

Insights about people and families living with diabetes

Diabetes Co-Design Project, Waitematā and Auckland District Health Boards

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Document purpose

This document was intended to provide Co-Designers with an understanding of the current challenges and opportunities in regards to the experiences of people and families living with type 2 diabetes in Auckland and Waitematā.

Over the course of two workshops, Co-Designers used this document, as well as their own knowledge and wisdom, to collaboratively design a new model of care that responds to the challenges and opportunities identified in this document. In other words, describes how things should be organised in order to support people and families to manage their diabetes as well as possible.

Background

In mid-2016, Auckland and Waitematā District Health Boards commissioned **innovate change** to lead a Co-Design process to create a new model of care to better support people and families living with type 2 diabetes.

This document is the key output from the first stage of the Co-Design process, in which a rapid information review and a range of interviews were carried out to uncover the lived experiences of people, whānau, aiga and families living with diabetes.

innovate change is a social change agency . We use creative and participatory approaches to build social connectedness that enables youth development, whānau well-being and positive ageing. Find out more here: <http://www.innovatechange.co.nz/>

Co-Design is a method and a mindset. It involves gathering different perspectives, insights and experiences from people directly affected by an issue to create solutions to a challenge, problem or opportunity. Co-Design is underpinned by the mindset that people are experts in their own lives and should have the opportunity to play an active role in the decisions that shape their lives.

A model of care broadly defines the ways in which health services are delivered, and describes how care and services will be delivered to people. In this case, people and families living with diabetes. We create models of care to help ensure people get the care they need, in the ways they need it.

Methodology

A rapid information review was carried out to inform the design of the enquiry framework with people living with diabetes and key informants.

While a model of care should effectively meet the needs of many population groups, we focussed on hearing from Māori, Pacific people and those from lower socio-economic areas. This is because these groups have relatively higher rates of diabetes, poorer access to health care, and poorer health outcomes. We spoke to a range of people, including:

- Those with lived experience of type 2 diabetes
- Those supporting someone living with diabetes
- Those with professional expertise in supporting people with diabetes (key informants).

Within this group of 22, we spoke to Māori, Pacific (Tongan and Samoan), and Indian people. Across these groups, we spoke to people newly diagnosed (ranging from last month, to six months ago), those who have struggled to manage their diabetes for many years (10 - 20 years), those who have experienced serious complications from their diabetes (lower limb amputation), various ages, genders, and places of residence across Auckland and Waitematā.

In addition to speaking with people with lived experience of diabetes, we spoke to key informants whose roles spanned across primary and secondary care, both district health boards and several public health organisations (PHOs).

Direct quotes are included throughout this document, and an alias has been given to each participant to ensure they remain anonymous.

The approach was qualitative and focussed on gaining depth, not breadth. The insights that follow focus largely on the lived experiences of people and families living with diabetes. While a rapid information review was carried out to inform the research design, the insights are not, and should not be considered, a comprehensive or systematic review of the literature related to diabetes.

Key terms used throughout this document

Diabetes - throughout the document 'diabetes' always refers to type 2 diabetes.

General practice - a place in the community where general practitioners (GPs), nurses and other health professionals work.

GP - a general practitioner, sometimes known as a family or general doctor.

Managing well - describes a person living with diabetes who has good blood sugar control, and does not experience additional complications e.g. sight loss, foot problems, impotence, kidney damage.

Not managing well - describes a person living with diabetes who does not have good blood sugar control and likely experiences additional complications. In medical terms, HbA1C > 75 mmol/mol).

Person - used in place of 'patient' to describe a person living with, or supporting someone living with, diabetes.

Primary care - health care received in the community, usually from a GP or nurse. It refers to diagnosis and treatment, health education, counselling, prevention and screening.

Secondary care - care provided by a specialist or facility. For example, in a hospital.

Self-management - involves a person doing things that protect and promote their health, as well as monitoring and managing the symptoms and signs of their illness. The amount they do this alongside health professionals varies.

Supporters - anyone who plays a 'support' role to a person living with diabetes.

Whakamā - feeling shame, shy, bashful or embarrassed. In this context it also relates to feeling a sense of withdrawal, or an inability to engage and communicate about their health concerns because of fear of judgement.

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Personas of people and families living with diabetes

A persona is a character that represents a shared group of needs, motivations, attitudes and propensities towards certain behaviours. The following personas have been created as an assessment and planning tools for the Co-Design workshops. They can be used outside the Co-Design process to aid decision making about whether a change or improvement will work for a certain group of people.

These personas were created through analysis of interviews with people and supporters living with diabetes. They are not defined by ethnicity as the themes spanned across ethnic groups. While the characters have been given some personal characteristics to personalise them, people of different ages, areas of residence and genders can share the same characteristics of each persona.

