Sharing Patient Health Information:
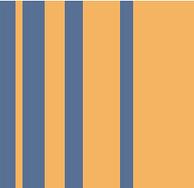# A review of health information privacy and electronic health records in New Zealand

May 2010

PALLIATIVE CARE COUNCIL
OF NEW ZEALAND

The Palliative Care Council of New Zealand
The Palliative Care Council (PCC) was established in 2008 by Cancer Control
New Zealand (formerly the Cancer Control Council of New Zealand) to provide
independent and expert advice to the Minister of Health, and to report on
New Zealand's performance in providing palliative and end of life care.

Contents

Glossary

ACC	Accident Compensation Corporation
DHB	District Health Board
EHR	Electronic health records
GP	General Practitioner
GP2GP	General Practitioner to General Practitioner Patient Notes Transfer Project
HIMSS	Healthcare Information and Management Systems Society
HISAC	Health Information Strategy Advisory Committee
HIS-NZ	Health Information Strategy for New Zealand
HISO	Health Information Standards Organisation
HL7	Health Level 7
ICD-10	International Classification of Diseases 10th revision
ICT	Information and communications technology
IHTSDO	International Health Terminology Standards Development Organisation
ISO	International Organization for Standardization
LOINC®	Logical Observation Identifiers Names and Codes
NGO	Non-government organisation
NHI	National Health Index
PRIMHD	Programme for the Integration of Mental Health Data
PrISM	Primary Information Systems Management
PROBE	Provincial Broadband Expansion project
SNOMED CT	Systematized Nomenclature of Medicine (Clinical Terms)
WAVE	Working to Add Value through E-information

Executive Summary

With the growing use of information and communication technology in health, the issues of access to, and sharing of, patient information are becoming increasingly important. The Palliative Care Council of New Zealand is aware that the inability of health care services to quickly and easily access patient health information can compromise treatment and care decision-making, especially when urgent treatment is required.

This report highlights and addresses concerns about the privacy and security of individuals' health information, and reviews the current state of electronic health records (EHR) in New Zealand, including a nationally disseminated system.

Information privacy and security

Concerns about EHRs are strongly focused on the privacy and security of personal information. Surveys conducted in New Zealand have identified quite high levels of concern among both the general public and health and disability staff about unauthorised access to, and use of, personal health information.

New Zealand does have quite well developed privacy legislation, which is primarily set out in the Privacy Act 1993 and further defined for the health sector in the Health Information Privacy Code 1994. The Health Act 1956 also contains clauses related to personal health information. This legislation supports the appropriate sharing of health information; however, it is often misinterpreted and is used instead as a way of declining information requests.

Although the privacy legislation is quite robust, there are some important caveats that must be considered in order to maintain the trust and confidence of the general public in relation to use of their personal health information. These caveats relate to the willingness and comfort of the general public to allow sharing of their health information. The role of the person requesting information, content of the information, and the level of individual identification are all important modifiers of willingness to allow sharing of health information. Additionally, Māori have expressed concern about rights of access to, and use of, personal health information. The principle of rangatiratanga, whereby Māori are guaranteed the right of ownership over their taonga, or knowledge, has been interpreted as meaning health-related data about Māori belongs to Māori, especially when it is used as grouped data.

A key message for health professionals and health and disability service providers is that *people feel that their health information belongs to them*, and health care providers must act as responsible custodians of that information. In addition, the New Zealand public *does* want to be informed about how their personal health information is going to be used, as well as being given the opportunity to consent, or not, to those uses.

Electronic health records

An EHR is a longitudinal collection of personal health information that is recorded, stored and accessed via a digital database. Information in the EHR may be both contributed by, and accessible to, multiple health care providers. Ideally, an EHR would be distributed across all health settings and be *centred on the person*, rather

than being a series of isolated information repositories located within various health care agencies.

Benefits of EHRs

Key benefits of improved information and communication technology in the health sector have been identified and include:
- improved coordination, cooperation and collaboration between services
- better access to more accurate and timely patient information, especially in remote areas
- improved safety and quality of care
- cost, time and workflow efficiencies
- improved clinical processes
- reduced hospital admissions, as more services will have timely access to patient information
- improved regional and national level data collection that could inform research, health promotion, performance assessment, policy development and business decision-making
- potential for more patient interaction.

EHR barriers

While there are potentially many benefits of a national EHR, there are currently some significant barriers to the implementation of such a system. Alongside concerns about privacy and security of health information, the two most important barriers are the:
- compatibility and connectivity of the multiple systems used across the health sector
- development and implementation of nationally agreed standards.

Other barriers include a lack of funding and resources for health information and communications technology (ICT), resistance by health care staff to take up ICT initiatives, challenges with computer literacy and access to equipment and training, and a lack of national leadership and direction for health ICT development in New Zealand.

Health information transfer in New Zealand

New Zealand has a relatively high level of modern technology available in the health sector and quite widespread electronic connectivity. The National Health Index (NHI) number puts New Zealand in a rare position of having an established national unique patient identifier. This is a cornerstone of any nationally disseminated system that allows all information on a particular person to be connected.

Strategic direction

Informing the development of health ICT in New Zealand are a number of key documents, including:
- *From strategy to reality: The WAVE project* (The WAVE Advisory Board to the Director-General of Health, 2001).
- *Health information strategy for New Zealand* (Health Information Strategy Steering Committee, 2005).

In addition, the Ministerial Review Group report (2009) has a focus on 'patient-centric' care, and recommends that "Health professionals across the different institutional settings would find it much easier to provide seamless care if they shared easy access to a common patient record".

Systems compatibility and connectivity

Internationally a great deal of work has been done on developing standards for health ICT to provide a 'common language' between systems. This includes clinical terminology, such as SNOMED-CT and LOINC®, and data exchange, for example Health Level 7 (HL7). The identification, preparation and publishing of health information-related standards in New Zealand is undertaken by the Health Information Standards Office (HISO). Overseeing the work of HISO is the Health Information Standards Governance Group.

Connectivity has been addressed in several key government ventures. The New Zealand Health Network is a secure broadband network for the collection and sharing of electronic health information within the health and disability sector. The Ministry of Health is currently developing an enhanced network called 'Connected Health'. In addition, the Provincial Broadband Expansion (PROBE) project, completed in 2005, provided the infrastructure for broadband internet access in provincial communities including health services. The government is now planning to bring ultra-fast broadband to 75 percent of New Zealanders over the next 10 years with a national fibre-optic network; health care providers are key stakeholders in this project.

While a recent survey of health care providers in New Zealand found widespread support for improved connectivity, communication and access to patient information, it also reiterated the barriers that continue to prevent this being achieved:
- Technology use varied widely across the sector and many respondents expressed frustration with incompatible systems.
- Responders indicated that privacy/security concerns and cost were major barriers to adopting new technology.
- Many organisations ran parallel paper and electronic systems due to issues with incompatible systems.
- The health and disability sector wanted the Ministry of Health to provide leadership and strategic direction in ICT developments.

