



Te Whaioranga

Te Whaioranga Website Research Report

May 2009

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Executive Summary

To inform the development of a web site (Te Whaioranga) for Pharmac, CWA undertook research (January-March 2009) that involved face-to-face interviews with whānau, phone interviews with health professionals and a focus group hui with Pharmac's Māori Advisory Caucus. (Appendix 1 provides detailed information on the rationale for the research methodology).

In addition to these primary sources of information, CWA analysed a number of key research documents (see Appendix 2), some of which were summarised and key themes extracted (see Appendices 3 – 6).

The purpose of the research was to collect objective views on what Māori whānau and health professionals wanted, in terms of an online health resource – thus avoiding any subjective design and development decisions when creating the web site.

It was also important for CWA to meet the needs of Pharmac, in having an online health resource and communication tool, summarised as follows:

1. To provide a place/portal for Māori health
2. To provide easy access to information for Māori whānau and health professionals
3. To ensure a high level of comfort in using the site
4. To set out a Māori glossary, complete with contextual information.

The findings of the research process illustrated congruity between the viewpoints of whānau and health professionals – in terms of the need for:

- tikanga Māori to be included on the Whaioranga site in a holistic, integrated way, e.g. Māori values/concepts, proverbs and te reo Māori;
- content to be current, easily accessible and couched in simple language;
- information to be included on traditional Māori healing (rongoā);
- a positive portrayal of Māoridom – to counter deficit thinking; and
- consideration of certain IT barriers when developing the site e.g. cost of home computers, lack of internet access, age barriers, and a preference for 'kanohi ki te kanohi' interaction.

The aforementioned findings were triangulated in the documentary evidence (Appendices 3-6), which specifically highlighted the need for:

- information to be communicated clearly and simply, couched in a positive tone, across a range of media, utilising illustrative case studies;
- content to be imbued with Māori cultural values and beliefs;
- health education resources to be targeted;
- consideration of the importance of a holistic, whānau-based approach to well-being; and
- more information on rongoā (traditional Māori healing processes).

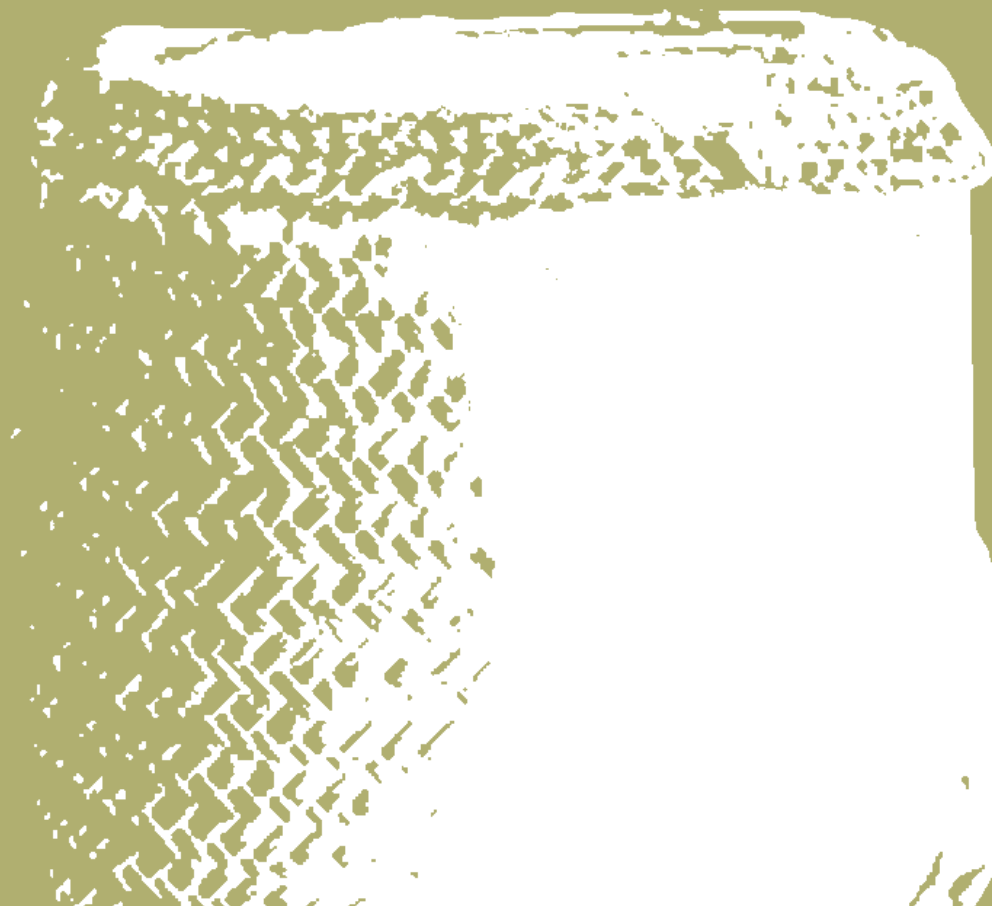
Based on the research findings, CWA herein sets out a draft site diagram, wireframes and makes recommendations in terms of:

- i) a 2-channel approach (whānau and health professionals), with the whānau side utilising Mason Durie's model of physical, spiritual and mental wellbeing
- ii) feature articles with whānau role models, to provide an authentic Māori voice in every section of the web site
- iii) the inclusion of 'welcoming' aspects on the home page e.g. mihi, karanga, karakia and waiata
- iv) a point of difference for this site
- v) a section on news and events ie paanui
- vi) the comprehensibility of medical information
- vii) suggestions for support/ supplementary information
- viii) a glossary of technical or medical terms
- ix) a facility for online inquiries

The point of difference in the Whaioranga site is that it can fill a need, especially with whānau, in drawing links between health issues, lifestyle, culture, family welfare and medicine usage.

*Nāu te rourou
Nāku te rourou
Ka ora ai te iwi*

With your efforts and mine, we will prosper/be well.



Introduction

In December 2008, CWA undertook the tasks of planning and conducting research to inform the development of the Te Whaioranga web site for Pharmac. The research was carried out between January 2009 and March 2009, during which time CWA conducted:

- face-to-face interviews with whānau;
- phone interviews with health professionals; and
- a focus group meeting with members of Pharmac's Māori Advisory Caucus.

In addition, a number of key research documents were also made available to the CWA team (see appendix 2). These were all analysed, with the main ones being summarised to determine key themes (see appendices 3 - 6). The analysis of these documents illustrated the complex and multi-layered health, economic and social issues affecting Māori.

Rationale for Research

The web site research was undertaken, with Pharmac permission, in order to collect objective views on what is important to Māori, in terms of an online health resource. The need to avoid subjective design and development decisions was vital in creating a web site that focused on both sets of stakeholders (whānau and health professionals), as well as meeting the needs of Pharmac in having an online health resource and communication tool. Appendix 1 provides detailed information on the rationale for CWA's research methodology.

The whānau research explored the values and needs of the target community, seeking clarity on what information was deemed to be important.

With the health professionals, we sought feedback on:

- issues associated with their keeping informed of Māori health issues;
- barriers to accessing information; and
- desirable features on the web site that would be beneficial for users.

To ensure that all sources of information were covered, and that the data was triangulated, it was important that CWA looked at:

- the original 'request for proposal' (see Appendix 7 for a summary);
- the documentary evidence that Pharmac provided (see Appendices 3 -6); and
- the information collected from whānau and health professionals.

The data collected during the research stage was used to guide subsequent decisions related to the visual design and development of the web site. This report by CWA sets out the thinking that should now underpin all areas of the web site (emanating from the findings of the research with whānau and health professionals). It also offers recommendations in terms of a cohesive solution for connecting with a Māori audience online.



Pharmac Goals for Website

The Te Whaioranga web site is one of the many action items that Pharmac is implementing over the coming years (see appendix 10) to achieve their 'Māori responsiveness' goals. From the outset of the project, it was CWA's intention that there would be an inclusive, consultative relationship between CWA, Pharmac and stakeholders.

To that end, the CWA team re-examined the original RFP (see appendix 7 for a summary), to confirm Pharmac's foci and trigger key discussion points, prior to any face-to-face research with whānau and health professionals. At a meeting with CWA in January 2009, Pharmac stated the following outcomes that were to be met within the site development:

1. An appreciation of the issues facing Māori in accessing and using pharmaceuticals
2. An emphasis on empowerment through knowledge
3. An understanding of the meaning behind the Te Whaioranga logo.

The specific aims of the Te Whaioranga site, as communicated by Pharmac, were:

1. To provide a place/portal for Māori health
2. To allow Māori to get information for themselves (whānau and health professionals)
3. To ensure a high level of comfort in using the site and ease in finding information
4. To engage the whānau audience but also appeal to health professionals
5. To provide easy access for whānau, thus reducing the workload of health professionals
6. To set out a Māori glossary (with up-front disclaimer) complete with contextual information (acting as pointers to other information on the site)

PHARMAC currently supports projects and programmes throughout the country. These programmes are:

- One Heart Many Lives;
- He Rongoā Pai, He Oranga Whānau;
- Gut Reaction;
- Diabetes;
- Wise Use of Antibiotics;
- We Can Make a Difference (WCMD); and
- Seminar Series

An important feature of the Te Whaioranga website is to maintain seamless links with other programme 'micro sites' and to incorporate elements of these programmes regularly, as news updates and items.



Findings: Whānau Research

To understand what whānau require from an online health resource (specifically the Te Whaioranga site), it was important for the CWA research team to first determine what questions needed to be asked of whānau, to avoid duplicating research that was currently done, or intended, by Pharmac.

With the help of Pharmac staff, a whānau-specific questionnaire was designed and implemented (see Appendix 8). The initial research material supplied by Pharmac (see Appendix 2) helped to guide the format of the questionnaire and frame the questions.

It was important in the design of the whānau questionnaire that each question was presented as an opening to initiate dialogue between the interviewer and interviewee, rather than using a format asking whānau simply to rate their (dis)agreement with a given statement.

The research questions focused on:

1. Where whānau currently got health information
2. Issues whānau experienced accessing health information
3. Patterns of use when looking for health information on the web
4. Sharing of information within the whānau
5. Features and types of information they would like to see on a Te Whaioranga web site

In total 60 whānau members were interviewed (28 males and 32 females).

Location	Matatini, Tauranga	Age 10 to 19	Age 20 to 29	Age 30 to 39	Age 40 to 49	Age 50+
Male	17	0	7	5	3	2
Female	17	2	2	5	2	6
Sub-Total	34					

Matatini, Tauranga - 19.2.2009 to 22.2.2009

Location	Other locations	Age 10 to 19	Age 20 to 29	Age 30 to 39	Age 40 to 49	Age 50+
Male	11	1	2	2	3	3
Female	15	0	0	5	7	3
Sub-Total	26					

Breakdown of people interviewed

Males	28
Females	32
Total	60

Question 1: Where do you go to get information about Māori health?

	Male	Female	Totals	Rated
I go to people who've had problems like mine	7	7	14	
I go to a doctor or a nurse	17	21	38	1st
I go to a tohunga (rongoā practitioner)	3	1	4	
I go to the library (or other community resource centre)		1	1	
I pick up bits and pieces on the kumara vine	8	12	20	2nd
I don't go looking for information about my health	2	1	3	
I look on the Internet	9	10	19	3rd
Other	3	8	11	

Feedback (other)

Contact an ex-primary health care worker

Google search rated amongst internet use

Read books, brochures

Consult family members involved in health care/practices (2 female)

Work in health sector (4 female)

Lot of information handed down

Contact health providers or local DHB

Consult kaumātua

Use internet to research illness of family member

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Question 2: What makes it difficult for you to get information about your health, or the health of a whānau member?

	Male	Female	Totals	Rated
I don't know who or where to go to	3	3	6	
I feel whakama asking questions about my body	7	6	13	2nd
I don't know what questions to ask or how to ask them	8	2	10	3rd
Sometimes I don't understand what the doctors/ nurses are explaining	7	8	15	1st
I feel scared in case I find out something bad/ugly	6	4	10	3rd
I have transport problems to get to the doctor, the library or the community centre	4	1	5	
Cost	2	7	9	
No difficulties	3	7	10	3rd

Feedback (other)

Not very aware of services available

Information given is not always clear; professionals need to be sympathetic of Māori needs in terms of information offered and medical language/terminology used.

Too much information to take in

Lack of consistency in mental health treatment (2 people commented)

Need for doctor or nurse to come down to whānau level

Not always sure about changes in drugs or introduction of new drugs - some don't work for whānau

No support when discharged from hospital – with long distances to travel home

NZ health care is very expensive

Prefer to talk to Māori health professionals, but they are not always available.

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Question 3: If there was a free heart-check service available, would you use it?

	Male	Female	Responded	Out of
Yes	24	27	51 people	out of 60
No	2	3	5 people	out of 60

Feedback (other)

Depends on provider – local doctor (yes) or another health provider (no)

Not comfortable with it

Health checks at more events

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Question 4: Do you use computers and the internet to get information about Māori health?

	Male	Female	Totals	Rated
Yes regularly	3	9	12	
Seldomly	5	7	12	
No	11	11	22	1st
I do use a computer, but not to get Māori health information	8	3	11	

If no, is this because				
I don't have access to a computer (but I can use one)	4	1	5	
I have a computer but don't have internet access	1		1	
I have a computer but don't have broadband, so it's too slow				
I can't use a computer	3	3	6	1st
Other	1	3	4	

If yes, do you trust the information you access on the internet?				
Yes	12	13	25	1st
No	3	4	7	

Do you share that information with others?				
Yes	16	16	32	1st
No	5	4	9	

Feedback (Not to get Māori health information)

No interest/not bothered
 Prefer face-to-face
 See a doctor instead

Feedback (Don't trust internet information)

Hard to prove web sites are trustworthy
 What's online differs to what you are told
 All information is not credible
 Aware of a lot of internet scams
 Not reliable

Feedback (Yes to sharing info with others)

Share information with family and friends
 Get info from DHBs and other health providers
 Depends on the information
 Only share important information
 Needs to be a trusted site

Feedback (No to sharing info with others)

Don't want to pass on incorrect information
 Privacy issues

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Question 5: Whose web sites do you use to get information about your health?

	Male	Female	Totals	Rated
Search engine	17	16	33	1st
I saw a web site address in a magazine or newspaper	5	3	8	
I heard about a web site on the radio	4	2	6	
I heard about a web site on TV	6	4	10	3rd
I found out about a web site address in the library	1	1	2	
From another iwi web site	5	1	6	
Other	6	6	12	2nd

Feedback (Which search engines)

Google rated highest

Yahoo

Wikipedia

Feedback (Which magazine or newspaper)

NZ Health & Food Guide

Mana

Fitness books

Feedback (Other)

Govt. department web sites

Hauora (health) links

Ministry of Health web site

Health pamphlets and brochures

DHB links

healthed.govt.nz

Word of mouth

quit.org.nz

nhf.org.nz (National Heart Foundation)

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Question 6: What do you like about the websites you use for information about your health?

