Health New Zealand
Te Whatu Ora

Consumer/Whānau Research Insights

27 June 2024

This research belongs to…

The communities that welcomed us into their lives and shared with us their stories so that we may understand how to create a health system that works for all communities in Aotearoa New Zealand. This research would not be possible without their generosity.

A big thank you to following organisations and individuals for introducing us into communities and supporting this research:

- Te Runanga o Ngāti Toa Community Engagement Group, Porirua
- Parklane Retirement Village, North Shore, Auckland
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- Whare Manaaki, Masterton
- Age Concern, Palmerston North (Marian Dean)
- Te Kura Kaupapa Māori o Tupoho, Whanganui (Turuhira Hautapu)
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- Hagley College, Ko Taku Reo Deaf Unit, Christchurch (Rebecca Thompson-Looij)
- Vaka Tautua Disability Group, Christchurch (Toleafoa Malu Tulia)
- Whānau Whanake Disability Support, Christchurch (Deb Bush)
- Mana Tipua LBGTQI+ Rangatahi Group, Christchurch (Kahu Tumai)
- Pillars Ka Pou Whakahou , Prisoner Family Support , Christchurch (Elle McEwan)
- Tagata Atumotu Trust , Ashburton (Salatielu Tiatia)
- Tongan Society of South Canterbury, Timaru (Siesina Latu)
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- Otago Red Cross (Kelly Campbell)
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- Dunedin MSD (Tanya Mayson & Teina Makira)
- Asian Family Services through Te Whatu Ora | Health NZ (Kitty Ko)
- Whanganui Neuro-diverse Community & the people who support them (Suze Haynes)

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Why this research is important

Digital technologies such as a digital health record and telehealth offers significant **potential to improve healthcare outcomes, reduce workload for healthcare providers, and enhance efficiencies within the healthcare system**. However, **these benefits cannot be realised without meaningful engagement and adoption from communities**. At the same time, if not done well, digital health technologies have the potential to increase existing inequities.

While **communities with the worst healthcare outcomes and those hardest to reach stand to gain the most** from digital health technologies, these communities paradoxically are the **least likely to engage with such technologies** without understanding what it means for them and their whānau.

Recognising these challenges, the DEE team embarked on a journey to **understand community views, expectations, and how we might gain buy-in** for using digital technologies in health services.

The insights from this community engagement and research journey are provided within this pack. Findings from this research are not only inform the development and adoption of digital health technologies, but they also **offer broader insights for improving the health system**.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

The Digital Enablement and Engagement Team

The team was led by Sarndrah Horsfall

Community engagements were facilitated by
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Eleanor MacTavish | Keita Twist | Manu Sione

The research was led by Dani Chesson, PhD
Kaupapa Māori research was led by Arianna Nisa-Waller
Research activities were coordinated by Margaret Wikaire

Project management and administrative support
Karen Ellis | Belen Ortega | Katherine Walker-Meade
Tom McLean | Zoe Chamel

Mō tatou, ā, mō ngā uri ā muri ake nei

This research journey of whānau voice has been about the ability to re-envision a future for our generations to come . To move from where we've been into future considerations for better health outcomes.

Tēnei te pupuri i te aroha ki a koutou
i tākoha i ngā kōrero ā whānau ki a mātou.
Nā koutou i whakarangatira ai i te kaupapa.

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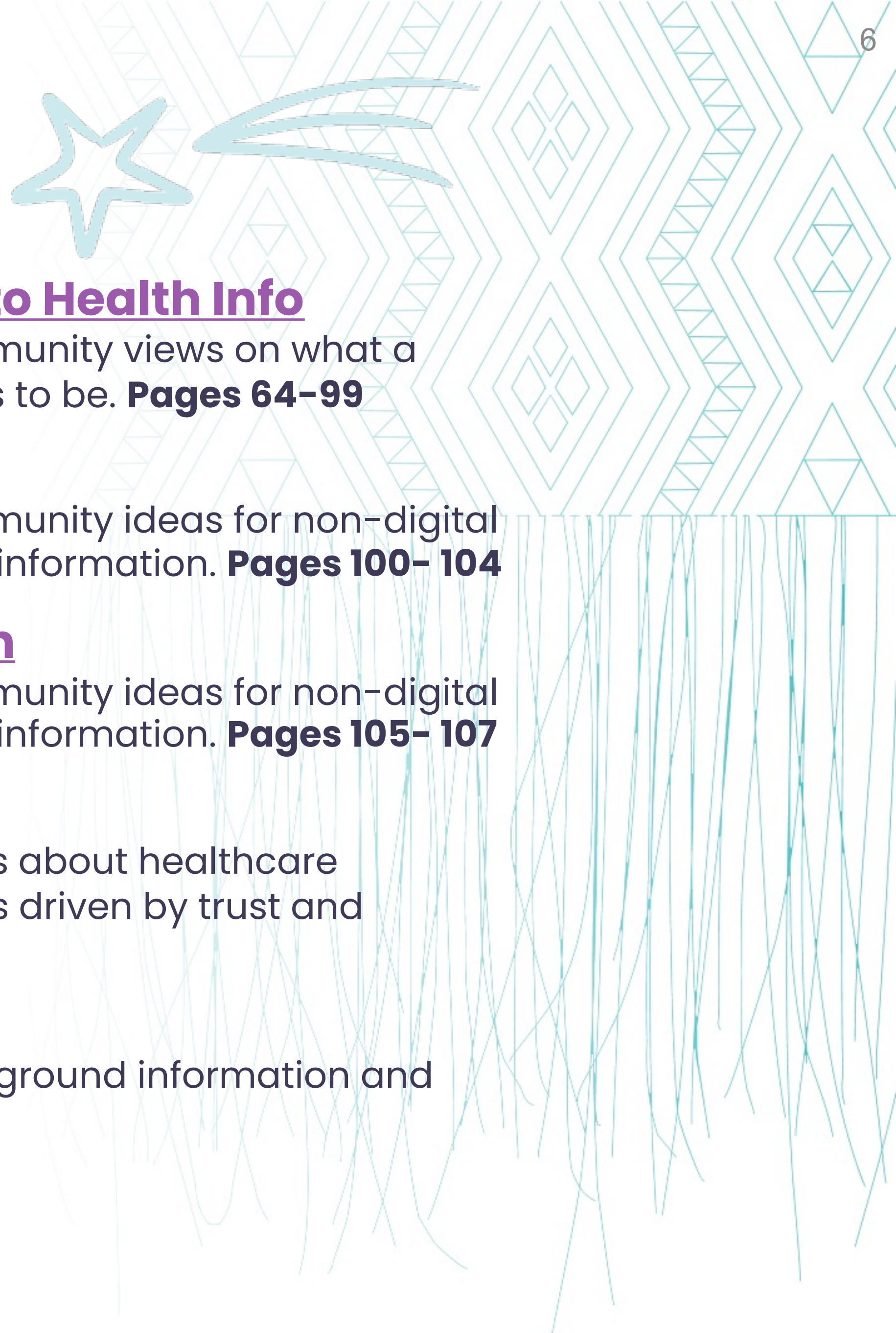

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Look back at what we aimed to do

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Research Planning

Research has a history of extracting from communities in a way that benefits researchers without giving anything back to communities. In this research, our goal was to drive research in a community-centred way and adopt our approach to what worked for communities.

Responding to Initial Feedback

Reviewing Previous Research
Communities told us that government agencies tend to show up to do research without knowledge of the research that was previously done making them feel unvalued.

So, we started this mahi by looking at existing work to understand current context, and what our focus areas needed to be.

Reviewing previously completed research identified three focus areas for our research (1) views of digital, (2) access and engagement (3) trusted sources

Co-Designing Research with Communities

Culturally Responsive Research
Communities shared with us how research made them feel unsafe and was not centred on what is culturally appropriate for them.

So, we formed the WCCDC Working Group together with the **DEE Community Business Partners** we shaped the research approach to be responsive to community needs.

A Kaupapa Māori Research Lead was engaged to develop a kaupapa Māori approach and lead research with Māori communities.

Research Insights at Pace to Inform Development

Research Sprints to Support Pace
A common criticism of research is how long it takes for actionable insights to become available. We wanted this research to inform in-flight work as well as future work being planned.

So, we experimented with ways of working by combining human-centred design practices, research processes, and agile practices.

We organised our work to happen in fortnightly sprints. The first week of the sprint we were out in communities doing research. The second week of the sprint we analysed and played back insights to internal teams to feed in to in-flight work as well as future work being planned.

Research Methodology

In this research we aimed to understand people's experiences of the health system and how enabling digital access to their health information may lead to a better healthcare outcomes.

The Research Method

Approach
- Mixed qualitative methods

Data Collection
- 1:1 virtual interviews
- Community based focus groups
- Open-ended email survey

Data Storage
- Data collected was securely stored in an access-controlled Miro board only accessible to the Research Team
- Data stored does not include self-identifying data such as name or contact details
- Raw data were securely destroyed after analysis.

Research Process

Engaging Communities
- Identifying communities to participate in this research took a community centric approach which started with the long-standing relationships held by the Digital Enablement and Engagement Team
- The literature review identified 7 communities where gaps existed in previous research; these communities were prioritised in this research to address the gap and provide a balanced view
- Demographic data was tracked to ensure representation across communities

Process
- The Digital Enablement and Engagement Team held community engagement sessions which enabled research team to build trust with communities and understand how to shape each research session to meet the needs of the community
- Once a community decided to be part of the research, they were provided the option of an in-person group session, individual virtual interview, or email survey. Sessions were booked based on community preference.

Informed Consent
- To meet the unique needs of each community, informed consent was made available in several formats: standard written format in English; NZSL in video format; a visually simplified version developed for the cognitively disabled community; and a tikanga Māori version for Māori and Pasifika communities.
- Written informed consent was provided ahead of sessions and reviewed at the start of each session.

Analysis, Insights, and Reporting

Analysis Approach
- Narrative analysis of stories shared within each focus group and interview
- Thematic analysis across focus groups and interviews

Insights and Reporting

A primary goal of this research was to deliver insights at pace to inform work that was in progress. To enable this,
- We held fortnightly playbacks for internal teams that provide quick insights
- The final playback on 26 Jun included deeper insights

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Building Trust

Many communities we met had low trust in researchers and government, due to past disappointments. Before we could start any research, we used existing DE&E team relationships with "trusted voices/faces" in communities to reach underserved communities. No one size fitted all. Their unique knowledge of how their communities received information, helped us increase ground-up engagement and build toward overall adoption of Health New Zealand digital products and channels.

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“How will this data be used against us?”

Building Community Trust

The process for building trust with communities varied for each community. The process below is a general outline of how we worked within communities to build a strong foundation for trust. Understanding the unique needs of each community, being open and willing to adjust our research process at pace to meet the needs of each community, led to deep, meaningful conversations and richer research insights.

Low Point of Trust

"I see many red flags here"
~ Waikare Marae Kaitiaki

Whakawhanaungatanga (building trust)

- Before any research was done, the Digital Enablement and Engagement (DEE) Team was established.
- The DEE team brought with them existing community relationships that provided pathways to building trust.
- The WCCDC working group was formed to support the co-design of the research approach and maintain accountability for consumer whānau voice.
- The WCCDC working group along with the DEE team provided introductions to communities which opened the door.
- Many 'cups of tea' were needed to build a relationship, establish trust, and co-create how the research will be done in each community before we were invited in to do that research.

A Bit More Trust

"Don't set us up to fail, give us funding, tell us what we are going to be given, then take it away, cut funding."

Whakawhanaungatanga (continuing to building trust)

- On meeting, we still weren't there yet, we knew we couldn't just jump right into the research.
- We took kai and we started with whakawhanaungatanga to get to know each other, strengthen relationships and build trust.
- We continued to build trust through our tikanga-led informed consent process.
- We held space for the difficult questions to be asked of us – being transparent when we didn't have the answers.
- We listened respectfully, without being defensive, acknowledging the experiences and stories shared with us as a precious gift.

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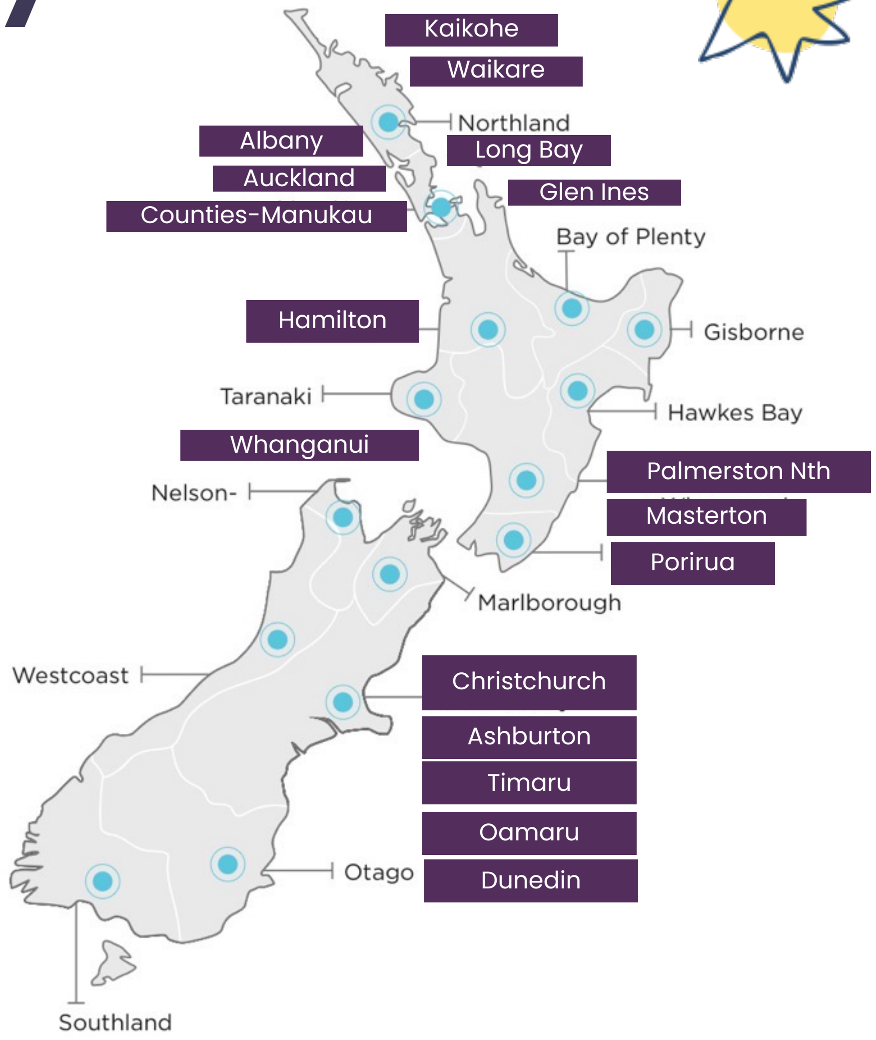
The Research Journey Across New Zealand

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

The Research Journey

New Zealand is a diverse country with 160 ethnic groups represented. The diversity of our country is not only based on who we are but also where we are located. This research travelled from the **top of the North Island to the bottom of the South Island** to better understand **unique regional perspectives and needs**.

Digital connectivity and the **amount of access to health services** is determined by their **geographic location**. This means that health services whether digital or in-person **need to consider geographic location**.



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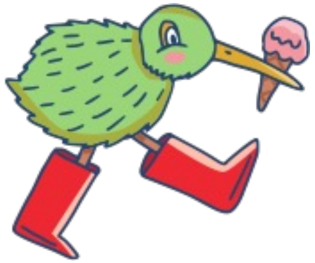
The Research Journey

Te Tai Tokerau (Northland)

Pono Kakā Ropu, Waikare Marae

Hiwa i te Rangi Teen Parent Unit Kaikohe



Masterton Community Meeting

Palmerston North Age Concern

Te Kura Kaupapa Māori o Tupoho Whanganui

Masterton
Whanganui
Palmerston North

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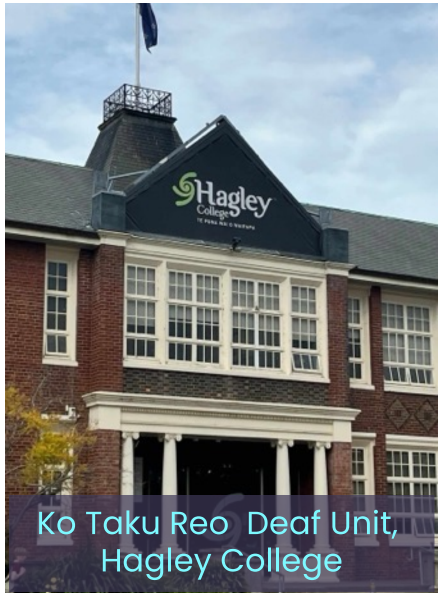
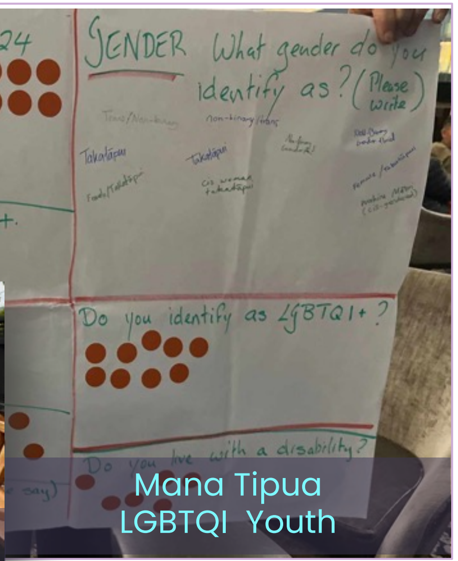
Ōtautahi (Christchurch)



Ko Taku Reo Deaf Unit, Hagley College

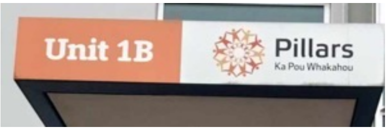
Vaka Tautua, Pasifika Disability Group

Multi-Generational Aīga/Whānau



Mana Tipua LGBTQI Youth

Whānau Whanake Disability Support



Pillars, Supporting the Families of Prisoners, Chch

Otago Rural Support, Oamaru

Tuesday, 26 April 2022 12:55

Migrant workers backbone of local meat works

Written by David Anderson

Silver Fern Farms Pareora, near Timaru, heavily relies on its overseas workers - mainly from the Pacific Islands - to keep the meat processing plant operating.

Timaru Tongan Freezing Workers

Otago Refugees

Dunedin Community Meeting

Ashburton Rural Family Navigators

Ashburton,Timaru, Oamaru, Dunedin

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And also..

Porirua

- **Stall** at Pinikilicious Pasifika Health Expo
- **One-on-one Interviews** with community members
- **Research Visit** with Te Runanga o Toa Rangatira Community Engagement Group.

Auckland/Manukau

Virtual Interviews with

- Asian Health Workers
- Refugees
- Pasifika Community IT Support Kaimahi

North Shore

- **Research Group at** Body Positive (HIV/AIDS Support Group) Weekend Retreat
- Parklane Retirement Village

Asian Family Services
Together enriching lives
0800 862 342

BODY POSITIVE
NEW ZEALAND
Tinana Ora Aotearoa

Manaiakalani
the hook from heaven

Glen Innes

Virtual Interviews with Young mothers and teachers through Manaiakalani Education Trust.

Whanganui

Email Research with the Neurodiverse Community

Phone & Zoom

Virtual Interviews with people in

- Hamilton
- Dunedin
- Kawakawa
- Christchurch

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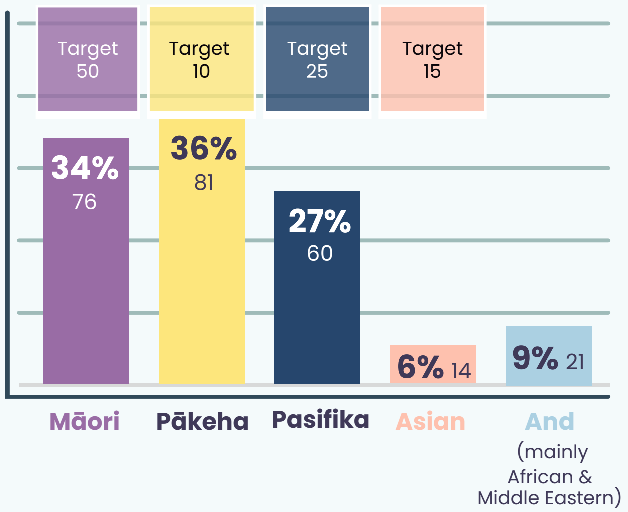
The voices of New Zealand

225

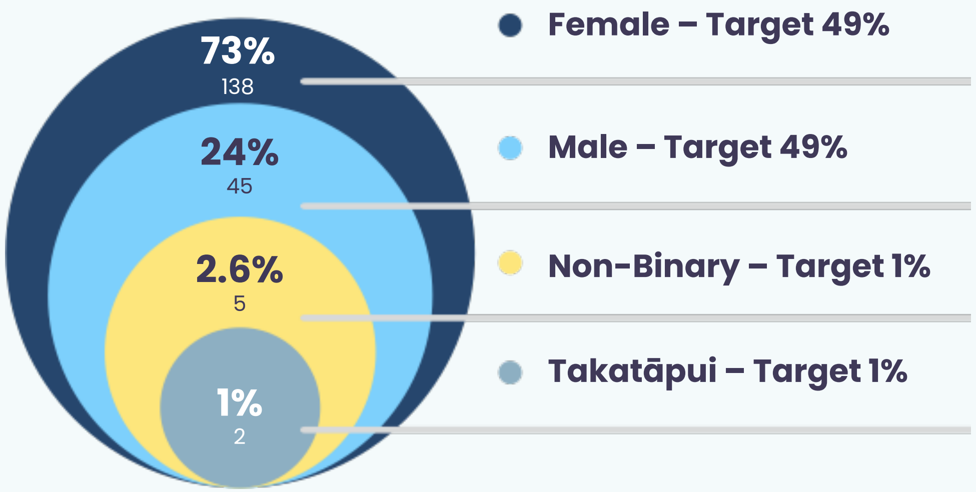
Total # of people

Aotearoa NZ is a diverse country that requires a health system that can meet the varying needs of its communities, as such a key goal of the research was to capture voices from all communities across the country.

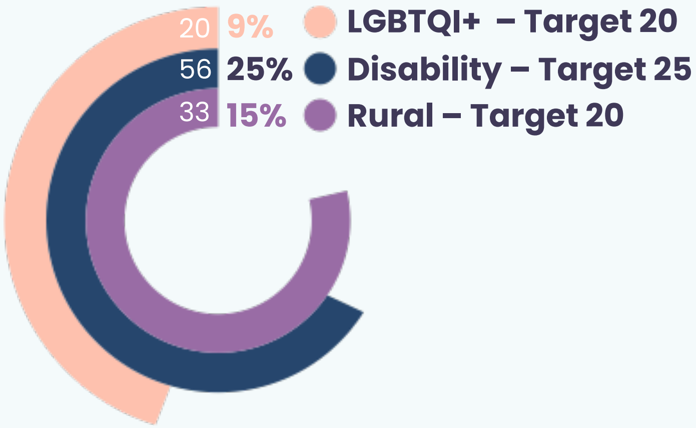
Ethnicity



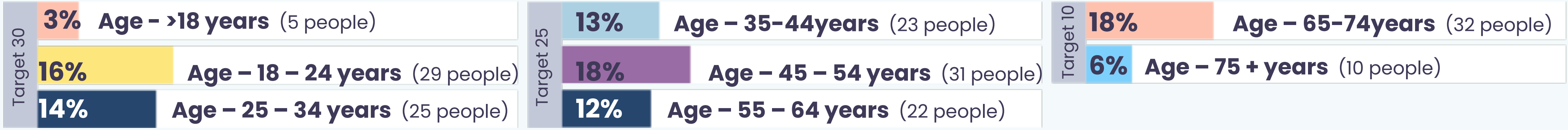
Gender



Important groups



Age group



Note: Not everyone disclosed all their demographic information. Some people nominated more than one ethnicity.

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Key Themes

Assess to digital health information means **having control over one's own health – information is power and this even more true for your health**

No one has come out here to ask us this before **Thank you for asking**

If it is in the too hard basket, if there are too many barriers, we won't use digital health records **Keep It Simple, Make It Easy for Us**

GPs are the gate keepers
the relationship you have with your GP is everything when it comes to the quality of care, early detection, and access to specialist services

Inclusive language and practices, cultural understanding **These are the things that help build trust within communities**

Health is a family matter
remember that looks different for everyone, don't define it for us, let us define it for ourselves, give us the autonomy to share our health information

Location, Location, Location
Access to health services is directly proportional to distance from main centres

Offer Options
Healthcare is personal, give individuals and families the option to tailor services to meet their needs

Local Community Navigators
It is local people who are on the ground with us that know us best… not Wellington

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It Needs to be SIMPLE & EASY

Every community we met spoke about the need for digital health records to be simple and easy to use – they will not access and engage if barriers are too high.

“Make sure this feedback is loud and clear because gov’t has a habit of making everything more complicated than it needs to be…KEEP IT SIMPLE”

“I tried to log into My Health Record to see what it was all about. It told me I had to verify. I tried to do that, but it didn’t work. I fiddled around with it … two hours later I’m still not in. It shouldn’t be this hard”

“Accessing my health information should not be harder than accessing my bank account”

Use things we are already familiar with

People across all communities are familiar with these, trust them, and expect them as the standard.

