

# From Strategy to Reality

## The *WAVE* Project

Kia hopu te ngaru



October 2001

Health Information Management and Technology Plan  
*Working to Add Value through E-information*

# The Advisory Board's 10 top priorities

1. Set up an independent organisation to lead IM/IT capability
2. Collect reliable ethnicity data
3. Implement the National Provider Index (NPI)
4. Fix up the National Health Index (NHI) - allow primary provider access, improve ethnicity data
5. Gather primary care information
6. Fix up pharmacy and laboratory data and provide primary care with access
7. Clean up messaging standards
8. Sort out Health Event Summaries - with data dictionaries, electronic discharges and referrals
9. Launch health portal
10. Make integrated care work by: developing standards for data exchange, security & network infrastructure

**And ... Involve patients!**

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# Foreword



**David Caygill**  
Chair  
WAVE Advisory Board

The *WAVE* project began under a different title. In December last year the Director-General of Health, Dr Karen Poutasi, invited 13 of us to join something then called the "Health Information Management and Technology Plan Advisory Board". In time this gave way to *WAVE*: Working to Add Value through E-information.

The task of overseeing this plan has been both challenging and absorbing. From diverse backgrounds, the Board members brought a common commitment to New Zealand's health services and a shared belief that better means of organising health information need to be employed.

The electronic revolution that began at the end of the twentieth century holds out the prospect of many advances for health services. To capture these opportunities requires agreement on common standards, languages, methodologies and other techniques, and ultimately in our view a new approach to health organisation. The *WAVE* project has sought to answer these challenges. After months of examining the issues, the Advisory Board concluded that the top priority is to establish an agency, to oversee and drive common information technology issues in the health sector. Without such a new organisation there is a risk that this project will have to be repeated in a few years' time. The health sector needs real competence and strength in its information management. It is imperative that this capability grows and develops in a systematic manner.

These arguments are made in more detail in the report that follows. Its core chapters reflect the separate work streams into which the *WAVE* project was divided. To some extent the separation between these work streams was artificial. Hopefully reading the chapters as a whole will build a picture of the present state of information management and technology in the health sector, as well as of what is needed in the future.

Each work stream consulted widely with a diverse range of interested parties and in a variety of different ways. The individual work streams reported regularly to the Board and ultimately recommended approaches that form the substance of this combined report. The Board's job became one of directing the work streams in the first instance and then of bringing together and synthesising the individual project reports. Ultimate responsibility for the recommendations lies with the Board.

It has been a privilege to chair the Advisory Board. I have greatly enjoyed working with other members as we grappled with (for some of us, at least) unfamiliar terminology and concepts. I know I speak for other members of the Advisory Board when I express our thanks to David Moore and the members of the project team who gave so freely of their time and expertise. Particular thanks are due to David for his outstanding leadership. But to everyone who contributed their time or merely shared their knowledge or opinions, I express the Board's thanks.

I hope the report that follows will encourage its readers to continue to seek better ways of recording, sharing, analysing and using health information. I am confident that taking these steps together will significantly enhance New Zealand's health and disability services and the health of New Zealanders.

**David Caygill**

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# Introduction - *project approach*

The importance of strategic information planning in health was first signalled in 1991, 10 years ago now, when the Department of Health published its "Health Information Strategy" for New Zealand. Then, in 1996, the Ministry of Health updated its strategic framework with "Health Information Strategy for the Year 2000". Over the past six years, the world of Information Technology has leapt ahead with the exponential growth of the World Wide Web, networked organisations and universal acceptance of electronic communication.

In December last year, the Director-General of Health (Dr Karen Poutasi) in consultation with DHBNZ, appointed an Advisory Board to facilitate the development, and acceptance by the health sector, of an Information Management and Technology plan. It was subsequently renamed *WAVE* - Working to Add Value to E-information and due for completion by June 30, 2001. The Board comprised representatives of a range of sector interests and was chaired by Hon David Caygill. The terms of reference required them to work for the common good of the public of New Zealand. The plan's intention was to improve health outcomes through effective use of health information at the least cost to the sector. *WAVE* commenced with an Advisory Board meeting on December 21, 2000 and now, nine months later, the project template is complete.

To achieve this goal, the Board worked with the sector and project team to design, organise and undertake any processes that revealed issues of concern (or possible further value). The Board was mandated to resolve issues that were either brought to their attention or which they revealed through their own analysis where that resolution could be brought about by their collective influence. The Board had no authority to commit expenditure on behalf of the Ministry of Health (or any other body) but it did have editorial independence.

The Board was supported by a project executive (Programme Director, David Moore) with a core team of staff from the Ministry of Health, District Health Boards and New Zealand Health Information Service (NZHIS). The team was split into eight project work streams:

- Strategy
- Knowledge
- Electronic Health Records
- Data Architecture
- Privacy
- Systems Infrastructure
- Investment
- Organisation Design

One of the Board's first activities was to define the goals of the teams and to draw parameters for the subsequent analysis. There was overwhelming consensus the plan needed to support the Government's integrated care initiatives: developing information systems to support patient-centric integrated care, with specific focus on wellness and disease management systems. The second priority was Governance: agreeing an on-going governance structure for information management and technology to ensure national coherence and consistency.



The research approach undertaken involved:

- Analysis of the current sector arrangements concerning health information and technology;
- Identification of enhancements for the next one to two years; and
- Compilation of a longer-term plan, with a view to developments occurring over the next three to five years.

The health and disability sector became actively involved when a Letter of Intent was sent in early February to sector participants, followed by a submission process. There was a high level of involvement, right across the sector. Some of the groups involved were:

- District Health Boards
- Ministry of Health agencies (NZHIS, SSSG, Health Benefits)
- Accident Compensation Corporation
- Office of the Privacy Commissioner
- Software vendors (SCL, Orion, Oracle)
- Consultancies (Deloitte Consulting, Cap Gemini Ernst & Young, KPMG)
- Government departments (State Services Commission, The Treasury)
- PHARMAC
- Alcohol Advisory Council (ALAC)
- Universities and Medical Schools
- NZ Blood Service
- Health Research Council
- IPAs (EastHealth, Pegasus, WIPA)

The work streams were open to participation from all parties, and information/ documents produced by the work streams were available to whoever wanted them.

The short/medium term focus was to provide the infrastructure, the knowledge and the tools required to utilise information effectively. It was important to capture the whole sector's interest and broad knowledge, so the project team decided to avoid consultants wherever possible as the sector needed to have final ownership of the problem, and the solutions.

Each work stream took a different approach:

- **Strategy:** the research tools were literature searches, facilitation of the consultation process and text analysis of relevant sections of the submissions, structured interviews (in conjunction with the Organisation Design work stream), review of sector submission responses to the *WAVE* project and workshops (primarily using the work stream leaders and managers) to bring together common points of intersection. All work streams analysed the consultation responses, which were broken out into relevant issues.
- **Knowledge:** literature searches of relevant topics, survey data, workshops and review of sector submission responses to the *WAVE* project.
- **Electronic Health Records:** literature reviews, workshops, a survey of DHB chief information officers and review of sector submission responses to the *WAVE* project.
- **Data Architecture:** an extensive range of workshops, oriented to specialist areas of interest, and review of sector submission responses to the *WAVE* project.
- **Privacy:** workshops, subsequent correspondence with specific consumer groups, three focus groups and review of sector submission responses to the *WAVE* project.



- **Systems Infrastructure:** technical analysis by five topic groups, input from consultants, a reference group, consultation on proposed industry information architecture, a meeting with input from around 40 participants and review of sector submission responses to the *WAVE* project.
- **Investment:** workshops and interviews on primary and community care capability, workshops with DHB Chief Information Officers, literature reviews, interviews about international approaches to IT investment, review of sector submission responses to the *WAVE* project.
- **Organisation Design:** workshops, structured interviews (in conjunction with the Strategy work stream), a reference group and review of sector submission responses to the *WAVE* project.

All of the work streams had a set of common steps:

- Current practice, including a review of current best practice
- Desired future state
- Gaps
- Implementation plan

The working papers and associated documentation of the project have been recorded on a CD Rom.

A further role (for the core team) was project management and administrative support. The core team provided a range of services, including a secretariat role to the Advisory Board, project tracking and templating, and syndication of the project amongst agencies (and within the sector) for resources, in both money and people.

The results of the submissions were analysed and presented to the Board at their monthly meetings and at special workshops, along with the findings from co-ordinated research activities managed by the work streams. The Board discussed the progress of each work stream as the teams worked through the identified issues to develop recommendations and an action plan. The findings soon began to reinforce each other, leading to a clear vision of the activities needed.

This report, *"From Strategy to Reality"*, documents those findings.

## Treaty of Waitangi Implications of Health Information



Tai Kake



Gwen Tepania  
Palmer

*E ngā mana, e ngā reo, e ngā waka, e ngā hau e wha  
Tēnā koutou, tēnā koutou, tēnā koutou katoa*

Māori have been frustrated by the inefficiencies, inconsistencies, and general lack of responsiveness of current health information systems. Providers, policy makers, researchers, iwi, hapu, whanau, and individuals are all concerned about accessing health information, privacy issues, and the poor coverage of health areas crucial to Māori<sup>1</sup>. Māori models of health<sup>2</sup> emphasise the importance of integrating information about health with the wider social and economic context. Current health information systems are fragmented, however, with different providers using different standards and IT systems that impede - rather than facilitate - the integration of health care. Our current systems do not effectively support Māori models of healthcare. The ethnicity definition used by different agencies and providers is inconsistent, so the data produced is poor. Gaps in data collections hinder sound analysis, policy and strategy development, and decision-making. This is the most important issue to tackle for Māori.

Māori providers don't have access to update or use ethnicity and other demographic components of National Health Index (NHI) numbers, yet collection of this information is crucial in improving NHI data quality.

Data - anonymous or not - has enormous spiritual and cultural significance for Māori, so may require more attention and protection than generally given. This has been a significant factor in the cervical and breast screening programmes. Data about the female reproductive parts of the body, *whare tangata*, is considered tapu therefore requires respectful treatment.

### Kawanatanga (Crown Obligations)

The Treaty of Waitangi established a Crown obligation for Māori to enjoy a health status at least as good as that enjoyed by non-Māori. The Government is committed to fulfilling its obligations to Māori to support self-determination for whanau, hapu, iwi and Māori organisations. This is impossible without reliable health ethnicity data, as this is a fundamental building block to improve the health of Māori in planning and providing appropriate services. Meaningful data and information can be used to empower Māori communities, thereby facilitating *rangatiratanga*. The inadequacy of current information systems (especially in primary care)<sup>3</sup> for collecting ethnicity data is an extreme concern. The Crown cannot monitor its progress in meeting Treaty obligations without reliable ethnicity data.

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1 Māori Standards of Health III - Pomare et al, Hauora 1995

2 Māori Health & Development - Durie, Whaiora 1994

3 The Collection of Patient Ethnicity Data in General Practice, prepared for Te Kete Hauora, MoH 1998

## **Tino Rangatiratanga (Empowerment)**

Health information and IT management systems can be powerful tools for addressing health issues<sup>4</sup>. For this power to be harnessed to benefit Māori, there must be more Māori actively working in all areas of the health information system, from operational through to strategic decision-making; in the collection, transmission, and storage of health information through to its analysis and dissemination. A robust highly integrated health information system is one tool for Māori to address effectively the long-standing health disparities they have endured.

The *WAVE* plan is an important development in highlighting and addressing Māori concerns about current health information systems. If the *WAVE* plan achieves only one thing - the collection of reliable ethnicity data - it will be a major advance for Māori. Implementation of the plan is a challenge, but also an obligation, for both Treaty partners.

*Gwen Tepania-Palmer & Tai Kake*

## **WAVE recommends**

1. Collection of reliable ethnicity data;
2. An annual audit of ethnicity data in health information systems;
3. Establishing a reliable baseline for Māori IT workforce capacity in the health and disability sector; and
4. Promotion of integrated health information systems.

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<sup>4</sup> New Zealand Health Strategy, MoH 2000



# 1. Strategic Setting - *laying the foundation*

## Introduction

The WAVE programme's objective has been to produce an information and technology plan for the sector, with the aim of improving health outcomes - through the effective use of information, at the least cost. Providers need better access to the best information to provide the best care for their patients<sup>5</sup>. WAVE has reviewed the current management of health information and technology, investigated how links between sector participants can be improved and gaps in knowledge identified and remedied. There were eight work streams within the programme - Strategy, Knowledge, Electronic Health Records, Data Architecture, Privacy, Systems Infrastructure, Investment and Organisational Design. Each work stream approached the issues from a different perspective, yet produced startlingly convergent and significant conclusions, particularly in identifying the major capability gap that needs to be bridged before we can make any major improvements in New Zealand information. The work stream results were part of a mutually reinforcing circle. "From Strategy to Reality" commences by examining the strategic setting, which provides the context for the discussion, before analysing the specific work streams.

Better information will help improve every New Zealander's health and independence by providing a sound basis for decision-making for planners, funders and providers. But information systems are only part of the equation. The on-going governance of these systems is equally crucial. Sustainability is critical in any health system, in both the organisational system and framework architecture; otherwise it will not be able to serve the sector as a whole.

The Government has set out a number of strategic imperatives for health and disability service provision. These are reflected in both the New Zealand Public Health and Disability Act 2000 and in subsequent strategies. These strategic imperatives shift focus to population-based and integrated models of health care and demand a rethink of our current information strategy.

The old model of health care (based on bricks and mortar) is shifting to one based on community care, provided by multiple providers. This shift has been caused by a number of factors including: a decreased rate of epidemic disease, new understandings of holistic care and an increasing flexibility of delivery options through improved networking technologies. This co-ordinated, or integrated, care covers primary and secondary providers, but also the various multi-disciplinary teams required to provide services to people in the broader community.

Allied with this is the growing impetus towards improving clinical quality, which also demands more sophisticated information systems. Our current information systems are incapable of providing a bird's eye view of the sector, nor can they easily share information. Action must be taken to help the Government achieve its stated goals. Information systems and the ensuing knowledge base are critical in quality health and disability service delivery.

It is a compelling case.

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<sup>5</sup> Patient is acknowledged to be a limited term, and inappropriate for those with disabilities who are more commonly referred to as 'clients', but the term 'patient' is in common usage in the health sector and has been used throughout this document.

## Government Policy

### Statutory Requirements

The New Zealand Public Health and Disability Act (2000) defines the sector's current structural framework. It explicitly notes the need:

*"To facilitate access to, and the dissemination of, information to deliver, appropriate, effective and timely health services, public health services and programmes, both for the protection and the promotion of public health, and disability support services."*<sup>6</sup>

### Health Strategy

The Government has released a number of key strategies providing direction for future development. The New Zealand Health Strategy sets the platform for action on health and highlights the role of information management and technology:

*"The ability to exchange high-quality information between partners in health care processes will be vital for a health system focused on achieving better health outcomes. Better access to timely and relevant clinical information can improve clinical decision-making and, therefore, health outcomes for individual patients. Privacy and confidentiality of personal information must be maintained at all times in compliance with the Privacy Act 1993 and the Health Information Privacy Code 1994."*<sup>7</sup>

### Primary Health Care Strategy

The New Zealand Primary Health Care Strategy outlines the framework for the delivery and organisation of the primary care services required and emphasises co-ordination of care:

*"People have diverse health needs, and use a number of services provided by different providers in various settings. It is important that there is co-ordination of care between these services, so that the best possible total package of care is provided to the patient without unnecessary duplication."*<sup>8</sup>

The strategy highlights information management as one of six key directions to improve quality continuously. It is quite explicit:

*"Accurate and useful information about enrolled populations and their health needs is critical to quality as well as to the successful adoption of a population health focus in primary health care."*

### Disability Strategy

The New Zealand Disability Strategy promotes a more inclusive society with its enduring framework to ensure government departments and agencies consider disabled people before making decisions. It recognises information as a tool:

*"Collect and use relevant information about disabled people and disability issues."*<sup>9</sup>

### Integrated care

Modern medicine is highly specialised, so increasingly patient care will involve a number of health providers - in other words, integrated care. WAVE's recommended framework is specifically designed to facilitate this development, which has been driven by clinical and financial imperatives. Without this framework, the move towards multiple providers will result in fragmented services, duplication (from lack of communication and co-operation) and the inability for any one provider to have an overall perspective on an individual's health and well-being.

Integrated information systems mean providers have access to all of the patient's appropriate medical history. Sound information reduces risk, guides quality improvement and supports research on better

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6 The New Zealand Public Health and Disability Act (2000) Section 3 (1) (d)

7 New Zealand Health Strategy, December 2000, Minister of Health

8 New Zealand Primary Health Care Strategy, Feb 2001, Minister of Health

9 New Zealand Disability Strategy, April 2001, Minister of Disability Issues

health care practice. Providers will have faster access to accurate information about services patients have already received, enabling more appropriate treatments; laboratory tests and x-rays will be duplicated less often; and the system will signal if combinations of prescribed drugs have harmful interactions. And planners and funders will be able to identify more easily where resources are most needed and will be able to recognise (and, therefore, reward) good practice.

The alternative unco-ordinated approach provides few incentives to work together and take a more preventative approach to disability and disease. Duplication leads to waste of scarce health resources. Waste also occurs when lack of co-ordination leads to treatment error or gaps, which can require expensive intervention at a later stage.

This improved knowledge base will not only improve the quality of care but should reduce the possibility of medical misadventure. Efficient use of information will reduce the cost of delivering health care, making it possible to offer more services. Reliable recording of ethnicity data, coupled with appropriate system development, will help ensure Māori and Pacific people can measure what is happening in their populations.

Integrated care ranges from the basic level where two providers share the same patient data on an individual, to more sophisticated models where organisations are responsible for funding, planning and contracting health and disability services for large numbers of people. At all levels, however, there is a focus on co-ordinating care across the boundaries of health and disability professions and organisations. Integrated information systems are a prerequisite to integrated care but, in turn, they depend on some foundation components that must be in place. These include agreed networks, standards, data sets and a privacy framework.

### **Critical need for health information**

Decision-makers will make more informed and, therefore, better decisions when they have access to quality information that is relevant, timely and accurate. Any publicly funded system must be scrutinised closely to ensure cost-effectiveness of interventions (based on clinical evidence) and rationing decisions.

Quality information is critical. At the clinical level, decision-makers do not always have the information at hand to help them make informed decisions. At the regional and national level, resources are often allocated with no clear understanding of the impact they are making on health outcomes.

Information systems do not exist in isolation from policy, programmes, or political imperatives. Historically there has been a tendency to tie information systems to organisational structures within the government health sector, making them vulnerable to any changes in the sector. The effect is often compounded by the rapid rate of change in both health technology and IT. This was illustrated during the inquiry into the under-reporting of cervical smear abnormalities in the Gisborne region between 1990 and 1996. The Committee of Inquiry examined the National Cervical Screening Programme's systemic issues. It found that the Programme had lacked a central register<sup>10</sup> to enable comprehensive compiling of data for each participating woman; instead there were 14 regional site registers (corresponding to the 14 Area Health Boards in existence when the Programme commenced). This, with other factors, contributed to the Programme's failure to gather reliable relevant statistical information.

### **Other objectives**

The WAVE Board identified a number of other, secondary objectives. These objectives are documented in the table below. Achievement of the highest priority objectives would mean that we had also gone a very long way to achieving the objectives set out in the table below.

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<sup>10</sup> There is now one register, and the other issues have been (or are being) addressed



**The WAVE Board soon identified the following aims:**

- Open up electronic communication
- Clear role accountability
- Health outcome focus
- A common and complete language
- Empower communities
- Develop analytical capability
- Develop an approach to sharing clinical records
- Reduce provider compliance costs

## Why Have a Health Information Project?

The amount of information available nowadays is overwhelming, but it is sometimes delayed, incomplete, inaccurate or simply difficult to access. Looking back in five years' time, the WAVE Board intends the Health and Disability sector to have changed significantly, driven by a well-respected information and knowledge organisation. For the first time, a bird's eye view should be possible across the whole sector, helped by clear information and systems standards, so providers should be able to network. This will help provide sound information helping doctors and providers to help patients. Everyone should experience improved service and care. There'll be better use of the health budget, reduced multiple diagnoses, fewer medical errors... better health for all. Here are some examples of how electronic information, based on quality and evidence-based knowledge, governed by national standards, will change people's lives.

**GPs** would be able to add value to patient consultations by knowing

- ✓ what treatments have been provided
- ✓ the latest treatment option for their condition
- ✓ the results of tests already taken
- ✓ more about the quality of care

**Patients** would know

- ✓ waiting times
- ✓ the relative safety of procedures
- ✓ about support groups
- ✓ their rights and choices

**House Surgeons and Registrars**, would

- ✓ know where their patients are located
- ✓ know what procedures and tests have been performed
- ✓ know whether their patients are allergic to medications
- ✓ have access to good clinical records and databases

**Midwives** would

- ✓ have access to past obstetric records
- ✓ have easy referral to Well-Child services

**Health managers** would be able to plan more successfully, knowing

- ✓ the health status of their populations
- ✓ the benefits, risks and costs of services
- ✓ more about the quality of care

**Public health specialists** would have a better understanding of many things, particularly

- ✓ who has been immunised
- ✓ who has not
- ✓ which services give the best immunisation results (particularly in areas such as hepatitis)

**The public** would be able to measure

- ✓ whether we are getting sicker
- ✓ or better
- ✓ whether our children are immunised
- ✓ which providers and DHBs are best
- ✓ whether the system is failing

**Māori** would be able to

- ✓ evaluate the accuracy of ethnicity data
- ✓ implement programmes to improve ethnicity data
- ✓ establish reliable baselines for priority health indicators
- ✓ evaluate the cost/effectiveness of service access, delivery and treatment
- ✓ quantify progress towards reducing health disparities
- ✓ quantify the resource allocations required for reducing Māori health disparities
- ✓ monitor access to, analysis and dissemination of, individual and aggregate Māori health data

**Software vendors and developers** would have

- ✓ lower costs and shorter development times
- ✓ a level playing field
- ✓ a strong base to export from
- ✓ an opportunity to shape national standards
- ✓ an aligned development objective

## **No downside**

The advantages in getting health information technology and information management right are best seen by the costs of inaction - poor systems development, isolated items of data, poor quality management systems, inefficient operational spend, and lack of fit with strategic priorities.

The benefits are compelling.

