Partners in Care co-design case study

Improving diabetes management for tāngata whaiora at Hauora Heretaunga

Health Hawke's Bay and Hauora Heretaunga

Context

Hauora Heretaunga is a very low-cost access general practice with an enrolled population of 6,291. Ninety-one percent (5,739) of the total enrolled population are Māori or Pasifika and/or live in high-deprivation communities (quintile 5). Approximately 7.6% (480) of the people in our community have diabetes. Of the 480 with diabetes, 226 (47%) have poorly controlled diabetes, clinically defined as a glycated haemoglobin (HbA1c) level greater than 64 mmol/mol. Poorly controlled diabetes significantly increases the risk of complications such as heart attacks, retinopathy (eye problems), amputations and end-stage kidney disease.

Poor diabetes control leads to poor health outcomes. According to *He Korowai Oranga: Māori Health Strategy* (Ministry of Health 2002), reasons for poor health outcomes are multifactorial and complex. However, we know that people with lower incomes suffer more ill health, and Māori at all socioeconomic levels have poorer health status than non-Māori. Identifying and addressing factors that cause poor diabetes control is professionally challenging, time consuming, requires effective consumer engagement, and often needs a system-wide approach. The driver for this project is to improve the experience and clinical outcomes through diabetes self-management and reduce health inequities for our Māori consumers and their whānau.

From August 2020 until April 2021, we worked with our patients and their whānau to design an effective diabetes management programme.

Equity aim

The aim of this co-design work is to understand the challenges that our whānau with diabetes face and work with them to design ways to improve diabetes control in an enrolled population (Hauora Heretaunga), of which 91% identify as Māori or Pacific and/or reside in the most deprived communities (quintile 5).

Start-up

The project team

This project was initiated by Health Hawke's Bay in response to the opportunity to join the national Partners in Care co-design capability building programme offered by the Health Quality & Safety Commission. It was endorsed by senior leaders, and the first workshop was set up to describe the co-design process and to support the project team to get started.

Our project team was initially formed with three members of the primary health organisation (PHO), two clinicians from the general practice and three consumers. There were a number of challenges, including the COVID-19 pandemic, which resulted in conflicting priorities and lack of engagement with the work. This impacted on the project team and the initial progress we made. However, once we gained a dedicated resource in the form of a project lead, we were able to maintain momentum.

Four consumers accepted an invitation to be a part of the project team, of which two have sustained their connection through to the completion of the project.

Baseline measures

Our original plan was to use the Partners in Health Scale (Battersby et al 2003), a generic assessment scale that was designed to support patients' understanding about managing a long-term condition and is relevant to the primary health care setting. We aimed to engage patients with diabetes from our population and support them in using the scale as a core part of our baseline data.

We collected information about our enrolled population who were living with diabetes; this included their ethnicity and HbA1c level, an average of the blood glucose (sugar) level over a two- to three-month period. An ideal HbA1c level is 48 mmol/mol, and we particularly focused on identifying those with a level greater than 64 mmol/mol (Table 1).

Table 1: Enrolled people with an HbA1c level greater than 64 mmol/mol

Ethnicity	HbA1c level between 64 and 75 mmol/mol	HbA1c level greater than 75 mmol/mol
Māori	44	130
NZ European	8	14
Pacific	4	26
Other	3	6
Total	**59**	**176**

As the project progressed, an insight from one of the consumer members of our project team radically changed our focus from looking broadly across our enrolled population to focusing on a single whānau and learning lessons that could then be replicated more widely. This change happened during a co-design meeting midway through the project. The activity prior to that point, including gathering experiences of consumers living with diabetes who had an HbA1c level greater than 64 mmol/mol, was still incredibly helpful and provided a better understanding of their needs.

Engage

An important part of engaging with people is to be able to consistently describe the project in a succinct way. We developed an elevator pitch, a short narrative that helps to engage people so they can contribute to the project. This elevator pitch was used to raise the visibility of the project, for those who were interested or were key stakeholders – mainly for staff at the practice and the PHO.