	Male	Female	Totals	Rated
good articles/content on how to take care of my health, or my whānau	7	9	16	
medical information (illness, specific Māori health issues etc)	7	9	16	
short "How To.." guides and fact sheets	7	9	16	
the look and feel of the design	7	4	11	
information is easy to find	12	9	21	1st
able to search for specific health topics within the site	12	9	21	1st
able to ask for more information (through enquiry forms and online forums)	7	5	12	
there is a list of contact details about where to go for help	8	12	20	2nd
ability to contribute my views on the web site	7	3	10	
links to other helpful information	5	8	13	
news and event updates (Pānui)	9	5	14	

Feedback (other)

Avoid medical jargon

Not too technical

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Question 7: The final section asked people's opinions on what would they would like to see on the Te Whaioranga web site.

	Male	Female	Totals
Health issues (kaumātua vs rangatahi). Difference in age gap (elders vs youth) e.g. Going to GP if older vs. getting info online	1		1
Simple language usage	1		1
Site needs to be seen to be made/run by Māori		1	1
Māori messages, proverbs and values	4	2	6
Koru symbol used on the site		1	1
Forums to post opinions	4	1	5
Rongoā information	1	6	7
Bilingual	6	3	9
Relevant information		1	1
Information is current and updated frequently	4	2	6
Organisation of information by age and gender	1		1
Comfort and trust must come through on the web site	2	2	4
List of Māori health organisations	3	4	7
Help for non-IT savvy people		1	1
Personal stories from Māori around health	2	2	4
Credible face of Māori (experts) to introduce the web site	1	2	3
Instructions for making rongoā		1	1
List of rongoā practitioners		1	1
Values and words referenced: "manaakitanga", "awhi", "wairuatanga" (spirituality)	1	1	2
Obesity information		1	1
Promotion of the web site	2	1	3
Medicinal marijuana	1		1
Stats and Evaluations on Māori health programs (local/regional and national)		1	1
Information about health grants and medical subsidies ("WINZ")	2	1	3
List of Māori health practitioners (location and expertise/specialities)	2	3	5
Information about access to disability tools (wheelchairs, crutches, etc)	1		1
Stats on DHBs	1		1
"How to..." guides (e.g. prevention, registering with GPs etc)		3	3
GP cost schedules (by region)	1	3	4
Self diagnosis		2	2
Download guides		1	1
Update on drugs (information and explanations)		1	1
Feedback options and information on response times to requests made	1	3	4
Call to young Māori to enter the health profession		1	1
Support contact details for emergencies		1	1
"Māori voice"		1	1
Te Whare Tapawhā (Mason Durie)		2	2
Home-care and support information		1	1
Additional support services & information (poverty and related inequality health issues; including free services)		5	5
Top 10 illnesses and guides to managing them		1	1
Local mobile services information	1		1
Glossary		1	1
Treatment plans		1	1
Drug side-effect information		1	1

Note: Numbers above indicate the amount of times a particular question or answer checkbox was ticked.

Summary of findings from the Whānau Research

Themes

The main themes emanating from the whānau research were as follows:

1. Sources of health information were mainly
 - the local doctor or nurse; and
 - the 'kūmara vine'
2. Difficulties in getting health information included:
 - lack of understanding of health professionals' advice;
 - feeling whakamā; and /or
 - not knowing (or feeling scared about) what to ask
3. Accessing health information on the computer was:
 - irregular, or not at all; but
 - generally trusted and shared

(NB Some respondents could not use a computer).

4. Points of access were:
 - mostly through Google; and
 - ads on TV.
5. Things that whānau requested on a health web site aimed at Māori were:
 - information that was easy to find, and current
 - ability to search quickly and easily for health topics
 - lists of health contacts and services available
6. Māori-specific aspects that needed to be integrated into the web site were:
 - inclusion of te reo Māori ie bi-lingual site
 - information about rongoā
 - lists of Māori health professionals & practitioners
 - use of Māori messages and proverbs to communicate whānau values
 - information about additional support services available for Māori.

Issues and Opportunities

The research with whānau raised some important issues impacting on the Te Whaioranga web site. It also provides some opportunities.

1. In general, most of the people interviewed do not use computers to access information about health issues. Some do not use the computer at all, while others prefer to talk directly to a health professional.
2. Of those whānau who did use the computer to get health information, the proportion of women was higher than that of men (3:1 ratio).
3. Those people who did access online health information generally shared this information with other whānau members. This is an interesting finding in light of the 2007 report on Social Connectedness in New Zealand, published by the Ministry for Social Development, which states that:

Being able to communicate and interact easily in the absence of frequent face-to-face contact helps maintain social connectedness. Access to a telephone and access to communication via the internet, especially emails, are particularly relevant as social indicators...

The internet also makes it easier to access a significant and growing repository of information and knowledge.



4. For Māori in New Zealand there is no central online point of reference for health information. While this is far from ideal, it does offer Pharmac a unique opportunity to promote and support Māori health and wellbeing through the Te Whaioranga site, creating a significant online presence in this area.
5. Notwithstanding this opportunity, the research indicates that there is some reluctance for the older generation to use the internet as a source of information on health issues. Instead, they tend to rely on younger whānau members or local health professionals (e.g. district nurses) to provide the information or seek clarification on current medicines. This underscores the need for us to create a supportive website, not only for the whānau members who may be ill, but also for rangatahi and health professionals to access, and possibly print out, relative information to help older whānau members.
6. Local doctors and nurses with an understanding of, and relationship with, whānau are ideal advocates to support and promote the Te Whaioranga site.

Te reo Māori me ōna Tikanga

Whānau requested the presence of Māori values and proverbs on the website to help them connect with the messages. A strong bias for a bilingual site also came through. People want to connect with a site that is purposefully created with a Māori focus – not a corporate 'jargon-laden' site.

With this strong plea, it is important that Māori-centered images and values permeate all parts of the web site. The site must embrace and celebrate Māori values, communicating a sense of manaakitanga, awahi and wairuatanga (spirituality).

Language /tone of written content

Respondents advised that any information and medical articles to be published on the site should be easy to understand. Similarly, medical

terminology should be avoided and replaced with simple language. Needless to say, all information needs to be current and kept up-to-date.

Informants reported that information about using medicines was invariably hard to understand. In addition, the material was too jargon-laden and presented problems for those with literacy problems, sight impairments and, in the case of aural instructions, hearing issues. The literature cited in Appendix 2 highlights the same issues.

Supporting information

As well as contact information for primary health services¹, whānau requested information about additional support services – specifically those services addressing prohibitive costs.

People requested information on the location of secondary services² and how to access these services. On the website, contact details of health professionals could be organised by rohe, with cost schedules or available subsidies for related services published alongside.

Supporting health service information could include:

- Information and statistics about DHBs
- Hauora links
- Government department links
- Fact sheets and guides
- Regional lists of GPs and health professionals
- Links to any relevant secondary health² or social services.

Supporting information needs to be supplied for whānau who feel whakamā or uncomfortable asking questions of health professionals. This point was documented in the report Māori Use of Medicines (2004) – and was reiterated during the whānau research phase.

¹ Primary health care relates to the professional health care received in the community, usually from your GP or practice nurse. Primary health care covers a broad range of health and preventative services, including health education, counselling, disease prevention and screening. (<http://www.moh.govt.nz/primaryhealthcare>).

² Secondary health care includes hospitals and referrals to other services, e.g. specialist referral or assessment. (<http://www.moh.govt.nz/publichospitals>)

Rongoā information

The need for information about (and access to) rongoā came through in the research. There remains, however, a question of where best to locate such information on the web site. That is, should this information be located in a section on its own, or should it be available within both the whānau and health professional sections, as a sub-link (side bar menu link)?

Trusted information

The Te Whaioranga web site offers Pharmac not only the opportunity to create a rich and helpful online resource for Māori, but to become a trusted source of information. This can be achieved by the inclusion of concepts and proverbs central to whānau, thus acknowledging:

- ngā tīpuna me ngā uri (the generation before and the generation to follow); and
- the need for whānau to stay well, to ensure the intergenerational transmission of te reo and mātauranga Māori.

Māori reference points throughout the web site would encourage people to ask questions without feeling whakamā, talked down to or excluded. Similarly, statements and brief comments from a broad range of whānau would make the site welcoming and inclusive.

Rather than focusing on whānau members who are ill, the website needs to celebrate those Māori who are living happy and full lives – acting as role models, achieving their potential, sharing lessons and affirming Māori values. The tone of the site should be away from deficit thinking – focused instead on aspirational thinking and Māori potential.

This positive approach needs to be exemplified with authentic Māori ‘voices’ that communicate with honesty.

Findings: Health Professionals' Research

Six phone interviews were carried out with health professionals. In addition, four of these people took part in a focus group session conducted with Pharmac's Māori Caucus.

These discussions focused on:

- the gathering of information in a health professional context;
- personal motivation to work within the health sector;
- aspirations for the future of Māori health; and
- their vision for the Te Whaioranga web site.

(See Appendix 9 for the health professionals' research questionnaire).



Summary of findings from the health professionals' research

An authentic voice

Respondents indicated the need for an authentic Māori voice to be communicated on the site. Combining Māori proverbs and values, as well as everyday images of Māori, was deemed to be extremely important. They advocated for content aimed at whānau, to be written and presented holistically, with proverbs integrated into the main body of the text, in a contextualised way.

Similarly, it was felt that links between the past, present and future, important for all whānau, needed to be reflected throughout the web site – and that photographs of Māori should convey normal whānau settings, not be staged or restricted to traditional settings like the marae.

Barriers and issues

Barriers to accessing the web include:

- Cost (e.g. no computer in the family home)
- Lack of internet access (and even phone lines) in rural areas
- Technology fears/ignorance e.g. kaumātua not accessing the internet even if a computer was available
- Preference for '*kanohi ki te kanohi*' interaction with doctors and health professionals – which may preclude them from ever seeking information from online sources.

It was acknowledged that many medical sites provided only complex medical information that needed to be demystified/ reversioned to be understood by whānau. The language used throughout the whānau section of the website should therefore be clear and unambiguous. Medical terminology and jargon should be replaced with easy to read advice and guidance e.g. factsheets; one pagers; visuals. And a glossary should be included to help whānau understand medical terms.

With certain whānau not accessing the web site (or using a computer) there needs to be a range of support materials that can be accessed by GPs and (district) nurses, and given to Māori patients. These resource materials could focus on whānau ora – written in clear, Māori-friendly, unambiguous language. Creating such resources would allow health professionals to print key information on flyers and factsheets for easy distribution to whānau.

Moreover, the research suggests that there is still a degree of stigma around certain illnesses (particularly mental health). Therefore, any information or factsheets that support health professionals to de-stigmatise these issues amongst whānau would be helpful.

Multiple channels (organised, for example, according to kaumātua, mātua and tamariki; tinana, hinengaro and wairua), with supporting key messages aimed at whānau, will be important on this site. There is a need to resist focusing on any one group (eg kaumātua) – because, as has already been stated, younger whānau may be the conduits searching for, and printing out, health information for their kuia/ koroua.

The lack of a shared understanding between GPs and whānau is still an issue in some areas, especially where GPs are outsiders. Support information on the web site for GPs and other health professionals, when dealing with Māori patients, is recommended.

What is needed?

There are currently many health information web sites available – some based in New Zealand and some overseas – with varying degrees of useful information. It is important for the Te Whaioranga site not to replicate web sites that are currently set up. It would be better to offer links to these web sites and focus on creating content for Te Whaioranga that fills the gaps, in terms of information for health professionals and whānau.

A number of key imperatives were suggested by the health professionals, as follows:

- Te Reo Māori needs to be integrated into the site – not just used as a decorative aside, but in a meaningful, contextualised way.
- There should be a focus on *whakawhanaungatanga* (relationships).
- Positive male and female role models should be visible.
- Information should be presented simply.
- The website should include information on medicines and their side effects.
- Whānau-centered support information should be easy to understand.
- In the case of the sharing of medicines amongst whānau members (borne of cost issues), the website should not

adopt a dictatorial tone. Instead, an 'informative advocacy approach' is needed, so that whānau feel they are not being rebuked or treated as being kuare.

- The benefits of current medical practices and initiatives should be highlighted e.g. clinical research and mental health programmes. There is a need to both raise awareness about health studies and also let people know how to get involved with programmes that will benefit all Māori.
- (District) nurses should be targeted as information conduits and relationship brokers.
- Non-Māori GPs and health professionals need to be acculturated to understand the benefits of a 'whānau' approach to wellbeing and medicine use.
- There should be a section on the site about rongoā – including information on any issues regarding the mixing of rongoā with western medicines.
- Messages should be framed in a positive way, supported by positive images – rather than focusing on the negative.
- Pharmac and CWA need to be aware of barriers to accessing the web site.
- There needs to be information, contact details and links not only for primary health services but also for secondary/ support services too.

What matters?

Regardless of developments in communication technologies, direct contact (*kanohi ki te kanohi*) is still central for Māori when seeking information about themselves or their whānau. Health professionals report that their best work happens when it is face-to-face (*Best Practice Journal No 13*). But for non-Māori GPs and health professionals to be truly effective in communicating with whānau, they must first understand the Māori perspective and how whānau-orientated values differ from the individually-centered Western norm.

Focusing on the positive aspects of Māori tikanga should be a key characteristic of the web site. Negative messages may reinforce stereotypes, and act as a disincentive to change. The focus should be on Māori living well, keeping well and enjoying life. Secondary to that should be support information for Māori who are ill or want to avoid becoming unwell. This is an important paradigm shift, starting from a positive position – which requires us to re-frame our language.

*He oranga ngākau,
he pikinga waiora.*

*Positive feelings in your heart will enhance your
sense of self-worth.*

Toi te kupu

Retain the language

Toi te mana

Retain dignity

Toi te whenua

And in so doing, retain one's identity with the land

Conclusions

In terms of **tikanga Māori**, there is congruity between what whānau and health professionals recommend as necessary and appropriate for engaging Māori on the Whaioranga site, namely the inclusion of:

- te reo Māori;
- whakatauki;
- Māori values and concepts; and
- an authentic Māori voice.

It was felt that these aspects needed to pervade the website, in a holistic, integrated way.

Similarly, both sets of respondents (health professionals and Māori whānau) reinforced the need for **information** to be current, easily accessible and set out simply.

The need for information on **traditional Māori healing** (rongoā) was also articulated by both groups – with health professionals requesting information on issues related to rongoā and Western medicines being used simultaneously.