Anton

35, living in Massey with diabetes

“Life feels a bit impossible”

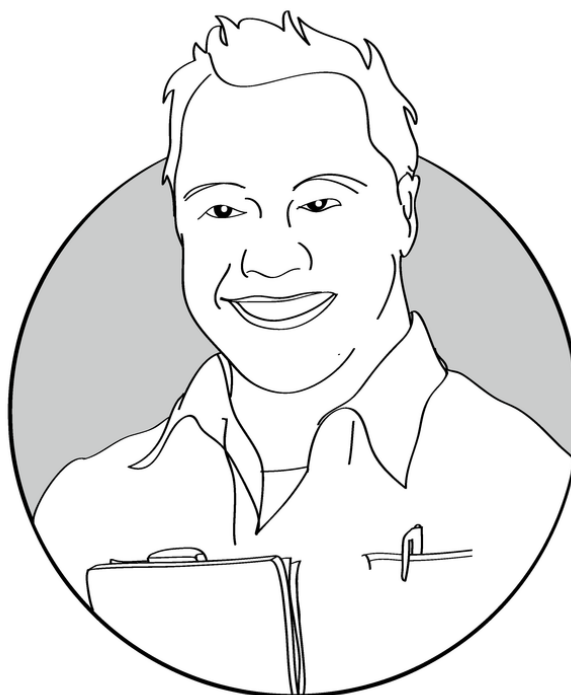
Anton was diagnosed with diabetes 10 years ago. When he found out he had diabetes, he was shocked. The same thing was happening to him that had happened to his parents. Along with the shock, came shame. Shame that he hadn't tried hard enough to prevent it, shame that he should have known better. Even after 10 years, it's still hard for Anton to accept he has diabetes.

Anton works six days a week, 12 hours a day in a physically demanding job. His boss and colleagues don't know he has diabetes, and he often ducks into the changing room at work to take his medication. He tries his best to fit in and avoid attention at work functions, social and family gatherings, and at church.

That sometimes means eating things he knows he probably shouldn't.

Anton finds it difficult to get to all the appointments his GP sends him to, often agreeing to appointments he knows he won't make. It's not that he doesn't want to go, work is just more important and hard to leave during the day.

Anton can't play rugby like he used to or take his kids to the park to run around, and the family boat never sees the sea. With a busy work and home life, fitting in exercise feels nearly impossible. Every time doctors tell him to lose weight he thinks, 'tell me something I don't know'. Don't they know losing weight is difficult when you're too tired and big to exercise?



Food is a big challenge. After being told to quit smoking and drinking, and his love life being negatively affected by diabetes, nice food is the only thing he has left to enjoy and all the things he really likes seem to be the things he's not supposed to have. After having diabetes for 10 years, he knows what foods he should avoid, but it's hard to avoid them with his wife and family are always eating nice food in front of him.

Maria

46 years old, living in Ōtāhuhu with newly diagnosed diabetes

"They tell me everything will be okay, it's not"

Maria was diagnosed with diabetes six months ago. It came as a complete shock even though she has a long family history of diabetes. On top of shame, Maria felt angry and scared. The feelings of anger and fear never went away.

Before she was diagnosed with diabetes, she'd take a bag lollies with her everywhere she went. Not being able to eat nice things with her family is hard. Maria's family have continued to eat the things she can't eat, and often ask her to bake sweet things, like chocolate cake, for them. Grocery shopping is hard, as Maria struggles to find things she actually likes eating. When the temptation grows too strong, she'll try to sneak nice things off her kid's plates. They respond by yelling at her to eat her vegetables, making her feel even worse.

Maria has been at home since she gave up her retail job. Her eyes got too sore looking at a computer and her body felt tired all the time. Being out of work leaves a lot of time to think and worry about diabetes, and what might happen in the future.

Maria's day is spent caring for her family - dropping the kids at school, cooking, food shopping, picking the kids up, picking her husband up from work, helping the kids with their homework, and, wishing the whole time she could hurry up and get into bed to go to sleep.

Maria wants to start exercising but she feels like her levels of exercise just keep going down, instead of up. She tried Zumba once, but it was too much, she couldn't even dance a whole song with her oldest daughter. It's hard to find something active to do, with way less energy and way less patience.

Maria trusts her doctor, who she's been seeing for a long time. Her doctor has given her very little information about her diabetes and hasn't connected her to any other services. She only sees him very briefly every few months to get more medicine. Maria doesn't look for support on her own - she'll wait for her doctor to tell her what she needs.



Heather

64 years old, living in Point Chevalier and supporting her husband with diabetes

“I wish he cared as much about his health, as I do”

Heather has spent the last six years caring for her husband (George) who has diabetes. As well as caring for him, she also helps to care for their grandchildren, and has a part-time job. While she really loves her husband, caring for him can feel tiring and frustrating. When she starts feeling tired and frustrated, she feels guilty, like a bad person and a bad wife.

Heather does all she can to support her husband to stay on track with his eating, movement and medication. When Heather can't cook for George, he sometimes doesn't eat, or buys things that she knows aren't good for him. Heather feels let down when George goes out and buys food he shouldn't eat, or takes lollies from their grandkids. Their grandkids sometimes worry granddad is going to die. Heather finds it exhausting to be the 'food police', to feel like she's nagging George all the time.



Diabetes has had a big impact on her relationship with her husband. It can feel like she's walking on eggshells around George's mood swings and fatigue. She wants George to feel included in their social life and always invites him to occasions. He often gets angry with her, saying he can't go and she should know better. What can she do?

On top of the moods, diabetes affects their intimate relationship as husband and wife. Their sex life has become non-existent. George has a low sex drive, impotence and feels embarrassed talking about sex with his doctor. Because he doesn't bring it up, and his doctor doesn't either, it doesn't get talked about. Again, what can Heather do?

Sometimes Heather feels powerless to positively influence her husband's behaviour, and can get angry and impatient with him. She wonders why her husband can't show the same level of commitment to his own health, when she is trying so hard.