Conclusion

New Zealand appears to be well positioned to enhance health information and communication systems to allow for much better and timelier access to patients' health information. However, at present a single nationally distributed EHR is not feasible. Instead, a system of multiple linked regional or organisation specific EHRs could be developed to construct a 'virtual' national EHR that would achieve many of the identified benefits of a single national system. In addition, a system providing a brief summary of a medical record, rather than full access to complete medical records, may be more acceptable to the general public.

First though, several fundamental barriers need to be addressed, including system compatibility and connectivity, the adoption of ICT standards, and ensuring information privacy and security is maintained. Further, there must be national

leadership and appropriate funding and resourcing for health ICT. There is also a need for information technology vendors, and system and software planners and purchasers to recognise the need for compatibility and connectivity of systems.

Education of both the public and health and disability sector is required to ensure appropriate understanding and interpretation of privacy legislation. One component of this is to ensure that individuals from whom health information is collected are fully informed about what their health information will be used for and who it may be shared with. A second is that health and disability staff must understand their obligations and how to respond appropriately to information requests.

New Zealand's capability to develop a national EHR is on a relatively firm path, with a number of important 'building blocks' already in place. Further development is going to require collaboration across government, health service providers and system vendors, as well as leadership and a strategic vision.

Introduction

The Palliative Care Council of New Zealand has been conducting a series of 'fact finding' visits with palliative care service providers across New Zealand in order to develop a national picture of issues and barriers to the delivery of high-quality palliative care. One issue that arose early in the visits was the timely access to patient information for patients being admitted to palliative care services, or for palliative patients presenting at emergency and outpatient departments requiring urgent medical care. The delay in access to this important patient information may adversely affect treatment decision and care. With health records being held by multiple organisations and services across primary and secondary care, the Palliative Care Council wanted to know what the barriers were to accessing and sharing patient health information across different settings, and whether there were ways of overcoming them.

With the growing use of information and communication technology in health, the issues of access to, and sharing of, patient information are becoming increasingly important. The volume of information available at the click of a mouse, and the ease with which that may occur, pose both positive and potentially negative outcomes. Two key issues related to the sharing of individuals' health information appear to be the interpretation and application of privacy legislation and the implementation of electronic health records. This paper presents a brief review of these two topics and how they impact on the efficient sharing of patient health information.

Background

At present in New Zealand there is a mix of both paper and electronic medical records in use, which may be held by multiple health care agencies. The result of this situation is a fragmented picture of an individual's health history and an incomplete view of the person's health by each agency (Chhanabhai et al., 2006). This has the potential to adversely impact on clinical decisions and limit opportunities for proactive health care, such as prevention and health promotion activities, across multiple agencies. Electronic health records (EHR) present an opportunity to improve safety and efficiency of health care delivery, and if appropriately designed and used, to also improve quality of care (The WAVE Advisory Board to the Director-General of Health, 2001). There are, however, a number of issues and concerns related to a national EHR, that will need to be addressed if such a project, in whatever form it may take, is to be successful. Some of the most significant concerns focus on the privacy and security of confidential health information.

Information Privacy and Security

Both health care professionals and the general public hold concerns about the privacy and security of electronic health information and the unauthorised access to, and use of, personal health information (UMR Research, 2009; Chhanabhai et al., 2006). The New Zealand public hold particular concerns about their information being 'leaked out' or shared without their knowledge, and the possibility of EHR information being accessed by a system vendor or hacker, and malicious software that may access or harm an EHR system (Chhanabhai & Holt, 2007). Clinicians' main concerns focus on patient consent, access rights, the level of patient information that should be accessible, and the security of data transfer (UMR Research, 2009). Others have also expressed concerns about patient consent for records held on a nationwide system, and the use of information in ways that were not originally intended (or consented for) (Privacy Commissioner, 2007; Chhanabhai et al., 2006; Davenport, 2003).

A survey of the general public, conducted in 2007, has confirmed concerns about the security and privacy of health information, and also found a higher level of concern for electronic records (Chhanabhai & Holt, 2007). However, respondents to this survey believed that appropriate security systems would make EHRs safer. Interestingly, over 60 percent of the survey respondents had never heard of EHRs. This is of concern given that almost all health care providers in New Zealand are now using some form of electronic record and health consumers should be made aware of how their health information is being used. Also of concern is that the general public does not feel well informed about how their personal health information may be used (Whiddett et al., 2006).

The previous Privacy Commissioner, Bruce Slane, held health information systems as one of his 'top three' privacy issues, due largely to the absence of public consultation and understanding of the development and use of EHRs – clearly evidenced by the above survey findings. In particular, his concerns centred on consent, the ability to collate all information on an individual from diverse databases, and the potential use of information by other organisations where that use was not originally intended (Slane, 1999).

Health information privacy in New Zealand

New Zealand does have quite well developed privacy legislation, which is primarily set out in the Privacy Act 1993 (New Zealand Government, 1993), and further defined for the health sector in the Health Information Privacy Code 1994 (Privacy Commissioner, 2008), which is closely based on the Privacy Act's information privacy principles. The Health Act 1956 also contains clauses related to personal health information. Nevertheless, problems do exist in the interpretation of these documents, which has resulted in the inappropriate withholding of information (The WAVE Advisory Board to the Director-General of Health, 2001). This misinterpretation is a result of poor awareness and understanding of the relevant privacy legislation by health providers and the general public. In a presentation to the 7th Annual New Zealand Medico-legal Conference, Bruce Slane pointed out that the Health Information Privacy Code does not restrict health professionals from appropriate sharing or disclosing patient information, but it does require them to inform the patient of such sharing or disclosures (Slane, 1999).

The Health Information Privacy Code 1994 deals with privacy in relation to the use of NHI numbers and the privacy and safety of personal health information. Particular examples of rules relevant to EHRs include (Privacy Commissioner, 2008):

- Rule 3 - obliges health agencies to inform individuals why information is being collected, what it will be used for, who will see it, responsibility of the individual disclosing information and rights of access.
- Rule 5 - ensures that health agencies take reasonable steps to ensure security of health information.
- Rule 10 - sets limits on how health information is used to ensure that it is used for the purpose for which it was gathered, unless specific exceptions apply.
- Rule 11 - sets limits on the disclosure of health information, as well as exceptions.

In addition, section 22F of the Health Act requires holders of health information to disclose that information in response to a legitimate request by "the individual about whom the information is held, or a representative of that individual, or any other person that is providing, or is to provide, services to that individual …" (New Zealand Government, 1956, p.38). It also contains clauses relating to the refusal of disclosure. See the case study in Appendix 1 for an example of how appropriate interpretation of the privacy legislation can assist in improving information sharing to impact positively on patient care.

Health information security

In addition to Rule 5 of the Health Information Privacy Code, the health sector also has a number of existing guidelines for the safe and secure use of electronic health information. In 2009 HISO published the *Health information security framework*, which aims to "ensure that health information is produced, stored, disposed of and shared in a way that ensures the information's confidentiality, integrity and availability" (HISO, 2009c, pg 3). The New Zealand Health Network also has a *Security policy for general practitioners and other health professionals*. Any organisation wishing to join the Network must meet the assessment requirements of the Health Network Code of Practice on an annual basis.

