



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

International Review of Health Information Governance Management

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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, 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 day and pre-school facilities¹

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

¹ Not all parts of the relevant legislation, the Health Act 2007, have yet been commenced.

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 to be repeated unnecessarily and, at best, appropriate treatment is delayed or at worst not given.

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

Under section (8) (1) (k) 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, the Authority is charged with evaluating the quality of the information available on health and social care (section (8) (1) (i)) and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available (section (8) (1) (j)).

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. It can support a much faster, more reliable and safer referral system between the GPs and hospitals.

Although there are a number of examples of good practice the current ICT infrastructure in health and social care is highly fragmented with major gaps and silos 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 – patients and service users, health professionals, policy makers and the general public to make choices or decisions based on the best available information. This is a fundamental requirement for a highly reliable healthcare system.

Through its health information function, 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 need to set standards for information governance in Ireland. This international review is the first step in the process of developing standards for information governance management which is part of the information governance standards development programme.

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Executive Summary

1. Background

The anticipated Health Information Bill will likely include legislative provision for the development of Information Governance (IG) Standards. The Health Information and Quality Authority (the Authority), in consultation with stakeholders, will be responsible for setting these standards, developing supporting guidance documents and monitoring compliance. The Authority's statutory functions under the Health Act 2007⁽¹⁾ provide the basis for the Authority to develop national standards for IG Management and to establish a method to monitor compliance. As part of the IG suite of standards the Authority will develop national standards for IG management.

IG refers to a strategic framework that brings coherence and transparency to information initiatives and which is responsive to the spectrum of issues and concerns of those involved. Issues such as information sharing, health surveillance, quality assurance, confidentiality, privacy, records management, freedom of information and data protection are all included⁽²⁾. It covers the structures, policies and practices used to ensure the confidentiality and security of health and social care records, and to enable the ethical use of them for the benefit of the individual to whom they relate and for the public good⁽³⁾. Good IG is essential to ensuring an appropriate balance using personal health information as required to provide appropriate and safe care and protecting the rights and interests of service users. The primary mandate of the Authority is to drive patient safety on health and social care in Ireland. In respect of health information this also includes ensuring that service users' interests are appropriately protected. This includes the right to privacy, confidentiality and security of their personal health information. With so much information being collected, used and shared in the provision of health and social care, it is important that steps are taken to protect the privacy of each individual and ensure that sensitive personal health information is handled legally, securely, efficiently and effectively in order to deliver the best possible care⁽⁴⁾.

In order to bring coherence, transparency and quality assurance to information initiatives in health and social care settings, an IG framework is required⁽⁵⁾. The framework covers the following areas:

- IG management
- Privacy and confidentiality management
- Information security management
- Data quality management
- Secondary use management.

IG management refers to having an appropriate management structure in place to support an IG framework for organisations. It encompasses the structures, and the development and implementation of policies and procedures relating to all aspects of IG and the continued assessment of compliance and development of improvement plans as appropriate. IG management can be described as the overarching theme or topic in IG in that it governs each of the other IG areas.

2. International Review

An initial desktop review of IG management and its key principles in health and social care identified four countries for further examination. Due to language constraints it was necessary to select English-speaking countries. The countries were chosen based on IG management initiatives and resources identified in the desktop review, the availability of information and the fact that initiatives in this area are ongoing in each of these jurisdictions. As such, the information presented is current and up to date and the initiatives deal with issues of relevance to the area. Further, similarities can be drawn between the health and social care systems in these countries and the Irish system meaning that the initiatives identified are more likely to be applicable to the Irish context. The review examines the following countries:

- England
- Scotland
- Canada
- New Zealand.

The review also documents two additional international resources that are not attributable to a specific country but that could provide useful information when developing an IG framework. The first of these is an ISO standard published in 2008 (ISO/IEC 38500⁽⁶⁾), which sets out a framework for good corporate governance of IT. Its purpose is to inform and guide those involved in designing and implementing the management system of policies, processes and structures that support good governance. The second resource discussed is a document published by Accenture in 2010, which outlines the IG challenges faced by organisations planning investments in e-health solutions and provides a framework to assist in overcoming these challenges⁽⁷⁾.

3. Findings

Of the information that was sourced in the course of this research the following are the key points:

- IG Management
IG management is a recognised IG topic in England and Scotland. Although it is not acknowledged in its own right in Canada and New Zealand, its principles and associated practices are recognisable in their IG strategies and policies

- Standards
Guidance documents, policies and strategies in England and Scotland discuss IG management and set out requirements in this area (as do those in Canada and New Zealand, under various headings) but there are no formal national standards, such as those that will be developed by the Authority²

- Responsibility
Responsibility for IG is assigned to various persons within organisations, for example Caldicott Guardians in England and Scotland and Privacy Officers in New Zealand. Responsibility is assumed by a number of committees in organisations in Canada, for example the Canadian Institute for Health Information (CIHI), however it is not clear if this is echoed throughout the Canadian health and social care sector

- Policies and Procedures
IG management policies and procedures have been developed at a provider level based on national guidance and codes of practice in England and Scotland. There is scope for providers in Canada to build on policies developed by organisations such as CIHI as these are based on legislation. It is likely that this will happen in the coming years as Canada is working towards a more pan-Canadian approach to IG

- Training and Education
In each of the countries explored, the importance of training and education in the area of IG is highlighted. Specific training and development programmes have been developed in recognition of this in both England and Scotland, while the issue is addressed in a number of policies and strategies in both Canada and New Zealand

² It is noteworthy that the term “standard” is used in a broad non-regulatory sense in England and Scotland, for example to refer to requirements in the IG toolkit. This differs from its use within the Authority in that standards developed by the Authority are provided for in legislation in the form of the Health Act 2007.

- Assessment and Compliance

Self-assessment of compliance with national (where available) and local standards and guidelines is a recurring theme in each of the countries, for example the IG toolkit in England and Scotland. Self-assessment is also discussed in the international resources included in this review emphasising the need to continuously monitor progress in this area and develop improvement plans as appropriate.

1. Introduction

1.1 Background and overview

The forthcoming Health Information Bill will include legislative provision for the development of Health Information Governance Standards. Health IG management standards will form part of a suite of health IG standards. The Health Information and Quality Authority (the Authority) will be responsible for setting these standards and monitoring compliance with them. As a first step in preparing for this function the Authority undertook an *International Review of Information Governance Structures*⁽⁸⁾ and an *As Is Analysis of Information Governance in Health and Social Care Settings in Ireland*⁽⁵⁾. In the course of these reports the following topics were identified as the core aspects of information governance:

- information governance management
- information security management
- data quality management
- privacy and confidentiality management
- secondary use management.

