance against health information standards through a review programme of health information.

### **3. What is HIQA's report on 'The need for reform of the health information system' about?**

Recent events, such as COVID-19 and the cyberattack on the Health Service Executive (HSE) health information systems, have highlighted the key role that health information plays in the delivery, management and planning of health and social care services. Given the fundamental need for high-quality health information systems to underpin our health and social care service, HIQA believes now is time to reform health information in Ireland. The report provides a broad overview of the current state of the health information system in Ireland identifying areas of good practice and also deficiencies that exist in the system. It sets out the basis for reform by making six recommendations to progress the national health information system. The position paper is underpinned by HIQA's experience in developing recommendations, standards and guidance over the last 12 years and the deficiencies identified through the health information review programme.

### **4. What is the current health information landscape?**

At local level, there are pockets of good practice of managing health information electronically and some hospitals have made significant efforts in this regard. However, many hospitals in Ireland are still using paper-based systems as the main patient record. Some large electronic health systems, such as diagnostics, have had good uptake in acute hospitals. For service providers, accessing these systems in community services, mental health services, and other services outside of the hospital system, however, is challenging as there are often separate and disparate IT systems in place that do not communicate or speak to each other.

The majority of GPs are using practice management systems and, while the data is managed at a local level, complexity arises when GPs need to share information beyond the practice or when data is needed at a national level. For example, a key deficit identified during the roll-out of the COVID-19 vaccination programme was that a system was not in place to identify vulnerable cohorts of patients, such as those with a chronic disease.

There is substantial private sector involvement in the delivery of healthcare in Ireland, ranging from GPs, pharmacies, and allied healthcare professionals to private hospitals. A well-functioning health information system requires data captured from all healthcare facilities, both public and private. The issue remains that currently

health information is not shared between public and private healthcare entities in Ireland and there is no public infrastructure to allow for the sharing of health information with the exception of the electronic referrals programme.

#### 4.1 Why do we need reform?

The health information landscape in Ireland is complicated. There are disparate health information systems that have evolved over time and are often fragmented and siloed. Despite some exemplars such as the national electronic Referrals programme and the National Information Medical Imaging System (NIMIS) which have seen good adoption throughout the health information system, Ireland continues to lag behind other European countries.<sup>(1)</sup> Challenges and shortcomings continue to exist such as significant variation in data quality, examples of duplication, access problems, deficiencies, and sub-optimal use of information. Health information is complex from a governance perspective with multiple organisations both inside and outside of the HSE involved in managing health information and there is no clear policy direction or single national strategy for health information. Health information systems are not always based on national standards which makes it difficult to send and receive information between systems in a safe and meaningful way.

### 5. What recommendations are HIQA making?

To improve and work towards a well-functioning national health information system, there needs to be a clear strategy, strong leadership and governance, legislation, adequate investment and an appropriate workforce, alongside a secure health IT infrastructure with a standards-based approach to safely share health information.

In order to collect, use and share good quality health information across the health and social care service, HIQA is calling for stronger political commitment to deliver on the following:

1. Strategy
2. Strategic leadership and governance
3. Legislation
4. Workforce
5. Health information standards and interoperability
6. Health information infrastructure and security.

## 5.1 What is HIQA recommending on strategy?

As part of our position paper on the need to reform the health information system, HIQA is calling for a national health information strategy to be developed that has achievable, time-bound objectives. Such a strategy should cover the entire health and social care information system, spanning national data collections and eHealth services, incorporating how people's health information should be collected, used and shared for both their direct care and for planning and improving services across both public and private settings. The strategy must be assigned appropriate funding to support its full implementation and progress should be reported on an annual basis.

## 5.2 What is HIQA recommending on strategic leadership and governance?

Currently in Ireland there is no governing strategic entity responsible for health information, across public and private health and social care services. This can lead to the absence of accountability and co-ordination of how health information is managed. There is an urgent need for a clear policy direction for health information, and a clear roadmap on how the different agencies within health and broader governmental organisations are coordinated.

Ireland can learn from experiences of other countries that have embraced having an independent entity responsible for strategic leadership of health information at a national level. In 2013, the eHealth strategy called out for eHealth Ireland to be established – an independent entity responsible for the overall governance and accountability of the eHealth strategy. This was never formally set up as envisaged.

