Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

International Review of National Health Information Sources

August 2011

Safer Better Care

About the Health Information and Quality Authority

The Health Information and Quality Authority is the independent Authority established to drive continuous improvement in Ireland's health and social care services.

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

Setting Standards for Health and Social Services — Developing person-centred standards, based on evidence and best international practice, for health and social care services in Ireland (except mental health services)

Social Services Inspectorate — Registration and inspection of residential homes for children, older people and people with disabilities. Inspecting children detention schools and foster care services.

Monitoring Healthcare Quality — Monitoring standards of quality and safety in our health services and investigating as necessary serious concerns about the health and welfare of service users

Health Technology Assessment — Ensuring the best outcome for the service user by evaluating the clinical and economic effectiveness of drugs, equipment, diagnostic techniques and health promotion activities

Health Information — Advising on the collection and sharing of information across the services, evaluating information 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. It is estimated that up to 30% of the total health budget may be spent one way or another on handling information, collecting it, looking for it, 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 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) the Health Act, 2007 the Authority 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 prevents 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 well-being, yet it can be very difficult to find consistent, understandable 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. A robust health information environment will allow all stakeholders – the general public, patients and service users, health professionals and policy makers – to make choices or decisions based on the best available information. This is a fundamental requirement for a high reliability healthcare system.

The Authority is addressing these issues and working to ensure that high quality health and social care information is available to support the delivery, planning and monitoring of services. One of the areas currently being addressed through this work programme is the development of a set standards for national health information sources in Ireland. As part of this programme of work, the Authority has already published a national catalogue and a survey of national health information sources to identify themes for the development of standards. The purpose of this document is to examine how other countries have approached this with a view to identifying the best approach to the development and monitoring of national standards for health information sources in Ireland.

Acknowledgements

The Health Information and Quality Authority would like to sincerely thank the representatives of various international agencies who participated in conference calls to provide information and clarification.

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Executive Summary

Background

A considerable amount of national data is collected on a regular basis about health and social services. This data is used for many important purposes such as informed decision-making, monitoring of diseases, planning of services and policy making. All stakeholders (the general public, patients and service users, health professionals and policy makers) need access to complete, valid and up-to-date information in order to make choices and decisions. It is vital that there is confidence in all aspects of the quality of this information as safe healthcare depends on access to, and use of information that is accurate, relevant, valid, timely and complete.

National health information sources (HIS) are defined as national collections of routine, currently collected health and social care data (including administrative sources, censuses, routine national surveys and national patient registries) in the Republic of Ireland. An example of a national HIS is the Hospital In-Patient Enquiry System (HIPE) which collects information on discharges from acute hospitals nationally.

The Health Information and Qualty Authority (the Authority) has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies in health information as is outlined in the Health Act, 2007. This remit is being addressed by the Authority through the national HIS Project.

Project Outline

The aim of this project is to develop a set of standards for national HIS in Ireland. The project comprises two major phases. The first phase involved the compilation and publication of a catalogue of national health information sources in Ireland(1). The focus for the Authority in preparing this catalogue was also to provide for the first time a ‘one-stop shop’ of all national patient-level health and social care data sources and population health registries.

The second phase of the project commenced with a survey of a representative sample of national HIS in Ireland in order to extract themes to inform the development of a set of national standards(2). An international review of the approaches taken by other countries in relation to national HIS was then prepared, the results of which are presented here.

This international review will provide evidence on the practices and processes being followed internationally in the area of health information sources, to inform the Authority in relation to international best practice. A robust set of standards for national HIS will in the long term provide benefits to all stakeholders, especially healthcare professionals, organisations and service users.

Findings

The findings presented in this review have shown that all the countries examined recognise the vital importance of national health information sources to ultimately improve the quality of care patients receive. The evidence of this lies in the efforts being made to improve and develop national health information sources. All the countries reviewed have begun harmonising their national health information sources using a variety of roadmaps, strategies and legislative approaches to bring the diverse range of data collected together, where appropriate.

All the countries reviewed have experienced similar problems to Ireland in relation to their national health information sources, such as variances in data quality, fragmentation of information and duplication of effort. While the health systems in the countries reviewed vary considerably and many different approaches are being adopted, a common thread has been the recognition of the importance of improving the usability and usefulness of national data sources. The development of national standards or operating principles for such data sources has been accepted as an important first step towards improving the quality of data, which will ultimately drive quality and safety of care for all users of the health and social care service.

Next Steps

The next step for the Authority will involve establishing an advisory group comprised of key stakeholders. This group will work with the Authority following a standard development protocol and use the themes and best practice identified to inform the development of draft standards for national HIS. The draft standards will then be published for broader consultation. Subsequently the Authority will submit a final set of national standards for approval and adoption to the Minister for Health.

1. Introduction

1.1 Aims and objectives

The purpose of this document is to review international experience and best practice with regard to the development of national health information sources. An initial desktop review of health information sources identified six countries for further examination. These countries were chosen based on initiatives identified in the desktop review and the availability of relevant information. Information was compiled from national documentation from each country and from informal discussions with personnel in key institutes in each jurisdiction. The review examines the following countries: Australia, Canada, Denmark, England, New Zealand and the Netherlands in detail with a short summary also provided of Hong Kong, Singapore and Scotland.

1.2 Definition

National health information sources (HIS) are defined as national collections of routinely collected health and social care data (including administrative sources, censuses, routine national surveys, and patient registries) in a country. An example of an Irish national HI source is the Hospital In-Patient Enquiry System (HIPE) which collects information on discharges from acute hospitals nationally.

1.3 Project Background

Under the Health Act 2007(3), the Health Information and Quality Authority (the Authority) has a statutory remit to develop standards, evaluate information and make recommendations about deficiencies on health information, as follows:

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

This remit is being addressed by the Authority through the National HIS Project. The aim of this project is to develop a set of standards for national HIS in Ireland. The project comprises of two major phases. The first phase of this project involved the compilation and publication of a catalogue of national health information sources in Ireland(1). The focus for the Authority in preparing this catalogue was also to provide for the first time a 'one-stop shop' of all national patient-level health and social care data sources and population health registries.

The next phase of the project involved conducting a survey of a representative sample of national HIS in Ireland in order to extract themes to inform the development of a set of national standards. This survey was conducted during the summer of 2010 with ten national HIS in order to identify the main themes for the standards(2).

The Authority recognises that the implementation of the proposed standards will take time, possibly even years. However as new designated sources are developed to fill gaps e.g. in primary and community care, it is expected that they will be required to adhere to the standards from the outset. For existing national HIS, a gradual approach is envisaged with the opportunity being taken when major upgrades to the sources are being undertaken to bring them into conformance with the standards.

The aim of this international review is to present the practices and processes adopted in other countries to develop national health information sources. It builds on work already completed in the production of the *Catalogue of National Health Information Sources in Ireland*(1) and the *Identification of Themes for Standards for National Health Information Sources in Ireland*(2) report. It provides information on the development of national health sources in six countries which are at different stages in the development and harmonisation of their national HIS.

1.4 Health Information Sources

Healthcare is under increasing pressure to harness the benefits of the information age. Patients expect their health information to be recorded, processed and used appropriately for their benefit. Healthcare professionals require access to complete, valid and up-to-date health information in order to make informed choices and decisions, for example, deciding on a treatment or care programme. Those who fund health systems require detailed performance and service utilisation information. In order to meet these demands a number of countries and international organisations have focused on the development of national sources of health information.

In Ireland, as elsewhere, national health information sources have evolved over time in a largely uncoordinated fashion leading to significant variation in quality, fragmentation, duplication, access problems and potentially increased costs. In terms of completeness, there are a number of major deficiencies. For example, there is only very limited data available from the primary and community care sectors, from out-patients or from Emergency Departments.

The Expert Group on Resource Allocation and Financing in the Health Sector set up by the former Minister for Health and Children highlights Ireland's "weakly developed IT infrastructure in the healthcare sector"(4) as a major block to pursuing international best practice on integrated healthcare and measuring the effectiveness of interventions. The OECD(5) states that "Information is essential to achieve a high quality, value for money, healthcare system."

By looking at other jurisdictions the Authority can gain an understanding of how national HIS have evolved in other countries. The experiences and insights from other countries which are further along on the journey to harmonisation of national sources will be invaluable to the development of national standards in Ireland.

Based on international best practice, it is possible to identify four key principles relating to health information based on maximising health gain for the individual and the population, namely:

- Health information is used to deliver and monitor safe and high quality care for everyone.
- Health information should be of the highest quality and collected as close as possible to the point of care.
- Health information should normally be collected once and used many times.
- The model for data collection should be 'fit for purpose' and cost-effective.

1.5 International review

The countries that are reviewed in detail in this report are Australia, Canada, Denmark, England, New Zealand and the Netherlands. A short summary of the findings from Hong Kong, Singapore and Scotland is also provided.

The countries were chosen as a result of a desktop review that identified a range of initiatives across these countries that could potentially contribute to developing standards for national health information sources in Ireland. Additional factors contributing to the selection of these countries for this international review include the availability of information in the English language, access to personnel in each jurisdiction and geographic spread.

For the six countries examined in detail a number of factors are reviewed; namely the governance structure that is in place for their national health information sources, the approach each jurisdiction has taken towards harmonising their national health information sources, current developments and whether they have strategic or national plans in place for their health information workforce.

This report is not an in-depth evaluation of each country's health information sources but rather a review of the processes and practices used to develop national HIS. The following sections contain a brief introduction to each country's health system along with a description of the governance and harmonisation process undertaken in the development of national HIS.

2. Australia

2.1 Introduction

The commonwealth of Australia has a population of approximately 22.5 million. It is the sixth-largest country in the world, comprising of six states and ten territories(6), with the population concentrated along the eastern and south-eastern coasts. 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 and Ageing. The Department has responsibility for providing leadership in policy making, public health, research and national health information management(7).

The Australian health system is regarded as being world-class, in terms of both its effectiveness and efficiency(8). It is a complex system with many types of public and private service providers and a variety of funding and regulatory mechanisms. In keeping with other developed countries, Australia's healthcare system faces relentless growth in demand due to an ageing population, increase in consumer expectations, rising health technology costs and increasing rates of chronic disease. This demand has caused profound and sustained growth in health expenditure.

Since 1993, the collection of national health information in Australia has been governed under the National Health Information Agreement (NHIA), whose signatories are the Australian Government Department of Health and Ageing, state and territory health authorities, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare (AIHW), the Department of Veterans' Affairs and Medicare Australia. The 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(9).

There are many organisations, councils and groups that are intrinsically involved with the governance and harmonisation of national health information. Table 1 provides an overview of the main entities and their functions.

Table 1: Major entities responsible for national health information sources in Australia

Name	**Function**
Information Governance	
Department of Health and Ageing	The Department of Health and Ageing has a diverse set of responsibilities, but their vision statement outlines their common purpose: 'Better health and active ageing for all Australians'.
National Health Information Management Group (NHIMG)	Supervises the development of national statistical data standards in particular the creation of the national health data dictionary (NHDD).
National Health Information Management Advisory Council (NHIMAC)	Advises health ministers on options to promote a national uniform approach to more effective information management in the health sector.
National Health Information Group (NHIG) **Re-named** National Health Information Management Principal Committee (NHIMPC)	Advises Australian Health Ministers' Advisory Council (AHMAC) on planning and management requirements and to manage and allocate resources to national health information projects and working groups.
National E-Health and Information Principal Committee (NEHIPC)	Advises AHMAC on e-health and information strategies, and to facilitate collaboration between the Commonwealth, States and Territories to implement these strategies.
National Health Information Standards and Statistics Committee (NHISSC)	Takes care of functions relating to national data development, incl. negotiating and agreeing on health data standards.
Australian Health Information Council (AHIC)	Provide independent expert advice to AHMC, through AHMAC on long term directions and national strategic reform matters for Information Management and Information and Communications Technology in health.
Agencies responsible for data collection	
Department of Health and Ageing	The Department collects data from several sources on a daily basis.
Australian Institute for Health and Welfare (AIHW)	Provides reliable, regular and relevant information and statistics on Australia's health and welfare. AIHW have also produced a guide to data development.
Harmonisation of National Health Information sources	
National Health Information Agreement 1993 ***Revised*** National Health Information	This agreement was established to coordinate the development, collection and compilation of nationally relevant health information and the endorsement and maintenance of

Name	Function
Agreement 2004-10 (NHIA)	national standards.
Health*connect*	Investigate the concept of and develop plans for a national network of electronic health records.
National E-health Transition Authority (NEHTA)	NEHTA's strategic plan is to lead the advancement of e-health in Australia.
METeOR	Australia's repository for national metadata standards for the health, community services and housing assistance sectors. Also responsible for developing the National Health Data Dictionary (NHDD).
Australian Commission on Safety and Quality in Healthcare	Responsible for developing a national strategic framework and associated work program to guide the Australian, State and Territory Governments in improving safety and quality across the healthcare system in Australia.

2.2 Governance of National Health Information Sources

Overall coordination of the public healthcare delivery system is the responsibility of federal, state and territory health ministers. They are supported by the Australian Health Ministers' Advisory Council (AHMAC), a committee of the heads of the Australian Government, state and territory health authorities. AHMAC advises Australian health ministers on policy, resources and financial issues(9).

Health information is fundamental to developing evidence on which health policies and programmes are based. There has been significant progress in Australia since the National Health Information Agreement (NHIA) was introduced in 1993 to support the alignment of their national health information sources. This allows the Australian Government to:

- assess the level and distribution of the health of populations
- measure the level, distribution and influence of determinants
- monitor and appraise health interventions
- quantify the inputs to the health system
- generate knowledge through research and statistics
- evaluate the performance of the health system
- understand the interrelationships of all of the above(10).

