International review of national health and social care data collections

July 2016

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent authority established to drive high quality and safe care for people using our health and social care 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 Health Information function

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

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

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

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

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

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented with major gaps and silos of information which prevent the safe, effective, transfer of

information. This results in service users being asked to provide the same information on multiple occasions.

Information can be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, clear and trustworthy information on which to base our decisions. As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international evidence.

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements. In accordance with the Health Act 2007, (sections 8(1) (j) and 8(2) (d)), one of the key functions of the Authority is to set standards for all aspects of health information. It is on this basis that the Authority is undertaking this project. The purpose of this international review is to inform the development standards for national health and social care data collections in Ireland.

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Introduction

1.1 Background

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 of Ireland which collects comprehensive information on cancer incidence and deaths in Ireland and the Hospital In-patient Enquiry Scheme (HIPE) which collects demographic, clinical and administrative data on discharges and deaths from acute hospitals nationally.

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

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

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

The Health Information and Quality Authority (HIQA) recognizes the important role played by national health and social care data collections and the potential to significantly increase the contribution of these collections to improve the quality and safety of health and social care in Ireland. As such, HIQA prepared the following publications with the aim of contributing to improvements in the overall effectiveness and efficiency of the national health and social care data collections.

- International Review of Approaches Countries Have Taken to integrate National Health and Social Care Data Collections (November 2014)[1]

- Recommendations on a More Integrated Approach for National Health and Social Care Data Collections (November 2014)[2]
- Catalogue of National Health and Social Care Data Collections in Ireland (March 2014)[3]
- International Review of Data Quality (April 2011)[4]
- Identification of Themes for Standards for National Health Information Sources in Ireland (April 2011)[5]
- International Review of Health Information Sources (August 2011)[6]
- Draft Standards for National Health Information Resources (November 2011)[7]
- Statement of Outcomes Report on the outcome of the public consultation on the Draft Standards for National Health Information Resources (July 2012)[8]
- Guiding Principles for Health and Social Care Data Collections (May 2013).[9]

1.2 Definition

National health and social care data collections are defined as national repositories of routinely collected health and social care data, including administrative sources, censuses, and national patient registries in the Republic of Ireland.[3]

1.3 Legislative context

Under the Health Act 2007[10], the Health Information and Quality Authority (HIQA) has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies on health information, as follows:

Section 8(1)(i) to evaluate available information respecting the services and the health and welfare of the population.

Section 8(1)(j) to provide advice and make recommendations to the Minister for Health and Children and the Health Service Executive (HSE) about deficiencies identified by the Authority in respect of the information referred to in paragraph (i).

Section 8(1)(k) to set standards as the Authority considers appropriate for the HSE and service providers respecting data and information in their possession in relation to services and the health and welfare of the population.

It is under this remit that HIQA is undertaking this project. This report will inform the development of standards for national health and social care data collections in Ireland.

The draft Health Information and Patient Safety Bill,[11] as laid out in the General Scheme published in November 2015, will include a provision to allow the Minister for Health to designate certain national health and social care data collections as 'prescribed health information resources'. The Bill also provides for HIQA to set standards for these prescribed resources and sets out how HIQA should monitor compliance with such standards and advise the Minister of any contraventions in this regard.

1.4 Objective

The objective of this report is to review international experience and best practice with regard to the development of standards and guidance for national health and social care data collections in the countries reviewed. This report will provide an update to the International Review of National Health Information Resources[6] and the International Review of Approaches Countries Have Taken to integrate National Health and Social Care Data Collections, 2014.[1] The combined international evidence will inform the development of standards for national health and social care data collections, which will be finalized in 2016. The primary purpose for developing these standards is to ensure that national health and social care information is of the highest possible quality, the availability of which will ultimately drive improvements in patient safety.

1.5 Methodology

This report will provide an overview of the relevant information from previous international reviews which have been carried out by HIQA and an update on any developments made in relation to national health and social care data collections since 2014 for specific countries. It will focus on the governance and management structures in place for national collections, data quality arrangements, standards, guidelines, monitoring and regulatory approaches. The countries reviewed include:

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

The countries were chosen as a result of a desktop review which identified where developments had taken place in relation to their national health information landscape. 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 standards for national health and social care data collections in Ireland. Contact was made with experts in each country to gain clarification and further information.

A desktop review was also performed to gather other important European and international evidence regarding data quality assessment of national collections. An overview of this evidence is provided in section 1.6. This evidence will support the development of the standards for national health and social care data collections and will also provide guidance for assessing compliance with the standards.

1.6 Overview of international guidelines and recommendations regarding assessment of data quality of national data collections

A number of important international reports in relation to data quality assessment have been published in recent years. Documents in relation to assessing the data quality of statistical systems have been published by Eurostat and The European Statistical System. The themes of assessing and evaluating the data quality of national disease surveillance systems and national patient registries are addressed by The European Centre for Disease Prevention and Control, The Cross Border Patient Registries Initiative (PARENT) and the Agency for Healthcare Research and Quality (AHRQ) respectively. The following reports were identified during the course of this review and a summary of each is provided in this section.

- The European Statistics Code of Practice, 2011[12] was published by Eurostat and sets the standard for developing, producing and disseminating European statistics.
- The Quality Assurance Framework, 2015[13] was published by the European Statistical System and identifies possible activities, methods and tools that can provide guidance and evidence for the implementation of the European Statistics Code of Practice.
- The Handbook on Data Quality Assessment Methods and Tools, 2007[14] was also published by Eurostat and aims at facilitating a systematic implementation of data quality assessment in Europe.
- Data Quality Monitoring and Surveillance System Evaluation, 2014[15] was published by the European Centre for Disease Prevention and Control. It aims

to support processes for monitoring data quality and evaluating surveillance systems in EU/EEA Member States.

- The Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries, 2015[16] was published by EU Cross Border *PAtient REgistries INiTiative* (PARENT). The guidelines were created to provide practical and 'hands on' advice to set up and manage patient registries. Four basic categories of factors influencing registry's data quality are suggested in this report; governance, data quality, information quality and confidentiality, security and ethical issues.

- Registries for Evaluating Patient Outcomes: A user's guide, 2014[17] was published by the Agency for Healthcare Research and Quality (AHRQ). The goal of this document is to provide stakeholders in both the public and private sectors with information they can use to guide the design and implementation of patient registries, the analysis and interpretation of data from patient registries, and the evaluation of the quality of a registry or one of its components.

- The Template for a Generic National Quality Assurance Framework (NQAF) and the Guidelines to Accompany the Template, 2012[18] was published by the United Nations Statistics Division (UNSTATS). The aim of these documents is to develop a template for a generic national quality assurance framework, with accompanying guidelines, to assist countries that may wish to formulate and operationalize national quality frameworks of their own, or further enhance existing ones.

- The Code of Practice for Official Statistics, 2009[19] was published by the UK Statistics Authority. The code applies to all UK bodies that are responsible for official statistics. Compliance with the code is a statutory requirement on bodies that produce statistics that have already been designated as National Statistics.

1.6.1 The European Statistics Code of Practice, 2014 (Eurostat)

The European Statistics Code of Practice sets the standard for developing, producing and disseminating European statistics. The European Statistics Code of Practice is based on 15 principles. A set of indicators of good practice for each of the principles is provided to show how compliance can be demonstrated. It builds upon a common European Statistical System (ESS). The quality criteria for European Statistics are defined in European Statistical Law which states that to guarantee the quality of results European statistics shall be developed, produced and disseminated on the basis of uniform standards and of harmonised methods. The 15 principles of the

European Statistics Code of Practice covers three main areas, namely the institutional environment, the statistical production process and the output of statistics.[12] These principles can be seen in Table 1.

Table 1: European Statistics Code of Practice[12]

Main Area	Description	Principles
Institutional environment	Institutional and organizational factors have a significant influence on the effectiveness and credibility of a statistical authority developing, producing and disseminating European Statistics. The relevant issues covered in principle one to six are:	1. Professional independence 2. mandate for data collection 3. adequacy of resources 4. quality commitment 5. statistical confidentiality 6. impartiality and objectivity
Statistical production processes	European and other international standards, guidelines and good practices are fully observed in the processes used by the statistical authorities to organize, collect process and disseminate European Statistics. The credibility of the statistics is enhanced by a reputation for good management and efficiency. The relevant aspects addressed by principles seven to ten are:	7. sound methodology 8. appropriate statistical procedures 9. non-excessive burden on respondents 10. cost effectiveness
Statistical output	Available statistics meet users' needs. Statistics comply with the European quality standards and serve the needs of European institutions, governments, research institutions, business concerns and the public generally. The important issues relayed in principles 11 to 15 concern the extent to which the statistics are:	11. relevant 12. accurate and reliable 13. timely 14. coherence and comparability across regions and countries 15. readily accessible by users.

1.6.2 Quality Assurance Framework (QAF), 2015 (European Statistical System)

The European Statistical System is a partnership between Eurostat, and the national statistical institutes and other national authorities responsible in each Member State for the development, production and dissemination of European statistics. The Quality Assurance Framework of the European Statistical System is a supporting document aimed at assisting the implementation of the European Statistics Code of Practice. It identifies possible activities, methods and tools that can provide guidance and evidence for the implementation of the Code of Practice. The framework covers principles 4 to 15 of the Code of Practice. The framework contains recommendations of activities, methods and tools which facilitate the practical and effective implementation of the indicators relating to each principle.

Some of the activities, methods and tools relating to commitment to quality include:[13]

- a quality commitment statement is a public document that lays out principles, practices and commitments related to quality in statistics which are consistent with the goals of the organization
- a clear organizational structure for managing quality
- definition of quality guidelines on how to implement quality management within the statistical production process
- a quality assurance plan which describes the working standards, the formal obligations and the set of quality control actions to prevent and monitor errors, to evaluate quality indicators and to control different points at each stage of the statistical production process.

Some of the activities, methods and tools relating to effective use of resources include:[13]

- human resources are evaluated annually, the evaluation covers allocation, performance and training needs
- ICT infrastructure should be reviewed regularly
- data linking and integration methods are pro-actively pursued subject to data security considerations
- quality indicators are developed and compiled to improve the methods for using administrative data for statistical purposes.

Some of the activities, methods and tools relating to accuracy and reliability include:[13]

- systems for assessing and validating source data, intermediate results and statistical outputs are developed, implemented and managed

- internal procedures and guidelines for data quality assessment exist and address accuracy and reliability issues
- results are compared with other existing sources of information in order to ensure validity
- internal procedures are in place to measure and reduce errors
- periodic quality reporting on accuracy is in place.

1.6.3 Handbook on Data Quality Assessment Methods and Tools, 2007 (Eurostat)

The Handbook on Data Quality Assessment Methods and Tools was published by Eurostat in 2007. It aims at facilitating a systematic implementation of data quality assessment in Europe. It presents the most important assessment methods: quality reports, quality indicators, measurement of process variables, user surveys, self-assessment and auditing as well as approaches in relation to labelling and certification. The handbook provides a concise description of the data quality assessment methods currently in use. It also gives recommendations on how these methods and tools should be implemented. Data quality assessment is a long term project. The main problem is not to start systematic data quality assessment, but to keep the process going on. Regularly, new incentives are needed for sustained motivation. Quick success should be promoted internally as well as externally, and the staff should be made aware of the progress reached so far.

Self-assessment is a comprehensive, systematic and regular review of an organization's activities and results referenced against a model/framework. The choice of the self-assessment tool is a strategic decision. It should be applicable to the environment of the organization and to the processes to be assessed. Some aspects are important when undertaking these exercises:[14]

Team organization — A good communication and transparent environment is needed. It is also important that the team believes in the model and that the effort will turn into an effective action plan.

Preparation of the self-assessment exercise — Self-assessment is based on evidence, documentation and indicators are gathered which are related to the assessed issues.

Self-assessment exercise — Strengths and weaknesses are identified, scores will be marked (according to the model in use) and the team should try to reach a consensus on the main findings of the self-assessment exercise.

Self-assessment report — The report should be structured according to the model in use for the exercise. It should stress strengths and weaknesses and should be very

clear on an action plan. Teams should be involved in the implementation of the action plan, and top management should also be supportive, making available extra resources if necessary. The self-assessment process is illustrated in Figure 1.

Figure 1: Self-assessment process, taken from the 'Eurostat Handbook on Data Quality Assessment Methods and Tools'[(14)]
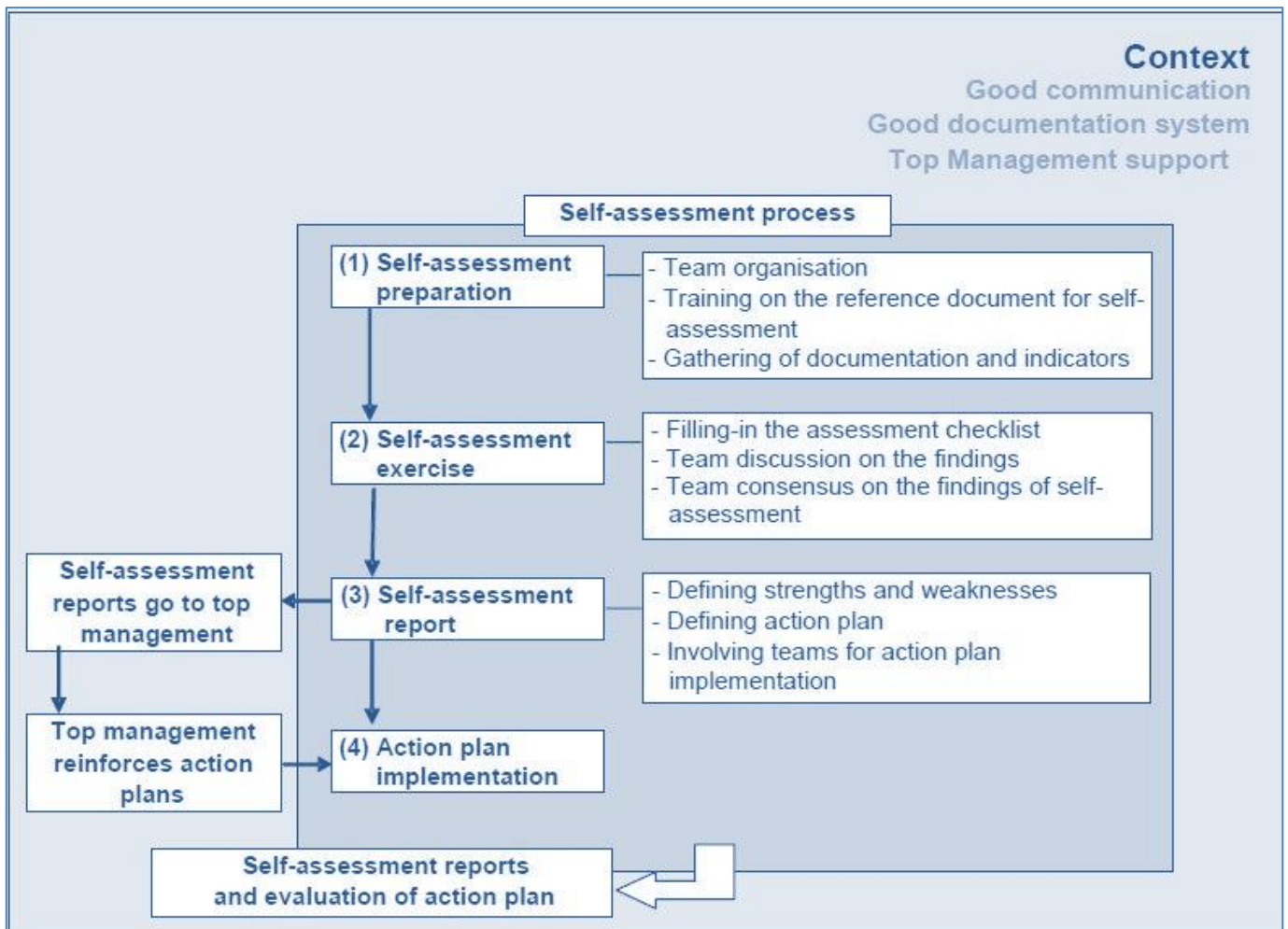
1.6.4 Data Quality Monitoring and Surveillance System Evaluation, 2014 (European Centre for Disease Prevention and Control)

In 2010, European Centre for Disease Prevention and Control (ECDC) conducted a survey among national surveillance coordinators which revealed substantial differences in practices with regard to monitoring data quality in EU Member States. Subsequently, a working group was established, with a mandate to develop a handbook on data quality monitoring and surveillance system evaluation. The overall objective of the project was to support processes for monitoring data quality and evaluating surveillance systems in EU/EEA Member States in order to provide accurate and timely information for decision-making.

It is important to monitor data quality and thus ensure that the collected data are meaningful so they meet the objectives of local, national and international surveillance systems. The quality of the initial data may determine the data quality at all stages of the reporting process. Monitoring data quality also helps to improve data analysis and interpretation in public health reports at all levels.

In defining where data quality monitoring should take place, one must assess the system as a whole and determine what is necessary and practical to record and measure. The point at which the value of data quality exceeds the cost of data collection and data analysis associated with a data quality measure can be considered as an appropriate focus when monitoring data quality. The process below summarises a strategic approach for setting up a data quality monitoring report with a concise list of data quality measures.

Step one — Identify and document the system's fitness for purpose. An information system is fit for purpose if it enables users to make an accurate assessment or prediction of the real-world situation it is trying to describe.

Step two — Document fitness-for-purpose measures for other users of the data. The system is fit for purpose if complete, valid and representative data are available in a reasonable timeframe.

Step three — Identify the process modelled by the system and choose measures to monitor the timeliness of data.

Step four — Identify collected dataset and the system rules in use, and choose measures to monitor the completeness and validity of data. Data completeness is an assessment of how often a field contains a value. Validity is a measure of whether the value in a given field is correct. Completeness and validity can be measured separately as a percentage to give an overall indication of how well a given field is populated within a database.

Step five — Use evaluation data to set up representative measures and inform the selection of additional monitoring measures. Monitoring data representativeness should be considered if systems rely on processes that vary over time or if the coverage of a population under surveillance fluctuates.

Step six — Review the chosen measures during every system evaluation. A system evaluation gives the system owner the opportunity to review the entire system, including elements which normally cannot be assessed during the continuous monitoring process.[15]

1.6.5 Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries, 2015 (EU Cross Border *PAtient REgistries INiTiative* -PARENT)

Data quality is influenced by a number of identifiable registry features. The four basic categories of factors influencing registry's quality are governance, data quality, information quality and privacy, security and ethical issues. Other quality influencing factors can be grouped under each category. These categories and factors, when grouped together, should provide a rough estimate basis for assessing registry performance.

Governance and management are the organizational foundations of patient registries which provide the framework to ensure that the registry achieves its objectives.

- Applying proper governance principles should ensure that strong operational procedures and processes are in place, clearly communicated and easy to access.
- Sufficient staff training is necessary to avoid data quality issues as well as security breaches and privacy violation.
- Resources should be adequate to ensure sustainability, continual relevance and maximum impact of the data for which the registry holders are responsible.
- Interoperability should be established through a gradual process of connecting internal processes of the stated stakeholders, therefore transforming the business processes towards convergence and making them mutual and public.
- Self-assessment should perform quality control and serve to identify the sources of potential data quality issues and assess them by using indicators on data quality dimensions, developing measurements for evaluation, subsequently used to correct issues and track improvements.

Data quality can be defined as the totality of features and characteristics of a data set that bear on its ability to satisfy the needs that result from the intended use of the data. High quality data are therefore data that are fit for use by data consumers.

- Data quality dimensions can be defined as a set of data quality attributes that represent a single aspect or construct of data quality. A set of data quality dimensions may include: accuracy, completeness, interpretability and accessibility, relevance, timeliness and coherence.
- Assessing data quality includes adequate management of each dimension. Failure in one dimension can severely hinder the usefulness of the final registry report.

Information quality is important as quality information gained from patient registries leads to informed healthcare management and better decision making.

- Information can be considered an output and the extension of the data collection process. Its quality is measured by the purpose of its use, which in the case of patient registries can be grouped into surveillance, outcomes, and scientific publication.

Quality is also influenced by features like confidentiality, security, privacy and ethical issues.

- This aspect of quality is concerned with ethical issues and confidentiality and privacy regarding use of personal health information, as well as the need for proper patient registry data security and clear provisions regarding secondary use of information.
- A privacy impact assessment (PIA) is a tool, process or method to identify, assess, mitigate or avoid privacy risks.[16]

1.6.6 Registries for Evaluating Patient Outcomes: A user's guide (Agency for Healthcare Research and Quality)

The Agency for Healthcare Research and Quality (AHRQ) is the lead Federal agency charged with improving the safety and quality of America's healthcare system. AHRQ develops the knowledge, tools, and data needed to improve the healthcare system and help Americans, healthcare professionals, and policymakers make informed health decisions. AHRQ works within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used in an effort to achieve the goals of better care, smarter spending of healthcare dollars, and healthier people.[20]The goal of this document is to provide stakeholders in both the public and private sectors with information they can use to guide the

design and implementation of patient registries, the analysis and interpretation of data from patient registries, and the evaluation of the quality of a registry or one of its components. The document defines a patient registry as an organized system that uses observational study methods to collect uniform data to evaluate specified outcomes for a population defined by a particular disease, condition or exposure, and that serves one or more predetermined scientific, clinical or policy purposes. Quality improvement registries use systematic data collection and other quality improvement tools to improve the quality of care on the local, regional or national level.