Inconsistent advice makes living with diabetes harder

People and their families living with diabetes frequently expressed frustration with inconsistent messages from health professionals. Being able to manage well is hard when people don't know what advice to follow. The Ministry of Health (2015) acknowledge the advice people and families receive varies in content and quality.

Helen has had diabetes for 20 years, and lost her foot due to complications in 2011. She explains: **"After 20 years, I feel like mixed messages are just a part of it all. I didn't understand the severity of my condition until my foot was taken off in 2011. I wish I'd listened, but it's too confusing to understand"**.

Mixed messages are especially common when a person is being seen by both primary and secondary care services. Some people may attend three - seven different services, often receiving conflicting advice.

In addition to mixed messages, people find evasive advice frustrating and unhelpful. A lack of clear advice can give people room to continue unhealthy habits (e.g. drinking soft drinks daily), or further deny the reality of having diabetes and possible serious complications that could come from not

managing their diabetes well.

Overwhelmingly, people told us they need providers to be 'straight-up' and share practical advice, instead of focussing on reassuring them everything is going to be okay.

Sam (recently diagnosed) felt frustrated it took so long to receive a clear diagnosis. **"I was told for a long time that I was borderline and that I should be careful, what does that mean? That just gave me room to keep behaving the way I was"**. Sam, and others, explained there's an inner acceptance that needs to happen before a person can take substantial actions to manage it. This acceptance is difficult without a clear diagnosis, and sound advice around what will help them to gain better control of their diabetes.

Michelle, who supports her mum shares her frustration with evasive advice. **"She was told 'you can have lollies in moderation'... I don't think that's a good thing because it justifies her eating lollies"**.

Helen shares: **"I wish the doctors were just straight up, they keep telling me everything is going to be ok, but it's not. I don't know how to make it ok"**.

QUESTIONS FOR CO-DESIGNERS

How might we use technology to bring consistent tailored advice to people and families living with diabetes?

How might we ensure all health professionals share the same kinds of messages with people living with diabetes?

How might we give people and families greater confidence in the advice they receive?



There is an opportunity to better support people living with diabetes, especially when they're first diagnosed

People and families living with diabetes told us there were a range of things that that could be improved.

1 | People who are newly diagnosed can feel left to figure things out on their own.

"I was given a pamphlet and that's it, I didn't know what else to do, where else to go, that is all the information I received". After that, Sam didn't look anywhere else. Others shared similar experiences of first being diagnosed. "I was just given a lot of books. I just remember throwing them in the rubbish". "I was told to buy an expensive book [called] 'What the Fat', so I did". Being given a brochure feels inadequate in addressing how life has changed, in understanding how diabetes works, and what can help.

Evidence tells us people often aren't given enough information when first diagnosed. Information is needed in a range of forms, and as early as possible (Corben and Rosen, 2005). While some people may source their own information, it seems GPs are giving very little information that resonates with them.

2 | While people and families value quality information, it can be hard to sustain the motivation to continue managing their condition.

James, who was diagnosed 10 years ago, finds ongoing motivation hard. He often finds himself off track with diet and exercise. "The hardest

thing is having to come up with the motivation myself". James feels like he doesn't have anyone to 'top up' his motivation. People frequently spoke about the value of check-ins, and of having someone to be accountable to. This didn't need to be a health professional, but often had been in the past.

3 | Many people had never been to a Diabetes Self-Management Education (DSME) course, and couldn't remember ever being offered the option.

Evidence suggests self-management education and support, as part of a broader wellness plan, can improve health outcomes and quality of life (Ministry of Health, 2015).

While DSME courses could be better promoted for people interested, the timing of courses are seen as impractical for people and families working and caring for one another. For example, courses held every Thursday from 6:15 - 8:15pm. The location of courses can be impractical for those living in poor transport, and high traffic areas. For some, shyness or whakamā prevented them from attending a course, or group sessions.

Where people can self-manage, there is an opportunity to explore ways of developing self-management skills in ways that work better alongside people's busy lives. For example, through coaching.

QUESTIONS FOR CO-DESIGNERS

How might we support newly diagnosed people without asking more of general practices?
What might motivational support for people with diabetes look like?

A photograph of a red rectangular sign with the word "CLOSED" in white, bold, sans-serif capital letters. The sign is hanging from a glass door or window. It is held in place by two small metal clips. Above the sign, a clear suction cup is visible, attached to the glass. To the right, a metal chain hangs down. The background shows a blurred view of a street with buildings and a car.

CLOSED

The current model of general practice does not effectively meet the needs of many people living with diabetes

The need to change service delivery for people with diabetes, and other long-term conditions is well documented in international and New Zealand literature (Coulter et al, 2013; Diabetes UK, 2011; Mays, 2013; National Advisory Committee on Health and Disability, 2007).

In regards to supporting people with diabetes, the Ministry of Health (2015:15) notes:

Primary care providers can support people to self-manage by making longer appointment times, following up proactively, linking people to peer support groups and assessing and responding to people's mental health needs...health care workers also need the knowledge, skills and confidence to have motivational conversations with individuals, family and whānau to encourage them to make lifestyle change and connect them to the right services.

Key informants referred to general practices that are providing good service to people living with diabetes. Practices that do well seem to have a combination of passion and interest in diabetes; high quality nurses and sufficient nursing hours; and great recall and administrative systems.