2FA Face ID Touch ID

*“You have to remember, at the end of the day, **most of us are just trying to raise our families, put food on the table**…the apps, websites, **and whatever else you create, isn’t top of mind for us**, but if you make it easy to use, and we **can see how it will help us, we will use it. Don’t waste our time** 'cause we don’t have a lot of it. “*

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The Crux of the Healthcare

The crux of healthcare comes down to one key questions, can I access the healthcare I need, when I need it? This research found New Zealanders fall into one of 4 categories when it comes to access and need.

- Over Served (high access, low need)
- Well Served (high access, high need)
- Served (low access, low need)
- Under Served (low access, high need)

These findings are supported by previous research finds that illustrate the those who need care the most are least likely be able to access it [1] [2].

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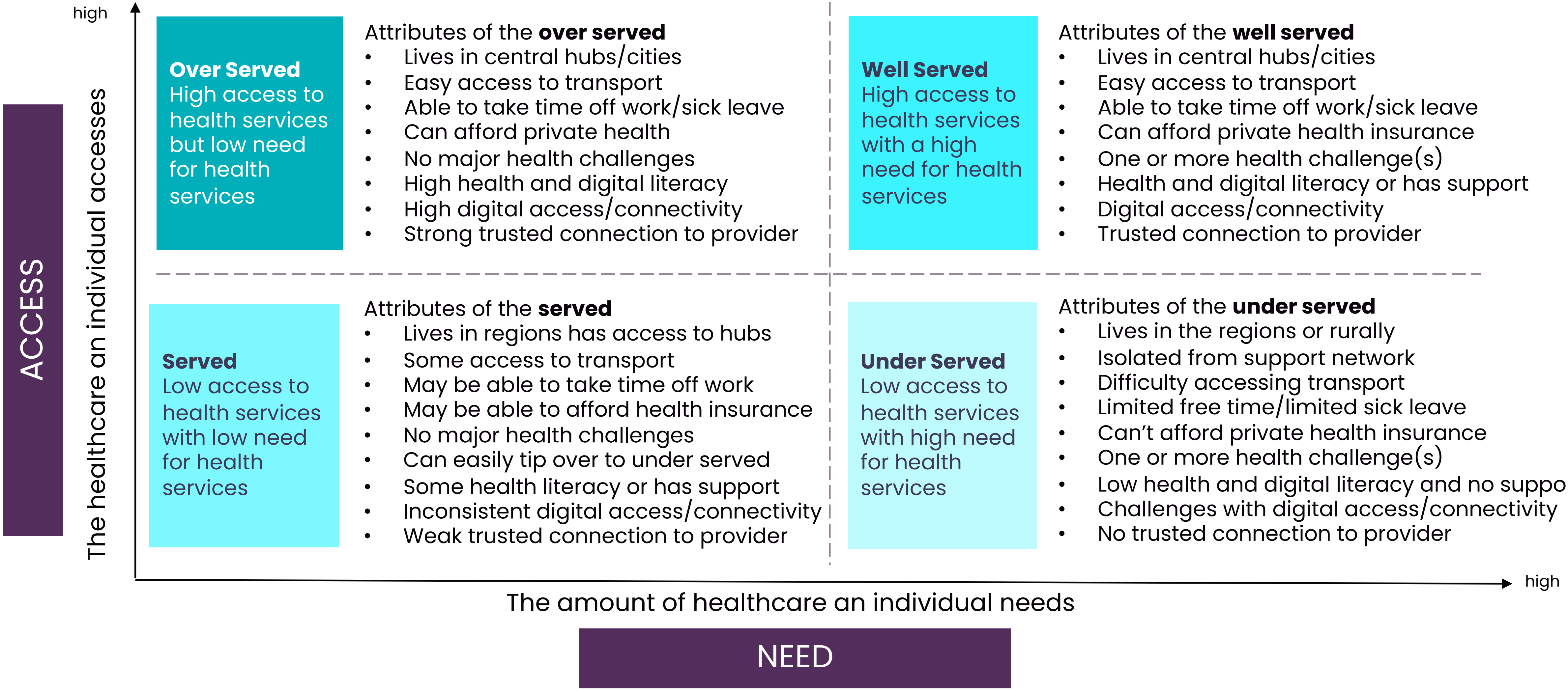
The crux of healthcare

Comes down to one question, can I access the healthcare I need when I need it?



ACCESS

The healthcare an individual accesses

high

Over Served
High access to health services but low need for health services

Attributes of the **over served**

- Lives in central hubs/cities
- Easy access to transport
- Able to take time off work/sick leave
- Can afford private health
- No major health challenges
- High health and digital literacy
- High digital access/connectivity
- Strong trusted connection to provider

Well Served
High access to health services with a high need for health services

Attributes of the **well served**

- Lives in central hubs/cities
- Easy access to transport
- Able to take time off work/sick leave
- Can afford private health insurance
- One or more health challenge(s)
- Health and digital literacy or has support
- Digital access/connectivity
- Trusted connection to provider

Served
Low access to health services with low need for health services

Attributes of the **served**

- Lives in regions has access to hubs
- Some access to transport
- May be able to take time off work
- May be able to afford health insurance
- No major health challenges
- Can easily tip over to under served
- Some health literacy or has support
- Inconsistent digital access/connectivity
- Weak trusted connection to provider

Under Served
Low access to health services with high need for health services

Attributes of the **under served**

- Lives in the regions or rurally
- Isolated from support network
- Difficulty accessing transport
- Limited free time/limited sick leave
- Can't afford private health insurance
- One or more health challenge(s)
- Low health and digital literacy and no support
- Challenges with digital access/connectivity
- No trusted connection to provider

high

The amount of healthcare an individual needs

NEED

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Influences of Access

Four key influencers of access

Location

The geographic location of your primary residence determines the level of health services you can access.

The closer to a major city the greater your access to health services. The amount of access decreases significantly in rural and remote areas.

Location also determines connectivity to digital services with rural communities having poor connectivity which is also more expensive than for their urban/suburban counterparts.

Economics

Even when a health service is available at no cost, other economic factors influence an individual's ability to access health services. These include:

- Ability to afford transportation cost
- Affordability of childcare
- A job that provides paid time off (or the ability to access services during non-work hours)

Literacy

Digital literacy increase access to health services because you can

- Search information online and find the help you need
- Google health terms you don't understand

As digital health records become commonplace, digital literacy will play a key role access to health services

Health literacy increases access to health because you are able to understand the information that is shared with you and make decisions about your health.

English literacy the primary language of the health system is English. English literacy is needed to navigate the health system as well as understand your health situation.

Relationships

Trust in the healthcare system plays a role in how you access health services. High trust leads to people accessing more preventative health services (e.g., screening) whereas low levels of trust leads to people waiting too long to access healthcare which increases the cost of care and delivers poor health outcomes.

Support from whānau, health navigators, and community support services increase your access to health services. When you feel you are on your own, it is too overwhelming.

GPs are seen as the gate keepers of health. Weak relationships with GPs leads to disengaging with health services whereas knowing you have a trusted partner to turn for help makes a meaningful difference.

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Navigating the Health System

The crux of healthcare comes to live when individuals are trying to access the services they need. Communities have a high degree of awareness about how the health system serves them when they need help the most.

These journeys combine the stories that communities shared with us to highlight their experiences. While the experiences are real, the names are not.

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Cancer Journeys

These journeys show how easily people can tip from being over-served, well-served, served, to under-served when dealing with a serious health condition. These journeys also show the positive impact of having a strong connection to a healthcare provider, complemented by a trusted voice/face to help people navigate unfamiliar, sometimes overwhelming, health systems.

Te Ao Mārama

See my whanau journey on pg.41

Over Served

I have **good access** to health services through **our local Māori health provider** and that is why my breast cancer was picked up early. ①

Until I got cancer, I didn't go to the doctor much. I did the normal smears and mammograms, but I **didn't need** to go to the doctor.

Well Served

From getting my mammogram results, being referred to the specialist, to being scheduled for surgery it **all moved very quickly**.

As a breast cancer survivor, I have regular check-ups. **Waiting for a Dr to call with results is the worst** part. I wish they would just send me the results.

Once you've been through cancer, you are always worried it's coming back, and a part of you is ready for it, **so just let me see what's going on.** Don't make me wait.

① Too many Māori women die way too young because things get missed, what's made **the difference for me is having a provider that I feel connected to and trust**.

Saofa'i

See my whanau journey on pg.37

Served

About two years ago now, I **went to get tested for bowel cancer**. When the results came in my **Dr told me I had a blockage**. ⑤

Under Served

I thought that meant I was okay I **didn't think that meant anything was wrong**. So, I traveled back to Samoa to visit family.

When I was there, I started to feel really unwell when I ate. I knew something was wrong. It was **when I saw the Dr in Samoa that I learned I had cancer**. ①

They tell you how important it is to get tests, and **even when you do what you are told the system fails you**.

All that time I didn't know I was sick. The Dr didn't explain, **I wasn't told I needed to do anything else. No one even called me to follow up**.

Well Served

I am very lucky, as soon as they told me it was cancer, **my daughter stepped in and got me to the right Dr, I had surgery**, and I am okay now.

Maya

Served

I **started to have stomach pains.** The Dr gave me some medicine for my stomach.

I **went back to the Dr because I was feeling worse**. He told me I was probably stressed. But **I knew something** was wrong. ④

Under Served

This Dr has only been there for 1 year and only seen me a few times, **why does he think he knows my body better than me**? ①

This went on for months, I tried to get an appointment with another Dr but couldn't. **Finally I went to A&E** because the pain **was getting worse**, I could barely eat and that's when I found out I had **ovarian cancer**.

I was diagnosed with **stage 4, there is a good chance I won't live to see my babies grow up**. If I had a different Dr or my Dr knew me, understood me, maybe things would be different? ③

They tell you to go to the Dr to get checked out, I did that, and he didn't listen. It comes down to the Dr and the relationship you have with them.

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Maternity Journeys

These journeys show the relevance of cultural context in health. Many communities told us that when their healthcare provider shows a lack of cultural understanding, they don’t trust that provider. This lack of trust contributes to being under served because people will hold back on questions. These maternity journeys are further illustrated in previous research [3].

Rose

See my whanau journey on pg.31

Well Served

① **My first pregnancy was high risk**, so my care was **moved under an obstetrician**. I have **private health insurance**, so I was able to go through the private system and it was very good. My obgyn **really understood me. I felt heard and listened to**.

Under Served

Once my baby was born, I was **moved back to the public hospital for the recovery** part and that is when **things went bad.** We were told that my mum couldn’t stay with me. This was very upsetting because **in Chinese culture the mum is always there with you.** ⑤

① I had a **c-section, so I was very drowsy and weak afterwards**. I was alone and my baby was crying, I kept ringing the nurse for help, and they **kept telling me to pick up my baby**. I tried to explain that I was **feeling weak, unstable and wasn’t comfortable standing up**. I was scared I would drop my baby. It was very scary.

I was alone and scared, and there was no one to help me. No one to listen to me. **Health isn’t just about medicine it is also about care.** I understand that nurses and doctors are overwhelmed but why can’t we have a system that allows family members to help with the care part?

⑤ In **Chinese tradition**, after you give birth, we **don’t eat or drink anything cold**, we only eat and drink warm things. I tried to explain this, I asked if I could have warm water, but they **kept giving me cold things**. There was very little understanding or care given to what was important to me culturally.

② In NZ healthcare is about fixing what is wrong with you, they **don't see you as a whole person** and what is important to your overall wellbeing.

Alani

Under Served

My first pregnancy, where we lived there **weren't a lot of midwives available**, so I didn't really have a choice in who I went with. She was nice enough but just **didn't understand Samoan culture**. ④ ⑤

I had a few complications during my pregnancy and because **mum's English isn't very good, I had to do a lot of translating.** This was hard because some medical terms, there isn't really a Samoan word for. It is also difficult to be a translator when you are **trying to understand what is happening** with your body.

It was my first pregnancy and there were complications. I had so many questions. There were also things that **mum wanted me to do that were traditional things she did when she was pregnant**. Because of my complications I didn’t know if they were okay to do but I felt too embarrassed to ask.

That first pregnancy I used Dr Google most of the time. What the NZ health system doesn’t understand is how hard it is when what the **health system says to do conflicts with what traditional medicine** tells you to do. You **don’t want to disrespect your family**, you also want to make sure you **don’t harm your baby**. I felt very lonely.

Well Served

① When I got pregnant with my second baby we **moved to Auckland**. I was spoilt for choice in midwives or at least felt that way. I was able to **find a Samoan midwife** who understood Samoan culture. ⑤

My second pregnancy was so wonderful. Mum and I could talk about anything with the midwife. **She was able to explain to mum why I am considered a high risk pregnancy** and why I had to do certain things that mum didn’t have to do when she was pregnant.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Neurodivergent Journeys

These journeys show how neurodivergent individuals experience the health system. A system this community views as not designed for them. The Neurodivergent Community expressed concern that if healthcare does not work to understand their needs, they will get left behind as healthcare becomes more digitally enabled.

Lee

Well Served

① The **GP Office I go to understands that I am Autistic**. They know that waiting rooms stress me out, so they make sure I get the first appointment of the day and let me wait in the exam room. They take good care of me.

Under Served

② **Appointments at the hospital are terrifying**. The letters they send you **don't have enough information.** They tell you how to get to the building but not what to do once you are in the building.

When I go somewhere I am **not familiar with**, I have to navigate traffic, busy reception areas, loud noises, lights shinning on me, perfume and after shave, **all of these things are overwhelming** for me. Then I finally arrive **and now I have to speak with the doctor.**

③ The Dr sees me anxious, and they are **already making judgements about me**. Then they view my file and **the first thing they see in my file says I have significant mental health issues**. My mental health file is 40 years old. **Before they knew what Autism was, you were diagnosed as having mental health issues** because that's all they had.

Even after I was properly diagnosed as being Autistic, the first thing that comes up when they see my file is that I have significant mental health issues. **Nowhere does it say that I am Autistic or explain the support I need.** Every time I have to explain I am Autistic.

Verbal communication is hard for me, the words that I say and the words that I mean are not the same. Drs write down whatever I say but they **never check if that is what I meant to say.** Then I am **not allowed to see what is written down** and this creates a lot of wrong information being written down. ③

③ **Once a Dr writes something in your record it is believed even if it is not right, t**here are things in my file that are wrong, but I can't get them changed. They think I'm lying.

Damen

Under Served

I am on the spectrum, I have a learning disability, and vision issues. What I struggle with the most is having to do things online.

The **health system is not for people like me** and now they are making it even harder for people like me because **everything is online**. ⑥

My vision issues make it **hard for me to look at screens** for a long time and **a lot of sites are not easy to use for people with vision issues.**

Getting letters in the mail, being given **paper documents helps me stay on top of things.**

I hate it when **Drs tell you to go look up something online, this is confusing** for me, where do I go? What website? How do I know if what I am looking at is reliable? ⑥

The **internet is a scary place when you have a brain like mine**. So why can't the Dr go to the website and **print out information for me**?

The world is going digital but **understand online doesn't work for everyone**. People need to have options. If online works for you then do that, if paper works for you then do that, if phone works for you then do that. ②

⑥ I **worry** that **access to healthcare** is going to get **worse for people like me**.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Chronic Condition Journeys

These journeys shows the challenges faced by people who are living with chronic health condition and how a trusted relationship with their GP or primary healthcare provider is vital to receiving the support required to manage their condition on a day-to-day basis.

Toni

See my whanau journey on pg. 33

Under Served

① Where I live **none of the GPs are accepting new patients.** The other problem we've had is that because **my ex-partner is a known gang member, a few of the GPs have unenrolled us.**

Even when I was enrolled with a GP, I didn't go to the Dr much. I've been lucky I have not been sick enough to go. It is not something you think about when you are busy trying to raise your family and get food on the table.

Well Served

I didn't find out I had diabetes until I started my sentence. The nurse I met with when I first arrived in prison encouraged me to get a full check-up because she understood where I had come from. She told me that while I was there, I can get on top of my health.

① After I got some tests done, they told me I had diabetes. I didn't know what that meant or what I needed to do. The nurse was very good, she **told me what it means and some of things I need to do.** I also started medication.

Under Served

While I was serving my **sentence I did really well when managing my diabetes.** When I was released that was a different story. When you **go to prison you get unenrolled from your GP** and when I got out **all the GP registrations in the area were closed.**

I didn't know what to do because you cannot get medication without a GP. I wasn't sick enough to go to hospital. I also didn't have a lot of time to figure things out, I had to find work. **For many months I went without meds. Then I got very unwell and had to go to hospital.**

④ The **Dr at hospital referred me to a clinic where I get the help I need.** People shouldn't have to go to prison to get good healthcare and that is how it seemed because I got better care on the inside than out here.

Rahul

Well Served

The war started in **Syria so we had to leave.** The refugee process has many medical checks. My mum and I made sure we had my records to show my ADHD diagnosis. **After struggling for many years, learning that I had ADHD and being put on medication for it was life changing.** I was worried about not having my medications. I remember what it was like, and I didn't want to be in that situation again.

Under Served

When we arrived in NZ, I **tried to explain that I needed my ADHD meds** and tried to show them my paperwork. They didn't want to see it and **told me I had to be assessed by a NZ Dr** but I had to wait until we moved to where we'd be living.

We were sent to Dunedin to live. I tried to get enrolled with a GP. The **GP could not accept me until my medical file came from Mangere Refugee Centre.** It took 20 weeks for my records to arrive in Dunedin from Mangere.

Once I was enrolled, I had to wait another month to get an appointment with the GP because you need a **longer appointment for your 1st appointment,** and they didn't have any space available.

④ I tried again to show the GP my **medical documents from back home. He dismissed them.** This was upsetting. because I thought when I met my Dr they would believe me but he didn't trust me, I can't trust him. ① I was referred to a specialist who had a long waitlist. I had to **wait almost a year for a NZ Dr to tell me something I already knew.**

In NZ, **ADHD meds have a special authority that expires every six months. I** have to remember to book in an appointment months before the authority expires because appointments have long wait times. I am **constantly worried that I won't get an appointment in time and will run out of my medication.**

ADHD makes everyday things harder to do. I had to learn how to do new things, in a new country, speaking a language that was not my own, without any help for my ADHD…there isn't a word to explain what that was like.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

The Disability Journey

These journeys show how the health system fails to understand the reality of living with a disability and its implications for performing what may appear to be simple tasks but are in fact daunting challenges for people living with disabilities.

Daisy

Well Served

Daisy was born with a condition called CHARGE. She is deaf, has low vision, and is cognitively and physically disabled

Daisy's condition **requires ongoing care** which her mother and older sister help her manage.

Served

When Daisy **turned 16 two years ago, they moved her from Child Services to Adult Services.** The Drs and nurses that had treated her from when she was born were no longer involved in her care.

① **There was no handover** from Child Services to Adult Services. Maybe for most children this would not be an issue but **Daisy's' health needs are very complicated.** Those **Drs had been with her from day dot** so a handover would have been a good thing.

Under Served

The lack of a handover became an issue when Daisy had to go in for a procedure. The **Drs working on her didn't know her full history**. CHARGE presents differently in each person. **Daisy's mum tried to explain** to the Drs that Daisy's anatomy was different. She tried to get them to look at her old scans so they could understand what her insides were like. It was **only after a failed attempt at the procedure** that the Drs realised the **complexity of Daisy's case.**

④ **Daisy's mum hopes for a digital health record with a summary that explains Daisy's conditions and her disabilities.** Being able to access and share Daisy's scans would help her mum explain to Drs the complexity of her condition. As Daisy will always need support managing her healthcare, Digital Health Records should also be able to capture Enduring Power of Attorney.

Laura

Under Served

I was born with an inherited eye condition. From the time **I was about 20 I have slowly been losing my vision.** Eventually I will be **completely blind.**

⑥ Right now, I am fortunate because I have some vision. I am **limited on what I can do on the computer and on screens.** My eyes tire easily, and I can't focus for long periods of time.

I don't know how much being able to access my health information would help me especially as time ticks by and my vision will get worse. **What I worry about is, with everything going digital, what will it mean for people like me?**

The health system is very ableist. The needs of people with disabilities are an afterthought. You would think if anyone would understand disability it would be health, sadly that is not the case. I don't think anyone at health is thinking about how to ② **make health information accessible for the low vision and blind community.**

⑥ A couple of years ago, I had pneumonia and almost died. I've recovered well but **I have breathing problems. I require oxygen.** Even though this is technically not a disability, it is **limiting on my life.** If I want to go visit my family down south, I **have to organise my own oxygen refills. There isn't a national service that does this.** It is organised locally which feels like an assumption that if you need oxygen, you are not meant to be traveling. That's a **limitation the system puts on me.**

Well Served

Thankfully, I found a brilliant GP. She understands that I can't look at screens. She never asks me to do anything online. Either she or the nurse will always call me. If I need to know my lab results I can just call them. ① ③

Under Served

④ Going to see a **specialist is a terrible experience** for me. No where in my file does it say I have limited vision. **When I arrive they ask me to fill out paperwork**. When I tell them about my vision, they will get someone to help me. I have to sit there in the waiting room and **tell someone my personal information in front of complete strangers**. Maybe this is where a digital file can help me. **If my GP can put this info in then I won't have to answer those questions at the appointment**.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

What matters most

When navigating the health system, this is what communities identified as making the biggest difference for them

1 Trusted Connection

A trusted connection to a healthcare provider can be lifesaving. Communities describe GPs as the gatekeepers of their health. Where there is not a strong trust connection to their primary health care provider, people struggle to get the help they need. Where that connection is strong people feel supported in their healthcare journey.

2 Options, Options, Options

Healthcare is personal so one solution will not work for everyone. To create a better health system, we need to provide options so that whānau can select the option(s) that work best for them.

3 Co-Creating Medical Notes

Conversations with healthcare providers are primarily verbal, people are not able to see if what they say is what is written down. Having the ability to see what Drs are writing to clarify understanding would lead to better experiences and healthcare information. This is particularly important to the neurodivergent community.

4 What You Need to Know

Provide a way for me to tell healthcare providers the important things I want them to know about me. This is particularly important for people living with disabilities, people living with chronic illnesses, and the rainbow community.

5 Cultural Understanding

Healthcare is a very personal experience. Unlike many other government services, this is an area where people expect cultural safety. There is also a link between feeling culturally safe and engaging health services – when people feel culturally safe they are more likely to access the health services they need more readily than waiting till it is too late.

6 Don’t Leave Me Behind

The health system needs to be modernised and digital health information is a big part of that but don’t forget digital doesn’t work for everyone. Provide non-digital options for those of us who are not able to access digital…not because we don’t want to but because the needs of our brains and bodies don’t allow for it.

Whānau Journeys

Communities told us that health is not an individual journey. Healthcare is a shared experience that happens within families and communities.

To keep true to the experiences communities shared with us, we have taken a whānau centred approach to capturing and sharing their stories.

In this context, whānau is not limited to the traditional view of family as family takes different forms across different communities.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Whānau Journeys

These whānau journeys have been created to show the healthcare experiences of New Zealand communities. Each journey combines the commonalities of multiple stories that were shared with us by individuals. While the experiences are real, the names are not. Communities across New Zealand have shared their stories, in hopes that their experiences help Health NZ | Te Whatu Ora develop health products and services that improve future health outcomes for all who call Aotearoa home.

Cheng Whānau

Te Ao Mārama Whānau

Refugee Whānau

Wilson Whānau

Atawhai's Whānau

Immigrant Whānau

Moala Kāinga

He Hapu

Unhoused Whānau

Multi-Generational Whānau

Kaumātua (older people) Whānau

Deaf Whānau

Women of Sunny Farm Whānau

Rangatahi Uenuku Whānau

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Cheng Whānau Journey

The Cheng Family

The sandwich generation that must meet their elderly parent's needs, organise their children's and own health needs is common for women in migrant families. Finding health practitioners that are Chinese and make them feel culturally safe takes a huge weight off these women's shoulders. In their own words:

- Rosie is a mum who also helps take care of her elderly mum. She is currently pregnant with her second baby.
- Rosie is looking for a new midwife and hoping to find one that understands Chinese customs because her previous midwife didn't, and it made for a poor experience.
- Rosie's mum Lily immigrated to NZ seven years ago to be closer to Rosie and Mae.
- Lily's English isn't very good, so Rosie is very involved in Lily's healthcare.
- Mae is 4.5 years old and about to start school. She is excited to be a big sister soon.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Cheng Whānau Journey

Mae

① Mae is about to start school and needs to get her B4 School Checks done. Rosie has been struggling to get this appointment booked because there are three different appointment needs in three different locations.

② Mae needs her immunization record for school. Rosie is worried about this because they have moved house and now live in a different DHB area. She isn't sure how the information from their previous GP will get moved over to their new GP.

Lilly

⑧ A few years ago, Lily had a stroke. She has recovered well but requires regular check-ups. Lily is dependent on Rosie to go with her to Drs appointments as her English isn't very good.

⑤ Lily wants the Chinese medicines she takes to be included in her medical file and is frustrated that she has repeat herself at every appointment.

⑨ Lily worries about being lonely at home all day with Rosie at work and Mei starting school. Luckily, she belongs to a strong community support group for older Chinese people. The group arranges group health days (such as vaccination days) which Lily loves to attend.