Health information and the general public

While all of the above demonstrates a fairly robust approach to health information privacy, there are some important caveats that must be considered in order to maintain the trust and confidence of the general public in relation to use of their personal health information. These caveats can be drawn from research conducted in New Zealand, which has demonstrated varying levels of agreement and comfort about health information sharing among the general public. Important findings from a survey by Whiddett et al. (2006) indicate that respondents were:

- willing to share all of their information with health professionals, especially if they were consulted first

- willing to share their information with health administrators and researchers if they were consulted first

- less willing to share information with other organisations (such a government agencies or private health insurers)

- increasingly reluctant to share information as it became more sensitive in nature, except with health professionals, especially their GP/practice nurse.

A more recent survey that investigated similar issues also found that the role of the person requesting the information, content of the information, and level of identification of health information were all important modifiers of willingness to allow sharing of information (Hunter et al., 2009). In summary, this study found that agreement to share information was:

- higher when the requestor was a health professional

- higher for sharing information as a brief summary of medical history, rather than a complete medical history

- less when identification was by name and address and higher when a medical record number was used or information was anonymised

- higher when the reason for accessing health information was directly related to clinical care.

The survey also found that respondents, if they were Māori, or aged 75 or older, were more likely to agree to share their personal health information, even when they felt less comfortable doing so, when information was requested by a health professional,. This was not so for the 18-19 year-old age group, who demonstrated low willingness to share their health information in any circumstance.

Māori have expressed concern about rights of access to, and use of, personal health information stored on individual organisation or centralised database systems. This issue is founded on the principle of rangatiratanga, whereby Māori are guaranteed the right of ownership over their taonga, or knowledge, which in this case is the health-related data about their people that is collected, stored and used as grouped data (Kamira, 1999). At its lowest level, Māori believe that their personal health information belongs to the individual it was collected from, while anonymised grouped data about Māori may belong to the whānau, a hapu, or an iwi. Therefore, Māori want to be consulted about the use of health-related data when it pertains to their people. Another very important issue is that when grouped health data, or collective knowledge, about Māori is used there must be some benefit to Māori (Kamira, 1999).

All of the issues discussed above are significant because if a patient does not feel comfortable with the use of their health information they may be reluctant to share sensitive information that is vital to treatment and care decisions, or they may delay or forgo treatment altogether (Hunter et al., 2009). Care must be taken in relation to who has access to personal health information, and how it is used to ensure there are benefits to those whose information has been used. While this concept is of particular concern to Māori, it should apply across all ethnic and population groups in New Zealand.

A key message for health professionals and health and disability service providers is that *people feel that their health information belongs to them*, and health care providers must act as responsible custodians of that information (McKechnie, 2009). In addition, the New Zealand public *does* want to be informed about how their personal health information is going to be used, as well as being given the

opportunity to consent, or not, to those uses. It is therefore important that any information and communications technology (ICT) project involving personal health information must be cognisant of the general public's views.

Electronic Health Records

Generally speaking, a health record is a longitudinal collection of patient health information generated by one or more encounters with a health service, with the record being maintained by health care providers. In most cases, these records are held by individual organisations or services. An electronic health record (EHR) follows this same basic principle, but the health information is recorded, stored and accessed via a digitalised database. Like any health record, information in the EHR may be both contributed by, and accessible to, multiple health care providers with appropriate security safeguards. Ideally, it will also allow for patient/consumer access. A comprehensive definition of an EHR has been proposed by the Healthcare Information and Management Systems Society (HIMSS).

> *The Electronic Health Record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports. The EHR automates and streamlines the clinician's workflow. The EHR has the ability to generate a complete record of a clinical patient encounter - as well as supporting other care-related activities directly or indirectly via interface - including evidence-based decision support, quality management, and outcomes reporting* (HIMSS, 2010).

Ideally, an EHR would be distributed across all health settings so that instead of a series of isolated information repositories *located within various health care agencies* a person may have visited, a nationally distributed EHR would provide a longitudinal record of *all* relevant health information and be *centred on the person*. An important part of any exercise involving the collection, storage and sharing of information on patients is that each individual must be able to be correctly identified by all parties involved. Therefore, a key component of an EHR is the ability to accurately identify any individual patient and link all of their information together through the use of a unique identifier.

Core components of an EHR are listed in Box 1. These components may be provided by one system or through integration of a number of ancillary systems.

Benefits of EHRs

A recent survey of New Zealand clinicians identified five key benefits of improved ICT in the health sector (McKenna, 2009):

- improved coordination between health care providers

- improved quality of care

- time efficiencies

- improved clinical processes

- better access to patient information, especially in remote areas.

In addition, other potential benefits of a national EHR may include: (UMR Research, 2008; Kerr, 2004):

- improved documentation of, and access to, clinical data, aggregated at regional and national level

- improved patient safety, such as the use of electronic prescribing and access to patient information including medical history, allergies and alerts, medications, etc

- improved cooperation and collaboration between clinicians and services; notably this would be between primary and secondary care services

- cost, time and workflow efficiencies, in particular related to prescribing, test-ordering and health-promoting interventions.

- clinical decision-making support functions, such as treatment algorithims

- reduced hospital admissions/ readmissions, as more services will have timely access to patient information to enable better treatment decisions, including GPs, ambulance and rural hospitals

- collection of anonymous patient information that could be used for health outcomes research, targeted health promotion programmes, clinical performance assessment, national policy development, and business decision-making

- shift in focus towards more holistic, proactive disease management

- potential for more patient interaction through access to personal records and targeted health information.

Box 1: Components of an EHR (based on National Institutes of Health, 2006)**.**

- **Administrative system**: includes registration, admissions, discharges and transfer data

- **Laboratory system**: integrates lab orders, results, schedules, billing and administrative information

- **Radiology system**: provides ordering, reporting and images

- **Pharmacy system**: providing electronic prescribing and associated medicines information, dispensing, billing and administrative information

- **Electronic health care practitioner order entry**: for example for laboratory, pharmacy and radiology orders

- **Clinical documentation**: electronic capture of clinical notes, which may include clinical assessments, clinical reports, care planning, medicine administration, consents, advance care planning, allied health professional notes. etc.

EHR barriers

While these potential benefits present a very positive picture of EHRs, and in particular the possibilities for improved patient safety and care with a national EHR, there are currently some significant barriers to the implementation of a nationally disseminated EHR. These barriers are common across all countries working on ICT in health care. Alongside the previously noted concerns about privacy and security of personal health information, the two most important of these barriers are (UMR Research, 2008; Warren et al., 2008; National Institutes of Health, 2006):

- issues of compatibility and connectivity between the multiple systems in use across the health sector

- the development and utilisation of nationally agreed standards

Across the health sector a multitude of hardware and patient management systems/electronic health records programmes are in use, supplied by a variety of vendors and set up as isolated, organisation or service-specific systems. This presents a number of obstacles related to interoperability and information sharing. In addition, many health care agencies still maintain hard copy records, sometimes alongside electronic records. This potential duplication can necessitate clinical records being photocopied or printed and sent as hard copy and then potentially scanned into another electronic database, all of which is time consuming and involves the potential for breaches of security and privacy of information. Another issue is the necessity for secure, high-speed networks for data transfer.

