



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

International review of approaches countries have taken to integrate National Health and Social Care Data Collections

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Safer Better Care

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About the Health Information and Quality Authority

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

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

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

Overview of Health Information function

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

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

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

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

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

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

Information can be lost, documentation is poor, and there is over-reliance on memory. Equally, those responsible for planning our services experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore,

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

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements. In accordance with the Health Act 2007, (sections 8(1)(j) and 8(2)(d)), one of the key functions of the Authority is to provide advice to the Minister for Health and the Health Service Executive (HSE) about deficiencies identified regarding health information. It is on this basis that the Authority is undertaking to make recommendations to the Minister for Health for a more integrated approach to national health and social care data collections in Ireland. This international review forms the basis of the evidence for the recommendations put forward to the Minister for Health⁽¹⁾, which are available at www.hiqa.ie.

1. Introduction

1.1 Background

Safe, reliable health and social care depends on access to, and use of, good quality information. Information is essential to achieve a high quality, value for money, healthcare system. 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.⁽²⁾ They provide a national overview of data relating to a particular health or social care service.⁽³⁾ National data collections collect a considerable amount of data on a regular basis to provide us with a wealth of information about our health and social care services.

Accurate, relevant and timely data is essential in order to identify and improve care provided, to inform decision-making, monitor diseases, plan services, inform policy making, conduct high quality research, and plan for future health and social care needs, both locally and nationally. Similar to the international experience, as documented in this report, national collections in Ireland have evolved over time in a largely uncoordinated fashion and this has led to the development of isolated 'silos' of information with significant variation in quality, fragmentation, duplication, access problems, and increased costs. This was recognised in the 2004 National Health Information Strategy⁽⁴⁾ which stated that "the health information landscape is characterised by numerous databases and systems that are essentially isolated and uncoordinated".

1.2 Work undertaken to date

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

- *The Catalogue of National Health and Social Care Data Collections in Ireland*^(5;6)
- *An International Review of Health Information Sources*⁽⁷⁾
- *Identification of Themes for Standards for National Health Information Sources in Ireland*⁽⁸⁾
- *Draft Standards for National Health Information Resources*⁽⁹⁾
- *Guiding Principles for National Health and Social Care Data Collections*⁽³⁾

These projects have laid the foundation for the current project being undertaken by the Authority to develop recommendations for a more integrated approach to the national health and social care collections in Ireland.⁽¹⁾ This document, an international review of the approaches taken in four countries, was the first step in developing these recommendations.

1.3 Purpose of this report

A number of challenges faced by national health and social care data collections in Ireland have been well documented^(8;10-12) and there is widespread awareness of these issues, and the need for them to be addressed. These issues include variable data quality, lack of robust governance arrangements, duplication of effort and information not being used to its full potential. The Authority has developed recommendations for a more integrated approach to national health and social care data collections. The first step in developing these recommendations was to undertake an international review of the approaches other countries have taken.

The final output from this project is a set of recommendations to the Minister for a more integrated approach to national health and social care data collections.⁽¹⁾ In accordance with the Health Act 2007, (sections 8(1)(j) and 8(2)(d)), one of the key functions of the Authority is to provide advice to the Minister for Health and the Health Service Executive (HSE) about deficiencies identified regarding health information. It is on this basis that the Authority is undertaking this project.

Other countries have faced similar challenges in respect of their national collections and are addressing these in various ways, all of which involve varying degrees of increased integration and harmonisation. The following countries were selected for review on the basis of an initial review of the literature, the availability of evidence and access to relevant personnel to inform the review:

- Canada
- New Zealand
- Australia
- England.

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

2. Summary of findings

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

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

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

The following sections provide a summary of the international evidence in the context of the known challenges facing the national health and social care collections in Ireland.

2.2.1 Strategic framework and governance arrangements

- In the four jurisdictions reviewed, there are key organisations that govern either all or the majority of national health and social care data collections. These organisations provide the strategic framework for the governance of the collections.
- Current governance arrangements for national data collections in the jurisdictions reviewed are provided for either through national legislation, national or bilateral agreements or agreements with district health authorities.

- Organisations that are charged with providing the strategic framework for the governance of national data collections are well placed to drive efforts in data quality and standardisation, vendor licensing and the implementation of eHealth initiatives such as Electronic health records (EHRs).
- Incentives for data providers to engage and work with the key organisations vary across the jurisdictions. In Australia, the health information system is linked to the allocation of funding to the states and territories, providing a clear incentive to comply with the terms of the National Health Information Agreement (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 Health and Social Care Information Centre (HSCIC) has a statutory remit to minimise the burden of national data collections on the National Health Service (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.

2.2.2 Standardisation and data quality

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

2.2.3 Use of information

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

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

Table 1 provides a high level overview of the models that are in place in each of the four jurisdictions reviewed.

Table 1: High level summary of international evidence

Country	Canada	New Zealand (NZ)	Australia	England
Population	35.4 million	4.5 million	23.5 million	53.9 million
Political structure	Federal constitutional monarchy: 10 provinces and 3 territories	Constitutional monarchy	Federal constitutional monarchy: 6 states and 10 territories	A country of the British monarchy
Key organisation	Canadian Institute for Health Information (CIHI)	Information Group, Ministry of Health (MoH)	Australian Institute of Health and Welfare (AIHW)	Health and Social Care Information Centre (HSCIC)
Mandate of key organisation	Voluntary and independent	Statutory	Statutory and independent	Statutory, an executive non-departmental public body
National data collections (NDCs)*	The majority of national data collections (NDCs) are housed within CIHI (n=28). Additional NDCs are housed within Statistics Canada.	All national data collections are within the Ministry of Health (n=15).	The majority of NDCs are housed within AIHW (n=84). Additional NDCs are housed within the Australian Bureau of Statistics and the Department of Health.	The majority of NDCs are housed within the HSCIC (n=121). Additional NDCs are within other charities and agencies, such as Public Health England.
Overall model for the governance of NDCs	A mostly centralised governance model with the majority of national data collections housed within CIHI.	Centralised governance model with all national health and social care data collections housed within the Ministry of Health.	A more de-centralised governance model exists with robust national agreements providing the governance arrangements for national data collections.	A mostly centralised model is in place with the majority of national health and social care data collections housed within the HSCIC.
Governance arrangements	Voluntary bilateral agreements are signed by CIHI with each of the individual provinces and territories.	The Ministry of Health signs an Operational Policy Framework with the District Health Boards.	The National Health Information Agreement (NHIA) provides the overarching framework for the governance of NDCs. Signatories include the AIHW, the Commonwealth government and various national agencies, and state and territory governments.	The Health and Social Care Act 2012 provides the HSCIC with a legal basis for requiring the submission of data. The HSCIC is in its second year of operation, hence is relatively new. Work is ongoing on the development and implementation of concordats and Memoranda of Understanding to address the burden generated by the NDCs.
Unique identifiers**	No unique national patient identifier exists. Provincial and territorial individual identifiers are in use. A pan-Canadian unique physician identifier is in use.	Unique national identifiers for individuals and practitioners are in use.	Unique national identifiers for individuals, providers and organisations are in use.	The NHS Number serves as a unique national patient identifier for every person registered with NHS England. Unique national identification codes are in place for organisational entities of interest to the NHS.

*A list of the national data collections of the key organisations is provided in Appendix 4.

**The terms used here are in line with those utilised in the different countries. For this table, physician, practitioner and provider are used interchangeably.

3. Canada

Canada has a population of 35.4 million.⁽¹³⁾ 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.⁽¹⁴⁾ Since 1990, Canada has been working on the development of a national health information system infrastructure through a series of roadmaps. The most significant development in the management of national data collections was the establishment of the Canadian Institute for Health Information (CIHI) in 1994.

3.1 Current model for management of national data collections

In accordance with the *Canada Health Act (1984)*⁽¹⁵⁾, ultimate responsibility for health information lies with Health Canada, a department of the federal government. Health Canada delegates responsibilities to CIHI, the central statistics office Statistics Canada, and Canada Health Infoway,⁽⁷⁾ a strategic investor in projects that support the Electronic Health Record (EHR). These three independent agencies that have significant roles in national collections are explored in greater detail in section 3.3.

CIHI manages the majority of the national health and social care data collections in Canada. As a secondary collector of data, CIHI collects a wide variety of data in the following areas: patient care in different settings, the health workforce, health spending and health system performance. CIHI is independent and data is received from providers on a voluntary non-legislative basis, allowing CIHI to provide and be perceived to provide, unbiased and credible health data and information. When CIHI was established, it managed three national collections; 20 years later, CIHI now manages 28 national collections.

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.⁽¹⁶⁾ 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.

Through the bilateral agreements with the Ministries of Health across Canada, funding provided to CIHI by the provinces and territories allows access to a core set of CIHI's information products and services in support of the following: national standards, national databases and registries, publications and selected comparative reports and education.

3.2 Journey to this model of integration

CIHI's establishment in 1994 followed a movement to improve health information in Canada. A National Health Information Council was formed in 1988 which recommended the establishment of a task force to assess the state of health information. After widespread consultation, the task force produced a report in 1991 called '*Health Information for Canada 1991*'. This report recognised that Canada had a high calibre centralised statistical system, while acknowledging that Canadian health information was in a poor state with information needs not being met for everything from policy to treatment, and a total lack of comparable data. The task force identified the lack of information which included: no inventory of data holdings, their location and the technical documentation on their source, concepts, definitions, coverage and quality assessment, as diminishing any collective ability to manage the overall data system.⁽¹⁷⁾

Following the recommendations of the task force, CIHI was established as an independent, pan-Canadian, not-for-profit organisation, through the merging of two non-governmental organisations, the Hospital Medical Records Institute and the Management Information Systems (MIS) Group. A number of employees and databases from Statistics Canada and Health Canada transitioned to CIHI in 1995.⁽¹⁸⁾ The establishment of CIHI as a neutral independent body can be attributed largely to the momentum created by the political community across Canada.

Health Canada has continued to work towards a comprehensive and integrated national health information system. Since 1999, federal funding in the form of block allocations has been provided to CIHI through a series of roadmap initiatives which provided important steps towards the harmonisation of the national data collections.

3.3 Structures and agencies involved

Of the three agencies (CIHI, Canada Health Infoway and Statistics Canada) that have roles in national collections, it is CIHI that plays the most significant role in the overall management of national data collections.

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organisation whose mandate is to lead the development and maintenance of comprehensive and integrated health information that enables informed policy development and effective health system management that improves health and health care.⁽¹⁸⁾ CIHI is accountable to the federal government for the collection, analysis and provision of health information that is pan-Canadian, reliable and comparable,⁽¹⁹⁾ providing a leadership role in coordination of a common approach for health information in Canada.

CIHI's total revenue for 2013 was CAN\$105.5 million, with a staff of approximately 718. The vast majority of this funding was, and continues to be, provided to CIHI by Health Canada through a series of multi-year grants and agreements, initially

through the Roadmap Initiative and later, the Health Information Initiative. CIHI is now leading on its sixth roadmap initiative.

In working to fulfil its mandate, CIHI:⁽¹⁸⁾

- Develops and manages health databases and registries.
- Identifies health information needs and priorities.
- Conducts analysis and special studies and participates in, and supports, health care system research.
- Supports the development of national health indicators.
- Coordinates and promotes the development and maintenance of national health information standards.
- Funds and facilitates population health research and analysis, conducts policy analysis and develops policy options.
- Contributes to the development of population health information systems and infrastructure.
- Provides appropriate access to health data under controlled conditions.
- Publishes reports and disseminates health information.
- Coordinates and conducts education sessions and conferences.

3.3.1 Canadian Institute for Health Information - key relationships

CIHI works closely with Canada Health Infoway (Infoway) and Statistics Canada. Since CIHI's establishment, Statistics Canada has been a key partner, serving on CIHI's governing board with regular liaison meetings occurring between the two bodies. CIHI and Infoway, a federally funded independent organisation, also have a long standing relationship, with the two organisations agreeing a Memorandum of Understanding (MoU) in 2003 which outlined their partnership in the area of electronic health records (EHRs).