Health professionals advocated a **positive portrayal of Māoridom** – to bring about a paradigm shift, in terms of changing the usual deficit thinking.

The feedback from both groups of stakeholders highlighted that there were **IT barriers** that needed to be considered in the development of the site. These include the cost of computers for home use; the lack of internet access in rural areas; age barriers inhibiting kaumātua from using the computer; and a preference by many Māori for “interaction with doctors and health professionals – which may preclude them from ever seeking information from online sources.

The aforementioned conclusions are triangulated by the research, as is evident in the summaries that appear in appendices 3 - 6, which specifically highlight that:

- information needs to be communicated clearly and simply, couched in a **positive tone**, across a range of media, utilising illustrative case studies
- content needs to be imbued with **Māori cultural values** and belief, to reflect, and honour, Māori tikanga;
- health education **resources** need to be targeted and designed in such a way as to accommodate the different sectors of the community;
- consideration needs to be given to the importance of taking a holistic, **whānau-based** approach to well-being; and
- there needs to be more information on **rongoā** - in particular, the scope for complementarity between western medicines and traditional Māori healing processes.

Recommendations

Based on the research findings, CWA sets out (on p33) a draft site map diagram with supporting wireframes (p34-40). We make the following recommendations.

The 2-channel approach

In order to provide audience-specific content throughout the website, CWA recommends a 2-channel approach. This will separate the website into two key areas – whānau and health professionals. Whānau-specific content will focus on ease of accessibility, ease of use, whānau-related health issues and the removal of all jargon or terminology that may act as a barrier to whānau being empowered through access to information. The type of key information and downloads available to whānau will need to be compiled in a specific way to meet their needs.

Our idea is to structure whānau content around Mason Durie's model of physical, spiritual and mental wellbeing – based on te tinana, te wairua me te hinengaro. Using te reo Māori will help set the tone of the site for whānau; it will also help to align with Māori values. A personal statement and photograph upfront would personalise the site, and add credibility, whilst at the same time avoiding the corporate 'voice' (which may be off-putting for whānau members). The supporting content would speak in physical, spiritual and mental dimensions.

These points are important as the site needs to be authentic and appeal to whānau in terms that they can relate to.

The needs of health professionals will differ from that of whānau. This section could hold technical and medically-laden health and research articles.

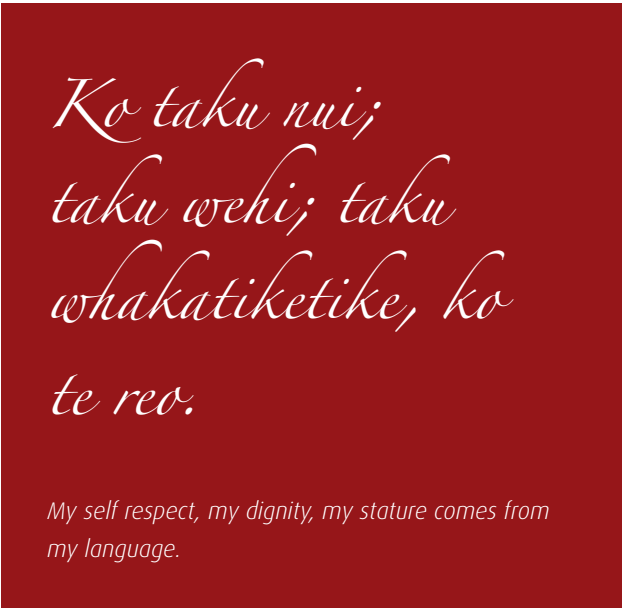
Feature articles/ case studies

Having a number of feature articles that exemplify whānau role models is an ideal way to support the concept 'for Māori, by Māori'. To that end, the website needs an authentic Māori voice to come through every section.

Ideally we would also recommend using photos of whānau – with accompanying quotes to set a very personal and positive message for all visitors. Short summaries and quotes could appear on the main key pages, inviting visitors to read longer related case studies.

Introducing visitors to the website

Unlike many tauīwi sites, the Te Whaioranga website needs to welcome all visitors. This could be done by having links to a karanga, karakia, mihi and waiata on the home page. Audio files could accompany each of these welcoming, 'grounding' links – presented as an option to listen to, or not.



*Ko taku nui;
taku wehi; taku
whakatiketike, ko
te reo.*

*My self respect, my dignity, my stature comes from
my language.*

Avoidance of duplication

It is important that the Te Whaioranga web site does not simply duplicate health information that is currently available online. The website's *Resources* section can act as a useful repository of web links, as well as providing strong information about primary and secondary healthcare services.

Where the Whaioranga site can fill a need, especially with whānau, is in drawing the relationships between health issues, lifestyle, family welfare and medicine usage. This can be done in an engaging and useful way by organizing content around Māori values/concepts and what information is needed to help whānau live a healthy, full life – taking care of each other and Papatuānuku.

News and events / paanui

The *News and Events* section could be divided into specific listings for whānau and health professionals. Newsletter subscriptions (monthly or quarterly) could be added to the site as a way of keeping people up to date with new health developments and advocacy initiatives.

News and events would need to be easy to upload and edit, as well as having the ability to auto-archive (such that old items are automatically listed within 'archive' links, without the need for Pharmac staff to manually carry out the task).

Access to medical information

Instead of simply providing clinical medical information for whānau, the site should ideally focus first on Māori wellbeing and then, secondarily, provide links to medical and associated healthcare information.

During the research, whānau requested that all medical information be easy to find on the site but, more importantly, easy to read and understand. There should be cross references to associated health issues related to the side effects of medicines, lifestyle choices and healthcare information – as well as summary factsheets. All should be easily accessible when whānau are in the *Medicines* section of the web site.

Whānau also requested information about secondary healthcare and support services on the website. These could be included in a Resources section along with information about DHBs and other key health service providers. Ideally, we would also recommend that all lists and data should have the ability to be arranged by:

- region (as in the case of the Ministry of Health site, where Maori health providers are searchable by rohe), or
- any other criteria that visitors may find useful.

This could be done by providing a simple criteria filter for visitors, to allow them to browse, search or arrange information in a way that suited their specific needs.

Because of the wealth of material on the Ministry of Health site, in terms of primary and secondary care, we could provide links to the relevant sections thereof – thus giving whānau the option to remain with Te Whaioranga, or follow a link to the Ministry's site.

For health professionals the ability to access and search current, and new, medical articles will also be important.

Support material

To address issues highlighted in the *Māori Responsiveness Strategy report* (2002), the website would be an ideal location for any fact or information sheets already created by Pharmac, as well as health guides, professional presentations, or e-training components. Support material could include:

- Simple summaries/overviews e.g. of main research reports (as exemplified in Appendices 3 - 6)
- Visuals created to illustrate step by step instructions on how to use medicines
- Information about safe use and storage of medicines
- Video and media content relating to advocacy programmes
- Information flyers about the Te Whaioranga website and the services on the site. (This could be used as a promotional tool for doctors and district nurses to pass onto whānau during visits or consultations).

The research shows that some whānau members, although needing information, may not access the web site but instead rely on rangatahi or district health nurses to access and download information for them. So, information needs to be organised in an easy-to-find way.

Optimising the pathway into the site

Because whānau entering the site are likely to do so via a search engine, care would need to be taken to ensure that landing pages for key words provide a rich entry point into the site, rather than assuming that most site visitors will first come to the homepage and browse through the site from there.

CWA would be able to work out a set of key words or terms that need to be covered. They would create a page that Google would send users to when they searched a particular key word/ term. This page would be a gateway into the different information on the site, as related to the key word/term.

There could be links to other key content on the site. Moreover, it could be set up in such a way that users arriving at these pages from an external source got 'snippets' of the welcome from the homepage. This approach would address the problem of people searching Google for 'gout' (as an example), and arriving at the site only to get a page with the glossary entry for that term.

Glossary

At certain points in the site there will be times when technical or medical terms may be used. Therefore it is CWA's recommendation that a glossary be added to the website. This glossary should also have the ability to cross-reference other terms and provide contextual information about how the terms are used or applied.

Question and Answer facility

To support the '*Glossary*' and '*Medical Information*' sections, the ability to send a question to Pharmac (using an online enquiry form) should be available from all sections of the website. This would be an interactive program, where people could enter their personal details, ask questions and get those questions answered (or, at least, have increased confidence to take their issues to the doctor thereafter). Moreover, immediate responses would inform the visitor when they should expect a reply to their question.

In addition, the ability to capture a reference to the page the visitor was viewing when they sent the question could also be sent to Pharmac, along with their question.

Additional Recommendations

These additional recommendations outline features or specific items that may not be completed within this stage of the website's development. However, CWA wishes to highlight certain discussion points for consideration after the first phase of the web site is complete.

Self diagnosis

A few whānau respondents were very keen to see a facility that would allow them to 'self diagnose' or verify a condition/illness – to save costs incurred going to the GP.

Multimedia 'hauora' game aimed at rangatahi

This was recommended by one of the health professionals, as a way to entice young people into the web site and also provide key health information/advice that rangatahi could follow up with their doctors.

Free online games are an ideal way to build viral marketing into the website, as people pass the link or downloaded games onto other whānau members.

Engaging screen savers that are available as free downloads from the website would also be an extremely easy way to support the marketing of the website.

These multimedia content elements would be good items for Pharmac to consider in their subsequent development of the Te Whaioranga website.

Forums

At this stage there may not be the capacity within Pharmac to manage and moderate online discussion forums. However, as a service, it would offer Pharmac the opportunity to build rich and informative communication channels with both whānau and health professionals.

Ideally each group should have their own specific discussion forum. Related topics could be posted and discussed together.

For the next phase of the web development, it may be worthwhile to discuss the option of CWA offering a management and moderation service for the forum, on an ongoing basis, to ensure that all discussion threads are monitored. This would reduce the daily workload of Pharmac staff.

Full video mosaic feature

For the next phase Pharmac could re-examine the possibility of adding a featured page of 12 to 16 video interviews of key people involved in the initial hui process and the publishing of the *Māori Responsiveness Strategy report* (2002).

Future marketing of the Te Whaioranga website

For the next phase of the website CWA would welcome an opportunity to work with Pharmac in researching, formulating and implementing a long-term online and offline marketing plan to help build greater awareness of Te Whaioranga.

Closing statement

Every child is born with personal 'tapu', emanating from Ranginui and Papatūānuku and their tamariki, ngā atua Māori³. Tapu teaches us to respect nature. As we go through life, we need to protect this 'tapu' (and other people's tapu), to ensure that the spark of life, the life principle, is at peace i.e. mauri tau – physically, socially, psychologically and spiritually. We are responsible for shaping our child's wairua and hinengaro⁴ in a positive way; we are the conduits for the values we want to instil – nō ngā tūpuna i tuku iho, as handed down from the ancestors.

*Ehara taku toa i te toa
taki taki, engari he toa
taki tini.*

My valour is not mine alone but that of many



³ The Māori demi-gods

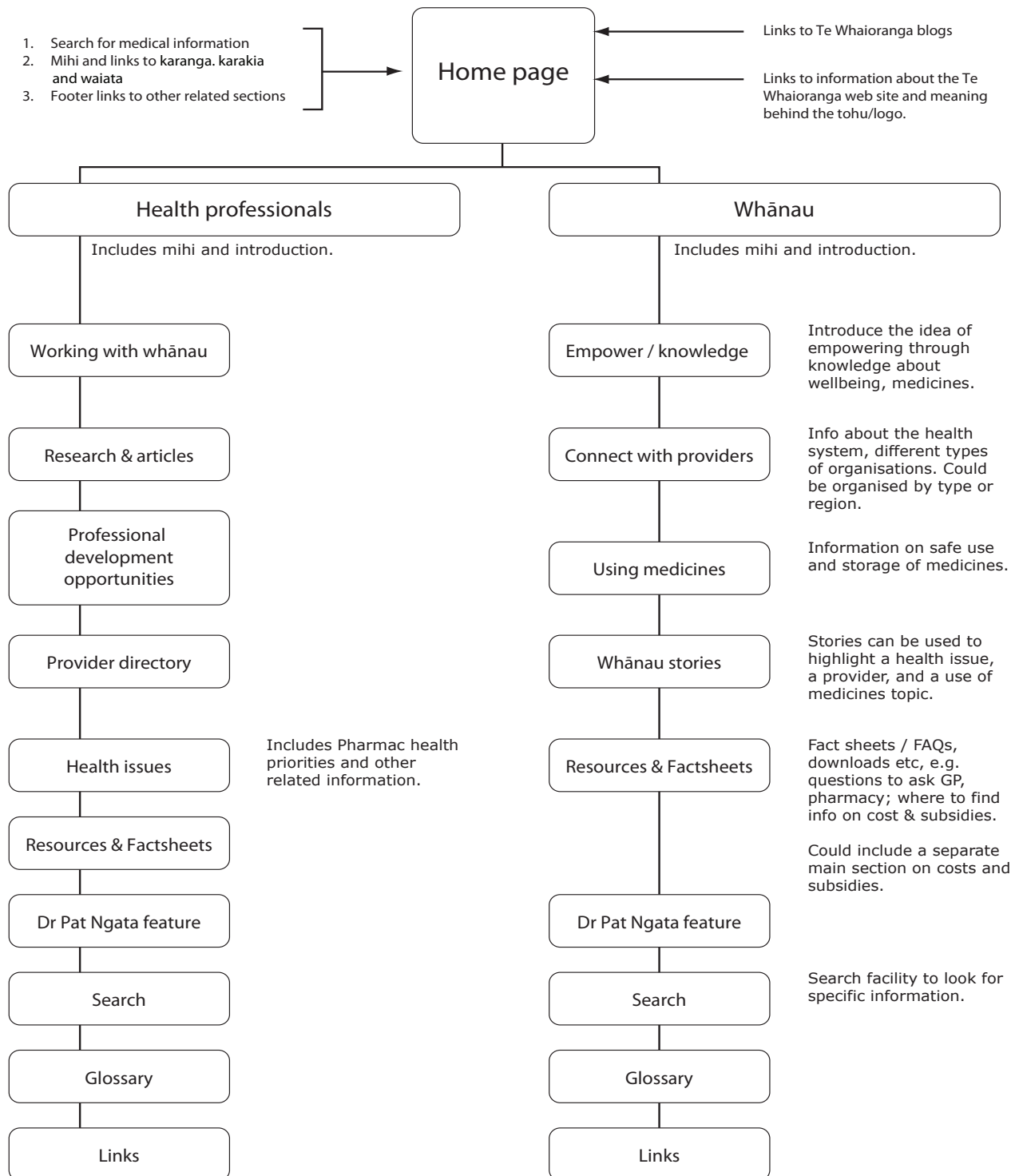
⁴ Mind

Site map diagram

Based on the 2-channel approach, the site map for Te Whaioranga would present separate sections (or points of entry) into the website for both whānau and health professionals.

