



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte



# Guiding Principles for National Health and Social Care Data Collections

*Safer Better Care*



# About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive continuous improvement in Ireland's health and personal social care services, monitor the safety and quality of these services and promote person-centred care for the benefit of the public.

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

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



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# 1 Introduction

A considerable amount of data is collected on a regular basis about health and social care services in Ireland. This data is used for many important purposes such as informing decision making, monitoring of diseases, planning of services, policy making, improving population health and for international reporting purposes. All stakeholders (the general public, patients and service users, health professionals, researchers and policy makers) need access to complete, valid and up-to-date information in order to make choices and decisions. Ultimately, the primary purpose of collecting this data should be to improve the quality and safety of health and social care services. It is vital that there is confidence in all aspects of the quality of this information as the delivery of safe and effective healthcare depends on access to, and use of information that is accurate, valid, reliable, timely, relevant, legible and complete.

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. They provide a national overview of data relating to a particular health or social care service. Examples include the National Cancer Registry Ireland (NCRI) which collects comprehensive information on cancer incidence and deaths in Ireland and the Hospital In-Patient Enquiry (HIPE) System, which collects demographic, clinical and administrative data on discharges and deaths from acute hospitals nationally.

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 with significant variation in quality, duplication, access problems, and increased costs. In terms of completeness, there are a number of major deficiencies. For example, there is very limited data available from the primary and community care sectors, from outpatients, or from emergency departments. The absence of a unique identifier for individuals across the health and social care system,<sup>(1)</sup> and also for healthcare practitioners and organisations,<sup>(2)</sup> results in duplication, fragmentation, increased costs and undermines the quality and safety of services. It also makes it very difficult to follow the care pathway of an individual.

Based on international best practice, four key overarching objectives relating to health information based on maximising health gain for the individual and the population, have been identified, 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.

Under the Health Act 2007,<sup>(3)</sup> the Health Information and Quality Authority (the Authority or HIQA) has a statutory remit to develop standards, assess value for money and cost-effectiveness, evaluate information and make recommendations about deficiencies in health information. The importance of information to the Irish health system has been highlighted by a number of government and external organisations.<sup>(4;5)</sup> The Department of Health has produced a number of key national strategy documents since 2001 highlighting the importance and need for quality health information to improve the safety and quality of patient care.<sup>(6-8)</sup>

In addition, the Minister for Health has mandated the *National Standards for Safer Better Healthcare*<sup>(9)</sup> which aim to give a shared voice to the expectations of the public, service users and service providers, and provide a roadmap for improving the quality, safety and reliability of healthcare in Ireland. These contain three detailed standards in the area of health information which centre on: the use of information, the management of information and information governance. These standards 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/population level.

Accurate, relevant and timely data is essential in order to identify and improve the care provided, to inform decision making, monitor diseases, plan services, inform policy making, conduct high quality research, and plan for future health and social care needs, both at national and local levels. The guiding principles presented in this document will provide a framework of best practice to enable national health and social care data collections to collect quality data, work towards driving improvements in health information, ultimately leading to safer better care for all.

## 1.1 Background

The initial work towards the development of these guiding principles was the compilation of a detailed catalogue\* of national health and social care data collections in Ireland, which is available on the HIQA website. This was prepared by collecting a summary description of each individual national collection, which was validated by the agencies responsible for management of the national systems.

A survey was then conducted by the Authority of 10 of these national collections in order to describe in more detail the availability of data, uses of data, access to data and the high level information flows. The overall aim was to identify and extract specific themes to inform the development by the Authority of an appropriate set of national standards.

\* The catalogue of national health and social care data collections in Ireland is currently being updated and will be published later in 2013.<sup>(10)</sup>

As part of this work, an international review of the approaches taken by other countries was also undertaken, which covered six countries in detail.<sup>(11)</sup> A number of best practice examples were identified from this review which helped to develop these guiding principles.<sup>(12-14)</sup>

The following themes pertinent to national health and social care data collections were identified, namely: governance and management, use of information, data quality, use of resources, information governance and workforce. An advisory group was convened in May 2011 (the members are listed in Appendix 1). This group worked with the Authority using the themes and best practice identified to develop draft standards using the findings from the catalogue, survey, and international review. A public consultation on the draft standards was also conducted and the findings were published.<sup>(15)</sup>

It is expected that the forthcoming Health Information Bill will include a provision to allow the Minister of Health to designate those national data collections to which the standards will apply.<sup>†</sup> In advance of the Health Information Bill, the Authority has decided to develop these guiding principles based on the draft standards agreed and consulted upon and underpinned by the *National Standards for Safer Better Healthcare*. This has resulted in an informed, evidence-based and collaborative approach to the development of these guiding principles for national collections of health and social care data in Ireland. The Authority will continue to work with stakeholders in order to identify other areas which may require more specific guidance in the future.

## 1.2 Purpose and scope of this document

The purpose of this document is to present guiding principles for all national health and social care data collections in Ireland. These eight principles will provide current and new data collections with advice and guidance on best practice.

**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.

<sup>†</sup> The term 'National Health Information Sources' has changed to 'National Health and Social Care Data Collections' since the publication of the Authority's previous documents, *Catalogue of National Health Information Sources in Ireland*, the *International Review of Health Information Sources*, *Identification of Themes for National Health Information Sources* and *Draft Standards for National Health Information Resources*.

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

Some examples of national health and social care data collections are provided in Table 1.

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

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

A typical example of the flow of data in and out of data collections is illustrated in Figure 1 on page 9.

The governance structures of national health and social care data collections in Ireland vary greatly. Some have been established on a statutory footing, for example, NCRI, whilst others are managed by external bodies or agencies on behalf of the Health Service Executive (HSE). For example, EUROCAT (a network for the surveillance of congenital anomalies) is run from three different sites in Ireland, which are funded by the HSE. However, each site is also subject to the rules and guidelines of the European EUROCAT network. The Health Information Unit within the Economic and Social Research Institute is responsible for managing the Hospital In-Patient Enquiry (HIPE) System, but it is under contract from the Department of Health to do this work.

