Information management standards for national health and social care data collections

2017

Safer Better Care

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 services in Ireland. HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered.

HIQA aims to safeguard people and improve the safety and quality of health and social care 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, HIQA 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 services in Ireland.

- **Regulation** – Registering and inspecting designated centres.

- **Monitoring Children's Services** – Monitoring and inspecting children's social services.

- **Monitoring Healthcare Safety and Quality** – Monitoring the safety and quality 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 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,[1] 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.

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Key terms used in this report

This section includes the key terms which are used in the standards. A full glossary is provided in Appendix 1.

National health and social care data collection: a national repository of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries in the Republic of Ireland.

Managing organisation: the organisation, agency, managing unit, institution or group with overall responsibility for the national health and social care data collection. The term describes the variety of arrangements which are in place for a responsible body to govern, manage and organise national health and social care data collections in Ireland. This may not always be a formalised organisation or a body established on a statutory basis.

Data quality framework: a document outlining the processes to systematically assess, document and improve data quality. While the specific components of a data quality framework may vary depending on the national health and social care data collection, it is likely to include:

(a)   *Data quality policies and procedures:*

   ■   the roles and responsibilities of staff with regard to data quality

   ■   specific processes to be undertaken to ensure data quality.

(b)   *Data quality key performance indicators (KPIs) and metrics:*

   ■   specific and measurable elements of practice that are designed to assess key aspects of structures, processes and outcomes which influence data quality.

(c)   *Data quality audits:*

   ■   regular review of data quality to identify any data quality issues or risks.

(d)   *Data quality improvement initiatives:*

   ■   measures for addressing data quality issues which may be identified through data quality audits, feedback from stakeholders, or international best practice, to drive improvement and prevent the recurrence of errors.

Data quality statement: a statement prepared to accompany all published outputs from the national health and social care data collection. The content of the data quality statement will vary depending on the data and information being published, but is likely to address:

- the key dimensions of data quality (accuracy, completeness, legibility, relevance, reliability, timeliness and validity)

- an overview of any classifications/terminologies that were used

- strengths and weaknesses of the data and information.

The inclusion of a data quality statement with published outputs provides explanatory and methodological information about the data and information contained in the output. The rationale for including a data quality statement is to facilitate data users to interpret the data and information and make informed judgments about its fitness for use.

Statement of purpose: a publicly available document which succinctly captures why the national health and social care data collection exists and clearly outlines its overall function and stated objectives. It may also outline the name of the managing organisation and governance arrangements, the year of commencement, the target population, funding arrangements and legislation that it must adhere to.

Statement of information practices: a generic document, made publicly available in an accessible format, that provides an overview of the use of information within the national health and social care data collection. It outlines the information practices undertaken by that particular data collection at a high level. It is likely to include:

- an outline of the data and information that is collected

- an explanation of how the data and information are used

- an overview of those with whom the information is shared and for what purpose

- a description of the way in which data subjects' information is protected and safeguarded

- an account of the way in which data subjects can access the information held about them.

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; governance, leadership and management; use of information; information governance; workforce; and use of resources.

Part 1

Background

1.1 Introduction

Accurate, relevant and timely data is essential in order to improve health and social care, to inform decision-making, monitor diseases, organise 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. 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, it is essential to promote, encourage and facilitate the use of the data.

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

National health and social care data collection	Description	Managing organisation
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 HSE — The HPO has been responsible for the management and administration of this scheme since 1 January 2014.
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).	The 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.

National health and social care data collection	Description	Managing organisation
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.

In Ireland, as in many other countries, our national health and social care 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 to improve the safety and quality of patient care has been outlined in a number of key national strategy documents in recent years.[2,3,4] In particular, 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.[5] The establishment of the Office of the Chief Information Officer in 2015 and the publication of the HSE Knowledge and Information Strategy represent other recent developments that emphasise the importance of the availability of quality health information.[6]

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, specifically:

- 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.[7]

The *Information Management Standards for National Health and Social Care Data Collections* presented in this document aim to support adherence to these principles.

1.2 Background

A number of key documents have been published by HIQA in recent years in relation to national health and social care data collections. A Catalogue of all national health and social care data collections in Ireland was first published in 2010 and was most recently updated in 2014. The current *Catalogue of National Health and Social Care Data Collections in Ireland* [8] features 108 data collections. National health and social care data collections vary in size from large data repositories, such as the National Perinatal Reporting System (NPRS), to smaller patient registries, such as the Alpha-1 Research Registry.

