

ORGANISING HEALTH INFORMATION IN AN EHEALTH ENVIRONMENT

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NATIONAL INSTITUTE FOR HEALTH INNOVATION

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1 The Health Meta-model

1.1 Introduction

It is becoming generally accepted that continuing to deliver healthcare to New Zealanders using today's model of care will, at best, become increasingly challenging and may, in due course, cease to be viable. Pressures from the growing shortages of clinical resource in a globalised market; spiralling costs and escalating patient expectations; the demographic march of an aging population; and the unrelenting rise up the health agenda of the chronically ill and the disadvantaged, all speak to the need to make changes to way healthcare is provided for our people.

New Zealand is not alone in facing these challenges; we march in step with other developed countries. However, where New Zealand once led, others are now showing the way. Nevertheless, there is a sense that we are at a moment in time when, through bold but considered decisions, we can make a step change in our ability to meet the challenges of today and tomorrow. We can bring to bear the innovative abilities of New Zealanders to adopt and adapt what we learn from others, in order to plot a path that is uniquely a New Zealand one.

This 'new way' is perhaps best articulated in the Ministry's Key Directions Primary Healthcare Strategy⁽¹⁾. The Strategy identifies the need to view patient care in an holistic fashion, with the removal of barriers between community, primary, secondary and tertiary care; the free movement of information across the continuum of care; the effective use of the technological tools that are now to hand; and most importantly the re-orientation of the provision of care so that the citizen/consumer/patient is at its heart. As Key Directions states:

"...from a patient point of view, we need to learn ways to see people in their cultural, social and physical contexts to better tailor care. People need to be empowered as they traverse the broader health system, and they need to be confident that they can access optimal care at each point of engagement."⁽¹⁾

The enactment of the Key Directions vision will encourage and empower people to more actively participate in all aspects of their own health and wellbeing, giving rise to the expectation of many individual and collective benefits:

- People will increasingly view their health holistically – not just in respect to illnesses and their treatment, but also wellness, lifestyle choices and with the inputs and support of their family and communities.
- People will have the opportunity of understanding more about their conditions, particularly chronic conditions, and become empowered and equipped with information and, in some cases, medical devices to actively participate in their own health monitoring and management.

- By empowering people in this way, scarce clinical resources, particularly primary carers, will be enabled to focus on the most pressing needs where their skills and experience can provide the maximum benefit.

Many drivers and challenges will need to be addressed if we are to make this journey successfully. The need for thoughtful and articulate leadership is clear. We need to enjoin all stakeholders – clinicians, managers, policy makers, suppliers and most importantly consumers - to be part of this movement and we need to understand how we can best provide the information that is needed across the continuum of health and the care it involves.

Progress along this path requires understanding of what we are doing, why we are doing it and what our expectations are in making this journey. At the request of the Ministry of Health, the National Institute for Health Innovation (NIHI) at the University of Auckland has carried out a research programme, which to paraphrase the brief from the Ministry:

‘provides conceptual advice on how to best organise health information, given our emerging objectives for eHealth. In considering the emerging objectives for eHealth, we have kept at the forefront of our minds the driver that we are reaching the limits of what we can achieve for chronic disease outcomes with a fragmented system. Addressing this driver calls for integration and, because of the nature of chronic disease, it also calls for more citizen co-production, i.e. moment-to-moment engagement of citizens in lowering their risk of disease, its progression, and living well with its presence.’

The review provides a meta-model for a healthcare system that is citizen-centric. The meta-model comprises a Conceptual Information Model, a set of Information Management Principles that will support the model and a Roadmap to enable its implementation. To develop the meta-model, NIHI has sought the views of key sector stakeholders and has researched what can be learned from the most relevant overseas experience.

The NIHI findings that are presented in this report provide a foundation stone that can be built on with further debate, investigation, analysis and practical experience in order to provide a better health system for New Zealanders into the future.

1.2 The Desired State

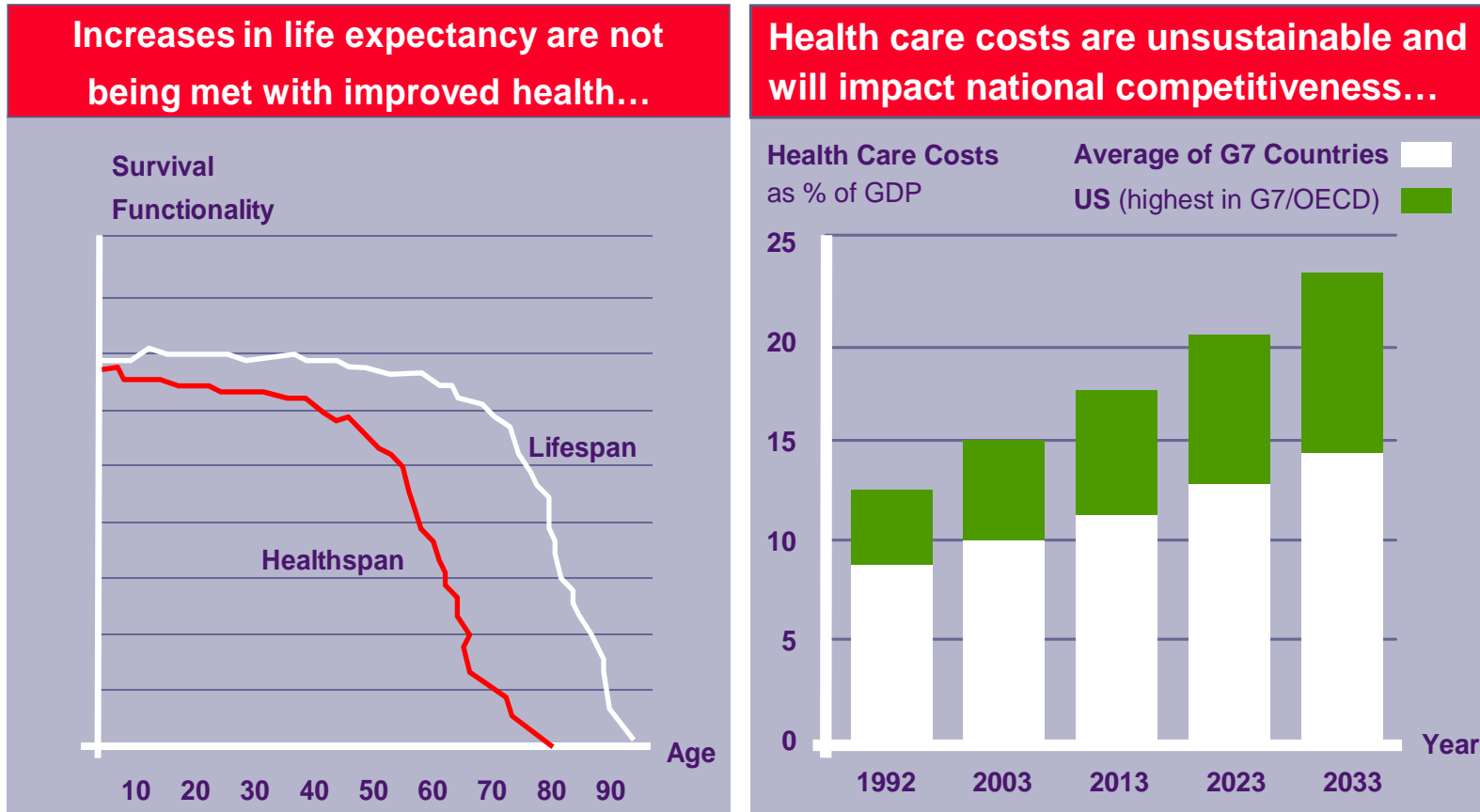
Context

New Zealand, in common with all developed countries, is facing increasing tension between the expectations of its citizens to have access to comprehensive and excellent healthcare services and the ability of the country to provide them. Among the many factors that are at play are:

- The increasing number of elderly as a proportion of the total population.

- The increasing prevalence of chronic disease caused by lifestyle choices and demographic factors.
- The globalisation of resources, with concomitant increase in costs workforce development and retention.
- Escalating pharma and technology costs implicit in treatment.
- Population distribution and cultural issues impacting equality of access.
- Access to information raising consumer expectations.
- A greater understanding of, and emphasis on patient safety.
- An increasing focus of the long term benefits of wellness focused lifestyle choices .

The two figures below provide graphic illustration of the challenges



Source: Pfizer, US Census Bureau

Source: OECD Data, Accenture

Figure 1: Health trends that are unsustainable

New Zealand's strategy to address these implied challenges is encapsulated in the Primary Health Care Strategy, Key Directions⁽¹⁾, and can be summarised as a re-orientation of the way we deliver healthcare. This represents not just a shift in emphasis from secondary to primary and community care, but an inversion of the traditional care landscape to place citizens at the centre. We will now seek to inform and empower consumers, to take a more active role in their health and condition management.

Empowerment

The concept of empowerment is central to citizen centric healthcare. The World bank defines empowerment as:

“the process of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes”

ICT harnesses much of its value through its capacity to leverage the collective power of human networks⁽²⁾.

An ideal health network should empower both individually and collectively, all its component stakeholders. It should facilitate the seamless connecting of relevant information between appropriate stakeholders, with each stakeholder adding value through their own specific expert synthesis, modelling and utilisation of the data.⁽²⁾

The leverage value of health ICT is afforded not just by connecting hospitals and GPs, but by recognising that citizens and their community of supports are central to the health network⁽²⁾.