Recently Lily has been having joint pain. She doesn't understand why she needs to go to the GP to be referred to a specialist even though she is willing to pay to see a specialist. In China she was able to go directly any specialist she wanted.

③ Lily has booked a trip back to China to see a Dr about her joint problems as the wait to see a specialist in NZ is too long.

Rosie is worried about her mum going back to China for medical treatments because since her stroke Lily's healthcare is more complicated. There isn't a way for Lily to share her NZ health record with her Drs in China. ⑦

Rosie

Rosie is pregnant with her second baby. She needs to select a new midwife as the previous one has retired.

She wants a midwife that can speak Mandarin so that she doesn't have to translate everything for her mum. She also wants a midwife that understands Chinese customs, "My previous midwife didn't understand, and it made things difficult."

④ She didn't know there was an easy way to find a midwife based on her criteria until a friend told her about the website. "Find Your Midwife" where she can search for a midwife who speaks Mandarin and check their availability.

① Rosie struggles with booking and keeping track of appointments. Between herself, her daughter Mae, and her mum Lily there is a lot for Rosie to keep up with. Even just finding the time to call for an appointment is difficult.

⑤ Rosie also struggles with keeping track of her family's prescriptions. Different members of her family have refills at different pharmacies and there isn't an easy way for her to track which medications have refills left.

We've recently moved house and getting our address updated has been so difficult - I have to tell them every time with every appointment for everyone in the family. ⑥

Opportunities

How do we increase awareness of the website resources that are available (e.g., findyourmidwife, info.health). ④

How can we make it easier for Rosie to book and track appointments for her and her whānau? ①

Many immigrants are frustrated by NZ's process of accessing specialists through your GP, ③ and return back home for specialist consultations and treatments.

⑨ There are many immigrant community support groups that provide strong support programmes for their people and are an excellent conduit into the community.

Profile + Login

Being able to update contact details in just one place is something I would use, this would have been so helpful when I moved house ⑥

Having a preferred language option on your profile would be great. ⑧

Medications & Immunisations

Being able to see how many repeats we have left would be very helpful ⑤

Would we be to add the Chinese meds that mum is taking here? ⑤

Would we be able to get a PDF print out of immunisation records? This would make it so easy for school - similar to how you can get a travel certificate) ②

Consent & Delegations

① It is great that I would be able to see each family member's profile and make appointments without having to log in and out of profiles

Would mum be able to give me access to her records as well? Or is it only children? We need to think about other family members too, it is not just children that we take care of ①

Allowing access to our medical records when overseas is really important. ⑦

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Wilson Whānau Journey

The Wilson Whānau Journey

The Wilson Whānau gives us a glimpse into a small-town NZ family with health challenges that, added to their location away from a city centre and extra social challenges at home, make their health journey increasingly difficult, if left unsupported.

- Toni and her māmā, Jen, have lived in Ashburton all her life.
- Toni has two children, Jason, aged 12 and Mari, aged 15.
- As Toni has been serving a prison sentence, her māmā Jen was given guardianship of Jason and Mari.
- In a few weeks, Toni will be released from prison and return home to Ashburton.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Wilson Whānau Journey

Toni (mum)

I will be finishing up my sentence in a few weeks time and heading back to live with mum in Ashburton.

When I started my sentence, I was unenrolled from my GP cause once you are on the inside you get seen by the prison Drs. ②

It's so hard to get enrolled with a GP in our community. Most of them have closed their books. ②

Because my ex-partner is a known gang member, a few GP practices have unenrolled me and my kids…it's like they still see us as being part of that life even though my ex and I separated years ago.

① I am worried because I have diabetes, When I leave prison, I will be given a few ② day's worth of meds, I am told that I will get help getting sorted but I've been let down by the govt so many times now that I'm expecting to just figure it out on my own.

I only found out I have diabetes while I was here, will all of the tests I've had here be set to my new Dr? What happens if I cannot ② find a GP that will accept me? How do I get access to my records? ⑦

Jen (grandma)

My daughter and grand babies have always lived with me but, for the past two years I've been their legal guardian.

Mari has always been mature for her age, from the time her mum started her sentence, Mari has been helping take care of Jason.

Jason has ADHD, he ③ is 12 very opposite to Mari, Jason isn't mature enough to manage all this himself. Mari at that age could have.

If Mari and I ④ don't stay on top of his appointments he won't remember he needs to go.

He knows how important it is for him to stay on his medications but still Mari and I have to everyday, remind him to take it.

I keep track of how many pills he has left, and Mari helps me with getting his repeats done.

Mari does most of it actually, I am only there because I am their legal ③ guardian, but Mari know all of her brothers' things.

Neither Mari or I are listed on Jason's birth certificate so I ⑥ don't know how this would help us.

But you know, we are used to things not working for us so I'm sure we will ① find another way to manage.

Mari (15 yr old)

I started taking ⑤ the pill when I was 13 years old. Even though I am now 15, mum and nan still don't know I take birth control

I don't mind mum and nan seeing all of my other information, I just don't want them to know that I am on birth control. So there needs to be a way to hide that.

My brother needs to go to the Dr a lot, he's on medications for his ADHD. It's too much for my nan to keep on top of , I have to help her.

Nan comes to all of his appointments with us, but I am the one that books them, I am the one that can answer all of the questions. I am also the one that asks all the questions.

Something people don't ③ understand is how many people help take care of their younger siblings. I was only 13 when mum went away and since then I have been helping with care for my brother.

It's not just my brother, ④ I also help nan. She's getting older and needs help too.

Nan had to go in for a breast exam and she was confused about it so I had to help her. I was only 15, I didn't even know ④ what a breast exam was.

Nan also doesn't feel comfortable asking the Dr questions, this is why I try to go with her to appointments ③ because she won't ask questions.

I had to grow up very quickly so I could help my family. I am not ③ bitter about it, more angry because people don't understand that this is the reality for a lot of young people.

Opportunities

People still have major distrust of the health system and have an expectation that it will fail them. ①

Not being enrolled with a GP is a scary place for whānau - it also means going without continuity of health services, medications etc. ②

Verification

⑦ The current verification process doesn't work for prisoners. They won't be enrolled in with GP, and likely not have valid IDs. Can there be an agreement with prison systems?

Consent & Delegations

Age of young people is not necessarily ③ an indicator of responsibility or responsibilities

Young people (under 16 or even under 12) often need to ④ help older whānau members to understand health processes and information

Those who suddenly have to take on a child caretaking role need ⑥ some way other than delegated parental consent to access child's health information.

Medicines

Medicines is an area where sexual health information ⑤ of teens runs the risk of being revealed to parents & caregivers

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Moala Kāinga Journey

The Moala Kāinga Journey

Multi-ethnic families are a growing demographic in Aotearoa. We reflect here their experience, working as a whānau group, to access health information and navigate the health system.

- Tokoni immigrated to Aotearoa from Fiji with his parents at age 10, growing up in Auckland.
- Terri is Pākeha with whakapapa to England.
- Tokoni and Terri have been married 5 years and have two children.
- Since starting their family, both are glad that Tokoni's parents live down the road, and Terri's parents are a 30-minute drive away.
- Tokoni and Terri hardly used healthcare or thought about health information until Terri suffered an emergency health event which, it turns out, may be hereditary.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Moala Kāinga Journey

Tokoni (dad)

I don't access healthcare much, the only reason I know anything about it is because I help my parents. ⑥

I notice that as my parents are getting older they have more and more Drs appointments, more things to check up on.

① My parents speak pretty good English but when it comes to medical things they don't really understand what the Drs are saying so I try to go with them whenever I can.

① I set up Manage My Health for my parents. I had to set up email addresses for them to do this. They don't use email so I have to remember what their email is and then also their passwords.

My parents don't really use Manage My Health, I set it up so I can go in and see things for myself. It is very helpful when I am not able to go to appointment with them.

Helping my parents with their health can get uncomfortable sometimes. There are some topics that you just don't talk about – it is a cultural thing.

It is very different for my wife Terri, she talks to her parents about everything. They even knew when we were trying to get pregnant, that is just not something I would ever talk to my parents about. ②

Terri (mum)

⑥ I have never really accessed healthcare much, other than getting my smears and stuff. And then when I was pregnant I did all the stuff you are supposed to do.

Then about a year ago, I had a cyst that burst, I was rushed to hospital. It was terrible.

③ This was the first time I ever thought about access to my health information. I was in so much pain and they were asking us so many questions. I couldn't think straight and Tokoni didn't know.

③ He rang my mum and she was able to help some. But there was just so much information about myself I didn't even know.

④ Later I learned that my mum had something similar happen to her, I never knew. So I wonder is this something we need to know in terms of family history?

I have been trying to get access to all of my information from when I was in hospital. I didn't think it would be this hard to get my own information. I want to have it, not that I would know what much of it means but at least if something happens to me in the future it can be shown to the Drs.

Joan (Terri's mum)

When Tokoni rung to tell me that Terri had been rushed to hospital I was so upset. I was so worried I couldn't compose myself.

I was trying get Tokoni all of the information the Drs were asking for but when you are in that state of mind, you can't think, you can't remember. And some of the questions, I wondered, why don't the Drs already know this stuff?

I felt so guilty. Something similar happened to me when I was about Terri's age. I never shared this with her. I don't know if it is the same thing, if it is hereditary or not, but I just wonder if they knew this happened to me could they have done something so she didn't have to go through the same thing? ④

It would be really good if there was a place where we can put in things we know about our family history so that it can be shared with others in the family. ④

Langi (Tokoni's mum)

Joan and I both help watch the grandchildren. Tokoni and Terri work a lot so I am glad that there is family around to watch the children.

When Terri was in hospital the grandchildren lived with me. Joan and I took turns with taking care of everyone.

While all of this was going on with Terri, the oldest grandchild was meant to start school, he was so excited about it.

Joan and I decided we would get him enrolled. It wasn't easy though. We didn't have access to his immunisations records. It was so hard to find them.

⑤ Joan called around to figure out where they were and then we couldn't get access to them because we weren't his parents.

⑤ We tried to explain but they told us that was the rule. So, we had to bother Tokoni about it – it felt bad to do that he was dealing with so much.

Opportunities

- ③ The opportunity for close chosen whanau to have access to records is so helpful in an emergency situation
- ④ Important for family health history to be recorded and accessible to whānau members
- ⑤ Ability to email IMMs info is great for school and preschool enrolments
- ⑥ Many people generally aren't interested in accessing their health information until they have a health event

Profile + Login

- ① Many older people don't have email addresses and can't remember their passwords
- ① Often family members of older people use their own email address for their parents

Delegation

- ② Some medical topics are taboo or not spoken about in certain cultures
- Access needs to be layered so you can choose what you share and with who ②

Accessibility

- Although immigrants may be able to speak English, they find the thought of internet access to their health records daunting ①
- Grandparents or other part-time carers having access to children's health records is important ⑤

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Multi-Gen Household Aīga Journey

Multi-Gen Household Aīga Journey

Many families live in multi-generational homes in NZ, due to the cost of buying first homes, helping care for children, and cultural expectations to care for aging parents. In their own words:

- We are a multi-generational aīga living in one household.
- Saofa'i and Alofa are in their 80s and have been married more than 52 years.
- They immigrated to NZ 40 years ago, have 5 adult children, and one of their daughters, Penina, live in the same household with them.
- Penina is in her 50s with 4 children, one of whom lives in the same household with her.
- Fara, Penina's daughter, and her partner Tom are aged 24, with a 2-year-old son.
- We combined households when Penina's marriage ended, Fara and Tom started their family, and Saofa'i and Alofa needed more support.
- A multi-generational household means that everyone gets the support they need. We all pitch in to help each other.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Multi-Gen Household Aiga Journey

Alofa

I am Alofa and I am 82 years old. Saofa'i is my husband, Penina is my daughter, and Fara is my grand daughter.

Some time ago, I had to go to the doctor because I was having some bad neck pain. They gave me some medicine.

① They didn't tell me what the medicine was or how it would help me, just to take it two times a day.

When I took the medication, I felt terrible, was dizzy, felt like I couldn't even get up. So, I stopped taking them.

③ This was an orange pill that made me feel bad. I stopped taking that one but I still take my white pill, that I have been taking for a long time now. That one doesn't bother me.

I stopped the orange pill and I started to go for swims, this really helped my neck feel better. Then I added some stretching too. For me this is also healthcare. It isn't always about pills. ①

Saofa'i

I am Saofa'i, Alofa is my wife. Penina is my daughter. I am 86 years old.

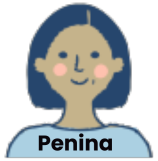
About two years ago now, I went to get tested for bowel cancer. When the results came in my Dr told me I had a blockage.

I had traveled back to Samoa for a visit when I started to feel unwell when I ate. I knew something wasn't right.

When I went to see the Dr in Samoa is when I learned that blockage meant I have cancer.

All this time I didn't know that I was sick. I just told my family what the Dr said. They didn't share any results with me, nothing in writing so at least Penina could have read it later.

② I am okay now. I know I am very lucky. Being able to have access to my health information, sharing it with my aiga would have helped me get the care I needed sooner.



Penina

I am Penina and I help care for my parents (Saofa'I and Alofa) and when needed also my grandson.

My grandson is two so lots of Dr's visits for different things. My daughter Fara and her partner both work so I help run him to the doctor when they need help.

My parents are elderly and while their health is good for their age, they still have lots of needs.

④ I have to keep on top of mum and dad's appointments and also their meds. If they don't like a medication they will just stop taking it and won't tell the Dr so I have to remember to update the Drs when we visit.

① For my parents, health isn't just pills and appointments, it is food, it is exercise, it is plants, so they get put off by the limited way health is viewed in NZ

Fara

I am Fara, Penina's daughter. I had my baby two years ago. Living with my mum and grandparents means that my baby is growing up with so much love and support.

I worry about mum. She is always taking care of everyone else, the aiga, the community, everyone, but doesn't look after herself much.

A few years ago she had to have surgery. Me and my sisters all helped care for her.

What I remember from that time is all of the appointments and medications we had to keep up with.

④ Because there were 4 of us taking turns caring for her, we were so worried that one of us would miss something.

④ One of us would always go to the Dr with her. Then have to remember all the things that was said so you can tell everyone else. This was really hard. Would have been good if the Dr could just give us something in writing to share.

Opportunities

Can this be linked to Facebook or FB Messenger somehow to make logging in easy – Facebook is commonly used by the Pasifika community

Being able to use photographs to make the profile more personalised to us would be a great option. And with the whānau members we add - having a photo of each of them would help to organise it especially with so many kids in one family or multi-generations added"

"Is there the option of spelling name phonetically and having option to add voice recording of how to pronounce name?"

① Wellness element, exercise, green scripts, need to capture more holistic approach

Log In

Banks commonly use pin numbers to sign in - can you use a pin number as an option to log-in?

It would be good to have 2 factor authentication

"In the Pacific community our IRD number means we can legally work, so we have committed it to memory. Would it be an option to use IRD number to log-in like a client number?"

"Many of our community do not have access to technology - can a phoneline be used to authenticate that way?"

Profile

"Family health history - is that going to be linked here?"

Need emergency contact information added to profile and as an alert

Next of kin

Need a section to flag special needs (e.g., interpreter, wheelchair access)

Specify my preferred language

Ability to set up multiple accounts with same email. Daughter setting up for parents. How do have same access as for children for your parents or someone else.

Medicines

"I would love to be able to say one is for hayfever, asthma, anxiety etc so my meds are organised in ways both me and my family know about"

③ Medicines - Is there the ability to update prescriptions?

Have a tab for long-term medications that has a long-term repeat script attached.

Could MHR flag review every 6 months for long-term meds and can that review be over the phone. Sadly some go without some of the lifesaving meds because of not being able to find time to attend physical appointments" ③

Care Plans

① Many people can't cope with recording and managing – care plans would be great but must be able to enter own notes. And also what to watch for, symptoms for alarm.

④ Amazing possibilities for sharing care responsibilities.

④ When tools like these don't exist, we make them up for ourselves, but that creates extra stress when all we want to do is focus on caring for our family

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Women of Sunny Farm Whānau Journeys

Women of Sunny Farm

The women of Sunny Farm represent farming family experiences and how women are often the key health decision-makers and caregivers. These stories show how location, varied financial situations, and limited connectivity greatly impact access to health services.

- Sunny Farm in rural Otago has been in Ryan family ownership for generations, and is run by Brian and Ruth Ryan.
- Ruth, aged 52, handles the business side of the farm and is heavily involved in her community.
- The Harvey family work for Sunny Farm, living in a separate house onsite. While Mark does most of the farm work, when the children are in school, wife, Becky, works the farm with him.
- Misty, a young Mum of two boys, is a seasonal worker on Sunny Farm during school hours to make extra money to support her family.

Findings from our research support the strategies discussed in the Rural Health Strategy [4].

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Women of Sunny Farm Whānau Journey

Ruth (owns and operates the family farm)

Digital access sounds great, but **what are you going to do about all the connectivity** issues we have? ①

We had Starlink put in, it was $1000 to install and costs us $159/month to cover our house and the cottage where Becky and her family live. Even with all that, there are still parts of the farm where we don't have internet or phone coverage

I don't understand why we focus so much on some groups, we are all NZers, why do we have to be labeled?

② Another problem with digital is, a lot of people don't have email addresses, my father is one of them.

③ There needs to be a phone option that he can call and talk to a real human-a human in NZ, not someone with English you can barely understand. My father has lived on this farm his whole life, he can't cope with accents, he just can't understand what they are saying so he gets confused.

④ I had to go all the way to Dunedin to get my breast exam, then I learned that there was a mobile bus that I could have gone to not even 30 minutes away, why don't we get told about these things?

Becky (employee who lives on the farm)

My husband and I have lived and worked on this farm for ages, all our children were born here, we have 7.

⑤ The fact that we have internet in our house is very rare in these parts. We only have it because Ruth has paid for the installation and we split the bill, otherwise we couldn't manage it.

We are a big family, and we haven't been able to find one GP that can fit us all in. Me and 3 of our children are at one. My husband and 2 of our kids are at another, and the younger two are at a different GP. ⑥

With 7 kids, there is so much info to keep up with, immunisations alone is a lot, just remembering whose had what, who needs what and that's just one thing.

④ The idea of being able to see health information for my entire family is great, especially if I don't have to set up a separate login for each person...if I had to do that it would just be more work for me and not very helpful.

Thinking about two of my kids, one is 13 and one is almost 12, they are not mature enough to manage their own health...they would have no interest ⑧

16 is a more reasonable age but this would depend on the child, some are very mature, very independent, some aren't, so it can't be a hard and fast rule

Misty (seasonal work, lives off the farm)

My husband works all the time, I work when I can, mostly around when the kids are in school.

⑤ We don't have internet at home, services just don't reach where we live. I can use the internet when I am at work on the farm or the New World provides free internet so I park up there when I need to access something.

⑤ My husband and I have smartphones, but a lot of our community uses the library computers because they don't have their own devices or they can't afford the data.

We moved here about three years ago, and still haven't been able to enrol with a GP, all the GPs have closed their books. ⑦

So, anytime one of the kids get sick we have to go to hospital or go to the GP as an unenrolled patient and pay more. With two school-aged kids that can be very expensive.

⑥ I know this isn't the right thing to do, but in this community, we save medications and share them around when someone else gets sick, if they get something similar and we have something left over. We know it's not the right thing to do but for a lot of us when we get sick we just don't have the money to go to the Dr. ⑦

The big thing we are dealing with right now is, my husband hurt his back, he's meant to go for a scan and we are waiting, but we haven't had any update. Has he been referred? The not knowing is stressful. I know there is a long wait for everything, but at least being able to see where we are in the process would help. ⑧

Opportunities

① People really worry about hereditary health issues. Knowing where they are in a health process or system is really important for their peace of mind.

⑧ Saying to people who have had tests that they'll get a phone call from their GP if there's a problem does nothing to ease their ongoing worry. People need to know and understand the results, even if they're good.

⑥ Cost and access to a GP is an inhibiting factor in all aspects of personal health management

GP shortage is a very common problem in rural areas and people are driven to desperate measures ⑦

Sign Up & Login & Assisted Chanels

⑤ Internet connectivity is a major issue in rural NZ, it cannot be assumed that everyone will be able to access MHR easily.

② Many people don't have email addresses.

③ Many people (especially older) could only access MHR if it involved a very simple process of talking to someone on the phone who they can easily understand.

Bookings + Notifications

④ People are excited about the potential for notifications of health events, mobile clinics, availability of vaccinations etc. in their area – especially in rural areas.

④ Parents and caregivers are really excited about being able to see all family health records in one place.

Consent & Delegations

The maturity of the young person plays a major part in determining whether they manage their own health record, there needs to be flexibility. ⑧

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Te Ao Mārama Whānau Journey

Te Ao Mārama's whānau

Some people are stretched between their own health journeys and caring for others but, with the help of whānau and community service providers they trust, they are managing. In their own words:

- I'm Te Ao Mārama, a 61-year-old wāhine and kuia of Oamaru. I whakapapa to Kai Tahu on Mum's side, have four grown-up kids, and 6 mokopuna living down the road.
- I am the oldest daughter, caring for parents who live with me. I am my parents' full-time carer, and I do volunteer mahi at the community pātaka kai (food bank).
- I've had my own breast cancer journey (a double mastectomy) which influences how I access healthcare as I have grown awareness of my parents' and my needs.
- I'm on regular medication for early onset arthritis and have regular tests to monitor this.
- Mum had a stroke so has mobility issues and needs to see our GP and attend a rehabilitation clinic.
- My dad is on medication for high blood pressure but is otherwise OK and helps me care for Mum.
- We are fully engaged in our marae and church community.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Te Ao Mārama's Whānau Journey

Tamariki & Mokopuna

I also help my daughter out by taking my mokopuna to appointments, this is challenging sometimes because I don't always have access to all of their health information. ①

I worry about accessing health information online for my whānau. What if I see something I am not meant to..My tamariki are grown, "my daughter would be crushed if she knew I was able to see her health information" ②

My daughter struggles with knowing when immunisations are due for my mokopuna, she has to ring the doctors and hunt for the information for each child. Not everyone keeps written records, especially when you are a working mum worried about the day to day stuff. ③

Hana

As the eldest daughter, I help mum and dad manage their GP, dental, and physio appointments – we have so much health information to manage I worry about missing something ①

My elderly mum needs regular bloods done but we don't know what her results mean and what should be important for us to know so we can look after her. Can health information be in plain language? ④

Mum and dad really struggle to remember what medications they are taking and why they are taking it. They also forget to tell me when they need repeats so I have to remember to track this for them. ⑤

Te Ao Mārama

As a breast cancer survivor, I have regular oncologist appointments and I also see my GP for managing my arthritis and blood work ❶

We have good access to health services through our local Māori health provider and feel quite connected there. They've had to call in some new doctors to help. Some of the new GPs are mistrusting of sharing health info with me about my mum and dad. There is a lack of consistency.

When doctors don't share health information with me about mum and dad, it makes it much harder for me to support them. If I don't know then I cannot help. Mum and dad don't always understand what the doctors say to them, so it is important that I get info from the doctors. ❷

Sometimes, the clinic gets so busy, that I am not told when my results are back. So, you just hope that no news is good news. For a cancer survivor that is hard because you always wonder if the cancer is back. It is so important hear the words, even if everything is okay. Even an email to say all is good, when time is difficult for doctors to meet. ⑧

Scans, lab results, referrals, I get all of these for me, mum, and dad emailed to me so they are all in my email but I have to go digging to find it. I am scared to delete the emails or save on my computer because I might lose them. ⑦

In my whānau we have a history of breast cancer, stroke, arthritis this is important for my tamariki and mokopuna to know – I worry about how this information will get passed down from generation to generation ⑥

Opportunities

How can we make it easier for Te Ao Mārama to book and track appointments for her and her whānau? ①

Make results easy to understand "I really like pictures or visuals. Perhaps a light system (red, amber, green) to let us know when we might need to get seen or need more urgent care" ④

How do we explain to whānau about giving access to others and controlling the information they can see ②

How do we enable quick communications between providers and whānau? ⑧

Profile + Login

I like being able to see the profiles of my tamariki within my account, having multiple accounts is difficult when you look after the health of your whole whānau ②

Would I be able to have mum and dad's profiles linked to me too? What about my mokopuna? ②

Would be good if all my labs, referrals, and scans could be saved here, much safer than email ⑦

I would want my health history to be available here so that whānau can see it in the future, I would want that linked to their accounts ⑥

Medications

I'd like to see how many repeats are left on medications ⑤

Being able to see all of my whānau medications in one place would help me make sure everyone stays topped up ⑤

I like that you can click to learn more about the medicine, that way I don't have to Google it ⑤

Can I make my own notes? So, I know what I am taking these meds for in words that make sense to me ⑤

Immunisations

It would be great if you can get notifications when immunisations are due ③

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Atawhai's Whānau Journey

Atawhai's Whānau Journey

Being part of NZ's youngest average populations, Māori mothers are among the youngest, yet many choo se not to access mainstream health services, preferring to remain within the support systems of whānau. Understanding why this is the case helps the health system cater for their needs. In their own words.

