



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Recommendations for a more integrated approach to National Health and Social Care Data Collections in Ireland

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Safer Better Care

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About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive high quality and safe care for people using our health and social care services. HIQA's role is to promote sustainable improvements, safeguard people using health and social care services, support informed decisions on how services are delivered, and promote person-centred care for the benefit of the public.

The Authority's mandate to date extends across the quality and safety of the public, private (within its social care function) and voluntary sectors. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, the Health Information and Quality Authority has statutory responsibility for:

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for those health and social care services in Ireland that by law are required to be regulated by the Authority.
- **Supporting Improvement** – Supporting health and social care services to implement standards by providing education in quality improvement tools and methodologies.
- **Social Services Inspectorate** – Registering and inspecting residential centres for dependent people and inspecting children detention schools, foster care services and child protection services.
- **Monitoring Healthcare Quality and Safety** – Monitoring the quality and safety of health and personal social care services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment** – Ensuring the best outcome for people who use our health services and best use of resources by evaluating the clinical and cost effectiveness of drugs, equipment, diagnostic techniques and health promotion activities.
- **Health Information** – Advising on the efficient and secure collection and sharing of health information, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

Overview of Health Information function

Health is information-intensive, generating huge volumes of data every day. Health and social care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is therefore imperative that information is managed in the most effective way possible in order to ensure a high quality, safe service.

Safe, reliable healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests – if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has a key role to play in healthcare planning decisions – where to locate a new service, whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under section (8)(1)(k) of the Health Act 2007, the Health Information and Quality Authority (the Authority or HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), the Authority is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented with major gaps and silos of information which prevent the safe, effective, transfer of information. This results in service users being asked to provide the same information on multiple occasions.

Information can be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions.

Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, clear and trustworthy information on which to base our decisions. As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice.

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements. In accordance with the Health Act 2007, (sections 8(1)(j) and 8(2)(d)), one of the key functions of the Authority is to provide advice to the Minister for Health and the HSE about deficiencies identified regarding health information. It is on this basis that the Authority is undertaking this project. This report outlines potential approaches to greater integration of national health and social care data collections with the aim of driving improvements in the quality and safety of health and social care in Ireland.

Summary of Recommendations for the Minister for Health

The purpose of this report is to provide recommendations to the Minister for a more integrated approach to National Health and Social Care Data Collections in Ireland. The implementation of these recommendations should reduce fragmentation and duplication and ensure a more consistent approach to improving the quality of data collected. Improvements in data quality will lead to increased confidence in the data, and therefore improved use. Quality information will lead to improvements in the delivery of safe care, decision making, monitoring and planning. This will also lead to an increase in the secondary use of information, for example research, within the parameters of data protection legislation. Adopting a more coordinated and strategic approach will result in better use of resources and increased efficiencies.

National health and social care data collections are defined as national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys, and national patient registries in the Republic of Ireland.⁽¹⁾ They provide a national overview of data relating to a particular health or social care service. Examples include the National Cancer Registry of Ireland which collects comprehensive information on cancer incidence and deaths in Ireland and the Hospital In-patient Enquiry Scheme (HIPE) which collects demographic, clinical and administrative data on discharges and deaths from acute hospitals nationally.

Based on international best practice, four key principles relating to health information have been identified, which are based on maximising health gain for the individual and the population, namely:

Health information principles

- Information is used to deliver and monitor safe and high quality care for everyone.
- Information should be of the highest quality and where appropriate, collected as close as possible to the point of care.
- Information should be collected once and used many times to deliver better outcomes for the public.
- Data collections should be 'fit for purpose' and cost-effective.

The current landscape of health and social care data collection in Ireland does not support adherence to these principles.

The Health Information and Quality Authority (the Authority) recognises the important role played by national health and social care data collections and the potential of these collections to greatly contribute to improving the quality and safety of health and social care. However, a number of barriers to improved effectiveness and efficiency of the national collections have been identified, as

documented in this report. Based on the challenges identified and the review of international evidence, the Authority has identified a set of recommendations for a more integrated approach to national collections.

The principal recommendation arising from this report is that a strategic framework, including a detailed roadmap, needs to be developed to inform policy development and lead to greater integration of our national health and social care data collections. Implementation of such a roadmap will take many years, but as other countries have found, will result in reduced fragmentation and duplication, therefore reduced costs and better value for money.

The following section sets out the Authority's recommendations to the Minister for Health based on the evidence documented in this report. A number of elements support each high level recommendation to provide more detail.

Recommendation 1

The development of a strategic framework for national health and social care data collections in Ireland should be prioritised, setting out a roadmap and informing policy development for these collections.

- A detailed roadmap should document the current health information landscape and identify where deficiencies and areas of duplication exist, clearly establishing how existing data collections fit into the framework in order to lead to greater integration.
- A national steering committee involving all relevant stakeholders should be established to develop this roadmap and oversee its implementation.

Recommendation 2

Oversight for all national health and social care data collections should be assigned to a specific organisation at a national level.

- A decision should be taken to determine the most appropriate agency or organisation to provide oversight for all national health and social care data collections and the most appropriate means to achieve this.

Recommendation 3

National health and social care data collections should be included in national information and ICT strategies, and also in the implementation of key ICT projects.

- The secondary use of information for national purposes should be considered when major national ICT projects are being planned and consideration of current and potential national data collections should be included in ICT strategies and plans
- The legislation underpinning the identifier for the individual, professional and the organisation is a major enabler for national data collections. Therefore national data collections need to be included at the planning phase of this major project.

Recommendation 4

All national health and social care data collections should comply with legislative¹ and regulatory requirements, such as national health information standards.

- Compliance with these requirements should be monitored and all national collections should be supported to achieve compliance.

Recommendation 5

The organisation responsible for the oversight of national data collections should develop a data quality framework to drive improvements in the data quality of all national data collections.

- All national collections should be required to demonstrate a commitment to assessing and improving the quality of the data they collect.
- A national health data dictionary should be developed and maintained in order to ensure standard data definitions and therefore data comparability between national data collections.

¹ This includes legislation such as the Freedom of Information Acts and the Data Protection Acts.

Recommendation 6

The use of, and access to, information from national data collections should be optimised to deliver better outcomes for the public, while protecting the privacy and confidentiality of personal data.