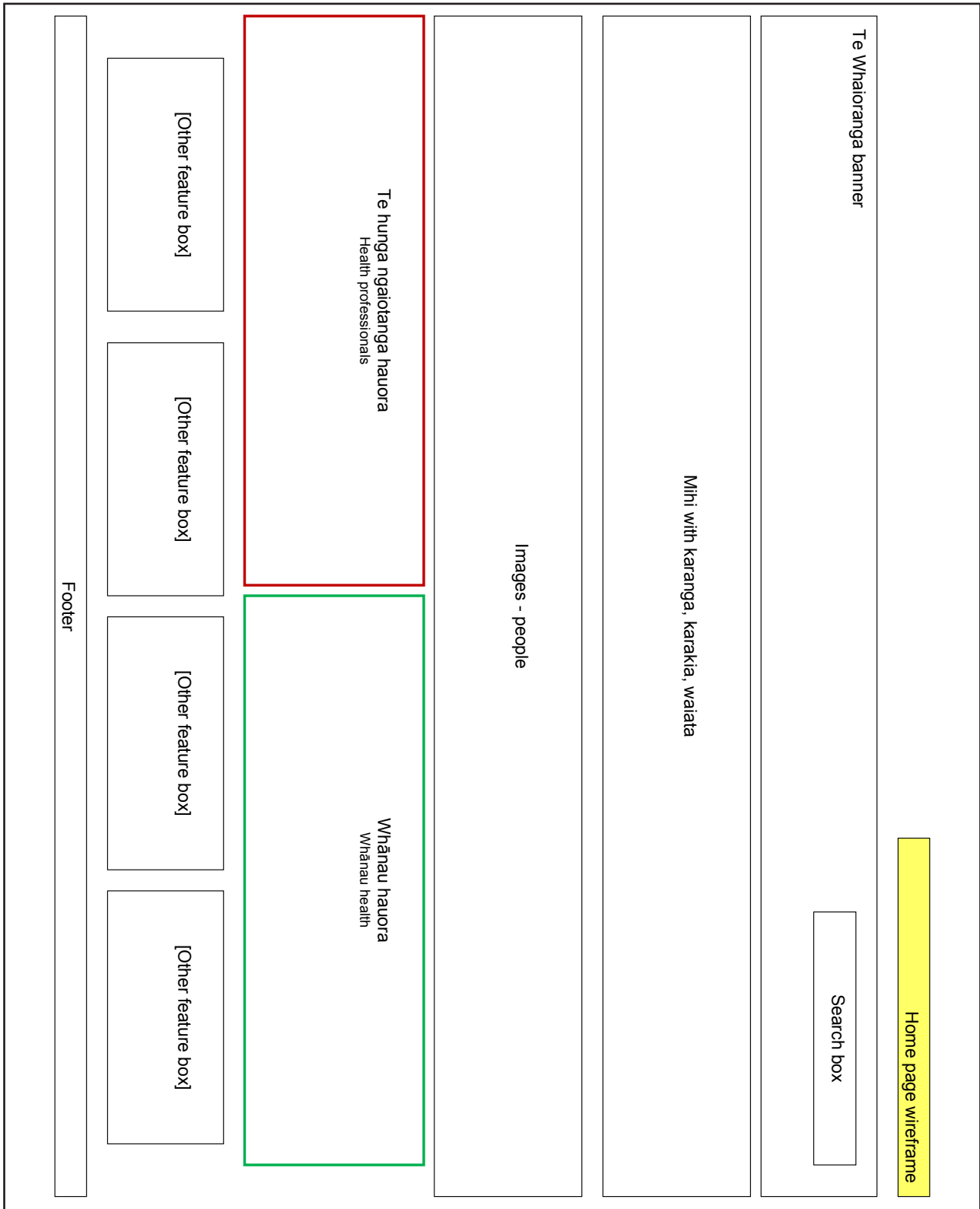
This approach will allow Pharmac to tailor all content, page titles, types of articles and associated links and sections to the needs of each specific group.

