

Why IT matters: your health and the public health

He iti rā, he iti māpihi pounamu A small contribution can be as valuable as a precious stone

Good evening. Thank you Penny for your kind words of introduction, and thank you to friends and family, and professional colleagues who have taken the time to come and hear this address. A special greeting also to those who are later watching the video recording, the opera lovers, those attending the LIANZA Conference this week, and other friends and colleagues around the country.

I've chosen a very challenging topic for my presentation. My research activities over the years have covered the three fields of interest - starting with my work on the evaluation of libraries and information services (library performance measurement), and from that base, as information technology, and later the Internet started to revolutionise information services, has extended into the fields of e-government, and e-health. The core purpose uniting these various research areas has been to investigate the effectiveness of information systems and services, whether these are library services and library databases, information services for health professionals, or government web sites serving citizens' needs. My research has been concerned with the factors that create effective information systems, motivators and barriers to the use of such systems, and whether they are meeting user needs. The fundamental purpose of this research is to help those designing and delivering information systems, in a variety of contexts, to better understand user needs, and to respond to them, in order to maximize information use.

I've chosen this evening to talk about health informatics, or e-health, but many of the issues are the same across all these domains. However, in saying that the topic for tonight's address is a challenging one, I mean to indicate that the field of health informatics is an extremely complex one. Although many people in the audience come from the field of Health IT, none of us has a complete understanding of the whole picture - its like a jigsaw puzzle in which we have a few sections of the puzzle in place, but some of the pieces are hidden, some are lost, some are the wrong shape, or maybe come from a different puzzle, and we don't have a picture of what we are trying to create. So hopefully, my interpretation of where we are, and what we need to do will fit alongside your perspective, and maybe help fit one or two more pieces of the puzzle into place.

In this talk I'd like to start by explaining why HealthIT matters, then I want to cover some key areas that illuminate this theme further. These include:

- Evidence based medicine

- How IT is used in the delivery of health care

- The NPfIT project in the UK's National Health Service

- Health IT Strategy in New Zealand, and the recent report of the Ministerial Review Group

I'll conclude with what I believe are some of the key lessons to be learned from these examples, and what I believe to be the way forward to a more effective use of IT in the

health sector.

There are many fields of health IT I could have covered. Topics I will not have time to cover tonight include: consumer health information, telemedicine, the impact of genetic information on health care, and mobile technologies - although the latter form part of the picture, and are necessary to complete the puzzle. In fact my focus will be more at the policy and infrastructure level than actual technologies and applications.

Why IT matters

The practice of medicine, and health care in general is heavily dependent on information. The clinician¹ in an interview with a patient (or health consumer) needs information from a range of sources in order to reach a diagnosis, consider a treatment, carry out a treatment, or develop a plan of care. Research has shown that a family practitioner, in one consultation have a large number of questions that need answering in order to reach a sound decision. These questions range from the patient's medical history and life style, what family support they have, what support services are available in the community, to what tests are available (or have been conducted) to support a diagnosis, what medication the patient is currently on, what existing or new treatments might be available, to contraindications for use of a specific drug, potential adverse reactions to a drug or potential drug interactions. These questions therefore include knowledge about the patient, their symptoms and lifestyle, and questions related to the current state of medical knowledge about the condition, and possible treatment. These latter questions arise in over 30% of consultations. Notes following recent discharge from a hospital are also critical.

In a hospital setting necessary information will include patient identity, diagnosis on admission, treatment (and any medications the patient is already taking or which have been prescribed in hospital), vital signs (temperature, respiratory rate, blood pressure, blood oxygen, heart rate, and level of consciousness) as well as test results. This information in both cases is needed at the point of care, and is critical in terms of patient outcomes. Ensuring that this information is available, accurate and current in all cases and at all times is the goal of health information systems. In addition, from this information, are drawn the population based data sets that are maintained by the government agencies to identify the health status of the population, incidence of specific diseases, the burden of disease in specific communities, current and future demand for services etc. Clinicians, whether GPs, hospital physicians, surgeons, nurses or other allied health professionals also need access to the latest knowledge available, based on research findings on the efficacy of diagnostic tests and treatments in their field. Health information systems, whether paper-based or online are therefore critical tools in the delivery of health care, and their effectiveness directly affects the quality of care delivered.

This is directly where the problem lies. The term 'medical error' is familiar to most people. The World Health Organisation estimates that 1 in 10 patients are affected by

¹ The term used by the NZ Office of the Auditor General to refer to those primarily involved in providing health services and disability support services to patients, such as physicians, surgeons, or nurses. (<http://www.oag.govt.nz/2007/auckland-dhbs/glossary.htm>)

medical error, (Bates et al, 2009) leading to the establishment of the international committees, and monitoring of the issue of “patient safety”. In the US, medical errors are estimated to result in 44,000 to 98,000 unnecessary deaths and 1,000,000 excess injuries each year. (IOM, 2000) In Canada a recent study found 7.5% hospitalisations were associated with adverse events, and that 1 in 6 patients with an adverse event died. (Forster, 2005) In New Zealand analysis of a random sample of records from 13 public hospitals in 1998, by Peter Davis and his team, showed that 12.9% of hospital admissions (events) related to an ‘adverse’ event, or preventable medical error; one fifth of these occurred outside a public hospital, and most had minor impact, but 15% of these events were associated with permanent disability or death. In general, adverse events added an average of over 9 days to a hospital stay (figures vary according to definitions). Based on this study, Health and Disabilities Commissioner Ron Paterson calculates that 1 in 200 people suffer an adverse event in health care and 1 in 25 of these results in serious and irreversible harm. These events range from medication errors (wrong drug, wrong dosage, predictable drug interaction or adverse reaction) to wrong procedure, and wrong patient.

