

## **CHAPTER III**

# **Kaitiakitanga and Health Informatics: Introducing Useful Indigenous Concepts of Governance in the Health Sector**

Robyn Kamira, Paua Interface Ltd and Rangatiratanga Canvases Ltd,  
Aotearoa (New Zealand)

### **ABSTRACT**

Indigenous contributions to governance in health informatics can be drawn from cultural concepts such as Kaitiakitanga, which implies guardianship, stewardship, governance and responsibility roles. This article explores Kaitiakitanga, its potential implementation in the Aotearoa (New Zealand) health sector, and its contributions to our thinking. After decades of unsuccessful attempts to positively shift the status of health for Maori, we must ask whether more control by Maori over information about Maori will make a difference.

Kaitiakitanga enables us to explore Maori perspectives and insights about health and information and calls for stronger inclusion of Maori in decisions. It acts as a guideline to address ongoing and complex issues such as collective ownership, the responsible publication of data, and whether benefits in health for Maori can be explicitly declared and met.

## INTRODUCTION

This article discusses the potential of Indigenous concepts of governance within a contemporary health informatics setting. Health informatics is an evolving socio-technical and scientific discipline. It deals with the collection, storage, retrieval, communication and optimal use of health data, information and knowledge (hereafter referred to simply as “information”).<sup>1</sup> The discipline attempts to assure quality healthcare for the community it serves.

Governance can be situated alongside health informatics, especially when considering the ethics, values and quality issues that impact on the care of people. Central to governance is decision-making and the process through which a group with delegated decision-making authority will direct their collective efforts. Governance involves multiple stakeholders to whom decision-makers are accountable: governance in New Zealand’s (Aotearoa’s) health sector deals with relationships between the Crown (Ministries, Government agencies, delegated authorities, etc), Communities, Maori and individuals. Governance also applies to guardianship over information to achieve the best interests of stakeholders, and involves achieving both “desired results and achieving them in the right way” (IOG). Since the *right way* is largely shaped by the cultural norms and values of the stakeholders, there can be no universal template for good governance. Information technology is significantly redefining governance by providing enhanced opportunities to collaborate with and influence policy makers. Similarly, information technology changes accountabilities by opening new possibilities for the dissemination of information about the performance of Government, District Health Boards and providers.

Indigenous contributions to governance in health informatics can be drawn from cultural concepts such as Kaitiakitanga, which implies guardianship, stewardship, governance and responsibility roles. This article explores Kaitiakitanga, its potential implementation in the Aotearoa health sector, and its contributions to our thinking. After decades of unsuccessful attempts to positively shift the status of health for Maori, the Indigenous people of Aotearoa, we must ask whether more control by Maori over information about Maori will make a difference. Kaitiakitanga can introduce a stronger position on ethics, values and quality when managing health data and optimise the benefits for both Maori and non-Maori alike.

Further, the inclusion of Kaitiakitanga concepts in governance structures, processes and roles in New Zealand's health sector in recent years points to a growing acceptance of Indigenous input. For example, the establishment of the Cervical Screening's Kaitiaki Group as a legislated body (MOH, 2002a), and the Northern Region Hepatitis Consortium's Treaty Relationship Company model (C. Bullen, personal communication, 2003) are examples where Indigenous ideas are perceived by their supporters to add value to governance.

The article specifically addresses collective ownership, collective privacy, responsible publishing and benefit. Kaitiakitanga implies that Maori will participate in *decisions* about health informatics and information technology, and influence policies and laws that support concepts of traditional protection, ownership and benefit that go beyond current laws and policies.

