Primary mental health support for people with diabetes

Ministry of Health – February 2018

Malatest International

Living Well with Diabetes

- The Ministry of Health funded two projects that aimed to improve access to mental health services for people with poorly controlled diabetes: Northland and Tairāwhiti
- The projects were funded for a finite term with the expectation that they would lead to sustainable changes
- Target groups for the project were people with poorly controlled diabetes (defined as HbA1c level of 64mmol/mol or higher) and an indication of mild to moderate mental health issues.
- Teams had flexibility to design the projects to meet local needs

The aim of the evaluation

To learn from the projects about the ability to achieve improved health outcomes for people with poorly controlled diabetes and for children and youth with type 1 diabetes through better access to primary mental health care.

Mixed methods – interviews, observations, HbA1c and weight data

Tairāwhiti

Four different models to reach whaiora:

- ‘Main-stream’ general practice with options:
  - To refer for packages of care
  - Social worker based at the practice
  - Refer to kaiawhina (located at a different practice)
  - Support from DHB based diabetes nurse specialist to build practice skills
- Kaiawhina model – autonomous but integrated with the practice. Awareness and recognition of the kaiawhina model

Tairāwhiti – what changed for practices

Mainstream general practices

- Few referrals because of: Lack of clarity about the project, lack of resourcing, reluctance to engage, staff turnover

But there was:

- Raised awareness for some of mental health/wellbeing in diabetes care
- Improved integration between primary and secondary care – diabetes specialist nurse helped raise skills and awareness of primary care team
- Social worker – helped take the pressure off people with diabetes by arranging housing etc

Tairāwhiti

- Kaiawhina model – autonomous but integrated with the practice (Puhi Kaiti).
- Kaiawhina – worked closely with diabetes specialist GP, clinical care nurse and practice manager to provide continuity of care and consistent communication and support for whaiora
- Supported 23 whānau

Tairāwhiti – the diabetes journey for whaiora

- Diagnosed and sent home with medication

  They threw me some pills and that was it… I was thrown in the deep end. (Whaiora)

- Initially had little understanding of importance of medication and lifestyle changes – may be described by providers as denial
- Don't always answer the door or the phone

  I liked her (nurse) but I didn't want to take the medication. I didn't have the heart to tell her, so I made sure I wasn't home when she came. (Whaiora)

- Dealing with health care staff while in crisis
- Barriers to management of diabetes –financial, confidence, transport

  It is a problem because I have bills and other things to pay. And then I only have $40 left and that is for our kai. (Whaiora)

- Having the right people providing care/support is critical – whakapapa, good rapport, trust, laughter