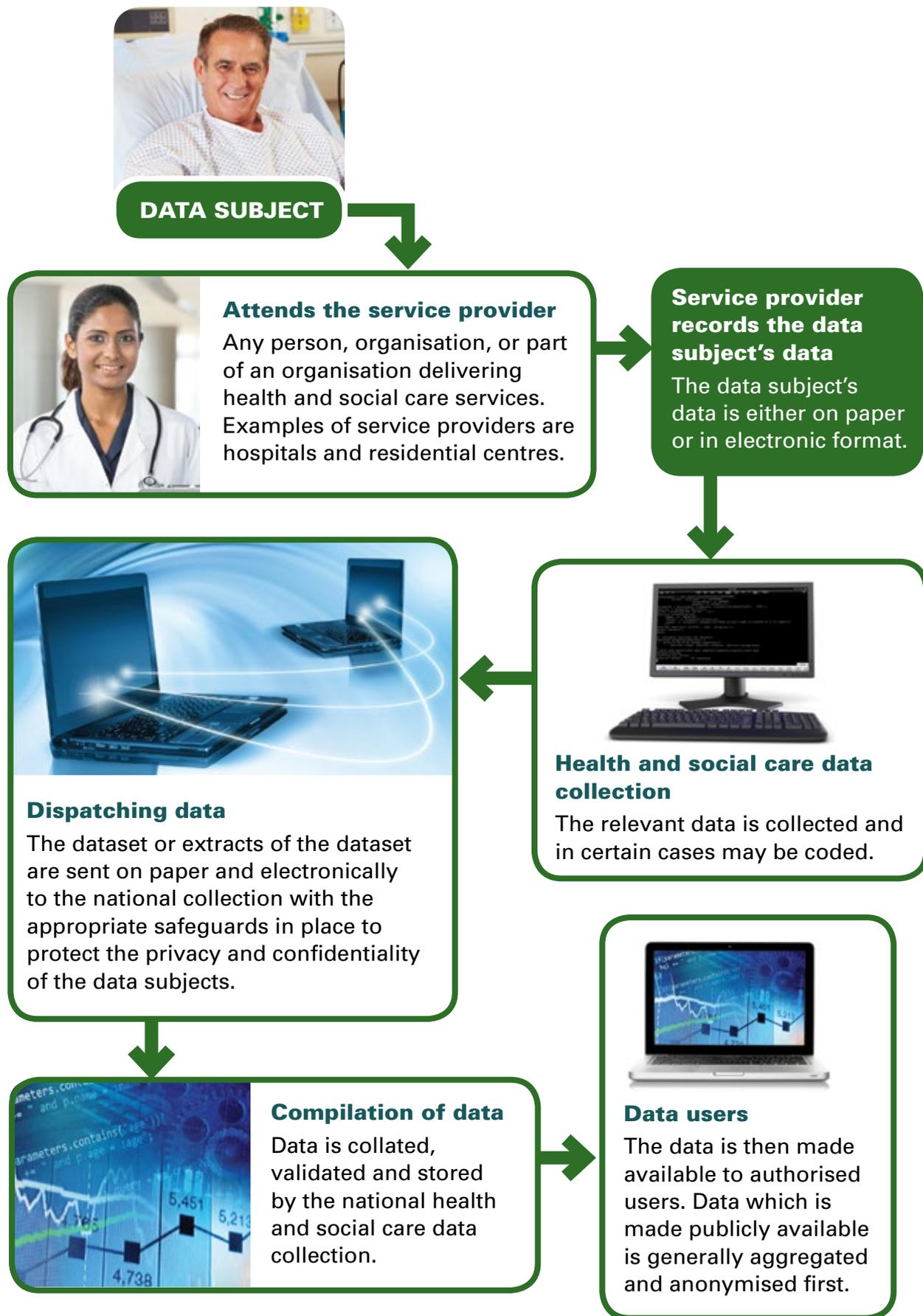
For this reason, we have aimed these guiding principles primarily at the management units/ organisations/ agencies responsible for management of the national collections. The term '**managing organisation**' is used throughout the document to convey the variety of arrangements in place for the national data collections.

The **managing organisation** of the national data collection is the organisation, agency, the responsible managing unit, institution or group with overall responsibility for the national data collection. Examples include the Economic and Social Research Institute (ESRI) in the case of HIPE, and the Health Research Board in the case of the National Intellectual Disability Database.

The term 'National Health and Social Care Data Collection' in this report is used to cover both the database itself as well as the system that supports the storage and management of the data.



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



## 2 Summary of the guiding principles

The following guiding principles incorporate national and international evidence and promote a practice that is up to date, effective and works towards greater consistency across all national data collections. These principles provide a basis for planning and measuring improvements as well as identifying and addressing gaps and quality issues. Therefore, the guiding principles will drive continuous improvement by providing achievable goals for the national data collections.

### **The benefits to national health and social care data collections of adopting these guiding principles include:**

- improved information governance to increase confidence in the confidentiality and privacy of health information
- the quality of information will be better assured
- the duplication of data entry effort will be reduced
- better use of public monies benefiting all users of health and social care services
- relevant information will be more accessible for informed decision making
- an increase in the reliability of information which will facilitate more strategic performance monitoring and planning
- improved ability to compare data and monitor trends over time
- health and social policies based on better information
- clear information on the limitations or restrictions of the data provided
- better health and social care data and information leading to better health and social care outcomes for individuals.

The Authority recognises that there is a wide variance in the size, structure and function of each national health and social care data collection. Therefore while the implementation of the principles should be proportionate to the size and complexity, they nevertheless constitute the key requirements for all national collections irrespective of size and complexity.

## The 8 Guiding Principles for National Health and Social Care Data Collections in Ireland

### PRINCIPLE 1

### GOVERNANCE ARRANGEMENTS

Formalised governance arrangements are in place to ensure that the objectives of the national health and social care data collection are met.

### PRINCIPLE 2

### STATEMENT OF PURPOSE

The managing organisation of the national health and social care data collection maintains a publicly available statement of purpose, setting out how it will achieve its stated objectives.

### PRINCIPLE 3

### LEGISLATION AND STANDARDS

The managing organisation of the national health and social care data collection is compliant with relevant legislation and standards.

### PRINCIPLE 4

### USE OF RESOURCES

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

### PRINCIPLE 5

### USE OF INFORMATION

The information produced by the national health and social care data collection is accessible to data users in line with legislation and disseminated to optimise its benefit.

### PRINCIPLE 6

### DATA QUALITY

The effectiveness of the national health and social care data collection in meeting its objectives is systematically monitored, evaluated, and continuously improved to ensure data quality.

### PRINCIPLE 7

### INFORMATION GOVERNANCE

The managing organisation of the national health and social care data collection has effective arrangements in place for information governance which protect the rights of people about whom it holds information.

### PRINCIPLE 8

### WORKFORCE

The managing organisation of the national health and social care data collection plans, organises and manages its workforce to deliver its objectives.

# 3 Guiding Principles for National Health and Social Care Data Collections

## 3.1 Governance arrangements

### PRINCIPLE 1

### GOVERNANCE ARRANGEMENTS

Formalised governance arrangements are in place to ensure that the objectives of the national health and social care data collection are met.

Governance and management are the organisational arrangements that provide the framework to ensure that the national health and social care data collection achieves its objectives. 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 set out the daily operations creating a culture which ensures that the processes and procedures that work towards achieving the objectives and fulfil the purpose of the resource are developed, implemented and adhered to. There should be a unified, coordinated focus of the objectives and purpose of the national health and social care data collection.