# A MAORI PERSPECTIVE ON INFORMATION AND TECHNOLOGY

Definitions of information technology need not be limited to those found in academic or information technology industry journals. Potentially, any means of storing, analysing and disseminating information can be included – *even our minds* (Kamira, 2002, p. 4). Maori concepts such as *Matauranga*, or intelligence, and *hinengaro*, or the mind, offer broader definitions and enhance what is generally understood about information technology. *Matauranga* refers to education and intuitive intelligence, and is linked to the divine. *Hinengaro* is the mind, the thinking, knowing, perceiving, remembering, recognising, feeling, abstracting, generalising, sensing, responding and reacting (Pere, 1991, p. 32). They are both vessels for knowledge.

Indeed, the broader Maori perspectives, such as those above, inform us why concepts of information technology as the information technology *industry* sees it are not only within the reach of Maori, but are also too simplistic since they do not include wider concepts of knowledge and understanding (Kamira, 2002, p. 5). It also explains why information technology is of great importance to Maori since the ancestor Tane-nui-a-rangi retrieved the *baskets of knowledge* from a celestial abode while coping with many dangers along the way (Barlow, 1991, p. 156), and that the dissemination of knowledge is thus a matter of great ritual and responsibility.

# **COLONISATION, TIRITI (TREATY OF WAITANGI) AND RELEVANCE FOR HEALTH INFORMATICS**

It was the Maori version of the Treaty of Waitangi, “Te Tiriti O Waitangi” that was signed by Chiefs at Waitangi on 6 February 1840 and subsequently in other locations. It is New Zealand’s founding document. While debate is ongoing regarding its status and implementation, the legal status of the Treaty is not enforceable as there is an absence of statutory incorporation (TPK, 2001b, p. 16).<sup>2</sup> Therefore, governance models that are based on the Treaty are dependent on the application of moral obligations of the Crown and the recognition of principles.

The Hunn report (1961) first highlighted the failings of the Crown to meet its Treaty obligations to Maori . The Government has attempted unsuccessfully since then to rectify the situation by focusing on socio-economic improvements for Maori. Yet, Maori continue to feature disproportionately in almost all of the negative statistics including unemployment, education, health, housing, domestic abuse and crime (Hunn, 1961; Williamson, 2001, p. 1; TPK, 2003). Particularly, the poor state of Maori health is well documented (MOH, 2002b, p. 2) and has sustained its negative status over many decades. Colonisation clearly undermined the economic and social base of Maori society and resulted in mass dislocation and loss of land, language and spirituality: this has led to urgent calls for reclamation and protection of Maori “assets”, including land, natural resources, language, belief systems, processes, etc. Active reclamation and protection of those assets are facilitated by movements such as Te Kohanga Reo (language nests), the Waitangi Tribunal, and Maori authorities, etc. This call also applies to health and wider

concepts of well being. As a result, Maori health provider groups aspire to become key providers for Maori and often coin the phrase “by Maori, for Maori” in the belief that other health services are not focused or responsive to the needs of Maori (Kamira, 1999-2000, p. 2).

Health informatics captures the need for technological capacity amongst all health providers, but access to that capacity for Maori providers is yet to be addressed fully. Anecdotal evidence suggests that the skills and equipment required for Maori providers to fully participate in health informatics is lacking (Kamira, 1999-2000, p.14). Recent reports indicate that Maori are not participating in information technologies to the extent of other New Zealanders (TPK, 2001a; Infometrics, 2001).

However, there is some evidence that Maori are beginning to enter the information technology industry (Infometrics, 2001, TPK, 2001a), and that they are forming professional and interest groups.<sup>3</sup> These shifts towards “mastery” of information technology will eventually enable Maori to make well informed decisions in health informatics. However, while it is an aspiration to build capacity in information technology in the broadest sense (Korowai Groups, 2002), this is some time away.

This leads us to the following questions:

1. Does the health sector enable Maori to make decisions about their health, or does it prefer to “look after” Maori?
2. What technological capacity would need to be available to Maori providers to assist aspirations to provide effective health care to Maori?

3. In the absence of technological capacity, what ways can Maori influence decisions about technology and health for their benefit?