- Atawhai is a 17yo māmā of a 15-month-old child, Ariki.
- She attends a young parent education programme in her rural hometown. The programme allows her to ensure she achieves her NCEA credits where she is planning on going into the nursing degree programme next year.
- Her baby Ariki is able to be with her at school.
- Atawhai lives at home with her nan Kara who is currently homebound due to her needing a double hip replacement. She has been on the wait list for surgery for 2 years.
- Atawhai is Kara's primary carer, and is in charge of booking doctor's appointments for her whānau, ensuring they all receive their medications.
- Nan Kara goes to the marae-based physio programme once a fortnight and looks forward to socialising with other kaumātua and strengthening her body through exercise tailored to her needs.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Atawhai’s Whānau Journey

Atawhai

Atawhai is exploring birth control options but worries about her nan Kara finding out ①

She wonders if she needs to wait until she is 18 so that her Nan can no longer access her health info ②

Atawhai helps Kara with her meds, she worries because between study and taking care of Ariki, she doesn't always remember to stay on top of her nan's meds ③

Atawhai was excited when she learned about Manage My Health, because she thought it would make it easier to help her nan and her son with their healthcare needs, but using that app was a disaster

Manage My Health was too confusing so she gave up and refuses to try it again

Ariki

Atawhai needs to call the Dr as she cannot remember when Ariki is due for his imms and she has lost her Well Child book

Ariki had a mild reaction when he got his last immunisation, but Atawhai cannot remember which immunisation he reacted to ③

Atawhai suspects that Ariki might have an allergy to dairy, as he’s had tummy troubles when she’s fed him yoghurt ④

Kara

Kara is homebound as she is on the waitlist for a double hip replacement

She is completely dependent on Atawhai for healthcare needs as well as day-to-day living

Kara is on pain management meds and requires physio as her mobility is limited

③ She goes to the physio and rongoa programme at her marae once a fortnight

⑤ At first Kara was skeptical about physio but because it was rongoa based she was willing to give it a go and now loves it

⑥ Kara is thankful that a mobility van from her marae picks her up to take her to the physio programme - it is one less thing that Atawhai has to do for her

④ Until a friend told her, Kara wasn't aware that her Iwi has negotiated with the local chemist for free blister packs for whānau

Opportunities

I want to be able to share my health data with my hapū/iwi ⑥

I want to be able to list all my iwi - there should not be a limit

I'd like there to be a place where I can see WHO has access to my records

Profile + Login

Need to capture both - birth assigned gender and self-identified gender (have the option to enter the second)

Want to control which information whānau see (there are things I don't want my nan to see) ①

Is there a choice when you're 18 to take your mum's name off access to your data? ②

Profile needs to have fields for Iwi, Donor, Blood Type

Medications

Would be great to have a pop-up "take your medication now" feature, like an alarm. ③

"having a history of your meds but something that says "active meds" so you can see what you took in the past". Important to have active meds highlighted at the top

space that tells you about what each medicine is actually treating? eg: gout, blood pressure, asthma, heart meds, birth control etc. Allow for whānau to be able to add their own nicknames to the meds tab.

Need to include rongoā rākau

Care Plans

have a timetable or care plan alert on MHR. eg: breakfast - take a pill now with kai etc or to even have the app send out notifications

this a place where whānau can see what is mutually agreed to?

good to archive care plans to have the history but to also have a tab that says "active care plans"

include rongoā Māori ⑤

Allergies

Need to include ALL allergies, plants, food, meds, environmental ③

Allergies should be classified as “life threatening” and “sensitivities”

Maybe a space for suspected allergies (not confirmed by Dr) so you can remember to talk to the Dr about it ④

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He Haerenga ā Hapū

He Haerenga ā Hapū

Even the elderly living within their hapu feel change, due to rural isolation and digital technology versus a lack of connectivity. It makes them feel like they miss services, while at the same time receive health info in forms that don't work for them. In their own words:

- Our marae is rurally based, 30min down a rough gravel road.
- Health services do not reach us due to our rural location, so we travel long distances to access medical care.
- Sometimes we're flooded in and can't access urgent care. As a rurally based marae, we have learned that we can't wait for services to come to us. We've found ways to bring services to us.
- We have our own generators so, during power outages, those needing electricity for medical devices can access them.
- We also run marae-based health programmes that bring Māori health professionals to the marae to offer treatments.
- In rural communities, connection with others is important, particularly for kaumātua often isolated at home with unmet health needs
- The digital world isn't a scary prospect for this rural hapū, we welcome managing our own health info from home, but connectivity is challenging where we live.
- We're guarded and don't trust outsiders with our info. It's difficult for us to share about our whānau and our health when we don't know where it's going and what story is being told about us, without us.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

He Haerenga ā Hapū

Heremaia

- Heremaia is a kaumātua living on his own as his tamariki live overseas
- He has several managed health conditions - diabetes, arthritis, and a heart condition
- Heremaia is on several medications to manage his health
- ① He struggles to remember all the medications and when refills are due
- ② His daughter, Anita who lives in Brisbane tries to support Heremaia's health but struggles with accessing his information

Pat

- Pat is the matriarch of her whānau and is experiencing hearing loss
- Her tamariki all had to move overseas for better work opportunities
- The closest place for her to get her hearing checked is a 2.5 hour drive each way
- To get her hearing assessed and get fitted for a hearing aid would require 2-4 trips
- Pat is on a limited income and cannot afford the time or transport
- The cost of a hearing aid is $4,500 which she cannot afford, the forms to fill out for assistance are too complicated
- It was all feeling too hard and Pat had given up
- ③ Her hapū stepped in to get her the resources needed so she can get her hearing sorted

Maioha

- Maioha is a 52 year old papa with three tamariki, two are teenagers and one is 12 years of age
- ④ Maioha and his whānau are just discovering that Type 2 diabetes is a hereditary condition through his whakapapa
- He's also just discovered that he also has Type 2 diabetes
- ⑤ Being newly diagnosed with Type 2 diabetes, Maioha is learning how to manage his condition, he struggles to keep up with all of the new things he is learning about managing his condition, especially the specifics about his meds
- ④ Maioha wishes he had known about Type 2 diabetes being in his family history, so he could have prevented his diagnosis
- ④ Maioha wants to make sure that his tamariki and future mokopuna know about the family history so that they can be proactive

Opportunities

- ③ How do we enable sharing health data with hapū/iwi/marae?
- ④ How can we use this to capture whānau health history so everyone knows what health conditions to look out for
- ② Enabling whānau overseas to have access

Profile + Login

- Email for login is good, common standard, could phone number be another option?
- Can voice ID be an option for login/verification – like my bank does
- Verification, would there be a drop down/autofill?
- Why only GP? What about hospital or specialist for verification?
- Profile should also include: devices (hearing aid, pacemaker), blood type, donor
- ③ Profile needs to capture iwi/hapū, with the ability to list all my iwi/hapū don't limit the #

Medications

- Knowing what I am taking the meds for in language I understand, not technical terms
- Ability to put my own notes in so I can remember what each medicine is for
- Visuals would be good, picture of what the medication looks like
- ① Reminder alerts when meds are due each day
- ① Reminders when meds are due to be refilled (e.g., counting down from day filled to # of pills provided)

Care Plans

- A place where all whānau can see what's been agreed to because they share care responsibilities across whānau
- ⑤ Can it have management plans for conditions like diabetes
- Can it have a space to capture tikanga preferences (donor, resuscitation instructions, next of kin to contact)
- Can it capture end of life plans

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Kaumātua (older people) Journeys

Kaumātua

NZ's elderly are varied and diverse with some able to afford a comfortable retirement and others struggling to afford the basics and health care, despite having high health needs. In their own words:

- While the rest of the world lump us into one category, there is a lot of diversity amongst us. Some of us live independently in our homes. Some of us live independently but receive support to manage some life tasks. Some of us receive full-time care when we cannot care for ourselves
- Some of us are comfortable using technology, and curious about using new technology
- Some of us are uncomfortable with technology, worrying about safety or not bothered with learning to use it
- Some of us have active social lives - involved in our communities
- Some of us have stepped back from our community
- Some of us have strong opinions on how things should be
- Some of us understand the need for change but are reluctant to change

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

"Just because I’m old,
doesn’t mean it’s all cobwebs
down there"

Kaumātua Journeys

Lori

Lori is an active 72 years old Pākeha woman. She lives independently in her home since her husband passed away five years ago. ①

She has an active social life, is highly involved in her local community.

Lori's 92-year old mum has moved into a retirement village because Lori isn't able to look after her mum's day-to-day care.

Although Lori's mum lives in a retirement village, Lori stays involved in her mum's healthcare needs ②

Lori is comfortable with using technology, she currently uses Manage My Health but is frustrated that not all of her information is there, she still has to ring up to have some of her information emailed to her ③

Catherine

Catherine is 74 years, Pākeha, and she lives in a retirement village which is based in a rural community.

Catherine is still able to manage most of her daily care on her own but feels secure that when she needs extra support that she can call on the kaitiaki at the retirement village.

④ Catherine isn't very comfortable with using technology. Her children got her a smartphone so that they can ring her. Other than answering calls from her children and grandchildren she doesn't know how to do anything else on her phone.

⑤ Catherine has arthritis and high blood pressure. She is on a care plan to manage both of these conditions. Her children always ask her questions about her medications and what the doctors have said, she can never remember what to say.

Paul

Paul is 82 years old and lives in the care centre at a retirement village.

Paul has recently been diagnosed with early stages of dementia and also has a heart condition.

Paul was living with his daughter after his wife died but needed to be moved into a care facility because of his dementia diagnosis.

Paul's healthcare is managed by the nurse at the retirement village. His children contact the nurse so they can keep informed of how their father is doing. ②

② Paul doesn't have a phone or an email address. At this stage of life all of his care is managed by his children and the nurse at the retirement village.

Ying

Ying is a 78 year old Chinese woman who 3 years ago shifted from China to live with her only son's family in NZ.

Ying doesn't speak English and knows no-one else in the small town where they live.

She was excited to live with her son's family and be near her granddaughter, Zhu, but Zhu is always studying or going to various activities

And the whole family are working long hours at their restaurant so that Ling is home alone from 9am to 11pm. She misses her friends in China and feels so lonely

Although she would like to help, Ying only seems to get in the way and keeps dropping and spilling things. She worries that something is happening to her but she doesn't like to bother her family.

Opportunities

Can we have access to our Xrays, scans, ultrasounds , cardiograms – so that I can see it and share with any provider I want to. ③

Feedback button – if I have a glitch or suggestion about the website or app.

I don't want my children to have access to my health information now, but later in life it would be good – can I set it up now so that access can be granted in the future? ①

Profile + Login

Log-in should allow both email or NHI number, not everyone has email, but everyone has an NHI number

You need to allow me to use my expired drivers license or passport – at this stage in life I don't have a valid one or want to get one

I already use RealMe so good that I can use it here too

Can someone who is involved in the community that knows you, vouch for you?

Consent + Delegation

Like that I get to choose who I share my information with

Ability to give temporary access – like if I was going in for surgery but once I was recovered, I can take their access away

Caregivers need to have access to this, and be able to get access without you having an account ②

There needs to be more detail levels of access, for example I want to select which medications to share, with whom, and for how long

I want to be able to control how much of my health history I share – my husband doesn't need to see anything from before we got together

Mental health and sexual health need to be specific controls for sharing

Care Plans

This would make it easy for my children to know what's going on without me having to answer a bunch of questions ⑤

Care plans need to have a way for me or my family to add notes

Also need to be able to control which care plans I share, with whom and for how long

Assisted Channels

There needs to be a real human I can speak to

There also needs to be an in-person options, somewhere you can go and someone can pull up your information and show you on the screen what is there. This doesn't have to be a healthcare professional just someone who understands how to use this. ④

It needs to be clear that this is different from calling health line – that might be confusing for some people

I would expect the phone option to provide me with all the same information I would get if I were to use to online option ④

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Rangatahi Uenuku Whānau Journeys

Rangatahi Uenuku (Young Rainbow) Journeys

Even at a young age, Rainbow community youth have experienced inequities in the health system. As major advocates for their whānau, this group is highly influential in their whānau. They view access to health information as taking control of health decisions, and often act as health advocates and IT help for their whānau to build digital inclusion and enablement. In their own words:

- Many of us are primary carers for our grandparents and older whānau members, even though we are under 16.
- Wellbeing pursuit is important for us and we want a voice to solve the inequities we have grown up with and continue to experience.
- We know of children in care roles for family members and are often advocates so by the time, we are adults, we have a good understanding of the health system's barriers to access.
- We don't trust government initiatives due to historical issues so what future can we expect?

The experiences captured in this research are further supported by previous research [5], [6].

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Do you realise we are the adopters for MHR? If this is works for us and we feel it is a safe place for us, we will get our families on to it. If it is not safe for us, we won't use it and neither will our parents, grandparents, or children.

Rangatahi Uenuku Whānau Journeys

Frankie
(they/them)

I am 15 years old and my Koro (grandfather) raised me.

Koro isn't listed on my birth certificate, but he has been the only parental figure I have ever known

He's very elderly and so I assume a carer role for him. He needs to have regular blood tests and specialist appointments. I track these for him and ensure he gets there.

Sometimes I take days off school when he is unwell and try my best to advocate on his behalf as he doesn't know how to work his phone so well and his eyesight isn't very good either

① I see that I don't meet the age to be considered an adult or even an advocate, how can MHR ensure I am not left out of Koro's health info?

Koro would need to access this too but the layout would be overwhelming for him. Is there a way to filter out the core fields we would need, maybe even just profile, meds and results? If you can make this customisable to the info we most need or use that would be a game changer

Hayden
(he/him/ia)

I am a 16-year-old takatāpui and my self-identified gender is as a tāne (male). I was born a female, so this has been part of my journey. ④

I've been flatting since I was 14 and making my own decisions. Been couch surfing at my mate's houses and our Rangatahi Uenuku coordinator has just found me a place to live. I haven't had a bed of my own or my own space for years now.

② My whānau don't know about my plans to fully transition and I don't want them to know.

I have struggled to find a healthcare provider that understands my situation. Most Drs are cis-gender and don't understand what I am going through. They still refer to me as "she" and use my dead name.

② I try to avoid going to the Drs because I don't feel safe or understood. This group has helped me find a therapist who I have been meeting with and she gets me so I keep going.

Shay (she/her/they/them)

I am 19 years old and live at home with my mum. Since I was 7, I have been looking after mum as she has chronic fatigue and is immuno-compromised

Making appointments and going to appointments for mum has been my whole life, I've been doing this since I was a child

One of the reasons I am so involved in the daily care of mum is because I am her translator because her English is not very good ③

While I help manage mum's health, I am very private about my health information. I wouldn't want my mum to have access to my info. ②

I haven't come out to mum yet, no one knows. When I was at the Drs last they asked me if I am sexually active. I told them I was, they assumed I was straight because I was then asked about birth control. I just told them I use condoms. I didn't feel comfortable telling them the truth. I don't think my Dr would understand.

Opportunities

"We are overwhelmed with client numbers and having different ones across government agencies. Is it possible to just have one client number registered for each person across agencies?"

Is there the option of setting up a physical kiosk in a public place like a library/hospital/provider foyer where you can sign-up, have ID verified in person, and access your information if you don't have your own device

Is there an area in profile for phobias or fears? Declaring these things might be helpful for health care providers

Login

Important to be given options around login that isn't just email or Real Me

Can you use a phone number to log-in and then use 2-factor authentication to log-in

"Options are important - face ID or Pin would make it easier to use"

"can you have a preferred language option at the point of login?" ③

"This reminds me of the WINZ website, and I feel distrustful of the way this looks"

Profile

"I think the contents are good but the layout is crap" It should be split - personal details one side with headings down the other. A tiled view is also better, easier to read than a long list.

How do you add emergency contact details to profile?

"I don't like the term preferred name, it's not inclusive" instead, change wording to either the name I want to be called is____ or Please call me____

Profile needs to capture both, sex at birth and also gender I identify as, having one space for gender isn't inclusive ④

Don't have "other" as an option, instead provide a space for me to fill in what I want (gender/pronouns/ethnicity ④

Verification

"if you are a valid person through Realme, why can't you just use that for authentication?"

"Is having Real Me going to exempt you from having to go through this step?" If Real Me is good enough for IRD, surely it is good enough for MHR?

Can we have a set of safety questions as a way of authenticating who we are?

"My colleague rang 18 different providers yesterday to enrol as a patient and couldn't enrol anywhere so need more options here instead of just using ID docs or via healthcare provider."

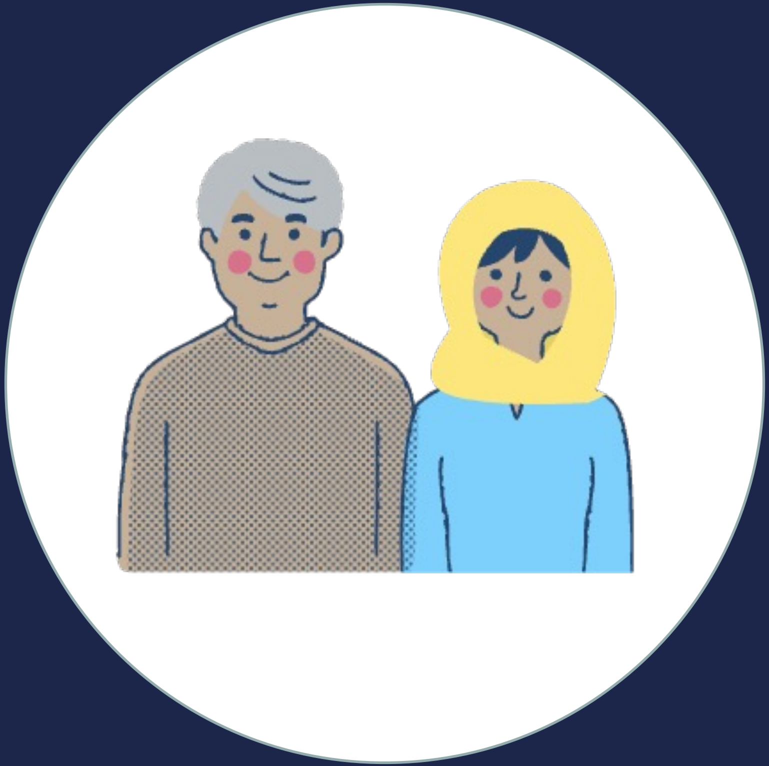
Delegation

① The minimum age requirement for getting access isn't practical, doesn't match the reality for a lot of whānau

Sexual health, mental health, and medications, labs related to these things need to be set up in a way that I can control who sees what ②

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Refugee Whānau Journeys



Refugee Whānau Journeys

Refugee families, as they settle into NZ, reflected on how – when not listened to by the health system - worked together as family to find their own solutions for accessing health services. In their own words:

- We were all forced out of our homeland and have made Aotearoa our home and have settled in Dunedin.
- Because we had to leave so much behind, we try to hold on to whatever bits and pieces we have left with us from our homelands – our language, our culture and food – all remind us of home.
- We are grateful to call NZ our home, yet Healthcare in NZ hasn't always been a good experience for us.
- We share our stories in the hope that things can get better.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

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Refugee Whānau Journey

Layla (mum of 4 from Syria)

People think we come here because it is easy, because we want to, but they don't realise, we left everything, our home, our family. When you are a refugee you are disconnected from your roots forever.

So we try to hold on to what we can, like our culture, food, language, whatever little bits we were able to bring with us.

My son Ahmed, he has a respiratory problem . We had all his paperwork from our Drs in Syria that explained how important it was for him to live in a warm climate. ②

When we arrived in NZ, we told them my son is sick and needs to live in a warm climate, but they didn't listen to us. I think they thought we just wanted to live somewhere nice. They sent us to Dunedin.

My son near ① died, and had to have surgery because his condition got worse.

We tried to tell the ① Drs about his diagnosis, we tried to give them the paperwork and we were told to throw it away.

⑧ We were told that he had to be examined by a Dr here to be diagnosed for a sickness he's had his whole life. We had to wait so long to see a Dr and he kept getting sicker and sicker. Why don't they believe us?

Samir (dad of 2 from Afghanistan)

My wife and two children have been in NZ for 3 years now. It has just been us as we are separated from our extended families.

My wife and I are working on our English but it's still not very good. Our children on the other hand, you'd never know they didn't speak a word of English three years ago. From school they learn fast.

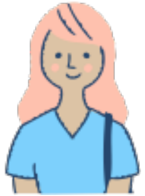
⑥ We try to bring our kids with us to appointments because it isn't always easy to get an interpreter and we worry we are going to miss something important.

Everything is harder when you can't speak the language. One time, I had to go to the Dr and I managed to get an interpreter. The Dr sent a prescription to the pharmacy but when I went to pick it up it wasn't there. ③

I was on my own so I couldn't explain or ask questions. I tried to get my son to call the GP but every time they called me back my son was at school.

I had to book another Dr's appointment and an interpreter to find out what happened to my prescription.

④ We have our own remedies that we use, we need to be able to put that into our record so that Dr can see in case it doesn't work well with a medication they give us.



Shabana (22 year old uni student, refugee from Burma)

I arrived here with my parents and two younger sisters when I was 7 years old so most of my upbringing has been in NZ

Even though I was brought up here, my parents are still very traditional, they hold on to their culture so we disagree a lot. For example, even though I am 22 years old I still live at home -for them, I cannot live anywhere else until I am married.

⑥ I am the tech support for my family so any time something needs to be done like setting up a phone, laptop, email, online account, I have to do it. I also, have to keep track of everyone's email and password because they forget.

Not only am I tech support but since arriving in NZ, when I was only 7, I have also been my family's translator. So, I am the one that knows everything about everyone's health.

⑤ It is interesting that you have to be 16 years of age to set up a health account or have access to one, if this was available when we arrived, I would have been the one to set it up for my family and manage it all for them. So, these age limits are not very realistic.

⑤ Why is it only birth parents that can access for children? Because I am the oldest, I do a lot of the looking after of my younger siblings, I am not the only one, this is the case for a lot of families from my community.

Opportunities

① How might we enable whānau to digitally upload their medical records into their profile?

Saying to people who have had tests that they'll get a phone call from their GP if there's a problem does nothing to ease their ongoing worry. People need to know and understand the results, even if they're good. ⑧

Medications

Have the prescription show up in the app so when you get to the pharmacy, if it isn't there you can show them on the app ③

We don't know how to explain to the Dr the home remedies we use, so if we can put them into the app and they can see ④

Profile

② Medical history and any major illnesses need to be part of your profile so that they can see this first

Consent & Delegations

⑤ What about sibling to sibling access? What if you are under 16 and responsible for your younger siblings?

⑥ Children (under 16) are often tech support and interpreters for their parents

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Immigrant Whānau Journeys

The Immigrant Whānau Journey

While Immigrant communities across NZ come from different countries, they share similar issues accessing health services. Most struggle making their voices heard. Diagnoses they received in their home countries of life-impacting conditions are ignored, along with the importance of cultural safety for them to participate in health. In their own words:

- We have all decided to make New Zealand our new home and are thankful we can do so.
- We live away from our homeland, but maintaining elements of our culture is important to us.
- While we come from different parts of the world, we have similar shared experiences when accessing the health system.
- The biggest difference we see between NZ health and the systems in India and China is not being able to access specialists without a GP referral even when you have insurance.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Immigrant Whānau Journeys

Connie
(immigrated from Mainland China)

My husband, son, and I immigrated to NZ 12 years ago. We first lived in Auckland because there is a big Chinese community there.

After my son finished university, he got a job in Christchurch. We moved down here with him. The Chinese community here is not as big as it is in Auckland.

① When we first moved here, none of the GPs in our areas were accepting new patients. We had to wait almost a year but finally we got enrolled with a Chinese GP practice.

One day my son was at work when he started to have chest pain and couldn't breathe. He was taken to hospital. When we arrived, at the hospital the Drs were talking to him about what to do.

We were told that because my son is 26 years old, that the decision of what to do was up to him. Even if we didn't agree he could make the decision for himself.

② They did not understand that in Chinese culture these decisions are made by the family.

We learnt that my son has a serious heart condition and the Drs had already talked to him about this. I was very upset because, the Drs should have told us first. It is our job to tell my son, not the Drs. ②

Ishani
(immigrated from India)

In India you have joint households. There is family always around. Even as adults you make decisions with the help of your parents. Being in NZ without family support is isolating. ②

Even though Healthcare in NZ is free, it isn't very good because you can never get an appointment. ①

I had a sinus infection and couldn't get a GP appointment for 2 weeks. They tell you not to go to the ED unless it is an emergency. Nobody wants to go to the ED to sit there for hours for something the GP can sort out. But what do you do when you aren't sick enough for the ED but also can't wait weeks to see the GP?

You wait so long for to see the GP and you only get 15 minutes to tell the doctor what you need. There is no time for relationship building. The NZ health system underestimates the importance ③ of having a relationship with your Dr.

GPs are the gatekeepers of your health. It is the GPs job to catch things and refer you to other health services if you need it, how are they meant to do that in 15 minutes?

In India, you can go straight to a specialist. You pay for it but for most working-class people it is affordable. ④

Some health things are hard to talk about. If you don't have a trusted relationship with your GP, you are less likely to bring them up and this is how things get missed. ③

Malosi
(immigrated from Samoa)

When I was 12 years old, my parents sent me to NZ to live with my Aunty and Uncle so that I could go to school here.

Identity documents are a challenge in my community because in Samoan culture you may have many names, depending on your hereditary lines, villages and so on. ⑤

My birth certificate has my birth name, but my Aunt enrolled me at my school and with a doctor in NZ as one of their children. I just kept going from there. My passport doesn't match other IDs. Verifying my ID is difficult.