Citizen centric healthcare, recognises that individuals and their community of supports are central to their own healthcare, and should be the central focus when developing a system that maximises leverage and empowerment, as described by the World Bank:

“Empowered people have freedom of choice and action. This in turn enables them to better influence the course of their lives and the decisions which affect them. However, perceptions of being empowered vary across time, culture and domains of a person's life.”⁽²⁾

Healthcare exists within a complex world of differing perceptions, needs, strengths, priorities and values. Utilising an empowered citizen centric model to help decide how we could best utilise health ICT, does not mean we do not recognise the complexities and realities of the system we currently work within. It does not mean we make the common mistake of trying to utilise technology to introduce or reproduce a rationality and uniformity that does not exist in the real world. It means that we utilise the model to help stimulate and structure our thinking as to how we would design a system that would increasingly place citizens and their communities at the centre, maximising their empowerment and ability to leverage the wider health network. One size or one style of empowered citizen centricity will not fit or suit all.

We will need to calibrate our responses to cope with different or evolving conditions and values with different solutions for different needs for different people at different times (3).

Factors arguing for this fundamental change in approach include:

- Mitigating the dependence on increasingly constrained clinical resources, by enabling citizens to better understand and manage their conditions.
- Enabling citizens to involve others - family, whanau, other communities of interest - in their wellbeing.
- Promoting the concept of team care, where clinicians and other allied professionals work collaboratively with the patient in the development of appropriate care plans.
- Providing to patients, particularly those with chronic conditions, the technology to measure and respond to changes in their condition.

An empowered citizen centric model implies that they will have the ability to access their own clinical and wellness data. Increasing access by consumers to their health data through 'health portals' such as Microsoft's HealthVault and Google Health, will facilitate and accelerate this movement. However, this increased empowerment of citizens does not imply that the current information pathways used between clinicians and between them and allied professionals will become redundant. Improving the provision of patient information across the continuum of care - being able to access with the appropriate consideration of the privacy and security of data, the right information, by the right care provider, at the right time - is still vital if we are to reduce medical errors, redundant processes and increase productivity.

These twin movements towards empowered citizen centricity and connected health are global movements. New Zealand is in some ways at the forefront of this movement, particularly in respect to primary care. However we cannot afford to continue to pursue an independent path. We must seek to adopt and adapt the learnings of other jurisdictions, to build our own tailored amalgam of good practice and to take advantage of what may, in retrospect, be seen as a moment in time when we can leapfrog ahead in the way we provide for the health and wellbeing of our citizens.

This review seeks to understand better the implications of these movements, to look at the principles we will need to adopt and to reflect on the experience of others, where they have ventured farther down these paths than we have yet in New Zealand.

2 The Development of a Meta-model

2.1 Overview

The Ministry of Health has commissioned Auckland University's National Institute for Health innovation (NIHI) in association with Philip Gandar from Synergia, to develop a reasoned provocation that envisions what this future healthcare model might be like and to propose the meta-model that represents it.

A meta-model can be defined as a heuristic set of propositions that challenge and expand people's existing models of how the world works, and how people think and talk about these models⁽⁴⁾. For this reason, a meta-model (rather than a model) has been developed – to support a step change to a more effective healthcare system in New Zealand and the way people think about health, that meets the changing health needs and demands of the country. The meta-model comprises a Conceptual Information Model, Information Management Principles, and an associated Roadmap.

The meta-model proposed by NIHI is an approach to looking at new ways of providing care, where a person (or patient or consumer) is empowered by being more informed and by having a greater ability to manage both their wellness and their health conditions.

NIHI has derived this meta-model through consultation with a wide range of stakeholders and a literature review of current practices within New Zealand and other jurisdictions. Real world vignettes have been created to illustrate and test how this citizen centric world might function. Information flows between all stakeholders have been demonstrated – clinicians and other care providers, citizens, their families, whanau and communities. Information Management Principles have been developed to support safe and effective application of the meta-model. A review has been conducted of what others have already done and are doing, to see what might adopted and leveraged to the New Zealand setting. Finally a Roadmap and an associated set of recommendations have been prepared that are aimed at taking us down the path of enacting the new vision.

2.2 Definitions

What does it mean to be '**citizen-centric**'? It means that the starting point is the person, rather than the healthcare system or healthcare professionals. As such, the term 'patient' (or 'consumer', 'citizen' or 'client') is only partially-appropriate; it is better to speak of a 'person' or an 'individual.' Moreover, in looking at the citizen, it becomes clear that we are interested in their social and environmental context, and their knowledge and their engagement, as well as their 'health record.' By extension, we need to recognise '**the family, whanua and communities of interest**' as potential stakeholders in the wellbeing of individuals.

In the context of chronic illness, a citizen-centric view incorporates each individual's experience of illness and the sense they have created around a life that they have adapted to their condition. Most significantly, 'citizen-centric' means the citizen is *in* the system (at its centre) – they have the first and most integral part in producing health outcomes. This stands in contrast to a view where the health system is something that acts *upon* patients.

With a citizen-centric perspective, we can consider informing and empowering patients. The Internet already provides more readily than ever before the opportunity to access generic health information (with some reservation in respect to quality control). With an '**integrated health information**' system, an individual's personal data can be made available. Data may not just include specifics about drugs, lab tests and appointments, but also more generalised lifestyle information about fitness programmes, diet etc. Appointments can be made electronically, informed choices can be made in terms of providers, and with the advent of '**secure email messaging**', initial consultations can be carried out electronically, removing the tyranny of time and place for both patient and provider.

Further extension of citizen-centricity enabled by technology lie in '**telehealth**', where consultations can take place using video technology to assist a remotely located clinician, and '**self management**', where chronic illness can be managed in domestic settings through the availability of measurement devices for vital signs and movement, connected to care providers, who can intervene where adverse events are detected. Patients are thus electronically connected (literally) to the full continuum of care.

This '**continuity of care**' in simplest terms, is the absence of fragmentation in information flow and resultant action. This can be envisioned in terms of five levels (see Figure 2: Levels of continuity):

1. Issue coherence – appropriate, informed action at a point in time.
2. Time continuity – coherence in approach to an issue over time.
3. Context continuity – appropriateness to social context of the individual (e.g., family, culture and community).
4. Setting continuity – appropriate action wherever needed.
5. Care network continuity – where there is trust among roles and functions and continuous quality improvement.

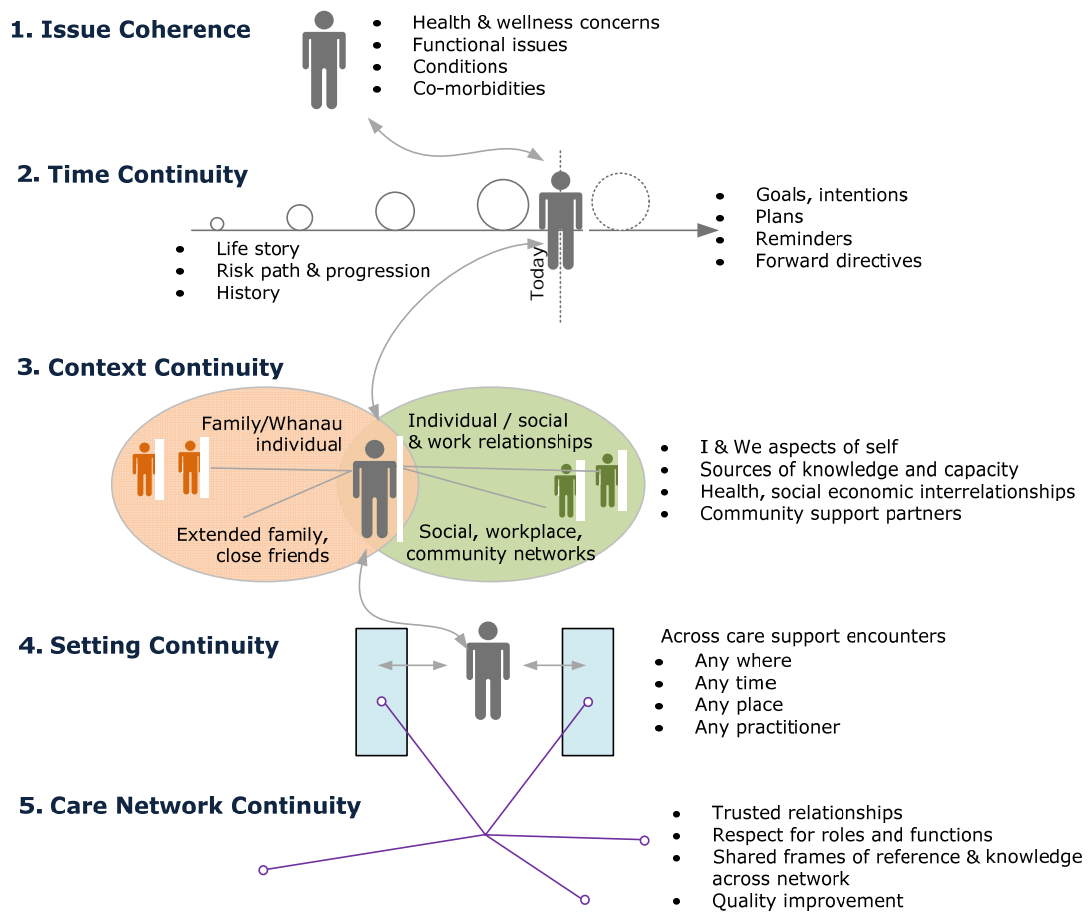


Figure 2: Levels of continuity

In developing an appropriate **‘Conceptual Information Model’** (a description of how information and the transfer of information between parties would be managed to meet the needs of the ecosystem), we need address to each of these levels of continuity.

2.3 Conceptual Information Model Rationale

The Conceptual Information Model must support the information needs of citizen-centric continuity of care at each level.

- Level 1 Issue Coherence (health record) is provided by incorporating the citizen centric definition of their health and wellbeing issues alongside ‘health defined’ issues of risks and diagnosed conditions. The critical function of issue definition is to provide a structure for activated partnerships between citizens, their support circle and health professionals that encompasses the breadth of a citizen’s own definition of their issues, as they see them, and those diagnosed or perceived by professionals. It frames the dialogue, focus and priorities within the context of each person’s life.