Since the NHIA in 1993, Australia has worked towards bringing all forms of health information management within a single governance structure, facilitating greater consideration of the relationship between different users of health information and understanding of synergies and differences in privacy, security, finances and management requirements(11). However, as Table 1 suggests there are still several groups responsible for information governance and the AIHW is currently working towards further streamlining and making the remaining groups stronger and more robust(12).

The Australian Health Ministers Conference (AHMC) membership comprises of all Australian Government, State, Territory and New Zealand Ministers with direct responsibility for health matters. It provides a forum for the Australian Government, State, Territory Governments and the Government of New Zealand to discuss matters of mutual interest concerning health policy, health services and programmes. They promote a consistent and coordinated national approach to health policy development and implementation. The Australian Health Ministers Advisory Council (AHMAC) is responsible for providing advice on strategic issues relating to the coordination of health services across the nation and (as applicable) with New Zealand. It operates as a national forum for planning, information sharing and innovation(13).

Figure 1 provides an overview of the groups in Australia that are responsible for national health information governance. The groups comprise of the Australian Health Minister Advisory Council, Australian Health Information Council (AHIC), National Health Information Mangement Group (NHIMG), National e-Health Transition Authority (NEHTA), National Health Information Group (NHIG), National e-Health and Information Principal Committee (NEHIPC) and the National Health Information Standards and Statistics Committee (NHISSC). Each group has a different remit and reports to the AHMAC and ultimately the AHMC, the exception is AHIC, they report directly to AHMC. The signatories of the NHIA committed to co-operate through the Australian Health Ministers Advisory Council to agreed governance arrangements for information management.

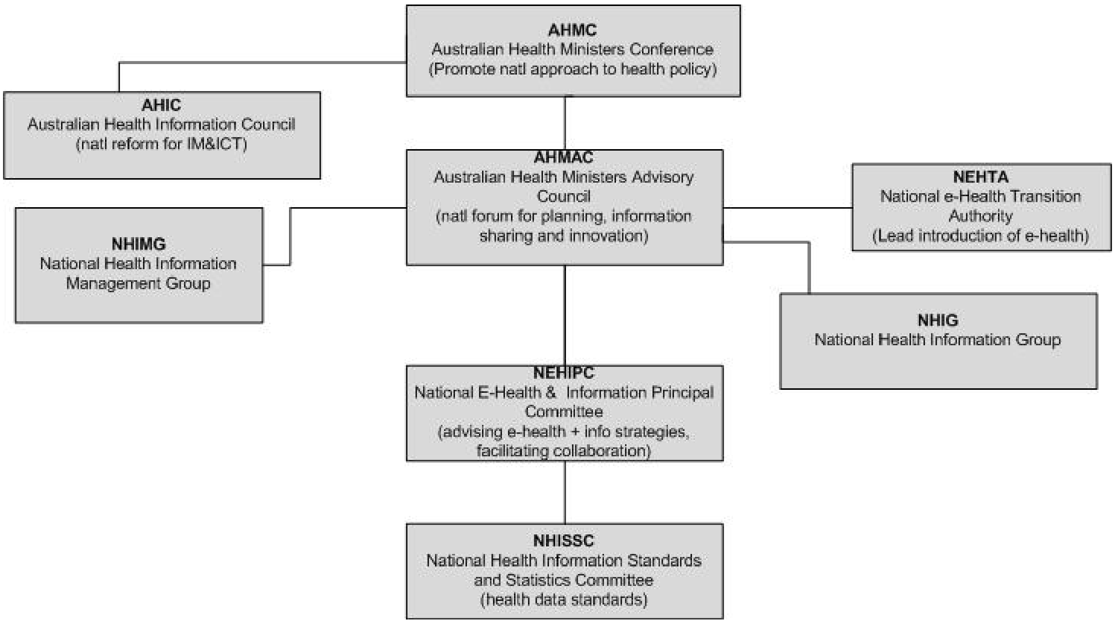

Figure 1: National Health Information Governance Structure in Australia

As can be seen from Figure 1, the AHMC has a number of entities with different functions, reporting into it. The National Health Information Management Group (NHIMG) was established in 1993 to supervise the development of national statistical data standards, and it was instrumental in the development of the National Health Data Dictionary (NHDD). The National Health Information Group (NHIG) was set up in 2003. It was renamed the National Health Information Management Principal Committee (NHIMPC) in 2006, with the remit to advise the AHMAC on planning and management requirements, and on how to manage and allocate resources to national health information projects and working groups.

The National E-Health and Information Principal Committee (NEHIPC) has overall responsibility for facilitating collaboration between the Commonwealth, States and Territories on e-health and information strategies(13). The National Health Information Standards and Statistics Committee (NHISSC) is responsible for providing strategic advice and endorsing health information standards. It also assesses the implications of implementing proposed national minimum data sets or making changes to existing national minimum data sets(14). The Australian Health Information Council (AHIC) provides advice to AHMC on long term directions and national strategic reform matters for Information Management and Information and Communications Technology in health from an end-user perspective. The National E-health Transition Authority is responsible for leading the advancement of e-health in Australia. Figure 1 presents a high level overview of the national health information governance structure.

2.3 Approach to harmonisation of Health Information Sources

In the federally-dispersed health system that exists in Australia, strong governance arrangements are needed to ensure that health information, collected under different health administrations, are consistent and therefore accurate and useful for policy, planning and programme management(15). For this reason, in 1993 the Australian Government developed the National Health Information Agreement which set about harmonising their national health information sources, and have made significant progress through developments such as the national health data dictionary (NHDD). The Department of Health and Ageing recently appointed a Chief Information and Knowledge Officer indicating their commitment to continue to address the challenges of streamlining and harmonising national health information sources.

In order to achieve harmonisation and potential interoperability, Australia has agreed to follow SNOMED-CT for clinical terms and the 10th international classification of diseases (ICD-10):

- SNOMED Clinical Terms (SNOMED-CT®) the internationally pre-eminent clinical terminology, has been identified as the preferred national terminology for Australia and has been endorsed by the Australian, State and Territory governments(16).

- Australia uses the 10th International Classification of Diseases. Australian National Centre for Classification in Health (NCCH) planned the transition, conducted code review and offered coder education.

2.3.1 National Health Information Agreement

In 1993 the National Health Information Agreement (NHIA) was developed to govern the collection of national health information in Australia. The signatories are the Australian Government, Department of Health and Ageing, state and territory authorities, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare (AIHW), The Department of Veterans' Affairs and Medicare Australia.

The 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(9).

The current National Health Information Agreement 2004-10 came into effect on 1 September 2004. It retains the main features and scope of the agreement developed in 1993(17) with updated provisions reflecting changes to national health information governance arrangement and other matters.

Specifically, the objectives of the National Health Information Agreement are to:

- ensure that the collection, compilation and interpretation of nationally relevant health information is appropriate and carried out efficiently
- provide a structure and consultative mechanism to ensure that health information and statistics available nationally are accurate, reliable and timely
- improve access to uniform health information by community groups, health and community services professionals, government and non-government organisations.

The objectives of the NHIA require the development of agreed definitions, standards and rules for collecting information and guidelines to coordinate access to, interpretation and publication of information. Australia do not have a central listing of data sources; they focus on the thematic areas, that is the national minimum data sets in health and data set specifications.

The National Health Data Dictionary (NHDD) is a major product of the NHIA. The dictionary contains meta-data standards for several health sectors including hospitals, drug and alcohol treatment, mental health and clinical data standards for diabetes and cardiovascular disease. It is the accepted authoritative source of national health information standards and classification systems. All definitions in the national data dictionaries are presented in a standard format based on ISO/IEC International Standard 11179-3 (18) (Information Technology-Metadata Registries-Part 3: Registry metamodel and basic attributes). The Health Data Standards Committee (HDSC) is responsible for maintaining the NHDD.

The HDSC is responsible for supporting the aims and objectives of the NHIA by co-ordinating the development and endorsement of national data standards used for administrative reporting and research in the health sector.

A national audit of health classifications was undertaken to identify the status of classification development and gaps in classifications. The scope of the audit includes all classifications, controlled vocabulary, nomenclature and thesauri used in health(19).

In 2001 the National Health Information Management Advisory Council (NHIMAC) outlined a national health information standards plan for Australia, known as the standards plan which formalises the importance of national standards and standards organisations in achieving an integrated approach to health information management. The scope of the standards plan includes both data and technical standards.

The standards plan sets out the processes and structures necessary to promote health information standards in Australia i.e. decision making, working and funding arrangements. It also identifies the policy themes driving national standards and establishes a responsive mechanism through which emerging standards are identified, prioritised and actioned(20).

2.4 Data Collection Organisations

2.4.1 Department of Health and Ageing

The Department of Health and Ageing is responsible for collecting data from a number of national health information sources which include:

- data from AIHW provides on public hospitals
- private hospitals directory provides private hospital data
- medicare benefits provides GP information
- pharmaceutical benefits provides data relating to the governments' subsidised pharmaceuticals
- other institutions provide information depending on requirements including research and survey purposes.

In many cases the information is collected at source, then translated to meet the minimum national data set requirements and only then transferred to the Department. This process is time-consuming, affecting the integrity, efficiency and timeliness of the data. For instance some information from hospitals can be twelve to fifteen months old and as a result of the delay receiving the minimum data sets it is difficult to go back and resolve any inaccuracies. It is the Department's intention to retrieve the information directly from source thereby eliminating the time lags and inaccuracies.

2.4.2 Australian Institute for Health and Welfare (AIHW)

The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent statutory authority established in 1987(14). AIHW is a central collection point for health data.

AIHW's website allows users to gain access to statistical data that can be used by Government departments, services providers, service users and the Community to guide decisions and policy making. The holdings include mortality data, administrative data and labour force statistics. Under the confidentiality provisions contained in the Australian Institute of Health and Welfare Act 1987, and also under the Privacy Act 1988, there are some data holdings that are not publicly available. Access to other data sets may be available subject to special approval, which in some cases must be given by the data providers themselves(14).

The national health information sources that the Australian Institute for Health and Welfare are responsible for include:

- National Cancer Statistics Clearing House - responsible for collating data from the eight state and territory cancer registers and report on Australias cancer levels and trends.
- National Hospital Data - reports on a range of data on hospitals, detailing the characteristics of public hospitals, non-admitted patient care, admitted patients and the care they receive in hospital, and elective surgery and emergency department waiting times.
- Chronic Diseases - focuses on 12 chronic diseases, the factors that they look at are complex causality, multiple risk factors, long latency periods, a prolonged course of illness and functional impairment or disability.
- Mental Health Data - contains detailed information from several mental-health related National Minimum Datasets.
- National Mortality Data - the mortality database consists of two data holdings, the mortality-underlying cause of death and the mortality-multiple causes of death.
- National Death Index - is a database developed and maintained by the Australian Institute of Health and Welfare, in Canberra. The database is a listing of all deaths that have occurred in Australia since 1980.

AIHW produce a wide range of publications on the health and social care sector based on its data holdings. The publications include statistical data, indicators and an overview of the state of health in Australia.

2.4.3 METeOR

METeOR is Australia's repository for national metadata standards for the health, community services and housing assistance sectors. The registry removes the necessity for duplication of effort as it provides users with a suite of features and tools for free to find, view and download over 2,600 data standards. This facility avoids wasting resources by creating similar standards and allows users to base their information systems on nationally endorsed standards and enables users to obtain data that is comparable across many different data collections. METeOR integrates and presents information about:

- the national health data dictionary
- the national community services data dictionary
- the national housing assistance data dictionary
- national minimum data sets
- data set specifications.

Metadata standards describe the expected meaning and acceptable representation of data for use within a defined context. The need for consistency of meaning is vital to facilitate information sharing both for primary and secondary use. Much of the work involved in establishing a data collection is in the development of metadata standards to ensure comparability and consistency of the data collected and produced from the collection(21).

2.4.4 The Centre for Health Record Linkages (CHeRel)

The Centre for Health Record Linkage (CheReL) was established in 2006 to create and maintain a record linkage system for health and human services in New South Wales (NSW) and Australians Capital Territory (ACT)(22). CHeReL creates and sustains a record linkage infrastructure for health-related data, and provides access to these resources to researchers, health planners and policy makers. The record linkage system has strict privacy-preserving protocols and provides a mechanism for health data to be used for projects that are for the benefit of the public(22).

2.4.5 Health*connect*

In 2001 Commonwealth, State and Territory Health Ministers initiated the Health*connect* project to investigate the concept of and to develop plans for a national network of electronic health records. Health*connect* implementations have leveraged existing eHealth projects and infrastructure, and progressed towards compliance with the National E-Health Transition Authority (NEHTA) and other nationally agreed standards to improve the availability of information in the health sector(23).

2.4.6 Data Development

The AIHW has published *A Guide to Data Development* which outlines sound data development practices that incorporate the necessary steps to produce high-quality data. The data development practices meet the needs of all users and attract the necessary level of agreement on content and authority behind the data specifications(24).

2.5 Current developments

The national health reform that is currently under discussion aims to deliver a nationally unified and locally controlled health system. It is intended that the agreement will bring about national health reform and will have the same signatories as the NHIA.

The Department of Health and Ageing in Australia is undertaking an organisation-wide focus on data performance and information to improve health outcomes and to support advances in the development of e-health. They are also developing and coordinating systemic approaches to harnessing information, knowledge, records management and intelligence. As part of this progression, a working group has been established to oversee the vision for a knowledge management strategy(12).