The initiatives needed to keep New Zealand's health system modern and to achieve the health benefits sought by the NZ Health and Disability strategies fall into three categories:

1. **Better management of existing and future investment:** There are some clear quick wins (a consolidated approach to e-procurement, management of sector licences) and some more difficult issues needing further evaluation (around the sharing of support services). The estimated savings are between \$10 million and \$20 million after the first year.
2. **Financial gains from better service management:** The main identified areas of gain are: avoiding duplicate laboratory tests, improved use of pharmaceuticals and reduced hospital admissions. These gains are likely to be substantial but there is some distance between defining benefits and accruing them. Information is a facilitator of these potential gains.
3. **Improved quality and quantity of life for patients:** There should be fewer adverse drug interactions, fewer mislaid laboratory tests, better understanding of what kinds of services work best, and, therefore, better results for patients.

## Improving patient care - a case study

A study led by Professor Peter Davis<sup>11</sup>, looked at the medical records of 1575 patients admitted to three Auckland hospitals during 1995, and found 10.7% of all the screened records registered an adverse event. One third of adverse events occurred outside hospitals. USA research found an average 6.5% of admissions have a potential adverse event, based on their health status (allergies, contra-indications). A USA study on Adverse Drug Events<sup>12</sup> identified approximately 1% as fatal, 12% life-threatening, 30% serious, and 57% significant.

A national formulary containing information about drugs (dosage, costs, adverse reactions and interactions etc) in one place and linked to an individual's clinical notes would simplify the prescribing process, save time and reduce the risk of mistakes.

Access to general and patient-specific clinical information at the point of care saves lives; just as information deficiencies contribute to errors, which can have serious (potentially fatal) consequences.

### Reduced costs:

Information systems can help control medication and laboratory tests, avoiding duplication. In 1999/2000, 15.1 million laboratory tests were ordered - a substantial figure for a country with only 3.8 million people. By 2000/2001, it increased to 17.5 million. The reason for this dramatic increase has not yet been formally identified, but anecdotal evidence points to duplicate testing as one factor in the growth. Access to clinical information at the point of care would enable providers to find the results of tests already done, which would reduce any duplication and the waste of valuable resources.

## The Challenge

Planning for the best use of health information must be guided by a set of national principles, including those developed for the implementation of a national health information systems infrastructure.

The infrastructure must:

✓ be secure	✓ be privacy compliant	✓ be based on common standards
✓ subscribe to the fundamentals of open systems	✓ collect data once, use many times	✓ view information as a strategic resource

### Cost implications

There are a number of implications from the actions recommended by the WAVE report: some concern policy direction, some concern behaviours and some have costs associated with them. Some costs are relatively 'hard', such as developing the national system building blocks. Some are dependent on actions to be taken, are more difficult and are on-going, unlike the cost of the technology. For instance, the cost of implementing a data set is usually the on-going cost of collecting it rather than the cost of licensing a coding system. Gathering new data is more expensive than formalising data already collected. Any implementation of data sets needs to be on a case-by-case basis, where there is a business case for extending reach. Much more data will be needed in the move to a population health focus.

The costs and benefits of these initiatives will fall in different places. The cost of inadequate laboratory test coding systems falls on laboratory providers, systems vendors and service providers (who lose tests so need duplicates). But costs also fall on patients who get a lower standard of care. Fixing problems like these means someone has to facilitate, or pay, for the central system building blocks - coding standards, messaging standards, a provider index and an improved patient index. These largely fall centrally but may be minimised by co-opting resources. The move to electronic information systems caused an initial problem at ACC, because the benefits accrued to ACC but the costs fell on the doctors. Recognising this, ACC now reimburses doctors for those costs.

11 "Adverse Events Regional Feasibility Study: Indicative Findings", Professor Peter Davis, Dept Public Health & General Practice, Christchurch School of Medicine, University of Otago et al, Universities of Auckland & Otago, NZ Medical Journal, May 11, 2001

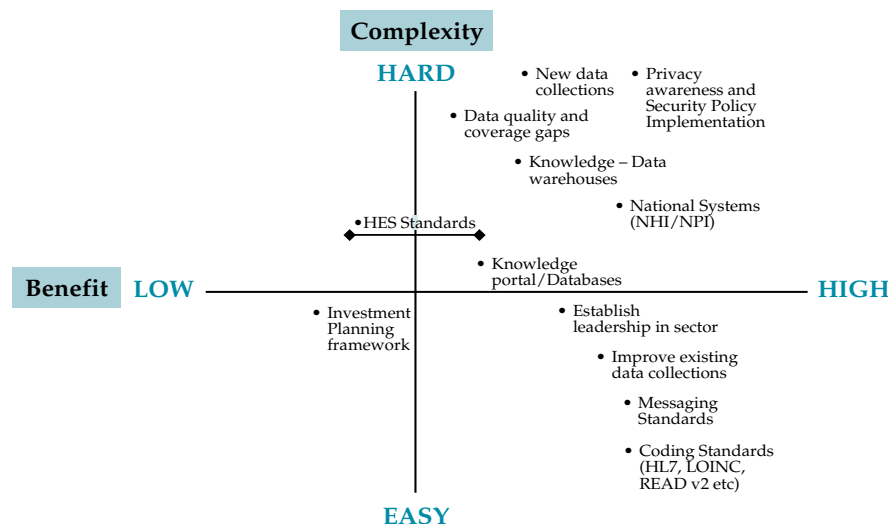
12 "Incidence of Adverse Drug Events and Potential Adverse Drug Events " American Medical Association Journal. Bates, Cullen, Laird, et al, July, 1995

The major identifiable costs are in the systems area and relate to the costs of enhancing (or putting in place) systems for patient and provider indices, a portal, data warehousing, etc. There will also be gains in reducing compliance costs for providers (some administrative processes around primary care could be automated) but primary care and others will probably incur other costs for network access and upgraded security.

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### Benefits and order of implementation

Some things will be relatively easy to achieve in the implementation environment such as agreeing messaging standards (high benefit, low complexity), tidying up pharmaceutical databases or establishing sector leadership in information and technology. Other areas are more difficult such as the collection of new data sets (high benefit, high complexity), ensuring quality data and rigorous maintenance of privacy standards. It is all underpinned by the need to respect medical complexity and the significance of patient information. Robust systems are essential, but are not easy to put in place.



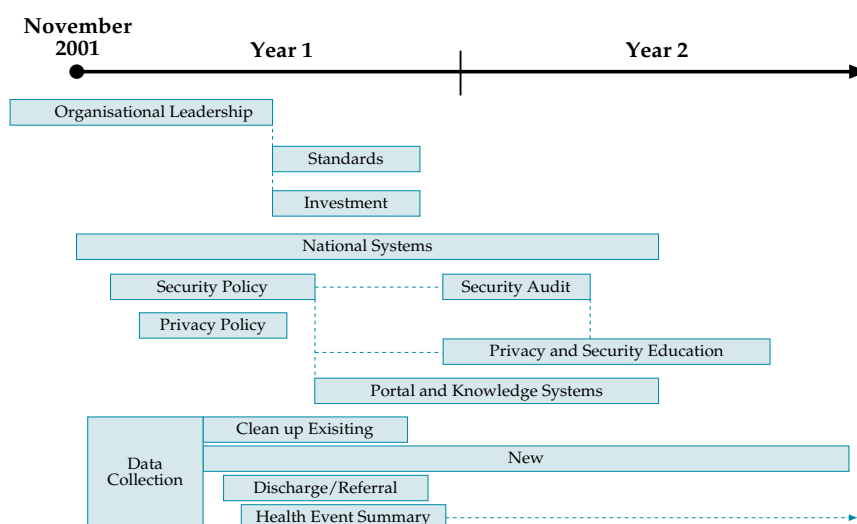
Every action interacts with another, which creates additional layers of complexity and strands of horizontal connection. Naturally some things will be done sooner, but the full benefit will be seen only when the system is completely operational, and networked. It is imperative to get systems up and running quickly to capitalise on the momentum *WAVE* has created.

The Advisory Board has considered priorities in health information, including which activities would have the greatest impact with the least cost. (These are listed on the inside front cover.) There are three obvious phases of activity:

1. Improving existing structures, making NHI work better, setting up pharmaceutical and laboratory data;
2. Establishing an Internet portal as a gateway to knowledge systems and applications; for example, a formulary for pharmaceuticals and a secure e-mail system; and
3. Setting up processes, on a rolling six-month cycle (deliberately out of sync with the planning cycle) to ensure evolutionary change reflecting the sector's needs as knowledge grows.

These processes must start with the DHB planning cycle, beginning November 2001.

The *WAVE* team has set out its views on the dependencies and likely timeframes, and a preliminary assessment has been given to the Ministry of Health.



## Success criteria

New Zealand will have succeeded if, in three years time, we have:

*Clear role accountability:* Ensured organisations involved in the delivery of information and payment services have clearly defined roles, avoiding duplication and maximising efficiencies.

*A focus on health outcomes:* Ensured information systems support the objective of improving health outcomes and being able to measure health outcomes.

*A common and complete technical language:* On-going development of robust data sets and data collections to assist DHBs in providing targeted care to their populations.

*Developed analytical capability:* Ensured improved analytical capability so data is used more effectively.

*Reduced provider compliance costs:* Developed information systems promoting reduction in costs for health and disability support service providers.

*Empowered communities:* Designed information systems catering for different cultural needs and empowering individuals and communities to manage their own health care.

## WAVE recommends

5. The sector's primary goal must be the integration of health information systems;
6. Its secondary goal must be to ensure on-going continuity and governance of health IM/IT from a sector perspective;
7. The top 10 priorities are:
  - a. Set up an independent organisation to lead IM/IT capability
  - b. Collect reliable ethnicity data
  - c. Implement the NPI
  - d. Fix up the NHI - allow primary provider access, improve ethnicity data
  - e. Gather primary care information
  - f. Fix up pharmacy and lab data and provide primary care with access
  - g. Clean up messaging standards
  - h. Sort out Health Event Summaries - with data dictionaries, electronic discharges and referrals
  - i. Launch health portal
  - j. Make integrated care work by: developing standards for data exchange, security & network infrastructure; and
8. DHB business plans must reflect the implications of WAVE.

# Making Sense in Health

## - *the programme director's personal reflections*



**David Moore**  
*Programme Director*

It's easy to make plans, harder to ensure they work. Successful strategy is usually marked by clarity of thought and depth of vision - far sighted, but with wide horizons. The health sector, like many government sectors, is awash with strategy documents but few become fully implemented. Why? It's often due to lack of connection to the audiences, or short cuts taken in the research work. My thoughts on the *WAVE* project, my personal perspective, should be read in the context of the *WAVE* Board's final deliberations, to give a fuller picture of what we have tried to achieve.

### **The genesis of *WAVE***

The Ministry of Health sponsored the *WAVE* project, but its genesis goes back to work undertaken at the Health Funding Authority, where its direct antecedent took shape under the Hospital Best Practice initiative, leading up to March 2000. This initiative highlighted a number of concerns, and began a number of sector change projects, but the information project rapidly became the focus - it was recognised as pivotal to all the other initiatives.

Unfortunately, at that time there was little appetite for continuing the information work stream but an initial paper, "Riding the *WAVE*" provided the backdrop for further discussions, efforts and even some blatant lobbying to have information issues put back on the agenda. I acknowledge the support of the Director-General of Health in putting *WAVE* back into the sector's work-plan. I would also like to give credit to Syd Bradley (Chairman of the Hospital Best Practice group) for his continuing support and staunchness in keeping the initiative alive.

### **Causes - a study in frustration**

Managing Personal Health gave me a number of experiences, covering a wide range: from exhilarating to... utterly frustrating. The sheer size of the challenge, the wonderful team that we recruited and the number of issues resolved successfully (from tertiary adjustors to a nascent primary care strategy). And the biggest frustration? Lack of information - about what happens in primary care, the quality and effectiveness of services and, most significantly, lack of information to support any change in contracting that might help the sector move away from the traditional institutional boundaries.

My personal view is the health sector has been largely flying blind when trying to peer between the different parts of the whole - unable to identify the most basic information, the use of its resources and what all the spending actually meant for patients. If you can get the right information, to the right people, at the right time... lives can be saved. But dumb systems make smart decisions impossible. There are some very basic questions we struggle to answer: How many patients cost the health system \$1 million or more last year? What is the likely cost of heart disease this year? How do pharmaceutical spending increases affect secondary care costs? How many admissions to hospital were unnecessary or could have been avoided?

Here's an indication of some of my greatest frustrations in health information:

1. The child immunisation database - an exercise in disappointment as, five years after it was proposed, little progress has been made due to lack of robust data. The process has been flawed as the information collected is based on Health Benefits data, designed for claiming (not immunisation monitoring), with limited mandatory standards or quality controls.
2. The National Provider Index (NPI) - hotch potch implementation due to unresolved privacy issues, ownership, co-ordination and leadership issues.
3. Disability Support Services (DSS) data warehouse - trial attempts failed due to incompatible data from disparate RHA systems (for example, each RHA defined disability services differently). Little further progress.
4. Maternal and Newborn Information System - captures only around 70% of data because of different provider contracting requirements.
5. The general medical service data warehouse - halted due to low coverage and differing data in different systems.
6. Lack of ethnicity data - planning, contracting and performance monitoring on this crucial issue was constrained to important but more strategic efforts, such as Māori treaty relationships, or the responsiveness of service.
7. Māori treaty relationships cannot work unless it's possible to demonstrate (and document) the way the health sector performs for Māori - which clearly cannot be done at present.

### **An international problem**

New Zealanders always look overseas to gauge whether our ideas are sensible. Every country recognises the issues of health information are crucial and the struggle to implement electronic information is an international one. Canada is addressing the results of its patchwork technological evolution in health care by spending \$C336 million on its Health Infoway. In the USA the Health Insurance Portability and Accountability Act of 1996 has been implemented with substantial compliance costs. Britain's Prime Minister, Tony Blair, has challenged<sup>13</sup> its National Health Service (NHS) to harness the information revolution for the benefit of patients, as part of a bold modernisation strategy<sup>14</sup> which includes Electronic Health Records (EHRs) for everyone in the country, round-the-clock on-line access to patient records for all NHS clinicians and genuinely seamless care for patients. In Australia, myriad federal committees have been established to examine the issues, while the individual states get on with implementation.

When I look at what *WAVE* sets out to do (in light of what other countries are doing), I know we can succeed where others are struggling. We're an innovative country, and able to crack into things that would pose huge problems for bigger nations.

### **It's a state of being, not a state of telling**

Constant changes to the structure of health services create the danger of progress being lost in their delivery. While we rebuild the edifice, it's important to remember our goal is to improve the health of all New Zealanders. It's a highly complex sector, a heavily networked ecosystem simultaneously full of dependent and independent institutional structures. In addition to the public perspective, there's the private one - where providers sometimes see themselves as victims, having to implement edicts to ensure cohesiveness across the sector.

Such an approach has the possibility of alienating providers, leading to tension, blighted relationships and information hiccups. We rely on providers to provide information, code, and develop new services. The *WAVE*

<sup>13</sup> Rt Hon Tony Blair "All Our Tomorrows" Conference. UK. July 2 1998

<sup>14</sup> NHS Information for Health, 1998



project reflected this dependency as much as possible and the recommendations recommend the governance of the proposed organisation as a joint issue for the sector to manage. It's not intended to be another bureaucratic structure, but one responsive to the sector's needs, and to provide leadership. Without this, expect to be back here in five years, thinking about the same problems, but on a bigger scale.

### **Missed opportunity**

New Zealand cracked some issues early, such as privacy and establishing National Health Index (NHI) numbers as unique patient identifiers. In that respect we're lucky, but these gains were made 10 years ago and New Zealand hasn't made much progress since, losing step with the rest of the world.

From my perspective, despite tremendous hard work on the part of many people in the sector, New Zealand has failed to capitalise on its early advantage. Little has happened about child health, disease states, or measuring clinical quality. Little has been done to leverage off significant individual successes. Our information infrastructure looks as weak as ever, despite the sector becoming more sophisticated. What's gone wrong?

Meanwhile, the rest of the world, both in and out of the health sector, has moved on. It's almost impossible to comprehend the speed and impact of the technology revolution. And even more important, we have missed the organisation and structural implications of the revolution - the building of alliances, the networking of individual (enterprise) capabilities and the ways relationships (ably assisted by technology and systems of inter-operability) can speed up the rate of change and, in health, improvement of services.

The link between strategy and technology is critical - without inter-operability, it's impossible to have integrated care. Technology, once understood, invigorates strategy. But it all begins and ends with cognition, which in turn is reinforced by making it all happen:

*"There are at least three perspectives on the interaction between strategy and technology. The first focuses on the effect of current technology on current strategy of the firm, the second on the effect of current strategy on future technology, and the third on the effect of current technology, strategy cultivates technology, and technology drives cognition of strategy. As we go from the first to the third, it becomes less conventional, less oriented to economics, more development-oriented and more process and organisation-oriented."*<sup>15</sup>

### **Making it hard for ourselves**

Information's unusual quality is that it grows more valuable when it's given away. The health sector itself has been openly critical about its propensity for being territorial and isolationist. This is wholly understandable. The sector is tight financially, has enormous change pressures and is saturated with demands - it's natural to defend what you've got to protect yourself from further diminution. Further, often short-term operational activities take preference over long-term strategic planning so everyone's view is through a particularly narrow lens (local or institutional), rather than the required wider and long-term focus. Many are still working in narrow silos of information and it's not unknown for health professionals to be markedly stubborn, and for health managers to be markedly protectionist. Despite the time and effort, to be frank, progress has been relatively uneven.

Some hold on to information because of its potential commercial benefit and this type of behaviour (at the micro level) drives the sector into some odd positions. But information facilitates understanding, which in turn facilitates better contracts, and better service delivery. Pooling information is more likely to lead to the creativity and innovation that really benefits the sector and patients.

A lot of it has to do with trust - it's not a strong point of New Zealanders. We have a low level of shared trust compared to other nations, which weakens business co-operation<sup>16</sup>. The conditions for shared trust in the health

15 "Dynamic Interaction Between Strategy and Technology", H Itami & T Numagami, Faculty of Commerce, Hitotsubashi University, Tokyo, Japan Strategic Management Journal, Vol 13, pp119-135, 1992

16 "Shared Trust in NZ : Strategies for a Small Industrial Country", Martin Perry, Institute of Policy Studies, Victoria University, Wellington 2001

sector are sometimes missing or have been inadvertently damaged by the on-going reforms and shifts in relationships. It's time for the sector to move onto a higher plane.

### **Who pays for getting it right - or getting it wrong?**

Clearly it's the taxpayer - who pays now, through Vote Health, when we get it wrong through inefficiency, waste and duplication. Patients pay too; through not getting the level of service they think they are funding. Currently, many of the costs fall inside the sector - for example, a non-functioning message system means an intermediary clips the ticket as the information is translated from one system to another. Individually these are small costs and hard to track, but the total systems cost is formidable.

Inevitably, over time, information systems will be modernised. The *WAVE* project's intention is to set out an agreed development path so money is spent prudently, with long-term planning in mind. It's impossible to spend prudently if you don't know how it's being done already. The *WAVE* approach, to bootstrap the health sector into the IT age, is neither a revolution nor an expensive INCIS-style approach. Costs are estimated at \$50 million over five years to install joint information system structures and the gateway portal to a co-ordinated health information system. That's not much to deliver health gains and savings in comparison to Vote Health's estimated budget in 2000/2001 of \$7.475 billion.

Does this mean the sector needs to spend more on Information Technology and Information Management? Ideally yes, although the inevitable constraints mean we should look first at the effectiveness of current spending. Greater transparency is needed; so spending can be tracked, then prioritised. The sector needs to recognise funding must relate directly to the benefit received. Common measurements and incentives will enable the sector to self-regulate by asking "how much does the patient benefit for each \$ spent on IM?" It's important people start thinking strategically so that health and IT strategies are aligned. Realistically, however, injections of capital will be required for some national information programmes such as the National Provider Index (NPI).

### **Strong beginnings, but only beginnings**

Efficient information management is essential to the delivery of quality health care, but made complex because information systems are expanding rapidly throughout the sector - and in different directions. Information is scattered, incomplete, or difficult to access when, and where, it is most needed. Health administrators (like DHBs) need substantially better information, right down to the local level, about the incidence of disease and the outcome of treatment programmes, the performance of providers and directions for further development.

The *WAVE* project has made a positive start. It has achieved much, in only a few months; it has certainly caused a few ripples. Most countries may have struggled to produce *WAVE*, but New Zealand has the advantage of a relatively small health sector; united on its need to address the issue, relatively unburdened by committees.

*WAVE* is only a beginning:

- The disability sector has had only brief attention - the Health Funding Authority did some keynote work on Disability, which should be moved forward and implemented. It is entirely consistent with, and builds on, work undertaken in *WAVE*.
- Pacific Island and Asian health have not yet been fully addressed - but the work to identify the gaps in ethnicity data is a start.
- Many of the projects (such as the investment work stream) set out a direction, and it's now time to bring current activity together with the *WAVE* direction.

It's already time to consider the daughters of *WAVE* - specifically addressing these issues and others identified during the project. Now we have begun to shift attitudes, and it's time to move to the implementation phase.

## David Moore's Perspective...

### **Successes:**

- Widespread uptake of computer Practice Management Systems by GPs
- Use of store-and-forward electronic laboratory results
- Implementation of a statistical national mental health database
- Integration of different hospital systems, using browser-based capability
- Diabetes Health Information Project & National Diabetes Working Group
- Our privacy legislation

### **Disappointments:**

- Incomplete and missing data sets
- Lack of leadership
- Disparate systems & duplication
- Lack of widely implemented information standards
- Slow development of an NPI
- NHI hasn't been implemented
- Lack of system compatibility so information can't be shared
- Difficulty accessing national data sets
- Lack of ethnicity data
- Confidence in privacy and security
- IT implementation and compliance costs
- Inequity of IT/IM funding around the sector
- Lack of capacity in terms of resource and expertise

### **Acknowledgements:**

- A clever NZ-based software industry
- Hard working, competent health IT professionals
- The dedication of health professionals who code data

### **Thanks to all involved**

The *WAVE* team would like to thank everyone who gave their valuable time and insights to assist us in formulating this report. A number of issues have been highlighted, and it's encouraging to see a strong willingness by people within the sector to co-operate in resolving these issues and dedicate their, in most cases already stretched, time to provide much-needed focus on this topic.