Current initiatives to reduce this occurrence (while acknowledging that human beings are prone to errors), and that workloads may contribute to this, have suggested several ways to improve this situation and improve patient safety. Primary amongst these are: developing a culture of safety, moving away from a “name, blame and shame” culture to enable health services to acknowledge and record errors in order to address them as system-based issues; better access to the most reliable ‘evidence-based ‘information’ to eliminate practices shown by recent research to be ineffective or even harmful;² and an emphasis on better communication and coordination of care. Two of these ways of improving patient safety involve information systems. My own analysis of the reports of the Health and Disability Commissioner over 2008 and 2009 (covering adverse events in reported to the HDC by patients or their families) suggest that on average, information, communication and coordination of care are key factors in 50% of cases - and these are only the cases where the adverse event resulted in death or irreversible harm, the kind of event which Ron Paterson has labelled “the canary in the coalmine”. The New Zealand Quality Improvement Committee, formerly the National Health Epidemiology and Quality Assurance Advisory Committee (EpiQual), which reports to the Minister of Health, is starting to address some of these issues through its National Quality Improvement programme. It is focusing, among other initiatives, on a Safe Medication Management Programme, an information systems based approach to this aspect of the problem of patient safety.

While no one would claim that technology and information systems alone can resolve these issues, and many other issues affecting the delivery of health care, well designed systems, with accurate, relevant, and timely information delivered to the clinician at the point of care, have the potential to significantly enhance quality of care in our health system. I believe this, Ron Paterson believes this, everyone working in the sector believes

² Examples cited on the BMJ ‘Best Treatments’ web site include: bed rest for heart patients, routine tonsillectomies, and the use of enemas before childbirth. Bed rest for back pain is another common example

this, and passionately wants to see it happen. And yet, as the Associate Minister for Health, Dr Jonathon Coleman noted at the recent Health Informatics New Zealand (HINZ) conference, despite the “breathtaking opportunity” for technology in health care to improve processes and outcomes, we have not yet seen this come to fruition. Productivity and outcomes have not kept pace with the investment in Health IT. The Director General for Health noted recently, that for a small country New Zealand compares relatively well with other OECD countries in its expenditure on health, which at 9.2% of GDP is higher than average of (8.9%),³ and according to the latest OECD report “New Zealand achieves relatively good health outcomes for comparatively modest health care outlays,” With less to spend we have to do better, and make more effective use of the tools at our disposal including technology.

I now want to turn to three circumstances where the potential for health IT to transform care has not been realised. The first of these is evidence based medicine, which relates to the doctors need to answer those questions that arise in 30% of consultations. Then I’ll turn to the need for information about the patient that addresses the rest of the questions necessary to make an informed clinical decision.

Evidence based medicine (evidence-based healthcare)

I want to begin by telling a story that I find quite moving. In 1972 George Liggins, after whom the Liggins Institute at the University of Auckland is named, and his colleague R.N Howie published a paper reporting the results of a randomised controlled trial investigating the effectiveness of the use of a short course of corticosteroids administered to women about to give birth prematurely. (Liggins and Howie, 1972) In subsequent years, several other trials took place comparing this treatment with a placebo. The Cochrane Collaboration, an international voluntary association of clinicians dedicated to the advancement of evidence-based medicine takes up the story.

By 1991, seven more trials had been reported, and the picture had become still stronger. This treatment reduces the odds of the babies of these women dying from the complications of immaturity by 30 to 50 per cent. Because no systematic review of these trials had been published until 1989, most obstetricians had not realised that the treatment was so effective. As a result, tens of thousands of premature babies have probably suffered and died unnecessarily (and needed more expensive treatment than was necessary). This is just one of many examples of the human costs resulting from failure to perform systematic, up-to-date reviews of RCTs of health care.

That story is incorporated into the logo of the Cochrane Collaboration below, the outer blue bands representing the CC of the Cochrane Collaboration, the inner graph, a nomogram, representing the seven RCTs conducted on the use of corticosteroids on mothers about to give birth prematurely, and the diamond at the bottom represents the findings of the systematic review of these trials, which reinforced the validity of the Liggins/Howie trial.

³ OECD Health data: How does New Zealand compare. <http://www.oecd.org/dataoecd/43/22/40905041.pdf>



The Cochrane Collaboration, named after British epidemiologist Archie Cochrane, publishes systematic reviews of critical topics in health care conducted by volunteer members allied with various Cochrane Centres around the world, according to strict protocols, to identify the most reliable evidence of efficacy of treatments, diagnostic tests and other interventions in health care. It is one of a number of organisations internationally dedicated to bringing the best evidential knowledge to clinicians. Also active as founders from the earliest years of the EBM movement were David Sackett and Gordon Guyatt of Department of Epidemiology, and the Health Information Research Unit at McMaster University in Canada, led by Brian Haynes, and the Centre for Evidence Based Medicine at Oxford University, also led in its early years by Dave Sackett.

Evidence based medicine, is defined by Sackett as "the conscientious, explicit, and judicious use of current best evidence" by clinicians (in whatever field, as nurses, physiotherapists or physicians) in their everyday practice. It is based on the systematic searching of the medical (or nursing or allied health) literature, the identification of well conducted randomised controlled trials, the "gold standard" in medical research,⁴ and the applications of findings to the clinical situation confronting the clinician. Even stronger evidence is presented by systematic reviews of RCTs, and these are preferred if available. This 'evidence' is then incorporated into the clinician's decision making along with his/her knowledge of the patient's preferences, and his/her own clinical experience.

Understanding this principle, of how scientific evidence is incorporated into clinical practice is the key to evidence based healthcare. Early resistance to 'cookbook medicine' and ongoing resistance to clinical guidelines even when they are based on evidence continues to be reported, most commonly on the grounds that the evidence, and its implications for practice do not 'fit' the clinician's experience. However, the EBM model

⁴ In an RCT participants are randomly assigned to treatment or controlled group, and assessed throughout the trial on this basis, against a predetermined set of outcome measures. Well conducted RCTs are double-blinded where possible, that is, neither the patient, nor the clinician participating in the trial, nor the assessor, knows whether any particular patient is receiving placebo or treatment.

recognizes that health care needs to be holistic, and individualized, and that not all treatments (or decisions not to treat), can be tested using RCTs. The principles of EBM include the ranking of levels of evidence that acknowledge other models of knowledge creation, including retrospective cohort studies, as long as they are used judiciously.⁵ Here, we need to go back to the key point that Dave Sackett makes over and over again "the practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research".(Sackett, 1996).