In November 2008, the Australian Commission on Safety Quality and Healthcare introduced Operating Principles and Technical Standards for Australian Clinical Quality Registers. An Australian Clinical Quality Registry is defined as a registry whose purpose is to improve the safety or quality of healthcare provided to patients. It was found that the Clinical Registers operate in a fragmented and inconsistent environment, the registry processes and technology were not uniform or standardised, creating significant inefficiencies and hampering interoperability with other information systems. As a result of these inefficiencies, guidelines were established for Clinical Registers to help patients and clinicians reach the best healthcare decisions. The operating principles suggest that the purpose of the Clinical Quality Register should be clearly determined. Data collection should be confined to items which are epidemiologically sound, i.e. simple, objective and reproducible. Data should be systematically collected with an identical approach used at each contributing institution. The Registries must consider the burden and cost of data collection together with the likelihood of loss to follow-up. Australian Clinical Quality Registries must ensure that complete registry data are collected from the eligible population. Protection of the Registries data must be ensured by using secure access controls, secure electronic transfer and electronic messaging systems(25).

2.6 Health Information workforce

The Australian Health Information Council (AHIC) identified the need to build the skills and knowledge of the Australian health workforce with regard to information technology and information management. The Health Information Workforce National Action Plan identified that the skills that need to be developed range from basic computer skills and information technology skills to specialist clinical information use, information management and health informatics expertise. In 2003 a health information workforce think-tank, conducted by the Department of Health and Ageing, identified the following priorities that are required to build the skillset of the Health Information workforce:

- leadership
- the business case
- planning
- support for research
- education
- development and retention of staff(26).

In 2009 the Health Informatics Society of Australia (HISA) undertook a review of the health informatics workforce in Australia. They found that there are too few health informaticians for the current workload and unless addressed, these workforce and skills shortages will be a major barrier to implementing the National E-Heath Strategy. The recommendation of HISA was to develop and implement Government policy in this area as a matter of national priority(27).

The National Health Information Management Principal Committee (NHIMPC) outlined in their strategic plan for 2007-08 to 2012-13 that they intend to develop an understanding of the evolving demand for informatics competencies and explore strategies for growing and developing the expert health informatics workforce, and the capacity of other professionals to undertake this work in the broader health system(11).

2.7 Summary

Australia set about harmonising its national health information sources in 1993 with the National Health Information Agreement. They have made significant strides toward achieving comparability and consistency of health information collected and produced.

- Australia have introduced a formalised process to govern and manage national health information sources, facilitating greater co-operation between states and territories. They intend to make their governance more robust and streamlined in the coming years.

- Significant advancements have been achieved establishing common definitions and understanding of meanings across all national health information sources. The national health data dictionary and minimum data sets have been developed enabling a standardised, national approach towards health information.

- There are several national initiatives that have achieved greater effectiveness and efficiency within the Australian health system, including the above mentioned national health data dictionary, a registry of metadata standards and more recently Australia introduced unique identifiers for individuals, health organisations and healthcare professionals.

- Australia recognises the importance of a skilled, well-educated workforce and intend to expand upon the capabilities of its health informatics workforce.

- A revision of the current National Health Information Agreement is underway building on the successes and achievements to date. This will further progress the cohesion of national health information sources in Australia.

3. Canada

3.1 Introduction

Canada is a parliamentary democracy and consists of a federation of ten provinces and three territories. It has a population of approximately 34 million people concentrated in the south of the country. Healthcare is publicly funded and predominantly free at the point of care through the national health insurance programme, often referred to as Medicare. Provincial and territorial governments are responsible for the funding, the administration and the provision of healthcare (including acute hospitals) and social services in their respective areas. Doctors are contracted largely on a ‘fee per service’ basis. The provincial and territorial governments also receive federal funding that is dependent on compliance with certain conditions laid out in the Canada Health Act (CHA)(28). The principles of the Canadian national health system are stated as: public administration of national health insurance plan, comprehensiveness, universality, accessibility and portability. Table 2 presents an overview of the main entities and their functions.

Table 2. Major entities responsible for national health information sources in Canada

Name	Function
Health Canada	The department of the federal government with ultimate responsibility for health information.
The Canadian Institute for Health Information (CIHI)	Collects data from the regions and provinces across a number of health areas for national analysis and reporting. CIHI develops a data dictionary for each data holding.
Statistics Canada	Has responsibility for conducting national health surveys, recording mortality and maintaining the national cancer registry.
Canada Health Infoway	Supports provinces and territories develop electronic health record (EHR) systems that comply with pan-Canadian functionality, privacy, security, interoperability and management standards.

3.2 Governance of Health Information Sources

Despite commonality among a number of the provinces, Canada does not have a national approach to the governance of health information sources. This is mainly due to the different legislative provisions across the territories and provinces and the evolution of various sources(29). However, efforts are being made to develop pan-Canadian mechanisms to support the governance of health information sources. This is evidenced in a White Paper developed by Canada Health Infoway in 2007 discussing the Information Governance of the Interoperable Electronic Health Record (EHR)(30).

While the provincial and territorial governments have most of the responsibility for delivering health and other social services, the federal government has ultimate responsibility for health information, as set out in the Canada Health Act. It has delegated this duty primarily to two independent, federally funded agencies, the Canadian Institute for Health Information (CIHI) and Canada Health Infoway. These agencies are respectively responsible for national data collections and for supporting the development of Electronic Health Records (EHR), in Canada. The national statistics agency, Statistics Canada, also has an important role to play in the provision of health information with responsibility for some national data sources such as the national cancer registry.

3.2.1 The Canadian Institute for Health Information

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organisation that provides data and analysis of the Canadian health system and the health of Canadians(31). CIHI's stated goal is to provide accurate, timely and comparable information and this is done through the publication of reports, compiled from information in national data holdings, on topics such as healthcare services, health spending, health human resources and population health. The institute's corporate strategy is summarised in the following six points:

- foster a data quality culture
- strengthen data quality infrastructure and capacity
- cultivate the data supply chain
- enhance external data quality collaboration
- promote communication and provide consultation
- initiate the fast-track priority projects fund.

CIHI is responsible for in excess of 27 national databases and registries that capture information about care provided across the three broad themes of clinical, human resources for health and finance. Data is supplied to CIHI by hospitals, regional health authorities, medical practitioners and territorial governments. The databases and registries held by CIHI include(31):

- Canadian Joint Replacement Registry (CJRR) – captures information on hip and knee joint replacements performed in Canada and follows joint replacement patients over time.
- Canadian Organ Replacement Register (CORR) – records information on the level of activity and outcomes of vital organ transplantation and renal dialysis activities in Canada.

- Continuing Care Reporting System (CCRS) - contains demographic, administrative and clinical data for residents in facility-based continuing care in Canada.
- Discharge Abstract Database (DAD) - contains demographic, administrative and clinical data for hospital discharges (inpatient acute, chronic, rehabilitation) and day surgeries in Canada.
- Home Care Reporting System (HCRS) - contains demographic, administrative and clinical data for clients receiving home care services in Canada.
- Hospital Mental Health Database (HMHDB) - contains demographic and medical diagnosis information for inpatient hospital stays for mental health disorders in Canada.
- National Ambulatory Care Reporting System (NACRS) - includes data for all hospital-based and community-based ambulatory care: day surgery, outpatient clinics and emergency departments. It currently contains Ontario emergency data only.
- National Rehabilitation Reporting System (NRS) - a national health information system for adult inpatient rehabilitation services.
- National System for Incident Reporting (NSIR) - a new reporting system to capture and share medication incident data from Canadian hospitals.

The Canadian Institute for Health Information also publishes information on health indicators, including measures such as life expectancy and expenditure, to monitor and compare performance. CIHI does not use legislation to enforce standards for data collections. Instead it engages in a programme of consultation, education and promotion. CIHI develops data holdings using stakeholder consensus and advisory groups to define what data variables to collect and which technical standards the variables should comply with. To ensure that measurements are comparable and that data collected is of good quality, CIHI has developed a data dictionary for each data holding which defines the minimum data set required. CIHI collates data from all the provinces to create the national data holdings. As well as analysing these data holdings on a national basis, it also provides provincial analysis to individual provinces on the core data and additional special interest data.

CIHI is directly involved in improving information systems and has a number of initiatives that aim to continuously improve data and information quality, including the Data Quality Framework. The Data Quality Framework(32) provides an objective approach to continuous quality improvement in the data sources for the national data collections. The framework provides an objective approach to applying consistent data-flow processes that focus on data quality priorities, assessing the data quality of a data holding and producing standard data-holding documentation with the ultimate goal of continuous improvement in data quality for CIHI’s data holdings.

CIHI routinely carries out a range of other data quality activities, including: providing education to data providers, providing and supporting coding standards for ICD-10-CA/CCI, publishing edit specifications for vendors’ abstracting software, participating in provincial/territorial data quality committees, providing annual reports on the status of data quality in each of the provinces/territories.

3.2.2 Canada Health Infoway

Canada Health Infoway (Infoway) is a not-for-profit organisation funded by the Canadian government that supports provinces and territories to develop electronic health record (EHR) systems that comply with pan-Canadian functionality, privacy, security, interoperability and management standards. Infoway coordinates the development of EHR systems through the provision of funding for projects that meet established criteria with the aim of having a pan-Canadian EHR. Infoway, together with its fourteen jurisdictional partners (provincial/territorial/federal health ministers), developed Vision 2015(33), an information and communications technology roadmap for healthcare in Canada.

Infoway has been implementing the EHR blueprint focusing on three areas, connecting, expanding and leverage with secondary data users. Infoway is responsible for implementing national technical standards for health information in Canada, including standards which are not directly related to EHRs. The Standards Collaborative is part of the Infoway organisation and is a collaboration between CIHI and Infoway to support and sustain health information standards nationally. The collaborative facilitates the timely, effective and secure exchange of health information between regions and healthcare organisations. To date a number of standards have been developed including Diagnostic Imaging Standards, Laboratory Standards, Public Health Surveillance Standards, Clinical Messaging Standards, and Privacy and Security Standards. The standards facilitate the communication of accurate health information and performance monitoring through the comparison of comparable data.

3.2.3 Statistics Canada

Statistics Canada 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 which it fulfils by reporting on secondary data and by conducting national health surveys, recording mortality and maintaining the national cancer registry. Statistics Canada works in close collaboration with CIHI on various initiatives.

3.3 Approach to Harmonisation of National Data Collections

A National Task Force on Health Information was set up in 1990 under the auspices of the National Health Council, the conference of Deputy Ministers of Health and the Chief Statistician of Canada. The purpose of the Task Force was to make strategic planning recommendations towards the development of effective health information systems for Canada. In the late 1990s a national consultation on health information was conducted with the key stakeholders by three organisations, The Advisory Council on Health Info-structure (part of Health Canada, the Canadian Ministry of Health), Statistics Canada and CIHI. This consultation process produced a common vision of a national health information system(34), which was the basis of a four-year national health information roadmap(35). The roadmap focused on providing answers to two basic questions: 'How healthy are Canadians?' and 'How healthy is Canada's healthcare system?' To answer these questions, the roadmap set out a national plan for improving existing national data sources and implementing new systems where gaps were identified. An annual and post evaluation of the roadmap implementation was undertaken to monitor progress, help ensure its success and reflect on its achievements.

The roadmaps were an important step towards harmonisation of national data holdings but they were not an immediate solution. An international review of national health information systems in 2001 highlighted that information systems in Canada were 'originally designed for purposes other than those for which they are now being used. The problem is in linking scattered databases, that were designed for different purposes. The use and interpretation of administrative data is a challenge.' (36)

In December 2002, the Federal/Provincial/Territorial Deputy Ministers of Health created the Advisory Committee on Information and Emerging Technologies (ACIET)(37). The Advisory Committee's mandate was to provide policy development and strategic advice on health information issues and on the effectiveness, appropriateness and utilization of emerging health products and technologies to the Conference of Federal, Provincial, and Territorial (F/P/T) Deputy Ministers of Health.(The committee was made dormant in 2005). The committee have developed a Pan-Canadian Health Information Privacy and Confidentiality Framework ("the ACIET Framework")(38). The ACIET Framework provides guidelines for common and consistent statutory provisions for the collection, use and disclosure of personal health information. The framework applies to both the public and private healthcare sectors and serves as a tool for regulators as they seek to develop consistent privacy requirements through the introduction or amendment of health privacy legislation. The ACIET Framework was finalised in January 2005 and endorsed by the Federal/Provincial/Territorial Conference of Deputy Ministers of Health, with the exception of Saskatchewan and Quebec.

A major step achieved thus far in the harmonisation of national datasets was the coding of all health information in national data holdings using the ICD-10-CA/CCI standard which is supported and promoted by CIHI. To ensure an objective and consistent approach to data quality improvement for the national health information sources CIHI also developed the Data Quality Framework(32) over the last decade. There is currently no national demographics dataset in use across Canada but geo-coding, based on the postal code system, is used for all addresses in national data holdings.

3.4 Current Developments

CIHI has been developing a number of initiatives to facilitate greater harmonisation of the national health information sources (including the Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS)). Despite the development of data dictionaries for each national holding there is no national data dictionary in place; this is an area on which work is currently being carried out. While individual health identifiers (IHI) are in use at provincial and territorial levels there are no national IHIs. Work is currently underway to introduce an individual identifier for healthcare providers(39).