- Level 2 Time Continuity (person centred) is provided by explicitly connecting issues to histories and plans. The model provides increased emphasis on citizen centric plans to address health and wellbeing issues with these plans incorporating those currently created through interactions with health partners. The critical function of plans should support informed and well supported experiential learning to improve the state of health and wellbeing, while increasing the proportion of planned, proactive care versus unplanned and reactive care.
- Level 3 Context Continuity (family/whanua focused) involves creating health and wellness support network roles within plans; by citizens as actors in their own health, with their 'circle of wellness' partners, and their partnerships with health or other professionals. The critical function of role definition is to provide greater emphasis and value on citizen 'co-produced' care support and reorient all care network support by health and other professionals towards a dual role of addressing limits or constraints where professional support is needed while building citizen capacity for self care/co-production.
- Level 4 Setting Continuity (care team) is created through the use of role definitions to structure planned actions and information generation/sharing across different care settings that a citizen encounters.
- Level 5 Care Network Continuity (community) is provided by building network 'self awareness' through using role definitions to facilitate network interactions, information exchange, trust and quality development.

2.4 Conceptual Information Model

Figure 3 below illustrates the Conceptual Information Model for citizen-centric continuity of care that has been derived as a result of the feedback, research and analysis carried out by the Institute. It identifies the types of information that must be available, as well as the major types of actors involved. It aligns to the requirements of the five levels of continuity as per Figure 3. Supporting details for Conceptual Information Model are given in Appendix A. Detailed testing of this model is explored in Appendix D.

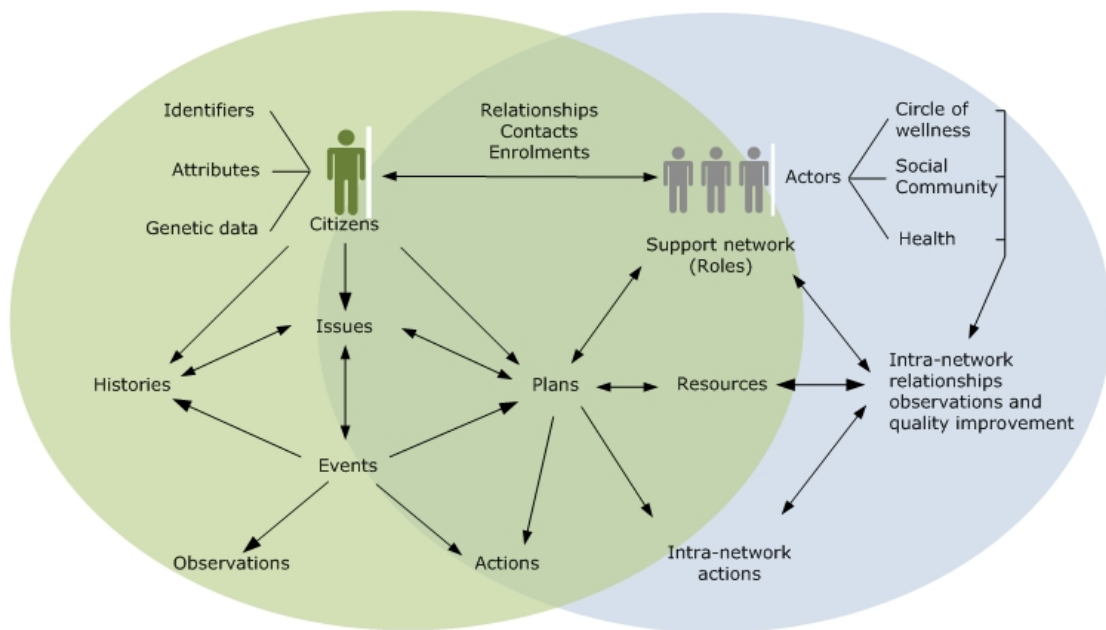


Figure 3: Conceptual Information Model

The Citizen Centric Continuity of Care Conceptual (CCCC) Information Model has some differences from the prevailing information models:

- The fundamental entity relationship shifts from being a patient/provider structure where health records are raised by providers (actors) about people as patients (objects), to one that is founded on partnerships, denoted by the two overlapping ovals, between actors.
- The implicit or explicit 'patient as object' relationship shifts to one where citizens are recognised as the prime actor in their health with support provided by partnerships with other 'co-actors' who form support networks composed of a range of roles.
- Citizens may have multiple support networks, depending on their issues, choices and the trust they give to their partners to act on their behalf. The definition of relationships is often implicit, assumed or poorly defined in current information models but becomes more critical in the CCCC model.
- Roles in addition to the traditional health provider or clinician roles are explicitly recognised as having validity and status in citizen centric care. In particular the concept of a 'circle of wellness' refers to family, whanau and friends who are part of structures that support wellness and care.
- The model creates an object called a 'health issue' that provides an integrating superset that includes wellbeing aspirations, ('I want to lose weight'), citizen defined problems and clinically defined risks and diagnoses. The 'issues' structure allows for a fuller range of psycho/social and living circumstances to be given status than those defined from a purely clinical perspective and

forms the basis for supporting self care as issues are supported through plans, network connections and resources.

- Issues may define partnership relationships, e.g. for each issue a citizen may choose to include or exclude parts of their support network.
- Plans become a more central and pivotal structure than exists in current information models. This reflects the need to connect health and wellbeing issues to intentional changes in state through actions within support networks utilising the resources within those networks, (including personal and circle of wellness resources in addition to health system resources). Plans may create the structure of the relationships of citizens and their support networks, for example a 'referral' in this model is a plan component that creates a new relationship to an existing support network, rather than being a transfer of care that is implied in the provider centric model.
- Histories, events, observations and actions are little changed under this model other than being enabled for a wider range of roles, e.g. a citizen or family member is enabled to undertake an observation such as a home measurement of blood glucose levels or record an action such as 'went for a walk of 30 minutes duration'.
- The model defines a class of 'inter-network' information entities that are necessary for care networks to function in support of continuity of care. This reflects the heavy dependency of the CCCC model on the concept of networks as entities independent of 'providers'. Citizen centric plans are likely to create changes to these networks, call on actions by partners within the network and use network resources. Many of these are analogous to existing inter-provider/clinician communications and information exchange that function to exchange knowledge and information with the network. For example, many 'referrals' from a GP to a specialist are better considered as 'requests for assistance and advice' by the GP rather than the traditional idea of a transfer of care. Similarly discharge summaries frequently contain a mix of citizen care information and advice, recommendations or directions to other network partners.

3 Information Management Principles

3.1 Purpose

Principles with rationale and implications have been developed to support the requirements of information management for citizen-centric continuity of care, with consideration of both individual and health-system-wide priorities. The articulation of these principles is intended to be sufficiently detailed to be used as a reference point by the Ministry of Health and the wider health sector in respect to information sharing and usage.

3.2 Proposed Information Management Principles

The Information Management Principles for citizen-centric continuity of care are set out below and have been validated against the vignettes that are set out in detail in Appendix B. These principles are prescriptive (some may say they are overly detailed) on some specific areas. They express a strong view that information must be shared (with the citizen and amongst providers) to an extent that audit comes to the fore as a key mechanism to enforce appropriate preservation of confidentiality. It is important to point out that these principles do *not* prescribe any particular implementation strategy (such as a regionally or nationally centralised database).

The Information Management Principles that support the meta-model are as follows:

1. ***Health information should be recorded in a form that allows all relevant actors to be able to trust that information where appropriate.***

Rationale

To minimise redundant observations and data entry, and to maximise the coordination of care, clinicians and other users must trust the information that is provided; they need to know enough about the information to determine its applicability and reliability for further decision making.

Implications

This principle directly leads on to the next two as a means of implementation and should help to deliver on the objective to “capture once, use many times.”

2. ***Health information must always identify source and method of derivation***

Rationale

This principle exists in large part to support Principle 1 above; i.e., to achieve maximum trust and hence re-use of information. This will be particularly strong where information is sourced from validated and standardised instruments such as an InterRAI assessment. Moreover, recording of

information source and method supports medico-legal roles of the health record and quality improvement efforts.

Implications

Recording of source should be readily automatable from current and future information systems (e.g., using HPI based on login). Recording of method is not particularly well standardised at present and will require further development with respect to software and data models. There is a further implication for busy and group environments (e.g., Emergency Departments) that individual providers should be authenticated (“logged on”) to machines by their appropriate individual identify – entering clinical data under another provider’s ID will undermine confidence in the data (e.g., “Is this management plan from the respected consultant the record indicates, or an intern that did a rotation in his department?”). Where the citizen enters their own data, their NHI could serve as the source identifier.

3. *Health information should be encoded to international standards wherever practical.*

Rationale

Use of standardised terminology promotes clarity of communications across healthcare settings, thus helping clinicians to trust and use information recorded by others. Moreover, standards facilitate higher levels of safe interoperability, such as the use of remotely-entered clinical information in electronic decision support systems. Standardised terminology also facilitates data integration, aggregation and comparison and improves our capacity for population health management.

Implications

Uptake of world-class standards should be pursued aggressively, notably with respect to subsets of SNOMED CT. In addition to promoting semantic interoperability nationally, this will aid comparisons on aggregate data (both within New Zealand and against international benchmarks) and will reduce the barriers for software to be internationalised (either for New Zealand software to be adapted to other markets, or vice versa), especially for clinical decision support tools.

4. *Primacy of patient safety*

Rationale

A fundamental principle of healthcare is “primum non nocere” (first, do no harm). Accordingly, the first function of health information and health information systems should be to protect citizens from harm, including iatrogenic harms from lack of information, such as contraindicated treatments.

