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

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.

Contents

About the Health Information and Quality Authority 2

Executive Summary 4

1 Introduction 12

  1.1 About the report 13

  1.2 Health information to support integrated care 13

  1.3 Health information landscape 14

  1.4 HIQA review programme 17

  1.5 Public and patient engagement in health information 19

2 Key enablers of a health information system 21

  2.1 Strategy 22

  2.2 Strategic Leadership and Governance 26

  2.3 Legislation 32

  2.4 Workforce 36

  2.5 Standards and Interoperability 41

  2.6 Health Information Infrastructure and Security 49

3. Conclusion 57

Glossary 61

References 65

Executive Summary

Health information is key to the efficient and effective running of our health and social care sector. Every time a service user interacts with the health and social care system, whether visiting their general practitioner (GP), public health nurse or attending a hospital visit, health information is created.

The Sláintecare implementation strategies have all highlighted the key role that health information will play to enable the Sláintecare programme to succeed. The national health information system also needs to align with the broader *Public Service Data Strategy* 2019-2023,(1) which sets out a 'vision with a set of goals and actions to deliver a more joined-up whole-of-Government approach to how data is used and managed within the public service'.

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. Many national health IT programmes of work have been progressed in a short time frame – such as the role the individual health identifier (IHI) played in the COVID-19 systems and in the roll-out of the vaccination programme. There is now an opportunity to build on that success. The COVID-19 pandemic highlights the need for ensuring information is available in a timely way to respond to and manage the delivery of health and social care at a local and national level and to inform strategic decision-making. The cyberattack experienced by the HSE has signified the critical role that the health information system plays in the front-line delivery of care.

Under the Health Act 2007, the Health Information and Quality Authority (HIQA) has a remit to identify deficiencies in health information and provide advice to the Minister for Health. This report draws from HIQA's experiential knowledge from developing recommendations, standards and guidance in health information over the last 12 years and more recently the development of a programme to assess compliance with health information standards. This position paper examined six core enablers for a health information system:

1. Strategy
2. Strategic Leadership and Governance
3. Legislation
4. Workforce
5. Standards and Interoperability

6. Health Information Infrastructure and Security.

These enablers were used to structure the position paper and, under each enabler, the report identifies international evidence, what is currently happening in Ireland and any gaps that exist. The findings were then used to make recommendations on reform. 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. Continued political commitment and governance of health information underpinned by legislation is needed. The first three enabler – Strategy, Strategic Leadership and Governance, and Legislation – are the foundation to achieve a robust national health information system.

Countries like Canada, Denmark, New Zealand and Australia have a long history of developing time-bound health information strategies and they report on their progress against those strategies. Over the past 20 years in Ireland, several strategies were published — the first national health information strategy in 2004 and Ireland's first eHealth strategy in 2013. Many objectives as set out in these strategies have still not been achieved. Currently, the Department of Health is drafting a new health information system strategy which is concerned with the secondary use of health data. In parallel, the Sláintecare Implementation Strategy 2018 places a significant emphasis on the need for eHealth to enable integrated care. Recently, the Sláintecare Implementation Strategy and Action Plan (2021 – 2023) was published. There is a need to consider developing a Health Information Strategy that takes a holistic and cohesive approach to managing health information, that is,- how health information is collected, used and shared for not only primary care purposes but also for secondary use and research purposes across public and private healthcare.

It is well recognised in any health service that without robust health information systems, a cohesive and integrated healthcare system is unachievable. Internationally some countries have identified the need for strong strategic leadership and governance and have allocated this role to one specific organisation that has appropriate governance structures, boards and committees established to oversee implementation of systems to enable the collection use and sharing of health information. For example, England has a single organisation, NHS Digital, dedicated to managing all aspects of health information including eHealth programmes and national data collections. Both Canada and Australia have one national organisation for governing all or the majority of national health and social care data collections and a separate organisation for governing Digital Health.

Currently, there are multiple agencies with responsibility for health information in Ireland. The Department of Health is responsible for health information policy. 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. HIQA has a remit under the Health Act 2007 to develop recommendations, standards and guidance on health information, and assesses compliance with those national standards. Although not an exhaustive list, some examples of organisations that currently have a legislative remit regarding health information include the Central Statistics Organisation (CSO) — which has played a vital role in response to COVID-19 — the National Cancer Registry, the National Standards Authority of Ireland (NSAI) and the Data Protection Commissioner. In addition, there are other organisations, such as the Health Research Board, the National Office for Clinical Audit (NOCA) and smaller national data collections that are involved in the collection of health and social care data in Ireland.

There is an absence of clear policy on how these different agencies are coordinated to essentially deliver on a more integrated health and social care system for Ireland. The eHealth Strategy (2013) originally called for an independent entity (eHealth Ireland) with responsibility for overall governance around eHealth implementation — including funding, legal enabling, public awareness and stakeholder engagement through building the eHealth ecosystem in Ireland — to work in partnership with Government and state agencies. However, eHealth Ireland was never formally established as a separate entity to the HSE. HIQA believe that the absence of a entity like eHealth Ireland leads to overall lack of accountability and coordination for information across the Irish health and social care system.

In the absence of a strategic entity (eHealth Ireland) to provide the necessary focus for strategic leadership and governance for health information, there has been and there will continue to be significant delays in achieving the vision of integrated care as set out in Sláintecare. A strategic entity (eHealth Ireland) needs to be enabled by policy, legislation and a robust strategy on health information.

Compared to other counties internationally, Ireland needs specific legislation for the collection use and sharing of health information. In addition many countries have legislated for the introduction of electronic health records (EHRs), standards for health information, and enacted legislation for secondary use purposes.

Some legislation is currently in place including the Health Identifiers Act 2014, the Data Protection Acts (1988-2018) to give effect to the EU-wide General Data Protection Regulation, and the Health Research Regulations (2018). Ireland currently does not have a legal framework in respect of specific health information systems or a national information governance framework for the collection, use and sharing of information across the public and private sector. This lack of legislation is hindering overall coordination between the key health information entities and organisations involved in health information and there is a need for continued political ownership in this regard. There is a need for the introduction of a legislative framework which covers people's health information across both public and private healthcare in Ireland.

Ireland has significantly under-invested in health information compared to other European countries. Significant resources were required to develop systems to help manage the response to the COVID-19 pandemic. Significant investment in health information systems is reflected in the HSE service plan for 2021 which identifies an additional 300 posts to support the HSE Office of the Chief Information Office. The investment in eHealth capital and staffing is also reiterated in the Sláintecare Action Plan. There is now a need to ensure that both an operational function and a separate strategic entity (eHealth Ireland) - is established with clear roles and responsibilities defined, in order to protect major national health IT programmes and to support their successful implementation in the future.

In Ireland, there are three separate organisations with different remits and roles in health information standards. HIQA has the legislative remit under the Health Act 2007 to develop national standards and assess compliance with those standards. The department have funded the HSE to establish the National SNOMED CT release centre The National Standards Authority of Ireland (NSAI) is responsible for the development of International Organisation for Standardisation (ISO). HIQA recommend the need for clear policy direction on the development of health information standards in light of the current fragmented structures that are in place for health information standards development. Also, the delivery of healthcare is changing rapidly and there is continued adoption of mobile health, health apps and telemedicine and how they are governend and managed needs to be set out at a policy level.

There is some valuable national health IT infrastructure in place in Ireland for the health identifiers, a national messaging broker for health information and infrastructure to support European cross-border exchange of health information. However, overall, the current ICT infrastructure is fragmented with major deficits. The cyberattack on the HSE has had a severe and immediate impact on the health services and has strongly emphasised the need for continuous investment and strengthening of our security infrastructure. HIQA believe that the development of a secure infrastructure is paramount and is the foundation for services such as a national shared care record that should be shared across primary and secondary use services in both public and private healthcare systems.

As a consequence of both the COVID-19 pandemic and the more recent cyberattack in May 2021, there is an opportunity to showcase the pivotal role that health information plays in supporting the front-line delivery of health and social care services and to support better decision-making for service providers and senior policy-makers. HIQA is cognisant that the current environment is extremely challenging and is aware of the invaluable work that all stakeholders have played in response to both the pandemic and the cyberattack. These events present an opportune time to review what structures and supports are needed to ensure Ireland has a robust health information system in place to respond and protect the health and social care service against future adverse events and to ensure the right enablers to deliver an integrated health and social care system are in place.

There is now a readiness for the Irish people to embrace technology in healthcare as evidenced from the Findings of the National Public Engagement on Health Information (2) that asked the public their views on how their health information should be collected, used and shared. The survey was led by HIQA, in partnership with the Department of Health and the Health Service Executive (HSE). It is part of a series of initiatives designed to ascertain the views of the general public in Ireland to help develop recommendations for the Minister for Health which will inform national policy in health information. This engagement found 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 most likely impact on public confidence 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 IT infrastructure is in place.

Advances in eHealth and digital health technologies will enable patients to have a much more participative, patient-centric and patient-empowered role. The acknowledgement that patients have an important role to play in their own healthcare requires that they be better supported and better informed to undertake this role effectively. The importance and need for public and patient engagement is therefore critical to policy development and supporting the successful implementation of a high-quality health service.

In order to reform the health information system in Ireland, HIQA has devised the following recommendations:

Recommendations 1: Strategy

- Continued political commitment is required to deliver a clear national health information strategy that addresses key enablers for an effective health information system, including effective governance and leadership, a sound legal framework, a viable workforce and appropriate funding mechanisms, Ministerial approved standards, and a robust and secure health IT infrastructure.

- The existing eHealth strategy is outdated and should be revised to reflect more modern eHealth developments, in line with the ongoing national health information system strategy that is currently in development.

- A national health information strategy should be developed that has achievable, time-bound objectives and is aligned with the Sláintecare 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 primary care and secondary use purposes across both public and private settings.

- A national health information strategy needs to be assigned appropriate funding to ensure that its objectives can be fully achieved.

- Implementation of the strategy should be reported on an annual basis.

Recommendation 2: Strategic Leadership and Governance

- To date, eHealth Ireland has not been established as was originally intended as a separate entity with responsibility for overall governance around eHealth implementation — including funding, legal enabling, public awareness and stakeholder engagement through building the eHealth ecosystem in Ireland. There is a need for a clear policy direction for health information, and clear roadmap on how the different agencies within health and broader governmental organisations are coordinated, to deliver an integrated approach to health information and support the health and social care system in Ireland.

- As set out in the eHealth strategy (2013), a strategic entity (eHealth Ireland) should be established, outside of the HSE, with a legislative remit to provide strategic leadership and governance to support the collection, use and sharing of health information in Ireland. In parallel, an operational function developing and supporting the systems required for the delivery of care should continue to exist in the HSE. The remit of this entity should be broader than eHealth and include the centralised coordination and governance of national data collections and the secondary uses of health information at a national level.

- Roles and responsibilities and accountability for this entity should be clearly defined, including how this entity would 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.

Recommendation 3: Legislation

- For a national health information system to play its full role in enabling a safe healthcare system, a sound legal framework is required. 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.

Recommendation 4: Workforce

- A more strategic approach is required to the allocation of resources in health information to continue 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 including a strategic entity (eHealth Ireland) outside of the HSE and an operational function within the HSE to support the systems required for the delivery of care. 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.

Recommendation 5: Standards and Interoperability

- A clear policy decision needs to be made on where the Health Information Standards function will reside.
- A health information standards setting function, and the function for assessing compliance with health information standards needs to be supported through legislation and resourcing and should include both the public and private health and social care sector, including public sector services outside of the HSE.

Recommendation 6: Health Information Infrastructure and Security

- 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.

1 Introduction

Accurate, relevant and timely health information is essential in order to improve the provision of patient care, to inform better decision-making, monitor diseases, plan services, inform policy-making, conduct high-quality research, and plan for future health and social care needs. Health information is a valuable resource. Many advances in healthcare depend upon the increasing availability and application of high-quality health information. A robust health information system will allow all stakeholders to make choices or decisions based on the best available information. This is a fundamental requirement to achieve a highly effective and reliable health and social care system in Ireland.(3)

In light of the COVID-19 pandemic, the launch of the Sláintecare Strategic Implementation and Action Plan 2021–2023 and the cyberattack on the HSE, the Health Information and Quality Authority (HIQA) has developed this position paper on the need to reform the health information system in Ireland.(4)

COVID-19 has highlighted the vital role that health information plays in supporting health and social care services in Ireland. The lack of maturity of Ireland's health information system made it even more challenging for the health service to respond to COVID-19 and highlights the need for high-quality standards-based health information to communicate across acute and community settings, including both public and private settings. COVID-19 has particularly highlighted challenges of managing and delivering an effective public health service in Ireland in the absence of fit-for-purpose, integrated information systems in relation to infectious disease surveillance, public health case management and immunisation. Despite the intrepid efforts made by the HSE in rapidly delivering health information systems for the management of COVID-19, there are still fundamental shortcomings in the overall health information landscape in Ireland. The lack of a fully operational individual health identifier impacted the roll-out of systems such as the COVID-19 Case Tracker, test and assessment appointment scheduler and COVID-19 referrals.(5) This presents an opportune time to build on the significant progress that was made in response to COVID-19.

In May 2021, one of the most serious, unprecedented cybercrimes was committed on the Health Service Executive's (HSE's) IT systems. The cyberattack on Ireland's health information systems has had a severe and profound impact on service delivery and has highlighted how health information systems are central to the day-to-day delivery of care for service users. As a consequence of the cyberattack and lack of access to systems and information capacity on services such as diagnostics, service delivery was severely impacted and resulted in delays in patient care with many cancellations of services. The incident has clearly emphasised the need for a more strategic focus on security, oversight and continuous investment to ensure strengthening of Ireland’s health information infrastructure.

The Sláintecare Strategic Implementation and Action Plan (2021–2023),(4) developed by the Sláintecare Programme Implementation Office, sets out priorities and actions for the next phase of the Sláintecare programme while being cognisant of the lessons learned from COVID-19. It identifies the eHealth implementation programme as fundamental for the ‘Reform Programme 1’ and significant investment in eHealth capital and staffing will be available for implementation health information systems over the course of the next three years.

1.1 About the report

This report aims to identify the areas of good practice and shortcomings that exist regarding health information in Ireland and to clearly emphasise the need for reform of the health information system to support the delivery of health and social care services. Given the fundamental need for high-quality health information systems, now is an opportune time to identify the key deficits which exist in Ireland’s health information system and to make recommendations for change to work towards a more integrated national health information system. It is important to illustrate that COVID-19 and the cyberattack has not signalled the need for the reform of the health information system, rather they have shone a spotlight on an issue that was already in need of urgent consideration.

To improve and work towards a well-functioning national health information system, there is a requirement for a clear strategy, adequate governance, legislation, a secure Health IT infrastructure with a standards-based approach to interoperability of health information systems, investment and an appropriate workforce for managing health information is required, all of which will be discussed throughout this report.(6)

1.2 Health information to support integrated care

Over the past 20 years, several strategies and reports have been published which have repeatedly emphasised the need for reform of health information in Ireland. As far back as 2004, the Health Information National Strategy (2004)(7) acknowledged that the way health information was managed, governed and regulated was insufficient, referring to the fragmentation, inconsistent and lack of standards that exist for the collection of health information. It highlighted how ‘the health information landscape is characterised by numerous databases and systems that are essentially isolated and uncoordinated’(7) which remains largely true today. Ireland’s first eHealth Strategy was published in 2013,(6) followed by the Sláintecare Report (2017),(8) Sláintecare Implementation Plan (2018)(9) and the recent Sláintecare

Implementation Strategy and Action Plan 2021-2023(4) which all emphasise eHealth as a key enabler of integrated care.