I would personally like to thank those who took active roles in this project, most usually as their night job, in addition to their day job. We owe it to them and to patients to move on and implement, not just the easy bits, but with the fundamental spirit of the project intact.

### **David Moore**

Programme Director



## 2. Knowledge - making patients better

### Introduction

*"Safety flaws are unacceptably common, but the effective remedy is not to browbeat the health care workforce by asking them to try harder to give safe care. Members of the health care workforce are already trying hard to do their jobs well. In fact, the courage, hard work, and commitment of doctors, nurses, and others in health care today are the only real means we have of stemming the flood of errors that are latent in our health care systems."*<sup>17</sup>

Medical error is difficult to quantify<sup>18</sup>. "In New Zealand the question of patient safety has, to date, been little researched"<sup>19</sup>. In the USA medical error is the cause of an estimated 98,000 deaths per year<sup>20</sup>, but it is not just about mortality. Medical error also means unnecessary operations, mis-prescribing and lack of prescribing. Most people are so tough that no one ever finds out, but the cost (human and financial) could be huge. Research in the UK, Australia and latterly in New Zealand shows similar results. The problem of medical error is rapidly becoming the number one issue in health around the world.

The problem of medical error is not about people - quality issues are a systems problem. Other industries have conquered quality issues with appropriate systems - of which knowledge systems are only a part, but an important part. New Zealand relies heavily on its medical professionals. They are supported by a range of important mechanisms (continuing education, peer review, etc) but they work largely without the support of IT and insights into practice that could be revealed by appropriate applications of IT/IM. It is about improving the processes, not looking to lay blame.

Similarly, we miss opportunities to be proactive about improving health. Managers and practitioners work with partial information about the patient in front of them, about the population around them, and about what their peers are doing. For instance, under-prescribing can mean illnesses progress faster and people have a poorer (and shorter) quality of life. Appropriate diagnosis and consequent interventions get patients better, faster; this saves time and money.

Knowledge management was, for the purposes of the WAVE project, defined as:

*"The development and effective use of health information/decision support systems which provide timely access for all health professionals and the public to high quality, relevant information from global information sources and from data collected and analysed within the New Zealand health system."*

It is important that we identify available systems, decide which are useful, and then implement good practice guidelines. Many doctors remain sceptical about the benefits of IT, although most already use computers - either for Electronic Health Records (EHRs) or doing home-based research on the Internet to support their clinical practices. Medical practitioners should have the ability to ask a question on patient treatment and get a speedy, accurate answer on the facts, guidelines and clinical pathways. Most doctors are not researchers, and operate at different knowledge levels. Some do their research after hours but not all have access to the right information. Others rely on informal professional networks - ringing a colleague when in doubt. Clinicians working in rural areas face a double disadvantage, lacking collegial support with limited access to recent medical publications. This professional isolation and limited opportunity for continuous education contribute to recruiting difficulties in remote areas.

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17 'Crossing the Quality Chasm', Institute of Medicine, National Academy Press, Washington DC, July 2001

18 There is a lot of literature around this subject, but the key references used are listed in "Adverse Events Regional Feasibility Study: Indicative findings", Professor P Davis, New Zealand Medical Journal, 11 May 2001, Volume 114 pp203 -205

19 "Adverse Events Regional Feasibility Study: methodological results", Professor Peter Davis, NZMJ, 11 May, 2001, Vol 114 pp200-202

20 "To Err Is Human - Building a Safer Health System", Kohn LT, Corrigan JM, Donaldson MS, editors Institute of Medicine, National Academy Press, Washington, DC April 2001

Some estimate medical information doubles almost every five years and, often, new knowledge makes established treatments obsolete. The information flood, long working hours and a busy schedule make it increasingly difficult for clinicians to keep up with, and incorporate, current knowledge. Within hospitals and large medical groups there are rigidly defined areas of specialisation. Patients often see a number of providers, in different locations, none of whom has access to complete patient information.

*"At no time in the history of medicine has the growth in knowledge and technologies been so profound... As medical science and technology have advanced at a rapid pace, however, the health care system has floundered in its ability to provide consistent high-quality care..."<sup>21</sup>*

The WAVE team sought to identify the right tools for creating a knowledge environment and, eventually, improving health outcomes. The more detailed objectives were to develop a practical definition of knowledge management, identify the stakeholders, identify knowledge management applications and the available tools, develop criteria and specifications for a knowledge management system (KMS), suggest a general KMS architecture for providers, and recommend a suitable KMS governance, organisational management and administration function.

## Current State

Practically all general practices in New Zealand use computers to some extent; an estimated 30 - 40% of GPs use some form of Electronic Health Record (EHR)<sup>22</sup> and 47.5% of NZ GPs<sup>23</sup> are using the Internet to support their clinical practice, but often outside office hours rather than at the point of patient contact.

In a WAVE survey<sup>24</sup>, clinicians most frequently mentioned using the knowledge tools of bibliographical and full text databases, followed by on-line journals, clinical decision support systems (CDSSs) and adjuncts to practice management systems (PMSs) - either bought or self-developed. Most systems have not been fully evaluated for the needs of clinicians and only those with value-added information (systematic reviews and guidelines) offered useful information. The most intractable problems of clinical information are the high value-added cost of filtered and relevant information (often requiring an expert clinician or specialised medical librarian), and the authority that will make information acceptable to the clinicians.

None of the evaluated CDSSs meet all criteria, or the providers' needs, but further evaluation of the following systems is recommended:

- Dxpain - designed to help with differential diagnosis. Its diagnosing capabilities were found to be accurate by several independent reviewers.
- PRODIGY - developed for the British National Health Service (NHS) with input from physicians, so not commercially driven. It is evidence-based, designed to assist GPs and practice nurses. It was well received by British physicians; formal evaluation will be finished by March 2002.

## Issues and Debate

### 1. Need for a culture change

It would be a gross over-simplification to expect KMS implementation by itself to yield broad-based improvements in processes and outcomes. A clear distinction must be made between increasing clinicians' knowledge, changing their attitudes towards it and helping them apply it. It will be difficult to achieve just the first two stages but the goal must be to achieve all three, leading to a change in clinical practice. Clinical actions, not just fresh knowledge or attitudes, will ultimately improve patient outcomes and health care systems.

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21 'Crossing the Quality Chasm', Institute of Medicine, National Academy Press, Washington DC July 2001

22 Good Electronic Health Records, Schloeffel, P; NZ Informatics Foundation News Update, April 1999

23 National survey conducted February - May 2001, Rowena Cullen, Victoria University of Wellington - unpublished report

24 WAVE survey, sent to health professionals, vendors and organisations in early 2001. The return rate was less than 20% so its conclusions can only be used to show general trends.

## 2. Information overload v. information needs

The explosion of medical knowledge makes it difficult for most clinicians to keep up with research, as well as assess the quality of evidence and its relevance; searching for information can also be very time-consuming. Clinical questions are often complex and wide-ranging, and guidelines, protocols and even CDSSs cover a narrow range of preventive, diagnostic and treatment areas, leaving clinicians with less support when more complex questions arise.

## 3. Supporting cognitive systems with information systems

Pharmacists have a scheme in its infancy, Comprehensive Pharmaceutical Care, which reviews prescribing, for individuals, on a long-term basis, with minimal use of medicines. This is a good use of the pharmacist's extensive training, and of integrated health information. It would be sensible for many patients to have a medicines-related care plan with predetermined goals. Clearly, the GP does not have time for this type of intensively individual therapy and monitoring.

## 4. Data problems

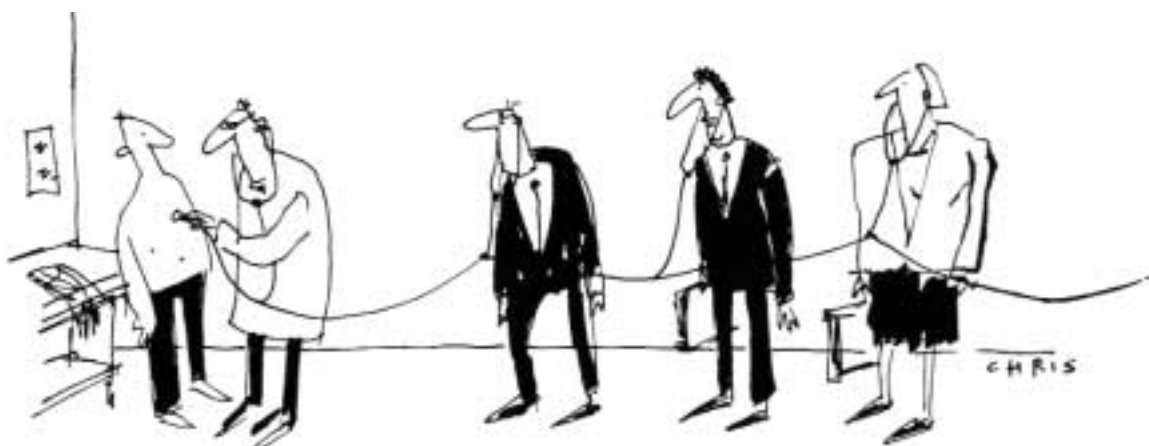
Health providers are collecting large amounts of data, yet important information on ethnicity or health status is not being captured. The collected data is stored in a variety of databases but not fed back and is, therefore, of only limited use. No organisation currently has a mandate (or resources) to mine existing health care data sets systematically. Lack of links (such as NHI) between databases makes research at the population health level difficult. Most IPAs mine data sets held by their member GPs, but to varying degrees.

## 5. Disparity in accessing information

Health professionals working in tertiary care centres and medical schools have access to a wide range of health care information, but access for providers in rural areas is limited. Subscriptions to medical journals at an average annual fee of \$US150 are expensive, therefore most non-university libraries have only a small selection. Similarly, access to medical databases requires a subscription fee, as currently only MEDLINE (which does not cover the information needs of allied health professionals and of mental health) is available at no cost. MEDLINE does not provide full text articles, however, and document delivery through local medical libraries or commercial suppliers for primary health care providers is expensive (\$NZ15 - \$20 per journal article). In addition, primary care providers have generally little assistance in gathering information - and often lack the necessary research skills.

## 6. Distribution of guidelines and care pathways

Guidelines and clinical pathways are tools supporting treatment for all patients, regardless of location. There has been considerable effort and funding for developing clinical guidelines but their distribution has not been managed proactively - often health professionals are unaware of their existence. It is not enough simply to publish guidelines; to implement them effectively requires several interventions and an interactive approach with providers, which in turn needs additional funding. For example, the estimated cost to promote the Hormone Replacement Therapy (HRT) guideline by the NZ Guidelines Group was \$NZ80,000.





## 7. Making drugs safer

Correct drug prescribing has a large impact on patient outcomes and on health care cost. A national formulary containing information about drugs (dosage, adverse reactions and interactions, contraindications, cost) in one place and linked to patients' clinical notes would support a safer and more effective prescription practice.

### Here's one example of what can be done - saving money and improving access to knowledge:

A purchasing consortium was formed (the Ministry of Health, 12 DHB libraries and Queen Elizabeth Hospital) to provide access to the four core databases recommended by the Medical Council of NZ: Medline (biomedical), CINAHL (nursing and allied health), Psycinfo (mental health) and Evidence Based Medicine Reviews (EBMR, which includes the Cochrane Library).

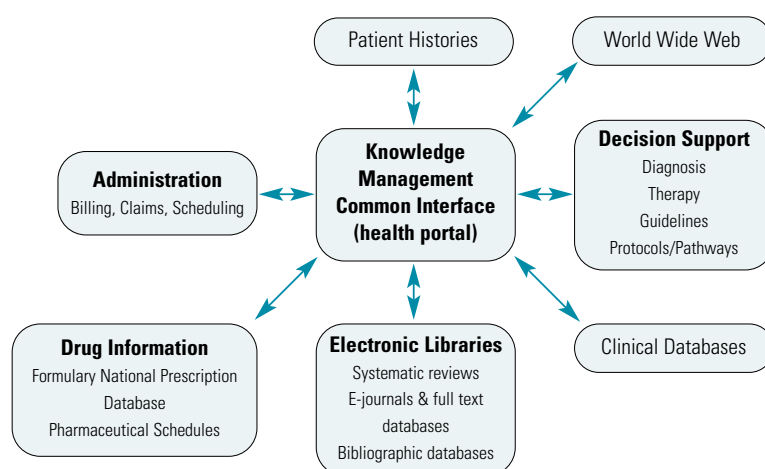
**The joint purchasing power resulted in annual savings for the Ministry library alone of \$US11, 000.**

## Future State

Knowledge Management Systems (KMSs) can address the issues raised above. They support clinical decisions by integrating many pieces of data on a single screen, raising clinical alerts (based on laboratory data and on patient characteristics), indicating when a test is unnecessary, providing costs and indications of tests and providing links to appropriate academic resources. Some of these are already operational, but with incomplete information. Learning, and appropriate evaluation frameworks need to be wrapped around the systems, to evaluate whether a difference is being made or whether, like the Microsoft paper clip, they are simply being switched off. KMSs sit in the centre of a health system. The developing era of team approaches and co-ordinated care needs to be recognised.

Providers will use an Internet portal (a common health interface) within five years, to access the information needed to treat patients in a timely manner at the point of care. Individual providers will be able to design their own versions of the system, incorporating information sources tendered and provided locally (eg: by a DHB/medical library, or a professional association) or contracted to a major external provider. The main components of a KMS are: electronic library services, clinical guidelines, a national drug formulary, CDSS, clinical databases and a web-based resource, such as the NZ Guideline Group. Links to an individual patient's clinical notes will enable proactive patient-specific information; for example, an alert will appear on screen when a drug is prescribed to which a patient has had an adverse reaction

## Integrated Knowledge Management System Architecture



## EHRs and Knowledge

Knowledge systems do not stand alone. There is a strong link between knowledge systems and development of an approach to electronic health records.

Dr Peter Davis, Professor of Public Health, Christchurch School of Medicine, believes electronically based information systems are a key to reducing adverse events by eliminating human error.

*"The medical record system is quite archaic. We have basically got people writing on it and scribbling on it, and then you have one for the community, one for the hospital and there could be another different one in another hospital. Bringing that all together would seem to me to be a start to try to avoid some of the more preventable things, such as: Does a person have an allergy? What treatment have they had before?"<sup>25</sup>*

## A developmental approach

Identifying the key gaps inhibiting implementation of a more fully functional KMS has not been difficult, but it is challenging to find ways to close them. Programmes are needed to evaluate interventions that effectively reduce or eliminate these gaps.

The WAVE team recommends taking small evolutionary steps into the development of KMSs. Firstly, existing data and systems should be identified and consolidated; identifying the areas that would help most and cost least (primarily in the pharmaceuticals area); then guidelines and continuous improvement systems should be developed for the sector. An overall risk/ benefit framework needs to be developed to allow the building of systems to assist health professionals in their work. WAVE also recommends further investigation of the electronic library systems set up in New South Wales and Britain, as useful models for a similar health portal for New Zealand. Both systems (CIAP and NeLH) were set up by government agencies and designed with input from clinicians.

Much of this is new business for the health sector. There is a need to establish some capability to make this happen. At present there are fragmented elements scattered about, but nothing cohesive.

## WAVE recommends

9. Immediately improving access to currently available medicines information (the Pharmaceutical Schedule, medicine data sheets, Consumer Medicines Information that are available on-line already);
10. Developing a common interface to simplify user access to the electronic information sources currently available, ie: a health portal available on all providers' desks;
11. Systematically making available the collected data so current practice can be verified against guidelines, the information could be used for research, planning, benchmarking and for the introduction of quality improvement programmes;
12. Developing and introducing a national formulary (including an electronic prescription ordering system, best practice prescribing, cost, and NZ-specific guidelines);
13. Enabling bibliographical database access for all health providers, using the newly established DHB/Ministry of Health library consortium as a pilot to study the implementation and benefits of providing access to the four major databases: Medline (biomedical), CINAHL (nursing and allied health), Psycinfo (mental health) and Evidence Based Medicine Reviews (EBMR, which includes the Cochrane Library);
14. Establishing a risk / benefit-based framework of analysis for future investment in knowledge systems and ensuring it links closely with quality improvement in the sector;
15. Establish the organisational capability to facilitate the growth and management of data sets from a wider perspective than current efforts; and
16. Establishing a central body to exercise leadership, to drive the standards setting and governance functions (including design, implementation, promulgation) necessary to implement and order future environment.

**Recommendations 15 & 16 were made by all the work streams**

# 3. Electronic Health Records

## - clinician talking to clinician

*"Astonishingly, humans maintain suitable records for their buildings and cars, but records on maintenance of their own bodies are neither comprehensive nor accessible to the humans themselves or to all health maintenance technicians (called 'doctors'). Maintenance technicians often have to repeat tests and treat with no record of repair and chemical therapies, environmental and personal influences, genetic dispositions, or inappropriate use. But humans find it acceptable that their record is a set of separate, incomplete, technician-specific notes, often scribbled on paper and partly illegible."*<sup>26</sup>

*"One crystallizing event for health care would be the promulgation of a standard for electronically maintaining and sharing patient records. Today, providers ... have partial versions of each patient's record, each kept in its own format. Large portions of the record are handwritten, and parts of it are X-rays and other specialist information kept in analogue form. For lack of a standard, physicians re-collect the same information; records can be transferred only by physical delivery; protocols and outcomes can be compared only through laborious and inaccurate human interpretation; and plans, drug companies, and researchers cannot measure outcomes systematically."*<sup>27</sup>

### What is an Electronic Health Record?

An Electronic Health Record is an electronic longitudinal collection of health information, based on an individual patient, entered by health providers, which can be distributed over a number of sites, and in a number of settings. The record is controlled by an agreed access policy. *[Full definition in Glossary]*

## Introduction

Electronic Health Records (EHRs) cause passionate debate. Some view them as the apex of health information management, while others condemn them as expensive, unnecessary toys. In Britain, large amounts of money have been poured into their implementation, but with little result so far. But missionary zeal alone is not enough; instead we must go back to basics - why do we need EHRs?

The move to integrated care, as reflected in the NZ Public Health and Disability Act 2000, requires clinicians to co-ordinate care, making the ability to share patient information paramount. EHRs are a key in the intersection of primary and secondary care, particularly in areas such as heart disease and diabetes management. It is hardly surprising people are alarmed about their health information being part of a large network so there needs to be a framework that meets privacy requirements. The link between security and privacy is important, particularly in the World Wide Web environment as the Internet poses a new set of potential threats. It is important to remember access is the key, not storage. There is a wide range of architectural models for the aggregation of information, but patient information is most widely used by providers, where it is usually most accurate and most relevant.

New Zealand needs to move quickly, but there are budget constraints. Incremental, organic improvements can be made as the sector becomes ready, and able, to move towards EHRs.

The WAVE team focused on ways information can be exchanged between providers in order to provide health and disability services to the individual. EHRs involve health information as defined in the Health Information Privacy Code 1994.

<sup>26</sup> Healthcare Informatics, C Peter Waagemann, May 2001, [www.healthcare-informatics.com](http://www.healthcare-informatics.com) (Health Informatics Online, a division of McGraw Hill Companies). Peter Waagemann is chair of three USA standards groups: including the American National Standards Institute's Healthcare Informatics Standards Board.

<sup>27</sup> "Blown to Bits - How the New Economics of Information Technology Transforms Strategy", Philip Evans & Thomas Wurster, Harvard Business School Press, 2000

## Current State

Providers who adopted electronic record keeping early are now becoming vocal over the current system's shortcomings in providing a platform for integrating their patients' care. They are concerned about the quality of health information (inadequate, untimely, inaccurate), illegible manual documentation, inefficient manual processes (too many different forms, used inconsistently), inadequate use of health information for audit purposes, lack of support for clinical best practice, lack of integration of health information from multiple sources, lack of co-ordination between providers, lack of easy-to-use common user interface, and increased use of non-integrated computer systems, leading to fragmented IT infrastructure and high ownership costs.

### Primary Care activity

The relatively high level of electronic records in primary care is heartening on the surface, although there may be different interpretations of the term. It does, however, indicate sufficient infrastructure to support a co-ordinated approach to EHRs. WAVE sampling<sup>28</sup> of primary care providers and software vendors indicated:

- 57% of GPs use Patient Management Systems (PMSs) to record & store prescription and some clinical data;
- 71% will be using PMSs within two years;
- 89% will be using PMSs within three years.

This indicates sufficient electronic capability to provide a reasonable platform to support EHRs. It is unlikely that the current level of electronic capability was developed to help the sharing of patient records; it is more likely the driving force was to promote the efficient management of patient record keeping.

### Secondary Care Activity

Our research into DHBs showed<sup>29</sup>:

- 6 have implemented, or substantially implemented, a local clinical data repository;<sup>30</sup>
- 5 will implement one within two years;
- 3 will implement one within five years.

The survey identified at least three DHBs sufficiently well advanced to enable sharing of their knowledge, which will be important when choosing the method to roll out information technology to other DHBs.

## Issues and Debate

Issues around EHRs range from the conceptual to the more substantive.

### Big Bang?

Implementation of EHRs could be tackled in two ways:

- The incremental approach, with a step-by-step roll out. This is the Health Event Summaries (HESs) model as proposed in the Health Information Network for Australia based on a distributive, non-proprietary network, working in tandem with the current infrastructure of the sector. All basic information is captured including GP consultations, hospital discharge reports or referral, pathology investigations, and other provider summaries.
- The big bang approach, premised upon a 'one stop shop' approach with a new information infrastructure. One example is the Good Electronic Health Record (GEHR) model where the record engine is the core. Clinical information is defined according to archetypes created locally to cover local medical practice, and must conform to the basic model so it can be exchanged between providers. This approach would need a new information infrastructure, so would cost considerably more, and create immediate funding issues.

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<sup>28</sup> A combination of questionnaires and site visits, conducted by the WAVE team, early 2001

<sup>29</sup> Based on responses to WAVE questionnaires sent to the information managers at 21 DHBs - 14 responded

<sup>30</sup> See Glossary for definition

Feedback shows the preferred option is an incremental approach, as it would minimise disruption, help stakeholder acceptance in the change management process, improve accountability for future proofing, and cost less. Furthermore, an incremental approach does appear to be happening, although it lacks a national approach, which would reduce the risk of inconsistencies across the sector.

### Big Brother

Should there be a single server or a number of them, distributed regionally? Whichever is implemented, there must be reasonable security safeguards in place, along with stakeholder buy-in. It is important the model chosen supports the function and meets the needs of those it serves.