- The organisation responsible for the oversight of national data collections should develop a national health information portal as a central repository of national health information.
- There should be a requirement that all eHealth initiatives give consideration to the secondary use of information to maximise health gain.
- Where possible, data should be captured accurately once, near the point of care, and then used for both primary and secondary purposes, such as research, within the appropriate safeguards.

1. Introduction

1.1 Overview

Definition

National health and social care data collections are defined as national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys, and national patient registries in the Republic of Ireland.

National data collections range in size from large national data repositories, such as the National Cancer Registry Ireland (NCRI) and the National Intellectual Disability Database (NIDD), to smaller patient registries such as the Alpha-1 patient registry, (which compiles detailed information on patients in Ireland with the genetic disorder *Alpha-1 antitrypsin deficiency*, that can cause lung and liver disease).

The most recent *Catalogue of National Health and Social Care Data Collections*⁽²⁾ (March 2014) identifies 108 national collections of health and social care data in Ireland. Examples of national health and social care data collections are outlined in Table 1.

Table 1: Examples of national health and social care data collections in Ireland

National Health and Social Care Data Collection	Description
National Cancer Registry of Ireland (NCRI)	Maintains a national registry of cancer incidence and cancer deaths in Ireland.
Cervical Check	A population register containing demographic and clinical data of eligible women for the purposes of screening.
Cystic Fibrosis Registry of Ireland	Contains electronic medical records for patients with cystic fibrosis in Ireland.
National Perinatal Reporting System (NPRS)	Collects data on all live births and stillbirths occurring in Ireland.
Primary Care Reimbursement Service	Collects claims data for all payments for publicly funded healthcare services provided by GPs, pharmacies, dentists, optometrists and ophthalmologists in Ireland.

The governance structures of these national data collections in Ireland vary greatly. Some have been established on a statutory footing, while others are managed by

external bodies or agencies on behalf of the Health Service Executive (HSE). For example, EUROCAT (a network for the surveillance of congenital anomalies) is run from three different sites in Ireland, which are funded by the HSE and to some extent run by the HSE. However, each site is also subject to the rules and guidelines of the European EUROCAT network. The flow of data within and from national health and social care data collections is outlined in Figure 1 on page 12.

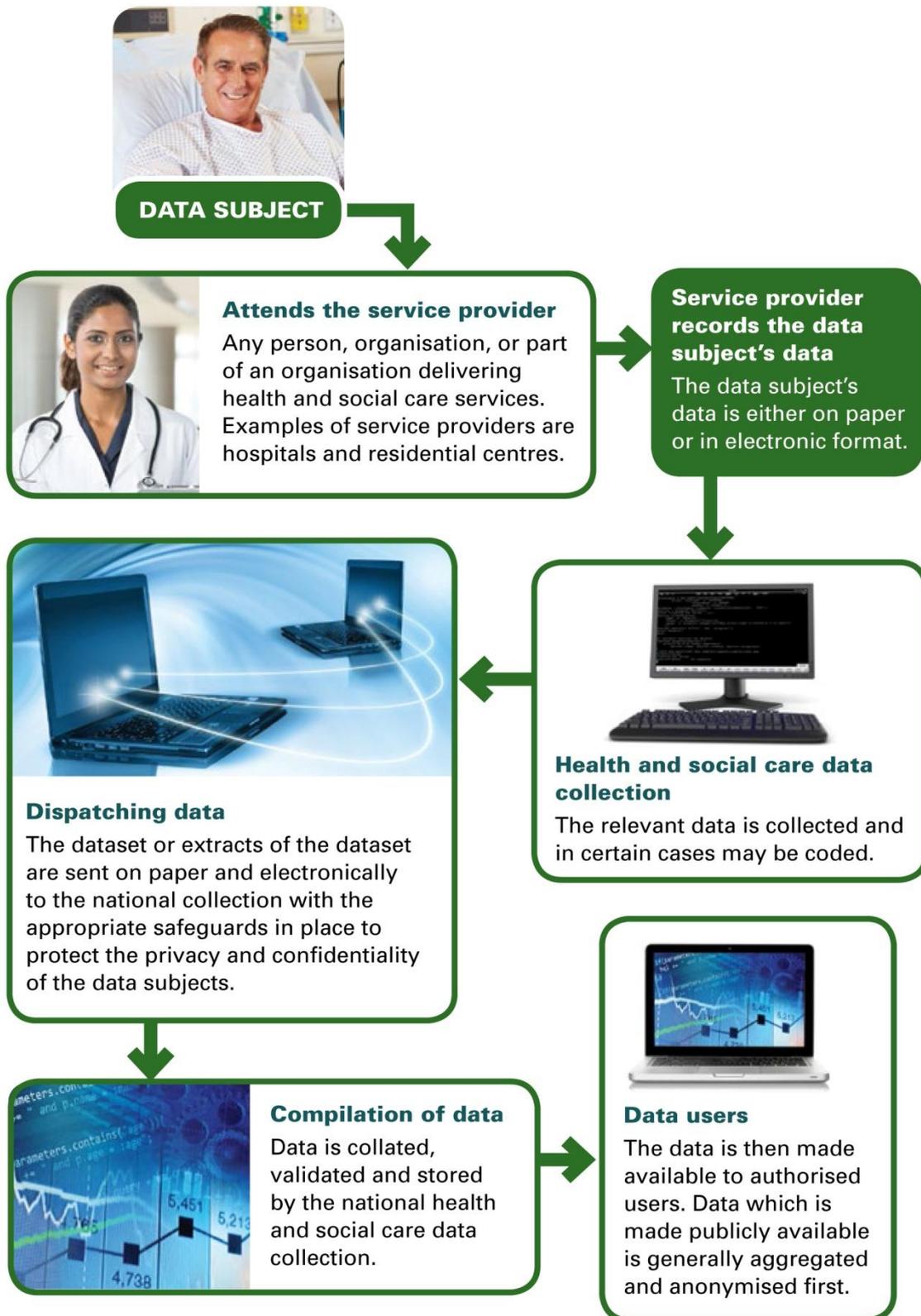
Accurate, relevant and timely data is essential in order to identify and improve care provided, to inform decision-making, monitor diseases, plan services, inform policy making, conduct high quality research, and plan for future health and social care needs, both locally and nationally.