However, more broadly within Auckland and Waitematā District Health Boards the current model of general practice is not consistently and effectively meeting the needs of people living with diabetes, particularly for Māori and Pacific people. Some of the key issues are

detailed below.

1 | Not all general practices are equally skilled or interested in diabetes care, leading to people and families receiving varied care quality. Sandra remembers seeing a GP: “they were not interested in my questions, they said ‘we don’t have time for questions, other people have been late’. They don’t give a shit... some do, and some don’t”.

Some people found it took a change in general practice, health service or GP for them to better understand their condition and the management of it. With a change in health professional, people who had lived with diabetes for 10 or even 20 years, felt it was only within the past few years they had come to understand their condition and what they really needed to be doing differently.

“After a while I told [him] to change GPs because I felt like they were too soft and just let him off sometimes. He’s changed GPs now and everything is really thorough. I feel a lot more confident now”.

“After a while my husband said I should check out another service, I changed to a Whānau Ora service and I’m much happier and feel looked after”.

“This is the first time in over 20 years I have truly understood my condition. However, when I was transferred back to the other District Health Board... it all went out the window”.

2 | For some general practices, there is a lack of continuity and consistency in staff.

Consistency and rapport matters to people and families living with diabetes.

3 | A number of people and families rely heavily on their GPs to connect them to services they want or need. GPs don't always know about what's available, how to refer, or have time to do so. This can lead to people failing to receive recommended care and support, and experiencing poorer health as a result (National Health Committee, 2007).

Unless their GP directs them, some people won't access additional services or supports on their own, or may feel like they can't use a service without their GP first suggesting they should. This can be related to feelings of confidence, anxiety and/or whakamā.

Mele described feeling scared, anxious and angry a lot of the time. **"There is nothing that helps to feel less scared and angry"**. When prompted to consider other services or supports she may have used, such as a psychologist, she shared: **"A psychologist... I haven't been there. If a doctor said go there, I would"**. The closest Mele has come to peer support was bumping into someone else picking up their medication and having a short conversation.

4 | General practice staff have a limited ability to support people outside of traditional medical issues. For example, in trying and failing to eat healthy, change family eating habits, navigating special occasions, travel, exercise, sex, dealing with changes in personal relationships or an ongoing lack of motivation. These issues, which some may call 'social issues' are often the most challenging issues people living with diabetes experience.

5 | The current appointment structure (5-15 minute appointments) doesn't allow time to identify and manage an array of health and social needs that often coexist for people with diabetes. As described by Corben and Rosen (2005, p. 9) "long term conditions are not time efficient" - and the model of general

practice that is dominant is designed for efficiency. Those living with diabetes can require additional time with health professionals (Corben et al, 2005; Ministry of Health, 2015) - time that GPs cannot easily give them within the current model.

Pearl who was diagnosed earlier this year shares: **"I stopped wanting to go to my GP because I was five minutes late one time and he told me off"**.

6 | Judgements by GPs about what people need, want, and can afford can be significant barriers to people accessing the services they want and need. John had numbness in his feet, and was cutting himself while trying to cut his toenails. When he told a GP, the GP made a decision not to refer him because he thought he couldn't afford it. **"They didn't refer me on to a podiatrist because they thought I couldn't afford it"**. *Note: John would have had to pay his own way as the visit was outside the three funded visits per year.*

A key informant reflects **"GPs have so many ideas about the patient...they just write them off and whole groups of patients miss out"**.

Sometimes GPs may simply forget to offer something, or have had so many people turn a service down they don't think to offer it again.

7 | Due to the busyness of general practices and convoluted referral processes (including complex eligibility criteria), referrals to other services often take a long time to be made, if at all. People reported waiting months to be referred to a specialist.

8 | While many people visit their general practice every few months to get new medication, it is felt they get very little value of those visits. Summer felt like her husband did not really get any support from his previous general practice, which felt like a waste because he was going regularly. **"He used to just go into the doctors to get his**

medication and leave... that was it”.

9 | At some practices, people wait for hours to be seen. This reduces their desire to go back and repeat the experience they had last time. As a key informant explains: **“it’s not decent care...the result is patients do not go frequently enough”**.

10 | Most general practice services are predominantly offered between 8am and 6pm on weekdays. Because some practices are inflexible around the scheduling needs of people and families, people struggle to find a time that suits them and may decide not to go at all.

11 | There appears to be lack of shared understanding among general practices of when people should be referred to specialist services. This has led to people being seen in secondary care when it may not be needed, and people who should be seen in secondary care not being seen.

A key informant shares: **“I don’t think GPs are referring enough to specialist services. We should be seeing the 10% of clinically complicated cases, and at least helping with those in the 90% who are poorly managing”**.

12 | A number of people spoke highly of practice nurses with specialist skills in diabetes. While this is valued, general practices often don’t have enough practice nurse hours or expertise.

Newly diagnosed, Sam shares: **“I felt comfortable with the nurse and she was asking me questions that I didn’t think to ask myself, she then went on to tell me to make**

sure to ask these questions to the doctor. I went in confidently and made sure my questions were answered”.

Evidence is clear that strong primary care is a key enabler to better outcomes related to diabetes. However, general practices are often under a significant amount of pressure, and are being asked to prioritise, take part in, and report on a broad range of initiatives and challenges.