3.5 Workforce

Most staff working in the area of health information in Canada have a formal qualification in health information ranging from a certificate to a PhD depending on their role. CHIMA (Canadian Health Information Management Association) represents more than 5,000 certified Health Information Management professionals who work in the area of clinical coding from across Canada and is the main organisation responsible for formal training. COACH is the Canadian Health Information Association and is a professional organisation for the promotion of health information across Canada.

Five key health information organisations in Canada (Canada Health Infoway, Canadian Health Information Management Association, COACH, Information and Communications Technology Council and the Information Technology Association of Canada) commissioned a report on the health informatics workforce in Canada to characterise job roles and activities, quantify the workforce, and anticipate future needs based on low, medium, and high growth scenarios(40). The study looked at seven categories of workers, assessing job roles and specific challenges for each between the public and the private sector. In aggregate, the authors estimated the 2009 Health Information Technology employment in Canada to be 32,450. Furthermore the study predicted that employment levels would grow to between 35,020 and 41,030 by 2014, depending on changes in capital and healthcare expenditure. The authors also noted that Canada, like most countries, will face a substantial training need for many current and future personnel. Not only does 27% of the current 2009 workforce require additional formal training and experience, but potentially up to 78% of the 2014 workforce will require additional training under the high growth scenarios. The key finding of the report on the Canadian health information workforce is that there is a serious risk to the implementation of EHR due to a shortage of staff and skills in health information(40).

3.6 Summary

In Canada, healthcare is publicly funded and predominantly free at the point of care through the national health insurance programme. The provincial and territorial governments have most of the responsibility for delivering health and other social services. The following are some of the initiatives Canada has taken to harmonise its national health information sources:

- Since 1990 Canada has been working on developing a national health information system infrastructure through a number of roadmap strategies. It began looking at the problem of linking national health information sources and improving sources for which the focus and use had evolved.

- Three independent, federally funded agencies, the Canadian Institute for Health Information (CIHI), Canada Health Infoway and Statistics Canada have responsibility for national health information sources.

- CIHI is responsible for over 27 national databases and registries that capture information about healthcare. Data is supplied to CIHI by hospitals, regional health authorities, medical practitioners and territorial/provincial governments.

- All national datasets are coded using the ICD-10-CA/CCI standard which is promoted by CIHI.

- A Data Quality Framework has also been developed by CIHI.

- Canada Health Infoway (Infoway) is a not-for-profit organisation funded by the Canadian government that supports provinces and territories develop electronic health record (EHR) systems.

- Canada does not have a national individual health identifier but health identifiers are in place at provincial and territorial levels. Data dictionaries have been developed for all the national data holdings but an overall national data dictionary is not yet in place.

4. Denmark

Denmark is a constitutional monarchy and a parliamentary democracy. It has a population of approximately 5.5 million people and is divided into five regions and 98 municipalities for administrative purposes. The Ministry of Interior and Health is in charge of the administrative functions in relation to the organisation and financing of the healthcare system, including psychiatry, healthcare insurance and pharmacies(41). Operational responsibility for healthcare is devolved to the five regions and operational responsibility for social care is devolved to the municipalities.

The regions own and run hospitals and finance general practitioners(GPs), specialist physiotherapists, dentists and medicines. There are a number of municipalities within each region and they are responsible for providing nursing homes, home nurses, health visitors and facilities for people with disabilities, services for those with drug and alcohol problems and school health services.

All Danish citizens receive a unique personal identification number at birth called a CPR number (*Danish*: det Centrale Personregister) which is required to access any government service including healthcare with the exception of emergency care. All residents of Denmark have free access to healthcare including GPs, ophthalmologists, dentists, ear nose and throat specialists and emergency wards(42). Access to specialist consultants and hospital care usually requires a letter from a GP with the exception of accidents and acute illness.

Denmark has received considerable attention for its early development of national registries, early adoption of information and communications technology and messaging between providers in healthcare, as well as the more recent introduction of shared services such as the National Patient Index, which is a patient care summary database, and the e-health portal (www.sundhed.dk)(43). Table 3 presents an overview of the main entities and their functions.

Table 3. Major entities responsible for national health information sources in Denmark.

Name	Function
The National Board of Health (Sundhedsstyrelsen) of Denmark	The Board sets national guidelines for the delivery of healthcare and is responsible for the national databases and registries that capture information about healthcare provided across all five regions of Denmark.
The National Board of Health (Sundhedsstyrelsen) of Denmark	The Board has direct responsibility for a number of national sources of health information and also collaborates with various agencies for data collection.
Digital Sundhed - Connected Digital Health in Denmark (SDSD)	Responsible for developing a national strategy to enable the digitalisation of the health information infrastructure(44).
MedCom	Promotes the use of ICT in healthcare and is also responsible for the Health Data Network (SDN), which is a secure network linking the entire healthcare sector.

4.1 Governance of Health Information Sources

4.1.1 Danish National Board of Health

The National Board of Health (Sundhedsstyrelsen) of Denmark is a state agency under the auspices of the Danish Ministry of Interior and Health. The Board has a number of roles to play in the healthcare sector. Of most interest to this review is its role in setting national guidelines for the delivery of healthcare and its responsibility for the national databases and registries that capture information about healthcare provided across all five regions of Denmark. The data is mainly compiled for administrative purposes and the information is used for many purposes including service planning and research. Data is supplied by hospitals, regional health authorities, medical practitioners and a number of healthcare related agencies. The National Board of Health has direct responsibility for the following registries and data sources:

- National Patient Register (Landspatientregisteret) – records all non-psychiatric hospital admissions, outpatient treatments and emergency room visits across all public and private hospitals.
- Medical Birth Register – records all births in Denmark.
- Malformation Register – is a national dataset of congenital anomalies used for surveillance and research.

- National Board of Health Register for Legal Abortions – records all hospital based abortions.
- In Vitro Fertilisation Register – information is recorded on all initiated in vitro fertilisation/intracytoplasmic sperm injection cycles since 1994.
- Health Reimbursement Register – records administrative information on services provided by GPs and other primary healthcare professionals. It does not hold any patient specific diagnoses or outcome data.
- Patient Safety database – records all adverse events that occur in a healthcare setting.

The National Board of Health also has responsibility for other registries which are compiled by external agencies on their behalf including:

- National Psychiatric Central Register – records all psychiatric admissions to public and private facilities. It is managed by the Centre for Psychiatric Research at Aarhus University.
- Cancer Register – records cancer incidence based on individual medical records of cancer patients. Data is collected and managed by the Danish Cancer Society(45).
- Causes of Death Register – records all deaths in Denmark. Data is managed by the Danish Institute for Clinical Epidemiology (DICE).

The Board grants permission to individual hospitals or heathcare organisations to develop specific patient registries. While these registries must adhere to broad guidelines on data security and management, there are no national standards or definitions for such registries. There are currently about 80 national clinical registries in Demark, most of which have developed independently to meet a specific need e.g. Danish Transfusion Registry collects information on all blood transfusion since 1997.

The Board has also developed the basic structure for health records (BEHR) which is a generic information model for clinical information systems detailing a national standard for EHR(46).

4.1.2 National Patient Index

The National Patient Index (NPI) is Denmark's approach to the formation of a patient summary. The NPI is a database which maintains a summary record of each episode of care a patient receives at any healthcare provider. Therefore it allows an overview of existing health information on a given patient from different and not necessarily otherwise integrated IT (source) systems. A fully integrated index will be in place by the end of 2013.

In Denmark, every resident is provided with a permanent and unique civil registration number (CPR) which comprises of 10 digits including age and gender. The CPR number is a unique identifier which enables individual-level linkage between different registries. Due to the sensitive nature of the data being linked, the Danish Data Protection Agency is responsible for ensuring strict data protection legislation and guidelines are followed. A vast volume of health-related studies are published on Denmark every year as a result of the availability of large quantities of rich health information.

4.1.3 Digital Sundhed – Connected Digital Health

The inter-departmental state organisation, Connected Digital Health in Denmark (SDSD) is responsible for developing a national strategy to enable the digitalisation of the health information infrastructure(44). To achieve this aim Digital Sundhed consults widely with healthcare providers in the regions and municipalities, as well as stakeholder organisations. To date, Digital Sundhed have developed four strategy documents the most recent of these covering 2008 to 2012(44). The strategy has three specific goals:

- digitalisation, as a tool for the employee to improve quality and productivity
- better service and inclusion of citizens and patients
- stronger cooperation to create digital connectivity.

The implementation of the strategy is described in a number of action plans. The strategy also highlights one of the key lessons Digital Sundhed have learnt in developing Eectronic Patient Record (EPRs) is the need to break large and ambitious goals into smaller incremental steps(44).

4.1.4 Danish National Health Data Network (MedCom)

MedCom was set up in 1994 to promote the use of ICT to address the high administration costs of the paper-based healthcare sector ICT. It is a collaboration between the Ministry of Interior and Health, the National Board of Health, Danish Regions, Local Government Denmark, the Ministry of the Interior and Social Affairs and the Danish Pharmaceutical Association. The purpose of the organisation is to ensure the appropriate development, testing and quality of electronic communications in healthcare. MedCom is also responsible for the Health Data Network (SDN), which is a secure network linking the entire healthcare sector. The SDN can be used, for example, to establish web service communication, consult external databases, exchange images and hold video conferences. The Health Data Network has worked on common data definitions and developed interoperability standards but it has not produced a national data dictionary or extensive common data sets. One contributor to this is the lack of a nationally agreed set of standards for clinical information.

4.1.5 Danish e-health portal

The Danish eHealth portal (www.sundhed.dk)(43) provides online services to the general public and healthcare professionals. Features for the general public include booking appointments, prescription renewal, access to performance reports, waiting list information and access to their personal electronic healthcare record (EHR). Features for healthcare professionals include access to a patient's appointment calendar, web access to laboratory results, access to a patient's prescriptions and EHR and secure e-mail service. The portal collates health information from a wide variety of national health information sources and uses the MedCom Health Data Network to access and exchange information.

All Danish citizens have access to their personal EHR which is hosted on a section of the eHealth portal called the eJournal. All hospitals upload their electronic patient records (EPRs) to the eHealth portal regularly so that up-to-date clinical information can be accessed by relevant healthcare personnel providing care to that patient at an approved healthcare provider site.

4.1.6 The Danish Institute for Quality and Accreditation (IKAS)

The Danish Institute for Quality and Accreditation (IKAS) manages the Healthcare Quality Programme (DDKM) which is a method of accreditation which develops standards for healthcare organisations relating to:

- general areas such as medication, patient involvement, resuscitation and inter-sector transfer
- organisational management, data safety and technology
- various specific disease areas such as gastric ulcers and diabetes.

4.1.7 Other agencies

There are a number of other important national sources of health information which are managed by external agencies. These include:

- The Danish Registry of Medicinal Products – a national prescription registry which records every prescription dispensed from pharmacies in Denmark; each drug is classified according to the International Anatomical Therapeutic Chemical (ATC) system. The data is collected and managed by the Danish Medicines Agency
- Sickness Benefit Register – collects data on recipients of social welfare sickness benefit payments and is collected from the regions by the Municipal Data Centre (KMD).

4.2 Approach to Harmonisation of National Data Collections

The 2002 national information technology strategy(46) states that shared information is the foundation for seamless care and patient involvement. Work towards harmonisation of national data collections in Denmark has been undertaken through a succession of National IT strategies with the ultimate goal of creating an integrated national health information system(46). One of the main drivers of these strategies has been the move towards the implementation of EHRs. The creation of the Health Data Network and the use of a unique identifier (CPR) have facilitated the secure exchange and sharing of information between national HI sources.

The recent translation of SNOMED-CT into Danish in particular has been an important development in the roll-out of this clinical terminology across national health information sources in Denmark.

Denmark currently has no national data dictionary but it does have common datasets within specific clinical areas. Data is currently collated by the health portal allowing patients and healthcare professionals to view data in one place from a wide variety of sources.

The National Health Board has recently set up a working group to reduce duplication of effort in the collection and storage of data across national registries and databases. The aim is to facilitate greater sharing of clinical information between registries, to collect data once and re-use many times.

4.3 Summary

In Denmark healthcare is publicly funded and free at the point of care to residents irrespective of income. The regional and municipalities have most of the responsibility for delivering health and other social services. Denmark has received global attention for their early development of patient registries, ICT and electronic messaging between healthcare providers. The following are some of the initiatives Denmark has taken to harmonise its national health information sources:

- The National Board of Health is responsible for setting national guidelines for the delivery of healthcare as well as the development of national patient registries and databases.
- The inter-departmental state organisation, Connected Digital Health in Denmark (Digital Sundhed), is responsible for developing a national strategy to enable the digitalisation of the health information infrastructure.
- MedCom is a government agency tasked with ensuring the appropriate development, testing and quality of electronic communications in healthcare. It is also responsible for the Health Data Network (SDN), which is a secure network linking the entire healthcare sector.
- Denmark is investing heavily in supporting the development of EHRs.
- A large part of SNOMED-CT has been translated into Danish.
- Denmark currently has no national data dictionary but it does have common minimum datasets developed within specific clinical areas.

5. England

5.1 Background

The National Health Service (NHS) in the United Kingdom (UK) was established in 1948 to provide healthcare to the population. The NHS provides free healthcare to all residents of the UK except for a small charge for prescriptions, dental and optical services. The NHS is financed by the taxpayer but is managed separately for England, Scotland, Wales and Northern Ireland. Strategic Health Authorities (SHA) in England have responsibility for 10 geographical areas. The NHS is further divided into Trusts, which have responsibility for providing care across different services in health such as acute hospital services and ambulance services.