Elevator pitch for staff

> *We are doing a co-design project at Hauora with people involved with diabetes (patients, staff and other stakeholders). Our aim is to improve the ability of consumers to manage their diabetes. We plan to measure changes in outcomes through their self-reported experience and through clinical measures (eg, HbA1c). We will engage with our consumers to understand their experiences and receive their ideas for what would support them managing their diabetes. We will then make a plan to implement these ideas and measure outcomes.*

The following elevator pitch was used with consumers when approaching them to take part in the initial survey.

Elevator pitch for consumers

> *We are doing a co-design project which involves patients and medical staff at Hauora. This project is to find out more information around your diabetes and how we can do things better. We plan to ask you four questions, collect the information, make some changes and have feedback available for you as a participant. This will only take 5 minutes of your time and will be kept confidential. Are you willing to participate?*

We engaged with consumers in three different ways.

1. Two consumers worked as project team members. As members of the project team they were invited to all meetings, consulted with regarding strategy, and involved in every decision as we progressed with the project. They provided feedback on all documentation and wording. In order to provide support to the consumers, they were connected with the Diabetes Nurse as their primary point of contact with the project team. This enabled communication between the consumers and the team, which supported their ongoing involvement in the project team.
2. Our second engagement with consumers was to identify consumers living with diabetes who had an HbA1c level greater than 64 mmol/mol and invite them to share their lived experience through a survey and a separate hui. Invitations were made opportunistically in their clinical consultations when they came in to the practice for scheduled appointments.
3. Thirdly, Margaret, one of our consumers from the project team, engaged informally with her friends and whānau, sharing her experience and learning from being involved in the project. Margaret then acted on behalf of the project team and intentionally engaged with them to explore more about the value of engaging with whānau together to improve their ability to manage their diabetes.

Capture

Survey data

In order to capture the experience of consumers living with diabetes who had an HbA1c level greater than 64 mmol/mol of the current service, clinicians (a nurse and a clinical pharmacist) approached consumers while they were in the surgery for an appointment. After using the elevator pitch to explain the project, we asked these consumers if they were willing to share their feelings and experiences about how they manage their diabetes by completing an initial four-question paper-based survey (Appendix 1). They were able to either respond to the survey while in the surgery or could take it away and return it at a later date. Twelve surveys were completed by participants, who were predominantly Māori and from a wide age group (Table 2).

Table 2: Demographics of the consumers who completed the paper-based survey

Gender	Male: 5 Female: 7
Age	Age range: 45–80 years Average age: 58 years
Ethnicity	Māori: 10 Samoan: 1 Indian: 1

Understand

During this phase we met as a project team to review the data and learnings that we had.

A starting point was to review the survey data to see if we could identify themes. We went through each of the questions and responses one by one and summarised the main focus of the consumer responses. We wrote these on Post-it notes and put them on a large sheet of paper with the survey question at the top. We then organised the Post-it notes into groups based on the similarity of their focus.

Responses from the initial four-question survey

Question 1: What do you find easy when looking after your diabetes?

The responses focused on information, knowledge and understanding, taking medication and managing their diet.

> *'Knowing that I have learnt quite a lot about diabetes from the Doctor and Specialist and that I understand it.'*
>
> *'Having information available on how to manage my diabetes including the diet.'*
>
> *'Some things are difficult but breathing, walking, sleeping is easy.'*
>
> *'Taking pills is easy except that sometimes I find it challenging mentally as I have an underlying belief that medication is not always beneficial.'*
>
> *'At first it was just trying to accept it but now I have the information and support from the team to help me manage my diabetes.'*
>
> *'Having information so that I know what to eat and what to avoid.'*
>
> *'Having smaller portions and zero sugar in the house makes managing my diet easier.'*

Question 2: What do you find difficult when looking after your diabetes?

Self-management and knowledge and behaviour regarding food were prominent responses.