In 2013, HIQA published *Guiding Principles for National Health and Social Care Data Collections,*[7] which provide current and new national health and social care data collections with advice and guidance on best practice.

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 *Recommendations on a More Integrated Approach for National Health and Social Care Data Collections*.[9] These recommendations emphasise the need for a strategic framework to inform policy development in this area. 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.

HIQA has published detailed guidance on best practice for information governance. These publications include a booklet entitled *What You Should Know About Information Governance: a guide for health and social care staff* and a more detailed guidance report entitled *Guidance on Information Governance for Health and Social Care Services in Ireland*.[10,11] HIQA has also published specific guidance in relation to data quality, including a booklet for health and social care staff on data quality to promote awareness of the dimensions of data quality and the importance of high-quality data and information for the delivery of health and social care.[12]

1.3 Interaction with other national standards

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.[13] 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. There are three detailed standards in the area of health information which centre on the use of information, the management of health information and information governance. These standards apply to all healthcare services (excluding mental health) provided or funded by the Health Service Executive (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.

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 standardising how demographics are recorded and removing duplication and variation within and between service providers when collecting patients' and service users' demographic data.[14]

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.[15] This will support the health identifiers operator to facilitate the secure and effective exchange of health information by uniquely identifying healthcare professionals, organisations and service users, thereby improving the quality of health and social care services data.

1.4 Methodology

The standards were developed in line with HIQA's standards development process. This was informed by a detailed review of international literature, which is published on the HIQA website.[16] An advisory group of experts and key stakeholders was also convened to provide advice and guidance on the development of the standards. Membership of this group is listed in Appendix 2.

A public consultation was carried out in relation to the draft standards. The feedback from the public consultation was analysed, considered and used to inform the finalised standards. Following the consultation, HIQA analysed submissions and revised the standards as appropriate. A summary of these submissions is presented in a Statement of Outcomes document on **www.hiqa.ie**.

1.5 International evidence

The development of the standards presented in this document was underpinned by a detailed international review of best practice in this area. In July 2016, HIQA published an *International Review of National Health and Social Care Data Collections*.[16] The countries reviewed in detail were Australia, Canada, England, New Zealand and Scotland. 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. 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. Some of the key findings are highlighted below.

1.5.1 Data quality

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 focuses on a consistent work cycle to support data quality, assessment of data quality and the production of standardised documentation. The Data Quality Framework seeks to ensure that there is continuous improvement of data quality.[17]

■ 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 dimension of data quality is addressed. They provide concise, publicly available quality summaries on the data quality issues in an easily accessible format.

1.5.2 Information governance

The need for effective information governance was recognised in all of the countries reviewed. Some examples of this include the Information Governance Toolkit that was published in England in 2015 and Canada's recently implemented Privacy Impact Assessment Policy.[18,19] Australia has also developed a Data Governance Framework, which provides an overview of the Australian Institute of Health and Welfare's data governance arrangements.[20] 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.

1.5.3 Health information standards

The five countries reviewed endorsed health information standards (including technical standards), conducted activities to improve data quality and employed 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 Systematised Nomenclature of Medicine-Clinical Terms (SNOMED-CT) and versions of the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10). The standardisation of data contributes to higher quality, trustworthy data that is fit for use across interoperable systems. This is crucial to enabling the integration of national data collections and making regional, national and international comparisons.

1.5.4 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.

1.6 Purpose of the standards

The primary purpose of these *Information Management Standards for National Health and Social Care Data Collections* is to provide a roadmap to improve the quality of national health information and data, which will ultimately contribute to the delivery of safe and reliable health and social care. 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 Legislative remit and scope of the standards

National health and social care data collections are national repositories of health and social care data. They are considered to be 'secondary use' of health information. This relates to information, collected in the course of providing care, being used for additional purposes, such as for policy making, for planning services or for research. Examples include the Hospital In Patient Enquiry System (HIPE) and the National Perinatal Reporting System (NPRS), within the Healthcare Pricing Office of the HSE.

Under the Health Act 2007 and subsequent amendments to the Act, HIQA has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information.[1,21] The scope of the *Information Management Standards for National Health and Social Care Data Collections* presented in this document currently extends to national health and social care data collections as per HIQA's remit under this legislation.