Tairāwhiti – the kaiawhina role

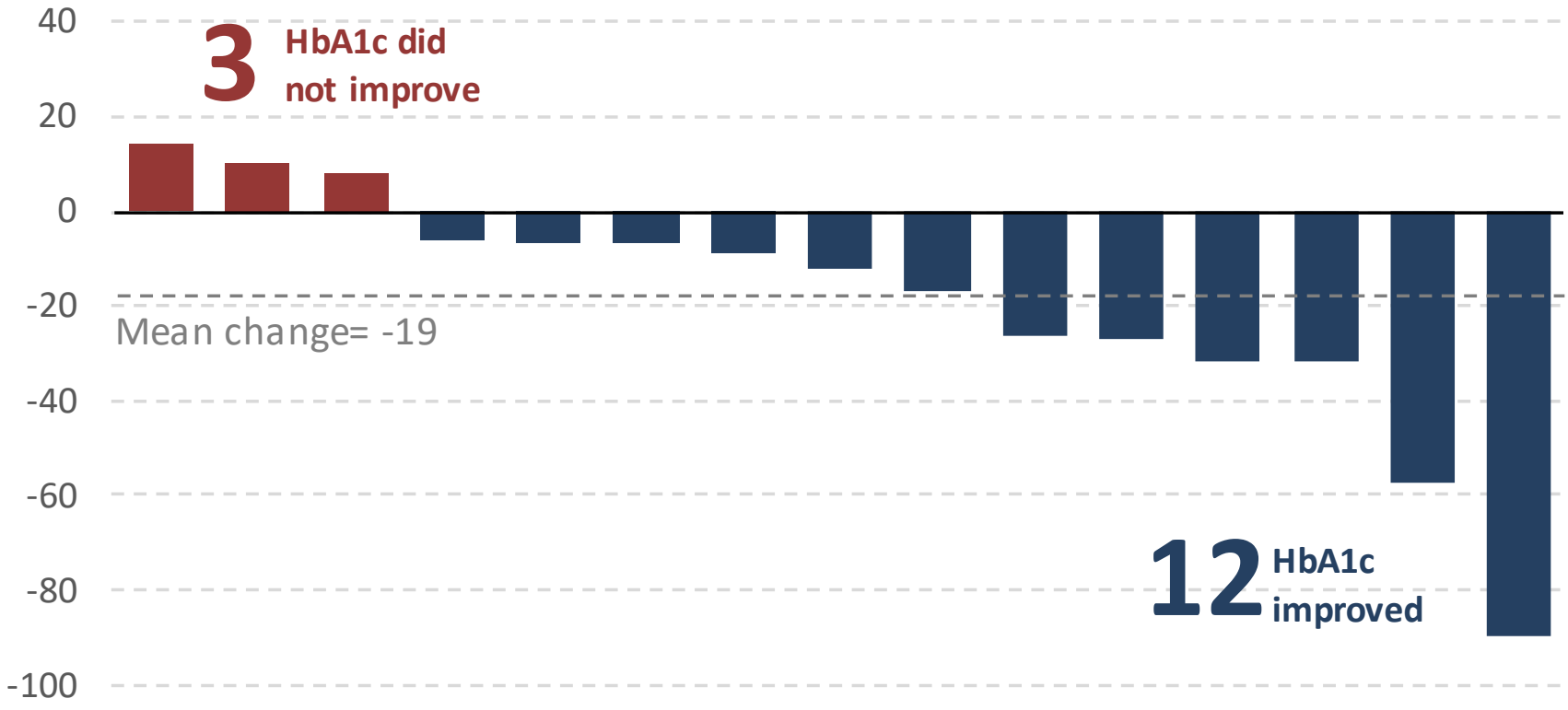
- Having the right person in the role to get a ‘foot in the door’
- Mental health background meant kaiawhina was ‘not afraid to ask’
- Continuity and tenacity – developing relationships

  Over time I was able to come into her house, sit down and have a good korero about what’s