Standards are a vital first step in the process of establishing interoperability of systems, software components and between disparate services. The availability of agreed, ideally robust, international standards is fundamental because of the requirement for a 'common' language by which the systems, software and services can communicate (Beale, 2009). This includes not just standardised clinical terminology, but also the means by which systems and software interact; how they package, send and unpack data in a way that maintains context and content, as well as allowing for analysis of what is often complex information possibly from numerous sources (National Institutes of Health, 2006). Standards are also required for security and confidentiality of information, in addition to an overall governance structure to ensure quality and accountability.

Other important barriers that have been identified within the New Zealand health care environment, include: a lack of funding and resources for health ICT; resistance by health care staff to take up ICT initiatives; challenges in data entry related to computer literacy, equipment and access to training; some health care sectors being left out (such as ambulance, not-for-profit organisations and central agencies); and a lack of leadership and direction for health ICT development (McKenna, 2009; UMR Research, 2008; Kerr, 2004).

Health Information Transfer in New Zealand

While the establishment of a nationally distributed EHR is not likely to occur in New Zealand in the near future, there has been quite an amount of work done to set in place the foundations for the development of health ICT in this country.

Unique identifier – the National Health Index (NHI)

Since 1977, New Zealand has employed a national unique health identifier, now known as the National Health Index (NHI) number. An associated NHI database contains basic demographic data about individuals, as well as being linked to a medical warning system (New Zealand Health Information Service, n.d.). This database is maintained by the Information Directorate of the Ministry of Health (previously by the New Zealand Health Information Service). The NHI serves to: 1) identify individuals and relate their personal information to a unique identifier, 2) link data held about the same individual in different databases, and 3) ensure longitudinal consistency of information held about individuals, for example if they change their name, say by marriage, their NHI remains constant and is linked to their new name.

In relation to the use of the NHI, there is concern that many people in New Zealand are unaware of the NHI and how it is used in relation to their personal health information (Hunter et al., 2009; Whiddett et al., 2006).

Strategic direction

In 2001, the Director-General of Health commissioned a five-year strategic plan for information and technology developments; the Working to Add Value through E-information (WAVE) report (The WAVE Advisory Board to the Director-General of Health, 2001). In relation to EHRs, the WAVE report recommended:

- implementation of capability and connectivity within the health sector

- development of standards

- District Health Boards (DHBs) documenting commitment to capability, connectivity, and standards development, as well as implementation plans for ICT

- GPs should be encouraged to adopt electronic clinical record software

- hospitals should implement clinical data repositories or an integrated clinical interface

- adoption of HL7 v3 electronic health information standards

- ensuring organisational capability to develop EHRs in the health and disability sector.

Following on from the challenges and priorities identified in the WAVE report, and as an update to the 1996 *Health information strategy for the year 2000*, the *Health Information Strategy for New Zealand* (HIS-NZ) was launched in 2005. The strategy aims to support a nationally coordinated approach to health ICT with a focus on "better use of information between service providers across the New Zealand health

and disability sector" (Health Information Strategy Steering Committee, 2005). Building on the WAVE report recommendations, the strategy suggests that the key components for integrating health sector information systems are:

- standards for information exchange ⎫ **foundations**
- privacy and security safeguards ⎬
- national connectivity ⎫
- applications that support productivity ⎬ **structural elements**
- national data collections ⎭
- capital investment framework ⎫
- accountability frameworks ⎬ **governance framework**
- collaboration frameworks ⎭

In addition to the documents noted above, the 2009 Ministerial Review Group report has an explicit focus on 'patient-centric' care and has made many recommendations aimed at improving the patient experience through better coordinated care. The Review Group specifically recommended that "Health professionals across the different institutional settings would find it much easier to provide seamless care if they shared easy access to a common patient record" (Ministerial Review Group, 2009). One component of this recommendation is the development of shared electronic access to a common patient record.

Development of standards

Internationally a great deal of work has been done on developing standards for health ICT, including clinical terminology and data exchange. Two key standards for clinical terminology are Systematized Nomenclature of Medicine (Clinical Terms) (SNOMED CT) developed by the International Health Terminology Standards Development Organisation (IHTSDO, n.d.) , and Logical Observation Identifiers, Names, and Codes (LOINC®), which aims to standardise laboratory, clinical observation and diagnostic study results (Regenstrief Institute, Inc., 2010). There are also a number of organisations producing standards for data exchange designed to provide a 'common language' between systems. The more prominent of these include HL7 (http://www.hl7.org), openEHR Foundation (http://www.openehr.org), the European Committee for Standardization (http://www.cen.eu) and the Healthcare Information Technology Standards Panel (http://www.hitsp.org).

In 2005, the Health Information Strategy Advisory Committee (HISAC) was established to support implementation of the Health Information Strategy (Cizadlo, 2009). This Committee acts as an independent strategic advisory group to the Minister of Health. HISAC's vision is "To achieve high quality health care and improve patient safety, by 2014 New Zealanders will have a core set of personal health information available electronically to them and their treatment providers regardless of the setting as they access health services" (HISAC, 2009a). Another recommendation of the Ministerial Review Group Report was that HISAC be disbanded and that the proposed National Health Board establishes a new committee to oversee planning, funding and sector work on the health IT agenda (Ministerial Review Group, 2009). The Minister subsequently appointed HISAC as the new National Health IT Board.

The Health Information Standards Organisation 2010 (HISO (2010)) is the current incarnation of the previous Health Information Standards Organisation, which was formed in 2003 (Cizadlo, 2009). HISO is located within the Ministry of Health's Information Directorate and its role focuses on identifying, preparing and publishing health information related standards and providing advice to the National Health IT Board. Overseeing the work of HISO is the Health Information Standards Governance Group, which provides overarching governance and direction for health information standards in New Zealand (HISAC, 2009b). The Governance Group also endorses standards, which are subsequently published by HISO.

In an effort to encourage consumer input into health ICT, HISAC is currently running a project called the Health Information Consumer Forum. The Forum provides an opportunity for consumer groups and advocates to advise HISAC on ways to engage with the general public on the development of the health information environment in New Zealand (HISAC, 2009c).

The following standards have been developed and published, or endorsed, by HISO (HISO, 2009a).

- New Zealand Medicines Terminology Recommendation Report HISO 10024
- Health Information Security Framework 10029 - formerly known as the Authentication and Security Standard
- ePharmacy Business Process and Messaging Standard
- Programme for the Integration Mental Health - PRIMHD
- Data Concept Repository Process Standard
- Pathology and Radiology Messaging Standard
- Referrals, Status and Discharges (RSD) suite of standards
- Endorsement of ICD-10-AM and ICD-O
- Health Level 7 v3 Endorsement
- Health Practitioner Index Data Set and Code Set
- Primary Health Care Practice Management Systems - Publicly Available Specification
- New Zealand Pathology Observation Code Sets (Orders and Results) Business Process
- Endorsement for the use of ISO 11179 for use of a HISO guideline
- Health and Disability Sector Ethnicity Data Protocols.