There are a number of ways of making this 'evidence' available to clinicians. The wide availability of Medline, the largest medical database in the world, freely available online as PubMed enables direct searching of the medical literature using key indexing terms such as RCTS and systematic reviews, (a major international project involved retrospective 'tagging' of earlier studies using RCTs before the index term was routinely adopted. The Cochrane Collaboration has been doing its critical work for two decades now, evaluating the evidence of treatments and diagnostic tests in thousands of systematic reviews, evidence-based Guidelines Groups have been set up in many countries and a number of journals (such as *Clinical Evidence*), and online services (*Bandolier*) have been established to bring synthesised evidence with commentary about implications for practice to practitioners at their desktop. Not all such resources are freely available, although most were in their early years. Clinicians without access to some of these resources (especially Cochrane reviews, although the abstracts are freely available online) are significantly disadvantaged in seeking out the best evidence available.

Despite all this effort, however, and even in settings where clinicians have full access to the most reliable information sources, the Cochrane Collaboration continues to maintain that only "10% to 35% of medical care is based on RCTs." Furthermore, a 2007 analysis of 1016 systematic reviews from all 50 [Cochrane](#) Collaboration Review Groups found that only 44% of the reviews concluded that the intervention investigated was "likely to be beneficial", 7% concluded that the intervention was "likely to be harmful", and 49% concluded that evidence "did not support either benefit or harm". (El Dib, 2007) Given that most Cochrane reviews focus on common problems and common treatments, this conclusion is as concerning for the health consumer as it is for the medical practitioner.

My own research in this area was revealing. I first responded to a request from Margaret Gibson-Smith, Medical Librarian at the Philson Library at the University of Auckland, who had set up a scheme to deliver copies of articles to GPs who requested them after reading reviews of articles in the medical literature which were believed to be relevant to general practitioners, published in the *New Zealand Family Physician* (published by the Royal New Zealand College of General Practitioners). The scheme was not successful- GPs didn't use the service and Margaret asked me to find out why. As with most such requests, it was not that simple. I set out to investigate how family physicians seek and apply information to support their clinical decision making. I found them reliant on

⁵ A clear explanation of 'Levels of evidence' are available at the centre for Evidence Based medicine's web site at <http://www.cebm.net/index.aspx?o=1025>

colleagues and specialists and textbooks, and a few odd articles they had collected. They made little use of medical libraries, where more current information would have been available, because of constraints of time, and cost, and lack of confidence. With the advent of the Internet, I reengaged with this group and subsequently conducted a survey of a random sample of members of the College of General Practitioners. The Internet, PubMed, and some specialist web sites were now available to this group, but again, they relied heavily on colleagues and textbooks, and demonstrated a limited ability to search online resources. (Cullen, 2002) Although the majority of Internet use was related to Pubmed, and the site of the RNZCGP, this ranked only just above medical libraries as a preferred sources of information. Search skills were fairly basic, and only 10% knew to search for RCTs, systematic reviews, as evidence-based information. In subsequent interviews with a small subgroup of survey participants attitudes towards Evidence Based Medicine were mixed, some very positive about it, some with mixed feelings and some positively hostile. The situation has improved somewhat since then, although the College's web site lists a very meagre list of evidence based resources, under a general notice indicating that the College does not endorse the views expressed on any of the sites listed.

Over a decade later I'm still engaged, along with colleagues in NZ medical libraries, in investigating how well young registrars and house surgeons seek and use information, who were given various levels of instruction in searching, appraising and applying evidence at the beginning of their clinical training years, are now able to find and apply the best evidence as they embark on their clinical careers. Our findings, consistent with those of colleagues at McMaster and in Oxford, show that their success is very mixed, and that their skill level, on average, falls far short of enabling them to find and apply the best scientific evidence to answer a clinical problem. There are still many barriers preventing clinicians from accessing this evidence, barriers of time, ability to search the literature, identify, and evaluate the best evidence available, and lack of skills in applying new knowledge to the clinical decision making process. These are critical skills for the clinician. Medical knowledge increases at an exponential rate. There are over 19 million articles in the main medical database Medline, one new systematic review is added to the Cochrane database of systematic reviews each day, new medical research soon outstrips these reviews, and it is still taking over 5 years for a well-proven intervention to affect routine clinical practice. This holds true in both primary and secondary care settings.

One solution to this problem has been to provide carefully synthesized and packaged information to the clinician's desktop - integrated on occasion with the patient management system they are using. But such systems cannot anticipate all clinical questions that might arise, and such systems themselves can rapidly become out of date. Even when synthesised knowledge is available (access to resources such as the Cochrane Database of Systematic reviews, or other simpler publications such as *Clinical Evidence*, designed to provide just this kind of support for evidence-based clinical decision making, recent research at the HIRU at McMaster still shows that clinicians asked to search for information to resolve a clinical problem, and provided with access to appropriate resources are able to find correct information only about 40% of the time. (McKibbin and Fridsma 2006) . This study was of physicians in family practice. Our own recent research into the ability of young hospital based clinicians to search, appraise and apply

the best evidence based information in response to a set scenario relevant to their specialist field, was of a similar order. (Cullen, Clark, and Esson, 2009) This has major implications for practice, if we go back to the accepted definition of evidence based practice "the conscientious, explicit, and judicious use of current best evidence" by clinicians.

Several key points here should be noted: Firstly Medline, the database most people know in its freely accessible form, PubMed, created and maintained in the US by the National Library of Medicine, is a huge database containing over 19 million records of articles (and links to the full-text of as many as possible, preferably in its own database of freely available articles, PubMed Central). It requires skilled searching, using its own specialised set of index terms, MeSH. The 25,000 indexing terms in MeSH are arranged in a hierarchical structure representing a systematic approach to medical knowledge, the most effective way of searching the database. PubMed also operates by means of a set of sophisticated algorithms that map users' search terms to the MeSH headings by which the contents of the database are organised, based on NLM's own Unified Medical Language System. The UMLS provides systematic linkages between over 100 different sets of terminology used in the healthcare sector, including the international hospital discharge codes (ICD10) used in New Zealand, standard Nursing codes (NIC/NOC) and the READ codes used to categorise disease in New Zealand in the patient record systems used in the primary care sector. It uses open source software to enable software developers to incorporate the system into any health care system they are building, whether this is a patient record system, a database of scientific literature, a set of clinical guidelines, or a public health data set.

