Health
Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Draft Information Management standards for national health and social care data collections

July 2016

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent Authority established to drive high quality and safe care for people using our health and social care and support services in Ireland. HIQA's role is to develop standards, inspect and review health and social care and support services, and support informed decisions on how services are delivered. HIQA's ultimate aim is to safeguard people using services and improve the quality and safety of services across its full range of functions.

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. 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 health and social care and support services in Ireland.
- **Regulation —** Registering and inspecting designated centres.
- **Monitoring Children's Services —** Monitoring and inspecting children's social services.
- **Monitoring Healthcare Quality and Safety —** Monitoring the quality and safety of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment —** Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.
- **Health Information —** Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care and support services.

Overview of the Health Information function of HIQA

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 very important 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 an important 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 (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), HIQA is charged with evaluating the quality of the information available on health and social care and making recommendations in relation to improving its 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 promote 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 people using services being asked to provide the same information on multiple occasions.

In Ireland, information can also 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. HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements.

Contents

Key terms used in this report

Term	Explanation
National health and social care data collection	National repositories of routinely collected health and social care data, including administrative sources, censuses, surveys, and national patient registries in the Republic of Ireland.
Managing organization of the national health and social care data collection	The organisation, agency, the responsible managing unit, institution or group with overall responsibility for the National Health and Social Care Data Collection.
Data Quality Framework	A document which outlines the approaches to systematically assess, document and improve data quality and includes policies, procedures and information relating to data audits.
Data Quality Statement	This highlights key aspects of data quality, including strengths and weaknesses so that potential data users can make informed judgements about fitness for use.
Data subject	An individual who is the subject of personal health or social care data for example, a patient admitted to a hospital or a child receiving the service of a social worker.
Data user	Any user of data or information produced by the national health and social care data collection. The data is used for a number of purposes, including to provide logistical and strategic national planning, improve population health and social care and to develop and inform research. Examples of data users include, Department of Health, academic institutions and the general public.
Data provider	Any person, organisation, or part of an organisation contributing data to the national health or social care data collection, for example, a hospital, general practitioner or laboratory.

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The membership of the Expert Advisory Group is as follows:

Kevin O'Carroll (Chairperson)	Health Information and Quality Authority (HIQA)
Aidan Clancy	Department of Health (first meeting)
Alan Cahill	Department of Health
Barbara Foley	HIQA
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Collette Tully	National Office of Clinical Audit
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Harry Comber	National Cancer Registry Ireland
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Marina Cronin	National Office of Clinical Audit (first meeting)
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Patricia Ryan	Patients for Patient Safety Ireland
Paul Crowley	Central Statistics Office
Paula Kavanagh	HISI Nursing and Midwives Group
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Part 1 – Background

1.1 Document outline

Part 1 of this document provides the background to this project, defines national health and social care data collections, outlines the work that HIQA has done in this area to date and summarises the relevant international evidence. It also places the standards in the context of relevant legislation and other standards and policies.

Part 2 presents the information management standards and associated features for national health and social care data collections. The standards are grouped into six themes entitled Person-centred; Leadership, Governance and Management; Use of Information; Information Governance; Workforce; and Use of Resources.

1.2 Introduction

Accurate, relevant and timely data is essential in order to identify and improve health and social care, 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 at national and local levels. Accordingly, a considerable amount of data is collected about health and social care services in Ireland.

National health and social care data collections are national repositories of routinely collected health and social care data in the Republic of Ireland. They play a crucial role by providing a national overview of a particular health or social care service. Ultimately, their primary purpose is to improve the quality and safety of these services. There is little point in investing considerable time, effort and resources into producing a high-quality data collection if the data is not used to the maximum benefit of the population it serves. Therefore, in order to do that, it is essential to promote, encourage and facilitate the use of the data.

Historically in Ireland, as in many other countries, our national data collections have evolved over time in a largely uncoordinated fashion. Although there are examples of very good practice, this lack of coordination has led to a fragmented health information infrastructure. In terms of completeness, there are a number of deficiencies. For example, there is limited data available from the primary and community care sectors, from outpatients, or from emergency departments.

The importance and need for high-quality health information in improving the safety and quality of patient care has been outlined in a number of key national strategy documents from the Department of Health, including *Quality and Fairness – A Health System for You; Health Information: A National Strategy;* and in

Building a Culture of Patient Safety — Report of the Commission on Patient Safety and Quality Assurance.(1,2,3)

In addition, the *e-Health Strategy for Ireland*, published in December 2013, highlights the importance of access to quality health data sources to drive improvements in the quality and safety of care.(4) The establishment of the Office of the Chief Information Officer in 2015 and the publication of the *HSE Knowledge and Information Strategy* represent other important developments.(5)

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

- health information is used to deliver and monitor safe and high-quality care for everyone
- health information should be of the highest quality and where appropriate collected as close as possible to the point of care
- health information should be collected once and used many times
- data collection should be 'fit for purpose' and cost-effective.(6)

Implementation of the standards will support national health and social care data collections to ensure that their data and information is of high quality and is accurate, valid, reliable, relevant, legible and complete.

1.3 Background

HIQA recognizes the important role played by national health and social care 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, HIQA has undertaken a considerable body of work with the aim of contributing to improving the overall effectiveness and efficiency of the national health and social care data collections, including the following:

- Catalogue of National Health and Social Care Data Collections in Ireland(7)

- Draft Standards for National Health Information Resources± (8)
- Guiding Principles for National Health and Social Care Data Collections(6)
- Recommendations on a more integrated approach for National Health and Social Care Data Collections.(9)

A more detailed description of some of the key documents is provided below.

Catalogue of National Health and Social Care Data Collections in Ireland

The aim of the catalogue is to enable all stakeholders to readily access information about health and social care data collections in Ireland. The current version of the catalogue was released in 2014 and features 108 data collections, which include:

- national data collections of health and social care
- national surveys
- national censuses
- regional collections of national importance
- national registries.

The broad scope of the catalogue is in keeping with its aim to increase awareness of, and access to, the large diversity of data collections which have been developed and maintained in Ireland.

Draft Standards for National Health Information Resources

In 2011, HIQA developed *Draft Standards for National Health Information Resources* to drive improvements in national health information. The draft standards were broad in nature and reflected international good practice, as identified in an international review published that same year.(10) The overarching themes of the draft standards document were:

- governance and management
- effectiveness
- person-centred approach
- use of resources
- workforce.

± The term 'National Health Information Sources' has changed to 'National Health and Social Care Data Collections' since the publication of HIQA's previous documents, such as *Catalogue of National Health Information Sources in Ireland* and the *International Review of Health Information Sources*.