The components of these themes, when developed and implemented in an organisation, comprise an IG framework. In order for an IG framework to work effectively in any organisation, it is essential that the appropriate management structures exist to support and drive the culture of IG within an organisation. The Authority will develop standards and guidance in each of these areas which will comprise a suite of IG standards for the Irish health and social care sector.

1.2 What is IG management?

IG management refers to having an appropriate management structure in place to support an IG function within an organisation. Dedicated staff members should have responsibility for the management of IG within an organisation and all staff members should be adequately informed of and trained in their responsibilities in this regard⁽⁹⁾. It encompasses the structures, and the development and implementation of policies and procedures relating to all aspects of IG and the continued assessment of compliance and development of improvement plans as appropriate. As such IG management can be interpreted as the overarching theme or topic of IG in that it governs the other aspects. It is important as a theme in itself in that it brings together each of the other aspects and enables IG as a whole to operate effectively and efficiently as part of the culture of any organisation.

1.3 IG management in Ireland

The “As Is” analysis of IG⁽⁵⁾, conducted by the Authority in 2009, explored the current status of each of the IG topics in the Irish health and social care sector. The document focused on areas of identified good practice and presented an overview of the IG guidance that is in place at a national level. From an IG management perspective, the document examined the structures for and provision of policies and procedures in a number of health and social care organisations. The review undertaken demonstrates that different management structures, processes and procedures have emerged in relation to the management of information in the organisations studied. This is in part due to different governing structures and the types of information collected. It must be acknowledged that significant developments have taken place in the form of IG management structures; the establishment of IG teams at an executive and at the local level, for example the Information Governance Committee in the National Maternity Hospital⁽¹⁰⁾; but what has been developed varies significantly not only across but also within organisations. This, in addition to feedback from stakeholders, highlights the need for guidance around IG management responsibilities in Ireland. The Authority is in the process of developing this single coordinated point of reference in the form of IG management standards and supporting guidance. The first step in this process is an IG management review.

The purpose of this document is to inform the Authority of international experience and good practice in the field of IG management. The information discovered will, in conjunction with stakeholder consultation, inform the development of national health IG management standards in Ireland.

This document explores the tools, standards, processes and assessment methodologies that are in place in respect of IG management in the health and social care sector. This document examines initiatives in:

- England
- Scotland
- Canada
- New Zealand
- additional international resources.

The countries were chosen based on IG management initiatives and resources identified in an initial desktop review, the availability of information and the fact that initiatives in this area are ongoing in each of these jurisdictions. As such, the information presented is current and up to date and the initiatives deal with issues of relevance to the area. Further, the countries selected are English-speaking and similarities can be drawn between their health and social care systems and the Irish system meaning that initiatives identified are more likely to be applicable to the Irish context. The purpose of this international review is to identify common themes that will, in conjunction with stakeholder engagement, inform the development of IG management standards.

2. England

2.1 Introduction

The National Health Service (NHS) was established in 1948 and provides free healthcare to all residents of the UK with the exception of some dental, optical and prescription charges. The NHS is managed separately in England, Scotland, Wales and Northern Ireland but it is funded centrally from national taxation. In England, responsibility for the NHS is devolved to ten Strategic Health Authorities (SHA) that are responsible for managing health and social care services in each of their geographical areas. The NHS is also divided into a number of trusts, each of which is responsible for different aspects of healthcare. Primary Care Trusts (PCT) are responsible for providing primary and community services and for commissioning secondary care services for residents of their respective areas. Acute trusts, also referred to as hospital trusts, manage hospitals and are commissioned by PCTs to provide secondary health services. There are a number of other types of trusts including mental health trusts, care trusts and ambulance trusts.

2.2 Overview of Information Governance Management

A review carried out by the Care Record Development Board (now the National Information Governance Board) in 2005 on the IG practices in the UK Department of Health and the wider National Health Service (NHS) commented on the absence of a single coordinating body which could be an authoritative source of advice or arbitration, where there was a disagreement about best practice. The overall finding of the review was that although the Department of Health (UK) and the NHS were striving towards good IG practices, arrangements needed to be strengthened⁽¹¹⁾.

A number of the recommendations made relate specifically to strengthening IG management in organisations as follows:

- all organisations providing health and social care are required in addition to having a Caldicott Guardian³, to have clear processes within their overall governance structure to ensure compliance, oversight and monitoring of IG within that organisation
- a clear job description and competencies are created for Caldicott Guardians and training, support and guidance is provided for Caldicott Guardians and IG committees.

³ A Caldicott Guardian is a senior person responsible for information governance in an organisation.

There are a number of initiatives in place in England that support the strengthening of IG management such as:

- the IG Toolkit
- NHS Connecting for Health IG Training Tool
- Caldicott Guardians
- Provider level IG management policies and strategies

These are discussed in the sections that follow.

2.3 The IG Toolkit

The IG toolkit is a nationally agreed electronic self-assessment form designed to facilitate organisations to self-assess the way they handle or process information. The toolkit provides a framework to bring together the requirements, standards and best practice that apply to the handling of information⁽⁸⁾. All NHS organisations are required to assess their compliance with the IG requirements through the IG toolkit and publish an annual report on compliance. The toolkit enables organisations to measure their compliance with a range of information handling requirements, for example the Data Protection Act 1988 (England) and the Information Security Management NHS Code of Practice⁽¹²⁾.

The toolkit is constantly evolving to reflect the requirements of and changes in the healthcare environment, with version eight being published in 2010.

There are different “views” for different types of organisation, for example acute hospital trust, general practice and social care. The first version of the toolkit contained only the acute hospital view. The criteria to be met to achieve compliance with each standard vary in number according to the business of the organisation. The contents of a particular view are dependent, in part, on the risk of unauthorised or inappropriate disclosure of patient information.

The toolkit consists of 45 requirements that are subdivided into six work areas as follows:

- IG management
- confidentiality and data protection assurance
- information security assurance
- clinical information assurance
- secondary use assurance
- corporate information assurance.

The requirements relating to IG management, as per version eight of the toolkit, are as follows⁽¹³⁾:

- there is an adequate IG Management Framework to support the current and evolving IG agenda
- there are approved and comprehensive Information Governance Policies with associated strategies and/or improvement plans
- formal contractual arrangements that include compliance with information governance requirements are in place with all contractors and support organisations
- employment contracts which include compliance with information governance standards are in place for all individuals carrying out work on behalf of the organisation
- IG awareness and mandatory training procedures are in place and all staff are appropriately trained.

