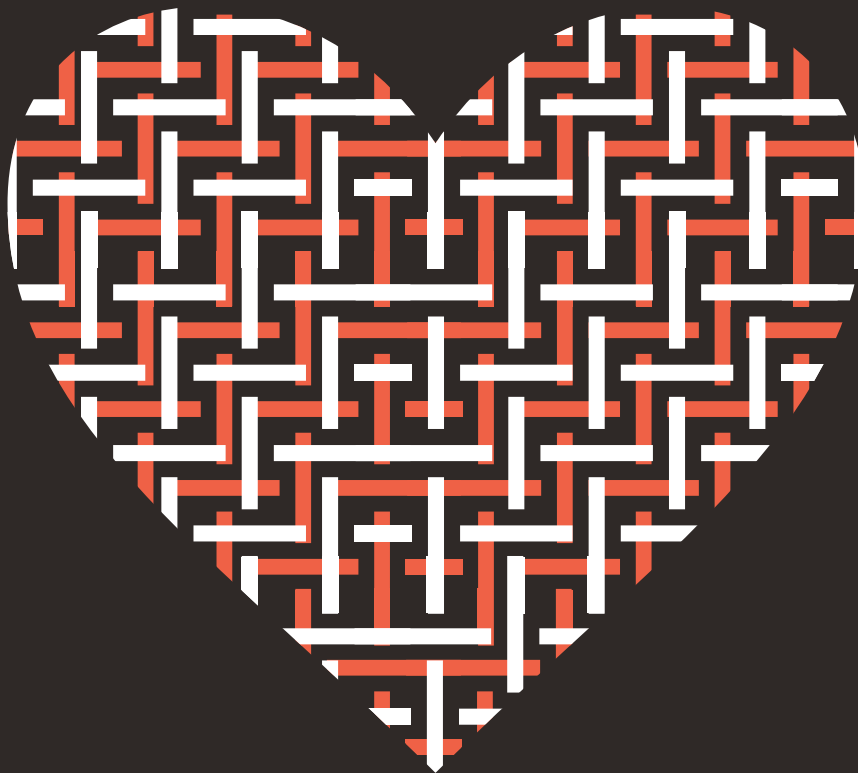


NGĀ KOKONGA NGĀKAU

Perceptions and experiences of
Māori Heart Health in Te Tai Tokerau



October 2018

He kokonga whare, e kitea; he kokonga ngākau, e kore e kitea.

A corner of a house may be seen and examined;
not so the corners of the heart.

He mihi aroha ki a koutou te whānau i ā koutou
pūrākau, i ō koutou whakaaro, i tō koutou āwhina.

Thank you to:

the generous people who showed incredible
manaakitanga and shared their taonga with us;
their pūrākau, whakaaro and knowledge.

the people who are working on this important
kaupapa to improve the hauora of Māori in
Te Tai Tokerau.

*“To be Māori is to serve and volunteer. Anything is
achievable through manaaki. If we bring ourselves to
care enough, we can save the world.”*

This report explores the findings of a rapid social
innovation project commissioned by The Heart
Foundation and led by Kataraina Davis (Ngāti
Whātua, Ngāpuhi) and Rachel Knight (Ngāi Tahu)
from Innovation Unit.

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we help create a world where more people belong
and contribute to thriving societies. We build
alliances with ambitious places, organisations and
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The case for change

Improving Māori heart health outcomes is a critical priority if we are serious about addressing health equity in Aotearoa.

Māori experience a disproportionate burden of Cardiovascular Disease (CVD) related death and disease¹; they are two and a half times more likely to die from CVD than non-Māori.⁸

CVD is the leading cause of death in Te Tai Tokerau³ where Māori make up 33% of the total population. Between 2013 and 2033 the Māori population is projected to increase by 26%, compared to only 6% for non-Māori.³

Māori die nine years earlier than non-Māori in Te Tai Tokerau³, and the preventable rate of death for Māori in Te Tai Tokerau is 3 times higher than the rate for non-Māori.⁹ It is estimated that 57% of these preventable deaths are caused by long-term conditions such as CVD and diabetes.⁹

Te Tai Tokerau faces unique challenges – it is a large region, and its geographically dispersed population often experience high rates of socio-economic deprivation and high health needs.¹³

Māori are
2.5^x
more likely to
die from CVD
than non-Māori.³

Māori die
9 years
earlier³ and
3^x
more often from
preventable deaths
than non-Māori in Te
Tai Tokerau⁹.

Background

Earlier CVD risk assessments for Māori

Earlier this year, the Ministry of Health published a consensus statement on Cardiovascular Disease (CVD) Risk Assessment and Management for Primary Care. One of the key changes was a recommendation that all Māori should have a CVD risk assessment at a younger age; 30 for Māori tāne, and 40 for Māori wāhine, 15 years earlier than previously recommended.

The Heart Foundation has embarked on a journey to understand how it might contribute to enabling Māori to be screened at a younger age and to reduce their CVD risk.

Social Innovation process

The Heart Foundation, supported by Innovation Unit, has initiated a social innovation process based in Te Tai Tokerau to:

- engage with whānau in Te Tai Tokerau to understand the enablers and barriers to having a CVD risk assessment
- rapidly review existing information on this topic
- engage with key stakeholders to understand what is already happening in this space and their perspectives on the challenges and opportunities
- develop a set of insights on the key challenges and opportunities for change, and
- co-design and test potential solutions.

This report is focused on the insights gained from engaging with whānau in Tai Tokerau to understand their lived experience, to inform a co-design process.

Methods

Discovery questions

To define the scope of what we wanted to understand, we created the following four key discovery questions to guide our discovery process:

1. *What are the barriers and enablers for Māori to have a CVD risk assessment at a younger age?*
2. *What are their perceptions of CVD as an issue?*
3. *How is this audience best reached?*
4. *What would enable this group to take steps to lower their CVD risk?*

Rapid information review

Innovation Unit conducted a rapid information review to find out what was already known about Māori perceptions and experiences of CVD and what works to improve Māori heart health. These findings informed discussion guides for our conversations with whānau, and contributed to the final insights. A full reference list can be found on page 27.