Similar to the international experience, national collections in Ireland have evolved over time in a largely uncoordinated fashion. This led to the development of isolated 'silos' with significant variation in quality, fragmentation, duplication, access problems, and increased costs. This was recognised in the 2004 National Health Information Strategy⁽³⁾ which stated that "the health information landscape is characterised by numerous databases and systems that are essentially isolated and uncoordinated".

In accordance with the Health Act 2007, (sections 8(1)(j) and 8(2)(d)), one of the key functions of the Authority is to provide advice to the Minister for Health and the HSE about deficiencies identified with health information. It is on this basis that the Authority is undertaking this project.

The final output from this project is a set of recommendations to the Minister for Health for a more integrated approach to national health and social care data collections. International evidence suggests that harmonising national data collections leads to improved efficiencies and value for money, as well as improved data quality and usability of information for everyone's benefit.

Figure 1: Flow of data within and from national health and social care data collections



1.2 Background

Based on international best practice, four key principles relating to health information have been identified, which are based on maximising health gain for the individual and the population, namely:

Health information principles

- Information is used to deliver and monitor safe and high quality care for everyone.
- Information should be of the highest quality and where appropriate, collected as close as possible to the point of care.
- Information should be collected once and used many times to deliver better outcomes for the public.
- Data collections should be 'fit for purpose' and cost-effective.

The current landscape of health and social care data collection in Ireland does not support adherence to these principles.

The Authority recognises the important role played by national data collections and the potential to significantly increase the contribution of these collections to improve the quality and safety of health and social care in Ireland. As such, the Authority has undertaken the following projects with the aim of contributing to improvements in the overall effectiveness and efficiency of the national collections:

- *The Catalogue of National Health and Social Care Data Collections in Ireland*^(4;5)
- *An International Review of Health Information Sources*⁽⁶⁾
- *Identification of Themes for Standards for National Health Information Sources in Ireland*⁽⁷⁾
- *Draft Standards for National Health Information Resources*⁽⁸⁾
- *Guiding Principles for National Health and Social Care Data Collections*⁽⁹⁾

These projects have laid the foundation for this current report, recommending a more integrated approach to national collections. *The Guiding Principles for National Health and Social Care Data Collections*², where implemented, will work towards addressing the challenges identified at the level of individual data collections, such as variable data quality. However, it has also emerged from the Authority's work in this area that a number of issues that urgently require improvement are more

² Due to the delay in publication of the Health Information Bill, the Authority developed and published *Guiding Principles*⁽⁹⁾ based on the draft standards.

system-wide challenges, and these cannot be addressed through standards for the collections.

One such issue is the absence of a strategic framework and oversight of the national collections. It is not sufficient to simply address the individual collections; it is also necessary to look at the overall national strategy for health information and to adopt a more coordinated and strategic approach. Such an approach will result in better use of resources and increased efficiencies by reducing duplication, which will, in turn, result in greater value for money. The ultimate benefit will be improved quality and safety of health and social care through better information to support decision making and planning.

Legislative context

Under Section 8 (1) (k) of the Health Act 2007 (ref), the Authority has responsibility for setting standards (for the Executive and services provided by the Executive), for all aspects of health information and monitoring compliance with those standards. In addition, under Section 8 (1) (j) the Authority is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available.

It is anticipated that the forthcoming Health Information Bill will provide for HIQA to set standards for “prescribed health information resources”. It is intended that this legislation will enable these prescribed resources to require another data controller to provide information for the purpose of the effective operation or the prescribed resource. This is to enable 100% coverage for these important resources. It is intended that only a very limited number of resources will be prescribed. A framework is to be established that will allow the Minister for Health to prescribe, in specified circumstances, certain *Health Information Resources* kept by particular data controllers. However there remains a gap for health information resources/national data collections that are not prescribed by the Minister under the Health Information Act and fall outside the remit of the Executive.

1.3 Importance of greater integration for the success of key projects

Integration of national health and social care data collections is extremely important for the success of a number of key government initiatives currently underway.

In December 2013 the Department of Health launched an *eHealth Strategy for Ireland*.⁽¹⁰⁾ The strategy states that eHealth is the means of ensuring that the right health information is provided to the right person at the right place and time in a secure, electronic, accessible and meaningful format, for the purpose of optimising the quality and efficiency of healthcare delivery. One of the benefits of eHealth is in the area of health monitoring and reporting. An effective eHealth system leads to an improved ability to support surveillance and management of public health

interventions, as well as an improved ability to analyse and report on public health outcomes.

An integrated standards-based approach and interoperability of systems are key features of the eHealth Strategy. A strategic framework and better integration of the national data collections is a key building block that must be in place if the vision in the eHealth strategy is to become a reality. As Ireland begins to implement this strategy, it will be essential to consider not just the primary use of health information for the purposes of delivering care, but also the myriad of rich secondary uses which ultimately lead to better services.

The Department of Health has recently been working towards implementing a number of key initiatives that will dramatically change the health and social care landscape as outlined in *Future Health*⁽¹¹⁾; namely *Money Follows the Patient*⁽¹²⁾ (MFTP) and the introduction of a system of Universal Health Insurance (UHI). Good quality national health information is also vital to the success of the Government's new public policy initiative, *Healthy Ireland*.⁽¹³⁾ The "Research, Data and Innovation Plan" as described in Theme 5 in *Healthy Ireland* will set out a strategic course of action to address generation, synthesis, analysis and transfer of the highest quality and most up-to-date health information and scientific knowledge. Better integration and more seamless operation of the national collections are therefore important building blocks for the success of all these initiatives. A coding classification system has been identified as crucial for MFTP as well as the development of a national medical data dictionary to ensure fair and consistent coding of services across providers.⁽¹²⁾ Information is also one of the key building blocks identified as necessary for the implementation of UHI.⁽¹⁴⁾

A key principle identified from international evidence, and also outlined in the *eHealth Strategy*, is that if possible, information should be collected once, as close as possible to the point of care or service delivery and then re-used for primary and secondary purposes (subject to the appropriate protection of privacy and confidentiality of individuals). However, overall responsibility for the development of information systems to support service delivery in the public system is with the HSE, whereas responsibility for the development of systems to support national data collections lies with many different organisations. This binary approach undermines the principle of 'create once; use many times' leading to further duplication and increased costs.