Guiding Principles for National Health and Social Care Data Collections

In 2013, HIQA published *Guiding Principles for National Health and Social Care Data Collections*. These guiding principles and all subsequent publications have used the term 'national health and social care data collections' instead of 'national health information resources' to describe the collections. The guiding principles were compiled in order to provide current and new data collections with advice and guidance on best practice. The eight guiding principles relate to:

- governance arrangements
- statement of purpose
- legislation and standards
- use of resources
- use of information
- data quality
- information governance
- workforce.

Recommendations on a more integrated approach for national health and social care data collections

In order to address the need for a more integrated approach for national health and social care data collections, in 2014 HIQA published, and submitted to the Minister for Health, a set of *Recommendations on a more integrated approach for National Health and Social Care Data Collections*.(9) The published recommendations are outlined in Appendix 1. The implementation of these recommendations has the potential to reduce fragmentation and duplication and ensure a more consistent approach to improving the quality of data collected. The recommendations were informed by an international review.(11)

1.4 International evidence

HIQA has compiled an up-to-date review of international approaches in relation to national health and social care data collections, which will be published in late 2016. Desktop research was conducted to gather important European and international evidence regarding national data collections and statistical systems. A number of important international reports such as *The European Statistics Code of Practice* and *The UN Statistics Template for a Generic National Quality Assurance Framework* were used to guide the development of the standards.(12,13)

Five countries were in reviewed in detail, with an initial desktop review being performed and follow-up interviews being undertaken with experts in each country who provided more detailed information and clarification. The focus of the review was to determine the current situation in each country in relation to national data collections that would provide evidence to support the development of these standards. The countries reviewed in detail were:

- Australia
- Canada
- England
- New Zealand
- Scotland.

A number of key themes emerged in the international review, including the importance of data quality, information governance, use of health information standards and the need for improved use of information.

Data quality

Key international documents, such as the *Quality Assurance Framework of the European Statistical System*, emphasize the importance of data quality.(14) Data quality is promoted and strengthened through auditing, reporting, producing guidance documents and delivering education. Each country reviewed makes significant efforts to improve the quality of the data collected.

- Data Quality Frameworks are widely used internationally. An important example of a data quality framework is that which has been developed by the Canadian Institute for Health Information (CIHI). CIHI's Data Quality Framework sets out an approach to systematically assess, document and improve data quality for all data holdings.(15)
- Data Quality Statements are in use by a number of countries, including Australia and England. Data quality statements are documents which provide information on a range of aspects of the quality of the data being reported. They enable data users to understand any limitations of the data and make informed judgments about their use of the data. Data quality statements should give information on how each area of data quality is addressed. They provide concise, publicly available quality summaries on the data quality issues, in an easily accessible format.

Information governance

The need for effective information governance was recognized in all of the countries reviewed. Some examples of this include the Information Governance (IG) Toolkit that was published online in England in 2015 and Canada's recently implemented Privacy Impact Assessment Policy.(16,17) Australia has developed a Data Governance Framework which provides an overview of the Australian Institute of Health and Welfare's data governance arrangements. It provides information on:

- key concepts in data and data governance, including structures and roles
- the legal, regulatory and governance environment in which the Australian Institute of Health and Welfare operates
- data-related policies, procedures and guidelines
- compliance regimes.

Health information standards

The five countries reviewed were seen to enforce or endorse health information standards (including technical standards), conduct activities to improve data quality and employ unique health identifiers and electronic records. All of the countries reviewed are using data quality enhancing tools such as minimum datasets, national data dictionaries and classification and terminology systems.

Each of the countries was also seen to use standard classification and terminology systems such as SNOMED-CT and versions of ICD-10. The standardization of data contributes to higher quality, trustworthy data that is fit for use across interoperable systems. This is crucial to enabling the integration of data collections and making regional, national and international comparisons.

Improved use of information

All countries reviewed are making efforts to improve use of information:

- There is a movement towards increasing transparency and improving the availability of information. Online data catalogues and health information portals are in use across the jurisdictions.
- There is recognition of the principle of "collect once, use many times". This emphasises the value of collecting information once — as near to the point of care as possible — and using it multiple times, with careful consideration as to what data is being collected, why it is being collected and what is the most efficient way to collect the data.

- There is acknowledgement by the countries reviewed of the need for data to be better used to fulfil its potential and make greater contributions to patient care and health system delivery, with all countries seen to be developing their data linkage capabilities.

The international review has shown that all countries reviewed recognize the vital importance of national health and social care data collections to ultimately improve the quality of care patients that receive. The evidence of this lies in the efforts being made to improve and develop national health and social care data collections in the countries concerned.

1.5 Definitions

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.

Throughout this document the term 'national health and social care data collection' is used to cover both the database itself and the process of collating, analysing and disseminating data. National health and social care data collections vary in size from large data repositories, such as the National Physical and Sensory Disability Database (NPSDD) to smaller patient registries such as the Alpha-1 Research Registry. A detailed list of national health and social care data collections is provided in the catalogue.(7) For the most part, national health and social care data collections are regarded as 'secondary sources' of health information. Secondary use of information in this instance may relate to information which was originally collected in the course of providing care, being used for purposes other than direct care to people using services.

Another important concept that is used throughout the standards is the 'managing organization'. It is recognized that the governance and management arrangements of national health and social care data collections in Ireland vary significantly. To attempt to address this variance, a generic term for managing organization has been defined as outlined here.

'Managing organization': is defined for the purpose of this work as the organization, agency, managing unit, institution or group with overall responsibility for the national health and social care data collection.

The term ‘managing organization’ is also in use in the Catalogue for National Data Collections and the Guiding Principles for health and social care data collections.(6,7) This generic term is used to describe the variety of different arrangements which are in place for a responsible body to govern, manage and organize national health and social care data collections in Ireland. This may not always be a formalized organization or a body established on a statutory basis.