The NLM is itself one of the National Institutes of Health, a set of 28 government agencies, such as the National Cancer Institute, and the National Human Genome Research Institute, dedicated to supporting scientific investigation to enhance human life and reduce the burden of disease and disability. With a public good mission (research funded by the people should be made available to the people) it is a major proponent globally of Open Access to knowledge for the benefit of humankind. But Open Access in itself is not enough. To fulfill the vision, of open access to medical knowledge for everyone in the sector we need a set of infrastructural tools, we need to get synthesized knowledge to the clinician's desktop in a form which is compatible with their workflows, and meets their needs for clinical decision making, whether this is for nursing, medical or other health decisions; we need to integrate information literacy skills into medical and nursing training, and most of all develop a culture of awareness of the need to incorporate the most scientifically reliable and relevant information possible into the clinical decision making process. Leadership from the top of the medical and nursing professions down to the lowliest of practitioners is needed, and that, to date, has been sorely lacking, according to the Director of the Oxford Centre for Evidence Base Medicine, Paul Glasziou.

Health IT in the delivery of care

We turn now to the application of IT in the delivery of health care, moving from scientific knowledge and the dissemination of new advances, to the delivery of health care which desirably incorporates that knowledge. Information technology in health care

can do many things: the application familiar to most people is the individual patient record kept on a computer in the GP's office, usually linked to a server somewhere in the practice (or outside it) and accessible for a variety of workstations throughout the practice. This routinely includes a summary of the patient's personal demographic data, their current health status, a record of consultations, clinical notes, diagnosis, treatment and prescriptions, along with system wide capability for appointments and billing. Current estimates are that 99% of NZ GPs use such systems, a very high figure internationally. A Patient Management System will routinely include an online prescribing facility, based on a list of drugs available in New Zealand, standard dosages, warnings, and whether they are subsidised or not. It may also have the capability to connect with other providers (pharmacies, the nearest DHB, and lab testing facilities.) More advanced systems in use in many New Zealand GP clinics include what are called clinical decision support systems, care pathways and 'reminders' of appropriate tests and treatments for specific conditions, systems for analyzing data on a population basis to ascertain trends, etc. Suppliers of these systems are generally medium sized New Zealand health IT companies which have been very successful in this sector, although there are plenty of international products in the market place.

At the secondary and tertiary care level (hospitals offering limited or high level services), the uptake of electronic systems is less uniform, and less successful, but even more critical. When problems occur they tend to be somewhat dramatic and large sums of money are involved. A graphic example is provided by the recent announcement by the CEO at Capital Coast Health of the need to replace the current patient record system with a new electronic health record system at a cost of \$4.3 million. The existing Allegra software is can no longer cope with the demands made on it, is no longer supported and has had a problematic history. CEO Ken Whelan reported that not only was it likely that the DHB had lost "millions of dollars" in patient revenue in the past few years, but that numbers of patient discharge summaries were either not produced or not sent (to referring GPs) between 2006 and 2008. The system will be replaced with an up to date electronic health system integrated with the existing patient management system, that will be accessible to authorized parties through a web-base portal.

Providers of IT systems in the sector range from in-house DHB developed systems, through a number of New Zealand companies (usually marketing overseas products) to the major internationals (including Microsoft, IBM, and IBAHealth). Although reliance on the historical model of mountains of damp, disordered, misfiled and missing paper-based records is largely a thing of the past, a recent survey of New Zealand clinicians conducted by UMR for the Ministry of Health showed that three quarters of DHB clinicians reported that at least once a day they could not find the patient electronic information they needed in order to optimally treat their patients; an even higher proportion agreed that incompatible patient management systems were the most significant barrier to accessing information electronically. (Ministry of Health, 2009) Qualitative research conducted by UMR for the MoH in 2008 showed that most hospital clinicians were in agreement that the potential for IT to enhance coordination between healthcare providers and therefore improve the quality of care, to improve clinical process and data quality, and to reduce costs by avoiding duplication of information and the repetition of tests is not being realized. (Ministry of Health 2008)

A number of reasons have been suggested for this situation. These include: incompatible systems (in our 21 autonomous DHBs there is no requirement to develop systems compatible with other DHBs, with systems used in primary care settings within the DHB region, or with other healthcare providers, such as pharmacies, specialist clinics etc.); a lack of mandatory standards that would support higher levels of interoperability between systems; the fact that business process and requirements (based on competitive tendering by private sector vendors) tend to drive acquisition and implementation of systems, rather than clinical practice and clinical need; and the fact that the health sector is itself fragmented with inefficient systems for transferring information. Lack of resources (especially resources directly targeted to interoperability rather than delivery of care), lack of leadership in the sector, and concerns over patient privacy and the security of patient records are also identified as key factors. The conclusion drawn by the Ministry of Health and many others in the sector is that if national strategies for improving interoperability in the sector, as outlined in the Health Information Strategy-NZ 2005 (HIS-NZ 2005), are to be met, leadership from both the Ministry and the DHBs, and funding dedicated to this task, will be necessary.