Systems compatibility and connectivity

New Zealand has a relatively high level of modern technology available in the health sector and quite widespread electronic connectivity (McKenna, 2009; Newsham, 2008). A survey on ICT use by the health and disability sector was conducted by UMR Research Ltd, under contract to the Ministry of Health in 2008. The survey was sent to over 7,000 DHB and non-DHB clinicians and ICT decision-makers, of whom 32 percent responded. Ninety three percent of ICT decision-makers indicated that their organisation had internet access, with 88 percent having high-speed internet (most of these were GP organisations) (UMR Research, 2009). The survey found widespread support within the health sector for improved connectivity and communication and access to patient information. It also identified a number of barriers to achieving this:

- Technology use varies widely across the sector and many respondents expressed frustration with incompatible systems.

- Responders indicated that privacy/security concerns and cost were major barriers to adopting new technology.

- Many organisations ran parallel paper and electronic systems due to issues with incompatible systems.

- The health and disability sector wants the Ministry of Health to provide leadership and strategic direction in ICT developments.

While this survey indicates extensive uptake of electronic patient administration systems in both primary and secondary care, compatibility and connectivity continue to present hurdles to achieving an integrated health information network. This situation is further illustrated by Newsham (2008), who proposed a method for evaluating the health informatics systems used by private companies contracted by the Accident Compensation Corporation (ACC) to provide community rehabilitation services. Newsham identified cost, uncoordinated ICT system development resulting in lack of interoperability, and non-standardised record keeping and audit capabilities as barriers to successful implementation of an integrated system. These issues are also common in other countries wanting to develop national EHRs. Nevertheless, New Zealand is making progress in this area, and there are a number of agencies working on these issues.

In relation to compatibility, HL7 appears to be the most commonly adopted standard in New Zealand, with a New Zealand Users Group being established to progress the use of HL7 (http://www.hl7.org.nz/). HL7 has also been endorsed by HISO as the preferred standard for health information communications (HISO, 2009a). HISO is also considering endorsement of SNOMED, and LOINC® is being investigated for use in New Zealand as well.

The issue of improved connectivity has been addressed in several key government ventures. The New Zealand Health Network, previously known as the 'health intranet', was launched in 1999 and is a secure broadband network for the collection and sharing of electronic health information within the health and disability sector (Ministry of Health, n.d.). At present the Health Network provides access to the National Health Index and Health Practitioner Index, Pharmac Special Authorities, and the HealthPAC payment systems. The Ministry of Health is currently working on a new project called "Connected Health", which will take the Health Network to a new level of functionality. The aim of Connected Health is to create interoperability across the whole health and disability sector, using an internet-based 'network of networks' (Ministry of Health, 2008). All providers in the Connected Health network will need to make specific components of their institution's system available to the network independent of their main system. It is proposed that coordinated procurement strategies will be developed as part of Connected Health to ensure consistency in product implementation across the health and disability sector.

Another initiative, called the Provincial Broadband Expansion (PROBE) project, was undertaken jointly by the Ministry of Education and the Ministry of Economic Development and completed in 2005. This projected funded the infrastructure to provide broadband internet access to all schools in New Zealand, and as an offshoot

also allowed provincial communities access to broadband (D. Harré, personal communication, 19 February 2010). This network has been utilised by health services to establish regional networks. In the next stage of evolution, the government is planning to bring ultra-fast broadband to 75 percent of New Zealanders over the next 10 years by funding the infrastructure for a national open-access fibre optic network. The project will initially be concentrating on priority broadband users such as businesses, schools and health services (Ministry of Economic Development, 2009).

Project examples: working towards better information exchange in New Zealand

Given that New Zealand appears to be in a good position to develop its health ICT to better meet the needs of patients and health professionals, what evidence is there that this potential is being utilised? In fact, there are a number of projects, both completed and in progress, that are utilising the international and national resources discussed in this review to provide a variety of integrated health information systems, although none yet that are truly nationally disseminated. Here are some examples …

GP records follow patients – GP2GP

The General Practitioner to General Practitioner Patient Notes Transfer Project (GP2GP) was initiated by HISAC in 2007 and subsequently taken over by the Ministry of Health. This project was commenced in response to the recognised need for health information to 'follow the patient', ie be patient centric, rather than being kept in isolated systems within individual medical practices (Primrose et al., 2009). This is particularly important when someone moves residence and registers with a different practice.

GP2GP aims to establish a system that will allow GP patient management systems to send and receive a person's medical record electronically, as opposed to the current practice of either printing or photocopying an entire record and posting it to another practice, where information is then re-entered or documents scanned into the system (Ministry of Health, 2009). As well as saving time and improving security, GP2GP will ensure a complete medical history is available to the receiving GP.

The project is developing standards for a dataset and data model for primary care EHRs, as well as establishing standards for primary care information and data messaging. It is hoped that these standards will be able to be expanded in the future to allow other health providers to use the system (Primrose et al., 2009). Interoperability is a key issue for the project, and so HL7 is likely to be chosen as the agreed messaging standard. Another important consideration for this project is safety and security of patient information, and so the project will incorporate extensive testing to ensure information is secure and that nothing is lost, altered or added during the electronic transfer process (Primrose et al., 2009). A security review and privacy impact assessment is also part of the design process. The expected implementation date is June 2010.

Patient information access Coast wide – PrISM

A good example of a regional system exists on the West Coast. The Primary Information Systems Management initiative, called PrISM, was established in 2004/2005 and is maintained by the West Coast DHB. It is a regionally integrated EHR that is available district wide and incorporates a patient administration system, laboratory test results, and digital radiology (Greenwood, 2007). PrISM links to MedTech 32, the system used by GP practices allowing access by GPs to laboratory results, PACS (digital radiology), patient management and the clinical information system. The system can be accessed anywhere in the district, including remotely, by utilising the PROBE project broadband infrastructure (West Coast DHB, 2007). This means that hospital staff, district nurses and GP practices anywhere on the West

Coast can access patient information relevant to a patient's care episode. Future plans are to include access for Māori providers, school dental services and NGOs.

This situation is somewhat unique, in that the DHB owns most of the GP practices and so it has been able to implement standardised systems and also control EHR access through employment agreements.

Shared care now also shared information – PalCare

PalCare is an EHR intended specifically for palliative care services and hosted on a secure web server. It is designed to integrate patient information from acute and community care episodes into a single 'view' of the patient (eClinic, 2009). Originally introduced in Whangarei by North Haven Hospice, many other hospices across New Zealand have now chosen PalCare as a replacement for their health records system.