Each requirement within the toolkit contains:

- a requirement statement (for example as listed above)
- four levels of attainment ranging from zero to three⁴
- the evidence required at each attainment level
- the improvements that must be made to enable an increased score to be obtained.

Organisations are obliged to measure their compliance with a particular requirement, award themselves a score that reflects this compliance, ensure evidence of their attainment is available if requested by auditors, and make annual improvements.

The toolkit has continued to evolve and change annually in response to a changing IG agenda and feedback from stakeholders. Although limited resources limit the auditing of results, the toolkit has proved to be a useful resource in that it is a cohesive, nationally coordinated point of reference for service providers in respect of their IG responsibilities. It enables service providers to identify areas where their performance is weak and demonstrates the ways in which improvements can be made.

⁴ The attainment levels demonstrate to organisations the work required in order to achieve the next level and continue to improve in the area. The individual scores for each requirement are calculated as an overall percentage and the organisation is colour-coded using a traffic light system to represent their overall score.

2.4 NHS Connecting for Health IG Training Tool

Ongoing training and education of staff in relation to developments in IG and their associated responsibilities are core components of IG management. Training in relation to IG has received much attention in England in recent years culminating in the development of the IG training tool (IGTT).

The NHS Connecting for Health (CfH) is a directorate of the Department of Health and was established in April 2005 primarily to deliver the National Programme for Information Technology (NPFIT)⁵⁽¹⁵⁾. CfH supports the NHS in providing better, safer care, by delivering computer systems and services that improve how patient information is stored and accessed. One example of such support is the IGTT.

The NHS IGTT is a free online training resource produced by the Department of Health for the NHS and its partner organisations⁽¹⁶⁾. As this is centrally provided the content is quality assured and kept up to date in light of any changes to IG policy or legislation. It is planned to update the tool annually to reflect any such changes. IG training and awareness was a key requirement of the Cabinet Office Data Handling Review 2008⁽¹⁷⁾ and lack of IG training provision continued to be of concern in the Care Quality Commission study of IG processes⁽¹⁸⁾ in 2009. In an effort to overcome this the NHS Operating Framework 2010/2011⁶⁽¹⁹⁾ includes a requirement for annual basic IG training to be provided through the NHS IGTT⁽¹⁶⁾.

One of the IG management requirements in the IG toolkit is⁽¹³⁾:

Information Governance awareness and mandatory training procedures are in place and all staff are appropriately trained.

In order to attain level one of this requirement an organisation must have developed an IG training programme that includes training needs analyses, induction for new starters and the completion of online basic training using this NHS IGTT. Attaining level two requires the organisation to ensure, in line with the NHS Operating Framework 2010/2011, that all staff members complete IG training through the mandatory module(s) in the NHS IGTT⁽¹³⁾. Attaining higher levels requires further embedding of IG training programmes as part of the culture of the organisation.

⁵ The NPFIT is a national initiative to develop and modernise the IT infrastructure to support patient-centred care and services. This infrastructure will form the basis for the integration and sharing of patient information across the NHS⁽¹⁴⁾.

⁶ The operating Framework for the NHS in England 2010/11 was published by the Department of Health in 2009. It sets out the national priorities for the year.

A number of trusts have developed IG training policies based on the IGTT and the requirements of the IG toolkit. East Riding of Yorkshire Trust, for example, has developed a training policy for 2010-12⁽²⁰⁾ to ensure that IG training is provided appropriately to all staff in line with the requirements of the toolkit. The policy, which applies to all employees of the Trust, states that IG training is mandatory for all staff who have access to personal data. Training must be completed every three years and must be renewed if there is a system change in the interim⁽²⁰⁾. The content of the training is reviewed on an annual basis to ensure that it continues to meet the IG agenda.

2009/11 Information Governance Training Policy⁽²¹⁾ outlines the IG training expectations adopted by NHS Wandsworth and Community Services Wandsworth. The policy focuses on the IGTT and identifies four modules of the tool as the core mandatory training requirements for all persons having access to personal information. The core modules are⁽²¹⁾:

- introduction to IG
- information security guidelines
- secure transfers of data
- password management.

Staff may be required to take on additional training modules depending on their roles and responsibilities within the organisation.

2.5 Caldicott Guardians

Many of the trusts have appointed a senior manager who has overall responsibility for the IG agenda. At an operational level they also appoint an IG lead and an Information Officer/Caldicott Guardian who is responsible for IG in that organisation.

In March 1999 a Caldicott Framework was established following recommendations of the Caldicott Committee in its *Report on the Review of Patient-Identifiable Information*⁽²²⁾. The report made a number of recommendations for regulating the use and transfer of personally identifiable information. Central to the recommendations was the appointment in each NHS organisation of a “guardian” of personal clinical information to oversee the arrangements for the use and sharing of clinical information.

The Caldicott Guardian plays a key role in ensuring that the NHS, councils with social services responsibilities and partner organisations satisfy the highest practical standards for handling patient identifiable information⁽²³⁾. All organisations are required to have a Caldicott Guardian at a senior level within the organisation.

Acting as the 'conscience' of an organisation, the Guardian actively supports work to facilitate and enable information sharing and advises on options for lawful and ethical processing of information as required. The Caldicott Guardian also has a strategic role, which involves representing and championing IG requirements and issues within the organisation at board or management team level and, where appropriate, at a range of levels within the organisation's overall governance framework. This demonstrates responsibility and accountability at a local/provider level and reinforces that there is a structured approach to IG.

2.6 IG Management Strategies and Policies

Many information governance standards, policies and codes of practice have been developed by the Department of Health and the NHS at a national level. A number of NHS trusts/organisations have developed local IG policies based on these.

IG management, having been identified as one of the key tenets of information governance, is therefore the focus of a number of these local policies and strategies. Each of the policies reviewed deals with the requirements of the IG toolkit and how to achieve compliance⁽²⁴⁻²⁷⁾. Many of the policies also detail the roles and responsibilities of various individuals within organisations, which is a key feature of IG management. The Wiltshire policy⁽²⁴⁾, for example, outlines the roles and responsibilities of:

- the Caldicott Guardian
- the IG lead
- information systems managers
- line managers
- the HR team.

At a provider level, IG committees/groups have also been formed to ensure that effective policies and management arrangements covering all aspects of IG are implemented in line with the policy or strategy in question. The Cumbria PCT, for example, has established an IG steering group which has delegated authority from the Board. The group is chaired by the Head of Clinical Governance and membership includes the IG Manager and the Caldicott Guardian. The group has responsibility for the development and implementation of IG policies and action plans. A key function of the group is to monitor and review untoward occurrences and incidents relating to information governance and ensure that effective remedial and future preventative action are taken⁽²⁸⁾.