#### **The following are examples of the governance and management structures that a national data collection should have in place:**

- a named individual within the managing organisation who has overall responsibility and accountability for the national collection, for example, a chief executive officer or equivalent
- an oversight committee that develops the strategic direction and ensures that the mission and values are upheld. The oversight committee should include representatives for all stakeholders including data subject(s), data quality and data user(s) representatives
- a management committee that is responsible for focusing on the operational functions. For example, a clinical data collection management committee could be made up of the senior management in the data collection, including the chief executive or equivalent, a clinician and a data quality representative
- a documented organisational chart that clearly shows the structure and hierarchy within the data collection

- the responsibilities and accountabilities of the workforce should be documented and communicated to the workforce
- strategic business plans to achieve the aims and objectives of the data collection. The oversight committee and management should ensure these plans include current and future needs.

Appropriate governance arrangements will ensure that robust operational procedures and processes are in place, clearly communicated, and easy to access for everyone involved in the data collection.

**The following are examples of what a national health and social care data collection should implement as part of its governance arrangements:**

- regular assessment of the data collection to ensure it is aligned with its statement of purpose
- ensure quality data is collected, the data is evidence-based, and aligned with the information needs of the population covered by the data collection
- design and implement a data quality framework
- ensure the data quality framework facilitates improvement in data quality
- have policies and procedures to achieve the objective(s) of the data collection, for example, having policies and procedures that guide the workforce in good information governance practices
- ensure that workforce planning is in place, that the workforce is aligned to meet the purpose and objectives of the data collection, and that development of workforce skills and competencies is actively encouraged
- conduct regular risk assessments to ensure compliance with legal and regulatory requirements take place
- implement formalised agreements with all third parties in order to ensure that there are no ambiguities around timelines, deliverables, responsibilities and accountabilities.

## 3.2 Statement of purpose

### PRINCIPLE 2

### STATEMENT OF PURPOSE

The managing organisation of the national health and social care data collection maintains a publicly available statement of purpose, setting out how it will achieve its stated objectives.

A **statement of purpose** succinctly captures why the data collection exists and what it does. The statement of purpose should be reviewed regularly and updated as required to ensure that it reflects any changes to the objectives and aims of the data collection. For example, it may be necessary to add new data items in order to fulfil new requirements. It is important that the managing organisation of the national collection maintains an awareness of emerging information needs and be prepared for the future requirements of the population they serve. An example of a statement of purpose is provided in Appendix 2.

## 3.3 Legislation and standards

### PRINCIPLE 3

### LEGISLATION AND STANDARDS

The managing organisation of the national health and social care data collection is compliant with relevant legislation and standards.

Oversight committees (or equivalent) must be aware of, and adhere to, the appropriate national and international, general and health-specific legislation that pertain to their organisation in respect of their obligation as managers of the national collection. Examples of legislation and standards that are relevant to national data collections can be found in Appendix 3.

The managing organisation should have a process in place to ensure that it is aware of the enactment, modification or repeal of any legislation relevant to it as it relates to its role in managing the data collection. A 'risk register' should be in place to ensure compliance with legislation.

## 3.4 Use of resources

### PRINCIPLE 4

### USE OF RESOURCES

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

The managing organisation responsible for 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 must make sure that its resources are adequate to ensure the sustainability, continual relevance and maximum impact of the data for which it is responsible. Resources include human, physical, financial and natural resources.

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 data collection. The allocation of resources is therefore a fundamental factor in the delivery of quality data.

The following are examples of ways of working toward efficient use of resources:

- where possible, data collections should work with each other to reduce and remove duplication and develop greater efficiencies
- consultation with the workforce should take place, to encourage ideas and suggestions on ways to gain the greatest value from the available resources
- consultation with data users to encourage ideas and suggestions on how to gain the greatest efficiencies from their resources
- the management team should develop annual plans based on priorities and available resources of the data collection.

## 3.5 Use of information

### PRINCIPLE 5

### USE OF INFORMATION

The information produced by the national health and social care data collection is accessible to data users in line with legislation and disseminated to optimise its benefit.

Each national collection holds a rich source of data. In order to gain the greatest benefit from the data, it needs to be accessible and used. National data collections have an obligation to make sure that the use of their data is optimised to achieve the best value for money, and provide the greatest benefit to users in order to maximise health gain.

#### 3.5.1 Primary and secondary use of health information

All data collections contain records about individuals (data subjects) who are using or have used health and/or social care services. In the vast majority of cases these records contain personal information as defined in the Data Protection Acts – even though they may only release de-identified (non-personalised) data. When personal health information is collected by the service provider from the data subject or from other sources on the data subject's behalf, for the main reason of providing health and social care, this is called the primary purpose.<sup>(16)</sup>

Primary information is used to provide health or social care to the data subject. Secondary use of information relates to information collected in the course of providing care, being used for purposes other than direct service-user care. Secondary uses of information include managing, delivering, auditing, evaluating existing or potential health services, for planning purposes and for research.

Most national data collections are regarded as secondary rather than primary sources of information, although the data they contain is generally sourced from primary data.

Table 2 provides some examples of current secondary uses of information.

**Table 2. Examples of secondary use of data in health and social care data collections**

Health and social care national data collection	Purpose
Hospital In-Patient Enquiry (HIPE)	Primary data is taken from the healthcare records of data subjects by HIPE data collectors who code the data and enter it into the HIPE system. The coded data is then used for secondary purposes, for example, strategic planning, measuring care provided by acute hospital services and research.
National Intellectual Disability Database (NIDD)	Primary data is collected by service providers in order to provide comprehensive care to all those who use/need disability services. The Health Research Board has access to a subset of this information via the National Intellectual Disability Database to inform national and regional planners of these services by providing information on trends in demographics, current service use and future service need.
National Cancer Registry Ireland (NCRI)	Tumour registration officers collect data on behalf of NCRI from the data subjects' healthcare record and laboratory information systems, and once collated the data is used for a wide variety of secondary uses, including planning for cancer care services, policy development, education, research and identifying the financial impact of cancer in Ireland.

### 3.5.2 Making data available

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. In order to maximise the potential of the collection to support improvement in quality and safety of health and social care as well as health gain generally, it is essential to promote, encourage and facilitate the use of the data. Depending on the nature and resources available to the managing organisation, data can be made available through a variety of different mechanisms. These can range from, for example, publishing an annual report based on the data in the collection – such as the annual report on Activity in Acute Public Hospitals in Ireland published by the ESRI<sup>(17)</sup> or the annual report on surveillance of notifiable diseases in Ireland from the Health Protection Surveillance Centre<sup>(18)</sup> – to providing extracts to users on request, to providing tools to allow users to access the data itself (e.g. via the HIPE Online Portal [HOP] or the NCRI data analysis tools).