> *'Eating right; my diet and exercise has been difficult to maintain.'*
>
> *'Eating the wrong foods and knowing it's not OK.'*
>
> *'Finding an affordable menu, knowing what foods are good for you.'*
>
> *'Knowing what foods have sugar in them and how much.'*

Question 3: What would help you to manage your diabetes?

Responses focused heavily on self-management of medications and ongoing support about other aspects of diabetes, including diet and exercise.

> *'I need more understanding about my medication.'*
>
> *'I've had the education, but keep going off the rails, knowing the right foods to eat, exercise, testing regularly is difficult.'*
>
> *'Knowing that I have the support from the Taiwhenua health team.'*
>
> *'Losing weight.'*

Question 4 asked if tāngata whaiora (those who were seeking health) were interested in being involved in the project in an ongoing way. If so, they gave us their contact details.

Reviewing the responses from the survey was a very stimulating experience and consolidated a number of insights that we were beginning to have about which areas to focus on for the project. Margaret was not able to attend this meeting, but we organised a specific meeting to share the responses with her. Unbeknown to us at the time, she subsequently shared this information informally with her friends and whānau, and that led to the change of direction of our project.

Improve

Co-design meeting midway through the project

While having a kōrero (conversation) about the results of the survey, Margaret talked about how she had gained a lot from being involved in the project team and learning more about diabetes. This had provided her with confidence to talk about diabetes with her whānau, many whom have diabetes. Experiences of living with diabetes had not been openly discussed by this whānau in the past.

Margaret mentioned that she had been talking with her whānau about her work on the project, and her whānau started asking questions that prompted discussions about diabetes in a way that they had never talked about it before. Margaret was able to provide some advice, guidance and support to them. As she told the story, Margaret shared some initial ideas that had come from the hui (meeting), and this led to the suggestion for Margaret to hold another more formal hui with as many of the whānau as chose to participate.

Margaret approached the members of her whānau who had diabetes and invited them for coffee and something to eat followed by a hui to share their 'diabetes journey'. This essentially changed the path of the project from looking broadly across our enrolled population to focusing on a single whānau and learning lessons that could then be replicated more widely.

The whānau hui

The whānau hui took place in a local library with support from the librarian.

It started with a sharing of how things were going in everyone's general life, and then whānau spent time completing the four-question survey that had been used with other consumers as a starting point for their conversation about managing diabetes. Much of the kōrero was centred on food, and it became apparent that this whānau had knowledge about what foods were most appropriate for them, but they were not always choosing those foods. This led to discussion about

using ‘good’ foods in meals, with the group sharing experiences about what foods they did use and how they prepared meals. During the hui the whānau watched a ‘healthy cooking’ video presented by Nadia Lim, a prominent New Zealand chef. Again, this helped the whānau to realise that they did know a lot about healthy food, reassuring them that they were already doing well but also that they could also increase their range of healthy meals. During this hui, notes were made, and we formed a mind map of the discussion (Appendix 2).

Towards the end of the kōrero, the whānau made the following list of what they could do to maintain momentum and support each other.

1. Commit to attending exercise sessions at a community centre – going to three sessions a week, either together or individually when available.[1]
2. Go to the doctor to ask for additional support to manage their diabetes and for access to a Green Prescription.[2]
3. Meet fortnightly in a hui for a sharing session about how things were going.
4. Develop a menu plan together, starting with a focus on breakfast.
5. Share meal ideas – for example, one whānau member cooking dinner over Zoom meeting while others watch.
6. Individuals would share the lead of initiating activities.

As a result, a number of changes happened. Many focused on diet – for example, replacing ‘full sugar’ fizzy drinks with ‘zero sugar’ fizzy drinks and also increasing the amount of water they had each day. In addition, the whānau had increased confidence to ask questions at their medical appointments.

Measure

Whānau hui

Since the initial whānau hui when Margaret’s whānau agreed to focus more on their health and wellbeing, the following progress has been made on the ideas that were identified.