Health information has received much attention in the last few decades in England and has been covered in a number of publications, one of which is *Information for Health An Information Strategy for the Modern NHS from 1998 – 2005 A national strategy for local implementation.* This strategy sets out 'a radical programme to provide NHS staff with the most modern tools to improve the treatment and care of patients and to be able to narrow inequalities in health by identifying individuals, groups and neighbourhoods whose healthcare needs particular attention'(47).

There was a change of government in 2010 which brought about even more emphasis on the importance of health information and its use in healthcare in particular for the patient and this is evidenced in a white paper entitled *Equity and Excellence: Liberating the NHS.* This states 'that nationally comparable information is published in a way that patients, their families and clinical teams can use'(48). It also outlines the vision and changes that will occur in the NHS that has at its core that 'patients will be at the heart of everything we do'(48). Table 4 presents an overview of the main entities and their functions.

Table 4 Major entities responsible for national health information sources in England

Name	Function
The Information Standards Board (ISB)	ISB is responsible for the approval of information standards for the NHS and adult social care in England.
National Information Governance Board for Health and Social Care (NIGB)	Promotes, improves and monitors information governance in England. Provides advice to the Secretary of State for Health, health and social care organisations, practitioners, researchers and service users.
NHS Information Centre (IC) for health and social care	Responsible for collecting, analysing and presenting national data and statistical

Name	Function
	information on health and social care.
Secondary Uses Service	Comprehensive source of data facilitating a broader use of health data such as performance monitoring, payments and research.
NHS Connecting For Health (CFH)	Main role is developing and maintaining the NHS national information technology infrastructure. CFH hosts a national data dictionary for England.

5.2 Governance of Health Information Sources

The following is a description of the organisations and sections of the NHS responsible for developing and implementing standards that apply to national health information sources in England.

5.2.1 The NHS Information Centre (IC) for health and social care

The IC is responsible for collecting, analysing and presenting national data on health and social care in England(49). This data is published on such areas as national returns, activity performance, lifestyle, workforce and estates data. The IC also drives the use of information to improve decision making and deliver better care to patients. The IC is a Special Health Authority but under the current reform plan for the NHS published in the white paper *Equity and excellence: Liberating the NHS* (48),it will be placed on a more secure statutory footing with powers over organisations in relation to data collection. It will become the central repository for health information collected and disseminated in England. The IC reports on over 120 different national and official statistics every year are available on their website(49).

An example of some of the national sources of health information in England are:

- Hospital Episodes Statistics (HES), a data warehouse containing details of all admissions to NHS hospitals in England
- The Health Survey for England (HSE), an annual survey of the state of Health and health related behaviours, first carried out in 1991(50)
- Primary Care Trust Prescribing Data
- The NHS Breast Screening Programme.

An Information Catalogue is also published by the IC which has an online searchable facility containing details relating to current, proposed and past national data collections in the health and social care area(51). For example details are available on:

- Accident & Emergency Clinical Quality Indicators
- Colposcopy clinics, referrals, treatments and outcomes
- Adult cardiac surgery dataset.

5.2.2 NHS Connecting for Health (CFH)

NHS CFH is concerned with developing and maintaining the information technology infrastructure in the NHS(52). It has developed an NHS Interoperability Toolkit which contains standards and frameworks for making IT systems interoperable(53). It also has a clinical division, which 'ensures that all national services and applications have the appropriate clinical input, are fit for purpose and deliver real benefits for both the NHS and patients'(54). Connecting for Health hosts an Information Governance Toolkit which allows all organisations in the NHS and any partners to assess themselves against the DH policies and standards with regard to information governance.

Within the NHS, there are a number of additional services which contribute to data quality standards and these are outlined below.

5.2.3 NHS Data Dictionary

This national data dictionary was developed and is maintained by CFH. This service is seen as a 'reference point for assured information standards to support healthcare activities within the NHS in England'(55). The use of a data dictionary allows for the standardisation on the data collected across the NHS in England and the ability to measure the quality and quantity of patient care provided across England. Some of the areas covered by the dictionary are maternity, cancer and accident and emergency data(55).

5.2.4 NHS Connecting for Health - UK Terminology Centre

This centre "provides support for SNOMED-CT, Read Codes and the Dictionary of Medicines and Devices"(56). SNOMED-CT has been adopted as the standard clinical terminology for the NHS in England. Read codes are widely used in primary care. The technology centre's website(56) hosts information on topics such as national standards and also maintains the NHS Dictionary of Medicine and Devices.

5.2.5 NHS Classifications Service

This service is responsible for the classification standards (ICD-10 and the Office of Population Censuses and Survey's Classification of Surgical

Operations and Procedure – 4th version), products and guidance. In essence, it sets out the standards for clinical coding in the NHS. ICD-10 is used in the NHS acute sector to code diagnosis and the reasons for a patients episode of care. Classification of Interventions and Procedures (OPCS-4) is maintained, supported and developed by the NHS Classification Service for use in the Admitted Patient Care Commissioning Data Sets (CDS). They also provide training and education for clinical coders(57).

5.2.6 Information Standards Board

The Information Standards Board (ISB) is tasked with independent approval, assurance and governance of information standards for the NHS and adult social care in England(58). The Board comprises all the national organisations involved in the health and social care area in England, including the NHS Information Centre, Nursing & Midwifery Council and Intellect. The ISB standards apply to anyone using the NHS infrastructure and systems which includes the Department of Health (DH). The Board works within the policy framework of the DH and the chairman is accountable to the DH Director General for Informatics(49). The ISB has a facility called the library section available on its website which includes information on all standards that are approved, work in progress or withdrawn standards(58).

5.2.7 Secondary Uses Service

A substantial amount of health and social care data is collected in the NHS. For an efficient and effective use of this data the NHS has established the Secondary Uses Service (SUS). This is a joint collaboration between the Information Centre and Connecting for Health. This service can be seen as ‘the single source of comprehensive data to enable a range of reporting and analysis’(59). The SUS allows data to be used for purposes other than care and treatment of patients i.e. performance monitoring, reconciliation and payments(59). To further enhance harmonisation the SUS has also developed a novel tool which allows the providers of data to assess the quality of their data submitted ‘this tool reports on the validity of key data items’(60).

5.2.8 National Information Governance Board for Health and Social Care (NIGB)

This is an independent statutory body which was set up to promote, improve and monitor information governance in England. The NIGB provides this advice to the Secretary of State for Health, but also advises health and social care organisations, practitioners, researchers and service users(61). NIGB aims to provide advice, guidance and support on how information is used in health and social care in England and has produced a number of publications in this area. These include guidance documents on the NHS Care Record Guarantee and Social Care Record Guarantee(61).

5.3 Harmonisation of data collection

There are a number of national organisations responsible for health information in England including the Department of Health (DH), Connecting For Health (CFH), Information Standards Board (ISB) and the Information Centre (IC). In particular the ISB has been the major driving force behind harmonising national standards for data sources in England. The DH has placed enormous emphasis on the importance of health information at a national level with particular reference to accountability(48).

Connecting for Health takes the lead in providing an IT infrastructure. The standards for IT ensure that all NHS infrastructure and any organisations using NHS infrastructure or systems conforms to standards developed by NHS CFH. When newly developed software is planned, a clause is placed into all contracts signed with commercial vendors. This clause places the onus on the vendor to incur the costs and make the necessary updates to the software as a result of newly developed standards and any revisions/ additions to the national data dictionary(62).

There are a number of national data sources that lie outside the remit of the IC, for example the Health Protection Agency and eight regional cancer registries. There are also nine regional public health observatories (PHO) which are funded by the Department of Health(63). These PHOs operate at regional level working in collaboration to provide and analyse population health information. Data is also collected by charities in England, an example being the National Renal Registry in which funding is received from the Department of Health. These charities currently publish their own data.

5.3.1 Legislative changes

There are many proposed changes in the new Health and Social Care Bill in the UK which will impact on national sources of health information(64). These changes will place the Information Centre on a statutory footing giving it additional legislative powers regarding data collection. The IC will become the central collector, repository of health information and disseminator of health, public health and social care data.

5.3.2 Data Linkage

The Information Centre is enabled to carry out data linkage under Section 251 of the NHS Act 2006 and approval has also been received from the National Information Governance Board (NIGB)(65). A number of data items are commonly used to create linkages including NHS number, name, address, location and postcode. Linkages are also routinely conducted between the Office of National Statistics (ONS) and the Hospital Episode Statistics (HES) in order to review mortality rates in hospitals and for mortality events that occur shortly after discharge from hospitals.

5.4 Workforce

Much emphasis has been placed on the importance of the health informatics workforce within the NHS and has resulted in both the NHS Chief Executive and the Department of Health Permanent Secretary commissioning a report entitled *Health Informatics Review* (66), in which it clearly outlines the framework for staff in the NHS and covers both the areas of information management and technology. This report defines the need to improve skills of existing staff from ward clerk, management to Board members through training. The NHS careers department has grouped the speciality of health informatics into the following categories; clinical informatics, information management, knowledge management and information and communication staff.

A programme was developed to advise on the level of professionalism in health informatics called UKChip. This programme operates a voluntary registration of persons who hold defined standards of competence and also agree to a common code of conduct(67). Currently there are three levels of registration for this council and the level of registration depends on the qualifications and level of experience of each individual. For clinical coders working in the NHS, a qualification has been developed called the National Clinical Coding Qualification(68). Other initiatives have been developed in the area of clinical coding also. These include accreditation for trainers, the use of a clinical coding manual, a clinical coding help desk and audit framework. In the area of data quality, best practice guidelines have also been published(69).

The importance of clinical involment in national sources of health information has been outlined in the recent discussion document entitled *Hospital Episode Statistics* (HES): Improving the quality and value of hospital data(70). It also has stated that that ‘there is a need to engage the frontline clinical staff in the data collection process in order to improve data quality’(70). This document outlines ‘the main reasons why clinicans would wish to use national sources of data’ for example assessment of workload and efficiency, clincial audit, quality assurance and patients safety(70). The importance of included data awareness in the training of medical students has also been identified in this document.

A new role established is that of the Chief Information Officer (CIO) for Health which sits in the Department of Health and had its first appointment in 2008. The CIO has a major part to play in the harmonisation of the national information systems from the perspective of an overall information strategy, information flows and to ensure there is no duplication across the service.

5.5 Summary

In England, healthcare is publicly funded and free at the point of care to residents irrespective of income. The NHS has overall responsibility for delivering health and other social services. The following are some of the initiatives England has taken to harmonise its national health information sources:

- The Information Standards Board (ISB) approves all information standards for the NHS.

- The Information Centre (IC) is a repository for information and data is used for secondary purposes, such as performance activity, lifestyle, workforce and estates data. An example of some of the major data holdings includes Hospital Episodes Statistics (HES) and the Health Survey for England (HSE).

- Legislative changes are currently proposed which will place the Information Centre on a statutory footing, centralise more of the data collections within the IC and improve efficiency of data collection.

- The Secondary Uses Service (SUS) is a data warehouse which has been established for the effective and efficient use of data within the NHS.

- The Information Centre has published an Information Catalogue, which contains details of current, proposed and past national data collections in health and social care area.

- A national data model and dictionary is provided for by Connecting for Health (CFH) and is implemented on an incremental basis. It covers areas such as maternity, cancer and accident and emergency data.

- Linkage of data by the IC is enabled under Section 251 of the NHS Act and approval is also received from the National Information Governance Board (NIGB).

- SNOMED-CT has been adopted as the standard Terminology for the NHS. Read codes are in use in the primary care sector. ICD 10 is in use in the acute sector. Classification of Interventions and Procedures (OPCS-4) is used in the Admitted Patient Care Commissioning Data Sets (CDS).

- Much emphasis has been placed on the workforce, skills and qualifications across all areas within health information, in particular the need for clinical involement in hospital sources of health information.

6. New Zealand

6.1 Introduction

New Zealand has a population of approximately four million people who predominantly reside in urban areas. The Ministry of Health (Ministry) has overall responsibility for health and disability and provides advice to the Minister of Health and, in turn, the government of New Zealand on policy issues. For administrative purposes, New Zealand is divided into 21 District Health Boards (DHBs) that either provide or fund health and disability services for the population in each of the DHBs(71). Primary healthcare, including GP services, are contracted by DHBs to primary healthcare organisations (PHOs) who either directly provide the services or indirectly through member providers.

Recent changes to the Ministry of Health structure include the creation of a National Health Board (NHB) to improve coordination between the 21 DHBs and supervise expenditure of public health funding. The new NHB, which is a ministerial committee working within the Ministry of Health, aims to consolidate national planning and funding of all IT, workforce planning and capital investment. Table 5 presents an overview of the main entities and their functions.

Table 5. Major entities responsible for national health information sources in New Zealand

Name	Function
National Health Board (NHB)	Centralised agency responsible for the collection and dissemination of all health information.
Health Information Standards Organisation (HISO) 2010	Supports and promotes the development, understanding and use of fit-for-purpose health information standards.
National Health IT Board (NHITB)	A subcommittee which provides strategic leadership and funding for information systems.

6.2 Governance of national health information sources in NZ

New Zealand has a centralised structure for its national repositories of health information with the National Health Board of the Ministry of Health being responsible for the collection and dissemination of all health-related information in the country.