Quality is defined as the confidence that the design, conduct, and analysis of the registry can be shown to protect against bias and errors in inference or erroneous conclusions drawn from a study. Requirements for quality assurance should be defined during the registries inception. In determining the utility of a registry for decision making it is critical to understand the quality of the procedures used to obtain the data and the quality of the data stored in the database. Critical factors in the quality of the data include how data elements are structured and defined, how personnel are trained and how data problems, such as missing, out of range, or logically inconsistent values, are handled. As a general rule, quality should be evaluated by elements that directly impact the ability of the registry to achieve its main objectives. In other words, a registry must be fit for purpose. This report divides the desirable attributes and practices of a registry into two groups:

- The essential registry practices that are desirable for every study. These elements of good practice are applicable to all patient registries. While it may not be practical to achieve all the elements it is useful to consider these characteristics when evaluating a registry.
- Optional practices that could enhance scientific rigor and that are particularly important for certain purposes, but may not be achievable because of certain constraints.

With regards to data quality assessment this report suggests a quality component analysis, which involves an investigation of the components that may affect the results obtained. In the quantity component analysis, a differentiation is made between two domains: research quality, which pertains to the scientific process and evidence quality, which relates to the data/findings emanating from the research process.

Examples of essential practices in relation to research quality:[17]
- Carefully consider the issues of protection of human subjects. This includes privacy, informed consent, data security and study ethics.

- Create a quality assurance plan that addresses data editing and verification and plan an approach for handling missing data.

Examples of optional practices in relation to research quality:
- Specify publication policies in advance of collecting data and re-evaluate at regular intervals.
- Consider how and when to allow third parties access to data, if feasible, and the process for any such data access.

Examples of essential practices in relation to data/findings:
- Employ data checks using range and consistency checks.
- Consistency of results to be compared and contrasted with other relevant research.

Examples of optional practices in relation to data/findings:
- Evaluate the reproducibility of coding.
- Use validated analytic tools for the main analysis. For example, commercially available analytic packages. Describe the data elements used in any models.

1.6.7 The Template for a Generic National Quality Assurance Framework (NQAF) and the Guidelines to accompany the Template, 2012 (United Nations Statistics Division)

The development of the Template for a Generic National Quality Assurance Framework (NQAF) and the Guidelines to accompany the Template was undertaken by the Expert Group on NQAF in response to a request by the United Nations Statistical Commission at its forty-first session in 2010. The Template is intended to be used as a tool to provide the general structure within which countries that choose to do so can formulate and operationalize national quality frameworks of their own or further enhance existing ones. Additional work carried out by the Expert Group included: a mapping of the Template to existing quality frameworks (i.e. the European Statistics Code of Practice, the International Monetary Fund's Data Quality Assessment Framework, Statistics Canada's quality assurance framework, and the Proposal for a Regional Code of Good Statistical Practice for Latin America and the Caribbean); a Glossary of quality-related terms; and an inventory of national and international quality references. The framework consists of 19 specific guidelines in relation to management of statistical data. The guidelines are divided under four broad themes:
- managing the statistical system
- managing the institutional environment
- managing statistical processes
- managing statistical outputs.

Each guideline is accompanied by a description, elements to be assured and supporting mechanisms. The guidelines are listed in Table 2.[18]

Table 2: Guidelines for the Generic National Quality Assurance Framework (NQAF)[19]

Managing the statistical system	1. Coordinating the national statistical system
	2. Managing relationships with data users and data providers
	3. Managing statistical standards
Managing the institutional environment	4. Assuring professional independence
	5. Assuring impartiality and objectivity
	6. Assuring transparency
	7. Assuring statistical confidentiality and security
	8. Assuring the quality commitment
	9. Assuring adequacy of resources
Managing statistical processes	10. Assuring methodological soundness
	11. Assuring cost-effectiveness
	12. Assuring soundness of implementation
	13. Managing the respondent burden
Managing statistical outputs	14. Assuring relevance
	15. Assuring accuracy and reliability
	16. Assuring timeliness and punctuality
	17. Assuring accessibility and clarity
	18. Assuring coherence and comparability
	19. Managing metadata.

A brief outline is provided of what is involved in the assessment or evaluation of quality, this includes:

- measuring product and process quality — use of indicators, quality targets and process variables and descriptions
- communicating about quality — quality reports
- obtaining feedback from users
- conducting assessments — labelling and certification
- assuring continuous quality improvement.

The management of quality is an integral part of the management of every programme within an agency, and an important component of the agency's management as a whole. Various frameworks will exist within an agency and it is important that these frameworks work towards achieving good quality through close interaction. The following are some of the quality and other management frameworks which are important to quality:

- performance management
- resource management
- ethical standards
- continuous improvement
- governance.

1.6.8 Code of Practice for Official Statistics, 2009 (UK Statistics Authority)

Official statistics are fundamental to good government, to the delivery of public services and to decision-making in all sectors of society. They provide Parliament and the public with a window on society and the economy, and on the work and performance of government. Observance of a common Code of Practice, by all the public bodies that produce official statistics, is central to maintaining a unified statistical service that meets the needs of government and society and is both trustworthy and trusted. This code is consistent with the European Statistics Code of Practice. The code contains eight principles and, in relation to each, a statement of associated practices. It also contains three more detailed protocols — on user engagement, on the release of statistics and on the use of administrative data for statistical purposes. The code has been framed to support assessment of compliance by the UK Statistics Authority. The eight principles are:[19]

1. The production, management and dissemination of official statistics should meet the requirements of informed decision-making by government, public services, business, researchers and the public.

2. Official statistics, and information about statistical processes, should be managed impartially and objectively.
3. At all stages in the production, management and dissemination of official statistics, the public interest should prevail over organizational, political or personal interests.
4. Statistical methods should be consistent with scientific principles and internationally recognized best practices, and be fully documented. Quality should be monitored and assured taking into account internationally agreed practices.
5. Private information about individual persons (including bodies corporate) compiled in the production of official statistics is confidential, and should be used for statistical purposes only.
6. The cost burden on data suppliers should not be excessive and should be assessed relative to the benefits arising from the use of statistics.
7. The resources made available for statistical activities should be sufficient to meet the requirements of this Code and should be used efficiently and effectively.
8. Official statistics, accompanied by full and frank commentary, should be readily accessible to all users.

1.6.9 Summary of international guidelines and recommendations regarding assessment of data quality of national data collections

- Official European statistics are regulated by the principles in the European Statistics Code of Practice, whose purpose is to ensure the quality and credibility of the data. These principles refer to, among other things, professional independence, the protection of confidentiality, the reliability of the results, their precision, timeliness, punctuality, accessibility, clarity, comparability and coherence.[21]

- The European Statistical System Quality Assurance Framework is a supporting document aimed at assisting the implementation of the European Statistics Code of Practice. It identifies possible activities, methods and tools that can provide guidance and evidence for the implementation of the Code of Practice, some examples include a clear organizational structure for managing quality, the development of quality indicators and internal procedures and guidelines for data quality assessment.[13]

- The Handbook on Data Quality Assessment Methods presents the most important assessment methods including quality reports, quality indicators, measurement of process variables, user surveys, auditing and self-assessment. Self-assessment is a comprehensive, systematic and regular review of an organization's activities and results referenced against a model/framework.[14]

- ECDC highlights the importance of monitoring data quality and thus ensure that the collected data are meaningful so they meet the objectives of local, national and international surveillance systems. The quality of the initial data may determine the data quality at all stages of the reporting process. Monitoring data quality also helps to improve data analysis and interpretation in public health reports at all levels.[15]

- The EU Cross Border Patient Registries Initiative (PARENT) provides practical and 'hands on' advice to set up and manage patient registries. The primary dimension of registries' quality is the quality of the data. Four basic categories of factors influencing registry's data quality are governance, data quality, information quality and confidentiality, security and ethical issues.[16]

- The Agency for Healthcare Research and Quality provide information on the design and implementation of patient registries, including the evaluation of the quality of a registry or one of its components. Critical factors in the quality of the data include how data elements are structured and defined, how personnel are trained and how data problems, such as missing, out of range, or logically inconsistent values, are handled. Quality should be evaluated by

elements that directly impact the ability of the registry to achieve its main objectives.

- The Template for a Generic National Quality Assurance Framework (NQAF), with accompanying guidelines, has been developed to assist countries that may wish to formulate and operationalize national quality frameworks of their own, or further enhance existing ones. Guidelines are provided on managing the statistical system, the institutional environment, statistical processes and statistical outputs.
- The UK Statistics Authority Code of Practice for Official Statistics contains eight principles with corresponding practices and three detailed protocols — on user engagement, on the release of statistics and on the use of administrative data for statistical purposes.

1.7 Summary of international evidence

Table 3: Summary of international evidence

Country	Australia	Canada	England	New Zealand (NZ)	Scotland
Population	23.86 million	36.04 million	54.3 million	4.68 million	5.3 million
Political structure	Federal Constitutional monarchy: 6 states and 10 territories	Federal constitutional monarchy: 10 provinces and 3 territories	A country of the British monarchy	Constitutional monarchy	Constitutional monarchy
Key organization	Australian Institute of Health and Welfare (AIHW)	The Canadian Institute for Health Information (CIHI)	Health and Social Care Information Centre (HSCIC)	Ministry of Health (MoH)	Information Services Division (ISD)
Mandate of key organization	Statutory and independent	Voluntary and independent	Statutory, an executive non-departmental public body	Statutory	Statutory, a division of an executive non -departmental public body
National data collections (NDCs)	The majority of data collections are housed within the AIHW (n= 84) Additional NDCs are housed within the Australian Bureau of Statistics and the Department of Health.	The majority of data holdings are within the CIHI (n=27). Additional NDCs are housed within Statistics Canada.	There are 198 data collections in England. 56 of these collections are housed within the HSCIC (n=56) Additional NDCs are within other charities and agencies e.g. Public Health England, NHS England and the Care Quality Commission.	All national collections are within the MoH (n=15). National population health surveys (n=11)	All datasets are held in the ISD (n= 106)

Country	Australia	Canada	England	New Zealand (NZ)	Scotland
Overall model for the governance of NDCs	A de-centralised governance model with national agreements.	A mostly centralised governance model.	A mostly centralised model.	Centralised governance model.	Centralised governance model.
Governance arrangements	The National Health Information Agreement (NHIA)	Voluntary bilateral agreements are signed by CIHI with each of the individual provinces and territories.	The Health and Social Care Act 2012 provides the HSCIC with a legal basis for requiring the submission of data.	The MoH signs an Operational Policy Framework with the District Health Boards.	
Key Legislation	The Australian Institute of Health and Welfare Act 1987, (NHIA) (2013)	The Canada Health Act (1984)	The Health and Social Care Act 2012	The Health Act 1956	Statistics and Registration Service Act 2007
Unique identifiers*	Three types of unique healthcare identifiers exist: an individual healthcare identifier (IHI), a healthcare provider identifier-individual (HPI-I) and a healthcare provider identifier-organization (HPI-O).	Pan-Canadian unique health identifiers (UHIs) are not in existence currently. A pan-Canadian unique physician identifier is in use. Jurisdictional UHIs are used, with every person possessing an individual health insurance number.	The NHS Number serves as a unique national patient identifier for every person registered with NHS England. Unique national identification codes are also in place for organizational entities (ODS) of interest to the NHS.	The Health Identity Programme is a single integrated system using the National Health Index (NHI) number and practitioners, the Health Practitioner Index (HPI).	The Community Health Identifier (CHI) - a unique numeric identifier. It's a computer based population index that supports primary care services.
National Data Dictionary	Yes	No	Yes	No	Yes

Country	Australia	Canada	England	New Zealand (NZ)	Scotland
Data Quality	Australian Capital Territory (ACT) data quality framework, 2014 Australian Bureau of Statistics (ABS) Data Quality Framework	CIHI's Data Quality Framework sets out an approach to systematically assess, document and improve data quality for all data holdings. (Revision due in 2017)	HSCIC Data Quality Assurance Strategy for 2015-2020.	The MoH drives improvements in data quality through the work of data quality analysts, the provision of technical guidance documents and education and support services.	ISD's data quality assurance team assesses and advises on all aspects of data quality.
Key Learning	Data Quality Statements Data Governance Framework A Framework for Australian Clinical Quality Registries 2014	The CIHI Data Quality Framework	HSCIC information governance (IG) toolkit Revision of the Caldicott principles, 2013	National Collections Annual Maintenance Project (NCAMP)	The National Information and Intelligence Framework for Health and Social Care for Scotland: 2012-17

Australia

Australia has a population of 23.86 million.[22] A federal system of government is in place with powers shared between the Commonwealth government and the six state governments. Two internal territories and one island territory hold a limited right to self-govern. Overall coordination of the public health system is the responsibility of all Australian health ministers, that is, the Commonwealth and state and territory ministers. Managing the individual Commonwealth, and state and territory health systems is the responsibility of the relevant health minister and health department in each jurisdiction.[23]

The Australian Government, through an independent statutory authority called the Australian Institute of Health and Welfare (AIHW), collects health and welfare related data and information, conducts analysis and reports on health and welfare in Australia. Robust national agreements are in place which provide governance arrangements for national data collections.

This chapter will provide information on:

- an introduction to national health and social care data collections in Australia
- health information standards
- health identifiers
- the legislative context regarding national data collections
- data quality programme for national data collections
- data linkage
- updates in relation to national health and social care data collections in Australia
- the Australian Institute of Health and Welfare (AIHW) future plans.

2.1 Introduction

The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act[24] to provide reliable, regular and relevant information and statistics on Australia's health and welfare. AIHW is an independent corporate Commonwealth entity established in 1987.[25] The AIHW consults with the Australian Bureau of Statistics (ABS), Australia's official national statistical agency, to develop specialized statistical standards and classifications relevant to health, health services and welfare services.[26] Due to the dispersed complex nature of Australia's health system, strong governance arrangements have been employed to engage stakeholders to fulfil national objectives. Governance arrangements and mechanisms

on many aspects of health information are established under the Health Council of the Coalition of Australian Governments (COAG).

Australia has worked towards better integration of national collections and health information across its vast system through a series of national agreements, most notably the National Health Information Agreement (NHIA). The NHIA drives a national standardized approach to health information through endorsing the use of national data standards, classifications and national minimum datasets. A national health data dictionary is available through METeOR, the national metadata online registry for health and welfare related metadata. It allows for greater consistency and comparability among the data collected across the states and territories.[1]

As of 2015 AIHW manages 84 data collections.[27] The Australian Bureau of Statistics has named 10 AIHW held data sets among its list of 74 Essential Statistical Assets for Australia. The 10 essential AIHW data sets cover fields as diverse as housing assistance, homelessness, perinatal health, disability, cancer, hospitals and hospital activity, alcohol and drugs, and mortality.[28] AIHW's data holdings include:

- administrative data sets — such as the national hospital databases and the National Aged Care Data Clearinghouse
- survey-based collections — such as the National Drug Strategy Household Survey, the National Infant Feeding Survey, the National Social Housing Survey and the National Prisoner Health Data Collection.

2.2 Health information standards

The National Health Information Standards and Statistics Committee (NHISSC) is a sub-committee of the National Health Information and Performance Principal Committee (NHIPPC). NHIPPC is one of several principal committees that report to the Australian Health Ministers' Advisory Council (AHMAC). AHMAC provides support to the Standing Council on Health under arrangements for the Council of Australian Governments (COAG). The functions of the National Health Information Standards and Statistics Committee include:[29]

- providing strategic advice to NHIPPC on national health information needs and priorities
- considering the implications for the statistical system of new and emerging health information issues
- Overseeing the development of, and recommend to NHIPPC endorsement of:
    - data standards for inclusion in the National Health Data Dictionary
    - mandatory National Minimum Data Sets for national implementation

- – best practice Data Set Specifications for inclusion in the National Health Data Dictionary
- in conjunction with the Australian Collaborating Centre for the WHO Family of International Classifications, advising NHIPPC on the development, implementation and maintenance of the Australian Family of Health and related classifications (including endorsing classifications for inclusion in the Family) and endorse maps to classifications to be used for statistical reporting on national health information
- providing advice for NHIPPC on national statistical protocols and standards such as: data linkage, geocoding and data anonymisation protocols
- monitoring and seeking opportunities to improve the identification of Indigenous status and Indigenous issues in national data collections and reporting and recognition of Indigenous health issues in the development of national data standards that underpin administrative reporting and research in the health sector
- working with other national information committees to promote consistency between health, community services and housing assistance information.

2.2.1 Data dictionary

The AIHW manages METeOR, Australia's online repository for national metadata standards primarily for the health sector but also for community services and housing assistance sectors. The national data dictionaries are a reference of standardized, accepted terms and protocols used for data collection in the Health, Community Services and Housing sectors. These terms reflect a vast array of health, community services, housing and research expertise. The National Health Data Dictionary, the National Community Services Data Dictionary and the National Housing and Homelessness Data Dictionary have been developed. National minimum datasets are also available through METeOR.[30]

2.2.2 Classification and terminology

The National E-Health Transition Authority (NEHTA) is responsible for defining a national approach to clinical terminology. Within NEHTA, the National Clinical Terminology and Information Service (NCTIS) is responsible for managing, developing and distributing terminology to support the eHealth requirements of the healthcare community. NEHTA's clinical terminology solutions include Systematized Nomenclature of Medicine Clinical Terms, Australian Release (SNOMED CT-AU) and

Australian Medicines Terminology (AMT). From November 2015, the AMT is included as a formal subset of the SNOMED CT-AU release in preparation for future integration work.

The National Centre for Classification in Health (NCCH) also plays an important role. Based in the University of Sydney, the NCCH is the leading centre of expertise in health system classifications and their applications in Australia. The NCCH leads the Australian Consortium for Classification Development (ACCD), which works to develop casemix and statistical classification systems on an ongoing capacity. The NCCH and ACCD have been leaders on the development of the following classification and terminology systems currently in use in Australia:

- International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM)
- Australian Classification of Health Interventions (ACHI)
- Australian Coding Standards (ACS)
- Australian Refined Diagnosis Related Groups (AR-DRG).

The AIHW is the Australian Collaborating Centre for the WHO Family of International Classifications. In this role AIHW participate in the WHO's work to develop the International Classification of diseases, 11th Revision (ICD-11) and other international health classifications. With the support of the Australian Health Ministers' Advisory Council, the AIHW established the Australian Health Classifications Advisory Committee in 2014-2015 to assist and advise in this work, particularly in relation to Australia's participation in the ICD-11 development activities.[31]

2.3 Health identifiers

The Department of Human Services operates the national Healthcare Identifiers Service. This service hosts three types of unique healthcare identifiers: an individual healthcare identifier (IHI), a healthcare provider identifier-individual (HPI-I) and a healthcare provider identifier-organization (HPI-O). The Healthcare Identifiers Act 2010 specifies that healthcare identifiers are to be used for healthcare and related management purposes with penalties in place for misuse.[32]

2.4 Legislative context

The Australian Institute of Health and Welfare (AIHW) was established as a statutory authority by the Australian Institute of Health and Welfare Act 1987[24] to serve as a

custodian of major national health and welfare data collections. The Act ensures that the data collections which are managed by AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.[33] A legislative framework has evolved over time consisting of intergovernmental agreements, namely the National Health Reform Agreement[34] (NHRA) (2011), the National Healthcare Agreement (NHA) (2012) and the National Health information Agreement[35](NHIA) (2013). Furthermore a number of National Partnership Agreements that contain defined data reporting requirements are associated with the NHA and the NHRA, for example the National Partnership Agreement on Improving Public Hospital Services[36] and the National Partnership Agreement on Preventive Health.[37;38] AIHW works in collaboration with the jurisdictions and organizations to ensure high quality data and published reports. While some health collections are mandated for collection as they are considered to be national minimum data sets, other collections are provided on a best efforts basis.[39]

Under the terms of the current NHIA (2013), the AIHW is responsible for:

- receiving, validating and disseminating information as the key national custodian of administrative health data collections
- managing data collected by the AIHW, under the NHIA, in accordance with the Australian Institute of Health and Welfare Act 1987, other relevant legislative requirements, and the NHIA
- in consultation with the ABS, developing specialized statistical standards and classifications relevant to health and health services
- undertaking performance reporting on the healthcare system
- assisting other parties to the NHIA in using and interpreting national health information
- ensuring that the National Health Data Dictionary and other quality control standards are maintained and enhanced
- undertaking the role of metadata registrar for the NHIA
- making METeOR education and training resources available to stakeholders.

The AIHW is also bound to comply with the Privacy Act 1988[40], which incorporates a series of Australian Privacy Principles (APPs). The APPs regulate how the AIHW obtains, stores, uses and discloses personal information.

2.5 Data quality programme for national data collections

Under the NHIA, responsibility for the quality and completeness of contributed data remains with the data provider. AIHW works in collaboration with data providers to improve the quality and timeliness of data releases through:[41]

- providing guidance and support, for example, the AIHW published A Guide to Data Development[42] which outlines sound data development practices that incorporate the necessary steps to produce high quality data
- supporting the production of national data standards, datasets and metadata
- making these standards, datasets and metadata available online through the Metadata Online Registry (METeOR) and as updates to national data dictionaries
- implementing improved validation processes (including the Validata™ product) to support a richer array of data edits, reduce multiple handling of data and provide a better data audit trail
- producing data quality statements for the data collections for which it acts as custodian and making these statements available through METeOR
- maintaining an internal audit function where a subcommittee of the AIHW Board, the Audit and Finance Subcommittee, authorizes and oversees the AIHW's audit programme and reports to the AIHW Board on data (and financial) audit matters.