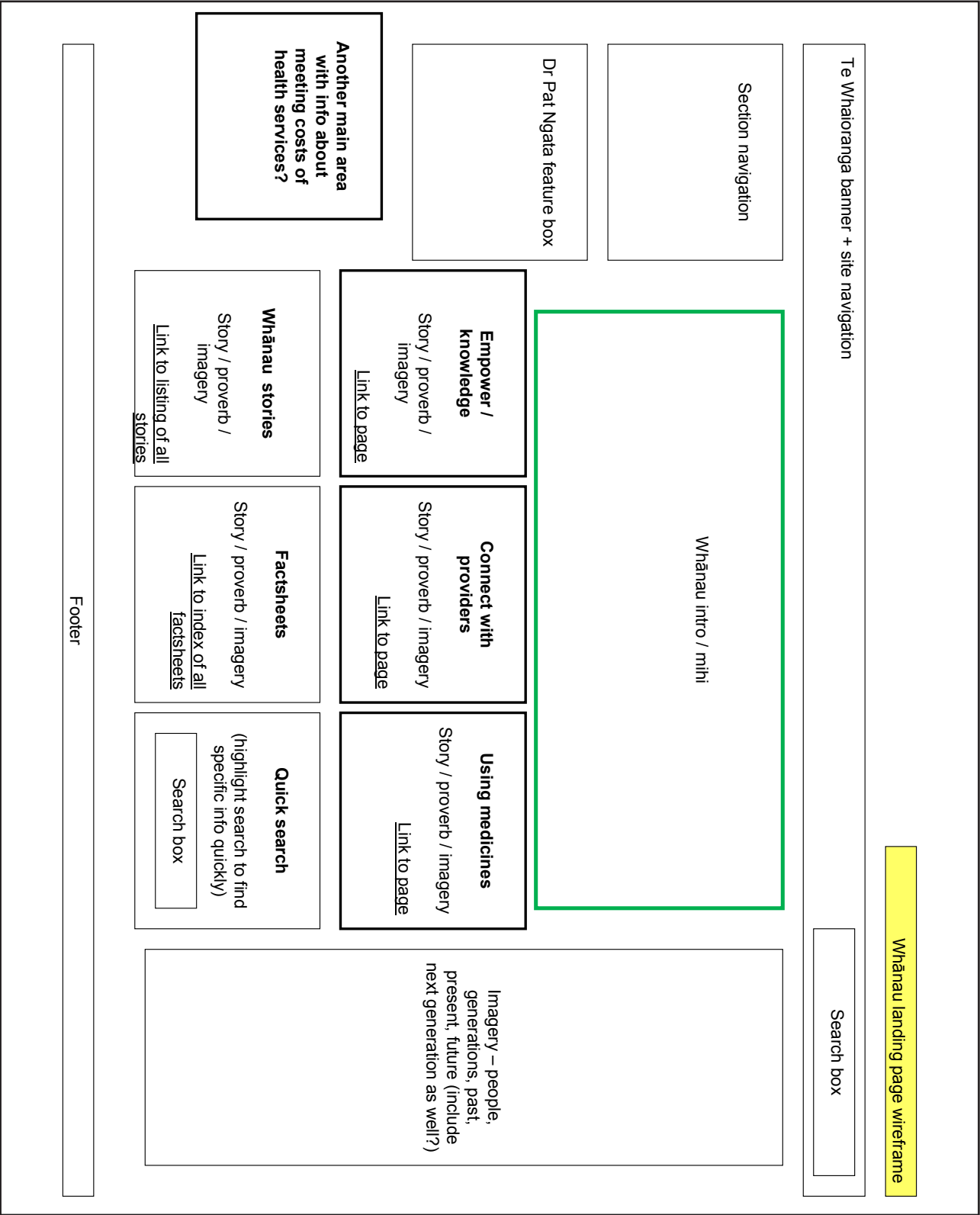
Site map diagram

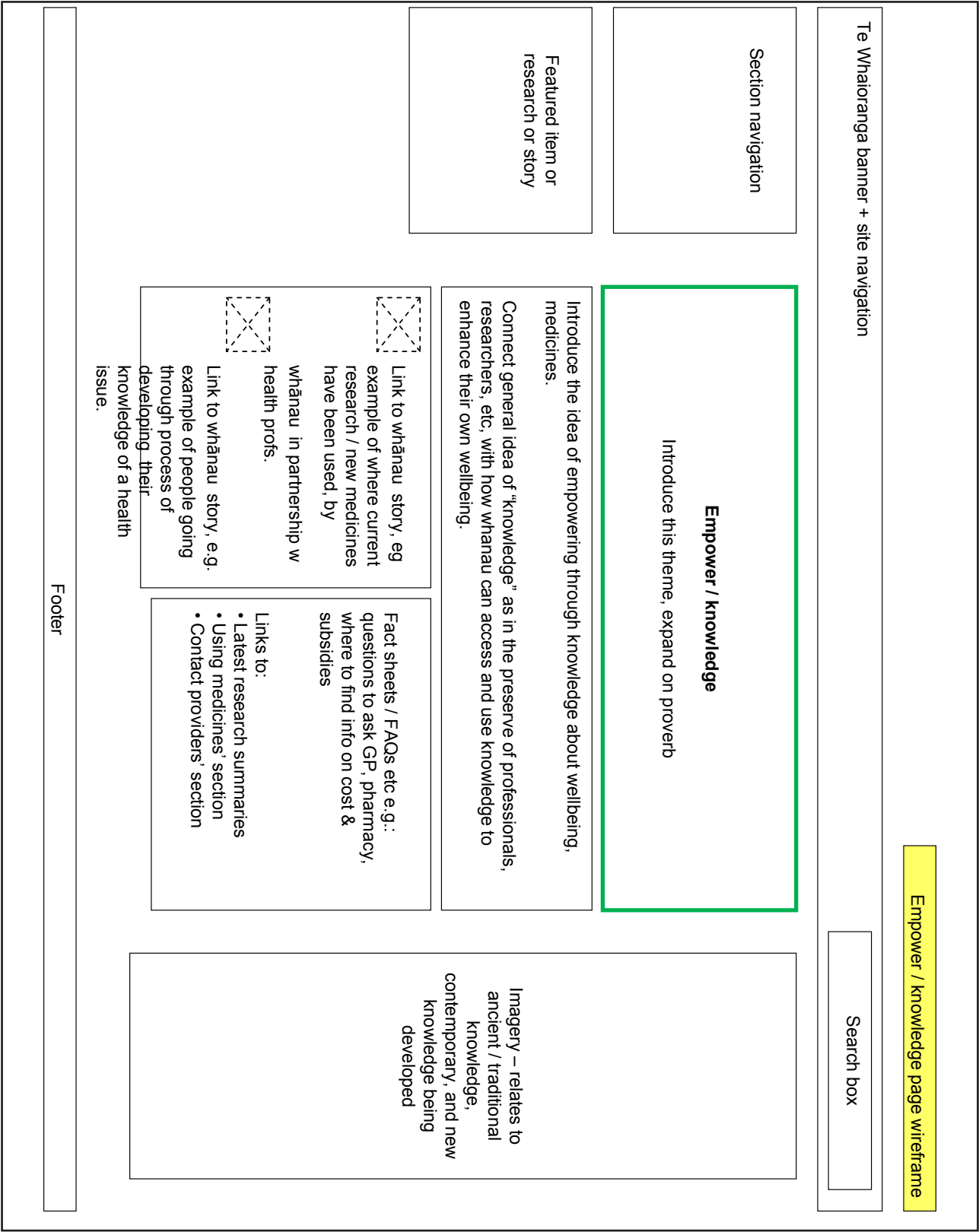


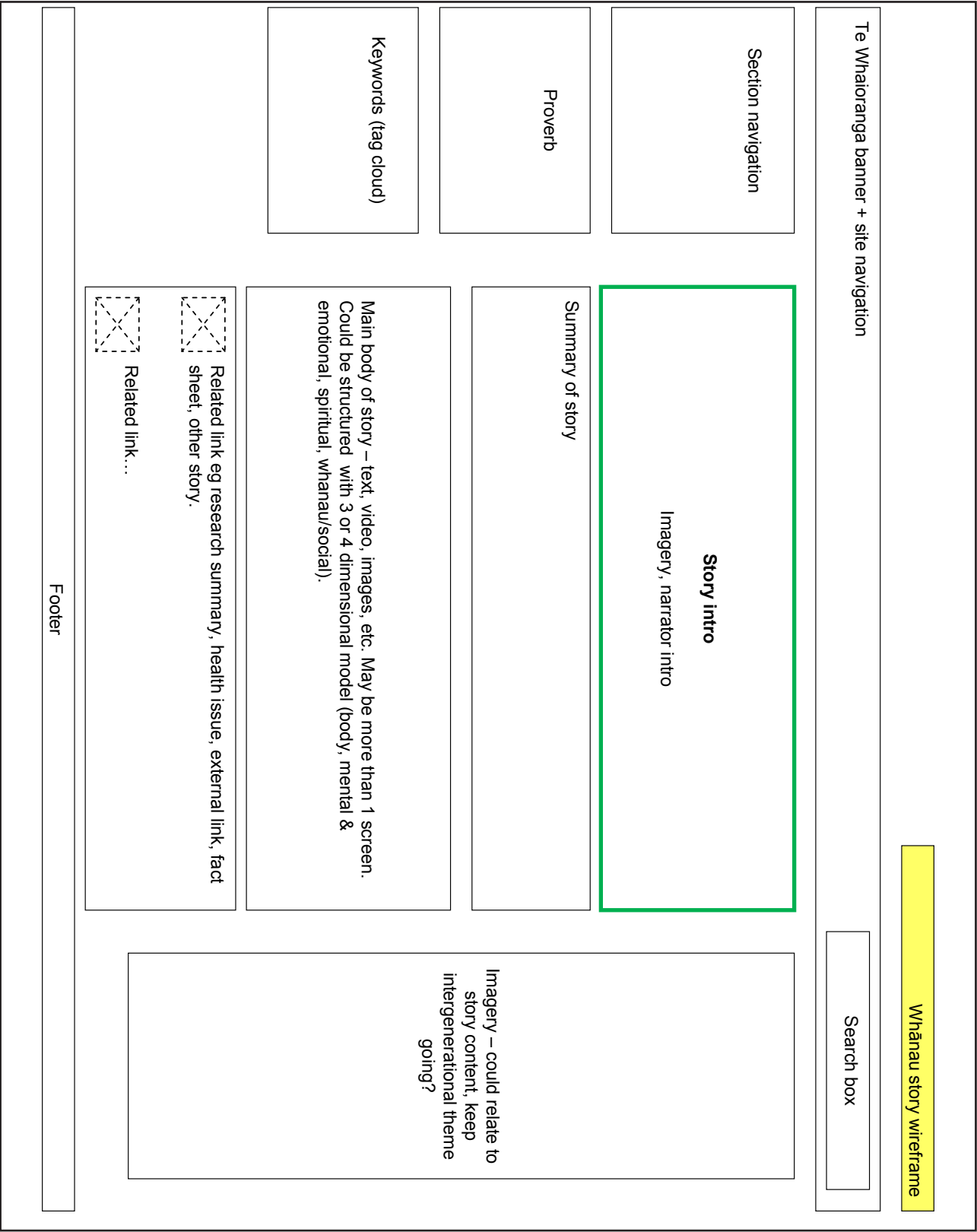
Wireframes

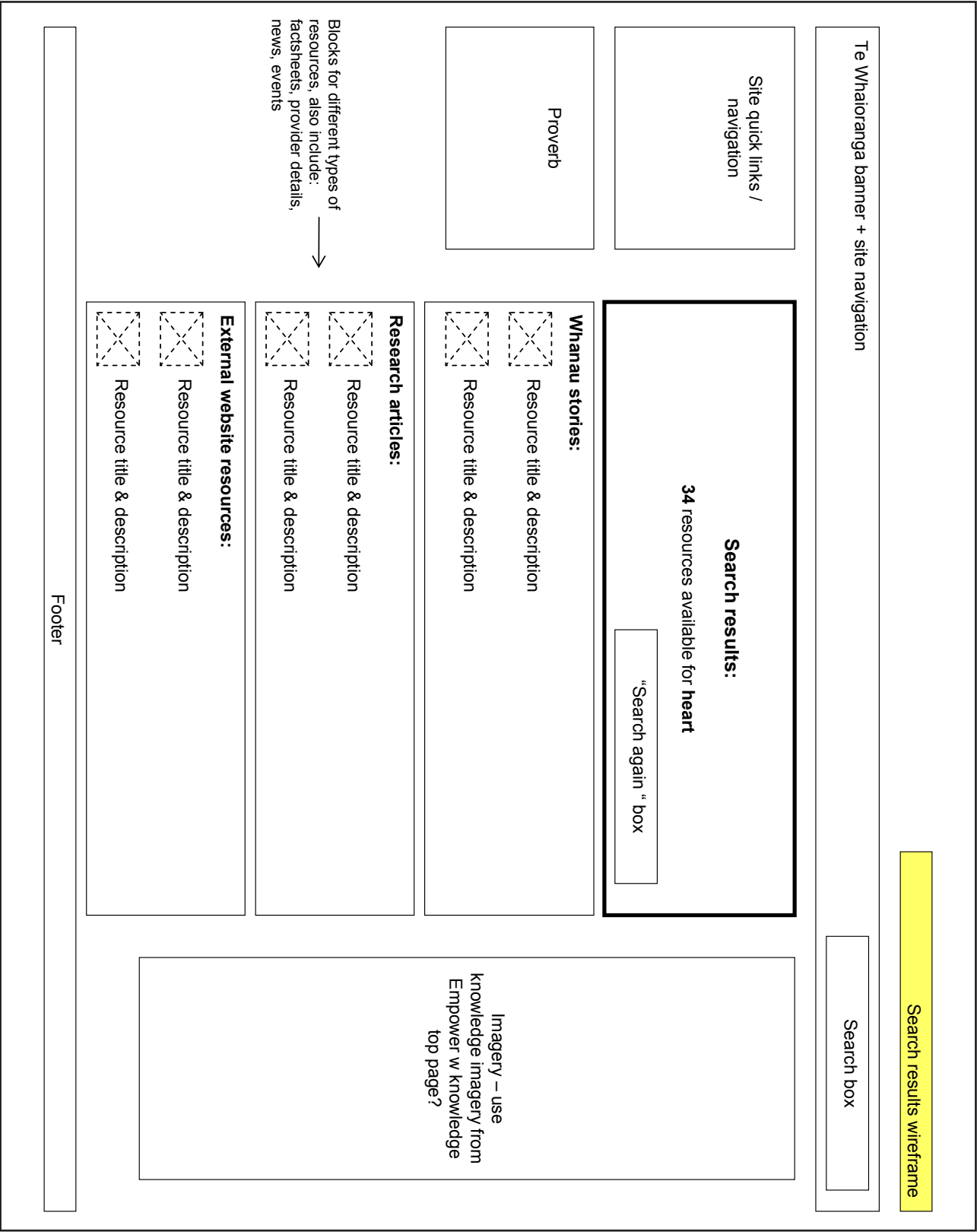
Following the site map diagram, the wireframes are used to indicate the types of content, images and links that will appear on specific pages within the website.

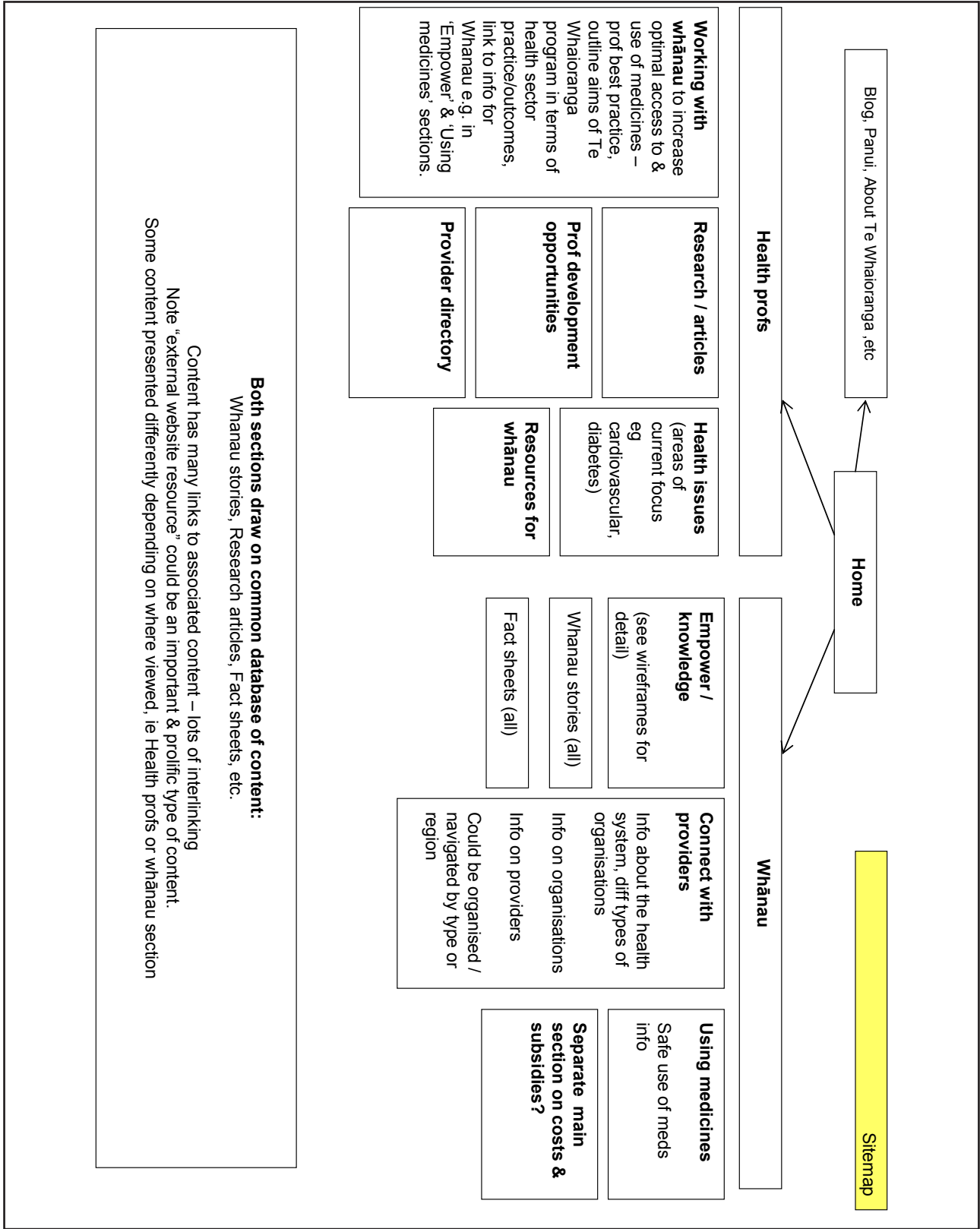












Possible types of content for Te Whaioranga:

Whānau story (could be the way much of the wellbeing, health issues, safe use of medicines information is delivered)

Research article (with descriptions for whānau, health professionals, + summary for whānau)

Fact sheet

Health provider / organisation record

External website resource

News item, Event item

Medication / treatment (including rongoā) information – or keep this within whānau stories?

Health issue info – as above, keep this within whānau stories?

Information page – e.g. for safe use of medicines info. (Or this might be better delivered as whānau stories and associated factsheets & FAQs?)

FAQs (these could be added to)

Multimedia resource (e.g. Flash interactives)

Quiz

Glossary term

Structure of a whānau story:

Title, hero image

Associated proverb, mihi

Keywords

The story itself – i.e. text, images, photos, video.

Summaries, e.g. for different audiences / uses e.g. one story might be used to highlight a health issue, a provider, and a use of medicines topic.

Associated:

Research articles

Health issues

Medications/treatments

Fact sheets

External website resources

Providers/organisations

Events/Panui



Appendices

Appendix 1

CWA's RATIONALE FOR RESEARCH-BASED APPROACH TO DESIGN

Executive Summary/Overview

The purpose of this paper is to outline CWA's rationale for incorporating a research component into the development of the Whaioranga website.

In designing the website, CWA wants to be clear about:

- what Pharmac is wanting to communicate to its Māori stakeholders; and
- what are the core values, shared by Pharmac and its Māori stakeholders, that will encourage Māori engagement with the site.

To do this well, we need to invest time in up-front planning, investigation and consultation – before addressing the creative aspects. To that end, we propose three main stages. The first (and very important stage) will be to *waananga*/research stakeholder values and needs. The second will be to design the site – with the third stage being to develop, build and test the website for user accessibility.

CWA has identified the benefits, outcomes and challenges of incorporating a *wananga*/research component into the development of the Whaioranga website.

Going forward, we are keen to consult with Pharmac in terms of accessing stakeholders and working out how best to determine shared values (Pharmac and stakeholders). Our intention is that this will be a collaborative process – between CWA, Pharmac and stakeholders.

With the overriding kaupapa being 'whānau ora', CWA wants to ensure that Pharmac's online communications epitomise the values that underpin whānau well-being – so that there is a 'connect' between what Pharmac stands for and what Māori people believe in. Ko tā mātou tino hiahia kia mau ki te kaupapa whakahirahira – he rongoā pai, he oranga whānau⁵.

This document provides information about the research stage of our process; specifically:

- i) the rationale for integrating a research component;
- ii) the challenges;
- iii) the proposed research methodology;
- iv) multi-channelling opportunities;
- v) outcomes; and
- vi) the output.

The output from the research stage will be a 'road map' document outlining:

- a summary of our findings;
- information about the type of content needed; and
- a flow diagram showing the top-level structure for the website.

Aim of CWA's Research Process

The aim of the research-based process we'd like to follow, leading up to the actual design of Pharmac's website, is to provide clarity around what Pharmac is trying to communicate, to whom – and, in particular, what are the shared values⁶ (between Pharmac and its Māori stakeholders) that need to be conveyed in order to engage Māori.

Introduction

Case study research⁷ highlights the importance of planning and research before addressing design aspects. The research also shows the need to drill down and focus on what's important to stakeholders. Failure to make a connection with the target group, and losing contact with their values, can be totally detrimental.

With such lessons in mind, we intend to take an evidence-based approach – with research driving the design process. The literature on design tells us that this kind of approach has changed the way creative designers do their mahi – in that it's forced them to validate any aesthetic decisions. It's also enhanced designers' accountability to the client – and, most importantly, to the clients' stakeholders.

As already indicated, the underlying reason for our proposed approach is to determine what are the core values that Pharmac wants to communicate to its Māori stakeholders – in order to engage them. In terms of Pharmac's core values, an example (sourced from its Māori Responsiveness Strategy) might be the element of inclusivity – which acknowledges that people don't achieve things alone: *Ehara taku toa i te toa takitahi, he toa takitini*.

Different stakeholder groups

If Pharmac intends for the site to be multi-channeled, consideration will need to be given to what values are unique to each group of stakeholders. Some examples of multi-channeling might be to segment the site according to:

- whānau (rangatahi, matua, kaumaatua);
- Māori health and social service providers (GPs, nurses, tohunga); and
- the Māori health workforce (DHBs, PHOs, Māori health researchers).

OR, alternatively, the segmentation could be done in line with Mason Durie's model of Māori health around:

- te tinana (physical);
- te hinengaro (cognitive); me
- te wairua (spiritual).

Website Development

In regards to developing the website, we propose three main stages. The first (and most important stage) will be to *waananga*/research stakeholder values and needs. The second will be to design the site – with the third stage being to develop, build and test the website for user accessibility.

1. In the **wananga / research stage**, our aim is to determine what Pharmac is trying to communicate, and what are the values shared by Pharmac and its Māori stakeholders. This is a really important stage of the process, and

⁵ Our desire is to hold fast to the essence of your work – families staying healthy with medicines

⁶ Katarina Mataira, a long-standing Māori educationalist, emphasises the importance of human values in everything we do. She says that 'education without character, politics without principles, commerce without reality, and science without humanity are not only useless – they are positively dangerous'. (NZEI Te Rourou, Nov 2008)

⁷ Woolworths in UK; and Telecom's Ferret site in New Zealand

would take about 70% of the project time. (It should be noted that the wananga/research stage subsequently impacts on both the design and technical aspects of the website).

2. Once we are satisfied that there is indeed alignment between Pharmac's values and its stakeholders' values, we would move to incorporating these values into the **design stage**.
3. Thereafter is the **implementation stage**, where the design is:
 - implemented into individual sections and pages; and
 - tested for accessibility, usability and functionality – before release.

Benefits of Research Process

The main benefit of our prefacing the design phase with wananga/research is that it removes the element of designer (or client) subjectivity – which means that decisions are not based solely on aesthetics or gut feelings. In working with Pharmac, we want to ensure that our design decisions are based on the values that are meaningful to Pharmac and their Māori stakeholders. We want to be able to assure Pharmac that we've considered your views and the views of your stakeholders – and have acted on them.

Outcomes and Output

In terms of outcomes, this process is going to help Pharmac (and CWA) to engage, and communicate more effectively with, Māori stakeholders. It will ensure that there is no 'disconnect' between how Pharmac sees itself and how Māori see Pharmac. It will help us to better understand the people with whom Pharmac is aiming to communicate – so that the Whaioranga site is:

- Māori- friendly (across a range of Māori stakeholders);
- interactive (a-paa);
- appealing audio-visually (a-taringa / a-karu); and most importantly
- aligned with Māori values.