Insights from key stakeholders

In order to understand the current challenges and opportunities for change from a health system perspective, we talked to key stakeholders including leaders from the District Health Board, Primary Healthcare Organisations, Māori health providers and others working to improve population health at a community level.

Key insights highlighted by those we talked to included that there is:

- a lot of work happening in the Te Tai Tokerau primary care system to improve access, particularly around addressing acute pressures and enabling a whānau-led approach, but progress on this will take time
- a lot of activity connected to improving CVD outcomes in communities across Te Tai Tokerau but there is currently no coordinated effort to increase Māori CVD risk assessment rates
- low awareness amongst key stakeholders of the new CVD consensus statement and the drop in age for Māori risk assessment
- a strong appetite for doing more to improve Māori heart health outcomes in Te Tai Tokerau, and
- that 'One Heart Many Lives' was very well accepted in Māori communities in Te Tai Tokerau, and provided an umbrella that supported collaboration between health providers.

Conversations with whānau

To bring the voices of those with lived experience, we spoke with 15 Māori people who:

- live in Te Tai Tokerau
- are within the new screening age range (30+ for men and 40+ for women)
- have not had a CVD screening assessment but are now eligible.

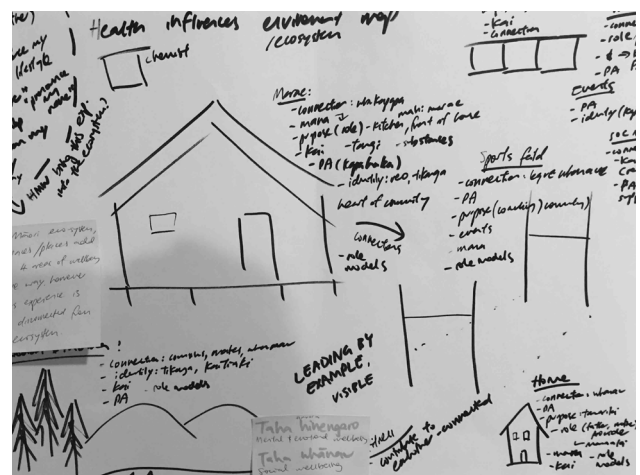
Of these people:

- 3 identified as wāhine, aged 40-52
- 12 identified as tāne, aged 31-42
- 4 lived in remote rural locations, 10 lived in urban areas/small towns, and 1 lived in a city.

To ensure we heard a range of perspectives, we interviewed a range of people across Te Tai Tokerau; starting in Whangarei, and making our way further north to the east coast through Te Hiku o te Ika to the west coast. The conversations were in people's homes, work places or marae, and usually took about an hour.

Our empathy-focused interviews were grounded in a kaupapa Māori approach to ensure issues of CVD were explored within a Te Ao Māori world view.

Whānau were acknowledged for sharing their taonga; their time, pūrakau, whakaaro and knowledge, through koha and kai.



Key insights

Whānau are everything, and are intrinsically linked to wellbeing

'Whānau' is a strong and widely used term when Māori talk about their health. It is often used to describe their key purpose, and support for being well, and individuals who were highly pro-active with their health described it as a whole-whānau effort.

Surprisingly, references to friends (outside of whānau) were rare, and some of the strongest whānau influences were not currently alive. Family who had passed still often guided their thoughts, and the potential of future tamariki and mokopuna were strong reasons for people to be well⁴. Furthermore, although many men described the challenges of getting to, accessing, and interacting with a doctor, most did whatever they could to get around these barriers if their children were unwell.

Lastly, the key trigger for most people to change their behaviour to live a healthier lifestyle was the shock of losing someone very close to them (such as a parent), or having a child – or the idea of future children – prompt them to be healthier.

“My whānau are my reason for everything. The reason I'm here and the reason I want to be well.”

“That whānau support is a big thing. If you don't have that it's rat-shit. I feel for the lonely ones. I heard of two people dying from heart attacks and being found two days later – I don't want to die lonely.”

“Anything to do with health is a whole-whānau and whole-community thing. We try to be healthy together.”

“It makes your heart happy, doing it with whānau – that makes it healthy.”

Opportunities

How might we create whānau-centric CVD screening experiences?

How might we create health experiences that support whānau to be well together?

The doctor experience is disconnected from Te Ao Māori

People described how their connection to their identity as Māori had a strong influence on their wellbeing. The spaces that were important to them such as the home, marae, sports field, and the land, all lifted their hauora by providing them with social connections, physical activity, sustenance, and reinforcing their way of being in Te Ao Māori.

In contrast, they described their doctor experience as largely disconnected from their health ecosystem. This was both in a physical sense in terms of travel distance and a lack of visibility of doctors in their community, but also in how their experience of visiting the doctor often came at odds with – or even undermined – their core values as Māori.

While the physical disconnection made it logistically difficult for some people to get to the doctor, negative experiences created feelings fear, whakamā (shame), frustration, confusion and miscommunication which caused some people to avoid going to the doctor unless absolutely necessary.

Opportunities

How might we reinforce Māori identity by demonstrating core values (such as manaakitanga and whānaungatanga) at every point in the CVD screening experience?

How might we design the CVD risk-assessment experience to fit into people's existing hauora ecosystems?

"I'm Māori before anything else."

"If they don't try to pronounce my name right, that's the first chip at me ever coming back. Using reo – anything that reinforces who I am as Māori."

"Through my work dealing with the doctors, I've seen a lack of Māori understanding; no effort to try and pronounce names, and a lack of empathy for their circumstances."

"[He] is the only Doctor that is visible in the community. Other GPs you only see if you go into their practice."