The AIHW uses seven dimensions to evaluate the quality of health data sources, an approach that aligns with the Australian Bureau of Statistics (ABS) Data Quality Framework. The seven dimensions of quality used are: institutional environment, relevance, timeliness, accuracy, coherence, interpretability and accessibility.[43]

2.5.1 Data Quality Statements (DQS) policy and guidelines

A data quality statement is a document which provides information on a range of aspects of the quality of the data being reported by AIHW. The intention is to enable users to understand any data limitations and to make informed judgements about their use of the data. AIHW data quality statements are based on the Statistics Canada Quality Assurance Framework[44] and the European Statistics Code of Practice.[12;39] There are nine main dimensions of a data quality statement which are listed below.

Summary of key issues — The intention of this component of the data quality statement is to provide a brief summary of the key issues that users should be aware of when using the data. Aspects that should be included, where relevant, are:

- brief description of the data source
- main issues affecting accuracy
- response rate for sample surveys
- major changes since previous cycle affecting consistency
- main classifications used.

Description — This dimension gives information about the collections. Aspects that should be included, where relevant, are:

- description of the data source
- context in which the collection originated
- related national minimum datasets.

Institutional Environment — This dimension gives information about the origin of the data collection and the arrangements under which the collection is governed and administered. This enables an assessment of the surrounding context, which may influence the validity, reliability or appropriateness of the data.

Timeliness — Timeliness is an important consideration in assessing the quality and usefulness of data. Aspects of timeliness which should be addressed, where relevant, include:

- the reference period (to which the data pertain)
- the frequency with which data are provided to AIHW
- the frequency of publication of data
- the agreed date for provision of initial data to the AIHW
- the actual date at which all necessary data first became available to AIHW
- the intended first release of a publication/report
- the actual first release of data from the collection.

Accessibility — Accessibility is a key component of quality as it relates directly to the capacity of users to identify the availability of relevant information, and then to access it in a convenient and suitable manner. Aspects of accessibility which should be addressed, where relevant, include:

- how to access relevant publications and reports, including hotlinks to website
- how to access relevant data sets, including hotlinks
- information on how to access data which is not available online or in reports, i.e. via the Communications, Media and Marketing Unit in the first instance
- information on how to seek access to very detailed data.

Interpretability — Interpretability refers to the availability of information to help provide insight into the data. Information available which could assist interpretation may include information about the variables used, the availability of metadata, including concepts and classifications.

Relevance — This dimension refers to how well the data meet the agreed purpose of the data collection in terms of concepts measured and the population represented. Enough information needs to be provided to enable each user to make an

assessment of whether the data collection addresses the issues most important to them. It is under the 'relevance' dimension that key information would be given about the broad definitional and coverage aspects of the data.

Accuracy — Accuracy refers to the degree to which the data correctly describe the phenomenon they were designed to measure. This is an important component of quality as it relates to how well the data portray reality, which has clear implications for how useful and meaningful the data will be for interpretation or further analysis. In particular, when using administrative data, it is important to remember that statistical outputs for analysis are generally not the primary reason for the collection of the data.[45]

Coherence — Coherence refers to the internal consistency of a statistical collection, product or release, as well as its comparability with other sources of information, within a broad analytical framework and over time. The use of standard concepts, classifications and target populations promotes coherence, as does the use of common methodology across collections. It is important to note that coherence does not necessarily imply full numerical consistency, rather consistency in methods and collection standards.[45]

2.5.2 Australian Capital Territory (ACT) Data Quality Framework, 2013

ACT Health developed a regional data quality framework in 2013.[46] The framework draws from the Australian Bureau of Statistics (ABS) data quality framework and the respective data quality framework developed by the Canadian Institute for Health Information (CIHI). The framework can be applied to all data collections within the Directorate including databases, systems, registries and reports. The framework applies to all staff members that create, modify, use and interpret data including executive, management, data management, clinical and administration staff.

Information Management Principles:

- Purpose — Authoritative information is provided to meet the needs and priorities of the ACT Government and the people that use health services.
- Governance — Information is managed in an ethical and efficient manner to support patient care, planning, research and service delivery.
- Collection — Information is collected and collated efficiently and effectively to minimise the burden on respondents.
- Quality — Quality information is produced that is relevant, timely, accurate, coherent, transparent and accessible.

- Use and Disclosure — The analysis, interpretation and reporting of health and health-related information occurs in accordance with relevant legislative and privacy codes.
- Security — Information is protected and preserved throughout the information lifecycle.

The information management principle of quality is further supported by three sub-principles:

- information is of a quality that makes it fit for purpose
- information about data (metadata) is developed and is accessible to all users of information
- correction of data is done in or as close as possible to the source system.

The Data Quality Framework provides an organization wide approach to applying the quality principle within the Information Management Framework.

Data Quality Framework components: [46]

- The Data Integrity Strategy describes and prioritizes a number of initiatives that strengthen the approach to information, collation, use and security.
- The Data Quality Policy focuses on the roles and responsibilities of staff ensuring that data are accurately recorded, updated and maintained over time to support a credible rigorous source of information.
- The Data Quality Improvement Cycle addresses the processes, models and methodologies used to create or change data management processes as part of a data quality initiative. There are five stages of the Data Quality Improvement Cycle; recognize, assess, implement, monitor and prevent.
- The Data Quality Assessment Tool comprises the seven dimensions of data quality. Each dimension is divided up into a number of data characteristics that may be used to systematically assess the fitness for purpose of data. There are 29 characteristics in total.

A data quality indicator tool and the ACT Health Data Quality Statement are provided in the document. Data quality indicators should be made available on all data quality documentation, with any contextual information for data or on reports themselves. ACT Health considers that interpretability and accuracy are of equal importance. The Data Quality Indicator uses a matrix to assess data quality against interpretability and accuracy when providing reports or data. It is recommended that when assessing the quality of a data item, dataset or other data product, a Data Quality statement is developed. The statement should present information about the quality of a data item or a collection of data items, using the Data Quality Framework. Data

Quality Statements should report both the strengths and the limitations of the data so that potential users can make informed decisions about fitness for use.

2.6 Data linkage

Under the terms of the current NHIA (2013), national and bilateral statistical data linkage and related datasets are supported by all parties for further analysis, policy development, planning and research in health.[35] AIHW's work in this area has centred on data integration governance and technical capability, with the creation of a Data Integration Services Centre (DISC). The DISC is used by researchers or by the AIHW itself, to link data, either across data collections, or longitudinally in a single data collection in a secure environment. The DISC and the AIHW's Data Linkage Unit have been combined under one AIHW unit head. This unit works to ensure that access to linked data for researchers is provided in line with privacy obligations and that processes and infrastructure are in place to support data custodians and researchers in undertaking efficient data linkage. Data integration projects undertaken by the AIHW or using AIHW data can only proceed with AIHW Ethics Committee approval.[47] The AIHW has previously published Data Linkage and Protecting Privacy: a protocol for linking between two or more data sets held within the Australian Institute of Health and Welfare.[48]

2.6.1 Commonwealth Integrating Authority

The AIHW has been accredited by the Cross Portfolio Data Integration Oversight Board (CPDIOB) as a Commonwealth Integrating Authority. This accreditation allows the AIHW to undertake high risk, complex data integration projects involving data from national, state and territory agencies. While AIHW and the Centre for Data Linkage in Western Australia have a national jurisdiction, there are a number of data linkage units operating at the state and territory level such as the Centre for Health Record Linkage (CHeReL), located in the Ministry of Health in New South Wales.[49] All integrating authorities that handle identifiable information must comply with the requirements of the Privacy Act 1988 but must also pay heed to jurisdiction specific privacy legislation and legislation affecting data custodians. This may require either the consent of the individuals to the disclosure of personal information, or an overriding public interest test certified in accordance with the relevant secrecy provision.[48] AIHW abides by the principles outlined in A Guide for Data Integration Projects involving Commonwealth data for statistical and research purposes.[50]

2.7 Update of key developments

This section will provide details on:

- AIHW developments including expansion of data holdings
- development of a data governance framework, 2014
- development of a Framework for assessing data sources for population health monitoring, 2014
- publication of Guidelines for the disclosure of secondary use of health information for statistical reporting, research and analysis, 2015
- development of a Framework for Australian clinical quality registries, 2014.

2.7.1 Australian Institute of Health and Welfare (AIHW) developments

Following a decision by the Australian Government, the National Health Performance Authority ceased operations as of 30 June 2016 and transferred its functions to the Australian Institute of Health and Welfare and the Australian Commission on Safety and Quality in Healthcare.[51]

The AIHW took over all functions related to the Performance and Accountability Framework (PAF) reporting from 1 July 2016. The National Health Performance Authority was an independent government agency that monitored and reported on the performance of public and private hospitals, primary healthcare organizations and other bodies that provide healthcare services to the community. AIHW made some achievements in 2014/15 in relation to improved quality and timeliness of information. National standards were promoted in the provision and reporting of information through METeOR's information standards repository. The National Community Services Data Dictionary was updated and the National Health Data Dictionary was updated twice in this time period. 2,268 metadata items were made standard or endorsed in METeOR and 472 metadata items were superseded, retired or archived. AIHW continue to operate their Data integration Services Centre which is used by researchers or by the AIHW itself, to link data, either across data collections, or longitudinally in a single data collection in a secure environment. AIHW state that during this period they reported earlier in the collection cycle than in previous years on some collections such as the alcohol and other drug treatment services collection.[27]

2.7.2 Data Governance Framework, 2014

The Australian Institute of Health and Welfare (AIHW) published a Data governance framework in 2014. This framework provides an overview of AIHW's data governance arrangements. It provides information on: [47]

- key concepts in data and data governance
- the legal, regulatory and governance environment in which AIHW operates
- core data governance structures and roles
- AIHW data-related policies, procedures and guidelines
- systems and tools supporting data governance
- compliance regimes.

Data governance is described as a system of decision rights and accountabilities for information-related processes, executed according to agreed-upon models which describe who can take what actions, with what information, and when, under what circumstances, using what methods. In other words, it describes the source of authority for making decisions about data, the roles/structures authorized to make decisions, and the basis upon which those decisions are made.

Data Management comprises the 'agreed upon models' in the definition above. It is the development, execution and supervision of plans, policies, programs and practices that control, protect, deliver and enhance the value of data and information assets. Data management may be divided into several components as seen in Figure 2.

Figure 2: Data management components, AIHW Data Governance Framework[47]
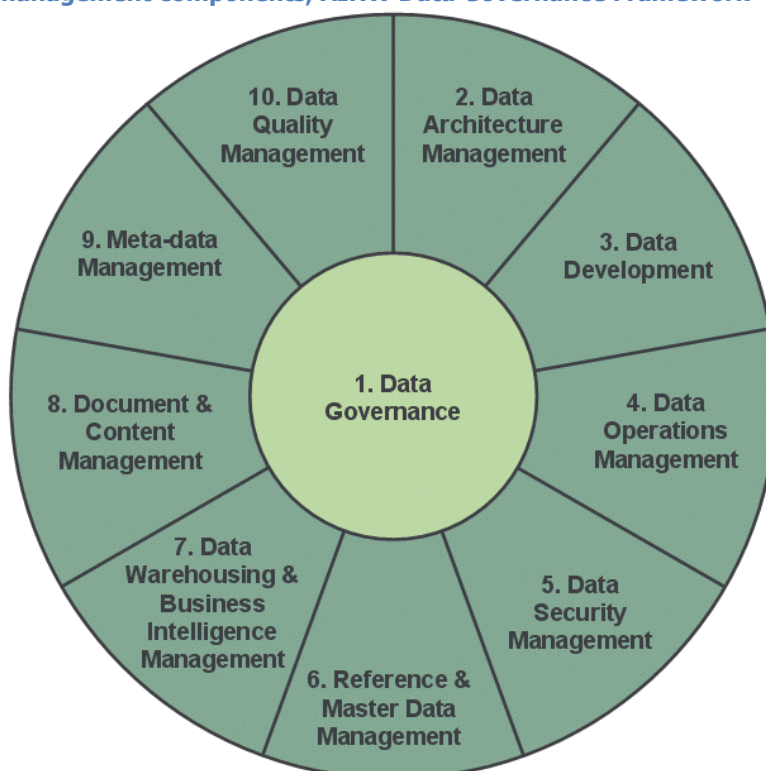
These data governance arrangements apply to data which has been collected and or enhanced by AIHW, collected on AIHW's behalf and obtained from all external sources. A combination of supporting legislation, roles, policies, practices and supporting tools and technologies are required to deliver effective data governance in AIHW. The framework applies to data held by AIHW in structured and semi-structured formats. Data held by public sector agencies are recognized as a national resource that should be made available for community access and use, unless there are legal reasons certain information should be protected. All data collections are subject to policies processes, and controls. However, additional strict constraints regarding collection, storage, use, linkage and disclosure apply to identifiable information. These include the requirements of the privacy laws of Australian states and territories and of the commonwealth, and numerous other legislative and internal controls designed to protect individuals from the improper use or release of their information.

The AIHW's internal data policies, guidelines and procedures are designed to ensure that all staff, and especially those with delegated authority to make data-related decisions, have clear sources of information to guide them in performing their roles effectively and appropriately. These documents cover the acquisition, management, linkage, security, confidentiality, quality, publication and retention of data.

Systems and tools relating to data governance include:

- ICT systems
- AIHW data catalogue
- METeOR
- Validata™.

Validata™ is an online validation tool. It is a time-saving online data receipt and validation tool. Validata™ can quickly pick up anomalies and unlikely occurrences in supplied data, and is now being extended across AIHW data collections and to some of their data providers.

The Ethics Committee requires regular monitoring of the progress of projects it has approved and audits of particularly sensitive data collections. The audits occur as part of the internal audit programme, with outcomes reported to the Board through the Audit and Finance Committee. Data collections held by AIHW may also be subject to audit by data providers and by statutory office holders such as the Auditor-General and the Privacy Commissioner.

2.7.3 Framework for Assessing Data Sources for Population Health Monitoring, 2014

The AIHW Framework for Assessing Data Sources for Population Health Monitoring, 2014[52] outlines an assessment framework for determining the suitability of specific data sources for population health monitoring. When identifying potential data sources for population health monitoring, it is important to ensure they are 'fit-for-purpose'.

The AIHW has developed a 3 step process to assess potential data sources for population health monitoring.

Step 1: Collects information about the data source using a data source information template. Data source characteristics such as type, purpose, description, management and contact details are collected. Details regarding methodology including the scope, geographical coverage and frequency/timing of the data source are also collected.

Step 2: Identifies the potential to inform key monitoring areas using a priority monitoring information template. Some examples of priority information include information on risk factors, incidence, prevalence, prevention, management, treatment, quality of life and mortality.

Step 3: Assess the quality of the data, using a modified version of the Australian Bureau of Statistics (ABS) Data Quality Framework 2009, to determine its 'fitness-for-purpose' by establishing its utility, strengths and limitations. A data quality assessment template is provided and contains key questions relating to seven data quality elements; institutional environment, relevance, timeliness, accessibility, interpretability, accuracy and coherence, depicted in Figure 3.[52]

Figure 3: Seven elements of data quality, Framework for Assessing Data Sources for Population Health Monitoring [52]
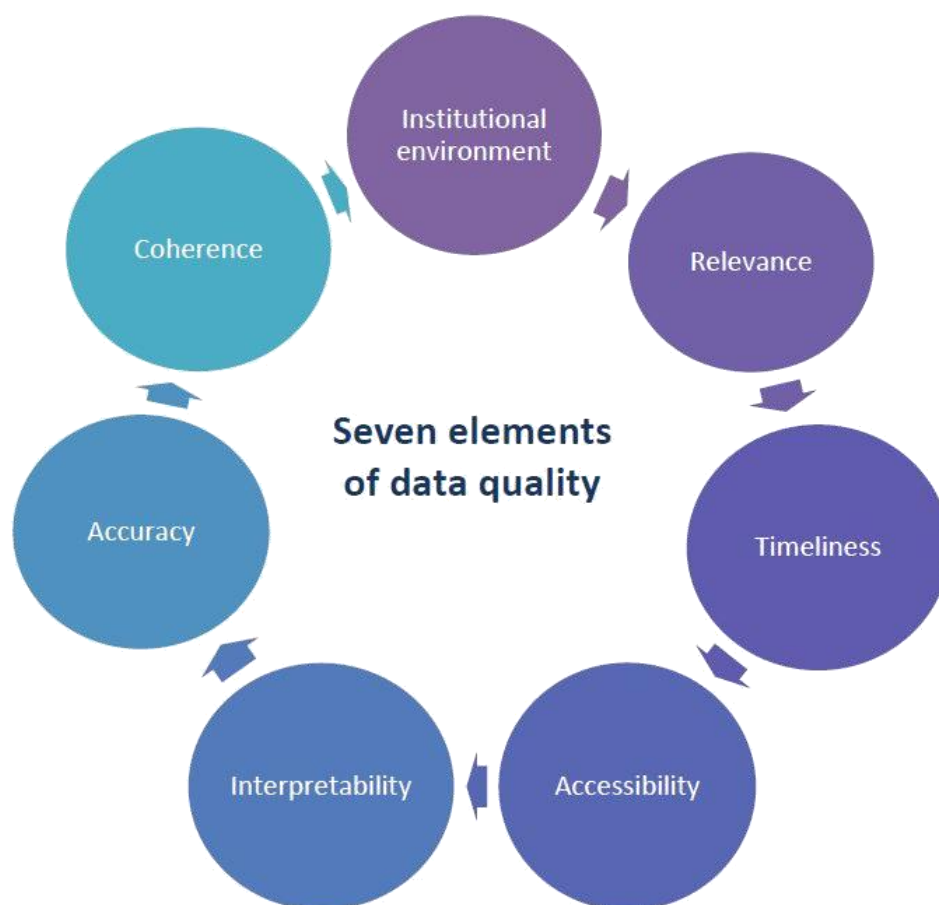
Source: Adapted from the ABS's *Data Quality Framework* (ABS 2009).

2.7.4 Guidelines for the Disclosure of Secondary Use Information for Statistical Reporting, Research and Analysis, 2015

Guidelines were developed by the National Health Information Standards and Statistics Committee (NHISSC) in 2015 to set out principles and techniques regarding the disclosure of secondary use health information for statistical reporting, research and analysis. [53] They replace the Guidelines for the Use and Disclosure of Health Data for Statistical Purposes developed by the Statistical Information Management Committee (SIMC) in 2007. These guidelines are appropriate for health information held by National Health Information Agreement signatories such as National Minimum Datasets and Dataset Specifications disclosed for purposes of statistical reporting, research and analysis. The aim of these guidelines is to assist data custodians to manage the risk of identification of individual patients/clients and

the identification of previously unknown information about that patient by defining a number of underpinning principles and recommending some of the available techniques. The principles and techniques are listed in the document along with case studies which illustrate the techniques. Examples of important principles include:

- information is a strategic national asset and agencies should provide as much public access as possible whilst minimising the risk of personal information disclosure
- data disclosure must comply with legislation and interagency agreements, including but not limited to information privacy principles, secrecy, consent, commercial-in-confidence, Freedom of Information and Commonwealth data integration principles
- all data custodians should have, adopt or develop their own guidelines which conform to legislation specifically applicable to them and utilise the principles and techniques outlined in these articles

2.7.5 Australian Clinical Quality Registries

An Australian Clinical Quality Registry is defined as a registry whose purpose is to improve the safety or quality of healthcare provided to patients. Australian Clinical Quality Registries build on data collected from events in daily healthcare and use this information to assess care provision and implement quality improvements where required. Clinical registries are databases that systematically collect health-related information on individuals who are:[54]

- treated with a particular surgical procedure, device or drug, e.g. joint replacement
- diagnosed with a particular illness, e.g. stroke
- managed via a specific healthcare resource, e.g. treated in an intensive care unit.

The Australian Commission on Safety and Quality in Healthcare developed a Framework for Australian Clinical Quality Registries in 2014. The framework is guided by the Strategic Principles for Clinical Quality Registries and recommends national operating practices in accordance with the Operating Principals for Clinical Quality Registries. The operating principles can be found in Appendix 1, the ten strategic principles are listed below.

2.7.6 The ten strategic principles for clinical quality registries

Principle 1: Consumers, clinicians, management and governments receive regular reports from Clinical Quality Registries on appropriateness of care (process and compliance with guidelines), and effectiveness of care (patient outcomes) to support ongoing improvement of healthcare in Australia.

Principle 2: Clinical Quality Registries, operating in close coordination with expert national clinical groups, provide an effective mechanism for design of indicators of quality of care, comprehensive data collection and analysis, and outlier management within a sound clinical governance framework.

Principle 3: National data governance arrangements and best practice infrastructure provide support for comprehensive reporting, monitoring and management of clinical practice variance.

Principle 4: Where existing data flows do not support analyses of quality of care, Australian Clinical Quality Registries are efficient and effective in providing consumers, clinicians, management and government with information for managing and improving delivery of health services.

Principle 5: Dedicated investment in Australian Clinical Quality Registries supports infrastructure, data cleansing, reporting and analysis of quality of care, based on succinct datasets captured routinely by clinicians at the point of care.

Principle 6: Australian Clinical Quality Registries have sound governance arrangements with strong clinical leadership and a demonstrated framework for quality improvement.

Principle 7: Prioritisation of Australian Clinical Quality Registry support is premised on gaps in existing data flows, the significance of the national burden of disease and the cost of interventions, the existence of variation in practice and outcomes, the ability to improve quality of care including reduction in practice variation, availability of national clinical leadership and consideration of existing data, and cost/benefit options.