The *New Zealand Health Strategy* (Ministry of Health, 2016b) places an emphasis on providing integrated care, or a ‘team approach’ to better supporting people living with diabetes and other long-term conditions. For example, combining a number of services in one place, co-ordination with initiatives in other sectors, or providing access to specialists from remote locations. As part of this ‘team approach’ there is an opportunity to explore ways secondary care services might better support primary care, to improve the care people receive in their communities.

QUESTIONS FOR CO-DESIGNERS

What might a different model of primary care look like that provides intensive support to people managing diabetes?

How might secondary care support primary care to better care for people living with diabetes?

What would it look like for people with diabetes to use primary care services that wanted, and had time for them?

How might we ensure people have access to primary care services that are enthusiastic, knowledgeable and proactive around the support of people with diabetes?

There is little support for people who support others living with diabetes

While supporters have an important role to play (Coulter et al, 2013; Expert Working Group, 2010; Ministry of Health, 2016a and 2016b), caring can have negative impacts on the overall well-being of supporters (Guest et al, 2015). There is little to no support available for supporters.

People supporting someone living with diabetes, in particular someone struggling to manage their diabetes, may experience:

1 | Feelings of frustration that their level of commitment isn't matched by the level of commitment their loved one shows in caring for themselves.

Michelle, who supports her mum explains: **"I feel most frustrated when I see Mum eating things she knows she shouldn't be. It's draining being the 'food police'. This affects the whole family. If we are committed to support her, she should show the same commitment. We have to hide the lollies, the kids yell at their nana about the food she eats"**.

2 | Feeling powerless to control or affect the actions of the person they're trying to support.

Summer, who supports her husband living with diabetes explains: **"shopping is hard, I control the budget and shopping list but sometimes he will pop out and buy his own things"**.

3 | Negative impacts on the quality and nature of the relationship they have with the person.

This can be due to feeling like they're 'policing' the other person's life (bringing resentment), and due to a change in a couple's sex life.

Summer also explains about her relationship with her husband: **"We just can't enjoy each other anymore (sexual relationship).... it is affecting me, it's an important part of our relationship"**. Moods are also a big issue in their lives: **"sometimes we feel like we are walking on eggshells because of [his] mood swings"**.

QUESTIONS FOR CO-DESIGNERS

How might we support people supporting someone living with diabetes?
How might we enable carers to feel confident and capable in their role?



Family, aiga and whānau can be the greatest enabler to people living with diabetes doing well

Family, aiga and whānau have an enormous role to play in supporting, (or conversely, undermining) a person's ability to manage their diabetes well. Involving family and whānau can have a positive impact on a person's ability to manage well (Expert Working Group, 2010). The New Zealand Health Strategy (Ministry of Health, 2016b) emphasises a shift from a focus on the individual, to a broader focus on family.

People supporting someone living with diabetes, in particular someone struggling to manage their diabetes, may experience:

Some people rely heavily on their children for medicine reminders and avoiding sugar. James explains: **"my oldest son, he's my nurse - he's always grabbing the medicines"**. For others, partners play a big role. **"When I was diagnosed my partner helped me to clear out our pantry, we did it together, he had also done some of his own research"**. Changes made by family, aiga and whānau can make it significantly easier for a person to manage their diabetes well.

While it can help to have family present at health appointments (for example, in reducing miscommunication, and in understanding the needs of a person living with diabetes) (Expert Working Group, 2010) it may not always be practical to do so.

There is an opportunity to think differently about keeping family, aiga and whānau in the loop, without requiring them to attend all appointments.

While family, aiga and whānau can help, they can be a barrier to managing well.

They may have different understandings of health and wellness, as well as what 'being supportive' means. A key informant explains **"[I] have an obese white women with a Niuean husband. We've tried to chat about weight things, and eating less, but she says 'he doesn't feel like I'm eating enough and he gets at me'"**.

James' kids pressure him into eating sweets with them. He finds it hard to say no. **"I buy sweets for the kids but I can't eat them. They then ask me to eat them with them"**. In addition, his wife often buys food she knows he shouldn't eat.

Family, aiga and whānau may also be a source of shame, especially in families where diabetes is common. This may prevent people from sharing their diagnosis, leading to denial, lying, and feeling isolated. Sam, whose parents both have diabetes explains: **"when I was diagnosed, I felt - ewwww shame! How am I going to tell my family? There's a sense of shame, my whole family have it, I should have been more careful"**.

QUESTIONS FOR CO-DESIGNERS

How might we keep family, aiga and whānau 'in the know', without them having to go to every appointment or session?

How might we support family, aiga and whānau to know and practice what is most supportive to their loved one with diabetes?



The complexity and cultural importance of food is not well understood

Food was a significant and recurring theme. People talked about the enormous challenges related to maintaining a change in diet. As one person summarises “food is our biggest battle”. Not being able to eat food we love, alongside our family, friends and communities can be painful and isolating. For most people food is intertwined with family life, joy, socialising, celebrations, belonging and cultural participation.

Mele talks about her family: “they enjoy themselves and their food. I sometimes pick at their food and they shout ‘mum, the sugar’, I say ‘shut up’. There is separate food in our house. There is the good and nice food, but that’s not for me”.

Mark explains what it feels like to be asked to give up the food he loves to eat “as Mormons we don’t drink smoke or drink so all we have is food. Food makes everything hard”.

A simple task like grocery shopping can be a constant battle as Mele explains. “It’s not easy to find food you like eating. Shopping is hard, I pick mine and they pick theirs”.

