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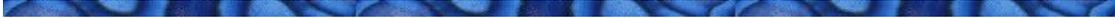
The kidZnet Project:  
Guiding Cultural & Ethical Issues for  
Iwi  
Kamira 1999

and

Report For  
Iwi Cultural and Ethical Issues In  
KidZnet  
Kamira 2000

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# MIHI

E nga maunga, e nga awa  
E nga parikarangatanga  
Tatu atu ki nga takutai moana  
Nga tai e wha  
Tena koutou, tena koutou, tena koutou katoa

He tohu whakamahara ake ki nga tini mate  
E hinga atu nei, e hinga mai nei  
Kua whatu ngarongaro atu ra koutou i te tirohanga kanohi  
E te kahui rangatira  
Haere ki nga Hawaiki o nehe ma  
E kore a muri e hokia  
Oti atu ki te po

Kei nga kaihautu o te waka o hauora  
E taki whakapiki nei i te ora, i te kaha, me te maramatanga o te hunga  
kawitiwiti  
E patua nei e nga momo mauui o te wa  
E hora ake nei i nga mihi a ngakau ki a koutou katoa  
Mauri ki runga  
Tihee mauri ora

# The kidZnet Project: Guiding Cultural & Ethical Issues for Iwi

© November 1999

Prepared by Robyn Kamira for the kidZnet Management Group

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## 1 BACKGROUND

### 1.1 WHAT IS THIS DOCUMENT ABOUT?

The state of Maori health is well documented and in particular, Maori children have a poorer state of health than other children in New Zealand. Partly as a result, Maori provider groups aspire to become key health providers for Maori children 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 children or their whanau.

This document recognises a required commitment to the health care of Maori children by managing their information effectively via kidZnet, a proposed integrated child health information solution. In essence, a *pro-active* approach is proposed for Maori health providers and consumer groups during consultation. The consultation process is ultimately about enabling these groups to have input to the project while it is still developing.

It is hoped that this document will draw and refine comment and critique on the ethical and cultural issues of kidZnet, specifically pertaining to whanau, hapu, Iwi and Maori<sup>1,2</sup>.

This document precedes a recommended process<sup>3</sup> with Rotorua groups that will close the initial consultation stages with Maori for both Hamilton and Rotorua. It can be distributed to groups that may include:

- Iwi health providers in Rotorua and Hamilton
- Maori health providers in Rotorua and Hamilton
- Iwi and Hapu groups as consumers of health services within Rotorua and Hamilton
- kidZnet management and steering groups
- Health Funding Authority

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<sup>1</sup> For distinction between Iwi, Hapu, Whanau and Maori refer to the glossary.

<sup>2</sup> For the purposes of this document the word ‘Maori’ will be used to generally include all of the above unless specified.

<sup>3</sup> Refer Appendix 2: Consultation Schedule

## **1.2 WHAT IS KIDZNET?**

The kidZnet project proposes an integrated information solution for children and their health providers in both Hamilton and Rotorua cities. This system can be available to children who *use* services in the city areas whether or not they actually reside within Hamilton or Rotorua city boundaries.

It is a computer network that shares limited data from the distributed and independent computer databases within many health providers environment including General practices, Plunket, Midwives, Iwi services and secondary services. A child who has a computer record at any of the participating health providers will be able to visit another provider and have his or her summarised records available if necessary to check for things like allergies, immunisation status, and illnesses. The intended benefits of this information availability includes an increase of thorough and safe health service provision to children, no matter where they go for health services within Hamilton or Rotorua.

It is intended that kidZnet will facilitate the movement of electronic records of children from the *distributed* computer systems of providers to a computer repository (server). This server will store or filter records from computer databases from a number of health providers in a summarised form. A health provider will be able to link his or her computer to the server via the network and request data on a unknown child that has attended the health service. Within a very short time the child's summarised record will be received and the health provider will be better informed.

Initially, the kidZnet system will retain *well child* data and later also intends to contain *sick child* data. *Population data* will be available from the outset.

## **1.3 POSSIBLE INFLUENCE OF MAORI ETHICAL VIEWS?**

This document only applies to the kidZnet project. However, the writer recognises there are implications for other information systems where data on Maori is collected. The outcomes of this consultation process may influence other Health Funding Authority or government funded projects. In particular, intellectual property, tino rangatiratanga and Treaty issues are more likely to be considered when implementing projects such as this where data and computer solutions are key elements.

## **1.4 HOW THE TREATY RELATES TO ETHICS**

The Treaty of Waitangi 1840 can be implemented in current day activities as a localised and living model for Iwi and Maori to apply tino rangatiratanga<sup>4</sup>. It can also act as part of an ethical framework by which Maori can begin to

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<sup>4</sup> Tino Rangatiratanga implies a great degree of control and direction.

measure the appropriateness of decisions made during the development and management of kidZnet.

Iwi are partners to the Treaty of Waitangi and as such:

- Article II of the Treaty guarantees Maori control and enjoyment of their valued possessions – tangible and intangible. This includes the health of their children.
- Article III of the Treaty affords Maori the attainment of equal human and social rights.

A political analysis of the Treaty is not provided, as there are many appropriate and more in-depth sources of information available to the reader<sup>5</sup>.

## **1.5 WHO INFORMED THIS DOCUMENT?**

This document is the result of an ongoing consultative process. During 1998 in Hamilton, a key informant survey, discussions and hui resulted in recommendations. Also, a broad key informant process was undertaken in Rotorua as a pre-consultative process to determine some of the likely issues that would arise from that area before wider consultation takes place.