The strategies typically outline the approach the PCT or other trust will take to ensure that it develops effective IG processes throughout the organisation, which will enable the PCT to deliver its objectives and meet its statutory requirements. They also typically refer to an action plan arising from a base line assessment against the standards set out in the IG toolkit⁽²⁴⁻²⁷⁾, demonstrating a commitment to continuous improvement.

2.7 Summary

England has a well-developed, structured approach to IG, with clear lines of accountability and responsibility and documented mechanisms for continued improvement in the area. IG management is one of the core tenets of IG in England. It is identified as the overarching theme in the IG toolkit with requirement questions specifically assigned under the heading of IG management for each organisation type to which the toolkit applies. The system of appointing Caldicott Guardians is well established reflecting the commitment to responsibility and accountability. Training and education of all staff, tailored specifically to their roles within organisations, further demonstrates the commitment to continuous improvement and dedication to protecting and enhancing the rights of service users in respect of their personal health information.

3. Scotland

3.1 Introduction

In Scotland, NHS services are provided by territorial NHS Boards covering geographical areas, and Special Health Boards and agencies covering the whole of Scotland. Territorial NHS Boards provide most services and buy in certain specialist or back-up services as required, they are responsible for the service provided⁽²⁹⁾.

3.2 Overview of Information Governance Management

The Scottish approach to health IG has been heavily influenced by the English model. The system is structured at a national level with clear lines of accountability and a self-assessment toolkit, echoing the English IG toolkit and facilitating continuous improvement. IG standards were developed in 2007 in addition to a subsequent self-assessment tool both of which address IG management as a core component of IG. The Scottish Executive Health Department views IG management in the form of a comprehensive IG framework, as being one of the core components of IG.

There are a number of initiatives in place in Scotland aimed at achieving a high standard of IG management as follows:

- *NHS Quality Improvement Scotland Clinical Governance and Risk Management Standards*⁽²³⁾
- *NHSScotland Information Governance Standards*⁽²⁴⁾
- The NHS Scotland IG Toolkit
- The Caldicott Framework
- *The Competency Framework for Information Governance*⁽²⁵⁾

3.3 NHS Quality Improvement Scotland Clinical Governance and Risk Management Standards

In Scotland, NHS Quality Improvement Scotland (QIS) has responsibility for setting national clinical governance and risk management standards⁽³⁰⁾ and monitoring performance. IG is one element of these standards, the aim of which is to assist NHS boards to develop and improve IG locally. These standards contain six high level headings about IG.

The first of these standards requires that a governance framework is in place which promotes the ethical and lawful use of information in enhancing decision-making to support and drive improvement. This first standard is the overarching requirement of IG management⁽³⁰⁾:

"...A governance framework is in place, which promotes the ethical and lawful use of information in enhancing decision-making to support and drive improvement."

Following the development of the clinical governance and risk management standards, the Clinical Information Steering Group asked NHS National Services Scotland (NSS) to progress the IG agenda and develop a set of IG standards⁷ to underpin the clinical governance and risk management standards.

3.4 NHSScotland IG Standards

In September 2007 NHSScotland set out IG Standards⁽³¹⁾ as agreed with the Scottish Executive Health Department and NHS Quality Improvement Scotland⁸ (NHS QIS).

The sub-sections within the standards relate to:

- IG policy and planning
- confidentiality
- administrative records
- patient records
- data protection
- Caldicott
- information security
- data quality.

Of these, the IG policy and planning standards are of most relevance to IG management. The policy and planning standards include⁽³¹⁾:

- the Board of the organisation has agreed a plan for the implementation and monitoring of the IG policy
- the Board's IG plan includes appropriate training for all staff on the elements of IG

⁷ These standards broadly align with those used by the NHS in England but are called requirements within the IG toolkit in England.

⁸ NHS Quality Improvement Scotland is responsible for publishing standards for information governance which are used to assess NHS boards' effectiveness in this area of activity. NHS QIS conducts an annual assessment requiring NHS boards to complete a self-assessment which is verified by a subsequent visit and verification process.

- all staff contracts contain clauses that clearly identify staff responsibilities for confidentiality, data protection and security
- IG is embedded in the Board's business planning cycle and risk management agenda
- there is a clearly identified, suitably qualified and supported IG coordinator within each organisation.

The aforementioned standards are examples of those that relate to IG management, covering the areas of training and education, accountability and responsibility, monitoring and assessment and the implementation of appropriate policies.

3.5 The NHSScotland IG Toolkit

NHSScotland has developed an IG toolkit similar to the version developed in England. The aim of the toolkit is to assist organisations to comply with the national IG initiative, and record progress against IG standards in the following six areas:

- IT security
- Caldicott Guardians
- data protection
- freedom of information
- records management (including management of corporate and clinical records)
- quality management.

Similar to the English model, each requirement has four attainment levels to measure compliance and improvement levels. Each NHS Board submits a return but may set up several units or divisions that can provide their own input. The toolkit allows consolidation of these outputs to feed into the Board's overall return. Each Health Board in Scotland provides returns to NHS National Services Scotland on a quarterly basis. Up until 2010 the results were audited by QIS and NSS collated the information to provide an annual report to each Board in advance of the audit taking place. At the time of writing this review discussions are ongoing between NSS and the Scottish Health Department around how and by whom the results will be audited.

3.6 The Caldicott Framework

Similar to the English framework, the Scottish framework requires each NHSScotland organisation to appoint a senior clinician, such as the medical director, as Caldicott Guardian⁽³³⁾.

In 2007 the Scottish Executive published a *Caldicott Guardian Manual*⁽³³⁾ detailing the role of the Caldicott Guardian. The manual covers different organisation types and their associated requirements. For example, individual general medical and dental practices, pharmacists and opticians do not need to appoint a Caldicott Guardian, but do need to have an IG lead who, if they are not a clinician will need support from a clinically qualified individual. This demonstrates responsibility and accountability at a local/provider level and reinforces that there is a structured approach to IG.

3.7 The Competency Framework for Information Governance

The importance of education and training around IG issues for staff is a key theme in IG management and is very much to the fore in Scotland. In 2008 NHS National Services Scotland and NHS Education for Scotland collaborated to develop a *Competency Framework for Information Governance*⁽³²⁾. The framework provides broad guidance on the recommended content, delivery and governance of education and training to support effective IG practice across a range of staff groups. The framework is organised into five 'domains' reflecting different aspects of information handling, and four competency levels each describing a different level of responsibility in the given area. This approach is designed to enable training providers to tailor education and training to the specific needs of individuals and groups⁽³²⁾. The four levels of competence range from foundation level competence to advanced knowledge and skills. This reflects the fact that most members of staff have responsibility for handling personal health information as part of their role.