going on, what’s actually happening. Her partner comes in and we have a good korero but we always bring it back to diabetes (Kaiawhina)

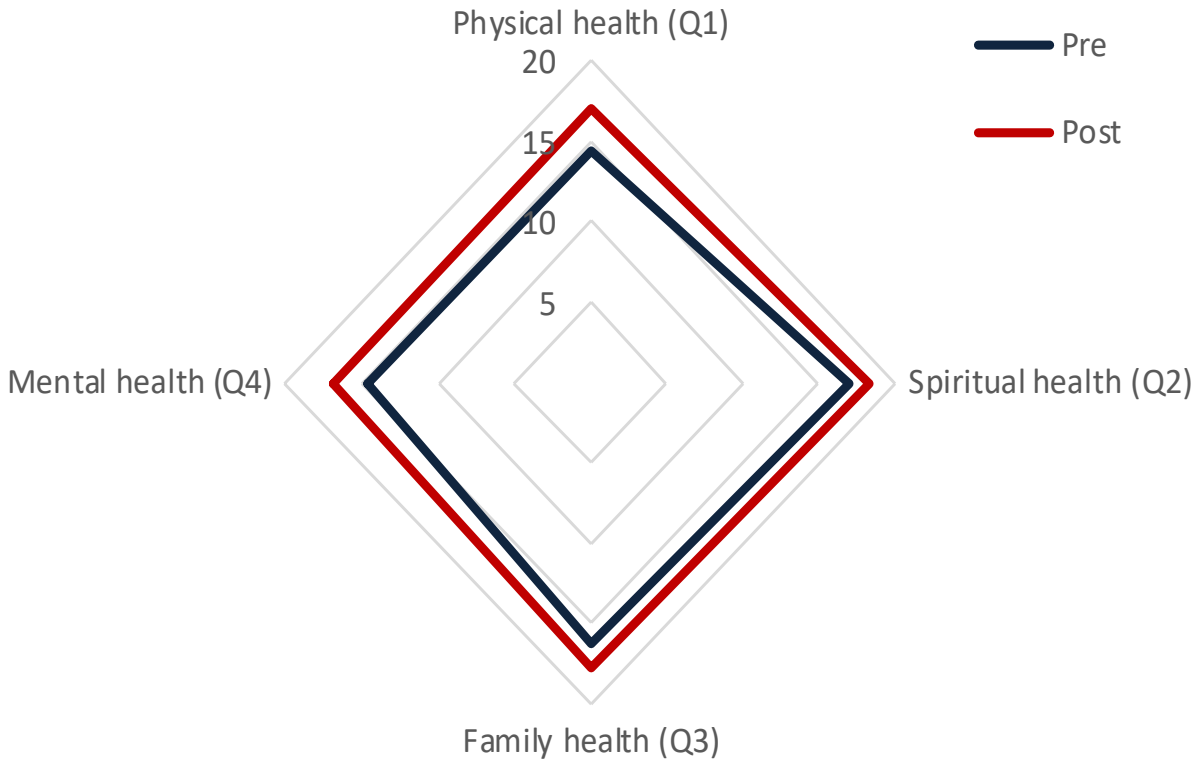
- Practical support –WINZ, travel to the hospital
- Linking with other services –Supergrans, cooking, gardening
- Walking the talk –visibly living a healthy and active life