Key informants represent themselves or their organisations as opposed to Iwi or Maori in general. They were approached due to their involvement in Maori health, in Maori or Iwi activities and as possible health provider or consumer advocates. A list of organisations from which key informants were approached is in Appendix 1: Key Informant Organisations.

The consultative process has focused on:

- The information needs of Maori health providers to enable the provision of better care to Maori children?
- The protection of data on Maori children that is provided by an individual health provider when it is moved onto a shared and integrated computer system such as kidZnet?
- What cultural or ethical issues arise from having a computer system receive and disseminate data about Maori children?
- If Maori children can not advocate for themselves or articulate their interests with regards to kidZnet, then who should do this?

A prior document *An Ethical Framework for Cultural Issues – Discussion document for kidZnet*, released in December 1998 outlines the issues that arose from consultation and discussion with Hamilton Maori health providers. This document now supersedes that December 1998 document and is a combination of both consultation and pre-consultation stages in Hamilton and Rotorua.

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<sup>5</sup> Example: Claudia Orange, "The Treaty of Waitangi", Wellington, 1987

Documents that may be read in conjunction with this one include:

- Simpson Grierson Law., *Privacy Impact Assessment and Commentary on the kidZnet Child Health Information Project*, July 1999.

## **1.6 WHY WE ASKED FOR OPINIONS ON ETHICS AND CULTURE**

The multiple interests of all stakeholders have the potential to submerge Maori interests. This document attempts to raise the profile of Maori interests towards potential health gains for Maori children.

A pro-active ethical approach is necessary to achieve health gains for Maori children because existing tools (eg. legislation, government policies) are not sufficient. The ongoing historical poor health of Maori children implies that the current ways of doing things are not working. By doing things the same way, we are guaranteeing the same poor results.

Maori do not traditionally have control over data and information especially in relation to information technology. The kidZnet project is an opportunity to discover what gains can be made if Maori are actively involved in decisions about data and information that affects Maori children.

Finally and most importantly, identifying the ethical and cultural issues and then incorporating them into kidZnet will help to promote, protect and validate the assets (knowledge and skills) that Maori whanau and Maori health providers contribute.

## **1.7 WHO ARE MAORI STAKEHOLDERS?**

Maori stakeholders can make decisions, participate, negotiate, consult and be informed along with the wider stakeholder provider group. The Maori stakeholders should be clearly and specifically identified so that they can participate fully in consultation and all aspects of the development of kidZnet.

Maori children are not seen in isolation. The child is considered to be a *part* of the whanau, and the whanau is potentially the most appropriate advocate and representative for the child. The whanau can also choose to be represented by the hapu or the larger Iwi group. The whanau, hapu and Iwi as stakeholders are able to represent Maori children as *consumers* of health care.

Maori health providers are the most appropriate *professional* group to represent the interests of Maori children and their whanau. A Maori health provider may be a hapu or Iwi organisation, an urban group, or a combined tribal group. This group may have a mandate from hapu or Iwi to provide health care to its people.

Key informants note that some Iwi and hapu may hold a *dual* stakeholder role as both health *provider* and *consumer*.

At this time, Maori stakeholder groups in both Hamilton and Rotorua comprise Iwi and Maori health providers, Maori parents, Iwi and hapu consumer groups, and others. These stakeholder groups can become wider to include whanau and others who work with and for Maori children.

Key informants maintain stakeholder groups should not be omitted from participation just because they are tribally outside of the geographical boundaries of the Rotorua and Hamilton cities. By way of explanation, some Iwi and hapu are not within the two city boundaries defined by the kidZnet pilot project. However, they represent children who commute to health services in "town" because equivalent services are not available in the outlying areas. Furthermore, whanau of other children who live in the city and use city health services may identify with outlying Iwi.

## **1.8 HOW THIS DOCUMENT SUPPORTS CONSULTATION**

This document is a consultation guide for the cultural and ethical issues according to Hamilton groups and Rotorua key informants. It should be noted that:

- This document does not arise from a *completed* consultation process with Maori.
- This document is compiled from references to debate at a national level regarding intellectual and cultural property, earlier consultation with Hamilton<sup>6</sup> and pre-consultation key informant interviews<sup>7</sup>.
- Ongoing decisions on system specifications, implementation and management of the information system are in progress. In this regard, this document may not necessarily apply to future stages of the information system's development. Consultation should be treated as a 'living' and ongoing process.
- Maori are not a homogenous group and the issues identified here may not apply to all. In particular, differences may exist between the Hamilton and Rotorua groups.
- Maori, rather than the funder or the wider management group, have an ongoing right to define the concepts described within this document and should not be permanently locked into definitions made at one point in time. For example, concepts such as *kaitiaki* and *whanau* must remain fluid and a more concise definition can be provided as needed to guide a particular decision.

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<sup>6</sup> Kamira, R., "An Ethical Framework for Cultural Issues – Discussion Document for kidZnet" December 1998.

<sup>7</sup> See Section 1.5: Who informed this document?

## 1.9 WHY ARE WE ONLY CONCERNED WITH GROUPED DATA?

This document is not concerned with *individual data* for a Maori child as the Privacy Act 1993 and the Health Information Privacy Code 1994 is considered appropriate to deal with this. Individual data issues are addressed in the wider document *Privacy Impact Assessment and Commentary on the kidZnet Child Health Information Project for kidZnet Management Group*<sup>8</sup>.