"We have a problem asking for help from people from other cultures. I'm too embarrassed to go see a pākehā doctor and what they might do - how do I change that mindset?"

Heart issues are rife but rarely talked about

Almost every person we spoke with could draw on first-hand experience of losing a loved one to heart attack or heart failure. However, heart issues are rarely talked about, and are so common that they are borderline normalised and accepted as a part of life.

Although people tended to have a general awareness around healthy habits and behaviours, no one had heard of 'CVD' and very little was known about how it could be identified, prevented or managed. This contributed towards a lower perceived priority, or feelings of fear and worry for themselves and their whānau.

Opportunities

How might we increase awareness that much of CVD is preventable?

How might we make the language around 'CVD' more accessible to all whānau?

How might we facilitate conversations about heart issues and so that whānau can help prevent unnecessary tangi?

How might we spark conversations about heart issues in a way that celebrates life and wellbeing?

"We all have family members who have passed away from heart attacks...It's a part of our lives. It's around, everywhere."

"As a kid going to tangi, you'd ask, What did uncle die of? Heart attack. What did aunty die of? Heart attack."

"I've always known about it. Heart attacks and cancer."

"I've never heard about 'CVD'. Just heart attacks, heart failure, heart disease and stroke."

"I have no idea what happens at a CVD assessment. I've never heard about it. How would I know how to talk about it?"

"It's a matakau area to talk about for us."

"I don't know how to express it to my brothers - how to have that conversation - they just don't get it. They don't think anything is wrong with them, so they won't get a screen. They'll say 'we're all good.'"

Leading by example is more influential than information alone

Although some people told us that increased health education was needed to build CVD literacy, most people described how seeing trusted community champions lead by example was a more important way of creating behaviour change. This is supported by research that shows that engaging community leaders for health initiatives is an effective way to engage with hard-to-reach populations.¹⁴

Similarly, seeing doctors working in their community built trust in them, and raised the doctors' mana.

Opportunities

How might we leverage community champions to get whānau screened?

How might we create opportunities for health staff to work with communities in new, Māori-centric ways?

"The Doctor straight up told me what I needed to do to be well, but I didn't do it...I need to make my own decisions."

"It's more about leading by example. Not what you should, or have to do."

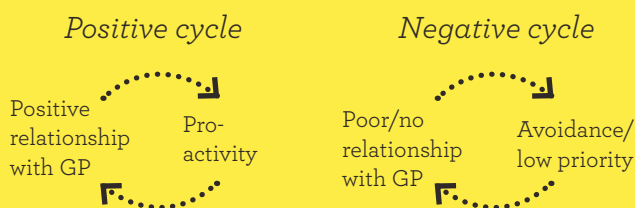
"We don't force our whakaaro on them."

"We need local champs. Seeing someone they know – from their grass-roots – doing it makes it ok."

"I do trust people in my own community, but they have to be doing the mahi ...It's about the right, trusted people who are community-minded...mahia te mahi, kano hi kitea (get the work done, seeing people do the work)."

People are more likely to see a doctor if they have a positive relationship

Those who described a positive, trusting relationship with their GP were generally more proactive in going to visit the doctor. People also described how having to go to the doctor regularly (such as for an unwell parent or child) helped them to build a better relationship with their GP. On the other hand, those who had no or a poor relationship with their GP were more likely to avoid going to the doctor, or would travel further to see a doctor that they had a positive relationship with – which increased travel time barriers.



"They don't need to be a Māori. Just someone who cares."

"I've never had a bad experience with a GP. I think it's because I'm pro-active – they know me and my family."

"My relationship with the doctor is better now that I'm looking after my dad and have to take him."

"I'll go to Auckland to see the doctor if I need them. Doctors here don't understand my needs – I get hōhā going here."

"I became a number. It wasn't personalised."

"I've never had a good relationship with a doctor, because of my history. It feels like they don't care, like I'm just being judged."

Opportunities

How might we create opportunities for GPs to build trusting relationships with people to encourage proactivity?

How might we create more opportunities for GPs to engage in Te Ao Māori?

Men's fear of the screening process or result can override fear of dying

Men and women both described the pressure put on men to provide for their families, which often came at the cost of their own wellbeing. Many also described men's 'stubborn' avoidance of the doctors, however, this was often driven by fear that the process or outcome may undermine of their mana or their role in the family.

For many men, the fear of what a screening process might entail – often coming from a lack of understanding – contributed towards this avoidance, as well as the fear of finding out that they may not be able to be around for their whānau. This is supported by other research showing that Māori men can believe knowledge of health risks or ill health creates stress and contributes to further ill health.⁹

In contrast, men's partners were often described as the pro-active driver in the relationship, especially around health.

Opportunities

How might we increase mana through the screening process and health pro-activity?

How might we make the screening processes visible and accessible to reduce fear and whakamā?

How might we support whānau members (especially partners) to encourage change?

“My brothers all work very hard to provide for their families...Dad was all about the mahi too – make sure you provide for your family. It's so they don't have to struggle but I still see them struggling. When does it end? When will you keel over? You need to appreciate what you have now.”

“I always felt pressure as the oldest boy to provide for the family. Dad left the family when I was a teen, and that's when the pressure started.”

“Māori men are stubborn – our pride gets in the way... When it's your turn to go, it's your turn.”

“We're scared that we may find out something that we don't want to know. Sometimes we'd rather just not know.”

“I'm not scared of the outcome, I'm scared of what they (doctor) might do. It's like a prostate check; I'm not going to let anyone probe me – shove a finger up my arse.”

“My biggest fear is losing my family unnecessarily, and my family losing me – early.”

Personas

.....

What personas are (and aren't)

Personas are fictional people based on real research data. They provide a snapshot into a group of peoples' broader lives and what's important to them, as well as their lived experience of a particular issue. They are not intended as segments or to be representative of all Māori people in Te Tai Tokerau, but provide a useful lens to apply when developing new solutions.