1. Whānau have attended exercise and physical movement classes at Camberley Community Centre. Sometimes they attend together and sometimes they go individually. Margaret’s feedback following the classes is *‘We lifted ourselves up’, ‘It was a positive way of achieving’*.
2. Four whānau members have a Green Prescription from their GPs. These are personalised to each person’s differing needs, and tāngata (people/individuals) are able to access similar services as they walk the journey alongside each other.
3. Whānau hui have taken place fortnightly on an ongoing basis face-to-face and via Zoom. The effect of these regular meetings has:
   a) strengthened relationships
   b) increased the visibility of diabetes as a shared concern

[1] See Appendix 3 for flyer identifying exercise sessions.

[2] A Green Prescription is a health professional’s specific written advice to a patient to be physically active as part of the patient’s health management. See https://www.health.govt.nz/our-work/preventative-health-wellness/physical-activity/green-prescriptions/how-green-prescription-works

c) benefited from the positive power of a shared experience and understanding *'we've got diabetes, let's accept it and make it a bit easier on ourselves'.*

4. There are different levels of meal planning within the group. Most have committed to having a healthy stir-fry on Friday nights. Some are making stir-fry during the week as well. All have made changes to their eating habits (eg, replacing fizzy drinks with water) and report that they are feeling better.
5. Margaret organised a Zoom call and prepared a healthy dinner while two whānau members watched. They reported that *'they enjoyed the meal and connecting with whānau'*. They have used that format every now and again and have also engaged in other activities such as connecting informally face-to-face and on the phone.
6. Finally, two of the participants of the whānau hui had their HbA1c tested before and after the hui, which resulted in significant changes (Table 3).

Table 3: HbA1c test results before and after the whānau hui

Person	Date tested (pre-hui)	HbA1c (mmol/mol)	Date tested (post-hui)	HbA1c (mmol/mol)
Māori female, 53 years	4 February 2021	91	12 May 2021	58
Māori male, 65 years	8 March 2021	105	26 May 2021	69

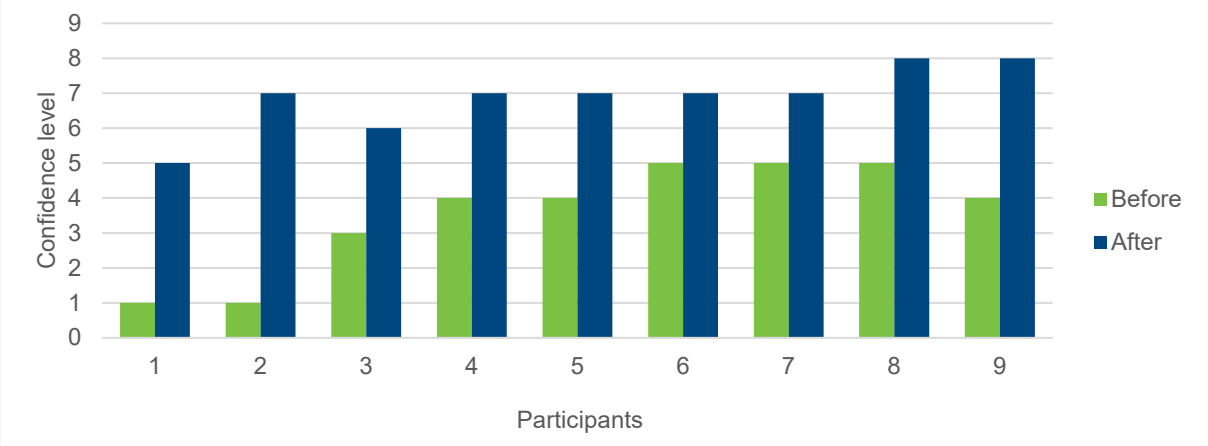
We developed a second survey to be completed by Margaret's whānau to measure the impact of the whānau hui and subsequent activities on their confidence, knowledge and empowerment (Appendix 4).