In Wellington, the implementation of PalCare at Mary Potter Hospice has revolutionised their management of patient information, and opened the way for other services involved in the care of their patients to view and contribute to patient health records. The move to PalCare has involved a planned approach to training and resourcing. This has included reconfiguring the In-Patient Unit staff base to provide more computer space, providing community teams with portable computers and investing in a wireless network (Mary Potter Hospice, 2009). A Primary Care Liaison nurse was employed to coordinate the roll out of access to the system to GPs and the local DHB hospital. While the system is not 'inter-connected' with EHRs at the other services, it does allow viewing of, and adding to, the PalCare medical notes. As well as enhancing patient care, the PalCare system has significantly improved the hospice's data collation and reporting abilities. Users outside of the hospice are required to have a digital security certificate on their computer and sign a confidentiality agreement. They are then able to access records for only the patients whose care they are involved in through the secure server using a unique user and password authentication. Non-hospice logins are also tracked for audit purposes. GPs were provided with a "User's Guide" to assist them in accessing the PalCare system.

Similar PalCare access projects have been undertaken or are in progress around the country, and a national PalCare Users Group has been established to work with the Australian vendor to ensure PalCare continues to meet the needs of services in New Zealand.

Improving treatment safety in Auckland – TestSafe

The TestSafe initiative between the three Auckland DHBs (Auckland, Counties Manukau and Waitemata) has been established to improve information sharing among community and hospital healthcare providers (TestSafe, 2008a). TestSafe allows healthcare providers to access diagnostic results and reports for their patients from both DHB facilities and community laboratories. The system uses a secure on-line database that only allows access by healthcare providers involved in a patient's care. Patients are able request that their information is not shared. Community-based users connect via the New Zealand Health Network, which in turn connects to the DHB infrastructure to access the system. TestSafe is funded through the DHBs (M. Furlong, personal communication, 18 February 2010).

Work is currently underway to include information on medications dispensed by community pharmacists. This will enable pharmacists in the Auckland region to:

- determine what medications have been dispensed to their patients from any pharmacy in the Auckland region

- identify and track potential inappropriate drug seekers

- access laboratory results when prescriptions are being dispensed, e.g. check latest INR results when dispensing a prescription for Warfarin (TestSafe, 2008b).

Dispensing information will also be available to hospital clinicians so that they are able to have more informed discussions with patients, improve patient therapy and ensure safer prescribing. At present medicines dispensed by hospitals are not recoded in the system because hospitals do not use the Guild/Pharmac codes, which are used to present the data. This situation will hopefully be addressed by the introduction of a standardised Medicines Terminology for New Zealand. This is currently being investigated by HISAC, who have proposed the adoption and adaptation of the SNOMED CT-based Australian Medicines Terminology (HISO, 2009b).

TestSafe South is another regional initiative, based on the TestSafe Auckland model, being undertaken across Canterbury and Nelson Marlborough DHBs. The aim again is to improve information sharing among primary and secondary health services.

Chronic conditions management – a regional approach

The Midlands DHBs are currently developing a chronic conditions management system that aims to implement a regional approach to the care of people with cardiac and respiratory diseases, diabetes and renal disease. It is hoped that this system will enable electronic clinical decision support tools, electronic prompts, reminders, electronic patient records, and data analysis capability to support planning and population health initiatives (HIQ 2008).

It is envisioned that the chronic conditions management system will bring together information such as patient demographics, problem list data, laboratory test results, encounter data and care plan information from existing primary and secondary computer systems. The proposal is to convey data using HL7 v3 Clinical Document Architecture and then present patient information via a simple web browser application to clinicians at point of care (A. Kenworthy, personal communication, 21 January 2010).

At present dataset definitions and system reference architecture are close to being finalised, and the project's next step is to look at what solutions can be implemented in Midland DHBs. Some data is already centralised, such as laboratory test results, while other data is proving more difficult to obtain, for example encounter history and care plan data from primary care providers, as the data is not centralised.

Conclusion

New Zealand appears to be well positioned to enhance health information and communication systems to allow for much better access to patients' health information. The NHI puts New Zealand in a rare position of having an established national unique patient identifier. This is a cornerstone of any nationally disseminated system that allows all information on a particular person to be connected. In light of the current issues of systems incompatibility, a single integrated nationwide EHR is not generally considered workable or practical, and this fact is highlighted in the HIS-NZ (Health Information Strategy Steering Committee 2005). However, it is feasible that a system of multiple linked regional or organisation-specific EHRs could be developed to construct a 'virtual' national EHR utilising a network approach (Leech 2004). This type of EHR would achieve many of the identified benefits of a distributed EHR for patients, clinicians, health services, researchers and central health agencies. In addition, a system providing a brief summary of an individual's medical record, rather than full access to the complete medical record, may be more acceptable to the general public (Hunter et al. 2009).

There are of course multiple challenges that will need to be addressed in order to realise such a system and ensure its success. Fundamental barriers include system compatibility and connectivity issues between health service providers, and the development and implementation of standards. Issues of privacy and security of information are also cause for concern. Additional obstacles include funding and resourcing, clinician acceptance and ICT literacy, and the need for national leadership for ICT development in the health and disability sector. Key priority areas that address these challenges have been identified in UMR Research's 2009 *Connected Health* research report. These include achieving better access to primary and secondary care records, improving electronic communication/accessibility in remote locations, enhanced training and collaboration, better communication with patients, improved internal and multi-site electronic communication, better use of electronic assessment and diagnostic tools, and increased electronic reporting (UMR Research 2009). There is also a need for information technology vendors to recognise the need for systems compatibility and build into software the necessary data exchange components based on agreed standards. It is also vital that system and software planners and purchasers understand compatibility and connectivity needs when they commission ICT projects.

In relation to the safety and confidentiality of health information, the current privacy legislation in New Zealand, in the form of the Privacy Act and Health Information Privacy Code, supports the appropriate sharing of medical information, alongside the legal requirement under section 22F of the Health Act that health care providers share health information in response to a legitimate request. Currently held concerns about the sharing of, or access to, health information are likely due to misinterpretation of the Privacy Act and HIPC. Some key responses are required to this situation, to ensure that the requirements of the Act and Code are complied with, but not at the expense of patient safety and care. Most importantly, individuals from whom health information is collected must be fully informed about what their health information will be used for and who it may be shared with, including their right to withhold consent for the sharing of their personal information. The public must feel assured that appropriate security measures are in place to protect their personal information. In addition, education of both public and health and disability sector

employees is required to dispel the misunderstandings and support appropriate interpretation of the Act and Code to ensure legislation is complied with and that patients receive the best possible care from well informed health care professionals.

The example projects summarised in this report show that distributed electronic health information systems can be established, and that these are making a difference to patient care. These projects have required alliances between health services and information technology suppliers, as well as collaboration among health service providers across multiple settings. However, what these projects also demonstrate is the number of isolated ICT initiatives occurring without necessarily considering the wider health ICT environment.

New Zealand's capability to develop a national EHR is on a relatively firm path, with a number of important 'building blocks' already in place. Further development is going to require collaboration between government agencies, health and disability service providers and system vendors, as well as national leadership and a strategic vision.

References

Beale, T. (2009). *The crisis in e-health standards*. Retrieved 18 January 2010, from
http://wolandscat.net/2009/09/17/the-crisis-in-e-health-standards.