The National Health Service (NHS) and the National Programme for IT

It is exactly this kind of scenario, repeated across the world, that led to the very ambitious National Programme for IT (NPfIT) developed by the UK National Health Service. The project was formally established in 2002 by an NHS agency established for this purpose, Connecting for Health. The core element of the project was a single centrally managed electronic patient record system, the NHS Care Records Service (NHS CRS) for all UK citizens, a national 'Spine' which was intended to provide for secure, audited access to this record by authorized health professionals in 300 hospitals, plus the 30,000 odd GPs working in the UK. Other elements included a dedicated broadband infrastructure to support this access, a "Choose and Book" system to allow patients and GPs to book appointments with specialists in the secondary care sector, an electronic prescribing system, and a PACS system (electronic medical images from CT and MRI scans)

The project was initially budgeted at 2.3 billion pounds over three years. By 2006 that estimate had ballooned out to 12.4 billion over 10 years. (National Audit Office, 2006) Some estimates are as high as 20-40 billion. (Fleming, 2005) And there is little to show for this expenditure nearly 6 years later. Often described as the largest public sector IT project in the world, NPfIT has virtually bankrupted more than one IT company, seen public servants move in and out of the programme as though through a revolving door, and caused anger and dismay throughout the UK health sector. The House of Commons Public Accounts Committee has issued several damning reports of the project, the latest of which suggests that the critical healthcare records system remains some years off delivery. Although over 95% of GPs are connected to the system, only 50% are using the electronic outpatient booking system "Choose and Book," while other core services such as electronic prescribing is used by only 8% of GPs. (UK Public Accounts Committee, 2009)

As part of the central care records system, a software programme Lorenzo, developed in

partnership between global IT giant CSC, and UK-based health IT company iSoft which was taken over in 2007 by the much smaller Australian based IBA Health is currently being rolled out in a number of NHS Trusts in the North, Midlands and East regions of the NHS. However, by the end of 2008 Lorenzo had not been deployed across any NHS Acute Trust (equivalent to our DHBs) and only one Primary Care Trust. At the same time, British telco BT is implementing its Cerner Millennium programme through NPfIT in London and Southern England in conjunction with CSC, after Fujitsu lost its Cerner based contract in 2008. The fourth company involved, Accenture handed its control of North East and East Midlands to CSC when it cut its activities in NPfIT to picture imaging only, as part of the PACS system.

The reduction of IT providers in the National Programme for IT from the original 4 to 2 has raised questions about initial arguments for competitive tendering, and the failure of any of the 4 providers to deliver workable live networked systems has seen many Trusts and clinicians opt for local solutions. Individual GPs and leading members of the British Medical Association have made calls for NPfIT to be scrapped, and for NHS Connecting for health to free up public funds for local initiatives, focused on local patient-centred systems, and an end to “expensive government policies, commercial contracts, and management consultants”. (E-HealthInsider, 2009a) Reports of doctors “almost in tears of because of how frustrated they are at being prevented from doing their jobs by the IT system”, (E-HealthInsider, 2009b) major (and substantiated) concerns about privacy and security of patient records,⁶ lack of clinical involvement in the development of systems, and the consequent inability of systems to support clinical care at the required level are constantly levelled at the programme. This adds up to an almost universal lack of confidence on the part of healthcare providers in the UK that NPfIT can deliver the urgently needed IT systems (which in the current environment would need to be more sophisticated than anything that Lorenzo or Cerner Millennium can offer), to support delivery of care in the 21st century. “Waiting is not an option” stated the CEO of Rotherham NHS Foundation Trust explaining his intention to buy an alternative system to improve patient care and boost productivity. (E-Health Insider, 2009c) But there is a lot of waiting going on.

The only studies I have identified that systematically investigate problems with NPfIT and its implementation have been conducted by Jane Hendy, currently a member of the Health and Care Infrastructure Research and Innovation Centre ([HaCIRIC](#)), Imperial College, London, when she was at the Department of Public Health and Policy at the London School of Hygiene and Tropical Medicine. Two investigations, published in 2005 and 2007, based on interviews and case studies in 4 ‘acute hospital trusts’ in England were conducted at an interval of 18 months. (Hendy, 2005; Hendy 2007) These studies showed clearly that while individual clinicians can see the benefits of electronic health records, lack of information and support from the national programme (including financial support), issues to do with organizational culture, the need to comply with

⁶ Apart from some well documented losses of patient data when laptops carrying patient information have been stolen from clinics, the idea floated by the Conservative party that patient records in the NHS spine should be handled by Google health, with access by individuals to their own record by means of a userid and pin number, created an outcry when leaked by the Times in July 2009.

centralized bureaucracy, coupled with lack of recognition of small local EPR initiatives create a very negative attitude towards the NHS approach. Solutions proposed by NPfIT were seen as reducing functionality, as being unresponsive to local conditions, expensive, bureaucratic and making impositions on local budgets, while being unable to deliver tangible benefits. Clinicians identified risk to patient safety as a major demotivator in cooperating with NPfIT.

An independent report commissioned by the Conservative party, and chaired by Glyn Hayes, former GP, and Chair of the British Computer Society's Health Informatics Forum, while stopping short of calling for the abandonment of NPfIT, outlines how it could be combined with localization of the programme, with a renewed focus on "the care of the patient and the work of the clinician in delivering this care", rather than what the report describes as a "dataset mentality" focused on management information. (Hayes, 2009) The report advocates: a national strategy that recognizes centrality of the patient-clinician relationship; the importance of IT in delivering health care (recognising it has become as critical to health outcomes as any other professionally agreed and standardised activity); localisation, and choice of system supported by greater focus on data quality and the use of mandatory standards (for data and terminology and functionality); and a national architecture that would support interoperability between localised systems, and specialised small databases. The report also recommends that the role of government is not to pay for the development of systems, but look for existing products that are both fit for purpose, and fit the national architecture. Implementation plans should incorporate clinical engagement, and focus on change management procedures. Mandatory training in information governance, patient involvement in their records, audit trails and discipline for breaches of patient confidentiality should be implemented. Evaluation should be an ongoing activity, part of system selection, implementation and assessment, related to risks and benefits as well as transparent and available to stakeholders. These recommendations tell much about the shortcomings of NPfIT, and constitute a major indictment of the NPfIT programme. The report has, on the whole, had a very positive reception, although its recommendation that private firms, including Microsoft and Google should be allowed to host independent patient records online, has raised more than just eyebrows!