We received nine responses, which indicated changes in experiences after the whānau hui. The survey questions and results are provided below.

Questions 1 and 2 (Figure 1)

1. Please rate your **confidence** in your ability to manage your diabetes **before** you had whānau hui and whanaungatanga [a relationship through shared experiences and working together which provides people with a sense of belonging] with Margaret.
2. Please rate your **confidence** in your ability to manage your diabetes **after** you had whānau hui and whanaungatanga with Margaret.

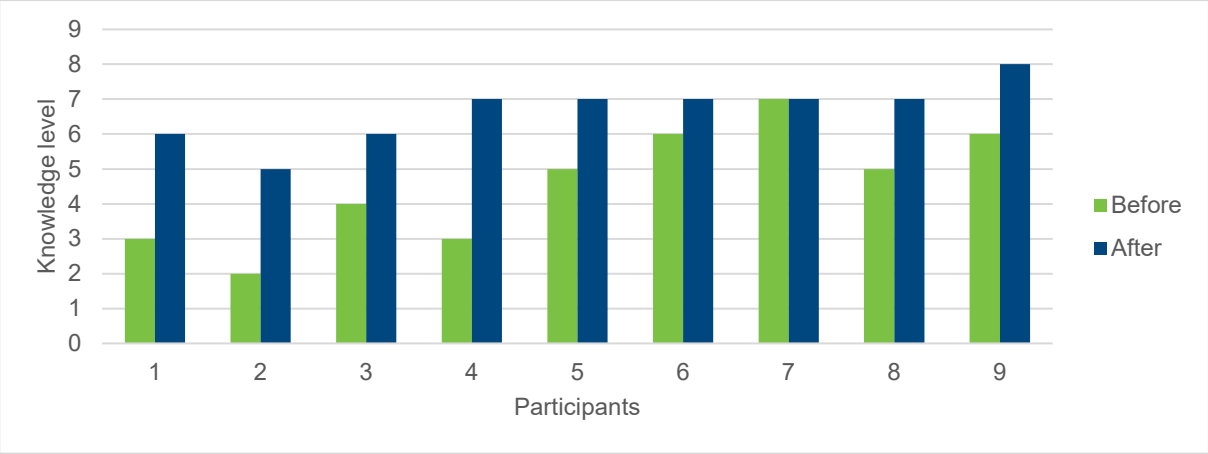
Figure 1: Pre- and post-hui self-reported assessment of confidence levels relating to questions 1 and 2



Questions 3 and 4 (Figure 2)

3. Please rate your **level of knowledge** about diabetes and managing diabetes **before** you had whānau hui and whanaungatanga with Margaret.
4. Please rate your **level of knowledge** about diabetes and managing diabetes **after** you had whānau hui and whanaungatanga with Margaret.

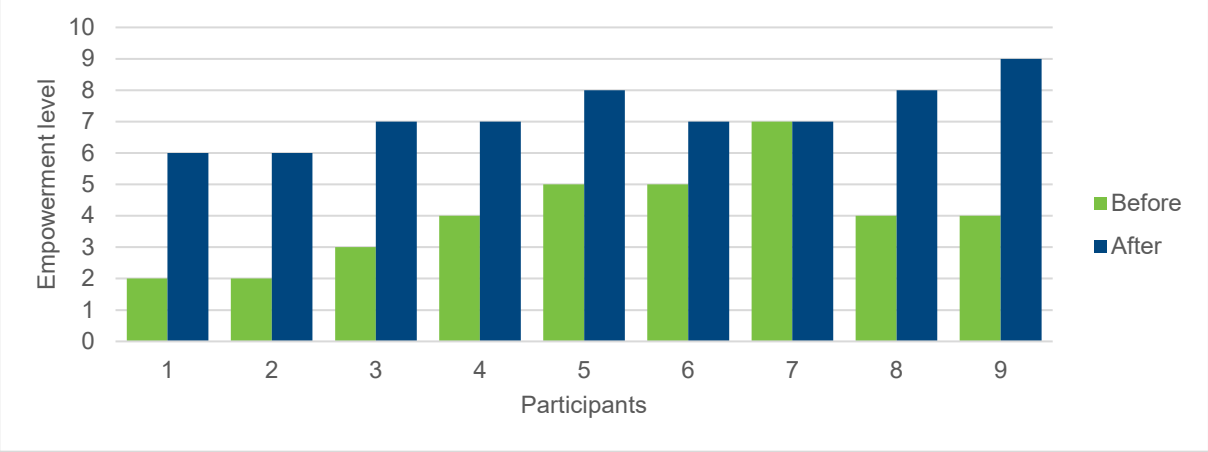
Figure 2: Pre- and post-hui self-reported assessment of confidence levels relating to questions 3 and 4