Canada 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. 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.⁽²⁰⁾

Through Infoway's work in strategically investing in projects across Canada, it fosters and accelerates the development and adoption of digital health information systems. In supporting the development of EHR systems, Infoway is working towards the generation of data that is more complete and comparable. The EHRs

utilised in all jurisdictions intend to enable the establishment of data repositories that will house, manage, and disclose information for secondary use.⁽²¹⁾

Statistics Canada

Statistics Canada, established in 1971, is the federal agency responsible for reporting on national, provincial and territorial statistics. Under these responsibilities, it has a major role to play in health information, operating 18 health-related surveys and statistical programs such as the Canadian Health Measure Survey and the Canadian Cancer Registry.⁽²²⁾ It provides a single point of contact for health information standards in Canada and works in close collaboration with CIHI on various initiatives.⁽⁷⁾ Statistics Canada supplies resources through information on data standards and methodology, international metadata standards and standard classifications. CIHI asserts that its partnership with Statistics Canada provides both a rich source of data and expertise to complement the work of CIHI.

3.4 Data collections managed by the Canadian Institute for Health Information

Since 1994, CIHI has worked with its partners to build and maintain 28 pan-Canadian databases and registries that allow for comparisons among jurisdictions.⁽²³⁾ CIHI also manages two provincial databases. CIHI's databases are related to acute and ambulatory care, continuing and specialised care, pharmaceuticals, workforce and health spending. CIHI receives data from hospitals, regional health authorities, medical practitioners and governments, as set out in its various agreements. CIHI has developed tools for the data providers to submit data, including the electronic Data Submission Service (eDSS). An application has also been developed that provides feedback to the data providers, the Canadian MIS Database (CMDDB) Submission Reports.⁽²⁴⁾ The extent to which identifiable information is collected varies with the source. Some provinces report data to CIHI with the jurisdictional individual health card number, while others report using an encrypted identification number that cannot be re-identified by CIHI.⁽¹⁶⁾

Each of the 30 data collections is listed on the CIHI website (www.cihi.ca) with details provided on the type of care each collection relates to. Specific information is also provided at the individual data holding level, including data source, coverage, availability, classification, data elements and the annually published data quality reports. Support is available to clients of CIHI, for example, clients can use the eQuery Tool to search an existing repository of questions and answers on data-related topics. In the coming year, CIHI plans to commence the development of a data repository and reporting capability for patient experience data.

3.4.1 Indicators

CIHI's databases are used to calculate a range of clinical, financial and other indicators across the health system and for specific populations.⁽²⁵⁾ In partnership with Statistics Canada through the Health Indicators Project, CIHI has developed common indicators with the provinces and territories that align the databases in relation to the available information. This increases both the participating

jurisdictions in the data collection process and increases the level of data comparability.⁽¹⁹⁾

3.4.2 Establishing a new data collection

Each of CIHI's data collections has an advisory committee whose members have a stake or interest in that particular holding. When establishing a new data collection, initial interest is built through a consultation process. Generally once this process has begun, interest among stakeholders builds further, increasing confidence in the potential new data collection. There have been cases where provinces and territories have mandated the collection of certain data once its value became evident in other jurisdictions.

3.4.3 Accessing the Canadian Institute for Health Information's data collections

Much of CIHI's data is publicly accessible, with clients of CIHI having access to further data. CIHI signs data sharing agreements with other agencies, for example Cancer Care Ontario (CCO). The CIHI Portal provides access for CIHI clients to facility-identifiable data in a web-based analytical environment. Researchers, decision-makers and health managers can request specific data from one or more of CIHI's databases, with the option to retrieve data at an aggregate or record level. CIHI processes custom data requests on a cost-recovery basis and all requests are processed with the turnaround time determined by the type and complexity of the request.⁽²⁶⁾

Central to CIHI's privacy programme is the Privacy and Security Framework 2010. CIHI's *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data* (2010, Updated in April 2014)⁽²⁷⁾ is part of this framework and serves to protect the privacy of Canadians. The bilateral agreements with the provinces and territories require that CIHI complies with standards of privacy and confidentiality as prescribed by law in the different jurisdictions as well as CIHI's *Privacy Policy* and CIHI's *Health Workforce Privacy Policy*. CIHI does not disclose personal health information except under limited circumstances and where the recipients have entered into a data protection agreement or other legally binding instruments with CIHI.⁽²⁸⁾

3.5 Benefits of the Canadian model

As a result of having such an integrated approach, CIHI has been able to take the lead on a number of initiatives which have improved the quality, availability and use of information in Canada as a whole as well as within the collections individually.

3.5.1 Data quality

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.⁽²⁹⁾

CIHI has developed a data quality programme that is recognised nationally and internationally for its comprehensiveness and high standard. 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⁽³⁰⁾ 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: accuracy, timeliness, comparability, usability, and relevance. 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.

CIHI regularly performs a series of activities to help monitor data quality and prevent and detect data quality issues. These include:⁽²⁹⁾

- 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 (including re-abstraction studies using medical records) 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.

3.5.2 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.⁽⁷⁾ CIHI standards and data submission products and services are available to clients. These include:^(18;31)

- 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.

CIHI utilises data dictionaries to describe how it processes data and to assist the data providers to develop their data submissions for CIHI. While data dictionaries are in place for each collection, there is no national data dictionary in existence.

The Standards Collaborative

CIHI was involved in the establishment of the Standards Collaborative. The Collaborative was established to support and sustain health information standards nationally and is now part of Infoway. With 665 organisation and individual members, the mandate of the Collaborative includes establishing standards to support Infoway's work in fostering and accelerating the deployment and use of eHealth solutions and providing services to support and maintain these standards.⁽³²⁾ To date, a number of standards have been developed which facilitate the communication of accurate health information and performance monitoring through the comparison of data.

Classifications and terminologies

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.⁽⁷⁾ 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.⁽³³⁾ 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.

3.5.3 Unique 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 government of their new jurisdiction. There is a system of national provider identifiers; the National Physician Database features the Unique Physician Identifier (UPI) which allows for the tracking of physicians over time and location.⁽³⁴⁾

3.5.4 Data linkage

Data linkage in CIHI is still in its infancy with current efforts directed at producing reports that link data from different collections. CIHI's *Privacy Policy* (2010, updated in 2014)⁽³⁵⁾ 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 from third-parties are submitted to CIHI's Privacy, Confidentiality and Security Team for approval against a range of criteria outlined in the *Privacy Policy*. When CIHI is conducting data linkage activities, it generally does so without using identifiable information such as names or the individual health insurance numbers. CIHI aims to use the Client Linkage Index (CLI) or other comparable methodologies when conducting data linkage. The CLI is a central repository which assigns a meaningless unique number to all records which enables or facilitates record linkages at the patient level in an anonymised fashion.⁽³⁶⁾

3.5.5 Vendor Licensing Agreements

CIHI has undertaken a role in vendor licensing in order to protect its data collections and the integrity of its products, which are essential for data providers to submit data to, and communicate with, CIHI. The current Vendor Licensing Agreement is effective from 2013/14 – 2015/16. The Agreement provides vendors with the necessary CIHI products to enable them to develop and support their software to meet the electronic submission requirements for CIHI's data collections. Once CIHI receives the signed three-year licensing agreement and the annual products selection form, vendors automatically receive CIHI products as they become available.⁽³⁷⁾

3.6 Canada's future plans

There is recognition in the Canadian health information community that more needs to be done, with opportunity for further improvements. CIHI and Infoway have created *Better Information for Improved Health: A Vision for Health System Use of Data in Canada*.⁽³⁸⁾ This Canadian vision paper for the health system use of electronic health information in Canada was endorsed by the federal, provincial and territorial governments in 2013. It recognises the solid progress that has been made in areas such as laboratory information systems, drug information systems and electronic medical records (EMRs) but acknowledges that the integration of this data is not yet optimal.

Together CIHI and Infoway acknowledge the need for the secondary use of data requirements to be built into the electronic health systems currently being deployed throughout the health system, provinces and territories, to avoid large retrofit costs later on. One of the guiding principles outlined in the vision paper relates to data collection, availability and use that support health information decision-making with efforts focused on putting guidelines in place to ensure that data is standardised to maximise usability for both primary use of data and health system purposes.⁽³⁸⁾

CIHI is also focusing efforts on integrated e-reporting, and recently started the Integrated e-Reporting (IeR) Initiative. The IeR initiative is a structured planned approach to bring together health information historically maintained in silos to a single reporting environment, with expected outcomes of reduced costs and enhanced standardisation.⁽³⁹⁾ CIHI expects clients will have access to a single continuum view that spans and integrates multiple databases, with benefits relating

to enhanced ability to make comparisons, and better understanding and access to data.⁽⁴⁰⁾

3.7 Canada - Summary

- The Canadian Institute of Health Information (CIHI) is independent of government and serves as the custodian of the majority of national health and social care data collections in Canada.
- All provinces and territories in Canada have voluntarily entered into bilateral agreements with CIHI, which guide the type of data that must be submitted to CIHI and provides access for the provinces and territories to CIHI's products and services.
- CIHI has a well developed data quality programme and works to improve data quality at different levels of the health system, from training of data providers to building awareness of data quality issues among Deputy Ministers.
- CIHI promotes the use of national standards among the provinces and territories relating to data, transmission, clinical coding and privacy and security.
- CIHI maintains data dictionaries for the individual national collections and there are jurisdictional unique health identifiers in place.
- Data linkage is still in its infancy, due in part to the complexities of engaging with 13 different jurisdictions and their differing privacy legislation.
- CIHI utilises Vendor Licensing Agreements to improve interoperability across the Canadian health information system and to achieve better value for money.

4. New Zealand

New Zealand has a population of 4.5 million.⁽⁴¹⁾ 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 this work is the Ministry of Health (MoH) and its various business units, with advice from various boards and committees. One of these business units, the National Health Board (NHB), holds responsibility for the funding, monitoring and planning of District Health Boards (DHBs) and designated national services, and for national, regional and local integration.⁽⁴²⁾ Twenty 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.⁽⁴³⁾

4.1 Current model for management of national collections

New Zealand is a country with a centralised and harmonised structure in place for health and social care data collections. Stipulated in different pieces of legislation is the Ministry's obligation to collect data. It has responsibility for the collection and dissemination of all health-related information in the country. The MoH collects data from different parts of the health sector (mostly from routine administrative systems) through the utilisation of health services, or the mandatory reporting national collections, and from national population health surveys.⁽⁴³⁾

All data is collected in the national interest and the collections are housed in the Ministry's data warehouse, with no national collection located outside of the Ministry. The MoH's Information Group has operational responsibility for the 15 national collections.

The Ministry of Health signs an Operational Policy Framework (OPF) with the twenty DHBs each year. The OPF sets out the business rules, policy and guideline principles that outline the operating functions of DHBs⁽⁴²⁾ and the responsibilities of the Ministry in relation to national health information management and reporting requirements. The roles and responsibilities of the DHBs and the MoH under the terms of the Operational Policy Framework 2013/14⁽⁴⁴⁾ are set out in Table 2.

Table 2: Roles and responsibilities of the DHBs and the Ministry of Health under the Operational Policy Framework 2014/15

DHBs agree to:	Ministry of Health agrees to:
Provide the Ministry with the requisite data for a number of National Collections Systems (NCS).*	Consult with sector stewardship groups when changes are proposed to the data collected in the national collections.
Ensure that it, and all of its providers of publicly funded health services submit data to the national collections systems that: <ul style="list-style-type: none"> ▪ Use the current version of the data dictionary, code set or dataset published for each national collection. ▪ Conform with Ministry requirements for data format and quality of data. 	Communicate with software vendors when changes to the national collections are approved.
Ensure that any DHB providers of purchased services directly supply the Ministry with data required for inclusion in the National Collections, and that providers will notify the Ministry of any changes that will affect the supply of data.	Provide DHBs with: <ul style="list-style-type: none"> ▪ a point of contact for communication ▪ monthly reports showing DHB performance ▪ feedback on DHB performance ▪ technical support to clinical coding staff.
Ensure that all changes to the systems that support NCS reporting or reporting requirements are subject to appropriate compliance testing, as determined by the Ministry.	Monitor data submitted directly to the national systems for compliance with data delivery timeframes and levels of accuracy, as outlined in the file specification for each collection.
Each DHB and its service providers will use the current version of standards specified by the Ministry, when electronically submitting national health data.	Ensure that processing of all National Health Information Batch Systems: <ul style="list-style-type: none"> ▪ are complete within two working days of receipt of data from a provider ▪ that the appropriate infrastructure is maintained ▪ that the National Health Index (NHI) system is available according to mutually agreed service levels.
	In respect of any changes to the reporting requirements for NCS: <ul style="list-style-type: none"> ▪ provide six month advance notice ▪ report to DHBs on implementation progress and provider compliance requirements or status.