An overview of the situation in New Zealand

The recent report to the Minister of Health, *Meeting the Challenge: Enhancing Sustainability and the Patient and Consumer Experience within the Current Legislative Framework for Health and Disability Services in New Zealand*, by a Ministerial Review Group, chaired by Murray Horn, echoes some of the same themes. The MRG comprised clinicians, public health specialists and administrators from across the sector, including the current Director General of Health. The group was charged with addressing a range of current concerns in the sector: the aging population, workforce issues, problems with the structure (21 DHBs), concerns about New Zealand's performance against certain 'health indicators' compared with other OECD countries, public concern with waiting times for elective surgery, continual reports from the Health and Disability Commissioner on preventable medical errors, and the fact that the New Zealand economy is not large enough to sustain healthcare system we want. As the report notes, we need to be more

effective and productive to ensure that our healthcare system is financially sustainable in the medium to long term. The recommendations, which are made within the existing ‘legislative framework’ i.e. retaining the existing 21 DHBs with no major and disruptive restructuring in the sector, focus on nine themes:

- New models of care – focusing on a patient-centred, seamless patient journey through the system, greater use of primary and community care ‘closer to home’;
- Stronger clinical and management partnerships – giving health professionals more voice;
- Sharper focus on patient safety and quality of care, and more services from current resources;
- National approach to introduction of new technology and clinical procedures, in response to need;
- Putting the right services in the right place by ensuring that is structured to respond to need;
- Ensuring the right capacity is in place for the future through workforce, capital and IT planning;
- Building a sustainable workforce;
- Shifting resources to frontline (reducing back office costs by avoiding duplication);
- Improving hospital productivity.

The only key structural changes recommended are the formation of a National Health Board, which will be responsible for monitoring the performance of DHBs and national planning in key areas such as IT, a requirement that the DHBs plan on a regional basis (which will require greater cooperation), the introduction of a new Crown entity to provide shared services to DHBs, a reduction in the (admittedly) excessive number of committees advising and reporting to the Minister/Ministry and a revamped more powerful Quality Improvement Committee.

The key issues identified by the MRG are frustration in the health sector about the lack of coordination of services and problems related to the autonomy of the 21 DHBs and 82 PHOs delivering primary and secondary health care in New Zealand, duplication of effort with a concomitant waste of resources, a lack of coherent planning in the sector, and a lack of clinical leadership. Resolution of nearly all of these issues is reliant on IT for solutions. So what are the Recommendations of the report related to IT? As the report turns to IT, it notes:

The explosion of information and technology available within health has both positive and negative effects . . . the sector is currently inundated with too much information, and too many IT projects . . . these current national and provider systems are not easily linked up to provide a ‘patient or person-centred view.

The report recognises the critical role of high quality information systems in any attempt to improve the quality and consistency of care, and in reducing the impact of the ‘bell curve’. The reports argues that the use of average success rates (found in the main percentiles of a bell curve) disguises the fact that at either end of the curve there will be services with both excellent and less than acceptable outcomes, with a great mass of

mediocre performance in the middle. Shifting that mass towards excellent performance, the report argues, would do more to increase the quality of care on average than focusing on the poorest performers. To do this requires reliable data collection and analysis to enable clinicians to monitor their work. In the secondary sector this would be the responsibility of the new quality committee, building on the acknowledged success of the existing QIC. In primary care an acceleration of the recently introduced Quality Information for General Practitioners programme (QI4GP) is recommended, again an initiative highly dependant on IT. The report also recommends that DHBs should be required to integrate, at least at the regional level, some of their back end systems, which are largely IT driven, under national mandates created by the newly established National Health Board.

Acknowledging the “significant and integral part information plays in determining how health services are delivered,” Annex 3 of the report lists some high level goals for IT in the NZ health sector. The report acknowledges a high level of IT uptake in the NZ health sector, especially in primary care, but also points to the negative impact of fragmented systems, containing information which is not easily shared, communicated, or accessed by patients and providers. Past attempts to integrate services, and past investment by the Ministry in national initiatives and actions such as the Key Directions approved in August 2008 show familiar patterns of significant top down expenditure, deadlines not met, and little to show for the investment. The report specifically mentions the National System Development programme (NSDP) which under budget but overtime, has in fact little to show for the \$27.9 million invested to date. Some projects are criticised for being top-down, lacking input from clinicians, and others for lacking any national scope.

Canvassing the options for both a clinically effective combined with a cost effective solution to this problem, the report rejects a “single sector-wide enterprise system”, and proposes instead “the implementation of a safe, shared and transferable patient electronic health record for [the] New Zealand health sector using a distributed approach based on interoperability standards set by the existing Health Information Standards Organisation HISO.” (Ministerial Review Group, 2009, Annex 3 p12). It also notes that this will require the development of a national IT architecture that “clearly shows how a distributed patient-centred electronic health information system works for consumers and providers.” The report also suggests that existing successful IT initiatives at the level of general practice (e.g. electronic GP to GP Notes Transfer system being trialled, the PHO Performance Programme, electronic referrals, electronic discharges, and electronic laboratory), should be integrated and rationalised under a compatible primary care information system, aligned with this architecture. The vision articulated is for a patient-centred, rather than a provider-centred approach to IT systems in the sector.

The nature of the ‘patient electronic health record’ envisaged, however, is not well defined in the report. (Nor is the proposed ‘consumer portal’ that presumably provides access to this record, and associated reliable consumer health information.) We have to rely on signals such as the focus on patient-centred care, the constant use of the word ‘safe’ with reference to the shared record, the reference to ‘consumers and providers,’ and a passing reference to an ongoing role for the existing HISAC Consumer Forum in

relation to the “safe sharing of health information, community dialogue and education”. While this is reassuring, as with much of the report, the devil will be in the detail, and there is little detail that can be spelled out in such a wide-ranging report. Concerns expressed in New Zealand, by the Privacy Commissioner, the HISAC Consumer Forum, and by the Health and Disability Commissioner, echo those in the UK. Issues of privacy, security, identity and authentication (of those able to access the record), audit and sanctions, will be key issues in the acceptability, and therefore the success of the proposal for a ‘safe, shared and transferable patient electronic health record”

The report makes several references to HISO and its role in developing standards, which are critical to interoperability between health information systems. Through its governance body, which includes membership across the sector (e.g. The Medical Council, The Nursing Council, Chief Medical Officers Forum, DHB CIO Forum, Accident Compensation Corporation) HISO is currently charged with investigating, consulting and adopting standards covering the definition of data and the exchange of data in relation to: medicines terminology, authentication and security, e-pharmacy business process and messaging, clinical data, pathology and radiology tests, and ethnicity data. Most of these are closely based on either ISO standards or other internationally accepted standards, such as the clinical coding systems READ, SNOMED, ICD-10, lab test codes such as LOINC, or messaging standards such as HL7(which operates at level 7 of the OSI model-applications).