Implications

This principle primarily favours accessibility of information, but it also requires

control of harm that may ensue from inappropriate divulging of personal health information. Patient safety is enhanced by Information Security. Information Security recognises not just the importance of confidentiality, but also safe information systems that provide evidential data integrity and availability to those with a legitimate reason for access. This principle mandates a balancing of real harm from inappropriate use of information to harm from lack of information. In light of the levels of harm that are inherent in today's fragmented system due to the lack of availability of information such as complete current medications (and rationale for medication), problem list and lab results it seems likely that this balance point lies toward a much more 'open' health information system than we have today (this is made more specific with Principle #5). That said, this is a difficult measurement challenge on both sides of the equation (potentially involving significant delays in realisation of harm). A further implication of this principle is that information should be shared in non-identifying form for quality improvement as long as the likely benefit outweighs the likely harm (this is further emphasised in Principle #6).

5. *All individual health information will be made available to all clinicians engaged in care of a patient with the understanding that there are 'get permission or break glass' components and ubiquitous audit trails*

Rationale

Clinicians must have a complete picture in order to minimise harm, avoid redundant action and act in harmony with the plans already in place, especially for individuals with complex/chronic conditions. Moreover, the concept of 'engaged in care of a patient' must extend beyond the moments that patient and provider are in direct contact. The Wagner Model, for instance, calls for a "Prepared, proactive practice team" – the clinician must have the right to review, and possibly recall, patients based on complete information. As part of being proactive, the importance of opportunistic care interventions must be recognised and enabled. When a patient has presented with one matter, it may be an ideal opportunity to engage them in addressing other key identified health issues such as smoking, diet, medication adherence or immunisations.

Implications

The default state of health information is that it is shared amongst providers. Only a stringently parsimonious set of data will be considered 'break glass' by default and even that will be accessible if the clinician is willing to defend their actions on subsequent review. A German-style smartcard is not an acceptable option – it is inadequate to the requirements of continuity of care to have the clinician be 'surprised' by the data on each occasion that the patient presents. That said, authentication of health workers must be strong to protect citizens from unauthorised access (e.g., by someone falsifying the credentials of a particular provider or an authorised provider accessing data outside of the patients they are actually caring for).

6. *Health information of all individuals will be shared in privacy-protected form to support healthcare quality improvement*

Rationale

An intrinsic purpose for all health information is to serve to strengthen the healthcare system itself. Beyond the care of the individual at the moment of data collection, health information underpins local, regional and national quality assessment and capacity planning, and informs audit and research aimed at identifying both modest and fundamental innovations in healthcare delivery.

Implications

This principle is *not* meant to apply a free-for-all on health data. Any protocols requiring health information access should be controlled by appropriate Review Boards. The Principle acts as an enabler for all protocols that Review Boards find to be valid and efficacious. It will be necessary to guard against 'coordination' of queries (where no one individual query identifies an individual, but a set of queries, and possibly some outside knowledge, does). It should be possible to provide a process that is easy enough to support audit and research, and yet sufficiently well-monitored as to make it very unlikely for inappropriate individual interests to be able to subvert the system in a timely fashion (e.g., to coordinate queries to ascertain the status of a visiting celebrity). Note that Principle #4 allows that harm of this sort is possible, just that it is difficult enough to be outweighed by benefits.

7. *Statutory adherence*

Rationale

Compliance with legislative requirements is a key responsibility of all government departments and a key underpinning of accountable government. Even for the non-government components of the healthcare sector, many of the same requirements either are applicable (especially due to the relationship with Government agencies) or are appropriate (due to the far-reaching implications and uses of health data).

Implications

Relevant statutes include, but are not limited to: the Official Information Act 1982, The Public Records Act 2005, Privacy Act 1993, Copyright Act 1994, Statistics Act 1975, Holidays Act 1981, Employment Relations Act 2000, Tax Administration Act 1994, Public Finance Act 1989, the Health Privacy Information Code and the New Zealand Public Health and Disability Act 2000.

8. *Citizens can access their own health information*

Rationale

This is fundamental to a citizen-centric model – the citizen has access to everything they need to participate as fully on their own behalf as they want.

They are respected as able to 'handle' the information and entitled to try to understand it fully. This message comes through as central with respect to the Kaiser Permanente and Group Health systems and is implicit in care plan centred models such as the Flinders Model.

Implications

This principle makes a consumer portal providing access to a cross-provider electronic health record an essential feature of the healthcare system. This does not mean that storage must be central (integration might be virtual, and it might be by logical high-level groupings such as regions), but a highly fragmented system would provide an unacceptably fragmented view to the health consumers. This principle puts a stark light on the question of just what 'private' data providers might keep, as compared to that which they share with other providers and the patient, and this requires further refinement and standardisation. A review of actual practice in systems such as Kaiser Permanente would shed considerable light on the appropriate management of this issue if frank feedback can be achieved (the answer was not apparent from review of documents and international interviews were outside of the methodology of the present project). There are arguments for delaying the release of information into the patient view until a clinician has an opportunity to assess the significance of the information and place it in context for the patient (e.g., for a laboratory, radiology or pathology result). Conversely, however, there is a counter-argument that the patient may play a key role in ensuring results are followed up in a timely fashion, and individuals deserve timely availability of their information wherever possible. Moreover, there are relatively rare instances where information may be legally withheld from an individual because its release would be deemed to put another individual at risk.

9. *Citizens can contribute to their own healthcare record*

Rationale

This provides further citizen empowerment and supports the notion of engagement in care planning and plan execution for the purpose of improved health outcomes, particularly in chronic disease management.

Implications

This enables home monitoring with observations entered by the individual. It also can be interpreted to enable personal queries, functionally along the lines of secure email from patients to doctors. It enables the notion of personal notes that are maintained along with health professional notes. It is important to note the interaction with Principle 2 – citizens can contribute to their own record, but as they do so the information will be clearly indicated as coming from them (it should not be confused with information provided by clinicians).

10. *Citizens can define additional access rights on their health information for other citizens, including granting of full proxies and other more limited access rights for specific purposes*

Rationale

To enable a 'circle of wellness' including those with very high access rights on through to those with very purpose-specific rights (e.g., one might be sharing an exercise log or bodyweight readings as part of a peer fitness network). This recognises that healthcare and appropriate behavioural change often occurs within a relationship or group supportive context, and these supports are often not clinical or professional in nature but, rather, are family, friends and community. At the highest level, a citizen can make another citizen a 'proxy' so as to acknowledge that person as a full partner in their care.

Implications

The Principle is about the ability of citizens to create access rights for other citizens; it is not about withholding information from healthcare professionals. Amongst citizens, there must be an effective and timely mechanism for removal of rights as well as addition (e.g., in the case of a marriage break-up) and it may be appropriate for the broader system to prompt citizens with reminders in this regard. A further challenging area in need of refinement is with respect to adolescents who are out-growing the default proxy of their parents or guardians. Another challenge relates to when a right becomes a perceived obligation; that is, there is a need to recognise that some citizens may not want a spouse or other family member having access to their record but may feel unduly obliged or pressured to enable their proxy.

11. *Citizens can review who has accessed their health information and have a clear and effective means of directing queries concerning such access*

Rationale

This allows a citizen to have confidence in the appropriateness of the handling of their health information. Citizens must be able to get a comprehensible log of accesses and have a reasonably efficient and effective means of querying accesses that they feel may have been inappropriate. This is a vitally important principle in conjunction with other principles above that promote relatively open access of citizen information by healthcare providers.

Implications

Healthcare professionals will be aware that their access to health records is subject to scrutiny by the individuals whose records are viewed. Citizens, however, will require education on the number of individuals and related services that may access their record or part of their record for legitimate reasons, but with whom they did not come directly in contact. These include service management, administrative, information management staff and coders, auditors, service planners and funders, and clinical staff providing supervision or second opinions. This principle could have a high cost related

to over-diligent follow-up by a minority of health system users – some of this cost may be defrayed by a well-constructed FAQ and an access log that gives a sense of the roles in which accesses are made.

3.3 Meta-Model Development Approach

In order to derive the meta-model the NIHI team conducted extensive research through interviews with stakeholders and a literature review. Initial findings were then reviewed with an expert panel and tested against a series of vignettes, derived to illustrate how real world health scenarios would be managed within the context of this new model of care. Full details of all these findings and the vignettes are set out in Appendices of this report. Here in the main body we have provided a summary of these findings.

3.4 Findings of First Person Discussions and Literature Review

These findings come from the stakeholder interviews and the expert panel discussion. A set of interviews was conducted with stakeholders who were identified as being able to contribute significantly to the development of a meta model for information in supporting continuity of care. Chronic condition management was used to focus discussion around continuity of care as it by definition crosses traditional boundaries in the health sector and has to take into consideration the social context of a person who has a chronic condition. The interviews revealed the following themes:

- A description of ‘who the patient is’ and what this means in the context of citizen centric health care. The ‘patient’ is whoever presents to a healthcare provider, and is defined loosely as a person who is sick, who may be accompanied by someone (care giver, family member, friend), and lives in a social context that is sometimes determined by and/or determines their health status. The social context is often invisible or inaccurately represented to, or perceived by, the person’s healthcare provider. A citizen is someone with rights and responsibilities and experiences health on a continuum of being well to end-of-life illness (ranging from full participation in health maintenance to complete handover to providers when fully incapacitated) – there is a loose overlap between the concepts of citizen and patient. The citizen centric approach to healthcare implies a person’s rights to access information, participate in decisions about their health, and act on advice, guidance, evidence of best care planning and responsiveness to co-production of personal health care planning and management strategies.
- A description of ‘who the provider is’ and what this means in the context of citizen centric health care. The provider is loosely defined as a person who provides health care services within the confines of their speciality or service in which they provide care. Their relationship with their patient is defined by their description of themselves as providers. Shared care encompasses the

inclusion of other health care providers in the delivery of care for people, including handing 'patients' over to other providers when required. Successful shared care of people requires inter-provider trust and co-ordination of care.