3.8 Summary

The IG model that has emerged in Scotland has been heavily influenced by developments in England – this can be seen in areas such as the establishment of an IG toolkit and the emphasis on the role of Caldicott Guardians. In terms of IG management NHSScotland has outlined a number of the key principles in various documents and initiatives. One of the key developments in this area is the *Competency Framework for Information Governance*⁽³²⁾. The framework supports effective IG practice across a variety of staff levels through education and training. The implementation of such a framework facilitates awareness raising of IG at all levels throughout an organisation and cultivates a culture of IG allowing good IG practices to become the norm.

4. Canada

4.1 Introduction

Canada's population of approximately 34 million people is governed as a parliamentary democracy consisting of a federation of ten provinces and three territories. The federal government is responsible for matters that concern Canada as a whole, such as international trade and national defence. Provincial and territorial governments fund and are responsible for the administration and provision of healthcare and social services in their respective areas. However, the provinces and territories do not have exclusive legislative powers, as they also receive federal funding that is dependent on compliance with the Canada Health Act, 1984 (CHA)⁽³⁸⁾.

4.2 Overview of Information Governance Management

A review of IG management practices in Canada has revealed that although there are some pan-Canadian IG mechanisms in place, most of the structures and systems in place provincially are by no means nationally cohesive. This is primarily due to legislative differences between the provinces. Many healthcare organisations have independently established structures and processes with a chain of accountability for handling privacy breaches and security incidents. However, efforts are being made to move towards a more inclusive, pan-Canadian approach.

Although the term *IG management* is not generally used explicitly in Canada, a number of its principles can be identified in the other aspects of IG, for example privacy and confidentiality. As such the IG management initiatives are more fragmented than those identified in other countries such as England and Scotland in that they are discussed as part of other IG initiatives rather than as a separate aspect of IG. Various organisations, such as those discussed in the paragraphs that follow, support the idea that structures and frameworks are of utmost importance in IG.

The key themes of accountability, responsibility and the need for training and assessment are identified in a number of policies and frameworks as discussed in the sections that follow.

4.3 Canada Health Infoway

Infoway is a not-for-profit federally funded organisation that collaborates with the provinces and territories, health care providers and technology solution providers to accelerate the use of electronic health records (EHRs) in Canada⁽³⁹⁾. Each province is responsible for the development of its own EHR system; however, Infoway provides a technology blueprint, vendor certification and standards to foster interoperability and best practice across the provinces and territories⁽³⁹⁾. In 2007, Infoway developed and published a *White Paper on Information Governance of the Interoperable Electronic Health Record* (iEHR)⁽⁴⁰⁾. This document discusses the issues surrounding rules, requirements and mechanisms involved in handling personal health information, and it provides the basis for discussion by stakeholders to deal with their jurisdictional approaches to IG. In order to successfully introduce a pan-Canadian iEHR, Infoway recognises that provincial and territorial approaches to IG must be cohesive. Infoway ensures privacy is embedded as part of the design of iEHR systems by making it a requirement of all Infoway funded projects related to the iEHR or personal health information that privacy impact assessments (PIAs) are undertaken⁽³⁹⁾.

The White Paper provides an overview of current IG practices in Canada and internationally and discusses the issues to be addressed in order to achieve a cohesive pan-Canadian IG framework to facilitate the implementation of an iEHR. The IG management issues discussed include:

- who is responsible for determining the extent of personal health information that individual end-users may access?
- what IG rules support the flow of personal health information and who is ultimately accountable for ensuring compliance with these rules?⁽⁴⁰⁾

As a result of the issues raised in this document, Infoway sponsored the establishment of a Privacy Forum in 2007 in order to foster discussions on these issues. The Privacy Forum includes representatives from each federal, provincial or territorial Ministry of Health and Privacy oversight body. In December 2008, a Health Information Privacy (HIP) group was established independent of the Privacy Forum. The main focus of the HIP is to develop common understandings of health IG between jurisdictions and provinces to help facilitate pan-Canadian IG initiatives. Infoway identifies areas of best practice in provinces or territories and through the HIP, ensures that these practices are recommended across other provinces and territories. During 2009, discussions and recommendations made by the Privacy Forum have fed into the HIP and contributed to the development of a set of principles focussing on cross jurisdictional understandings of accountability, patient notification and consent to health information sharing⁽⁴¹⁾. Infoway continues to fund and support both groups.

Both groups have prioritised the following key aspects of IG raised in the White Paper:

- accountability
- secondary use
- information consent
- inter-jurisdictional data flows

4.4 The Canadian Standards Association's *Model Code for the Protection of Personal Information*

The Canadian Standards Association's *Model Code for the Protection of Personal Information* (1996)⁽⁴²⁾ sets out ten privacy principles. The model code describes recommended IG structures at a pan-Canadian level and are widely regarded as an important governance model⁽⁴³⁾. The principles that relate specifically to IG management are:

- accountability for personal information
- openness and transparency about personal information practices
- challenging compliance.

Most health organisational privacy policies are based on this code, which has been formally incorporated as Schedule 1 of the Personal Information Protection and Electronic Documents Act (PIPEDA)⁽⁴⁴⁾.

4.5 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⁽⁴⁵⁾. CIHI has offices in Ottawa, Toronto, Montreal, Edmonton and Victoria and analyses health information and data received from hospitals, regional health authorities, medical practitioners and governments. Although not involved in the provision of direct clinical care, CIHI analyses a large volume of patient identifiable health information, which presents a unique challenge in terms of ensuring this information is properly protected.

CIHI maintains a comprehensive privacy programme as the protection of individual privacy, the confidentiality of records and the security of information are essential to their operations. A cornerstone of this programme is a set of strict principles and policies that govern how CIHI collects, stores, analyses and disseminates data. These are outlined in the documents, *Privacy and Security Framework*⁽⁴⁶⁾ and *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010*⁽⁴⁷⁾.

Although these policies have been developed specifically by CIHI they are aligned with the federal Personal Information Protection and Electronic Documents Act (PIPEDA)⁽⁴⁸⁾. As such they could be used as a basis for other organisations developing a suite of IG policies and procedures.

The privacy programme details the structures that should be in place and the associated responsibilities and transparency of accountability, all of which are key features of IG management. The Program discusses⁽⁴⁸⁾:

- a Privacy Secretariat committed to developing a culture of privacy at CIHI;
- an active Privacy, Confidentiality and Security Team that includes representation from across the organization;
- a Chief Privacy Advisor, who provides advice and counsel on privacy matters;
- Privacy and Data Protection Committee – Subcommittee of the CIHI Board of Directors
- mandatory staff training to keep health information protection matters front and centre; and
- outreach activities to keep stakeholders advised.