Furthermore, the 'Use of information' is incorporated in the *National Standards for Safer Better Healthcare* as an essential component for delivering a high-quality safe health and social care service.(10)

1.3 Health information landscape

Every time a service user interacts with the health and social care system, whether visiting their general practitioner (GP), public health nurse or attending a hospital visit, health information[1] is recorded about the service user. This health information is key to the effective running of the health service. Health information is hugely valuable both for managing direct patient care and also for secondary use purposes, such as health service management policy and decision-making.

Improved flow of health information can ensure a more efficient health service by providing information when and where needed, facilitate quicker and more evidence-based decision-making, reduce waste by cutting out repeated work, and improve patient safety due to fewer errors. The flow of health information needs to support the continuity of care along a patient's care journey both within the hospital and also across organisational boundaries, such as with GPs and community services, or public and private hospitals . Health information needs to be collected, processed, communicated and used appropriately to ensure service users, relatives and healthcare professionals maximise its full potential. Finally, health information needs to flow outside the delivery of care for secondary use, generating information for service management, planning and policy.

Health information is utilised at a:

- systems level in order to run a modern health service — in Ireland the HSE or Tusla is responsible at a national level
- policy level in order to determine policy and legislation for health information — in Ireland responsibility lies with the Department of Health.

The ultimate goal is to collect health information once and reuse it many times for different purposes. There is significant potential for use of clinical data beyond its primary intent of patient care. Reuse of clinical data is essential to fulfill the

---

[1] Health information is defined as information, recorded in any form, which is created or communicated by an organisation or individual relating to the past, present or future, physical or mental health or social care of an individual or group of individuals (also referred to as a cohort). Health information also includes information relating to the management of the health and social care system.

promises for high-quality healthcare, improved healthcare management, reduced healthcare costs, population health management, and effective clinical research.(11)

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, as well as paper-based systems for tracking patient referrals, out-patient appointments and patient records. A national integrated medical imaging system is largely accessible online and this has had universal uptake in all acute hospitals. 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 with each other.

GPs have recognised the value of investing in electronic practice management systems. 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. The Irish health system incorporates public, voluntary and private elements in the production, delivery and financing of healthcare. A well-functioning health information system requires data captured from all healthcare facilities, both public and private. However, 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 eReferrals programme.[2] People move between these services and that is why we need information to flow efficiently between these services.

In 2015, the HSE identified a number of key national strategic eHealth programmes detailed in the Knowledge and Implementation Plan (2015),(12) and aligned with what other countries have prioritised:

- Individual health identifier[3]
- eReferrals

---

[2] A national eHealth strategic programme to make it possible for all acute hospitals to accept referrals electronically

[3] An individual health identifier (IHI) is an 18 digit number that is used to uniquely and safely identify a patient. An IHI is assigned to the patient for life and is not re-used after the patient's death.

- Electronic health record
- National Children's Hospital
- Primary Care IT
- Cancer Care eHealth Programme
- Open data for health
- ePharmacy
- Maternal & Newborn Clinical Management System
- National Medical Laboratory Information System
- National Integrated Medical Imaging System
- Cloud First Policy.

Each of these strategic programmes is currently at varying stages of maturity and while work is ongoing in these programmes, uptake and implementation has been slow. Despite some exemplars, such as the national eReferrals 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 in this regard.(13)

The aforementioned strategies highlighted the critical need for the individual health identifier — the cornerstone to enable a joined up healthcare system in Ireland. Significant progress in establishing the infrastructure for the individual health identifier has been made. It is well renowned that the implementation of any health information system including the operationalisation of an IHI is extremely complex and challenging. The individual health identifier was legislated for in 2014;(14) however, the implementation and roll-out has been delayed partly due to the transformational change required and socio-technical[4] challenges encountered with its implementation — and all health information systems — throughout hospitals and GPs. The delayed enactment of legislation and the lack of emphasis placed at a strategic level in terms of driving forward the implementation of the individual health identifier has contributed to its slow adoption.

Delivery of a national electronic health record (EHR) for Ireland is the foundation for the reform of the healthcare system.(15) Rolling out integrated care and a truly joined up single health service needs to be underpinned by a national EHR and IHI, as outlined as key enablers in the eHealth strategy (2013), with summary and shared care records listed as a key priority in the Sláintecare Strategic Action Plan 2021–2023. A new strategic direction has been taken as cited in the new Sláintecare

---

[4] Healthcare is an example of a highly complex socio-technical system and is composed of many interdependent organisational, information and technical components. Socio-technical refers to the interrelatedness of social and technical aspects of an organisation , that is, the people, processes and technology and the fundamental need to design a health information system considering all three perspectives, and not only the technology viewpoint.

Strategy Implementation and Action Plan (2021-2023) to deliver on the summary and shared care records instead of a national EHR.

1.4 National health and social care data collections

National health information repositories, known as 'national health and social care data collections', are extremely important sources of health information. They provide vital information to help ensure a safe, reliable and timely healthcare service, as well as to promote and protect health. However, they have evolved over time in a largely uncoordinated fashion, and remain fragmented and siloed. There are existing challenges such as significant variation in data quality, duplication, access problems, deficiencies, and sub-optimal use of information. There is a significant cost associated with the collection, use and storage of this 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 the data is used to its full potential.

The health information landscape in Ireland is complex from a governance perspective, with several 'managing organisations' currently responsible for collecting and storing these datasets including the HSE, Government departments, independent organisations outside of the HSE, charities, hospitals and universities. Notably, there are a number of key national data collections using data collected from within the HSE, which are managed by external organisations. Examples of these include the National Office for Clinical Audit (NOCA) and the National Treatment Purchase Fund (NTPF).(16) Compared with the approach undertaken by a number of countries internationally, there is currently no strategic entity in place with oversight of data collections in Ireland. This deficit was apparent during the COVID-19 pandemic, as there was no national register for chronic diseases to identify vulnerable cohorts of citizens.

In the absence of national governing structures and a national strategy for the Irish national health information system, since 2017 HIQA has sought to drive improvements in the collection and use of health information in Ireland by formally reviewing individual national data collections for compliance against the information management standards for national health and social care data collections. 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),(17) the Hospital In-Patient Enquiry (HIPE)(18) scheme, the Primary Care Reimbursement Service (PCRS),(16) the Computerised Infectious Disease Reporting (CIDR)(16) system, and the National Incident Management System within the HSE.(19)

Through this review programme, HIQA has identified a number of key challenges that currently exist in governance, leadership and management arrangements of these national data collections, as well as in relation to information governance, data quality and the effective use of information. In all five organisations reviewed, there was a lack of robust governance arrangements to ensure the quality of data and effective use of information. These findings are of concern given that the data from these systems underpin key functions of the health service including incident management, healthcare planning, delivery, funding, health promotion and research in Ireland. For example, HIPE data is used to provide performance measurement for the National Patient Safety Office, as well as the source of data for the Activity Based Funding Programme, and CIDR data is required to manage the surveillance and control of infectious diseases in Ireland. The NIMS system is essential in respect of incident management and embedding a culture of patient safety reporting and learning.

Across the five reviews undertaken, HIQA specifically found a common need across the organisations to:

- enhance leadership through effective oversight structures.
- place a strategic focus on information management through the development of strategic and business planning, as well as developing robust performance assurance frameworks to ensure good information management practices.
- outline specific roles and responsibilities for information management through a formal scheme of delegation.
- develop a data quality framework and an accessibility and dissemination plan to optimise the use of information.

The importance of having good quality national health information to inform key decision-making for public health management was emphasised in HIQA's review of the CIDR system, published in November 2019, which raised a number of shortcomings in relation to information management practices and governance arrangements of this key system. The review noted that the public health service in Ireland relies heavily on information that is held in CIDR to be able to monitor and control infectious diseases. The system was established in 2004, however it was noted that it had not evolved to meet the needs of users and key stakeholders and to meet the increasing demands of a modern infectious disease surveillance system. Some of the challenges noted in the review were highlighted significantly during the course of the pandemic when the surge in COVID-19 cases in the third wave prompted a malfunction in the system; this meant that public health staff were unable to input data in relation to positive COVID-19 cases for a number of days in late December and early January 2021.

While the review programme has highlighted a number of examples of good practice in Ireland in relation to national data collections, there are also some significant gaps, silos of information and duplication in the country's health information landscape. HIQA identified a lack of a national strategic direction for national data collection, data quality and analytics and use of data — leading to duplication of resources, even within the HSE — and a lack of adequate assurance within the HSE in relation to the quality of national health information.

1.5 Public and patient engagement in health information

Advances in a national health information system will enable patients to have a much more participative, patient-centric and patient-empowered role. The acknowledgement that patients have an important role to play in their own healthcare requires that they be better supported and better informed to undertake this role effectively.

The importance and need for public and patient engagement is therefore 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.(20) 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. Lessons can be learned from the UK experience. In 2013, England attempted to implement a national database of patient interactions with the healthcare system called 'care.data'. Following three years of debate and controversy, the scheme was closed in 2016 as there was no consultation with the public. England has made substantial efforts in engaging with the public since then. The '*Understanding Patient Data'* organisation was set up to support better conversations about the uses of health information between healthcare providers, government and the public. This has helped England rebuild trust by emphasising the need and requirement to keep the public informed about how their personal health information is used. New Zealand and Canada also have good examples of effective public engagement such as the '*Data Futures Partnership - Our Data, Our Way'* and Canada Health Infoway's '*Canada's Better Health Together'* workshop.

HIQA, in conjunction with the Department of Health and the HSE, recently carried out the first National Public Engagement on Health Information in Ireland.(21) 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 most 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. The following section of this report will outline the key enablers and recommendations that HIQA are proposing to improve and work towards a well-functioning national health information system.

2 Key enablers of a health information system

Based on reports from the World Health Organization (WHO) and the eHealth strategy (2013), there are basic requirements that underpin a health information system — principally the need for appropriate strategic leadership and governance structures, robust legislation, and resources and expertise at national and local levels. These requirements are needed alongside a secure health information infrastructure and standards to enable the secure collection, use and sharing of health information across the health system, both public and private. According to the WHO, 'directing and coordinating eHealth development, achieving consensus on policy, protecting individuals and groups and assuring oversight and accountability in the various aspects relating to use of information and communication technologies (ICT) for health are all part of an eHealth governance function at the national level'.(22)

The following themes are explored throughout section 2 of this position paper:

1. Strategy
2. Strategic Leadership and Governance
3. Legislation
4. Workforce
5. Standards and Interoperability
6. Health Information Infrastructure and Security.

2.1 Strategy

There is increasing acknowledgement from policy-makers that there needs to be a more robust health information system in Ireland. International literature suggests that countries with a well-established health information system have clear strategic direction through the implementation of a national strategy, clear roadmaps and associated funding for the collection, use and sharing of health information. A 2016 survey conducted by the WHO regional office for Europe reported 30 European countries out of 47 surveyed have adopted a national eHealth policy or strategy.(23)

Canada, Denmark, New Zealand and Australia have developed rolling strategies that are time-bound and report against timelines and progress. Since 1990, Canada has been working on the development of a national health information system infrastructure through a series of strategies and roadmaps. Denmark has had national health information strategies since the late 1990s. Over the years, the Danish strategies were built upon some basic policies, including advocating for: a multi-vendor environment, adherence to commonly agreed standards and terminologies, profiles and exchange interfaces for electronic communication and making national standardisation the responsibility of the Ministry of Health who can then delegate operational responsibilities to appropriate entities.(24)

In 2017, the Australian Digital Health Agency delivered the Australian National Digital Health Strategy (2018-2022)(25) with seven priorities identified including the 'My Health Record' system, secure messaging, interoperability and data quality, medication safety, enhanced models of care, workforce education, and driving innovation. New Zealand's Ministry of Health recently developed an interoperability roadmap which is a key part of the Ministry's digital health strategic framework which will 'accelerate a shift to a fully interoperable digital health ecosystem'.(26,27)

In Ireland, over the past 20 years, several strategies and reports have been published. As far back as 2004, the national health information strategy was developed and Ireland's first eHealth Strategy was published in 2013.(6) Both aforementioned strategies raised awareness for the urgent need for the:

- Individual health identifier to enable a joined up healthcare system in Ireland.
- Key eHealth programmes to be established, such as a national electronic health record and electronic prescriptions, to be deployed and operationalised and a
- Standards-based approach to be implemented to ensure interoperability of health information across the health service both private and public.

The eHealth strategy (2013) also recommended the establishment of eHealth Ireland to provide clear sponsorship, accountability and timelines for implementing a national strategy; however, this entity has not been established as originally intended.

Some aspects of the strategies have been progressed but others have been significantly delayed. To date, there has been significant progress in establishing the infrastructure for the individual health identifier and good progress with some other health information systems such as electronic referrals and the national integrated medical imaging system (NIMIS). HIQA recognise that the implementation of any health information system is extremely complex and challenging. Overall there has been slow progress with the implementation of eHealth programmes including the National Laboratory Information Management System (LIMS) and the national electronic health record (EHR) programme.

Since the publication of the eHealth Strategy (2013), the strategic policy framework has evolved, with the Department of Health publishing the Sláintecare Report (2017)(28) which outlines a vision for the provision of integrated care in Ireland. Sláintecare details a 10-year plan for health reform with the aim of providing universal access to timely, quality and integrated care for all citizens in Ireland and to progress the health system 'towards integrated primary and community care, consistent with the highest quality of patient safety in as short a time frame as possible'.(28) Delivering this ambitious goal needs sustained and progressive change across the Irish health system and requires continued political consensus, leadership and investment.(28)

Under the Sláintecare Implementation Strategy (2018)(9) and the recent Sláintecare Implementation Strategy and Action Plan 2021-2023(4) eHealth is identified as an enabler of integrated care, and is aligned with the COVID-19 Nursing Homes Expert Panel Measures for 2021 (Recommendation 6.3) which specifies the need for an IT system to support 'residential, home support, day care, needs assessment and care planning, so as to support the provision, management, delivery and reporting of services, and especially for planning alternative service provision and planned capacity development in the event of evolving public health measures'.(29) There is a need for a clear vision for ICT enablement of older persons services but without the key building blocks of strategy, strong leadership and governance underpinned by legislation in place, it is unlikely this vision will be realised.

The eHealth objective has been broken into achievable components, and outlines key critical eHealth and technology actions. The initial programmes that will be supported include the continued rollout of individual health identifiers as part of eVaccination Programme, progression of the GP Research Hub and commence the roll-out of Health Visualisation Platform Programme. By 2023, the plan is to progress eHealth initiatives in line with plan and funding including:

- National waiting list management systems
- ePharmacy and ePrescribing
- Home support and residential care management systems
- Health performance and visualisation platform
- Decision support pathways
- Electronic discharge
- Shared care record
- InterRAI assessment tool
- Citizen Portal.