- Citizen centric care for people with chronic conditions focuses on the citizen, and not on the 'patient' or 'person', implying rights and responsibilities as well as a radical shift from defining the sick person from the perspective of the provider. Over and above the characteristic 'doctor-patient relationship' in the current model of healthcare, it becomes imperative to create an environment in which trusted relationships can be created, but not limited to the 'doctor-patient relationship'. A new kind of responsiveness is needed for the issues that people face – these issues are not articulated in clinical language, nor are they dealt with in a clinical manner other than by clinical people. To be able to be responsive within these newly defined trust-based relationships, there needs to be an information partnership. A good information partnership could lead to continuity of care within and across health care boundaries and could support the development of capacity in the community over time for preventing and dealing with illness.

If the health sector is citizen centric in its approach to health risks, threats, illnesses and other aspects of the healthcare spectrum, then it is essential to engage the 'we' in peoples' support networks. People do not live in a social vacuum – the social context of people's health is essential to building continuity dependability into the care network. To achieve this, there is a need for developing trust and respect in the supporting networks of people, which in turn may result in a growing capability to work and learn together in the interests of mutually supported health activities and outcomes. Should a person need complex care in such a complex environment, the person should be able to take advantage of the right context and functions in a multi-provider collaborative shared care structure.

However, the kind of paradigm shift to citizen centric care requires the right policy context that supports enacting actual person centric continuity of care. This means, for example, that funding models will need to align with new strategic business plans for health care providers so that continuity is defined by the person's (in their social context) need for care, rather than the provider's capacity to provide care according to the system's business model for care. Statutory changes are implied by this approach but were not explored in the interviews or by the expert panel.

- There was a focus on how information supports the notion of citizen centric continuity of care for people with chronic conditions. Information about a person's health is dynamic and usually relates directly to the person concerned. One way of thinking of this information is in terms of an 'envelope' of information that goes with them everywhere and into which different people dip for information relevant for updating their records and providing and/or supporting care, e.g. clinical, or for obtaining information that assists someone in providing this person with health care services.

However, the information about a person and their health is not limited to their personal experience of their health or their interaction with health providers. This results in others seeking information from the person's 'envelope' and applying it in a number of different ways, e.g. clinical, service usage, financial, social. Each person who seeks information from a person will do so according to their training, the reason for seeking information, e.g. curing an acute disease, and recording that information for future reference, e.g. aggregation for the purpose of research or policy development or financial reimbursement. However, accessing, using, documenting and reusing information is a complex activity, regardless of whether the service sought and provided was person centred, part of a continuum of care or a component of preventive health service delivery.

The concepts summarised above were presented to an expert panel, alongside a provisional version of the Conceptual Information Model for citizen centric. There were considerable disparities in the feedback from panel members and in some areas it has proven very difficult to identify common themes. From the discussion, it can be deduced that:

The model should not be confined to information, chronic conditions, continuity of care and person centric care. It should be extended to the whole health system, which requires radical change in order to incorporate the principles of the model. This change should include:

- Investigation into the relationships between providers and the role of non-clinical participants in the proposed model.
- Investigation of the dysfunctional relationships between providers of care in order to repair them. The information would then follow more easily.
- Investigation into the role of primary care, the community and the social context of many chronic conditions. The emphasis on these three components of the healthcare setting would result in radical change in how healthcare is delivered and would facilitate the paradigm shift from provider centric care to person centred care with the potential for continuity regardless of boundaries.
- Agreement that a future-focussed vision is good but that we need to identify what could be achieved in the short term to support the future vision. This could be construed as an inability to see the long term future vision or to shift from the existing provider focussed paradigm to the proposed people centric paradigm. However, it could also be an indication that small incremental steps towards the future vision may be a useful approach to use, as described by Heeks et al⁽⁵⁾ when they write about the gap between the current reality and future concept being too big to cross when a vision requires radical change.
- Technologically, we can develop systems for the future, but that this would be a challenge in light of our historical difficulty in defining requirements for such

a system. What is required to develop this future information system that has no boundaries, is leadership and the ability to articulate what the vision is and how it could be incorporated into enabling technology. Research reflects the need for such leadership, as reflected in Day's research⁽⁶⁾. Such leadership is rare and needs to be developed. Critical success factors for implementing such technology should be researched for the implementation of this meta model.

- Measurements for the proposed KPIs may prove difficult as health outcomes related to 'soft measurements' such as subjective improvements in pain management may prove difficult to but important for such measurement. The delineation between the model development and implementation has created a boundary that makes refinement of the model difficult to achieve.

3.5 Vignettes

Summary

The meta-model development process has yielded a set of vignettes – hypothetical (but grounded) stories of citizens living their parts in the envisioned future healthcare system. The vignettes and associated discussion are detailed in Appendix B, but in summary they cover:

- Susan, a self-actualising and asymptomatic citizen embracing what is offered. She self-manages her diabetes well as using a portal to provide test data directly to her GP. She is part of an online community with shared interests. She is part of a 'care team' that collaboratively manage her care plan. In the vignette she has a road accident and is taken to hospital in a coma.
- John, a citizen with overt symptoms struggling to take up what is offered. He understands he needs to be more vigilant in taking his medication and modifying his lifestyle choices, but real life gets in the way. He is bamboozled by medical terminology used by his care providers. He collapses and is taken to hospital.
- Peter and Joan, an elderly couple with complications who are becoming more dependent on the broader system around them. She has multiple co-morbidities and he is struggling to look after her in their home. They are not computer literate and are dependent on their care team to liaise with each other to provide an holistic approach to her conditions. She is committed to a hospice.
- Huia, an elderly Maori woman with multiple chronic conditions, navigates the health system with her family. She is interested in the treatments and test results and is keen to use a portal to her health information with help from her grandson. Huia is pleased to see that this electronic access to her health information can also have an effect on her whanau.

The personas in these vignettes serve as test cases for the recommended meta-model as well as a further articulation of the vision of citizen-centric continuity of care.

3.6 Testing the Proposed Information Management Principles Against Vignettes

If these Information Management Principles are tested against the Vignettes, several observations can be made:

- Susan is the ‘power user’ of Principles 8, 9 and 10. She’s the one who will be reviewing her appointments online, who will be adding home observations, and who might add limited access rights (e.g., she may share bodyweight and related data with her weight management group for mutual motivation). She’s also the likely user to exercise Principle 11 and review (and possibly query) accesses of her record.
- Both John and Susan benefit from emergency access to their record when they are unable to provide explicit consent (explicit use of Principle 5).
- John, and Peter and Joan benefit from the ability of care providers to coordinate ‘behind the scenes’ and create care plans using the individual health data (explicit use of Principle 5 with implicit benefits from Principle 1, 2 and 3).
- The healthcare team taking care of these people will be using Principles 1 and 2 with the view to providing safe care (Principle 4 and 5) within the New Zealand statutory framework (Principle 7). While not visible in the Vignettes, Principle 6 may be invoked such that data from any of our citizen personas may be used in confidentiality-preserving ways for quality improvement.
- Huia and her family are able to take advantage of Principles 6, 8, 9 and 10 in their whanau context in which Huia is able to include her whanau in decisions about her health while simultaneously giving them appropriate access to parts of her health record.

A more detailed testing of these vignettes and the Information Management Principles can be found in Appendix C. These Information Management Principles will need further validation against additional and refined usage Vignettes, with Maori consultation being among the most obvious outstanding issues.

3.7 Information Model Relationship with Vignettes

Due to the nature of its derivation, the Conceptual Information Model as proposed has some elements (such as genetic information) that do not come into play in the Vignettes as written. However, we are able to see many of the information entities, actors and actions in the vignettes; for example:

- Susan has a Care Provider Team including her GP and optometrist, along with an Appointments schedule (that is part of her larger Care Plan). It is implied that she has Goals/Targets around HbA1c, blood pressure and bodyweight; and she has current, and historical, observations in these areas. Moreover, she has a Circle of Wellness that includes her “online support group” on whom she may have conferred limited access rights to her data (perhaps to her bodyweight). Having diabetes in her Problem List was an aid to the Emergency care team.
- John has a relevant and complicating Social History including his alcohol and diet habits, and lack of exercise. His Stage of Change and Health Knowledge data leave a lot of room for improvement. He’s building a history of significant events related to his diabetes that highlight the poor management to date. There appears to be a Care Plan (or at least Appointments) set up for him, although he’s only making a slow start in engaging in it for himself.
- Peter is probably set up as a Proxy for Joan. Joan has a long Problem List and probably a long list of Current Medications and somewhat intricate Medication History. She also has at least a GP, Nursing staff and a Specialist in the Care Provider Team. This team is able to view their collected data, including Observations such as lab tests, which should help to minimise adverse drug events and redundant tests for Joan. There may be Care Plans in place for each of Joan and Peter, although it’s not clear whether anyone is coordinating and reviewing them. Their larger Circle of Wellness may be deficient as no-one else is mentioned in this regard.
- Huia has a complex combination of co-morbidities, which are exacerbated by her need to remain employed to take care of her family. Her Care Plan is likely to be best understood by her GP, who appears to assume she’s not interested in it or ways of accessing it via the computer. Her Social Networks are strong and she responds to her health needs as a member of a network rather than an individual. Her care provider does not view her Social Network as part of the Care Plan, or significant Actors in her health, even though the provider acts within a Network as well. Huia’s view of her Circle of Wellness extends to her whanau and others whom she may influence.

4 Analysis of Overseas Models and Appropriateness to NZ

Introduction

We have carried out a desk-research review of a pre-selected set of other jurisdictions, in order to see what progress has been made around the development of models of care that are aligned with the citizen centric vision. The limitations of such research, without supplementation by site visits and face-to-face interviews, must be acknowledged and speaks to the need for more in depth in-situ reviews of these jurisdictions.