*National Collections Systems include the National Health Index (NHI), Health Practitioner Index (HPI), National Minimum Data Set (NMDS), Medical Warning System (MWS), National Booking Reporting System (NBRS), Programme for the Integration of Mental Health Data (PRIMHD), Before School Checks Information System (B4SC) and National Non-Admitted Patient Collection (NNPAC).

4.2 Journey to this model of integration

The health information system in New Zealand has developed considerably over a number of years through strategies and roadmaps that have been published with a strategic focus on national collections. Following on from the *Working to Add Value through E-Information* (WAVE) report in 2001, a Health Information Strategy for New Zealand was developed in 2005. The importance of a national view of data collections was recognised and an emphasis was placed on the gradual improvement of these sources over time to ensure they provide better value to the sector. A number of specific strategies were proposed. These included the creation of new national collections, improved data quality and compliance, and appropriate coding. The use of consistent standards and coding was seen as vital in order to generate valid and quality national health related data.

Early efforts in the area of health information were ahead of their time with a National Health Index (NHI) to identify patients initiated in the 1980s and a National Cancer Registry collecting data since the late 1940s. The introduction of regional services planning has addressed the challenge of varied IT systems across the DHBs, as now regional information technology systems are in place.⁽⁴⁵⁾ While much progress has been made with the use of IT, challenges around governance, funding and capabilities remain.⁽⁴⁶⁾ The development of a National Health IT Plan by the Ministry of Health in 2010 prioritised strategic areas of regional and national investments for achieving the eHealth vision.

New Zealand has focused significant effort in the area of eHealth. One hundred per cent of New Zealand's general practices use an EMR system. New Zealand's progress on interoperability is well noted, as standard messaging allows different care providers to communicate with each other.⁽⁴⁷⁾

4.3 Structures and agencies

The Ministry of Health is the key agency with responsibility for national collections. In addition to the Ministry itself, the following are also involved:

- The Ministry's Analytical Services Team
- Health Benefits Limited
- The National Health Information Technology Board.

4.3.1 The Ministry of Health

The Ministry of Health operates and manages the IT network infrastructure that underpins national data collections and systems used in service delivery.⁽⁴⁸⁾ Through this, the MoH manages the national collections. Within the National Health Board of the MoH, the Information Group serves as the key group that supports the delivery of sector and Ministry priorities regarding health information. The National Collections and Reporting Group sits within the Information Group. A goal of the National Collections and Reporting Group is to make timely and accurate data readily

available throughout the health sector. There are 65 full-time staff members in the National Collections and Reporting Group.

The Ministry of Health's Analytical Services Team sits within the National Collections and Reporting Group. All requests for data held in the national collections are processed by the information analysts in the Analytical Services Team.⁽⁴⁹⁾ This team assists in defining the specifications for an information request and are familiar with the strengths and weaknesses of the data in each of the national collections. The team also offers a peer review service to ensure that national collections data is reported appropriately when published by other organisations.

4.3.2 Health Benefits Limited

Health Benefits Limited (HBL) is a ministerial owned, national shared services organisation. HBL was formed in 2010 to reduce costs and deliver savings through the effective and efficient delivery of administrative, support and procurement services for DHBs, through the development of national contracts. HBL provides services such as human resources and shared payroll, information technology and facilities management, financial management and information systems, and procurement and supply chain.⁽⁴³⁾ It assists in preventing duplicate reporting of clinical data by utilising the same contract across the country. This helps to develop opportunities that would otherwise be difficult for an individual DHB or a smaller group of DHBs to develop on their own.

HBL is currently probing the value of a national infrastructure platform. There are currently 40 data centres working at local and regional levels with an estimated expenditure of NZ\$60-70 million on IT infrastructure annually. The suggested vision involves a single governing organisation, involving eight or less data centres. The proposed benefits include improved reliability and service levels, more predictable future operating costs and a less variable environment.⁽⁵⁰⁾

4.3.3 National Health Information Technology Board

The National Health Information Technology Board (NHITB, IT Health Board) is a sub-committee of the National Health Board. The role of the IT Health Board is to provide strategic leadership on information systems across the health and disability sector, and to ensure that the IT strategy is reflected in capital allocation processes and capacity planning decisions.

Through its programme, the IT Health Board works to progress investments to support an improved health information model and set a direction for the appropriate and effective use of personal health information. The IT Health Board published the National Health IT Plan in 2010 and updated the plan in 2013. The IT Health Board is currently working on the development of a five-year IT Plan for 2015 to 2019. Four priorities were identified for IT investment in 2014 and beyond: electronic medication management, national clinical solutions, regional information platforms, and community-based integrated care initiatives.⁽⁴³⁾

4.4 Data collections managed by the Ministry of Health

The Ministry of Health manages 15 national data collections of health and disability information, with the Information Group holding operational responsibility for these.⁽⁴³⁾ On the MoH website (www.health.govt.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.

There is a secure network between the MoH and the DHBs for the transfer of data and all national collections data is stored in the Ministry's data warehouse. Files are archived locally and there is a disaster recovery plan in place. A file retention and disposal schedule is provided through *The Retention of Public Records Act (2005)*.

4.4.1 Developing a new national collection

In the MoH, the need for a new national collection can be identified, for example, where information is already being collected using spreadsheets and it is not possible to maintain this system. There is a clear process for developing a new national collection in New Zealand; stages of this process include: developing a business case for the new collection, establishing a reference group and developing reporting requirements for the new collection. It typically takes two to three years to set up a new national collection and one further year to stabilise the collection.

4.4.2 Accessing the Ministry of Health's data

The MoH provides information services to the public. Summarised data from the national collections are available through MoH publications from the Analytical Services Team. There is a central section on the Ministry of Health's website for accessing health data and statistics collected and produced by the Ministry of Health and the wider health sector. The warehouse is directly accessible by certain users and accessible to a wider group upon request and approval. All requests for data held in the national collections are processed by the information analysts in the Analytical Services Team.⁽⁴⁹⁾ All requests for individually identifiable data are assessed on a case-by-case basis.

The MoH Data Access Policy⁽⁴⁹⁾ outlines the circumstances under which personal health information can be disclosed to researchers, for example, where it is not desirable or practicable to obtain the authorisation of the relevant individuals. The *Health Information Privacy Code (HIPC) 1994*⁽⁵¹⁾ provides a set of rules that protects the privacy of individually identifiable health information.⁽⁵²⁾ When providing data to external parties, the HIPC is applied, and approval from the Ethics Committee must be sought before the data is released. The approach to consent for the secondary use of information varies between hospitals but often a provision for consent for the secondary use of information is included on hospital admission forms. Privacy officers operate in the DHBs.

The Ministry shares data with the Health Quality and Safety Commission (HQSC) to inform the Commission's work in identifying key health and safety indicators to inform, monitor and report on improvements in safety and quality. The HQSC accesses a range of data held by the Ministry, including the national minimum dataset, patient administration system details, laboratory data and adverse events.⁽⁵³⁾

4.5 Benefits of the New Zealand model

New Zealand has a centralised model of national data collections. With this approach, the Ministry of Health has been in a position to drive improvements, standardising the national IT health infrastructure, improving interoperability and facilitating and conducting data linkage. The National Health IT Plan has been a force in this, acknowledging that efforts in this area would reduce fragmentation and inconsistency, improve the ability to audit and maintain security, support greater reliability of service, which would allow a choice of standards-compliant applications and services, all contributing to greater cost effectiveness.⁽⁵⁴⁾

4.5.1 Data quality

While there is no evident national data quality framework in New Zealand, there are a range of activities in place to ensure data quality. Previously, efforts in working to improve data quality involved a team of auditors visiting the DHBs to conduct data quality audits. This is no longer the approach as it was very resource intensive. Currently, certain hospitals that hold expertise in this area offer their services to other hospitals.

The following are the data quality initiatives that have been identified in New Zealand:

- DHBs have data quality teams that address data quality issues as they arise.
- The 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.

4.5.2 National Collections Annual Maintenance Project

The National Collections Annual Maintenance Project (NCAMP) has been in operation for approximately 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 six 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 health care system and its users.

4.5.3 Standards

The IT Health Board is the governing body for health information standards in New Zealand. The Health Information Standards Organisation (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.⁽⁴⁸⁾

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 Health Care 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.⁽⁵⁵⁾

Data dictionaries

Up to late 2013, New Zealand was utilising METeOR, Australia's repository for national metadata standards for the health, community services and housing assistance services. This system was advantageous in that it managed a community of experts who could debate and agree definitions. However, the use of METeOR in the New Zealand context presented challenges when reporting, in part due to its complex structure and frequent queries around coding.

New Zealand intends to develop an overall national data dictionary. It has reviewed METeOR and has started liaising with the International Organization for Standardization (ISO) on this.

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.

Classifications and terminologies

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.⁽⁴³⁾ 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.

4.5.4 National Health Index

The Ministry of Health describes the National Health Index (NHI) as the cornerstone of health information in New Zealand. The NHI is a mechanism implemented by the Ministry of Health that assigns each person a unique identifying number (known as the NHI number) that holds demographic information, specifically: name, address, date of birth, sex and ethnicity. National NHI coverage is estimated at 98%.⁽⁴³⁾ An encrypted form of the NHI number is used in statistical databases to help protect the privacy of individuals while enabling data linkage.

The Health Practitioner Index (HPI) is a data warehouse of registered health practitioners, and includes the Common Person Number which is a unique practitioner index. Work is ongoing by the IT Health Board for the implementation of a single replacement programme for the NHI and HPI, called the Health Identity Programme. This integrated system is expected to improve accuracy, accessibility and integration, linking clinicians, organisations and facilities⁽⁵⁶⁾ while improving the reliability and quality of data in comparison to the NHI and HPI.

4.5.5 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.⁽⁵⁵⁾

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.⁽⁵⁷⁾ 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.

4.6 New Zealand's future plans

- A National Health IT Plan for the period 2015 to 2019 is currently under development.
- New Zealand is working towards the creation of electronic health records for every person. New Zealand has a target for the end of 2014, that all patients and the providers who care for them will have secure electronic access to their health information.
- New Zealand recently piloted a new electronic Patient Report Form (ePRF) system. This system allows paramedics to record and send a clinical summary of care to emergency departments and to a patient's GP, utilising SNOMED CT to allow for consistent recording of patient information.
- There is increased cross government sharing of administrative data and there is a strong interest in including health data in this effort. A pilot research project of cross-agency interest has been developed where the effects of chronic conditions and acute health events are linked to future employment, earnings, benefit receipt and health status of an individual.

4.7 New Zealand - Summary

- New Zealand has a highly centralised model for its national collections, with all of the national data collections housed within the Ministry of Health (MoH). Because of this model, the MoH can drive integration across its national data collections.
- This centralised approach where national data is located in a single data warehouse has many advantages. The MoH is well placed to drive improvements in data quality, system interoperability and data linkage.
- This centralised approach also allows for an Analytical Services Team in the MoH to efficiently provide analytical expertise, rather than having the expertise diluted by being spread across multiple agencies.
- The Operational Policy Framework (OPF) signed by the District Health Boards (DHBs) outlines obligations of both the DHBs and the MoH, requiring the DHBs to conform with Ministry requirements on metadata standards, data submission and data quality.
- The MoH 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.
- New Zealand plans to develop a national data dictionary; current data dictionaries for the individual data collections are available.
- The well established system of unique individual and healthcare provider identifiers provides a strong foundation for longitudinal aggregation and data linkage.
- New Zealand demonstrates a strong interest in data linkage and has worked to progress its use across the health sector and more recently, wider government.
- 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.

5. Australia

Australia has a population of 23.5 million.⁽⁵⁸⁾ The Commonwealth of Australia is comprised of six states and ten territories. 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. While overall coordination of the public healthcare delivery system is the responsibility of federal, state and territory health ministers, the health service in Australia is governed centrally by the Department of Health (formerly known as the Department of Health and Ageing).⁽⁷⁾

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. The AIHW consults with the Australian Bureau of Statistics (ABS), Australia's official national statistical agency, to develop specialised statistical standards and classifications relevant to health, health services and welfare services.⁽⁵⁹⁾

5.1 Structures and agencies involved

There are a number of councils, organisations and committees involved in health information in Australia, including the AIHW, the ABS, the Department of Health and the Department of Human Services. Table 3 sets out the roles of these agencies at a high level with further detail provided about the AIHW in section 5.4.