Work is currently ongoing on a national policy document on health information — the health information system strategy — but publication has been delayed.(30) In 2017, the Department of Health consulted stakeholders on a draft Health Information Policy Framework via workshops and online public consultation in order to obtain the views of service users, healthcare professionals, health researchers, health service providers and other key stakeholders on policy proposals for health information. This was specifically in the areas of health information legislation, governance, operational arrangements and patient and professional awareness to inform and guide the ongoing health information work programme. The intention was to use the findings to finalise a health information policy framework in 2019 and develop a data strategy for the Irish Health Service in 2020, which is currently under development.

However, the health information system strategy is separate to the eHealth Strategy and the Strategic Action Plan 2021–2023. Having two separate strategies to manage health information is not aligned with international experiences. Internationally, countries are moving in the direction of having a more consolidated approach towards health information. This approach explores collecting health information once and leveraging health information from primary use systems — such as electronic health records — to reuse it for the purpose of care and secondary use, such as informing policy, research. This ensures more evidence-based decision-making for managing health and social care services. For example, Australia has developed a framework to guide the secondary use of data from their national electronic health record called the 'My Health Record'. The framework describes the governance mechanisms and technical processes that need to be implemented before data can be released from the electronic health record for research, policy and planning secondary purposes.(31)

Other prominent reports and policy documents, such as the Programme for Government and the Project Ireland 2040 National Development Plan, attribute how health information — focusing mainly on eHealth — has the ability to transform the Irish care delivery system to a more patient-centric, integrated and cost-effective system. Digital health transformation is a complex and challenging process which requires dedicated resources and effective planning. It requires change across every level of the health and social care system including the: macro level (healthcare provision and financing policy), the meso level (at the individual organisational level) and the micro level (in terms of individual change to how healthcare professionals and managers provide care).(32) This is particularly true at the meso level – regardless of policy reform, there is significant effort required to achieve 'practice transformation' which encourages healthcare professionals to adopt new ways of working and in the transformation of workflow and culture.(33)

2.1.1 Conclusions and recommendations

Health information is a key enabler for health service reform in Ireland that requires close scrutiny from policy-makers. Most technologies discussed in Irish policy on health information are concerned with communications between health service providers themselves and with their patient, that is electronic health records, patient portals, telehealth and electronic prescribing.(34) Currently, there is no overarching health information strategy that takes a holistic approach to managing how health information is collected, used and shared for both primary care purposes and secondary use, such as health service management and quality improvement.

Despite the acknowledged importance of health information for driving continuous improvement in health outcomes, and although there are various strategies and reports on health information in Ireland, deficiencies in the health information system in Ireland still exist. Strategies have repeatedly called for the need for the individual health identifier and for priority projects like the national electronic health record, ePrescribing and a standards-based approach for sharing health information. As previously stated, the eHealth strategy (2013) recommended the establishment of eHealth Ireland which has not been established as originally defined in the strategy. Some aspects of the strategies have been progressed but some are at varying levels of implementation.. An eHealth Strategy (2013) has been developed and is still largely relevant but this strategy is now out of date and needs to be revised to reflect modern initiatives in the health information space, that is artificial intelligence (AI), Fast Healthcare Interoperability Resources (FHIR) standards. The Sláintecare Implementation Strategy and Action Plan (2021-2023) will provide direction on the eHealth pillar and the Department of Health are currently working on a Health Information System Strategy which is more concerned with the secondary use of health data. While Sláintecare identifies individual eHealth projects, there is a need for a more strategic approach and a comprehensive action plan and roadmap for health information needs to be developed.

Therefore, HIQA recommends that:

Recommendations 1: Strategy

- Continued political commitment is required to deliver a clear national health information strategy that addresses key enablers for an effective health information system, including effective governance and leadership, a sound legal framework, a viable workforce and appropriate funding mechanisms, Ministerial approved standards, and a robust and secure health IT infrastructure.
- The existing eHealth strategy is outdated and should be revised to reflect more modern eHealth developments, in line with the ongoing national health information system strategy that is currently in development.
- A national health information strategy should be developed that has achievable, time-bound objectives and is aligned with the Sláintecare 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 primary care and secondary use purposes across both public and private settings.
- A national health information strategy needs to be assigned appropriate funding to ensure that its objectives can be fully achieved.
- Implementation of the strategy should be reported on an annual basis.

2.2 Strategic Leadership and Governance

International evidence suggests that countries with a mature and well-functioning health information system have strong national leadership, governance and management with clear organisational responsibility for managing health information systems.

Ireland has much to learn from the experience of other countries in relation to leadership, governance and oversight of their health information system and the approach to governing the collection, use and sharing of health information. England is one such example whereby a single organisation — National Health Service (NHS)

Digital — has been assigned to manage the collection, use and sharing of health information. NHS Digital provides digital services for the NHS and social care, including the management of large health informatics programmes and is also the national collator of information about health and social care, including national comparative data for secondary uses, developed from the long-running Hospital Episode Statistics which can help local decision-makers to improve the quality and efficiency of front-line care.(35)

In many countries internationally, responsibility for the governance and management of the majority of national health and social care data collections is assigned to one or more specific agencies or organisation. In countries such as Canada, New Zealand, England, Australia and Finland(35,36,37,38,39,40) there are key organisations that govern either all or the majority of national health and social care data collections. These organisations provide the strategic framework for the governance of the collections. In addition, in some countries with a more centralised oversight model, such as New Zealand, advances have been made in creating additional secondary sources of health information, termed 'virtual registries'. From these registries, data from multiple sources may be collated and combined to provide information in relation to a specific disease in a very cost efficient and streamlined format; for example, the New Zealand Virtual Diabetes Register (VDR).(41,42)

Other examples internationally where robust governance structures exist at a national level for eHealth programmes include Scotland, Denmark and Canada.(42,43) In these countries, governance of the eHealth programmes is well-structured with appropriate boards, groups and committees established. There is an emphasis on stakeholder engagement and communication between the various, boards and groups. They have clear roles and responsibilities and have a wide-ranging remit, with good reporting structures in place.

In Ireland, the key organisations at a national level that have varying responsibilities and play an important leadership role in the delivery of the health information system include the Department of Health, the HSE and HIQA.

The Department of Health has overall responsibility for leadership and policy decision-making in the Irish health sector. There are two separate divisions within the Department of Health that have responsibilities for health information, including the Research and Development and Health Analytics Division which currently leads on health information policy specifically on the secondary use of health data. The Sláintecare Programme Implementation Office has an eHealth and health information systems division which is responsible for:

- developing the eHealth Strategy

- setting priorities, facilitating the delivery of health information systems through managing the availability of resources and funding the delivery of health information system projects
- monitoring the HSE's progress against the delivery of the HSE service plan
- the Sláintecare Implementation Strategy and Action Plan 2021-2023.

The Sláintecare Programme Implementation Office is advised by the Sláintecare Implementation Advisory Council and reports to the Minister for Health and Cabinet Committee on Health. There is a channel of communication between the Department of Health Sláintecare Implementation Office (eHealth and Health Information systems division) and Senior Management in the Health Service Executive Office of the Chief Information Office (OCIO); however, more formal reporting arrangements are a work in progress and there is a desire to build stronger linkages with senior management in the HSE OCIO. Currently, there is restructuring ongoing within both the Department of Health and the HSE. There is a need to view health information from a holistic perspective including – eHealth, national data collections and the secondary use of health data.

The HSE is tasked with implementing and providing Ireland's public health services in hospitals and communities nationally for every citizen in Ireland. The HSE is responsible for managing a number of key national data collections, such as the Hospital In-Patient Enquiry (HIPE) and Primary Care Reimbursement Service (PCRS) schemes. The HSE's OCIO is responsible for both the operational (supporting the systems required for the delivery of care) and strategic aspects of implementing national eHealth programmes. Governance arrangements are structured as follows: the Chief Information Officer reports to the Chief Executive Officer of the HSE, reports to the HSE Board, which in turn is accountable to the Minister for Health in the Department of Health. At a programme level, the HSE established a Digital Advisory Group to support programme and project governance structures to ensure that eHealth enabled projects are delivered and supported as a way of enhancing accountability.

Integral to the 2013 Irish eHealth strategy was the need to establish an entity called eHealth Ireland to realise the vision of the eHealth strategy and drive forward the eHealth agenda.(44) The aim was for eHealth Ireland to be responsible for overall governance around eHealth implementation including funding, legal enabling, public awareness and stakeholder engagement through building the eHealth ecosystem in Ireland and to work in partnership with Government and state agencies. eHealth Ireland was originally intended to operate outside of the HSE and would be accountable to a Board; however, this never transpired. An eHealth committee, which functions in an advisory role, was created and composed of senior representatives from the HSE, the Department of Health, HIQA and international experts among others. Although an eHealth Ireland committee exists, it is not a committee that provides oversight and governance and accountability.

Under the Health Act 2007,(45) HIQA has the legal remit to define national standards for health information systems, make recommendations and provide guidance on the same to the Minister for Health to inform evidence for policy-making, and to assess compliance on standards within the HSE, HSE-funded services and Tusla.

Although not an exhaustive list, some examples of organisations that currently have a legislative remit regarding health information include the Central Statistics Organisation (CSO) — which has played a vital role in response to COVID-19 — the National Cancer Registry, the National Standards Authority of Ireland (NSAI) and the Data Protection Commissioner. In addition, there are other organisations, such as the Health Research Board, the National Office for Clinical Audit (NOCA) and smaller national data collections that are involved in the collection of health and social care data in Ireland. Regarding the response to the recent cyberattack on the HSE, four different State agencies are concerned with various aspects of cyber security. All four entities have different Government departments and different strategies in place.(46)

2.2.1 The need for governance in health information

Ireland’s health information system is highly fragmented with major gaps and silos of information which prevents the safe, effective, transfer of information. This disparity is demonstrated in the National Childcare Information System (NCCIS) which captures critical data on children who are the subject of a child protection or welfare referrals. However, there is no linkage with that system and the HSE information systems that also contain vital information on children’s healthcare.

The HSE is a large organisation and needs data to operate effectively. In recent years, the number of national data collections hosted outside of the HSE has increased; for example, NOCA is now responsible for the governance of nine major national clinical audits, including the National ICU Audit. This means that data pertaining to some key sources of health information required for the functioning of the health system in Ireland, such as hospital wait times and ICU figures, need to be shared between the HSE and separate agencies or entities. This strengthens the need for more robust governance arrangements for data and information management to be in place.

Some advances, however are being made in relation to a plan for more integration of health data within the HSE. Under the Data Research and Evaluation Programme of the Sláintecare Action Plan, a new Integrated Information Service (IIS) within the

OCIO in the HSE is being developed with the goal of consolidating existing data, collecting new data, and ensuring high-quality national and international evidence is accessed, synthesised or generated to inform decision-making.

Outside of the HSE, the National Statistics Board has identified the need for a National Data Infrastructure (NDI) to facilitate the linkage of data across the public sector, incorporating permanent unique identifiers and common data standards. In its recently published strategy (May 2021), it noted that health data should be included as part of this infrastructure. One of the key recommendations is that the Department of Health should develop a comprehensive infrastructure for health and related data. It also notes that the lack of a comprehensive infrastructure for secure data access, storage, sharing and linkage of routinely collected health, social care and related data has been a challenge for health research to date causing policy-relevant studies to be abandoned or inordinately delayed. The Health Research Board publication in May 2016 also voiced these difficulties for health research and proposed the DASSL (data access, storage, sharing and linkage) model.[5]

2.2.2 HIQA

As outlined in section 1.4, since 2017 HIQA's review programme identified a number of key challenges that currently exist around governance, leadership and management arrangements of national data collections. HIQA has also previously emphasised the need for robust governance to be established regarding national eHealth programmes. Recommendations to the Minister for Health on ePrescribing (2018)(47) and on a national electronic patient summary (2020) identify the urgent need for governance of these programmes.

Although these recommendations are made at programme level, based on review of more successful systems internationally, HIQA advocates for an organsation that has complete oversight, enhances accountability and oversees strategic implementation of major large scale projects to ensure they work together cohesively rather than separately.

---

[5] The DASSL (Data Access, Storage, Sharing and Linkage) model, proposed by the Health Research Board in 2016, addresses the requirements for data access, sharing and linkage experienced by Irish researchers and identifies the infrastructure and services that need to be developed as part of the Irish data and statistical infrastructure going forward. Currently, a Proof of Concept for the 'DASSL' model is being advanced with the aim of demonstrating a proof of concept for technical infrastructure that will inform a national solution for the safe and controlled access, storage, sharing and linkage of research data and routinely collected health and social care datasets.

2.2.3 Conclusion and recommendation

Unlike other jurisdictions, there is no governing body with responsibility for national data across multiple public and private agencies to ensure co-ordination of the health information system at a national level.

The eHealth Ireland entity was not established as per its original remit and although the HSE is the governing body for its data, the responsibility for national data is far-reaching and spans beyond the HSE into Tusla and private agencies. The main aim of eHealth Ireland should be to provide strategic direction, be accountable for and govern the health information system at a national level for both public and private healthcare. In addition, HIQA believes that responsibility for the use of eHealth and health information for secondary purposes should not be viewed as separate entities as it will lead to further fragmentation and even more information siloes in the system. It is essential that health information can be collected once for patient care and then re-used for the purpose of secondary use care to help inform policy, research and to ensure more evidence-based decision-making for managing health and social care services.

In relation to oversight of national data collections, compared with the approach undertaken by a number of countries internationally, there is currently no centralised body in place with such responsibility in Ireland leading to a lack of accountability. In respect of national information governance, there is no national information framework for the sharing of information across the public and private sector. In the absence of clear policy and strategy and the associated funding, the various agencies responsible for health information are set up to fail.

Therefore, HIQA recommends that:

Recommendation 2: Strategic Leadership and Governance

- To date, eHealth Ireland has not been established as was originally intended as a separate entity with responsibility for overall governance around eHealth implementation — including funding, legal enabling, public awareness and stakeholder engagement through building the eHealth ecosystem in Ireland. There is a need for a clear policy direction for health information, and clear roadmap on how the different agencies within health and broader governmental organisations are coordinated, to deliver an integrated approach to health information and support the health and social care system in Ireland.

- As set out in the eHealth strategy (2013), a strategic entity (eHealth Ireland) should be established, outside of the HSE, with a legislative remit to provide strategic leadership and governance to support the collection, use and sharing of health information in Ireland. In parallel, an operational function developing and supporting the systems required for the delivery of care should continue to exist in the HSE. The remit of this entity should be broader than eHealth and include the centralised coordination and governance of national data collections and the secondary uses of health information at a national level.
- Roles and responsibilities and accountability for this entity should be clearly defined, including how this entity would 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.

2.3 Legislation

Legislation and regulations are important strategic instruments to ensure that a national health information system is fit-for-purpose, helping to strengthen the implementation of health information systems and ensuring more efficient collection, use and sharing of health information across the health sector.

Historically, the European Union (EU) has focused mainly on promoting the development and implementation of health information networks and electronic health records (EHRs) for enabling and improving health data exchange between different care providers and member states. Most notably, the introduction of the European Commission cross-border directive 2011/24/EU (2011)(48) related to the European National Contact Point Programme for the provision of a patient summary record along with electronic prescribing.

In addition, a EU-wide framework known as the General Data Protection Regulation (GDPR)(49) came into force across the EU on 25 May 2018. This regulation provides for higher standards of data protection for individuals and imposes increased obligations on organisations that process personal data. It puts an onus on member states to establish a clear legal basis for the processing of personal health information for primary, secondary and for research purposes. Under GDPR Article 5, processing of personal data, including anonymisation and analysis, must comply with a number of key data protection principles. Article 9 of GDPR specifically deals with the processing of 'special categories' of personal data, including data concerning health.