  He has got a team of people doing the walks around town together, and then up the Kaiti Hill. See how many times you can go up Kaiti Hill a day. It is not as hard as you think it is. (Whaiora)

Pre- and post-HbA1c measures for whānau engaged in provider 1's Living Well with Diabetes programme (n=15)

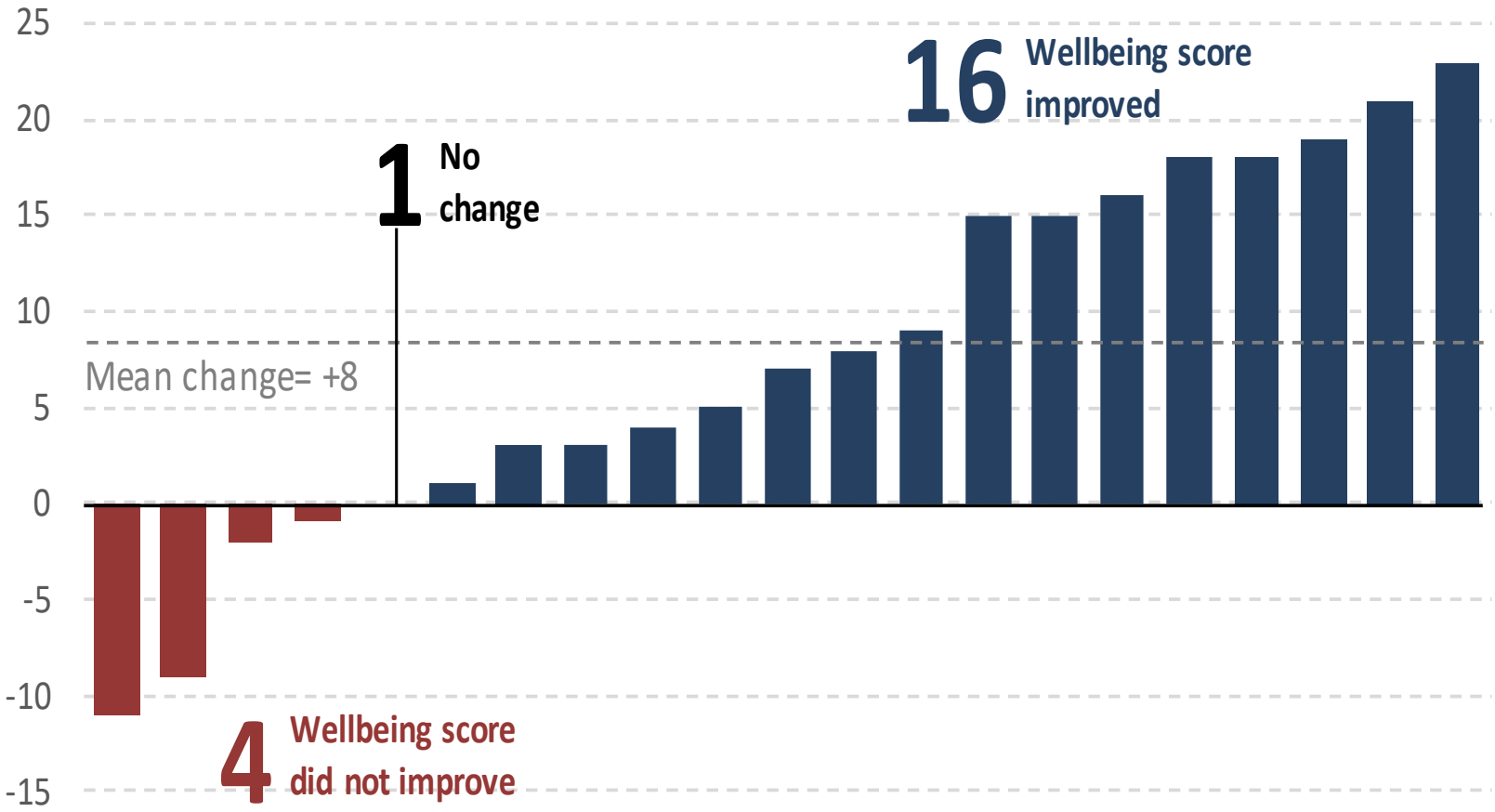


Tairāwhiti – changes in Hua Oranga



- Mean pre and post-scores for 21 people – one provider
- Scores are out of 80
- Larger scores are more positive
- Consistent results for other providers but very small numbers

Figure 3: Pre- and post-Hua Oranga for whānau engaged in provider 1's Living Well with Diabetes programme (n=21)



Changes were most marked in the areas of physical and mental health.

Tairāwhiti – what worked

- Visual aids – i.e. charts showing HbA1c levels changing

  It really helped when he (doctor) would draw stuff for me. Something I could see. (Whaiora)

- Consistent kaiawhina visits –sense of humour, trust, practical support

  He gives me a bit of a growling! (Whaiora)

  We don't have a car. If I need to go to the hospital I just call (Kaiawhina) and he will come and pick me up.(Whaiora)

- Flexi-fund – provision of good walking shoes
- Positive role models – people in the community who successfully managed diabetes
- Community initiatives – Kaiti Hill Challenge
- Programme resources - car available to kaiawhina

Tairāwhiti – what did not work

For whaiora

- Left to their own devices
- Different advice from different doctors/nurses
- Lack of understanding about seriousness of diabetes
- Plethora of medication –up to 32 pills twice a day

For providers

- Connecting with whaiora by phone
- Lack of information about the programme
- Lack of engagement with the programme

When someone starts saying you must do this, you must do that -I get hoha. But I promised (Kaiawhina) I would try my hardest to do that. That I would change my lifestyle. I am not in denial anymore…There is no excuse