Whatever the mechanism used for dissemination, it is important that it is done on a timely basis without undue delay. It may be appropriate, for example, in certain circumstances to release provisional data. In any event, national health and social care data collections should publish a calendar which sets out the planned schedule for the release of data/reports.

To enable and promote appropriate use of data as much as possible, the national data collection can:

- Publish data quality audits and quality assurance results to assure data users of the merit and worth of its data.
- Publish its use of data policy on the Internet, which includes information about how to access the data.
- Ensure all detailed data requests are subject to a review by an appropriate committee before data is released, and that the committee members' names are publicly available.
- Have clear procedures in place that describe how to access data from the initial request for data through to data generation and final dissemination. This allows a data user to clearly see the stages of the information request.
- Have clear procedures in place in the event that an access request is denied.
- Encourage data providers to use information, for example, to audit and monitor the work of their organisations.
- Provide a data dictionary to enable data users to accurately use and interpret the data.

- Clearly communicate the terms and conditions of using their data, including the type of analysis, the purpose for using the data, the primary and secondary source of the data, the organisation/researcher requesting the data, proposed research outputs, the security and confidentiality measures that are in place.
- Include in an annual report its new initiatives to encourage usage of data.
- Monitor/ audit the actual usage of its data.

Table 3 sets out examples of how national collections can maximise the use of their data.

**Table 3. Examples of how to maximise the use of information from national data collections**

- Make the data available and report on the data within a reasonable time frame.
- Publish the use of data policy on the Internet, which includes information about how to access the data and terms and conditions for using the data.
- Have clear procedures on the process to access data from the initial request for data through data generation and final dissemination.
- Encourage use of data by data providers, for example, the use of clinical statistics by hospitals to monitor their own performance.
- Specialist training is provided for certain data users if required.
- Provide a data dictionary to enable data users to accurately use and interpret the data.
- Publish a calendar on an annual basis that identifies the intended dates to publish standard reports or datasets.

## 3.6 Data quality

### PRINCIPLE 6

### DATA QUALITY

The effectiveness of the national health and social care data collection in meeting its objectives is systematically monitored, evaluated, and continuously improved to ensure data quality.

The primary objective of each data collection is to inform the population it serves and its data users in order to improve upon the quality of care and service provided. In order to achieve this objective there must be full confidence and trust in the data collection, and this can only be achieved if the data meets all of the dimensions of quality data outlined in Figure 2.

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

The Authority has produced a booklet on data quality, entitled *What you should know about Data Quality: A guide for health and social care staff*. This booklet can be found on the HIQA website, [www.hiqa.ie](http://www.hiqa.ie). The booklet provides detailed explanations and examples for each of these dimensions. Figure 2 outlines the dimensions of data quality and Table 4 provides a description of each term.

**Figure 2. Dimensions of data quality**



**Table 4. Description of data quality dimensions**

Dimension	Description
<b>Accuracy</b>	Accurate data refers to how closely the data correctly captures what it was designed to capture.
<b>Completeness</b>	Complete data is data that has all those items required to measure the intended activity or event.
<b>Legibility</b>	Legible data is data that the intended users will find easy to read and understand.
<b>Relevance</b>	Relevant data meets the needs of the information users.
<b>Reliability</b>	Reliable data is collected consistently over time and reflects the true facts.
<b>Timeliness</b>	Timely data is collected within a reasonable and agreed time period after the activity that it measures and is available when it is required and as often as it is required.
<b>Validity</b>	Valid data is collected in accordance with any rules or definitions applicable for that type of information. These rules check for correctness and meaningfulness before data is used.

### 3.6.1 The benefits of data quality

Decisions are only as good as the information on which they are based. Quality health and social care is dependent on the access to and use of quality data. Quality data strives to exhibit the dimensions set out above.

The benefits of quality data include:

- Complete, accurate data facilitates strategic, national and local planning for health and social care.
- Policy makers have reliable, timely data to inform the development of national and local policies.
- Quality data contributes to research by providing accurate evidence that is used to develop and improve population health and social care.
- There is an accurate overview of the characteristics of the target population allowing health and social care providers and planners to put appropriate preventative or promotional measures in place.

### 3.6.2 Examples of how to achieve data quality

The following provides some examples of steps that data collections can take to achieve quality data.

- Assign a named person responsible for data quality.
- Uniquely identify all data subjects, where possible.
- Have policies and procedures in place ensuring best practice on all aspects of data quality including data collection, validation, storage and processing.
- Regular data quality training is provided to the workforce.
- Validation and other data quality spot-checks are regularly carried out to support the collection of complete and valid data.
- Key performance indicators (KPIs) are in place to provide objective measures of data quality.
- Records retention and disposal policies are based on legislation and best practice.

### 3.6.3 Standards for data quality

The use of data standards ensures that there is consistency and comparability, and it promotes responsibility and accountability for the quality of data collected and reported on by national data collections.

Standards work towards ensuring the greatest value and impact is achieved for improving population health and social care. In certain cases the data collections may be mandated to comply with specific standards, but in others they can be helpful sources of best practice. The following standards work towards ensuring there is a common, consistent understanding of each data variable. They also help with sharing data and supporting interoperability.

In the event of planning an upgrade or developing a new system, the managing organisation of national health or social care data collections should confer with the Authority and together determine the most advisable standards to adopt or adapt to meet their needs. The main standards are data dictionaries, classifications and clinical terminologies.

### 3.6.4 Data dictionary

The purpose of a data dictionary is to standardise definitions for data items and therefore ensure consistency in the collection of data.<sup>(19)</sup> In order to ensure the validity and reliability of the data items collected, national health and social care data collections should have a data dictionary in place that clearly defines the data items it collects and provides their associated definitions. A data dictionary provides a clear summary of all data items captured by the national data collection and is a significant step towards removing the possibility of confusion or ambiguity for each data item. Appendix 4 contains a proposed structure of a data dictionary, and explanatory notes.

### 3.6.5 Standard terminological systems

The objective of a standard terminological system is to establish a standard language for health and/or social care information. It removes the possibility for ambiguity, misinterpretations and differing interpretations of the same term. There are two main categories of standard terminological systems in use in healthcare, classifications and clinical terminologies.

#### Classification systems

Classification systems provide a uniform, meaningful and relevant framework that is used as a common language. The benefits of using classification systems include:

- organisation of information into standard groupings of diseases, which allows for easy storage, retrieval and analysis of health information
- sharing and comparing health information between countries, regions, hospitals, and other healthcare settings
- provide the basis for the compilation of national statistics e.g. mortality and morbidity statistics.

Examples of classification systems are the International Classifications of Diseases (ICD) 9 and 10 and national extensions ICD-10-AM and ICD-9-CM.

#### Clinical terminologies

Clinical terminologies are a structured collection of descriptive terms for use in clinical practice.<sup>(20)</sup> Terminologies are designed to be 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.