HIQA has a statutory remit to set standards for the HSE, the Child and Family Agency, and service providers and to monitor compliance with those standards, as outlined below.

- Section 8(1)(k): to set standards as HIQA considers appropriate for the Executive, the Agency and service providers respecting data and information in their possession in relation to services and the health and welfare of the population.

- Section 8(1)(l): to advise the Minister for Health, the Minister for Children and Youth Affairs, the Executive and the Agency as to the level of compliance by the Executive and service providers with the standards referred to in paragraph (k).

1.8 Assessment of compliance with the standards

HIQA will develop a structured programme of assessing compliance with the *Information Management Standards for National Health and Social Care Data Collections* within its legislative remit. Recognising that these standards are new, information sessions will be held to support national health and social care data collections to comply with these standards. HIQA plans to initiate a review programme during 2017, which will commence with the distribution of a 'self-assessment tool' to national health and social care data collections within HIQA's legislative remit. This programme will be phased, and HIQA will continue to engage with national health and social care data collections in advance of the commencement of the process.

1.9 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 arrangements

- more informed decision-making

- higher quality and safer care for everyone

- better use of public funds, 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 organisations 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 health and social care agencies

- there will be an increase in the reliability and accessibility of information, which will facilitate greater performance monitoring

- information used for service planning and service delivery will be of higher quality.

1.10 How the standards are structured

Ten standards have been developed within six themes. The standards themselves are outcome based, which means that each standard provides a specific outcome for the managing organisation of the national health and social care data collection to meet. This outcome is described in the 'standard statement'.

The list of features provided under each standard statement heading is not an exhaustive list, and national health and social care data collections may meet the requirements of the standards in different ways.

The standards are divided into six themes:

Theme 1: Person-centred – how the national health and social care data collection safeguards the needs and privacy of the individuals about whom data and information is collected and shared.

Theme 2: Governance, Leadership and Management – the structures put in place by the national health and social care data collection to ensure accountability, robust governance and legislative compliance.

Theme 3: Use of Information – how the national health and social care data collection structures data and information, ensures that data quality is optimised and confirms that data and information are accessible and disseminated to data users.

Theme 4: Information Governance – how the national health and social care data collection ensures that personal information is handled legally and securely.

Theme 5: Workforce – how the national health and social care data collection plans, organises and develops its workforce to achieve its objectives.

Theme 6: Use of Resources – how the national health and social care data collection plans and manages the resources available to achieve its objectives.

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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. A statement of information practices is an effective tool which can be used by national health and social care data collections to clearly outline what information is collected, how this information is used and shared, and the safeguards that are in place to protect the information. Privacy impact assessment (PIA) is another common tool used internationally to protect and enhance individuals' privacy and to protect the rights of individuals. The process involves an evaluation of broad privacy implications of projects and relevant legislative compliance. Where potential privacy risks are identified, a plan is put in place, in consultation with stakeholders, for ways to avoid or mitigate such risks.

Standard 1

The managing organisation 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 the following:

1.1 Effective arrangements are 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 for the national health and social care data collection is developed and made publicly available. This clearly outlines what information is collected, how this information is used and shared and the safeguards that are in place to protect the information.

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 for the national health and social care data collection.

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

1.6 Arrangements are in place to enable individuals to access a copy of personal information held about them in line with legislation and to have any factual inaccuracies corrected.

1.7 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.

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* Health Information and Quality Authority. Guidance on Privacy Impact Assessment in Health and Social Care. (2010)

** An individual health identifier (IHI) is a number that safely identifies a person who has used, is using, or may use a health or social care service in Ireland. The Health Identifiers Act 2014 is the legislation that underpins the introduction of health identifiers in Ireland. The HSE, as delegated by the Minister of Health, has established a Health Identifiers Programme to establish the registers that will contain the health identifier numbers and to implement this programme across the health and social care system.

1.8 Training is provided to the workforce in accordance with their specific roles and responsibilities to ensure the privacy of people about whom the national health and social care data collection holds data and information.

Theme 2: Governance, Leadership and Management

Effective governance, leadership and management are the organisational arrangements required to provide a framework to ensure the objectives of the national health and social care data collection are met. These organisational arrangements ensure that appropriate processes, policies and procedures are developed, implemented and adhered to by the national health and social care data collection.

A well governed and managed national health and social care data collection is clear about what it does and how it does it. The objectives and purpose of the national health and social care data collection should be clear and unambiguous.