However, this document does address *grouped data* including statistical information obtained by gathering groups of individual records on children. An example of this type of grouped data can be found in documents like *Our Children's Health: Key Findings on the Health of New Zealand Children* where data on Maori children has been collected, analysed and presented to the public.

It will be possible through kidZnet to gather large numbers of records pertaining to hapu or Iwi, or data that identifies Maori children. Examples follow:

- Children who belong to Ngati Whenua<sup>9</sup> have a disproportionate occurrence of asthma when compared to other children.
- Maori children between 0 and 5 years are less likely to be immunised than non-Maori children.

The advantages of obtaining such information are clear. However, *knowing* this alone is not sufficient to achieve a health gain for Maori children. The key informants ask how this type of information will be acted upon so that the interests of the child are protected and advanced? Who should decide what data should be collected and by whom, and for whose benefit? Some of these questions are discussed in the following main section, *Cultural, Ethical and Other Emerging Issues*.

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<sup>8</sup> Discussion document by Simpson Grierson Law, July 1999.

<sup>9</sup> Ngati Whenua is a name that has been created for this document as an example Iwi and does not actually exist.

## **2 CONSULTATION**

### **2.1 WHY CONSULT?**

Consultation for kidZnet is an ongoing process and is intended to address the needs and requirements of Maori children and their whanau, and the health providers who offer care to them. Consultation enables people to articulate the issues and facilitate information exchange to collectively work together. A schedule of consultation for Rotorua is in Appendix 2: Consultation Schedule.

Both Hamilton and Rotorua groups agree that there are some important benefits in obtaining data on Maori children to allow for the development of customised health care programmes in an effort to increase the benefits and target specific groups. All health providers can be better informed about where the health needs are.

However, key informants to this consultative process emphasise that the decisions about data on Maori children needs to be considered carefully. This is because there are other factors that conflict with the basic premise that Maori children need to be healthier and Maori health providers and others need to be able to deliver a better service to these children. These factors have been identified as including the existence of a competitive regime for health funding, and political, social, spiritual and cultural variables that extend health and well being into all aspects of a Maori child's environment.

The issues that are raised here illustrate the need to have a clear understanding and support for effective relationships, processes and outcomes that result in health gains for Maori children.

### **2.2 WHAT SHOULD CONSULTATION LOOK LIKE?**

Many key informants state that consultation is a regular and frequent activity involving Maori organisations, which often results in poor returns. They are concerned that this exercise will be similar and want the issues drawn from this consultation process to be acted upon.

Rotorua groups have not yet completed their consultation process and key informants wish to help define the way they should be consulted with. To some extent the key informants have indicated how this might occur<sup>10</sup>.

Key informants in both Hamilton and Rotorua also point out that while consultation is necessary, it is almost impossible for Maori health providers to access experts in information technology who can adequately translate the technical jargon into social, political and cultural implications. Some say that it is possible that this document will alleviate this problem. However, they suggest that the kidZnet management present the project *kanohi ki te*

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<sup>10</sup> Appendix 2: Consultation Schedule.

*kanohi*<sup>11</sup> to the key informant group in Rotorua prior to the consultation hui. Those individuals can then assist in informing their own people prior to the hui.

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<sup>11</sup> Face to face presentation is a preferred method of communication and acknowledges a cultural method of interaction. A presentation by kidZnet management is considered to be a show of respect and genuine interest in Maori views.

## **3 CULTURAL, ETHICAL & OTHER EMERGING ISSUES**

The following sections identify the issues in relation to kidZnet's development, implementation and ongoing management. While the purpose is to determine cultural issues it is apparent that there are embedded broader issues that will also apply to other stakeholder groups. A summary of the issues appears in Appendix 3: Issues Summary.

### **3.1 WHO OWNS KIDZNET?**

Ownership of intellectual and cultural property is being debated heavily in many areas as attempts to apply a 'non-Maori' concept of ownership may lead to conflict where traditional Maori concepts (such as kaitiaki, rahui, tapu) have been an accepted norm. Many Maori consider that these mechanisms were and still are ample means of defining boundaries, protecting and nurturing. In this regard, it can be difficult to apply non-Maori mechanisms (such as legislation, policy and legal title) to things, which in pre-European times were not necessary. This section addresses the ownership issues.

#### **3.1.1 OWNERSHIP**

There are two facets when considering matters of ownership:

- The physical ownership of kidZnet (ie. the computer information system, equipment, database, etc).
- The intellectual ownership of the information held on kidZnet (ie. the knowledge and information).

The physical ownership of kidZnet does not imply intellectual ownership. Therefore, even if a particular organisation pays for the computer consultants, computers, printers, modems, software, etc., it cannot then assume the right to make decisions about the type of data that is collected and what happens to it. This would need to be the subject of negotiation with all stakeholders.

Key informants assert that Maori stakeholder input about ownership is *critical* for "buy-in" to the kidZnet project.

#### **3.1.2 INTELLECTUAL PROPERTY**

Western law defines intellectual property as the outcomes of ideas or processes that have been the result of human intervention – that is, knowledge created from the mind (Mead 1997, Jackson 1997).

According to Putahi Associates (1999) in terms of rangatiratanga under the Treaty, Maori assert that they were guaranteed the right to exercise ownership over their taonga and the decision-making rights on use and

protection that flow from ownership. Taonga, in the 'knowledge' sense, includes data that might be collected, stored and used as grouped data from kidZnet.

Maori see the issues of intellectual property as a subset of the broader rights of ownership. Until the fundamental ownership issues raised by Maori under the Treaty of Waitangi are mirrored in legislation - as individual privacy is under the Privacy Act 1993 - 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).