At the end of the research stage, CWA will deliver a 'road map' document outlining:

- a summary of our findings from the interviews, focus groups and documentary analysis (in terms of stakeholder needs and values);
- information about the type of content needed; and
- a flow diagram showing the top-level structure for the website.

Challenges of Research Process

The research process presents challenges, including:

- i) understanding Pharmac's key audience/s
- ii) accessing stakeholders and prior research
- iii) maximising limited resources.

One of the main challenges for CWA in this process is to determine who indeed is the key audience. For example, is it Māori whānau, or Māori health providers or the Māori health workforce – or are all three of equal importance?

Another challenge is our accessing stakeholders (to capture their views) and accessing previous Pharmac research findings (to help shape our research questions for stakeholders). It may be possible for us to 'piggyback' on one/some of Pharmac's regular hui.

The final challenge is that, although there are many research tools that can be used (e.g. surveys/questionnaires, focus groups, face-to-face/telephone

interviews, mail outs, and documentary analysis), the resourcing available is finite. Therefore, we recommend that the most efficient and effective methodologies to fit our purposes would be:

- i) Documentary analysis eg tracking reports on consultation outcomes and research findings;
- ii) Focus groups (comprising two distinct stakeholder cohorts – namely, whānau as users and health professionals as providers); and
- iii) 1:1 interviews with 'experts'.

Finally, in light of Pharmac knowing their stakeholders better than CWA, we would be keen to co-construct the questions that need to be asked of stakeholders during the research phase.

Summary

To summarise, in designing Pharmac's website, CWA needs to be sure about:

- what it is Pharmac is wanting to communicate;
- to whom (primarily); and
- what are the core values shared by Pharmac (as stated in its *Te Whaioranga Māori Responsiveness Strategy Action Plan*) and its stakeholders.

This is a collaborative process. We want to ensure that the structure and content on the website meets the needs of Pharmac and its stakeholders.

Conclusion

In designing Pharmac's website, we need the help of Pharmac and its external stakeholders. And we need to invest time in up-front planning, investigation and consultation – before addressing the creative and technical aspects. Otherwise, ka kotiti haere tātou katoa – and there will be a 'disconnect' between what Pharmac stands for and what Māori people believe in.

In conclusion, we return to Pharmac's aim ie 'whānau ora' through the safe use of medicine. It is important to CWA that the site epitomises the values that underpin whānau well-being. We want to ensure that our design decisions are based on the values and needs that are relevant to Pharmac and its Māori stakeholders – not on aesthetics or gut feelings; hence the research component being included in CWA's overall process.

This process is about making a connection with Māori. It's about communicating shared core values – and meeting a need. It's about whānau well-being – kia tū rangatira ai i te Ao Māori me te Ao Hurihuri hoki.

Appendix 2: References supplied by Pharmac for CWA use during the research

1. Pharmac Annual Plan 2001/2002 (Pemberton)
2. Māori Responsiveness Strategy 2002 (Pemberton)
3. Māori Responsiveness Strategy - PHARMAC Consultation Hui Report (A Report for PHARMAC on the Results of Consultation on the Draft Māori Responsiveness Strategy, Jan. 2002)
4. Māori Use of Medicines - Consultation Report September 2004 (Katene)
5. Implementing Pharmac's Māori Responsiveness Strategy (January 2006 - Draft report, M Wilson)
6. A Qualitative Investigation of the Impact and Barriers to Use of Antipsychotic Medication by Māori Tangata Whaiora in Aotearoa (Pharmac Oct. 2006)
7. Te Whaioranga Māori Responsiveness Strategy Action Plan - November 2007 (Published by Pharmac)
8. Best Practice - May 2008 issue (Published by BPAC)
9. Māori use of medicines for cardiovascular disease. (Dr Nicole Coupe (PhD), Kereru Research, Evaluation & Development (KRED) Ltd.) (June 2008)
10. World Internet Project, New Zealand (ICDC, AUT University, National Library of New Zealand, Internet NZ)

Appendix 3

CWA'S OVERVIEW OF BEST PRACTICE JOURNAL No. 13, May 2008 Improving Māori Health

The *Best Practice Journal* is published and owned by BPAC, an independent organisation currently funded through contracts with Pharmac and DHBNZ. The role of BPAC is to promote health interventions that meet patients' needs and are evidence-based, cost-effective and appropriate for the New Zealand context. They develop evidence-based resources that describe, facilitate and help overcome barriers to best practice.

This particular issue, number 13, is the first issue dedicated to Māori health. It covers 8 areas relevant to Māori – namely:

- the priority of reducing health inequalities,
- disparities in health care,
- the development of a framework for health professionals,
- the prevalence of cardiovascular disease and diabetes in Māori,
- the high incidence of asthma and chronic cough in Māori children,
- the success of community intervention to eradicate rheumatic fever,
- the significance of gout as a health issue for Māori, and
- the demystification of traditional Māori healing.

1. Diverse realities of Māori

Key points:

- Māori have poorer health outcomes, die younger and have higher rates of chronic disease than any other New Zealanders
- Reducing health inequalities is a government priority
- The Māori Health Strategy (Te Korowai Oranga, 2002) focuses on families (not individuals) i.e. whānau ora. Yet our health-care system is based on individuals, which is the antithesis for many Māori
- Relationships are crucial (e.g. doctor: patient; doctor: whānau) to establish mutual respect, understanding and trust
- Māori form a diverse group on a continuum; they are not homogeneous. So there is no one answer for all.
- Cultural competencies are important, due to the diversity within NZ society
- The availability of Māori health providers does not let mainstream providers 'off the hook'.

2. Disparities and Care

Key points

- There is a need for health programmes that target the most vulnerable (i.e. Māori) and integrate 'cultural competencies'
- The worst health issues for Māori are cardiovascular diseases, diabetes, cancers and smoking-related diseases. (The latter are the most modifiable)
- Relationships are crucial i.e. establishing rapport with Māori
- The research highlights disparities in GP care e.g.
 - fewer follow-up tests
 - fewer respiratory drug prescriptions

- fewer referrals
- less consultation time

3. Practical solutions for improving Māori health

This article presents a seven step framework, as a practical guide for health professionals to effectively work with Māori, as follows:

Step one: Develop a practice plan for addressing disparities

Step two: Set realistic, prioritised practice goals e.g. recording ethnicity data (using IT software as an aid)

Step three: Build relationships with Māori patients and whānau

Step four: Engage and educate Māori patients in their health-care

Step five: Mutually agree on realistic, patient-centred goals

Step six: Make it easy for Māori patients to return

Step seven: Create partnerships with Māori patients, whānau and the community

Key points

- Māori are often reluctant to visits GPs out of fear, mistrust, feelings of whakamā, or previous negative experiences
- GPs need to engage Māori in discussing wider health issues, viewing a patient's visit as an opportunity for education. For example, if Māori present with gout, the GP should conduct a cardiovascular disease risk assessment. Similarly, if a Māori patient presents with a cold or flu, the GP should engage in discussion about smoking cessation
- GPs could adopt proactive strategies e.g. making follow-up appointments, sending reminders or putting patients' names on a recall list
- A patient-centred approach is required i.e. hearing patient's story about how their illness is affecting them – focussing on their feelings, ideas and expectations
- Relationship-building is crucial for creating trust i.e. clinician with patient and whānau. This involves taking time to establish 'connections', really hearing the patient perspective and reflecting back – so that the management plan is more likely to bear positive health outcomes. It also means building relationships with the wider community e.g. school, marae, business
- Effective communications are conducive to building relationships e.g. checking to make sure there is a shared understanding; using open questions; and getting patients to paraphrase back the essence of the discussion
- There are better health outcomes if the treatment plan is co-constructed with the patient and their whānau – thus capturing the subjective view of the patient (which may have a cultural overlay) as well as the clinical and scientific perspective
- Goals for treatment need to be:
 - patient-centred,
 - measurable (e.g. 'reducing the use of asthma reliever to three times weekly'),
 - achievable (i.e. one thing at a time),
 - realistic for the patient (and the whānau), and
 - co-constructed
- Mason Durie advocates a culturally-appropriate approach; otherwise there are biases, preconceptions, misunderstandings and wrong assumptions

- Certain body language should not necessarily be interpreted as acquiescence or consensus. For example, if Māori remain wahangū (silent), this could be because they value harmony and respect for authority; it does not necessarily equate to agreement. This in turn may mean that, after their visit, they may not follow the treatment plan
- Knowledge of Māori language is a bonus, especially with kaumaatua, as are brochures printed in Māori (although research shows that there is a preference to include some English translations)
- There is the potential for complementarity of care (e.g. mainstream alongside traditional Māori healing) – especially in cases where there are access issues

4. Cardiovascular disease and diabetes in Māori

Key points

- The onset of cardiovascular disease and diabetes is earlier in Māori. Therefore, screening needs to start earlier (i.e. early risk assessments) – by engaging Māori patients, going beyond the presenting problem, and documenting risk factors
- Establishing relationships is important, as is being aware of Māori values and beliefs
- There is added value in clinics being a 'one-stop shop' – with GPs and specialists at the same location. (This has implications for our website)
- The case study Aukati Kai Paipa is used to illustrate the importance of whānau involvement and the integration of Māori values
- Emphasis is placed on the need for simplicity in crafting messages and goals

5. Asthma and chronic cough in Māori children

Key points

- Asthma and chronic cough are more prevalent in Māori children – which means they have more days off school and higher hospital admission rates (which affects their educational attainment)
- Socio-economic deprivation is a factor, such that health professionals need to go beyond the immediate presenting issue and explore such things as housing, costs (for doctor visits and scripts), heating and transport
- Whānau need to be involved in the treatment plans, using their child's health as a motivator. (This 'bottom-up' approach has implications for our website, where there needs to be provision for Māori input and feedback)
- It is important for health professionals to know, and work with, the health beliefs of whānau
- Mason Durie's *tapawhā* framework is viewed favorably
- It is important for health professionals to ascertain the prior knowledge of whānau about the presenting illness – and for there to be a shared understanding of expectations
- Kanohi ki te kanohi (face to face) consultation is helpful, as is using a visual medium to simplify instructions
- There needs to be a more accessible repository for Pharmhouse data (e.g. our website)
- There is potential for GPs and Māori providers to work in partnership, complementarily

6. Rheumatic fever

Key points

- Community-based intervention is powerful. Its strength lies in its 'bottom-up' approach and in maximising providers' local knowledge
- Patients are 'engaged' – and goal setting is realistic
- Opportunities are seized for whānau education
- There is true partnership between health providers, schools, whānau, pharmacists and the wider community

7. Gout in the Māori community

Key points

- Māori men have the highest gout rate in the world. Approximately 10% of Māori males have gout.
- There needs to be clarity and simplicity in communicating health messages, supported by visual clues
- Messages need to be 'reframed' in tone and style so that they are positive – and not focussed on deficits
- Relationships are important because Māori patients will be more committed to their health if they trust and respect their GP

8. Demystifying Rongoā Māori: Traditional Māori Healing

Key points

- The traditional healing system of Māori includes herbal remedies, spiritual healing and physical therapies. Its practitioners are tohunga
- The domain of rongoā Māori includes plant-based remedies, mirimiri (massage), and karakia (prayer)
- The aim of rongoā Māori is to recreate balance /harmony/order – so that there is synergy between one's spiritual, psychological, emotional, cultural, social, environmental, physical and family health
- Good relationships, and effective communications, with Māori patients are imperative – to encourage them to share information in regards to their use of rongoā (in case using two different health regimes is problematic)
- There is scope for diversity and complementarity across the different practices, so that spiritual aspects are taken care of. This is exemplified in a case study about the Taupo PHO contract (2007), where cooperation across providers meant that rongoā Māori was used concurrently with Western medicines
- The Ministry of Health's Rongoā Development Plan (2006) outlines how traditional practices can be integrated i.e. not an *either/or* situation but an *and/and* scenario
- Because of the barriers to accessing mainstream health care (e.g. geographic, cultural, financial, transport), Māori may prefer to see a tohunga

Overall Themes (relevant to our website development)

- a. **Relationships** are crucial, as is a **patient- centred approach**. This is highlighted in this quote from a Wellington GP, Ken Greer, in his description of the art of medicine:

The humanity of medical care is a major part of the discipline, with science an

ingredient only. Our professional ethos of care and beneficence is best served by practitioners who practise the art of medicine with wisdom, humility, compassion and, above all, a healthy scepticism for new knowledge.

- b. The integration of **cultural values** is imperative
- c. **Whānau** need to have a voice and be included in goal setting, treatment planning and providing feedback
- d. There is a need for **targeted health education resources**
- e. **Messages** should be simple and clear, couched in a positive tone, across a range of media, utilising illustrative case studies
- f. There is scope for **complementarity** ie western medicines working alongside traditional Māori healing processes
- g. Mason Durie's **tapawhā model** provides a framework for channelling information
- h. **Partnerships** are important and lead to more effective outcomes

Appendix 4

CWA'S OVERVIEW OF RESEARCH REPORT:

A Qualitative Investigation of the Impact and Barriers to Use of Antipsychotic Medication by Māori Tangata Whaiora in Aotearoa (2006)

Context of Research

This research came about because Pharmac was interested in finding out how they could improve Māori mental health patients' uptake of antipsychotic medication. The research looked at barriers to establishing a medication regime and what supports were conducive to sustaining that regime.

The research was framed in such a way as to inform the development of health education resources for Māori – specifically in regards to antipsychotic medications.

Research methodology

In the first part of the research, a literature review was conducted to determine the current context that Māori access, and experience, antipsychotic medication. Thereafter, focus group hui (called workshops) were held to elicit Māori patients' views and experiences – with a view to being able to tailor Māori health resources more appropriately.

The literature review discovered major differences in the way that Māori use mental health services. Typically they enter the services later; they are generally more troubled by this stage. Also typically, they stay in those services for a shorter time.

The research team conducted four workshops, each five hours long. A discussion guide was used to cover key themes. Each workshop adopted Māori tikanga in its approach e.g. manaakitanga. Sampling was not random; instead, existing networks were used.

There's more to mental health than medication⁸

Findings

The main findings of the research are listed below, with suggested implications for CWA as it considers the development of a web site to promote Pharmac's Te Whaioranga strategy.