This issue has attracted considerable debate and criticism from a wide field, including members of this project team. People are passionate about some issues, particularly the perception that a single data server could be a move towards 'big brother' where the state is able to plot every individual health move. This debate needs to continue nationally - support from stakeholders will be critical.

### Different Ways of Working

Essentially there are two business models for the electronic transmission of data: push (messaging) and pull (searching). The push model is the most commonly used. It is health episode-based; for example: a discharge letter sent to a GP from the hospital, or the GP writing a referral letter to a specialist. The push model is widely used in the sector as it is relatively easy (requires messaging only and little information architecture), highly functional (meets needs) and already in place as it is familiar. The push model is likely to remain dominant for some time as it fits well with the natural rhythm of clinicians working with clinicians and can dramatically assist workflow management.

Pull transactions are requests for information in a file (paper or electronic). Often the information will be sited away from the request (through time or geography), for example: the GP, treating a new patient, who wants to access all relevant health information to ensure all treatment options are considered and any relevant medical history is taken into account. It is likely integrated care will require a mix of push and pull transactions, so any approach adopted needs to allow use of both business models.

### The Hidden Issues

Data standards are one of the hidden issues, but this is not just about formalised codes. There has been an obsession with using data for financial claims, but issues of patient care have nothing to do with dollars. Data sets and language need to be deepened to incorporate medical content. This will be a big issue over the coming years as doctors increasingly move towards using electronic media such as stream video, recorded voice, diagnostic images, etc. Agreed terminology is essential for the consistent management and exchange of electronic information. In turn this will promote integrated care, as different providers will be using the same terminology, or definitions. Currently information is held in a variety of data formats, using a range of electronic and paper-based systems, which hampers the ability of providers to talk to each other electronically.

Common messaging standards are required to enable communication across disparate systems. There is strong consensus from stakeholders for Health Level Seven (HL7) that is increasingly being adopted for healthcare messaging internationally, and incorporates XML format. Both are non-proprietary standards.

## Just Imagine...

You're a 23-year-old now living in Wellington, with a 4-year history of abdominal pain, seeing a new GP. The GP concludes (from your description) that the intensity and quality of your pain varies; it's mostly lower abdominal, and of variable laterality. The GP sees no exacerbating or relieving features.

You grew up in Auckland, where your GP treated the same complaint. A variety of haematological and radiological investigations were performed, but you don't know the clinical details. The results of specialist consultations were always unclear to you. You just know they didn't work! About 2 years ago, you moved to Christchurch, where you consulted another GP. You've no idea which tests were done, but the doctor's questioning today reminds you about the Barium x-ray.

A week ago you moved to Wellington and have already visited two other GPs, with an examination last night at the emergency rooms. No one can identify the problem. You are now in the third GP's consulting rooms - fed up, in some pain and determined to stay until a solution is identified. 30 minutes later, after completing a past medical history, a family and lifestyle history and a physical examination, the GP now needs past medical information to complete the analysis and make a diagnosis.

You've now been seen by multiple physicians (family and specialist) and have had multiple investigations. Your GP, a fine clinician, realises many diagnoses must have been ruled out, but none of this information is available. So, what's the plan?

### **The GP has two options:**

- 1) Start from scratch, repeat all the investigations and specialist consultations and just hope luck delivers the test or tests that had not been done previously, the one that might yield the answer. It's a time-consuming and expensive process (for the health system), as the procedures will be repeated. It's also uncomfortable, and unnecessary, for the patient to have the investigations repeated.

*Or*

- 2) The GP could ring all the doctors you've already seen, which relies on your remembering their names, their being available and...there's no system in place yet to compensate the GP for special investigative work.

### **That's today. But post *WAVE* implementation:**

The *WAVE* plan would provide the building blocks for implementation of systems that could, with your support and that of other providers, enable GPs to:

- Log on to the network to find your complete electronic files, with links to all your details;
- Read each doctor's notes, each lab and x-ray report, even viewing the x-rays if necessary;
- Track your prescription history to identify what had been tried, and for how long;
- Note that you'd been seen by two other GPs only this week, with one prescribing an antibiotic;
- Notice you'd been to the emergency room the night before, and know which tests were done;
- Review with you the diagnostic and therapeutic investigations already done, then discuss a plan of further care. All from the office. 100% complete. 100% accurate.

### **And that's just the beginning...**



## Future State

It is essential to develop a co-ordinated approach so the health and disability sector can share relevant health information. Ideally, the information should be available immediately at the point of care, irrespective of the patient's location. If someone living in Hokitika needs urgent medical attention one night whilst visiting Kaikohe, the medical practitioner should be able to access the relevant health information immediately.

The world, however, is not ideal so the approach must be realistic and practical. An incremental move towards seamless information flows is needed between the primary and secondary sectors, in order to support improved health outcomes and, in time, integrated care. The development path should be decided according to the sector's needs. It would be desirable for the development path to be less than five years.

The recommendations place particular focus upon hospitals and GPs but as electronic capability and coverage improve, it would be desirable to include other providers incrementally.

### Development plan for EHR

The *WAVE* team recommends a proactive stance on the development of EHRs - which is core to developing systems for integrated care. The approach, therefore, needs to be goal-oriented, with deadlines. These goals are structured as follows: firstly, different parties in the sector need to be connected up with the capability for electronic versions of the existing transaction load; secondly, templates must be designed and protocols implemented for disease management. Thirdly, the development of these standards needs to be driven off a proactive timetable, which should be refreshed every six months.

Some DHBs will, because of local conditions, want to tackle some issues before others; for instance, infectious diseases before asthma. The *WAVE* Board believes, a priori, initially the three disease states should be cardiovascular, diabetes and asthma, which may be easier to track if there is a demonstrated commitment for an end goal. The most appropriate expression of that goal is an HES, which supports the 13 priorities in the Health Strategy. DHBs need to be asked for responses to the proposal, particularly on disease management, after considering their own requirements, then a two-way discussion will be required to get comprehensive coverage.

The sector needs to establish some organisation competency and focus on developing EHRs. An overall information organisation should be established with the requisite authority and capability then given the responsibility of ensuring implementation of these recommendations. It should set goals and monitor progress in six monthly increments. A credible forum should be established with the competency and resources to reach consensus on the HES structure, data and messaging standards, guided by the charter and by-laws of the HL7 international organisation.

Steps should be taken to achieve stakeholder buy-in (especially from clinicians and consumers, and Māori stakeholders) as these recommendations will raise specific issues, including organisational and privacy-related concerns. Needless to say, appropriate privacy impact assessments should be conducted to ensure privacy compliance when these recommendations are being implemented.



## WAVE recommends

17. DHBs should implement capability for connectivity between hospital and health care providers including that for electronic exchange of Referral Letters<sup>31</sup> and Discharge Summaries and other useful information (eg: emergency department attendance notifications) between hospitals and healthcare providers, within two years;
18. Developing standards for the transmission of Health Event Summaries (HESs) between providers over the next six months, based on the existing Referral and Discharge letter standards, commencing usage within 12 months; with roll out completed within three years;
19. Giving priority to the immediate development of necessary standards and some live implementation of disease management programmes;
20. DHBs should document their commitment to Recommendations 17 - 18 in strategy and accountability documents, demonstrating consistency with the 13 priorities in the NZ Health Strategy;
21. Supporting and encouraging GPs not currently using electronic clinical record software to do so within the next 12 months;
22. Encouraging hospitals to implement clinical data repositories or an integrated clinical interface within three years<sup>32</sup>;
23. Developing DHB implementation plans for the above within three months;
24. Adopting HL7 v3 as the underlying structure for HES; and
25. Ensuring there is organisational capability to develop EHRs in the health and disability sector.

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<sup>31</sup> Definitions are contained in the Glossary, at the back of the document

<sup>32</sup> Please refer to Glossary for full definitions



## 4. Data Architecture

### - *talking a common language*

#### Introduction

Some people regard data as a tool for boffins or the World Health Organisation to compare international health trends. In reality, data (used properly) helps people to become healthier and more independent. Statistics provide us with only general trends, whereas data actually shows us where we can act to improve individual people's health. For example, statistics tell us 8.3% of Māori adults<sup>33</sup> have diabetes; but data tells a nurse which patients attending tomorrow's diabetes clinic at the marae are managing their insulin levels well, and who needs more support.

Surveys tell us children are poorly immunised; data identifies which primary care organisation looks after those children, and which vaccines are being missed. Statistics state the national caesarean rate is climbing past 20%; data indicates the reasons and whether babies and mothers are healthier as a result. Statistics state the population is ageing and will need rest-home care; funders use data to ensure they fund only those drugs which are effective at maintaining people in healthy independence. And EHRs help people track their own cholesterol levels and give them confidence they are getting enough exercise and managing their diet. Child abuse is a national issue; data shows which children have seen too many doctors for them to be just accident-prone. Microbiologists know drug-resistant bacteria are a major problem in hospitals; event-based data lets them find and treat the theatre staff that operated on the infected person.

#### Identifying those who need help

Cholesterol-lowering drugs offer significant protection to those at risk of heart attacks, but simply making these drugs available is no guarantee their benefits will be realised. To ensure real health gains, it's essential to target the right people - Māori are particularly at risk of dying from cardiovascular disease. New Zealand has done well by international standards but there are still a significant number of people who should be on these drugs.

Those at greatest risk need to be identified and treated. Recent work by PHARMAC<sup>34</sup> has shown the value of collecting and analysing data, identifying a significant gap between availability and uptake of the drugs:

- An estimated 160,000 New Zealanders are eligible for statin cholesterol-lowering drugs
- But only 92,200 people have had statins approved
- It's estimated only 68,000<sup>35</sup> people take statins (at a monthly cost of \$3.1 million)
- Many people who need the drugs are either not using them regularly or not receiving them at all
- 60% of those eligible have either not visited their doctor to receive the drugs, or have not been prescribed them
- But use of the drugs is increasing, as only 16,000 patients were using them in 1997
- Uptake is highest amongst those with previous heart problems, but may be lowest amongst Māori and Pacific people. We can't tell without ethnicity data linked to an NHI index

Data has many uses, with aligned benefits, so it is imperative for accurate, detailed data to be available promptly to everyone - individuals wanting to maintain their health and independence, patients using health services, health professionals, and the clinical and funding agencies supporting them and ensuring resources are used to the greatest effect. Sound data is essential for the effective management and continuous improvement of health and disability support services.

33 NZ Health Survey, Ministry of Health, 1997

34 PHARMAC analysis August 2001

35 Based on HBL dispensings data

Data standards are the foundation for achieving this vision as information systems can work well together only when they share common definitions, and when clinicians record the same basic data about each condition. Unfortunately, data standards in the health sector are most notable by their absence. The problem is recognised across the sector and, fortunately, there is also a high level of agreement on the solution - national co-ordination to develop and promote standard data sets and coding standards. There is clear consensus that the highest priority issues are:

1. The quality of NHI numbers for patients; and
2. The need for an NPI to identify health professionals.

Then the major gaps in existing data sets need to be filled by collecting information from outpatient and primary care consultations.

## Current State

Most current data standards are too weak to support integrated care, with wide variation in the collection standards. At one extreme, Census data is excellent - complete, consistent across the country and over a period of time. But there is no agreed standard in primary care consultations or outpatient information with very little detailed data collected and no national collections. It is, for example, not easy to establish how many pregnancies women have had (the information can be sensitive when it involves abortions or late miscarriages) making it difficult to develop quality data for an anonymised statistical data base to analyse delivery characteristics for pregnancies; hospital laboratory tests cannot be analysed nationally; data on non-subsidised prescriptions stays at the pharmacies, ethnicity data is not collected properly and the mental health data collections do not include results.

Data needs to be relevant (preferably clinically) and help the person providing it to do his or her job better. Data really only lives when it can be compared; for instance, a doctor comparing his care pathway with that of a known and respected peer; or data which helps a health manager to understand where health services could be reshaped to maximise patient benefit for the limited money available. It needs a co-operative, living and learning approach, which does not currently exist in the sector.

The need for good data can be clearly seen in pharmaceuticals. Health Benefits uses technology appropriate for a claims and administration operation - what it used to be - but now people want to use information different ways. Doctors need to know their prescribing behaviour (compared to their peers and their budget); pharmacists want to help doctors by looking at the doctors' prescribing habits; and DHBs want to identify their budget, risk and expected health benefits. At present the sector is ill equipped to do this - the data set is well specified but not well implemented. GP and patient identifiers are missing and the data is hard to access. Health Benefits is updating its technology, which will align with anything WAVE recommends, but every day of delay is a day of lost value, both in poorer health outcomes and poorer financial management.

The limitations in pharmaceuticals and laboratory data are so significant that the implementation of the primary care strategy, implementation of capitation and efficient management of referred services are not possible. At the moment DHBs and providers are expected to take responsibility for funding or manage contracts, yet cannot account for their spending.

Inconsistent use of NHI in all data collections is another issue as NHI is critical in linking data about patients across different health services, and to group types of patient. Māori health policy has been hampered by the lack of simple data showing whether Māori are getting appropriate health care, yet the NHI is the data element that specifically allows analysis by ethnicity.

## Māori Health and the NHI - a case study

*Tai Kake is a doctoral researcher, specialising in mental health and based at Wellington's School of Medicine and Health Sciences. Tai is also a member of the WAVE Advisory Board (See biographical details, Page 75)*

Currently I am working with Professor Pete Ellis on a research project comparing the effects of two antipsychotic drugs on thought processes in people with schizophrenia. The drugs are risperidone and olanzapine, and are used to treat the symptoms of schizophrenia. I am particularly interested in these drugs because the Māori rate of psychiatric admission with a diagnosis of schizophrenia is approximately twice that of the general population. Olanzapine is relatively new and the study will compare its effectiveness in improving thought processes with the older drug risperidone. I am especially interested in comparing the effectiveness of these drugs in Māori patients, as there's currently no evidence for this group.

Recently I approached PHARMAC to obtain data on current prescribing patterns for risperidone and olanzapine in New Zealand. I requested information on the average daily dose patients receive according to age, gender and ethnicity. Historically, Māori have had poor access and poor utilisation of mental health services and treatments. Anecdotal evidence suggests Māori have received higher doses of antipsychotics than non-Māori. I would like to obtain the ethnicity data associated with the prescribing of olanzapine and risperidone to determine how many Māori are being treated with these drugs and what dose they are receiving.

PHARMAC informed me that information on the age and gender of patients receiving the two drugs could be obtained, but ethnicity data would be very difficult to access and was unreliable due to problems in the NHI system. Limitations of the NHI meant current electronic systems couldn't provide the answers to my questions about Māori access to these two medicines. I was advised the best solution would be a physical search of all the paper prescription requests. That would be a considerable task, time-consuming, logistically difficult, and still wouldn't provide a reliable measure of Māori utilisation of these drugs.

This seems incredible in today's world of advanced IT. Researchers should not have to resort to such time-consuming, expensive exercises to obtain standard prescribing information. The poor reliability of the NHI (particularly with respect to ethnicity) impedes the Crown's attempts to efficiently identify disparities in Māori access to appropriate and effective treatments for serious mental illnesses. And whether these disparities are being effectively addressed.

## Issues and Debate

WAVE has shown how health information will deliver better health care, but most of the data foundations needed for that future state are shaky and incomplete. Strengthening those foundations is a large task, which has to be split into achievable steps:

### International standard for New Zealand - HL7

The strongest way to integrate systems is to establish a shared data model that maps data used in computer systems to the concepts and activities of the real world. When all systems share the same definitions (for example, 'person', 'event', 'referral') connecting systems and data becomes much simpler. Most countries have developed a sector data model to some extent - the NHS publishes one in Britain and the Australian states are working to merge their individual models. The WAVE team examined a number of international models to find the best model for New Zealand.

The Health Level 7 Reference Information Model (RIM) version 3 has several advantages over other data models:

- ✓ It is part of a wider framework with its origins in messaging standards so it can provide a tight link between the data model and inter-system messages. It even sets out template processes for the design of each new message.
- ✓ It is becoming the formal international standard for health sector data.
- ✓ It is non-proprietary.
- ✓ There is an established base of HL7 (version 2) systems in New Zealand, especially in systems exchanging messages with laboratories. Version 3 creates an opportunity to build on these systems and to move them to standardised, XML-compliant messages<sup>36</sup>.



### National Health Index

The NHI needs little work as its definitions are widely accepted and generally used consistently; it just needs some work to express it in the HL7 v3 formats. The problem is implementation as the NHI is missing from many major data sets (such as community pharmaceuticals) and, when used, the data quality is poor (eg: over 10% of newborns end up with more than one NHI). More than anything else, it must be ensured that every New Zealander is allocated a unique NHI number.

### National Provider Index

Current provider numbers raise similar issues as the NHI, but the situation is worse - there is no agreed standard definition and no master reference database. GPs have to remember their pharmaceutical claims number, an ACC claim number, their Medical Council number, and several others. And a registration number like "12345" could belong to a nurse, a dentist, and a doctor all at the same time!

The NPI will have many different uses: organisations sharing information (say, for hospital referrals) will not have to maintain their own lists of each referring professional; health professionals will have only one number to identify themselves to ACC, any DHB or pharmacy. Identifiers will be published for every agency that makes claims, receives and give health funding, and for each site where health services are delivered. The NPI can even be used as the main address on electronic messages.

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<sup>36</sup> XML = eXtensible Markup Language, designed for exchanging data across the Web, in a simple, human-readable form

The NPI, like the NHI, can link data collections together. Primary Care Organisations want to use this to profile their members (for example, by total prescribing) so they can report back on the quality of care. Clinical quality audits rely on collating data about each professional.

### **WAVE's key views**

- The Health Level 7 Reference Information Model (RIM) version 3 should be adopted.
- The NPI definition should be developed in HL7 format (using XML), so it can be implemented across all data sets.
- The standard NPI should consist of three parts - health provider, agency and facility. This has been specified before, but not implemented.
- READ v2<sup>37</sup> should be used for primary care diagnoses and procedures to which the main alternative is READ v3; however most organisations are intending to upgrade directly to the SNOMED-CT system. READ is already used by ACC. Clinicians in outpatient and secondary care have expressed interest in using READ codes, as they give more detail than the ICD-10 codes already used.
- A pharmaceutical index should bring together disjointed pharmaceutical coding systems (eg: pharma codes, prescribing codes, hospital coding systems).
- LOINC should be used for laboratory tests and results

An accompanying article by Dr Sam Chan (Page 47) details the work put into adopting the LOINC system.

Key gaps in coding standards include primary care diagnoses and procedures, treatments, laboratory tests and results, electronic prescribing, outpatient diagnoses and outpatient services. In the remaining areas, there is still insufficient information to pick or endorse a particular coding system.

### **Data collections**

There are quality issues in all the data sets and data collections. Even the most mature national data collection (the hospital NMDS<sup>38</sup>) has many issues about the detail of definitions; for example, what most DHBs describe as a transfer from one ward to the next, is described in Canterbury as a discharge from Christchurch hospital and an admission to Burwood! Audit of entered data is rare. Each data collection needs its own programme of continuous quality improvement, led by its user groups.

The WAVE Board recommends the systematic improvement of all the existing data collections, because of significant gaps. These are the most important actions, but there are major gaps in other areas, in particular disability services.

<sup>37</sup> READ is endorsed as the standard for coding by GPs, but they are not expected to code everything - the proposed national data collection for primary care would seek codes for only a few key conditions

<sup>38</sup> National Minimum Data Set: the collection of data from every discharge from public and private hospitals



## Every Day in New Zealand...

Here's a snapshot<sup>39</sup> of what goes on in the health and disability sector, every day:

157 babies are born
73 people die
105,000 prescriptions are filled
40,000 laboratory tests are analysed
4000 outpatients visit hospitals for care
432 people have elective surgical operations
19 people are diagnosed with diabetes
1960 people are seen in Emergency Departments
1167 people are admitted to our hospitals
50,000 people take one of the new antidepressants, eg: Prozac
50,000 take a cholesterol-lowering drug
21 people have heart attacks
637 children are immunised
2124 children and adolescents have a dental check up
27 people are admitted to hospital with asthma
ACC receives 3,000 new claims
50,000 people visit their GP

Five significant gaps need to be filled to give a complete view of all the services people use:

1. **Health status:** perhaps the most fundamental and successful measure of a health system, rather than sickness. There are simple, standard measures for assessing health and disability status (the last Census contained one).
2. **GP consultations** are the baseline for primary care quality. Prescriptions per visit, tests per visit, admission rates - all need a basic count of how often people visit the doctor. The collection of this data only needs READ codes for major disease states (such as asthma or diabetes), so GPs will not be asked to code every visit.
3. **Emergency department visits** are not recorded in an identifiable way, or with any diagnosis beyond the standard 'triage score'. Care will be improved if emergency data is routinely linked to subsequent admissions (or to GP follow-up). Clinicians and planners need access to a data collection combining data from hospital emergency departments, private A&E clinics, and general practice to understand properly whether the demand for urgent care is being met.
4. The **outpatient sector** is at the cutting edge of medical services and integrated care. It has changed dramatically in recent years: inpatient procedures are becoming day-surgery, day-surgery is becoming ambulatory outpatient care, and recovery is shifting to 'hospital in the home'. GPs now manage their patients who are in hospital, and hospitals are developing services in the community. They need day-to-day data to deliver better care, and long-term data to prove the changes are beneficial.
5. **Disability Support Services (DSS)** are only now being standardised so they can be aggregated to provide more useful, nationally consistent information. 20% of New Zealanders have a disability<sup>40</sup>. There is not enough data on which to base DSS service development and delivery decisions. The sector accounts for \$1.6 billion (1999/00)<sup>41</sup> of Vote: Health spending.

<sup>39</sup> Based on 'Improving Our Health Te Whai Ora: Ngā Tohu i te Pai, Marking Our Progress', Health Funding Authority, November 2000

<sup>40</sup> Disability in NZ - Overview of 1997-1997 Surveys, HFA/MoH

<sup>41</sup> Facts about DSS - Ministry of Health briefing for the incoming Labour Government, 1999

## Future State

The required information has been identified, it is just a matter of getting the data sets organised, then starting to code up the information. Filling the five gaps listed above will be a large task. The first step is to develop standard data set definitions that are useful to all stakeholders. The largest step is to implement them. For example, only four hospitals are currently able to collect outpatient and emergency data to anything like the level of detail required. Hospitals will have to standardise their admission processes - for example, Wellington Hospital's 45 personal health outpatient clinics all have their own admission form - and capture standardised data for the several million annual outpatient visits. General practices will have to continue their computerisation of patient notes to help develop the regional and national data collection systems, before transferring them into the national data warehouses to provide Health Event Summaries so researchers, clinicians, and funders can use the information to improve health services. The WAVE Board strongly recommends that progress be charted against the draft action plan, and that every six months its goals, timing and resources are refreshed. Clearly this needs to be done - New Zealand needs to rediscover the practice of health information.