Chhanabhai, P. & Holt, A. (2007). Consumers are ready to accept the transition to
online and electronic records if they can be assured of the security measures.
Medscape General Medicine. Retrieved 27 January 2010, from http://www.
medscape.com/viewarticle/549468.

Chhanabhai, P., Holt, A., & Hunter, I. (2006). *Consumers, security and electronic
health records*. Dunedin: University of Otago. Retrieved 25 January 2010, from
http://eprints.otago.ac.nz/191/1/dp2006-01.pdf.

Cizadlo, T. (2009). *Health information standards in New Zealand*. Paper presented at
Health Informatics NZ Conference in Oct 09, Rotorua. Retrieved 21 January 2010,
from http://www.hinz.org.nz/uploads/file/2009conference/P25_Cizadlo.pdf.

Davenport, W. (2003). *The personal health record: Address to the 2003 privacy
issues forum*. Retrieved 3 August, 2008, from
http://www.privacy.org.nz/assets/Files/ 51474265.pdf.

eClinic. (2009). *PalCare*. Retrieved 22 February, 2010, from
http://www.eclinic.com.au/newweb/index.php?option=com_content&task=view&id=
64&Itemid=103.

Greenwood, D. (2007). Health looks to ICT to deliver better patient care. *Auckland:
Computerworld*. Retrieved 15 February 2010, from
http://computerworld.co.nz/news.nsf/news/45BB236C41E2C260CC2573020018D
FF9.

Health Information Strategy Steering Committee. (2005). *Health information strategy
for New Zealand 2005*. Wellington: Ministry of Health. Retrieved 25 January 2010
from http://www.moh.govt.nz/moh.nsf/0/edb64619d460f974cc2570430010fb71?
OpenDocument.

HIMSS Healthcare Information and Management Systems Society. (2010). *EHR
electronic health record*. Retrieved 25 January 2010, from
http://www.himss.org/ASP/topics_ehr.asp.

HIQ. (2008). *Regional chronic care management information systems requirements*.
New Plymouth: Midlands District Health Boards. Retrieved 22 February 2010, from
http://www.tdhb.org.nz/funding_planning/documents/chronic_disease_manageme
nt_requirements.pdf.

HISAC. (2009a). *Health information standards governance group and health
information standards office*. Retrieved 27 August 2008, from
http://www.hisac.govt.nz/moh.nsf/pagescm/7384.

HISAC. (2009b). *About HISAC: Purpose. health information strategy advisory
committee*. Retrieved 27 August 2008, from
http://www.hisac.govt.nz/moh.nsf/indexcm/hisac2-about-purpose.

HISAC. (2009c). *Health information consumer forum*. Retrieved 15 February 2010, from http://www.hisac.govt.nz/moh.nsf/indexcm/hisac2-projects-forum.

HISO. (2009a). *Approved standards*. Retrieved 16 February 2010, from http://www.hisac.govt.nz/moh.nsf/indexcm/hisac2-standards-approved.

HISO. (2009b). *New Zealand medicines terminology recommendation report, HISO 10024*. Wellington, Ministry of Health. Retrieved 19 February 2010, from http://www.hisac.govt.nz/moh.nsf/pagescm/7628/$File/medicines-terminology-recommendation-report09.pdf.

HISO. (2009c) *Health information security framework: Essentials and recommendations HISO 10029.1*. Wellington: Ministry of Health. Retrieved 15 February 2010, from http://www.hisac.govt.nz/moh.nsf/pagescm/7616/$File/10029-1-hisf-essentials-and-recommendations-v1-menu.pdf.

Hunter, I.M., Whiddett, R.J., Norris, A.C., McDonald, B.W., & Waldon, J.A. (2009). New Zealanders' attitudes towards access to their electronic health records: preliminary results from a national study using vignettes. *Health Informatics Journal*, 15(3), 212-228.

IHTSDO. (n.d.). *About SNOMED-CT*. Retrieved 23 February 2010, from http://www.ihtsdo.org/snomed-ct/.

Kamira, R. (1999) *The kidZnet project: Guiding cultural & ethical issues for Iwi*. Auckland: Paua Interface Ltd.

Kerr, K. (2004). The electronic health record in New Zealand – part 1. *Health Informatics New Zealand Journal*. Retrieved 26 August 2008, from http://www.hinz.org.nz/journal/2004/03/The-Electronic-Health-Record-in-New-Zealand---Part-1/892.

Leech, K. (2004). The virtual patient record. *Health Informatics New Zealand Journal*. Retrieved 26 August 2008, from http://www.hinz.org.nz/journal/2004/03/The-Virtual-Patient-Record/891.

Mary Potter Hospice. (2009). *Strength in community 2008 – 2009 (Annual Review)*. Wellington, Mary Potter Hospice. Retrieved 22 February 2010, from http://www.marypotter.org.nz/MPH%20AR09%20Web.pdf.

McKechnie, D. (2009). Information exchange between electronic medical record systems. Wellington: New Zealand Health IT Cluster. Retrieved 25 February 2010, from http://www.healthit.org.nz/download/files/Interoperability_Communication_Consultation_Draft.pdf.

McKenna, R. (2009). Investigating the potential to improve the free flow of health care information – a survey of New Zealand clinicians and health providers. *Health Care Informatics Review Online*, 13(4), 9-20. Retrieved from http://www.hinz.org.nz/uploads /file/Journal_Dec09/McKenna_P9.pdf.

Ministerial Review Group. (2009). *Meeting the challenge: Enhancing sustainability and the patient and consumer experience within the current legislative framework for health and disability services in New Zealand.* Report of the Ministerial Review Group. Retrieved 22 February, 2010, from http://www.beehive.govt.nz/release/ministerial+review+group +report+released.

Ministry of Economic Development. (2009). *Ultra-fast broadband investment initiative*. Retrieved 19 February 2010, from http://www.med.govt.nz/templates/ContentTopicSummary_41902.aspx.

Ministry of Health. (2008). *Connected health architectural framework*. Wellington: Ministry of Health. Retrieved 19 February 2010, from http://www.healthit.org.nz/download/files/CH_Architectural_Framework_v1.0_Published.pdf.

Ministry of Health. (2009). *Primary health care GP2GP patient records transfer*. Wellington: Ministry of Health. Retrieved 21 January 2010, from http://www.moh.govt.nz/gp2gp.

Ministry of Health. (n.d.). *New Zealand health network general information.* Retrieved 17 February 2010, from http://www.moh.govt.nz/moh.nsf/Files/health-network/$file/new-zealand-health-network-generalinfo.pdf.

National Institutes of Health. (2006). *Electronic health records overview*. McClean, Virginia: National Institutes of Health National Center for Research Resources. Retrieved 22 February, 2010, from http://www.ncrr.nih.gov/publications/informatics/EHR.pdf.

New Zealand Government. (1956). *Health Act 1956 No 65 (as at 26 June 2009)*. Retrieved 22 February, 2010, from http://www.legislation.govt.nz/act/public/1956/0065/latest/DLM305840.html?search=ts_act_health+act_resel&p=1&sr=1.