HIQA are calling for the establishment of a strategic entity (eHealth Ireland) to provide strategic leadership and governance for health information. This entity should be independent of the HSE and have a legislative remit for health information at a national level. In parallel, a function should continue to exist in the HSE to support the operation of systems required to support the delivery of care.

Adequate resources should be assigned to each function, with clear roles and responsibilities defined for each function to ensure the successful implementation of future health information programmes of work.

Finally, it should be clearly defined how the strategic entity (eHealth Ireland) should interact with key agencies such as the Department of Health, HSE, HIQA and Tusla in order to deliver a more integrated national health information system.

### 5.3 What is HIQA recommending on legislation?

Legislation is essential for a successful health information system but currently, no such legislation exists to govern health information in Ireland. We believe legislation and regulations are required and are calling for political ownership in this regard. A legislative framework should set out clearly how information should be collected, used and shared for people interacting with the health and social care system. This should also include legislation on national eHealth priorities, including summary and shared care electronic health records and should ensure that the privacy of personal information is appropriately addressed. Legislation is required to enable the secondary use of health information from primary care, community services, public and private hospitals. This will ensure it can be used appropriately, reported on by public and private providers and safely shared across the health and social care system.

### 5.4 What is HIQA recommending on workforce?

A more strategic approach is required to how resources are allocated in health information, including around workforce and staffing. This will enable the delivery and operations of national health information systems, while also ensuring long-term strategic objectives for health information are met. Therefore, separate functions are required to deliver a national health information system with a strategic function and an operational function. Adequate resources should be assigned to each function, with clear roles and responsibilities defined to ensure they are aligned in achieving end-goals in order to protect existing major health information systems and to support the successful implementation of future health information programmes of work.

### 5.5 What is HIQA recommending on health information standards and interoperability?

HIQA has called for reform of our health information system. Included in this reform is the need for investment in national standards for health information. National health information standards are needed to facilitate the collection, use and sharing of meaningful information between healthcare providers in a timely and safe manner.

Assessing compliance of health information systems against national standards identifies areas of good practice where services can improve.

A health information standards setting function, and the function for assessing compliance with standards needs to be supported through legislation and resourcing,



and a clear policy decision needs to be made on where a health information standards function will reside.

## 5.6 What is HIQA recommending on health information infrastructure and security?

A secure, robust infrastructure is important to support the collection and sharing of people's health information across public and private healthcare systems. Given the recent cyberattack on the Health Service Executive (HSE) and its severe impact on the health services, there is a need for continuous investment and strengthening of a secure health information infrastructure to support the integration of people's health information across public and private healthcare systems.

## 6. Why do we need these changes?

The COVID-19 pandemic and the cyberattack on the HSE health information systems, highlighted the vital role that health information plays in supporting health and social care services in Ireland. While the HSE rapidly delivered health information systems to manage COVID-19, there are still fundamental shortcomings in the overall health information landscape in Ireland, many of which are longstanding and which made the response to such crises more challenging. Health information is complex from a governance perspective with multiple organisations both inside and outside of the HSE involved in managing health information. At present, there is no overarching governance structure for health information in Ireland. As set out in the eHealth strategy, a single governing organisation should be established to urgently provide strategic leadership and governance for health information, outside of the HSE, underpinned by robust legislation. In the absence of a single governing organisation, there will be significant delays in achieving the vision of integrated care as set out in Sláintecare. It is this absence of accountability and governance and a lack of legislation that has led to the anomalies that are described in the position paper.

## 7. What will the benefits with reform of the health information system?

A well-functioning, integrated national health information system involves the collection, use and sharing of health information across the health and social care service. Health information systems – such as electronic health records, electronic prescribing, electronic referrals, patient portals, and national data collections – can be used by everyone in healthcare, from patients to clinicians to public health officials and policy-makers to help improve patient outcomes, inform research and influence policy-making decisions. Health information systems that communicate

with each other in a safe and meaningful way can bring about multiple efficiencies in our health and social care service.

Access to health information is crucial for patient safety and continuity of care. Most patients are aware that information about them needs to be shared among the healthcare professionals delivering care. Patients often need treatments from different healthcare providers who reside in different healthcare settings such as general practice, acute hospitals, community and mental health settings. A robust health information infrastructure and electronic health records, underpinned by an individual health identifier, would allow healthcare providers to safely access health records. Using a secure integrated health information network and national standards to exchange health information creates efficiencies and cost savings.