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

Standard 2

The managing organisation of the national health and social care data collection has effective governance, leadership 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 the following:

2.1 An identified individual with overall executive accountability, responsibility and authority for the national health and social care data collection.

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

- an oversight committee or board, that develops the strategic direction and ensures that the mission and values are upheld

- a management team, or equivalent, that is responsible for planning and delivering its objectives

- other governance groups as appropriate to fulfil its functions

- strategic and operational plans

- a documented organisational 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 Formalised agreements* are in place with data providers that support the provision of quality data.

2.5 Key performance indicators (KPIs) are used to measure and report on the performance and effectiveness of the national health and social care data collection.

2.6 Risk assessment is conducted on an ongoing basis to identify and manage risks effectively.

2.7 An process is in place for capturing positive and negative feedback, including a formal complaints procedure for reviewing and investigating complaints received by the national health and social care data collection.

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* Formalised agreements between the national health and social care data collection and data providers outline the responsibilities and deliverables of both parties and the associated timelines. This could take the form of, for example, a service level agreement.

Standard 3

The managing organisation maintains a publicly available statement of purpose that accurately describes the aims and objectives of the national health and social data care collection.

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

3.1 A statement of purpose is in place for the national health and social care 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 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 that the objectives of the national health and social care data collection are being fulfilled.

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 organisation 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 the following:

4.1 Clearly documented and implemented arrangements are in place that allow the national data collection to provide assurance of compliance with relevant Irish and European legislation and codes of practice.

4.2 Risk assessment is conducted and documented for any identified gaps in compliance with relevant legislation and codes of practice. Appropriate, timely action is taken by the national health and social care data collection to achieve compliance.

4.3 Training is provided 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 maximise 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 accurate, complete, legible, relevant, reliable, timely 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. 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.[12]

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 organisation of the national health and social care data collection complies with health information standards and nationally agreed definitions to enable comparability and sharing of information.

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

5.1 The use of health information standards, such as messaging standards, to support interoperability and comparability of information.

5.2 The use of standard terminological systems, such as classification systems and clinical terminologies, in order to:

- facilitate the organisation and analysis of data

- enable sharing and comparability of data

- provide the basis for the compilation of national statistics.

5.3 A data dictionary is developed and implemented to ensure consistency in data collection and to enable data users to accurately use and interpret data. The data dictionary:

- complies with nationally and internationally agreed definitions where they exist

- is version controlled and all reports include details of which version is in use

- is updated in a timely manner to incorporate changes to standards and nationally agreed definitions

- is publicly available.

Standard 6

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

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

6.1 An identified individual with responsibility for systematically assessing, monitoring and reviewing data quality to ensure data is accurate, complete, legible, relevant, reliable, timely and valid.

6.2 A data quality framework is in place that outlines the approaches to systematically monitoring, assessing, evaluating and improving the quality of data held in the national health and social care data collection. This may include the development of:

- policies and procedures in relation to data quality

- key performance indicators (KPIs) and metrics in relation to data quality

- data quality audits

- data quality improvement initiatives.

6.3 Collaboration with data providers and other key stakeholders is undertaken to inform and improve data quality methodologies and enhance comparability, including activities such as benchmarking and peer-review.

6.4 Information and communication technology (ICT) resources are used effectively and are aligned to standards to continuously improve and assure data quality.

6.5 Ongoing data quality training is provided for the workforce to promote data quality awareness and prevent occurrence of errors. This is informed by data quality audits and the best available evidence.

Standard 7

The managing organisation of the national health and social care data collection disseminates data and information appropriately and ensures that data users can access data and information in a timely manner to meet their needs.

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

7.1   The national health and social care data collection encourages, promotes and facilitates use of its data in order to maximise usage and to improve the quality and safety of health and social care.

7.2   Arrangements are in place to ensure that data users can gain access to and use data from the national data collection in line with legislation and government policy, for example, through Ireland's Open Data portal.[*]

7.3   The use of data from the national health and social care data collection is routinely monitored for relevance and usability.

7.4   Effective dissemination of data and information is planned in order to meet the needs of key stakeholders. This includes regular reporting, including the publication of annual reports, in a timely way.

7.5   The development of resources to support the needs of data users, such as web-based tools for data analysis and manipulation.