In Pasifika communities, it's common to be raised by people who aren't your birth parents. There's no legal arrangement. It's just a cultural norm in our community.

In my case, my birth parents lived in Samoa and I lived in NZ with my Aunty and Uncle for my education. My Aunty took me to the doctor, so it was important for her to have my health information. ⑥

In the Samoan community Facebook is a key place for information, especially for our elderly. We also use Facebook Messenger to chat with family.

If you want us to adopt digital health, make it easy for us. Link it to something we already use or make it similar to things we are familiar with. If you make it too hard, we won't use it. Most of us are raising our families and trying to put food on the table. If it is not easy to use, we won't use it, not because we don't want to, but because we don't have time. ⑦

Opportunities

② NZ Health system, needs to be aware of other cultural practices when delivering health services in our multicultural country.

① The problems caused by a shortage of GPs in NZ are wide ranging and affect every aspect of health care for many NZers, but especially for new immigrants

③ Establishing a good relationship with a GP who cares is vital to how satisfied people are with their experience of the health sector. This is especially so for isolated and lonely new immigrants.

④ Immigrants find it difficult to understand why they cannot access specialist services directly

Verification

⑤ Using official documents for verification is not that simple for immigrants because it may be quite legitimate in their country for one person to use different names on different documents

Consent & Delegations

⑥ Often immigrant children are not cared for in NZ by their birth parents. If the birth parents are in another country how can they consent to access by the caregiver ? Especially as that adult is responsible for the health of the child

Adoption

⑦ Immigrants in NZ have their own social media networks that can be tapped into for access to immigrant communities and to promote adoption of services

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

“My long-term health issue is that I am a refugee”

Temporarily Unhoused Whānau Journeys

Temporarily Unhoused Whānau

Some whānau are not in permanent housing for varied reasons that are historical and personal. To be safe, they need support in navigating the health system. In their own words:

- We find ourselves temporarily without a permanent home.
- Some of us deal with mental health challenges.
- Some of us deal with drug and alcohol addiction.
- Some of us deal with mental health challenges, and drug and alcohol addiction, while without a permanent residence.
- Currently we are all living in a temporary residence that supports men to get back on their feet.
- Our kaitiaki (caregiver) helps us navigate health services so we can get the care we need.
- It's difficult to access services we need because we don't have basics like a phone number or identification.
- We don't have regular access to digital information.
- Device and data cost aren't within our reach but our whare will soon have a computer we can all share.

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

Unhoused Whānau Journeys

Simon

Simon is a young Pākehā male who is currently unhoused and struggling with mental health and addiction challenges

He currently lives at The Whanau House where with support from his kaitiaki he is getting support to access services ①

Simon knows how important it is to stay on top of his meds. Being unhoused makes it difficult to keep track of his healthcare – the system assumes everyone has a permanent home. ②

Simon uses different pharmacies, and accesses healthcare from different places, he doesn't understand why his mental health history isn't available across the health system ③

He doesn't have a smartphone and the only access he has to the digital world is through public computers ①

Dale

Dale is a kaumatua with mental health challenges. He has been in the health system since he was a child.

Dale has had many traumatic experiences within the healthcare system and is not very trusting of the system.

Dale has low vision so finds it difficult to read. ④

While Dale has lots of whānau he does not live near them and doesn't stay in touch with them.

He relies on his kaitiaki at The Whanau House to help him navigate the health system. ①

Kaitiaki Lyn

As Kaitiaki at The Whanau House, Lyn supports the tāne who reside there to access the services they need. ①

Many of the tāne that reside at The Whanau House are disconnected from their whānau. Because Lyn interacts with these tāne on a daily basis, she is more aware of their healthcare needs than their whānau.

Lyn also knows that many of the tāne do not want their whānau to know where they are or have access to their health information, but they do trust her with this information. ①

Many of the requirements needed to access services is out of reach for these tāne. Things like email addresses, answers to security questions, phone number, address – are not things they have. ⑤

Lyn works with each tāne to get access to services. This ranges from making appointments, to driving them, to collecting their medications. ②

Opportunities

- Can we give support workers (e.g. Lyn) access to our profile without having an account setup? ①
- Should be able to book an appointment through website/app and link back to a calendar (not just for yourself but anyone else you have access to)
- Medical Alerts, should be a separate tab that lights up red when there is information in it. This info should be shared with St Johns, A&E, ED so they know the really important things to watch out for ①

Profile + Login

- I don't have an email address, not sure what RealMe is ⑤
- **S**ecurity questions are useless, I don't know what any of those things are
- I haven't met anyone who has come through our whare who has any of this, it out of reach for us. ⑤
- Voice or facial recognition, PIN #, fingerprint are options that would work for us ⑤
- Email addresses, GP registration, identity documents are barriers to access for us ⑤

Medications

- This needs to include my mental health medications, all my medications in one place – BRILLIANT! ②
- Dentists and optometrists should also have access – they write prescriptions too
- Medications, any pharmacy you walk into should have all of your prescription details ③

Assisted Channels

- I have low vision so I want the option to go somewhere and have someone read my information to me. ④
- A phone number to call would be good too, so they can read it to me. ④
- I don't have a phone so a phone number to call isn't helpful

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Deaf Whānau Journeys

Deaf Community Whānau Journeys

Deaf people's challenges in accessing health information and services are complex. Their stories bust myths and offer steps they say - if taken early – will save the Health system unnecessary costs down the road.

- We are rangatahi of the deaf community. Many of us also have other health conditions including low vision.
- The hearing community believes communicating in writing is a viable option for the deaf. Not true. English is not our first language, NZ Sign Language is!
- It's also assumed that our whānau know how to sign - they don't.
- Healthcare professionals believe that because we cannot hear or see well, it's OK to do stuff to us without explaining what's happening. Just because we are deaf doesn't mean we don't want to know what is being done to us in medical procedures.

The experiences captured in this research are further supported by previous research [7].

Note: *These stories come from meetings we had with several families across NZ. While the experiences are real, the names are not.*

“Don’t build this for the abled and then add accessibility, build it with accessibility from the start or just tell us that this isn’t built for us, so we don’t waste our time”

Deaf Whānau Journeys

Jamie (profoundly deaf, low vision)

I am a live-in student at my school which means that I live in two different cities

The fact that I live in two different places makes my access to healthcare complicated

My GP, when I am at school, never has the information that my GP back home has so I always have to request for info to be sent back and forth but there is always something that goes missing ①

It's gotten so complicated that my mum said no more and I am just registered with my GP back home. This means that when I need to see the Dr while I am in school I either have to go to A&E or as an unenrolled patient and pay extra

I am about to turn 18 but I would still want my mum to see some part of my health information - but this is my choice to give her access

There are some things I don't want to share with mum, anything related to sexual health and the meds I am taking for anxiety. I don't want her seeing this info.

I already have a My Health Record account and I have Manage My Health account. This is information about myself and it is important for me to see it and know what is there. I want mum to have access but I want to be in control of my health. ②

Holly (deaf, physically disability)

② I am frustrated! My health information, especially from when I was a child is not shared with me - I have a right to know

③ when I show up at Dr's appointments often they don't know I am deaf

Healthcare providers often assume we can communicate via writing, what they don't understand is that when you are deaf English isn't your first language ④

Reading medical stuff in English is no different for me than it would be for someone who only spoke Greek ④

⑤ I also have low vision so being asked to fill out forms is challenging, unless documents are on my device so I can use my reader, it's all just a blur

③ I want healthcare providers to know that I am deaf, that I need an interpreter, that I have low vision BEFORE I show up for the appointment. Make it so that it works for people like me.

Jo (profoundly deaf)

My family and I moved to NZ a few years ago. Communicating with the health system is very difficult for us because, no one in my family knows NZSL and their English isn't good

④ I often get text messages about my health information, they are in English (which I don't read well) and they use words I don't understand - so I have to get someone, usually one of my teachers to explain what the text means in sign language

This is embarrassing, I don't always want my teachers to know all this information about me but I don't really have any other option and I trust my teachers

Going to the Dr is very stressful, I've had Drs just come up to me and start touching me, I know that is their job but no one bothers to tell me what they will do, why, they think because I am deaf I don't need to know

③ Because Drs don't know how to sign they don't think it is important for me to know what they are doing - this is not right

Ami (teacher, hearing)

Often when our live-in students need to go to the doctor we accompany them because we know that there won't be an interpreter to support our students

⑤ Because we don't have their health records we often have to try to get a hold of the parents to be able to answer the questions the Drs ask

⑤ Most of our students' parents don't know NZSL so we are often pulled into very personal family and health conversations

For example, I once had a student come to me worried that they were dying, they thought they were bleeding from their bum, turns out she had just started her period but no one told her this would happen to her

There were no resources available for the deaf community to explain menstruation

Menstruation, puberty, contraception, reproduction, sexual health, mental health, these things are relevant for the deaf community as well

Opportunities

What happens if you have 2 GPs (home and student) can this be designed so both GPs and me have the same info? ①

Can we access records from years back , would like to know what they say about me, and also previous allergies info, hearing tests etc ②

Don't build this for the abled and then add accessibility, build it with accessibility from the start or just tell us that this isn't built for us so we don't waste our time

Where can I put on here *I am deaf, DO NOT call me*. My preference is a video call with NZSL or text in easy to understand English ④

Profile + Login

"sign language needs to be added as a preferred language" ⑤

The ability to indicate who my preferred interpreter is

Ability to indicate implants, when I went in for my MRI, they didn't know I had cochlear implants, it caused my head to stick to the side of the machine

Need to add in what other ID docs would work, looking at this I would assume you need a drivers license

Verification: photos over icons. When you have low vision icons are tricky

③ Ability to indicate that I am deaf, low vision, and limited mobility

Delegation

We are learning independence, need to be able to look at previous records, that only parents or guardians can see now. ②

Once I am 18 I want the choice to take access away from my parents

② Sexual health, mental health, and some meds I wouldn't share with mum

Access needs to be layered so you can choose what you share and with who

Accessibility

We can't just rely on text OR rely on just listening. We need the option of both to adopt this

⑤ An immersive reader within the webpage, often it takes you out of the website and then you lose context and becomes too taxing to use

⑤ Need a read out loud option

"Anything that is not visually fatiguing is great"

"We want to be able to click on a word (med terms) and a video pops up that shows us in NZSL what it means

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

“I've been deaf a long time. Make sure my health info always says I'm deaf so that I don't experience further barriers”

Envisioning Access to Health Info

This research explored the concept of a digital health record that would enable individuals to access their own health information through an app or website.

In general, communities like the idea of being able to access their information digitally as long as it is done in a safe and secure way. Communities also expressed the need for non-digital ways to access health information.

This section covers details on how they envision digital access and the features that are important for communities.

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What digital access means

When we asked communities what digital access means for them, this is what they shared with us.

What would it mean to be able to access my health information digitally?

- Transparency … healthcare providers have access to my information, and I don't, digital access can level this power imbalance
- Control … in healthcare there is so much out of my control, being able to see my own health information and share it with whoever I choose gives me a sense of control
- Autonomy … when I see my results for myself, when I can read the doctor's notes after my appointment, I am more engaged in my own health, it makes it more real for me
- Portability … whether I am home or visiting mum on the south island or traveling overseas, I can take my health information with me

Caregiving Made Easier

Whānau Centred Care

Would enable families to share care responsibilities for individuals who are managing chronic or major health issues. Examples share with us include, diabetes management, post-surgery care, cancer treatment.

Digital has a lot of upside however…

Digital has the potential to increase health inequities if we don't remember the challenges some communities face, such as…

Connectivity

Communities across Aotearoa NZ still lack high speed internet making it difficult to access information online.

Affordability

The cost of data is unaffordable to many families which means they have to ration the data they use.

Literacy

Some people may not have the skills to be able to engage with their health information online.

Access will mostly likely be …

Through a smartphone as this is the most common device across communities.

Using the app over a website because an app is perceived to be more secure than a website.

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Make Logging in Easier

Communities want more options for logging, if the options are limited this will pose a barrier for many people.

Thoughts on current options

RealMe Tēnei Au

- Many young adults are using this and find it easy to use
- Among elderly, some find it easy while others cannot figure out how to use it
- Many schools and community service groups are helping people set up their RealMe

E-mail!

- Logging in with email does not work for everyone
- Many older people do not have email
- Many families have one email address for the entire family

> *"Accessing my health information should not be harder than accessing my bank account"*

Ideas raised by the community

- Phone number and NHI number needs to be an option for logging in

myIR

- People are frustrated that everyone govt agency has different criteria
- Is there the ability to log-in with credentials from another service
- Log-in with IRD # was the most common suggestion

- Many apps and services allow loggin-in with Google, this reduces the number of log-in and passwords to remember

- For many communities FB is the hub of everything, it is a trusted source. Can there be a way to connect to MHR through FB

Link it to things we already use

2FA Face ID Touch ID

People across all communities are familiar with these, trust them, and expect them as the standard.

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Verifying My Identity

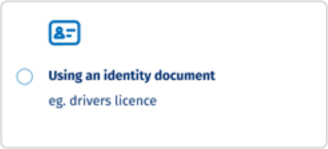
Verification is important, but it needs to be less complicated otherwise it will be a barrier for many communities. If you make it too difficult people will not use it.

Thoughts on current options

○ **Using your healthcare provider**

You need to be registered with a GP practice or medical centre

- Many of the people we spoke with are not enrolled with a GP or PHO
- 79% of GPs in NZ have closed enrolment (as at Mar-2024)
- For many whānau access to health is only available through A&E or hospital



○ **Using an identity document**

eg. drivers licence

- Many elderly people no longer have valid passports or driver's licenses
- People who are temporarily unhoused often don't have identify documents
- Young people often don't have a driver's license or passport

RealMe® Tēnei Au

- Many people are not aware if their RealMe account is verified or not verified
- The view is if you log in through RealMe you should not need to go through another verification process

> *"Having a form of ID is a privilege that some people cannot afford"*

A Pain Point When Accessing Government Services

Key Point of Frustration…
"Every time I need to access a government service, there is a different log-in verification process"

- Getting an IRD # requires going through a validation process – why can't we just this to verify our identity?
- If I am already working with WINZ or MSD why do I have to verify again with Health NZ?

An Alternative Option Needed

- Verification will be a barrier for many people in the community (e.g., temporarily unhoused)
- The option for a trusted person in the community to vouch for you is needed for those whom ID verification is not feasible

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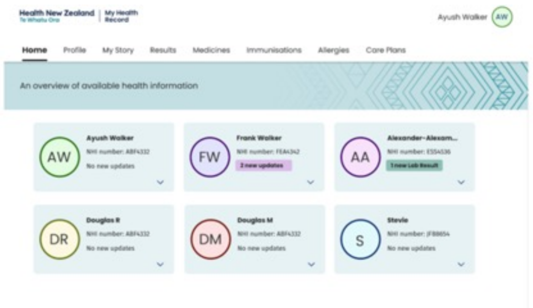
The Important Features

When accessing health information digitally, communities have identified what will be most useful for them.

Whānau View

Across communities, health is viewed as being family centred (not individualistic), the ability to see the whole family's health information in one place is seen as a game changer.



To be effective the whānau view needs to

- not have a limit on the number of family member that can be linked
- don't define who family are as this is different for every family
- remember many New Zealanders have family overseas that they may want give access to
- provide the ability to remove access from anyone quickly if their relationship has changed
- have an audit trail of who has accessed your information
- allow people to select who can see what and for how long

Immunisations

- The biggest benefit communities see in this, is to be able to send immunisation records to schools
- Would be help to keep kids on track with vaccinations

Medicines

- People struggle to keep track of their medications, specially those that are on multi medications
- Being able to see all medications in one place will help people stay on top of what they need to do

Allergies and Reactions

- This is seen as being a potentially lifesaving feature
- Want the ability to capture both medically confirmed allergies and suspected allergies

Results

- Seeing their results makes the outcome more real for people which means they are more likely to take action
- People view having their results available as having autonomy over their healthcare
- There is recognition that some results will require a conversation with a Dr

Booking and Scheduling

- Being able to book appointments online is seen as a way to have autonomy over their healthcare
- People feel if they can book appointments for themselves, it will take some admin load off of healthcare practices who are already stretched thin.

Care Plans

- Would enable families to share care responsibilities for individuals who are managing chronic or major health issues. Examples share with us include, diabetes management, post-surgery care, cancer treatment.

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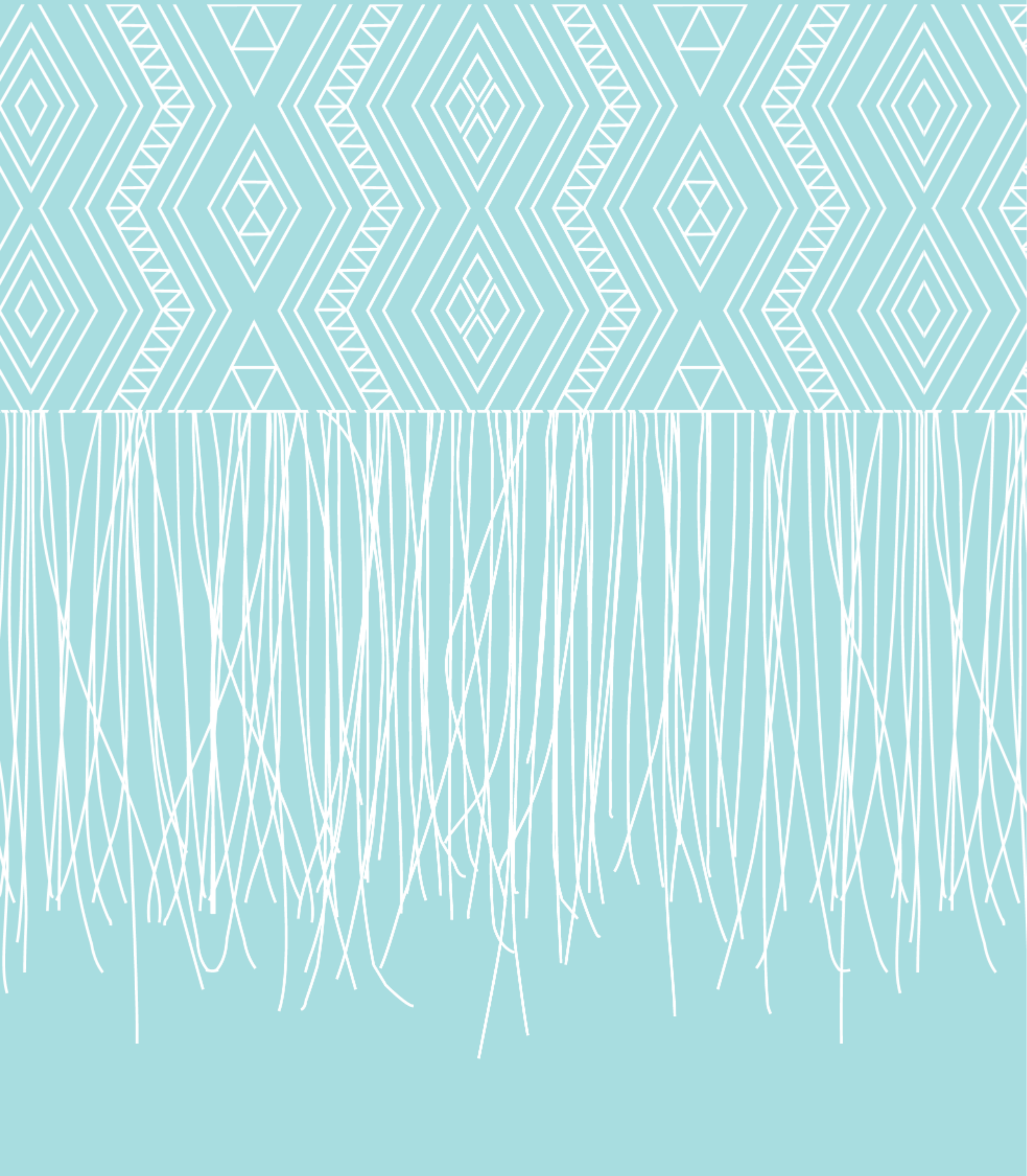
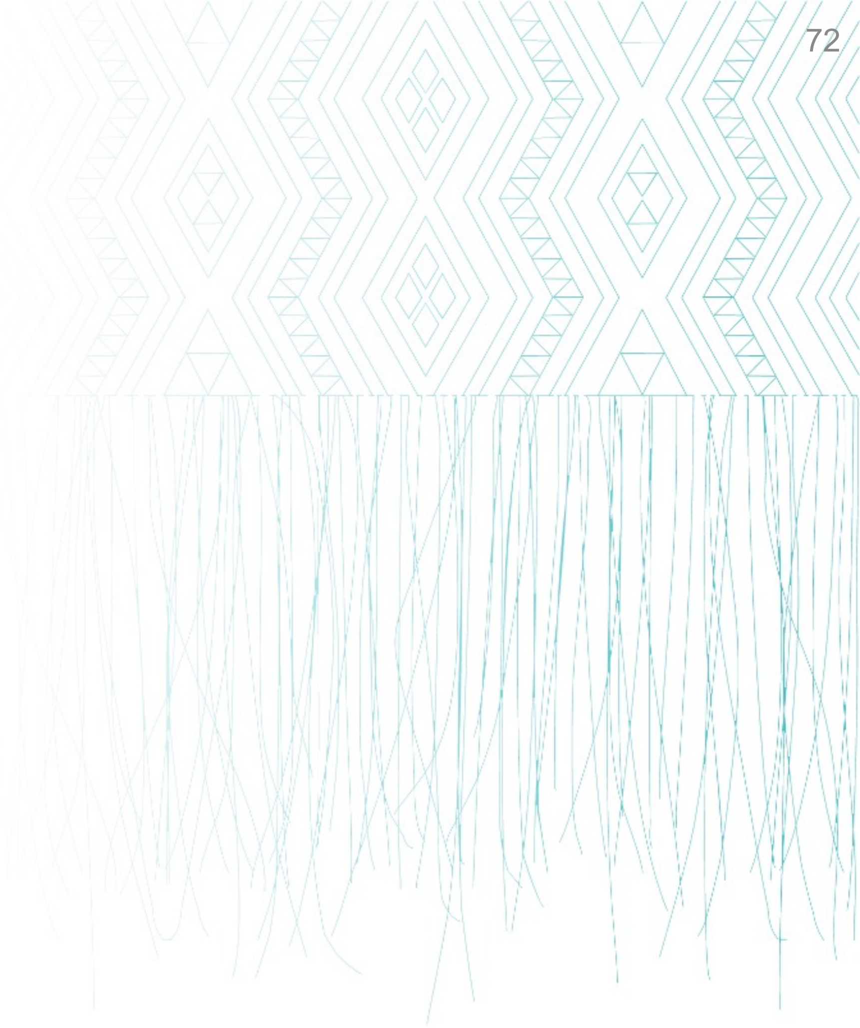


Immunisations

Immunisations

Communities see very practical ways to use this feature



How communities will use this

- Handy to have immunisations for our Tamariki to show daycare and school
- This will help me stay on top of when my kids are due for vaccines
- When you are applying for a travel visa could grab it from here to include in your application

What communities want

- Remind me when my family members are due for immunisations and allow me to book an appointment online
- Share when the next immunisation campaign is being run near my neighbourhood, so I can book in.
- Include immunisations you get at the pharmacy not just the GP
- Provide a way to upload immunisations you might have received while overseas

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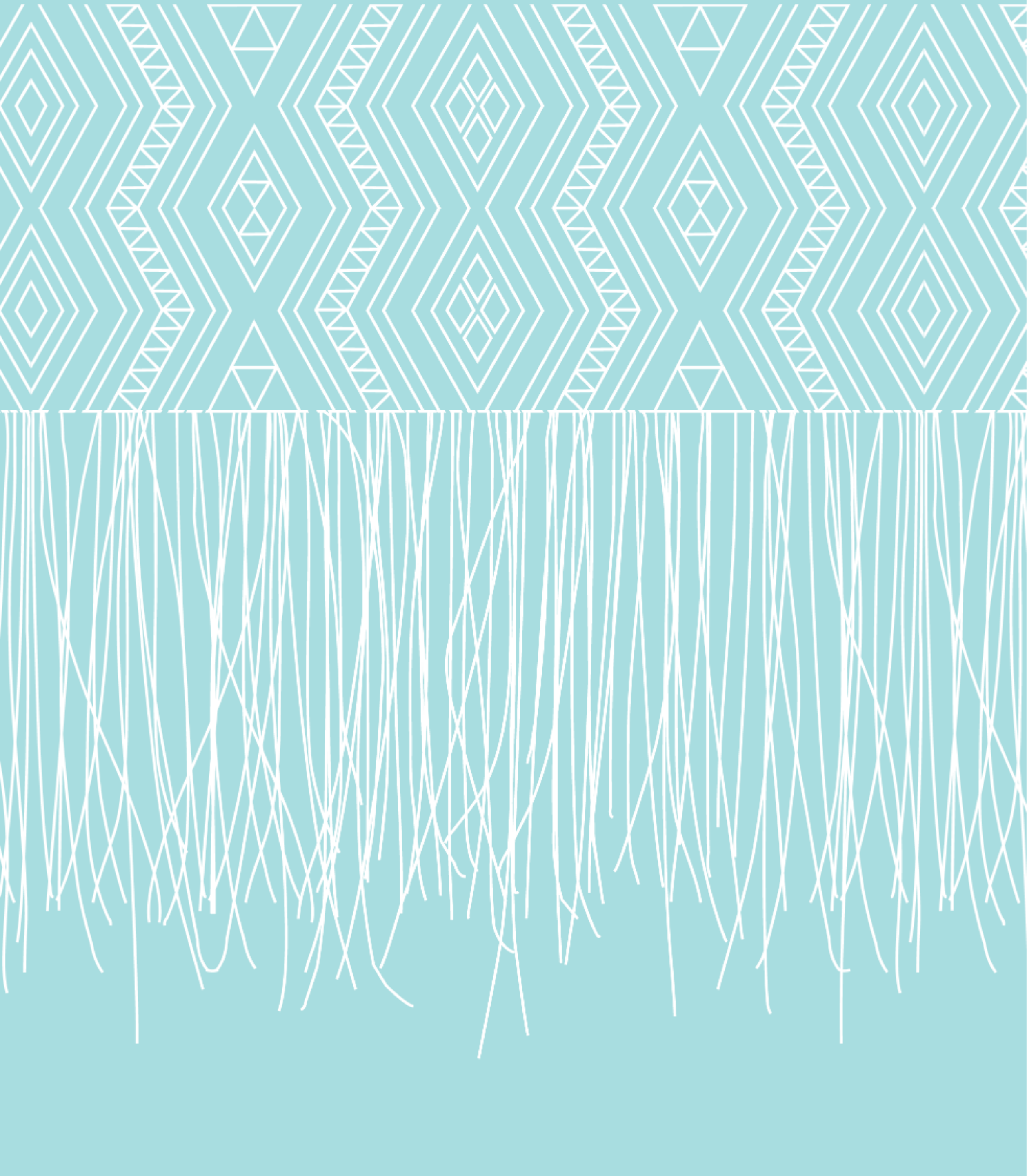


Medicines

What a meds view need to enable

The biggest challenges with medication is that there isn't a collective view across healthcare providers and pharmacies. Individuals are expected to remember all their medications, and this is a challenges for many people.