Legislative frameworks vary considerably from jurisdictions where legislation was introduced specifically for electronic health records, to jurisdictions where legislation was passed specifically for large scale digital solutions for health and social care. Ireland remains at the early stage of developing policy for a national electronic health record and have not adopted specific regulatory rules on EHRs.(50) Several brief examples below illustrate a variety of approaches.

Estonia began the digitisation of government services in 1991, laying the foundations of the legislative framework for electronic services. Legislation was passed in 2002 specifically to enable the exchange of health data, equalising digital and paper records. The national infrastructure for government eServices, including eHealth, was established in 2004, while key components for healthcare, such as strong authentication, obligations to send data, and patients' rights were introduced through legislation in 2007. The Estonian nationwide information-exchange platform (acting as Estonians national EHR) was established in 2008. It connects all providers and allows data exchange with various other databases. Healthcare providers are connected to the system and patient health data is stored centrally. All healthcare providers have a legal obligation to send certain health data to the health information system.(51)

In Finland, there has been legislation since 2007 that makes it mandatory for most healthcare organisations to send electronic patient records to a national repository and ePrescription Centre (Kanta). The same legislation gives the National Institute of Health and Welfare (THL) a mandate to give executive orders for essential requirements needed for systems connected to the national health IT services. Finland has also introduced legislation specifically in relation to the secondary use of health data. The Act on Secondary Use of Health and Social Data 2019 has been introduced to facilitate the effective and safe processing and access to the personal social and health data for steering, supervision, research, statistics and development in the health and social sector. The secondary uses as referred to in the Act includes scientific research, statistics, service planning and management, supervisory activities, teaching, and other purposes.(52)

In all Nordic countries, specific health information standards and their use are regulated by law. However, the scope and strength of these regulations do vary. National standards are usually defined and published in official catalogues. National bodies are mandated to keep these updated and accessible for healthcare enterprises and system developers.(42)

As part of the ongoing health information programme of work, the Department of Health in Ireland introduced the Data Protection Act (Section 36(2)) (Health Research) Regulations 2018(53) and are actively considering other regulations under the Data Protection Act to underpin and clarify the legal basis for the information flows necessary to support integrated care in a secure and confidential manner. Following enactment of the GDPR at European level, the Data Protection Act was also amended in 2018 to give effect to the GDPR and to address specific matters impacting on this legislation in Ireland, including replacing the Office of the Data Protection Commissioner with the 'Data Protection Commission' as the responsible body for enforcement of the legislation and data protection standards.

Regarding legislation on eHealth services, the individual health identifier (unique personal numbers used across all public health and social services) was legislated under the Individual Health Identifier Act (2014)(14), in advance of setting up electronic health records for all Irish citizens. In September 2015, a delegation order was commenced to allow the HSE to develop and operate the individual health identifier on behalf of the Minister for Health. The Act specified the list of demographic details that will be held by the Individual Health Identifier Register.

Similarly, there are gaps in legislation in the area of electronic prescribing. There is a legal requirement in Ireland to produce a paper prescription for patients to present to their pharmacist and legislation is required to allow for electronic prescribing. In response to the outbreak of COVID-19, temporary amendments to the Medicinal Products (Prescription and Control of Supply) Regulations 2003 (as amended)(54) and the Misuse of Drugs Regulations 2017 (as amended)(55) have been made by the Minister for Health to ensure that patients can continue to access their ongoing treatment and 'regular' medicines during the ongoing pandemic. Although COVID-19 highlighted the urgent need for electronic prescribing, this temporary solution should be reviewed and positive lessons learned from this initiative should be built upon. However, HIQA is of the opinion that a long-term solution to ePrescribing should be based on proven international and national standards for health information and therefore this temporary arrangement is not a sustainable model in the long term.(56) However, there is a need to legislate and implement an electronic prescribing solution as outlined in HIQA's recommendations on implementing electronic prescribing.(47)

There is specific legislation already in existence which allows for the collection and processing of specific personal data in Ireland; for example, Infectious Disease Regulation, 1981(57) and National Cancer Registry Board (Establishment) Order, 1991(58), and the Statistics Act, 1993.(59) On top of that, several new Acts and Bills, as well as amendments to legislation and regulation, have been introduced or proposed since 2016 which will have implications for the governance, processing and availability of health data.

In relation to research, specific legislation for the processing of personal data for health research purposes was enacted in 2018 – the Health Research Regulations.(53) Those regulations provide the legal framework that governs the collection, use and sharing of an individual's personal information for health research purposes. In January 2021,(60) the regulations were amended to address a number of specific areas, in particular in relation to consent. In this regard, the amended regulations address:

- deferred consent for the processing of personal data for health research in exceptional situations, informed consent for health research obtained during the time of the EU Data Protection Directive, explicit consent for processing personal data in a health research context.

Early revisions of the Health Information Bill have existed since 2007 and it subsequently evolved to become the Health Information and Patient Safety Bill to take account of the patient safety elements contained in it. The Health Information and Patient Safety Bill includes a range of measures particular to health information, including the provision of a regulatory framework for 'data matching' — personal information gathered for one purpose by a health organisation that is later 'matched' with personal information gathered for a different purpose by the same organisation. The rationale is that the collection of these separate strands of information will serve to provide health professionals with a better and more complete understanding of an individual within the health system. In 2017, the Health Information and Patient Safety (HIPS) Bill(61) underwent a public consultation process. A number of concerns were raised by stakeholders who had concerns regarding the buying and selling of personal health data, compliance with GDPR and the lack of a mechanism for establishing 'a prescribed data matching programme' or a prescribed health information resource, and as a consequence this bill was changed and not enacted in its original form. The Patient Safety (Notifiable Safety Incidents) Bill(62) was subsequently published in 2019 and will mandate the open disclosure of certain incidents occurring in the course of the provision, to a person, of a health service in both the public and private sector. Additionally, it contains an exemption to the Freedom of Information legislation for a record that is a clinical audit and it proposes to expand the power of HIQA to set and monitor standards in the private health sector. In the absence of legislation for Health information, the Patient Safety Bill, does not address the need for legislation for the collection, use and sharing of health information.

An amendment was made to the Infectious Diseases Regulations in 2020 to allow for COVID-19 to be added to the list of diseases designated as an 'infectious disease' for the purposes of the Health Act. This amendment provides for collection of health data related to COVID-19.

2.3.1 Conclusion and recommendation

Ireland lags behind other European countries regarding legislation to support the health information system. Legislative measures currently in place include the Health Identifiers Act 2014, the Data Protection Acts (1988-2018) to give effect to the EU-wide General Data Protection Regulation, and the Health Research Regulations (2018). Ireland currently does not have a legal framework in respect of specific health information systems or a national information governance framework for the collection, use and sharing of information across the public and private sector. This lack of legislation is hindering overall coordination between the key health information entities and organisations involved in health information and there is a need for continued political ownership in this regard.

Therefore, HIQA recommends that:

Recommendation 3: Legislation

- For a national health information system to play its full role in enabling a safe healthcare system, a sound legal framework is required. 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.

2.4 Workforce

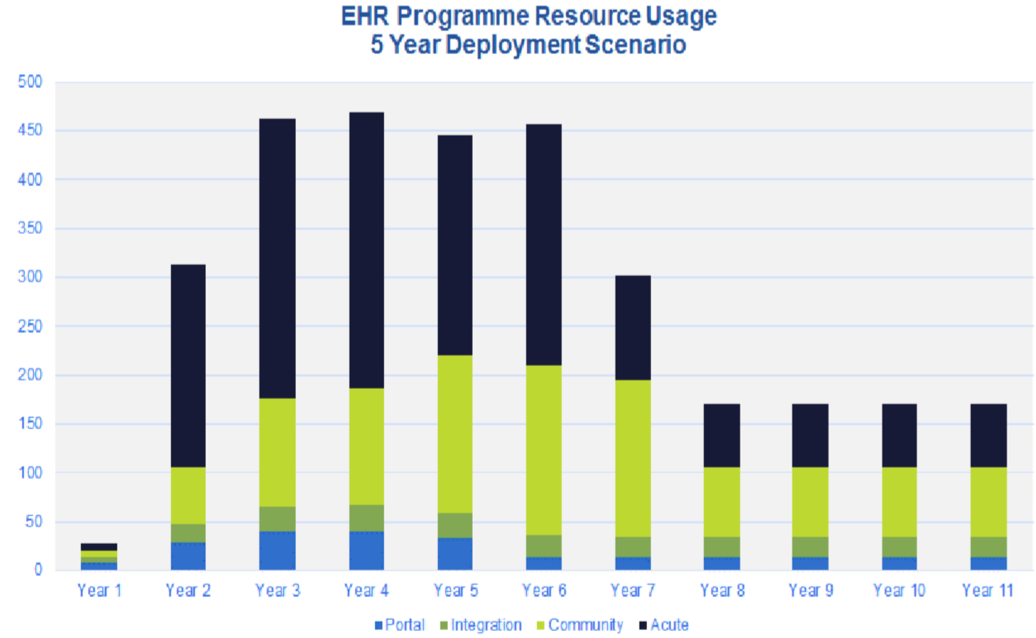
When compared to other EU states, Ireland has historically under-invested in health information, including the resources required to support the delivery of a robust health information system. The eHealth strategy (2013) identified that the annual information communication technology (ICT) budget for healthcare in Ireland was approximately 0.85% of total healthcare expenditure compared to an EU average of between 2% and 3%.(6) In the years prior to 2012, the HSE was significantly under-resourced and had a significant deficit in spending its ICT budget.

In 2015, the National Electronic Health Records Strategic Business Case(63) outlined the need for the investment of up to €875 million over a 10-year period to deliver a National Electronic Health Record across the Irish health system. This investment equated to approximately 0.65% of the total health system budget over that time period. Based on international experience of the implementation and adoption of electronic health records (EHRs) the characteristics and challenges of the Irish health system, and the level of ambition set out in this strategic case, it was envisaged the programme is most likely to span a 10-year period of transformation. The delivery of health and social care services in Ireland was considered unsustainable without significant reform.

The business case identified resources required for two different implementation scenarios for a national EHR — a five-year implementation scenario and a nine-year implementation scenario. It was envisaged that up to 450 resources would be required through years two to six of the plan, with the following resource type required over the course of the project. The resourcing requirements by year and by resource types required are:

- Clinical – resources with a clinical background including consultants, senior registrars, nursing professionals and health and social care professionals. They will lead and guide the design and delivery of the solutions from a clinical perspective to ensure that they are clinically safe and fit for purpose.
- Technical – resources that provide technical leadership during the programme such as Technical and Solution Architects.
- Configuration – resources that work with the clinicians and the suppliers to help setup the solutions so that they meet the requirements.
- Project Management Office (PMO) – resources who provide leadership, managerial and administrative support and oversight. This also includes resources that will lead the gathering of requirements, conduct readiness assessments and lead procurement activities.
- Delivery – resources responsible for implementing the desired solutions in the hospital groups and community healthcare organisations including areas such as managing the local implementations, testing, training and data migration activities.

Figure 1.0 Full-time Programme Resource Usage – Five-Year Deployment Scenario (*Graph taken directly from EHR national business case)(63)



Subsequent investment and financing of the Office of the Chief Information Officer (OCIO) has seen an increased growth in funds allocated for ICT projects to support the delivery of health and social care in Ireland with an allocation of €55 million through 2016 and 2017, increasing to €60 million in 2018, €85 million in 2019 and €95 million in 2020. The Sláintecare Implementation Strategy and Action Plan 2021–2023 cites the 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. Goal four of the Sláintecare Implementation Plan (2018),(9) 'Enable the System to Deliver Its Goals' identified the need to build a sustainable, resilient workforce that is supported and enabled to deliver the Sláintecare vision, put in place a modern eHealth infrastructure and to improve data, research and evaluation capabilities. However, the business case for the EHR programme was not approved and a new strategic direction has been taken as cited in the new Sláintecare Strategy Implementation and Action Plan (2021-2023) to deliver on the summary and shared care records instead of a national EHR.

The HSE National Service Plan (2021)(64) demonstrates a significant investment in ICT services is 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, but also of capitalising on the best of the clinical, cultural, information and technological changes that are occurring. A recruitment programme is underway. This is very much needed to 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) outlines an additional 300 resources to support the work of the HSE OCIO. While this is extremely positive, it does not cover the resources required to ensure strategic implementation of national projects for health information. As previously mentioned, the HSE's OCIO is responsible for both the operational and strategic roll-out of national eHealth programmes and major ICT projects. Senior management in the OCIO are currently undertaking dual roles, ensuring the strategic direction and delivering and maintaining health information systems. As set out in the eHealth strategy (2013), a strategic entity (eHealth Ireland) should be established, outside of the HSE, with a legislative remit to provide strategic leadership and governance to support the collection, use and sharing of health information in Ireland.

The HSE has spent €110.5 million on cyber security in the five years between 2016 and 2020 and planned to spend another €37.3 million this year prior to the cyberattack and has invested 'considerable funding into cyber security'.(65) The HSE intiially estimated that the cyberattack would cost approximately €100 million, including the cost of getting systems back up and running, the cost of upgrade and business costs associated with the delays and impact the cyberattack has had on services. At a Oireachtas Committee in May 2021, the National Cyber Security Centre's annual budget of €5 million was discussed and it was noted Ireland should be spending 10 times that amount on cyber security, at €50 million per year in order to be spending at the same level as the UK on a per capita basis.(66) By June 2021, an Oireactas committee was informed that the revised overall cost to the HSE could potentially amount to half a billion euro. This estimate takes into account the restoration of systems, the technical, infrastructural and human costs associated with the cyberattack. Additionally, there are capital costs associated with replacing a number of devices across networks and upgrading systems to a higher standard. Although the HSE has invested €82 million in malware protection, a huge challenge is that there is an extremely old legacy network in the HSE. International expertise and technical expertise from specialist providers was also sought, as well as clinical costs and local IT costs needed to strengthen resourcing in this area.(67)

As was intended by establishing eHealth Ireland, there is a real need to ensure that there is both an operational function and a separate strategic entity (eHealth Ireland) established in order to protect major health information projects and to support successful implementation of health IT programmes in the future. Ireland needs to invest heavily in an adequately skilled and trained workforce to deliver on systems and services required to improve health information in Ireland in both strategic and delivery roles. While the increase in capital investment and resources is welcome, a more strategic and long-term approach is required for planning of recruitment of resources in health information.

Education of the user workforce

To capitalise fully on the benefits that digital solutions can offer, the workforce needs to understand how to use them. All health professionals should be familiar with digital health solutions available to them, and be educated on how to use them in an effective, responsible, and ethical way, with the interests of the patient at the centre. Also, patient's involvement in their own self-management enabled by mobile health (mHealth) solutions is more evident than ever and there is an educational role needed to support this.