7.6   Information is made publicly available on how to access data and information. A procedure is in place outlining the terms and conditions for data requests, including details of:

- the type of analysis

- purpose for using the data

- proposed outputs

- proposed data retention period

- transparency around potential fees for specific data requests

- the process for ethical approval, if applicable.

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[*]   The concept of Open Data is about making data held by public bodies available and easily accessible online for re-use and re-distribution, including health and social care data. Ireland's Open Data Portal, data.gov.ie provides access to official data in open format. The portal was launched in 2014 and is operated by the Department of Public Expenditure and Reform.

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

7.8 Explanatory and methodological information is provided with all published outputs to facilitate accurate interpretation of data and information. This includes the provision of a data quality statement to accompany each published output which provides an assessment of the dimensions of data quality.

7.9 ICT is effectively used by the national data collection to disseminate data and information in accessible formats.

7.10 All information published by the national health and social care data collection is clearly identified as being provisional, final or revised, including reasons for any revisions, to aid understanding and use.

7.11 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 health and social care. Individuals must be confident and assured that their health and social care data and information is being held securely in compliance with legislation. It is important that individuals are informed of what data is held about them, whether in electronic or paper records.

Reliable and well-structured information governance practices facilitate:

- the collection of high-quality data

- arrangements being in place to ensure that informed consent is obtained where it is necessary

- information being made available to individuals, through a statement of information practices, about how their information will be used

- appropriate sharing of relevant personal information

- the maintenance of the privacy and confidentiality of individuals in line with legislation

- data and information being held securely, using effective systems, security measures and appropriate role-based access

- ongoing auditing and monitoring of the information governance practices within the national health and social care data collection.

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 individuals about whom data is being collected.

Standard 8

The managing organisation 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 the following:

8.1 Identified individuals are in place whose roles include:

- overall responsibility and accountability for information governance for the national data collection

- duties of a data protection officer as laid out in legislation.*

8.2 Responsibilities are assigned to staff to ensure that staff are aware of their respective roles and responsibilities regarding information governance and to embed a culture of information governance within the national data collection.

8.3 Effective arrangements to assess and manage information governance risks. This includes:

- reporting of information governance performance as part of standard risk management arrangements

- a process is in place to deal with breaches of information governance policies and procedures to ensure that effective remedial action is taken.

8.4 Clearly documented and implemented arrangements that allow the national health and social care data collection to demonstrate compliance with relevant information governance legislation and standards.

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* The forthcoming European General Data Protection Regulation sets out the requirements for the designation of a data protection officer.

8.5 Documented policies and procedures to support all aspects of information governance, which are aligned to relevant legislation, standards and evidence-based guidance, are in place, including:

- Privacy and confidentiality

- Data protection

- Freedom of information

- Information security and breaches

- Data retention and destruction

- Disaster recovery

- Process of obtaining consent.

8.6 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.

8.7 A procedure is in place outlining the terms and conditions for data requests to ensure the protection of data subjects' personal data and information.

8.8 Data and information is shared in a timely and secure way within and between national health and social care data collections, in line with legislation and best available evidence, to ensure that personal information is handled legally and securely.

8.9 Regular information governance audits, including information security, are conducted and effective action is taken where necessary to address identified areas for improvement.

8.10 Complaints received in relation to any perceived misuse or inappropriate use of data or information are reviewed and thoroughly investigated as part of the overall complaints process.

8.11 Regular training is provided to staff to ensure that they have the necessary skills and competencies to support information governance. Training and education programmes are tailored to the roles, responsibilities and level of access to personal information.

Theme 5: Workforce

The workforce is made up of all those who work in or for the national health and social care data collection. 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 9

The managing organisation of the national health and social care data collection plans, organises 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 the following:

9.1 Strategic workforce planning, including succession planning, is developed, implemented and monitored by the national health and social care data collection.

9.2 Planning, organisation 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.

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

- data quality

- all aspects of information governance, including information security, privacy and confidentiality

- legislation and standards

- relevant national/international developments.

9.4 The workforce is supported to provide feedback to drive continuous improvement and ensure that the functions of the national health and social care data collection are delivered effectively.

9.5 Evaluation of training, education and development programmes is conducted and analysed to reflect changes to legislation, standards, guidance and best available evidence, and, where necessary, further training is delivered.

Theme 6: Use of Resources

Resources are defined as including human, physical, financial and ICT resources. The managing organisation 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 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 being used.