Examples of clinical terminologies are SNOMED CT (Systematized Nomenclature Of Medicine - Clinical Terms) and READ codes.

The benefits of using clinical terminologies are:

- more accurate and precise recording of clinical information at the point of care
- improved retrieval of relevant clinical and social care information
- enabling clinical audit
- monitoring the responses to treatments providing.

While many national data collections may have been developed before the widespread use of standard terminological systems, in the event of planning an upgrade or developing a new system, terminological systems that will meet the current and future needs of the data collection should be considered.

## 3.7 Information governance

### PRINCIPLE 7

### INFORMATION GOVERNANCE

The managing organisation of the national health and social care data collection has effective arrangements in place for information governance which protect the rights of people about whom it holds information.

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 people who use health and social care services.

The Authority has published detailed guidance on best practice for information governance. The publications available include a booklet, *What you should know about information governance: A guide for health and social care staff*, and more detailed guidance, *Guidance on information governance for health and social care services in Ireland*, both of which can be found on [www.hiqa.ie](http://www.hiqa.ie).

#### 3.7.1 Personal health and social care information

Some data collections have the legislative remit to collect personal health and social care information, for example the National Cancer Registry Ireland collects name, address, diagnosis and treatments, and consent is not required. Other data collections do not collect name and address but collect personal information such as date of birth, partial address or diagnosis.

While data is pseudonymised by some data collections – i.e. the data collected limits the degree of identifying personal characteristics, such as using initials or by coding certain data variables – this data is still considered to be ‘personal information’ under the Data Protection Acts as it could potentially still identify the person.

Personal health and social care information ceases to be ‘personal’ only when it has been anonymised to the point that it can no longer be linked to a known individual, i.e. the removal of all possible identifiers and ensuring no other data or combinations of data could identify the individual.<sup>(21)</sup> However, it is difficult to fully anonymise data, as typically there is some link back to the individual or a mechanism to reverse any coding that has taken place in order, for example, to audit the quality of the data.

Once information has been irrevocably anonymised, the provisions of the Data Protection Acts no longer apply.<sup>(21)</sup> Data collections are obliged under the Data Protection Act and Freedom of Information Acts<sup>(22, 23)</sup> to ensure:

- data subjects consent to their personal data being collected
- privacy, confidentiality and security of personal health and social care information is ensured
- data subjects can gain access to their personal information.

The Data Protection Acts 1988 and 2003 place an obligation on the managing organisations of data collections to have appropriate security measures in place to prevent unauthorised access to, or unauthorised amendment, disclosure or destruction of the data.

### 3.7.2 Consent

There are two types of recognised consent, explicit and implied.

**Explicit consent** is consent that is clearly unmistakably stated. It may be obtained in writing, verbally, or in any other form where the consent is clearly communicated. Where such consent is required it should always be recorded, dated and preferably signed and witnessed. **Implied consent** means that consent can be inferred by the actions of the data subject. For example, a referral from a general practitioner (GP) to a consultant implies consent that information will be shared both ways. All consent must be informed to be valid.

All individuals should be in control of how their information is used. Data subjects should also 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 data collection if they choose not to.

The basic principle of using personal health and social care information is that the data subject is aware of how their data is being used.

If the data collector does not have direct contact with the data subject, tools such as a statement of information practice can be used to communicate with the data subjects (see 3.7.3).

The appropriate contact person to gain access to the data subject's information should be clearly outlined in the statement of information practice, the data collection's website and/or patient information leaflets.



Table 5 outlines a number of the steps that the managing organisation of a data collection can put in place to ensure good information governance practices are in place. It should be noted that this list is not exhaustive.

**Table 5. Some examples of good information governance practices**

- a named person responsible for information governance
- policies and procedures are based on best practice for all aspects of information governance
- regular training for the workforce on relevant information governance policies and procedures
- a statement of information practice or similar tool to communicate with data subjects
- formalised agreements to set out the strict procedures with third parties regarding access to data subjects' data
- ability to audit all access to data subjects' information
- paper and electronic files containing data subjects' information are stored securely when not in use and have a specified retention period
- individual login details and passwords are assigned to those in the workforce who have access to data subjects' information
- login details and passwords are regularly updated and redundant logins are removed.

### 3.7.3 What is a statement of information practice?

A statement of information practices is a generic document made available to service users. It should be clearly displayed in hospitals, GP surgeries and by all other health and social care providers outlining information practices undertaken by that particular service.

A statement of information practice should:

- set out what information is collected
- explain how the information is used
- identify with whom the information is shared
- explain the purpose of sharing the information
- identify the safeguards that are in place to protect the information
- detail how data subjects can access information held about themselves
- outline the procedures for making a complaint.

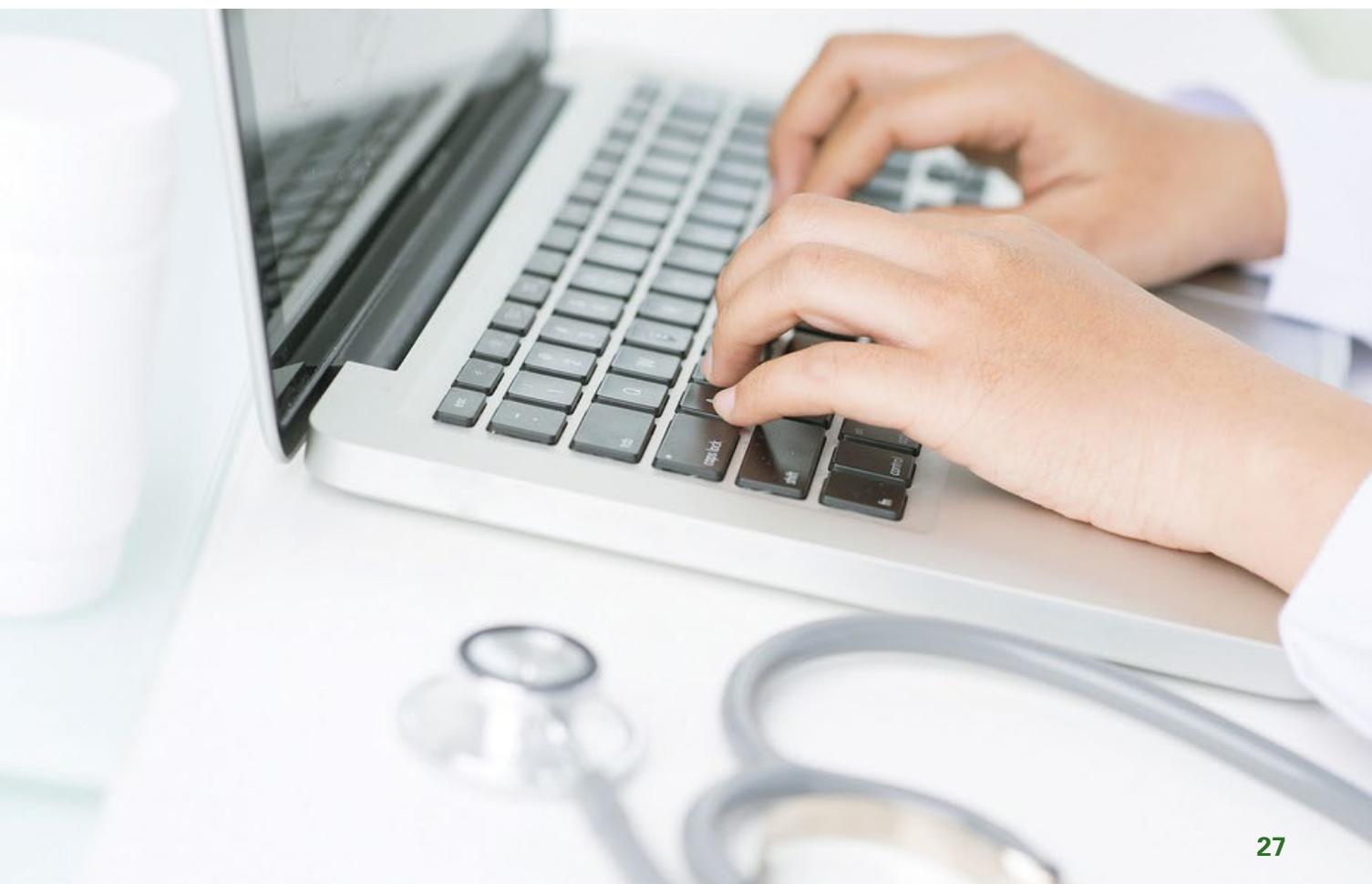
### 3.7.4 Privacy Impact Assessment (PIA)