Some examples of national data collections and an outline of their respective managing organizations are provided in Table 1. A full list is provided in the Catalogue of National Health and Social Care Data collections in Ireland.(7)

Table 1. Examples of national health and social care data collections in place in the Republic of Ireland

National health and social care data collection	Description	Managing organization
National Cancer Registry of Ireland (NCRI)	Maintains a national registry of cancer cases and deaths in Ireland.	National Cancer Registry of Ireland (NCRI) — The NCRI is a publicly appointed body established in 1991 on a statutory basis. It is funded by the Department of Health.
Hospital In-Patient Enquiry Scheme	Collects demographic, clinical and administrative data on discharges from, and deaths in, acute public hospitals nationally to maintain a timely accurate national database of hospital discharge activity.	Healthcare Pricing Office (HPO) of the Health Service Executive (HSE) — The HPO is responsible for management and administration of this scheme since 1 January 2014.
National Physical and Sensory Disability Database (NPSDD)	Outlines the specialised health services currently used, or needed, by people with physical/sensory disability.	Health Research Board (HRB) — the NPSDD is managed by the HRB on behalf of the Department of Health. It was established in 2002.
Computerised Infectious Disease Reporting (CIDR) System	Manages the surveillance and control of infectious diseases in Ireland and monitors organisms' ability to resist antibiotic drugs (antimicrobial resistance).	Health Protection Surveillance Centre (HPSC) of the HSE — HPSC is responsible for collecting and collating infectious disease notifications since 2000. The CIDR system is a shared national information system for the CIDR partners, including the HPSC.
Irish Hip Fracture Database (IHFD)	A web based system that uses the HIPE (Hospital In-patient Enquiry) portal infrastructure. It audits care standards and outcomes for patients with hip fractures.	National Office of Clinical Audit (NOCA) — NOCA is an independent body funded by the HSE. It is responsible for the governance of the IHFD, along with a number of other national audits.

HIQA 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. It also acknowledges the challenges that are faced by the national health and social care data collections and emphasises the opportunities afforded by national and international collaboration to support national data collections improve data quality methodologies. HIQA has published *Recommendations on a more Integrated Approach to National health and social care data collections*, which highlights the need for a strategic framework to inform policy development.(9)

The *National Standards for Safer Better Healthcare*, published in 2012, describe a vision for quality and safety in healthcare which includes the use of accurate and timely information to promote effectiveness and drive improvements.(18) One of the eight themes, 'Use of Information', highlights the importance of actively using information as a resource for planning, delivering, monitoring, managing and improving care. These standards apply to all healthcare services (excluding mental health) provided or funded by the HSE.

The *Information Management Standards for National Health and Social Care Data Collections* therefore complement the *National Standards for Safer Better Healthcare* and collectively provide a roadmap to improve the quality of health information and data, which will ultimately contribute to the delivery of safe and reliable healthcare.

1.6 Purpose of the standards

The primary purpose for developing standards for national health and social care data collections is to ensure that information that is used to monitor patient care, the quality of care received and the delivery of that care is of high quality and is complete, accurate and valid. Compliance with these standards will help to instil confidence in patients, clinicians and all other stakeholders that healthcare decisions are made based on high-quality information, the availability of which will ultimately improve patient safety.

1.7 Methodology for standards development

The standards were developed in line with HIQA's standards development process, as outlined earlier in this document. A review of international literature, including guidelines, policies and standards, from other jurisdictions was conducted to determine international best practice. An Expert Advisory Group was also established with relevant experts, as listed on page ix of this document.

A public consultation will be carried out in relation to the draft standards. The feedback from the public consultation will be analysed, considered and used to inform the final version of the standards.

The final version of the standards will then go through a standards approval process. Approval to publish these standards will be sought from the Executive Management Team and from the HIQA Board. Once approval is obtained, the standards will be sent to the Minister for approval and publication.

A separate guidance document will be published to accompany these standards to provide additional support to national health and social care collections on how to achieve compliance with the standards.

1.8 Benefits of the standards

Standards will help to promote improvements in national health and social care data collections by forming a basis for planning and identifying and addressing gaps and quality issues. They provide a framework of best practice to enable national health and social care data collections collect quality data and work towards advancing improvements in health information, which will ultimately lead to safer better care for all. Other wider benefits to the public and to the health and social sector are listed below.

Health and social care users will benefit from:

- improved information governance
- more informed decision-making
- higher quality and safer care for everyone
- better use of public monies benefiting all users of health and social care services.

Health and social care professionals will benefit as:

- the quality of information will be better assured
- information will be delivered in ways that better support its intended use
- relevant information will be more accessible for informed decision-making
- the time spent accessing and recording information will be reduced
- the quality of health and social care services research will improve.

Health and social care organizations will benefit as:

- more valuable, accurate information will be available
- information will be more easily accessible
- the duplication of data entry effort will be significantly reduced
- risk management will be improved
- there will be improved access to information which will allow greater comparison between healthcare agencies
- there will be an increase in the reliability and accessibility of information, which will facilitate greater performance monitoring
- the information used for service planning and service delivery will be of higher quality.

1.9 Legislative framework and scope of the standards

Under the Health Act 2007, HIQA currently has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information, as follows:

- Section 8(1)(i) to evaluate available information respecting the services and the health and welfare of the population
- Section 8(1)(j) to provide advice and make recommendations to the Minister for Health and Children and the Health Service Executive (HSE) about deficiencies identified by HIQA in respect of the information referred to in paragraph (i)
- Section 8(1)(k) to set standards as HIQA considers appropriate for the HSE and service providers respecting data and information in their possession in relation to services and the health and welfare of the population.

The General Scheme of the Health Information and Patient Safety Bill, published in November 2015, allows the Minister for Health to designate certain national health and social care data collections as 'prescribed health information resources'.(19) Once this legislation is fully enacted, this will allow HIQA to set standards for these 'prescribed resources' and to monitor compliance with these standards.

The draft information management standards for national health and social care data collections presented in this document apply to national health and social care data collections as previously defined (see Section 1.5). The standards will inform and put on a mandatory footing how national health and social care data collections will be governed and managed in the future.

The standards are broad in nature in order to embrace the wide variety of national health and social care data collections in Ireland. It is essential that all staff members within each national health and social care data collection understand and adhere to the standards in order to ensure compliance at every level. The HIQA methodology for standards development is outlined in Section 1.7.

1.10 How the standards are structured

The 11 standards in this document are grouped according to six themes: person-centred, leadership, governance and management, use of information, information governance, workforce, and use of resources. Under each theme, one or more standards are laid out.

Each standard comprises two sections; the standard itself and associated features. The features provide some guidance to national health and social care data collections on how to meet the standard. The features listed give examples of how the standards can be met; they are not an exhaustive list and there may be other ways for national health and social care data collections to show that they have met the standards.

1.11 Interaction with other national standards

HIQA has developed *National Standards for Safer Better Healthcare* which aim to give a shared voice to the expectations of the public, people using services and service providers. They aim to provide a roadmap for improving the quality, safety and reliability of healthcare in Ireland.(18) These contain three detailed standards in the area of health information: the use of information, the management of information and information governance. The *National Standards for Safer Better Healthcare* clearly outline the responsibilities for healthcare providers to appropriately collect, manage and use health information to support care delivery, as well as quality monitoring and improvement. It is impossible to improve care without good data, whether at the service, regional or national and or population level.