In summary, a more integrated approach to national collections would contribute to the success of these initiatives. Addressing each of the challenges outlined Section 3 of this report would have a significant impact on these projects. A more integrated approach will mean strategic oversight of the information landscape, standardisation of information that is collected and reported, and crucially, improvements in data quality that will not only have implications for quality and safety but also increase confidence in the ability to make informed, evidence-based decisions. The requirements for the initiatives outlined in this section will also serve to further

improve the national collections, for example, the proposal to develop a national medical data dictionary, standardised datasets and interoperable IT systems. However, these benefits will only be fully realised if there are mechanisms for cooperation between the collections and strong governance arrangements in place to encourage their use and to facilitate their implementation. It should also be considered that even with integration of national data collections in place, the absence of an Individual Health Identifier for health and social care is a major deficiency in the health information landscape.

1.4 Example of data integration currently underway

There are examples where efforts have been made towards integration, one such example is the project currently undertaken by the Health Research Board (HRB). The HRB had previously commissioned a review of its health information data collections which found that all of the five collections³ required significant upgrades and improvement if the quality of the data was to be relied upon. The report also recommended back-end integration to improve efficiency both within the HRB and at the level of local data collection. The HRB outlined that the changes proposed would enable it to continue to meet its current and future reporting obligations, would guarantee the integrity of the data provided in a timely manner and also provide for internal efficiencies.

Each of the five collections, which will become four when the National Intellectual Disability Database and the National Physical and Sensory Disability Database are merged, will move to an online system. The project will be undertaken on a phased basis and it has been decided that the National Drug Treatment Reporting System (NDTRS) will be the first system to undergo the changes. Where possible, the same data elements will be used across all collections and a standard common data dictionary will be developed for use. This will lead to improvements in data quality and also make the data more usable and comparable. The integration process will also have implications for resources within the HRB. While up to now staff have been assigned to one of the five collections and work solely within that specific area, the collections will become more standardised which should allow for staff to work within any of them, as their skills will be more transferrable. This is a core benefit of the project as it will future-proof any loss of staff with such specialised skills.

While there is a significant cost associated with this project, initial estimates provided by the HRB indicate that the costs will have been recouped within five years of the four collections being up and running on the new system.

³ The five health information data collections in the HRB are the National Drug Treatment Reporting System (NDTRS), the National Drug-Related Death Index (NDRDI), the National Psychiatric In-Patient Reporting System (NPIRS), the National Intellectual Disability Database (NIDD), the National Physical and Sensory Disability Database (NPSDD).

2. Summary of international evidence

2.1 Overview and methodology

The challenges associated with national health and social care data collections in Ireland have been previously documented^(7;15-17) and there is widespread awareness of these challenges and the need for them to be addressed. These issues include variable data quality, lack of robust governance arrangements, duplication of effort and information not being used to its full potential. The purpose of this project was not to revisit the challenges that have already been identified but rather to summarise them and outline how they could be addressed. This report provides a summary of the issues and brings together previously published evidence of the challenges and their impact.

An international review was undertaken to document experiences in integrating national collections. The full text of the international review is available at www.hiqa.ie. Other countries have faced similar challenges in respect of their national collections and are addressing these in various ways, all of which involve various degrees of increased integration and harmonisation. The following countries were selected for review on the basis of an initial review of the literature, the availability of evidence and access to relevant personnel to inform the review:

- Canada
- New Zealand
- Australia
- England.

The international review involved both desktop research and semi-structured interviews with key individuals in each of the countries. The focus of the desktop review was to determine the current situation in each of the countries in terms of how their national data collections are managed. The Authority spoke to a number of key professionals from the jurisdictions reviewed and their time and contribution to this project are greatly appreciated. The focus of the discussions with the jurisdictions was to determine their journey to the current structures in place for national data collections, to gain an insight into the challenges encountered and to explore lessons learned from their experience. A list of the agencies that provided information for the international review is provided in Appendix 3.

The Authority developed a series of recommendations aimed at addressing the challenges identified in the Irish system based on the approaches that have been taken to integrate national health and social care data collections internationally.

2.2 Summary of international evidence

Ireland has much to learn from the experience of other countries in the area of national data collections. These lessons particularly relate to the benefits arising from their approaches, the innovative solutions and initiatives employed and their journey to this point, as they worked to overcome the often universal challenges faced in integrating national data collections. The majority of the jurisdictions reviewed began harmonising their data sources using a variety of roadmaps, strategies and legislative means to bring together the diverse range of data collected. This has not been a short-term process, progress has been incremental. For example, in Canada, in the twenty years since its establishment, the Canadian Institute of Health Information (CIHI) has led six roadmaps and initiatives and has increased the number of national data collections it houses from three to twenty-eight.

While the health systems in the jurisdictions reviewed vary considerably and the approaches taken also differ, a common thread has been the recognition of the importance of improving the usability and potential of national data collections. In the four countries reviewed, responsibility for the governance and management of the majority of national health and social care data collections is assigned to one or more specific agency or organisation. There is a focus on only collecting the information that is needed and there is an evident movement towards health systems where data is captured accurately once, near the point of care, and then used for both primary and secondary purposes. Feedback from the jurisdictions outlined that constant engagement and achieving consensus with data providers was critical.

It is important to highlight that the countries reviewed began their journeys to integration from a similar starting point to the current situation in Ireland. This was characterised by health information that was of variable quality, duplication and fragmented systems, which contributed to cost inefficiencies and poor value for money.

Key findings from the international evidence

2.2.1 Strategic framework and governance arrangements

- In the four jurisdictions reviewed, 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.
- Current governance arrangements for national data collections in the jurisdictions reviewed are provided for, either through national legislation, national or bilateral agreements, or agreements with district health authorities.

- Organisations that are charged with providing the strategic framework for the governance of national data collections are well placed to drive efforts in data quality and standardisation, vendor licensing and the implementation of eHealth initiatives such as electronic health records.
- Incentives for data providers to engage and work with the key organisations vary across the jurisdictions. In Australia, the health information system is linked to the allocation of funding to the states and territories, providing a clear incentive to comply with the terms of the National Health Information Agreement. In Canada, where entering into a bilateral agreement with the Canadian Institute of Health Information (CIHI) is done on a voluntary basis, the provinces and territories benefit from access to CIHI's products and services.
- Strong governance arrangements can address the challenge of duplication and fragmentation in data collection, contributing to greater cost efficiency. This is especially evident in England where the Health and Social Care Information Centre (HSCIC) has a statutory remit in monitoring the burden of national data collections on clinical and administrative staff. In this regard, the HSCIC is well placed to address the issue of duplication, and has already discontinued a significant number of data collections.