With so much health and social care information being collected, used and shared by national data collections, it is important that steps are taken to protect the privacy of each individual and ensure that sensitive personal health information is handled legally, securely, efficiently and effectively in order to deliver the best possible care.

**Privacy impact assessments** (PIAs) are a common tool used internationally to protect and enhance individuals' privacy. PIAs are used across all sectors but are particularly useful for healthcare providers in assisting with the identification of potential risks in the collection and use of personal health information as this information is categorised as being sensitive. The primary purpose of a PIA is to protect the rights of individuals.<sup>(24)</sup>

The PIA process begins at the planning stage of any new or significantly amended programme, initiative, system or project that involves the collection, use or disclosure of personal health and social care information. The process involves the evaluation of broad privacy implications of projects and relevant legislative compliance. Where potential privacy risks are identified, a search is undertaken, in consultation with stakeholders, for ways to avoid or mitigate these risks. The management of privacy risk is an ongoing process, therefore management should ensure that there is a process to conduct, review and update PIAs on a regular basis.

HIQA has provided detailed guidance on how to conduct a PIA which is available on the Authority's website at [www.hiqa.ie](http://www.hiqa.ie).<sup>(24)</sup>



## 3.8 Workforce

### PRINCIPLE 8

### WORKFORCE

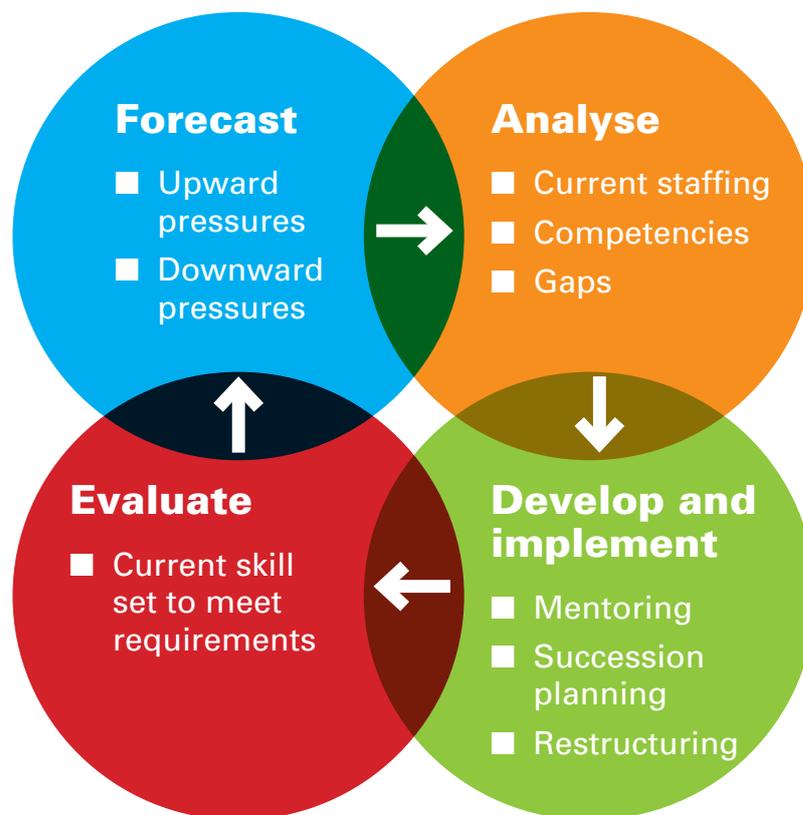
The managing organisation of the national health and social care data collection plans, organises and manages its workforce to deliver its objectives.

The workforce is made up of all those who work in, for, or with the national health or social care data collections.

The workforce is the core of each data collection. They are integral to the provision of quality data which contributes to the work of the national collection to improve population health and wellbeing. National collections require staff with specialist skills and qualifications to meet their objectives and produce quality data. When the management team set the objectives of the national collection, it must determine the workforce requirements to deliver on these objectives. The individual members of a workforce must be skilled and competent and the workforce as a whole must be planned, configured and managed to achieve these objectives. If the managing organisation has accurately planned for the skills and competencies that it requires within its allocated budget, the national collection is better prepared to achieve its objective.

#### 3.8.1 Workforce planning

Workforce planning is an essential tool to shape the national data collection to deal with expected and unexpected events. It should identify the optimum structure of the national data collection, and the development needs of the workforce. A national data collection operates most effectively when the right people with the right knowledge, skills and competencies are deployed appropriately to deliver quality data. A model for how to conduct a workforce planning process is outlined in Figure 3.

**Figure 3. Example of how to conduct a workforce planning process**

The following are examples of the benefits of workforce planning for a national data collection:

- Have a strategy in place for allocating resources in a manner that will ensure the objectives of the national health and social care data collection are met.
- Prepare for contingencies that could prevent the national collection from meeting its objectives.
- Have a strategic basis to allow the managing organisation to make business plans.
- Be proactive rather than reactive in anticipating the needs of the workforce of the national collection.
- Maximise the effectiveness of the national collection.