The *National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland* will support the implementation of these standards by standardizing how demographics are recorded and removing duplication and variation within and between service providers when collecting patients and service users' demographic data.(20)

The *Information Governance and Management Standards for the health identifiers operator in Ireland* is another important development, which will underpin the introduction of the health identifiers with a robust governance framework. This will support the health identifiers operator to facilitate the secure and effective exchange of health information by uniquely identifying healthcare professionals, organizations and service users, thereby improving the quality of health and social care services data.

1.12 Implementation of national standards

HIQA recognizes that implementing the proposed standards will take time. However, as new national health and social care data collections are developed, it is expected that they will be required to adhere to the standards from the outset.

For existing national health and social care data collections, an incremental approach is expected with the opportunity being taken when major upgrades to the health and social care data collections are being undertaken to bring them into conformance with the standards.

HIQA also recognizes that there may be resource issues associated with the implementation of these national standards. This places a high importance on how national health and social care data collections plan and use their available resources to ensure a high-quality, safe and sustainable service.

1.13 Public consultation process

These draft national standards are available for public consultation for a five-week period until Monday 15 August 2016. It is really important for HIQA that it hears people's views on what they think will improve the Draft Information Management Standards for National Health and Social Care Data Collections. HIQA is publishing these draft standards so that people can have their say and tell HIQA what they think about the standards. HIQA invites all interested parties to submit their views on the draft national standards, and their use, as part of an overall strategy to drive safer better healthcare in Ireland. For example:

- Do you think that all the areas you consider important are covered?
- Are the standards and features clear and easy to understand?

HIQA has also published a public consultation form that is divided into three sections:

- Questions about you and your organization.
- General feedback questions which ask for your comments and feedback on the consultation document in general under different headings such as 'layout and design', 'comprehensiveness', and so on.
- Specific feedback questions which asks for your feedback on the consultation with respect to the specific standards and features that are presented under each theme.

The closing date for receipt of comments is Monday 15 August 2016 at 5pm.

How to make a submission

A number of consultation questions have been prepared for your consideration when reviewing the standards. These questions are not intended in any way to limit your feedback, and other comments are welcome.

There are several ways to tell us what you think.

Complete the online consultation feedback form by clicking here. This will bring you to an online version of the consultation feedback form.

Your comments can be submitted by downloading and completing the consultation feedback form available from www.hiqa.ie and emailing your completed forms to datacollections@hiqa.ie

You can print off a copy of the feedback form at http://www.hiqa.ie and post it to us at:

Health Information and Quality Authority
Standards for National Health and Social Care Data Collections
Unit 1301
City Gate
Mahon
Cork.

For further information or if you have any questions:

You can talk to the consultation team by calling 021 240 9300.

How will we use your comments?

Following the consultation, HIQA will analyse the submissions and make further amendments to the draft standards. The main amendments will be presented in a statement of outcomes document, which will be made publicly available with the final version of the national standards.

This is your opportunity to participate in the development of Information Management Standards for National Health and Social Care Data Collections. We wish to thank you in advance for taking the time to submit your comments.

Summary of the Information Management standards for national health and social care data collections in Ireland

Standard 1	The managing organization of the national health and social care data collection has effective arrangements in place to protect the privacy of people about whom it holds information.
Standard 2	The managing organization of the national health and social care data collection has effective leadership, governance and management arrangements in place with clear lines of accountability to ensure that its objectives are met.
Standard 3	The managing organization of the national health and social care data collection sets out how it will achieve its stated objectives by maintaining a publicly available statement of purpose.
Standard 4	The managing organization of the national health and social care data collection is compliant with relevant legislation and codes of practice.
Standard 5	The managing organization of the national health and social care data collection complies with health information standards, guidance and nationally agreed definitions, as appropriate, to enable comparability, interoperability and sharing of information.
Standard 6	The managing organization of the national health and social care data collection systematically assesses, monitors and improves the quality of data held in the national health and social care data collection to ensure its objectives are met.
Standard 7	The managing organization of the national health and social care data collection provides data and information in accessible formats to data users in a timely manner.
Standard 8	The managing organization of the national health and social care data collection disseminates data and information appropriately to optimise its benefit.
Standard 9	The managing organization of the national health and social care data collection has effective arrangements in place for information governance which ensures that personal information is handled legally and securely.
Standard 10	The managing organization of the national health and social care data collection plans, organizes and develops its workforce to effectively deliver its objectives.
Standard 11	The managing organization of the national health and social care data collection plans and manages the allocation and use of resources to ensure its objectives are met.

Part 2 – Information Management Standards for National Health and Social Care Data Collections

Theme 1: Person-centred

National health and social care data collections must ensure the protection of the rights of people about whom they collect information. Taking a person-centred approach will ensure that the privacy, confidentiality and quality of personal health information is assured and that national health and social care data collections collect, use and store data and information in a safe and effective way.

A person-centred approach focuses on the needs and privacy of the individuals about whom the data is recorded. Best practice in this regard allows national health and social care data collections to ensure that personal information, such as that contained in a health or social care record is dealt with appropriately, in order to deliver the best possible care to people who use our health and social care services.

One of the fundamental principles of using personal health and social care information is that the data subject is aware of how their data is being used. As part of this, all individuals should be aware that they have the right to opt out, that is they do not have to allow their data to be included in a national health and social care data collection if they choose not to.

There are a number of national health and social care data collections who have a legislative remit to collect personal health information for a specified purpose such as the National Cancer Registry Ireland (NCRI); and also in the case of the Computerised Infectious Disease Reporting (CIDR) system where under infectious diseases regulations, consent is not required.

For the purposes of these standards the term **'managing organization'** refers to the body responsible for the management of the national health and social care data collection.

It is used to describe the organization, agency, the responsible managing unit, institution or group with overall responsibility for the national health and social care data collection.

These standards are aimed primarily at the 'managing organization' of the national health and social care data collection.

Standard 1

The managing organization of the national health and social care data collection has effective arrangements in place to protect the privacy of people about whom it holds information.

Features of a national health and social care data collection meeting this standard are likely to include:

1.1 Effective arrangements in place to ensure the privacy, confidentiality and accuracy of personal health data and information held in the national health and social care data collection.

1.2 A Statement of Information Practices which clearly outlines how the managing organization collects, uses, shares and protects data and information, is developed and is publicly available.

1.3 Development and use of privacy impact assessments (PIAs) to assure that data subjects' rights to privacy, confidentiality and security are appropriately protected.