## **8. How much will reform of the health information system cost?**

There is a significant cost associated with the collection, use and sharing of health information, therefore strong governance structures and national oversight arrangements are essential to ensure the data and information is managed appropriately — that is, to make sure the data is of highest quality and is used to its full potential. The vision of an integrated health and social care system, and delivering care to people in the community — away from the acute setting — requires a robust national health information system.

Compared to other EU states, Ireland has historically under-invested in health information, including the resources required to support the delivery of a robust health information system. A recent Economic and Social Research Institute (ESRI) report (2021) stated that a 'health budget has also increased, we estimate that less than 0.8 per cent of the budget in 2021 will be spent on ICT and eHealth'.<sup>(2)</sup>

The Sláintecare Implementation Strategy and Action Plan 2021–2023 cites an eHealth programme as 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 three years.<sup>(3)</sup>

The HSE National Service Plan (2021)<sup>(4)</sup> demonstrates a significant investment in ICT services required to support the delivery of healthcare in Ireland. In 2021, the eHealth capital allocation is €120 million. Of this, an investment of €25 million is ring-fenced to ensure recovery from COVID-19, as well as to capitalise on the best of the clinical, cultural, information and technological changes that are occurring.

A recruitment programme which is underway and is very much needed will yield medium and longer-term dividends in terms of the scale of ambition of the health

service and the reform programme. The HSE National Service Plan (2021) identifies the need for an additional 300 resources required to support the work of the HSE Office of the Chief Information Officer. These staff are operational and, while this is extremely positive, it does not cover the resources required to ensure strategic implementation of national projects for health information. The HSE is responsible for both the operational and strategic rollout of national eHealth programmes and major health information technology (IT) projects.

## **9. What work has HIQA published in health information?**

Over the last decade, HIQA has developed national health information standards, such as document standards, electronic prescribing standards, messaging standards, clinical information, modelling standards and information governance and management standards (refer to HIQA website). In recent years and in order to progress the implementation of national standards, HIQA has developed recommendations to inform how national eHealth programmes for electronic patient summaries and electronic prescribing should be structured.

To improve the quality of health information, HIQA has published *Guidance on a Data Quality Framework* which underpins the information management standards for national data collections. Through its review programme, HIQA evaluates the approaches that organisations have taken to address data and information quality. To date, five major national data collections have been reviewed in depth by HIQA with regard to their information management practices, including Breastcheck (National Screening Service),<sup>(5)</sup> the Hospital In-Patient Enquiry (HIPE) scheme,<sup>(6)</sup> the Primary Care Reimbursement Service (PCRS),<sup>(7)</sup> the Computerised Infectious Disease Reporting (CIDR) system,<sup>(7)</sup> and the National Incident Management System within the HSE.<sup>(8)</sup> The focus of HIQA's eHealth services review programme includes reviewing governance arrangements in relation to eHealth services and assessing compliance of eHealth services with national standards developed by HIQA.

## **10. How is HIQA engaging with patients and the public on health information reform?**

The importance and need for public and patient engagement is critical to successfully implement a high-quality health service. Internationally, the successful introduction of new eHealth initiatives and digital technologies in healthcare has been informed by public engagement. A review of international evidence in relation to this, undertaken by HIQA in 2020, has shown that the need for public engagement, and building a culture of trust in relation to the collection, use and sharing of health information, is extremely important. A key finding from this review

was that it is necessary to effectively consult and engage with the public in order to successfully implement eHealth initiatives and consent models for health information. The public should be able to trust that their personal health information is safe and used appropriately in ways that are acceptable to them. Public engagement is essential in order to learn what is acceptable to people and what level of trust currently exists. Engagement must also be ongoing in order to build and maintain public trust. Additionally, it is very important to educate the public on the benefits of information sharing across the health system.

HIQA, in conjunction with the Department of Health and the HSE, recently carried out the first National Public Engagement on Health Information in Ireland. The engagement showed that people see the importance of health information, for both direct patient care and for uses beyond direct care, such as service planning, quality improvement and research. The public also clearly recognises the value in moving towards a more electronic health system and the need to safeguard that data as they believe it will contribute to timely and appropriate care. The recent cyberattack on the HSE will likely impact on public confidence, however, and the incident provides further impetus to drive forward a strategy to build public trust and confidence in a health information system that can provide assurances that a safe and reliable health IT infrastructure is in place.

HIQA will continue to engage with patients and the public through all of our work in relation to health information via representation on advisory groups, public consultation and seeking out the views of patients and the public in relation to our work.

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