Questions 5 and 6 (Figure 3)

5. Please rate how **empowered** you felt to interact with health services and manage your diabetes effectively **before** you had whānau hui and whanaungatanga with Margaret.
6. Please rate how **empowered** you feel to interact with health services and manage your diabetes effectively **since** you have had whānau hui and whanaungatanga with Margaret.

Figure 3: Pre- and post-hui self-reported assessment of confidence levels relating to questions 5 and 6



The survey also provided space for whānau to provide additional comments, all of which noted benefits experienced as a result of the hui and subsequent activities.

> *'Support from whānau made a difference.'*
>
> *'Supporting one another with our diabetes, sharing what we know.'*

'Reconnecting with whānau to talk about our Diabetes, and where we are all at and what we need to do to manage it better… meal options, sharing information.'

The following comment indicates the participant's experience both before and after the whānau hui.

'I was always just nodding my head when Health Services are talking about my diabetes [before hui], now I feel more confident [after hui], to ask Health Services at my consultations .'

Our next steps

We know that many people in a single extended whānau can have diabetes. The new insights and learning that we gained through Margaret as she talked to her whānau were not planned in this project but have been an exciting development and key to our co-design process. The insight is that there is a level of safety and comfort when people learn together. The notion of 'whānau to whānau', preferably kanohi ki te kanohi (face to face), is something that we will continue to explore with other whānau where multiple members are living with diabetes.

Working as a co-design team

Working as a co-design team was a rich and rewarding experience. We came together as a group of people with different professional backgrounds and life experiences and with a few threads of connection. Over the months of working together we wove into a team with complementary skill sets where every voice was heard and contributed to the work of the project.

There were initial challenges in that we were initially speaking three different languages (that of the consumer, clinician and the PHO), each with our different agendas and ways of working. However, we had a shared purpose of working together to make a difference for whānau by improving the service and support that they receive from our practice.

The differences in ways of working that contributed to our success were:

- greater emphasis on whakawhanaungatanga (establishing connection and relationships)
- importance of opening and closing each hui with a karakia (a prayer)
- slowing the pace and outcome expectations of the meetings
- really listening to what each other was saying and getting to know the context behind what was being said (a spirit of enquiry)[3]
- increased openness to experimentation and doing things a different way
- a willingness to learn as we go
- increased need for patience, and the good and willing spirit of all those involved

[3] This became the foundation of our co-design session.

- flexibility in our approach and thinking about what the next step would be, which contributed to a preparedness to respond to the inspiration of project team members and follow the lead of the person who was carrying the 'warm up' of the group[4]
- dedicated time for the project lead to drive ongoing progress.

One of the unintended results of the project team consumers' involvement in the project and subsequent engagement with whānau was that knowledge and health literacy were built within the whānau, making a difference to their experiences of living with diabetes. They felt empowered and the family culture shifted where the whānau's 20 years of experience of diabetes had not been talked about. Now there are conversations happening where individual experiences are being shared and they are learning from each other.

The content of this case study was contributed and agreed to by all members of the project team.