Principle 8: Data governance for the collection, holding and analysis of patient-level, Australian Clinical Quality Registry information is managed as part of the national health information agenda, in a framework that protects patient privacy and complies with regulation. National data governance arrangements are essential to making the data collection, ethics approvals and reporting activities of Australian Clinical Quality Registries more efficient.

Principle 9: A secure, future-proof and scalable Australian Clinical Quality Registry design and infrastructure should support and host multiple Registries. Efficiency and best practice are best achieved through the operation of a small number of Australian Clinical Quality Registry systems or centres.

Principle 10: Australian Clinical Quality Registries must meet the requirements of national operating principles.[55]

The framework identifies a set of prioritisation criteria for Australian clinical quality registries to support the strategic principles for a national approach to the development of clinical quality registries.

The framework specifies national health information arrangements for clinical quality registries which are a mechanism by which the jurisdictions can authorize and secure record-level data, within high-priority clinical domains, to measure, monitor and report on the appropriateness and effectiveness of healthcare. A national infrastructure model, principles, guidelines and standards are provided under the national arrangements. The purpose of health information arrangements for clinical quality registries is to:

- facilitate national monitoring and reporting of the effectiveness and appropriateness of healthcare for the purpose of informing improvements in healthcare quality and safety
- complement existing health information arrangements including legislation, regulation and policies
- augment the National Health Information Agreement-for example the scope of the National Health Information Agreement does not cover the private hospital sector. However an explicit intention of the Framework is to include the private hospital sector within the national health arrangements
- provide assurance to participating stakeholders that minimum requirements regarding clinical quality registries information custodianship, security and accreditation are specified in official arrangements.[55]

2.8 Future plans

The AIHW Corporate plan for 2015–16 to 2018–19 is guided by eight priorities. The priorities of interest to this review include:

- data linkage
- value added feedback to data providers
- data quality.

In the coming years furthering AIHW's data linkage capabilities will be a priority. AIHW aims to improve the availability of integrated health and welfare information and successes will be assessed against the Performance Budget Statement performance targets. Agreements will be developed with governments to guide a more streamlined and timely data access and approvals pathway for national and state territory health and welfare data linkage. AIHW provide service level reports back to organizations to help them improve service level delivery to their clients. Data providers are also provided with nationally comparable and de-duplicated

versions of their data. AIHW will aim to enhance value added feedback to providers by working with more data providers to deliver feedback in a way which suits their needs. AIHW will take an increasingly strategic approach to data quality. Existing data quality mechanisms will be explored and internal monitoring of instances where data quality issues occur will be carried out to facilitate continuous improvement. During this period a data quality assurance framework will be developed and success will be measured by data quality metrics which emerge from that process.[28]

Many organizations in Australia are looking into new methods of data mining. There is a shift of focus to try and gain the most information and insight from data which is readily available. The quality of this data may not be optimal but the aim is to use new technologies to use this data to its full potential.[39]

These future plans will be influenced by the Australian Government Public Data Policy Statement which was released in December 2015. The data held by the Australian Government is a strategic national resource that holds considerable value for growing the economy, improving service delivery and transforming policy outcomes for the Nation. The Australian Government commits to optimise the use and reuse of public data; to release non-sensitive data as open by default; and to collaborate with the private and research sectors to extend the value of public data for the benefit of the Australian public. At a minimum, Australian Government entities will publish appropriately anonymised government data by default:[39]

- on or linked through data.gov.au for discoverability and availability
- in a machine-readable, spatially-enabled format
- with high quality, easy to use and freely available API access
- with descriptive metadata
- using agreed open standards
- kept up to date in an automated way
- under a creative commons licence unless a clear case is made to the Department of the Prime Minister and Cabinet for another open licence.

2.9 Summary- Australia's approach in relation to national data collections

- The Australian Institute of Health and Welfare (AIHW) is the statutory body that manages the majority of national health and welfare data collections in Australia. AIHW currently have 84 data collections.
- The National Health Data Dictionary, the National Community Services Data Dictionary and the National Housing and Homelessness Data Dictionary are all available through METeOR.[30]
- Australia has three types of unique healthcare identifiers: an individual healthcare identifier (IHI), a healthcare provider identifier-individual (HPI-I) and a healthcare provider identifier-organization (HPI-O).
- A legislative framework has developed over time consisting of intergovernmental agreements. The National Health Information Agreement gives AIHW certain responsibilities in relation to health information.
- AIHW have developed a policy and guidance document in relation to data quality statements. Data quality statements enable users of data reported by AIHW to understand any limitations and to make informed judgements about their use of the data.
- The Australian Capital Territory (ACT) Health Data Quality Framework comprises the data integrity strategy, the data quality policy, the data quality improvement cycle and the data quality assessment tool.
- AIHW published a Data governance framework[47] in 2014. This framework provides an overview of AIHW's data governance arrangements including guidance on supporting legislation, roles, policies, practices and supporting tools and technologies which are required to deliver effective data governance.
- The Australian Commission on Safety and Quality in Healthcare has published a Framework for Australian Clinical Quality Registries in 2014. The framework is guided by 10 strategic principles.[55] A national infrastructure model, principles, guidelines and standards are provided under the national arrangements.

3. Canada

Canada has a population of 36.04 million.[56] It is a constitutional monarchy with a federal system of government. Responsibility for the delivery of healthcare is largely given to the country's ten provinces and three territories. As a result, Canada is home to a number of information systems for the collection, reporting and analysis of health data.[57] The National Health Information Commission (NHIC) was set up in 1988 and from this came a task force which resulted in the formation of the Canadian Institute for Health Information (CIHI). The establishment of CIHI in 1994 was the most significant development in the management of national data collections.[58]

This chapter will provide information on:

- an introduction to national health and social care data collections in Canada
- health information standards
- health identifiers
- the legislative context regarding national data collections
- data quality programme for national data collections
- data linkage
- updates in relation to national health and social care data collections in Canada
- Canadian institute for Health Information (CIHI) future plans.

3.1 Introduction

Some of the agencies with significant roles in the national collections of Canada include, the Canadian Institute for Health Information (CIHI), Statistics Canada, Canada Health Infoway, Health Canada and the Public Health Agency of Canada. CIHI manages the majority of the national healthcare data collections. CIHI is an independent, not-for-profit organization established in 1994 by Canada's deputy ministers of health to improve the quality and availability of Canadian health data. Most of CIHI's funding flows from federal, provincial and territorial governments. In collaboration with key stakeholders, CIHI plays a leadership role in setting standards for data collection and for meaningful data analysis to support both front-line and system uses of health information.[59]

Bilateral and data sharing agreements signed between CIHI and provinces, territories, agencies, organisations and data requestors set out the types of data that may be transmitted and released and in what way data may be used.[60]

CIHI has a well developed data quality programme and works to improve data quality at different levels of the health system. CIHI promotes the use of national standards among the provinces and territories relating to data, transmission, clinical coding and privacy and security. CIHI also maintains data dictionaries for the individual national collections.

CIHI collects comparable, pan-Canadian data on different aspects of the health system. When CIHI was established it managed three national collections. At the time of writing CIHI has 30 data holdings, the data holdings collect information on:[61]

- hospital care — e.g. Hospital Morbidity Database
- community care — e.g. Home Care Reporting System
- specialized care — e.g. Canadian Organ Replacement Register
- pharmaceuticals — e.g. National Prescription Drug Utilization Information System Database
- patient safety — e.g. National System for Incident Reporting
- health workforce — e.g. Health Workforce Database
- spending — e.g. Canadian MIS Database
- international comparisons — e.g. Commonwealth Fund Survey
- access and wait times — e.g. Wait Times.

3.2 Health information standards

CIHI has taken a lead role in developing and implementing national standards to enhance the consistency and accuracy of Canadian health information. CIHI does not use legislation to enforce standards for data collections. Instead it engages in a programme of consultation, education and promotion.[6] CIHI standards and data submission products and services are available to clients. These include:[62;63]

- classification and coding standards to assist healthcare professionals to maintain, understand and apply clinical data standards
- data architecture to describe how technical information technology standards support the collection, analysis and sharing of health-related data
- standards for Management of Information Systems (MIS Standards) provide an integrated approach to collecting, integrating and reporting financial and statistical data on the day-to-day operations of health service organisations
- case mix systems and other grouping methodologies to plan, monitor and manage the services provided.

3.2.1 Data Dictionaries

While there is no comprehensive national data dictionary in existence, each of the national databases has its own data standards/data dictionary to ensure consistent data from across the country. A corporate reference data model (CRDM), is also in place with a supporting data dictionary. The intent of this data model is to guide new database development and when existing ones are redeveloped, that they are more aligned with electronic health record standards (HL7 etc). There are some differences in some of the data elements that are common across existing data holdings, primarily because they were developed at different times (and predate the CRDM).CIHI also utilise an Indicator Library, which provides information on the health system performance indicators CIHI produces.[64]

3.2.2 Classification and terminology

CIHI supports a number of classifications for use in the collection and analysis of data in healthcare. All national data collections are mandated to be coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Canada (ICD-10-CA) standard.[6] The Canadian Classification of Health Interventions (CCI) was developed to accompany ICD-10-CA which classifies a broad range of interventions, to be used comprehensively throughout the health system.[63] The Canadian Coding Standards (CCS) supplements ICD-10-CA and CCI through the provision of additional information that could not be provided for in ICD-10-CA and CCI. The International Classification of Functioning, Disability and Health (ICF) is also a CIHI supported classification.

Systematized Nomenclature of Medicine Clinical Terms (SNOMED-CT) has been designated by the Standards Collaborative as a pan-Canadian standard for clinical healthcare terminology for Electronic Health Records (EHR). Launched in 2006, the Standards Collaborative is a group within Infoway that maintains and publishes health information standards, and provides implementation and support services to members.

3.3 Health identifiers

Pan-Canadian unique health identifiers (UHIs) are not in existence currently. However jurisdictional UHIs are in use, with every person possessing an individual health insurance number (which is not linked to their tax or revenue number, also referred to as the health card number). If a person moves province or territory, a

new but unique number will then be issued to them by the provincial government of their new jurisdiction. There is a system of national identifiers in place for physicians; the National Physician Database features the Unique Physician Identifier (UPI) which allows for the tracking of physicians over time and location.[65]

3.4 Legislative context

In accordance with the *Canada Health Act (1984)*[66], responsibility for health information lies with Health Canada, a department of the federal government. The provincial governments are responsible for the delivery of the health services and the information they need to manage their system. Different legislative provisions exist across different territories and provinces within Canada. Bilateral and data sharing agreements signed between CIHI and provinces, territories, agencies, organisations and data requestors set out the types of data that may be transmitted and released and in what way the data may be used.[60] Bilateral agreements have been signed with the Ministries of Health in all of the provinces and territories. The bilateral agreements set out the terms, exchanges of promises, conditions and provisions to which both CIHI and the province or territory agrees. The agreements generally cover three year periods and may be amended in accordance with its terms.

CIHI adheres to all applicable privacy legislation, including the Ontario *Personal Health Information Protection Act*, which authorises CIHI to receive personal health information as a prescribed entity.[1]

3.5 Data quality programme for national data collections

Data quality is a key corporate priority and is fundamental to CIHI's mandate. While direct responsibilities for data quality fall to the jurisdictions, CIHI recognises that improving data and information quality is a collaborative effort and works with its data suppliers to support improvement activities. Their collaborative approach is designed to meet the changing and expanding user requirements and expectations of CIHI's data collections.[67]

CIHI has developed a data quality programme that is recognised nationally and internationally for its comprehensiveness and high standards. The goal of the programme is to continuously improve data and information quality within CIHI and the broader health sector. Within the programme is CIHI's widely cited Data Quality Framework, 2009[68] which details an approach to systematically assess, document

and improve data quality in all of the data collections. The Framework measures quality against five dimensions, 19 characteristics and 61 criteria of quality. The dimensions and characteristics are shown in table 4. The components of the framework include:[64]

- a data quality work cycle (planning to implementing to assessing)
- a data quality assessment tool
- documentation about data quality including assessment reports, data quality documentation for users and metadata requirements.

Table 4: CIHI Data quality framework assessment tool: 5 dimensions and 19 characteristics[64]

Coverage	Comparability	Timeliness	Usability	Relevance
Coverage	Data dictionary standards	Data currency at release	Accessibility	Adaptability
Capture and collection	Standardisation	Documentation currency	Documentation	Value
Unit non-response	Linkage		Interpretability	
Partial (item) non-response	Equivalency			
Measurement error	Historical comparability			
Edit and imputation				
Processing and estimation				

After the Framework is applied to data received, CIHI identifies how to improve the data and supplies documentation to enable users of the data to judge whether the data meets their needs and how to use the data.[69]

CIHI regularly performs a series of activities to help monitor data quality and prevent and detect data quality issues. These include:[64;67]

- the programme area responsible for the data holding completes a full assessment using the data quality framework assessment tool at least once every three years, or if the holding undergoes significant change
- providing educational sessions to data providers on data requirements and data quality issues
- offering a coding query service to health information management professionals and other data collectors
- building systems that automatically check for data quality issues and providing feedback to data suppliers
- assessing and documenting the quality of data and providing this information to suppliers and users of the data
- preparing annual jurisdictional reports on the status of data quality for provincial and territorial deputy ministers
- reabstraction studies which are used to evaluate clinical data in acute care.

The CIHI Data Quality Framework is being revised in 2016. There is a need to update the description of how CIHI manages the quality of its data and information products and a need to effectively assess the broad range of its data sources and ensure its quality management practices are efficient and in line with international best practices. Full assessment now takes place every three years and short progress reports are provided in the intervening years. The goal of updating the data quality framework is to better assess information quality. CIHI will develop and incorporate tools to assess and manage the quality of indicators, reporting tools and analytical products. The current framework is focussed on the data quality of CIHI's data collections, but also needs to include:[64]

- how the information is presented, accessed and can be understood
- how the information fits together to paint a coherent picture
- the quality management of the processes involved in transforming the data into the information.

The update is being informed by two key international resources which have been developed by the United Nations (UN) in conjunction with national statistical organisations; the General Statistical Business Process Model (GSBPM)[70] and the National Quality Assurance Framework (NQAF).[18] The revised framework is expected to be published in 2017.

3.6 Data linkage

Until recently data linkage in CIHI had been an ad-hoc, manual process which was carried out by data analysts. Current efforts are directed at producing reports that

link data from different collections. CIHI's Privacy Policy (2010, updated in 2014) details the circumstances under which data linkage can be undertaken, both within the Institute and by third parties. Data linkage within a single data holding for CIHI's own use is generally permitted while data linkage across data collections is subject to internal approval against a range of criteria. Requests for data linkage are submitted to CIHI's Privacy, Confidentiality and Security Team for approval against a range of criteria outlined in the Privacy Policy.[71] CIHI has recently introduced a corporate standard methodology for patient-level record linkage to facilitate more consistent and efficient record linkages in an anonymised fashion. The standard is based on the combination of the encrypted Health Care Number (HCN) and the jurisdiction issuing the HCN, and has excluded records with data quality concerns (for example, HCNs identified as being used by more than one person).[72]

3.7 Update of key developments

This section will provide details on:

- current developments underway in CIHI include the expansion of its data holdings and setting the standard for EMR data
- CIHI's privacy and security programme including an updated list of privacy and security policies and protocols and details on CIHI's privacy impact assessments
- Canada Health Infoway
- Statistics Canada.

3.7.1 Canadian Institute for Health Information (CIHI)

CIHI currently has 30 data holdings and has achieved 100% electronic data submission across all data holdings in 2014-2015. During this period CIHI has explored data surveillance techniques, taking cues from the finance and insurance sectors. The data holdings now include information from the patients' perspective.

Working alongside Canada Health Infoway and other partners, CIHI is aiming to support a priority set of standardised primary health care data by 2017. CIHI launched a new web tool, Your Health System: Insight. This is the third of a series of Your Health System tools — part of a broad Health System Performance program of work. Your Health System: In Brief and In Depth provide publicly available facility, regional and provincial indicators.[73] The new tool is used by clients (e.g. individual health care facilities, regional health authorities, participating provincial and territorial ministries/departments of health) to get quick, easy access to their results

on key performance indicators, as well as the underlying data. It offers clients access to open-year data, increased flexibility to understand performance drivers and pan-Canadian comparisons so they can understand what's driving their performance, compare their results with others' across Canada and improve their part of the health system.[74]

3.7.2 CIHI's privacy and security programme

CIHI has a comprehensive privacy and security programme to protect the confidentiality and security of the Canadian health care data holdings. Part of this programme is a set of strict privacy and security policies. This list of privacy and security policies and protocols is current as of March 2016: [75]

- Privacy and Security Framework, 2010 (Updated Apr. 2014)
- Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010 (Updated Apr. 2014)
- Privacy and Security Risk Management Framework (Sep. 2015)
- Policy on Privacy and Security Risk Management (Sep. 2015)
- Privacy and Security Incident Management Protocol (Sep. 2015)
- Policy on Health Facility Identifiable Information (Jul. 2015)
- Policy on the Security of Confidential Information and Use of Mobile Devices/Removable Media (Jul. 2014)
- Privacy and Security Training Policy (Sep. 2013)
- Information Security Policy (Mar. 2013)
- Privacy Policy on the Collection, Use, Disclosure and Retention of Health Workforce Personal Information and De-identified Data, 2011 (Jun. 2011)
- Privacy Impact Assessment Policy (Dec. 2010).

CIHI completes Privacy impact assessments on all its data holdings. Privacy impact assessment documents evaluate and address the privacy impacts of programmes and systems. In 2014-2015 a new privacy and security training module was developed.

CIHI adopted and implemented a Privacy Impact Assessment Policy[76] in 2009 as its governing document on privacy impact assessments (PIAs). While PIAs were in use before this, the policy formally governs how and when PIAs should be carried out. PIAs have been conducted for all CIHI databases containing either personal health information or health workforce personal information. They are renewed every five years at a minimum or more often if circumstances change or it is deemed necessary.[76]

3.7.3 Canadian Health Infoway

Established in 2001, Infoway is a not-for-profit federally funded organisation that works with partners to accelerate the development, adoption and effective use of digital health solutions. All federal, provincial and territorial governments in Canada are Infoway members. In 2003, CIHI and Infoway began working in partnership to develop and maintain standards required for the introduction of the EHR data definitions and standards relating to primary care. Infoway defines an electronic medical record (EMR) as a computer-based medical record specific to one clinician's practice or organisation. Electronic health records (EHR) are different in that they provide a complete health record for a patient over the course of their lifetime.[77] Canadian Health Infoway published an Annual Report for 2014-2015. This reports that there are more than 91,000 clinicians using an electronic health record (EHR) and 77% of family doctors are now using electronic medical records (EMR). Infoway published *Privacy and Security Requirements and Considerations for Digital Health Solutions*, which identifies issues and factors that vendors, jurisdictions and organisations will want to consider as they adopt new digital health solutions. A new Jurisdictional Implementers' Group focusing on digital health enterprise architecture was established during 2014-2015. It aims to address topics like data quality, data analytics, mobile computing and cloud computing.[78]

3.7.4 Statistics Canada

Statistics Canada was established in 1971 and ensures access to a trusted source of statistics on Canada. A large portion of Statistics Canada's activities is devoted to meeting the needs of federal, provincial and territorial government policy departments and providing ongoing measurement of Canadian socio-economic dynamics and emerging trends. Statistics Canada's mandate derives primarily from the Statistics Act. The Act requires that the agency collect, compile, analyse and publish statistical information on the economic, social and general conditions of the country and its people. Statistics Canada plays a major role in health information in Canada, operating numerous health-related surveys and statistical programs such as the Canadian Health Measures Survey and the Canadian Cancer Registry.[79] CIHI provide Statistics Canada with administrative clinical data that they collect.[72] Statistics Canada uses administrative data for statistical purposes to complement survey data, or in lieu of surveys and to support statistical operations. Using administrative data means the agency is able to improve data quality, meet new and ongoing information needs, reduce data collection costs and save time for those who respond to surveys. Statistics Canada supplies resources through information on

data standards and methodology, international metadata standards and standard classifications.[79]

3.8 Future plans

3.7.2 Canadian institute for Health Information (CIHI) future plans

CIHI published a strategic plan for 2016-2021.[80] The strategic plan has the mandate to deliver comparable and actionable information to accelerate improvements in healthcare, health system performance and population health across the continuum of care. The plan has three strategic goals with corresponding priorities to be achieved in the next 5 years.

1. Be a trusted source of standards and quality data.
   - increase the use of health data standards to achieve quality data
   - make data collection easier and improve timeliness
   - close the data gaps in priority areas
   - make data more accessible.
2. Expand analytical tools to support measurement of health systems.
   - compare health systems in priority areas.
   - expand analytical products using innovative approaches, including data linkage and predictive modelling
   - enrich the information infrastructure, grouping methods and decision-support tools
   - transform CIHI's digital presence into a core strategic asset.
3. Produce actionable analysis and accelerate its adoption.
   - produce analyses that contribute new information and insights, working with external partners and with intended end-users to create a culture of co-development
   - engage with stakeholders to enable better use of health data and information
   - provide customized products and services to support local decision-making needs.

During the five year period CIHI will place particular importance on patient experience, quality and safety, outcomes and value for money.