The importance of Open Standards in healthcare

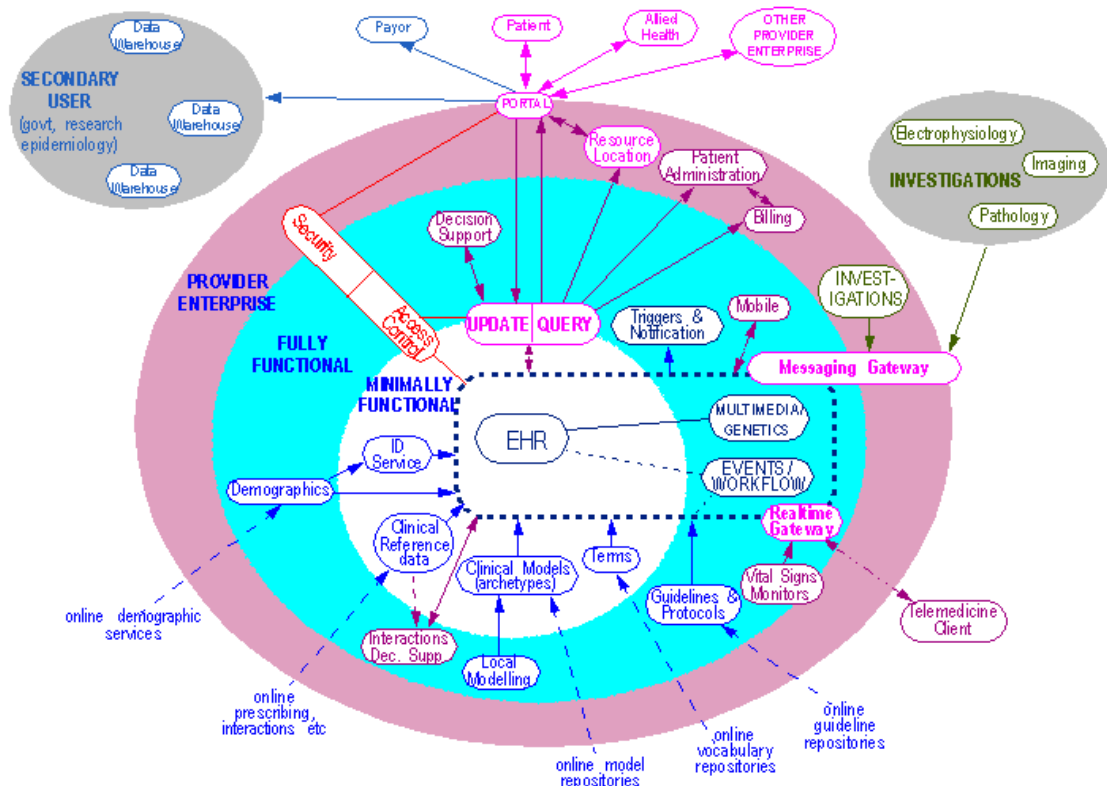
A number of these are open standards, developed by not-for-profit organisations reliant on voluntary working parties, much like the W3C, which develops and maintains standards for exchange of information on the WWW, and whose XML platforms and ‘schemas’ are integral to open standards. A prime example is, SNOMED CT (the Systematized Nomenclature of Medicine-Clinical Terms) which began as collaborative venture between the NHS and the American College of Pathologists, now licensed by the International Health Terminology Standards Development Organisation (IHTSDO), an international not-for-profit organization based in Denmark) SNOMED-CT claims to be the most comprehensive, multilingual clinical healthcare terminology in the world and to make a significant contribution improving the quality and safety of healthcare and eliminating avoidable deaths and injuries that occur because of poor communication between healthcare practitioners.

Open standards such as HL7 and SNOMED-CT are critical, but to some extent limited in their value if they are not matched by open architecture. Organisations such as IHTSDO are increasingly recognising the need to work cooperatively with other international organisations developing standards and specifications for electronic health records, and the interface between the individual patient record, and systems maintained by other healthcare providers. The OpenEHR Foundation, the global organisation dedicated to the development and promotion of an open electronic health record architecture as the basis of a patient-centred healthcare system, takes its mission from the same problem, noting as so many others have done, “ICT is used ubiquitously elsewhere, but is far from effective in Healthcare. The main problem in health is the lack of shareable and computable information.”

The OpenEHR Foundation notes:

The principal challenge for health ICT is to represent the *semantics* of the sector, which are far more complex than in other industries. Doing this requires a knowledge-oriented computing framework that includes ontologies, terminology and a semantically enabled [health computing platform](#) in which complex meaning can be represented and shared. At the same time it must support the economically viable construction of maintainable and adaptable health computing systems and patient-centric electronic health records (EHRs).

The essence of the OpenEHR architecture, therefore, is a model for a health computing platform that combines a set of specifications, open source software and tools in order to create “high-quality, re-usable clinical models of content and process - known as archetypes - along with formal interfaces to terminology.”



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(underneath this diagram, lies a complex set of data dictionaries, source code and algorithms that enables each part of the model to interact with each other part, and with external systems).