A Comprehensive View

There needs to be a collective view of all medication someone has been prescribed

"Every pharmacy in NZ needs to be able to see all of my medications"

"Meds prescribed by GPs, hospitals, specialists, optometrists, dentists, school nurses, it all needs to be here"

"All my medication including my mental health medication need to be included"

Notes

Ability to add notes against each medication prescribed

"Can we make notes against our meds using voice recording rather than just typing ?"

"Ability to put notes in so I can remember what each medicine is for"

"I'd like to put in notes about how a specific med made me feel, if I had a reaction to it or it worked well or didn't"

Self-Name Nicknames

Provide the ability to add a nickname for each of their meds

"I would love to be able to put a nick name for my meds, this one is for hay fever, asthma, anxiety etc so that it makes sense for me and my family"

"Medical language and the scientific name for them is not how you know your meds. You know this one is for my diabetes and this one is for my blood pressure etc. That's how we understand meds."

Whānau View

Incredibly useful to have a family view of meds, especially for getting repeats filled

"I manage the meds for my parents and my children so this family view of meds is something I would use all the time, and would make this so much easier"

Integrated Medicines

For many communities, medicine isn't just about what you get from the Dr

"We have a lot of home remedies that we use that I'd like to be able to add here"

"Rongoa Māori needs to be included here"

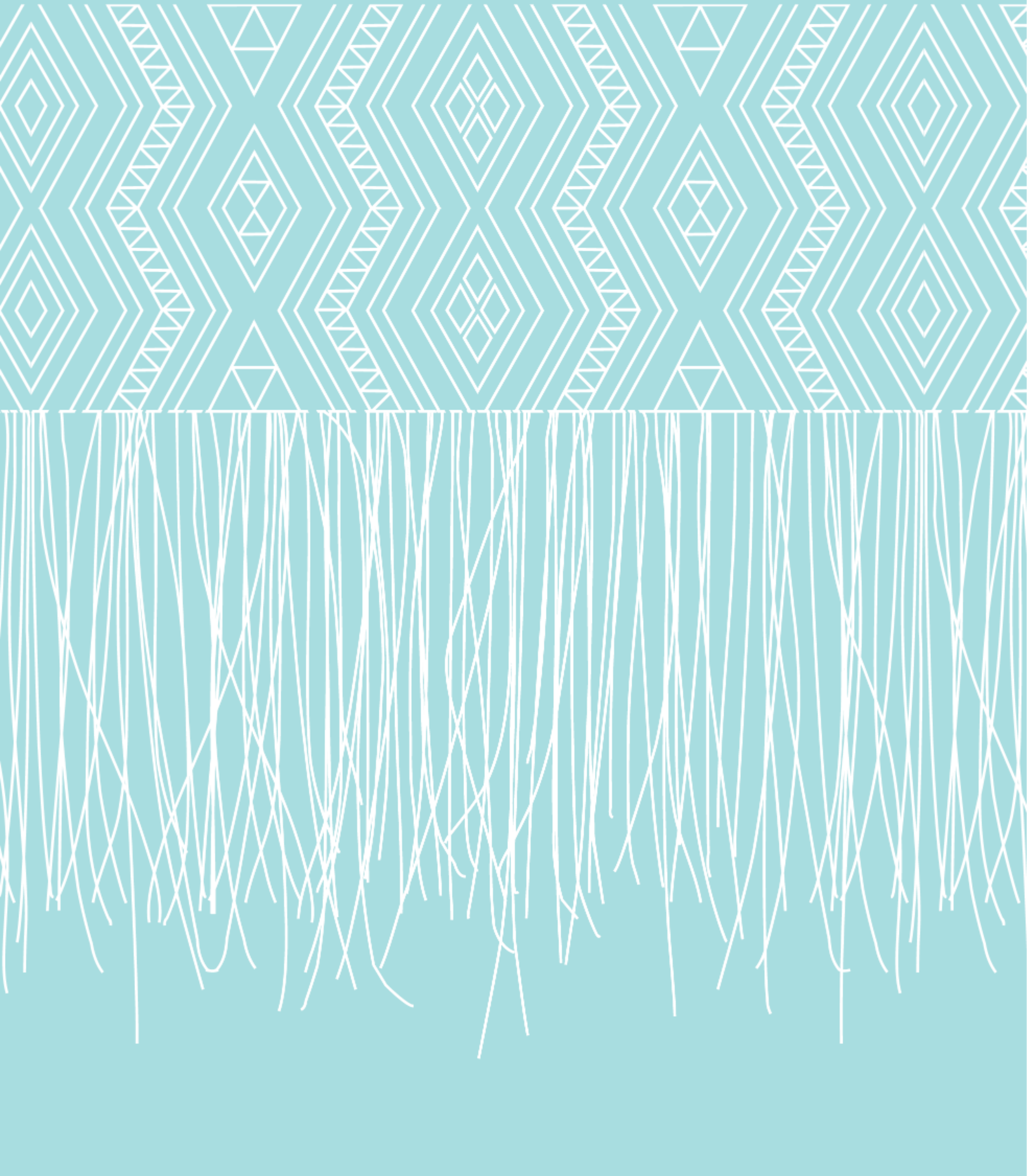
Repeats

There is frustration that not all pharmacies can see repeats and the lack of reminders when repeats are due

"I should be able to walk into any pharmacy in NZ and get my repeat script filled"

"There needs to be a way to tell you how many repeats you have left"

"For meds I can regularly, send me a notification to remind me when I need to get my repeat filled"



Allergies

How people see allergies working

Not all allergies are the same, there need to be a rating level (e.g., mild, med, severe). There also need to be a distinction between self-identified allergies, suspected allergies, and medically confirmed allergies. Allergies need to include ALL allergies (food, products, medicines, environment) and organised so life threatening allergies are easily noticed.

This is filled out by your Dr

Confirmed Allergies

Medical	**Severity**

Food	**Severity**

Environment	**Severity**

to here

This is filled out by you to talk to your Dr about

Suspected Allergies

Medical	**Notes**
Name of Meds:	Severity: Type of reaction:

Food	**Severity**
Name of Food:	Severity: Type of reaction:

Environment	**Severity**
Cause:	Severity: Type of reaction:

When an allergy has been confirmed, move it from here

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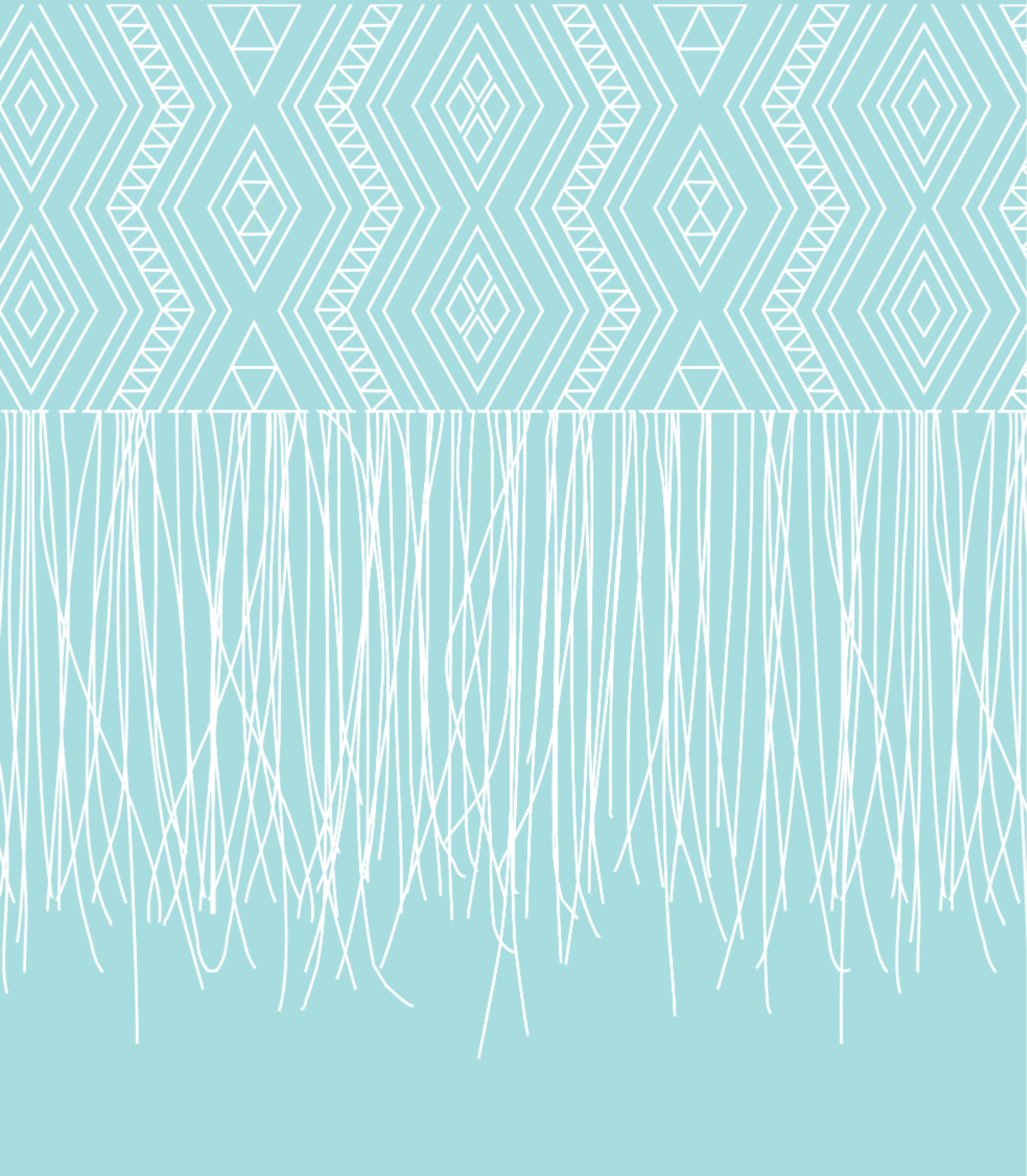

Results

Results

Results mean…

- all blood work
- x-rays
- sonograms
- cardiograms
- MRIs
- mammograms
- smear results
- any scan or lab work that is done
- mental health diagnosis
- vision and hearing tests

The difference it would make

The tangible nature of seeing results helps people prioritise their health

"I didn't realise all the painkillers I was taking were damaging my **kidneys until I saw the blood work results** and saw what normal levels were compared to mine. **Had I seen this sooner** I would have **made different choices**"

"It means peace of mind. **Drs don't call if the results are good**, but you still worry, **what if you are that person that fell through the cracks**. If I can see the results it just gives me that assurance without taking up the Dr's time."

"**All this time I didn't know that I was sick**. I just told my family what the Dr said. They didn't share any results with me**, nothing in writing so I didn't know that I didn't understand** what the Dr was saying."

"When you get results what is **missing is** what do these results mean for me ? and **what do I need to do to keep them stable or better manage?** When you **can see it in writing it makes it more real**."

When the results are good news

Quick Responses when results are good

For **regular checks** (e.g., iron or blood sugars) a **text** to say "normal" or "start iron tablets" a quick note like this works well, I don't need a call for ongoing things

When it's all good, **a quick acknowledgement** to say **"all good"** in a text message, would mean I won't worry

When the results are bad news

People acknowledge that sometimes results will require a conversation with a healthcare provider, but people want options

For bad news, Dr needs to **call first and then make** the results available

I have ongoing scans to see if my cancer is back, I'd like it better if I can see the results, **waiting for the Dr can take a long time and that's even worse than reading bad news for myself**

Results

For results like…

For blood work tests like:
- blood sugar
- cholesterol
- iron levels
- PSA tests
- thyroid
- liver function
- kidney function
- hormone levels

Visuals are helpful for understanding and an indication of how it compares to previous results

> If I could also see the historical results, so I can know if I am getting better or worse at managing my cholesterol…like a trend line

Results View

At a minimum share **results as they are**, but if the outcome we want is for people to take action based on their results, we need to …

Provide easy to understand visuals like this (only an example)

Show where someone's results are compared to what's "normal"

Provide actions on what people can do to improve their results next time

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Results

For results like…

- Smear results
- STD results
- Pregnancy tests

Provide next steps and provide the ability to mark as confidential so I can control who can see them

- ADHD diagnosis
- Learning disability diagnosis
- Mental health diagnosis

Include these in your record so that it is in one place and provide the ability to mark confidential so I can control who can see them

- Hearing tests
- Vision tests
- All scans and x-rays

Provide the actual images/reports along with Dr's explanation/notes and what next steps are/what actions have been taken

Transparency of the process

People feel they are in the dark, not knowing if their tests have been ordered, has the GP received them, and this causes unnecessary worry and calls to the GP office … what if you could ….

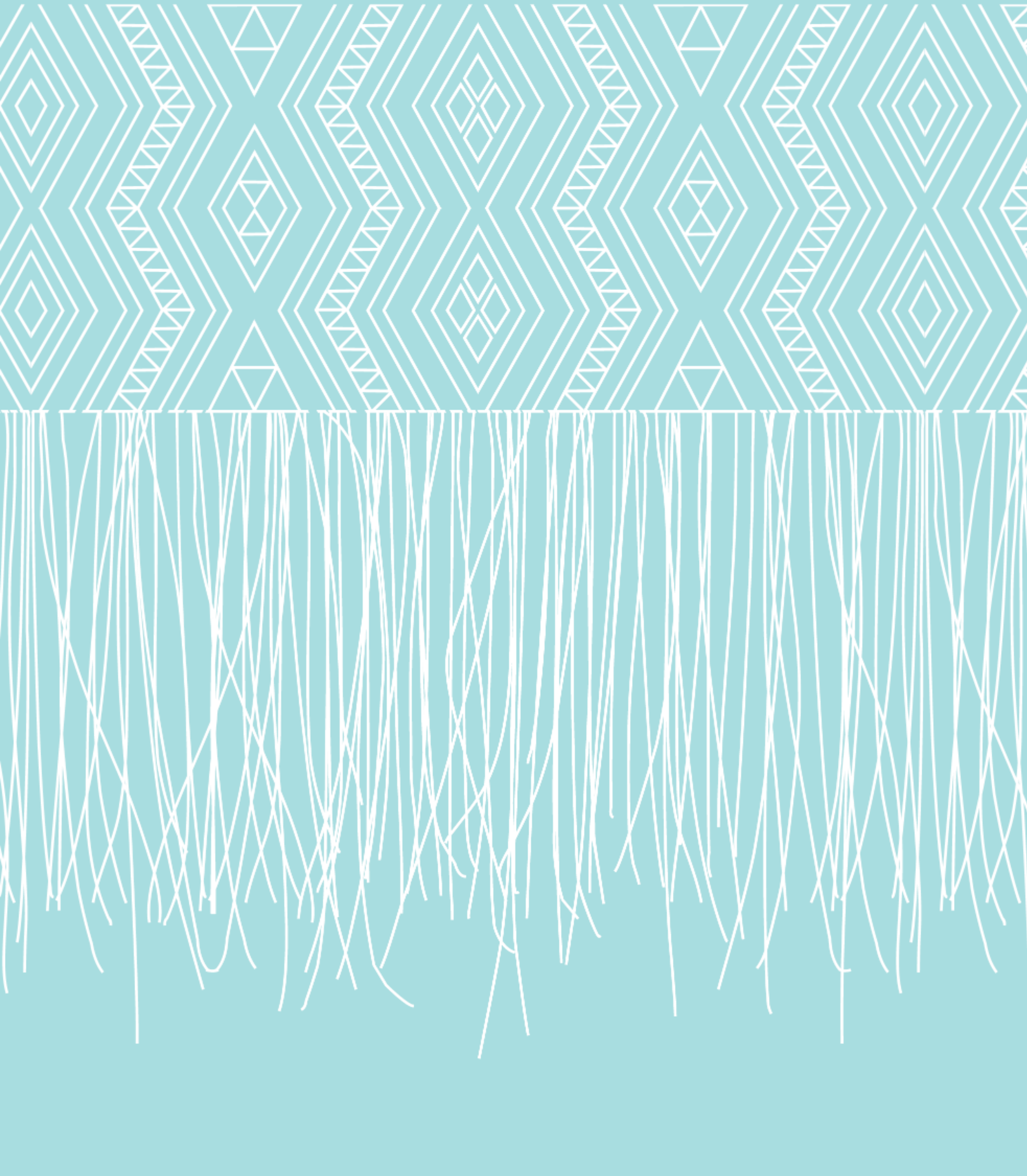
- Get a quick alert on where things are? A text message or an alert on the app.
- Or log into your account and see where it is in the process

Autonomy to manage one's own health

Having access to view results provides a sense of autonomy for people, this is their information and knowing that information means they are driving the care of their health

"I believe that we **have right to treated with respect** and to be told the results. We are paying for this, we have a right to **see what they say for ourselves**"

"It feels **wrong that I have to chase my GP, to beg to get access to my own health** information…I just about had to do an OIA to get copies of my scans, that's just not right"



Booking and Scheduling

Booking & Scheduling

What do people want to be able to book online

The #1 thing are GP appointments

Smears & Breast Exams

Specialist Appointments

Immunisation Appointments

Why do people want to be able to book appointments online

Hours of Operation

For shift workers, working mums, or even stay-at-home mums, the hours when medical practices are open aren't times of the day they are able to call to make an appointment

Volume of Appointments

For many whānau one person is responsible for managing health appointments for their entire family, this means they have to call different places to get appointments and manually track who needs to be where, when. Sometimes this means having to call back and shift existing appointments to make another appointment work.

Booking & Scheduling

Book Online

Mum with 4 Tamariki	When I remember or find the time to call to make an appointment, the GP office is already closed. If I can book online, then I can do it at a time that works for me.
Mum with 2 kids also looking after elderly parents	Being able to go back and see if an earlier appointment becomes available, you know like if someone has cancelled
Working Middle Aged Male	It would be easier for me to just call up the Dr and make an appointment…if my partner was booking it, she would probably use online
Elderly Male living independently in a retirement village	I would never book online; I have always rung the GP office and they do it for me, then I write down the appointment in my diary

Calendar View

If there could be a calendar view of the appointments that I already have so I can group them together or spread them out, whatever works for my family at the time. Also, being able to go back and see when I had a previous appointment.

Different appointments at different places, it is so hard to keep up, I would like to be able to see all of the appointments for my family in one place, sometimes we miss appointments just because I forgot to write it down

Have it so that no matter how the appointment was made, online or by phone that it shows up on a calendar. If my partner goes online to make me an appointment she can see that I have already done it.

“And, what if you were able to automatically add the appointments to your Google or iCal?”

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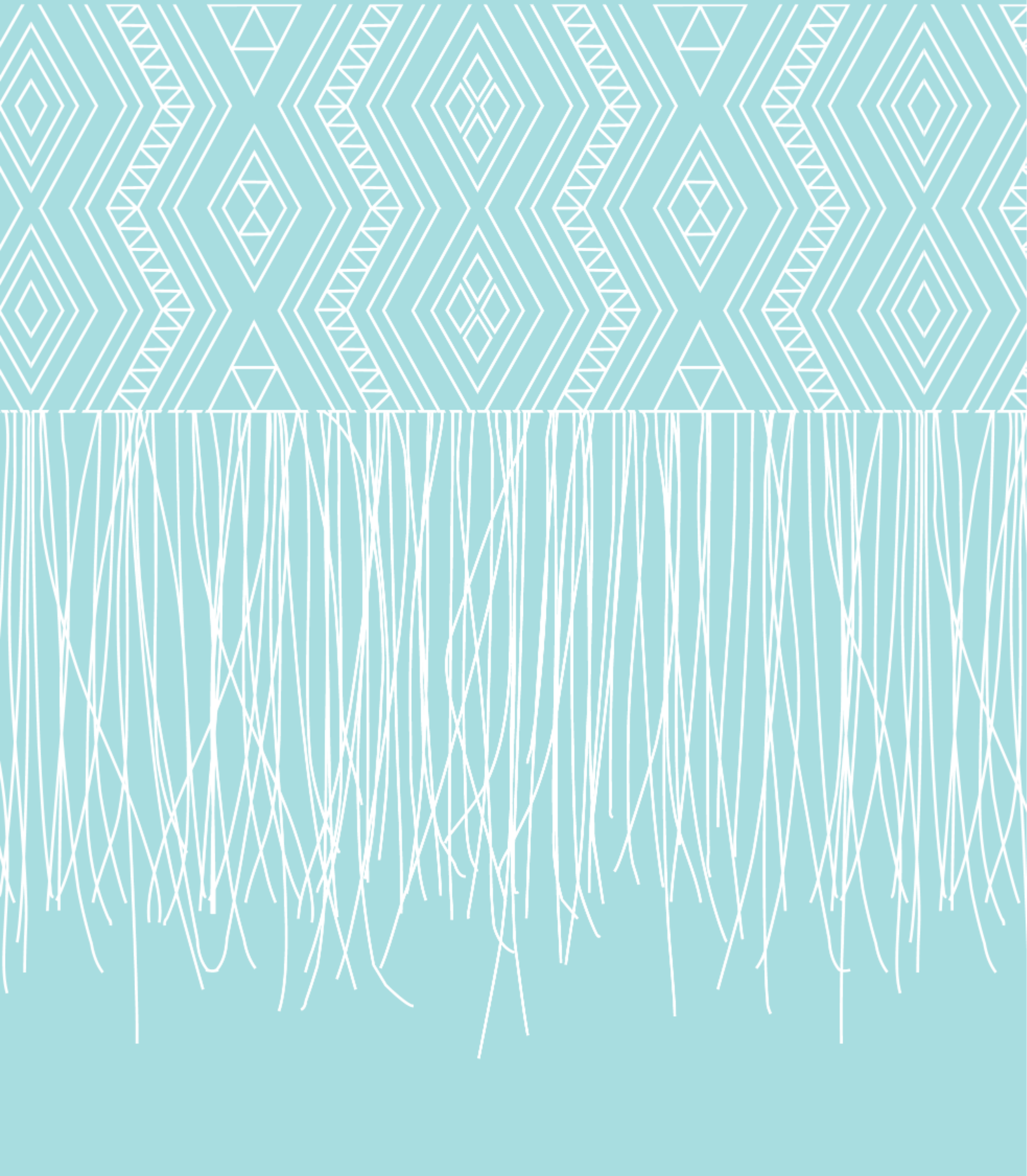
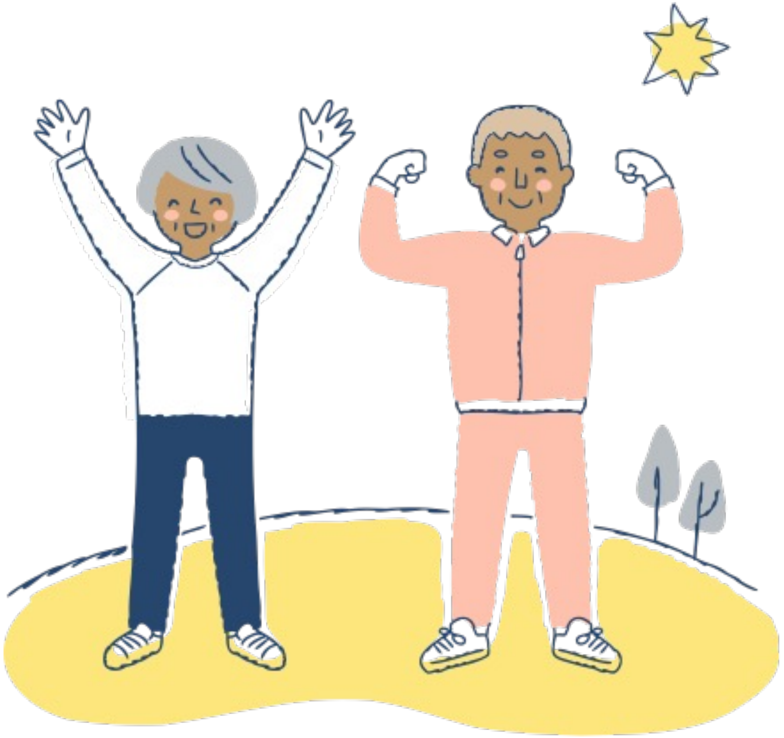


Care Plan



Views on Care Plans

This feature is valued by families who are managing chronic conditions as well as major health events.