3.9 Summary- Canada's approach in relation to national data collections

- There are three agencies with significant roles in the national data collections of Canada, the Canadian Institute for Health Information, Statistics Canada and Canada Health Infoway.
- CIHI currently has 30 data holdings and has achieved 100% electronic data submission across all data holdings in 2014-2015.[74]
- Data dictionaries are in place for each collection. However, there is no comprehensive national data dictionary in existence.
- Pan-Canadian unique health identifiers (UHIs) are not in existence currently. However jurisdictional UHIs are in use, using individual health insurance numbers.
- CIHI has a well developed data quality programme and works to improve data quality at different levels of the health system. CIHI's Data Quality Framework sets out an approach to systematically assess, document and improve data quality for all data holdings. CIHI are currently updating this framework.
- CIHI has a comprehensive privacy programme to protect the confidentiality and security of the Canadian health care data holdings. Part of this programme is a set of strict privacy and security policies, many of these have been updated in 2015.[75] CIHI completes privacy impact assessments on all its data holdings. Privacy impact assessment documents evaluate and address the privacy impacts of programmes and systems.[76]

4. England

The population of England is 54.3 million.[81] The National Health Service (NHS) in the United Kingdom was established in 1948 and is funded centrally from national taxation, but is managed separately in England, Scotland, Wales and Northern Ireland. NHS England and 211 Clinical Commissioning Groups (CCGs) are responsible for the majority of NHS services. NHS England is also divided into a number of Trusts, which have responsibility for providing care across different health services such as, acute hospital services and ambulance services. The passing of the Health and Social Care Act 2012 [82] brought about significant changes in the area of health information in England.[1]

This chapter will provide information on:

- an introduction to national health and social care data collections in England
- health information standards
- health identifiers
- the legislative context regarding national data collections
- data quality programme for national data collections
- data linkage
- reducing burden and bureaucracy
- updates in relation to national health and social care data collections in England
- future plans.

4.1 Introduction

The Health and Social Care Information Centre[*] (HSCIC) in England is the national provider of information, data and IT systems for health and social care. HSCIC is an executive non-departmental public body, sponsored by the Department of Health. The HSCIC began operating in 2013 and manages the majority of national health and social care data collections in England. Data is collected from a range of NHS trusts, local authorities and independent-sector organizations.[1] There are also a number of other bodies with responsibilities in the area of health information in health and social care in England. These include the Care Quality Commission (CQC), the National Quality Board and the Department of Health.

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[*] From July 2016, the Health and Social Care Information Centre (HSCIC) will trade under the name NHS Digital.

The HSCIC works closely with national organizations: NHS England, the Department of Health and the bodies that commission its services. The HSCIC works under the National Information Board (NIB), a body that provides an integrated commissioning arrangement for informatics services for health and social care in England. The Standardisation Committee for Care Information (SCCI) also plays an important role. It oversees the development, assurance and approval of information standards, data collections and data extractions.[1]

As of May 2016 there are 198 data collections in England. 56 of these collections are within HSCIC. Other organisations who manage data collections include the NHS England, the Care Quality Commission (CQC) and Public Health England. HSCIC has a statutory responsibility for all data collections including those not held within HSCIC.[83]

The HSCIC's Burden Advice and Assessment Service (BAAS) offers advice, guidance and support for the health and social care system (both nationally and locally) on minimising the burden and bureaucracy of data collection, freeing up staff time to care. The HSCIC website lists 41 data collections in the BAAS Schedule of HSCIC Approved Collections as of April 2015. Some examples include:[84]

- annual medical and dental workforce census
- diagnostic imaging dataset
- community information dataset
- mental health and learning disabilities dataset
- sexual and reproductive health activity dataset
- NHS staff earnings survey.

The HSCIC along with the Department of Health and the Cabinet office announced in February 2016 that it plans to open a Centre of Excellence for big data and data science. The aim of the centre would be to embed data science approaches in public services, including healthcare.[85]

4.2 Health information standards

The HSCIC uses standards, underpinned by supporting guidance, to specify rules for the collection, processing, management and sharing of information to support patient care. These rules may include technical standards, data standards or information governance standards. Information standards are central to the HSCIC as it works to "improve greater interoperability through information standards, prioritising areas where greater interoperability can reduce burden, improve data

quality and validation processes, and ultimately supports integrated care delivered."[86]

The Health and Social Care Act 2012 requires that health and care organizations have 'due regard' for information standards, meaning that organizations must follow the standards or have a defensible reason for not doing so. Enforcement is through the regulatory framework and incentivised by commissioners.[1]

The HSCIC also publishes national datasets for a number of health areas such as diabetes, cancer and mental health, which define a standard set of information that is generated from care records. These datasets are structured lists of individual data items, providing a definition and a set of permissible values, codes and classifications, allowing for the compilation of information for secondary uses.[1]

4.2.1 National data dictionary

The NHS Data Model and Dictionary provides a reference point for assured information standards to support healthcare activities within the NHS in England. The NHS Data Model and Dictionary is maintained and published by the NHS Data Model and Dictionary Service and all changes are governed by the Standardisation Committee for Care Information.[87] As a national resource for those who participate in the collection of data and management of information in the NHS, it serves to standardize the data collected across the NHS.

4.2.2 Classification and terminology

The HSCIC utilises classifications and terminologies as 'building blocks' to enable the development and implementation of information standards.[1]

The UK Terminology Centre within the HSCIC is responsible for the management of SNOMED-CT, Read Codes† and other healthcare terminology products and clinical classifications. The Clinical Classifications Service (CCS) in the HSCIC is the definitive source of clinical coding guidance and sets the national standards used by the NHS in coding clinical data. The CCS provides guidance, education and training for clinical coders in the NHS, and also offers a query service.[88] The Clinical Classification Service (CCS) supports, maintains and develops the OPCS Classification of Interventions and Procedures (OPCS-4). Also in use is the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10).[1]

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† Read codes are a coded thesaurus of clinical terms.

4.2.3 The Standardisation Committee for Care Information (SCCI)

The Standardisation Committee for Care Information (SCCI — pronounced Sky) is a subgroup of the National Information Board (NIB), responsible for delivering the information standards component of national informatics governance in health and social care in England. The SCCI is responsible for the identification, commissioning and successful implementation of information standards, collections and extractions, ensuring that new (and pre-existing) data collections are technologically suitable and adhere to current standards. The SCCI governs the approval process, through which standards must proceed. SCCI has asked HSCIC to provide support and guidance to all users throughout the lifecycle of an information standard, data collection or data extraction. This service, known as the SCCI process, is broad-based and will respond to changing circumstances. However, where required, it provides: [89]

- general developer support and guidance
- maintenance of the development and assurance methodologies
- planning and scheduling of all releases once approved by SCCI
- a service to assess the validity of ideas submitted as potential standards and collections
- development of a comprehensive and inclusive set of requirements
- provision of specialist advice as part of the development process
- critical appraisal of all releases before submission to SCCI for approval
- publication and notification services.

There are two types of standards set through the SCCI: [83]
- Standards about the processing of information, published by the Department of Health or NHS England. In this case, organizations must "have regard" to these standards.
- The form and manner of data collections, published by HSCIC as a data provision notice. In this case, organizations must provide data in the prescribed form/manner.

4.3 Health identifiers

Data linkage is facilitated by unique identifiers. Each person registered with NHS England is assigned an individual ten digit number called an NHS number, allowing healthcare staff and providers to match a patient with their records. The HSCIC also operates an Organization Data Service (ODS) that provides unique identification codes for organizational entities of interest to the NHS, such as hospitals and General Practitioner (GP) practices.[1]

4.4 Legislative context

The Health and Social Care Centre (HSCIC) was established under the Health and Social Care Act 2012 and is the body that has statutory responsibility for collecting data from across the health and social care system. The Health and Social Care Act 2012 provides the HSCIC with a legal basis for requiring the submission of data. The Act states that the HSCIC's statutory data quality role is to assess the extent to which the data it collects meets applicable published standards and to publish the results of the assessments. In addition, the HSCIC may give advice or guidance on data quality relating to the collection, analysis, publication or other dissemination of data and information. The Act also states that the Secretary of State for Health and NHS England are responsible for preparing, or adopting, and publishing the information standards against which the HSCIC assesses the quality of data it receives.[90] The Act sets out the HSCIC's responsibilities, which include:

- collecting, analysing and presenting national health and social care data
- setting up and managing national IT systems for transferring, collecting and analysing information
- publishing codes of practice to set out how the personal, confidential information of patients should be handled and managed by health and care staff and organizations
- building up a library of indicators that can be used to measure the quality of health and social care services provided to the public
- helping health and care organizations improve the quality of the data they collect and send to the HSCIC, by setting standards and guidelines to help them assess how well they are doing
- creating a register of all the information that is collected and produced, and publishing that information in a range of different formats.

In order to apply controls to data collections, the HSCIC is signing concordats (agreements) with each national arm's-length body‡ (ALB), committing the ALBs to working with the HSCIC and other ALBs to reduce the burden. Essentially the concordat will also enable the HSCIC to make arrangements for rationalising different national data collections with the intention of consolidating them through the HSCIC[92], as required by the Health and Social Care Act 2012. Signatories of the concordat commit to managing national requests for information using a single, transparent process.[93]

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‡ Arm's-length bodies are Government-funded organizations which work closely with local services and other arm's-length bodies. The Department has three types of arm's-length bodies: Executive agencies; Executive Non-Departmental Public Bodies; and Special health Authorities.[91]

Under the Health and Social Care Act 2012, the Care Quality Commission (CQC) has a new statutory duty to monitor and seek to improve the information governance of health and social care providers. Following the Act, the CQC were also required to set up a National Information Governance Committee (NIGC) to provide independent and objective advice on the development and delivery of CQC's information governance monitoring functions.

4.5 Data quality programme for national data collections

The HSCIC has a statutory data quality role and undertakes a range of data quality activities, including setting and maintaining data standards. The HSCIC assesses the data it collects against national standards and reports the findings which are published on the HSCIC website. Every official and national statistical publication within HSCIC provides a data quality statement to show how each area of data quality is addressed by the publication.[94]

The HSCIC has published three experimental official statistics publications that report on data quality. *The Quality of Nationally Submitted Health and Social Care Data England, Annual Report, 2014,* is the third experimental official statistics publication to report on the quality of data collected by the HSCIC from health and social care organizations in England. The purpose of the publication is to give health and social care organizations, and other interested parties, information about the:

- progress the HSCIC has made against the planned data quality activities and capabilities published in the 2013 report
- methodologies used to assess the quality of data received for some key data assets, including links where available
- reports produced that present the results of those data quality assessments, including links where available
- case studies describing some of the benefits that result from improving data quality.[90]

4.5.1 Data Quality Statements

Every official and national statistical publication within the HSCIC provides a data quality statement to show how each area of data quality is addressed by the publications. Once the analysis of the quality is complete, a data quality statement is produced as an appendix within each of the publications that summarises the data quality issues found. The following areas are covered in the data quality statement:

- relevance
- accuracy and reliability
- timeliness and punctuality
- accessibility and clarity
- coherence and comparability
- trade-offs between output quality components
- assessment of user needs and perceptions
- performance, cost and respondent burden
- confidentiality, transparency and security.

4.5.2 Quality Information Committee

The National Quality Board exists to provide a forum where the key NHS oversight organizations can come together regionally and nationally to share intelligence, agree action and monitor overall assurance on quality. The Quality Information Committee provides advice to the Department of Health, on behalf of the National Quality Board, about strategic priorities for quality information in healthcare, quality information issues where action is required at national level and implementation of the government's information strategy. The Quality Information Committee was established to improve alignment within the system and focus on the improvement of care for people through the better use of information. The Quality Information Committee has undertaken a number of reviews including a first national review of data quality in the health and social care system. The report made a number of recommendations including the need for a minimum definition of data quality in the health and social care.

4.6 Data linkage

HSCIC provide access to a wide range of data products and services through Data Access Request Service (DARS). Changes in legislation coupled with growing public concern over the appropriate use of data have led to the need for greater rigour and transparency when dealing with requests for data. Guidance on each of the five stages — application, approval, access, audit and deletion — is provided through the DARS Process. All decisions and actions are bound by law and policies. The process ensures appropriate legal basis for the receipt, process and flow of data to the user. Safeguards are in place to store and handle the data safely and securely. Each request for data, other than for anonymous data, is evaluated by the Data Access Advisory Group (DAAG). Data sharing contracts and data sharing agreements are

used and data sharing audits are carried out to ensure that data users meet their obligations.[95] Adherence to the Code of Practice on Confidential Information is also audited.[83]

4.6.1 Accredited Safe Havens

Under the Health and Social Care Act 2012, the HSCIC is prohibited from releasing data to other bodies that is weakly pseudonymised, unless there are controls to prevent re-identification and in circumstances where the data inadvertently identifies an individual; there must be a clear legal basis for this. Under the NHS Act 2006, an Accredited Safe Haven (ASH) is an accredited organization or part thereof, which is contractually and legally bound to process data in ways that prevent the identity of individuals to whom the data relates, from being identified.[96] Under the legislation, only the HSCIC and other ASHs are permitted to link data and this is restricted to linkage for limited disclosure or limited access. Accreditation is subject to regulation, with organizations complying with stipulated conditions, and data sharing contracts are put in place to reinforce compliance. Linkage of identifiable data from more than one organization for any purpose other than direct care must only be done within an ASH. It is expected that there will be relatively few ASH's and that the HSCIC, itself being an ASH, will design criteria and audit these havens.[69]

4.7 Reducing burden

The Health and Social Care Information Centre (HSCIC) defines burden as a professional assessment of the time and associated costs incurred by organizations in England resulting from the implementation, on-going use and eventual de-commissioning of an information standard, data collection or data extract.[97] The total burden is approximately 180 million pounds. This equates to 0.2% of the total NHS turnover. Some data collections, data extracts and information standards carry a large burden, the information governance toolkit, for example, carries a £15 million burden. The aim is to ensure that the burden is minimal for the benefits gained.[83]

There is a strong focus on reducing the burden and bureaucracy in the NHS. HSCIC has been designated a statutory role to monitor the burden generated by national data collections on the frontline. The HSCIC has noted that there needs to be a better appreciation of the volume of data that is required by the national data collections, the effort that goes into collecting, processing and validating the data and the value of the asset that the data creates. The introduction of concordats (agreements) and Memoranda of Understanding by the HSCIC serves as a means to

apply controls to the national collections and reduce duplication of effort and the burden on service providers.[86]

The HSCIC's Burden Advice and Assessment Service (BAAS) offers advice, guidance and support for the health and social care system (both nationally and locally) on minimising the burden and bureaucracy of data collection, freeing up staff time to care. BAAS has responsibilities under the Health and Social Care Act 2012 to:

- minimise the burden of data collections on health and social care organizations
- offer advice and guidance to other national organizations on minimising the burden of their data collections
- advise the Secretary of State for Health on ways in which the burden of data collection might be minimised.

BAAS works in conjunction with the National Information Board (NIB) and partners across health and social care to:

- assess burden and provide recommendations to minimise the burden involved in new and existing information standards, data collections and extractions
- engage with the health and social care system to identify and facilitate the sharing of good practice around how data is collected, collated and distributed
- encourage collaborative working to promote efficient use of technology in making the best use of information to support delivering care.

For each standard, collection or extraction HSCIC burden assesses, and in collaboration with Standardisation Committee for Care Information (SCCI) Services, a report including recommendations to collection owners and data providers around how burden may be minimised and share good practice examples is produced.[97]

4.8 Update of key developments

This section will provide information on:

- Health and Social Care Information Centre (HSCIC) developments including an information governance framework for health and social care
- a privacy impact assessment by the HSCIC in 2013
- the Information Standards Board for Health and Social Care developed the Information Governance Standards Framework, 2010
- Care Quality Commission (CQC) updates including new duties in relation to information governance such as a new model for inspection and a review of standards of data security for patients' confidential data in the NHS
- revision of the Caldicott principles, 2013

- HSCIC developed the Code of practice on confidential information, 2014
- the Department of Health published The Power of Information in 2012 which aims to give all patients access to their own health records and Personalised Health and Care 2020: A Framework for Action which encourages use of digital technologies and better use of information to improve health.

4.8.1 Health and Social Care Information Centre (HSCIC) — Information governance (IG) toolkit

Formerly the responsibility of Connecting for Health, the HSCIC now provide guidance on information governance in health and social care in England. The Information Governance Framework for health and social care is formed by those elements of law and policy from which applicable information governance standards are derived, and the activities and roles which ensure that these standards are clearly defined and met. Due to the range and complexity of the standards and legal rules relating to information governance, the Department of Health has developed sets of information governance requirements, available in the IG Toolkit. The toolkit enables NHS and partner organizations to measure their compliance and assess themselves or be assessed against Information Governance policies and standards, including implementation of the Caldicott recommendations. The IG Toolkit is an online system, hosted by HSCIC. Version 13 of the IG Toolkit went live on the HSCIC website in May 2015. [98]

The IG Toolkit contains a number of requirements. These requirements vary according to the type of organization using the IG Toolkit. The requirements for HSCIC are under the following five headings, examples of requirements are given in each case: [98]

1. Information governance management
   - There is an adequate Information Governance Framework to support the current and evolving information governance agenda.
2. Confidentiality and data protection assurance
   - The information governance agenda is supported by adequate confidentiality and data protection skills, knowledge and experience which meet the organizations assessed needs.
3. Information security assurance
   - There are documented information security incident/event reporting and management procedures that are accessible to all staff.
4. Clinical information assurance

- An information quality assurance programme is in place to drive improvements across the organization.
5. Corporate information assurance
   - Documented and implemented procedures are in place for the effective management of corporate records.

4.8.2 Privacy impact assessments (PIA)

Privacy impact assessments (PIA) were launched in the UK by the Information Commissioner in 2007. A PIA published by the HSCIC in 2013 explains what the HSCIC does to safeguard patient privacy. In relation to privacy, the main change relates to powers the Health and Social Care Information Centre has under the Health and Social Care Act to collect and process patient identifiable data. The measures outlined in the PIA include the introduction of strong security controls, publishing and implementing security policies and publishing information about its processing as required for compliance with the Department of Health's Information Governance Framework.[99]

4.8.3 Information Standards Board for Health and Social Care — Specification: Information Governance Standards Framework, 2010

This Information Governance Standards Framework sets out the policy framework for a collection of potential standards, related to legislation and existing guidance. It is the formal definition of the overall scope of information governance standards. The target audience includes chief information officers, information governance leads, Caldicott Guardians, data protection officers, information security officers, records managers, data quality leads and others involved in information governance. The Standards Framework consists of 19 policy statements, underpinned by legislative requirements and formally adopted procedures and guidance applicable to appropriate health and social care organizations. The policy statements are organized under the following headings:[100]

- management and accountability
- process
- people
- assessment and audit.

4.8.4 Care Quality Commission (CQC)

As of May 2016 the Care Quality Commission (CQC) holds information from four data collections. These include:[101]

- National Survey of Patient Experience
- Notification of deaths of detained patients
- CQC Post-inspection Provider Survey
- CQC Post-registration Provider Survey.

Under the Health and Social Care Act 2012, the Care Quality Commission (CQC) has a new statutory duty to monitor and seek to improve the information governance of health and social care providers. Following the Act, the CQC was also required to set up a National Information Governance Committee (NIGC) to provide independent and objective advice on the development and delivery of CQC's information governance monitoring functions.

In 2013, the CQC published a three year strategy which set out a clear, newly defined purpose for CQC and proposed significant changes to the way it works, reforming the model of inspection. The new model of inspection was trialled during 2013 and 2014 and included questions about information security and information sharing in routine inspections. Some providers in the sample were issued with compliance actions for poor record-keeping, unsecured storage, poor information sharing, or ineffective mechanisms to report quality information to the board to support effective oversight of quality and risks across services.

Following this trial in 2013 and 2014, the CQC has made significant progress in fulfilling its new statutory duty to monitor the information governance practices of registered health and social care providers. It has made questions about information governance a "key line of enquiry", to be asked in inspections of all health providers and it has strengthened the information governance component in adult social care inspections. The next stage is for the CQC to be able to show that enhanced monitoring leads to improvements in practice.[102]

The CQC is also undertaking a review of standards of data security for patients' confidential data across the NHS. The aim of this review is to develop clear guidelines for the protection of personal data against which every NHS and care organization will be held to account.[103] The review will provide advice on the wording for a new model of consents and opt-outs, to enable patients to make an informed decision about how their data will be shared.[104] The review aims to produce recommendations on how the new guidelines can be assured through CQC

inspections and NHS England commissioning processes. It is planned that a final report of the review will be submitted to the Secretary of State in 2016.[103]

4.8.5 Revision of the Caldicott Principles

The 1997 report of the Review of Patient Identifiable Information, chaired by Dame Fiona Caldicott (the Caldicott Report), made a number of recommendations for regulating the use and transfer of person identifiable information between NHS organizations in England and non-NHS bodies. One recommendation was that every flow of patient-identifiable information should be regularly justified and routinely tested against the Caldicott principles. In 2013, the "Caldicott2" Review Panel revised the Caldicott Principles and recommended that they should be adopted and circulated throughout the health and social care system.

The Caldicott2 principles are as follows:[90]
1. justify the purpose(s) for using confidential information
2. don't use personal confidential data unless it is absolutely necessary
3. use the minimum necessary personal confidential data
4. access to personal confidential data should be on a strict need-to-know basis
5. everyone with access to personal confidential data should be aware of their responsibilities
6. comply with the law
7. the duty to share information can be as important as the duty to protect patient confidentiality.

All organizations registered with the CQC are expected to comply with the Caldicott principles. Each NHS organization is also required to have a Caldicott Guardian ― a senior person that is responsible for protecting the confidentiality of patient and service-user information and enabling appropriate sharing of information. The Caldicott Guardian also has a strategic role, which involves representing information governance requirements and issues at Board or management team level and, where appropriate, at a range of levels within the organization's overall governance framework.