Northland

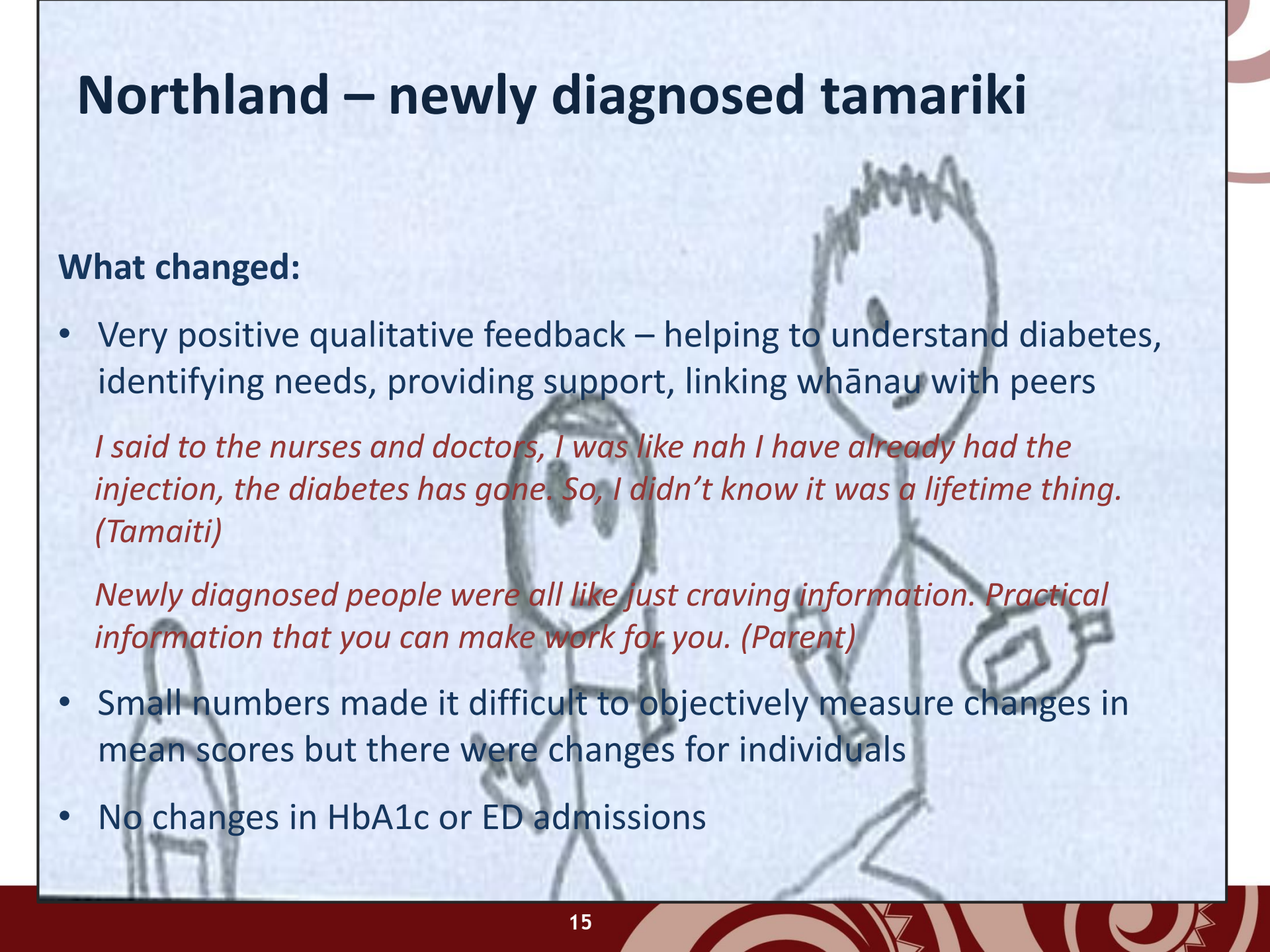
New approaches for tamariki, rangatahi, adults

The tamariki programme - Te Ahuatanga o te mea mate huka programme - Aimed to improve access to professional support for whānau with tamariki with newly diagnosed or poorly controlled type one diabetes or whānau who have tamariki with poorly controlled type one diabetes

Rangatahi programme – Company of Giants theatre group

The adult programme – a selection of programmes to promote wellbeing and address mental health issues

Northland – newly diagnosed tamariki



What changed:

- Very positive qualitative feedback – helping to understand diabetes, identifying needs, providing support, linking whānau with peers

  I said to the nurses and doctors, I was like nah I have already had the injection, the diabetes has gone. So, I didn't know it was a lifetime thing. (Tamaiti)

  Newly diagnosed people were all like just craving information. Practical information that you can make work for you. (Parent)

- Small numbers made it difficult to objectively measure changes in mean scores but there were changes for individuals
- No changes in HbA1c or ED admissions

Northland – 'poorly-controlled' tamariki

What changed:

- Outreach support to identify barriers, promote understanding, bridge between whānau and the clinical team

  She has been a great support because I could just ask her, can you come into my meeting just to be my mentor and just listen. (Parent)

- Addressing barriers to care that included mistrust of health services and feeling judged

  And we can have the strictest diet, we can do everything that is required of us and we still get, if she ends up in hospital we always get… that it is medical neglect. (Grandparent)

- Communicate with tamariki

  She [tamaiti] takes notice of what (kaiawhina) says. Whereas for us she is inclined to say I don't have to do that…but (Kaiawhina) will say you need to have it… so (tamariki) takes a little bit of heed to that. (Parent)

Northland – 'poorly-controlled' tamariki

What changed for tamariki:

- Benefits included learning new ways to manage T1DM and gaining support from others who understood what it is like to live with diabetes:

  I really enjoy it. (The programme) gives me new ways and helps me a lot more. How to deal with it (T1DM) and how to live with it. (Tamariki)

  (The programme) made everything a lot easier than it was…They understood where I was coming from. (Tamariki)