New Zealand Government. (1993). *Privacy Act 1993 No 28 (as at 01 December 2009)*. Wellington: New Zealand Government. Retrieved 22 August, 2009, from http://www.legislation. govt.nz/act/public/1993/0028/latest/DLM296639. html.

New Zealand Health Information Service. (n.d.) *National Health Index*. Retrieved 25 February 2010, from http://www.nzhis.govt.nz/moh.nsf/pagesns/264?Open.

Newsham, S. (2008). How do health informatics systems improve quality and cost efficiency in ACC contracted community rehabilitation teams, *Health Care and Informatics Review Online*, 12(1), 22-28. Retrieved 22 April 2010, from http://www.hinz.org.nz/uploads/file/Journal_Mar08/Newsham_P22.pdf.

Primrose, J., Hicks, S. & Anthony, R. (2009). *GP2GP patient notes transfer*. Paper presented at Health Informatics NZ Conference in Oct 09, Rotorua. Retrieved 27 January 2010, from http://www.hinz.org.nz/uploads/file/2009conference/P39_Hicks.pdf.

Privacy Commissioner. (2007). *Background research report on the national health index. Privacy Commissioner*. Retrieved 8 August 2008, from http://www.privacy.org.nz/assets/Files/44547321.pdf.

Privacy Commissioner. (2008). *Health Information Privacy Code 1994* (new edition December 2008). Auckland: Office of the Privacy Commissioner. Retrieved 8 August 2008, from http://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-2008-revised-edition.pdf.

Regenstrief Institute, Inc. (2010). *LOINC background*. Retrieved 23 February 2010, from http://loinc.org/background.

Slane, B. (1999). *Health information: some issues at the close of the 20th century. Address by the Privacy Commissioner at the 7th Annual New Zealand Medico-legal Conference, 1999*. Retrieved 3 August 2009, from http://www.privacy.org.nz/health-information-some-issues-at-the-close-of-the-20th-century/?highlight=health%20informa tion:%20some%20issues.

TestSafe. (2008a). *GP's - Provider FAQ's – General*. Retrieved 26 February 2010, from http://www.testsafe.co.nz/gps/providerfaqs_1.html.

TestSafe. (2008b). *Pharmacy*. Retrieved 26 February 2010, from http://www.testsafe.co .nz/pharmacy.html.

The WAVE Advisory Board to the Director-General of Health. (2001). *From strategy to reality: The WAVE project.* Wellington: The WAVE Advisory Board to the Director-General of Health. Retrieved 8 August 2009, from http://www.moh.govt.nz/moh.nsf/0/F34F8959738E992CCC256AF400177998.

UMR Research. (2008). *Connected health. A qualitative study*. Wellington: Ministry of Health. Retrieved 21 January 2010, from http://www.moh.govt.nz/moh.nsf/pagesmh/9612/$File/ict-research-2008.pdf.

UMR Research. (2009). *Connected health. A quantitative study*. Wellington: Ministry of Health. Retrieved 21 January 2010, from http://www.moh.govt.nz/moh.nsf/pagesmh/9612/$File/ict-research-2009.pdf.

Warren, J., & Kingsford, D.G. (2008). *Strategic directions for health informatics content interoperability in New Zealand*, Wellington: Health Information Strategy Action Committee. Retrieved 21 January, 2010, from http://www.hive.org.nz/sites/default/files/NZ_Interop.pdf.

West Coast DHB. (2007). *Primary health care on the West Coast: Kotahitanga (Working Together): Draft primary health plan v 5.6 2006 – 2009: Rewritten version, March 2007, final 18 June*. Retrieved 26 February 2010, from http://www.westcoastdhb.org.nz/publications/about_us/projects/sustainability_proj ect/Primary%20Health%20Care%20Plan.pdf.

Whiddett, R., Hunter, I., Engelbrecht, J. & Handy, J. (2006). Patients' attitudes towards sharing their health information. *International Journal of Medical Informatics*, 75, 530-541.

Appendix 1: Case Study

In order to improve patient care and enhance its data collection and reporting capability, a hospice decided to introduce a new electronic patient administration system. They chose a product that uses a secure web server to host the system, as this would allow for remote access, as well as letting health professionals outside their service access the system.

As part of the implementation of the new system, the hospice put in place several security and privacy measures, including a digital security certificate and confidentiality agreement for users outside of the hospice. They also added a new section to their patient consent form that informs the patient who their health information will be shared with. Access to patient records by external health care providers is restricted to only those patients that they are also caring for, so, for example, a GP can only view the records of their current patients.

The local DHB hospital also has a specialist palliative care team that provides consultation and advice for patients admitted to the hospital, or those seen in outpatient clinics and the emergency department, with palliative care needs. This team is very eager to be able to access the hospice's patient record system, as most of the patients they are asked to see are also under the care of the hospice. However, a problem has arisen in that the hospice will only grant access to individual patient records upon request. The hospital team feel this approach will adversely affect their ability to access patient information in a timely manner. This is especially so for patients presenting at Emergency or Outpatients with acute problems, but also for inpatients who are newly referred to the hospital team for advice. The team would like to have access to all patients on the hospice's system so they can quickly get information on a patient's current treatment and care plans. The hospice however, wishes to ensure it is upholding its responsibility for patient privacy and make sure its system security is maintained, as per Rule 5 of the Health Information Privacy Code 1994.

A potential solution to this problem can be found by appropriate interpretation of the legislation governing health information and also considering the research findings on the general public's willingness to allow sharing of their personal health information.

Section 22F of the Health Act requires agencies to disclose health information about a person to health agencies that are (or are going to be) providing health services to that person. While specific consent to the disclosure isn't required, the request can be refused if there's reason to believe the person wouldn't want it disclosed, or it's not in their interests to disclose. However, research suggests that people are willing to allow their information to be shared with other health professionals, even when it is sensitive in nature, especially if the information is to be used for clinical care.

The hospice would need to take steps to ensure that the patients (and/or their representatives, if they're not in a position to give consent or exercise their own rights) know about the potential disclosure. This relates to Rule 3 of the Health Information Privacy Code 1994. Again, research has shown that patients do want to be fully informed about, and give consent to, health information disclosure. The hospice is already obtaining consent for the sharing of patient information, and as long as this includes sharing information with the DHB hospital palliative care team, this requirement is being met.

In addition, the hospital staff who intend to access the hospice's system would need to sign a confidentiality agreement with the hospice, which specifies access criteria and obligations of the staff member in relation to use of the system, to enable them to have full access to the hospice patient record system. Again, the hospice already has this process in place, but it may need slight modifications for hospital-based health care staff and to allow for full patient record system access.

The hospice's system allows for tracking of system access by outside users, and an audit could be undertaken after three months or so to quantify the levels of access by external users and ensure appropriateness of that access.

Patient information that is collected by the hospice is intended to ensure appropriate care and treatment of that patient. The purpose to which the information will be used by the hospital palliative care team is the same, as it will be used to guide treatment and care of the patient when they are in hospital. Thus, Rule 10 of the Health Information Privacy Code 1994 is also being complied with.