The project team

Name	Role	Email address
Ants Whaipakanga	Consumer	anthony.whaipakanga@ttoh.iwi.nz
Margaret Callaghan	Consumer	Withheld
Martin Munyaradzi	Project team member Hauora Heretaunga	martin.munyaradzi@ttoh.iwi.nz
Mary-Ann De La Haye	Project team member Hauora Heretaunga	mary-ann.delahaye@ttoh.iwi.nz
Ina Graham (resigned)	Project team member Health Hawke's Bay	Withheld
Rebecca Mackenzie	Project lead Health Hawke's Bay	Rebecca.mackenzie@ttoh.iwi.nz
Olivia Mador-Puna (maternity leave from March 2021)	Project team member Health Hawke's Bay	Withheld

References

Battersby M, Ask A, Reece M, et al. 2003. The Partners in Health Scale: The development and psychometric properties of a generic assessment scale for chronic condition self-management. *Australian Journal of Primary Health* 9(4): 41–52. https://doi.org/10.1071/PY03022

Ministry of Health. 2002. *He Korowai Oranga: Māori Health Strategy*. https://www.health.govt.nz/system/files/documents/publications/mhs-english.pdf

[4] This meant not necessarily sticking to roles and responsibilities that were established at the outset of forming the project team.

Appendices

Appendix 1: Initial four-question survey

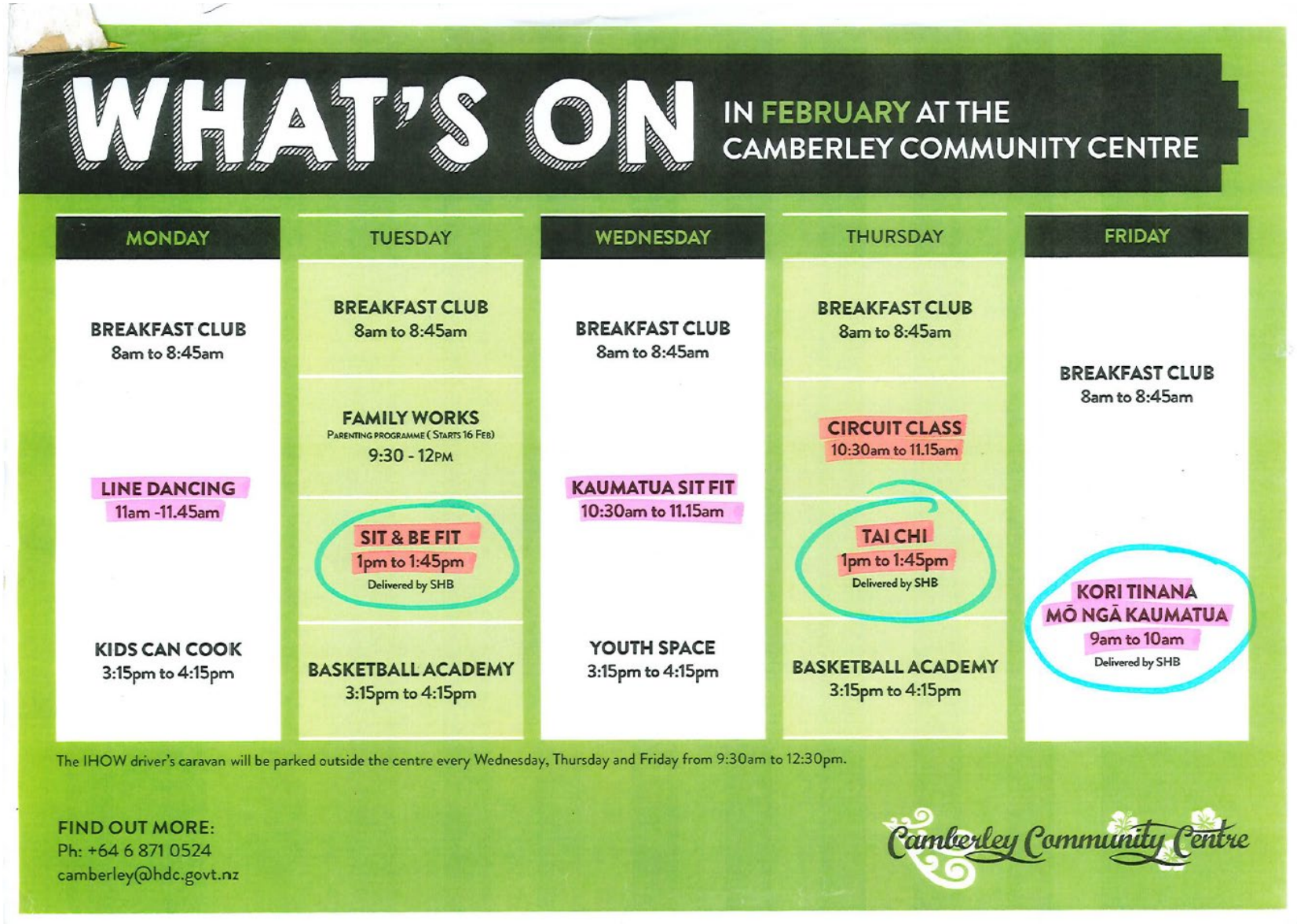
Partners in Care co-design case study

We are doing a co-design project which involves patients and medical staff at Hauora. This project is to find out more information around your diabetes and how we can do things better. We plan to ask you four questions, collect the information, make some changes and have feedback available for you as a participant. This will only take 5 minutes of your time and will be kept confidential. Are you willing to participate?

1. What do you find easy when looking after your diabetes?
2. What do you find difficult when looking after your diabetes?
3. What would help you to manage your diabetes?
4. Would you be interested and available to give us further feedback for this project?
   If yes, record name and contact number.

Appendix 2: Mind map of the hui discussion

Appendix 3: Exercise sessions available for whānau to consider