Table 3: Bodies and agencies that engage with AIHW in the area of national data collections

Agency	Role or function
The Coalition of Australian Governments (COAG)	<ul style="list-style-type: none"> ▪ Serves as the top intergovernmental forum in Australia; members are Commonwealth, state and territory ministers. ▪ The role of the COAG is to promote policy reforms that are of national significance, or which need coordinated action by all Australian governments. ▪ Maintains eight councils including the Health Council.
Australian Health Ministers' Advisory Council (AHMAC)	<ul style="list-style-type: none"> ▪ Provides support to the Health Council of COAG. ▪ Considers matters relating to the coordination of health services across Australia; acts as a forum for planning, information sharing and innovation.
COAG's four independent National Health Reform agencies: <ul style="list-style-type: none"> ▪ National Health Performance Authority (NHPA) ▪ Australian Commission on Safety and Quality in 	<ul style="list-style-type: none"> ▪ These four agencies have important data development, analysis or reporting responsibilities. ▪ The four organisations interact with AHMAC mainly through the National Health Information and Performance Principal Committee (NHIPPC) and its committees.⁽⁶⁰⁾ ▪ The NHPA works with the AIHW as the Institute supports the Authority in the development of

Agency	Role or function
<p>Health Care (ACSQHC)</p> <ul style="list-style-type: none"> ▪ Independent Hospital Pricing Authority (IHPA) ▪ National Health Funding Body (NHFB) 	<p>performance indicators and the publication of the performance indicator specifications on METeOR.</p> <ul style="list-style-type: none"> ▪ The AIHW and the ACSQHC have signed an MoU that reflects their joint commitment to working collaboratively towards a more informative and usable national system of information that enhances the safety and quality of health care.⁽⁶¹⁾
<p>Department of Health</p>	<ul style="list-style-type: none"> ▪ Pursues the achievements of specified outcomes in association with 21 portfolio agencies and 4 statutory agencies. ▪ Manages a number of hospital related data collections containing information about hospital activity in the public and private systems. ▪ Collects data from the state and territory health authorities by financial year, under the Australian Health Care Agreements; coverage is reported at 100%.
<p>Australian Bureau of Statistics (ABS)</p>	<ul style="list-style-type: none"> ▪ Australia's official national statistical agency; headed by the 'Australian Statistician'. ▪ Responsible for the Health and Disability Program.¹
<p>National eHealth Transition Authority (NEHTA)</p>	<ul style="list-style-type: none"> ▪ A private company that leads a national approach to eHealth to support private, national, state and territory reforms, by developing a national eHealth infrastructure.⁽⁶³⁾ ▪ Funded by the Commonwealth and state and territory governments.⁽⁶⁴⁾
<p>Population Health Research Network (PHRN)</p>	<ul style="list-style-type: none"> ▪ A national network established to build a nationwide data linkage infrastructure capable of securely and safely managing health information from around Australia; the AIHW is a member. ▪ Works to provide researchers and other data users with the training and information required for applying and accessing data approved for linkage.

5.2 Current model for management of national collections

Due to the dispersed complex nature of Australia's health system, strong governance arrangements have been employed, predominantly in the form of national agreements, to engage stakeholders to fulfil national objectives. Governance arrangements and mechanisms for many aspects of health information are established under the Health Council of the Coalition of Australian Governments (COAG).

¹ The Health and Disability program develops, compiles and disseminates information about the health of the Australian population. It does this through a range of health information collections including:⁽⁶²⁾ Causes of Death Collection, Australian and National Health Surveys and the Patient Experience Survey.

A legislative framework has evolved over time consisting of intergovernmental agreements, namely the *National Health Reform Agreement* (NHRA) (2011), the *National Healthcare Agreement* (NHA) (2012) and the *National Health Information Agreement* (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*⁽⁶⁵⁾ and the *National Partnership Agreement on Preventive Health*.^(66;67)

The NHIA provides the overarching framework for the governance of national data collections. One of the purposes of the NHIA is to govern structures and processes through which commonwealth, state and territory health departments, national statistical authorities and national health reform bodies work together to improve, maintain and share national health information.

5.2.1 National Health Information Agreement

The National Health Information Agreement was established to coordinate the development, collection and dissemination of health information in Australia, including the development, endorsement and maintenance of national data standards.⁽⁶⁸⁾ The scope of the NHIA includes data, standards, definitions, classifications and terminologies for data collections and performance indicators.⁽⁶⁴⁾ The NHIA promotes the efficient, secure, confidential and timely use of information across the complete lifecycle from development to use, supporting the reuse of information. The current NHIA commenced on 1 October 2013 and will continue until the signatories deem it necessary to terminate and devise a new agreement. Otherwise the NHIA will be reviewed by the Australian Health Ministers Advisory Council (AHMAC) five years after it commenced operation. The NHIA is built on the Commonwealth model; the Commonwealth allocates a percentage of funding to each state and territory depending on performance. Performance indicators that are linked to these allocations are set by the Health Ministries and Treasuries with the AIHW providing advice.

Details of the NHIA are provided in Table 4.

Table 4: The National Health Information Agreement

Signatories to the NHIA	Core activities covered by the NHIA	All parties to the NHIA agree to:
<ul style="list-style-type: none"> ▪ State and territory health departments ▪ The Commonwealth of Australia represented by the Australian Bureau of Statistics, the Department of Health and Ageing (now the Department of Health), the Department of Veterans' Affairs and the Department of Human Services ▪ The Australian Institute of Health and Welfare ▪ The Australian Commission on Safety and Quality in Health Care ▪ The Independent Hospital Pricing Authority ▪ The National eHealth Transition Authority ▪ The National Health Performance Authority ▪ The National Health Funding Body ▪ The National Health and Medical Research Council. 	<ul style="list-style-type: none"> ▪ Facilitation or establishment of nationally agreed projects in health information management. ▪ Development and maintenance of a National Health Data Dictionary (NHDD) to underpin data development and collections. ▪ Development of health data classifications and standards. ▪ Endorsement of National Minimum Data Sets (NMDSs) and dataset specifications (as defined in the NHDD) containing data elements consistent with NHDD definitions and classifications. ▪ Integration and harmonisation of health, community services, housing assistance and income support data definitions, classifications and standards, where possible. ▪ Data linkage across health and other social policy sectors. ▪ Dissemination of consistent national information. 	<ul style="list-style-type: none"> ▪ Adhere to the national standards provisions of the Agreement. ▪ Support national information infrastructure in the health sector. ▪ Provide information for NMDSs that have been approved by AHMAC and comply with their specifications. ▪ Actively and cooperatively pursue the resolution of any difficulties that arise in the provision and collection of health data, including providing suggestions for improving the quality and relevance of minimum dataset items. ▪ Provide information and specialist advice on activities and collections for which they have responsibility. ▪ Acknowledge an obligation to use best endeavours to provide data within agreed time lines and actively pursue improvement in the consistency, timeliness and accuracy of data provided, to the standard of the best jurisdiction.

5.2.2 Governance of the National Health Information Agreement

The National Health Information and Performance Principal Committee (NHIPPC) is the AHMAC Principal Committee responsible for arrangements under the National Health Information Agreement (NHIA), including responsibility for overseeing the implementation of the NHIA itself. The NHIPPC has responsibility for:

- Advising AHMAC on information strategies, needs and priorities for health information.
- Facilitating collaboration between the Commonwealth Government, and states and territories to implement these strategies.

The National Health Information Standards and Statistics Committee (NHISSC) is one of the standing committees currently operating under the NHIPPC. The NHISSC oversees the development of, and recommends to the NHIPPC the endorsement of:

- Data standards for inclusion in the National Health Data Dictionary.
- National Minimum Data Sets (NMDSs) for implementation.
- National eHealth informatics standards.

NHISSC is also responsible for providing advice on the technical aspects of national performance indicator specifications. Public reporting and performance indicators both serve as a means of managing non-compliance with the NHIA.

5.3 Journey to this model of integration

Australia has undergone significant structural changes, with an evident move towards a more centralised approach. The reform agenda (the National Health Reform Agreement⁽⁶⁹⁾ and other national agreements and partnerships) has prioritised an integrated approach to health information. Since the introduction of the NHIA in 1993, Australia has worked towards bringing all forms of health information management within a single governance structure and centralising a number of national collections, facilitating greater consideration of the relationship between different users of health information.⁽⁷⁰⁾ The governance mechanisms used have evolved over time. The content of the national agreements has grown more complex over time; early agreements were very low-level, less meaningful and lacking the depth of those in place today.

Australia claimed to be the first country to have assembled such a large scale, integrated piece of national infrastructure with the introduction of eHealth solutions, such as healthcare identifiers and Secure Messaging Delivery (SMD).⁽⁷¹⁾ These solutions assist in the creation of national standardised quality data which the AIHW can use to produce information on health and care status and services. More recently, efforts in the area of eHealth saw progress in the area of electronic health records (EHRs). The Personally Controlled Electronic Health Record (PCEHR) system started in 2012 after many years of work by the National E-Health Transition Authority (NEHTA). Electronic medical records in the ambulance service have also been introduced in some states.

Following the release of Australia's budget in May 2014, there are indications that the Australian Government is moving towards centralised control of the public sector, with the intention of improving efficiency and reducing duplication. This will have significant implications for the structures outlined above, as proposals were made to merge several organisations, including the AIHW.

5.4 The Australian Institute of Health and Welfare

The Australian Institute of Health and Welfare (AIHW) was established as a statutory authority by the *Australian Institute of Health and Welfare Act 1987*⁽⁷²⁾ to serve as a custodian of major national health and welfare data collections. The AIHW contributes to the health and medical research effort in Australia by analysing data on health and health services, making data holdings available to researchers, supporting researchers with data integration services, and developing and promoting information standards for the health sector.⁽⁷³⁾ Much of the data that the AIHW reports at national level is received from state and territory government departments.⁽⁶¹⁾ The AIHW analyses data and publishes statistical reports, web pages and other documents on the status of Australians' health, and their health and care services.

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

- Receiving, cleansing and disseminating information as the key national custodian of administrative health data collections and promoting national consistency of definitions and 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 specialised statistical standards and classifications relevant to health and health services.
- Undertaking specific research, using national data to improve the efficiency and effectiveness of 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 has a number of formal relationships with other agencies and works with state and territory governments through a variety of national information committees. The AIHW also holds key relationships at the federal level and manages relationships with the Department of Human Services and the health agencies formed under the National Health Reform Agreement.⁽⁶¹⁾ In 2012 to 2013, the AIHW recorded revenue of AUD\$52 million; the government of Australia funded 30% of this revenue. The majority of the balance of funding was revenue generated from commissioned projects.⁽⁶¹⁾ The AIHW has an approximate workforce of 300, with 14 staff members in the Data Integration Unit.

5.5 Data collections managed by the Australian Institute of Health and Welfare

As of 2013, the AIHW was managing 84 national health and welfare data collections.⁽⁶¹⁾ The data in these collections primarily originates in administrative data collections operated by the state and territory government departments. The AIHW operates a central register of its data holdings with a catalogue of these data holdings accessible online. Using the national data collections, AIHW publishes a number of area-specific health indicator publications, for example, in the areas of child social exclusion and the health of Australia's males.

States and territories routinely remove identifying information from datasets before submitting data to the AIHW. There are exceptions where datasets with identifiable information are submitted to AIHW, for example, cancer incidence data. A high level of importance is placed on the protection of privacy for individuals. A *Privacy Policy* (approved July 2014) is published on the AIHW website (www.aihw.gov.au) which details handling practices of personal health information.

5.5.1 Accessing the Australian Institute of Health and Welfare's data

AIHW provides access to the data holdings, subject to approval that is provided either by the Institute, or the data providers. The data custodian for each individual dataset is responsible for authorising access to data in accordance with the AIHW's requirements on confidentiality and privacy, as well as requirements set by data providers. The AIHW can provide access through internally prepared tables in response to specific requests, with a charge applied for this service.