Instead of simply telling people to stop doing something, effective behaviour change interventions focus on creating value for people. If food provides value for people, how

might we create similar value without the food we’re asking people not to eat?

The current experiences of some nutrition and dietary services haven’t been positive, or have felt inadequate in changing food habits long-term. Soon after she was diagnosed, Sandra went to a session on diet and diabetes. She explains about the facilitator: “She had a set presentation. She was a person that really didn’t care, just does what they’re asked. She wouldn’t answer any of my questions. She was just like a sales person”.

Summer explains that while a home visit wasn’t bad, but it was inadequate “I had a nutritionist come to visit one time, she came, talked about food for about 20 minutes, gave me a few recipes that I’d never heard of and then went about her business”. The once-off visit didn’t change the way Summer and her husband eat at home.

People appreciate when health professionals understand and attempt to incorporate what their lifestyle and culture ask of them in relation to events, rituals and occasions.

“When I’ve worked with Māori nurses, they just understand what is involved in my role [Kaumātua], that I attend many hui and they just know the food that is served and what that means”.

QUESTIONS FOR CO-DESIGNERS

How might we support people to eat differently while still actively participating in the celebrations, events, and social time they want to?

How might we eating differently not be seen as going without?



Current services mean lots of appointments and lots of waiting

People and families living with diabetes are often required to attend many different appointments, and they are often booked at times and places that don't work for them. Appointments are often booked for people, with little to no choice about when and where they're seen.

As many people work, or are supported by someone who does, a lack of times outside of standard working hours is a barrier. In addition to little choice, there is inflexibility in changing appointments.

As well as attending many appointments, people and families often wait everywhere the person they're supporting is required to go. Supporters and carers often report feeling like they're being 'mucked around' by the health system. For example, showing up to see a specialist, waiting for up to five hours and then being sent home to come back another day. Waiting has a significant impact, with people and families taking time off work, as well as the impact on a person's willingness to engage with a system that doesn't seem to respect their time, and is organised around the systems needs, not theirs.

After having diabetes 20 years, John is exasperated by how slow referrals can be. **"When doctors say they're going to do something, then they need to do that. When I've been referred, sometimes I've been waiting more than three months... if I get referred on at all"**.

Even though he's often frustrated, he doesn't want to be a hassle and doesn't follow-up. **"I won't follow-up because I know they're busy people"**.

The kind of excessive waiting people report experiencing is a classic sign of a poorly designed service and system. As (Adams, 2010:65) describes, it's easy to label someone as 'disengaged' when "the interaction with the health care system is confusing, inconsistent, or involves labyrinthine system navigation".

There is an opportunity to reduce the number of appointments people and families need to attend, and decrease pressure on the health system and on people and families living with diabetes. A simple example is undertaking multiple screens for diabetes risk factors (feet, eyes and kidneys) in one appointment .

There is also an opportunity to have people pick their own appointments at times and places that work for them. This aligns with one of the core themes of the New Zealand Health Strategy 'people powered health', that's about "enabling individuals to make choices about the care and support they receive" (Ministry of Health, 2016b:16). In addition to focussing on enabling greater choice, the strategy places importance on the delivery of care close to home, especially for people managing diabetes and other long-term conditions.

QUESTIONS FOR CO-DESIGNERS

How might we enable people to choose their own appointment times, every time?

How might we dramatically reduce the number of appointments people have to go to, while ensuring people still feel supported?

What health professionals want is often not the same as what people living with diabetes want

When health professionals do not appreciate and engage with what people want, people stop engaging with them, as the National Advisory Committee on Health and Disability (2007:13) notes:

What the patient needs and wants is often not quite the same as what the health professional believes is 'best' for the patient. At the clinical intervention and diagnosis end of the spectrum, practitioners decision is essential but self-management of lifestyle behaviour needs a person-centred approach throughout.

There are high personal costs for people living with diabetes and it is important for health professionals supporting them to engage with these key issues.

1 | Damaged relationships and connections with family, friends, work colleagues and community

Mele explains **"I used to like helping the kids with their homework, now I think 'hurry up so I can go to bed'"**. Diabetes has affected the relationship she has with her kids in a negative way. **"I get angry, I'm yelling... I think it has to do with the diabetes"**. Mele's experience was common among other parents living with diabetes.

One person, living with family explains: **"sometimes I see a tall tree. I look up and feel like I'm sitting on top of the tree. I want to do things other than thinking about diabetes all the time"**.

Extremely important for people living with diabetes is the impact diabetes can have on sex drive, and ability to have sex for men and

women. Summer, who supports her husband shares: **"we just can't enjoy each other anymore"**. James, who has been living with diabetes for the past 10 years shares about his love and sex life: **"it's not what is used to be"**. He also said he had never talked to a health professional about the problem, and they haven't asked.

2 | Living with a diabetes can involve feelings of anxiety, fear and depression that don't go away and may feel hard to talk about.

Mele, who has had diabetes for the past five years and hasn't received any emotional or mental health support shares: **"nothing helps to feel less scared and angry"**.

Peter summarises: **"I've got no more fun to do anymore. I've stopped smoking, drinking, eating nice things, [the] sex life isn't what it used to be"**.

3 | It can be difficult for people to work out ways of doing things they used to enjoy with less energy and patience.