- Participants reported a general lack of understanding in the community about mental health, which resulted in social stigmatisation. This lack of understanding was also prevalent in their own families.
So... resources are needed on the web site to educate whānau and the wider community (especially employers) to overcome their being judgemental.
- The side effects of the antipsychotic drugs (e.g. drowsiness, which led to health and safety issues in the workplace; and loss of libido) were a barrier, causing some participants to discontinue their use. Moreover, patients reported that the side-effects were not explained to them effectively. This was exacerbated by literacy problems.
So ... information on the web site, explaining the side-effects of drugs, needs to be framed in simple terms.
- Emphasis was placed on the importance of cultural values in the Māori view of health – which is:
 - holistic (as represented in Durie's *tapawhā* framework),
 - whānau-centered, and

- inclusive of Māori cultural practices/concepts eg tapu and noa; karakia; mirimiri; mate Māori; te reo; kapa haka; and the power of whānaungatanga.

This psycho-social emphasis, imperative for recovery, is in contrast to the bio-medical approach of tauiri (non-Māori), with its focus on the physical side e.g. pills, and injections. The Western model is also hampered by cross-cultural miscommunication, where medical staff and users of the health services are often 'talking past each other'. This can lead to patients' mistrust of health professionals and resistance to their advice, which ultimately impacts on their recovery.

So... the website needs to be imbued with Māori values and beliefs.

- Similar to the previous finding is the impact of 'kaupapa Māori' ie the provision of health care from a Māori context, where Māori beliefs/values/practices are incorporated into the health service. This approach is consistent with the wider aims and aspirations of Māori development, which focus on Māori potential and Māori success. The premise is that Māori participation (in terms of access and optimal use) will increase if traditional practices are included in the treatment of their health.

Participants felt that, although their symptoms were being treated, the underlying cause of their sickness was not being addressed. Rose Pere's 'Te Wheke' model and Mason Durie's 'tapawhā' framework were cited as good examples of how traditional Māori views could be integrated into the treatment of Māori patients, with the emphasis on wairua (spiritual considerations) being at the core of hauora (health/ well-being).

So... information on the web site needs to reflect, and honour, Māori tikanga.

- The main barrier to accessing Māori mental health care and treatment was mistrust and suspicion, borne of previous bad experiences. This explains why Māori enter the service later, by which time they are manifesting more severe symptoms. Research participants called for police (who are frequently asked to assist the Crisis Intervention Team) to have more education on how to deal with mental health patients.
So... the website resources need to be designed in such a way as to target specific sectors of the community, to enhance understanding and reduce social stigma.
- The main enabler to a positive mental health outcome was having good communication between consumers (patients with whānau support) and providers, thus creating an effective relationship conducive to a speedier recovery.

So ... the information on the website needs to be communicated clearly and simply, with consideration given to the importance of taking a holistic approach and involving whānau in patients' recovery.

Key themes

The researchers reported certain key themes worthy of consideration in the development of health educational resources for Māori, specifically the need for:

- A web site that would include:
 - a range of resources;
 - a forum;
 - links to other relevant sites;

⁸ This is the theme for the 2009 mental health expo in Wellington

- research;
- general information; and
- an interactive program where people could enter their personal details, ask questions and get those questions answered (or, at least, have increased confidence to take their issues to the doctor thereafter).
- Multimedia approaches to information dissemination e.g. DVD, video and simple print (due to literacy issues); case studies/people's stories; and practical strategies/suggestions on how to manage medications.
- Resources that incorporate Māori cultural values e.g. using Durie's *tapawhā* framework as a basis for resource development. (This has implications for our decision-making around multi-channelling on the website).
- Tailored resources targeted at different sectors, to 'normalise' mental illness eg employers, police, whānau, GPs, pharmacists and mental health staff.
- Patient-focused resources (ideally co-constructed with mental health patients to ensure the right messages are being conveyed, the right way).
- Information about the potential complementarity of Western medicines and other treatments e.g. rongoā, vitamins, herbal medicines. (Participants talked about the need for psychiatrists to be informed about the unique properties of Aotearoa's flora and how these could be maximised, to reflect a genuine spirit of partnership between those who prescribe Western medicines and Māori experts in the field of rongoā).
- An 0800 line, to preserve anonymity and provide non-judgemental answers.

Appendix 5

CWA's Summary of
Māori Use of Medicines (A consultation report by Kotuku Solutions Ltd, first published in September 2004)

Executive summary

Aim

The aim of this consultation was to identify and develop suitable educational resources for Māori regarding:

- Appropriate and safe use of medicines
- Storage of medicines

Objectives

- Increase the awareness of using medications safely and appropriately
- Develop education resources for the patient and their whānau
- Promote medications as part of managing overall health care
- Consider the cost effectiveness of using Māori translations
- Expand the use of Māori media
- Target promotions at population groups and specific geographic areas

Six consultation focus groups/target groups:

- Young parents
- Kaumātua (taua and poua / kūia and koroua)
- Māori clinicians / health professionals
- Pakeke (tāne and wāhine / male and female)
- Rangatahi (tāne and wāhine)
- Rural / remote users.

NB 80% of participants were wāhine (female).

Conclusions

- Perception among the Māori community that they are treated differently by health professionals
- Insufficient information being provided regarding the accessing of medicines and the safe use thereof
- PHARMAC is not visible to the Māori community

Themes in report

Theme 1: PHARMAC in the community

- Not visible among the Māori community
- Need to develop their profile in the community
- Need to develop a multifaceted communication and education approach
- Need to provide a face-to-face (kanohi ki te kanohi) presence in the Māori community
- Need to have open and honest dialogue

Theme 2: Māori Health and Health Services

- Health issues are related to the effects of colonisation
- Inconsistent attitudes and services emanate from health professionals
- Māori have differing needs compared to the general population

- Participants identified barriers:
 - Cost
 - Feeling intimidated
 - Not being listened to
 - Being stereotyped
 - Accessibility to services
 - Culturally inappropriate services
 - Mistrust of health service professionals
 - Perceived time constraints on health professionals
- Over representation in lower socioeconomic statistics
- Tendency to share and/or re-use medicines
- Inconsistent information is being provided
- Advocacy and support from Māori service providers and whānau would assist in improving Māori access to health services
- Personal attitudes to health services have an effect

Theme 3: Safe Use of Medicine

- Cost is a significant barrier
- Insufficient information is provided by health professionals
- People do not know where to access information
- Information provided is inconsistent
- Little information is provided on the safe use of medicines
- Literacy needs, hearing and sight impairments should be recognised

Theme 4: Collaboration

- Safer use of medicines for Māori may improve through a collaborative approach
- More information needs to be distributed to the Māori community

Theme 5: Rongoā

- More Māori are accessing and using alternative remedies
- Many are using alternative medicines in conjunction with pharmaceuticals
- More information must be provided to the Māori community regarding the use of alternative medicine with pharmaceuticals

Theme 6: Target Groups

- PHARMAC should recognise the specific needs of individual groups

Theme 7: Media

- Implement a comprehensive marketing and communication strategy that meets the specific needs of the Māori community

Details of main themes

PHARMAC in the Community

1. PHARMAC is not visible among the communities targeted.
2. PHARMAC needs to develop its profile in the community and provide more information regarding access to medication, safe use of medicine, and subsidised medicine.

Māori health

1. Inconsistent practices are occurring among health professionals in the community.
2. There is a strong feeling that Māori are treated differently compared to non-Māori
3. Many negative assumptions are made by health professionals regarding Māori behaviour and attitudes
4. *"There is a loss of confidence in Western medicine for Māori today. Our Māori health status has remained poor, relative to that of Pākehā" (Pomare, 1995). "Also, many Māori feel that Western health services lack a spiritual dimension, or taha wairua. Māori under-utilise mainstream primary care services". (Malcolm, 1996 - As quoted by Professor Mason Durie).*
5. There is a need for advocacy and support from whānau and Māori service providers.
6. There is little synergy between Māori health and social service providers, and the more traditional health services.

Health Services Professionals

1. Māori are not only low income earners, but are also over-represented in other lower-socioeconomic statistics, including poor housing, lower education results, and higher representation in justice statistics.
2. *New Zealanders from socioeconomically disadvantaged groups are more likely to experience certain illnesses. (1996/97 New Zealand Health Survey)*
3. Cost is a significant barrier for Māori to access health services.
4. Māori often find the health environment and the attitude of GPs intimidating, with health professionals holding the power.
5. Māori feel uncomfortable to ask questions of health professionals.
6. Māori put up with pain and illness until it reaches a crisis
7. Most of the services provided are not perceived as culturally appropriate
8. Assumptions and stereotypes are made regarding Māori
9. Māori are not provided with all the information
10. Inconsistent information is provided
11. There is little synergy between the GP and chemist
12. Not enough information is provided generally
13. Not enough information is provided on the side effects of medicines specifically
14. Sometimes too much information is given, which cannot be assimilated or recalled
15. GPs are too focused on the time frame

Prescriptions

1. Cost for accessing prescriptions was a barrier
2. *The most popular single reason for not collecting a prescription item was cost, mentioned by 37.1% of respondents. (1996/97 New Zealand Health Survey)*
3. Majority of people did not know about subsidised medicines or how to find out information regarding them

Safe use of medicines

1. The safe use of medicines is related to the costs of accessing health services and prescriptions
2. Māori only access medicines as a last resort
3. Māori tend to share their medicines with whānau and friends, so as to save on GP and chemist expenses
4. There is little information or education provided regarding the safe use, storage and disposal of medicines
5. Printing, and language used on medicines, was inappropriate in that it was difficult to read and/or understand. The information provided currently does not take into consideration people with sight, hearing or literacy impairments.

Chemist/Pharmacy

1. There is inconsistency in the information provided by chemists
2. Assumptions are made by chemists about Māori
3. Little information is provided regarding the side effects of medicines
4. Instructions provided are often unclear and sometimes chemists' labels cover what is perceived to be relevant information
5. There are differences in perception around instructions
6. There is inconsistency in the provision of "blister packs" for the elderly
7. Having trade names versus generic names for medicines develops confusion for clients
8. There is inconsistency in the provision of information cards ("Yellow Cards") regarding medicine information and usage
9. Current information provided does not cater for people with disabilities

Collaboration

1. There is a lack of collaboration and information sharing between GPs and chemists
2. The Māori community specifically require more information regarding medicine access and use.

Communication

1. The Māori community have little or no knowledge of PHARMAC and its role and function
2. The most effective method to engage with Māori is face-to-face (kanohi ki te kanohi)
3. Whānau have identified that they are not provided with adequate information regarding medicines from either GPs or chemists
4. More information needs to be provided regarding the consumers' rights to ask questions of health professionals, and the availability of subsidised medication
5. Māori don't question professionals due to being "whakamā" or feeling intimidated by health professionals

Rongoā / Alternative medicines

1. Rongoā (traditional healing) and its practitioners, known as tohunga, have seen the Māori world transformed by colonisation
2. Many Māori today are looking for alternative ways to treat illness and tend to be relying less on GPs and pharmaceuticals

3. Self healing using alternative medicines, rather than pharmaceuticals, is becoming more common
4. In some cases, people are using alternative medicines in conjunction with pharmaceuticals

Target group specifics

Young parents

1. The evidence suggests that the Māori population are younger in comparison to the general population, and have over 20% more children than the general population
2. This target group is overly represented in many of the lower socioeconomic factors including health, employment, housing and justice
3. Nearly half of Māori children live in a sole parent family
4. The most significant barrier to accessing health services, and the appropriate use of medicines, was cost.

Kaumātua

1. The highest rate of prescription item use is in the 75 plus age group
2. Older people are more likely to have ongoing health problems
3. This target group represents the past. They are the kaitiaki (guardians) of Māori culture, and hold reverence and mana for Māori
4. The cost of accessing health services and medicines is a major barrier for this group.
5. Kaumātua are also influenced by attitudinal barriers eg GPs' negative, stereotypical attitudes
6. In former times, GPs had intimate knowledge regarding families, and treatments were personalised
7. Mistrust of the services is common, with patients often feeling "intimidated" and "powerless"
8. Time constraints are perceived by this group to be the only point of importance to GPs
9. The kaumātua are raised in believing that the GP "knows all" with regards to medicine, and should not be questioned
10. Kaumātua tend not to ask questions regarding the medicines prescribed
11. The 'waste not, want not' philosophy of many older people has a direct impact on the safe use and storage of medicines, as they tend to hoard medication
12. Older tāne tended to not access health services until they were often very ill
13. Kaumātua are afraid to take medicines on a regular basis because they do not want to become addicted or 'junkies'
14. Health professionals do not take into consideration issues of hearing and sight loss when providing information

Rangatahi (youth)

1. Young Māori, aged between 13 and 18 years of age, are the lowest users of medicines
2. Rangatahi do not have a full understanding of health services
3. Young Māori tend not to ask questions; they simply agree with the doctor
4. Rangatahi do not want to appear stupid with their doctor; they are whakamā

5. Young Māori felt that the information provided by the health professionals was often too 'technical'
6. Rangatahi tended not to use the full course of medication
7. Information provided in schools was not sufficient to inform them of how and where to access health services
8. The 'wāhine' in this group who accessed birth control drugs felt that they were not provided with relevant information regarding the side effects

Rural

1. In rural areas it was very difficult to access health services, especially in the weekends
2. There was a higher rate of GP 'turn over' in rural areas, which led to difficulty establishing relationships
3. Chemists and specialist services were also limited in rural areas
4. Rural people have to travel significant distances to access the appropriate services
5. When a GP practice is closed, the remaining GP services in rural areas tend not to have the capacity; there are no services until a new GP commences
6. Chemists provide 3 month prescription orders but, due to geographical isolation (causing shortages), patients are often not provided with the full 3 month course.

Media

1. There needs to be an effective communication strategy in conjunction with, and targeted at, the Māori community
2. PHARMAC needs to further develop its profile in the Māori community by initiating more kanohi ki te kanohi relationships
3. Written media should be colourful, and have pictures/images that appeal to Māori
4. Effective media include pamphlets, information sheets, television, radio, and education flip charts for Māori providers
5. The radio is an effective medium for members of the kaumātua group
6. Pamphlets are also effective for kaumātua
7. The Māori community should be involved in the dissemination of information eg Māori Women's Welfare League. Also Women's Refuge, gyms, clubs, community notice boards and marae

Effective targeting options:

- Information sheets in medication packs
- Education workshops
- 0800 PHARMAC information number
- PHARMAC website
- "Use your mouse" type initiatives

Recommendations

Communication / Marketing

PHARMAC is encouraged to:

- further develop their marketing and communication strategy
- consider varied communication methods
- provide more information and education to Māori regarding the safe use of medicines

- recognise the importance of, and provide assistance to, particular target groups

Education / Research

There needs to be:

- education targeted at health professionals
- collaboration between health professionals and Māori health and social services
- support from whānau and Māori providers
- research and analysis to determine the effectiveness of interventions
- a random audit sample of health professionals
- an appropriate training package for health professionals
- research on the implications of combining pharmaceuticals with alternative medicines
- more research into the use and effects of rongoā Māori, with the findings disseminated

Prescriptions / Information

It is recommended that Pharmac:

- subsidises the provision of "blister packs" for the elderly
- reviews the 3 month prescription period
- reviews the appropriateness of the packaging and labelling of medicines
- develops innovative ways to ensure ALL health consumers can understand the information required to appropriately access and safely use medicines

Collaboration

Pharmac is encouraged to:

- promote and advocate effective information sharing and collaboration
- assist in the development of a more collaborative approach
- research the development of collaborative working arrangements between GPs, chemists and Māori health and social service providers
- advocate for GPs and chemists to provide consistent information to patients
- advocate to chemists the consistent use of information cards for clients, especially the elderly

Appendix 6

CWA's Summary of

Consultation Report

Pharmac Māori Responsiveness Strategy (January 2002)

This report was published after nine hui were held across the country, to discuss Pharmac's Māori Responsiveness Strategy. Around 200 people were canvassed. Kaumātua (attached to Kāhui Tautoko Ltd.) represented Pharmac at all hui, as Pharmac did not have key Māori staff⁹ at the time of the consultation.