6.2.1 National Health Board

The National Health Board(72) (NHB) of New Zealand is a Business Unit of the Ministry of Health. It was established in November 2009 to improve the quality, safety and sustainability of healthcare in New Zealand. The NHB is responsible for ensuring that the health and disability sector is capable of meeting the evolving needs of the sector predominantly through planning activities. The reporting structure between the National Health Board and the Minister of Health is outlined in Figure 2.

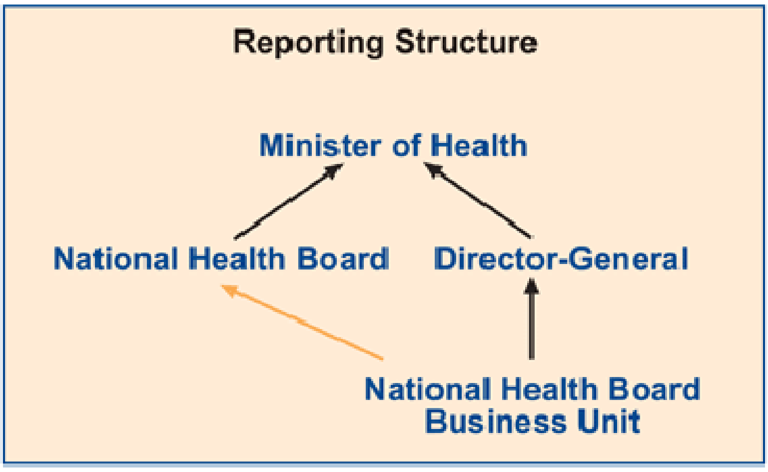

Figure 2. Reporting structure between the National Health Board and the Ministry of Health (New Zealand).

The Sector Services Division(73) of the National Health Board has operational responsibility for national collections of health and disability information in New Zealand. Examples of such national collections include:

- National Minimum Dataset (Hospital Events) (NMDS) - is a national collection of public and private hospital discharge information, including coded clinical data for inpatients and day patients.
- New Zealand Cancer Registry (NZCR) - a population-based register of all primary malignant tumours diagnosed in New Zealand, excluding squamous and basal cell skin cancers.
- National Immunisation Register (NIR) - contains all registered immunisation enrolments and events of children born since 2005 and all immunisation events from the 2005 Meningococcal B Immunisation Programme.
- National Health Index (NHI) - is a mechanism for uniquely identifying every healthcare user. It assigns each person a unique number (known as the NHI number). The NHI includes demographic information such as name, address (including domicile code), date of birth, sex and ethnicity.
- Pharmaceutical Collection (Pharms) - is a data warehouse that supports the management of pharmaceutical subsidies.
- National Non-admitted Patient Collection (NNPAC) - includes event-based data relating to medical and surgical outpatient events and emergency

department events. This includes information on the type of service provided and the health specialty involved.

- Health Practitioner Index (HPI) - uniquely identifies health practitioners, practitioner organisations (employers) and facilities (the physical address where the healthcare takes place) in three separate indexes.
- General Medical Subsidy collection (GMS) - contains data on the fee-for-service payments made to doctors for patient visits.
- Laboratory Claims Collection (Labs) - contains claim and payment information for community laboratory tests.
- Maternity and Newborn Information System (MNIS) - contains information relating to the maternity and newborn services that are provided up to nine months before and three months after a birth.
- Medical Warning System (MWS) - is an alert service linked to National Health Index numbers. It warns healthcare providers of known risk factors that could be important when making clinical decisions about patient care.
- Mental Health Information Collection (data warehouse) (MHDW) - is a high-level national database that allows the Ministry of Health to manipulate and report data to monitor the implementation of the national mental health strategy.
- Mortality Collection (MORT) - classifies the underlying cause of death for all deaths registered in New Zealand and all registered stillbirths (foetal deaths).
- National Booking Reporting System (NBRS) - contains information by health specialty and booking status on how many patients are waiting for elective surgery, and how long they have had to wait before receiving it.

The Ministry of Health and District Health Boards sign an Operational Policy Framework (OPF) each year which sets out the accountabilities of DHBs in relation to the provision of services and includes DHBs responsibilities in relation to national health information management and reporting requirements(74). The National Health Board receives data from the various DHBs that has been collected when service users interact with the healthcare system and then stores it in a number of national collections.

The Ministry of Health hosts a coding query service and maintains an online historical database of queries and associated responses. The Ministry also publishes a large number of technical documents to support DHBs and service providers return data in an agreed format. The technical documents include various data dictionaries by speciality, information on ICD-10-AM coding, information about diagnosis-related groupings, procedures for the collection of ethnicity data and specifications on file formats for returning data.

6.2.2 The National Health IT Board (NHITB)

In October 2009, the Health Information Strategy Advisory Committee (HISAC)(75) was replaced with the National Health Information Technology Board of New Zealand(76). As a subcommittee of the National Health Board, the IT Health Board provides strategic leadership on information systems across the health and disability sector. The NHITB also administers a primary healthcare IT grants fund and target particular areas to deliver key aspects of a national health IT plan. The NHITB is supported by a number of advisory groups including the Health Information Standards Organisation (HISO (2010)).

The links between the National Health IT board and the other sectors of the Ministry of Health are outlined in Figure 3.

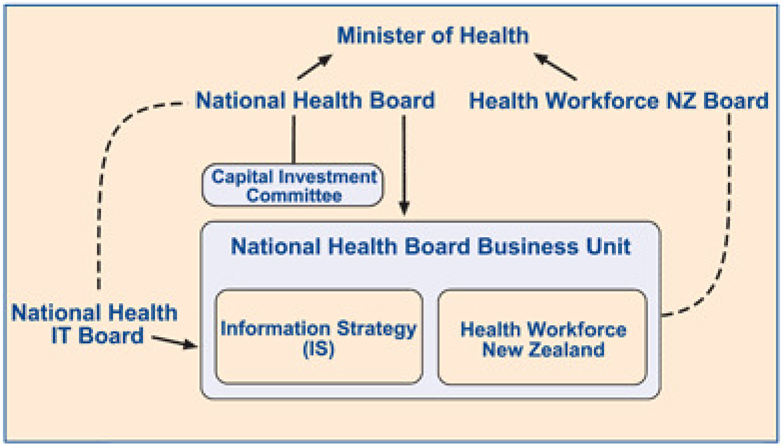

Figure 3. Relationship between National Health IT Board and the Ministry of Health (New Zealand).

6.2.3 Health Information Standards Organisation

HISO (2010)(77) is an advisory group that supports and promotes the development, understanding and use of fit-for-purpose health information standards to improve the New Zealand health system. Prior to 2003 Health Information standards were developed by Standards New Zealand, which was the main standards body in New Zealand. Following a review of information infrastructure the Health Information Standards Organisation (HISO) was created to lead the development and implementation of health information standards in New Zealand with the aim of improving health outcomes and safety through a coordinated and consistent approach. Subsequent restructuring recently resulted in a new standards advisory group with new reporting arrangements to be known as HISO (2010) to differentiate it from the previous organisation. HISO (2010) is an independent body, accountable to National Health IT Board of the National Health Board in relation to health information standards development in New Zealand. HISO (2010) are responsible for approving standards for use in the New Zealand health and social care system and also commission the development of standards based on identified priorities.

6.3 Approach to harmonisation of national data collections

6.3.1 Background

In 2001 the Ministry of Health in New Zealand published a plan for health information entitled the *WAVE* project(78) (Working to Add Value through E-information).

The main objective of the WAVE project was to produce an information and technology plan for the sector with the aim of improving health outcomes through the effective use of information, at the least cost. This was to be achieved through a review of the current management of health information and technology, investigation of how links between sector participants could be improved and how gaps in knowledge could be identified and remedied. Some of the key recommendations of the WAVE project outlined in terms of national data collections were as follows:

- improving the quality of existing data collections, especially the quality of ethnicity data
- filling the gaps in the existing collections
- creating new data collections where needed, starting with outpatients, emergency departments, and primary care consultations (for key disease states)
- on-going rolling review of all data sets every six months, to ensure continuous improvement
- data collections must be of a suitable standard and quality, and be accessible to District Health Boards (DHBs) and providers to obtain information to improve the quality of healthcare
- data collection should be more readily accessible for research purposes.

In 2005, the recommendations of the WAVE project were taken forward and a new *Health Information Strategy for New Zealand* (79) was developed led by the Health Information Strategy Steering Committee. The importance of a national view of national data collections was taken and an emphasis was placed on the gradual improvement of these sources over time to ensure they provide better value to the sector. The national collections in place in New Zealand at that time were assessed and a number of key issues were highlighted such as the lack of data from certain sectors and inconsistencies in coding of data by the national collections. A number of specific strategies were proposed to enhance decision-making within the sector. These included creation of new national collections, better data quality and compliance and appropriate coding.

A *Health Information Strategic Action Committee* (HISAC)(75;76) was established by the Minister of Health in August 2005 to provide governance and oversight of, and leadership for the implementation of the Health Information Strategy for New Zealand (HIS-NZ). This committee was given specific functions in terms of progressing work on the twelve action zones of

HIS-NZ. One of these specific action zones pertained to "access to national data collections and national health information systems".

It was stated that access issues existed because of the fact that national systems had developed over time largely independent of each other, without reference to a shared information strategy, policy or IT architecture.

The overall aims of this work were to:

- remove or at least significantly reduce barriers to accessing national systems so that access processes and technologies will function more consistently, predictably and reliably.
- ensure that the information accessed from national systems is more usable and useful, i.e. it is "fit for purpose".
- simplify accessing health information.
- reduce unnecessary duplication of systems, data and data entry effort.
- ensure that access to national systems is appropriately governed so that access is established and maintained effectively, efficiently and appropriately.
- provide more capability and flexibility to analyse information sourced from national systems.

A roadmap was developed focussing on the following key areas:

- governance
- data quality
- discovery
- interfaces
- tools
- access control.

A committee entitled the 'National Data Collections Sub-Committee' was also set up to specifically look at national sources of health information. The work of the committee involved the following tasks:

- Working with the Ministry of Health and other agencies to agree the purpose, use and establishment of National Collections.
- Working with the Ministry of Health to establish and implement standards, best practice guidelines, protocols and evaluation methodologies for National Collections both individually and collectively and to monitor their application.
- Working with the Ministry of Health to establish and implement standards for managing the application of the unique identifiers such as HPI and NHI and review the application of the standards.
- Establishing and monitoring accountability arrangements for National Collections.
- Reporting on the effectiveness of the stewardship and custodianship of National Collections in supporting the implementation of the HIS-NZ.

- Reviewing existing National Collections for alignment with HIS-NZ.
- Reviewing the alignment of any new National collections with the overall Strategy.
- Evaluating current data collections against the criteria for a National Collection.
- Specifying data standards for future National Collections including business rules, definitions, quality, and access.
- Monitoring collection of data and compliance with good practice guidelines and standards for National Collections.
- Identifying and addressing cross National Collection issues.
- Promoting and advocating for the effective implementation of National Collections.

6.3.2 Current developments

In October 2009, the Health Information Strategy Advisory Committee (HISAC) was replaced with the National Health Information Technology Board of New Zealand(76). A National Health IT plan(80) was launched by this Board in September 2010. Components of this plan include:

1. Development of an information model (national data collections are a component of this).
2. Development of eight work streams, of which population health is one. National collections fall under this. There are plans in place to standardise national collections according to agreed data standards determined by HISO. It is also hoped to commence combining some of the national collections and regional data repositories in order to create new opportunities for research.
3. In terms of national collections, plans are in place to improve data collected by measuring outcomes, recording the use of procedures and medications and recording mortality and cancer incidence.

A catalogue of the national health information collections was published by the New Zealand Ministry of Health(81) entitled '*Guide to the National Health Information Collections*'.

Currently there is no national health data dictionary in place but the National Health IT Board has recently obtained a licence to link in with METeOR in Australia (part of the Australian Institute of Health and Welfare) to adapt their national data dictionary for use in New Zealand (See section 2.4.3). The result of this will be that New Zealand will be able to maintain a national health data dictionary with minimal resource requirements(82).

Many advances have been made in the roll-out of the clinical terminology SNOMED-CT across the health sector in New Zealand. All national data repositories are due to begin using this terminology in the near future(82).

6.4 Health Information Workforce

Health Informatics New Zealand (HINZ)(83) was established in 2000. It is the primary professional organisation for those working, studying and interested in health informatics in New Zealand. HINZ supports its members by providing access to up-to-date information on national and international developments in health informatics, facilitating networking, and supporting the development of the health informatics workforce in New Zealand. In the Strategic Plan 2007-2010 published by HINZ, 'the lack of a trained health informatics workforce is apparent and a constraint on developments' was highlighted. This is a priority area for HINZ.

One of the key factors in the success of the new National Health IT Plan in New Zealand was identified as working with the health sector to develop the skills and understanding required to deliver the changes enabled by information solutions. The Health IT Board recognises that the skill sets required for successful implementation of information solutions are scarce and require many years of experience to develop properly. The Board has stated that it will work with Health Workforce New Zealand to:

- Facilitate improved understanding of the importance of information solutions by health sector leaders in supporting the delivery of care, the measurement of outcomes, quality improvement and research.

- Develop the leadership role of clinicians in ensuring that effective and sustainable solutions are designed and implemented as part of the quality improvement cycle.

- Encourage the development of health IT professionals who naturally partner with clinicians, manage change effectively and create solutions that are effective, fit for purpose and intuitive to use.

- Build information management skills into training programmes.

The Board has also stated that it will work with the universities to encourage the education of health and IT professionals in health informatics, and to incorporate applied research into their methodology and approach.