However, it has been possible to draw some conclusions based on the evidence available and this is set out in the following table and subsequent discussion.

Pros	Cons	What's Unclear	What's Applicable to NZ
New Zealand			
<p>Good projects (notably, Chronic Care Management in Counties Manukau)</p> <p>Whare Tapa Wha model</p> <p>Decision support uptake in General Practice (e.g., PREDICT and 'Best Practice')</p> <p>Primary: Secondary interoperability</p>	<p>Mostly a fragmented system</p> <p>A governance structure that inhibits coordinated strategies</p> <p>Little or no development around consumer involvement, self management, portals etc,</p>	<p>How much to aim for concentration of 'care coordinator' role on General Practice, or look to others in 'case manager' role or a more diffuse 'community-based' support role?</p>	<p>Fuller roll-out and support for Chronic Care Management 'case management'</p> <p>Testing the water on self management</p> <p>Further exploration of Maori perspective models (recognition of importance of whanau, and spiritual and emotional well-being)</p>
Kaiser Permanente			
<p>Integration (comprehensively – billing, clinical, scheduling)</p> <p>Active management of patients and good CVD outcomes</p> <p>Consumer portal with doctor-patient email ('shared care')</p> <p>Enterprise Data Repository</p>	<p>Private plan in a competitive market that doesn't cover all citizens – elite and doctor-driven</p> <p>Minimal attention to citizen's social context or supports</p> <p>'Doctors as leaders' model is good as far as it goes –</p> <p>Patients can opt out of KP, but otherwise have no input into data usage</p> <p>Minimal whanau concept</p>	<p>Depth of clinical content in consumer portal / management of sensitive results and provider hypotheses</p> <p>Whether their purchased solution, which is implemented in a context of competition and choice, is a good strategy to emulate</p>	<p>Reduce interoperability/standards issues through single source solution but interoperability standards still apply for a single sourced solution. <i>All</i> solutions are required to integrate with some 3rd party apps.</p> <p>Consumer portal with doctor-patient email</p>

Pros	Cons	What's Unclear	What's Applicable to NZ
Partners Health Care (Boston)			
<p>Algorithms to anticipate high use patients (with interventions); identify and track key patient populations</p> <p>Guidelines for efficiency in the use of high-cost drugs and radiology tests</p> <p>Connected Cardiac Care program (home telemonitoring)</p>	<p>No evidence of whanau/community approach</p>	<p>Architecture (news of move to SOA with Siemens)</p>	<p>Algorithms to anticipate high use patients; tracking and management</p> <p>Efficient use of expensive resources</p> <p>Home telemonitoring</p>
LDS/InterMountain			
<p>Outcomes focus, clinical process improvement and culture of measurement</p> <p>Integration</p>	<p>No sense of the need for consumer involvement</p> <p>Clinicians are employees – limited voice in approach</p>	<p>Unclear on just what their 'integration' entails (formerly a home-grown monolithic system)</p>	<p>Culture of measurement and process improvement</p>
Group Health (Puget Sound)			
<p>Consumer focus, including prominent portal – Patient Centre Care</p> <p>Planned Care Model</p> <p>Opportunistic care and outreach (patient activation strategies)</p> <p>Secure messaging for remote consultation</p>	<p>No sense of the need for consumer involvement</p> <p>Clinicians are employees – limited voice in approach</p>		<p>Consumer portal</p> <p>Both planned and opportunistic care</p> <p>Patient activation</p> <p>Secure messaging</p>

Pros	Cons	What's Unclear	What's Applicable to NZ
Denmark			
<p>Consumer portal heavy on practical functions (e.g., renew prescriptions, book appointments)</p> <p>Functional integration</p> <p>Use of peer pressure through public monitoring of participation in electronic messaging</p>	<p>Dependency on development of standards</p> <p>Reliance on pragmatic clinical and consumer approach to issues</p>	<p>How much of the existing infrastructure was replaced to increase functionality and facilitate integration?</p>	<p>Highly pragmatic approach to providers, consumers, clinicians and issues</p> <p>Consumer portal</p>
Canada			
<p>Focus on national (Infoway) development of standard architecture and allied processes.</p> <p>Carrot (\$\$ incentives) approach to adoption by provinces</p> <p>Strategy for innovation</p>	<p>A lot of variation province to province</p> <p>Focus on architecture has yet to be proven – each province effectively going their own way</p> <p>Very low adoption in primary health</p> <p>Innovation level well behind NZ in most non-secondary areas.</p>	<p>What have they achieved so far for what are extremely large investments?</p>	<p>Infoway architectures provide detailed blueprints – applicable to NZ?</p> <p>Disease management approach provides blueprint for NZ.</p>

Pros	Cons	What's Unclear	What's Applicable to NZ
UK National Health Service – England			
<p>Ambitious all-of-country/all health approach</p> <p>Common User Interface</p> <p>Social mandate</p> <p>'Population management' approach</p> <p>Experience in huge scale IT renovation</p> <p>HealthSpace portal</p> <p>Drive towards health information standards</p>	<p>Centrally driven prescriptive model, doctor/system centred care</p> <p>Major problems with patient consent and clinical resistance</p> <p>Climbdown on prescribed solutions</p> <p>IT Led programme</p>	<p>Although the cross care setting single solution model (one size fits all) has largely failed and there problems in areas of patient consent, there are a number of successes around QMAS (Quality Management and Analysis System), EPS (Electronic Prescription Service) CUI and centralised bookings that need evaluation</p>	<p>Population Management</p> <p>Consumer portal</p> <p>Centralised booking</p> <p>Centralised prescribing</p> <p>Centralised Quality Management System</p> <p>Drive towards common clinical processes</p> <p>CUI</p>
UK National Health Service – Scotland			
<p>Pragmatism</p> <p>"patient focused, clinically led, and benefits driven" e-Health programmes</p> <p>Improvement collaboratives</p>	<p>Very little tangible progress vs NZ</p>	<p>Clinical portal pre-work in several regions worth further review</p>	<p>Improvement collaboratives as a pragmatic mechanism for achieving solutions involving many stakeholders</p>
UK National Health Service – Wales			
<p>Similar size and maturity</p> <p>My Health Online portal</p> <p>Chronic care model (maps to 'population management')</p>	<p>Very early in adoption cycle</p>	<p>Uptake and experience of My Health Online</p>	<p>Consumer portal development</p> <p>Chronic care model</p>

Pros	Cons	What's Unclear	What's Applicable to NZ
Australia			
Promotion and development of standards Interest (including models and trials) in coordinated care and self-management support	Little sustained achievement Primary/secondary governance split limits relevant development		Active engagement in standards to empower sector

Table 1: Analysis of Overseas Models and Appropriateness to NZ

4.1 Discussion

Several jurisdictions are recognised as being at the forefront of integrating information across the continuum of care. A few only have made genuine progress around integrating consumers into their own healthcare management. There are even fewer examples of genuine self management – where people monitor and manage their own conditions with clinical intervention being triggered largely by exception. There is almost no evidence of anyone recognising in their care provision the concept of a person (or ‘patient’) within the context of their family, whanau and community.

- There is a small but significant movement towards consumers using portal style approaches to collate health and wellness data that enables greater control over their healthcare. There is some evidence that people (or ‘consumers’) are using secondary sources to become better informed about their conditions and possible treatment options, but this has not been a specific focus of this report. Group Health is a leader in this space, but Kaiser and now NHS HealthSpace and My Health Portal in Wales are making progress in the consumer portal space, all showing revolutionary elements on citizen engagement, such as routinisation of doctor-patient email and a shared health record that’s visible to the consumer. We also see a highly practical portal in Denmark as among the best national example of this approach, rich in features such as patients scheduling their own appointments.
- In terms of patient activation, Partners Healthcare is outstanding for its risk identification with case management (for high risk / high complexity) and for its integration of home telemedicine. LDS/Intermountain also warrants further investigation for specific innovative technologies to provide proactive and evidence-based care that influence the bottom-lines of cost and health outcome
- A polarisation of approach appears to be emerging as to how best to put in place the information strategies and systems that must underpin this movement. On one hand, some organisations, the most prominent examples of which are Kaiser Permanente, Intermountain/LDS and Partners Healthcare, have enjoyed significant success with an approach that has involved the development of a fully integrated, dominant, largely single-sourced IT system, which mitigates the need for the apparently Sisyphus-like task of developing interoperability and messaging standards.

In contrast national, publicly funded health services continue to follow the path, currently adopted by New Zealand, where incompatible systems are linked through the adoption of common messaging standards and syntaxes. The most notable examples of this approach are Denmark⁽⁷⁾ and Wales⁽⁸⁾.

- Two interesting examples of what may be described as hybrid approaches are in England and Canada. In England a prescribed dominant single-system

approach evolved into a more flexible best of breed strategy. They are in for the long haul and are learning from their mistakes; their use of HL7 version 3, HL7 Templates and the Microsoft Common User Interface (CUI) is ground-breaking. In Canada, where a federal initiative to define a standard architecture was used in conjunction with the incentive of significant funding, attempted with only partial success, to apply conformity to their provinces.

- NeHTA Australia demonstrates national leadership in defining standards at a number of levels (e.g., medication terminology) in an effort to create the environment for the sector to achieve continuity of care benefits without the government building the system per se.
- The relative positioning of these jurisdictions is illustrated in Figure 4 below.

Single-source		'Spine' plus standards	
Kaiser	England →	Denmark	Australia (no spine, either)
Group Health		Canada	
LDS	Scotland		
(VA)	Wales		
Partners?			