There are quality control measures in place to ensure that individuals and organisations are unlikely to be identified from the data.⁽⁵⁸⁾ Identifiable data held by the AIHW cannot be released to third parties, except with the consent of both the AIHW Ethics Committee and the data provider. The AIHW Ethics Committee was established under the *AIHW Act* and is empowered by law to review all proposed releases of identifiable information. The Ethics Committee also manages other requests, such as those regarding the creation of new customised datasets and data linkage projects. AIHW data collections are subject to independent audits to ensure that their integrity and security are maintained.

5.6 Benefits of the Australian model

The following sections set out the benefits of the oversight role provided by the AIHW and the use of agreements in Australia.

5.6.1 Data quality

Under the NHIA, responsibility for the quality and completeness of contributed data remains with the data provider. AIHW works to improve the quality and timeliness of its data releases through:

- Providing guidance and support, for example, the AIHW published *A Guide to Data Development*⁽⁷⁴⁾ 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, authorises and oversees the AIHW's audit programme and reports to the AIHW Board on data (and financial) audit matters.⁽⁷⁵⁾

The AIHW uses seven dimensions to evaluate the quality of health data sources, an approach that aligns with the ABS Data Quality Framework. The seven dimensions of quality used are: institutional environment, relevance, timeliness, accuracy, coherence, interpretability and accessibility.⁽⁷⁶⁾

5.6.2 Standards

The parties to the current *NHIA* (2013) agree to comply with standards, definitions, classifications and protocols for data collected for the purposes of national information collections within the scope of the agreement. The *NHIA* (2013) also stipulates that the AIHW will undertake a registrar and data standards expertise role on behalf of the appropriate information and data standards endorsing body.

The AIHW manages the national health and welfare data standards through its work with the national information committees. Data standards adopted by the ABS and authoritative international organisations are employed by AIHW wherever possible and variations are made explicit where this is not possible.

The Metadata Online Registry

The AIHW manages METeOR, Australia's Metadata Online Registry for health, community services and housing assistance. Metadata standards in METeOR work to ensure that health data is defined and collected in a consistent manner both within collections and across collections. The AIHW enables other authorities to become registration authorities for data standards on METeOR and collaborates with registering authorities and the national information committees to achieve national endorsement of standards. Within METeOR are the National Health Data Dictionary, and the National Minimum Data Sets (NMDSs), which detail the minimum set of data elements agreed for mandatory collection and reporting at the national level.⁽⁷⁷⁾ The *NHIA* stipulates that METeOR will be the authoritative source of indicators, which will be agreed, calculated and mandated for use by parties to the *NHIA*.

Classifications and terminologies

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 health care community. NEHTA's clinical terminology solutions include Systematized Nomenclature of Medicine Clinical Terms, Australian Release (SNOMED-CT AU) and Australian Medicines Terminology (AMT).

Another significant actor in this area is the National Centre for Classification in Health (NCCH). 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).

5.6.3 Unique 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-organisation (HPI-O).

5.6.4 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.⁽⁶⁴⁾ 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. A statistical linkage key is employed to link data that has a very small but deliberate error rate.

The DISC works closely with the AIHW's Data Linkage Unit to ensure that access to linked data for researchers is provided in line with privacy obligations⁽⁷⁸⁾ 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. 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.⁽⁷⁹⁾

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 (where the risk of re-identification exists), 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.⁽⁸⁰⁾ All integrating authorities that handle identifiable information must comply with the requirements of the *Privacy Act 1988* and secrecy provisions generally. 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.⁽⁸¹⁾

5.7 Australia's future plans

There will be significant structural changes in the health information sphere in Australia in the year ahead, as the government works to effectively manage the vast and complex system by integrating a number of organisations. In May 2014 the Department of Health stated that the government will work with states and territories with the intention of creating a new Health Productivity and Performance Commission during 2014-2015. It is expected that this new commission will be formed by merging the functions of the AIHW, the ACSQHC, the Independent Hospital Pricing Authority (IHPA), the National Health Performance Authority (NHPA), the National Health Funding Body (NHFB) and the Administrator of the National Health Funding Pool.⁽⁵⁹⁾

5.8 Australia - Summary

- The AIHW is the statutory body that serves as custodian of the majority of national health and welfare data collections.
- 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 has evolved over time to meet the changing needs of the sector, providing the overarching framework for the governance of national data collections, and coordinating the development, collection and dissemination of health information in Australia.
- The health information system in Australia is linked to the allocation of funding to the states and territories, providing an incentive to comply with the terms of the NHIA, which is governed by a national committee.
- The NHIA drives a national standardised approach to health information through endorsing the use of national data standards, classifications and national minimum datasets.
- Aside from supporting the production of standards, datasets and metadata, the AIHW supports data quality through technical documents, validation processes, data quality statements and data quality audits.
- A national health data dictionary is available through METeOR, the metadata online registry. It allows for greater consistency and comparability among the data collected across the states and territories.
- In Australia, there is a system of unique identifiers in place for individuals, individual healthcare providers and organisational healthcare providers.
- Data linkage is well established within the AIHW. The AIHW maintains a Data Linkage Services Unit and is one of two accredited commonwealth integrating authorities.

6. England

England has a population of 53.9 million.⁽⁸²⁾ 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*⁽⁸³⁾ brought about significant changes in the area of health information in England, which are outlined below.

6.1 Current model for management of national data collections

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 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 organisations.

6.1.1 Busting bureaucracy and reducing the burden

In the aftermath of the NHS Confederation Report, "*Challenging Bureaucracy*" (2013)⁽⁸⁴⁾, the Secretary of State asked all national bodies to collaborate on the reduction of the administrative burden associated with national data collections. The HSCIC has been designated a statutory role to monitor the burden generated by national data collections on the frontline. Reducing this burden is a priority of the HSCIC and measures are being taken to address this challenge. 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 HSCIC recently completed a study "*Busting Bureaucracy, Collaborative audit findings and recommendations*" (2014)⁽⁸⁵⁾ which assessed how burden and bureaucracy manifests itself for clinical and administrative staff. The findings included:⁽⁸⁵⁾

- One of the biggest burdens is the duplication of information needed at various points throughout the patient journey.
- A large percentage of the electronic systems in use within the audited Trusts are local or bespoke systems specific to a particular ward, offering no integration with wider information systems.

Addressing the burden and duplication in the NHS are seen as attempts to improve operational and financial efficiency. The HSCIC is working towards improving its

systems and having a more strategic approach to the data it collects and how that data is used.

The HSCIC's work in this area includes:

- Spine 2, the new key information system, was introduced in August 2014. The updated system is now located in-house and is expected to improve overall performance and reduce costs.
- The HSCIC discontinued 66 data collections (for example, the Swine Flu Vaccine Uptake), following a Department of Health Fundamental Review of Data Returns.⁽⁸⁶⁾ The HSCIC anticipates that the changes to the collections will result in work savings of at least 98 person-years and a reduction in annual costs of approximately £5.8 million.⁽⁸⁷⁾
- The Department of Health Fundamental Review of Data Returns also identified opportunities for more efficient methods of data extraction, allowing the HSCIC to utilise these to reduce the burden further.
- The HSCIC operates the Burden Advice and Assessment Service (BAAS), which works to minimise the burden of data collections on the NHS, as outlined in section 6.5.4 of this report.

6.1.2 Agreements

In order to apply controls to data collections, the HSCIC is signing concordats (agreements) with each national arm's-length body² (ALB), committing the ALBs to working with the HSCIC and other ALBs to reduce the burden. The HSCIC expects that the concordats will alleviate the burden arising from the introduction of new datasets and changes to existing datasets, as well as the significant ad-hoc reporting requirements placed on the Trusts. 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⁽⁸⁹⁾, 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 to:⁽⁹⁰⁾

- Ensure that they only collect information where there is a clear business purpose that justifies the administrative burden.
- Establish clear criteria which can be used to measure the administrative burden.
- Ensure that all aggregated and non-personal information collected is made available for others to use, in the interests of transparency and avoiding duplication.

To support this, the HSCIC are working to agree Memoranda of Understanding (MoUs) with each of the national bodies. These will establish service level agreements for meeting their data requirements and targets for reducing the impact on direct care organisations. The MoUs will contain a set of core standards to which

² Arm's-length bodies are Government-funded organisations which work closely with local services and other arm's-length bodies. The Department has three main types of arm's-length bodies: Executive Agencies; Executive Non-Departmental Public Bodies; and Special Health Authorities.⁽⁸⁸⁾

the HSCIC will commit. These MoUs were under development at the time of writing this report.

6.2 Journey to this model of integration

When it came into effect in April 2013, the *Health and Social Care Act 2012* brought a series of reforms and significant changes to the health information system in England, at both local and national levels. Organisations such as the Information Standards Board and the NHS Information Centre are no longer in operation, with key functions being absorbed by existing or newly established organisations and bodies. In April 2014, new governance arrangements for information standards, data collections and data extractions brought further changes to exercise the new powers designated to various sections of the health and social care system, as a result of the Act.

It is as a result of these changes that the HSCIC has become the body central to the oversight and management of national data collections.⁽⁸⁷⁾ The establishment of the HSCIC as the national provider of high-quality information, data and IT systems for health and social care, was intended to create significant improvements in the delivery of key national informatics and information services.

6.3 Structures and agencies involved

The HSCIC works closely with national organisations: NHS England, the Department of Health and the organisations and bodies that commission its services. The HSCIC works under the National Information Board (NIB), a new body that provides an integrated commissioning arrangement for informatics services for health and social care in England. Another significant actor is the Standardisation Committee for Care Information (SCCI) which oversees the development, assurance and approval of information standards, data collections and data extractions.⁽⁹¹⁾ The role of each of these agencies is set out in table 5 below, with the roles of the HSCIC and the SCCI explored in greater detail in sections 6.3.1 and 6.3.2 of this report.

Table 5: Agencies involved in national data collections in England

Name	Function
Health and Social Care Information Centre (HSCIC)	<ul style="list-style-type: none"> ▪ Executive non-departmental public body that manages and oversees the majority of national health and social care data collections; involved in the design and delivery of new data collections. ▪ Inherited a number of responsibilities from the now defunct NHS Information Centre and NHS Connecting for Health.
National Information Board (NIB)	<ul style="list-style-type: none"> ▪ Provides for the first time, an integrated commissioning arrangement for informatics services for health and social care in England; committed to ensuring that information standards are coherent, enabling different IT systems to communicate with each other and driving more integrated services.

	<ul style="list-style-type: none"> Formerly known as the Informatics Services Commissioning Group (ISCG).
Standardisation Committee for Care Information (SCCI)	<ul style="list-style-type: none"> Serves as a subgroup of the NIB; oversees the development, assurance and approval of information standards, data collections and data extractions. Replaces the Information Standards Board.
NHS Confederation	<ul style="list-style-type: none"> Membership body for all organisations that commission and provide NHS services; representing and supporting members, influencing health policy and providing leadership across the entire NHS.

6.3.1 The Health and Social Care Information Centre

The Health and Social Care Information Centre (HSCIC) is the design and standards authority for the health and social care system. The HSCIC manages and oversees a number of large data collections (121 routine mandatory data collections as of April 2014), covering many aspects of health and social care. These collections contain data collected from a wide variety of NHS trusts, local authorities, and independent sector organisations. While the HSCIC is involved in the design and delivery of new collections, it does not have a role in determining what data should be collected.⁽⁸⁷⁾ The HSCIC operates on a cost recovery basis, charging to cover the cost of processing and delivering services. The HSCIC has approximately 2,100 staff, with an annual budget of £210 million, during its first year of operation.⁽⁸⁹⁾

The *Health and Social Care Act 2012* 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 organisations.
- 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 organisations 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

The HSCIC supports the delivery of IT infrastructure and information systems to ensure information flows efficiently and securely across the system in order to improve patient outcomes. These infrastructure and systems include:

- Spine 2, a collection of national applications, services and directories that support the NHS in the exchange of information across national and local NHS systems.
- Summary Care Record (SCR), an optional electronic patient record that contains information on a patient's medicines, allergies and any bad reactions to medicines previously taken (further information can be added if the patient consents).
- NHS Number, the unique patient identifier held by every person registered with NHS England.
- Clinical Audit Platform, a single standard technical platform for all of the clinical audits.