In 2016, the Digital Skills for Health Professionals Committee of the European Health Parliament surveyed over 200 health professionals of different backgrounds and age categories about their experience with digital health solutions across 21 Member States. A large majority of participants reported to have 'received no training, or insufficient training, in digital health technology. Most reported using some digital skills in their practice more than once a week, and basic IT skills and electronic patient records were used daily by more than 50% of the participants.' In conclusion, Health professionals voiced the need for continuous practical and hands-on training throughout their careers. The Digital Skills for Health Professionals Committee made recommendations to support the EU agenda for digitising healthcare including widening digital literacy in healthcare and continuous education of health professionals in the knowledge, use and application of digital health technology.(68)

2.4.1 Conclusion and recommendation

Ireland has significantly under-invested in health information compared to other European countries. COVID-19 and the cyberattack on the HSE has raised awareness of how crucial health information is for managing healthcare services. The HSE had to allocate huge resources into developing systems to manage the response to the pandemic and this was reflected in its service plan for 2021 which identifies the need for an additional 300 resources to support the HSE OCIO. Investment in eHealth capital and staffing is also highlighted in the Sláintecare Action Plan. While the increase in capital investment and resources is welcome, a more strategic and long-term approach is required for planning resources in health information.

It is paramount that clear roles and responsibilities are defined when establishing the two separate functions — a strategic entity (eHealth Ireland) function and an operational function should continue to exist in the HSE to support the systems required for the delivery of care — to ensure they do not work in silos and are able to work together to enable successful health information systems. As highlighted throughout this report, a well-balanced governance structure is needed to support the delivery of a robust health information system and the appropriate resources and roles will be needed in this endeavour.

Therefore, HIQA recommends that:

Recommendation 4: Workforce

- A more strategic approach is required to the allocation of resources in health information to continue 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 including a strategic entity (eHealth Ireland) outside of the HSE and an operational function within the HSE to support the systems required for the delivery of care. 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.

2.5 Standards and Interoperability

At the core of an integrated health and social care system is the need to share information between healthcare practitioners both within and across organisational boundaries. This requires a standards-based approach to health information and interoperability, that is to say projects are underpinned by international and national standards.

Across health information, standardisation is required at many levels — data standards, data dictionaries, metadata standards, key performance indicators, interoperability and messaging standards, classification and terminology standards. Processes are required to ensure that data quality is incorporated into the collection and use of health information. Assessing compliance of systems with health information standards may also be undertaken along with the assessment and certification of health information systems for compliance with standards. Evidence internationally suggests that organisations are established, independent of the organisation tasked with the delivery of health and social care, to lead on the standardisation of data across the health information system and that adoption and implementation require policy and regulation and assessment of compliance.

Denmark in particular is one country which has invested significantly in a standards-based approach to health information. Denmark commenced its journey with the establishment in 1994 of MedCom and focused on developing health information standards and technical interoperability that allows the most common electronic messages to pass between various stakeholders in the healthcare system — referrals, discharge summaries, prescriptions.(69) In 2011, it was reported that the system was almost now fully electronic with all frequent documentation being transferred electronically.

Building on this, Demark has successfully progressed providing citizens with access to their health information through a national patient portal.(70) Patients can view their medical information, schedule appointments, request repeat prescriptions, view waiting time information for hospitals and view hospital 'rankings' in order to help choose where they attend. Additionally, Denmark has successfully developed a standards-based shared medication record across primary and secondary care which was mandated for use by clinicians in 2014.(71) In addition, policy and regulations in Denmark drove the implementation of standards-based electronic health records in primary care and hospitals. The fiscal agreement for 2002 between the government and hospital owners states that electronic health records based on common standards had to be implemented in all Danish hospitals by the end of 2005. Further fiscal agreements have mandated the adoption of EHRs under the primary care physician contract and specialist consultants' contract.(72) MedCom was the first European Competence Centre to follow the ISO9001:2015 standard in the process for testing and certification of healthcare IT-systems, resulting in high-quality and uniform test and approval of systems.

Studies have concluded that MedCom has produced financial benefits. A cost-benefit analysis conducted in 2006 by the market research firm Empirica estimated that the cumulative present value cost of MedCom prior to end of 2005 was €536 million, and the benefit was €872 million. Empirica estimated that a typical GP, serving 1,300 patients, saves 30 hours per week of secretarial work by using the MedCom standards.(73)

In the UK, NHS Digital is the national information and technology partner to the health and social care system. The organisation is an executive non-departmental public body of the Department of Health and Social Care. It has a broad remit as the national provider of information, data and IT systems. IT systems and services which provides for the NHS include NHS mail, summary care records, electronic prescription service and the national electronic referral service. In addition, NHS Digital has responsibility for standardising, collecting and publishing data and information from across the health and social care system in England. Finally, it is the standards setting body for all NHS data and has developed many information standards relevant to health and social care. It has developed and maintains a vast catalogue of standards, such as:

- the NHS Data Dictionary defines low level attributes and data elements, which can be combined in classes and business definitions subsequently used to develop national datasets.
- clinical and administrative data sets.
- clinical indicators across health and social care.
- information standards such and the UK editions of the SNOMED CT, the International Statistical Classification of Diseases and Health Related Problems (ICD) 5th edition, the Classification of Interventions and Procedures (OPCS), the Dictionary of medicines and devices (dm+d) and the Unified test list (UTL).
- data security standards and a supporting data security and protection toolkit. All organisations with access to NHS patient data and systems must use this toolkit to provide assurance that they are practising good data security and that personal information is handled correctly.

In order to connect to services such as the electronic prescription (ePrescription) services, vendors are required to have the systems to be certified by NHS Digital and are provided with a spine compliance certificate. In addition, NHS Digital provides the Interoperability Toolkit (ITK) which is a national standard defining requirements and rules for the creation and transport of electronic health information. The ITK supports interoperability within local organisations and across local health and social care communities. Vendors can self-assess against the toolkit and certificates are awarded following successful submission of test results and supporting evidence. Finally, SNOMED CT[6] has been adopted as the national clinical terminology in England and as of 1 April 2018 SNOMED CT was required to be used across primary care settings.(74,75,76)

In other jurisdictions, national standards are developed and their use is mandated through legislation. In Finland there has been legislation since 2007 that makes it mandatory for most healthcare organisations to store electronic patient records to a national repository and ePrescription Centre (Kanta). The same legislation gives the National Institute of Health and Welfare (THL) a mandate to give executive orders related to the essential requirements of systems connected to the national health IT services, and to specify the content and terminology of records stored to the national health IT services. Norway has regulations for the use of ICT standards for

---

[6] SNOMED CT supports th**e** development of comprehensive high-quality clinical content in electronic health records. It provides a standardized way to represent clinical phrases captured by the clinician and enables automatic interpretation of these. SNOMED CT based clinical information benefits individual patients and clinicians as well as populations while supporting evidence-based care.

health and social care services. The purpose of the regulations is to ensure that organisations that provide healthcare adopt ICT standards to promote secure and effective electronic collaboration.(42)

Ireland lags behind countries internationally in developing standards-based information systems for health and social care. Originally recommended in the National Health Information Strategy for Ireland in 2004 and re-iterated in the eHealth Strategy (2013), Ireland still has significant steps to take to ensure that information is available at the time of service delivery and can subsequently be used in the planning of service delivery.

Currently, over 120 national data collections exist in Ireland. In addition, national eHealth programmes are in progress such as the National Integrated Medical Imaging System and the National Maternity and Newborn Clinical Information System. In the near future, significant programmes will be undertaken including a national ePrescribing programme and the development of a shared care records and patient portals. It is imperative that national health information standards are defined for these systems to ensure the effective and secure communication of health information.

The development of national standards for health information in Ireland is fragmented, with responsibility spread across numerous organisations, and is not adequately resourced to succeed. Furthermore, it lags behind other countries in areas such as the implementation of modern interoperability standards, including clinical terminologies such as Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) and messaging standards such as the Health Level Seven (HL7) Fast Healthcare Interoperable Resources (FHIR) and Clinical Document Architecture.

There are three separate organisations with different roles and responsibilities and oversight for the development, management and governance of national health information standards:

- HIQA has a legislative remit under the Health Act 2007, as amended, to develop recommendations, standards and compliance with those standards, and guidance in health information (See Table 1.0 and Table 2.0 below).
- The department of health have funded the HSE Office of the Chief Information Officer (OCIO) within the HSE and they has published frameworks and technical specifications for health information through its Enterprise Architecture and Design Authority business function for the purpose of procurements of health information systems.
- The National Standards Authority of Ireland (NSAI) is responsible for the development of Irish standards, representing Irish interests in the work of the

European and International standards bodies, European Committee for Standardization (CEN) and International Standards Organisation (ISO).

Health Information and Quality Authority (HIQA)

HIQA, through its legal remit in health information, has developed national health information standards which can be divided into groupings – document standards, electronic prescribing standards, messaging standards, clinical information, modelling standards and information governance and management standards as outlined in Table 1.0 below.

Table 1: National standards on health information

Title	**Year Published**
National Standard on information requirements for a national electronic patient summary	2018*
National Standard on information requirements for national community-based electronic prescribing	2018*
General Practice Messaging Standard (Version 4.0)	2017*
National Standard for a Dispensing Note including a Clinical Document Architecture specification	2016
National Standard for a Procedure Dataset including a Clinical Document Architecture specification	2016
National standard adverse reaction dataset and clinical document architecture (CDA) template	2016
National standard diagnosis dataset and clinical document architecture (CDA) template	2016
National standard demographic dataset and guidance for use in health and social care settings in Ireland (Version 2.0)	2016
Information Governance and Management Standards for the Health Identifiers Operator in Ireland	2015
ePrescription dataset and clinical document architecture standard	2015
Data model for an electronic medicinal product reference catalogue – a National Standard	2015

National Standard for a Clinical Summary (Patient Discharge)	2013
Report and Recommendations on Patient Referrals from General Practice to Outpatient and Radiology Services, including the National Standard for Patient Referral Information	2011

*Indicates the national standards for health information that have been formally approved by the Minister for Health to date.

HIQA develops information standards which are then submitted to the Minister for Health for approval. To date, only three standards have been formally approved by the Minister: *National Standard on information requirements for a national electronic patient summary* (2018),(77) *National Standard on information requirements for national community-based electronic prescribing* (2018)(78) and the *General Practice Messaging Standard (Version 4.0)* (2017)(79).

The General Practice Messaging Standard is the basis for electronic messages and communications sent between GPs and hospitals, including electronic referrals. Other information standards, such as those related to ePrescribing, have not been implemented to date due to slow progress in the roll-out of a national community electronic prescribing programme first mentioned in 2015.

In recent years and in order to progress the implementation of national standards, HIQA has developed Recommendations on electronic patient summaries, electronic prescribing, SNOMED CT terminology, patient referrals and a unique health identifiers for individuals and for healthcare practioners and organisations.

Through its review programme, HIQA evaluates the approaches that HSE organisations have taken to address data and information quality. While there are some examples of good practice, there are significant gaps, such as the absence of a strategic approach to addressing data quality within the HSE.

Internationlly in numerous jurisdictions internationally including Canada, UK, Australia and Denmark, there has been a move towards assessing compliance to national standards

HIQA's current remit is limited to assessing compliance of health information standards within the HSE and does not assess services provided by private health and social care providers.

Health Service Executive

The HSE's Office of the Chief Information Officer (OCIO) develops technical specifications for health information and has progressed this through their business function — the Enterprise Architecture and Design Authority*.* However, unlike HIQA, it does not have a legal remit for mandating national standards.

To date, some of the key initiatives in the area of health information standards from the Enterprise Architecture and Design Authority include the development of a Standards Catalogue and the establishment of the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) National Release Centre.(80)

The Standards Catalogue outlines the technical, data exchange and security standards needed to support the secure interoperable exchange of health information across HSE health information systems. The catalogue provides a practical, clear guide outlining the most suitable standards that HSE health information systems should use which follow European and international trends. The catalogue provides an overview of each standard, a brief description of the Standards Development Organisation (SDO), and a formal procedure and associated policies to support the use and maintenance of the document.

Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is a global terminology for use in clinical information systems.(81) It was developed to improve the quality of clinical data in patient records in order to help improve the overall quality of care received by patients. Following recommendations from HIQA, the Irish Government adopted SNOMED CT as a national terminology standard and became a member of SNOMED International (2016). The SNOMED CT National Release Centre of Ireland was established to meet Ireland's responsibilities to administer the national license for SNOMED CT, as outlined by SNOMED International. The National Release Centre has developed an Irish Edition of SNOMED CT, based on input from national stakeholder organisations and in line with guidance from SNOMED International. The National Release Centre currently operates within the HSE's Enterprise Architecture and Design Authority and was originally established within this function to meet a local business requirement – that is, to satisfy requirements of a national eHealth programme the (National Laboratory Information Management System programme).

However, there is an absence of a strategic road map in relation to terminologies and classification overall in Ireland as SNOMED CT operates in the HSE, while the ICD-10 AU classification[7] is the responsibility of the National Healthcare Pricing Office. Although there is a governance structure and a strategy for the SNOMED CT terminology, there is a need for a national policy for the implementation of both terminologies and classification cohesively and this needs to be adequately resourced. Indeed, there needs to be a national interoperability strategy that

---

[7] Australian edition of ICD-10 known as **ICD-10-AU** is well established in Ireland through HIPE reporting.

incorporates all national health information standards that is governed by a single organisation.

National Standards Authority of Ireland

The National Standards Authority of Ireland (NSAI) is Ireland's official standards body, operating under the National Standards Authority of Ireland Act (1996) representing Irish interests in the work of European and international standards bodies — European Committee for Standardization (CEN) and International Standards Organisation (ISO) — and for the publication and sale of Irish standards. It collaborates with International ISO and CEN, participating in the work of ISO Technical Committee 215 and CEN Technical Committee 251 for Health Informatics. At a national level, National Standards Authority of Ireland (NSAI) hosts a Health Informatics Standards Consultative Committee (HISC) with members from the healthcare industry, academics, regulators, government, healthcare providers, clinicians, IT experts and healthcare software developers covering topics such as architecture, nursing and health terminology, network management, interoperability, security and safety and pharmacy medical device software. HIQA and the HSE are represented on the HISC. The purpose of the committee is to disseminate standards developed by ISO and CEN and to include a national response when standards are progressing through the approval phase of the development process. Standards developed by the National Standards Authority of Ireland are optional and not mandated for use in Ireland.

2.5.1 Conclusion and recommendation

Internationally, countries that have a single organisation responsible for the development of health information standards include NHS Digital England, Digital Health Australia and the Ministry of Health in New Zealand.

In Ireland, the development and implementation of national standards is fragmented and uncoordinated with no overarching governance arrangements to oversee their development, deployment, certification, testing and compliance. As outlined above, multiple entities with different roles and some overlap of standards exists. Three separate entities develop national health information standards: HIQA has a legal remit under the Health Act 2007 to develop national standards, the HSE through its procurement process develops technical specifications, and the NSAI has a remit to develop standards, including those on health information. Historically, the area of standards development for health information has been under-resourced and there is a real need for highly skilled resources to be assigned and upskilled in this complex area. There is a lack of policy and strategic direction regarding standards development evidenced by the lack of a process to approve national standards and recommendations developed by HIQA.

National standards for health information have been developed but there are significant gaps in the types of standards required. In addition, there is no supporting legislation or regulations in place that require adoption of nationally developed standards. Finally, assessing compliance with standards or certification of health information systems has not been undertaken at a significant level nationally.

Therefore, HIQA recommends that:

Recommendation 5: Standards and Interoperability

- A clear policy decision needs to be made on where the Health Information Standards function will reside.
- A health information standards setting function, and the function for assessing compliance with health information standards needs to be supported through legislation and resourcing and should include both the public and private health and social care sector, including public sector services outside of the HSE.