## WAVE recommends

26. Adoption of the Health Level Seven (HL7) version 3 standards for data models and XML messages;
27. Implementation of the NHI, including collecting ethnicity data;
28. Improving the quality of NHI databases, and ensuring the NHI is included in major information flows;
29. Completing the NPI definition (using HL7 v3) and ensuring it is used by all major systems and included in data collections;
30. Implementing coding standards for primary care diagnoses (READ or its successor), procedures, and treatments; laboratory tests and results (LOINC); a pharmaceutical index; outpatient diagnoses and outpatient services;
31. Improving the quality of existing data collections, especially the quality of ethnicity data;
32. Filling the gaps in the existing collections;
33. Creating new data collections where needed, starting with outpatients, emergency departments, and primary care consultations (for key disease states);
34. An on-going rolling review of all data sets every six months, to ensure continuous improvement;
35. Data collections must be a suitable standard and quality, and be accessible for DHBs and providers to gain information to improve the quality of health care; and
36. Data collection should be more readily accessible for research purposes.

## Diabetes - a case study

Diabetes in New Zealand is a major health problem<sup>42</sup>. Currently it is a health issue on the same scale as heart disease and hypertension but, unlike the others, its incidence is rising quickly. In the USA diabetes and its complications are already estimated to represent 10% of healthcare costs<sup>43</sup>, and in New Zealand estimated costs probably exceed \$240m every year. An estimated 115,000 people are known to have diabetes, and as many again may be undiagnosed. Pacific Island and Māori people, the fastest growing section of New Zealand's population, are more prone to diabetes than Europeans<sup>44</sup>.

It's predicted that within 10 years<sup>45</sup> the incidence of diabetes will double as a result of an ageing population, the consequences of increasing obesity and physical inactivity, longer life expectancy and the increasing number of Māori and Pacific people in New Zealand.

One of the New Zealand Health Strategy priorities is to reduce the incidence and impact of diabetes; the infrastructure to manage this disease has been progressively implemented since 1997. New Zealand's disease management approach looks at the full clinical impact of diabetes, rather than viewing patients' care as a series of fragmentary encounters with different parts of the healthcare system.

New Zealand is leading the way internationally with its information-driven approach. There are primary care organisations promoting quality improvement, good uptake of computerisation in primary care, an NHI that can be used to link data about diabetes in the community to hospitalisation and mortality, and a nationally consistent minimum data set for diabetes registers that are updated annually. Several primary care organisations have developed high-class information programmes<sup>46</sup> and this knowledge will refine guidelines and delivery systems.

The Diabetes Health Information Project has been completed and a National Diabetes Working Group established, which are defining the data requirements and updating the evidence-based guidelines for the treatment of diabetes in primary care. A privacy impact assessment was done as part of the project. Primary care providers can now offer free, annual checks to all people with diabetes. The project allows the evidence-based laboratory tests and examinations to be reviewed, provides a treatment plan agreed with the individual, and forwards information to the primary care organisation that is used to monitor the quality of care and patients' needs. Aggregated (non-identifiable) data is used to help manage the disease throughout New Zealand. About 25,000 people have already had a free annual check, and the number is increasing rapidly.

### INSIGHTS INTO DIABETES:

- Diabetes is the single biggest cause of blindness in working age adults
- Diabetes is the single biggest cause of renal disease
- 50% of New Zealanders are overweight or obese, increasing their susceptibility to diabetes
- 45% of Māori with diabetes smoke
- Women with diabetes are six times more at risk from heart disease than women without diabetes
- Middle-aged Māori are 10 times more likely to be hospitalised for diabetes than Europeans
- Māori with diabetes are twice as likely to die from it than NZ European people with diabetes
- Diabetes is about 3 times more common in Māori adults than Europeans
- Māori appear to have a specific susceptibility to renal failure
- Māori are 15 times more likely to need dialysis for diabetic renal failure

42 Professor Jim Mann, Professor in Human Nutrition & Medicine, University of Otago, "Type 2 Diabetes - Managing for Better Health Outcomes" PriceWaterhouseCoopers & Diabetes NZ Inc, April 2001

43 "US Public Health & the 21st Century: Diabetes Mellitus", The Lancet, Vol 356, August 26, 2000

44 In 1985, WHO (World Health Organisation) estimated 30 million people had diabetes. In 2000 it was estimated to affect 130 million worldwide, with WHO predicting 300 million by 2020

45 Dr Sandy Dawson, Ministry of Health, August 2001

46 For example, Pinnacle IPA, Waikato; First Health, Auckland and Paradigm, Hawkes Bay

## 5. Privacy - *a matter of balance*

### Introduction

New Zealand's well-developed privacy legislation is a significant help to the health and disability sector; but it needs to be understood better by the sector and the public. There are many misconceptions: the legislation is not about keeping things private or 'secret' but, instead, about ensuring information is used consistently with the purpose for which it was obtained and that is understood by those from whom it was obtained. The Privacy Act is often blamed, incorrectly, for the withholding of information when this has nothing to do with the legislation.

Health information (in this context) is about identifiable individuals - not anonymous or anonymised data - including medical history, disability details, services provided, and test results. Some information is particularly sensitive - most people are willing to have their name and address divulged, but not their diagnosis details. Some conditions carry social stigma; others cause discrimination and hamper job opportunities. In the extreme, privacy concerns can stop people seeking needed medical attention.

Funders and policy makers need demographic and aggregated information to monitor service delivery and target spending. Statistics are sometimes needed longitudinally so patterns can be monitored. Consequently, health information provided for national and regional data collections for statistics must initially be about identifiable individuals, to enable the information to be linked. Once in the collections, the identifiers can be encrypted, ensuring individuals' anonymity. The use of this information for good management of the health service is both necessary and expected by patients and taxpayers alike.

### **The Privacy Act is often blamed incorrectly, through ignorance...**

Examples include:

- The hospital that wouldn't tell a priest one of his parishioners was dying.
- A school assembled food parcels, then asked a volunteer organisation for a list of suitable recipients. The organisation refused.
- A father asked a lab for his infant son's test results. The lab refused.
- The father of a child needing surgery rang the hospital to assess its urgency. The hospital refused to discuss the case.
- Parents being refused permission to see their children's school reports.

**The Privacy Act justified none of these actions.**

Identifiable health information is exchanged between providers to ensure the right things are done, at the right time, and to the right person. Gradually, checks are being put into the system to ensure the combined service offered (for instance, a diabetes service which crosses the boundary of hospital and primary care) is working as well as it could. The Privacy Act sets out a framework for assessing appropriate use of personal information. Applying the framework through a Privacy Impact Assessment identifies the balance - some loss of privacy for some gain in personal benefit.

Pushing privacy too far can put the health sector into untoward situations; for example, families of the mentally ill have experienced difficulty in obtaining information, to which they are rightfully entitled. Concerns over patient privacy were, however, paramount when the cervical screening programme was introduced. The *WAVE* team's preliminary assessment (based on limited consumer focus group feedback) is that patients would like the right information to go to the right person, at the right time, for the right reason. Research must continue on understanding patient issues, in a more systematic manner than in the past.

The corollary is that respect for identifiable patient information is vital; it is a duty of care on all participants in the health sector. More than that, it is a competency and capability that must be identified, measured and changed over time.

To some extent, there is also an inevitable clash between providing health services and privacy. Whenever someone needs help from the community, funders need to know where the money is going, to ensure it is being used correctly. This is part of the accountability for using public funds - from prioritising the most needy, to protecting against fraud.

## Current State

The challenge of protecting information, whilst making it available for appropriate purposes, has never been greater. Which information about identifiable individuals should be shared for specific purposes? What information should be kept private? What is the cost of this privacy in health gains? Such questions present a growing dilemma with today's abundance of information, people's increasing awareness of their rights and the need to maximise the health gains for taxpayers' dollars. Expectations about the use of information vary depending on the group being considered - individuals, health providers, health funders, the Ministry of Health and researchers.

The good news is that the framework is sound. New Zealand's Privacy Act and Health Information Privacy Code are the envy of some other countries, but there are significant failings in the way the sector responds to the Act and Code. There is a general lack of awareness of what the Act and Code means, for example, the privacy legislation is not based on people's specific consent, and countries that have tried to establish that type of framework have struggled.

Significantly, the sector has largely failed in its duty to inform the public about what information is being collected, and why; for instance, how many patients know their NHI number? How many people even know that they have an NHI number? In many countries patients are given a card with the number printed on it.

Privacy is about good housekeeping and, arguably, the implementation so far has been poor. Management of personal information is sometimes careless; for instance, paper-based medical records have been disposed of inappropriately, or patient issues inadvertently revealed at a GP's reception desk. Individuals and providers are often unaware of the additional purposes for which information is used, beyond the delivery of services to a particular patient.

## Issues and Debate

There are a number of issues: lack of understanding of the framework, difficulties in achieving the balance implied by that framework, and a need for greater follow-through.



### Access and ownership

The privacy legislation creates the right for individuals to access and request correction of their personal and health information; it does not create 'property' rights. Information can be used for specific purposes by the agency holding the information and third parties. Health agencies should consider themselves the guardians of information, so must ensure its protection through adequate storage and security safeguards - they do not own it, as frequently alleged.

### Security and the NHI

Concern has been expressed about the accuracy of the NHI and the wide misunderstanding of the intention to share information. The Privacy Commissioner has expressed concern about the risk of unique identifiers becoming a de facto universal identifier. Restrictions on the use of the NHI make this unlikely, but the following comment by the Commissioner illustrates his concern:

*"Any unique identifier that facilitates the exchange and matching of personal information held by different agencies and within different record systems is perceived to be a threat to privacy. This may also lead to the socially undesirable practice of compiling composite profiles of individuals which may lead to any and every aspect of their lives being open to potential scrutiny by governments or private enterprise."*<sup>47</sup>

### Awareness v consent

People's perceptions of what the privacy legislation covers is a problem, not helped by some of the legal advice given to health agencies. People are not well informed about the way their information is used but the Health Information Privacy Code sets out the requirements. Patients must be made aware of how their information will be used. Difficulties arise with any subsequent use not contemplated at the time of collection, or when an agency is expected to provide information to another agency other than for direct health care.

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<sup>47</sup> "Necessary and Desirable - Privacy Act 1993 Review" - Report of the Privacy Commissioner, November 1998



## **Patient awareness of National Health Index (NHI)**

It is time to get the NHI out of the closet. It is a unique identifier for everyone accessing public health services; linking information to the person, so a longitudinal record can be developed. Most people have an NHI number, although few know it. Since 1995 all babies have been assigned an NHI number and providers now assign one to anyone apparently without one.

Providers and consumers need to be informed about its purpose. This will enhance confidence providing those purposes are justifiable. Providers also need to be open about the information to be linked by NHI number and the reasons. Adequate protections need to be in place to ensure its proper purpose.

## **Mandatory collection of health information**

Certain patient information may be collected to provide services, such as the legal requirement for ACC claims. At other times, the specific information may be considered sufficiently important for the agency to make the collection mandatory. Generally, the agency collecting the information must ensure the patient is aware the collection is mandatory, state its authority, why it is collecting the information and the consequences of not complying.

## **Opting on or opting off**

Sometimes patients are offered the option to join related initiatives such as screening or disease management programmes, or 'well child' programmes. This is not a generally expected use of information, and often involves a series of providers sharing information about treatment. 'Opt-on' is used when individuals agree to participate; 'opt-off' when they do not.

## **Māori**

The privacy framework is based upon OECD<sup>48</sup> guidelines and so has Western European cultural origins, where privacy is an individual-based concept. Māori have a different cultural perspective and view aggregated information as being just as sensitive as individual information. Those differences mean that information could be more sensitive at times, and less sensitive in other situations. Sometimes it is necessary to get special permission before using Māori data. Māori also believe information about one individual belongs to the whole whanau<sup>49</sup>, which can cause problems with particularly sensitive data, which Europeans would assume was private to the individual.

## **Medical research**

Using information for medical research requires balancing confidentiality against the benefits from improving the quality of care through research. The Health Research Council has developed guidance notes for research which are generally more stringent than those required by the Health Information Privacy Code.

## **Security issues**

The rapid growth of digitised, EHRs raises concerns about security (discussed on Page 43 in this document) but electronic safeguards can radically enhance the degree of comfort consumers can have about their information. Security, when properly implemented, helps to ensure information can be used only for the purpose for which it was obtained. Information security consists of both physical and technological mechanisms. Holders of information must have in place reasonable safeguards to protect it from loss, access, use, modification, or unauthorised disclosure and other misuse. The standards required depend on the information's sensitivity.

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48 Organisation for Economic Co-operation and Development

49 Maatatua Declaration, June 1993



It is certainly true security safeguards raise operational and technical challenges. There have been a number of significant breaches of security abroad and, therefore, care needs to be taken to ensure privacy is ensured through use of high quality security systems.

## Future State

In December 1997, Dame Fiona Caldicott<sup>50</sup> reviewed patient-identifiable information in Britain. Her Report's influential principles are equally applicable in New Zealand; with an additional principle required for us, to ensure patients understand how their information will be used:

- Justify the purpose
- Do not use patient-identifiable information unless absolutely necessary
- Use the minimum necessary patient-identifiable information
- Access to patient-identifiable information should be strictly need-to-know
- Everyone with access to patient-identifiable information should be aware of their responsibilities
- Understand and comply with the law

The Caldicott Report and most of the important issues raised here are about awareness and behaviour, facilitated (but not driven) by systems or technology. The WAVE Board believes strongly the health sector needs to explicitly build confidence in its management of personal information through a systematic programme of education and self-improvement. It should begin by telling patients what the NHI is and how the attached data is used.

The NHI is the agreed national identifier for health information to achieve the gains of integrated care. As a corollary:

- Everyone must have an NHI number;
- It must have specified purposes; and
- Protections must be put in place to prevent its misuse.

Patients must be made aware of the purposes (care and public health) for which their information is obtained and used. Clearly, this goal will be achieved only with a focused, progressive awareness campaign for individuals and health agencies about the NHI, its purpose and what information may be linked, including current national data collections.

At the moment, management of the overall competency of the sector on privacy issues is poorly defined. Capability should be put in place to provide leadership in managing health information, specifically from a privacy perspective. It would be:

- The guardian of all national data collections, including the NHI and screening/disease registers;
- Responsible for managing the NHI;
- Responsible for providing guidance on privacy issues, including the use of privacy impact assessments prior to the development of information systems or large data collections;
- Responsible for developing (in consultation with the sector) guidelines, audit tools and protocols. Such guidelines and protocols could cover the use of the NHI, who (and under what circumstances) should have access to information about an identifiable individual and when access should be anonymous; and
- Responsible for monitoring how well the protocols are working.

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50 The Caldicott Committee: Report on the review of patient-identifiable information, UK, December 1997

### In a perfect world...

- Patient information is used to provide the best possible care, it's properly protected against misuse and people know why it's being used. Patients have control over the use of their information.
- Providers have access to relevant information about patients to enable the best care, with appropriate sharing of information between providers.
- Funders have access to information, not necessarily about identifiable individuals, to target funding; to monitor the health outcomes and the services delivered. Only in specific cases would funders need information about identifiable individuals.
- Policy makers have access to demographic information about disease patterns, health needs analysis and populations' health status to enable targeting funding. National data collections for statistical purposes are properly protected.
- Researchers have access to relevant anonymous information and, when necessary, about identifiable individuals to enable them to research and develop disease management tools leading to improved health.

### WAVE recommends

46. Completing an initial awareness campaign for patients about the purpose and use of health information, by December 2001;
47. Running an awareness campaign on the NHI, by December 2001;
48. Considering development of a Code of Practice (under the Privacy Act), specifically dealing with the NHI number;
49. Progressively testing health information flows and collections (including national data collections and screening programmes), existing and proposed, against the privacy legislation and the six Caldicott principles;
50. Implementing education programmes to reinforce awareness of privacy issues, including confidentiality and security requirements;
51. Progressively developing guidance and resources to help agencies make decisions about the management of information about identifiable individuals;
52. Developing and implementing web-based privacy audit tools;
53. Building a supporting network of Privacy Officers to assist health organisations (large and small) to learn from each other, and to benchmark performance on the management of privacy;
54. Developing the organisational capacity to manage privacy issues proactively;
55. Developing protocols to protect the exchange of information between different providers, and between providers and third party agencies (such as funders, researchers and policy makers);
56. Using provider (rather than patient) information wherever possible and facilitating this with introduction of the NPI;
57. Undertaking further consumer consultation (possibly through a national workshop, but also through a continuing programme of applied research); and
58. Giving consideration to establishing a consumer advisory board to ensure on-going acknowledgement of consumer interests in privacy-related matters.

## If only... a case study in frustration

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It seems extraordinary. New Zealand has never had a standard coding system for laboratory tests. Back in 1998, the Association of Community Laboratories (ACL) asked me to find a simple way to implement a universal code. I thought this would be a short project, which turned out to be wildly optimistic as it soon consumed all my spare time - at some cost to my wife and family - over three long years.

The aim was to provide a common reference for the identification of laboratory tests, regardless of source, which would allow standardised interchange of test data between medical practices, hospitals, laboratories, insurers and health authorities. There were absolutely no resources available, so the Internet became an invaluable aid to finding coding systems that would suit a small country like New Zealand. I was glued to it every weekend.

Early on, in May 1999, I attended the Ministry's Health Standards Communications Working Group (WG4) to assess support for my plans. I wanted their support for my research, before approaching the NZHIS and the HFA to gain national support. Sadly it was the last meeting that group ever held.

It soon became apparent there was no forum for discussion or consultation although input and support from labs across New Zealand was essential to ensure my recommended system was accepted. The only solution was to develop my own road show. Lack of resources meant this was only feasible if fitted into my own work-related trips. I had meetings with labs in Auckland, Hamilton, Wellington, Christchurch and Dunedin over a period of eight months. It was a laborious process because at the same time - throughout the whole project - I was working full time as a pathologist.

My research identified LOINC<sup>51</sup> as a suitable system. It's used in the USA and Canada, Europe (Switzerland and Germany), and under consideration for Australia. LOINC provides a standard set of universal names and codes for identifying individual laboratory tests, plus clinical and diagnostic study observations. It is also being cross-referenced to coding systems already used for different specialties in our health system. It was developed by the Regenstrief Institute in the USA, and maintained licence free. LOINC operates on a widely understood universal vocabulary used internationally for result reporting and request ordering. Its use in New Zealand would solve the problems - simplifying information handling, facilitating information exchange and improving integration between systems. There were a few problems - use of US spellings and imperial measures, for example - but overall, LOINC was almost too good to be true!

ACL agreed to my recommendation of LOINC, but that was just the beginning. I had no formal authority to represent NZ interests therefore no formal links to the Regenstrief Institute. It's run by a committee of US state, university and government representatives and I'm just a pathologist from a very small country, with no official credentials. It would have been much easier if I'd been a member of a committee or on their mailing list. I knew a new version of LOINC was imminent (Version 1.0N, due February 2000) but my lack of formal relationship meant I had to rely on the Internet to keep track of any developments.

In June 2000 we organised a universal coding workshop at Waiheke Island with some help from a lab software company. It was well attended by about 30 participants from community and hospital laboratories (all using

<sup>51</sup> Logical Observation Identifier Naming Convention

different systems), plus representatives of IPAs who were very supportive at the time. Joint support was vital to the project. The doctors wanted immediate action, and LOINC was chosen. The Regenstrief Institute offered assistance to establish a New Zealand chapter and it was suggested a subscription could be used to fund development and maintenance through a local LOINC website. Then Standards NZ advised us on the necessary process to establish LOINC as a national standard, starting with a code of practice.

At last we were heading in the right direction! I was really happy about the progress, although aware we had much to do. I've never been interested in politics because I like to put my training and experience into helping individual patients directly. Using LOINC would be a real boon, although I appreciate its benefits are not easy for the layperson to see or appreciate. It's important to remember doctors have widely varying IT skills, so any system must be useable. But it was so frustrating trying to develop LOINC when there was no system for co-ordination, no network, no forum for discussion. If only we could get everyone around the table to thrash out the issues.

Standards NZ offered to draw up a code of practice in August but the fee, largely for secretarial services was nearly \$23,000 (+GST). So, who should pay? Should the hospital laboratories contribute? Should software houses pay? Should the Government fund it, especially as community laboratories receive 95% of their funding from the Government? Sadly, the proposed code of practice had to be abandoned, due to lack of funding.

Meantime, there were systems issues. The full LOINC system now has 28,000 different codes (both for ordering and resulting), many of which are irrelevant to New Zealand (some chemicals, drugs, or infectious organisms). So I decided to devise a subset. ACL, which asked me to do this work originally, wanted about 160 tests, but other users had different needs so I finally selected 1,500 codes for 640 tests. I distributed the result and order subsets to community and hospital laboratories in October 2000 and February 2001.

Another workshop was held in Auckland last April. It was a real test of my business partners' patience (don't forget, I was still working full time as a pathologist). I had no funding, little organisational help and wanted to bring in overseas speakers. At the last minute a key speaker declined to come... so I had to step in and ended up doing half the presentations! It was attended by 27 people, all paying their own way. Actually it went very well and we were committed to preventing the growth of a clinical Tower of Babel.

Then I hit a major snag. I was walking into a much bigger problem... based on our nation's pride in being able to do anything with a bit of No. 8 fencing wire. Any universal code for laboratory tests has to be electronically compatible, which means it must comply with HL7, which is in the process of being upgraded making it better for both resulting and ordering.

New Zealand is a small country, with relatively few health providers. On investigation, a host of discrepancies in reports from laboratories ostensibly adhering to the HL7 standard was found. It became evident some have adapted the international HL7 standard to their own ends, moving it away from the internationally monitored standard. This bastardised version, "HL8" is becoming an international joke but for LOINC it was the last straw. I could adapt LOINC to "HL8", but this would move both systems even further from the international standards. If there were a national body responsible for health information standards we would be using a standard and updated version of HL7.