Standard 10

The managing organisation 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 the following:

10.1 Strategic and operational plans are in place to effectively manage the use of resources, including human, physical and ICT resources, to ensure continued sustainability.

10.2 Resource decisions are transparent, in line with national policy and informed by:

- risk assessment

- engagement with key stakeholders

- best available evidence

- cost-benefit analysis, where appropriate, of data user needs to assess all resourcing decisions and to ensure that priority needs are met.

10.3 ICT resources are planned and managed effectively and are aligned with national ICT policies to ensure they are fit for purpose and meet the objectives of the national data collection.

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

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Appendices

Appendix 1 - Glossary of terms

Classification systems: these provide a uniform, meaningful and relevant framework that is used as a common language. An example is the International Statistical Classification of Diseases and Related Health Problems 10th Revision (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. An example is SNOMED CT (Systematised 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. It has 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 organised 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 standardise definitions and ensure consistency of use. It is a tool to aid in the standardisation 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 data quality policies and procedures; key performance indicators and metrics; audits; and improvement initiatives.

Data quality statement: a statement prepared to accompany all published outputs from the national health and social care data collection which highlights the dimensions of data quality, including strengths and weaknesses, so that potential data users can make informed judgments about fitness for use.

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.

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.

Formalised agreements: agreements between the national health and social care data collection and data providers that outline the responsibilities and deliverables of both parties and the associated timelines. This could take the form of, for example, a service level agreement.

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): the organisation 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 organisational 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 Hospital In-patient Enquiry (HIPE) 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, 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 responsible for the governance of the Irish Hip Fracture Database (IHFD), along with a number of other national audits.

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

National Cancer Registry of Ireland (NCRI): the body that maintains a national registry of cancer cases and deaths for the whole population in the Republic of Ireland.

Oversight committee: a committee that 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.

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 or 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 publically available document which succinctly captures why the national health and social care data collection exists and clearly outlines its stated objectives.

Value for money: an assessment of 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 it are data collectors in hospitals.

Appendix 2 - Expert Advisory Group

The Health Information and Quality Authority (HIQA) would like to thank all of the individuals and organisations who provided their time, advice and information to support the development of these Information Management Standards for National Health and Social Care Data Collections.

The membership of the Expert Advisory Group is as follows:

Name	Organisation
Aidan Clancy	Department of Health (first meeting)
Alan Cahill	Department of Health
Barbara Foley	HIQA
Breda Smyth	Health and Wellbeing Division, HSE
Brenda Long	Primary Care Reimbursement Service, HSE
Catherine Duggan	HIQA
Catriona Keane	HIQA
Collette Tully	National Office of Clinical Audit
Declan Patton	Royal College of Surgeons in Ireland
Deirdre Mulholland	Quality Assurance and Verification Division, HSE
Deirdre Murphy	Healthcare Pricing Office, HSE
Doug Beaton	Health and Wellbeing Division, HSE
Eugene Farrell	Office of Chief Information Officer, HSE
Harry Comber	National Cancer Registry Ireland
Keith Perdue	Irish College of General Practitioners
Kevin Balanda	Institute of Public Health in Ireland
Kevin O'Carroll (Chairperson)	Health Information and Quality Authority (HIQA)
Marina Cronin	National Office of Clinical Audit (first meeting)
Maura Flynn	HIQA
Patricia Ryan	Patients for Patient Safety Ireland
Paul Crowley	Central Statistics Office
Paula Kavanagh	HISI Nursing and Midwives Group
Rachel Flynn	HIQA
Sarah Craig	Health Research Board
Tracy O'Carroll	HIQA
Victoria O'Dwyer	HIQA

Appendix 3 - List of abbreviations

Abbreviation	Explanation
AIHW	Australian Institute of Health and Welfare
CIDR	Computerised Infectious Disease Reporting
CIHI	Canadian Institute for Health Information
HIPE	Hospital In-Patient Enquiry
HIQA	Health Information and Quality Authority
HPO	Healthcare Pricing Office
HPSC	Health Protection Surveillance Centre
HSE	Health Service Executive
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
ICT	Information and Communications Technology
IG	Information Governance
IHFD	Irish Hip Fracture Database
KPI	Key Performance Indicator
NCRI	National Cancer Registry of Ireland
NOCA	National Office of Clinical Audit
NPRS	National Perinatal Reporting System
SNOMED-CT	Systematised Nomenclature of Medicine-Clinical Terms