2.6 Health Information Infrastructure and Security

To realise the full benefits of a national health information system, a shared infrastructure[8] and common approach for the exchange of health information across the health and social care service needs to be implemented. The objective of a large-scale health information infrastructure is to unify the health information collected and maintained by many disparate individual organisations. The ability to exchange patient information across multiple organisations, both public and private, has the potential to improve data quality, reduce cost, and increase patient satisfaction and ensures the delivery of care is more coordinated and efficient.(82)

Widespread efforts to develop the policy and technical infrastructure required for health information exchange have been undertaken by many countries internationally.(83) The National Health Service (NHS) in England acts as a national, single-payer[9] health system with highly centralised governance and management structure which allows for the adoption of a highly centralised approach to

---

[8] The components of IT infrastructure are made up of interdependent elements, and the two core groups of components are hardware and software. Hardware uses software — like an operating system — to work. And likewise, an operating system manages system resources and hardware. Operating systems also make connections between software applications and physical resources using networking components.

[9] Single-payer healthcare is a type of universal healthcare in which the costs of essential healthcare for all residents are covered by a single public system. Single-payer systems may contract for healthcare services from private organizations or may own and employ healthcare resources and personnel.

architecture, standards compliance, and procurement process. The NHS in England has developed a connectivity framework, which includes the NHS Spine — a core backbone IT infrastructure — and includes a set of services such as:

- The personal demographic service
- The 'GP2GP' which is a standard based record transfer service that enables general practitioners to transfer records from one practice to another
- Summary care record
- Electronic prescribing service
- Electronic Referral Service
- Picture archiving and communication service and the
- Secondary uses service which is a repository for healthcare data in England which enables a range of population health initiatives that include payment, public health planning and policy development.

Recent developments include enabling the sharing of child protection information via the Child Protection Information System, and developing ways to allow easier access to demographic data through the Spine Mini Service. The Health and Social Care Network (HSCN) facilitates connectivity between the NHS, local authorities and social care providers and uses modern industry standards including cloud computing and provides access to digital services resident on the private NHS network formerly known as N3. The connectivity framework also has a Registration Authority – a system for registering clinical and administrative users of NHS IT systems and issuing Smart Cards with role-based access controls and NHS Mail, a secure encrypted mail service.

In Scotland, existing infrastructure consists of repositories for medical images (PACS), laboratory results and scanned documents (SCI-Store), three regional portals enabling clinicians to view their patients' health and care records, and a national system for exchanging electronic clinical information such as referral letters and discharge documents between primary and secondary care (SCI-Gateway). Successful health information exchange and record linkage across different parts of the service depend on the use of a unique patient identifier known as the Community Health Index (CHI) number, which is associated with a central population register. Delivery of a new cloud-based National Digital Platform (NDS) is a key objective within Scotland's latest eHealth strategy, released in 2018. Based around a central Clinical Data Repository, this aims to provide a single patient-centred health and social care record of core data, available to authorised professionals and citizens themselves, supported by a national citizen identity management system and a NHS staff identity system.

At European level, Ireland is aligned with the EU Directive of Cross Border Exchange of Health Data. The Irish Open National Contact Point (open NCP) infrastructure has been established and Ireland has committed to develop the infrastructure to enable transmitting health data to another member state. In European Commission Test Events (Projectathons), Ireland using the open NCP architecture has proven that it is possible to share patient summary data to the required EU standards to healthcare professionals throughout the EU. The intention is that the architecture can be leveraged by the national patient summary and electronic prescribing programmes, consequently laying down a foundation for the future national electronic health record. The infrastructure is based on Integrating the Health Enterprise (IHE) profiles, an initiative by healthcare professionals and the industry to improve the way computer systems in healthcare services share information. The IHE aims to enable the seamless and secure access to health information that is usable whenever and wherever needed. The IHE promotes the harmonised use of established health information standards and its profiles are used at European and national levels.

The Access to Information Health Identifiers Service (A2I/HIDS) programme is tasked with delivering core functions to support the introduction of national health identifiers in Ireland including the technical infrastructure with appropriate external interfaces to support and maintain the national register (IHI system). The technical infrastructure for the Health Identifier Index is in place and populated with 6.7 million individual health identifiers (IHIs) relating to current and former residents of Ireland. The Access to Information/Health Identifiers Service is also responsible for the national health email service known as Healthmail, which is a secure, private, bounded email service for the exchange of patient identifiable clinical information. COVID-19 Emergency Legislative Provisions recognised Healthmail as a national electronic prescription transfer service, and was used to support the COVID-19 response by providing a secure mechanism for sharing demographic data within the HSE itself and with external organisations, such as long-stay residential facilities. This has been used extensively to support COVID-19 testing for the residents and staff of long-stay residential facilities, such as nursing homes and the sharing of contact data for contact tracing purposes.

In response to COVID-19, the HSE's OCIO suggested improvements to the national health information infrastructure through the:

- migration of key platforms to Cloud for resilience and reliability such as the HSE Helpline and HealthMail or HealthLink

- expansion of infrastructure capacity to serve increased digital and clinical demands, for example clinical teleconferencing and
- the provision of significant volumes of hardware and technology in COVID-19 facilities to support models of care.(84)

International literature suggests that countries that have successfully achieved an effective technology infrastructure for sharing health information had effective political leadership regarding the policies and processes necessary for information to move between healthcare providers. HIQA is aware that there are significant challenges to achieving health information exchange as Ireland has limited existing national infrastructure, compounded by the complexity of implementing standards for enabling health information exchange and managing legacy software and entrenched data practices. However, one of the major incentives driving health information exchange initiatives is to enable better data for research, management and policy. Development of a secure network infrastructure is important and this should be shared across public and private healthcare systems. Public investment in these 'building blocks' is warranted and is a key enabler to the applications and services that will be deployed on top of the infrastructure, such as the national electronic health record.

One of the most serious, unprecedented cyberattack was committed in the State with a significant ransomware attack on HSE systems on 14 May 2021. The cyberattack focused on accessing and encrypting data stored on the HSE's central servers, impacting all national and local health systems. It had a severe and immediate impact on the health and social care services. The HSE's Corporate Risk Register (CRR) identified cyber security as a risk, outlining the impact that a breach would have on health services and how it would directly impact on patient safety as a result of staff being unable to deliver ICT and specialised medical device dependant services. The risk register shows that considerable work was planned to improve the security of the HSE's networks throughout 2021.(65)

The initial response following the cyberattack focused on containment and damage limitation. The National Cyber Security Agency activated its crisis response plan providing support and assistance to the HSE in responding and recovering from the incident. The HSE locked down its systems, health and social care services lost access to electronic systems and records, and had to revert to paper-based systems. This impacted significantly on services with disruptions and delays and cancellations of patient visits with radiology, diagnostics and patient administration systems the worst affected. As appointments were cancelled or rescheduled across the country, the HSE emphasised 'modern healthcare is so reliant on information technology systems'.(65)

Currently, there are a number of State organisations concerned with various aspects of cyber security. At a national level, there are four different agencies involved in cyber infrastructure including the National Cyber Security Centre, Garda National Cyber Crime Unit, the Defence Forces Communications and Information Services (CIS) Corps and the Defence Force Joint Military Intelligence Directorate (J2) and the National Security Analysis Centre (NSAC), which comes under the Department of the Taoiseach. All four entities report to different Government departments and have different strategies in place.(46)

Internationally, cyber security attacks are happening more frequently with healthcare providers often the target. On Friday 12 May 2017, a global cyberattack, known as WannaCry, affected a wide range of countries and sectors. In the UK, the NHS was impacted by the cyberattack. The NHS responded well to the incident, with no reports of harm to patients or of patient data being compromised or stolen. The Department of Health and Social Care's Data Security Leadership Board commissioned the Chief Information Officer for the health and social care system in England to carry out a review of the WannaCry cyberattack. The review aimed to analyse the lessons learned, assess actions taken and make clear recommendations on what further measures were required to ensure the entire health and social care system can withstand and reduce the risk and impact of any future cyberattack.(85) Some of the areas needing improvement cited in the report included 'improved discipline and accountability around cyber security at senior leadership and Board level, the importance of swift and effective patching of systems when new security updates are released, and historic underinvestment in network security and up-to-date software.'(85) The report made 22 recommendations based on the following themes:

- National Data Guardian data security standards
- Information Governance Toolkit and new Data Protection Security Toolkit
- cyber resilience of social care
- leadership
- business continuity and management of third parties
- capability and resources
- training and development
- role of NHS Digital in supporting the service before incident
- incident management.

In terms of the response to the incident, the following themes were explored:

- managing communication during an incident
- data collection during the incident
- role of NHS Digital in supporting the service during an incident
- availability of resources to manage incident.

The UK National Data Guardian published 10 data security standards, designed to address basic cyber vulnerabilities. It was suggested in the review that adherence to these standards by the UK health and social care system could have significantly mitigated the impact of the WannaCry attack on the NHS. The NHS endeavoured to embed those standards in the long term.(86)

The incident has clearly emphasised the need for continuous investment and strengthening of the HSE's security infrastructure. Robust business continuity plans should be available in the event of a cyberattack which should be regularly tested, reviewed, updated locally and have oversight at the highest levels of the health and social care system.

As mentioned earlier, the cyberattack on the HSE will likely impact on public confidence 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 IT infrastructure is in place.

The infrastructure to support the Irish health and social care service should be viewed from a wider perspective and consideration given to policy developed for ICT across the whole of the public service. The Office of the Government Chief Information Officer (OGCIO), established in 2013, plays a leadership role in accelerating digital Government service delivery and innovation including through the development and application of a range of ICT policies. The OGCIO has a broad remit which includes leading on the Public Service Data Strategy 2019-2023(1) which sets out a 'vision with a set of goals and actions to deliver a more joined-up whole-of-Government approach to how data is used and managed within the public service' to work towards improving how data is governed, managed and re-used in a secure, efficient and transparent manner, for the benefit of citizens, businesses and policy-makers. The OGCIO have also developed the Data Sharing and Governance Act 2019, the, the eGovernment Strategy 2017-2020, the GovTech 2019 actions, and the Public Service ICT Strategy. The latter seeks to deliver better outcomes and efficiency through innovation and excellence in ICT across the public service, and encompasses five pillars of build to share, digital first, data as an enabler, improve governance and increase capability.

Telemedicine

With the onset of COVID-19, there was an urgent need to provide services between patients and clinicians remotely as a safe alternative to face-to-face consultations. Given how patients have engaged with the health and social care system and how some services were delivered remotely during the pandemic, the adoption of telemedicine[10] was accelerated. The National COVID-19 Telehealth Steering Committee provision for telehealth solutions to help manage both routine and COVID-19 related consultations in hospitals and in the community (87) A web-based platform called 'Attend Anywhere' is used for virtual clinics including video and audio conferencing, screen sharing and messaging during clinical consultations.(88) It has been well documented globally that telehealth yielded significant benefits during the COVID-19. Routine care continued during the pandemic with the use of telemedicine.

However, to further progress the uptake of telemedicine and to harness its full potential, certain fundamentals are needed - training and development for service providers and greater education on the process for clinicians and patients, acknowledgement that equitable access to telemedicine for cohorts of patients such as older persons may not be viable, appropriate funding, accreditation and robust systems and platforms to manage video consultations.(89) The National COVID-19 Telehealth Steering Committee mandated a Remote Patient Monitoring Working Group to examine international evidence for use of remote patient monitoring solutions, and to develop guiding principles and solution evaluation criteria for their implementation and have developed an 'Operational Governance Guidance for Telehealth Implementation' for both acute and community.

Providing service users with access to their own health information and engaging them as co-designers of their health record can promote better trust in the health and social care system and ultimately can result in better patient outcomes. Mobile Health (mHealth) defined by the Global Observatory for eHealth of the World Health Orgazination defines mHealth as 'medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices'.(90) This includes mobile devices including smartphones and tablets, as well as devices that provide real-time patient monitoring like FitBits and other wearables. The Health Products Regulatory Authority (HPRA) has a regulatory role to monitor the safety of medical devices in Ireland after they are placed on the market. This includes mobile applications (Apps) in healthcare commonly used by healthcare professionals and the general public such as Apps for diagnosing a disease or medical condition. Health Apps can be

---

[10] Telemedicine: the use of technologies to deliver healthcare remotely or at a distance

useful in healthcare as they can be used easily and can quickly perform various activities or provide access to information when needed. The HPRA have published recommendations on selecting and using Healthcare Apps.(91) A commendable example is the 'COVID Tracker App', funded by the Department of Health and deemed a major success during the pandemic given people's trust in the app and the high uptake rate.(92) The delivery of healthcare is changing as evidenced by the acceleration in the adoption of telehealth and the increasing use of health apps. However, frameworks and guidance for use of health apps and medical devices need to be developed.

2.6.1 Conclusion and recommendations

There is some substantial infrastructure in place in Ireland for the collection, use and sharing of health information including the individual health identifier, HL7 messaging broker for transforming and exchanging electronic messaging, Healthmail server for secure email and the infrastructure for European cross-border exchange of health information.

The recent cyberattack on the HSE health information system has had a severe impact on the health services and has emphasised the need for continuous investment and strengthening of our security infrastructure.

Therefore, HIQA recommends that:

Recommendation 6. Health IT Infrastructure and Security

- 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.

3. Conclusion

A robust national health information system in Ireland underpins the provision of efficient and safe health and social care services. However, Ireland's health information system needs to be reformed to ensure that it is strategic, responsive, agile, secure and fit for purpose. We need continued political commitment to deliver a clear national health information strategy, alongside effective governance and leadership, a sound legal framework, a viable workforce and appropriate funding mechanisms, Ministerial approved standards, and a robust and secure health information infrastructure.

HIQA is cognisant of the significant work that all key stakeholders have played over the years to progress the national health information system, and in particular the efforts to respond to COVID-19 and the cyberattack on the HSE. This position paper has highlighted these areas of good practice, including high levels of ICT use in general practice and certain secondary care and tertiary care settings. For example, the national eReferrals programme, national implementation of PACS systems for patient administration, National Information Medical Imaging Systems (NIMIS) and the Healthlink messaging broker that uses standards to exchange messages between primary and secondary care for tasks such as laboratory orders, results and radiology.

However, Ireland still lags behind countries internationally in terms of health information and this report has identified significant gaps. There is a lack of appropriate governance structures, policy and legislation at a national level. HIQA recognise that the implementation of any health information system is extremely complex and challenging. In some instances, there has been significant delays in progressing the deployment and operationalisation of health information systems, such as the individual health identifier and the national laboratory system. There are deficits in the overall national information infrastructure, with no national infrastructure to link public and private entities, such as between acute public hospital and data generated in the private sector, including general practitioners (GPs). The impact of such an underdeveloped, fragmented health information system is the risk it creates to patients' care and safety.

However, many national health IT programmes of work have been progressed in a short time frame – such as the role the individual health identifier (IHI) played in the COVID-19 systems and in the roll-out of the vaccination programme. There is now an opportunity to build on that success.