1.4 A privacy and confidentiality policy is developed and implemented.

1.5 Where consent is required an appropriate structure is in place to ensure that consent has been obtained in accordance with legislation, standards and best available practice.

1.6 Individuals are identified uniquely within the national health and social care data collection to avoid duplication and mis-identification, in line with national standards and best practice. Once implemented, the Individual Health Identifier (IHI) is used routinely to uniquely identify individuals within the national health and social care data collection.

Theme 2: Leadership, Governance and Management

Effective leadership, governance and management are the organizational arrangements required to provide a framework to ensure the objectives of the national health and social care data collection are met. A well governed and managed national health and social care data collection is clear about what it does and how it does it.

Governance arrangements also set out the daily operations of the national health and social care data collection. Robust governance arrangements effectively ensure that the processes and procedures that work towards achieving the objectives and fulfilling the purpose of the data collection are developed, implemented and adhered to.

The objectives and purpose of the national health and social care data collection should be clear and unambiguous.

Under the theme of leadership, governance and management, standards are presented in relation to the need for robust governance arrangements, a statement of purpose and legislation.

Standard 2

The managing organization of the national health and social care data collection has effective leadership, governance and management arrangements in place with clear lines of accountability to ensure that its objectives are met.

Features of a national health and social care data collection meeting this standard are likely to include:

2.1 There is a named person with overall executive accountability, responsibility and authority for the national health and social care data collection.

2.2 A well-defined governance and organizational structure is in place to ensure that the current and future needs of the national health and social care data collection are met, including:

- an oversight committee, or equivalent, that develops the strategic direction and ensures that the mission and values are upheld
- a management committee, or equivalent, that is responsible for planning and delivering operational functions
- strategic business plans
- a documented organizational chart.

2.3 Governance arrangements that clearly set out lines of accountability and responsibilities for all staff members are communicated throughout the organisation to ensure a shared understanding of roles.

2.4 Formalized agreements are in place with data providers that support the provision of quality data.

2.5 A process is in place to monitor, review and evaluate the effectiveness of the national health and social care data collection to achieve its objectives.

2.6 Ongoing assessment of risk is conducted to ensure the national health and social care collection identifies and manages risks to the achievement of its stated objectives.

2.7 A process is in place to capture positive and negative feedback from stakeholders.

2.8 A formal complaints system is in place to regularly review and investigate all perceived misuse or inappropriate use of data.

Standard 3

The managing organization of the national health and social care data collection sets out how it will achieve its stated objectives by maintaining a publicly available statement of purpose.

Features of a national health and social care data collection meeting this standard are likely to include:

3.1 A statement of purpose is in place for the national health and social data collection that clearly and accurately outlines what it sets out to achieve.

3.2 A statement of purpose for the national health and social care data collection which is publicly available in an accessible format.

3.3 A process is in place to review the statement of purpose, as and when required, to ensure sustainability.

3.4 Notification of, and consultation with, relevant parties regarding the development of, or any proposed significant changes to, the statement of purpose.

Standard 4

The managing organization of the national health and social care data collection is compliant with relevant legislation and codes of practice.

Features of a national health and social care data collection meeting this standard are likely to include:

4.1 Clearly documented and implemented arrangements are in place that allows the national health and social care data collection to demonstrate compliance.

4.2 Risk assessment is in place to ensure compliance with relevant legislation and codes of practice.

4.3 Training is undertaken to ensure that staff are aware of, and adhere to, the legislation and codes of practice relevant to their role.

Theme 3: Use of Information

National health and social care data collections must ensure that the use of their data and information is optimised to achieve the best value for money and provide the greatest benefit to users in order to maximize health gain. Each national health and social care data collection holds a rich source of data. In order to gain the greatest benefit from the health and social care data and information, the data and information must be relevant, accurate, timely, accessible and valid.

The primary objective of each national health and social care data collection is to inform its data users in order to improve upon the quality of care and service being provided to the population it serves. In order to achieve this objective there must be full confidence and trust in the national health and social care data collection and this can only be achieved if all of the dimensions of data quality are met.

The quality of data can be determined through assessment against a number of quality dimensions which include accuracy, validity, reliability, timeliness, relevance, legibility and completeness of data.(21)

Under the theme of use of information, standards have been set out to cover the areas of compliance with health information standards, data quality and quality improvement as well as accessibility and dissemination of information.

Standard 5

The managing organization of the national health and social care data collection complies with health information standards, guidance and nationally agreed definitions, as appropriate, to enable comparability, interoperability and sharing of information.

Features of a national health and social care data collection meeting this standard are likely to include:

5.1 Terminologies and classification systems are used where appropriate in order to:

- facilitate organization and analysis of data
- enable sharing and comparability of data
- provide the basis for the compilation of national statistics.

5.2 The national health and social care data collection clearly defines and structures the data collected to enable users to accurately use and interpret data.

5.3 Minimum datasets are in place, which outline the minimum number of data elements agreed for mandatory collection and reporting for a national health and social care data collection. These are regularly updated and made publicly available.

5.4 Updates and changes to the data dictionary and minimum datasets are publicly available.

Standard 6

The managing organization of the national health and social care data collection systematically assesses, monitors and improves the quality of data held in the national health and social care data collection to ensure its objectives are met.

Features of a national health and social care data collection meeting this standard are likely to include:

6.1 A named individual has overall accountability for systematically assessing, monitoring and reviewing the quality of data held in the national health and social care data collection.

6.2 A Data Quality Framework, that outlines the approaches to systematically assess, document and improve data quality, which includes policies and procedures and information relating to data audits, is developed and implemented.

6.3 A Data Quality Statement, which highlights key aspects of data quality, including strengths and weaknesses so that potential data users can make informed judgements about fitness for use, is provided to accompany all published reports and other outputs, as appropriate, to provide an assurance of data quality.

6.4 Key performance indicators (KPIs) are defined using an evidence-based approach. Performance is measured and published at regular intervals.

6.5 Ongoing data quality training is provided to the workforce to promote data quality awareness and prevent occurrence of errors.

6.6 The national health and social care data collection works closely with data providers to monitor, evaluate and improve data quality.

6.7 Collaboration with key stakeholders, including activities such as benchmarking and peer-review, is undertaken both nationally and internationally to inform and improve data quality methodologies and enhance comparability.

6.8 Information and communication technologies are used effectively and technological resources are aligned to standards to continuously improve and assure data quality.

Standard 7

The managing organization of the national health and social care data collection provides data and information in accessible formats to data users in a timely manner.