How personas are created

Personas are created after qualitative research has been conducted, through a process of identifying patterns in the participants' contexts, perceptions, and behaviors. Scales are created to explore the similarities and differences between the individuals and to establish groupings. These groupings provide the basis for the personas, which are then fleshed out with more detail directly from the participant's interviews included in that group.

How to use personas

Personas are useful for showing how a group of people think about and behave in relation to a particular issue or service. They can be used to evaluate and inform solutions and help internal staff understand the perspectives and motivations of people who they might not often get the chance to interact with, however, personas should not be used *instead of* directly engaging with the people who have lived experience of a service or issue.

Elaine

Kaimanaaki



Elaine lives in Whangarei with her partner and two teenage children. She has whakapapa in Ngāti Hine, and her marae is in Moerewa but she usually only goes back for tangihanga. Outside of work, she spends a lot of time with her wider whānau. *“My sisters-in-law are my greatest friends.”*

Although Elaine knew that heart problems were common in her family, her Mum passing away a few years ago was a real shock. Now she worries about her brother who works in a high-stress job, and her sister who’s a *“bit of a party girl”* even with her own heart issues. *“They don’t think anything is wrong with them, so they won’t get a risk assessment...Men in particular are very stubborn – my husband had viral meningitis before our wedding, and we almost got married in hospital because he kept saying ‘I’m alright.’”*

When the kids were younger, Elaine’s mother made her take them to the doctors whenever they got sick, so over time Elaine built a relationship with her local GP. *“He understands Māori, and understands our family.”* Sometimes medical jargon can make it hard to follow what her GP says, but she’s happy to ask questions and her chemist helps explain any medication that she or her whānau need.

Elaine recently quit smoking after her daughter saw an anti-smoking ad on TV and asked if she was going to die. The question really threw her, and she wants to get more proactive about her health but doesn’t know anything about the CVD risk assessment process. *“I wouldn’t even know where to go and get screened...I know it’s important, but it’s like at election time – where is the voting booth?”* She wants to support her whānau to be healthy, and wishes she knew how to broach the conversation with them. *“I want health and happiness for them, their children, and their moko...I just don’t know how to express it to them – how to have that conversation – they just don’t get it.”*

Opportunities to reach

- Doctor, chemist
- Facebook (uses to stay in touch with family, and events in her area)
- Children/school

Background



42 years
of age



4 siblings
2 children



Urban

Lifestyle



Project
manager



Gardening,
baking, cooking



Time with
family



Kids' sports
games &
kapa haka



Facebook



Travel with
family

Health & risk assessments

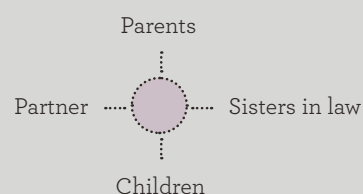
Key enablers

- Supportive partner & family
- Positive GP relationship

Key barriers

- Awareness (of risk assessment process)
- Hard-to-follow medical jargon
- Rumour that local GP will move away

Key influences



Johnny

Mana Tāne



Two years ago, Johnny bought a house and moved back to Kaitaia from playing league in the city, to teach at a local high school. He spent most of his teenage years growing up in the city with his aunty and uncle, but decided that it was time to come home. *“I got lost in the league world...I’ve come home to work for my people.”* One of 11 kids – including 9 whāngai siblings – Johnny comes from an active and influential family. His Mum is principal of a local kura and his Dad is very active in the waka ama and sporting community. When Johnny’s not playing or coaching league, he organises sports events for young people and spends time on the marae when he can. *“We run a lot of the events here in Kaitaia. They give people something to look forward to and a reason to stay well.”*

Johnny is trusted in the community – especially by young people – and this responsibility is a constant reminder to him to be the role model he needs to be. He’ll often have ‘sports’ kids come around to his house to get away from their own home environments.

Johnny hasn’t had much of a reason to go to the Doctor since moving to Kaitaia, but does miss having a good relationship with his Doctor back in the city. Although none of his whānau have had heart problems, he knows it’s a massive issue for his community. *“I know I’m pretty different compared to people here...”* Johnny doesn’t have any children, but wants to live longer to have them, and knows his future wife will be a big supporter in his life. He sees his wider community – and his responsibility to serve them – as the biggest influence on his behaviour and decisions. Johnny has a great respect for his parents (*“they’re great role-models”*) and also listens to his older cousins who *“helped bring me home.”* He relies on his league-whānau to pick him up if he ever feels down, and sometimes koreros to his best friend; his dog.

Opportunities to reach

- Is strong influencer in community – can role-model for others
- Marae or sporting events
- Parents
- 'Sports kids'
- League whānau

Background



32 years
of age



10 siblings



Small
town

Lifestyle



High school
teacher



Fast food



Mahi
marae



League,
kapahaha,
sporting
events



Highly active
on social
media



Drinks a
little, smokes
the 'odd cone'

Health & risk assessments

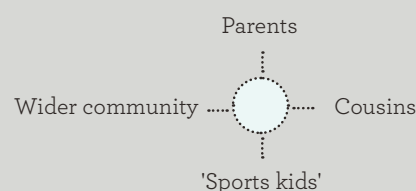
Key enablers

- active lifestyle and family
- strong role models
- responsibility to role model