Northland – the key elements of Te Ahuatanga o te mea mate huka

- The kaiawhina's background and experience, her clarity about her role and ability to engage with whānau
- The outreach focus of the programme
- The kaiawhina's role in:
  - Providing practical support and tailoring to individual whānau needs
  - Connecting whānau with each other for peer support and mentoring
  - Supporting the decisions of the clinical team and helping whānau to communicate and understand information about diabetes
  - Improving communication and engagement between whānau and health and social services/organisations

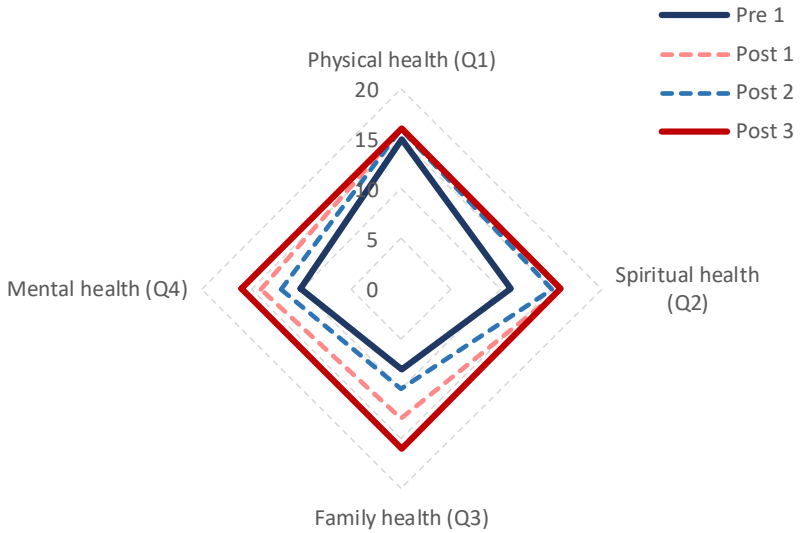
Northland – rangatahi programme

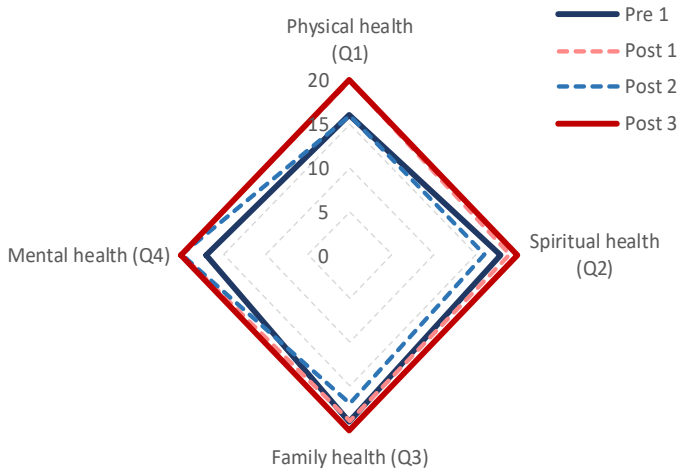
- A series of workshops delivered by the Company of Giants theatre group
- The initial service specification was to form strong, meaningful and lasting relationships between the rangatahi as the core members of the group as a support network
- Three workshop series attended by small numbers of rangatahi
- One young person explained that the difference between the Company of Giants workshop and other workshops was the focus on growth and goals and not solely on diabetes

- https://m.youtube.com/watch?v=tbIc8Z_26KY

Northland - rangatahi

- **What we learned – supported increased wellbeing**





In the third workshop, I found compared to the second one that there was a lot more revolved around what type one diabetes is to ourselves as individuals and ways that we can talk about our experiences and share those experiences with other people... being able to capture what type one diabetes is to us as individuals and being able to portray that and our lived experience to our family and friends, and the people at the DHB…it was really good. (Rangatahi)

Northland – Rangatahi – benefits for whānau

You have your own kind of ideas and feelings when your child is diagnosed so attending that, presentation, it just made you more aware of what your child and other children are going through, you know. From their perspective. So that was enlightening.

It made her feel that she's not the only one, … I do think it might have influenced her just a little bit.

Since that production, my husband has actually become more involved with my [child's] diabetes. Because he's always just kind of been in the background. It has made a huge difference. He actually took her to an appointment the other day which, he just doesn't do. And he's stopped buying [unhealthy] things.