Features of a national health and social care data collection meeting this standard are likely to include:

7.1 Arrangements are in place to ensure that data users can gain access to, and use, data and information from the national health and social care data collection, in line with legislation and national policy.

7.2 A data dictionary for the national health and social care data collection is developed and implemented to ensure consistency in data collection. The data dictionary is regularly updated and is publicly available.

7.3 Information is made available to the public on how data is handled and about how to access data and information.

7.4 Clear policies and procedures are in place for data users in relation to the process of requesting and accessing data.

7.5 The terms and conditions in relation to data requests are clearly communicated including details in relation to: the type of analysis; purpose for using the data; proposed outputs and proposed data retention period.

7.6 Explanatory information is provided with data and information to facilitate accurate interpretation of data and information.

Standard 8

The managing organization of the national health and social care data collection disseminates data and information appropriately to optimise its benefit.

Features of a national health and social care data collection meeting this standard are likely to include:

8.1 The national health and social care data collection encourages, promotes and facilitates use of its data in order to maximize its use and to improve quality and safety of health and social care.

8.2 The use of data from the national health and social care data collection is routinely monitored for relevance and usability by the managing organization.

8.3 Effective dissemination of data and information is planned in order to meet the needs of key stakeholders.

8.4 The national health and social care data collection develops resources to support the needs of data users, such as web-based tools for data analysis.

8.5 All information published by the national health and social care data collection is clearly identified as being either provisional, final or revised, to aid understanding and use.

8.6 The national health and social care data collection produces regular reports, including annual reports, which are made publicly available in a timely way to meet the needs of data users.

8.7 A calendar is released on an annual basis that identifies the intended dates for the publication of reports and datasets.

Theme 4: Information Governance

The principles of good information governance allow national health and social care data collections to ensure that personal information, such as that contained in a health or social care record, is handled legally, securely, efficiently and effectively in order to deliver the best possible care to service users. People must be confident and assured that their health and social care data is being held securely in compliance with legislation. It is important that people are informed of what data is held about them, whether in electronic or paper records.

Information governance involves the development of processes and procedures for handling personal information that support the efficient location and retrieval of records where and when they are needed. It also includes the appropriate sharing of relevant personal information between health and social care professionals involved in the provision of care with a view to informing the development of this care.

Reliable and well structured information governance practices facilitate:

- the collection of high quality data to facilitate data users to support service delivery, quality improvement, performance reporting and planning
- the maintenance of the privacy and confidentiality of service users in line with legislation
- information to be held securely, using effective systems, security measures and appropriate role-based access by authorized persons to information
- appropriate safeguards to be put in place for the secondary use of information, whereby service users are informed of how their information will be used so that there is a shared expectation of secondary use
- arrangements to be put in place to ensure that consent is obtained where it is necessary.

Individuals need to be confident that their privacy is being appropriately protected. The national health and social care data collection must ensure that it is meeting the needs of its users while respecting the privacy of the people whose data is being collected.

Standard 9

The managing organization of the national health and social care data collection has effective arrangements in place for information governance which ensures that personal information is handled legally and securely.

Features of a national health and social care data collection meeting this standard are likely to include:

9.1 A Data Protection Officer is appointed with designated responsibilities for information governance.

9.2 The national health and social care data collection assigns appropriate responsibilities for information governance to staff to embed a culture of information governance in the organisation.

9.3 The managing organisation has effective arrangements in place to assess and manage information governance risks and to ensure accountability.

9.4 The national health and social care data collection complies with relevant information governance legislation and standards.

9.5 Policies and procedures based on best available evidence are in place to protect the privacy of people whose personal health information is being collected, including but not limited to the following:

- Information governance
- Freedom of information
- Privacy and confidentiality
- Data protection
- Information security and breaches
- Data retention and destruction.

9.6 Access to confidential data and information is role-based and an audit trail is in place to enable tracking of access to data subjects' personal data and information.

9.7 Formalized agreements are in place to set out the procedures with third parties regarding access to data subjects' personal data and information.

9.8 Data and information is shared in a timely and secure way, within and between national health and social care data collections, as appropriate, using effective information communications technology (ICT) and technological resources in line with legislation, codes of practice, national standards, guidance and best available evidence.

9.9 Regular information governance audits are conducted and appropriate actions are taken to address areas for improvement.

9.10 Regular training is provided for the workforce on relevant information governance policies and procedures to ensure that they have the necessary skills and competencies to support information governance.

Theme 5: Workforce

The workforce is made up of all those who work in, for, or with the national health and social care data collection. The workforce is integral to providing quality data which contributes to the work of the national health and social care data collection to improve population health and wellbeing. National health and social care data collections require staff with specialist skills and qualifications to meet their objectives and produce quality data.

In order to meet the objectives of the national health and social care data collection, its workforce requirements must be identified. The individual members of the workforce must be skilled and competent while the workforce as a whole must be planned, configured and managed to achieve these objectives.

Workforce planning is an essential tool to support the national health and social care data collection in dealing with expected and unexpected events. It should identify the optimum structure of the national health and social care data collection and the development needs of the workforce. National health and social care data collections operate most effectively when the right people with the right knowledge, skills and competencies are deployed appropriately to deliver quality data.

Standard 10

The managing organization of the national health and social care data collection plans, organizes and develops its workforce to effectively deliver its objectives.

Features of a national health and social care data collection meeting this standard are likely to include:

10.1 Strategic workforce planning, including succession planning, is developed, implemented and monitored.

10.2 Planning, organization and management of the workforce is in place to take account of the:

- assessed needs of data users
- national and international best available evidence
- size, complexity and objectives of the national health and social care data collection.

10.3 An ongoing training, education and development programme is developed with a specific focus on, but not limited to the following key areas:

- data quality
- information governance
- legislation and standards
- relevant national/international developments.

10.4 The workforce is supported to ensure continuous improvement and professional development using best available evidence, so that the functions of the national health and social care data collection are delivered effectively by appropriately trained staff.

10.5 Evaluation of training programmes is conducted and analysed, and where necessary, further training is delivered.

Theme 6: Use of Resources

Resources are defined as including human, physical, financial, and information and communications technology (ICT) resources. The managing organization of the national health and social care data collection should plan and manage its resources to ensure that they are used as efficiently and effectively as possible in order to achieve their objectives. It should strive to ensure that its resources are adequate to ensure the sustainability, continual relevance and maximum impact of the data and information for which it is responsible.

As all resources are finite and budgets are limited, careful planning and stewardship of the use of resources is essential to ensure they are used in the most efficient, useful and effective manner. How resources are deployed significantly impacts on the quality of the information provided and the future sustainability of the national health and social care data collection. The allocation of resources is therefore a fundamental factor in the delivery of quality data.