Key barriers

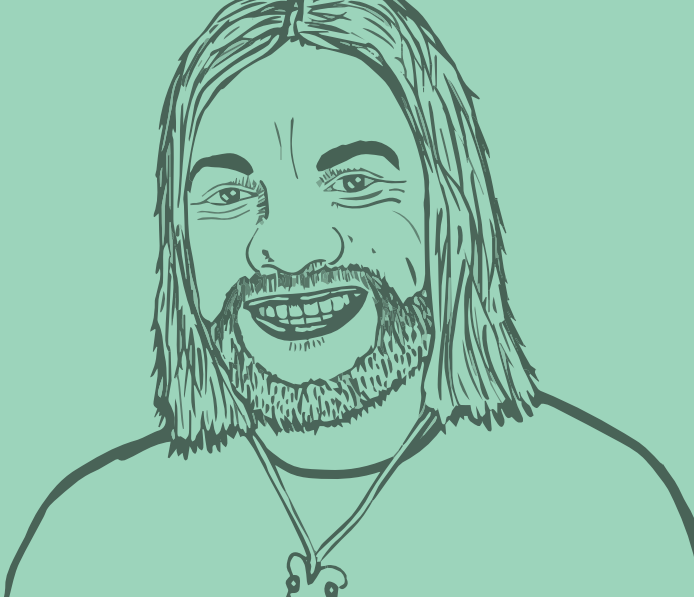
- lack of doctor relationship
- health language confidence

Key influences



Haimona

Kaitiaki



Haimona lives with his partner and three kids in a papakainga on his large iwi farm on the beautiful east coast of Te Tai Tokerau. When he's not outside looking after the farm, he spends long hours in the marae kitchen or practicing kapahaka, and on weekends he plays league. Haimona is very connected to his environment and sees himself as kaitiaki of moana and ngāhere. *"My whenua is my whānau. I love it just as much."* The nearest supermarket is close to an hour away, so he hunts and dives with his cousins for fresh kai every other day.

Heart issues run rife in Haimona's family – his Nana and father died of a heart attack along with numerous aunties and uncles on his dad's side, and his older brother had one recently but thankfully lived. *"CVD is a part of our life. It's around, everywhere."* He often misses his Dad, and asks himself, "what would dad do in this situation?". Over the last few months, Haimona himself has had some chest pains and has been getting sick often, but he won't go see a doctor because he'd have to take half a day away from the farm. *"It's too much hassle. If I'm not feeling like I'm dying, then I'm fine."* Cost is also a barrier for Haimona, but if his kids become unwell he'll take them any time and pay any cost. He wants his kids to be healthy so that someday he will have his own mokopuna, and he wants to stay well so that he will be around to meet them. *"My biggest fear is losing my family unnecessarily, and my family losing me early."*

The only doctor that Haimona has seen in the past 8 years is a visiting GP who he has a strong trusting relationship with. He often gets advice and talks to them casually outside of a medical context. Haimona would probably listen if that GP told him to get a risk assessment, but otherwise he wouldn't know where to start: *"I have no idea what happens at a CVD assessment. I've never heard of it. How would I know how to talk about it?...I won't go (to the Doctor) if I've got nothing to talk about."*

Opportunities to reach

- Partner *"my partner is my driver."*
- Visiting doctor and nurse
- Marae
- League

Background



35 years
of age



5 siblings
3 children



Rural

Lifestyle



Works on
iwi farm



Diving, hunting,
kapahaka, league



Mahi
marae



Drinks,
smokes
'green'



No phone
reception



Generator-
run home

Health & risk assessments

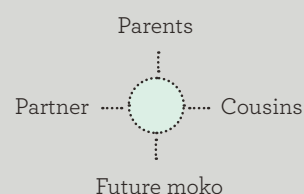
Key enablers

- Active lifestyle, strong social connections
- Positive relationship with visiting doctor

Key barriers

- Cost & perceived priority
- Time/access/transport
- Awareness (of process, purpose)