2.2.2 Standardisation and Data quality

- All four jurisdictions enforce or endorse health information standards (including technical standards), conduct activities to improve data quality and employ unique identifiers and electronic records.
- Ensuring data quality is key for the organisations reviewed with efforts in this area including auditing, reporting, producing guidance documents and delivering education.
- The standardisation of data, for example, through the consistent application of classifications and terminologies, contributes to higher quality trustworthy data that is fit for use across interoperable systems. This is key to enabling the integration of data collections and making regional, national and international comparisons.

2.2.3 Use of information

- There is a movement towards increasing transparency and improving the availability of information. Online catalogues and portals are seen across the jurisdictions, providing opportunities for the secondary use of information in accordance with national and local privacy, security and confidentiality arrangements.
- National data collections can create a significant burden on clinical and administrative staff, draining both human and financial resources. Across the countries, there was recognition of the value of collecting information once, as near to the point of care as possible and using it multiple times. Careful

consideration should be given to what data is being collected, why it is being collected and what is the most efficient way to collect the data.

- There was acknowledgement of the need for data to be better used to fulfil its potential and make greater contributions to patient care and health system delivery. All four countries expressed a demonstrable interest in data linkage across collections and the value it presents, with variations in the extent to which they engage. Data linkage is still in its infancy in Canada while in England, the HSCIC routinely links a number of collections. New Zealand has been progressive in this area, filling an information gap by using existing collections to create a virtual register.
- There was a realisation of the importance of considering the requirements for the secondary use of data when developing systems for capturing and managing data for primary use, for example Electronic Medical Record (EMR) systems.

3. Challenges identified in relation to national data collections in Ireland and suggested recommendations

Issues in relation to health information (such as the quality of information, lack of standardisation, lack of integration and information not being used to its potential) have been cited repeatedly in the healthcare investigations undertaken by the Authority, one example being the Galway investigation.⁽¹⁸⁾ Evidence of these challenges is also documented in the recent Chief Medical Officer's (CMO's) report into Portlaoise hospital.⁽¹⁷⁾ Lack of central oversight and limited governance arrangements are key contributing factors to these issues.

The core challenges in relation to national health and social care data collections can be summarised as follows:

- Absence of a strategic framework and national oversight
- Need for standardisation and improved data quality
- The use of information is not being optimised.

Each of these core issues is discussed below in further detail, using current examples in Ireland. The examples included are an attempt to highlight issues across all national collections and the system as a whole, rather than to single out individual collections. Each example used has been previously published in key reports by the Authority or others and was chosen on the basis that it serves to emphasise the particular challenge that is being outlined. Recommendations to address each of these issues are then put forward by the Authority.

3.1 Absence of a strategic framework and national oversight

Similar to the international experience, national collections in Ireland have evolved over time in a largely uncoordinated fashion. This has led to the development of isolated 'silos' with significant variations in quality, fragmentation, duplication, access problems, and increased cost inefficiencies. There are also significant gaps in coverage, notably in primary care, where the majority of healthcare services are delivered.⁽⁷⁾

Historically, there has been no organisation to manage the development of national data collections in Ireland. Given the evolution of the healthcare environment in Ireland, many of the national collections had been in existence long before the creation of the HSE or the Authority.⁽⁷⁾ The purpose and scope of the individual collections varies immensely, as does their evolution. Many were created to meet a specific need, while others were developed by interest groups and agencies. Some national collections are purely administrative, some are clinical or epidemiological, some are still paper based while others are working towards an electronic patient record. It is not always possible to find consistent, clear and trustworthy information on which to base clinical and service planning decisions. Strategic decisions require

information from multiple sources to be brought together, but this information is often spread across multiple diverse and independent data collections and is virtually impossible to integrate. This is further complicated at present with the lack of an Individual Health Identifier (IHI). Ultimately the lack of integrated data leads to important decisions being made based, at best, on incomplete information. Furthermore, the development of registries on such an 'ad hoc' basis means that frequently they are unsustainable, particularly smaller clinical registries.

The absence of a strategic framework is something which has been long recognised as documented in *Quality and Fairness: A Health System for You*⁽¹⁹⁾ in 2001 and in the National Health Information Strategy⁽³⁾ in 2004. The National Health Information Strategy⁽³⁾ referenced an audit of value for money in the Irish health system in 2001.⁽²⁰⁾ Among the reasons identified for the inability to demonstrate value for money were:⁽²⁰⁾

- A highly fragmented approach to implementing information systems and non-standardisation of data within and between agencies militate against benchmarking, the comparability of data, and the sharing of information between various stakeholders and agencies
- A lack of a centrally cohesive and consistent approach contributes to an uneven pace of development of services.

These barriers have proved difficult to overcome in the absence of a strategic framework for national health and social care data collections.

The absence of an organisation to manage or oversee the development of national collections has unquestionably resulted in duplication of effort, for example there are four different agencies involved in the compilation and reporting of perinatal mortality data as documented in section 3.3.2 of this report. Where a need has been identified for the collection of a particular set of information, the traditional response has been to establish a new collection. This generally happens without first undertaking a thorough review to assess if the information is already being collected, or determining if the scope of an existing national collection could perhaps be expanded or altered to meet this need. Such an approach has considerable cost implications, with little attention paid to the optimal use of resources and value for money.

In each of the jurisdictions examined in the international review there are key organisations that govern either all, or the majority of national health and social care data collections. Strong governance and oversight arrangements at a national level would help address the challenge of duplication and fragmentation in data collection, contributing to greater cost efficiency. An oversight organisation would also be well placed to implement the other recommendations in this report, for example to drive improvements in standardisation and data quality and promote the increased use of information to deliver better outcomes for the public.

Absence of a strategic framework and national oversight – Recommendations

Recommendation 1:

The development of a strategic framework for national health and social care data collections in Ireland should be prioritised, setting out a roadmap and informing policy development for these collections.

- A detailed roadmap should document the current health information landscape and identify where deficiencies and areas of duplication exist, clearly establishing how existing data collections fit into the framework in order to lead to greater integration.
- A national steering committee involving all relevant stakeholders should be established to develop this roadmap and oversee its implementation.

Recommendation 2:

Oversight for all national health and social care data collections should be assigned to a specific organisation at a national level.

- A decision should be taken to determine the most appropriate agency or organisation to provide oversight for all national health and social care data collections and the most appropriate means to achieve this.