Examples of how to put plans in place for an appropriate workforce are outlined in Table 6.

**Table 6: Examples of how to plan for an appropriate workforce**

- Ensure specialist skills required are in place or accessible as required.
- Be aware of potential *downward* pressures, i.e. events which will decrease the need for staff, for example, advances in information technology.
- Be aware of potential *upward* pressures, events which will increase the need for staff. For example, a significant increase in the population served.
- Conduct a gap analysis every three to five years to identify any differences in the demand and supply of the workforce.
- Review a full range of options when filling a skills gap, for example, is it more sensible to up-skill and train current staff, or to hire a new staff member or outsource the work?
- Succession planning needs to be in place for key skills and management positions.
- Be flexible.

## 4 Appendices

### Appendix 1: Members of the National Health Information Sources Advisory Group

Professor Jane Grimson (Chair), Health Information and Quality Authority (HIQA)

Dr Kevin Balanda, Institute of Public Health

Alan Cahill, Department of Health

Dr Rita Collins, Healthcare Informatics Society of Ireland Nurses and Midwives Special Interest Group

Dr Harry Comber, National Cancer Registry Ireland

Peter Connolly, Health Service Executive (HSE)

Sarah Craig, Health Research Board

Dr Davida de la Harpe, HSE

Susan De Mulder, HIQA

Berni Dunne, Central Statistics Office

Professor Tom Fahey, Royal College of Surgeons in Ireland

Dr Barbara Foley, HIQA

Rachel Flynn, HIQA

Bernie Hyland, HSE

Dr Howard Johnson, Royal College of Physicians of Ireland

Vincent Jordan, HSE

Cathriona Molloy, Patient Focus

Patrick Moore, HIQA\*

Dr Deirdre Mulholland, HIQA\*\*

Tracy O'Carroll, HIQA

Dr John O'Donoghue, University College Cork

Dr Keith Perdue, Irish College of General Practitioners

Mr Kieran Tangney, Royal College of Surgeons in Ireland

Professor Miriam Wiley, Economic and Social Research Institute

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\* Patrick Moore left the Advisory Group in October 2012.

\*\* Dr Deirdre Mulholland left the Advisory Group in December 2012.

## Appendix 2: Proposed statement of purpose

A proposed outline structure of a statement of purpose is shown here:

- full legal name of the national health and social care data collection
- website
- contact details
- name of responsible managing agency/ unit/ organisation
- year commenced operation
- overall function and purpose
- aims and objectives
- list of service/ data providers
- commissioning organisation
- legal basis for establishment
- source of funding
- governance and management structure
- national legislation and standards that national data collection must adhere to
- international legislation and standards that national data collection must adhere to
- version number
- date the statement of purpose is effective from
- signatures of all parties responsible for statement of purpose.

## Appendix 3: Examples of relevant legislation

The following are examples of just some of the national legislation that is relevant to national health and social care data collections; it is not intended to be a definitive list. National data collections should ensure that they are aware of and comply with all relevant legislation.

### **Legislation, regulations, constitutional framework**

Bunreacht na hÉireann. 1937

Data Protection (Access Modification) (Health) Regulations, 1989

Health (Provision of Information) Act, 1997

Infectious Diseases (Amendment) Regulations 2011

Infectious Diseases Regulations, 1981

Data Protection (Amendment) Act 2003

Data Protection Act, 1988

Freedom of Information (Amendment) Act 2003

Freedom of Information Act, 1997

Health Act 2007

Health Act, 1947

Statistics Act, 1993

### **Data Protection Acts 1988 and 2003**

In 1988, the Data Protection Act<sup>(25)</sup> was passed in order to implement the 1981 Council of Europe Convention for the Protection of Individuals with Regard to the Automatic Processing of Personal Data.<sup>(26)</sup> The Act regulates the collection, processing, keeping, use and disclosure of computerised personal information relating to living identifiable individuals. The Data Protection Act of 2003<sup>(32)</sup> strengthened individuals' rights (as data subjects) in relation to their personal information and imposed more obligations on those who keep such information (data controllers). The Data Protection Act of 2003 also extends data protection law to manual records and introduces special provisions in relation to categories of sensitive information, including personal health information.

### **The Freedom of Information Acts 1997 and 2003**

The Freedom of Information Act 1997,<sup>(22)</sup> as amended by the Freedom of Information Act 2003,<sup>(23)</sup> grants individuals the legal rights to access both personal and non-personal information and to have their personal information amended if it is inaccurate. The Office of the Information Commissioner has been established to review decisions by, and practices of, public bodies in addition to the operation of the Acts.<sup>(22)</sup>

### **European Statistics Code of Practice 2011**

The European Statistics Code of Practice<sup>(27)</sup> is relevant to all national collections reporting national statistical data to the Department of Health for submission to Eurostat.

## Appendix 4: Proposed data dictionary structure

Data dictionary structure	Explanation of term
<b>Dataset</b>	This relates to the group of data elements to which a particular data element belongs. For example, in the case of name, address, date of birth – each of these data elements are part of a demographic dataset.
<b>Data element name</b>	This is the name of the data element, which should explain what it refers to.
<b>Data element ID number</b>	This is a reference number for the data element.
<b>Definition</b>	The definition should clearly explain what is meant by the data element.
<b>Context</b>	This should explain the context in which the data element is collected – what it is used for?
<b>Data type</b>	Data type refers to the type of data that is recorded for each particular data element – for example, it could be numeric, alpha-numeric or a coded value.
<b>Field length minimum</b>	The minimum number of characters to be entered.
<b>Field length maximum</b>	The maximum number of characters to be entered.
<b>Instruction for answering field</b>	This section provides information to the person filling in the information – for example, if the information is to be derived directly from the person to whom it relates or obtained from service users' records.
<b>Codes and values</b>	This field should give clear definitions of each of the codes and values that are captured as part of the data element.
<b>Verification rules</b>	This section outlines ways in which the accuracy of the data element can be verified.
<b>Comments/guidelines</b>	This section provides guidance to the person collecting the data element.
<b>Related data elements</b>	Related data means any other data elements that are linked to or closely related to the particular data element in question – for example <i>referral status</i> and <i>outpatient appointment</i> are related data elements.

## 5 Glossary of terms

Term	Explanation
<b>Anonymised data</b>	All identifiers have been removed from personal data ensuring the data can no longer be linked to the individual.
<b>Data</b>	The building blocks for information. These can be described as numbers, symbols, words, images and graphics that have been validated but yet to be organised or analysed. <sup>(28)</sup>
<b>Data collector</b>	A data collector is responsible for collecting and in some instances coding the data for a national health and social care data collection.
<b>Data controller</b>	A data controller is the individual or the legal person who either alone or with others, controls and is responsible for the keeping and use of personal information on computer or in structured manual files.
<b>Data dictionary</b>	'A descriptive list of names (also called representations or displays), definitions, and attributes of data elements to be collected in an information system or database. The purpose of the data dictionary is to standardize definitions and therefore have consistency in the collection of data.' <sup>(19)</sup>
<b>Data processor</b>	A data processor processes personal data, but does not exercise control over the personal data. Their responsibilities instead concern the necessity to keep personal data secure from unauthorised access, disclosure, destruction or accidental loss. <sup>(29)</sup>
<b>Data quality</b>	Data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner. <sup>(30)</sup>
<b>Data subject</b>	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.