Based on the evidence and international examples provided in this position paper and given HIQA's experience over the last 12 years in the area of health information, HIQA has made a number of recommendations for reform of the health information system in Ireland. These are as follows:

Recommendations 1: Strategy

- Continued political commitment is required to deliver a clear national health information strategy that addresses key enablers for an effective health information system, including effective governance and leadership, a sound legal framework, a viable workforce and appropriate funding mechanisms, Ministerial approved standards, and a robust and secure health IT infrastructure.
- The existing eHealth strategy is outdated and should be revised to reflect more modern eHealth developments, in line with the ongoing national health information system strategy that is currently in development.
- A national health information strategy should be developed that has achievable, time-bound objectives and is aligned with the Sláintecare 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 primary care and secondary use purposes across both public and private settings.
- A national health information strategy needs to be assigned appropriate funding to ensure that its objectives can be fully achieved.
- Implementation of the strategy should be reported on an annual basis.

Recommendation 2: Strategic Leadership and Governance

- To date, eHealth Ireland has not been established as was originally intended as a separate entity with responsibility for overall governance around eHealth implementation — including funding, legal enabling, public awareness and stakeholder engagement through building the eHealth ecosystem in Ireland. There is a need for a clear policy direction for health information, and clear roadmap on how the different agencies within health and broader governmental organisations are coordinated, to deliver an integrated approach to health information and support the health and social care system in Ireland.

- As set out in the eHealth strategy (2013),a strategic entity (eHealth Ireland) should be established, outside of the HSE, with a legislative remit to provide strategic leadership and governance to support the collection, use and sharing of health information in Ireland. In parallel, an operational function developing and supporting the systems required for the delivery of care should continue to exist in the HSE. The remit of this entity should be broader than eHealth and include the centralised coordination and governance of national data collections and the secondary uses of health information at a national level.
- Roles and responsibilities and accountability for this entity should be clearly defined, including how this entity would 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.

Recommendation 3: Legislation

- For a national health information system to play its full role in enabling a safe healthcare system, a sound legal framework is required. 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.

Recommendation 4: Workforce

- A more strategic approach is required to the allocation of resources in health information to continue 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 including a strategic entity (eHealth Ireland) outside of the HSE and an operational function within the HSE to support the systems required for the delivery of care. 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.

Recommendation 5: Standards and Interoperability

- A clear policy decision needs to be made on where the Health Information Standards function will reside.
- A health information standards setting function, and the function for assessing compliance with health information standards needs to be supported through legislation and resourcing and should include both the public and private health and social care sector, including public sector services outside of the HSE.

Recommendation 6. Health IT Infrastructure and Security

- 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.

Glossary

Continuity of care	Continuity of care can be defined as the extent to which a person experiences an ongoing relationship with a clinical team or member of a clinical team and the coordinated clinical care that progresses smoothly as the patient moves between different health and social care services.
Data	Data are numbers, symbols, words, images, graphics that have yet to be organised or analysed.
Data Dictionary	A descriptive list of names (also called representations or displays), definitions, and attributes of data elements to be collected in an information system or database. The purpose of the data dictionary is to standardise definitions and therefore have consistency in the collection of data.
Data Quality	Data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner.
eHealth	eHealth enables health information to be managed in a coordinated way. The World Health Organization (WHO) defines eHealth as 'the cost-effective and secure use of information and communications technologies in support of health and health-related field, including health care services, health surveillance, health literature, and health education, knowledge and research'.
ePrescribing	ePrescribing can be described as a three-step approach. First, at the time of prescribing medications for a patient, the prescriber's clinical information system generates the prescription in electronic format. Second, the electronic format of the prescription is transmitted to a message exchange or mailbox and, when the patient presents in a pharmacy requesting their medication, the pharmacist retrieves the electronic prescription from the message exchange. Third, the pharmacists dispenses the medication and reports on the medicines given to the patient.
Health information	Health information is defined as information, recorded in any form, which is created or communicated by an organisation or individual relating to the past, present or future, physical or mental health or social care of an individual or group of individuals (also referred to as a cohort). Health information also includes information relating to the management of the health and social care system.
Health information system	Throughout the literature, the term 'health information system' varies, often with no clear or precise definition and has become an umbrella term encompassing a number of systems — both electronic and paper-based — for capturing and transferring health information.

	For the purpose of this paper, a health information system encompasses all health information sources required by a country to plan and implement its national health strategy. Examples of these data sources are electronic health records (EHRs), surveillance data, census data, population surveys, and national health and social care data collections.
Individual health identifier (IHI)	An IHI is an 18 digit number that is used to uniquely and safely identify a patient. An IHI is assigned to the patient for life and is not re-used after the patient's death.
Information	Information is data that have been processed or analysed to produce something useful.
Information and communications technology (ICT)	The tools and resources used to communicate, create, disseminate, store, and manage information electronically.
Information governance	The arrangements that are in place to manage information to support national health and social care data collections' immediate and future regulatory, legal, risk, environmental and operational requirements.
Interoperability	The ability of health information systems to work together within and across organisational boundaries in order to advance the effective delivery of healthcare for individuals and communities.
Key performance indicators (KPI)	Specific and measurable elements of practice that can be used to assess quality and safety of care.
Metadata	Can be defined as 'data to explain data'. Metadata provides summary information in a structured way about the content of a resource such as a report, a book or a dataset.
National electronic health records (EHRs)	A national electronic health record (EHR) is a complete digital record of a patient's journey, throughout their life, across all health and social care settings, for every citizen. An EHR contains the information documented by healthcare professionals when they interact with that patient — for example, the patient's symptom history, past history of illnesses and operations, clinical observations made by the professional such as a blood pressure reading, blood and other test results, X-rays and scan results, prescriptions and other treatments, care advice, the course of the illness, preventive and public health activities such as immunisations, and activities undertaken by patients to stay healthy. An EHR system can support

	healthcare professionals by facilitating, for example, the use of checklists, alerts, and predictive tools, and embedding clinical guidelines, electronic prescribing and the ordering of tests.
National Data Collections	National registries of health information give a collective view of health information to inform health service management and policy development. National health and social care data collections are defined as national repositories of routinely collected health and social care data, including administrative data sources, censuses, surveys, and registries in the Republic of Ireland. Some examples include: ▪ Administrative data collections, for example Primary Care Eligibility & Reimbursement Service. ▪ National routine surveys, for example the National InPatient Experience Survey. ▪ National censuses, for example the Census of Population. ▪ Longitudinal research studies, for example ‘The Irish Longitudinal Study on Ageing (TILDA)’. ▪ Patient registries, for example Cystic Fibrosis Registry of Ireland.
National shared care record	A national shared care record enables healthcare providers in different settings — for example, primary care and hospitals — to view patient records for direct patient care. It brings together information from various systems into a single place for care professionals to use to support the delivery of care.
Patient portals	A patient portal is specially created to allow online access for individuals to their own healthcare information through apps on their smartphone or other devices, or using a website. In many countries, patients use a patient portal to access to their electronic health record, where they can see their latest test results, clinical correspondence, request repeat medications and to request appointments. Some patient portals also enable patients to add their own health information, to maintain their own record of home monitoring for conditions such as diabetes. In another example, the record may provide a parent with the ability to add supplementary entries to an incomplete vaccination record for their child. The clinician reviewing the record can then review these and the original entries to gain a better understanding of the child’s vaccination history.

ePrescribing	ePrescribing is the process of sending medical prescriptions from healthcare professionals. In Ireland, there is a legal requirement in Ireland to produce a paper prescription for patients to present to their pharmacist, but legislation is being drafted to allow for eprescribing.
Secondary use of data	Using clinical data for a different purpose than the one for which it was originally collected.
Terminology standards	Terminology standards ensure semantic interoperability — that is, that healthcare systems understand and use data in the same way, as defined by the terminology standard. They can ensure that higher quality data is recorded during the patient visit and that this high quality data is available for epidemiological research and statistical reporting after the visit. Terminology standards can be divided into two broad categories: clinical terminologies and classifications. ▪ **Clinical terminologies** define the meaning of all terms in a clinical domain clearly and independent of any specific purpose. Clinical coding at the point of care has been shown to significantly improve the overall quality of clinical data. Examples include Systematised Nomenclature of Medicines – Clinical Terms (SNOMED CT) and Logical Observation Identifiers Names and Codes (LOINC). ▪ **Classifications** define a set of 'non-overlapping classes in single hierarchies' according to the classification rules and are more suited to the recording and analysis of secondary use data, such as for epidemiological research or to generate health statistics. They provide the framework to generate administrative, public health and research information from routinely collected clinical data. Examples include the World Health Organization (WHO) International Classification of Disease (ICD) and the International Classification of Primary Care.

References

1. Department of Public Services and Reform. Public Service Data Strategy 2019-2023 2018. Available from: https://www.gov.ie/en/publication/1d6bc7-public-service-data-strategy-2019-2023/. Accessed on: 04/06/2021.

2. Health Information and Quality Authority. *Findings of the National Public Engagement on Health Information*. 2021. Available from: https://www.hiqa.ie/reports-and-publications/health-information/national-public-engagement-health-information. Accessed on: 05/10/2021.

3. Health Information and Quality Authority. Guidance for a data quality framwork 2018. Available from: https://www.hiqa.ie/sites/default/files/2018-10/Guidance-for-a-data-quality-framework.pdf. Accessed on: 10/05/2021.

4. Department of Health. Sláintecare Implementation Strategy and Action Plan 2021-2023 2021. Available from: https://www.gov.ie/en/publication/6996b-slaintecare-implementation-strategy-and-action-plan-2021-2023/. Accessed on: 13/10/2021.

5. eHealth Ireland. The A2i-HIDs team supporting the HSE's fight against Covid 2021. Available from: https://www.ehealthireland.ie/news-media/news-archive/2021/the-a2i-hids-team-supporting-the-hses-fight-against-covid.html. Accessed on: 13/10/2021.

6. Irish Department of Health. eHealth Strategy for Ireland 2013; (28 June 2018). Available from: http://www.ehealthireland.ie/Knowledge-Information-Plan/eHealth-Strategy-for-Ireland.pdf. Accessed on: 13/10/2021.

7. Department of Health and Children. *Health Information A National Strategy*. 2004. Available from: http://www.dohc.ie/publications/pdf/nhis.pdf. Accessed on: 5/19/2011.

8. Committee on the Future of Healthcare. *Slaintecare Report*. 2017. Available from: https://www.gov.ie/en/publication/0d2d60-slaintecare-publications/#the-slaintecare-report. Accessed on: 18/03/2021.

9. Irish Department of Health. *Slaintecare Implementation Strategy*. 2018. Available from: https://www.gov.ie/en/campaigns/slaintecare-implementation-strategy/. Accessed on: 10/05/2021.

10. Health Information and Quality Authority (HIQA). National Standards for Safer Better Healthcare 2012. Available from: https://www.hiqa.ie/system/files/Safer-Better-Healthcare-Standards.pdf. Accessed on: 13/10/2021.

11. S. M. Meystre, C. Lovis, T. Bürkle, G. Tognola, A. Budrionis, C. U. Lehmann. Clinical Data Reuse or Secondary Use: Current Status and Potential Future Progress. *Yearb Med Inform*. 2017; 26(1):[38-52 pp.]. Available from: https://pubmed.ncbi.nlm.nih.gov/28480475. Accessed on: 13/10/2021.

12. Health Service Executive. Knowledge and Information Strategy 2015. Available from: http://www.ehealthireland.ie/Knowledge-Information-Plan/Knowledge-and-Information-Plan.pdf. Accessed on: 13/10/2021.

13. World Health Organisation and OECD. State of Health in the EU Ireland Country Health Profile 2019. Available from: https://www.oecd.org/ireland/ireland-country-health-profile-2019-2393fd0a-en.htm. Accessed on: 14/10/2021.

14. Department of Health. HEALTH IDENTIFIERS ACT 2014 2014. Available from: http://www.irishstatutebook.ie/eli/2014/act/15/. Accessed on: 01/06/2021.

15. Health Service Executive Ireland *Progress for Electronic Health Record* [Online]. Available from https://www.ehealthireland.ie/Strategic-Programmes/Electronic-Health-Record-EHR-/Progress/. Accessed on: 13/10/2021.

16. Health Information and Quality Authority *Review of information management practices in the HSE Computerised Infectious Disease Reporting (CIDR) system* [Online]. Available from https://www.hiqa.ie/reports-and-publications/health-information/review-information-management-practices-hse. Accessed on: 13/10/2021.

17. Health Information and Quality Authority *Review of information management practices at BreastCheck* [Online]. Available from https://www.hiqa.ie/sites/default/files/2018-03/Review-nformation-management-practices-BreastCheck_March-2018.pdf. Accessed on: 13/10/21.

18. Health Information and Quality Authority *Review of information management practices in the HSE Primary Care Reimbursement Service (PCRS)* [Online]. Available from https://www.hiqa.ie/sites/default/files/2019-03/Review-of-information-management-practices-in-the-hse-Primary-Care-Reimbursement-Service-(PCRS).pdf. Accessed on: 13/10/2021.

19. Health Information and Quality Authority. Recommendations on information management practices within the HSE's National Incident Management System (NIMS) 2021. Available from: https://www.hiqa.ie/hiqa-news-updates/hiqa-publishes-recommendations-information-management-practices-within-hses. Accessed on: 24/08/2021.

20. Health Information and Quality Authority (HIQA) *International review of consent models for the collection, use and sharing of health information* [Online]. Available from https://www.hiqa.ie/sites/default/files/2020-02/International-Review–consent-models-for-health-information.pdf. Accessed on: 21/04/2021.

21. Health Information and Quality Authority. National Public Engagement Survey on Health Information 2020. Available from: https://www.hiqa.ie/reports-and-publications/health-information/national-public-engagement-survey-health-information. Accessed on: 13/10/2021.

22. World Health Organisation *eHealth Governance* [Online]. Available from https://www.who.int/ehealth/governance/en/. Accessed on: 28/05/2021.

23. World Health Organisation. From Innovation to Implemenation eHealth in the WHO European Region 2016. Available from: https://www.euro.who.int/en/publications/abstracts/from-innovation-to-implementation-ehealth-in-the-who-european-region-2016. Accessed on: 01/06/2021.

24. Schmidt S. A. J. Adelborg K. Sundbøll J. Laugesen K. Ehrenstein V. Sørensen H. T. Schmidt M. The Danish health care system and epidemiological research: from health care contacts to database records 2019. Available from: https://www.dovepress.com/the-danish-health-care-system-and-epidemiological-research-from-health-peer-reviewed-fulltext-article-CLEP. Accessed on: 13/10/2021.

25. Australian Digital Health Agency *Australian National Digital Health Strategy 2018-2022* [Online]. Available from https://www.digitalhealth.gov.au/australias-national-digital-health-strategy. Accessed on: 13/10/2021.

26. New Zealand Ministry of Health *Digital Health 2020* [Online]. Available from http://www.health.govt.nz/our-work/ehealth/digital-health-2020. Accessed on: 13/10/2021.

27. Ministry of Health New Zealand. HISO 10083:2020 Interoperability roadmap: Driving the shift to a fully interoperable digital health ecosystem. 2020. Available from: https://www.health.govt.nz/publication/hiso-100832020-interoperability-roadmap. Accessed on:

28. Ireland Department of Health. *Slaintecare Report*. 2017. Available from: https://www.gov.ie/pdf/?file=https://assets.gov.ie/165/270718095030-1134389-Slaintecare-Report-May-2017.pdf#page=1. Accessed on: 10/05/2021.