3.2 Need for standardisation and improved data quality

Lack of standardisation of data and associated issues are well documented, most recently in the Chief Medical Officer's report into Portlaoise.⁽¹⁷⁾ The key problem is that data is not comparable across systems and it is difficult to obtain a complete picture on which to assess quality of services, measure overall improvement and make service planning decisions. There are inconsistencies in terms of the information being collected and reported both at the administrative and clinical levels. A detailed example of the lack of standardisation in the context of perinatal mortality data is provided in section 3.3.2.

The quality of data can be determined through assessment against a number of dimensions which include: accuracy, validity, reliability, timeliness, relevance, legibility and completeness.⁽⁹⁾ Data quality is extremely variable with some organisations employing dedicated data quality staff, some have highly developed

internal audit measures while others have none of either. But even in such cases where the organisation itself makes considerable effort to ensure quality, there can be concerns, particularly in respect of completeness and timeliness. For example, it came to light during the Authority's investigation into the services provided at Mallow General Hospital (MGH)⁽¹⁶⁾ that the HIPE data reported by MGH indicated that there were 36 major bowel cancer surgeries carried out at the hospital during 2009, whereas the theatre register for the same period showed that the actual number was 56.

While generally speaking data is of variable quality, there is evidence of good practice in assessing the quality of data and working towards improvements. In 2012 the NCRI published *Data Quality and Completeness at the Irish National Cancer Registry*.⁽²¹⁾ The report contains details of a review of data quality which examined the comparability, completeness and validity of the data. The NCRI complies with international standards and criteria in the recording of all major data items, and has been consistent in its application of these since registration commenced in 1994. The report states that the results of the review suggest that the completeness, validity and timeliness of the data at the NCRI are of a good standard, although there is some variability between different types of cancer.

3.2.1 Data dictionaries

The absence of a national health data dictionary is a clear deficiency in Ireland, in terms of consistency of reporting and the ability to compare data. However, a number of data collections have developed their own data dictionary which means that they, individually, are consistently collecting the same information – and the definitions of the data being collected are clear to users, reducing the risk of incorrect analyses.

While it is important to note that there is no requirement for the collections to be consistent or to take account of each other's definitions, difficulties do arise, for example, when trying to compare and or integrate the data to inform decision making or research.

The fact that many of the national collections have not published data dictionaries means that it is possible the data is not being collected or recorded consistently as staff are not working to a standard set of agreed definitions. This also limits the usability of the data, for example, for researchers, as the exact meaning of the data may not be clear and is therefore open to misinterpretation.

3.2.2 Perinatal mortality data

While the Chief Medical Officer's report to the Minister for Health on the perinatal deaths in Portlaoise Hospital Maternity Services (PHMS) focuses on the services provided at PHMS, it also points to issues at a national level, highlighting the complexity of perinatal mortality statistics and the fact that reporting on these is

hampered by the lack of consistent definitions nationally and internationally. This results in discrepancies in reported rates of perinatal mortality. The report highlights the weaknesses and inconsistencies in perinatal data collection, collation and reporting, which lead to inaccuracies and inconsistencies in the data reported depending on what source is used. The report states that the current and disparate nature of reporting of perinatal data in Ireland leads to confusion, adds to the workload for maternity units and is an additional strain on current scarce health service resources.⁽¹⁷⁾

The report identified four different agencies involved in the compilation and reporting of perinatal mortality data. The four agencies involved are the General Register Office (GRO), the National Perinatal Reporting System (NPRS), the National Perinatal Epidemiology Centre (NPEC) and the Central Statistics Office (CSO). This results in discrepancies in reported rates of perinatal mortality. These variations are the result of a number of factors, including the agencies from which the numbers are derived. Table 5 taken from the CMO's report demonstrates the variations in reporting.⁽¹⁷⁾

Table 1: National perinatal deaths 2006-2012 by source of data; CMO Report, 2014.⁽¹⁷⁾

	2006	2007	2008	2009	2010	2011	2012
NPRS	493	557	565	572	550	493	458
NPEC	-	-	-	-	-	456	444
GRO and CSO combined⁴	515	560	624	587	574	542	Not available

⁴ Data for GRO refer to stillbirth notifications and data for CSO refer to registered neonatal deaths.

Need for standardisation and improved data quality – Recommendations

Recommendation 3:

National health and social care data collections should be included in national information and ICT strategies, and also in the implementation of key ICT projects.

- The secondary use of information for national purposes should be considered when major national ICT projects are being planned and consideration of current and potential national data collections should be included in ICT strategies and plans
- The legislation underpinning the identifier for the individual, professional and the organisation is a major enabler for national data collections. Therefore national data collections need to be included at the planning phase of this major project.

Recommendation 4:

All national health and social care data collections should comply with legislative⁵ and regulatory requirements, such as national health information standards.

- Compliance with these requirements should be monitored and all national collections should be supported to achieve compliance.

Recommendation 5:

▪ The organisation responsible for the oversight of national data collections should develop a data quality framework to drive improvements in the data quality of all national data collections.

- All national collections should be required to demonstrate a commitment to assessing and improving the quality of the data they collect.
- A national health data dictionary should be developed and maintained in order to ensure standard data definitions and therefore data comparability between national data collections.

⁵ This includes legislation such as the Freedom of Information Acts and the Data Protection Acts.

3.3 The use of information is not being optimised

Each national collection is a rich source of data. This refers not only to routine data collections such as administrative data sources and patient registries but also to national surveys and censuses as the data collected is very valuable and has many potential uses to inform and improve health and social care services. In order to maximise benefits from the data, it needs to be accessible and used. One of the Authority's Guiding Principles⁽⁹⁾ is: *The information produced by the national health and social care data collection is accessible to data users in line with legislation and disseminated to optimise its benefit.* National data collections have an obligation to ensure that the use of their data is optimised to achieve the best value for money, and provide the greatest benefit to users in order to maximise health gain. However, this must be done within the parameters of the Data Protection legislation and in such a way that protects the rights of the people to whom the information relates.

Data needs to be usable or 'fit for purpose'. If data or reports produced on the data are difficult to use, they will be of limited value no matter how accurate, timely or relevant.

As mentioned in section 3.3.1, the absence of data dictionaries leads to information not being used to its full potential as users may misinterpret or use the data inaccurately. Two further issues are accessibility and the use of resources, which are outlined in the sections below.