Maori stakeholders have intellectual property interests in the data and information contributed to, drawn from, and produced by kidZnet, particularly if grouped data is based around ethnicity, Iwi and hapu.

The Rotorua key informants are adamant that intellectual property is likely to be an important issue amongst the Maori health providers. This is consistent with the Hamilton groups.

The intellectual property assertions include:

- Maori will define (i.e. what goes onto the database, how it is stored (security) and presented (interface), accessed, and used, etc).
- Maori will protect, promote, and develop information on and for Maori.

If the source of data is clear, then the intellectual property is also likely to be clear. However, if the grouped data comes from more than one source the intellectual property may be unclear. In this case ownership of intellectual property may not be definable and therefore its management by the Kaitiaki group<sup>12</sup> will be significant.

### **3.1.3 OWNERSHIP AT LOWEST LEVEL**

Key informants discussed the idea that ownership remains at the lowest level. This implies that an individual child owns his/her record first and foremost. Then after that, a whanau, a hapu, then an Iwi may own non-personal grouped data. For example, data pertaining to specific Iwi Groups will be perceived to belong to that Iwi and not its umbrella waka group. This does not necessarily mean that the Iwi Group would not support an application by its waka group to access its data. However, it may wish to confirm its children as first beneficiaries.

### **3.1.4 COLLECTIVE OWNERSHIP**

Collective ownership is not a new concept to Maori and this type of ownership arrangement for kidZnet, amongst a range of stakeholders, would most likely be acceptable to Maori providers. However, collective ownership of kidZnet still does not imply intellectual ownership of *data* about Maori.

The concept of collective ownership or community ownership was discussed by most of the key informants as being a critical factor for Maori participation.

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<sup>12</sup> Refer 3.2. Who will look after kidZnet?

However, some ask how that ownership will be transferred from the Health Funding Authority as the funder of this project, to Iwi and the community. There will be strong resistance to government ownership through the Health Funding Authority or a similar body. They want assurance that other external bodies will not assume ownership of kidZnet in the future.

### **3.2 WHO WILL LOOK AFTER KIDZNET?**

The establishment of a Kaitiaki group<sup>13</sup> or Governance group is being proposed as a mechanism for a guiding overview role. The formal structure of the group has yet to be defined. However, it is envisaged that this group will administer the ethical and custodial guidelines that will be developed for kidZnet. This group will also consider applications for the release and use of grouped data.

The following points will be of importance to Maori:

- The membership and appointment of the Kaitiaki group is significant. The Maori stakeholders should determine the appropriate type of Maori representation.
- The structure of the Kaitiaki group as a part of or aside from the Governance group is significant. The Kaitiaki group may comprise of all of the stakeholder groups (Maori and non-Maori) or just Maori. Its structure will determine the position of the Kaitiaki group within or outside any other aligned management group.
- The Maori members of the Kaitiaki group 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 to Maori and prevents inappropriate filtering of information. This may include collation, research, use and development of kidZnet.

*Key informants have suggested options for the Kaitiaki group. These include:*

1. Kaitiaki group is separate from Governance group and makes recommendations to the Governance group.
2. Kaitiaki group is separate from Governance group and has representative member(s) on the Governance group.
3. Kaitiaki group is separate from the Governance group and has equal decision making powers.
4. Kaitiaki group is the Governance group and comprises 50/50 of Maori stakeholders and other.
5. Kaitiaki group is a subset of the Governance group.

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<sup>13</sup> The proposed kaitiaki group would have caretaker/guardian responsibilities for kidZnet.

Recommendations from key informants and Maori stakeholders in Hamilton indicate options 3, 4 and 5 are likely to be acceptable. The key informants in Rotorua are unable to predict what Rotorua Maori stakeholders would prefer.

Some key informants suggest that existing Iwi and Maori health structures should be used as they already have mandates, rather than create a completely new group to oversee kidZnet. They emphasised that these structures should not be undermined.

However, others maintain that a lack of a coordinated view amongst these groups mean use of these existing structures will not work – they say these groups may have a conflict of interest if they hold a kaitiaki role as well as being health providers.

Further discussion on the structure of both the Kaitiaki and/or the Governance group is necessary.

### **3.3 WHAT IS COLLECTIVE PRIVACY?**

Privacy can encompass both the individual and the collective. For example, an individual can have his/her privacy protected via the Privacy Act 1993. Whereas, a whanau, hapu and Iwi feel they have a right to privacy that is not currently supported by legislation. This document focuses on collective privacy as a means to protect data and information about a whanau, hapu or Iwi. It is a key issue when data collection occurs on identifiable groups that wish to manage or control data on themselves.

### **3.4 MAORI CHILDREN AS FIRST BENEFICIARIES**

Maori have experienced exploitation of their intellectual property throughout history. For example, a loss of accuracy and integrity of Maori history has occurred through the publishing of numerous books. Also, the patenting of rongoa<sup>14</sup> by pharmaceutical companies threatens Maori use and development of their traditional practices. The benefits of these activities are not *realised* by Maori.

If Maori children and their whanau provide data such as ethnicity, Iwi and hapu, then key informants say those children should benefit from that data.

Some situations may prevent Maori children from becoming the first beneficiaries of data collections. For example, limited access by Maori providers to kidZnet due to insufficient computer equipment or a lack of research skills may be a barrier. 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 children, nor contain the detail required to initiate effective action.