James sums it up by sharing: **"life is a bit impossible. My wife is working too, we have kids, we're so busy we're always getting takeaways or fast food"**. He thinks back to what he used to do, that he doesn't feel he can do anymore: **"before I used to do lots of things with the kids...take them to the running track. It's harder now. We were always fishing on the weekend, not so much anymore"**. James doesn't talk to his doctor about life feeling impossible, and his doctor doesn't ask what it feels like to live with diabetes.

While Mele wants to exercise, she doesn't know how to get started. Simply being told to

exercise isn't making things easier or more achievable for her. **"I've been to Zumba once, it was so fast. One song and I'm sitting down and watching... I haven't been back".**

4 | Some people face financial barriers

In addition to personal costs, some people face financial barriers to managing their diabetes well. While some found their medication(s) expensive, others were frustrated at parking costs for hospital clinics. For some people, the disposal charges for needles was a barrier. **"There is a charge to dispose your used needles, another charge we can't afford, therefore we have to hide the used needles somewhere and it's unsafe".**

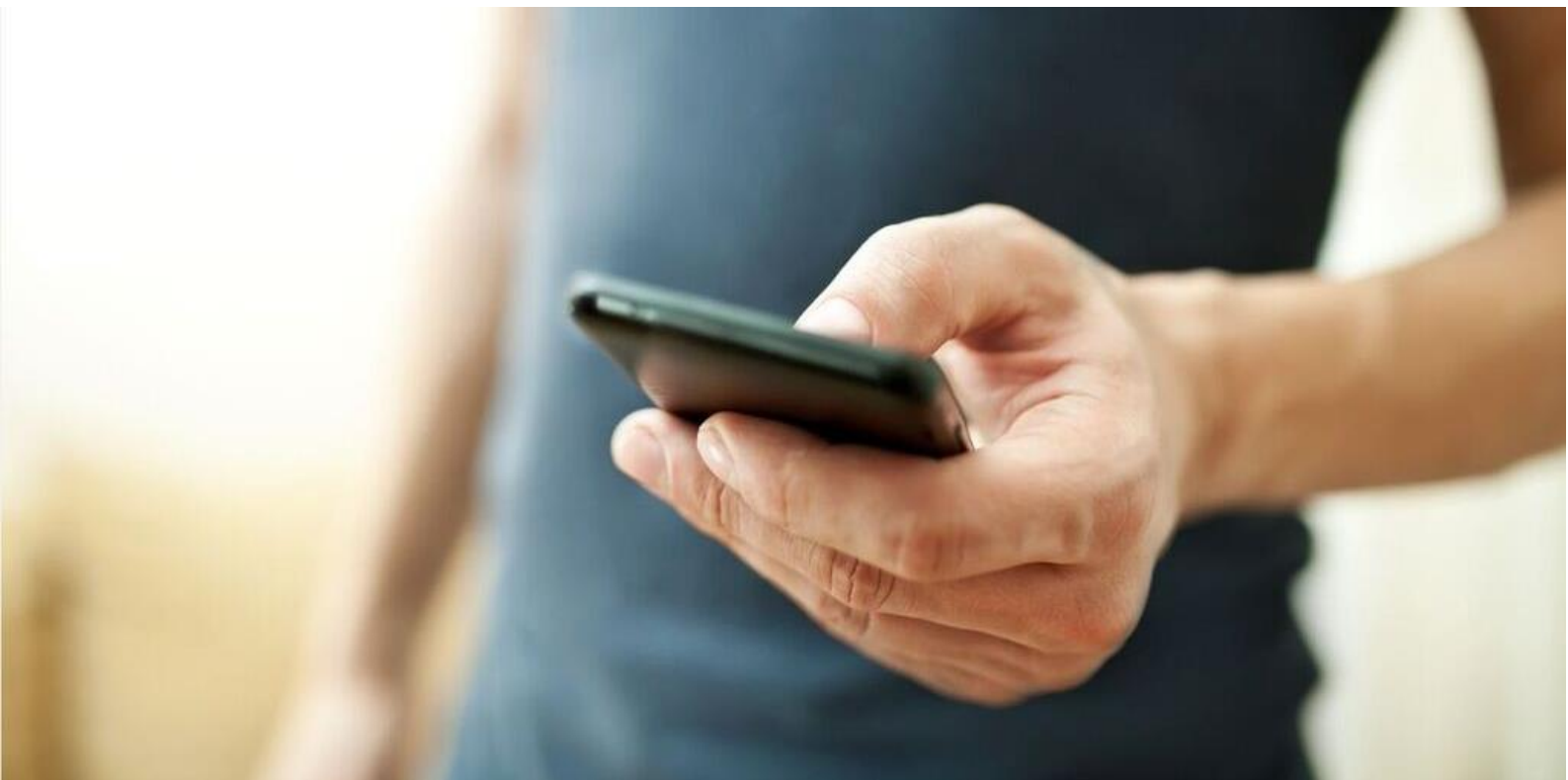
While these things are experienced in varying levels day-to-day by people living with diabetes, they're not always front of mind for health professionals who may be more

concerned with things like medication adherence. While a number of people spoke about wanting and needing to talk about sex and relationships, or feeling scared all the time, they noted health professionals often don't ask - so they don't either.

Summer, who supports her husband shares: **"We're always talking about [his] eyes, or feet, I want to talk about his moods and our sex life and how that's affecting our relationship but I don't know how to bring it up. It's too embarrassing to talk about for [my husband]. I had to call the nurse back and tell her it's affecting us".**

QUESTIONS FOR CO-DESIGNERS

How might we reduce the disconnect between what health professionals want and people living with diabetes want?