29. COVID-19 Nursing Homes Expert Panel. Examination of Measures to 2021 2020. Available from: https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/. Accessed on: 13/10/2021.

30. Department of Health. Report of the Public Consultation Process on the Draft Health Information Policy Framework 2018. Available from: https://www.lenus.ie/bitstream/handle/10147/623935/FINAL-HI-Policy-Framework-Consultation-Report-November-2018-PDF.pdf?sequence=1&isAllowed=y. Accessed on: 13/10/21.

31. Australian Government Department of Health. Framework to guide the secondary use of My Health Record system data 2018. Available from: http://www.health.gov.au/internet/main/publishing.nsf/content/F98C37D22E65A79BCA2582820006F1CF/$File/MHR_2nd_Use_Framework_2018_ACC_AW3.pdf. Accessed on: 01/06/2021.

32. Health Service Executive ECHAlliance, eHealth Ireland. Health in the Digital Society Digital Society for Health DHSS Task Force 4- Digital Transformation 2017. Available from: https://www.ehealthireland.ie/news-media/news-archive/2017/task-force-pdf-update.pdf. Accessed on: 16/07/2021.

33. J. S. Weissman, Bailit, M., D'Andrea, G., & Rosenthal, M. B. . The design and application of shared savings programs: Lessons from early adopters. *Health Affairs*. 2012; 31. Accessed on: 13/10/2021.

34. Jacquemard Tim. L&RS Spotlight: eHealth in Ireland – Social and ethical values in Irish policy on eHealth *Oireachtas Library & Research Service*. 2021. Available from: https://data.oireachtas.ie/ie/oireachtas/libraryResearch/2021/2021-03-31_spotlight-ehealth-in-ireland-social-and-ethical-values-in-irish-policy-on-ehealth_en.pdf. Accessed on: 14/07/2021.

35. National Health Service. About NHS Digital 2021. Available from: https://digital.nhs.uk/. Accessed on: 28/05/2021.

36. Canada Institute for Health Information *About CIHI* [Online]. Available from https://www.cihi.ca/en/about-cihi. Accessed on: 13/10/2021.

37. New Zealand Ministry of Health *Collections* [Online]. Available from https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections. Accessed on: 13/10/2021.

38. NHS England *National collections* [Online]. Available from https://www.england.nhs.uk/contact-us/privacy-notice/how-we-use-your-information/our-services/national-collections/. Accessed on: 13/10/2021.

39. Australian Institute of Health and Welfare *Our data collections* [Online]. Available from https://www.aihw.gov.au/about-our-data/our-data-collections. Accessed on: 13/10/2021.

40. Statistics Finland. Health 2021. Available from: https://www.stat.fi/til/ter_en.html. Accessed on: 13/10/21.

41. New Zealand Ministry of Health *Virtual Diabetes Register (VDR)* [Online]. Available from https://www.health.govt.nz/our-work/diseases-and-conditions/diabetes/about-diabetes/virtual-diabetes-register-vdr. Accessed on: 13/10/21.

42. Nordic Council of Ministers. eHealth standardisation in the Nordic countries 2019. Available from: http://norden.diva-portal.org/smash/get/diva2:1340369/FULLTEXT01.pdf. Accessed on: 12/11/2020.

43. eHealth Ontario. EHR Connectivity Strategy 2020. Available from: https://ehealthontario.on.ca/en/it-professionals/ehr-connectivity-strategy. Accessed on: 13/10/2021.

44. eHealth Ireland *About eHealth Ireland* [Online]. Available from https://www.ehealthireland.ie/. Accessed on: 28/05/2021.

45. Department of Health and Children. Health Act 2007 2007. Available from: http://www.oireachtas.ie/documents/bills28/acts/2007/a2307.pdf. Accessed on: 13/10/2021.

46. Independent Irish News. HSE cyber attack reveals how our IT infrastructure is lagging behind 2021. Available from: https://www.whatsoninsouthernireland.com/hse-cyber-attack-reveals-how-our-it-infrastructure-is-lagging-behind/. Accessed on: 04/06/2021.

47. Health Information and Quality Authority. Recommendations for the national, community-based ePrescribing programme in Ireland 2018. Available from: https://www.hiqa.ie/sites/default/files/2018-10/EPrescribing_Recommendations.pdf. Accessed on: 13/10/2021.

48. European Parliament and the Council of the European Union. DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare 2011. Available from: https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:en:PDF. Accessed on: 04/06/2021.

49. *General Data Protection Regulation (GDPR) [online]* [Online]. Available from https://gdpr-info.eu. Accessed on: 13/10/2021.

50. Timelex Milieu *Overview of the national laws on electronic health records in the EU Member States - National Report for United Kingdom (England)* [Online]. Available from https://ec.europa.eu/health/sites/health/files/ehealth/docs/laws_report_recommendations_en.pdf. Accessed on: 28 March 2019.

51. European Commision. Mission-oriented R&I policies: In-depth case studie - Case Study Report e-Estonia 2018. Available from: https://jiip.eu/mop/wp/wp-content/uploads/2018/10/EE_e-Estonia_Castanos.pdf. Accessed on: 01/06/2021.

52. Government of Finland. Secondary use of health and social data 2019. Available from: https://stm.fi/en/secondary-use-of-health-and-social-data. Accessed on: 01/06/2021.

53. Department of Health. DATA PROTECTION ACT 2018 (SECTION 36(2)) (HEALTH RESEARCH) REGULATIONS 2018 2018. Available from: http://www.irishstatutebook.ie/eli/2018/si/314/made/en/pdf. Accessed on: 01/06/2021.

54. Department of Health. S.I. No. 540/2003 - Medicinal Products (Prescription and Control of Supply) Regulations 2003 2003. Available from: http://www.irishstatutebook.ie/eli/2003/si/540/made/en/print. Accessed on: 01/06/2021.

55. Department of Health. S.I. No. 173/2017 - Misuse of Drugs Regulations 2017. 2017. Available from: http://www.irishstatutebook.ie/eli/2017/si/173/made/en/print. Accessed on: 01/06/2021.

56. Medical Council PSI - The Pharmacy Regulator, and Health Service Executive. Guidance for Prescribers and Pharmacists on Legislation Changes to Facilitate the Safe Supply of Medicines during the COVID-19 Pandemic 2020. Available from: https://www.thepsi.ie/Libraries/COVID/Guidance_for_prescribers_and_pharmacists_on_legislation_changes_to_facilitate_the_safe_supply_of_medicines_during_the_COVID-19_pandemic.sflb.ashx. Accessed on: 13/10/2021.

57. Department of Health. S.I. No. 390/1981 - Infectious Diseases Regulations 1981. 1981. Available from: http://www.irishstatutebook.ie/eli/1981/si/390/. Accessed on: 04/06/2021.

58. Department of Health. S.I. No. 19/1991 - The National Cancer Registry Board (Establishment) Order, 1991. 1991. Available from: http://www.irishstatutebook.ie/eli/1991/si/19/made/en/print. Accessed on: 04/06/21.

59. STATISTICS ACT, 1993 1993. Available from: http://www.irishstatutebook.ie/eli/1993/act/21/enacted/en/html. Accessed on: 04/06/2021.

60. Department of Health. Amendments to Health Research Regulations 2021. Available from: https://www.gov.ie/en/publication/b46c2-amendments-to-health-research-regulations/. Accessed on: 04/06/21.

61. Department of Health. REVISED GENERAL SCHEME OF THE HEALTH INFORMATION AND PATIENT SAFETY BILL 2017. Available from: https://assets.gov.ie/11441/ce1d167063254135a89e72aa7a96c728.pdf. Accessed on: 04/06/2021.

62. Department of Health. Patient Safety (Notifiable Patient Safety Incidents) Bill 2019 2019. Available from: https://www.oireachtas.ie/en/bills/bill/2019/100/. Accessed on: 04/06/2021.

63. Health Service Executive Office of the Chief Information Officer. National Electronic Health Record Strategic Business Case Version 1.0 2016. Available from: https://www.ehealthireland.ie/strategic-programmes/electronic-health-record-ehr-/progress/national-business-case.pdf. Accessed on: 04/06/2021.

64. Health Service Executive. National Service Plan 2021

2021. Available from: https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2021.pdf. Accessed on: 04/06/2021.

65. The Irish Times. HSE knew the cyberattack risks but couldn't get ahead of the hackers 2021. Available from: https://www.irishtimes.com/news/ireland/irish-news/hse-knew-the-cyberattack-risks-but-couldn-t-get-ahead-of-the-hackers-1.4571803. Accessed on: 13/10/2021.

66. Raidió Teilifís Éireann. Committee hears Ireland should spend '10 times more' on cyber security 2021. Available from: https://www.rte.ie/news/2021/0525/1223759-hse-cyber-attack/. Accessed on: 04/06/2021.

67. The independent. Paul Reid appeared before an Oireachtas committee 2021. Available from: https://www.independent.ie/breaking-news/irish-news/cost-of-hse-cyber-attack-could-rise-to-half-a-billion-euro-40572038.html Accessed on: 13/10/2021.

68. COMMITTEE ON DIGITAL SKILLS FOR HEALTH PROFESSIONALS EUROPEAN HEALTH PARLIAMENT. DIGITAL SKILLS FOR HEALTH PROFESSIONALS 2016. Available from: https://www.healthparliament.eu/wp-content/uploads/2017/09/Digital-skills-for-health-professionals.pdf. Accessed on: 14/09/21.

69. MedCom. About MedCom 2020. Available from: https://www.medcom.dk/medcom-in-english/about-medcom. Accessed on: 12/11/2020.

70. sundhed.dk. Background - sundhed.dk 2016; (20 Dec 2017). Available from: https://www.sundhed.dk/borger/service/om-sundheddk/ehealth-in-denmark/background/. Accessed on: 13/10/2021.

71. MedCom. Shared Medication Record 2019. Available from: https://www.medcom.dk/medcom-in-english/national-activities/shared-medication-record. Accessed on: 04/06/2021.

72. Olejaz M Juul A Rudkjøbing Aet al. Denmark: Health system review: health systems in transition. WHO, on behalf of the European Observatory for Health Systems and policies 2012. Available from: https://www.euro.who.int/__data/assets/pdf_file/0004/160519/e96442.pdf. Accessed on: 04/06/2021.

73. Gartner. Case Study: Denmark's Achievements With Healthcare Information Exchange 2006. Available from: https://www.eric.org/forms/uploadFiles/9e4500000022.filename.10_-_Denmark_Gartner_-_Case_Study_HIE.pdf. Accessed on: 04/06/2021.

74. NHS Digital *About NHS Digital* [Online]. Available from https://digital.nhs.uk/about-nhs-digital. Accessed on: 13/10/2021.

75. NHS Digital *Electronic Prescription Service National Statistics* [Online]. Available from https://app.powerbi.com/view?r=eyJrIjoiZmRlZjY3MWItZDk2My00NTIxLWE5NmUtZDhiN2NjMDY2NjQ0IiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMiIsImMiOjh9. Accessed on: 24 January 2018.

76. Snomed International *SNOMED CT: The Global Language of Healthcare* [Online]. Available from http://www.snomed.org/snomed-ct. Accessed on: Apr 6th, 2017.

77. Health Information and Quality Authority *National Standard on Information Requirements for a National Electronic Patient Summary* [Online]. Available from https://www.hiqa.ie/reports-and-publications/health-information/national-standard-national-electronic-patient-summary. Accessed on: 29 January 2019.

78. Health Information and Quality Authority. National Standard on Information Requirements for National, Community-based ePrescribing 2018. Available from: https://www.hiqa.ie/sites/default/files/2018-12/information-requirements-for-national-community-bas....pdf. Accessed on: 13/10/2021.

79. Health Information and Quality Authority. General Practice Messaging Specification Version 4.0 2017. Available from:

https://www.hiqa.ie/sites/default/files/2017-10/General-Practice-Messaging-Guidance-version-4.0.pdf. Accessed on: 13/10/2021.

80. SNOMED CT National Release Centre of Ireland. SNOMED Clinical Terms National Release Centre of Ireland Governance Group Strategy for 2018 2018. Available from: https://www.ehealthireland.ie/our-team/enterprise-architecture/snomed-ct-/snomed-national-release-centre-of-ireland-strategy-published.pdf. Accessed on: 13/10/2021.

81. SNOMED International *What is SNOMED CT?* [Online]. Available from http://www.snomed.org/snomed-ct/what-is-snomed-ct. Accessed on: Apr 7th, 2017.

82. Pan E Walker J, Johnston D, Adler-Milstein J, Bates DW, Middleton B. . The value of health care information exchange and interoperability. 2005. Available from: https://pubmed.ncbi.nlm.nih.gov/15659453/. Accessed on: 04/06/2021.

83. Zafar A Dixon B, Overhage J. A Framework for evaluating the costs, effort, and value of nationwide health information exchange. *Journal of the American Medical Informatics Association : JAMIA*. 2010; 17(3):[295-301 pp.]. Available from: https://pubmed.ncbi.nlm.nih.gov/20442147/. Accessed on: 04/06/2021.

84. Health Service Executive OCIO. OoCIO Response to Covid 2020. Available from: https://hsedigitaltransformation.ie/sites/default/files/presentations/daf-07-2020/3.summer_daf_2020-f_thompson_presenation.pdf. Accessed on: 09/08/2021.

85. NHS England. Lessons learned review of the WannaCry Ransomware Cyber Attack 2018. Available from: https://www.england.nhs.uk/wp-content/uploads/2018/02/lessons-learned-review-wannacry-ransomware-cyber-attack-cio-review.pdf. Accessed on: 04/06/21.

86. National Data Guardian for Health and Care. Review of Data Security, Consent and Opt-Outs 2016. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF. Accessed on: 04/06/2021.

87. HSE *Virtual Health* [Online]. Available from https://healthservice.hse.ie/staff/coronavirus/working-from-home/virtual-health/virtual-health.html. Accessed on: 14/06/2021.

88. eHealth Ireland *Attend Anywhere* [Online]. Available from https://www.ehealthireland.ie/national-virtual-health-team/attend-anywhere/. Accessed on: 14/06/2021.

89. Anthony C. Smith, Emma Thomas, Centaine L. Snoswell, Helen Haydon, Ateev Mehrotra, Jane Clemensen, et al. Telehealth for global emergencies: Implications for coronavirus disease 2019 (COVID-19). *Journal of Telemedicine and Telecare*. 2020; 26(5):[309-13 pp.]. Available from: https://doi.org/10.1177/1357633X20916567. Accessed on: 2021/06/14.

90. World Health Organization. mHealth: new horizons for health through mobile technologies. 2011. Available from: https://apps.who.int/iris/handle/10665/44607. Accessed on: 13/10/2021.

91. Health Products Regulatory Authority *Medical Devices* [Online]. Available from https://www.hpra.ie/homepage/medical-devices. Accessed on: 14/09/2021.

92. I. R. O'Keeffe K. Rekanar, S. Buckley, M. Abbas, S. Beecham, M. Chochlov, et al. Sentiment analysis of user feedback on the HSE's Covid-19 contact tracing app. *Irish journal of medical science*. 2021; 1-10 pp. Accessed on: 13/10/2021.

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

For further information please contact:

HIQA
George's Court
George's Lane
Smithfield
Dublin 7
D07 E98Y

Phone: +353 (0)1 814 7400
Email: info@hiqa.ie
URL: www.hiqa.ie