Some key informants have expressed concern that “data harvesting” by some groups could put Maori children at risk where data gathered by others

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<sup>14</sup> Rongoa: Maori healing remedies, techniques and ingredients

and used in inappropriate ways thereby undermining the aspirations of Maori. They feel that the collection of data on Maori currently being undertaken by various groups undermines the child and his/her whanau by relating negative results which do not result in benefits to the child.

Mechanisms to promote Maori children as first beneficiaries may include:

- Protocols around the type of grouped data to be collected with the input of Maori stakeholders and implemented by the Kaitiaki group.
- The development of initiative(s) via a planning group when grouped data about Maori children is identified.

### **3.5 CAN MAORI HEALTH PROVIDERS PARTICIPATE IN KIDZNET?**

Key informants assert that Maori providers need to be better informed about kidZnet and play a participatory role along with other stakeholders such as general practitioners.

Traditionally, Maori have been passive participants in information technology. With a few exceptions, information technology is only available to groups that have access to funding or skills.

Participation by Maori health providers is important to all of the kidZnet stakeholders. This is because a critical mass of participation is necessary to ensure the effectiveness of kidZnet. The key informants agree that there may be serious participation problems amongst Maori health providers. Infrastructure barriers such as lack of equipment and skills, or the inability to invest in technology are considered to be possible obstacles.

Key informants emphasise that full participation by Maori providers is necessary and should be supported (ie. training, equipment, upgrades and infrastructure including telephone lines, location, security, modems, management and technical support, etc.)<sup>15</sup>

### **3.6 EXISTING STRUCTURES**

Key informants affirm that recognition of current ways of relating between hapu, Iwi and Maori health providers in the city should be taken into account. They prefer that these existing and future structures and relationships not be jeopardised if and when another structure to manage kidZnet is put in place.

Maori health providers have defined boundaries both physical and otherwise, which determine the areas of activity. One key informant urges the recognition of hapu autonomy also. There is a strong territorial focus

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<sup>15</sup> Section 4.2: Stocktake Review recommends a review of equipment, skills, etc., amongst Maori health providers.

between Iwi and hapu and other Maori groups and key informants say kidZnet should not compromise nor challenge this.

### **3.7 WHAT ABOUT PROVIDER AND KIDZNET MANAGEMENT RELATIONSHIPS?**

Key informants state the need to develop a trusting professional relationship between Maori stakeholders and other health providers, and Maori stakeholders and the kidZnet management. They say Maori stakeholders will want to know who the *partners* in kidZnet are.

Key informants assert that Maori stakeholders will not want large government organisations such as *Work and Income NZ* and *Children, Young Persons & their Families Service* to have access to kidZnet. Maori experiences of these types of organisations are not positive. If parents and caregivers do not have confidence that their intellectual property or confidentiality is being protected they could give inaccurate information that reduces the integrity of kidZnet as an effective and accurate source of data on a child. Many key informants said this is a common way that their clients deal with requests for information where no trust exists.

### **3.8 HOW CAN KIDZNET MANAGEMENT SUPPORT MAORI?**

The kidZnet management team can further the aspirations of Maori around tino rangatiratanga and increasing the “*by Maori, for Maori*” concept with regard to health services to children, by supporting:

- The Treaty<sup>16</sup> obligations for cooperation, collaboration and negotiation between stakeholders.
- The genuinely informed buy in and uptake of kidZnet by Maori stakeholders.
- Maori health services for Maori children (sustaining Maori/Iwi services).
- Maori health expertise for Maori children (capacity building).
- The expansion of Maori health providers to provide more choices for Maori children and their whanau.
- Maori stakeholder ownership and management of health gains for Maori children.
- Maori efforts to retain tino rangatiratanga over data on Maori including its identification, data collection, data analysis, research, and health gains, etc.
- Maori stakeholders active participation in all aspects of the development and management of kidZnet (eg. policy, ethics, specifications, etc.)
- The responsible and productive use of statistical data on Maori children. There should be a clear statement of purpose and use for the collection of grouped data and resulting research findings. This statement of purpose must also identify the intended contribution to a health gain for Maori children.
- Regular revisits to this and other documents, processes, etc.
- Maori structures such as Iwi, hapu, whanau, urban Maori and any organisations managed by, and accountable to Maori children and their whanau.
- The representation of Maori children in general even if they are not affiliated to a formal structure.

### **3.9 WHAT ABOUT DATA WAREHOUSING?**

Some key informants question the proposed structure of kidZnet in terms of its technical design. Although they feel unable to critique it effectively due to

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<sup>16</sup> Treaty of Waitangi.

a lack of expertise in computer systems technology, they question the need for a *centralised* database as the only means to achieve the perceived goals of kidZnet. They are keen to know more about the proposed technical design and the intentions around centralising the database.

### **3.10 HOW DO WE AVOID MONO-CULTURAL DATA SETS?**

A range of variables can influence health amongst Maori children. For example, health problems for Maori have their roots in historical, political, economic and social circumstances, and the undermining of their cultural integrity.

Therefore, Maori health providers may want to define the type of data that will incorporate their perspectives and will support a better understanding and ultimately a better health gain for Maori children.

For example, Maori health providers may see the whanau as the central foundation for Maori children. Therefore, the kidZnet database should not limit the concept of whanau by providing only a nuclear family method of organising its data (eg. the computer database record should allow for the inclusion of an extended whanau way of data organisation?)