CIHI are working to strengthen their privacy programme by aligning their policies and practices with current standards such as those recommended by Infoway, enhancing data protection tools and activities and increasing awareness of the privacy programme itself⁽⁴⁸⁾.

4.6 Newfoundland and Labrador Centre for Health Information

The Newfoundland and Labrador Centre for Health Information (NLCHI) was established to provide quality information to health professionals, the public and health system decision makers. The NLCHI aims to develop a confidential and secure health information network (HIN) as a foundation for a provincial EHR and maintains that it is a model for other Canadian jurisdictions. Canada Health Infoway funds this network with a view to other jurisdictions using the same model to facilitate a pan-Canadian interoperable EHR. The NLCHI holds health and social care databases for the province of Newfoundland & Labrador⁽⁴⁹⁾. The centre is divided into four divisions as follows:

- health information network
- data standards and information
- research and evaluation
- privacy and confidentiality.

These divisions are the key elements to the development of a provincial health information system. The NLCHI has dedicated privacy policies and procedures governing health information in each division.

The HIN is governed by *the Privacy, Confidentiality and Access Principles and Guidelines for the Health Information Network*⁽⁵⁰⁾. The principles and guidelines are based on the ten principles outlined in the Canadian Standards Association's *Model Code for the Protection of Personal Information*⁽⁴²⁾. The Guidelines relate each of the ten principles from the Model Code to the HIN stating the policies and procedures required by each organisation involved in the collection, use and disclosure of personal health information to ensure the privacy of health information is protected. Accountability for drafting and implementing the required policies and procedures lies with a "Custodian", usually the most senior person within an organisation. This reflects the IG management themes of responsibility and accountability and having policies and procedures in place at an organisational level.

The NLCHI has published their *Privacy and Access Policies and Procedures*⁽⁵¹⁾ as part of their administrative policy manual. This document details the IG responsibilities, accountabilities, policies and procedures for the health information gathered, used and disclosed directly by the NLCHI and also for the conduct of privacy impact assessments and the training and awareness of staff around IG and protection of personal health information.

4.7 Summary

The following significant developments in IG management have taken place in Canada:

- efforts have been made toward a more pan-Canadian approach in the development of the *Canadian Standards Association Model Code for the Protection of Personal Information*
- Canada Health Infoway produced a white paper in 2007 on IG for the interoperable electronic health record, outlining a number of IG management issues to be addressed
- establishment of the Privacy Forum in 2007 and the Health Information Privacy Group in 2008 to progress the IG management issues raised in the white paper
- CIHI has developed a national health information privacy programme which is aligned with the PIPEDA
- the NLCHI has aligned their provincial health information network guidelines *Privacy, Confidentiality and Access Principles and Guidelines for the Health Information Network*⁽⁵⁰⁾ with national principles such as the *Model Code for the Protection of Personal Information*⁽⁴²⁾, which include provisions around training, accountability and responsibility for various IG issues.

It has been recognised that a national approach to IG is required to ensure a consistent approach to IG management and efforts are being made to achieve this through the work of the Advisory Committee on Information and Emerging technologies (ACIET), Canada Health Infoway, CIHI and various provincial health information agencies such as the NLCHI. It is clear from the Canadian experience that a national approach to the management of IG is necessary to facilitate the development of initiatives such as the interoperable EHR. Aspects of IG management such as the importance of accountability and responsibility for IG are present in most of the initiatives reviewed. This supports the idea that strong IG management principles provide a basis for all other aspects of IG and are necessary for the development and maintenance of good IG practice.

5. New Zealand

5.1 Introduction

New Zealand has a population of approximately 4 million and is governed by a parliamentary democracy system. The government is fully integrated nationally with no separate states or territories⁽⁵²⁾. The Minister of Health in New Zealand has overall responsibility for the health and disability system. The health service is funded and delivered by 21 district health boards (DHBs) who report directly to the Minister of Health⁽⁵³⁾. Recent changes to the Ministry of Health structure include the creation of a National Health Board (NHB) to improve coordination between the 21 DHBs.

The New Zealand health system is one that has undergone a number of reforms and transformations in the past number of years – particularly in relation to health information and governance structures. The *Working to Add Value through E-information (WAVE) Report - From Strategy to Reality* published in 2001 made 79 recommendations towards improving the quality of New Zealand health information management and ultimately the quality of healthcare throughout the country⁽⁵⁴⁾. In 2005 a *Health Information Strategy for New Zealand* was launched resulting in the restructuring of a number of health information committees⁽⁵⁵⁾, with transformations ongoing at the time of writing.

5.2 Overview of IG Management

Although there are some initiatives around health IG management in New Zealand, the term, *information governance management*, is not generally used to describe the management structure in place to support an IG framework in the New Zealand Health and Disability Service.

However, similar to the Canadian experience, there are a number of structures and initiatives in place, which support the principles of IG management. These include:

- The Health Information Standards Organisation (HISO) (2010)
- *The Health Information Privacy Code*⁽⁵⁶⁾
- *The Health Network Code of Practice*
- The Privacy, Authentication and Security (PAS) Policy.

5.3 Health Information Standards Organisation (2010)

Following an intense period of restructuring and changes in functions and areas of focus and responsibility of health information committees and sub-committees, the Health Information Standards Organisation (HISO) (2010) was established in 2010, as distinct from and a replacement to the original HISO established in 2003. The purpose of the HISO (2010) is to support and promote the development, understanding and use of fit-for-purpose health information standards to improve the New Zealand health system⁽⁵⁷⁾.

Membership of the HISO committee includes representatives of the Ministry of Health, The Medical Council, The Nursing Council and Health Informatics New Zealand. The role and key tasks of the HISO (2010) are set out in the terms of reference⁽⁵⁸⁾. A number of these are significant to IG management, for example:

- advising on, and recommending to the Information Technology Health Board, the way forward in relation to health information standards, their development, implementation and maintenance. The IT Health Board is a sub-committee of the National Health Board which is a division of the Ministry of Health. Their role is to ensure that health sector policy is supported by appropriate health information and information technology (IT) solutions⁽⁵⁹⁾
- providing communications and education to the health and disability sector about the benefits and role of health information standards in the sector and the work of HISO (2010)
- communicating and championing the health information standards agenda; developing a coordinated view of the relative importance and need for proposed health information standards in New Zealand
- advising on, and making recommendations to the National Health IT Board about issues of compliance, and ensuring adequate compliance mechanisms (monitoring, auditing and reporting) are in place⁽⁵⁸⁾.