Key influences

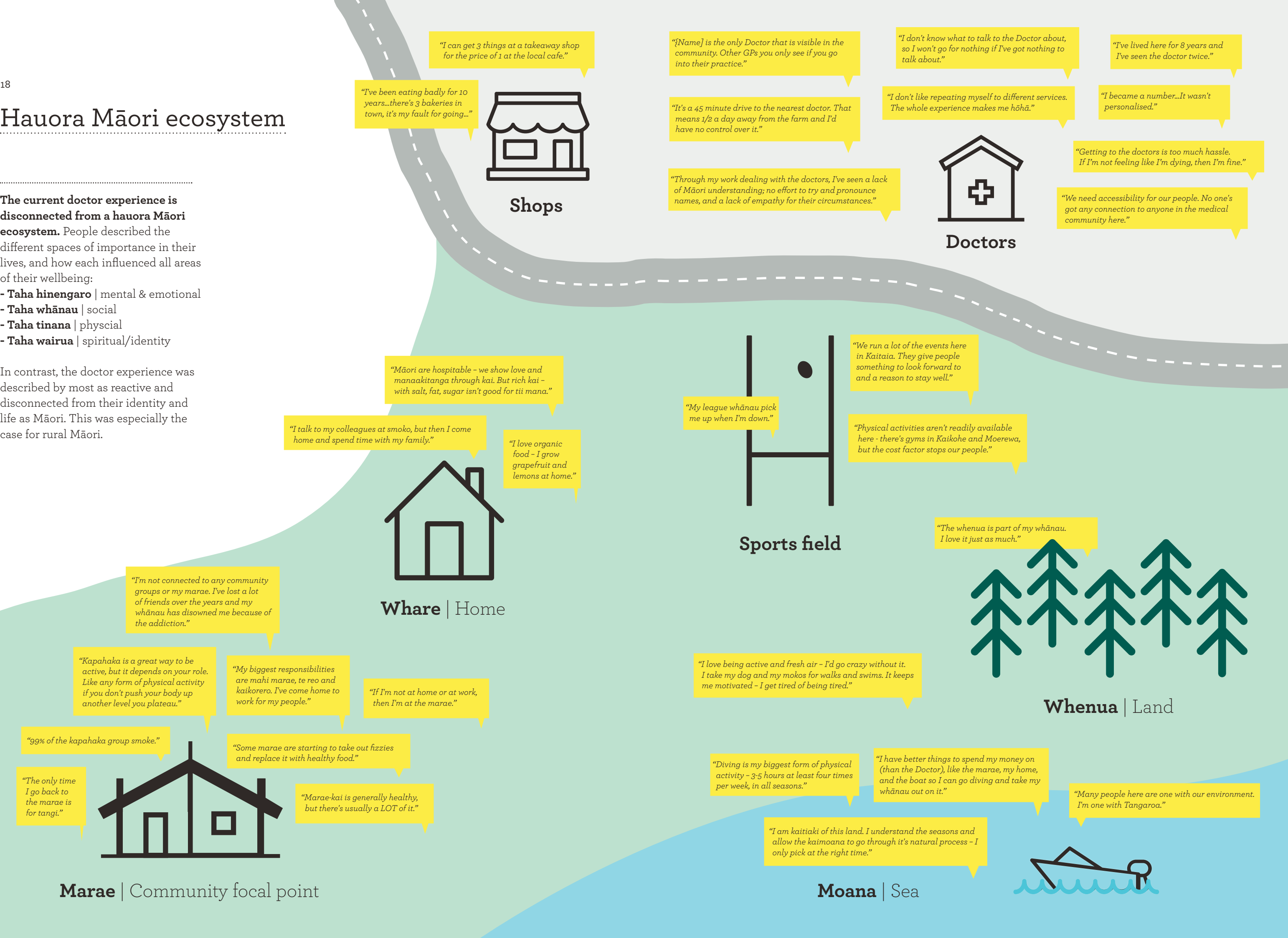


Hauora Māori ecosystem

The current doctor experience is disconnected from a hauora Māori ecosystem. People described the different spaces of importance in their lives, and how each influenced all areas of their wellbeing:

- **Taha hinengaro** | mental & emotional
- **Taha whānau** | social
- **Taha tinana** | physcial
- **Taha wairua** | spiritual/identity

In contrast, the doctor experience was described by most as reactive and disconnected from their identity and life as Māori. This was especially the case for rural Māori.



Whakapapa influences on hauora

Whānau is a strong and widely used term when Māori talk about their health. However, those we spoke with described how people in their immediate and extended family had very different types of influences on them. Surprisingly, some of the strongest influences were not currently alive. Friends and family who had passed still often guided their thoughts, and the potential of future children and mokopuna were strong reasons for people to be well.

Atua | Gods
are my providers

Tupuna | Ancestors
are my reminders

Kaumātua | Respected Elders
are my teachers

Mātua | Parents
are my guidance

Aunts & Uncles
are my role models

Partner
is my driver

Me

Siblings & cousins
are my friends

Tamariki | Children, nieces, nephews
are our advocates and future leaders

Mokopuna, ngā uri whakaheke | Grandchildren, descendants
are my purpose

“I am kaitiaki of this land. I understand the seasons and allow the kaimoana to go through it's natural process – I only pick at the right time.”

“Many people here are one with our environment. I'm one with Tangaroa.”

“My biggest fear already happened, when my father passed. I don't fear my own death any more, because I know he's waiting for me.”

“At the time I think I need to change my whole life; eat healthy, be more active – I don't want it to happen to me. But over time it goes off the radar until another friend or whānau dies.”

“He (brother) has a deep respect for his Mum, aunties and elderly woman. He'd do anything for them. If enough of them prompted him to get screened, it would stay on his conscious.”

“I stay well for my whānau – my mum and dad mostly. They're great role models.”

“I miss my parents and often think, ‘what would mum and dad say? What would they do?’ They were the wisest people I've ever known.”

“I wish my relationship with my dad was better before he passed, so he could guide me.”

“She pushes me to do everything – not just to do with health. She's the backbone of our family.”

“My partner is feisty. She's the one who nags me to do everything.”

“My cousins give me stuff to do, people to hang out with.”

“My partner is my driver. She makes me feel great, and I want to stay great for her.”

“Friends' he whakaaro pākeha. (Friends' is a pākeha concept).”

“My friends are my whānau. My sisters-in-law are my greatest friends. I could count on one hand the number of friends I have that aren't related.”

“We need to let our tamariki lead by example... seeing parents follow their kids makes me smile in my puku.”

“I used to be a chain smoker but my son saw an ad on TV and said 'Mum you're going to die'. He got my grandma to promise to quit too if I did.”

“The only reason I go to the doctor is when my kids are sick. I'll take them any time and pay any cost for them.”

“Our babies are our advocates.”

“That older generation is too far gone – they're stuck in their ways. You need to target the kids – they influence their parents.”

“I don't have any kids, but I want to live longer to have them.”

“My kids and my moko are my drivers – I want to spend more time with them and see them hit 21.”

“I love them (moko) more than my kids.”

“I want my mum to be around to meet my future moko, for their connection to their whakapapa.”

“The kids' wellbeing is important – I want mokopuna, whakapapa.”

Lifestyle-change: barriers

People described how the following things got in the way of changing their lifestyle for the better.



Early experiences

- Such as:
- hearing of people passing away
 - attending tangi (funerals)
 - loved ones' health scares & scars
 - seeing someone die
- “Going to tangi, you’d ask, What did uncle die of? Heart attack. What did aunty die of? Heart attack.”
- “I’ve seen one person pass away from heart attack – it’s not something I’d wish upon anyone. They were 35, their eyes dropped back and they were frothing at the mouth. It was 15 years ago but I still see visions of it.”
- Unhealthy whānau habits**
- “I love food...growing up, that’s what I was taught to do. If you’re sad, have kai. If you’re bored, have kai. Happy? Have kai.”



Increased awareness; fear for self & whānau

- “As you get older, it’s always there on your conscious. I fear passing away early. We’re (siblings) all in our late 40s-50s, and our expectation is that our time is coming. Our generation has a genuine fear for our family and friends.”
- Heart attacks are rarely spoken about**
and are so common that they are borderline normalised and accepted
- “My worry is cancer – I’ve never thought about heart failure. Shit, why haven’t I thought about it!? All my nana’s family died of heart attacks.”
- Low health related self-efficacy**
Not knowing what power they have to create any change
- Becoming less active over time**
- “Dad was a sports man, so growing up we were around sports all the time. Now I’m not as active, I feel the changes in my body – I don’t feel as well.”
- No perceived reason for pro-activity**
and low perceived priority without reason (such as trigger)
- “I don’t know what to talk to the Doctor about, so I won’t go for nothing if I’ve got nothing to talk about.”
- “Typical Māori – they work hard and they play hard.”