The treatment of whakapapa is generally of great interest to Maori. At this point, it is not clear to what degree family relationships and links will be incorporated into kidZnet. The potential collection of family relationships and links to other family records may create whakapapa as a potential by-product. While it is likely that only Iwi providers would collect this sort of data, the issues surrounding these types of by-products of information systems are under current debate at a national level.

In this regard, the initial analysis by computer system designers should include consultation with the Maori stakeholders.

### **3.11 COMMUNICATING IN TE REO MAORI**

Standard correspondence in Te Reo Maori should be offered by kidZnet. For example, it is intended that system generates standardised correspondence that will be sent to parents and caregivers. Given the growing numbers of speakers of Te Reo Maori it is appropriate to provide the option of letters written in the Maori language to parents and caregivers.

### **3.12 IS KIDZNET BEING MARKETED TO MAORI?**

Some key informants feel that kidZnet is being marketed in a way that does not attract Maori health providers to participate. They say the “corporate” and “big brother” feel does not appeal to Maori and that a more subtle approach will be better received. It is felt that some resistance and suspicion about kidZnet is being fueled by this style of marketing.

They claim the name *kidZnet* has developed its own identity and does not reflect the benefits and services that Maori health providers are interested in. They also do not want to see a Maori name given to the project as a way of attracting Maori health providers to it.

## **4 RECOMMENDATIONS**

### **4.1 CONSULTATION**

The recommendations are:

- That the kidZnet presentation team present kidZnet to the key informant group in Rotorua face-to-face (kanohi ki te kanohi) prior to consultation.
- That this document be distributed amongst all participating groups.
- That the Maori media such as Te Arawa radio and Iwi panui / newspapers be used to promote the consultation hui.
- That formal consultation occurs as per the schedule in Appendix 2.
- That these questions be answered at the consultation hui:
  - How and why was kidZnet established?
  - Who is kidZnet management now and in the future?
  - Who owns kidZnet now and in the future?
  - What are the benefits to Maori children and health providers?

### **4.2 STOCKTAKE REVIEW**

The recommendation is:

- That a review of the hardware and software capacity of Maori health providers in both Hamilton and Rotorua be undertaken to determine their ability to participate in kidZnet.

### **4.3 SYSTEMS REQUIREMENTS ANALYSIS**

The recommendations are:

- That Maori providers be included in the initial systems design where requested in consultation with computer system design team.
- That a representative works with the technical team during the systems development phase and communicate with Iwi/Maori providers regarding design issues for consideration.

## 5 GLOSSARY

Hapu	sub-group of related whanau within an Iwi
Hui	gathering of people for a specific purpose
Iwi	group of affiliated hapu, sub-group within a waka
Kaitiaki	implies guardianship, stewardship, governance and responsibility roles
Maori	general term for all descendents of indigenous peoples of Aotearoa
Panui	notice or newsletter either written or spoken
Rongoa	healing remedies, techniques and ingredients
Taonga	valued possession both tangible and intangible
Te Reo Maori	the Maori language
Tino Rangatiratanga	implies the ability to make decisions and control one's direction
Waka	group of affiliated Iwi and hapu
Whakapapa	genealogy
Whanau	members of same family grouping including extended family members

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## 7 APPENDIX 1: KEY INFORMANT ORGANISATIONS

### **General key informant organisations included:**

Health Funding Authority (Hamilton, Auckland).  
Te Puni Kokiri (Ministry of Maori Development).  
New Traditions project team (Hamilton).

### **Key informants for Hamilton were affiliated with the following organisations:**

Maori community workers  
Maori mental health workers  
Maori Public Health Nurses  
Plunket Maori staff  
Te Roopu Awhina – Parentline  
Raukura Hauora O Tainui  
Te Kohao Health staff  
Templeview Medical Centre  
THA Midland Maori unit  
Various Maori health providers

### **Key informants for Rotorua were affiliated with the following organisations:**

Korowai Aroha  
Ngangaru (National Maori Health Provider Committee)  
National Council of Maori Nurses  
Maori Advisory Health Group Clinical Training Agency  
Te Kete Hauora  
Te Runanga O Ngati Pikiao  
Te Whanau Poutirangiora a Papa  
Tipu Ora  
MISO Trust (Maori Integrated Service Organisation).  
Lakeland Health  
Te Whanau Poutirangiora a Papa.  
Te Mana Hauora o Te Arawa.  
Te Runanga O Ngati Pikiao.  
Tipu Ora Trust.  
Te Arawa Maori Trust Board.  
Te Puni Kokiri.  
Rotorua District Council.  
Brauda Research Organisation.

## 8 APPENDIX 2: CONSULTATION SCHEDULE

The management of kidZnet wishes to ascertain the cultural and ethical issues arising from the proposed establishment of a computerised database of children's health records, in Rotorua and Hamilton cities. This proposal sets out the intended process and outcomes for an Iwi consultation process in Rotorua alone. Consultation has previously occurred in Hamilton.

Robyn Kamira will undertake aspects of this process in cooperation with kidZnet's project manager, Susan Bramley.

### **STAGE ONE: KEY INFORMANT APPROACH**

A key informant approach will be utilised with Iwi and Maori health organisations and health consumers in the Rotorua region and others in the field. This approach is commonly used to determine a range of issues before further investigation or consultation occurs at a later date. Key informants will represent themselves or their organisations as opposed to Iwi or Maori in general.

#### **OBJECTIVE**

To gather an indication of the range of cultural and ethical issues in the Rotorua region before wider consultation takes place.