A well-run national health and social care data collection is aware of how all these elements are used and seeks out opportunities from new evidence and emerging technologies to best use its resources.

The careful management of publicly-funded national health and social care data collections has a dual role. It ensures the funders are receiving the best possible return on their investment, and service users can be confident that the national health and social care data collections ensure they are making the best possible use of their available resources, to provide high-quality information. When allocating public funds, national health and social care data collections need to do so in a transparent manner so it is clear to service users and the public how they are allocated.

Standard 11

The managing organization of the national health and social care data collection plans and manages the allocation and use of resources to ensure its objectives are met.

Features of a national health and social care data collection meeting this standard are likely to include:

11.1 Strategic and operational plans are in place to effectively manage the use of resources and ensure the continued sustainability of the national health and social care data collection.

11.2 Collaborations take place with key stakeholders including other national and international data collections, where possible, to develop synergies and promote improvements in relation to the use of resources.

11.3 Human, financial, physical and information communications technology (ICT) resources are appropriately allocated to achieve the objectives of the national health and social care data collection.

11.4 Effective information communications technology (ICT) and technological resources are in place and are aligned with national ICT and health information strategies and plans to support the national health and social care data collection to meet its objectives.

11.5 Resource decisions are transparent and deliver value for money, informed by:

- risk assessment
- engagement with key stakeholders
- best available evidence
- cost-benefit analysis, where appropriate, of user needs to assess all resourcing decisions and to ensure that priority needs are met.

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Appendices

Appendix 1 — Recommendations on a more integrated approach for National Health and Social Care Data Collections

Recommendation 1: The development of a strategic framework for national health and social care data collections in Ireland should be prioritized, setting out a roadmap and informing policy development for these collections.

Recommendation 2: Oversight for all national health and social care data collections should be assigned to a specific organization at a national level.

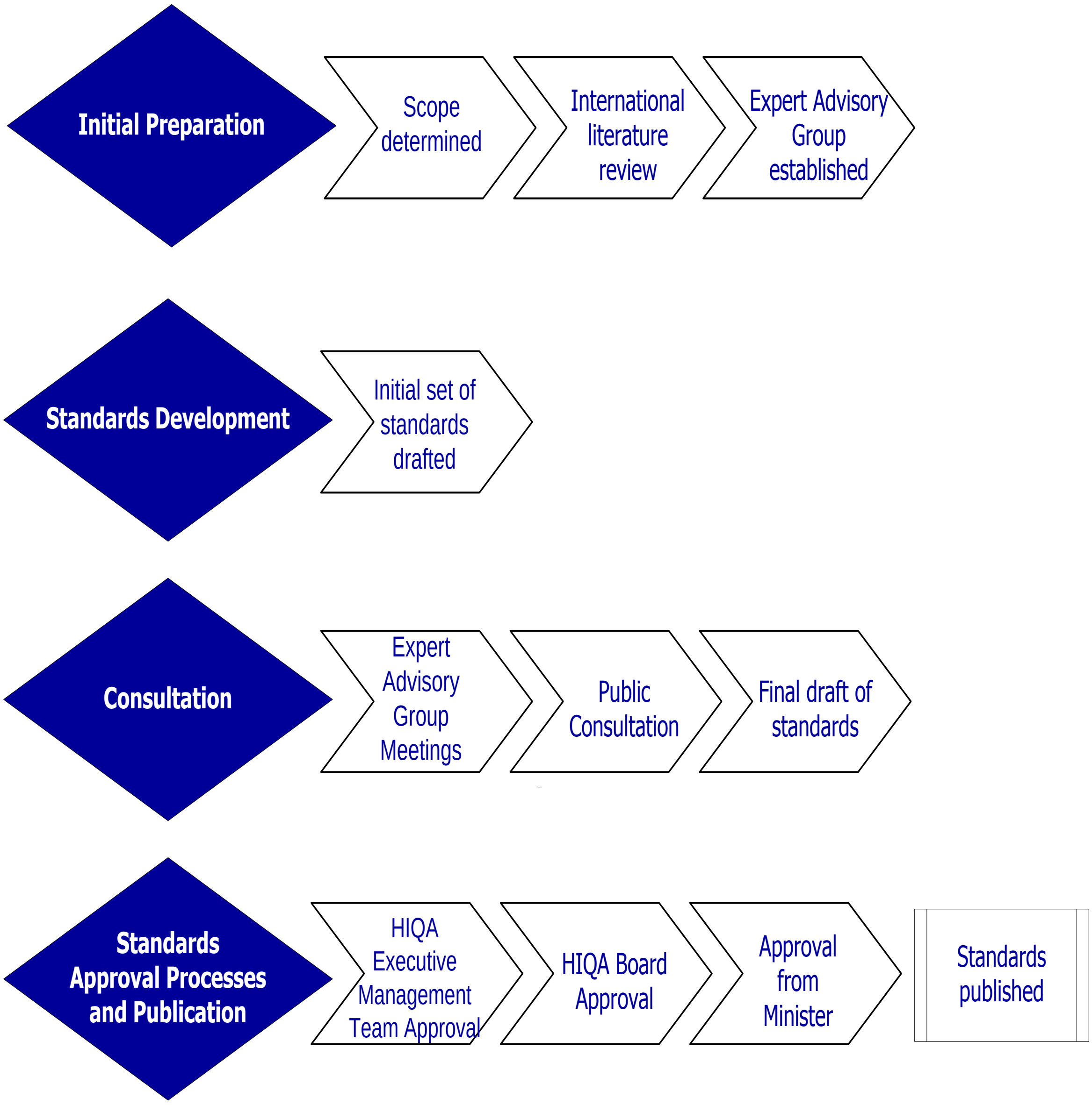
Recommendation 3**:** National health and social care data collections should be included in national information and ICT strategies, and also in the implementation of key ICT projects.

Recommendation 4: All national health and social care data collections should comply with legislative and regulatory requirements, such as national health information standards.

Recommendation 5: The organization responsible for the oversight of national health and social care data collections should develop a data quality framework to drive improvements in the data quality of all national health and social care data collections.

Recommendation 6: The use of, and access to, information from national health and social care data collections should be optimized to deliver better outcomes for the public, while protecting the privacy and confidentiality of personal data.

Appendix 2 — Outline of the HIQA standards development process



Appendix 3 — Glossary of terms and abbreviations

Classification systems: these provide a uniform, meaningful and relevant framework that is used as a common language. An example is the International Classifications of Diseases (ICD) 10.