I am worried but I am also very much encouraged by the extensive support given to the LOINC project by my colleagues in community and hospital labs, in general practice, and by software developers. It is interesting to know Australia is also thinking of reducing the huge LOINC master set into a subset for their use. I have done so much with so little resource. The same kind of work for a state in USA is normally done by at least one person in full time employment.

The LOINC project is so close to completion but it just needs a little bit of time, a little bit of funding, and a little bit of support nationally and internationally.

**Sam Chan**

## 6. Systems Infrastructure

- *providing the electronic glue*

### Introduction

Throughout history, whenever universal standards have emerged the results have been dramatic. We now take for granted that most countries have a standard gauge for their railway systems, but it was not always like that. Australia introduced one in 1940; the United States in the 1880s. Once introduced, a standard gauge meant goods could be shipped across country more quickly, and at considerably less cost. The WAVE project is about exploring parallel issues in New Zealand's health sector.

Other industries have similar problems, so the need for secure exchange of information is not unique. The American automotive industry has developed a secure, high-performance Extranet to facilitate electronic parts ordering; it is a network based on rigorous security standards, and has now expanded into other industries, including several hospitals.

There are a number of strategic forces developing in the health and disability sector that are driving New Zealand towards the architectural components necessary for information access and sharing. For the purposes of this document, health outcomes are viewed as a function of key healthcare delivery strategies: 'integrated care' and 'population health management'.

At the local level, connecting caregivers electronically is an opportunity to deliver better health care. Caregivers have an increasing need to access comprehensive information at the point of care, but fragmentation of the sector's computer systems makes this goal technically complex. Primary caregivers (GPs, Māori and Pacific providers, non-Government organisations such as Plunket), hospitals and government health agencies have all developed their computer systems in isolation, which poses a big problem when, as frequently happens, a patient needs care or attention from more than one.

There is also the risk of information being misplaced in future, especially if any information is recorded inaccurately or in slightly different form. These organisations do not share their electronic patient records, even when they share the patient.

### The Challenge

WAVE's objective was:

*"To identify and design an architectural framework for a nationally consistent platform that will provide all major interest groups in the sector with an effective and efficient IT infrastructure to improve healthcare outcomes for New Zealanders."*

Designing the sector's Systems Infrastructure is a significant challenge. The structure needs to be organic and flexible; must leverage existing systems developments; promote easy, low cost application development; and provide a high quality, reliable and secure infrastructure for the transfer of health information.

Systems Infrastructure is a framework for the development of information management and technology capability; it represents the bridge between the customer's requirements and the required technical design. The challenge was to get the healthcare community on-line, connected and managed in an organised, cost-effective manner. The sector's infrastructure needs were focused upon, between (not within) providers,

funders and policy-makers. A framework had to be developed for electronic information capture, storage and exchange capabilities within the sector:

- It needed to be permissive, allowing participants (large and small) to be connected rapidly and benefit from efficient information exchange.
- It needed to recognise the levels of security required and provide a clear framework for systems and technology developers, vendors and managers.

In some respects it might be easier to start with a clean slate, but that is not possible. Instead, the islands of information must be worked with, identifying the best way to build bridges connecting all the different organisations, with their different systems and databases.

There is no point in trying to develop one common, central system because, apart from the expense, it would cause great antagonism and lose rather than create value - the health sector has put huge intellectual and financial investment in the existing systems that, in many cases, have made significant improvements. The advantages of the different systems must be recognised as the sector works towards sharing information. Also, different organisations are at different stages of IT development and have different priorities, as well as different financial capacities to invest in IT/IM.

The *WAVE* Board weighed up these issues and concluded that the appropriate response was to adopt up-to-date, open architectures, relying on specification of standards for inter-operability, and bootstrapping off the World Wide Web.

Supplier submissions argued that one or other specific technologies was appropriate. Equipment brand names were not discussed, which (apart from some narrow technical issues) are irrelevant in an environment of open system standards, as is the data flowing across the network, which was an issue for the EHR and Data work streams.

The recommended framework for developing Systems Infrastructure is not static. It is the current view of what is required over the next 3 - 5 years, which will evolve as changing business requirements and technology influences standards and specifications. It is important to note these are not mutually exclusive domains; instead they overlap into the other areas of Data, Electronic Health Records, Organisational Design, Investment and Privacy.

## Current State

The health sector has endured significant structural changes several times over the past decade. It faces a number of issues in the drive towards efficient, value-added information exchange, but the greatest is the lack of overall leadership, resulting in unclear ownership and accountabilities for strategic direction and implementation. There are many policy, structural, and technical constraints hindering the development of cost effective processes and creating an environment that allows poor performance, inefficient information management and technology practices.

A stock-take reveals:

- Limited sector-wide ownership and commitment to national information assets
- The lack of a standards setting and governance body and framework
- The lack of standards - implemented and enforced
- A fragmented sector, with significant system duplication and inefficiencies
- Inefficiency in electronic data exchange, with ad hoc developments



- Limited uptake of the Health Intranet, a Virtual Private Network (VPN) developed on the initiative of NZ Health Information Systems
- Inconsistent and non-aligned national data sets, with information 'silos' and 'orphans' inherited from earlier regimes
- Poor access to systems (eg: NHI) and information by the wider sector
- The benefits of a networked, electronic environment beyond the reach of smaller organisations with limited resources and IT specialists
- Unco-ordinated approaches to digital certificates
- Limited skills in the sector for handling standards and sector architecture
- Rapid pace of technology change, posing resource and security challenges
- Growing use of the Internet

## Issues and Debate

A number of debates arose; for instance, debate around security issues and use of the Internet, debate around authorisation and identification, debate around approaches to housing and making data available.

Questions raised included:

- How can sensitive information be collected, exchanged, made available to many interested parties - yet kept secure?
- Should information exchange be confined to privately managed networks, or permitted across the more open public Internet?
- Is it acceptable to send encrypted data over an uncontrolled environment that anyone can access?
- Should data be exchanged by a known and trusted community of care providers?
- How can telephone companies be encouraged to provide good service?
- How can good quality infrastructure be achieved without burdening providers, and making the cost of participation too high?
- Encryption of data is obligatory, but should we be permissive about which carrier is used, and whether by Virtual Private Network (VPN), or over the Internet?
- How should multiple network service providers interconnect (in a decentralised and more contestable environment) allowing all users access to all national services?
- How should users be authenticated and access to systems and information controlled?
- Should individual health network service providers manage it or should a central approach (such as an National Provider directory service) be used?

## The Security Debate

It became clear that the sector lacks base knowledge about the threats and risks it faces, and the policy environment and trade-offs implicitly being made between increased functionality versus increased security. In particular, it became clear previous initiatives did not have a security policy backdrop and few people in the health sector had a full understanding of the nature of the technologies, and associated risks and benefits.

The WAVE team looked at the VPN versus World Wide Web debate. Currently Telecom is the only provider, although others are expected to enter the market. The Health Intranet Governance Body (HIGB) promotes standards for privately managed networks providing security measures (network layer



encryption, and bundled intruder and virus protection). The contrary view believes the open Internet interchanges (using Web browser data encryption) are more likely to succeed, particularly for smaller organisations with limited resources (zero client environment - where standards for protection fall on the entity holding and managing the information).

International evidence shows mandated health networks tend to be too inflexible; for instance, the National Health Systems NHI Direct is not widely regarded as a success. But there is also clear evidence VPN can be useful and cost-effective.



Shaping the competitive environment between alternative suppliers of network services was another issue. Clearly, it would be an issue if the health sector were to be 'locked-in' to one service provider, whether intentionally (through contract) or unintentionally (through adoption of an inappropriate industry standard), with likely consequences such as poor service and high future costs.

### How to store and access data?

Data warehousing is the ultimate end point for the information not used for provider decision-making about individuals. Quality data on populations will be crucial in the DHB environment, particularly in initiatives such as capitation and population-based service development. The demand for access to utilisation and cost data at Primary Health Organisation (PHO) level is already starting.

There was strong agreement the current ad hoc data warehousing developments should not continue, but should they be replaced with a single warehouse or should links between existing and future data warehouses be established?

## Future State

A principles-based approach was taken to design the Systems Infrastructure, mostly about being pragmatic, evolutionary and robust to future structural change. It was agreed the proposed Systems Infrastructure must:

1. Be isolated from structural change in the health sector;
2. Build on existing assets;
3. Be pragmatic and affordable to diverse stakeholders;
4. Avoid or minimise duplication and waste of resources;
5. Reduce compliance costs;
6. Be open to innovation;
7. Leverage open standard technologies;
8. Encourage consistency by being standards driven;
9. Provide for contestability in the provision of products and services; and
10. Be incremental and evolutionary.

Five fundamental areas were identified:

<b>Health Networks</b>	<ul style="list-style-type: none"><li>• Network infrastructure and transport mechanisms to exchange data within the healthcare sector connecting healthcare entities</li></ul>
<b>Security</b>	<ul style="list-style-type: none"><li>• Risks surrounding health information protecting healthcare information</li></ul>
<b>Messaging</b>	<ul style="list-style-type: none"><li>• Data and transactions to be delivered over the Electronic Health Network supporting integration of different entities and ensuring a common language</li></ul>
<b>Operational Systems</b>	<ul style="list-style-type: none"><li>• Applications that support health population management supporting the national delivery of healthcare</li></ul>
<b>Data Warehousing</b>	<ul style="list-style-type: none"><li>• Systems and applications focused on decision support supporting thinking about the delivery of healthcare</li></ul>

The WAVE Board discussed the security issues at some length, realising that instead a unified approach is needed to security, which is 90% behavioural, and 10% technological. The World Wide Web is considered appropriate, providing a security framework is put in place; but development of VPN can also be encouraged. In particular, the organic nature of the sector had to be recognised - the sector will always be a difficult environment to control with a wide range of users, from the sophisticated to those to whom IT is an incidental nuisance.

The building blocks of security are well established and set out in international standards. The WAVE project team formed the view the security framework should be developed as follows:

- Adopt and modify an international standard;
- Put it in place on a voluntary basis and identify the significant gaps;
- Modify to achieve a reasonable, mandatory standard of security; and
- Assess and improve over time.

On two important issues:

- Use of the VPN should be optional; and
- Use of the Internet is acceptable, but encryption of personal health information in transit should be obligatory, using agreed high quality data encryption.

Modern cryptography is very secure<sup>52</sup>. It's been calculated a 128 bit symmetric key would, on average, take more time to crack by brute force than the solar system has left before the sun goes nova and swallows the earth. Similarly, it's estimated it would take roughly the same time to crack a 1024 bit asymmetric key. It's far more likely someone would accidentally reveal a pass phrase than the ciphers would be cracked. As someone said, "human beings crack far more quickly than modern ciphers". Some governments (USA and Israel, in particular) are reputed to have excellent code breaking systems, but if they were seeking someone's medical records, they might find it quicker to bribe someone for the hard copies!

More important are the issues of appropriate authentication and identification - digital certificates will eventually become mandatory. A higher validation standard (rather than just passwords and Internet protocol addresses) will be needed with drivers such as electronic prescribing, but the addition of digital certification should be sufficient. Implementation of digital certification is a major technical and cost issue, given the size and scale of the sector, but having a common certificate for access through a co-ordinated

<sup>52</sup> <http://www.thawte.com/support/crypto/key.html#security>

gateway will minimise the cost. The process would be much simplified if certificate issuing were connected with, for instance, doctor registration. This needs to happen very quickly.

### **Agreement on messaging and uniting operational systems**

The messaging issues were easier. HL7 is already in use and its latest version will converge with XML. Individual service providers can develop and maintain their own message addressing and routing. Everyone agreed national patient and provider identifier systems are vital. Adoption and implementation of messaging standards resolves one of the issues that Dr Sam Chan explains on Page 47, where he compares the problem to New Zealand's historic love of doing almost anything with No 8 fencing wire.

### **Data warehousing**

The *WAVE* team had a clear view on data warehousing - all those who need access should have access, enabled by technology. There are many tools to enable access and analysis. An overwhelming principle is that users must easily understand data relationships, which could be achieved through a range of solutions. The choice is an implementation issue, but data warehousing needs a co-ordinated approach.

### **A health portal**

Finally, it became clear a national gateway, a portal<sup>53</sup>, is needed for providers to access national and other systems. This is a navigational tool giving easy access to Health Benefits, ACC or any sector system, application or provider. It would mirror the State Services Commission approach for the whole government sector. GPs and other primary care providers are busy people and a portal would allow an easy opening into a plethora of health information resources - currently walled up by isolated systems and inoperable data definitions. There are different ways of putting in place this infrastructure, each with its own cost implications.

### **Overall benefit**

The desired situation is a connected community of funders, providers and patients where quality information is easily and securely available, at the time required, to all authorised users.

The proposed Systems Infrastructure will provide the following benefits:

- Technology enabling Integrated Care (NHI, NPI);
- Standards setting to enable disparate caregivers to work together;
- Infrastructure to connect caregivers, enabling information sharing to provide improved care;
- Standardisation and rationalisation to avoid duplication and waste;
- Leadership and clear guidelines to policy-makers, funders, providers, vendors, and support service agencies alike;
- The platform to drive the sector into a new networked environment over the next three years;
- Increased value for the data collected, stored, and shared allowing the data to be leveraged for greater returns to the sector (and ultimately patients);
- Open access to key systems and data collections for authorised parties, so greater efficiencies, insight and knowledge can be created and shared;
- A single point of access to the collective national health care information assets, shielding users from back-end structures and systems; and
- An environment supporting the development of innovative and inter-operable solutions within a framework of standards.

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<sup>53</sup> Portal = individually customisable desktop allowing the user to access applications - on-line medical journals, the PHARMAC database, NHI or the local hospital booking schedule.

## Implementation

The proposed future state will require a detailed implementation plan to put the recommendations into operation over the next three years. The *WAVE* Board has set out its view. Success depends on the co-operation and collaboration of key government agencies and the general health sector. IT vendors, network service providers and technical specialists must be consulted. Other *WAVE* recommendations (in particular those from Organisational Design, EHR, Data and Investment) are relevant to governance, leadership and funding of the proposed developments.

## **WAVE recommends**

59. A single health portal as a gateway for access to national healthcare information systems;
60. A unified security framework, with an initial, voluntary policy document to be produced in three months, covering all aspects of security;
61. Six monthly reviews and upgrading/ tuning of the framework based on feedback from application;
62. The encryption of personal health information in transit, to 128 bit standard;
63. The introduction of digital certificates in a manner which avoids practitioners needing more than one;
64. Beginning discussions with professional registration organisations to link digital certification with registration;
65. Voluntary use of Virtual Private Networks;
66. Actively encouraging new entrants to the VPN market and so creating an environment of multiple competing networks;
67. Maintaining existing multiple funder systems (ie: ACC, Health Benefits, etc) but rationalised over time (eg: claim and payment processing), accessible through the national health portal;
68. The NHI with direct access to sector participants controlled by portal-based access control rights;
69. A NPI established as a single directory service, for use in authentication, network message handling, and data warehousing, with delegated registration and maintenance functions to relevant bodies;
70. The integration of national data warehouses, linked by an NPI and the NHI; and
71. The use of XML-based HL7 v3 standards for messaging.

## Top Trends in Health IT

Peter Aagaard, senior business analyst at the Ministry of Health, analysed international trends relevant to Health IT and incorporated the opinions of leading consultancy firms including Gartner Group and Cap Gemini Ernst & Young.

*Here's the result:*

- Technologies centred on the Internet particularly around browsers, Wireless Application Protocols (WAP) and similar remote-access technologies, IP-based protocols and systems development based on security standards such as IPSec and SSL.
- Greater use of the Internet for publishing medical journals and similar publications although uptake will depend on the development of standards for authentication, authorisation and accounting; particularly for person-to-business (P2B) applications.
- Remote monitoring of home-care patients and telemedicine; including embryonic development of remote virtual reality surgery techniques and distance diagnosis, using visual imagery. All will depend on greater bandwidth availability.
- Data entry bottlenecks will reduce through the development of natural language speech input for clinicians (particularly via hand-held devices), natural writing recognition and voice-controlled devices. Computer-generated speech from text will reduce clinicians' need to read, freeing up time for other uses.
- Hospital purchasing will increasingly be managed through e-procurement. Emerging business-to-business (B2B) models will allow greater control of inventory levels and reduced transaction costs. Suppliers and buyers will become more integrated, leading to more seamless organisational processes.
- Increased use of systems supporting information sharing (including Enterprise Resource Planning [ERP] systems and electronic claiming) allowing for more integrated data across hospital departments and other healthcare delivery participants; leading to lower transaction costs, greater data accuracy and, ultimately, improved health outcomes.
- Evidence-based medical initiatives and continual quality improvement initiatives rely on the transformation of quality data into useable knowledge. There will be greater use of transaction data for value-adding activities like data mining, case mix analysis and knowledge development.
- National consistency in data and messaging standards, and national use of identifiers for consumers, providers and, particularly, Māori. Inter-operability of data will facilitate improved patient care by allowing more accurate and timely information to be available at point of care, and for service development and monitoring - a necessity for integrated care initiatives.
- Healthcare and administrative processes organised around off-the-shelf software due to its low cost. Low cost hardware and expensive development costs are resulting in more standardised administrative and healthcare delivery systems; for example, the Application Service Providers (ASPs) software rental model.
- Move towards simplified authentication through digital certification and/or biometric identification, together with mechanisms such as Portals and Light Directory Access Protocol (LDAP) to control access. Legislation (for example, the NZ Electronic Transactions bill) will help define a legal framework.

## 7. Investment - *spending wisely*

### Introduction

IT spending in New Zealand's health sector is rather mysterious. No one knows how much is actually being spent as the figures lie buried in different, often conflicting, accounting methods. Despite New Zealand's relative advance in technology and telecommunications, current investment is probably not delivering value for money because of a piecemeal approach and very limited co-ordination. There is still a strong focus on spending IT money on governance and compliance, rather than on systems aligned to health goals, clinical efficiency and sector integration. As a nation, New Zealand is fertile ground for all IT can offer, as our characteristics (small population, no big regional differences or state divisions, and a strong tradition of achieving quite a lot, at relatively little cost) provide an excellent environment for success.

New Zealand has a reasonable IT skill level across the wider health sector, in particular newly qualified doctors, general practice, pharmacy and community laboratories. But the potential is under-utilised. Public hospital patient information, and related clinical systems, are ageing and may require replacement within the next three years. In some cases, key clinical systems are not present in larger hospital environments and very few hospitals have the ability to inter-connect with the primary care sector.

There are some positive views of technology in the sector. Pharmacists describe their systems as "excellent, efficient and expensive", a positive asset, essential to quality pharmacy practice. Their systems are valued for the time saved in administration, management and organisation of their businesses. Pharmacy systems, in addition to dispensing functions, are used for stock control, collating prescribing data, claims, clinical record keeping, recording drug interactions, providing information for medication reviews and running business finances. One pharmacist commented, "pharmacies could not function today without information systems". Independent Practitioner Associations have invested in IT for administration and information systems; larger IPAs have dedicated IT specialists on their staff.

Devolution gives rise to challenges in respect of strategy, policy and systems. Everyone accounts for IT differently, with no template for how money (operational or capital) is spent. In Auckland, one IT budget includes a hospital call centre. In the Waikato, an SMS<sup>54</sup> computer system costing \$9 million has just been written off because it failed to deliver what was required. But, rather than attribute blame, it is more constructive to consider whether this would have happened if there were a IT business case framework, a collaborative project team to help with implementation and a set of standards around IT project best practice. At Capital and Coast Health DHB the same system is working, albeit needing large support staff numbers to keep it operational and the vendor has advised that support will soon be withdrawn for that version of the product.

Providers state their wish to make informed decisions about IT investment, but the large amounts of information collected and collated in tendering processes are not actively re-used between providers.

Another example of lack of co-ordination is in Digital Radiology systems - a high cost area with potential savings through collaborative action. Instead three different equipment and software packages have been chosen throughout the country within a relatively short period of time. Logic would suggest there are obvious advantages in bulk buying and savings in implementation and support costs by joint/collaborative effort, but providers have elected to undertake the selection and implementation individually and bear the corresponding costs.

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<sup>54</sup> Shared Medical Systems

Some DHBs have collaborative initiatives underway with the primary sector and some recognise the value in leveraging off Internet browser technology to provide an integrated view of separate systems. The sector's use of IT would be more effective if such efforts could be harnessed sector-wide. Health budgets will always be strained so sustainable, responsible and well-informed investment linked to health goals is critical right across the primary, secondary and tertiary sectors.

## **IT Opportunity**

The *WAVE* project provided an opportunity to look at IT across the spectrum of primary and secondary care, following the path of the patient rather than a specific group of providers. Although the focus was largely on secondary care and opportunities for DHBs to maximise investment opportunities, there is recognition of how systems need to interact between sectors and the corresponding standards and collaboration to encourage it.

## **Current State**

Despite some positive signs, there is no overall cohesive direction. This is particularly evident in the secondary sector where many are patching together existing systems, with some success or no success. New computer systems are being considered without any sector-wide planning or formal discussion. Currently, responsibility is devolved to DHB boards and CEOs. Auckland has just completed a large computer study, yet its close neighbours Waitemata and Counties Manukau have jointly run a similar and parallel exercise. If some DHBs can work together, why not all? Smaller DHBs want to work co-operatively with others to share risk and obtain maximum value. How different are the DHB needs? DHBs' systems strategies are at varying stages of development. There is a willingness to share data, but not systems.

The sector is diverse (Auckland DHB alone has four major hospitals and seven separate autonomous business units). Informal networks exist, but the exchange of complex information should be formalised and co-ordinated. Sector co-ordination is too big and challenging an issue to rely simply on friendships. DHBs must be encouraged to help each other yet, with no incentives; co-operation is not seen as important when they are busy with their own problems. Inevitably, different DHBs have different strengths - sophisticated IT in some main centres, but not necessarily in the smaller areas. Then, within each DHB, there are hundreds of different systems. The primary care community faces similar issues as many GPs have their own systems (ranging from GP Patient Management Systems to Excel and Access databases) that are rarely linked with other providers or hospitals for information exchange.