At the time of writing, the HISO (2010) committee have only met twice, however, they have developed a draft framework for health information security as one of its first prioritized areas for health information standards requirements⁽⁶⁰⁾.

Based on the HISO (2010) terms of reference and the work undertaken to date, it appears that the national health information standards developed in the future will significantly contribute to strengthening health IG management in New Zealand.

5.4 The Health Information Privacy Code 1994

The *Health Information Privacy Code 1994*⁽⁵⁶⁾, published by the Office of the Privacy Commissioner, which was updated in 2008, applies specific rules to agencies in the health sector to better ensure the protection of individual privacy. With respect to health information collected, used, held and disclosed by health agencies, the code supersedes the 12 information privacy principles in the Privacy Act⁽⁶¹⁾.

The Privacy Act made provision that any code of practice based on the Act developed by the Privacy Commissioner for a specific sector, would become lawful⁽⁶¹⁾. This means that the rules contained within the *Health Information Privacy Code*⁽⁵⁶⁾ are legally binding. The code also includes a commentary around each rule which acts as a guidance to organisations explaining how to comply with the rule and ensures that personally identifiable health information is protected. Within the rules and commentary are sections relevant to IG management, namely that⁽⁵⁶⁾:

- any staff involved in the collection of personally identifiable health information are adequately trained in privacy issues
- appropriate security policies and procedures are in place in organisations collecting, using or disclosing personally identifiable health information. The commentary also suggests appropriate content for such policies
- policies and procedures are in place to deal with any privacy breaches that may occur
- within each health agency, there is at least one person to be known as the “privacy officer” within that agency whose responsibilities include⁽⁶¹⁾:
 - encouraging the agency to comply with the code
 - dealing with requests made to the agency under the Act and code
 - working with the Privacy Commissioner in relation to any investigations conducted under the Privacy Act in relation to that agency
 - otherwise ensuring compliance by the health agency with the Act and the code.

These guidelines around training, appropriate policies and procedures and responsibility and accountability are key tenets of IG management and this commentary within the code provides for the implementation of these principles at a provider level.

5.5 The Health Network Code of Practice

The Health Network is a communications infrastructure which allows health information to be exchanged between healthcare providers in a secure way. Included on the Health Network are applications such as the National Health Index Online Access Health (NOAH) system which allows providers access to the national registry of unique identifiers⁽⁶²⁾. The New Zealand Ministry of Health is responsible for the management of the overall governance of the Health Network. Users of the Health Network must be registered and must comply with certification and security requirements for their local environments. Each member is subject to conformance checks against criteria contained in the *Health Network Code of Practice*⁽⁶³⁾.

The *Health Network Code of Practice*, published by Standards New Zealand, is based on New Zealand health and privacy legislation, industry principles for the protection of personal health information and the International Standards Organisation (ISO) information technology standards. Health Network members need to demonstrate that they have policies and procedures in place to address third party access, personnel security, physical and environmental security, systems development and maintenance and technical compliance as well as risk management for any security breach⁽⁶²⁾. This provides a requirement for providers to demonstrate compliance with a number of the principles of IG management.

5.6 The Privacy, Authentication and Security (PAS) Policy

The Privacy, Authentication and Security (PAS) Policy is under development by the Ministry of Health with the purpose of bringing together and acting as a single reference point for all national guidelines on health information privacy and security policy. This includes the consolidation of the information contained in both the *Health Network Code of Practice* and the *Health Information Privacy Code*⁽⁶⁴⁾.

The PAS policy principles contain the following planned initiatives that relate to IG management⁽⁶⁵⁾:

- training measures required for those involved in the collection, use or disclosure of health information and provision of training guides
- a code of practice for each major participant involved in implementing or using information systems for the health sector
- practical implementation guidelines

- definition of accountability for developing and implementing policy
- a self-assessment checklist for the sector and the implementation of a national register of systems that contain confidential patient data
- an approach to monitoring privacy and security compliance.

5.7 Summary

Although the term IG management is not used in New Zealand, the principles associated with it are recognisable in a number of areas. These include:

- The Health Information Standards Organisation (HISO) (2010)
- *The Health Information Privacy Code*
- *The Health Network Code of Practice*
- The Privacy, Authentication and Security (PAS) Policy.

In particular, the most prominent IG management themes evident in all of the identified resources are on staff education and training in IG, responsibility and accountability and compliance with privacy legislation. The current activities of the new HISO (2010) support the idea that robust IG management is important to the development of a strong IG framework in New Zealand.

6. International Resources

Although IG management is not a term widely used outside of the United Kingdom, its principles and associated practices are identifiable in IG strategies and frameworks in other countries, such as those documented in Canada and New Zealand. Similarly, developments have occurred that are not attributable to a specific country, for example ISO standards and other review documents. Two such developments are discussed in the sections that follow in terms of their applicability to IG management.

6.1 ISO/IEC 38500: Corporate governance of information technology

The objective of the ISO standard⁽⁶⁾ is to provide a framework of principles for Directors to use when evaluating, directing and monitoring the use of information technology in their organisations. It is also intended to inform and guide those involved in designing and implementing the management system of policies, processes and structures that support governance. It is applicable to organisations of all sizes from the smallest to the largest regardless of the extent of their use of IT.

Although this standard specifically relates to governance arrangements around IT, the recommendations if implemented would contribute to strengthening health IG arrangements – particularly in respect of IG management. The standard specifies three main tasks that the management of organisations should undertake in respect of the governance of IT⁽⁶⁾:

- evaluate
- direct
- monitor.

These actions can be applied to the management of IG in that the management team of the organisation should continually evaluate the IG needs and responsibilities of the organisation, the development and implementation of appropriate policies and procedures should be appropriately directed by senior management. Compliance should then be monitored on an ongoing basis in order to develop improvement plans where necessary.

The standard sets out a framework for good corporate governance of IT, the first principle of which is responsibility. The need for monitoring acknowledgement and understanding of responsibilities is discussed with emphasis on monitoring the performance of those with specific responsibilities. This assists in building a culture of accountability. Through these themes the ISO standard is applicable to the development of an IG management framework, the development and implementation of associated policies and procedures, the assignment of responsibility for the various aspects of IG and the ongoing monitoring and assessment of compliance.

The standard further reinforces the themes of responsibility and accountability under the principle of conformance. This principle recommends regularly evaluating the extent to which legal and professional obligations are being met and the organisation's internal conformance to its own systems. The necessity to establish regular and routine mechanisms to do this is also discussed in addition to the need for associated policies to be developed and raising staff awareness of the relevant guidelines to be followed. These themes and principles resonate those identified in the course of this IG management review as documented in the previous sections.