Clinical terminologies: a structured collection of descriptive terms for use in clinical practice, used by clinicians to describe the assessment of, and care given to, patients during a consultation, at a point in time as close to the consultation as possible. An example is SNOMED CT (Systematized Nomenclature Of Medicine - Clinical Terms).

Computerised Infectious Disease Reporting (CIDR): "an information system developed to manage the surveillance and control of infectious diseases in Ireland. It also monitors organisms' ability to resist antibiotic drugs (antimicrobial resistance)."(22)

Data: the building blocks for information and have been described as numbers, symbols, words, images and graphics that have been validated but yet to be organised or analysed.(23)

Database: a collection of data that is organized so that its contents can easily be accessed, managed, and updated.

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 ensure consistency of use. It is a tool to aid in the standardization of data definitions".(24)

Data quality: data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner.(25)

Data Quality Framework: a document which outlines the approaches to systematically assess, document and improve data quality and includes policies, procedures and information relating to data audits.

Data Quality Statement: this highlights key aspects of data quality, including strengths and weaknesses so that potential data users can make informed judgements about fitness for use.

Data subject: an individual who is the subject of personal health or social care data for example, a patient admitted to a hospital or a child receiving the service of a social worker.

Data user: any user of data or information produced by the National Health and Social Care Data Collection. The data is used for a number of purposes, including to provide logistical and strategic national planning, improve population health and social care and to develop and inform research.

Formalized agreement: this is a formal agreement reached between a number of parties clearly outlining the roles and responsibilities of each party.

Health Protection Surveillance Centre (**HPSC):** provides information for the control and prevention of infectious diseases in order to protect and improve the health of the Irish population.

Healthcare Pricing Office (HPO): responsible for management and administration of the Hospital In-Patient Enquiry Scheme.

Hospital In-patient Enquiry (HIPE): a computer-based system designed to collect demographic, clinical and administrative data on discharges and deaths from acute hospitals in Ireland.

Information and communication 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.

Information: information is data that has been processed or analysed to produce something useful.

Interoperability: "the ability of National Health and Social Care Data Collection to work together within and across organizational boundaries in order to advance the effective delivery of healthcare for individuals and communities".**(26)**

Irish Hip Fracture Database (IHFD): a web based system that uses the HIPE (Hospital In-patient Enquiry) portal infrastructure. It audits care standards and outcomes for patients with hip fractures.

Key Performance Indicators (KPIs): specific and measurable elements of practice that are designed to assess key aspects of structures, processes and outcomes.

Management committee: this committee is responsible for focusing on the operational functions of the National Health and Social Care Data Collection.

Managing organisation of the national health and social care data collection: the organisation, agency, the responsible managing unit, institution or group with overall responsibility for the National Health and Social Care Data Collection.

Minimum dataset: a minimum data set is the least agreed number of data elements collected for reporting purposes.

National health and social care data collection: 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 Office of Clinical Audit (NOCA): an independent body funded by the HSE. It is responsible for the governance of the IHFD, along with a number of other national audits.

National Physical and Sensory Disability Database (NPSDD): a set of information that outlines the specialized health services currently used or needed by people with physical/sensory disability.

National Physical and Sensory Disability Database (NPSDD): a set of information that outlines the specialized health services currently used or needed by people with physical/sensory disability.

NCRI: maintains a national registry of cancer cases and deaths for the whole population in the Republic of Ireland.

Opt-out: the ability of a data subject to have their data removed or not included in a National Health and Social Care Data Collection.

Oversight committee: develops the strategic direction and ensures that the mission and values are upheld.

Personal health information: 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.(9) The term personal health information is broad and includes such matters as personal information relating to the physical or mental health of the individual, as well as any genetic data or human tissue data that could be predictive of the health of the individual or his or her relatives or descendants. In essence it covers any information relating to an individual that is collected for or in connection with the provision of a health service.

Population health: refers to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services.

Primary Care Reimbursement Service (PCRS): database of payments made to healthcare professionals such as doctors and pharmacists who provide services and drugs to public patients.

Privacy impact assessment (PIA): a process designed to identify and address the privacy issues of a particular initiative. It considers the future consequences of a current or proposed action by identifying any potential privacy risks and then examining ways to mitigate or avoid those risks that have been identified.(27)

Risk assessment: the overall process of risk analysis and risk evaluation.

Service provider: any person, organisation, or part of an organisation delivering health or social care services and contributing data to the National Health and Social Care Data Collection, for example a hospital, pharmacy, general practitioner, optician, screening services, residential care for older people, children's residential centres.

Service user: any person who uses or is a potential user of a health or social care service. For example a patient, client or resident.

Stakeholder: a group/person/expert who is significantly involved with/affected by the work of the National Health and Social Care Data Collections.

Statement of information practices: a document, made available to service users that sets out what information the service collects, how it is used, with whom it is shared and for what purpose, the safeguards that are in place to protect it and how service users can access information held about them.

Statement of purpose: a document which details the aims and objectives and a description of the National Health and Social Care Data Collection. It should also contain a description of the data being collected, how the data is collected, who is collecting the data and identify the intended users of the National Health and Social Care Data Collection.

Value for money: assesses whether or not an organisation has obtained the maximum benefit from the goods and services it both acquires and provides, within the resources available to it.(28)

Workforce: the combination of staff directly employed by the National Health and Social Care Data Collection, and those who work on its behalf in other organisations, are referred to throughout this document as the 'workforce'. An example of those who work on behalf of the National Health and Social Care Data Collection but may not be directly employed by the National Health and Social Care Data Collection are data collectors in hospitals.

Appendix 4 — List of abbreviations

Abbreviation	Explanation
AIHW	Australian Institute of Health and Welfare
CIDR	Computerised Infectious Disease Reporting
CIHI	Canadian Institute for Health Information
EAG	Expert Advisory Group
GP	General practitioner
HIPE	Hospital In-Patient Enquiry Scheme
HIQA	Health Information and Quality Authority
HPO	Healthcare Pricing Office
HRB	Health Research Board
HSE	Health Service Executive
ICD	International Statistical Classification of Diseases
ICT	Information and communications technology
IG	Information Governance
IHFD	Irish Hip Fracture Database
IHI	Individual Health Identifier
KPI	Key Performance Indicator
NCRI	National Cancer Registry Ireland
NOCA	National Office of Clinical Audit
NPSDD	National Physical and Sensory Disability Database
PCRS	Primary Care Reimbursement Service
PIA	Privacy impact assessment
SNOMED-CT	Systematized nomenclature of medicine-clinical terms
UN	United Nations

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