Appendix 4: Survey to understand self-identified levels confidence, knowledge and empowerment before and after the whānau hui and subsequent activities

Partners in Care co-design case study

We are doing a co-design project which involves you and your whānau and medical staff at Hauora. This is focused on how we can support you to manage your diabetes better and have a better experience of living with diabetes. We are asking you these questions to get a sense of what change you have experienced as a result of your whānau hui with Margaret. This will only take 5 minutes of your time and will be kept confidential.

1. Please rate your **confidence** in your ability to manage your diabetes **before** you had whānau hui and whanaungatanga with Margaret (please circle one).

1	2	3	4	5	6	7	8	9	10
Not at all confident									**Very confident**

Comment

2. Please rate your **confidence** in your ability to manage your diabetes **after** you had whānau hui and whanaungatanga with Margaret (please circle one).

1	2	3	4	5	6	7	8	9	10
Not at all confident									**Very confident**

Comment

3. Please rate your **level of knowledge** about diabetes and managing diabetes **before** you had whānau hui and whanaungatanga with Margaret (please circle one).

1	2	3	4	5	6	7	8	9	10
Not much knowledge									**Lots of knowledge**

Comment

4. Please rate your **level of knowledge** about diabetes and managing diabetes **after** you had whānau hui and whanaungatanga with Margaret (please circle one).

1	2	3	4	5	6	7	8	9	10
Not much knowledge									**Lots of knowledge**

Comment

5. Please rate how **empowered** you felt to interact with health services and manage your diabetes effectively **before** you had whānau hui and whanaungatanga with Margaret (please circle one).

1	2	3	4	5	6	7	8	9	10
Not empowered									**empowered**

Comment

6. Please rate how **empowered** you feel to interact with health services and manage your diabetes effectively **since** you have had whānau hui and whanaungatanga with Margaret (please circle one).

1	2	3	4	5	6	7	8	9	10
Not empowered									**empowered**

Comment

7. Any final comments

Comment