Trigger to change behaviour

- Such as:
- child prompts parent to be healthier
 - birth of child/mokopuna (grandchild) inspires parent to change lifestyle
 - personal health scare/symptoms
 - loved one (such as parent) becomes unwell or passes away
- “I used to be a chain smoker but my son saw an ad on TV and said ‘Mum you’re going to die’. He got my grandma to promise to quit too if I did.”
- “Dad passing was a big shock – he was always a healthy man – it was mum who was sick all the time. It was a wake-up call for me.”
- Not knowing how to talk about it**
- “They (siblings) don’t think anything is wrong with them, so they won’t get a screen. They’ll say ‘we’re all good.’”
- Pressure to prioritise whānau over own wellbeing**
- “Society places a lot of pressure on males to be performers, when they are just human like the rest of us.”
- Low perceived priority**
- “Knowing about heart attacks is important, but I have too many other things to sort out first. It’s just not a priority.”
- “I’ve been having chest pains and have been getting sick easily...I know I have problems but I haven’t been to the Doctor.”
- “My sister has a hole in her heart but she’s a party girl – she drinks and smokes a lot.”



Get to doctor *only if they or loved one has symptoms*

- Mindsets**
- whakamā of screening process⁴
 - fear of results
 - perceived priority (when faced with below barriers)
 - pride/stubbornness
- “Guys are proud and try and tough it out. You have to take them there (hospital/doctors).”
- Knowledge**
- of what to do or where to go for a screening process
 - of what the screening process will entail (can drive fear/anxiety)
- “I wouldn’t even know where to go and get screened...it’s like at voting time; we know it’s important, but where is the voting booth?”
- Access**
- no or unreliable transport option
 - long travel times
 - long wait times
 - few options for ‘good’ doctors
- “The nearest doctor is an hour and 45 minutes’ drive away. It’s crazy when it’s easier to go to the doctor by putting you on a ferry.”
- “Doctor wait times are long – they’re booked days/weeks ahead and you could turn up just to wait for an hour. We got mum’s eyes screened down in Auckland instead.”
- Cost⁹**
- transport (car maintenance, WOF, fuel)
 - Doctor /screening fee
- “The \$18 doctor fee is a lot of money for our families here. It’s a huge barrier; \$18 on a Friday – is what I’ve got left going to get me through the weekend?”
- “My son got ingrown toe-nails – it cost me \$300 and I’m still trying to pay it off. Now I operate on his toes myself instead.”
- Time⁹**
away from work or other commitments



Diagnosis

- Lack of/lost Doctor relationship**
- “I became a number. It was the same receptionist and admin lady, but the practice was different. There were 4-5 doctors, and your name just got called out. It wasn’t personalised.”
- “There’s only one good doctor in Kaitaia and he’s moved to Auckland.”
- Negative experience at/with Doctors**
- lack of receptionist confidentiality
 - Doctor’s lack of understanding/ respect of Māori identity and worldview⁹
- “I’ll go to Auckland to see the doctor if I need them. Doctors here don’t understand my needs – I get hōhā going here.”
- “I’ve never had a good relationship with a doctor, because of my history. It feels like they don’t care, like I’m just being judged.”
- “Confidentiality is a problem in these small towns. The receptionist at my local GP is my cousin.”
- Health language barriers⁴**
- too much information
 - Doctor use of jargon
- “Newer doctors spend more time getting to know the issues, but older doctors speak in medical terms.”
- “I don’t like the doctor – half the time I can’t remember what he says.”



Take medication, regular check-ups

- Low health literacy**
Not knowing/understanding:
- how important the medication is and what will happen if they stop taking it
 - reasons behind instructions from information not communicated in a user-friendly way
- “I’m not allowed grapefruit, but I have no idea why.”
- “I threw away the pamphlets from the doctor. As long as I take my pills I’ll be ok...I’m scared to go off them, I wonder if they are keeping me alive.”
- “My sisters refuse to even have Panadol – they don’t want to have medicine in them, but they need it.”
- Seeing no change in, worsened, or unaligned physical symptoms⁸**
being told that health status is at odds with how they are feeling
- “I’ll go to the doctors feeling good on the outside but I mustn’t be good on the inside because they say my blood pressure is still too high.”
- “I’m the only one of my siblings on these pills, but I’m also the most active. I don’t know why I’m like this...”
- Lack of support from doctor**
- “I don’t want to place blame, but I’ve never felt supported to get clean by my doctor – only by my counselling group.”