4.8.6 Code of practice on Confidential Information

This code of practice was developed by HSCIC and describes good practice for organizations handling confidential information concerning, or connected with, the provision of health services or adult social care. Various information regimes will apply to these practices, including; the Data Protection Act, the Freedom of Information Act, Environmental Regulations and general data security and information governance guidance. The code of practice is structured around a series of information handling activities. These activities follow the life cycle of information-handling from the intent to process a type of confidential information, through establishing and implementing systems to process it, to the eventual destruction of the collected confidential information.[105]

4.8.7 The Power of Information, 2012

In 2012, the Department of Health published, "The Power of Information", a ten-year strategy that aims to transform the way patients get and use information about their health. *The Power of Information* sets out plans to give all patients easy and continuous access to their own health records by 2015. Key ambitions laid out in the strategy include:[106]

- an information-led culture where all health and care professionals — and local bodies whose policies influence our health, such as local councils — take responsibility for recording, sharing and using information to improve our care
- the widespread use of modern technology to make health and care services more convenient, accessible and efficient
- an information system built on innovative and integrated solutions and local decision-making, within a framework of national standards that will ensure that better quality information can move freely and safely around the system.

4.8.8 Personalised Health and Care 2020: A Framework for Action

In November 2014, the National Information Board (NIB) published Personalised Health and Care 2020: A Framework for Action. This Framework, which has now been adopted as government policy aims to enable citizens, patients, service users and frontline staff to take advantage of the opportunities offered by digital

technologies and better use information to improve health and social care outcomes. The key themes within the framework include:[107]

- citizens to have full access to their care records and access to an expanding set of NHS accredited health and care apps and digital information services
- providing care professionals and carers access to all the data, information and knowledge they need[108]
- making the quality of care transparent through the publication of comparative information on services and feedback from what patients and carers say.
- public trust to ensure that citizens are confident about sharing their data to improve care and health outcomes
- innovation and growth to make England a leading digital health economy in the world and develop new resources to maximise the benefits of new medicines and treatments
- supporting care professionals to get the knowledge and skills needed to make the best use of data and technology
- ensuring best value for taxpayers so that current and future investments in technology reduce the cost and improve the value of health services and support delivery of integrated care regardless of setting.

4.9 Future plans

The HSCIC have published a Data quality assurance strategy for 2015-2020. The vision of the strategy is to provide the most consistent, comprehensive and accessible information available about the quality of national health and social care data by 2020. The priorities set out in the strategy include:

- developing evidence-based data quality assurance assessment criteria and data consistency
- building and maintaining a library of data quality assurance assessments for use with different types of standards
- visiting organizations to provide face to-face, hands-on support for data quality improvement.[94]

HSCIC hopes to improve data linkage capabilities in the future, there is a focus on the need for improved ICT systems and improved data quality to support this. HSCIC is also considering a data quality maturity index which would rate data collections on how mature they are in relation to the use and adoption of technology.[109]

4.10 Summary- England's approach in relation to national data collections

- The Health and Social Care Information Centre (HSCIC) in England is the national provider of information, data and IT systems for health and social care and lies within the Department of Health, it has a statutory responsibility for collecting data from across the health and social care system.
- The NHS Data Model and Dictionary provides a reference point for assured information standards to support healthcare activities within the NHS in England.
- The NHS number serves as a unique identifier for individuals[1]
- HSCIC has published three experimental official statistics publications that report on data quality. The Quality of Nationally Submitted Health and Social Care Data England, Annual Report, 2014, is the most recent of these reports.
- HSCIC have published a Data Quality Assurance Strategy for 2015-2020. The vision of the strategy is to provide the most consistent, comprehensive and accessible information available about the quality of national health and social care data by 2020.
- The HSCIC's Burden Advice and Assessment Service (BAAS) offers advice, guidance and support for the health and social care system (both nationally and locally) on minimising the burden and bureaucracy of data collection, freeing up staff time to care.
- Formerly the responsibility of Connecting for Health, the HSCIC now hosts the IG Toolkit. Version 13 of the IG Toolkit went live on the website in May 2015.
- In 2013, the Caldicott2 Review Panel revised the Caldicott Principles and recommended that they should be adopted and circulated throughout the health and social care system.
- The Code of practice on confidential information describes good practice for organizations handling confidential information concerning, or connected with, the provision of health services or adult social care.

5. New Zealand

New Zealand has a population of 4.68 million.[110] It is a parliamentary democracy, an independent country and a constitutional monarchy. The Minister of Health, with the Cabinet and government, develops policies and provides leadership for the health and disability sector. Supporting the Minister in his work is the Ministry of Health (MoH). The National Health Board has responsibility for the funding, monitoring and planning of District Health Boards (DHBs) and designated national services, and for national, regional and local integration.[111] 20 DHBs across four regions administer the health system for the most part, planning, managing, providing and purchasing health services for the population of their district.[112]

This chapter will provide information on:

- an introduction to national health and social care data collections in New Zealand
- health information standards
- health identifiers
- the legislative context regarding national data collections
- data quality programme for national data collections
- data linkage
- updates in relation to national health and social care data collections in New Zealand
- future plans for national health and social care data collections.

5.1 Introduction

New Zealand has a centralised and harmonised structure in place for its national health and social care data collections, with all data collections housed within the New Zealand Ministry of Health. There are other data collections containing national or regional data that are held outside of MoH, but these are not deemed 'national collections'. The Ministry's obligation to collect data is stipulated within different pieces of legislation. It has responsibility for the collection and dissemination of all health-related information in the country. The Ministry of Health's Client Insight and Analytics Directorate, along with National Infrastructure and Systems Directorate have operational responsibility for national collections of health and disability information.

The Ministry of Health signs an Operational Policy Framework (OPF) with the 20 District Health Boards (DHBs) each year. The OPF sets out business rules, policy and guideline principles that outline the operating functions of DHBs[111] and the

responsibilities of the Ministry in relation to national health information management and reporting requirements.

The Ministry of Health drives improvements in data quality through work carried out by the data quality analysts, the provision of technical guidance documents and education and support services. Data dictionaries for the individual data collections are available. New Zealand has a well established system of unique individual and healthcare provider identifiers. The National Collections Annual Maintenance Project (NCAMP) provides a frequent participatory opportunity for evaluating whether the national collections continue to meet the needs of the public, allowing for the identification and prioritisation of areas for improvement.[1]

The Ministry of Health manages 15 national data collections of health and disability information, with the Client Insight and Analytics, and National Infrastructure and Systems Directorates holding operational responsibility for these.[113] On the MoH website (www.health.gov.nz), information specific to the individual collection is provided alongside each data collection. For example, information presented on the Cancer registry includes purpose, commencement, availability and technical details on identity reporting, ethnicity, geographical coding, coding systems, data limitations and data quality measures. Some examples of data collections held by the Ministry of Health include:

- The Medical Warning System — this is an alert service linked to National Health Index numbers. It warns healthcare providers of known risk factors. that could be important when making clinical decisions about patient care
- The Mortality Collection — classifies the underlying cause of death for all deaths registered in New Zealand, and all registrable stillbirths (foetal deaths).
- The National Non-Admitted Patients Collection (NNPAC) information includes event-based purchase units that relate to medical and surgical outpatient events and emergency department events.
- The New Zealand Cancer Registry (NZCR) is a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous and basal cell skin cancers.

Information is also provided on current and recent surveys, there are 11 surveys listed, these include:

- New Zealand Health Survey
- Alcohol and Drug Use Survey
- Nutrition Survey
- Oral Health Survey.

5.2 Health information standards

The Health IT Board is the governing body for health information standards in New Zealand. The Health Information Standards Organization (HISO) is the expert advisory group for standards of the IT Board, working to advise on, identify, scope, develop and endorse standards. HISO areas of focus include ensuring security of information, the use of health identifiers, eMedications standards, and the use of the standard laboratory test codes.[114]

HISO has endorsed the following standards for use across the health and disability sectors, which support the National IT Plan:

- Health and Disability Sector Ethnicity Data Protocols
- ISO/IEC 11179, information technology - metadata registries
- Primary Healthcare Practice Management Systems (PHCPMS)
- Health Level 7 (HL7), for the transfer of data across systems
- International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM)
- International Classification of Diseases for Oncology (ICD-O)
- Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT)
- Medicine Reconciliation and Medication Charting.

The Operational Policy Framework 2013/14 between the MoH and the DHBs outlines the standards the DHBs must adhere to in fulfilling their role to provide health data. The adoption of published data standards is seen as fundamental to New Zealand's ability to collect and link clinical datasets.[115]

5.2.1 Data dictionaries

The MoH has published a number of collection specific data dictionaries, including the National Minimum Dataset (Hospital Events) data dictionary, the National Non-Admitted Patient Collection Data Mart data dictionary and the New Zealand Cancer Registry data dictionary.[116]

5.2.2 Classification and terminology

New Zealand has clinical coding policies in place to guide efforts in this area, and selected classifications and terminologies have been endorsed by HISO. The Operational Policy Framework (OPF) sets out the different classifications and terminology to be used by the DHBs in their work.

Coding classifications used in hospitals in New Zealand are: the International Statistical Classification of Diseases and Related Health Problems Tenth Revision, Australian Modification (ICD-10-AM), the Australian Classification of Health Intervention (ACHI) and the Australian Coding Standards (ACS). For new eHealth applications, HISO supports the creation and use of code sets based on SNOMED-CT, the clinical healthcare terminology system.

Governance in this area is provided by the application of the Australian Coding Standards (ACS), New Zealand Conventions (NZC) and National Minimum Dataset (NMDS) reporting requirements. Support is available to data providers; the Ministry of Health hosts a coding query service and maintains an online historical database of queries and associated responses.[1]

5.3 Health identifiers

The Ministry of Health has undertaken a major upgrade of New Zealand's health identity systems. Through the Health Identity Programme, the 20-year-old technology supporting the two main health identity databases — the National Health Index (NHI) and the Health Practitioner Index (HPI) — has been replaced with a single integrated system. The Health Identity Programme's work focuses on the technology that supports these indexes.

A person's National Health Index (NHI) number is stored on the National Health Index along with that person's demographic details. The National Health Index and associated National Health Index numbers are used to help with the planning, coordination and provision of health and disability support services across New Zealand. The NHI can also be used to link patient health events together at an individual and cohort level for analysis and statistical purposes. The National Health Index is associated with the Medical Warnings System (MWS), which is designed to warn healthcare providers of any known risk factors that may be important when making clinical decisions about individual patient care. The Health Provider Index identifies health practitioners, health provider organisations and facilities (the physical address where the health care takes place) in three separate indexes.[117]

5.4 Legislative context

There are numerous pieces of legislation that have a direct bearing on national collections in New Zealand:[118]

- The Health Act 1956[119] gives the Ministry of Health the function of improving, promoting and protecting public health. It contains specific provisions which govern the disclosure of health information about identifiable individuals by and between health service providers and other agencies with statutory functions.

- The New Zealand Public Health and Disability Act 2000[120] describes one of the objectives of the Ministry of Health as being to facilitate access to, and the dissemination of information to deliver, appropriate, effective, and timely services.

- The Privacy Act 1993[121] provides the general framework for promoting and protecting individual privacy. It does so by establishing certain principles with respect to the collection, use, disclosure of and access to information relating to individuals. It applies to public and private sector agencies. It also established the role of Privacy Commissioner to investigate complaints about interferences with individual privacy.

- The Health Information Privacy Code 1994[122] is a Code of Practice issued by the Privacy Commissioner under Privacy Act which gives extra protection to health information because of its sensitivity. It covers all health agencies, and protects all personal health information relating to an identifiable individual. The Ministry has a responsibility to ensure it complies with this code in respect of all health information entrusted to it.

- The Health (Retention of Health Information) Regulations 1996[123] were introduced to set a minimum period of 10 years for which health information has to be held by health or disability service providers. It also covers the form in which health information is to be retained and the obligations associated with the transferring of health information, for example, when a service provider ceases business.

- The Official Information Act 1982[124] was established to make official information more freely available. Its relevance is when a request for information held by the Ministry of Health is from someone who is not the subject of the information or their personal representative.

5.5 Data quality programme for national data collections

The Ministry of Health drives improvements in data quality through work carried out by the data quality analysts, the provision of technical guidance documents and education and support services. While there is no evident national data quality

framework in New Zealand, there are a range of activities in place to ensure high data quality in the national collections. Previously, efforts in working to improve data quality involved a team of auditors visiting the DHBs to conduct data quality audits of ICD-10-AM clinical coding on inpatient records. This is no longer the approach as it was resource intensive. Currently, certain hospitals that hold expertise in this area offer their services to other hospitals.

The following are a selection of the data quality initiatives that have been identified in New Zealand:[69]

- DHBs have contractual responsibility to provide data of excellent quality (via the OPF).
- The MOH and DHBs are in regular communication about specific records that are identified as outliers or appear to be incorrect. DHBs are encouraged to amend the records and resubmit them to the national collections, irrespective of how old the record is.
- The national collections include a large number of business rules that identify records for DHBs to review.
- DHBs have data quality teams that address data quality issues as they arise.
- DHBs follow a procedure where data files are pre-processed before submission to the MoH, which assists in identifying errors and ensuring alignment with business rules.
- Data quality analysts in the MoH provide feedback to data collectors and data users in relation to data quality, and work with service providers to ensure reporting requirements are understood.
- Data quality analysts in the MoH may query any data quality issues or request further verification of data submitted.
- The MoH publishes technical documents (including information on ICD-10-AM coding and data dictionaries) to support organisations to submit data in an agreed format.
- The MoH hosts a coding query service and maintains an online historical database of queries and associated responses.
- Regional education programmes are delivered to clinical coding personnel.
- MOH is involved when DHBs implement software or hardware changes to ensure that extracts are fully tested before data is reported to the national collections.

5.5.1 Primary Care Ethnicity Data Audit Toolkit

The Primary Care Ethnicity Data Audit Toolkit provides a resource for assessing the quality of ethnicity data in New Zealand's primary healthcare settings and supporting quality improvement. Ethnicity data have been collected in the New Zealand health sector for a number of years. However, variations in ethnicity data policies and practices have limited the quality and completeness of the data and, therefore, its usefulness. This toolkit includes three practice-administered tools to assess the quality of ethnicity data and systems for data collection, recording and output within primary healthcare settings, and provides guidance on quality improvement activities. It also provides primary care practices with:[125]

- a way of benchmarking how well an organization is currently complying with the *Ethnicity Data Protocols for the Health and Disability Sector* the current health and disability sector standard
- information on the current minimum standards for the collection, recording and output of ethnicity data within the sector
- further information and links to useful resources to guide quality improvement within an organization.

The Toolkit helps assess primary healthcare ethnicity data against the standard for the health and disability sector and, more broadly, against current best practice. There are three stages in the audit process:

Stage one — the systems compliance checklist — the systems compliance audit checklist allows an organization to assess whether their practice is collecting, recording and outputting ethnicity data in compliance with the *Ethnicity Data Protocols for the Health and Disability Sector* and the *Ethnicity Data Protocols Supplementary Notes*.

Stage two — the staff survey — this stage of the audit allows you to assess staff understanding of, and current processes for, the collection and recording of ethnicity data and to identify specific staff training needs.

Stage three — the ethnicity data quality audit — the purpose of this stage of the audit is to assess the quality of ethnicity data currently held in the practice management system (PMS) against a 'fresh' collection of self-identified patient ethnicity data using the supplied audit form. The audit steps include:[125]

1. data collection
2. data analysis
3. take action.

5.5.2 Compliance testing for national data collections

The National Patient Flow programme is a multi-year programme of work aimed at measuring the patient journey through secondary care services.[126] The Ministry of Health in New Zealand is developing a framework for evaluating whether DHBs are capable of sending their data to this collections and to determine whether the data will be of high enough quality to use. The purpose of compliance testing is to ensure that DHBs can:[127]

- send a file of the right format
- send all the record types (mandatory ones as a minimum)
- receive the return files and process them into their system
- demonstrate that all of the data that should be reported to the collection is included in the extract , including all health specialty codes, data from all facilities, all services, privately and publicly funded records
- send production sized files
- demonstrate there are no patterns in the error or warning records for production sized files, i.e. no evidence of data quality issues either with the data when that is being reported or with the way the DHB extract is being created. This will involve MOH data quality analysts gaining an understanding of a wide range of issues including:
    - the way services are delivered at the DHB and across facilities
    - the way that data is extracted to be included in the extract
    - how the extract and return files are managed
    - vendor processes
    - how patches or new releases are managed at the DHB.

5.6 Data linkage

There is a lot of interest in linking data collections in New Zealand. This is evident in the Government's Better Public Service Priority aim to find new and better ways to improve outcomes for New Zealanders through expanding the Integrated Data Infrastructure (IDI) managed by Statistics New Zealand. Researchers can approach the MoH to conduct data linkage for research purposes. Each request is subject to review, and if identifiable information is needed, approval from the Ethics Committee is sought and the HIPC is applied before any data is released. The use of the National Health Index for the past 20 years provides ample opportunity for longitudinal aggregation and linkages.[115] In 2015, Statistics New Zealand published

the Data integration manual: 2nd edition.[128] The manual's purpose is to guide best practice and share the insights gained from experience. The manual will assist agencies collaborating with Statistics NZ, and others interested in data integration, to understand the basic concepts, theory, and processes involved in data integration, as well as providing practical advice.

New Zealand's experience in data linkage provides important learning. A data linkage project was undertaken that used risk factors to identify vulnerable children. However once this information was produced, the Ministry faced ethical, moral and privacy issues about using this information which led to the discontinuation of the project. A successful example of data linkage is the creation of the Virtual Diabetes Register in the absence of a national diabetes data collection. Data from six databases in the MoH is linked by the NHI to generate data on diabetes prevalence, which is sent to the patients' GPs for a final validation.[129] This register was created by the Ministry of Health and the New Zealand Society for the Study of Diabetes, at a lower cost than a traditional national data collection.

5.7 Update of key developments

This section will provide information on:

- Ministry of Health developments including improved data submission and an independent report on the benefits of a single electronic health record
- information on the New Zealand National Collections Annual Maintenance Project (NCAMP)
- National Health IT Board update including a new IT update for 2015 to 2020.
- The Health Information Standards Organization published a Health information security framework in 2015
- The Cancer health information strategy was developed to set the strategic direction until 2020. The strategy provides guidance on priorities for improving the quality of cancer information.

5.7.1 Developments in the Ministry of Health in relation to national health information

The Ministry enables researchers and analysts to look at health information together with other information collected across government, without compromising privacy, by making national health information collections available through Statistics New Zealand's integrated data infrastructure.[130]

The Ministry of Health Annual Reports for years ending June 2014 and 2015 report that almost all of the data submitted by District Health Boards relating to the National Minimum Dataset and the National Booking and Reporting System was processed within two working days of receipt.[130;131]

The Minister of Health requested an independent report on the benefits of a single electronic health record in New Zealand. There are five key findings in the report.

- Quality and productivity benefits are available by rationalising the systems used by secondary care facilities (e.g., hospitals).
- Creating a 'single' electronic health record that physically consolidates health information in one place will improve decision support and care coordination especially for complex patients with multiple long-term conditions.
- Primary care needs to be connected real-time with the 'single' electronic health record.
- Implement closed loop medicine management, as this is the area that offers the highest benefits in terms of patient safety and quality.
- Develop consumer portal access to improve the ability to serve up information from a physical repository in real-time, through digital channels to consumers. Consumer engagement around their health and wellness is key to implementing a preventive or primary care-led strategy.[132]

5.7.2 National Collections Annual Maintenance Project (NCAMP)

The National Collections Annual Maintenance Project (NCAMP) has been in operation for over ten years, allowing changes to the National Collections System (NCS). The project has an 18 month cycle. The process involves submitting ideas for change to the national collections throughout the year, followed by an assessment, consultation and evaluation process. Following agreement on the proposed changes, workshops with vendors and DHBs take place to inform all parties of changes. Upon approval, the MoH provides nine months notice to DHBs prior to changes being applied, after which full project delivery mode applies. All DHBs must ensure compliance before data can again be submitted into the NCS. There is an ongoing review of the maintenance schedule to ensure the national collections meet the changing needs of the healthcare system and its users.

5.7.3 National Health IT Board

The National Health IT Board is promoting national systems to support key clinical specialities, including maternity, older persons, cardiac health and cancer. National

systems can improve equity of access and consistency of care by reporting on quality initiatives and long-term trends. Some examples of work delivered during 2015 include:

- enabling information to be shared across disciplines for the delivery of maternity and neonatal services at the frontline through the national maternity clinical information system
- providing a comprehensive view of the patient's secondary healthcare referral pathway to measure access to elective and cancer services through the National Patient Flow collection
- introducing electronic systems into hospitals and the community to ensure accurate, up-to-date information about people's medications is accessible to support safe, effective and appropriate use of medicines through the eMedicines Programme
- rolling out community prescribing, which has been completed by almost all community pharmacies and has been installed in 36 general practices through the New Zealand Electronic Prescription Service (NZePS).[130]

A new *IT update for 2015 to 2020 was* announced in 2015 and is currently in the design phase. Six work streams have been set up to enable this: [133]

- informatics professionals
- health professionals
- digital hospital
- vendors and integration
- consumers
- architecture and standards.

The four priority areas focus on the development of a single national electronic health record, a digital hospital blueprint, a preventative health IT platform and the use of data to support health and social investments.

5.7.4 Health Information Security Framework

The Health Information Standards Organization published a Health information security framework in 2015. This updated standard sets out security management requirements for health provider organizations.