6.5 Summary

The New Zealand health system is publicly funded and free at the point of care to residents irrespective of income. The District Health Boards (DHBs) have most of the responsibility for delivering health and other social services. The following are some of the iniatives New Zealand has taken to harmonise its national health information sources:

- New Zealand has a centralised structure for its national repositories of health information with the National Health Board of the Ministry of Health being responsible for the collection and dissemination of all health-related information in the country.

- A National Health Identifier (NHI) has been in place in New Zealand since 1993 and a Health Practioner Index (HPI) is also in place.

- A number of roadmaps and strategies have been published with a strategic focus on national data collections the most recent being the National Health IT plan.

- Plans are currently in place for New Zealand to link in with METeOR in Australia for development of a national data dictionary.

- Advances are being made in the roll-out of the clinical terminology SNOMED-CT across the health sector in New Zealand.

- The importance of a skilled workforce has been recognised by the Health IT Board in New Zealand.

7. The Netherlands

7.1 Introduction

The population of the Netherlands is approximately 16.5million; it is one of the most densely populated countries in the world with the majority of its populace residing in urban areas. The Netherlands is divided into 12 provinces and 646 municipalities. The decentralised governing bodies have a significant portion of the responsibility for running the healthcare services.

In 2006, a major reform of the Dutch healthcare system came into effect, for many reasons, including the need to curb increasing healthcare expenditures. At the core of this new system is the Health Insurance Act (*Zorgverzekeringswet,* Zvw). The key characteristics of the health insurance reform introduced by the Health Insurance Act (Zvw) are that health insurers offer the basic health insurance package to citizens, the citizens, in turn, are obliged to take out health insurance. Insurers are obliged to accept all citizens and may not differentiate premiums based on the health risks of the insured. Health insurers can compete on premium level, the quality of their services and the quality of purchased care. Health insurers may offer a maximum discount of 10% on the nominal premium for collective contracts.
These contracts can be offered by a health insurer to a group of people (for example employees of a company, members of an association or a patient group). An essential characteristic of the new Health Insurance Act (Zvw) is that it is operated under private law. The relationship between insured persons and health insurer is private and can be renewed or ended once a year. Ending the contract cannot be done by the insurer, only by the insured person. The single exception to this rule is a situation in which the insured does not meet his or her legal obligations. Lastly, those on lower incomes are compensated for an excessive premium burden through the Health Care Allowance Act (Wzt)(84).

More than 90% of the population purchases supplementary health insurance coverage as well, such as for dental care, glasses, and physiotherapy. Low-income citizens can qualify for a Healthcare Allowance towards the cost of their premiums(85). There is a very strong primary care service provided by trained family physicians, district nurses, home care givers, midwives, physiotherapists, social workers, dentists and pharmacists. Each patient should be on a family physicians patient list and must be referred to specialist physicians by the family physician. Each individual within the Netherlands is identified with a unique citizen service number (burgerservicenummer/ BSN). The UZI-Register is responsible for providing unique identification to healthcare providers. Health insurers are identified with the unique Health Insurer identification (UZOVI).

There are several parties involved in health information and quality standards, depending on the area of healthcare or the type of information. Table 6 provides an overview of a number of theses organisations and their functions.

Table 6. Health Information Sources in the Netherlands

Name	**Function**
The Ministry of Health Welfare and Sport	The Ministry of Health Welfare and Sports' remit is to define policies that aim to ensure the well-being of the population in the Netherlands and aim to help the populace to lead healthy lives(84).
National ICT Institute for Health Care (NICITZ)	NICITZ provides insight into the Elektronisch Patienten Dossier EPD (EHR) and IT agendas for the coming years, including priorities and milestones.
Netherlands Institute for Health Services Research (NIVEL)	NIVEL is an independent research centre for primary care and general practice for the Dutch government and all other healthcare professionals.
National Institute for Public Health and the environment (RIVM)	The role of the RIVM in health and disease covers research and advice on new infectious diseases, protection against infectious diseases through vaccination and risks due to poisonous substances and exposure to radiation. RIVM also examines the most common causes of death in the Netherlands.
KiesBeter.nl	National health, healthcare and social care portal.
Dutch Hospital Data Foundation (DHD)	DHD is responsible for the collection of data in Dutch hospitals at the national level.
Integrated Cancer Centre for the Netherlands (INKL)	There are eight comprehensive cancer centres (CCCs) that collect data on a regional basis, they have been merged into one (INKL) as of January 1, 2011. This registry contains data on nearly all new cancer cases in the Netherlands.
Dutch Healthcare Authority	The Dutch Healthcare Authority (NZa) is the supervisory body for all the healthcare markets in the Netherlands. The NZa supervises both healthcare providers and insurers.
Netherlands Information Network in General Practice (NIN GP)	The aim of NIN GP is to collect representative data on primary care delivered by GPs on a national scale.
National Medical Registration (NMR)	The National Medical Registration (LMR) is managed by a private commercial company Prismant, and was set up for research and policy purposes. It provides aggregate data on hospital admissions. Almost all hospitals deliver data to the system.

7.1.1 Governance of National Health Information Sources

There are several parties involved in the governance of national health information in the Netherlands. They include the Ministry of Health Welfare and Sport, the National ICT Institute for Health Care (NICITZ) and the National Institute for Public Health and the Environment (RIVM).

7.1.2 The Ministry of Health Welfare and Sport

The Ministry of Health and Welfare and Sport's remit is to define policies that aim to ensure the well-being of the population in the Netherlands and aim to help the populace to lead healthy lives(84). The government is responsible for the accessibility and quality of the healthcare.

7.1.3 National ICT Institute for Health Care (NICITZ)

NICITZ was established in 2002, as an independent and neutral organisation. It is the national coordination point and knowledge centre for IT and innovation in the healthcare sector. In conjunction with the Dutch government it is trying to develop a nationwide system for secure and reliable electronic exchange of medical data(86). In consultation with and at the request of the healthcare sector, NICTIZ is continuously developing and refining national standards for electronic communications in healthcare. Furthermore, NICITZ supports the sector in developing functional IT solutions that can be used nationwide, and contributes to policy making on IT issues as they relate to healthcare on a national and international level. NICITZ uses international standards as much as possible like International Organization for Standarization(ISO), Health Level Seven International (HL7) and the European Committee for Standardization (CEN); for example, HL7v3 has been chosen for communication between healthcare providers.

7.1.4 National Institute for Public Health and the Environment (RIVM)

The National Institute for Public Health and the Environment (RIVM) is a recognised leading centre of expertise in the fields of health, nutrition and environmental protection. RIVM is developed and co-ordinated the National Public Health Compass, which is the gateway to information about health and disease, risk factors, care and prevention in the Netherlands. Nationwide experts, research-institutes and universities have been involved to contribute to the National Public Health Compass in their field of expertise. The Ministry of Health (VWS) has commissioned the Compass.

7.2 Approach to harmonisation of Health Information Sources

There is no over-arching legislation or standards that govern or guide national health information sources, but each national health information source may

be under legal obligation to produce and publish certain data; for example, the number of vaccinations administered in a particular time period.
The information produced by each national health information source is adequately robust and fulfills their purpose, as a result currently there is no drive in the Netherlands to harmonise the national health information sources.

The Netherlands uses the Clinical Terminology architecture called SNOMED-CT and the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) is used in the Netherlands to promote harmonisation and comparability.

7.2.1 National Data Collections

There are several national health information sources in the Netherlands that are responsible for collecting, distributing and analysing national health information. The Ministry of Health, Welfare and Sport keeps an online account of all medical information and registration systems in the Netherlands. The website http://www.zorggegevens.nl provides detailed information on all of the health information registers, databases, collectors of data, users of data and availability of the collected data (in Dutch only).

7.2.2 Netherlands Institute for Health Services Research (NIVEL)

NIVEL is the national institute for health services research in the Netherlands. It is an independent organisation with a dual mission: scientific and societal. NIVEL's core business is health services research. Health services research is the multidisciplinary field of scientific investigation that examines how social factors, financing systems, organisational structures and processes, health technologies, and personal behaviours affect access to healthcare, the quality and costs of healthcare, and ultimately our health and well-being. NIVEL is responsible for a number of national databases and information systems which allows it to produce international comparative studies regarding healthcare systems, evaluate the efficacy of innovation in healthcare, policy measures and health law, identify the effectiveness of policy measures and predict the need and demand for healthcare.

7.2.3 Dutch Hospital Data Foundation (DHD)

The Dutch Hospital Data Foundation (DHD) was founded in early 2008 by the industry organisations NVZ Dutch Hospitals Association and the University Medical Centers of the Netherlands (NFU) in order to direct the collection of data in Dutch hospitals at the national level. DHD have developed the 'National Hospital Care Basic Registration (LBZ) programme to create a one-entry registration and supply of hospital data to the DHD for a number of national purposes. The single registration and delivery should reduce the administrative burden for hospitals. DHD also has the task of promoting the provision of high-quality information on hospital care. As part of this task, DHD is charged with making available the data in the national hospital databanks. Interested parties can request information in accordance with the data request protocol(87).

7.2.4 Netherlands Information Network on General Practice (LINH)

A large percentage of General Practitioners in the Netherlands use an electronic medical record system. Data from these records are extracted and used to monitor GP care in the Netherlands. LINH collects data from a representative network of about 180 GPs located throughout the Netherlands and as a result LINH holds longitudinal data on morbidity, prescriptions and referrals. The supports health services research and quality of care research, to inform health policy and for epidemiological purposes(84).

7.2.5 National Medical Registration (LMR)

Aggregate data on hospital admissions is collected in LMR. Almost all hospitals deliver data to the system. The database contains data on admission, diagnosis, treatment and discharge, as well as characteristics of the patient and the hospital. The LMR provides data to Statistics Netherlands (CBS) and provides input for research(84).

7.2.6 Netherlands Cancer Care Registry

Netherlands Cancer Care Registry was established in 1989 and provides incidence data on a national level. Eight comprehensive cancer centres (CCCs) collect data on new cancer patients such as tumour type, incidence date and stage. On 1 January, 2011 the CCCs merged into one, which is now called the 'Integrated Cancer Centre for the Netherlands' (INKL).

7.2.7 Population Register (Bevolkingsregister)

Mortality data is collected in the population register. In the case of death, a death certificate (doodsoorzaakverklaring) produced by a physician or pathologist must be included in the population register. Dutch mortality statistics are produced by Statistics Netherlands (CBS).

7.2.8 Dutch Pharmacovigilance Centre (LAREB)

Adverse drug reactions (ADR) reported by physicians, pharmacists and patients are collected by LAREB. It registers approximately 4500 reports per year which must be annonymised to ensure the privacy of reporters and patients. The legal basis for this database is the Medicines Act (Geneesmiddelenwet). The aim of this data is to prevent harm from pharmaceuticals by tracing side-effects that were previously unknown.

7.2.9 Statistics Netherlands

Statistics Netherlands is responsible for collecting and processing data in order to publish statistics to be used in practice, by policymakers and for scientific research. In addition to its responsibility for (official) national statistics, Statistics Netherlands also has the task of producing European (community) statistics(88). Statistics Netherlands gather their information from a wide variety of national information sources and government institutions are legally obliged to share their information with them. Statistics Netherlands can link national health information sources, municipal registers and other relevant databases by using the BSN or other micro data, such as name or date of birth.

7.2.10 CIBG

CIBG (Centraal Informatiepunt Beroepen Gezondheidszorg - Dutch: Central Health Professions Centre) part of the Ministry of Health, Welfare and Sports is responsible for collating all hospital data that is submitted as a result of a combination of a legislative agreement and an understanding between the hospitals and CIBG. The data is not morbidity or mortality related but rather other factors that are related to the hospitals, for example financial and social.

7.3 Current developments

The National Public Health Compass is hosted and financed by the Ministry of Health Welfare and Sport. It provides quantitative and qualitative information about health and healthcare. A new version of the Compass is released every three months to ensure that it is as up-to-date as possible.
The Compass has the ability to answer national questions such as how many Dutch people suffer from certain chronic illnesses, what are the consequences of certain illnesses, what is the quality and cost of care, whether certain health programmes are effective (such as the Dutch smoking cessation program), what are the nutritional trends and how Dutch health compares with that of other countries.

The National Public Health Compass is meant for professionals who are active in the field of public health, including policy makers at the Ministry of Health, Welfare and Sport, regional and local authorities, municipalities, healthcare providers, patients, consumer organisations, insurers, researchers and health educators.

The centre for public health and forecasting provides information on health, healthcare services and health insurance via kiesBeter.nl. It is hosted and financed by the health ministry. KiesBeter.nl provides information on hospitals, health insurance, medication, GPs, Physiotherapists, residential care and nursing homes, homecare, mental healthcare and care for the disabled. The portal attracted more than 3 million visitors in 2008, an increase of roughly 50% compared with the previous year.

7.4 Health Informatics Workforce

There are no national strategic plans in place for the health informatics workforce.

7.5 Summary

The Netherlands healthcare is based on universal health insurance, which came into effect in 2006. This has resulted in fundamental changes in the roles of patients, insurers, providers and the Government.

- There are a number of organisations responsible for the governance of the national health information sources including the Ministry of Health Welfare and Sport, and RIVM (the National Public Health Institute).

- The Netherlands have unique identification in place for its citizens, healthcare providers (which includes healthcare practitioners and organisations) and health insurance companies which facilitates the linking and comparison of data across national health information sources by Statistics Netherlands.

- The Netherlands is progressing with the development of the Electronic Health Record (EPD) on an incremental basis.