3.3.1 Accessibility of information

Accessibility of information is a major barrier to the use of information. Plans for a Health Information Portal were outlined in the 2004 health information strategy.⁽³⁾ A key objective of the portal was cited as facilitating access to statistical data and databases to serve the needs of policy analysts, service planners, researchers, epidemiologists and others with health data requirements. Comprehensive and interactive metadata describing data sources and data analysis tools were to form an integral part of this portal.

In the absence of this national development, a number of the collections themselves have developed a portal or remote web-based system whereby information can be accessed, for example, HIPE, the Computerised Infectious Disease Reporting (CIDR) System, and StatCentral and StatBank operated by the Central Statistics Office (CSO), but these are in the minority. While these are important resources, it would be more cost-effective and efficient to have one national health information portal with access to summary statistical health and social care data on a national basis.

In many cases information on how to access or request information held by the national collections is not available to the public. This was recognised in the evaluation of the National Psychiatric In-Patient Reporting System (NPIRS) in 2012

in the form of a recommendation to increase the accessibility of NPIRS data to researchers.⁽²²⁾ It was recognised that the needs of researchers are often very specific and that while all such needs could not be expected to be responded to, that maximising the use of NPIRS for stand-alone and collaborative research should be encouraged. It was proposed that this would be facilitated by the provision of a new online application process for users seeking to access the data.

3.3.2 Administrative burden

The national collections themselves are unable to use the information they collect to its full potential.⁽⁷⁾ This is primarily as a result of the data collection process being very resource-intensive. If the data collection process was more efficient, more time and resources could be spent on analysing and evaluating the data. This is documented in the report on data quality and completeness in the NCRI⁽²¹⁾ and in the evaluation of NPIRS⁽²²⁾, both of which were outlined in section 4.3.

One such example is the review and extraction of data from hospital charts. The Hospital In-Patient Enquiry (HIPE scheme) collects demographic, clinical and administrative data on discharges from, and deaths in, acute public hospitals nationally. Data is taken from medical charts or records and coded by clinical coders before they enter the data into the HIPE system.

While the primary source of data for recording of new cases by the National Cancer Registry is from pathology reports, medical charts are also reviewed by Tumour Registration Officers (TROs) in some cases. Data Registration Officers employed by the National Registry of Deliberate Self Harm Ireland record data on persons presenting to hospital emergency departments as a result of an episode of deliberate self-harm, as defined by the Registry.

These are just three examples of agencies employing staff to collect and record information in hospitals, all reviewing the same medical records and charts in some cases. A further administrative burden for the NCRI is the checking of all registrations against the existing Registry database for duplication at the time of entry. Records can usually be matched on the basis of full name, address date of birth and medical record number. If no previous entry exists for the cancer episode, it is registered and the record added to the database.⁽²¹⁾ While this is a necessary step as it ensures that there are no duplicate entries in the system, it is very resource intensive.

The use of information is not being optimised – Recommendation

Recommendation 6:

The use of and access to information from national data collections should be optimised to deliver better outcomes for the public, while protecting the privacy and confidentiality of personal data.

- The organisation responsible for the oversight of national data collections should develop a national health information portal as a central repository of national health information.
- There should be a requirement that all eHealth initiatives give consideration to the secondary use of information to maximise health gain.
- Where possible, data should be captured accurately once, near the point of care, and then used for both primary and secondary purposes, such as research, within the appropriate safeguards.

4. Conclusion

The Authority recognises the important role played by the national data collections and the potential they hold. Many of the collections are incredibly rich sources of data that have significant potential to contribute to improving quality and safety both for the individual, but also for the population as a whole. However this potential is not being realised due to a number of factors which have been outlined in this report. These factors are primarily issues with data quality, lack of standardisation, duplication of effort and information not being used to its full potential, all of which can be predominantly attributed to a lack of a strategic framework and issues with governance arrangements. Increased cooperation and integration between the national collections in a formalised setting would go a long way towards addressing these issues and ultimately help the collections to realise their potential to collectively contribute to improving the quality and safety of health and social care services in Ireland.

A key principle identified from the international evidence, and also outlined in the *eHealth Strategy*, is that where possible, information should be collected once as close as possible to the point of care or service delivery and then re-used for primary and secondary purposes (subject to the appropriate protection of privacy and confidentiality of individuals). However, overall responsibility for the development of information systems to support service delivery in the public system is the HSE, whereas responsibility for the development of systems to support national data collections lies with many different organisations. This binary approach undermines the principle of 'create once; use many times' leading to further duplication and increased costs.

The principal recommendation arising from this report is that a strategic framework, including a detailed roadmap

The principal recommendation arising from this report is that Ireland should develop a strategic framework, including a detailed roadmap, leading to greater integration of our national health and social care data collections. Implementation of such a roadmap will take many years but as other countries have found, will result in reduced fragmentation and duplication and hence reduced costs and better value for money. It will also drive significant improvements in data quality and coverage, ultimately supporting improved healthcare through better information.

The key principles of this roadmap are as follows:

- It should map out the current health information landscape. This should include identifying where deficiencies and areas of duplication exist.
- It should clearly define the ultimate level of integration to be achieved for national collections and over what timescale.

- It should develop an overall governance framework for the national data collections which sets out how they all fit together.
- It should have clearly defined, realistic and achievable milestones.
- Responsibility for implementation of the actions should be clearly identified.
- Implementation should be underpinned by legislation where appropriate.
- All publicly funded national health and social care data collections, both existing and new, should be part of the roadmap and fit in to the framework.

The implementation of the recommendations proposed to the Minister for Health in this document should reduce fragmentation and duplication and ensure a more consistent approach to improving the quality of data collected. Improvements in data quality will in turn lead to improvements in the delivery of safe care, decision making, monitoring and planning of services as these will all be based on quality information. Increased secondary use of information, within the parameters of data protection legislation, will also be enabled. Adopting a more coordinated and strategic approach will result in better use of resources and increased efficiencies. Ultimately, driving improvements in our national data collections will lead to improvements in the quality and safety of health and social care for all using our services.