## WHAT IS KAITIAKITANGA?

Data – anonymous or not – has enormous spiritual and cultural significance for Maori so may require more attention and protection than generally given (MOH, 2001, p. 3). One way to provide this is to exercise the customary practices of Kaitiakitanga.

Kaitiakitanga (and the person or group who performs the Kaitiakitanga role – Kaitiaki), implies guardianship, protection, care and vigilance of data about Maori that is collected, stored and accessed. It introduces the idea of an inter-generational responsibility and obligation to protect, and enables the use of mechanisms such as *tapu*, the setting apart or restriction of knowledge or things, and *rahui*, the necessity to conserve, protect or restrict (Kamira, 2002, p. 22).

As governance decisions impact Maori and since the “right way” to govern is largely shaped by cultural norms and values of stakeholders, it is critical to extend current governance ideas if Maori are to successfully implement their Kaitiakitanga responsibilities. However, Indigenous governance issues are complicated. For example (adapted from IOG):

1. What form(s) of Indigenous governance are appropriate to the 21st century and suitable to the needs of Indigenous peoples?
2. What is the appropriate balance between contemporary and traditional forms of governance for Indigenous peoples?

3. What are appropriate strategies for creating Indigenous capacity to successfully manage their governance responsibilities today?

It is important that members of governance or kaitiaki groups have an understanding of the historical, cultural and social complexities in which Kaitiakitanga perspectives are grounded.

### **Kaitiakitanga and Health Informatics Issues**

The advantages of obtaining statistical information about health for Maori are clearly to profile groups that will assist in developing effective policies and assist Maori to better manage their own health (MOH, 2002b, p. 23). However, decades of negative statistics indicate that gathering this information does not measurably achieve health gains for Maori.

1. Is data and information being gathered without producing *knowledge* that will generate benefits?
2. How would concepts of Kaitiakitanga in health informatics make any positive difference?

The following sub-headings provide some insights.

#### *Data and Statistics*

The publication of negative statistics over many decades undermines Maori and their health and produces few benefits. Negative statistics invoke the concept of *Takahia*, the act of trampling, often used to describe being belittled. Government databases collect

abundant data about Maori: the data is analysed and published, and Maori are profiled through statistical findings that continue to reinforce the most negative stereotypes. Currently, health informatics and statistics that are generated from databases symbolise disadvantage for Maori, who are busily curbing continuous socio-economic decline. The Maori experience of information technology that is in the control of others is the repeated reinforced perception of failure (Kamira, 2002, p. 22).

This is not to say that ethnicity data or data which identifies particular Maori groups should not be collected. However, the accuracy through to the eventual publication of such data should be, ideally, constructive. Kaitiakitanga though the idea of *mana* – power or influence – can refocus the way that statistics are generated and published and demand a more productive and benefit-focused model.

### *Intellectual Property, Collective Ownership and Privacy*

Kaitiakitanga introduces the idea of *tiaki*. *Tiaki* is to look after and guard and is a responsibility or an obligation rather than a right due to ownership. It enables a less exploitive relationship to exist where data about Maori is for the purpose of improvement and benefit first and foremost. Maori see the issues of intellectual property as a subset of these broader rights of ownership and include concepts of collective ownership. Collective ownership in health informatics can imply that grouped data about a collective such as a *hapu*, or an extended family tribal group, is owned by that collective. In turn, this implies their rights to make decisions about that data and benefit from that data.

In contrast, Western law defines intellectual property as outcomes of ideas or processes that are the result of human intervention – that is, knowledge created from the mind

(Mead, 1997). Intellectual property laws both here and internationally tend to focus on commercial *ownership* and are inadequate as a way to protect Indigenous collective knowledge. Until the fundamental ownership issues raised by Maori under the Treaty of Waitangi are mirrored in legislation, the best that can be achieved is interim recognition of Maori values and rights to participate in decision-making within the limits of the existing system (Putahi Associates, 1999).