- There are currently no overarching standards or legislation in place for national health information sources in the Netherlands.

8. Other countries

A brief review of literature on the following countries was undertaken: Hong Kong, Scotland and Singapore. The findings will be discussed in this section.

8.1 Hong Kong

Hong Kong has a mixed public and private health system, with private services dominating primary care and public services the hospital sector. The Department of Health and the Hong Kong Hospital Authority are jointly responsible for the management and provision of public health including licensing of providers and setting standards. There are no unique health identifiers in place although individual national identity numbers are often used. The public system is developing an electronic patient care record, but does not have a national data dictionary in place. International coding standards such as ICD-10 and SNOMED-CT are used to varying degrees across national health information sources.

8.2 Scotland

Scotland has a public national health service similar in provision to other UK countries. Scotland is building on current health information sources through improvements, replacements and interoperability, rather than developing any major national systems(89). They have a unique national individual identifier (CHI number), an emergency care patient summary and a national data dictionary(90) in place. The health service has produced a number of strategy documents focused on quality in healthcare, the latest of which includes applying "information from quality data to drive consistently better care" as one of its priority areas.(91) Underpinning Scotland's quality and e-health strategy documents are the Institute of Medicine's six dimensions of quality: safe, effective, timely, efficient, equitable and patient centred(92).
Managed clinical care networks run by NHS Scotland have been set up across a number of clinical areas at local, regional and national level. These networks virtually bring together patients, clinicians and interest groups to ultimately improve patient care in a specific clinical area(93). NHS Scotland's Information Services Division (ISD) has direct responsibility for a number of national administrative, management and clinical sources. The ISD undertake various audits at sources to ensure the quality of the data.

8.3 Singapore

Public healthcare in Singapore is funded by the Ministry of Health who also licence and regulate the industry. Singapore introduced legislation to place its national disease registries on a legal footing under the auspices of one office (National Registry of Diseases Office)(94) in 2007. Prior to this, data had been collected on a voluntary basis. The National Diseases Office currently manages five registries but more will be added on a phased basis. Each registry has a governance committee appointed by the Ministry of Health. Data dictionaries are in place for each registry and work is currently underway to produce an amalgamated national data dictionary. A national drug dictionary has recently been published. No unique health identifiers are in place in Singapore for individuals, professionals or providers, with probabilistic matching used for data linkage. Most health information sources are using ICD-9 at present but are moving towards ICD-10 and SNOMED-CT as the national reference terminology.

Recently, a logical information model has been developed by the Ministry of Health Holdings (MOHH)(95) which outlines the information requirements for information exchange, including the requirements for data exchange between the national registries and databases in Singapore.

9. Conclusion

9.1 Summary of findings

This international review has shown that all the countries reviewed recognise the vital importance of national health information sources to ultimately improve the quality of care patients receive. The evidence of this lies in the efforts being made to improve and develop national health information sources. Historically, sources in these countries were developed in isolation, with each source dealing with a specific administrative purpose or clinical area. The sources were usually set up independently with no attempt made at coordination or information sharing between sources. All the countries reviewed have begun harmonising their national health information sources using a variety of roadmaps, strategies and legislative means to bring the diverse range of data collected together, where appropriate.

In terms of governance and management of the national sources in the countries reviewed, most have put some form of agreement in place between key stakeholders regarding the development of national health information sources. Countries such as Australia(17) have put formal agreements in place while other countries such as the Netherlands have developed more informal arrangements. The model for data collection also varies between countries. New Zealand, for example, has a centralised system with the NZ Ministry of Health(73) responsible for all of the major national data holdings. In Canada, the Canadian Institute for Health Information (CIHI) is responsible for almost all of the national datasets(31) and in the UK they are working towards this model with the NHS Information Centre beginning to manage more of the national datasets in that country(49). The importance of clinical involvement in the governance structures of national health information sources is also evident in the countries reviewed such as in the UK where the need for more clinical engagement in the Hospital Episode Statistics data has recently been highlighted(70).

Data quality was seen to be of critical importance in terms of the efficiency and effectiveness of the national sources in the countries reviewed. Many countries are employing data quality enhancing tools such as minimum data sets, national data dictionaries, and individual health identifiers. Australia(21), England(55) and Scotland(90) have developed full national health data dictionaries, while New Zealand is currently adapting the Australian version. All countries reviewed have begun by building on existing systems through a variety of agreed minimum datasets, common data definitions, quality frameworks and standards for their national data collections. Data quality improvement programmes are also in place in a number of countries such as the Data Quality Framework published by CIHI in Canada(32).

In terms of efficiency and effectiveness many countries are attempting to reduce duplication of effort and improve linkages between their national sources. The use of individual health identifiers assists in data linkage. In

Australia, the Centre for Health Record Linkage (CHeReL)(22) in New South Wales allows data from a number of national Health Information sources to be linked for research purposes. Canada, Hong Kong and Singapore were the only countries without a national health identifier for patients; however Canada has regional unique patient identifiers and Hong Kong uses national identity numbers. All countries reviewed are examining ways to improve the use of data from their national sources and how to make data available in a more timely fashion. Improving access to national data has been a key component in the approach towards improvement of their national data collections in New Zealand(75). Each country has also implemented international coding standards to some degree with the majority using some variation of ICD-10. Some countries such as New Zealand are beginning to implement SNOMED-CT for clinical terminology for all of their national sources(82).

The need for national health information sources to adopt a person-centred approach was something that all countries reviewed are working towards. Some of these initiatives include the use of individual health identifiers and adhering to regulation or legislation in place in relation to privacy, confidentiality and security of personally-identifiable data. Other matters being considered in detail regarding national health information include the issue of consent and making personal information accessible to the individual.

The workforce of national health information sources was recognised by all countries as being fundamental to the success of the health information source with all countries acknowledging the importance of a skilled, motivated and well governed workforce. The Department of Health and Ageing in Australia identified a number of key areas as priorities to build the skillset of a health information workforce namely leadership, the business case, planning, support for research, education and development and retention of staff(26). Other countries such as England have focussed on the need to improve the qualifications of staff such as clinical coders involved in national health information sources(68).

All the countries reviewed have experienced similar problems to Ireland in relation to their national health information sources such as variances in data quality, fragmentation of information and duplication of effort.
While the health systems in the countries reviewed vary considerably and many different approaches are being adopted, a common thread has been the recognition of the importance of improving the usability and usefulness of national data sources. The development of national standards or operating principles for such data sources has been accepted as an important first step in terms of improving the quality of data which will ultimately drive quality and safety of care for all users of the health and social care service.

9.2 Next Steps

The next step for the Authority will involve establishing an advisory group comprised of key stakeholders. This group will work with the Authority following a standard development protocol using the themes and best practice identified to inform the development of draft standards for national health information sources. The draft standards will then be published for wider consultation. Subsequently the Authority will submit the final set of national standards to the Minister for Health for approval and adoption.

10. Glossary of abbreviations

Abbreviation	Organisation / term
ACIET	Advisory Committee on Information and Emerging Technologies, Canada
AHIC	Australian Health Information Council
AHMAC:	Australian Health Ministers Advisory Council
AHMC:	Australian Health Ministers Conference
AIHW	Australian Institute for Health and Welfare
ATC	Anatomical Therapeutic Chemical (International Classification system)
CBS	Statistics Netherlands
CCRS	Continuing Care Reporting System, Canada
CFH	NHS Connecting for Health, UK
CHIMA	Canadian Health Information Management Association
CIBG	*Centraal Informatiepunt Beroepen Gezondheidszorg* (Dutch) - Central Health Professions Centre; Ministry of Health, Welfare and Sports, Netherlands
CIHI	The Canadian Institute for Health Information
CJRR	Canadian Joint Replacement Registry
CORR	Canadian Organ Replacement Register
COSD	Cancer Outcomes and Services Data Set, UK
CPR	Unique civil registration number, Denmark
DAD	Discharge Abstract Database, Canada
DDKM	Healthcare Quality Programme, Denmark
DHB	District Health Boards, New Zealand

Abbreviation	Organisation/term
DHD	Dutch Hospital Data Foundation
EHR	Electronic Health Record
EPR	Electronic Patient Record
GEPJ	Basic Electronic Health Record, Denmark
GGD	Dutch municipal public health services
GMS	General Medical Subsidy collection, New Zealand
HCRS	Home Care Reporting System, Canada
HES	Hospital Episodes Statistics, UK
HINZ	Health Informatics New Zealand
HISAC	Health Information Strategy Advisory Committee, New Zealand (replaced by NHITB)
HIS-NZ	Health Information Strategy for New Zealand
HISO	Health Information Standards Organisation, New Zealand
HMDB	Hospital Morbidity Database, Canada
HMHDB	Hospital Mental Health Database, Canada
HMN	Health Metrics Network.
HPI	Health Practitioner Index, New Zealand
HSE	The Health Survey for England
IC	NHS Information Centre, England
ICD-10-CA/CCI	Enhanced Canadian version of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems
ICSI	Intra-cytoplasmic sperm injection

Abbreviation	**Organisation/term**
IHI	Individual Health Identifier
IKAS	The Danish Institute for Quality and Accreditation
INKL	Integrated Cancer Centre for the Netherlands
ISB	The Information Standards Board
ISIS	The Infectious Diseases Surveillance Information System, the Netherlands
IVF	In Vitro Fertilisation
KMD	Municipal Data Centre, Denmark
LAREB	Dutch Pharmacovigilance Centre
LINH	Netherlands Information Network in General Practice
LMR	National Medical Registration, the Netherlands
MHDW	Mental Health Information Collection, New Zealand
MNIS	Maternity and Newborn Information System, New Zealand
MORT	Mortality Collection, New Zealand
MWS	Medical Warning System, New Zealand
NACRS	National Ambulatory Care Reporting System, Canada
NBRS	National Booking Reporting System, New Zealand
NCIN	National Cancer Intelligence Network, UK
NEHIPC	National E-Health and Information Management Principal Committee, Australia
NHB	National Health Board, New Zealand
NHDD	National Health Data Dictionary, Australia
NHI	National Health Index, New Zealand

Abbreviation	**Organisation / term**
NHIG	National Health Information Group, Australia (Re-named NHIMPC)
NHIMAC	National Health Information Management Advisory Council, Australia
NHIMG	National Health Information Management Group, Australia
NHISSC	National Health Information Standards and Statistics Committee, Australia
NHITB	National Health Information Technology Board of New Zealand
NHS	National Health Service, England
NICITZ	National ICT Institute for Health Care, the Netherlands
NIGB	National Information Governance Board for Health and Social Care, England
NIR	National Immunisation Register, New Zealand
NIVEL	Netherlands Institute for Health Services Research
NMDS	National Minimum Dataset (Hospital Events), New Zealand
NNPAC	National Non-admitted Patient Collection, New Zealand
NPI	The National Patient Index, Denmark
NRS	National Rehabilitation Reporting System, Canada
NSF	National Service Framework, England
NSIR	National System for Incident Reporting, Canada
NZA	The Dutch Healthcare Authority
NZCR	New Zealand Cancer Registry
OECD	Organisation for Economic Co-operation and Development.

Abbreviation	**Organisation / term**
ONS	Office of National Statistics, UK
OPF	Operational Policy Framework, New Zealand
PAS	Patient Administration System
PHO	Primary Healthcare Organisation, New Zealand
PHO	Regional Public Health Observatories, England
RIVM	National Institute for Public Health and the Environment, The Netherlands
SDN	Health Data Network, Denmark
SDSD	Connected Digital Health in Denmark
SHA	Strategic Health Authority, England
SNOMED-CT	Systematized Nomenclature of Medicine--Clinical Terms
SUS	Secondary Uses Service, England
WAVE	Working to Add Value through E-information, New Zealand

11. Definitions used

The following list provides an explanation of words and terms that have a particular meaning in the context of this document.

Clinical coding scheme: a comprehensive system which allows the recording, in a standardised manner, of all events/concepts that are found in a healthcare record. This allows comparison of events within and between records.

Data: data are numbers, symbols, words, images, graphics that have yet to be organised or analysed.

Data architecture: describes the data structures in use.

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.

Data dictionary: a data dictionary describes the rules for the data to be recorded in an information source. These can include the meaning of the data, dealing with missing data, relationships to other data, source of the data, usage, and format.

eHealth: the combined use of electronic communication and information technology in the healthcare sector.

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.

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

National Health Information Source: national health information sources were defined for the purposes of this project as national collections of routine, currently collected health and social care data (including administrative sources, censuses, national routine surveys, and patient registries) in the Republic of Ireland. These were also considered for the purposes of this project to be 'primary' information sources.

12. Appendix

Table 7 List of individuals who participated in conference calls.

Country	Name	Title	Organisation
Australia	Paul Madden	Chief Information and Knowledge Officer	Australia Institute for Health and Welfare (AIHW)
Canada	Julie Richards	Group Director, Standards	Health Infoway Canada
Canada	Mea Renahan	Director, Clinical Data Standards and Quality	Canadian Institute for Health Information (CIHI)
Denmark	Morten Bruun-Rasmussen	Chief Executive Officer	Mediq, Denmark
England	Andrew Frith	Director of Information Development	The Information Centre for Health and Social Care
New Zealand	Kathy Farndon	Manager of the Health Information Solutions and Standards team	Information strategy group of the Ministry of Health
The Netherlands	Vincent Van Polanen Petel	Senior Researcher	Central Bureau voor De Statistiek, (CBS, Statistics Netherlands)
Singapore	Linda Bird	Information Architect - Standards	Ministry of Health Holdings (MOHH), Singapore

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