6.3.2 The Standardisation Committee for Care Information

The Standardisation Committee for Care Information (SCCI) is responsible to the National Information Board (NIB) 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.⁽⁹²⁾ The SCCI governs the approval process, through which standards must proceed. The HSCIC provides direct support to the SCCI and to all users throughout the entire lifecycle of an information standard, data collection or data extraction.⁽⁹¹⁾

6.4 Data collections managed by the Health and Social Care Information Centre

As of April 2014, the HSCIC managed 121 routine national data collections.⁽⁹³⁾ A number of national collections remain outside the remit of the HSCIC, for example, the National Cancer Data Repository. Where possible, the HSCIC collects data from operational systems in an attempt to minimise the burden on frontline services. Through its website (www.hscic.gov.uk), the HSCIC provides information on approved, past and proposed data collections. The HSCIC outlined in its first annual report plans to publish a full catalogue of the data it collects and makes available for secondary uses, in July 2014. Further plans to extend this catalogue to include the data stored to support direct care were planned for October 2014.⁽⁸⁹⁾

6.4.1 Accessing the Health and Social Care Information Centre's data

The HSCIC manages a Secondary Uses Service (SUS), a data warehouse for healthcare data that was collected for primary use and through this service, is also used for secondary purposes, including healthcare planning, payment by results and developing national policy.⁽⁸⁷⁾

The HSCIC recently changed its process for requesting access to its data. The HSCIC publishes its Data Access Policy online⁽⁹⁴⁾ and it now operates a Data Access Request Service (DARS). There are three stages to the DARS process: application, approval and access. In operating this service, the HSCIC will utilise newly developed data sharing contracts and data sharing agreements, with plans in place to conduct audits of these contracts and agreements. With the exception of applications for aggregate data, all applications are evaluated by the Data Access Advisory Group (DAAG).

When considering an application, the HSCIC will consider the customer's evidence of consent of the individuals concerned.

6.5 Benefits of the English model

It is difficult to gauge the success of the model in England as it is still in what can be considered as a transitional phase. In January 2014, following extensive consultations, the HSCIC published its strategy for 2013 – 2015⁽⁹⁵⁾ outlining its priorities for the period, many of which will have a significant impact on the way in which national collections operate.

A number of initiatives, either planned or ongoing at the time of writing this report, are further explained in the next sections. While evidence on the success or otherwise of these ventures is not yet available or is very limited at this early stage, what is clear is that they could not even have commenced without the existence and operation of a central oversight body such as the HSCIC, being in place.

Even in advance of these recent changes, significant achievements can be documented in England, namely the development of a national data dictionary and a Clinical Classifications Service, both of which are detailed below.

6.5.1 Data quality

The HSCIC has a statutory data quality role and undertakes a range of data quality activities, including setting and maintaining data standards. While the organisations that provide the data to the HSCIC are ultimately responsible for the quality of the data, the HSCIC provides advice, guidance and methods on improving data quality to these organisations. There is a data quality function attached to each of the national collections and a corporate lead on data quality to provide oversight across the HSCIC. A number of assurance type checks are in place that assess the coverage and quality of data received by the HSCIC. The HSCIC has made a number of guidance documents available on its website.

The HSCIC assesses the data it collects against national standards and reports the findings. To date, the HSCIC has published two experimental official statistics³ publications that report on data quality. These reports provide information on the HSCIC's current and planned data quality activities and capabilities, data quality performance, key data quality issues experienced by the HSCIC, and what it perceives to be good and poor data quality practice by organisations that submit data to the HSCIC. The HSCIC data quality framework is currently being updated and the most recent of these reports details the proposed scope for a national data quality framework.^(96;97)

Further examples of current work on data quality by the HSCIC include:⁽⁹⁸⁾

- Data quality reports on Secondary Uses Service (SUS) data are produced in the form of SUS Data Quality Dashboards.

³ Experimental statistics are new official statistics that are undergoing evaluation.

- At scheduled dates throughout the year, the SUS team will send an extract from the database to the Hospital Episode Statistics (HES) team who will validate and clean the extract before deriving new items and making the data available for use.

6.5.2 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.”⁽⁹⁹⁾

The *Health and Social Care Act 2012* requires that health and care organisations have ‘due regard’ for information standards, meaning that organisations must follow the standards or have a defensible reason for not doing so. Enforcement is through the regulatory framework and incentivised by commissioners. The HSCIC has launched a new standards website to support professionals in information standards across the health and social care sector (www.infostandards.org), which provides an outlet for professionals in the sector to submit ideas and participate in ongoing work. The HSCIC is working to audit the current provision of information standards by March 2015, in order to identify gaps that must be addressed to ensure system-wide interoperability.

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.⁽⁸⁷⁾

National data dictionary

The NHS Data Model and Dictionary provides a reference point for assured information standards to support health care activities within the NHS in England.⁽¹⁰⁰⁾ As a national resource for those who participate in the collection of data and management of information in the NHS, it serves to standardise the data collected across the NHS.

Classifications and terminologies

The HSCIC utilises classifications and terminologies as ‘building blocks’ to enable the development and implementation of information standards.

The UK Terminology Centre within the HSCIC is responsible for the management of SNOMED-CT, Read Codes⁴ and other healthcare terminology products and clinical classifications. The Clinical Classifications Service (CCS) in the HSCIC is the definitive

⁴ Read Codes are a coded thesaurus of clinical terms.

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.⁽⁸⁷⁾ 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).

6.5.3 The Interoperability Toolkit (ITK)

The Interoperability Toolkit is a national standard defining requirements and rules for the creation and transport of data. The ITK contains a set of common specifications, frameworks and implementation guides to support interoperability within local organisations and across local health and social care communities. ITK accreditation is assigned to system providers that meet the requirements and rules as set out in the toolkit. The HSCIC's online ITK Accreditation Catalogue allows organisations to source information on all vendors and products that have been awarded ITK Standards Accreditation Certificates. The ITK is a response to the need to enable local system interoperability within and across NHS organisations, in order to share information held in local systems.⁽¹⁰¹⁾

6.5.4 Burden Advice and Assessment Service

In order to meet its statutory responsibility to minimise the burden of data collections on the NHS, the HSCIC has recently developed the Burden Advice and Assessment Service (BAAS). This service:⁽⁸⁷⁾

- Offers advice and sets the criteria to the developers of new data collections, information standards and extractions.
- Provides an assessment process to validate the level of burden incurred by introducing new information standards, collections and extractions.
- Provides a Data Collections Burden Reduction (DCBR) service which welcomes referrals of collections for review of the quality and suitability of the collection and its value to the NHS.
- Conducts a three year rolling review of all data collections, both local and national to provide a picture of what is being collected, why information is being collected and the benefit it brings. A total cost of the burden will also be reported.

6.5.5 Unique 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 health care staff and providers to match a patient with their records. The HSCIC also operates an Organisation Data Service (ODS) that provides unique identification codes for organisational entities of interest to the NHS, such as hospitals and General Practitioner (GP) practices.

6.5.6 Data linkage

The HSCIC can combine and link datasets at record levels in a secure environment. A bespoke data linkage product is available to customers of the HSCIC that provides a once-off extract tailored to the customer's requirements, potentially containing

patient identifiable data. There is an approval process that the customer must follow; the Data Advisory Access Group (DAAG) will review the application and will make a recommendation to the Senior Information Risk Officer. As with all applications for non-aggregate data, upon application, the HSCIC will consider evidence that the customer has gained consent from the individuals to whom the data relates.

The HSCIC routinely links a number of datasets, specifically the Hospital Episode Statistics, with four other collections, one of which is the Patient Outcome Measures.⁽⁸⁷⁾

Accredited Safe Havens

Under the *Health and Social Care Act 2012*, the HSCIC is prohibited from releasing data that is weakly pseudonymised to other bodies, 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*⁽¹⁰²⁾, an Accredited Safe Haven (ASH) is an accredited organisation 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.⁽¹⁰³⁾ 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 organisations complying with stipulated conditions, and data sharing contracts are put in place to reinforce compliance. Linkage of identifiable data from more than one organisation 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.

Care.data programme

NHS England has commissioned a new data service from the HSCIC that will link data across all care settings in England, both acute and non-acute. Through the care.data programme, data will be extracted from GP records on a monthly basis and uploaded onto and linked across the databases of the HSCIC. Patients have the option to opt out of the programme. The identifiers to be extracted are: NHS number, date of birth, postcode and gender. Only coded information about referrals, NHS prescriptions and other clinical data will be extracted.⁽¹⁰⁴⁾ The introduction of the care.data programme generated controversy in England with media reports indicating that large numbers of patients were not aware of the programme. NHS England agreed to delay the commencement of the care.data programme in order to increase public awareness and consult with different stakeholders. It is expected to be rolled out in the autumn of 2014 with a sample of GP practices.

6.6 England's future plans

A priority for the HSCIC over the next twelve months is to develop a strategy for the longer term development of its data and information systems.⁽⁸⁹⁾ The HSCIC has also announced plans to establish an Information Standards and Collections (including Extractions) Group (ISCEG) which will involve new structures, processes and outcomes to validate the development of new data collections and systems.⁽⁸⁵⁾

Efforts to reduce the burden are ongoing under the HSCIC Busting Bureaucracy programme. The HSCIC has developed a self-assessment tool and toolkit, and future efforts are focused on overseeing and supporting the use of the tool and toolkit. This will assist Trusts in developing a baseline of the level of burden and bureaucracy experienced and help them to reduce their levels of burden and bureaucracy.⁽⁸⁵⁾

6.7 England - Summary

- England is undoubtedly working towards a more integrated model of health information management, through the Health and Social Care Information Centre (HSCIC), as documented in the organisation's strategy for 2013 – 2015.
- It is too early to gauge the success of the initiatives that have been planned or recently commenced, but it is important to note that in the absence of a body such as the HSCIC, the priority areas may as of yet have remained unidentified.
- The introduction of concordats and Memoranda of Understanding (MoUs) 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.
- There is a focus on reducing the burden and bureaucracy in the NHS and achieving value for money, evident in the discontinuation of 66 national collections and the recent introduction of the updated information system, Spine 2.
- The HSCIC works to ensure data quality through the provision of guidance documents, terminology and classification services and an Interoperability Toolkit Catalogue.
- The HSCIC is experienced in data linkage, already routinely linking a number of data collections and is an accredited safe haven under the *NHS Act 2006*.
- The care.data programme, soon to be introduced by the HSCIC is progressing data integration across the NHS by routinely linking data from the primary and acute sectors to effectively track the patient journey.
- The NHS number serves as a unique identifier for individuals.

7. Key learnings from the international experience

- In several of the jurisdictions, strong momentum was needed to drive an improved approach to governing and integrating national data collections. In Canada, Martin Wilk's 1991 report on health information in Canada signified a turning point in health information in Canada. The report described Canadian health information to be in a 'deplorable state' and recommended the creation of an independent institute for health information, leading to the establishment of the Canadian Institute of Health Information (CIHI).
- Within the jurisdictions, the provision of comparable national data is of considerable value allowing for comparison and benchmarking. The absence of the key organisations detailed in this report would create contexts where these comparisons and benchmarking could not effectively take place as the infrastructure for this would be absent and confidence in the data would be compromised.
- Across the jurisdictions, there is evidence of the duplication in data collection and the negative consequences this can have. For example, in New Zealand, Statistics New Zealand and the Ministry of Health both publish mortality data which can differ. This is not only duplication of effort but also creates questions on which data is correct, therefore undermining confidence in all of the data.
- Careful consideration should be given to what data is being collected, why it is being collected and what is the most efficient way to collect the data. National data collections can create a significant burden on clinical and administrative staff, draining both human and financial resources. England has recognised this and is addressing the burden issues through its Busting Bureaucracy programme and its Burden Advice and Assessment Service (BAAS). There is recognition of the value of collecting information once, as near to the point of care as possible and using it multiple times.
- There is a realisation of the importance of considering the requirements for the secondary use of data when developing systems for capturing and managing data for primary use, for example, electronic medical record (EMR) systems. In Canada, CIHI and Infoway have acknowledged the need for the secondary use of data requirements to be built into the electronic health systems, provinces and territories, avoiding large retrofit costs later on.
- The creation of new national data collections provides an opportunity to implement lessons learned and to design systems that better facilitate the primary and secondary use of the data collected. In England, the Health and Social Care Information Centre (HSCIC) ensures that new collections are technologically suitable and adhere to standards, while in New Zealand, an approval process must be followed when creating a new collection, which includes developing a business case.