Term	Explanation
<b>Data user</b>	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, Department of Children and Youth Affairs, academic institutions and the general public.
<b>Database</b>	A collection of data that is organised so that its contents can easily be accessed, managed, and updated.
<b>Disaster recovery</b>	The process by which you resume business after a disruptive event such as a natural or human-induced disaster.
<b>Disease register</b>	A database that stores clinical and administrative data on patients with a specific disease.
<b>Formalised agreement</b>	This is a formal agreement reached between a number of parties clearly outlining the roles and responsibilities of each party.
<b>Primary Care Reimbursement Service (PCRS)</b>	A database of payments made to healthcare professionals such as doctors and pharmacists who provide services and drugs to public patients.
<b>HL7</b>	An organisation which provides a technical framework and standards for the exchange of electronic messages.
<b>Hospital In-Patient Enquiry (HIPE)</b>	A computer-based system designed to collect demographic, clinical and administrative data on discharges and deaths from acute hospitals in Ireland.
<b>Information</b>	Information is data that has been processed or analysed to produce something useful.
<b>Information and communication technology (ICT)</b>	The tools and resources used to communicate, create, disseminate, store, and manage information electronically.

Term	Explanation
<b>Information governance</b>	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.
<b>Interoperability</b>	'The ability of health information systems to work together within and across organisational boundaries in order to advance the effective delivery of healthcare for individuals and communities.' <sup>(31)</sup>
<b>Managing organisation of the national health and social care data collection</b>	The organisation, agency, the responsible managing unit, institution or group with overall responsibility for the national data collection. Examples include the Economic and Social Research Institute (ESRI) in the case of HIPE, and the Health Research Board in the case of the National Intellectual Disability Database.
<b>Minimum dataset</b>	A minimum dataset is the least agreed number of data elements collected for reporting purposes.
<b>National health and social care data collections</b>	National repositories of routinely collected health and social care data, including administrative sources, censuses, surveys, and national patient registries in the Republic of Ireland.
<b>National Intellectual Disability Database (NIDD)</b>	A set of information that outlines the specialised health services currently used or needed by people with intellectual disability. <sup>(10)</sup>
<b>National Psychiatric Inpatient Reporting System (NPIRS)</b>	A database which records data on all admissions to, and discharges from, psychiatric inpatient facilities in Ireland. <sup>(10)</sup>
<b>Opt-out</b>	The ability of a data subject to have their data removed or not included in a national health or social care data collection.
<b>Performance indicators</b>	Specific and measurable elements of practice that are designed to assess key aspects of structures and processes and to assess outcomes.
<b>Personal health information</b>	Personal information is data relating to an individual who is or can be identified either from the data or from the data in conjunction with other information that is in, or is likely to come into, the possession of the data controller. <sup>(25)</sup>

Term	Explanation
<b>Population health</b>	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.
<b>Privacy impact assessment (PIA)</b>	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. <sup>(24)</sup>
<b>Pseudonymised data</b>	The use of methods to replace personally identifiable information, for example, name, address, date of birth, with coding.
<b>Service level agreement</b>	An agreement between the service provider and third parties identifying the service and the parameters of same that the third party will provide to the service provider.
<b>Service provider</b>	Any person, organisation, or part of an organisation delivering health or social care services and contributing data to the national health or social care data collection, for example, a hospital, pharmacy, general practitioner, optician, screening services, residential care for older people, children's residential centres.
<b>Statement of information practices</b>	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.
<b>Statement of purpose</b>	A document which details the aims and objectives of the national health or social care data collection.
<b>Value for money</b>	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. <sup>(20)</sup>
<b>Workforce</b>	The combination of staff directly employed by the national health or social care data collection, and those who work on its behalf in other organisations.

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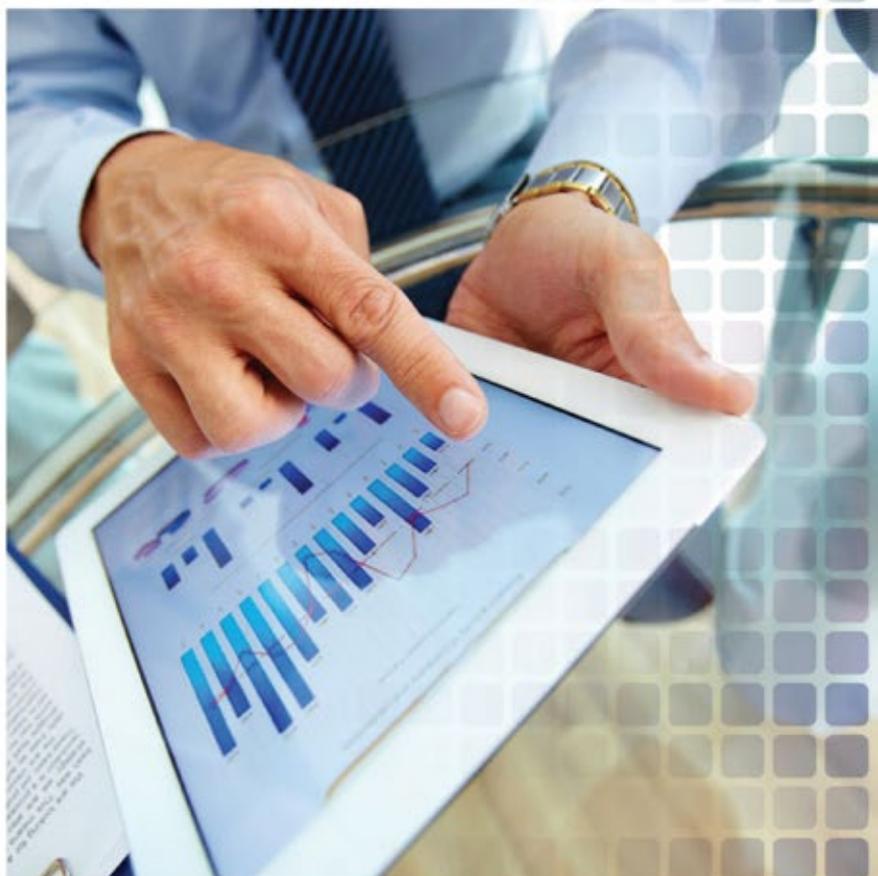
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