#### **PROCESS**

Ten key representatives will be selected from Rotorua's Iwi health service organisations or groups. Following an overview introduction of the project, the informants will be asked to respond to open questions identifying Maori ethical and cultural issues from their perspectives.

Key informants will be interviewed face-to-face where possible over two days.

The issues that arise will be added to the existing cultural ethical report that was developed with Hamilton and Tainui Iwi/Maori groups.

#### **OUTCOME**

"Guiding cultural and ethical issues for Iwi on the kidZnet project" - an entire document representing Maori views in both the Hamilton and Rotorua regions to date. This document will be distributed to Iwi and Maori in Rotorua as a pre-requisite for the next stage of consultation.

### **STAGE TWO: CONSULTATION**

This process will be undertaken cooperatively with kidZnet management representatives and the Health Waikato Ltd Maori unit.

#### **OBJECTIVE**

To understand the cultural and ethical issues of Iwi/Maori in the Rotorua region and report them with those from the Hamilton/Tainui region for inclusion in privacy/ethical documents being developed for kidZnet.

#### **PROCESS**

Distribute document “Guiding Cultural and Ethical Issues for Iwi on the kidZnet Project” to Maori health and consumer groups/individuals in Rotorua region prior to hui.

Hold hui in Rotorua.

Report outcomes of consultation for inclusion in privacy/ethical documents being developed for kidZnet.

#### OVERALL CONSULTATION OUTCOMES

Outcomes of the consultation for inclusion in privacy/ethical documents.

- Iwi/Maori health providers and consumer groups will have a clear understanding of the kidZnet project and the potential contribution to children’s health locally and nationally.
- Management of Iwi representative and group/organisations expectations in regards to the projects being developmental and the proposed outcomes.
- The gaining of Rotorua Iwi involvement with and influence of the project from the ‘ground up’.
- Clarification of the roles of the key parties: the Health Funding Authority, the Rotorua Child Health Trust, Rotorua General Practice Group, Health Waikato Ltd. and New Traditions.

## 9 APPENDIX 3: ISSUES SUMMARY

The following summary includes issues that emerged from both the Hamilton and Rotorua consultation process.

- 1. Who Owns kidZnet?** **Section 3.1**  
Ownership of intellectual property versus the physical database, ownership at the lowest (individual child, whanau) level, collective ownership.
- 2. Who Will Look After kidZnet?** **Section 3.2**  
Establishing a governance or kaitiaki group, its membership, structure, and decision-making powers.
- 3. What is Collective Privacy?** **Section 3.3**  
Rights to privacy of whanau, hapu and Iwi.
- 4. Maori Children As First Beneficiaries** **Section 3.4**  
Maori children receiving benefits from grouped data and kidZnet.
- 5. Can Maori Health Providers Participate in kidZnet?** **Section 3.5**  
Ability to participate through access to skills, equipment and funding.
- 6. Existing Structures** **Section 3.6**  
Ensuring kidZnet does not compromise existing Maori structures and relationships.
- 7. What About Provider & kidZnet Management Relationships?** **Section 3.7**  
Professional relationships, who the partners to kidZnet are.
- 8. How Can kidZnet Management Support Maori?** **Section 3.8**  
Supporting aspirations of Maori, for Maori children.
- 9. What About Data Warehousing?** **Section 3.9**  
The need to centralise the data.
- 10. How Do We Avoid Mono-cultural Data Sets?** **Section 3.10**  
Maori defining types of data to be collected.
- 11. Communicating In Te Reo Maori** **Section 3.11**  
Generating correspondence from the database in te reo Maori.
- 12. Is kidZnet Being Marketed to Maori?** **Section 3.12**  
Maori perception of kidZnet through its marketing.

## 10 APPENDIX 4: AUTHOR

Robyn Kamira (Te Rarawa, Te Aupouri) has a bachelor degree in computer science and Maori, a post graduate diploma in information technology, and is currently researching the impact of information technology on Maori towards a PhD. Through her research, Robyn has investigated the cultural issues arising from the adoption of information technology - issues such as intellectual and cultural property, and access. Her research has included projects such as those initiated by the Te Kohanga Reo National Trust, the Maori Land Court, Te Puni Kokiri, and both urban and Iwi based organisations.

Her practical experience spans ten years and includes the designing of computer systems including databases and Maori language computer programs. Robyn has worked for various Iwi organisations in a range of areas that impact on Maori including health, the environment, information systems and education.

# Report for Iwi Cultural and Ethical Issues In KidZnet. Stage Two: Consultation

Prepared by Robyn Kamira for kidZnet  
© May 2000

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## 1 TERMS OF REFERENCE

This report summarises new issues for Iwi around ethical and cultural considerations in conjunction with the documents *“The kidZnet Project - Guiding Cultural & Ethical Issues for Iwi”* November 1999, and *“An Ethical Framework for Cultural Issues: Discussion Document for kidZnet”* December 1998. This report should be read with *“The kidZnet Project - Guiding Cultural & Ethical Issues for Iwi”* November 1999.

Outcomes from this process include a greater understanding of Iwi issues and risks to the kidZnet project. Overall, consultation outcomes (as per the Stage 2: Consultation targets<sup>17</sup>) will require attention to the Iwi issues that have been identified over the last two years.

The report describes issues in addition to those in previous reports, and identifies risks. In particular, the final Te Arawa hui at Tunohopu resulted in the secretary for Te Mana Hauora o Te Arawa<sup>18</sup> withdrawing the support of that group. The implications of this and possible resolutions are briefly discussed. However, matters of this nature are considered critical and should be included in a planning strategy for Iwi by the partners in the kidZnet contract, Iwi representatives, and the project coordinator.