- Data quality is seen as fundamental for a variety of reasons, one reason being for the allocation of funding. For example, in England and Australia, clinical coding of data needs to be carried out in a complete and reliable manner in order to accurately allocate funding. This is also topical in Canada; CIHI recently published a report⁽¹⁰⁵⁾ that indicates that some health system funders in Canada are considering activity-based funding.
- There is an acknowledgment of the value of building on what is already there in terms of standards. For example, in Canada and Australia, both countries attempt to use standards built by the national statistical bodies in their respective countries. All four jurisdictions reviewed utilise international clinical classifications and terminologies such as SNOMED-CT and versions of ICD-10.
- Key organisations in the jurisdictions have been well placed to facilitate greater integration and interoperability across the systems, through efforts with vendor licensing and certification. In Canada and New Zealand, vendor licensing is utilised to create systems where data can flow effectively, as data providers are using the same vendors, software and software versions. In England, the HSCIC awards certificates to vendors who comply with common specifications and publish this information through the Interoperability Toolkit Catalogue for the use of service providers.
- The prioritisation of data linkage is crucial for maximising the use of information. This prioritisation of data integration and linkage is highly evident in New Zealand. Wider government efforts are evident in the Better Public Services aim outlined in section 4.5.5 above and the designation of 2013 as the 'Year of Big Data' in New Zealand. In the health sector, the Ministry created a 'virtual register' by linking six existing national data collections (at a lower cost than a traditional national data collection).
- A common theme across the jurisdictions is the need to widely consult and engage in working with data providers, to increase buy-in and build relationships. All of the jurisdictions invest in education as a method for building capacity and driving improvements in data quality. Efforts include delivering training to data providers in clinical coding, data requirements and data quality.
- The importance of investing resources in health information systems is widely noted, as is the appropriateness of the investment. For example, New Zealand invested resources in the casemix⁵ system but feedback has revealed that this particular system does not work well in the New Zealand context.
- It is clear that the models of national data collections and the efforts to improve data quality and system interoperability are creating overall systems that are more integrated, better enabling data linkage within and across collections. These improvements are increasing the usability of the data and improving the

⁵ Casemix is an internally accepted system that enables the comparison of costs and activity between hospitals.

availability of quality data, which enables service planners and providers to achieve greater operational and financial efficiencies.

Appendix 1: Glossary of abbreviations

Term	Explanation
ABS	Australian Bureau of Statistics
ACCD	Australian Consortium for Classification Development
ACHI	Australian Classification of Health Interventions
ACS	Australia Coding Standards
ACSQHC	Australian Commission on Safety and Quality in Health Care
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
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
CCG	Clinical Commissioning Group
CCI	Canadian Classification of Health Interventions
CCO	Cancer Care Ontario
CCS	Clinical Classification Service
CHeReL	Centre for Health Record Linkage
CIHI	Canadian Institute for Health Information
CLI	Client Linkage Index
CMDB	Canadian MIS Database
COAG	Coalition of Australian Governments
CPDIOB	Cross Portfolio Data Integration Oversight Board
DAAG	Data Access Advisory Group
DARS	Data Access Request Service
DHB	District Health Board
eDSS	Electronic Data Submission Service
EHR	Electronic Health Record
EMR	Electronic Medical Record
ePRF	electronic Patient Report Form
GP	General Practitioner
HBL	Health Benefits Limited
HES	Hospital Episode Statistics
HIPC	Health Information Privacy Code
HISO	Health Information Standards Organisation
HL7	Health Level 7
HPI	Health Practitioner Index
HPI-I	Healthcare Provider Identifier-Individual
HPI-O	Healthcare Provider Identifier-Organisation
HQSC	Health Quality and Safety Commission
HSCIC	Health and Social Care Information Centre
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
ICD-10-CA	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Canada
ICD-O	International Classification of Diseases for Oncology
ICF	International Classification of Functioning, Disability and Health

ICT	Information and Communications Technology
IDI	Integrated Data Infrastructure
IeR	Integrated eReporting
IHPA	Independent Hospital Pricing Authority
IHI	Individual Healthcare Identifier
ISCEG	Information Standards and Collections (including Extractions) Group
ISO	International Organization for Standardization
IT	Information Technology
ITK	Interoperability Toolkit
METeOR	Metadata Online Registry
MIS	Management Information Systems
MoH	Ministry of Health
MoU	Memorandum of Understanding
NCAMP	National Collections Annual Maintenance Project
NCCH	National Centre for Classification in Health
NCS	National Collections Systems
NCTIS	National Clinical Terminology and Information Service
NDC	National Data Collection
NEHTA	National eHealth Transition Authority
NHA	National Healthcare Agreement
NHB	National Health Board
NHFB	National Health Funding Body
NHI	National Health Index
NHIA	National Health Information Agreement
NHIPPC	National Health Information and Performance Principal Committee
NHISSC	National Health Information Standards and Statistics Committee
NHITB	National Health Information Technology Board
NHPA	National Health Performance Authority
NHRA	National Health Reform Agreement
NHS	National Health Service
NIB	National Information Board
NMDS	National Minimum Dataset
NZ	New Zealand
NZC	New Zealand Conventions
ODS	Organisation Data Service
OPF	Operational Policy Framework
PCEHR	Personally Controlled Electronic Health Record
PHCPMS	Primary Health Care Practice Management Systems
PHRN	Population Health Research Network
SCCI	Standardisation Committee for Care Information
SCR	Summary Care Record
SMD	Secure Messaging Delivery
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms
SNOMED CT-AU	Systematized Nomenclature of Medicine Clinical Terms – Australian Release
SUS	Secondary Uses Service
UHI	Unique Health Identifier
UK	United Kingdom
UPI	Unique Physician Identifier
WAVE	Working to Add Value through E-Information (Report)

Appendix 2: Glossary of terms

Term	Description
Audit	The assessment of performance against any standards and criteria (clinical and non-clinical) in a health or social care service. ⁽¹⁰⁶⁾
Benchmarking	A continuous process of measuring and comparing care and services with similar service providers. ⁽¹⁰⁶⁾
Classification	A method of organising/grouping 'concepts' in a systematic way (e.g. into classes) within a particular domain for a specified purpose. They are arranged into categories according to common attributes, qualities or properties. ⁽¹⁰⁷⁾
Clinical coding	The translation of medical information relating to a patient's encounter with a health care provider into alphanumeric code(s). This process makes it possible to perform analysis on health care activity by grouping diagnoses and procedures together. ⁽¹⁰⁷⁾
Clinical terminologies	A structured collection of descriptive terms for use in clinical practice. ⁽¹⁰⁸⁾
Cost effectiveness	The point at which the minimum amount of input (such as finance, human resources) is used to achieve a defined health outcome. ⁽¹⁰⁶⁾
Data	Data are numbers, symbols, words, images, graphics that have yet to be organised or analysed. ⁽⁵³⁾
Database	A collection of data that is organised so that its contents can easily be accessed, managed, and updated. ⁽³⁾
Dataset	Is the data that is collected by the information collections. The data is usually presented in tabular form. ⁽¹⁰⁹⁾
Data catalogue	Can be defined as a comprehensive list of datasets outlined in a systematic fashion. Data catalogues and data inventories are important resources in informing and increasing awareness among stakeholders on the existence, purpose and access to currently available information sources. ⁽⁷⁾
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. ⁽³⁾
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.' ⁽¹¹⁰⁾
Data provider	Are those that are responsible for the data collection. ⁽¹⁰⁹⁾
Data quality	Data that are complete, valid, accurate, reliable, relevant, legible and available in a timely manner. ⁽¹¹¹⁾
eHealth	The combined use of electronic communication and information technology in the healthcare sector. ⁽⁷⁾
Evidence	Data and information used to make decisions. Evidence can be derived from research, experiential learning, indicator data and evaluations. ⁽⁵³⁾
General Practitioner (GP)	A doctor who has completed a recognised training programme in general practice and provides personal and continuing care to individuals and to families in the community. ⁽¹⁰⁶⁾
Governance	In healthcare, an integration of corporate and clinical governance; the systems, processes and behaviours by which services lead, direct and control their functions in order to achieve their objectives, including the quality and safety of services for service users.

Health information	Health information is defined as information, recorded in any form, which is created or communicated by an organisation or individual relating to the past, present or future, physical or mental health or social care of an individual or group of individuals (also referred to as a cohort). Health information also includes information relating to the management of the health and social care system. ⁽⁷⁾
Healthcare	Services received by individuals or communities to promote, maintain, monitor or restore health. ⁽⁵³⁾
Information	Information is data that have been processed or analysed to produce something useful. ⁽³⁾
Information and communication technology (ICT)	The tools and resources used to communicate, create, disseminate, store, and manage information electronically. ⁽³⁾
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. ⁽³⁾
Interoperability	'The ability of health information systems to work together within and across organisational boundaries in order to advance the effective delivery of healthcare for individuals and communities.' ⁽¹¹²⁾
Key Performance Indicator (KPI)	Specific and measurable elements of practice that can be used to assess quality and safety of care. ⁽¹⁰⁶⁾
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. ⁽¹⁰⁹⁾
Minimum dataset	A minimum dataset is the least agreed number of data elements collected for reporting purposes. ⁽³⁾
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. ⁽³⁾
Performance indicators	Specific and measurable elements of practice that are designed to assess key aspects of structures and processes and to assess outcomes. ⁽³⁾
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. ⁽¹¹³⁾
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. ⁽⁵³⁾
Regulation	A sustained and focused control exercised by a public agency over activities that are valued by a community. ⁽⁵³⁾
Risk	The likelihood of an adverse event or outcome. ⁽⁵³⁾
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. ⁽³⁾
Service Provider	Any person, organisation, or part of an organisation delivering health or social care services and contributing data to the national health or social

	care data collection, for example, a hospital, pharmacy, general practitioner, optician, screening services, residential care for older people, children's residential centres. ⁽³⁾
Standard	A statement which describes the high level outcome required to contribute to quality and safety. ⁽⁵³⁾
Statement of purpose	A document which details the aims and objectives of the national health or social care data collection. ⁽³⁾
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. ⁽¹⁰⁹⁾
Value for money	Assesses whether or not an organisation has obtained the maximum benefit from the goods and services it both acquires and provides, within the resources available to it. ⁽¹⁰⁸⁾
Workforce	The combination of staff directly employed by the national health or social care data collection, and those who work on its behalf in other organisations. ⁽³⁾

Appendix 3: International agencies contacted

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

Appendix 4: National data collections of the key organisations

Canada – National data collections within CIHI as of August 2014⁽¹⁸⁾
Hospital Care
<ul style="list-style-type: none"> ▪ Discharge Abstract Database (DAD) ▪ National Ambulatory Care Reporting System (NACRS) ▪ Hospital Morbidity Database (HMDB) ▪ National Rehabilitation Reporting System (NRS) ▪ Continuing Care Reporting System (Hospital) (CCRS)
Community Care
<ul style="list-style-type: none"> ▪ Continuing Care Reporting System (Residential) (CCRS) ▪ Home Care Reporting System (HCRS) ▪ Hospital Mental Health Database (MHMD) ▪ Canadian Organ Replacement Register (CORR) ▪ National Trauma Registry (NTR) ▪ Canadian Joint Replacement Registry (CJRR) ▪ Medical Imaging Technology Database (MITDB) ▪ Canadian Multiple Sclerosis Monitoring System (CMSMS)
Pharmaceuticals
<ul style="list-style-type: none"> ▪ National Prescription Drug Utilization Information System Database (NPDUIS)
Patient Safety
<ul style="list-style-type: none"> ▪ National System for Incident Reporting (NSIR)
Workforce
<ul style="list-style-type: none"> ▪ Health Personnel Database (HPDB) ▪ National Physician Database (NPDB) ▪ Scott’s Medical Database (SMDB) ▪ Nursing Database (NDB) ▪ Occupational Therapist Database (OTDB) ▪ Pharmacist Database (PDB) ▪ Physiotherapist Database (PTDB) ▪ Medical Radiation Technologist Database (MRTDB) ▪ Medical Laboratory Technologist Database (MLTDB)
Spending
<ul style="list-style-type: none"> ▪ National Health Expenditure Database (NHEX) ▪ Canadian MIS Database (CMDDB) ▪ Canadian Patient Cost Database (CPCD)
Access and Wait Times
<ul style="list-style-type: none"> ▪ Wait Times

New Zealand – National data collections within the Ministry of Health as of August 2014⁽⁴³⁾