The health and disability sector-wide Health Information Security Framework advises how health information is created, displayed, processed, transported, has persistence and is disposed of in a way that maintains the information's confidentiality, integrity and availability. The framework is concerned with the

security of health information wherever it may exist. The areas addressed by the framework include:[134]

- governance
- organization of information security
- information security policies
- asset management
- human resources security
- physical and environmental security
- communication security
- operations security.

5.7.5 The Cancer Health Information Strategy

This strategy was developed by over 50 stakeholder groups and sets the strategic direction for the sector until 2020. It aims to provide comprehensive, accessible and accurate information to support the delivery of quality care across the cancer patient pathway. It outlines four strategic interventions and a framework for delivery. The strategic interventions are:

- establish a national framework for managing consistent change to cancer data information and intelligence
- standardize, digitise and make accessible cancer data at point of care
- aggregate relevant patient and cancer service data into cancer information
- analyse information, produce cancer intelligence and communicate it to stakeholders.

This strategy is an important building block of achieving person-centred health information.[135] The strategy provides guidance on priorities for improving the quality of cancer information over a five year period. It will be used to inform national, regional and local development and investment in cancer health information based initiatives.

There are a number of systems containing elements of health information in New Zealand. Progress has been made in standardising and linking information across the District Health Boards so that health providers may form a single view of each patient. However, there is still a long way to go before comprehensive, electronic and accessible patient records become the norm. National alignment and transparency of cancer information projects is critical. Collaboration will standardize data and processes, and remove duplication of effort.

5.8 Future plans

The New Zealand Health Strategy was updated in 2016. It outlines the high level direction for New Zealand's health system over the 10 years from 2016 to 2026. It lays out some of the challenges and opportunities the system faces; describes the future New Zealand wants, including the culture and values that will underpin this future; and identifies five strategic themes for the changes that will take them toward this future. The five actions areas outlined in the draft are people-powered, closer to home, value and high performance, one team and smart system.

The smart system strategic theme aims to increase New Zealand's national data quality and analytical capability to improve transparency across the health system. The vision for a smart system includes data being used consistently and reliably, with appropriate safeguards, to continuously improve services.

There are plans to improve ethnicity data in the national health collections. From 1 July 2017 it is intended that level 4 data will be collected for each ethnicity reported and that up to six codes can be stored. This change is required by Statistics New Zealand's requirements of all Departments collecting official statistics.

5.9 Summary- New Zealand's approach in relation to national data collections

- New Zealand has a centralised model for its national collections, with all the national data collections housed within the Ministry of Health.
- New Zealand does not currently have a national data dictionary. However, the MoH has published a number of collection specific data dictionaries.
- New Zealand's health identity system has undergone an upgrade. The Health Identity Programme focuses on the technology that supports the National Health Index and the Health Provider Index.
- The Ministry of Health carries out a range of data quality initiatives via data quality teams at the MOH and in each DHB and by publishing technical documents to support organizations.
- The Primary care ethnicity data audit toolkit provides a resource for assessing the quality of ethnicity data in New Zealand's primary healthcare settings and supporting quality improvement.
- Increasing New Zealand's national data quality and analytical capability to improve transparency across the health system is a top priority in the current New Zealand Health Strategy.
- The National Collections Annual Maintenance Project (NCAMP) process involves submitting ideas for change to national collections, followed by an assessment, consultation and evaluation period.
- The Health Information Standards Organization published a Health Information Security Framework in 2015. This updated standard sets out security management requirements for health provider organizations.

6. Scotland

Scotland has a population of 5.3 million.[81] It is a constitutional monarchy. Health services in Scotland are financed almost entirely out of general taxation and are largely free at the point of need and available to all inhabitants. Responsibility for health and for health services rests with the Scottish Cabinet Secretary for Health, Wellbeing and Cities Strategy who is accountable to the Scottish Parliament. Supported by officials in the Scottish Government health and social care directorates, ministers set policy, oversee delivery of services by the National Health Service (NHS) and regulate the small independent sector. Many of their functions are delegated to 14 integrated territorial NHS boards responsible for planning and delivering all health services — acute, primary and community — to the population in their areas.[136]

This chapter will provide information on:

- an introduction to national health and social care data collections in Scotland
- a summary of national health information structures in Scotland
- health information standards
- health identifiers
- the legislative context regarding national data collections
- data linkage.

6.1 Introduction

NHS National Services Scotland supports Scotland's health by delivering shared services and expertise, supplying essential services such as information and health protection. The Information Services Division (ISD) is a division of NHS National Services Scotland. It serves to provide health information, health intelligence, statistical services and advice that supports the NHS in progressing quality improvement in health and care. It also facilitates robust planning and decision making.

Scotland has a unique national identifier (Community Health Identifier), an emergency care patient summary and a national data dictionary in place. ISD has direct responsibility for a number of administrative, management and clinical sources. ISD undertake various audits at sources to ensure the quality of data.

6.2 National health information structures in Scotland

This section will provide information on:

- the Information Services Division (ISD) including information on the National Data Catalogue, data support and monitoring and data quality assurance
- the Information Sharing Board (ISB) which has led the development of the Information Sharing Strategic Framework
- the Scottish Government published The National Information and Intelligence Framework for Health and Social Care for Scotland: 2012-17
- the Public Benefit and Privacy Panel for Health and Social Care which serves as a centre of excellence for privacy, confidentiality, and information governance expertise in relation to health and social care in Scotland.

6.2.1 Information Services Division (ISD)

ISD is part of NHS National Services Scotland which provides national strategic support services and expert advice to NHS Scotland and its partners. ISD is responsible for managing national data for NHSScotland. ISD Scotland works in partnership with a wide range of organizations including NHSScotland unified boards, hospitals, general practitioners, local authorities, voluntary organizations, community health partnerships and many other care and service providers to build the national database which is a collection of national datasets. Some functions of ISD include:

- The National Data Catalogue
- Data support and monitoring
- Data quality assurance
- Scottish Morbidity Records (SMR).

National Data Catalogue — The National Data Catalogue (NDC) is a single definitive resource of information on Scottish Health and Social Care datasets that incorporates the Data Dictionary, information on the National Datasets and new developments. The National Data Catalogue has been produced to:

- improve provision of comprehensive metadata on national data through a single point of access
- eliminate duplication of information
- enhance support to research on health and social care

- encourage greater use and awareness of national data standards and definitions to improve the quality of information available to support health and social care services.[137]

ISD holds NHS health and health related data for over 5 million people in Scotland, which in some cases span an individual's whole life: from before birth, with the mothers antenatal records, through to that individual's death registration record. This is a wealth of information which can be linked, summarised and analysed to support research studies. The National Data Catalogue provides a full list of datasets held by ISD along with information about the datasets, for example, population coverage, overall data quality, and publications that use these datasets. As of April 2016 ISD's National Data Catalogue lists 106 data collections. The data collections provide information on:[137]

- cancer e.g. The Scottish Cancer Registry
- diseases e.g. Scottish Coronary Revascularisation Register
- hospital activity statistics e.g. Accident and Emergency (A&E) statistics
- screening e.g. Diabetic Retinopathy Screening
- waiting times e.g. Drug and Alcohol Treatment Waiting Times
- audits and registers e.g. Scottish Audit Surgical Mortality.

Data support and monitoring — The data support and monitoring team is part of the data management function which provides one of the ISD data intelligence groups' core business functions in monitoring the collection, processing, validation and quality control of NHS Scotland's national datasets. The team provides a data support and monitoring service to NHS Boards and other healthcare data providers in the submission of national data sets. The team works with system suppliers to facilitate the collection of these data sets and provides an advisory service to data users. The team provides this service for several national datasets, including:[138]

- maternity inpatient data
- System Watch (weekly data from NHS boards, Health Protection Scotland, Scottish Ambulance Service, NHS 24 and National Records of Scotland).

The services provided by the data monitoring service for these data sets include:

- processing weekly, monthly, quarterly and annual data submissions
- providing helpdesk support to NHS boards and other data providers who experience problems submitting data
- monitoring data submissions in terms of completeness and timeliness

- liaising with data providers to ensure data is validated against national standards and where appropriate highlight any issues and ensure they are resolved
- investigating any data quality issues highlighted and work with data providers and system suppliers as required to resolve them
- ensuring that all amendments required to resolve data quality issues are applied either by the data providers themselves or by ISD on their behalf
- advising data users of any data quality/completeness issues impacting on the use of data
- liaising regularly with data providers to ensure issues affecting or likely to affect data submission are identified at an early stage and addressed.

Data quality assurance — The ISD Data quality assurance team is responsible for evaluating and ensuring datasets are accurate, consistent and comparable across time and between sources, one key example of this is Scottish Morbidity Records (SMR). The team also quality assures non-SMR related data, for example, assessing the application of cancer waiting times guidelines and guidance on validation rules.[139] The team consists of six auditors who assess data accuracy nationally; they go out to individual hospitals across Scotland and assess a random sample of records at each one. For some hospitals, where all patient information is held electronically, the team will assess using direct or remote access to hospital information systems.[140]

Scottish Morbidity Records (SMR) — SMR data has been collected since the 1960's.[141] An example of an SMR dataset is the General / Acute and Inpatient Day Case dataset (SMR01) which collects episode level data on hospital inpatient and day case discharges from acute specialities from hospitals in Scotland. The General / Acute Inpatient and Day Case dataset is also part of ISD Scotland's linked database known as the Scottish Morbidity Database (SMD). The database links together the Scottish Cancer Registry (SMR06), Mental Health dataset (SMR04), and National Records of Scotland Death Records with the General / Acute Inpatient and Day Case dataset (SMR01).[142] While there are no apparent contractual arrangements between ISD and hospitals, a culture has developed where the hospitals follow certain rules in regards to the collection of SMR data. Standards and validation checks are built into the system at hospital level to ensure that quality data is collected at the point of service and error free data can then be sent to ISD.[141] SMR data is expected to be received by ISD 6 weeks (42 days) following the end of the month of discharge/clinic date.[143] The 'Dataset change control process' is a formal method for requesting changes, documenting evidence and recording reason for changes to the SMR dataset.[144]

6.2.6 Information Sharing Board (ISB)

The Information Sharing Board (ISB) was formed in November 2011. The ISB's primary concern is to ensure that integrated information supports the delivery of seamless health and social care. The ISB is coordinated by Scottish Government eHealth division but also has representation from local authorities, NHSScotland, the third sector and the Scottish Government. The ISB has led the development of the Information Sharing Strategic Framework. This framework focuses on the importance of appropriate data sharing between organizations and professionals when delivering health and care services. It sets out the protocols, high-level interoperability standards, ICT considerations, and governance arrangements that partnerships, particularly the Health and Social Care Partnerships, should consider in order to support joint working across integrated health and social care services for person-centred care.[145]

6.2.7 The National Information and Intelligence Framework for Health and Social Care for Scotland: 2012-17

The National Information and Intelligence Framework for Health and Social Care for Scotland, 2012-17 aims to ensure that information and intelligence is developed and used in a coordinated and coherent manner across Scotland. The framework, published by the Scottish Government, strives to support organizations working in health and social care to effectively and appropriately prioritize the development of information and intelligence by prioritising work in four key areas — each of which will be progressed by working groups. The four key areas are:[146]

- prioritisation of national data and information collections
- presentation of evidence for maximum impact
- efficient development and maintenance of the information evidence base
- maximise access to and use of intelligence and evidence.

The framework provides a driver diagram which can be seen in Figure 5. It also provides the following guiding principles which will help to align information and prioritisation across the health and social care sectors.

Strategic alignment — individual organizations across the health and social care sector in Scotland will align their information services and priorities to those identified in this framework, thus developing a health and social care information system that will benefit all users of information, avoiding duplication and promote learning from each other. Initially, emphasis will be on promoting better integration

of information and intelligence within NHSScotland. As health and social care integration progresses there will be a need for better integration and intelligence between NHSScotland, local authorities and partners. The underlying strategic direction can be summarised as simplify, standardize and share.

Maximising the use of data — information used for providing direct care will be used to ensure safe and high quality services for people, to monitor improvement and report on performance, to plan services and to aid high quality research and policy development. The key principle here can be summarised as collect once, use often. However, data set development and prioritisation decisions need to involve all stakeholders and should seek to promote data collections systems which meet multiple purposes. Governance and implementation strategies need to evolve to ensure multi-stakeholder involvement. It is essential that eHealth play a key role in ensuring that IT solutions promote the ability to use data for multiple purposes within organizations and across organizational boundaries. Data and information need to be better integrated between primary and secondary healthcare and between health and social care.

Transparency, openness and accessibility — the framework will encourage greater accessibility to information while balancing the protection of individual privacy. Linking data across sectors will also enhance the use of information and facilitate information and intelligence to improve the quality of care in Scotland, with the appropriate and proportionate governance arrangements. Information governance frameworks will develop and evolve to achieve the health and social care outcomes.

Responsiveness — there is a need to be responsive to stakeholders' changing and emerging information and intelligence priorities. There is a need to be able to adapt to new information requirements and new technological developments. This requires efficient governance structures and clear prioritisation processes rather than additional resources.

Equity and Equalities — it is important that everyone receives good quality services and to ensure that services are delivered equitably. Information for equality groups needs to be gathered, published and analysed. This will ensure equalities ambitions are achieved and meet the necessary statutory duties.

Efficiency and reducing the burden on data providers — all data collections should be undertaken as efficiently as possible, avoiding duplication and making best use of technology while reducing the burden on data providers. The prioritisation of information requirements needs to be informed by consideration of the costs and associated benefits.

Figure 4: National information and intelligence framework for health and social care in Scotland: Driver Diagram[(146)]

Aim *Outcome*	Primary driver *Changes*	Secondary driver *Areas for improvement/ implementation*	Action/ Enablers
Information and intelligence drives improved quality in health and social care	Information for improvement	Local and operational use of data; Health Board level operational use of data; Local Authority level operational use of data	Data visualisation tools; Benchmarking; Sharing evidence
	Information for assurance	Scrutiny; Performance management; Publically available	Prioritisation of information and intelligence; Alignment of indicators/measures to priorities; Relevant publications
	Minimise burden and cost	Collect once, use many times, many users; Align to priorities; Pressure on costs	Proportionate frequency/coverage of collections; Maximise automation of process data; Use across operational, scrutiny and analytical; Actively downwards manage costs
	Maximise intelligence, use and impact	Outcomes focussed; Data linkage – analytical and operational; Sharing across sectors; Information for research; Information governance; Data for strategic development	Realignment; Data linkage tools; Data sharing tools; Education and implementation of legislation/regulations; Understand and align organisational roles

6.2.8 The Public Benefit and Privacy Panel for Health and Social Care

The Public Benefit and Privacy Panel for Health and Social Care is a governance structure of NHSScotland. The panel operates a process of consistent and proportionate information governance scrutiny of requests for NHSScotland-originated data for a variety of purposes other than direct care, for example, for research, audit or healthcare planning. The panel merges the Community Health Index Advisory Group (CHIAG), NHS National Services Scotland Privacy Advisory Committee (PAC), and National Caldicott Guardians application processes to form a single application and scrutiny process across Scotland. The panel operates as a centre of excellence for privacy, confidentiality, and information governance expertise in relation to health and social care in Scotland, providing strategic leadership and direction in this area to NHSScotland boards, the research community and wider stakeholder groups. The panel also deals with scrutiny of requests to use NHSS datasets.[147]

The electronic Data Research and Innovation Service (eDRIS) provides a single point of contact to assist in the completion of applications to the Public Benefit and Privacy Panel for Health and Social Care and assist researchers in study design, approvals and data access in a secure environment. eDRIS aims to make conducting research easier, more efficient and more convenient.[148]

6.3 Health information standards

National Data Standards ensure that data are collected throughout Scotland according to the same classifications and rules and the data are interchanged between systems consistently and securely. Customers include clinicians, project and information managers, clinical coding staff, administrators, healthcare researchers, information analysts and software developers. Data Standards encompass a range of products and tools which include National Data Definitions and National Reference Files.[149]

6.3.1 National data dictionary

The national data dictionary is the main online source for health and social care data definitions and standards in Scotland. The data dictionary section on the ISD website provides access to all standard definitions and codes that are used by NHSScotland staff of all disciplines to improve data quality and integrity. It enables users to perform an A-Z definitions search. The use of these standard definitions and codes enables the interchange of data between information systems. ISD liaise with NHS in

England, Wales and Northern Ireland with the objective of achieving UK standards where possible. One part of the ISD data dictionary, the SMR validation manual contains all the validation rules related to SMR records. ISD provide a definitions and reference files service, this is an advisory service to NHS Scotland on the interpretation and application of the definitions, codes and recording rules. The team manage and maintain ISDs national reference files which are used in the validation of the national data. The team also manages national change control which is a formal process for managing changes to these national datasets. [137]

6.3.2 Classification and terminology

Clinical and health related data are collected on various national patient based datasets (e.g. Scottish Morbidity records, Scottish Cancer Registry). To ensure data is recorded consistently and accurately, nationally agreed coding systems are used. These are:

- The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) for diagnoses
- The Office of Population Censuses and Surveys' Classification of Surgical Operations version-4 (OPCS4) for procedures and interventions
- Read codes for primary care
- Clinical Imaging Procedure codes.

SNOMED-CT will eventually become the terminology of choice covering both primary and secondary care. It will encompass all coding systems mentioned above, allowing NHS Scotland to progress towards an electronic patient record. Read coding is being retired and will eventually be replaced by SNOMED CT. The last update will be the April 2016 release.[150]

6.3.3 Definitions and reference files service

The definitions and reference files service provides an advisory service to NHS Scotland on the interpretation and application of the definitions, codes and recording rules; principally those that relate to Scottish Morbidity Records (SMRs). The team manages and maintains ISDs national reference files which are used in the validation of the national data. The team also manages National Change Control which is a formal process for managing changes to these national datasets.

The electronic newsletter, the Definitions, Reference Files & Standards Bulletin, contains important information about changes to data recording, validation and

issues arising from quality assessment. An archive of all QDV Newsletters can be accessed through the ISD Data Dictionary.[151]

6.4 Health identifiers

The Community Health Identifier (CHI) number is a unique numeric identifier, allocated to each patient on first registration with the system. The CHI is a computer based population index whose main function at present is to support primary care services. CHI contains details of all Scottish residents registered with a General Practitioner and was originally envisaged and implemented as a population-based index to help assess the success of immunisation and screening programmes. It is therefore closely integrated with systems for child health, cervical cytology and breast screening call and recall. It is intended that this number, the Scottish equivalent of the new NHS number in England and Wales, should become the Unique Patient Identifier throughout the NHS in Scotland. Currently there are eight CHI databases each covering a defined geographical area and a search index. The search index ensures that people who have a CHI registration on more than one database have one of their CHI numbers allocated as the current and therefore unique CHI number.[152]

6.5 Data linkage

Scotland has long been a pioneer in the use of linked health service data for statistical research. This has resulted in a well-established capacity to use data linkage in evaluating interventions for the benefit of the population's health. The Scottish Government is enabling responsible, efficient and effective data linkage by:

- improving the ethical and legal governance arrangements around data linkage
- supporting increases in the technical capacity to securely and efficiently link statistical and administrative data.

This approach enables the research needed to inform policy decisions and service delivery. The Scottish Government is involved in supporting and delivering the following strategies and initiatives:[153]

A Data Vision for Scotland — the Scottish Government established a Data Management Board to support Scotland's advancement in the current global data revolution. In April 2014, the Board proposed a Data Vision for Scotland. This Vision will support trustworthy uses of data for public benefit, helping to maintain and

enhance Scotland's reputation for the safe, secure and transparent use of data. The Strategic Action Plan was published in December 2014 to deliver the Vision through the effective and responsible collection, management and use of data across Scottish Public Services.

The Data Linkage Strategy — following public consultation the Scottish Government published Joined Up Data for Better Decisions in 2012. This Strategy sets out ambitions for making better use of the data that already exists in Scotland. The Data Linkage Framework was established as a mechanism to deliver this.

The Data Linkage Framework — following development of the Data Linkage Framework (as outlined in the Strategy) there has been a marked increase in collaborative working, sharing of best practice and joined-up approaches to resource investment across a number of key public sector organizations underpinning data linkage across Scotland.

The Guiding Principles for Data Linkage — following extensive public consultation, the Guiding Principles for Data Linkage were published in 2012, demonstrating the Scottish Government's commitment to improving the decision making process for data users and data controllers in-line with increasing technical capacity. The guiding principles were developed to ensure that statistical and administrative data can be securely and efficiently linked for public benefit. There are 40 guiding principles which are divided under the following headings:

- public interest
- governance and public transparency
- privacy
- removal of names and direct identifiers
- consent
- security
- access and personnel
- clinical trials
- data sharing agreements and sanctions.

A Safe Haven Charter for Scotland — Published in November 2015, the Charter for Safe Havens sets out the agreed principles and standards for the routine operation of Safe Havens[§] in Scotland where data from electronic records can be used to

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[§] A Safe Haven refers to both physical location and an agreed set of administrative arrangements to ensure the safety and secure handling of confidential patient identifiable information.

support research when it is not practicable to obtain individual patient consent while protecting patient identity and privacy.

A Health and Biomedical Informatics Research Strategy for Scotland — The Health and Biomedical Informatics and Research Strategy sets out key areas for action and specific recommendations from the Health Informatics Research Advisory Group (HIRAG) on how Scotland should respond to the opportunities and challenges around the secure use of routinely collected patient data for research.

Health and Social Care Data Integration and Intelligence Project — Effective information systems will ensure that good evidence underpins the process of local strategic planning and decision making. To support this, the Scottish Government commissioned ISD to work in partnership with NHS Boards, Local Authorities and others to develop a linked individual level longitudinal social care dataset to be submitted by Integrated Partnerships.