Similarly, the Maori concept of privacy can encompass both the individual and the collective. An individual can have their privacy protected via the Privacy Act 1993. However, a *hapu*, or an extended family tribal group may feel they have a right to collective privacy that is not currently supported by legislation. Collective privacy is a means to protect data and information about groups of people rather than individuals and is a key issue when data collection occurs on identifiable groups that wish to manage or control data about themselves.

### *First Beneficiaries*

Kaitiakitanga introduces the idea of *awhina* – to assist or benefit. The ability to give what is truly needed without an expectation of reward means a clearer focus on more beneficial activities and responsible allocation of resources. The premise is that if Maori provide data then they should benefit from that data.

Some situations may prevent Maori from becoming the first beneficiaries. For example, limited participation by Maori providers in health informatics due to insufficient computer equipment or a lack of technological skills may be a barrier. Some Maori providers may need to rely on others to provide information, or they may only have

access to information that has been collected for other purposes and does not focus on Maori, nor contain the detail required to initiate effective action (Kamira, 1999-2000, p. 14).

Mechanisms to promote Maori as first beneficiaries may include:

1. Protocols around grouped data with the input of Maori stakeholders that *require* benefits to be identified as criteria for collection and publication.
2. The development of initiative(s) when grouped data about Maori is identified to develop standards on the collection and use of data, and standards regarding real benefits that are more actively promoted and delivered.

## **THE STRATEGY**

### **Mastery**

While there is little *evidence* that information technology has positive and long term impacts on the socio-economic status of people, the perception throughout the world is that information technology is a key driver for improving the world's socio-economic conditions (Riley, 1999), and that to ignore it will perpetuate or lead to even further disparities amongst the world's poorest and richest nations (UN, 2002). Maori will not be in a position to find out whether this is a *truth* for them unless they move from a passive role to mastery (Kamira, 2002, p. 17).

Apirana Ngata, a scholar and the first Maori university graduate in 1894, wrote in his granddaughter's autograph book (Huta, 2001).

E tipu e rea mo nga ra o tou ao

To ringa ki nga rakau a te pakeha

Hei oranga mo to tinana

To ngakau ki nga taonga a o tipuna Maori

Hei tikitiki mo tou mahunga

To Wairua ki te Atua

Nana nei nga mea katoa

Grow up o tender youth in days of your life

Your hands grasp hold of the tools of the Pakeha

For your material well being

Your heart to the treasures of your Maori ancestors

As a plume for your head

Your spirit to God

The creator of all things

This well known passage captures the desire and the ability of Maori to acquire the knowledge of other cultures (of the Pakeha, or non-Maori) and is an important strategy

for operating in a contemporary world, and for the uptake of information technology that would potentially improve health for Maori.

### **Using the Treaty / Tiriti Productively**

The Ministry of Health's WAVE report (MOH, 2001, p. 3) states that the Treaty of Waitangi established a Crown obligation for Maori to enjoy a health status at least as good as that enjoyed by non-Maori. Further, it states that the Government is committed to fulfilling its obligations to Maori to support self-determination for whanau (extended families) and Maori organisations. Kaitiakitanga can assist the Crown to achieve this obligation.

While Te Tiriti O Waitangi was signed and subsequently breached, attempts to bring it into a contemporary context have seen some progress. Concepts such as equity, partnership, collective ownership and protection (Treaty Articles II and III) can be expressed in relation to governance. Specifically, Maori are partners in the Treaty and as such:

1. Article II guarantees Maori control and enjoyment of their valued possessions – tangible and intangible. This includes their health.
2. Article III affords Maori the attainment of equal human and social rights and privileges. The Treaty implies that the *right* to good health can be exercised as per Article III regarding equity.

## **Validating and Promoting Maori Concepts**

Health informatic projects are an opportunity to discover what gains can be made if Maori are actively involved in decisions through Kaitiakitanga. Aspirations of *tinorangatiratanga* – the ability to make decisions and control one’s direction – are supported by Plumpre and Graham (1999), who conclude that three factors determine why some Native American tribes develop and some do not. They are:

1. Having the power to make decisions about their own future
2. Exercising that power through effective institutions
3. Choosing the appropriate economic policies and projects.