Managing My Son's Asthma
My ex and I share custody of our 7-year-old son who has asthma. He requires ongoing medications on a specific schedule. We have the schedule on our phones, and we can't always remember if we did his meds on time or not. Having a care plan that my ex and I can access with a place to record when we get the meds would make our lives much easier.

Managing My Diabetes
I am only now learning how to manage my diabetes and there are so many things to keep up with. I have to take my blood sugar and keep a record of it. There isn't one place for me to keep this information so when I go to the Dr I can show them. A care plan would help me keep better records and know what to do when.

Post-Surgery Care
When I had my knee surgery my daughter was here to help me. I also had a community nurse stop in during the day when my daughter was at work. I was on pain meds and could never remember when my daughter did or what the nurse told me to do. A care plan would have made it easy for the three of us to keep up with things.

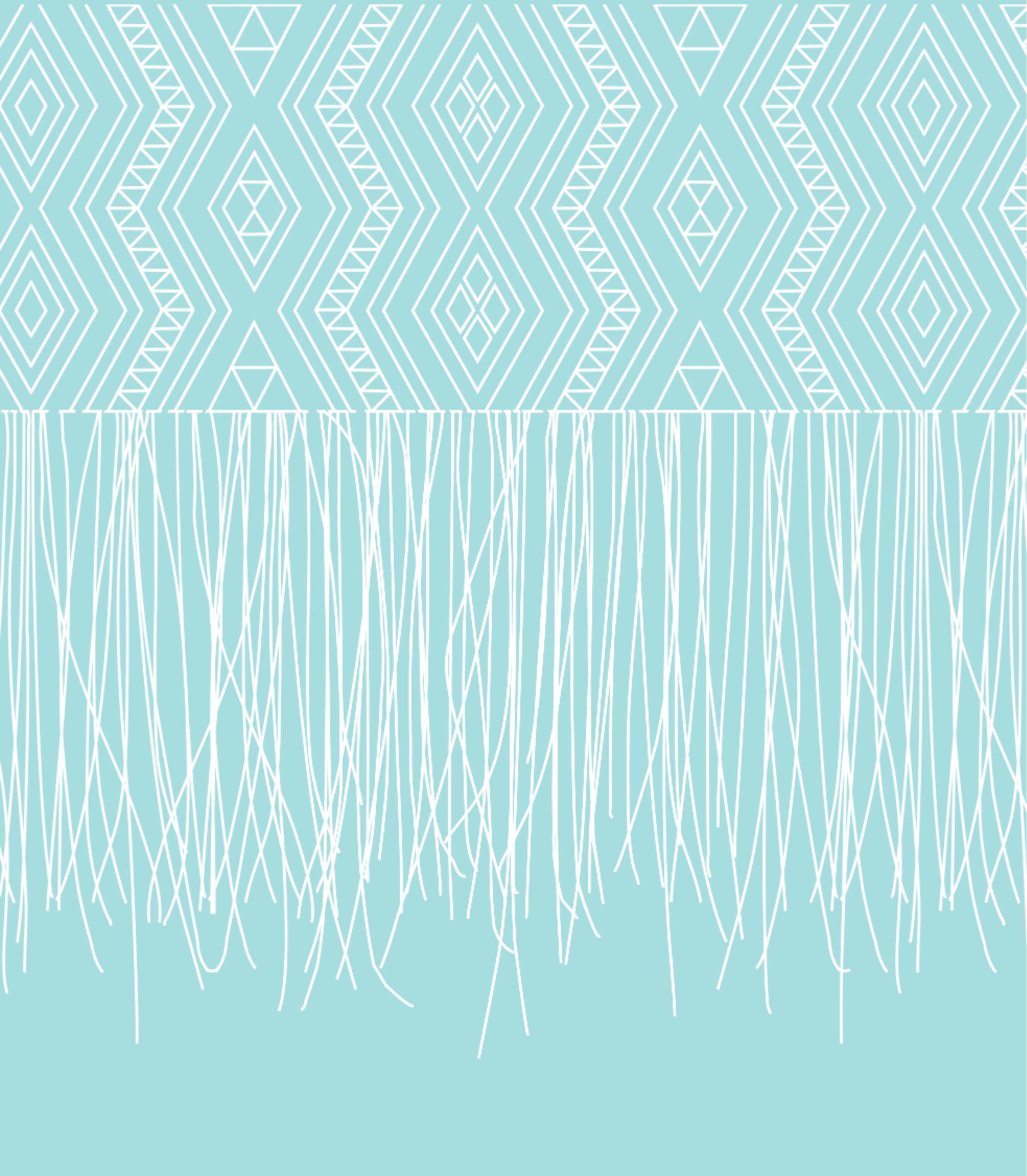
Cancer Treatment
When mum was going through her cancer treatments us kids all pitched in to help with her care. There were so many meds and appointments to keep up with. We made our own solution in a spreadsheet. A care plan with Drs instructions and where we could put in notes would have been very helpful.

What care means to communities

- Care plan is a place where whānau can see what is mutually agreed to because they share care responsibility
- This would be good for my adult kids to see what is happening, so I don't have to answer their questions.
- Would be good for those in retirement care facilities, rather than ringing the nurse, whānau can look for themselves what's happening with parent.
- Medications are confusing if there are several caregivers. This is great so that everyone can access same info and you are not reliant of family members sharing info.

How care plans need to function

- Caregivers, support workers, whānau, and individuals should be able access and be able to make note in care plan.
- Care plans should include a weekly view , that includes appointments and care routines (Important for adoption). Should be able to link to google or outlook calendar.
- Is it possible to have a timetable or care plan alert on MHR. eg: breakfast - take a pill now with kai etc or to even have the app send out notifications
- Can there be different care plans eg: end of life care, ACC care plan, diabetes management, physio plan
- Should be able to archive care plans to have the history but to also have a tab that says "active care plans"
- Can it have a space to capture tikanga preferences (donor, recitation instructions, next of kin to contact)



Sharing Health Information

- There is a positive reaction to having the ability to share health information with others
- The three main themes that emerged in community conversations are
  - age
  - functionality
  - whānau view

Sharing Health Information

What age is the right age for accessing and managing your own health information? There are mixed views across the community on the right age for managing your health information.

Under 16

Most people feel that under 16 is too young to manage your own healthcare. No one is opposed to under 16s being able to access their health information as long as there is an adult (parent or guardian that has access. Under 16s should also not be able to share their health information with anyone other than their parent

HOWEVER

There are children as young as 7 who are helping their parents/grandparents manage their health. Some of these children also manage their own health.

This is important because...

While the need to access health information before the legal age is not a need for the majority, those that do need it are high healthcare uses so the impact is higher.

At 16

Parent's View

There is disagreement amongst parents if at 16 their children should be able to cut off parents' access to health information as maturity varies from person to person at this age.

Parents **recognise teens may not access** sexual and mental health services if they knew their parents would find out.

Young People View

Some young people want their parents to have access. Some young people want to have their own access along with their parents.

ALL young people we spoke to said, they would not want their parents to see any sexual health or mental health services they access. Some of these young people said **they would not access** some of these services if they knew their parents would find out.

At 18

Young People View

At age 18, the choice needs to be up to the individual if their parents continue to have access. There are mixed views on if they would allow their parents continued access once they turn 18.

There should be a reminder that pops up for parents and the soon-to-be 18-year-old letting them know how their account will be different once they turn 18.

Parent View

Some parents still want to have access even after their children turn 18 - some feel it is their right to know and some feel their children would still need support after 18.

One Thing Everyone Agrees On ...

Segment sexual and mental health information so people can keep this information private.

Sharing Health Information

Warring Parents

Scenarios Shared with us

Relationship between the mother and father is **not functional, they are going through a breakup** and use the children as a pawn, they have logged into other systems and changed information **to turn that information into a weapon in court**, they might do this with health info as well if they have access.

In a **family violence** situation, where mum and children have left and dad doesn't know where they live, **dad could add children to his account and find out their address** or coerce children during visitations to give him access, this has happened with things like bank accounts in the past

Biological **father hasn't been in the picture since a terrible relationship break up**, mum has remarried, and **the step-father is involved day to day**. Biological father tries to interfere and cause harm in any way he can – this **might provide him another means to do so**.

These scenarios are based on the real-life experiences of individuals we've spoken to, no demographic information was captured for these people to provide an extra level of confidentiality

Design Considerations

Will there be a way to **hide contact details or any location information** for individuals escaping family violence situations?

In family violence situations is there a way to **block a biological parent** from getting access all together?

How will we acknowledge/integrate with court decisions regarding custody? If adding a child is **based on birth certificate what happens if a parent loses custody**?

What is the process for **flagging incorrect information** that a warring parent may have changed?

Sharing Health Information

Transitional Parents

Scenarios Shared with us

Mum is a solo parents, dad is not in the picture, mum is about to start a prison sentence and needs to **transition guardianship of the children to grandma**.

Children have been **placed in temporary foster care** until a permanent living situation can be organised with extended family, these situations can go on for a few months sometimes.

Parents live overseas and have sent their **children to live with relatives** in New Zealand so they can attend school here.

These scenarios are based on the real-life experiences of individuals we've spoken to, no demographic information was captured for these to provide an extra level of confidentiality

Many children in Aotearoa find themselves being **looked after by parents who are not their biological parents** for some period of time. These children **often have high health needs or unaddressed health challenges**, digital access to their health information would **enable their guardians to keep them on track and the record could travel with them** as they transition from one living situation to another.

Design Considerations

How will non-biological parents who are serving as guardians for some period of time be able to access children's health information?

Will foster parents have access? Who will grant them access?

How would this work for the 13, 14, 15 years of age gap?

Sharing Health Information

Functionality

Type of Access

When sharing health info, people want clarity on what the person you've given access to can do. This is how they see the options:

- **View Only** where you give someone access to only view your info
- **Along With Me** where someone helps, they can do some things for you (e.g., make appointments, but you have final say
- **Act On My Behalf** where someone has full authority to act on your behalf

What Information to Share

People want more choices on what information they share

- **Share All**
- **Share Profile Info**
- **Medications** (select each medication)
- **Results** (select each one)
- **Allergies**
- **Care Plans**
- **Diagnosis** (select each one)

For how long

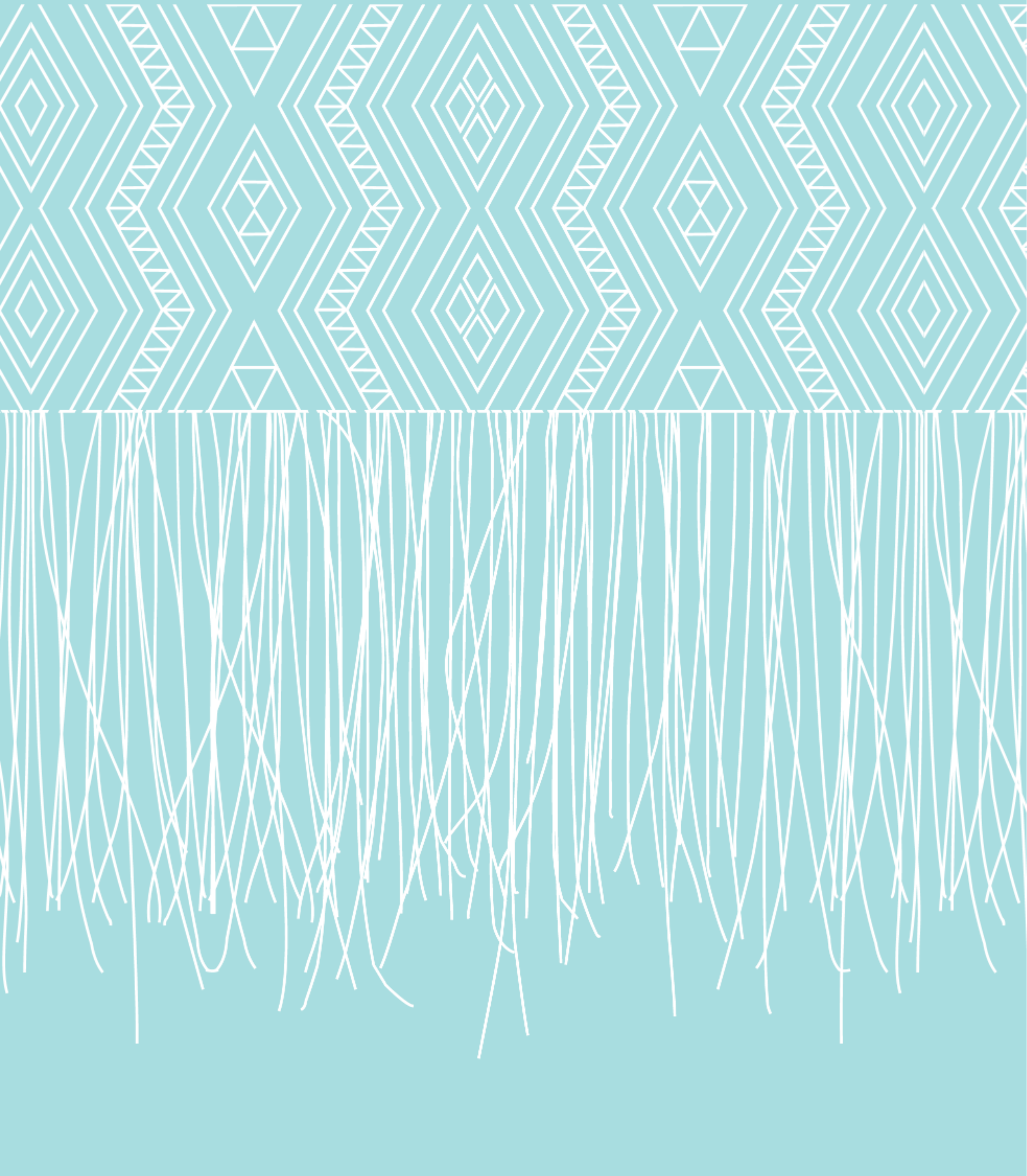
People want to control access timeframes. Provide time intervals for each option and set an access expiry date.

What people expect to see…

When they logged in and what they did

Who	Access Type	Info Shared	Timeframe	Activities
Mum	Along with Me	Share All	Rolling Access	
Aunty Sue	View Only	Profile	30 Days	
My Partner	Along with Me	Share All	Rolling Access	
Visiting Nurse	Along with Me	Care Plan Medications: Antibiotic, Vicodin	60 Days	

There should be a notification that pops up when access is about to expire. And an annual reminder for "Rolling Access"



Profile

Profile

The Important Information To Include

Communities want this information to be included in their profiles, all healthcare providers need to be able to see this information.

> "Inclusion is important, gov't has a history of excluding people. If you want me to use this, I need to feel this is a safe space for me…it needs to be inclusive."

Health Information

- Blood type
- Devises/Implants (e.g., hearing aid, pacemaker)
- Donor Status
- Key diagnoses (e.g., diabetes, asthma, autism)
- Major health events (surgeries, birth of children, cancer)
- Disability (e.g., deaf, low vision, neurodivergent)

- If it isn't possible to auto-populate this information, allow individuals to fill them in

Identity Information

- Sex at birth (female, male, intersex)
- Pronouns
- Gender Identity (fill in the blank would work best, if providing a list, avoid saying "other" instead as "something else, please specify" and provide a space)
- Preferred language (including NZSL)
- Accessibility needs (e.g., deaf requires interpreter, low vision cannot fill out forms)
- Iwi/hapū (without limitation on how many you can provide)
- Name pronunciation (record how my name is said)

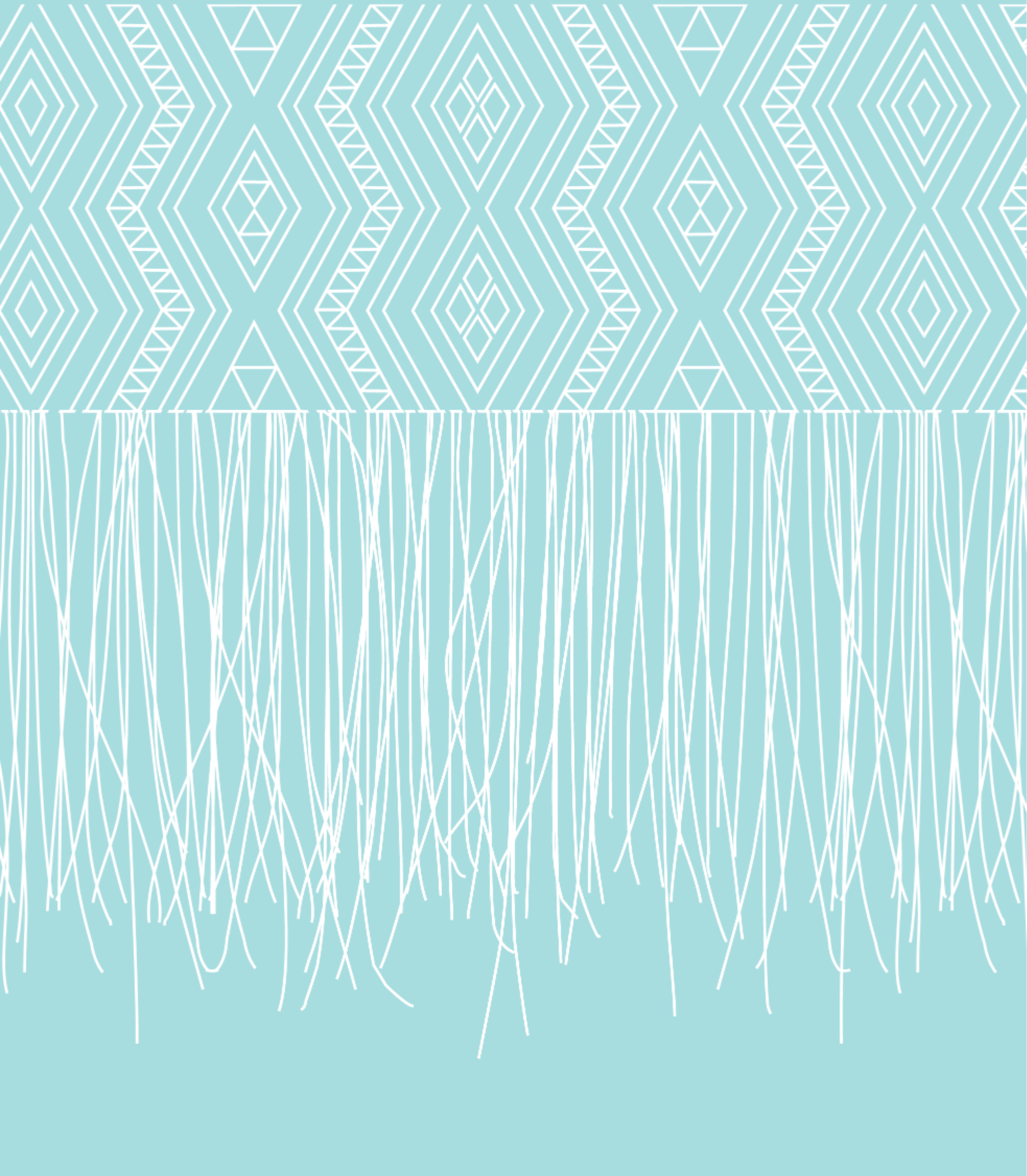
- For Rainbow youth, the inclusion of sex at birth, pronouns, and gender identity in health data is important and creates a sense of safety

- These are fields you should be able to fill in yourself
- Make them optional so if they don't apply to you, you can leave them blank
- Expectation is that when you fill this out, it is available to all healthcare providers (so you don't have to repeat yourself or fill out multiple forms)

Other information

- Emergency Contact Details
- GP Info (name, contact details)
- Other Healthcare Professionals (be able to list other health providers you work with on a regular basis)

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team



Access to GP Notes

Access to GP Notes

Communities feel GPs hold a lot of power over them and not being able to access the notes their doctors write about them supports this power imbalance. Access to GP notes is seen as a way to level the power imbalance. The benefits of access to GP notes are supported by previous research [8], [9], [10], [11]

Confirm Understanding

Sometimes what the Dr says and what people understand are not the same. Here are few a examples shared with us:

- *When I visit my GP, I am so anxious I don't remember what I am told. If I was able to go look at the Dr's notes when I get home that would help to make sure I am doing the right thing.*
- *When I talked to my Dr about my bowel cancer results, he told me I had a blockage, I thought this meant I was okay. It wasn't until months later that I learnt blockage means cancer and that I was sick. If the Dr's notes were available to me I could have shown them to my daughter and then we could have all had the same understanding.*
- *My neuro spicy brain mixes up words. Sometimes what I say and what I mean are not the same. If I could see what the Dr is writing then we can make sure we both understand.*

Sharing GP notes creates an extra level of security to make sure people understand the conversations they are having with their Drs and taking the required action.

Catch Incorrect Information

GPs can sometimes capture things that are said incorrectly, these mistakes can have impacts on healthcare. Here are a few examples shared with us:

- *My health file says I am a smoker. I have never smoked a cigarette in my life. What I said is that I grew up in house with smokers. Every time I go to the Dr they refer me to services to help quit smoking. When I try to get this mistake fixed they think I am lying, what the Dr has written is believed over what I say.*
- *It says in my file that I have anxiety, I was never diagnosed with anxiety. The Dr wanted me to go in for some lab work and I said I get anxious when I have to get bloods drawn. Now, I can't get insurance cover for mental health because they consider this a pre-existing condition.*

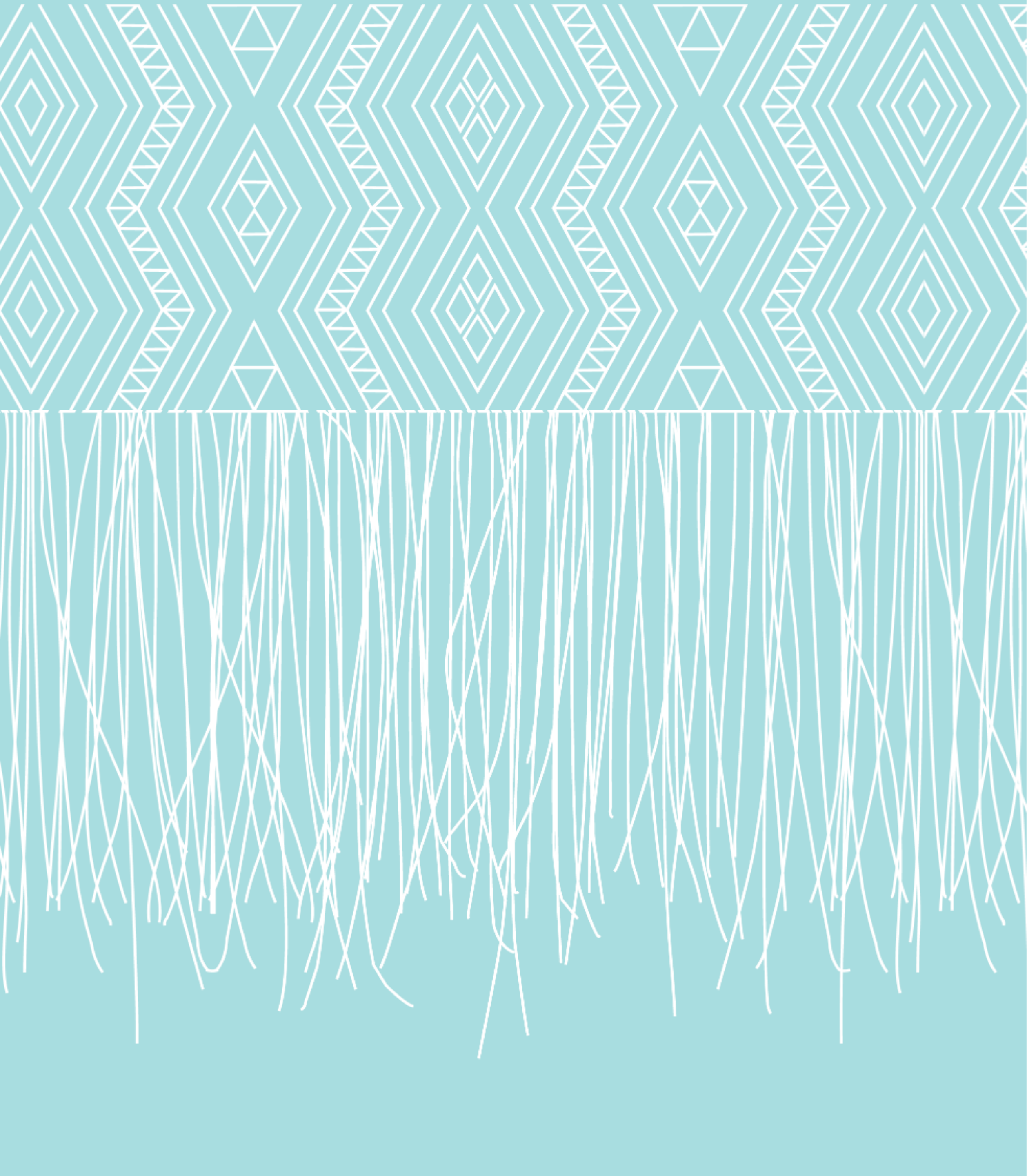
If GP notes were available so that people can review them, information can get corrected sooner and it would save a lot of effort getting things corrected later on.