People have better outcomes when they can access information about their health

People living with diabetes report feeling and doing better when they were able to access and understand their own information, make changes accordingly, and see the progress they are making (Adams, 2010; Hibbard and Gilburt, 2001; Murray et al, 2005).

As many people work, ensuring people have access to their personal health information is a core system enabler to supporting greater self-management (Ministry of Health, 2015). A key theme of the New Zealand Health Strategy is people-powered care. A core aspect of this is people being able to access and understand the information they need to manage their care (Ministry of Health, 2016b). It is important to note that access on its own will not lead to improved outcome, understanding is critical too.

Peter who has had diabetes for 20 years felt it he has managed best when he's been given a challenge to work on (e.g. improve his blood glucose), along with the tools to do it, and the visibility of how he's doing with his challenge.

Sandra (diagnosed earlier this year) likes to know how she's doing with her blood glucose levels so she can make changes to her diet and lifestyle. However, because she doesn't have any self-monitoring options, she finds it difficult and onerous to go to the doctor every time she wants to know her blood glucose levels.

As part of the 'Year of Care' programme in the UK, people are sent a letter with their results prior to an appointment with a health professional. The letter has allowed people to see how they're doing, come up with questions, and over time helped people to

better understand their condition (Diabetes UK, 2011).

While there are many dietary and exercise applications available, there are a fewer applications (web and mobile) that allow people to view, and act on their own information. For example¹, the [Digital Diabetes Coach](#) from the NHS, [mySugr Coaching](#), and [Glucose Buddy](#) from SkyHealth. It's important to note that an application shouldn't be implemented without first testing it with those who will use it to ensure it is usable and desirable.

QUESTIONS FOR CO-DESIGNERS

How might we share useful information about people's health with them?

Keep information up to date for the person?

What role could technology play in ensuring people had access to information about their health?

¹ See: <https://vimeo.com/164273457> | <https://mysugr.com/> | <http://www.glucosebuddy.com/>

People struggle to get value from health professionals who don't engage with their culture or what's important to them

People living with diabetes report feeling and doing better when they were able to access and understand their own information, make changes accordingly, and see the progress they are making (Adams, 2010; Hibbard and Gilburt, 2001; Murray et al, 2005).

Many people report struggling to connect with their general practice because they do not think the staff understand them, their culture, and what's important to them. Services that do not understand the cultures and values of the people they serve will not be able to provide the best support to them to manage their health.

A key informant shares: **"You feel you've tried hard and they're not getting it... we're stuck...how do we connect with them? I think we talk well to these people but we cannot seem to make these people understand"**. In situations like these, there may be a lack of understanding about what might be leading to the 'lack of connection', what additional support or training the health professional may be able to access, and what they could do differently to improve the situation.

People living with diabetes stressed the importance of being supported by health professionals who engage with what they value (which is unique to them), and what their culture asks of them (which may be bigger than them). It was stressed this doesn't always need to be a provider of the same culture, but someone able and willing to understand different values, perspectives and practices.

When health professionals don't engage with what is important to people, people begin to disengage from health professionals. Helen explains: **"I like having Māori staff working with me. They are already aware, and there is no need to explain everything all the time"**. Helen found she felt much better supported moving from a general practice, to a Whānau Ora service.

They also stressed the importance of being supported by health professionals who offer advice they can relate to, and are skilled in making it safe for them to talk about the things they value, but may be uncomfortable talking about. While Peter wants to talk about his sex life, he doesn't want to bring it up. **"I talked about it once with the man doctor, then I went back and it's always the lady one [I don't talk to her about it]"**.

QUESTIONS FOR CO-DESIGNERS

How might we ensure that everyone living with diabetes is supported by people and health professionals they feel connected to?

How might we support health professionals who feel unable to connect with people living with diabetes?



Performance managing people with diabetes can lead to shame

Perhaps dissimilar to other illnesses or conditions, people with diabetes can feel performance managed by health professionals. One key informant describes: “People are judged in regards to their performance in a way they’re not for any other medical problem. My guess is they don’t attend [because] they don’t want to come and be beaten up”.

Another describes, **“we [health professionals] traditionally tell people what to do...the word ‘compliance’ just slips out”.**

After attending appointments, a key informant describes, **“[they] feel like they’ve been told off... they feel guilty and like it was a waste of time”.**

The feeling of being performance managed can come to life through the language some health professionals may be using, for example ‘compliance’, ‘non-compliant’, ‘poor management’ or ‘adherence’.

This can lead to feeling shame, whakamā and guilt - a sense of withdrawal, or the inability

to engage and communicate about health needs because of fear of judgement.

Central Primary Health Organisation (2011:2-3) describes the effects of whakamā:

Some Māori clients may nod and say they have understood what a practitioner has said to them even though they may not have. Much of the time, these responses are due to whakamā, of not wanting to be an inconvenience or just embarrassed or shy. In many instances, the importance of meaningful connections can help alleviate whakamā.

To alleviate or address whakamā, a GP or nurse asking the right questions can open a door allowing the person living with diabetes and their loved one to elaborate on issues they may find hard to bring up. This is a matter of understanding what else might be important to the person living with diabetes and the person supporting them outside of the usual issues (such as eyes and feet).

QUESTIONS FOR CO-DESIGNERS

How might we design services and interactions that alleviate shame and whakamā?

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