Identifying the possible contributions from Maori through Kaitiakitanga and then incorporating them into health informatics will help to promote, protect and validate the assets (knowledge and skills) that Maori have and, importantly, may change the current negative health status that has become the norm.

## **HOW KAITIAKITANGA WOULD WORK TODAY**

### **Treaty as a Framework**

The Treaty of Waitangi can be implemented in current day activities as a localised and living model for Maori to apply *tinorangatiratanga* (decision making and control). It can act as a framework by which the appropriateness of decisions made during the

development and implementation of health informatics projects can be assessed against Articles II and III of the Treaty.

## **Recognising Existing Structures**

Existing Maori structures also perform governance and Kaitiakitanga roles through Runanga (Maori authorities, Trusts or similar). These are legitimate structures often established by mandate and should not be undermined but instead utilised where appropriate for health informatics projects. Maori governance roles will usually extend to a holistic range of areas along a continuum of wellbeing that extends far beyond the narrow constructs of health and all of its sub-categories.

## **Kaitiaki Groups**

Kaitiaki groups would have overview roles to look after data, information and knowledge sourced from, or about, Maori. These groups would set ethical, value and quality guidelines. Ideally, participation of a Kaitiaki group would begin at the initiation stage of an IT project through to implementation and post-implementation.

The following points regarding establishing such a group are useful:

1. The membership and appointment of Kaitiaki groups is significant and Maori stakeholders would determine the appropriate type of Maori representation.
2. The position of Kaitiaki groups as a part of, or aside from, broader governance groups is significant as accountabilities and relationships are determined.

3. Kaitiaki group members should have decision-making powers and be informed on all issues, not just perceived Maori ones. This ensures Maori are defining what is of interest and prevents inappropriate filtering of information.
4. The issue of accountability is linked to risk. Kaitiaki groups would take into account the different levels of risk, the shared-risk and the authority it would accept or have delegated to it.

### **Kaitiaki Members**

Kaitiaki members would represent stakeholder groups that would in turn expect them to pursue aspects of tino rangatiratanga (decision making and control). Kaitiaki members would be responsible for, and would ensure a focus on:

1. The Treaty
2. Safety and protection of Maori individuals and collectives
3. Benefit to Maori individuals and collectives

## **CONCLUSION**

Health informatics will need to include concepts of governance and Kaitiakitanga alongside its medical, technology and social discourses. Modern concepts of Kaitiakitanga can enable:

1. Maori to be explicitly identified as first beneficiaries of health informatics where relevant

2. Recognition of collective ownership, use, access, analysis and interpretation of data
3. Recognition of collective privacy as a valid form of control for grouped data (Kamira, 2002, p. 23)

Kaitiakitanga contributes useful Indigenous ideas that add value to governance and potentially may result in a health gain for Maori in the long term as they make decisions about information that will be expected to return benefits. Maori can, through Kaitiakitanga, actively and effectively influence policies and laws that support the protection and ownership of data and information towards improving health benefits.

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## ENDNOTES

<sup>1</sup> While there are a multitude of definitions for data, information and knowledge, this is a favourite of the author. Data is raw and has little significance beyond itself. Information is data that has been given meaning by way of relational connection; it provides answers to "who", "what", "where", and "when" questions. Knowledge is the appropriate collection of information; such that its intent is to be useful; it answers "how" questions (Bellinger, Castro, & Mills, n.d.).

<sup>2</sup> A political analysis of the Treaty is not provided, as there are many appropriate and more in-depth sources of information available such as TPK (2001b) and Orange (1987).

<sup>3</sup> E.g., Te Waka Wahine Wa-hangarau: Society for professional Maori women in information technology. Note, there are at least three Maori IT groups in the country