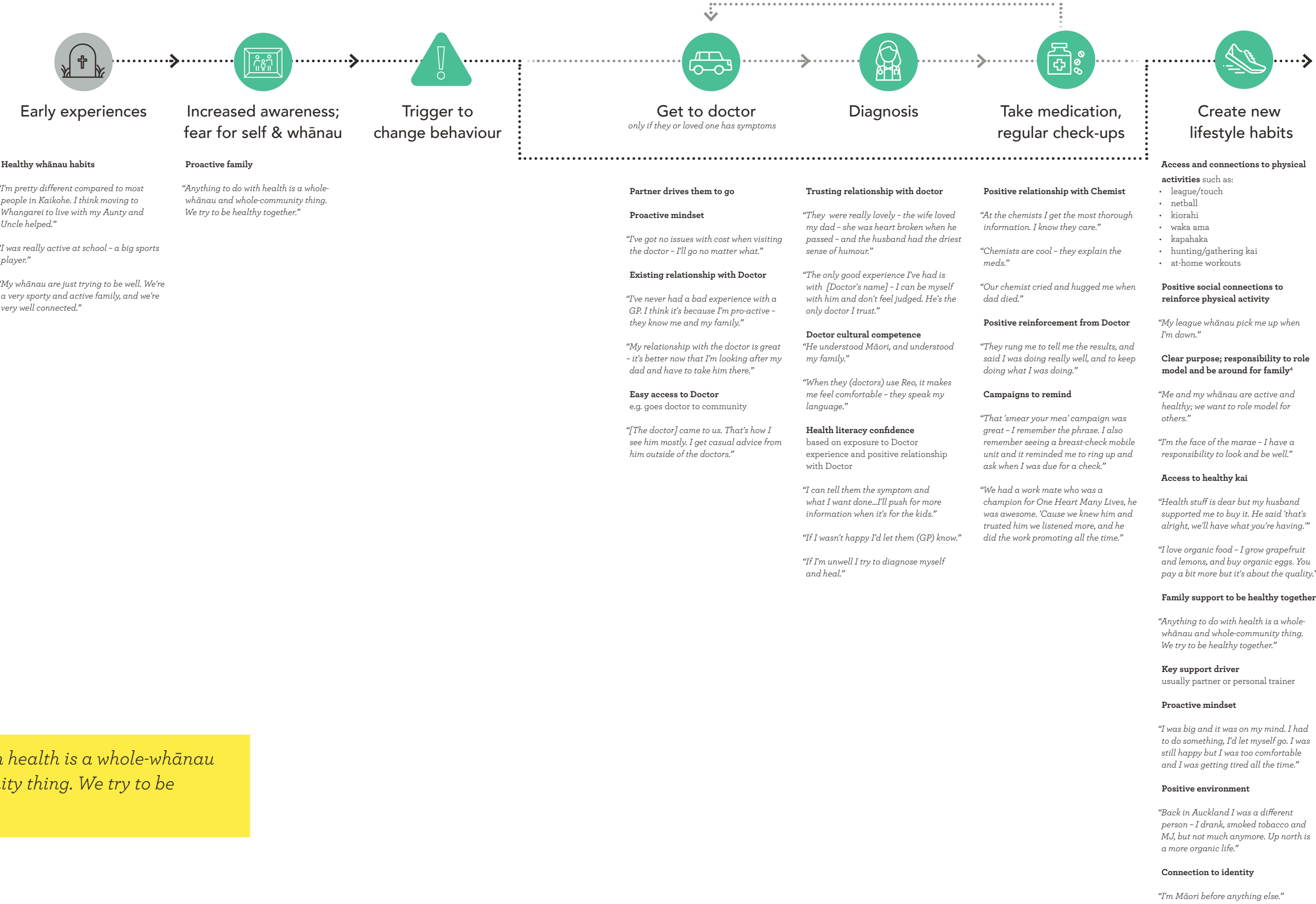
Create new lifestyle habits

- Such as:
- improve diet
 - increase levels of physical activity
 - reduce substance dependence
- Cost of and access to**
- healthy food
 - physical activities
- “I went on a diet and for \$200 we got half the amount of food we usually get. Our trolley used to be full.”
- “Physical activities aren’t readily available here – there’s gyms in Kaikohe and Moerewa, but the cost factor stops our people.”
- Unhealthy environment**
- high number of fast-food shops
 - negative influences
- “I’ve been eating badly for 10 years... there’s 3 bakeries in town, it’s my fault for going...”
- “Māori are hospitable – we show love and manaakitanga through kai. But rich kai – with salt, fat, sugar isn’t good for tii mana.”
- Lack of social support**
- “I miss Auckland – I have nowhere near as many friends here and I get lonely.”
- Lack of motivation/perceived priority**
- “I joined an aquatic centre, but it was a token gesture. I’ll go at some stage, but when, I don’t know. Probably when the membership runs out and I have to renew it.”
- Deeply ingrained lifestyle habits**
- “I want to change, but I have no idea how to.”
- “She (Grandma) said she’d give up smoking if I did, but she didn’t.”

“At the time I think I need to change my whole life; eat healthy, be more active – I don’t want it to happen to me. But over time it goes off the radar until another friend or whānau dies.”

Lifestyle-change: enablers

People described how the following things helped them change their lifestyle for the better.



“Anything to do with health is a whole-whānau and whole-community thing. We try to be healthy together.”

Te Reo Māori Glossary

| | |
|-------------------------------|--|
| Hōhā | Annoyed |
| Hauora | Health |
| Iwi | Tribe |
| Kai | Food |
| Kaimoana | Seafood |
| Kaitiaki | Guardian |
| Kanohi kitea | A seen face |
| Kapahaka | Māori performing arts |
| Kaupapa | Topic. Matter for discussion |
| Koha | Gift |
| Kōrero | Speak/talk |
| Kura | School |
| Mahi | Work |
| Mahia te mahi | Do the work (for the betterment of our people) |
| Manaakitanga / Manaaki | Hospitality |
| Mataku | Sacred, fear |
| Moana | Sea |
| Mokopuna | Grandchildren |
| Ngāhere | Forrest |
| Papa kāinga | Home base, village, communal Māori land |
| Puku | Stomach |
| Pūrākau | Stories |
| Tāne | Male |
| Tangaroa | God of Sea |
| Tangihanga / tangi | Funeral |
| Taonga | Treasure |
| Te Ao Māori | Māori world / world view |
| Te Hiku o te Ika | Far North |
| Te Reo Māori | Māori language |
| Te Tai Tokerau | Te Tai Tokerau, New Zealand |
| Waka ama | Outrigger canoe |
| Whakamā | Shame |
| Whakapapa | Ancestry / lineage |
| Wāhine | Female |
| Whanaungatanga | Establishing relationships |
| Whakaaro | Thoughts, ideas |
| Whānau | Family |
| Whāngai | To bring up, adopt, raise, feed |
| Whenua | Land |

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