Appendix 1: Glossary of abbreviations

Term	Explanation
AIHW	Australian Institute of Health and Welfare
CIHI	Canadian Institute for Health Information
CMO	Chief Medical Officer
CSO	Central Statistics Office
EMR	Electronic Medical Record
ESRI	Economic and Social Research Institute
GP	General Practitioner
GRO	General Register Office
HIPE	Hospital In-Patient Enquiry Scheme
HPO	Healthcare Pricing Office
HRB	Health Research Board
HSE	Health Service Executive
HSCIC	Health and Social Care Information Centre
ICT	Information and Communications Technology
IHI	Individual Healthcare Identifier
IT	Information Technology
MDE	Maternal Death Enquiry
METeOR	Metadata Online Registry
MFTP	Money Follows the Patient
MGH	Mallow General Hospital
MoH	Ministry of Health
MoU	Memorandum of Understanding
NCRI	National Cancer Registry Ireland
NDRDI	National Drug-Related Death Index
NDTRS	National Drug Treatment Reporting System
NHIA	National Health Information Agreement
NHS	National Health Service
NIDD	National Intellectual Disability Database
NPEC	National Perinatal Epidemiology Centre
NPIRS	National Psychiatric Inpatient Reporting System
NPRS	National Perinatal Reporting System
NPSDD	National Physical and Sensory Disability Database
NZ	New Zealand
PHMS	Portlaoise Hospital Maternity Services
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms
TRO	Tumour Registration Officer
UHI	Unique Health Identifier
UHI	Universal Health Insurance
UK	United Kingdom

Appendix 2: Glossary of terms

Term	Description
Audit	The assessment of performance against any standards and criteria (clinical and non-clinical) in a health or social care service. ⁽²³⁾
Benchmarking	A continuous process of measuring and comparing care and services with similar service providers. ⁽²³⁾
Classification	A method of organising/grouping 'concepts' in a systematic way (e.g. into classes) within a particular domain for a specified purpose. They are arranged into categories according to common attributes, qualities or properties. ⁽²⁴⁾
Cost effectiveness	The point at which the minimum amount of input (such as finance, human resources) is used to achieve a defined health outcome. ⁽²³⁾
Data	Data are numbers, symbols, words, images, graphics that have yet to be organised or analysed. ⁽²⁵⁾
Database	A collection of data that is organised so that its contents can easily be accessed, managed, and updated. ⁽⁹⁾
Data catalogue	Can be defined as a comprehensive list of datasets outlined in a systematic fashion. Data catalogues and data inventories are important resources in informing and increasing awareness among stakeholders on the existence, purpose and access to currently available information sources. ⁽⁶⁾
Data collector	A data collector is responsible for collecting and in some instances coding the data for a national health and social care data collection. ⁽⁹⁾
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 standardize definitions and therefore have consistency in the collection of data.' ⁽²⁶⁾
Data quality	Data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner. ⁽²⁷⁾
eHealth	The combined use of electronic communication and information technology in the healthcare sector. ⁽⁶⁾
Evidence	Data and information used to make decisions. Evidence can be derived from research, experiential learning, indicator data and evaluations. ⁽²⁵⁾
General Practitioner (GP)	A doctor who has completed a recognised training programme in general practice and provides personal and continuing care to individuals and to families in the community. ⁽²³⁾
Governance	In healthcare, an integration of corporate and clinical governance; the systems, processes and behaviours by which services lead, direct and control their functions in order to achieve their objectives, including the quality and safety of services for service users.
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. ⁽⁶⁾
Health information resource	"Health information resource means a register, index, database or other collection of records that contains data about more than one individual and is kept by a data controller for one or more than one of the purposes

	referred to in <i>section 55</i> ''(of the draft <i>Health Information Bill 2014</i>). ⁶
Healthcare	Services received by individuals or communities to promote, maintain, monitor or restore health. ⁽²⁵⁾
Information	Information is data that have been processed or analysed to produce something useful. ⁽⁹⁾
Information and communication technology (ICT)	The tools and resources used to communicate, create, disseminate, store, and manage information electronically. ⁽⁹⁾
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. ⁽⁹⁾
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.' ⁽²⁸⁾
Key Performance Indicator (KPI)	Specific and measurable elements of practice that can be used to assess quality and safety of care. ⁽²³⁾
National health and social care data collections	National repositories of routinely collected health and social care data, including administrative sources, censuses, surveys, and national patient registries in the Republic of Ireland. ⁽⁹⁾
Performance Indicators	Specific and measurable elements of practice that are designed to assess key aspects of structures and processes and to assess outcomes. ⁽⁹⁾
Personal health information	Personal information is data relating to an individual who is or can be identified either from the data or from the data in conjunction with other information that is in, or is likely to come into, the possession of the data controller. ⁽²⁹⁾
Primary care	An approach to care that includes a range of services designed to keep people well. These services range from promotion of health and screening for disease, to assessment, diagnosis, treatment and rehabilitation as well as personal social services. ⁽²⁵⁾
Regulation	A sustained and focused control exercised by a public agency over activities that are valued by a community. ⁽²⁵⁾
Risk	The likelihood of an adverse event or outcome. ⁽²⁵⁾
Service level agreement	An agreement between the service provider and third parties identifying the service and the parameters of same that the third party will provide to the service provider. ⁽⁹⁾
Service Provider	Any person, organisation, or part of an organisation delivering health or social care services and contributing data to the national health or social care data collection, for example, a hospital, pharmacy, general practitioner, optician, screening services, residential care for older people, children's residential centres. ⁽⁹⁾
Standard	A statement which describes the high level outcome required to contribute to quality and safety. ⁽²⁵⁾
Value for	Assesses whether or not an organisation has obtained the maximum

⁶ As presented in the Draft *Health Information Bill 2014*

money	benefit from the goods and services it both acquires and provides, within the resources available to it. ⁽³⁰⁾
Workforce	The combination of staff directly employed by the national health or social care data collection, and those who work on its behalf in other organisations. ⁽⁹⁾

Appendix 3: International agencies contacted

Jurisdiction	Organisation	Title
Canada	The Canadian Institute of Health Information (CIHI)	Manager, Corporate Strategy and PMO Strategy Operations
New Zealand	The Ministry of Health, New Zealand	Team Leader, National Collections and Reporting Group, Information Group
Australia	The Australian Institute of Health and Welfare (AIHW)	Head of Business Transformation Unit
		Head of Child Welfare and Prisoner Health
		Health Data Development Manager, METeOR and Metadata Unit
		Unit Head, Metadata and Classification Unit
England	The Health and Social Care Information Centre (HSCIC)	Assistant Director for Strategy and Policy

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