- General Medical Subsidy Collection
- Laboratory Claims Collection
- Medical Warning System
- Mortality Collection
- National Booking Reporting System
- National Booking Reporting System Data Warehouse
- National Immunisation Register
- National Maternity Collection
- National Minimum Dataset
- National Non-Admitted Patient Collection
- New Zealand Cancer Registry (NZCR)
- Pharmaceutical Collection
- Primary Health Organisation Enrolment Collection
- PRIMHD – Programme for Integration of Mental Health Data
- National Patient Flow

Australia – National data collections within the AIHW as of 2013⁽⁶¹⁾	
Continuing and Specialised Care Group	Housing, Homelessness and Drug Group
<ul style="list-style-type: none"> ▪ Residential Aged Care ▪ Community Aged Care Packages ▪ Extended Aged Care at Home and Extended Aged Care at Home Dementia ▪ Transition Care ▪ National Respite for Carers ▪ Juvenile Justice National Minimum Data Set Collection ▪ National Prisoner Health Data Collection ▪ Adoptions Australia Data Collection ▪ Intensive Family Support Services (Child Protection) Data Collection ▪ Child Protection National Minimum Data Set Collection ▪ Disability Services National Minimum Data Set Collection ▪ Admitted Patient Mental Health Care National Minimum Data Set Collection ▪ Mental Health Establishments National Minimum Data Set Collection ▪ Community Mental Health Care National Minimum Data Set Collection ▪ Residential Mental Health Care National Minimum Data Set Collection ▪ Palliative Care Performance Indicators Data Collection 	<ul style="list-style-type: none"> ▪ Specialist Homelessness Establishment Database Administrative Data Collection ▪ Specialist Homelessness Services National Minimum Data Set Collection ▪ Supported Accommodation Assistance Program Administrative Collection (legacy collection) ▪ Supported Accommodation Assistance Program Client Collection (legacy collection) ▪ Supported Accommodation Assistance Program Demand for ▪ Accommodation Collection (legacy collection) ▪ Victorian Homelessness Data Collection (legacy collection) ▪ Public Rental Housing Data Collection ▪ State Owned and Managed Indigenous Housing Data Collection ▪ Community Housing Data Collection ▪ Indigenous Community Housing Data Collection ▪ Australian Government Housing Data Set ▪ Private Rent Assistance Data Collection ▪ Home Purchase Assistance Data Collection ▪ National Social Housing Survey Data Collection ▪ Alcohol and Other Drug Treatment Services National Minimum Data Set Data Collection ▪ National Opioid Pharmacotherapy Statistics Annual Data Collection ▪ National Drug Strategy Household Survey Data Collection
Health Group	Information and Statistics Group
<ul style="list-style-type: none"> ▪ Australian Cancer Database ▪ BreastScreen Australia Database ▪ National Cervical Cancer Screening Database ▪ National Bowel Cancer Screening Database ▪ National Diabetes Register ▪ AIHW National Mortality Database ▪ AIHW Population Database ▪ Adult Vaccination Surveys Data Collection (legacy data sets) ▪ Pandemic Vaccination Survey Data 	<ul style="list-style-type: none"> ▪ National Death Index ▪ Health Expenditure Database ▪ Government Health Expenditure National Minimum Data Set Collection ▪ Welfare Expenditure Database ▪ Indigenous Health Expenditure Database ▪ Disease Expenditure Database ▪ National Health Workforce Data Set Collections: <ul style="list-style-type: none"> - nurses and midwives - medical practitioners

Australia – National data collections within the AIHW as of 2013⁽⁶¹⁾

<ul style="list-style-type: none"> Collection (legacy data set) ▪ Selected veterans and defence health databases and nominal rolls ▪ Chronic Disease Indicators Database ▪ Database on sources of anthropometric, alcohol and tobacco data ▪ Bettering the Evaluation and Care of Health (BEACH) survey data (collections before 1 July 2011), as data custodian ▪ Australian Infant Feeding Survey ▪ Risk Factor Prevalence Surveys ▪ Active Australia Surveys 	<ul style="list-style-type: none"> - dental practitioners (dentists, dental hygienists, dental prosthetists and dental therapists) - pharmacists - physiotherapists - podiatrists - psychologists - optometrists - osteopaths - chiropractors - Aboriginal and Torres Strait Islander health practitioners - Chinese medicine practitioners - medical radiation practitioners - occupational therapists
<p>Collaborating Units</p> <ul style="list-style-type: none"> ▪ Child Dental Health Survey Data Collection ▪ National Dental Telephone Interview Survey Data Collection ▪ Adult Dental Programs Survey Data Collection ▪ Australian Spinal Cord Injury Register ▪ National Perinatal Data Collection ▪ Australian Congenital Anomalies Monitoring System Collection ▪ National Maternal Deaths Data Collection 	
<p>Hospitals and Performance Group</p> <ul style="list-style-type: none"> ▪ National Hospital Morbidity Database ▪ National Public Hospital Establishments Database ▪ National Elective Surgery Waiting Times Data Collections (Removals and Census) ▪ National Non-admitted Patient Emergency Department Care Database ▪ National Outpatient Care Database ▪ Medical Indemnity National Collection ▪ National Emergency Access Target Database ▪ National Elective Surgery Target Database ▪ Hand Hygiene Audit Data Collection ▪ Staphylococcus aureus Bacteraemia National Data Collection ▪ Hospitals Reporting Unit Cancer Treatment Services Data Collection ▪ Supplementary Private Hospitals Data Collection (for the MyHospitalswebsite) 	<p>Social and Indigenous Group</p> <ul style="list-style-type: none"> ▪ Northern Territory Emergency Response Child Health Check Initiative data sets: <ul style="list-style-type: none"> - Child Health Check - Chart Review - Dental - Audiology - ENT Consultation - ENT Surgery ▪ Stronger Futures in the NT Child Hearing Health Coordinator data set ▪ Healthy for Life Data Collection ▪ Online Services Report Data Collection ▪ National Indigenous Primary Health Care Key Performance Indicators collection ▪ Closing the Gap Clearinghouse Research and Evaluation Register ▪ Closing the Gap Clearinghouse database

England – National data collections within the HSCIC as of April 2014⁽⁸⁷⁾

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| <ul style="list-style-type: none"> ▪ Diagnostic Departments: Radiology, nuclear medicine and medical physics ▪ Hospital Episode Statistics ▪ National Cancer Waiting Times Monitoring Dataset ▪ National Joint Registry ▪ NHS Stop Smoking Services Quarterly Monitoring Return ▪ Surveillance of Healthcare Associated Infection ▪ Estates Return Information Collection (ERIC) ▪ General Medical Practitioners Annual Census Collection ▪ General Ophthalmic Services: Workforce Statistics for England and Wales – Annual Return of Practitioners and Premises ▪ NHS Pharmaceutical Services ▪ Adult Screening Programmes Cervical Screening ▪ Colposcopy clinics, referrals, treatments and outcomes ▪ General Ophthalmic Services – England – Sight Tests ▪ Pathology laboratories – cervical cytology and outcome of gynaecological referrals ▪ Genitourinary Medicine Clinic Activity Dataset ▪ General Practice (including dental) written complaints ▪ Hospital and Community Health Services Complaints ▪ Annual medical and dental workforce census ▪ Annual HCHS non-medical workforce census ▪ Attribution Data Set (ADS) ▪ Vaccination and immunisation data return collected through COVER ▪ Central Alerting System ▪ Seasonal Influenza Vaccine Uptake Survey ▪ Non-medical Device Defects and Failures Reporting System ▪ NHS Information Governance Assessment ▪ Annual Plan Review Financial Template ▪ Dental Commissioning ▪ Medical Revalidation Annual | <ul style="list-style-type: none"> ▪ FT Consolidated Accounts Process ▪ Quarterly Financial Template ▪ Exception reports ▪ NHS Pension Scheme Contributions ▪ Critical Care Minimum Dataset ▪ Neonatal Critical Care Minimum Dataset ▪ Financial Monitoring and Accounts ▪ Equity ownership of special purpose vehicles in PFI scheme ▪ National Direct Access Audiology PTL and WT – Waiting Times Dataset ▪ Quarterly Monitoring of Cancelled Operations ▪ Patient Reported Outcomes Measures ▪ Health of the Population Return ▪ Health Checks for People with Learning Disabilities ▪ NHS Continuing Healthcare and NHS Funded Nursing Care ▪ Mandatory Surveillance of Healthcare Associated Infection for Orthopaedic Surgical Site Infection ▪ Advisory Committee on Clinical Excellence Awards – Collection of non-ESR items ▪ Venous Thromboembolism Risk Assessment ▪ National Maternity Services Data Set ▪ Paediatric Critical Care Minimum Dataset ▪ NHS Staff Earnings Survey ▪ Patient Safety and Healthcare Incidents ▪ Mixed Sex Accommodation Monthly Return ▪ Mental Health Return on Early Intervention, Crisis Prevention and Care Programme Approach Activity ▪ Child and Adolescent Mental Health Services Dataset ▪ Community Information Dataset ▪ Ambulance Clinical Quality Indicators ▪ Health Protection Electronic Notifications ▪ NHS Planning Round 2012-13 ▪ Abortion Statistics ▪ Chlamydia Testing Activity Dataset ▪ National Drug Treatment Monitoring System ▪ Bed Availability and Occupancy ▪ Quarterly Activity Flow ▪ UK Severe Influenza Surveillance System ▪ Systemic Anti-Cancer Therapy Data Set ▪ Integrated Performance Measures Return |
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<p>Organisation Audit</p> <ul style="list-style-type: none"> ▪ Ambulance Services Quality of Service ▪ Diagnostic Imaging Dataset ▪ Reference Costs Collection ▪ NHS Workforce Paybill Forecasts ▪ Information Sharing between A&Es and CSPs to tackle violence (Coalition Commitment) ▪ NHS Dental Epidemiology Programme ▪ Cancer Patients' Experience Survey Sample Data ▪ Family and Friends Test ▪ Daily Situation Reports ▪ Monthly Situation Reports ▪ Inpatients Formally Detained in Hospitals Under the Mental Health Act 1983 and Patients Subject to Supervised Community Treatment – England ▪ National Confidential Inquiry into Suicide and Homicide by People with Mental Illness ▪ Maternal New-Born and Infant Clinical Outcome Review Programme ▪ Radiotherapy Dataset ▪ Sentinel Rotavirus Immunisation Coverage Survey ▪ Clinical Commissioning Group Planning 2013/14 ▪ Programme Budgeting ▪ Winterbourne View – transforming care ▪ National Children's and Young People's Health Services Dataset ▪ HPV Immunisation Programme – Vaccine Monitoring Minimum Dataset ▪ Female Genital Mutilation Return ▪ Security Incident Reporting System ▪ National Neonatal Dataset ▪ Number of Physical Assaults on NHS Staff ▪ Re-forecast Template ▪ Capital Expenditure Reforecase ▪ Monthly Financial Template ▪ Quality Dashboards – NHS England Specialised Servies 	<ul style="list-style-type: none"> ▪ Sexual and Reproductive Health Activity Dataset ▪ Monthly Activity Flow ▪ Cancer Outcomes and Services Dataset ▪ Diagnostic Waiting Times and Activity Data Collection ▪ Referral to Treatment Monthly Returns ▪ Dementia Risk Assessment ▪ Improving Access to Psychological Therapies Dataset ▪ Health Visitor Minimum Data Set ▪ NHS Health Check Data Set ▪ Surplus Land for Housing ▪ GP Practice Staff Census ▪ Annual Census of Non-Principal General Medical Practitioners ▪ HIV and AIDS Reporting System ▪ Temporary Prenatal Pertussis Immunisation Coverage ▪ Mental Health and Learning Disabilities Data Set ▪ Adult Screening Programme Breast Cancer ▪ Adult Screening Programme Breat Screening ▪ Seasonal Influenza Vaccine Uptake in Frontline Healthcare Workers 2013-14 ▪ Learning Disabilities Census ▪ Paediatric Outpatient Survey ▪ Weekly Situation Report ▪ General Practice Annual Electronic Declaration ▪ National Clinical Audit of Rheumatoid and Early Inflammatory Arthritis ▪ Occupational Health Monitoring Register of Blood Borne Virus Infected Health Care Workers ▪ Smoking Status at Time of Delivery Return ▪ Breastfeeding and 12 Week Maternal Assessment ▪ Workforce Minimum Dataset ▪ Sustainable Development Survey ▪ Health Visitor Services Delivery Metrics
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