The MRG report makes no mention of OpenEHR, and it does not appear on the list of standards already approved or under consideration by HISO listed on the HISAC web site. Work currently underway in the Ministry of Health on bringing the proposed new NZ EHR is looking closely at the OpenEHR, and how it is being introduced in other countries. International cooperation between key organisations such as the IHTSDO

(SnoMED-CT) , the HL7 Board and the Open EHR Foundation is likely to result in a new set of open source tools that will be needed to underpin the interoperability necessary to create and support the implementation of the “safe, shared, transferable patient electronic health record” that lies at the heart of the vision of a safe, cost-effective, sustainable patient-centred health service in the report of the MRG.

The OpenEHR architecture, focused on the sharing of information between health care providers, clinicians, consumers, and public health researchers, already meets several of the principles underpinning the MRG’s recommendations. Its combined approach to the standardisation of data representation, and semantics (that is, clinical structure and meaning) along with a standardised approach to querying makes it an extremely powerful tool for interoperability between systems, and to support national e-health systems. It is fully compatible with proprietary systems which can provide complementary back-end and front-end systems that integrate across a defined interface. However, it was developed in the context of, and is committed to open source software, using open source languages such as PERL, Java, Eiffel, and .NET. Open source software allows the organisational user to have access to, modify, and share with others their improvements in the source code that drives the system (“what’s under the bonnet”), unlike proprietary softwares, which have been likened by the open source movement to “buying a car with the bonnet glued down”. Open source software can also be re-used in as many contexts as needed, without additional license fees, or fee per user, as is common with proprietary software.

The significance of open source software, (free and open source software is the increasingly preferred term) has yet to be realised in the health sector as in other domains, although the fact that in the past few years software giant Microsoft has started to sit up and take notice, developing its own Open Source Foundation, and its own source workshop to help users integrate its products with Linux suggest that something is happening. Governments around the world, particularly in Europe, are showing interest in open source software as a way of containing IT costs, and enhancing sustainability. A recent report for the Danish government (which has already committed to the use of OpenEHR in the delivery of its e-health services), notes that “strategic use of open source software can create value, reduce costs, and improve control of the software portfolio.”(Denmark, 2009) Open source software has no or minimal license costs (although implementation, running costs and services incur normal costs), can be adapted to suit the organisation, opens up a wider range of vendors to offer services, thus increasing competition and preventing ‘vendor lock-in’, and can be re-used, if necessary across a whole range of government agencies. (It has an additional benefit, in that it better guarantees the security of the contents- since organisational users can inspect the source code they can be assured that there are no hidden backdoors where data is being inappropriately used or extracted.) Open source software is therefore a contributor to innovation, competition, self-determination, reuse and value for money, interoperability and flexibility. These are the characteristics that are needed to drive IT in the health sector in New Zealand, and across government – and are major contributors to productivity and sustainability in the health sector as well as in the government sector.

Summary

It is time to pull all these threads together, and to sum up, to see what pieces of the jigsaw we have in our hand, and where they fit in.

Firstly, let us go back to the mantra of Open standards, Open architecture, Open source, and Open access, which I believe are the solutions to the problems

I have outlined. This approach is the only way to overcome the silos of healthcare which are currently preventing interoperability and the exchange of information which is necessary to improve the quality, safety, productivity and sustainability of our healthcare system. The building blocks are all there, the visionary work of pioneers such as Archie Cochrane, but also people like David Ingram and Sam Heard who have persisted in their efforts to get the OpenEHR accepted, and people in the Open source movement (including our recent visitor Richard Stallman). We must also acknowledge the vision shown by the Directors of the National Library of Medicine and the National Institutes of Health in the US, who have never wavered in their commitment to the principles of open access to knowledge and who have poured resources into initiatives like the Universal Medical Language System that helps make PubMed and Medline such powerful tools and provides the core integration between the knowledge base and clinical records because of the work done on the integration of UMLS and SNOMED. These things are all critical to achieving the vision.

But none of them would succeed in isolation, and without the commitment of everyone in the sector, including clinicians. In a way, the story has come full circle, the vision began with clinicians like Archie Cochrane and Dave Sackett, and Sam Heard, and the many who worked with them. But for a time, as the industry developed it seemed to be overtaken by migration of vendor companies, large and small, into the sector, who introduced a competitive model, based on RFI/RFP procurement model. That model is increasingly being discredited. The embracement of the open source philosophy offers government a new opportunity to break the hold of vendor companies over the IT sector, without denying them the opportunity to participate.

Furthermore, comparing the history of health IT initiatives in the UK and New Zealand, it seems that the British model of a top down large scale single enterprise sector-wide approach, based on the competitive model has not served the UK National Health Service well, and that a more distributed approach with limited national management (setting standards, overseeing interoperability) is likely to replace it. This model is not dissimilar to what we are likely to end up with in New Zealand. A distributed model, based on a “safe, shared, transferable patient electronic health record” based on international open standards, open architectures, and, I sincerely hope, open source software., managed by mandate by the National Health Board. It seems that as the field of Health IT matures (it is in reality barely 15-20 years old) consensus is building on the way forward.

At the same time, bringing clinicians back into the picture will not only ensure the clinical leadership that the MRG recommends, it is the only way to create a patient-centred healthcare system. Bringing clinicians back into the picture means developing a better understanding of workflows and culture, working to ensure that information systems are built to supply the information clinicians need, are not clip-ons on the back of

accounting systems, that their access to the knowledge base is seamless and timely, and compatible and integrated with patient records. In the end safety is about systems, making sure systems work, work for the clinicians at the coal-face, work for their patients, the consumers of health care, work for the organisations delivering health care services, and provide the necessary checks to reduce errors. The models are there, the delivery is still waiting.

This is a challenge, as the report of the MRG notes, but successfully meeting it requires one more thing – a knowledge base of the effectiveness of interventions in the delivery of health care. The evidence, that we require clinicians to be aware of and incorporate into their clinical decision making, barely exists in the field of Health IT. Decisions are made on the basis of a business model that is clearly not working. The MRG calls for more research, and rigorous evaluation in the sector. The Health Research Council has already responded with new categories of research funding for the evaluation of the delivery of health care. These are welcome signals. It is now up to those of us with a long standing commitment to health informatics to meet this challenge with rigorous and relevant research. If each of us can place just one piece of the puzzle in place, we will together build a better health care system for New Zealand.

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