GPs are under pressure and burnt out, how could digital health information help us work better with our GP to help lessen the load?

I believe I should have control over my own records, rather than feeling like my health information is being withheld from me

I had to submit an Official Information Request through the Privacy Act to see the notes in my health record…this creates a hostile relationship with my Dr … how am I supposed to trust my Dr if they won't share my own information with me?

GPs are the gatekeepers of my health, they hold a lot of power which is maintained by not sharing their notes.



My Whakapapa

(family health history)

Family History

Community conversations on the need for digitally capturing health whakapapa

"There should be a place for recording genetic/hereditary conditions and that information be accessible to whānau."

"We want to be able to make our own notes on hereditary health conditions for the generations we leave behind."

"My sister died of breast cancer. Would there be a way of noting conditions which might affect me or my children further down the track?"

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Family Health History

Communities want a way to capture and track family health history across generations.

Stop Repeating Ourselves

Communities are frustrated that at each new Drs appointment, they have fill out paperwork about their family health history. Digital health records need to enable putting this information in once and allowing all practitioners to access it.

Enable it so that families can connect their health histories like Ancestry.com does

Also allow me to update it as I learn more about my family health history.

Nothing Gets Missed

This isn't just about convenience it also helps mitigate a risk.

Drs appointments are nerve wracking experiences, and you tend to forget things. Something you forget to mention might be really important and you might not realise it.

> *At every Drs appointment they ask for your family health history. I don't always remember everything. It would be nice to not have to repeat myself all the time.*

> *Since learning I had diabetes, I also learnt that my granddad had it too. If I had known I would have been better about getting checked out. Knowing your family history empowers you to manage your own health.*

> *When I was diagnosed with breast cancer they told me it was the BRCA kind which is hereditary. I want to be able to link this information to the health records of my tamariki and mokopuna. When I am long gone I don't want them to forget.*

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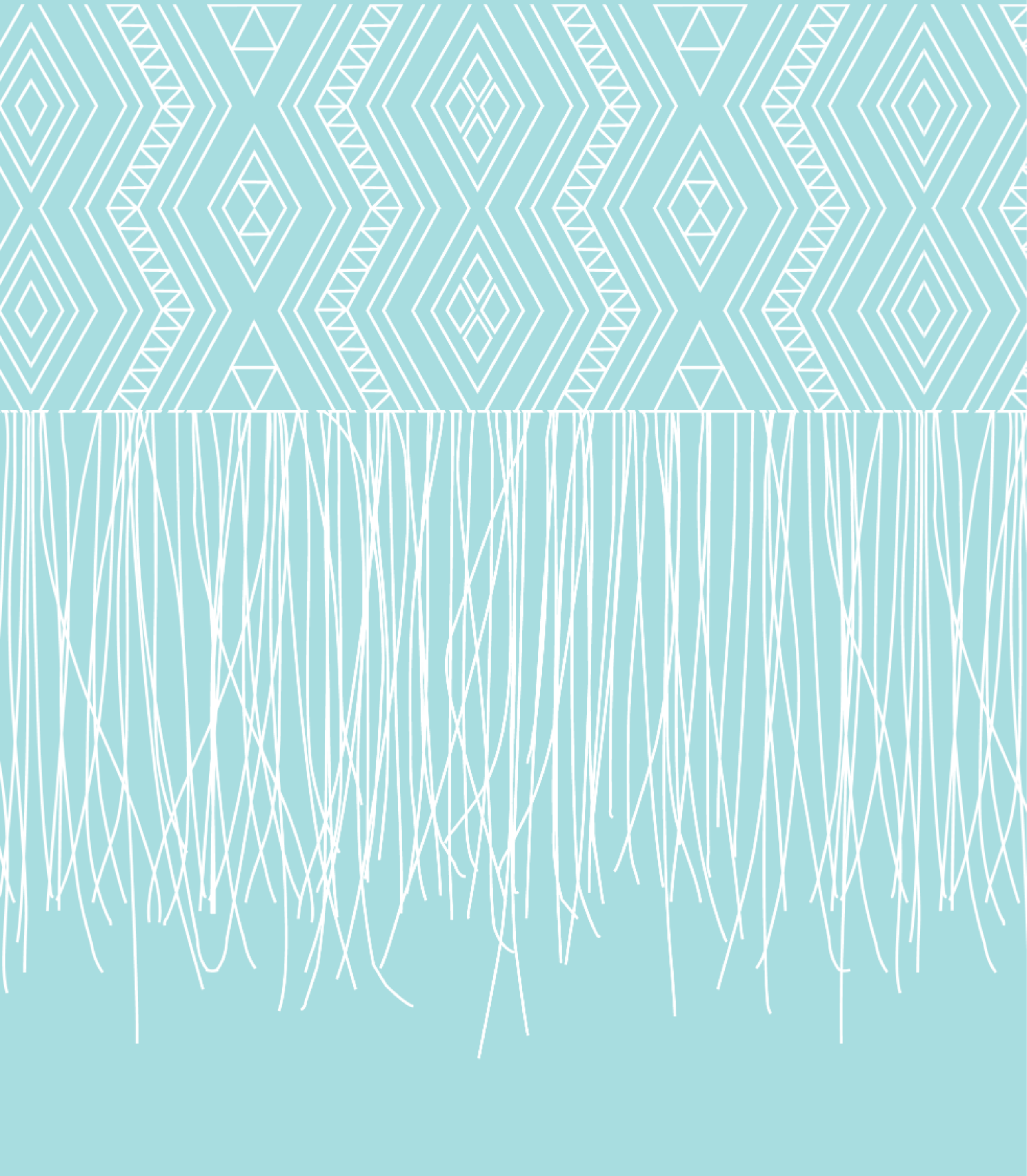


Global Access

Allow Access From Anywhere

There are two primary reasons communities want to be able to access their health information from anywhere in the world.

For when I travel

Communities want to be able to take their health information with them when they travel whether it is on holidays, overseas experiences (OEs), or moving to a different country.

This would be useful
- When you need to proof of vaccination for travel
- If you become unwell when traveling

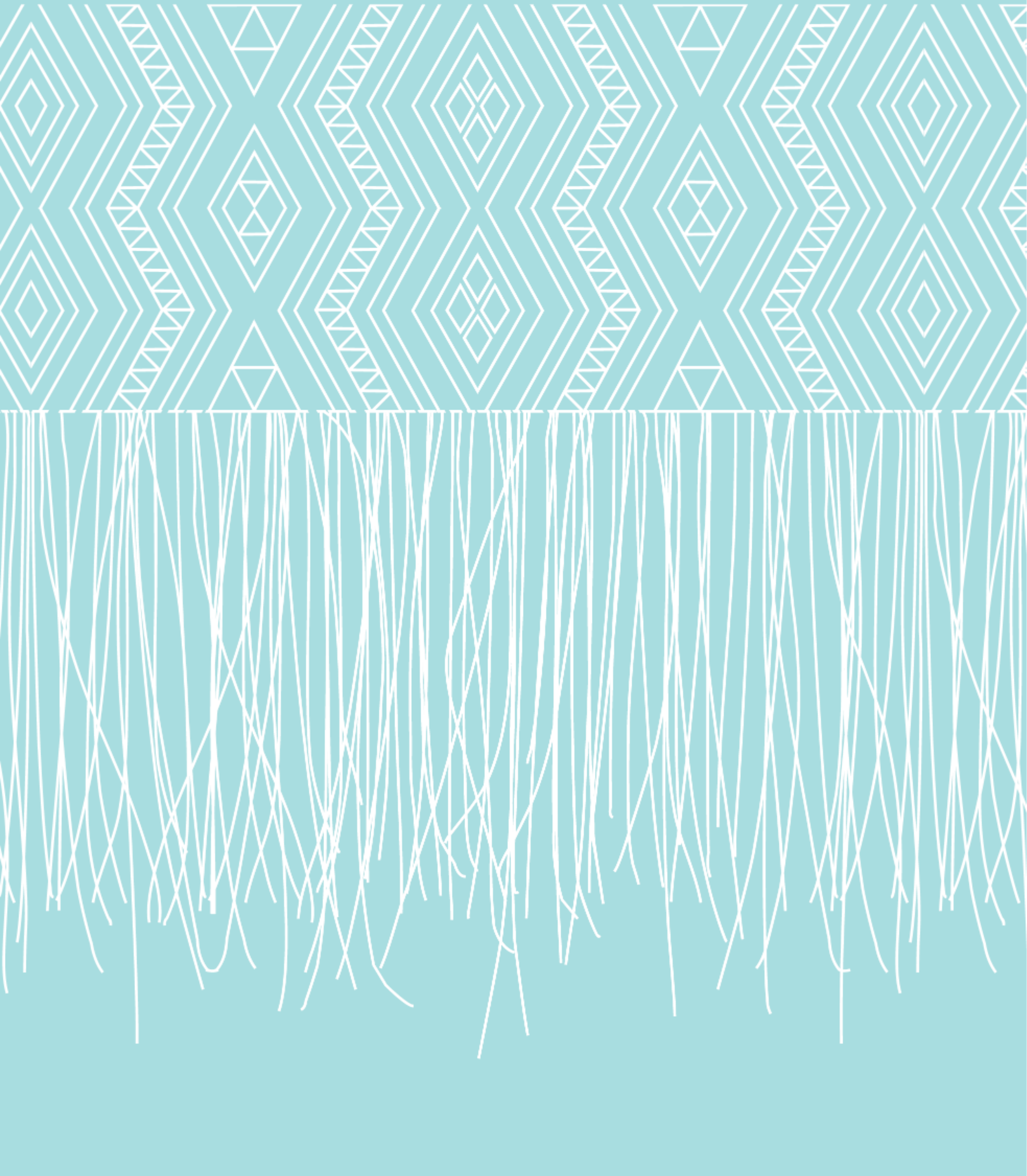
The elderly, those living with chronic illnesses, and those living with disabilities have a particular interest in this

For when my whānau are overseas

Many New Zealanders have whānau who travel to and live overseas. Communities want to be able to share their health information with their families regardless of where they are in the world.

This would be useful when someone is
- Managing a long term health condition that requires monitoring
- Recently been diagnosed with a health condition
- Having surgery or a medical procedures

Those with elderly parents have a particular interest in this



Telehealth

Telehealth

Communities have mixed feelings about telehealth.

The Potential

Telehealth is seen as a potential solution to the GP shortage as people could meet with a GP regardless of location and would enable getting an appointment sooner.

Communities also see the potential in telehealth being able to increase access to specialist. People in smaller communities have to travel long distances to access a specialist. For appointments that don’t require a physical examination this might be a good option.

The Challenges

The biggest potential for telehealth is to support rural communities, but the challenge is that many rural communities have connectivity challenges. To enable telehealth to the communities that need it most, connectivity challenges will need to be addressed.

Key Drivers for Adoptions

Individuals who have an existing strong connection with their healthcare provider are most likely to use telehealth.

Trust is a key driver of using telehealth – individuals with low trust in the health system are least likely to use telehealth.

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Assisted Channels

While many communities want to access their health information digitally, it is also recognised that there will always need to be other ways to access health information for those people who can't use digital. Communities have said non-digital channels should be offered in three options

1. Self-service kiosk(s) in safe public places
2. Phone or call centre
3. In-person through a trusted community source

Communities most likely to use an assisted channel are rural, elderly, temporarily unhoused, Māori, Pasifika, and those in a family violence situation.

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Three Assisted Channels

A self-serve kiosk in a safe public space (library, community centre, hospital) where you can set up an account, authenticate, and access your information. With the ability to print out your file so you can review it at home.

Phone Number/Contact Centre
You can call and speak with a real human, based in NZ. They can look up your information and read it to you. This phone number needs to be easy to remember (e.g., 222). It needs to be clear that this # is different from health line.

In-Person Options where someone from an existing community service can look up your info, show it to you on a screen, print things out. They can also help you set up your own account.

These individuals do not have to be medical professionals (e.g., Drs or nurses). They just need to have knowledge of how to access your information and read it to you. They should also know how to help you set up on your own device.

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Assisted channels as a self-service kiosk

A self-serve kiosk in a safe public space that has wifi connectivity.

Who it is there for…

Rural communities where it is common for whānau to not get internet service at home. They often hang out at places (e.g., New World) for the free wifi.

Temporarily unhoused young people who are not able to afford their own device or cannot afford a data plan.

Individuals in family violence situations where their personal devices are being monitored by an abusive family member.

The kiosk needs to…

Allow setting up an account, verification via face ID, and then access information

Have the ability to print information to review later or bring to an appointment

Provide information about services available locally (e.g., mobile breast screening)

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Assisted channels as a phone number

Phone Number/Contact Centre you can call to get your health information not health advice (doesn't need to be a health professional)

Who it is there for…

Rural communities where reliable connectivity is a challenge.

Elderly who don't have an interest in digital access, elderly who do not have a laptop or smartphone, and elderly who have devices but don't know how to use them.

The phone line needs to…

- Have an easy-to-remember number without writing it out
- Be manned by a real-human based in NZ
- Be manned by a clear English speaker, no accents
- Be clear that this is different to health line

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Assisted channels as an in-person

In-Person Options where someone from an existing community service can look up your info, show it to you on a screen, print things out. They can also help you set up your own account.

Who it is there for…

Māori communities where trust in the healthcare system is low and preference is to have someone based out of their marae

Pasifika communities would prefer to have someone in an existing community service they already access

Elderly in rural communities who are hearing impaired, struggle with technology, and prefer to do things in person

Refugee communities who are just learning how things work in New Zealand, need to be someone from services they are already accessing

The in-person service needs to be…

..through a trusted community service provider

..bundled into existing community services

..available outside of normal business hours

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Insights for Adoption

Enabling Community Adoption

Communities provided insights to inform how we might enable community adoption of digital health information

What we learnt	What it means for adoption
The lynch pins to adoption Rangatahi (young people) are **the key to adoption**. They will be the ones to show their parents, grandparents how to use MHA/MHR, and even help whānau add their children. Gen Z and Gen Alpha refer to themselves as “tech support” for their families.	But they won’t do this if they don’t feel MHR is safe and meets their needs. Rangatahi said it was important that MHR demonstrated or enabled: • **Inclusive** practices and language (using the correct pronouns, understanding cultural norms) • A **holistic view** of health (emotional, mental, physical wellbeing) • Genuine **human connection** across health services and particularly with their GP These findings are supported by previous research [12].
How is this different Many communities are already accessing their health information digitally. These communities question why Health NZ is developing another app/website and what difference will it make for them.	Here are the reasons people would move to a website or app provided by Health NZ | Te Whatu Ora • Not being limited to the information the GP is willing to share • The ability to see information from interactions across the health system in one place • A whānau (family) view that doesn’t require multiple log-ins
Work with people we already trust Communities are more likely to engage with and trust health services when they are presented through the trusted community service organisation(s) they already have established relationships with.	Partnering with community organisations that are already trusted by communities is critical for adoption, this is particularly important for • Immigrant and refugee communities • Rainbow community • Disability and neurodivergent community • Māori, Pasifika, and Asian communities

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Unanswered Questions

Questions from the community that need to be addressed as part of adoption

Health history
- How far back will my digital health record go?
- There are plenty of places that still use paper, will those documents be digitised?

Fees to use
- Will I have to pay a fee (subscription service) to use my digital health record through Health NZ | Te Whatu Ora?

Use of information
- How will my digital health information be used by healthcare providers?
- Who will have access to it? (want to know organisations and specific roles)

Multiple apps
- Will I have to cancel other digital health records I am using (e.g., Manage My Health, Health360) if I want to use what Health NZ | Te Whatu Ora provides?
- Can I use multiple health apps at the same time?

Digital health records at birth and death
- Will a digital health record automatically be created when you are born?
- Will my newborn baby be added to my digital health record automatically?
- What will happen to my digital health record when I die? Could whānau still access my health record if needed to help address genetic health issues?

Continuous feedback
- How do we continue to provide feedback for Health NZ | Te Whatu Ora's digital health record once this research is done?

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Inclusion & Trust

Many communities across New Zealand feel the current health system was not designed to meet their needs. This lack of inclusion leads to a lack of trust which lead to disengaging from health services. People put off health needs and wait too long to access the services they need. Ultimately the lack of inclusion and trust contributes to increased costs in delivering health services and poorer healthcare outcomes.

Lack of Inclusion

We have an opportunity to be more inclusive through the digital tools we are building

Lack of Inclusion

"The current health system was **not built for us"** – is a common theme across the **Rainbow, Disability, Māori, Pasifika, and Asian communities**

- Capture preferred pronouns and make them highly visible
- Provide ability to record name pronunciation (like LinkedIn does)
- Use inclusive language and images on website and app
- Make sure website and app meets accessibility standards
- Support multi-languages including NZSL
- Provide a space to capture disabilities

Rural communities also feel that healthcare is not designed with their environment in mind

- Provide ways to access health information for locations where connectivity is a challenge (phone and in-person)
- Notifications through the app/text messages of when mobile healthcare is in the area

The hours when health providers operate don't work for **shift workers, working and stay at home mums**

- Provide online appointment booking so people can organise their appointments outside of normal work hours
- Ability to request repeats online/through app so it can be done after hours
- Enable text/messenger communication with healthcare professionals, answering a call during the day isn't feasible for many people

These communities shared with us, what would make them feel included:

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Low Trust

Lack of inclusion, leads to lack of trust, which leads to lack of engaging in health services

Whānau from **Rainbow, Disability, Māori, Pasifika, Asian, Rural**, are less likely to engage in healthcare because they **don't trust it**, it wasn't designed for them, and they **don't feel safe**

Often these communities **don't access health services until it is too late**

This **adds to the cost** of delivering healthcare and leads to **worse health outcomes** in these communities.

Trust is **further eroded due to lack** of community engagement

"No one from health has ever come to speak with us, we are just told what to do but never asked what we need"
~ Rangatahi from Rainbow Community

"This is the first time anyone has come out to talk to us, we always get missed out"
~ Kaumatua from Northland

"It feels good that we are being asked for input, I hope it gets listened to"
~ Elderly living with disability in rural community

*This consumer and whānau research has **made a start to build trust** but there is **more work to do**. If we want all communities in New Zealand to **engage in and adopt** the digital solutions that we are building then the **solutions we deliver need to reflect the feedback and insights** they have shared with us.*

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

> ***We have shared with you our stories, some which are hard to share, we’ve done this in hopes that it will lead to a better health system. Don’t waste what we have given you and don’t come back until you can show us what you have done with the information we have already shared.***

Appendix

References

Findings from this research are further supported by previous research. Below is a sample of this research – note this is not an exhaustive list.

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Rona Carroll, Sonya J Morgan, Alex Ker, Susan M Garrett, Sally B Rose, Tracey Gardiner, Eileen M McKinlay, "*It was a very awkward consultation because I didn't know*"—general practice staff experiences and challenges in providing healthcare to gender and sexual minority youth in Aotearoa New Zealand, *Family Practice*, 2023;, cmad024, https://doi.org/10.1093/fampra/cmad024 [6]

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Wells, S., Mahony, F., Huang, Y., & Day, K. (2019). Perspectives of New Zealand patients and GPs at the beginning of patient portal implementation. *Journal of Primary Health Care*, *11*(4), 315-326. [11]

Gen Z is the Future of Health: https://www.thelinusgroup.com/gen-z-is-the-future-of-health-report [12]

Previous Research Consulted

Communities told us that the health system shows up to do research without acknowledging the research that was done previously, making communities feel the information they provide isn't valued. We started our research by consulting existing research to understand the scope of our work. Here is a sampling of the research that informed our work.

Te Whatu Ora Research

Digital Experience Framework Design Research (2023)

Healthcare Provider Research (2022-2023)

Vaccine Barriers and Motivations – Ministry of Health (2021)

Ministry of Health. 2013. Patient Experience 2011/12: Key findings of the New Zealand Health Survey. Wellington: Ministry of Health.

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Williams M, McMeeking S. 2022. Best Practice Approaches to Addressing Racism – Lessons for the Aotearoa New Zealand Health System (Stage Two Literature Review). Wellington: Ministry of Health.

External Research

Rongohia Te Reo, Whatu He Oranga – The Voices of Whānau Māori Affect by Cancer, Te Aho o te Kahu, Cancer Control Agency (2021)

Dobson, R., Baty, C., Best, G., Wells, S., Wang, K., Hallett, K., ... & Whittaker, R. (2022). Digital solutions for providing patients access to hospital-held health information: what are the design issues that need to be addressed?. *The New Zealand Medical Journal*, *135*(1556), 114-123.

Hägglund, M., McMillan, B., Whittaker, R., & Blease, C. (2022). Patient empowerment through online access to health records. *bmj*, *378*.

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Other Work Consulted

Māori Data Sovereignty – Te Kahui Raraunga Māori Data Governance Model

Te Kahui Raraunga Iwi Data Needs

Primary Care Personas – Northern Region (HealthAlliance)

The Alaska Community Health Aide Program (2023)

Consumer Portal Proof of Concept Evaluation – Northern Region Information Systems Strategic Plan (Health Aliance – 2021)

Whānau-centred Care in Whanganui - Whānau-centred Care in Whanganui | Ministry of Health NZ

Māori Health Models: Māori Health Models | Ministry of Health NZ

Counting Ourselves: https://countingourselves.nz/

This research was led by Dani Chesson, PhD through the engagements facilitated by the Digital Enablement and Engagement Team

Research Scope

Based on a review of existing research, this research work focused on the following based on existing gaps as well as to inform ongoing work within Hira and other initiatives.

Scope 1 Views on Digital

The What: This focus area will help us understand how consumer whānau feel about the digital availability of health information & services

The Why: So that we understand how to support consumer whānau with access to health information, specifically where barriers may exist

Research Questions

- How do people generally feel about accessing their health information in a digital format?
- What are the specific concerns around privacy and security?
- How will digital access to their health information help them manage their health?
- Who (providers and whānau) would they want to have access to their digital health information?
- What level of control do people want over their digital health information?
- What specific information do people want to see

Scope 2 Access and Engagement

The What: This focus area will help us understand how consumer whānau currently access health information, the channels they use (digital and non-digital)and how they engage with the health system & services

The Why: So that we understand the gap between current access and what will be available in the future: This will inform how we support adoption of Hira

Research Questions

- What level of digital access do people currently have?
- What do and don't they do currently digitally?
- Are people aware of zero website/do they know how to access it?
- What are the thoughts on language support?
- What are their current experiences with accessing health in terms of language?
- What are the non-digital ways that people want to engage with health?
- What would improve interactions for people living with disabilities?
- We are assuming the best option for non-digital is contact centre - is this true?
- How do people currently engage with health?
- Where do people currently get their health information from?

Scope 3 Trusted Sources

The What: This focus area will help us understand the trusted sources consumer whānau turn to for health information

The Why: So that we understand which organisations/vendors/communities we will need to partner with to make access to health information successful

Research Questions

- What are the preferred and trusted communication channels? (email, social, web, phone, mail)
- Do people know who we [Te Whatu Ora] are and what we do?
- What is our trust level? What would improve trust?
- How do people feel about Te Whatu Ora providing a consolidated view of their health data? (meds, update NHI, entitlements, labs & testing, GP data)
- Do people see GP data as more private/sensitive compared to other forms of health info?
- What would make people safe about the digital products Te Whatu Ora offers?
- Who do consumer whānau consider trusted sources for health information?

Sampling Method

This sampling method is based on social science research standards recommended for healthcare research. This sampling approach takes a needs-based approach leveraging data from HQSC Equity Explorer.

	#	% of total population	Minimum Sample Size
Total Population	5,199,100		
Māori	857,851	16.5%	50
Pasifika	421,127	8.1%	25
Disability	1,247,784	24%	25
Mental Health			20
LGBTQIA+		4.2%	20
Rural		16.3%	20
Asian		15.1%	15
Pakeha	3,639,370	70.2%	10
Gender Female	2,595,500		49%/49% balance
Gender Male	2,556,100		
Transgender/Non-Binary		.8%	1%
Age 15-39	1,745,400	33%	30
Age 40 – 64	1,589,500	30%	25
Age 65+	819,100	16%	10

To ensure that we are tracking to the sampling above, we will be collecting the following demographic information from consumer whānau

- Which ethnicity (or ethnicities) do you identify with
- Do you identify as LGBTQIA+?
- Are you a person living with a disability (yes/no – we will not collect specifics about the disability)
- Which gender do you identify as?
- Which age group do you belong to (18-24, 25-34, 35-44, 45-55, 55-65, 66+)

Staller, K. M. (2021). Big enough? Sampling in qualitative inquiry. Qualitative Social Work, 20(4), 897–904.
https://doi.org/10.1177/14733250211024516
HQSC Equity Explorer Equity Explorer | Te Tāhū Hauora Health Quality & Safety Commission (hqsc.govt.nz)

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