Figure 4: A continuum of level of support for solution diversity in jurisdictional architecture

4.2 Architecture

Is the architecture a key enabler or just a result of their history and culture? Is it the culture of process improvement that drives both the achievements and the architecture where integration is found? Integration happens in every possible way – it's achieved by Kaiser by single-vendor purchasing, by LDS through building a custom solution, and by Denmark by providing a spine for interoperability. Denmark uses HL7 version 2; Kaiser uses CDA. NIHI's parallel review of health standards reinforces the view that although there is strong commonality in terms of goals, there is considerable disparity in directions being taken.

As noted above, a distinction that can be drawn (as illustrated in Figure 4) is that jurisdictional solutions fall on a continuum from single-source solutions to those that rely more fundamentally on interoperability based on international standards. Moreover, our perception is that NHS England had attempted to press a solution that resembles the single-source (although based on some five solutions for various sub-jurisdictions), but, due to poor user acceptance, has moved to a solution more

resembling that of Denmark, and in fact is providing significant leadership in use of HL7 version 3 messaging and summary electronic health record design. With this continuum we see a resurgence of respectability for the single-source answer, most compellingly demonstrated by Kaiser Permanente's pushing through with Epic.

What about whanau? Many models provide supported self-management and case management, but none are really looking at the broader environment of the individual, at least insofar as to reflect a detailed consideration of the impact of family and community on health that holds a weighting at all equal to traditional clinical indicators. That said, the Welsh model stands out as a leader. The escalating pyramid of care maps to models used by other jurisdictions including NHS England and Partners Healthcare, but the Welsh model (see Figure 5 below) gives particular emphasis to 'health' at the base of the pyramid and role of self-care, lifestyle and community until one reaches the very highest levels of risk.

Proactive and Planned Management of Chronic Conditions

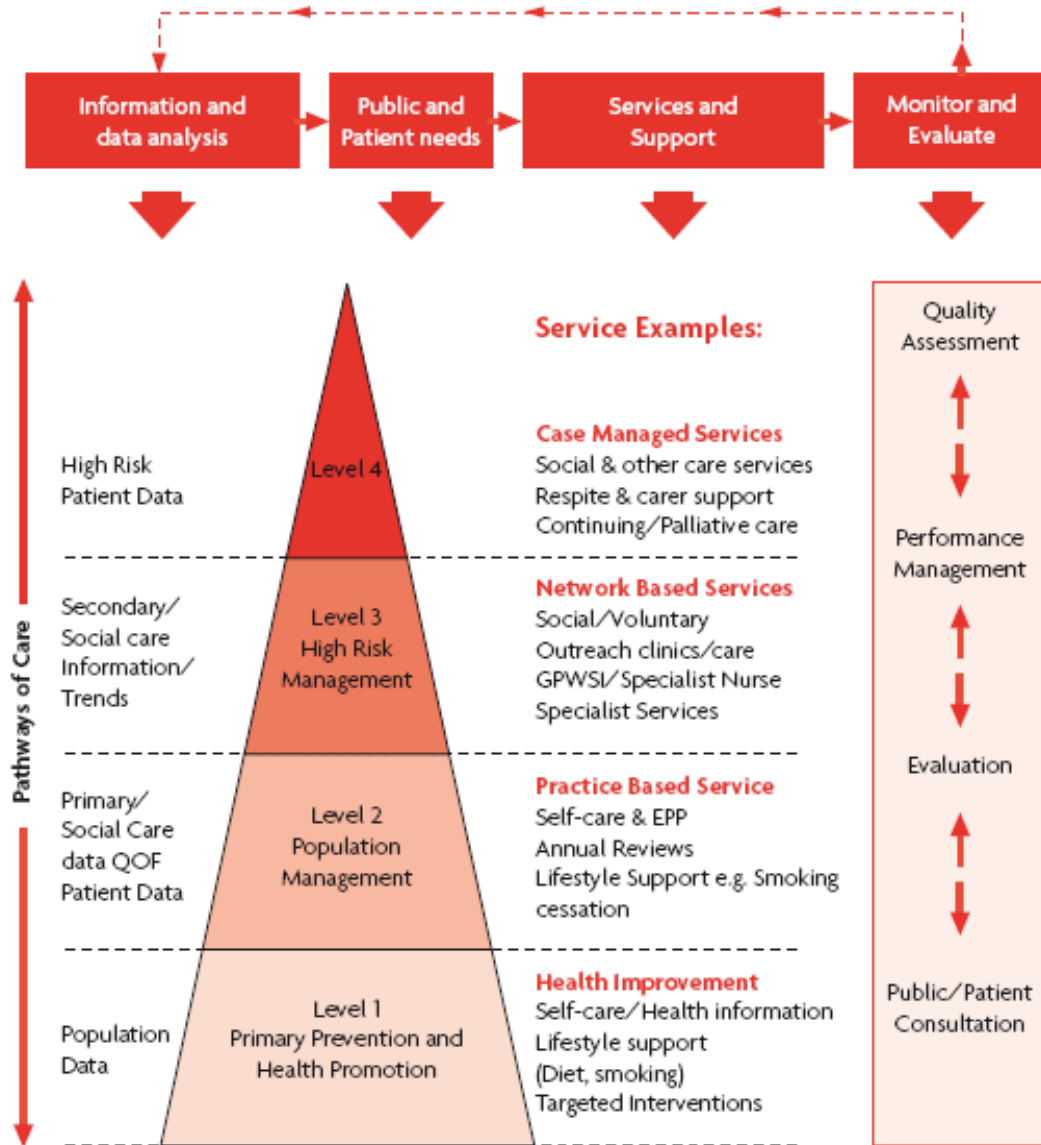


Figure 5: The Welsh Chronic Conditions Model⁽⁸⁾

4.3 Summary

Two points are worthy of emphasis:

1. No offshore example addresses all the issues, nor does any go more than partway down the path of achieving the true citizen-centric healthcare system that is at the core of the vision. We do have the opportunity of fast tracking the New Zealand implementation by picking the best from elsewhere; taking the opportunity we have to leapfrog what others have achieved putting into effect a uniquely New Zealand and world leading solution. For those that may

gainsay our ability to take such a leadership position, the rebuttal may lie in our proven record from the early 1990s of leading the world in the field of national data collections and more latterly in the use of clinical information systems in primary care.

2. Bringing about this revolution in the way we deliver healthcare is arguably necessary, but unarguably highly challenging. This review has examined some of the foundation stones upon which the new structure will be built, such as the Conceptual Information Model, the Information Management Principles and the evidence base from offshore. What is outside of the scope of our review however, is at least as important. We did not look in depth at the changes in clinical practice that would arise in a citizen centric world; we did no more than reference the challenges of privacy and security; and we did not seek or listen to the voice of the consumer. In looking at overseas exemplars, we constrained ourselves to reviewing their information management models and claims of success. We did not visit or communicate directly with any of them. We did not identify the differences in their constituencies and clinical environments, the costs of their solutions or their choices of suppliers. Determining the path we should take is, as we have said, a complex business and much work remains to be done before we can genuinely say our choices are informed.

5 Roadmap

5.1 The Way Ahead

Introduction

Achieving citizen-centric care will require significant information sharing over and above current practices, and a reformulation of the relationships amongst healthcare providers and between them and their patients. Making this care truly citizen centred will be a major paradigm shift in terms of the level of access citizens and their proxies have to the systems of the 'healthcare system' and an expansion in the types of information collected.

The greatest certainty is change – and it may be that the need to architect for extension and expansion is the most useful near-term message for system implementers.

Fundamental to the approach we recommend taking is to build on our knowledge base. This should take three forms:

1. Understanding more about what others are doing, why and with what result. We should selectively be carrying out onsite and detailed reviews of organisations such as Kaiser Permanente and Group Health, and countries such as England, Scotland and Denmark. These investigations need to look under the covers of anecdote and PowerPoint, to ascertain clinical and organisational cost and benefit, to understand the relevancies and differences to our New Zealand vision and to assess what can be taken and what should be left behind.
2. Although our research indicates a broad agreement as to the objectives we are seeking to achieve, this should not be read as a consensus as how we should achieve them, what the priorities should be or indeed what it would actually look like when we got there. This review uncovered significant disparities in these matters between our stakeholder consultees, and the consumers' voice was silent. We need to articulate why we need to collectively go on this journey, by consulting with and energising relevant stakeholders and by enabling the self selection of leaders who will provide momentum and guidance.
3. We should not believe we can import a total solution holus bolus. No two environments are completely the same and no jurisdiction has succeeded in the way we seek to. We must invest in innovation here in New Zealand, to trial new approaches, to develop or adopt the necessary standards, to enable the emerging leaders, to inform our choices and to develop the proof points that will guide our future path.

5.2 Recommendations

As outlined above, the roadmap to achieving citizen-centric continuity of care requires a multi-dimensional approach. It needs to recognise:

- Market forces that are already driving a dramatic change in the level of information accessed by patients, particularly the chronically ill.
- The increasing usage of citizen-centric tools such as Microsoft's HealthVault and GoogleHealth, which is likely to spread virally.
- The disaggregated nature of healthcare from an organisational, governance and leadership perspective.
- The relatively immature evidence base that currently exists to support the evolution towards citizen-centric care.
- The potential for resistance from some quarters to a movement that may be seen to undermine the role and mana of clinicians.
- The lack of a clear consensus around issues relating to data ownership, privacy and security.
- The relative lack of consumer involvement in the debate to now.
- The relatively immature and confused state of inter-operability standards.