6.2 Information governance – the foundation for effective e-health

In August 2010, Accenture⁹ published a report outlining the challenges faced by organisations planning investment in e-health solutions, many of which are IG issues. The report identifies five interrelated disciplines of IG and provides a framework for organisations to implement the necessary changes in relation to these disciplines⁽⁷⁾. The report essentially puts forward an Accenture IG Framework – a layer of processes, functions, policies and solutions that ensure the effective and secure creation, storage, communication, valuation and use of information⁽⁷⁾. The framework disaggregates IG into five disciplines as follows:

- data privacy
- data confidentiality
- data security
- data quality
- data integrity.

Although a number of these can be related to the generic themes identified in other countries, their components are focused very specifically on e-health and its associated challenges. The report does however set out a step-by-step process for developing effective IG that could be applied to any organisation.

⁹ Accenture is a global management consulting, technology services and outsourcing company. The Accenture Institute for Health & Public Service Value is dedicated to promoting high performance in the health care sector and in public service delivery, policy-making and governance. Through research and development initiatives, the Institute aims to help health care and public service organisations deliver better social, economic and health outcomes for the people they serve⁽⁵⁹⁾.

The process is in essence a guide to developing an IG framework, which is a useful tool in IG management. The high level steps are⁽⁷⁾:

- conduct a comprehensive risk assessment and gap analysis of current information governance provisions
- identify, analyse, evaluate and prioritise IG challenges
- design solutions and develop strategies to address these challenges
- develop a detailed implementation plan
- realise the benefits of effective IG.

This report, and the Accenture IG Framework, although specifically designed around e-health, is also a useful IG management tool for healthcare organisations in general terms.

6.3 Summary

The ISO standard and the Accenture IG framework are recent publications which reflect the continued shift in culture towards recognising the importance and necessity of IG. Both are focused on the governance of electronic information with the ISO standard dealing with the governance of IT and the Accenture framework tackling the IG issues around e-health. While the information and advice is very detailed in both and geared specifically toward e-health and IT the general principles are the same and both are useful references for IG management in terms of developing an IG framework, the various areas of responsibility and the structures, policies and procedures that are required for IG to operate effectively in an organisation.

7. Conclusion

The purpose of this document is to explore the experience internationally of IG management and its associated principles and practices. This review is the first step in the process of developing national standards for IG management for the health and social care sector in Ireland as part of a suite of IG standards. IG management can be described as the overarching IG theme. It is important as a theme in itself in that it brings together each of the other aspects and enables IG as a whole to operate effectively and efficiently as part of the culture of any organisation. The countries reviewed in detail were England, Scotland, Canada and New Zealand, and the review also explored additional resources that could be used internationally. Although the term IG management is not used in all of these jurisdictions, the key principles are addressed in the various IG policies and strategies.

7.1 Findings

Of the information that was sourced in the course of this research the following are the key points:

- IG Management
IG management is a recognised IG topic in England and Scotland. Although it is not acknowledged in its own right in Canada and New Zealand, its principles and associated practices are recognisable in their IG strategies and policies
- Standards
Guidance documents, policies and strategies in England and Scotland discuss IG management and set out requirements in this area (as do those in Canada and New Zealand, under various headings) but there are no formal national standards, such as those that will be developed by the Authority
- Responsibility
Responsibility for IG is assigned to various persons within organisations, for example Caldicott Guardians in England and Scotland and Privacy Officers in New Zealand. Responsibility is assumed by a number of committees in organisations in Canada, for example the Canadian Institute for Health Information (CIHI), however it is not clear if this is echoed throughout the Canadian health and social care sector
- Policies and Procedures
IG management policies and procedures have been developed at a provider level based on national guidance and codes of practice in England and Scotland. There is scope for providers in Canada to build on policies developed by organisations such as CIHI as these are based in legislation. It is likely that this will happen in the coming years as Canada is working towards a more pan-Canadian approach to IG

- Training and Education

In each of the countries explored, the importance of training and education in the area of IG is highlighted. Specific training and development programmes have been developed in recognition of this in both England and Scotland, while the issue is addressed in a number of policies and strategies in both Canada and New Zealand

- Assessment and Compliance

Self-assessment of compliance with national (where available) and local standards and guidelines is a recurring theme in each of the countries, for example the IG Toolkit in England and Scotland. Self-assessment is also discussed in the international resources included in this review emphasising the need to continuously monitor progress in this area and develop improvement plans as appropriate.

7.2 Next Steps

Prior to commencing the development of IG management standards and supporting guidance, the Authority sought to inform itself, through this review of the international experience. Having completed this review, the next step for the Authority was to identify the themes, that is, the areas to be covered under the umbrella of IG management.

To this end the Authority conducted an appraisal of the resources identified in the international review and assessed their applicability and relevance to the Irish health and social care system. The high level themes of each of the selected resources were then identified and tabulated to establish the frequency of occurrence thereby identifying the common trends and the key themes. The recording and tabulation of themes is documented in Appendix 1.

The key themes identified are as follows:

- IG management standards/framework
- Responsibility and accountability
- Policies and procedures
- Training and education
- Self assessment/compliance
- Transparency around information practices.

The next step is for the Authority to commence drafting the standards and supporting guidance, based on the themes that have been identified. This work will be completed in consultation with stakeholders.

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Appendix 1: Identification of Themes

	IG Management Standards / Framework	Policies and Procedures	Training and Education	Responsibility and Accountability	Self Assessment / Compliance	Transparency around Information Practices
IG Toolkit	Y	Y	Y	Y	Y	
NHS Connecting for Health IG Training Tool		Y	Y			
NHS QIS Clinical Governance and Risk Management Standards	Y					
NHS Scotland IG Standards	Y	Y	Y	Y	Y	
The Caldicott Framework (Scotland)	Y			Y		
The Competency Framework for Information Governance	Y		Y	Y		
White Paper on Information Governance of the iEHR	Y	Y		Y	Y	
Canadian Standards Association's Model Code for the Protection of Personal Information	Y			Y	Y	Y
CIHI Privacy Program	Y	Y	Y	Y		Y
Health Information Privacy Code	Y	Y	Y	Y	Y	Y
Health Network Code of Practice	Y	Y			Y	
PAS Guide	Y	Y	Y	Y	Y	
ISO/IEC 38500	Y	Y		Y	Y	Y
Information Governance – the foundation for effective e-health	Y	Y				

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For further information please contact:

**Health Information and Quality Authority
George's Court
George's Lane
Dublin 7**

Phone: +353 (0)1 814 7400

URL: www.hiqa.ie

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