The Health and Social Care Data Integration and Intelligence Project (HSCDIIP) is responsible for this development. The project is being carried out as a phased programme of work, split into the following work streams:[154]

- dataset
- information governance
- IT solution
- analytical outputs.

6.6 Summary- Scotland's approach in relation to national data collections

- The Information Services Division (ISD) is a division of NHS National Services Scotland and serves to provide health information, health intelligence, statistical services and advice.
- ISD is responsible for the National Data Catalogue — a single definitive resource of information on Scottish health and social care datasets.
- The data monitoring service within ISD monitors the collection, processing, validation and quality control of NHS Scotland's national datasets.
- ISDs data quality assurance team assesses and advises on all aspects of data quality including accuracy, consistency, completeness and definitions.
- The Information Sharing Board (ISB) aims to ensure that integrated information supports the delivery of seamless health and social care.
- The National Information and Intelligence Framework for Health and Social Care for Scotland, 2012-17 provides six guiding principles which aim to align information and prioritisation across the health and social care sectors.
- In Scotland the Public Benefit and Privacy Panel for Health and Social Care operates as a centre of excellence for privacy, confidentiality and information governance expertise in relation to health and social care. The panel provides strategic leadership and direction to NHSScotland boards, the research community and wider stakeholder groups.
- The data dictionary section on the ISD website provides access to all standard definitions and codes that are used by NHSScotland staff of all disciplines to improve data quality and integrity.
- The Community Health Identifier (CHI) number is a unique numeric identifier, allocated to each patient on first registration with the system. The CHI is a computer-based population index whose main function at present is to support primary care services.
- Scotland is considered a pioneer in the use of linked health service data for statistical research. The Scottish Government works to deliver several strategies and initiatives to support data linkage.

7. Conclusion

7.1 Summary of findings

The findings of this international review highlight the importance of national health and social care data collections for ultimately improving the quality of care patients receive. This was particularly evident in the efforts being made by the countries reviewed to improve and develop the quality of their national health and social care data collections.

7.1.1 Governance

In each of the countries reviewed there is a key organization that governs either all or most of the national data collections. Governance and management of the national data collections varies from country to country.

- New Zealand has a centralised system with the New Zealand Ministry for Health responsible for all of the major national data holdings
- in Canada the Canadian Institute for Health Information (CIHI) is responsible for most of the national data sets
- in Australia the Australian Institute of Health and Welfare is the statutory body that manages the majority of national health and welfare data collections
- in England the Health and Social Care Information Centre (HSCIC) is the body central to the oversight and management of national data collections
- NHS National Services Scotland supports Scotland's health by delivering shared services and expertise, supplying essential services such as information and health protection.

These organizations provide the strategic framework for the governance of the national data collections. Current governance arrangements for national data collections in the jurisdictions reviewed are provided for either through national legislation, national or bilateral agreements or agreements with district health authorities. Organizations that are charged with providing the strategic framework for the governance of national data collections are well placed to drive efforts in data quality and standardisation. Incentives for data providers to engage and work with the key organizations vary across jurisdictions. In Australia, the health information system is linked to the allocation of funding to the states and territories, providing a clear incentive to comply with the terms of the National Health Information Agreement (NHIA). In Canada, where entering into a bilateral agreement with CIHI

is done on a voluntary basis, the provinces and territories benefit from access to CIHI's products and services. Strong governance arrangements can address the challenge of duplication and fragmentation in data collection, contributing to greater cost efficiencies. This is especially evident in England where the HSCIC has a statutory remit to minimise the burden of national data collections on the NHS. In this regard, the HSCIC is well placed to address the issue of duplication and has already discontinued a significant number of data collections.

7.1.2 Data Quality

Data quality emerged as an important theme internationally and in each of the countries reviewed. The European Statistics Code of Practice along with supporting documents provides principles and tools which aim to ensure the quality and credibility of data. The European Centre for Disease Prevention highlights the importance of monitoring data quality and thus ensuring that the collected data are meaningful so they meet the objectives of local, national and international surveillance systems. The EU Cross Border Patient Registries Initiative (PARENT) describes four basic categories of factors influencing registry's data quality: governance, data quality, information quality and confidentiality, security and ethical issues. UNSTATS provides a National Quality Assurance Framework (NQAF) and accompanying guidelines to assist countries wishing to develop national quality frameworks of their own.

Each country reviewed makes significant efforts to ensure the quality of the data collected. The Canadian Institute for Health Information has a well developed data quality programme and works to improve data quality at different levels of the health system. CIHI's Data Quality Framework sets out an approach to systematically assess, document and improve data quality for all data holdings. Other countries, such as Australia draw on this framework as a good example of a data quality framework. The Australian Capital Territory (ACT) Health has prepared a data quality framework in which can be applied to databases, systems, registries and reports. The components of the framework include a data integrity strategy, a data quality policy, a data quality improvement cycle and a data quality assessment tool. England's Health and Social Care Information Centre (HSCIC) have published a data quality assurance strategy for 2015-2020. The vision of the strategy is to provide the most consistent, comprehensive and accessible information available about the quality of national health and social care data by 2020. In New Zealand the Ministry of Health drives improvements in data quality through work carried out by the data quality analysts, the provision of technical guidance documents and education and support services. In Scotland the Information Services Division's data quality

assurance team assesses and advises on all aspects of data quality including accuracy, consistency, completeness and definitions.

7.1.3 Data Quality Statements

Data quality statements are in use in Australia and England. These are documents which provide information on a range of aspects of the quality of the data being reported. Data quality statements enable data users to understand any limitations of the data and make informed judgements about their use of the data. The Health and Social Care Information Centre (HSCIC) provides a data quality statement with every official and national statistical publication. The Australian Institute of Health and Welfare's (AIHWs) policy is that data quality statements should be produced at collection level for all collections which are held by AIHW. Data quality statements should give information on how each area of data quality is addressed by the collection or publication. Data quality statements provide concise publicly available quality summaries on the data quality issues found, in an easily accessible format.

7.1.4 Standardisation

The five countries reviewed enforce or endorse health information standards (including technical standards), conduct activities to improve data quality and employ unique health identifiers and electronic records. All of the countries reviewed are employing data quality enhancing tools such as minimum data sets, national data dictionaries, and classification and terminology systems. Each of the countries uses standard classification and terminology systems such as SNOMED-CT and versions of ICD-10. The standardisation of data contributes to higher quality, trustworthy data that is fit for use across interoperable systems. This is key to enabling the integration of data collections and making regional, national and international comparisons.

7.2 Next steps

HIQA has used this international review to inform the development of draft information management standards for national health and social care data collections. The draft standards have been developed using a standards development protocol and with input from an advisory group comprised of key stakeholders. The draft standards were released earlier this month for public consultation. The feedback received as part of the public consultation process will be considered and will inform the development of the final standards. Subsequently HIQA will submit the final set of national standards to the Minister for Health for approval and adoption.

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9. Appendices

Appendix 1 — Operating Principles for Australian Clinical Quality Registries

Attributes of clinical quality registries

1. CQRs must be developed with clear and precisely defined purposes aimed at improving the safety and/or quality of healthcare.
2. For CQRs to provide the maximum value to the health system they must focus their core data collection on the essential elements required to serve their main purposes.
3. Data collected by CQRs must be confined to items which are epidemiologically sound, i.e. simple, objective, and reproducible, valid (including for risk adjustment) and related to a specific case definition.
4. Methods used to collect data in CQRs must be systematic, with identical approaches used at the different institutions contributing information.
5. Outcome determination should be undertaken at a time when the clinical condition has stabilised and the outcome can therefore be reasonably ascertained.
6. In determining the time to outcome assessment, CQRs must consider the burden and cost of data collection together with the likelihood of loss to follow-up.
7. CQRs should seek to ensure that complete CQR data are collected from the entire eligible population.

Data collection

8. The collection of data for a CQR should maintain an appropriate balance between the time and cost of data collection and the impact on patient care, particularly where clinicians are directly involved in data collection. The collection of data must not be an unreasonable burden on consumers, nor incur any cost to consumers.
9. Data capture should be performed as close as possible to the time and place of care by appropriately trained data collectors.
10. Data should be uniformly and easily accessible from the primary data source.
11. Standard definitions, terminology and specifications must be used in CQRs to enable meaningful comparisons to be made and to allow maximum benefit to be gained from linkage to other CQRs and other databases (if approved by relevant ethics committees, etc.).

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12. CQRs must use data dictionaries when they are established to ensure that a systematic and identical approach is taken to data collection and data entry. CQRs must publish their eligibility criteria, metadata, data dictionaries, etc.
13. To avoid duplicating data capture, CQRs should use data from existing data sources, including administrative data, where they are of a satisfactory quality.
14. CQRs should have the capacity to enhance their value through linkage to other disease and procedure CQRs or other databases.

Data elements

15. CQRs must collect sufficient patient identifying information to support the CQR's stated purpose. Most clinical quality registries would require individually identifiable data, for which use of national Individual Healthcare Identifiers is recommended.
16. Where patterns or processes of care have an established link to outcomes and process measures that are simple, reliable and reproducible, they should be considered for collection by CQRs.
17. Where possible, outcomes should be assessed using objective measures. Where this is not possible, outcome should be assessed by an independent person and undertaken using standardized and validated tools.

Risk adjustment

18. CQRs must collect objective, reliable co-variates for risk adjustment to enable factors outside the control of clinicians to be taken into account by the use of appropriate statistical adjustments.

Data security

19. To protect CQR data, CQRs must use secure access controls and secure electronic transfer and electronic messaging systems.
20. The collection, storage and transmission of clinical CQR data must be in accordance with relevant legislation, regulation, principles, standards and guidelines.

Ensuring data quality

21. CQRs must report as a quality measure the percentage of eligible patients recruited to the CQR.

22. CQRs must have a robust quality assurance plan which allows ongoing monitoring of the completeness and accuracy of the data collected.

23. CQR data should be checked in a sample of cases. This usually involves audit against source records. The sample size needs to be sufficient to produce reliable measures of data completeness and accuracy. The frequency of audits needs to be sufficient for data quality lapses to be identified promptly. Incomplete or inaccurate data must be identified by the data centre and remedied as soon as possible.

Framework for Australian clinical quality registries

24. CQRs should incorporate in-built data management processes such as data range and validity checks.

Organization and governance

25. CQRs must formalize governance structures to ensure accountability, oversee resource application, provide focus and optimise output from the CQR.

26. CQRs must establish policies to manage a range of contingencies arising from the analysis of data from the CQR, which includes a formal plan ratified by the CQR Steering Committee to address outliers or unexplained variance, to ensure that quality of care issues are effectively addressed and escalated appropriately.

Data custodianship

27. Custodianship of CQR data must be made explicit in contracts and/or funding agreements. CQRs should make clear, publicly available statements of data custodianship.

28. Data access and reporting policies for CQRs must be made available to persons wishing to use CQR data. CQRs should make data access and reporting policies publicly available.

29. Third parties wishing to access data and publish findings must seek approval from the CQR Steering Committee and obtain relevant Institutional Ethics Committee endorsement where identified or re-identifiable data is sought.

Ethics and privacy

With the exception of instances where data collection has been mandated through legislation or enabled through regulation or legislation:

30. Appropriate ethics approval must be obtained to establish and maintain the CQR.
31. CQR personnel must be familiar with and abide by the requirements set out in relevant privacy legislation, the *National Statement on Ethical Conduct in Human Research* and the *Australian Code for the Responsible Conduct of Research*.
32. Participants or their next of kin must be made aware of the collection of CQR data. They must be provided with information about the CQR, the purpose to which their data will be put and provided with the option to not participate. This must be at no cost to the CQR participant.
33. Where projects are undertaken using CQR data, IEC approval must be sought unless the project falls within the scope of an institution's quality assurance activity.

Information output

34. Data from CQRs must be used to evaluate quality of care by identifying gaps in best practice and benchmarking performance.
35. CQRs must report without delay on risk-adjusted outcome analyses to all CQR stakeholders in accordance with agreed reporting requirements of the CQR.

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36. CQRs should verify data collected using a formalized peer review process prior to publishing findings.
37. Clinicians and/or staff at contributing units should have the capacity to undertake ad-hoc analyses of the data they contribute to the CQR to enable monitoring of clinical care.
38. CQRs must produce a publicly-accessible, annual report detailing aggregated clinical and corporate findings.
39. CQR reports must be produced according to a strict timeline and should demonstrate funding to enable this to occur.
40. CQRs must have documented procedures, including methods employed, for reporting on quality of care, including addressing outliers or unexplained variance.

Resources and funds

41. CQRs should demonstrate sufficient funding is allocated to allow data collection, reporting and the institution of strong quality assurance procedures.

Appendix 2 — Glossary of abbreviations

Abbreviation	Organization/term
A&E	Accident and Emergency
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
CHIAG	Community Health Index Advisory Group
CIHI	Canadian Institute for Health Information
CQC	Care Quality Commission
CQR	Clinical Quality Registry
ECDC	The European Centre for Disease Prevention and Control
EEA	European Economic Area
EHR	Electronic Health Record
EMR	Electronic Medical record
ESS	European Statistical System
EU	European Union
GP	General practitioner
HIPE	Hospital In-patient Enquiry Scheme
HIQA	Health Information and Quality Authority
HSCIC	Health and Social Care Information Centre
HSE	Health Service Executive
ICT	Information and communications technology

Abbreviation	Organization/term
IG	Information Governance
ACCD	Australian Consortium for Classification Development
ACHI	Australian Classification of Health Interventions
ACS	Australian Coding Standards
AHRQ	Agency for Healthcare Research and Quality
ALB	Arm's-length body
AMT	Australian Medicines Terminology
AR-DRG	Australian Refined Diagnosis Related Groups
ASH	Accredited Safe Haven
BAAS	Burden Advice and Assessment Service
CCI	Canadian Classification of Health Interventions
CCS	Canadian Coding Standards
CHIAG	Community Health Index Advisory Group
COAG	Coalition of Australian Governments
CRDM	Corporate Reference Data Model
HISO	Health Information Standards Organization
HPI	Health Practitioner Index
HPI-I	Healthcare Provider Identifier-Individual
HPI-O	Healthcare Provider Identifier-Organization
ICD	International Statistical Classification of Diseases
IHI	Individual Health Identifier

Abbreviation	Organization/term
ISB	Information Sharing Board
ISD	Information Services Division
IT	Information Technology
METeOR	Metadata Online Registry
MIS	Management of Information Systems
NCAMP	National Collections Annual Maintenance Project
NCCH	National Centre for Classification in Health
NCS	National Collections System
NDC	National Data Catalogue
NEHTA	National E-Health Transition Authority
NHA	National Healthcare Agreement
NHI	National Health Index
NHIA	National Health Information Agreement
NHISSC	National Health Information Standards and Statistics Committee
NHRA	National Health Reform Agreement
NHS	National Health Service
NIGC	National Information Governance Committee
NMDS	National Minimum Dataset
NQAF	National Quality Assurance Framework
NZCR	New Zealand Cancer Registry
NZePS	New Zealand Electronic Prescription Service

Abbreviation	Organization/term
ODS	Organization Data Service
OPF	Operational Policy Framework
PAC	Privacy Advisory Committee
PARENT	The EU Cross Border Patient Registries Initiative
PHCPMS	Primary HealthCare Practice Management Systems
PIA	Privacy Impact Assessment
PMS	Practice management system
QIC	Quality information Committee
SIMC	Statistical Information Management Committee
SMR	Scottish Morbidity Record
SMR	Scottish Morbidity Record
SNOMED-CT	Systematized Nomenclature of Medicine Clinical Terms
UNSTATS	United Nations Statistics Division
UPI	Unique Physician Identifier

Appendix 3 — Glossary of terms that may appear in related literature

Term	Description
Audit	The assessment of performance against any standards and criteria (clinical and non-clinical) in a health or social care service.[155]
Benchmarking	A continuous process of measuring and comparing care and services with similar service providers.[155]
Classification	A method of organizing/grouping 'concepts' in a systematic way (e.g. into classes) within a particular domain for a specified purpose. They are arranged into categories according to common attributes, qualities or properties.[156]
Clinical coding	The translation of medical information relating to a patient's encounter with a healthcare provider into alphanumeric code(s). This process makes it possible to perform analysis on healthcare activity by grouping diagnoses and procedures together.[156]
Clinical terminologies	A structured collection of descriptive terms for use in clinical practice.[157]
Cost effectiveness	The point at which the minimum amount of input (such as finance, human resources) is used to achieve a defined health outcome.[155]
Data	Data are numbers, symbols, words, images, graphics that have yet to be organized or analysed.
Database	A collection of data that is organized so that its contents can easily be accessed, managed, and updated.
Dataset	Is the data that is collected by the information collections. The data is usually presented in tabular form.
Data catalogue	Can be defined as a comprehensive list of datasets outlined in a systematic fashion. Data catalogues and data inventories are important resources in informing and increasing awareness among stakeholders on the existence, purpose and access to

Term	Description
	currently available information sources.[158]
Data collector	A data collector is responsible for collecting and in some instances coding the data for a national health and social care data collection.
Data dictionary	'A descriptive list of names (also called representations or displays), definitions, and attributes of data elements to be collected in an information system or database. The purpose of the data dictionary is to standardize definitions and therefore have consistency in the collection of data.'
Data linkage	Data linkage is a process which temporarily brings together two or more sets of administrative or survey data from different organizations to produce a wealth of information which can be used for research and statistical purposes.[159]
Data provider	Are those that are responsible for the data collection.[3]
Data quality	Data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner.[4]
eHealth	The combined use of electronic communication and information technology in the healthcare sector.[160]
Evidence	Data and information used to make decisions. Evidence can be derived from research, experiential learning, indicator data and evaluations.[161]
General Practitioner (GP)	A doctor who has completed a recognized training programme in general practice and provides personal and continuing care to individuals and to families in the community.[155]
Governance	In healthcare, an integration of corporate and clinical governance; the systems, processes and behaviours by which services lead, direct and control their functions in order to achieve their objectives, including the quality and safety of services for service users.
Health	Health information is defined as information, recorded in any

Term	Description
information	form, which is created or communicated by an organization or individual relating to the past, present or future, physical or mental health or social care of an individual or group of individuals (also referred to as a cohort). Health information also includes information relating to the management of the health and social care system.[162]
Healthcare	Services received by individuals or communities to promote, maintain, monitor or restore health.[161]
Information	Information is data that have been processed or analysed to produce something useful.[163]
Information and communication technology (ICT)	The tools and resources used to communicate, create, disseminate, store, and manage information electronically.[163]
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.[163]
Interoperability	'The ability of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of healthcare for individuals and communities.'[164]
Key Performance Indicator (KPI)	Specific and measurable elements of practice that can be used to assess quality and safety of care.[155]
Metadata	Can be defined as 'data to explain data'. Metadata provides summary information in a structured way about the content of a resource such as a report, a book or a dataset.[3]
Minimum dataset	A minimum dataset is the least agreed number of data elements collected for reporting purposes.[163]

Term	Description
National health and social care data collections	National repositories of routinely collected health and social care data, including administrative sources, censuses, surveys, and national patient registries in the Republic of Ireland.[163]
Performance indicators	Specific and measurable elements of practice that are designed to assess key aspects of structures and processes and to assess outcomes.[163]
Personal health information	Personal information is data relating to an individual who is or can be identified either from the data or from the data in conjunction with other information that is in, or is likely to come into, the possession of the data controller.[165]
Primary care	An approach to care that includes a range of services designed to keep people well. These services range from promotion of health and screening for disease, to assessment, diagnosis, treatment and rehabilitation as well as personal social services.[161]
Regulation	A sustained and focused control exercised by a public agency over activities that are valued by a community.[161]
Risk	The likelihood of an adverse event or outcome.[161]
Service level agreement	An agreement between the service provider and third parties identifying the service and the parameters of same that the third party will provide to the service provider.[163]
Service Provider	Any person, organization, or part of an organization 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.[163]
Standard	A statement which describes the high level outcome required to contribute to quality and safety.[161]
Statement of	A document which details the aims and objectives of the

Term	Description
purpose	national health or social care data collection.[163]
Survey	Is an investigation about the characteristics of a given population by means of collecting data from a sample of that population and estimating their characteristics through the systematic use of statistical methodology.[3]
Value for money	Assesses whether or not an organization has obtained the maximum benefit from the goods and services it both acquires and provides, within the resources available to it.[157]
Workforce	The combination of staff directly employed by the national health or social care data collection, and those who work on its behalf in other organizations.[163]

Appendix 4 — International agencies contacted

Country	Organization	Name	Title of contact (s)
Australia	Australian Institute of Health and Welfare (AIHW)	Jen Mayhew-Larsen	Unit Head, Metadata and Classifications Unit
		Nick Von Sanden	Unit Head, Statistical and Analytical Support
		George Bodilsen	Unit Head, Hospitals Data
Canada	Canadian Institute for Health Information (CIHI)	Maureen Kelly	Manager of the Data Quality Department
England	Health and Social Care Information Centre (HSCIC)	Eve Roodhouse	Programme Head, Data linkage
		Matt Neligan	Transformation Director Information and Analytics
		Nicholas Oughtibridge	Head of Information Standards: Quality, Assurance, Appraisal and Testing
		Linda Whalley	Director of Strategy and Policy
New Zealand	Ministry of Health	Angela Pidd	Manager Client Insights and Analytics
Scotland	Information Service Division (ISD)	Christopher Jones	Information Manager Data Management
		Barry Watson	Data Quality Information Manager