## 2 NEW ISSUES

### 2.1 RESISTANCE TO GOVERNMENT/CENTRALISED DATABASES

There has been some resistance to government controlled information systems for decades. The ‘Maori’ experience of government data collections has tended to be

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<sup>17</sup> OVERALL CONSULTATION OUTCOMES:

- Outcomes of the consultation for inclusion in privacy/ethical documents.
- Iwi/Maori health providers and consumer groups will have a clear understanding of the kidZnet project and the potential contribution to children’s health locally and nationally.
- Management of Iwi representative and group/organisations expectations in regards to the projects being developmental and the proposed outcomes.
- The gaining of Rotorua Iwi involvement with and influence of the project from the ‘ground up’.
- Clarification of the roles of the key parties: the Health Funding Authority, the Rotorua Child Health Trust, Rotorua General Practice Group, Health Waikato Ltd. and New Traditions,

<sup>18</sup> An association of Maori health providers in Te Arawa

negative. That is, they are seen to constantly reinforce the 'state' of Maori and result in few positive outcomes.

The kidZnet project is understood by some firstly to be a government information system because it is government funded. While kidZnet is presented as a joint project funded by the HFA, it may be beneficial to also look towards its presentation as a community project. However, this can only happen if it is – and that would require a clear statement of position by the HFA or the Ministry of Health. Assurances around this may be impossible to achieve. Therefore, a risk strategy would include mechanisms to identify the boundaries of governance/kaitiakitanga and to increase support ensuring the purpose of kidZnet, as a tool to improve children's health care is the key focus.

## **2.2 TE ARAWA SUPPORT, STRUCTURES AND INFLUENCE**

There are key people from Te Arawa who have not participated actively in kidZnet and there are those who have not offered support. This could be due to political fatigue (where Maori are 'fighting fires' on many fronts including environment, education, social and political), limited understanding about kidZnet, or a belief that kidZnet will not provide the 'safety' around information from government control. Tainui also have people that may not support kidZnet. A strategy around this would be productive to the project. A risk strategy should be developed to manage a possibly less than 100% participation.

Both Te Arawa and Tainui have processes for representing Iwi and Hapu and will require this to be accommodated. Support may be withdrawn by a mandated group (see Section C: Iwi or Hapu Mandates) on behalf of other groups. It is important to communicate effectively and to actively and visibly address their requirements where possible.

## **2.3 IWI OR HAPU MANDATES**

A mandate is a common form of representation often sought by organisations that wish to represent or make decisions on behalf of Iwi and Hapu. This is often granted after one or many hui and discussion before the mandate is granted. It often applies in situations where negotiation or political representation must take place. Te Mana Hauora o Te Arawa and both the Tainui and Te Arawa Maori Trust Boards operate under mandates.

The kidZnet management group would not seek a mandate, as it does not propose to represent an Iwi or Hapu. However, people who represent an Iwi or Hapu on the governance/kaitiaki group may have a mandate. This enables the person or group to make decisions on day to day matters but they may possibly return to *the people* on more critical matters.

## **2.4 ACTIVE IWI PARTICIPATION DURING TESTING**

At this time Orion and the HFA information technology section may not include a Rotorua Iwi provider in the testing of the computer system. However, specific cultural and ethical issues should be tested (eg. ethnicity fields) as well as general critique. It would be beneficial to establish credibility with Iwi by including them on an ongoing basis.

## **2.5 RGPG RELATIONSHIP BUILDING WITH IWI**

Some Rotorua Iwi believe that kidZnet is a Tainui/Hamilton project. The perception by members of the Hamilton partnership and myself is that the Rotorua partners have not yet established a productive and ongoing relationship with *coal-face* Hapu and Iwi groups. This can be disadvantageous to both Iwi and RGPG as both groups have contributions to make to the project and this should be pursued as a critical activity. Also, an understanding of Te Arawa protocols would serve to reduce offence and develop productive partnerships within the Rotorua region.

## **2.6 THE IMMUNISATION DEBATE**

The immunisation debate is active in Maori circles and should be addressed in terms of understanding the role of kidZnet in assisting pro-immunisation groups. My understanding is that kidZnet is a tool for *recording* details such as immunisations administered and due, as well as decisions by caregivers not to immunise. The concern amongst some Maori is that kidZnet will enable GP's and others to *push* pro-immunisation information onto undecided caregivers, or caregivers that have stated their anti-immunisation choice but will be 'harassed' to change their mind. It has been stated that kidZnet will not change the behaviour of GPs or other health providers in this regard.

## **2.7 LACK OF EQUIPMENT**

A recent stocktake for technical capacity amongst providers shows a technology problem exists with some Iwi providers that do not have computer systems. This situation should be explored with the HFA, KMG, project coordinator and the health providers concerned.

## **3 RISKS**

The following are possible risks to the project and its credibility.

- Te Arawa rejects kidZnet
- Tainui rejects kidZnet
- Negative media attention
- HFA and the Ministry of Health fail to make commitments either way around governance, ownership and control
- Iwi cultural and ethical issues seen as just another consultation exercise with no outcomes
- Maori children do not benefit from kidZnet

## 4 RECOMMENDATION

Strategic planning is outside the scope of this report but should be addressed urgently by the project coordinator and the kidZnet management group. This may include impacting areas such as:

- Marketing & media
- Governance
- Testing
- Risk management
- Task prioritisation
- Understanding clear HFA position
- Communication
- Cultural training