The **Strategy Roadmap** needs to:

- Develop clarity and focus across the polarity tension over fundamental goals (as represented in the expert group).
- 'Create a model that is radical enough for the future' vs 'Focus on supporting today's innovations'.
- Use this process and outputs to scope governance issues.
- Add value for the CIOs that are wanting to move now (e.g. Northern Region/Central Region /Nelson Marlborough initiatives).
- Engage them as action research partners to test and refine 'meta-model v1'.
- Support the depth, quality and rigour of their thinking.
- Deepen research into overseas models to clarify their meta-model structure and adoption/adaptation/development issues for NZ.
- Develop impact analyses in respect to clinical roles and responsibilities, clinical care models and attendant processes.
- Develop a more nationally focused approach to governance and coordination.
- Identify and develop leaders.
- Evaluate the requirements for new and modified standards and plan for their development.

- Address identified engagement and consultation gaps.
- Use the 'meta-model v1.1' as first iteration.
- Develop more vignettes and test against model.
- Review standards development plans, including looking at the emerging standards around device integration.
- Develop an evidence base through further research and the development and implementation of proofs of concepts and pilots.

This last bullet is of particular importance and Figure 6 illustrates a model where progress is driven, under the umbrella of the national strategy, by the initiation and funding of carefully scoped proof of concept projects. Experiences from each project would be consolidated to develop an evidence base, to understand barriers to adoption, to promulgate concepts, to review the evolution of new care models, to identify sector leadership and to develop new governance models. In turn the outputs would further develop the detail of the Conceptual Information Model and the infrastructure of IT platforms that deliver on the meta-model vision.

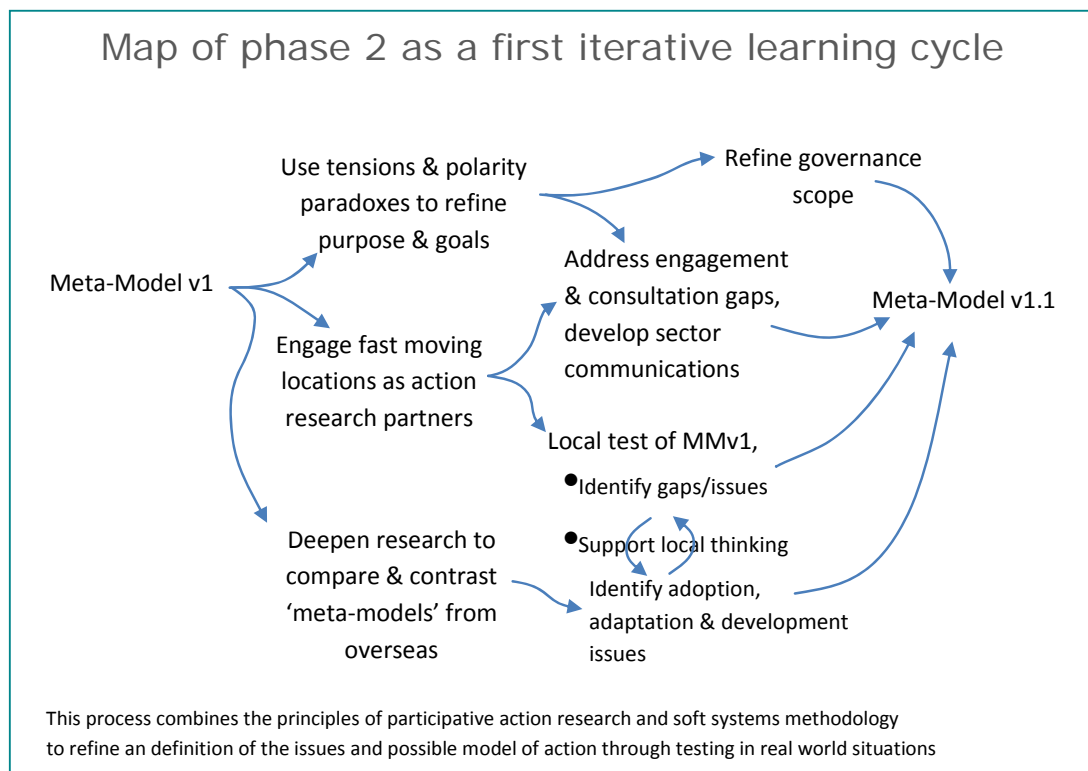


Figure 6: Progress through iterative implementations

5.3 Other Considerations

Some other considerations referenced above in terms of developing a citizen centric strategy are worthy of further consideration

Leadership

It is clear that for the nationwide implementation of this model to be successful, we need an effective leadership and governance model to go with it. The interviews, expert panel, literature review and conversations with colleagues and others, revealed that leadership for citizen-centric chronic condition management does not currently converge on a single model, nor does it support continuity of care. It is well known that healthcare in New Zealand is delivered from silos, and that leadership tends to come from and supports the silos, even when attempts are made to cross traditional boundaries.

The concepts of self-care and 'patient-centric care' have been around for decades but have not managed to achieve a significant level of traction. Exceptions, e.g. diabetes management at Counties Manukau DHB, could become the rule, assuming that a different kind of leadership is provided. This kind of leadership, or convergence of leadership from many types of service, is dependent on the relationships between leaders

- Of the same discipline, e.g. clinical.
- Across disciplines, e.g. clinical and allied health.
- Across different kinds of service, e.g. secondary and primary care.

However, it the expert panel discussion confirmed that these relationships are often broken, dysfunctional or absent. Doctors may no longer meet with one another to share the load of caring for complex patients: they may simply hand their patients over to one another. It appears that dialogue is increasingly being conducted by email with all its shortcomings. Regular meetings between GPs and their network of consultants at the local hospital may not happen and the closest they get to a team approach to patient care may be through a brief phone call or an e-referral.

Cultural Sensitivity

Cultural sensitivity is important in this model because the care for people with chronic conditions will be socially embedded. Even individuals in their most isolated moments are still socially (and therefore culturally) contextualised. A person who is the centre of their care does not experience their condition in a clinically bounded way. If the citizen-centred approach to care, involving continuity of care, is to succeed, then leadership from the communities in which these people live is essential. This is broader than consultation with and leadership from Maori, Pacific and other cultures. People seek leadership and will follow those with whom they resonate. In the context of chronic condition management and using the information

principles to facilitate their care, this leadership needs to come from their community.

Governance

A governance model needs to be developed to support the implementation of this model of chronic condition management to maintain leadership convergence (within, between and outside of healthcare services). For this model to succeed, the vision will need to be clearly articulated, and opportunities be provided for multiple viewpoints and multiple possible outcomes.

Process and role change

Processes will change dramatically as people increasingly engage actively in their own healthcare. Once the meta-model is in place, people will be encouraged to access and document their own data – this will change how healthcare personnel treat data. New forms of care practice and new roles will emerge. As new processes are adopted, the fulcrum of activity is expected to move into the community, with fewer and shorter hospital stays and the GP will become one of many consultants about a citizen's health. Some clinicians may feel threatened by what they may see as a more empowered and informed patient. Leadership in the community and in healthcare services will be required for process reengineering and change management.

Consumer involvement

In the present research, there has been very little explicit health consumer input for the formulation of a supposedly 'citizen-centric' meta-model. Formal stakeholder engagement exercises are a necessary further work component, with emphasis on groups who presently have sub-median health outcomes.

Organisations such as Kaiser Permanente may be able to devise their systems with minimal consumer input – they are answerable to the market (they need to sustain and grow patient enrolment), but no-one is compelled to be a Kaiser customer. For a national model for New Zealand, we must achieve appropriateness to Maori, Pacific, Asian, Pakeha/European and other health consumer stakeholders. We must get explicit input of younger, maternal and elderly segments. Moreover, input should be explicitly sought from those who have suffered mental illness. Input from this group will be of particular value both due to their poor overall, and particularly metabolic, outcomes, but also because of their particular sensitivities around information sharing.

One specific area where consumer input is needed is to identify appropriate means for identification of proxies (with more or less 'full' access writes to an individual's health information) and others with lesser rights (e.g., social supports – such as people trying to quit smoking together). Proxy nomination methods from Kaiser

Permanente and Group Health should be readily adaptable to New Zealand. Methods for identification of those with lesser rights may more resemble Facebook, but the model will require more extensive modification to achieve appropriateness for management of health and wellness.

Health information management principles must be tested for consumer reaction, both in the abstract and in the context of specific scenarios. This work will be informed from the results of the ongoing HRC-funded study entitled “New Zealanders' attitudes towards access to Electronic Health Records” being undertaken by Massey University, but will entail further specific questions for consumers.

All aspects of consumer portal user interface are of course also in need of consumer input. Largely, this is something that can be taken forward through a process of iterative refinement; however, the most important area for early input would be in how consumers wish to view audit information regarding who has accessed their record and why (since this will have a deeper impact on the system data model, clinical application processing and possibly clinical user interface design).

Finally, it is important to note that consumer *input* is not meant to imply consumer *design*. Each citizen is an expert on their own experience of health and illness. But health consumers are not (in general) experts on evidence-based medicine, chronic disease management methods (outside of their personal context), user interface design or system design and implementation. The role of consumers is to feed in requirements, and to provide reactions to proposed ways of working (and ultimately prototype implementations) that emerge from the design process.

Technology

Technology is an important enabler of change and can be built to support this evolution towards a citizen-centric care model. However technology should not be used to drive the change. To supply the required technology, the technologists need leaders to provide appropriately articulated requirements, and leadership in thinking so that the technology of the future can be built with a long-range vision rather than simply solving short term problems. Strategic linking of ICT to long-term plans is a well known difficulty, mostly related to strategists feeling that the technology is something that others do. This lack of ability to articulate the role of technology and information in the delivery of healthcare needs further exploration so that future leaders are equipped with the capacity to participate in future planning of the role of technology.

5.4 Summary

In summary, leadership and governance are fundamental to the success of implementing an information meta-model. Continuity of leadership will be required within, across and outside of health services, and will need to be sensitive to what is

happening in the cultural nature of communities. Generic leadership know-how will not be enough. Further exploration about leadership should cover the development of a national governance and leadership model

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