Pharmac was required to carry out the consultation, based on the New Zealand Public Health and Disability Act 2000. This required Pharmac to 'consult on matters that relate to the management of pharmaceutical expenditure with any sector of the public that may be affected by its decisions'.

The consultation report on Pharmac's Māori Responsiveness Strategy made reference to the seven principles of the New Zealand Health Strategy, highlighting the three Treaty principles of partnership, participation, and protection.

At the nine consultation hui, Pharmac presented their six strategies for discussion:

Improving business planning

Improving human resource development, to facilitate a Māori-centric culture within Pharmac

Improving processes and procedures to collect and analyse ethnicity data

Improving supply-side activities (i.e. expertise of Māori providers, health professionals and researchers)

Improving demand-side activities (ie targeted promotional material, Māori media channels, translators and te reo)

Improving Māori representation and participation in key decision areas

They also outlined their main health priorities, as follows:

Diabetes

Respiratory disease

Heart / cardiovascular disease

Mental health

Cancer and smoking

Arthritis / Gout

Tamariki Ora (ie well children - free under 6's medicines and GP visits)

Obesity

Other discussion topics included:

- Strong call for Pharmac to maintain relations with rongoā practitioners
- Priority of Māori recruitment on demand side, where there is a major role in providing information and education about medicines and their use
- Information campaign to inform professionals (doctors, pharmacists, etc)
- Lack of good information for whānau

- Need to make translated messages simple to read and use (e.g. "Kia mau ki to rongoā" - Hold on to your traditional medicines).

Barriers to use and access by Māori to medicines

1. Cost

- this is the GREATEST barrier eg cost of transport to visit professionals and cost of doctor visits (with some Māori in dire poverty).
- surcharges are an issue too

2. Transport

- distance to travel to see doctors presents problems

3. Health professionals' attitude

- poor communication by professionals
- poor information given by professionals
- professionals are poor at educating Māori about effective use of medicines
- consultations were often rushed
- there is a huge gap between whānau and professionals
- health professionals don't always build rapport with whānau (which impacts on gaining trust)
- professionals were not seen as key communicators
- many professionals were considered to 'look down' on Māori health services
- some whānau had given up on local health services out of sheer frustration
- whānau were often afraid to challenge doctors

4. Lack of good education and information

- there is confusion over whether this is the doctor's or pharmacist's role? Or both?
- the information is not produced in a manner that's useable for Māori
- there is a lack of appropriate, Māori-centric information
- the language as too technical / too wordy, which makes it hard for whānau to understand (such that their basic understanding of medicines is poor)
- information needs to be visual and simple
- information about helpful schemes and information packs is often not provided
- use of Māori in information campaigns was needed.

5. Health worker education

- need to provide information and training to Māori health workers and nurses
- whānau do not read medical information, so rely on health worker to interpret
- Māori health workers were better at communicating with Māori than other professionals
- respondents requested that Māori health workers be included in the

⁹ At the time of the consultation, Māori representation on the Pharmac Board was raised as an issue. At that stage, only one Māori Board member was planned. However, this was deemed by Māori as being not representative of their needs, not genuinely consultative, and not reflective of a true partnership with iwi. Māori requested 50/50 representation on the Board.

design of educational material and the delivery of messages about medicines

- few Māori nurses saw information that went to doctors
- health workers and nurses were seen as key communicators
- an interactive function on the Pharmac website is requested so that people can enter a drug and get information on costs etc
- it is acknowledged that the health nurse is doing role of educator, with no extra remuneration.

6. Changes in drugs / pill sizes

- changes in names, size and colour of pills were not explained by doctors or pharmacists
- whānau not told that some large pills should not be ground down in order to swallow
- changes were often confusing e.g. packaging; colour and shape of pills
- multiple medications were poorly labelled
- changes in medication and pill size were not clearly communicated

7. Ethnicity data

- lack of good ethnicity data, yet a need to establish good baseline data
- not all GPs and pharmacists were recording ethnicity data
- concerns raised about protecting ethnicity data
- issues around patient consent and willingness
- monitoring needs to be done by Māori researchers, not mainstream agencies

Māori health priorities

1. Mental health drugs
2. Cancer
3. Heart disease - High rate of heart disease in Māori, but a low number of Māori accessing certain heart drugs
4. Renal drugs (to combat diseases of the kidneys)

NB "Te Whare Tapawhā" - the 4 sided house or holistic health model, as promoted by Dr. Mason Durie:

- Whānau wellbeing
- Physical wellbeing
- Mental wellbeing
- Spiritual wellbeing

Rongoā Māori / Māori traditional healing

To gain government recognition (Ministry of Health or Medsafe), the funding of rongoā would be subject to validation. Rongoā practitioners do not want to risk the loss of intellectual property in the process.

Rongoā practitioners stressed the role of the National Body of Māori Traditional Healers (credited with the removal of the Tohunga Suppression Act that barred many healers from practising openly).

Rongoā practitioners stressed that Te Whare Oranga (House of Health) needed to be recognised.

"Rongoā is the first medicine here - and your pills are the alternative"

Benefits of rongoā:

1. Reduced cost for patients
2. Belief it is better for whānau
3. Accessing rongoā was an active choice, not an economic necessity

Rongoā issues:

1. Rongoā practitioners are not paid
2. There is a cost to operate the services they offer (equipment, travel, facilities)
3. It is difficult to secure funding

Pharmac confirmed it was not researching rongoā and, indeed, had no mandate to do so.

Appendix 7

Summary of Pharmac's Request For Proposal (RFP).

The requirements in the RFP were that:

1. The website be accessible to the public, in particular to Māori, and that it would function as a portal to a range of Māori-specific content, most of which is already available on line.
2. The look and feel of the website should reflect the intended audience: Māori health providers and NGOs, hapū/ iwi groups, runanga, Māori within DHBs and Māori researchers.
3. The Te Whaioranga site should provide a secondary function, allowing a high degree of Māori participation and feedback.
4. The website would allow for a secure database of all stakeholders, enabling Māori health stakeholders to be contacted directly for consultation, feedback and any announcements deemed to be of high interest to Māori.

Appendix 8: Whānau questionnaire

Te Whaioranga questionnaire for Whanau	
Name of interviewee	Age
Location of interview	Occupation
Date	Iwi
Interviewer	Gender

Introduction	
<p>CWA have been employed by Pharmac to design and build a Te Whaioranga web site that focuses on Maori health issues.</p> <p>To help inform the design and usability of the web site - and thus make it a truly useful resource to all Maori - we are conducting a questionnaire to gain an understanding as to what Maori really want from such a web site.</p>	<p>The request to create a web site is driven by findings published in the Pharmac report <i>"Maori Responsiveness Strategy Action Plan"</i>. Your comments will help inform both Pharmac and CWA as to exactly what you expect and need from a Maori health web site.</p> <p>All information gathered from this questionnaire will be kept in the strictest of confidence and not passed on to any third party.</p>

CONSENT

I have been asked to help CWA (Copeland Wilson & Associates Limited), on behalf of Pharmac, in their interview questionnaire about developing a Te Whaioranga web site for Maori Health.

I agree to allow CWA to interview me:

☐ Yes ☐ No

I understand that any information I give will be kept anonymous. This means that I will never be identified by name in anything that CWA writes or says. And no-one here, or at home, will be told about anything I say.

I agree to the right of CWA to make audio recordings of the interview:

☐ Yes ☐ No

I understand that I can refuse to answer questions and I can drop out at any time if I choose. I agree to take part in this interview.

DATE:

NAME:

SIGNATURE:

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Te Whaioranga questionnaire for Whanau

1. Where do you go to get information about Maori health?

- ☐ I go to people who've had problems like mine
- ☐ I go to a doctor or a nurse
- ☐ I go to a tohunga (rongoa practitioner)
- ☐ I go to the library (or other community resource centre)
- ☐ I pick up bits and pieces on the kumara vine
- ☐ I don't go looking for information about my health
- ☐ I look on the Internet
- ☐ Other

[illegible]

Te Whaioranga questionnaire for Whanau

2. What makes it difficult for you to get information about your health, or the health of a whanau member?

- ☐ I don't know who or where to go to
- ☐ I feel whakama asking questions about my body
- ☐ I don't know what questions to ask or how to ask them
- ☐ Sometimes I don't understand what the doctors/ nurses are explaining
- ☐ I feel scared in case I find out something bad/ugly
- ☐ I have transport problems to get to the doctor, the library or the community centre

3. If there was a free heart-check service available, would you use it ?

- ☐ Yes ☐ No

If not, why not?

Te Whaioranga questionnaire for Whanau

4. Do you use computers and the internet to get information about Maori health?

- ☐ Yes regularly
- ☐ Seldomly
- ☐ No
- ☐ I do use a computer, but not to get Maori health information

Why not?

If no, is this because

- ☐ I don't have access to a computer (but I can use one)
- ☐ I have a computer but don't have internet access
- ☐ I have a computer but don't have broadband, so it's too slow
- ☐ I can't use a computer (**Prompt:** go to question 8)

If yes, do you trust the information you access on the internet?

- ☐ Yes ☐ No

If no, why not?

Do you share that information with others?

- ☐ Yes ☐ No

If yes, who with?

If no, why not?

Te Whaioranga questionnaire for Whanau

Interviewer prompt:

CWA want to ensure that the information we gather will best inform both ourselves and Pharmac as to what key features the Te Whaioranga web site should contain; and what information is most useful to all Maori (health professionals and whanau).

We are going to ask you specific questions about the web site we intend to design and build. We wish to find out what web sites, if any, you currently use to find out about Maori health issues.

NOTE: If the interviewee does not use the internet to gather information about Maori health, then go to question 8 below.

5. Whose web sites do you use to get information about your health?

How do you find these web sites?

☐ Search engine

Which search engine(s) _____

☐ I saw a web site address in a magazine or newspaper

Publication name(s) _____

☐ I heard about a web site on the radio

☐ I heard about a web site on TV

☐ I found out about a web site address in the library

☐ From another Iwi web site

☐ Other

Te Whaioranga questionnaire for Whanau

6. What do you like about the websites you use for information about your health?

- ☐ good articles/content on how to take care of my health, or my whanau
- ☐ medical information (illness, specific Maori health issues etc)
- ☐ short "How To.." guides and fact sheets
- ☐ the look and feel of the design
- ☐ information is easy to find
- ☐ able to search for specific health topics within the site
- ☐ able to ask for more information (through enquiry forms and online forums)
- ☐ there is a list of contact details about where to go for help
- ☐ ability to contribute my views on the web site
- ☐ links to other helpful information
- ☐ News and Event updates (Pānui)
- ☐ Other

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Te Whaioranga questionnaire for Whanau

7. For you personally, what would make a good Te Whaioranga web site?

8. Have you any questions you would like to ask about Te Whaioranga?

KIA ORA FOR YOUR TIME TODAY E HOA. WE REALLY APPRECIATE IT.

Appendix 9: Health professional questionnaire

Te Whaioranga questionnaire for CAC and PTAC

Introduction

CWA have been employed by Pharmac to design and build a web site that focuses on Maori health. The web site entitled "Te Whaioranga" (Wellbeing) is intended to be a valuable online resource for both professionals and whanau.

To help inform the design and usability of the web site, and thus make it a truly useful resource to all Maori - CWA are conducting research to gain an understanding as to what Maori really want from such a web site.

The request to create a web site is driven by findings published in the Pharmac report "Maori Responsiveness Strategy Action Plan". Your comments will help inform both Pharmac and CWA as to exactly what you expect and need from a Maori health web site.

All information gathered from this questionnaire will be kept in the strictest of confidence and not passed on to any third party.

Te Whaioranga questionnaire for CAC and PTAC

1. Brief introductions of all people in the room

This image shows a single page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.

Te Whaioranga questionnaire for CAC and PTAC

2. Motivation

2.1 What were your reasons or motivation for becoming involved in CAC/PTAC

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Te Whaioranga questionnaire for CAC and PTAC

2.2 What motivates you to continue being involved in the Maori health sector?

Handwritten response:

Maori health sector is a very important part of our culture and we need to keep it alive and growing. We need to make sure that we are providing the best possible care for our people and that we are working together to make a difference. We need to make sure that we are providing the best possible care for our people and that we are working together to make a difference.

Te Whaioranga questionnaire for CAC and PTAC

2.3 What are your hopes and aspirations for future developments in Maori health (ngā moemoeā)?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

Te Whaioranga questionnaire for CAC and PTAC

3. How do you keep up to date with information around developments in Maori health?

[illegible]

Te Whaioranga questionnaire for CAC and PTAC

4. What would you expect to see on a Maori health web site?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Te Whaioranga questionnaire for CAC and PTAC

Interviewers

Date

Location

CONSENT

I (the undersigned) have been asked to help CWA (Copeland Wilson & Associates Limited), on behalf of Pharmac, to participate in a focus group about developing a Te Whaioranga web site for Maori Health.

I understand that any information I give will be kept anonymous. This means that I will never be identified by name in anything that CWA writes or says. And no-one here, or anywhere, will be told about anything I say.

I understand that I can refuse to answer questions and I can drop out at any time if I choose.

I (the undersigned) agree to take part in this focus group.

Matiu Dickson Signature: _____

Paora Stanley Signature: _____

Heather Thomson Signature: _____

George Laking Signature: _____

Appendix 10

Pharmac's Action Plan

Te Whaioranga, the action plan for the Māori Responsiveness Strategy, focuses on the following goals over the next five years.

1. To integrate Māori strategic priorities;
2. To enhance internal PHARMAC capability in relation to Māori health issues;
3. To improve the quality of data analysis in relation to Māori health;
4. To prioritise Māori health areas in Funding and Procurement;
5. To advance 'Optimal Use of Medicines for Māori; and
6. To ensure significant Māori representation and participation within PHARMAC.

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