## **Issues and Debate**

The following issues are most evident:

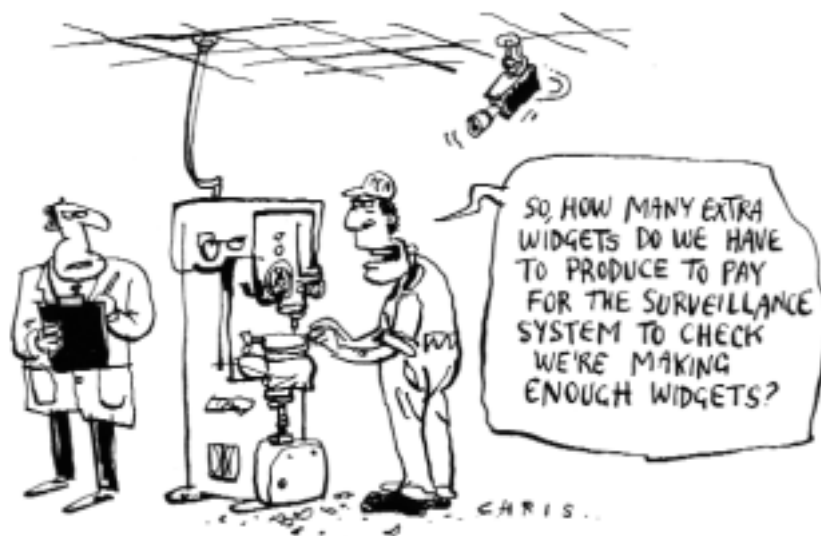
- Disparity of technical infrastructure (some old, some new, and some providers with little access to any IT);
- Not enough concentration of IT people to implement and maintain complex systems effectively sector-wide;
- Ageing infrastructure with older applications, some with older hardware;
- High cost of new applications mean they are often unaffordable for smaller providers;
- No central leadership or co-ordination; and
- Collaborative initiatives are supported in principle, though informal and ad-hoc in practice.



This lack of co-ordination has resulted in issues including: duplication of effort, systems and funding, and inequality of access to systems that help clinicians. The balance of effort needs to shift from an administration and accounting focus to an increased focus on clinical systems. Technology itself is not the answer. Giving clinicians a computer will not cure the problems; people must have an incentive to use systems, and they must see how technology can help in the provision of healthcare. Providers across the primary, secondary and tertiary sectors must be given certainty their IT investment is going to be worthwhile.

Given the issues uncovered during this project, is the current approach to funding IT sustainable and aligned to sector objectives?

WAVE identified a mindset of problem fixing rather than long-range strategy. Many initiatives were seen as fire-fighting or aiming investment at individual initiatives, rather than an overall cohesive strategy. This was manifest in the feedback from clinicians who often view IT as administrative and report focused, rather than providing valuable clinical information.



Finally, the debate about spending in healthcare IT is still focused on spending in hospitals. IT could be far more effective in its contribution to improved health outcomes. Strategic sector-wide spending prioritisation is needed. There is no sector-wide ability to enable IT resources to best meet health goals. The debate needs to move past hospitals, to include primary care, and to dentists, midwives, ambulances, etc. All need appropriate IT and the sector needs an investment strategy linking the strategic needs of the sector with the wide range of issues faced.

## Future State

A standardised, integrated approach is a real priority but beyond the sector's current capability. Investment issues facing the sector will not be addressed while providers remain completely independent in their choice of systems. The lack of integration between hospitals, the lack of co-ordination of development and investment, the lack of formal expectations and minimum standards now manifest themselves clearly. Small, but significant, steps to improve patient care and build sector capacity and confidence will be the most successful method of achieving health and efficiency gains through co-operation. Evaluation of spending priorities must focus on IT's contribution to making New Zealanders healthier and maximising the gains from sector co-ordination.

On the other hand, fixing the problem is difficult. There is no clear, single approach to resolving all the issues and no easy answer. The ad hoc development of systems has the advantage of close alignment with the hospitals' immediate needs but the environment is more complex now, and DHBs are being asked to work together, and with primary care. Future issues will require strong administrative systems, integrated

between providers and capable of identifying whether or not the job has been done - and how well. Systems will be required to produce a better and more balanced view of clinical and administrative information, particularly in tracking improvements and support in the areas of:

- Continuity of care across the sector;
- Clinical quality;
- DHB governance and monitoring of local health care in the wider sector;
- Clinical efficiency (including decreased waiting times for elective surgery and quality care);
- Effective use and monitoring of funds and services; and
- Healthy communities (improving lifestyles, for example smoking and diabetes).

Some secondary and tertiary providers such as South Auckland, Waitemata and Wanganui have realised the benefit of introducing clinical IT champions: doctors who can speak, with authority, to other doctors and to the IT experts about what is really needed. But this culture has not been embraced by all, particularly amongst IT specialists who can be isolated from the medical issues.

Taking into consideration the current issues and the future requirements of the sector, the *WAVE* project team posed the following questions:

- Should IT be centralised or remain decentralised?
- What functions would a centralised body undertake?
- What is the current central capacity and capability?

The *WAVE* Board concluded that a cohesive framework is required to ensure:

- Funds for IT are allocated to maximise the alignment of IT spending to health goals;
- A wider perspective is taken as IT assists the whole sector (rather than individual providers) in providing health, organisational and administrative services;
- Benefits for all are not lost by the inability of any one part of the sector to participate; and
- Adequate information to improve benchmarking and quality; for example, individual clinician profiling.

The sector needs to get smart. Where should it co-operate and act centrally (through standardisation and integration) and where should appropriate variety be allowed? Clearly, DHBs that bear the change and people costs of any system should take responsibility and ownership for it. The following would be a start:

- Developing standards for assessing and measuring IT spending against clinical and organisational objectives;
- Developing a central set of initiatives for common services, thereby realising benefits which might otherwise be too expensive;
- Facilitating a multi-skilled Reference Group to represent the sector on drivers and corresponding investment;
- Establishing an investment business case (weighted clinically, operationally and financially) which provides incentives for collaboration; and
- Introducing centralised (or clustered systems) to support core functions to help economies of scale.

### **Possible gains from collaboration**

Collaborative efforts, initially regionally but potentially nationally, are estimated to produce savings in the ranges indicated below. E-purchasing (particularly) and shared services (occasionally) have been adopted internationally because of their efficiencies and corresponding cost savings. Centralised (or regional)

initiatives are candidates for outsourcing or shared services because they are transactional in nature. These changes would allow DHBs to concentrate on areas creating more value (eg: clinical systems) rather than concentrating on transactional processes, converting largely fixed cost business into variable cost. We set some estimates out in the table below to trigger thinking rather than as firm estimates; appropriate analyses would be needed to support any of these initiatives.

Centralised visibility of impending initiatives will also provide an opportunity to identify possible 'beacon' sites, or projects for regional or national co-operation, and the sharing of resources in collaborative projects.

Area	Type of Saving	Indicative Savings
Central back office function	Out-sourced back office management, eg: purchasing (e-procurement is recognised as a potential mechanism for substantial savings)	\$ 5 — 25 million
Central digital radiology purchase	Implementation, licence, support & network costs	\$ 1 — 5 million
Central payroll	Licence, implementation & support costs	\$ 1 — 2 million
Central alerts/adverse drug reactions database	Software licence & support savings, savings in mis-prescribing	\$ 2 million
Central costing	Savings in licence, support & compliance; allows better benchmarking	\$ 2 million
Cluster Microsoft agreement	Savings in software licence & support	\$ 1 million
Common hardware	Central buying agency (not compulsory) Savings in hardware & support costs	\$ 500,000
Telephone & network bulk contract	Line rental across the sector, including mobiles	\$ 500,000
Benchmarking	Better sharing of resources, minimising duplication	\$ 200,000
Subscription management	Savings in annual subscriptions for health journals & publications through central negotiation	\$ 200,000

## Development Plan

An information organisation should be established to co-ordinate the selection, implementation and review of IT investment, to be responsible for:

1. Developing a framework of investment drivers ranking priorities according to health and disability improvements;
2. Facilitating sector co-operation in IT spending and systems acquisition, focusing on priorities and efficiency;
3. Facilitating project teams to implement new IT systems;
4. Providing a repository for IT project management, implementation (including IT-related process re-design) and post-implementation audit expertise;
5. Developing a common budget framework to allow consistency of reporting, visibility of activity and benchmarking;
6. Helping practitioners with low IT literacy levels;
7. Supporting and facilitating development of Māori IT capacity; and
8. Ensuring the IT needs of the primary providers are understood.

WAVE also proposes specific action on e-procurement, with direction to the sector to adopt a single system within 12 months.

## WAVE recommends within 12 months

76. Establishing an organisation to facilitate and lead co-ordinated development of health sector IT spend;
77. Consolidating a sector wide Information System Strategic Plan (ISSP), against which future DHB ISSPs can be developed;
78. Developing benchmarking of IT investment performance;
79. Establishing common templates for ISSP and business plan initiatives;
80. Co-ordinating implementations between hospitals and primary care;
81. Re-examining the DHB ISSPs in line with the IT strategy and DHB business plans and drivers;
82. Directing the information organisation to identify opportunities for implementation and standardisation with an increased focus on patient support across the sector; and
83. Implementation of a single e-procurement system.

### What Are Other Countries Doing?

Different countries are at different stages in their IT strategies, but a common theme is emerging - collaboration. Britain's NHS strategy<sup>55</sup> refers to the "integrated local implementation of national strategy" and uses the concept of 'beacon' sites for implementation of EHRs. Singapore's Eastern cluster (representing approximately 50% of their tertiary providers) has adopted common systems and is considering developing a shared services support group. Closer to home, Queensland Health is halfway towards implementing its five-year regional IT strategy using a central point for co-ordination and standards. It has 39 health districts divided into three similarly sized zones; until 2 1/2 years ago each district managed its own information system infrastructure but now there are central strategy and collaborative project teams acting as beacon sites for new initiatives.

*"A state level system is achievable and sustainable and NZ is similar in population size to Queensland. The economies of scale and ability to leverage investment and contracts are much more effective. You also create a network of talent with a strategic focus and cohesive direction." Anton Donker, Chief Information Officer, Queensland Health.<sup>56</sup>*

New South Wales encapsulates its policy in the principle of ensuring "capital investment is soundly based on service need and cost effective use of capital resources." Lead sites have been established to implement best practice in clinical information management, with a drive to build the health system's capacity and for staff to undertake benchmarking for performance improvement.

This collaboration has manifested itself in different forms. Strategies in Britain, Queensland and New South Wales discuss the consolidation and rationalisation of back-office systems but have focused on achieving this by regional or clustered initiatives. In Queensland, a state-wide pathology system has been implemented. New South Wales has a central initiative to make health journals and publications available to providers via the Internet. Queensland is rolling out a state-wide digital radiology project.

All these examples feature 'beacons' - sites that pool resources and budgets to implement and test the effectiveness of a solution, before rolling it out to other sites, rather than undertaking individual initiatives. This avoids repeating mistakes, provides economy of scale and the sharing of knowledge and resources.

While some countries are further ahead of New Zealand, many do not have central patient index capability or a national minimum data set. New Zealand is significantly ahead in central patient master indexes, giving the advantage of a common framework and view of patients on which to build collaborative initiatives.

<sup>55</sup> "Information for Health" - An Information Strategy for the Modern NHS 1998 - 2005, NHS Executive, 1999

<sup>56</sup> Teleconference, WAVE investment team with Anton Donker, April 12, 2001

## 8. Organisational Design - *building capability*

### Introduction

Quality health care delivery requires quality national systems. The health sector found it difficult to complete the *WAVE* project because some competencies are simply missing; for example, there is little experience in using the IT that assists other sectors to achieve significant quality and productivity gains. Some attempts have been made to co-ordinate systems at the sector level, but there is no sector reference point for leadership and guidance through which organisations can plan and co-ordinate their investments.

The health sector lacks any capability to co-ordinate, implement or design a coherent national information system. Different parts of the sector saw different bits of the issue, just like a myopic man staring at an elephant. If New Zealand does not get it right now, if it continues to focus on short-term fixes, then the problem will simply reappear. It is imperative to make some key decisions now, to establish an underlying capability to facilitate the evolution of ideas, providing a framework within which the sector can plan, implement and operate. National leadership, able to anticipate and respond to these needs, is vital if the sector is to deliver effective and efficient services.

Information systems are essential for decision-makers to make confident and transparent service delivery decisions. If these tools are flawed, inadequate or dysfunctional, then so will be the services. New Zealanders have high expectations that national systems will be run by well-managed and well-designed organisations. Any proposed change must not make matters worse - just like the medical requirement 'first do no harm'. Clear benefits must be needed before changing the current situation, given the sector concern about re-structuring and the inherent risks in organisational change.

### **Do it now, do it quickly, or we'll do it again**

The *WAVE* Board firmly believes the sector will be writing another large-scale sector information strategy in five years' time (listing the same deficiencies identified in past and current information plans) unless the key issue of sector capability is dealt with resolutely. Every *WAVE* work stream independently identified this area as the key problem, and the *WAVE* Board believes this recommendation is the key to ensuring the other recommendations can be progressed satisfactorily.

In the past there has been mixed success in implementing information initiatives in an attempt to knit the sector together. The Mental Health National Information Collection (MHNIC) is being rolled out; when completed it will provide a comprehensive statistical database containing clinical and service usage details so policy makers, researchers and the general public will know which services are being delivered to which groups, and where. By contrast the NPI (signalled in the 1996 Health Information Strategy) has languished. Fragmented effort means duplicate systems have been implemented which do not easily talk to each other, often reinventing what had been developed elsewhere, with no advantage.

There is no magic wand to fix the problems *WAVE* has identified. It is important the sector remains respectful of the nature of clinical enquiry. There is no instant (and inappropriate) American cookbook solution to resolve the issues. Once the system is operational, users will not have a homogeneous approach. A database may start with 15 dimensions, but once the Clinical Director starts using it, in a few years it may have 50 dimensions. This means an evolutionary, evidence-based, learning approach is needed in the development of systems.

At the bottom level we need people to set the technical standards, in a democratic way (rather like the international conventions on HL7 standards). At the middle level we need data sets (with input on their requirements from the doctors and nurses who will use them most). At the top level we need the eventual risk takers (Ministry of Health, ACC, DHBs) to make decisions about what information to collect - and what to ignore. Ultimately it will be the Minister and the Ministry that facilitate this, because the drive to establish sound knowledge systems is in the public interest.

### Do it with intent - over time and with money

It is imperative the sector starts thinking about its people and systems investments on a continuing basis. Just last year, money was stripped out of the Health Funding Authority's team. Similarly NZHIS<sup>57</sup> has lost most of its senior staff. 10 years ago NZHIS had an applied research team and a library that was considered a sector asset. Health Benefits has been criticised for focusing too much on claims and payments processing, and not enough on providing essential primary care information. Health Benefits is shifting to focus on information, and is automating significant elements of its processing, but the money saved from reductions in administration is likely to be swallowed by service deficits when it ideally should be directed to proactive systems modernisation. Organisations such as ACC have simply got on and made it happen, but with some friction due to a lack of a co-ordinating framework.

New challenges include the requirements of the NZ Health and Disability Act directing the sector, including DHBs, toward co-ordinated care initiatives. This direction is reiterated in the NZ Health Strategy and NZ Primary Health Care Strategy. A corollary of this strategic direction is the need for high performing information systems, and their associated organisations. Information user requirements will grow (with increasing sophistication) with the devolution of funding and purchasing to the DHBs, the shift to integrated and evidence-based care, the exponential growth in knowledge, rapid advances in technology and increasing consumer demand.

## Current State

The WAVE project team reviewed the way national services are delivered by the three information sections of the Ministry of Health<sup>58</sup> - Health Benefits (HB), Shared Services Support Group and NZHIS. Their services range from collecting, processing and disseminating health and disability information to administering contracts and processing subsidy payments.

At present, HB, SSSG and NZHIS are effectively one organisation with three semi-autonomous divisions.

<b>Health Benefits</b>	Reimburses providers (mainly GPs, midwives, laboratories, pharmacies) for government subsidy claims. It pays 15,000 providers about \$1 billion over 60 million transactions per year.
<b>Shared Services</b>	Has similar capability but pays to mental health and disability support providers. Also pays on bulk contracts negotiated by HFA with Primary Health Organisations and Hospitals. Maintains recording software contract for Ministry of Health & DHBs. 7,000 active contracts.
<b>NZHIS</b>	Produces statistics from collections held - inpatient hospital discharges, cancer registrations, causes of death & health workforce profiles. Also NHI, Medical Warning System on-line, the fledgling Mental Health Information National Collection (MHINC), National Booking Reporting System and ex-HFA funded primary care warehouses. Pharmhouse (pharmaceutical claims repository) is the best-known warehouse with over 265 million rows of data. NZHIS also maintains batch validation capability for these data collections.

<sup>57</sup> New Zealand Health Information Service

<sup>58</sup> NZHIS has been a separate business unit of the Ministry of Health for years. The incorporation of the Health Funding Authority (HFA) into the Ministry in late 2000 meant Health Benefits and the Shared Services Support Group became part of the MoH.



Each organisation provides call centre/help desk functions and maintains in-house data functions including system operators, programmers and analytical staff. All use contractors to supplement their permanent staff.

## Issues and Debate

NZHS, HB and SSSG are all information processing agencies sharing generic competencies (adding value to raw information, with substantial investments in the required technology and management infrastructures) but with distinctive differences in intellectual capital. Payment functions overlap between HB and SSSG (both process transaction payments using computer systems with similar capacity) and there are overlaps where SSSG and HB both collect primary care data, and SSSG and NZHS collect monitoring data from hospitals.

None of the organisations has been able to take a lead role in the development of *WAVE*, and all have been stretched to provide even minimal levels of support. All lack the capacity to analyse data - most acutely in NZHS where the competency is most critical. Sector leadership of information management is the most pressing issue. There is no clearly defined authority to take responsibility for strategy and no vehicle to move it forward. The result has been a slackening of momentum and lost advantage. This is in stark contrast to significant efforts in other countries; for example, Britain, Canada and Australia (both at the federal and state levels) have all developed comprehensive information management plans.

### **WAVE findings point to:**

- **Lost opportunities:** Existing strategic gains are not fully utilised; for example, NHI is a valuable national and strategic asset, but it is not fully utilised. A primary care data dictionary was planned and never implemented. The proposed National Provider index has languished. A potentially, mutually beneficial relationship with the medical software industry is undeveloped.
- **High transaction costs and lack of connectivity:** The independent operation of organisations has been unnecessarily expensive, with unacceptably high connection costs; yet even if they connected successfully, little of use would be transferred. Building up systems to bridge organisations is time consuming, costly, and usually unsuccessful so isolated islands of data still dominate the sector.
- **Loss of efficiencies through lack of attention to standards development:** Proprietary (non-open) standards have developed, development effort has been duplicated and systems are not easily capable of inter-operability.
- **Uncertain funding cycles and unco-ordinated investment:** No information agency has had a secure development path linked to a health strategy. Information agencies have been regarded as vehicles to disinvest, instead of part of the sector's core capability. Systems and applications have often been launched, without integration and in a wasteful manner. The result has been loss of organisation competencies, lack of development of new competencies and overall loss of sector momentum.

## Future State

The *WAVE* Board initially considered a single organisation to take advantage of the obvious synergies in data centre resource management and transaction validation, providing a 'one stop' shop for the sector and public. After rigorous debate (taking into account stakeholder risk from functions like payment systems, the national nature of the customer base for services like statistical analysis services and the 'public good' component of systems like the NHI), it was decided a two-organisation model provided a better fit for the services the sector requires.



The WAVE Board is clear on the two most immediate steps, reaching consensus that there should be two organisations:

1. A transaction-based, DHB-owned merger of the payment and claiming functions of SSSG and Health Benefits.
2. A sector-focused, co-ordinating organisation, established as a Crown-owned entity, to set data, privacy and systems operability standards for the sector, and to co-ordinate overall sector investment. WAVE is not talking here about function, investment approval or monitoring but of sharing sector knowledge and facilitating common approaches (eg: e-procurement).

There are immediate efficiencies and possible further shared service benefits from a national shared services organisation. Efficiencies could be gained by merging HB and SSSG because of their overlapping roles in managing operational payment systems. The new organisation would combine the back office functions currently carried out by HB and SSSG (contract administration, payments, audit and monitoring), giving potential to reduce the duplication of hardware and operational management overheads. This would give possible future opportunity for further efficiencies in the areas of DHB payroll and the PMS system.

These organisations, recently wound into the Ministry of Health after the demise of the HFA, should be unwound from the Ministry and merged. DHBs should take ownership of the organisation to control the transaction processing functions supporting their core business functions. Linking the governance structure to those most at risk (from failure of the organisations) provides an incentive for strong performance. A Board (approximately eight nominated DHB members) would govern the organisation and the Ministry of Health would have a role on the Board at least during the transition phase of devolving responsibility to DHBs.

The second (and more important) step is to establish an organisation responsible for on-going leadership, governance and development in the field of health sector IM and IT. A capability and competency needs to be established beyond the current levels and management of that competency, and its effect, or lack thereof, needs to be visible, and managed by all those affected by it in the sector.

This list of challenges is formidable but, above all, the organisational architecture must address three key requirements:

- Strong governance and facilitative leadership;
- Sector buy-in; and
- Responsiveness to sector needs and the Government's strategic objectives

#### **The WAVE Board agreed:**

- An organisation design response is needed, otherwise New Zealand is unlikely to make progress;
- A wider and more active involvement of stakeholders is needed;
- A Crown entity (ie: something substantially more than an Advisory Board or a committee) would be the best structure; and
- Its core function will be to facilitate the structures and standards for inter-operability in the sector.

The *WAVE* Board felt strongly that this organisation needed to be independent of the Ministry and governed by a board of directors drawn from sector stakeholders, to facilitate sector buy-in, provide transparency of funding and outputs and allow the information users some control. The organisation would be expected to give the key ingredient of sector leadership on health information that the Advisory Board feels is currently missing. Further, it would work to ensure compliance with promulgated standards, as well as facilitate development and implementation.

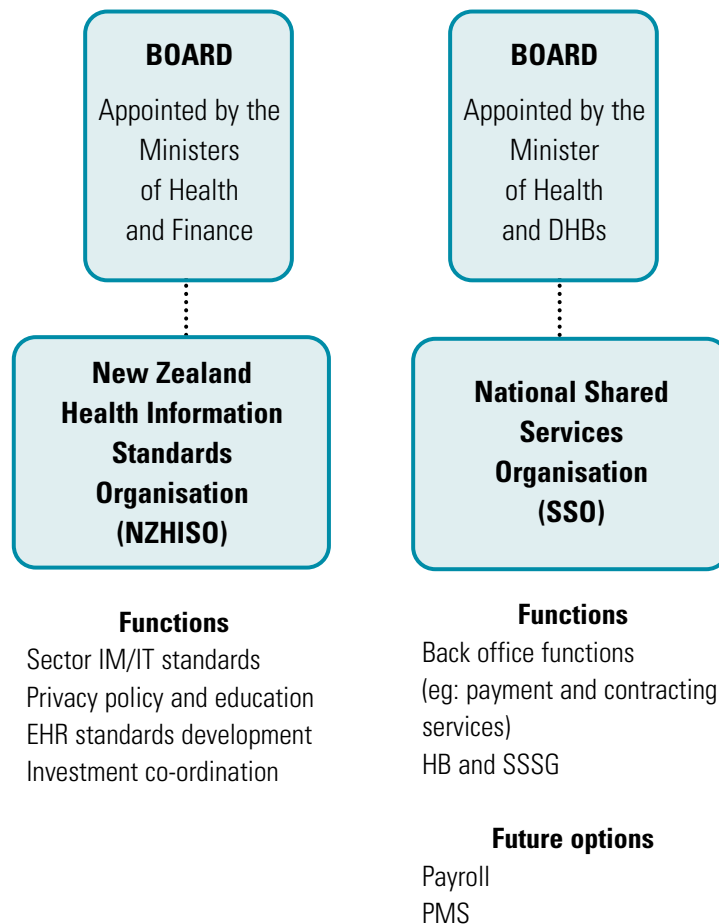
### New Zealand Health Information Standards Organisation

The second organisation *WAVE* proposes is designed to represent the sector's interests in the development of standards, and sector IM/IT policy and planning.

Governance is important - the leadership role needs to be able to work outside the bounds of the existing institutions, between the different stakeholders, and in concert with the overall direction of the sector. In institution design terms, this is a 'club' problem, as all need to buy-in and participate for each to get full benefit.

The task is critical - the organisation will be asked to deliver on the health information policy and implementation necessary to support the aims of the New Zealand Health Strategy - systems and data standards (such as the introduction of a unified security framework), development of electronic health records and co-ordination of sector investment, to find the best path to convergence in a highly complex, diverse sector. It would also facilitate and drive implementation. Clearly, also, the organisation be strongly linked to any health quality initiatives - information being crucial to quality.

#### INFORMATION ORGANISATION MODEL



## WAVE recommends

85. Two new organisations should be established:

- A Shared Services Organisation (SSO)
- A Health Information Standards Organisation (NZHISO) to determine sector IM/IT standards

86. Both organisations should be Crown entities

87. The organisations should be governed as follows:

- SSO - by a Board appointed by DHBs and the Minister of Health
- NZHISO - by a Board appointed by the Ministers of Health and Finance

88. Functions of the NZHISO would include:

- Sector standards, specifically to establish, review, implement and ensure compliance with agreed standards. The scope would include standards related to:
  - IM/IT, including related privacy standards
  - EHRs, including investment management

89. The Ministry of Health would maintain the following functions:

- Reporting and monitoring including NZHIS, NZHS (including tool kits), and reporting to Parliament
- Population-based funding formula policy and funding systems
- The Cancer Registry
- The National Screening Unit, with responsibility for the governance, monitoring and reporting on population screening programmes and associated information systems
- National data warehouses
- National Minimum Data Set (NMDS), Medical Warning System (MWS), NHI, NPI
- National frameworks

**Note:** The SSO would maintain payment and contract management systems.

90. The primary mode of operation of the NZHISO should be through:

- Working groups comprised of relevant mandated contributors
- The Ministry, DHBs, provider contracts and payments

91. The primary revenue of the organisations would be:

- SSO - from DHBs and the Crown, to the extent it acts as a DHB
- NZHISO - from the Crown, reflecting the public benefit involved

## 9. Summary of Recommendations

### Treaty Implications

1. Collection of reliable ethnicity data;
2. An annual audit of ethnicity data in health information systems;
3. Establishing a reliable baseline for Māori IT workforce capacity in the health and disability sector; and
4. Promotion of integrated health information systems.

### Strategic Setting

5. The sector's primary goal must be the integration of health information systems;
6. Its secondary goal must be to ensure on-going continuity and governance of health IM/IT from a sector perspective;
7. The top 10 priorities are:
  - Set up an independent organisation to lead IM/IT capability
  - Collect reliable ethnicity data
  - Implement the NPI
  - Fix up the NHI - allow primary provider access, improve ethnicity data
  - Gather primary care information
  - Fix up pharmacy and laboratory data and provide primary care with access
  - Clean up messaging standards
  - Sort out Health Event Summaries - with data dictionaries, electronic discharges and referrals
  - Launch health portal
  - Make integrated care work by: developing standards for data exchange, security & network infrastructure; and
  - DHB business plans must reflect the implications of *WAVE*.

### Knowledge

9. Immediately improving access to currently available medicines information (the Pharmaceutical Schedule, medicine data sheets, Consumer Medicines Information that are available on-line already);
10. Developing a common interface to simplify user access to the electronic information sources currently available, ie: a health portal available on all providers' desks;
11. Systematically making available the collected data so current practice can be verified against guidelines, the information could be used for research, planning, benchmarking and for the introduction of quality improvement programmes;
12. Developing and introducing a national formulary (including an electronic prescription ordering system, best practice prescribing, cost, and NZ-specific guidelines);
13. Enabling bibliographical database access for all health providers, using the newly established DHB/Ministry of Health library consortium as a pilot to study the implementation and benefits of providing access to the four major databases: Medline (biomedical), CINAHL (nursing and allied health), Psycinfo (mental health) and Evidence Based Medicine Reviews (EBMR, which includes the Cochrane Library);

14. Establishing a risk / benefit-based framework of analysis for future investment in knowledge systems and ensuring it links closely with quality improvement in the sector;
15. Establish the organisational capability to facilitate the growth and management of data sets from a wider perspective than current efforts; and
16. Establishing a central body to exercise leadership, to drive the standards setting and governance functions (including design, implementation, promulgation) necessary to implement and order future environment.

**Recommendations 15 & 16 were made by all the work streams**

## Electronic Health Records

17. DHBs should implement capability for connectivity between hospital and health care providers including that for electronic exchange of Referral Letters and Discharge Summaries and other useful information (eg: emergency department attendance notifications) between hospitals and healthcare providers, within two years;
18. Developing standards for the transmission of Health Event Summaries (HESs) between providers over the next six months, based on the existing Referral and Discharge letter standards, commencing usage within 12 months; with roll out completed within three years;
19. Giving priority to the immediate development of necessary standards and some live implementation of disease management programmes;
20. DHBs should document their commitment to Recommendations 17 - 18 in strategy and accountability documents, demonstrating consistency with the 13 priorities in the NZ Health Strategy;
21. Supporting and encouraging GPs not currently using electronic clinical record software to do so within the next 12 months;
22. Encouraging hospitals to implement clinical data repositories or an integrated clinical interface within three years;
23. Developing DHB implementation plans for the above within three months;
24. Adopting HL7 v3 as the underlying structure for HES; and
25. Ensuring there is organisational capability to develop EHRs in the health and disability sector.

## Data Architecture

26. Adoption of the Health Level Seven (HL7) version 3 standards for data models and XML messages;
27. Implementation of the NHI, including collecting ethnicity data;
28. Improving the quality of NHI databases, and ensuring the NHI is included in major information flows;
29. Completing the NPI definition and ensuring it is used by all major systems and included in data collections;
30. Implementing coding standards for primary care diagnoses (READ or its successor), procedures, and treatments; laboratory tests and results (LOINC); a pharmaceutical index; outpatient diagnoses and outpatient services;
31. Improving the quality of existing data collections, especially the quality of ethnicity data;
32. Filling the gaps in the existing collections;

33. Creating new data collections where needed, starting with outpatients, emergency departments, and primary care consultations (for key disease states);
34. An on-going rolling review of all data sets every six months, to ensure continuous improvement;
35. Data collections must be a suitable standard and quality, and be accessible for DHBs and providers to gain information to improve the quality of health care; and
36. Data collection should be more readily accessible for research purposes.

## Privacy

37. Completing an initial awareness campaign for patients about the purpose and use of health information, by December 2001;
38. Running an awareness campaign on the NHI, by December 2001;
39. Considering development of a Code of Practice (under the Privacy Act), specifically dealing with the NHI number;
40. Progressively testing health information flows and collections (including national data collections and screening programmes), existing and proposed, against the privacy legislation and the six Caldicott principles;
41. Implementing education programmes to reinforce awareness of privacy issues, including confidentiality and security requirements;
42. Progressively developing guidance and resources to help agencies make decisions about the management of information about identifiable individuals;
43. Developing and implementing web-based privacy audit tools;
44. Building a supporting network of Privacy Officers to assist health organisations (large and small) to learn from each other, and to benchmark performance on the management of privacy;
45. Developing the organisational capacity to manage privacy issues proactively;
46. Developing protocols to protect the exchange of information between different providers, and between providers and third party agencies (such as funders, researchers and policy makers);
47. Using provider (rather than patient) information wherever possible and facilitating this with introduction of the NPI;
48. Undertaking further consumer consultation (possibly through a national workshop, but also through a continuing programme of applied research); and
49. Giving consideration to establishing a consumer advisory board to ensure on-going acknowledgement of consumer interests in privacy-related matters.

## Systems Infrastructure

50. A single health portal as a gateway for access to national healthcare information systems;
51. A unified security framework, with an initial, voluntary policy document to be produced in three months, covering all aspects of security;
52. Six monthly reviews and upgrading/ tuning of the framework based on feedback from application;
53. The encryption of personal health information in transit, to 128 bit standard;
54. The introduction of digital certificates in a manner which avoids practitioners needing more than one;
55. Beginning discussions with professional registration organisations to link digital certification with registration;

56. Voluntary use of Virtual Private Networks;
57. Actively encouraging new entrants to the VPN market and so create an environment of multiple competing networks;
58. Maintaining existing multiple funder systems (ie: ACC, Health Benefits, etc) but rationalised over time (eg: claim and payment processing), accessible through the national health portal;
59. The NHI with direct access to sector participants controlled by portal-based access control rights;
60. A NPI established as a single directory service, for use in authentication, network message handling, and data warehousing, with delegated registration and maintenance functions to relevant bodies;
61. The integration of national data warehouses, linked by an NPI and the NHI; and
62. The use of XML-based HL7 v3 standards for messaging.

## Investment

63. Establishing an organisation to facilitate and lead co-ordinated development of health sector IT spend;
64. Consolidating a sector wide ISSP, against which future DHB ISSPs can be developed;
65. Developing benchmarking of IT investment performance;
66. Establishing common templates for ISSP and business plan initiatives;
67. Co-ordinating implementations between hospitals and primary care;
68. Re-examining the DHB ISSPs in line with the IT strategy and DHB business plans and drivers;
69. Directing the information organisation to identify opportunities for implementation and standardisation with an increased focus on patient support across the sector; and
70. Implementation of a single e-procurement system.

## Organisational Design

71. Two new organisations should be established:
  - A Shared Services Organisation (SSO)
  - A Health Information Standards Organisation (NZHISO) to determine sector IM/IT standards
72. Both organisations should be Crown entities;
73. The organisations should be governed as follows:
  - SSO - by a Board appointed by DHBs and the Minister of Health
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74. Functions of the NZHISO would include:
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75. The Ministry of Health would maintain the following functions:
  - Reporting and monitoring including NZHIS, NZHS (including tool kits), and reporting to Parliament
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  - The Cancer Registry
  - The National Screening Unit, with responsibility for the governance, monitoring and reporting on population screening programmes and associated information systems



- National data warehouses
- NMDS, MWS, NHI, NPI
- National frameworks

**Note:** The SSO would maintain payment and contract management systems.

76. The primary mode of operation of the NZHISO should be through:

- Working groups comprised of relevant mandated contributors
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- SSO - from DHBs and the Crown, to the extent it acts as a DHB
- NZHISO - from the Crown, reflecting the public benefit involved.

*Kaua e waiho ki te rā raumati - 'Don't leave it until summer'*

# WAVE Advisory Board



*WAVE Advisory Board (Back Row, from left): Tai Kake, Karen Guilliland, Robert Logan, Gwen Tepania-Palmer, Gregor Coster, David Clarke, Paul Cressey; (Front Row, from left): Debbie Chin, David Caygill, Syd Bradley, Murray Jack, Ross Black (absent: Bruce Gollop)*

**David Caygill (Chairman)** was an MP for 18 years and held a number of ministerial portfolios, including Minister of Trade and Industry ('84-'88), Minister of Health ('87-'88) and Minister of Finance ('89-'90). He was Deputy Leader of the Opposition ('93-'96). David returned to the legal profession after his retirement from politics in '96 and he is now a partner in Buddle Findlay, specialising in public law. He has a number of other roles, including chairman of the Accident Compensation Corporation. Last year David chaired the Ministerial Inquiry into the Electricity Industry.

**Ross Black** is chairman of Otago District Health Board, and director of Heart Surgery South Island Ltd and PHARMAC. He also chairs the advisory board of Health Benefits (formerly Health Benefits Limited), the Otago Emergency Air Ambulance Trust, Farra Dunedin Engineering Ltd and is a trustee of the Healthcare Otago Charitable Trust. He specialises in the effective leadership and governance of businesses / public organisations.

**Syd Bradley** was a director of the Canterbury Area Health Board ('89-'91), director of Healthlink South ('92-'98) and Healthcare Otago ('98-'99). He chaired Healthlink South Ltd ('96-'98), Canterbury Health Ltd ('97-'00) and the Health Funding Authority ('00). He chaired the Crown Health Association representing public health and hospital services ('98-'00). He was appointed Chairman of the Canterbury District Health Board in January 2001. He is chairman of the Christchurch International Airport, deputy chairman of NZ Post Ltd and chairman of Waipara Hills Wine Estate Ltd.

**Debbie Chin** is the Deputy Director-General of Corporate and Information Services at the Ministry of Health. She was formerly a partner at KPMG, which included a four-year secondment to the Department of Prime Minister and Cabinet, covering health and ACC. Debbie was a member of the National Health Committee from 1999-2000.

**David Clarke** has been with South Auckland Health since '93, first as Chief Financial Officer, then Deputy Chief Executive, then Chief Operating Officer. For the past four years he has been Chief Executive Officer of the newly renamed Counties Manukau District Health Board. He chairs Health Alliance Ltd and is a director of the NZ Institute of Management.

**Gregor Coster** is professor and head of General Practice, and Primary Health Care at the Auckland School of Medicine. Previously he has been a director of the Health Funding Authority and chairman of the Royal NZ College of General Practitioners. He is a member of Counties Manukau District Health Board and a director of PHARMAC. He recently wrote a paper for the Ministry of Health "Health Needs Assessment for NZ: Background Paper and Literature Review" to assist District Health Boards.

**Paul Cressey** is managing director of EastHealth Services Ltd, chairman of the Health Intranet Governing Body, chairman of Ronald McDonald House (Auckland) and a past chairman of the Child Cancer Foundation. He was a practising retail pharmacist for more than 20 years and has been both chairman and executive director in co-operative pharmaceutical wholesalers.

**Bruce Gollop** is a health management consultant and an occupational medicine specialist. He has been the acting chief executive of HealthCare Otago and general manager of Auckland Hospital, having been the Chief Executive of Northland Health from '93-'98. He was recently appointed Chief Executive of District Health Boards NZ.

**Karen Guilliland** is the National Director of the NZ College of Midwives, having been the founding president. She is deputy chairperson of the Health Workforce Advisory Committee and a director of PHARMAC. Karen is an elected member of the International Confederation of Midwives London-based executive council and its accredited representative to the UN Economic Commission's Bangkok office.

**Murray Jack** is Deloitte Consulting's public sector and health care industry practice leader for the Asia-Pacific-Africa region. Murray has significant experience in the health sector having directed several technology strategy projects and advised on the establishment of the NZ Health Information Service. Murray focuses professionally on technology management, development of tech-based services, outsourcing and the use of technology in government, health care and utilities.

**Tai Kake** is of Ngapuhi (Ngatihine-Ngatihau) descent and his marae is Pehiaweri at Tikipunga, Whangarei. He completed a Bachelor of Science with First Class honours in psychology at Victoria, then took up a research fellowship at the Wellington School of Medicine. In '99 he accepted a research fellowship with the International Cochrane Collaboration, based at the Ministry of Health. Tai is now manager for Research and Evaluation with the Alcohol Advisory Council.

**Robert Logan** has had a number of roles at Hutt Valley Health - specialist physician, cardiologist, service manager and, more recently, Director of Medicine; formerly he conducted cardiovascular research in Dunedin and Edinburgh. He has been a member of the Board of the National Heart Foundation and chairman of its Cardiac Care and Rehabilitation Committee. He is currently acting chairman of the National Health Committee, a member of the Timaru DHB and chairman of the NZ Medical Advisors Group.

**Gwen Tepania-Palmer** is descended from Te Aupouri, Ngati Kahu, (Ngapuhi) and Ngati Paoa (Tainui). Gwen has been a Health Research Council member, a founding member of the National Council of Māori Nurses, a mentor for the Māori Health Research Units and the Auckland University School of Medicine. Gwen is a member of the NZ College of Management.

**David Moore (Programme Director)** was formerly General Manager, Personal Health, Health Funding Authority; Director, Health Services for the Central Region, Transitional Health Authority; and the founding General Manager of PHARMAC. He continues as a PHARMAC Director. Before joining the health sector, David worked for The Treasury; Buttle Wilson & Co (now UBS Warburg NZ); Morrison & Co; and, in London, Deloitte Haskins & Sells (management consultancy division). David is of Ngai Tahu descent.

# Glossary

ACC	Accident Compensation Corporation
CDSS	Clinical Decision Support System
Clinical Data Repository	In a hospital this is a repository for clinical data from the various departmental systems or a data warehouse, which provides access to a patient's health information through a single log in. In primary care it is patient management or a clinical notes system, which holds information indexed by individual patient. A hospital can also construct a repository by putting a browser over the top of existing systems. Also called Electronic Medical Record.
DHB	District Health Board
Discharge Summaries	A clinical note summarising the care of a patient about to be discharged after an inpatient stay in a hospital, sent to a primary care provider who will need the information to carry on the care of the patient. Discharge Summaries may contain structured and free texts, clinical images where relevant/required and the results of investigations and new drugs prescribed.
DSS	Disability Support Services
EHR	Electronic Health Record. An electronic longitudinal collection of health information, based on the individual patient, entered or accepted by health care professionals, which can be distributed over a number of sites, and in a number of settings. The information is organised primarily in support of continuing, efficient and quality healthcare. The record (or records) is under the control of an agreed access policy. Information does not form part of the health record until a health care professional has taken responsibility for it and entered it into the record. The data is typically stored in a single clinical data repository at each site.  An EHR exists when a health care provider accesses health information from a clinical data repository(s) or a single national server, or multiple distributed servers, where the health information is stored, for information on their patient's health history. A longitudinal history is incrementally created for the patient as more health information is provided to this/these servers.
GEHR	Good Electronic Health Record
HB	Health Benefits
Health Event Summaries (HES)	A relatively new concept for providers, encompassing any clinical communication from one to another - in the course of the clinical management of a patient - summarising the patient's current care, which enables other providers to share in and co-ordinate the care. It must contain adequate information for the purpose. This definition includes the traditional referral and discharge letters, but includes a broader range of communications; including, for example, out patient letters. A complete definition of HES will encompass a wide range of possible variations and will develop as the concept becomes more fully embedded in clinical practice.
HES	Health Event Summaries
HIGB	Health Intranet Governance Body
HIMTP	Health Information Management and Technology Plan
HL7	Health Level Seven - internationally monitored standards for data supporting clinical patient care and the management, delivery and evaluation of healthcare services; to create flexible, cost effective approaches, standards, guidelines, methodologies, and related services for interoperability between healthcare information systems.

IPA	Independent Practitioners' Association
IPSec	Internet Protocol Security
ISSP	Information System Strategic Plan
IT	Information Technology
KMS	Knowledge Management System
LOINC	Logical Observation Identifier Naming Convention
MHINC	Mental Health Information National Collection
MWS	Medical Warning System
NHI	National Health Index
NHS	National Health Service (Britain)
NMDS	National Minimum Data Set
NPI	National Provider Index
NBRS	National Booking Reporting System
NZHISO	New Zealand Health Information Standards Organisation
NZHS	New Zealand Health Strategy
NZHS	New Zealand Health Information Services
Patient	Anyone who uses Health & Disability services, sometimes known as a client or customer
PHARMAC	Pharmaceutical Management Agency Limited
PHO	Primary Health Organisation
PMS	Practice Management System
Portal	Individually customisable desktop allowing the user to access multiple applications through one website
READ	Endorsed as the standard code for GPs
Referral Letters	A clinical note sent by a (usually primary) care provider to a specialist colleague (orthopaedic surgeon or cardiologist, for example) requesting assistance in the clinical management of a patient whose clinical condition is outside the GP's ability or resources. The contents of the referrals may contain structured and free texts, clinical images where relevant or required, along with the results of investigations to date.
RHA	Regional Health Authority, predecessor of Health Funding Authority
SSL	Secure Socket Layer, an internet protocol that defines the secure transmission of browser-generated data over the World Wide Web. It is widely used for credit card transactions. Secure sites usually are prefixed with 'https' instead of 'http'.
SSO	Shared Services Organisation
SSSG	Shared Support Services Group
VPN	Virtual private network, a private network configured within a public network
WAVE	Working to Add Value through E-information
XML	eXtensible Markup Language, designed for exchanging data across the Web, in a simple, human-readable form



# Contributors to *WAVE* project



*WAVE Core Team (Back Row, from left): Peter Aagaard, Tom Love, Chad Brown, Rebecca Blackmore, Simon Robb, Jana Faehnrich, Andrew Terris, Nigel Trainor, Elisabeth Harding (Front Row, from left): Amy Rountree, David Moore, Robbie Thomson, Phil Brimacombe (Absent: James Harris, Devon Diggle, Lesley Prest)*

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## **WAVE core team:**

Peter Aagaard, Rebecca Blackmore, David Moore, Simon Robb, Amy Rountree

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## **Data**

**Project Leader:** James Harris, Ministry of Health

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