Northland - rangatahi

What worked:

- Innovative approach
- The Company of Giants team and networks
- Clinical team presence
- Flexibility to respond to rangatahi in the group
- Rangatahi focus
- Peer support

Challenges:

- Recruitment
- Lack of clarity about focus on diabetes or on well-being
- Initial lack of comfort in talking about diabetes
- Clinical team presence
- Transitions from the programme

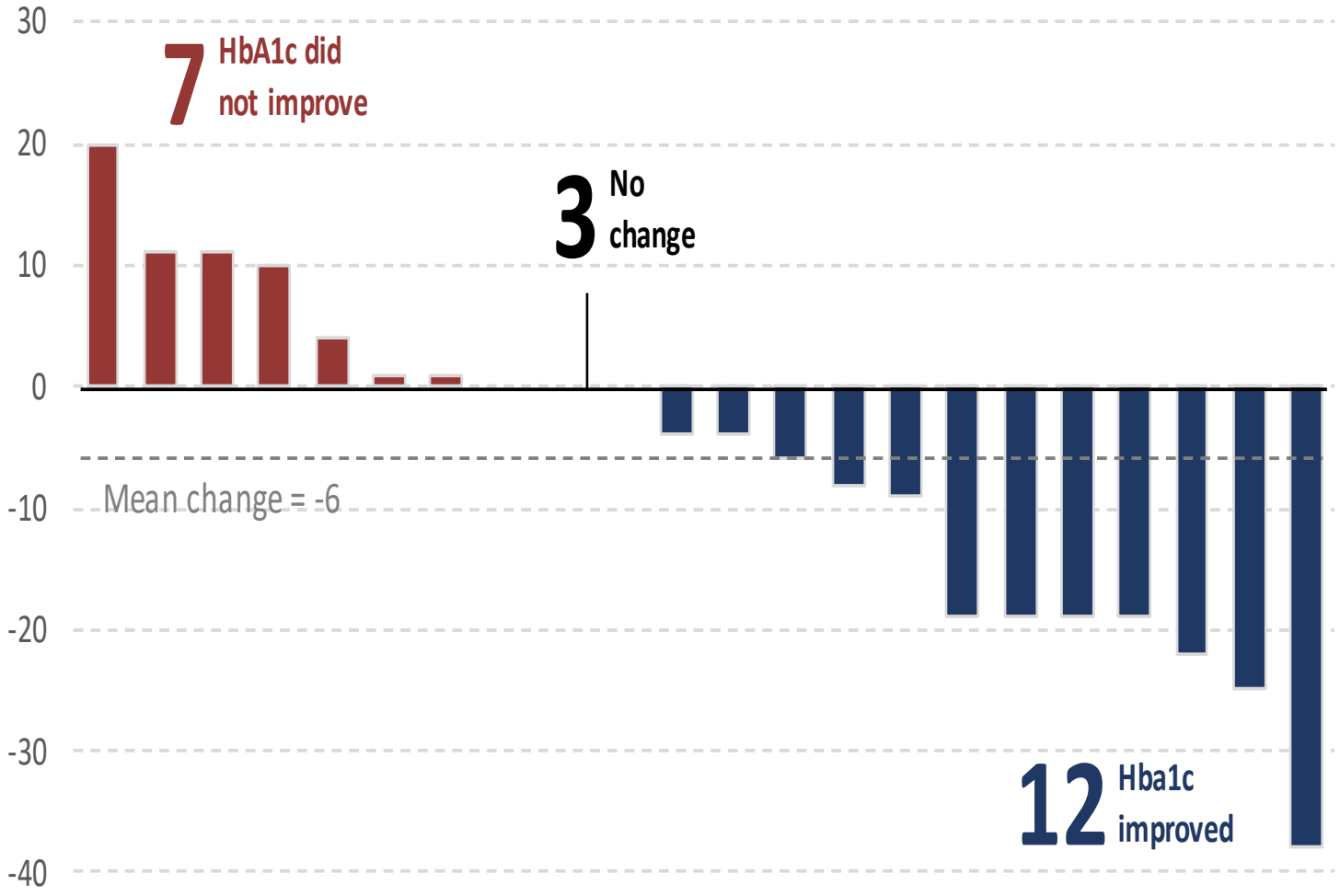
I think probably the biggest one was being a lot happier with the condition that I have. Like, before it was sort of like I've been sentenced with this thing, and I felt kind of like, alone. (Rangatahi)

Northland – adult whaiora

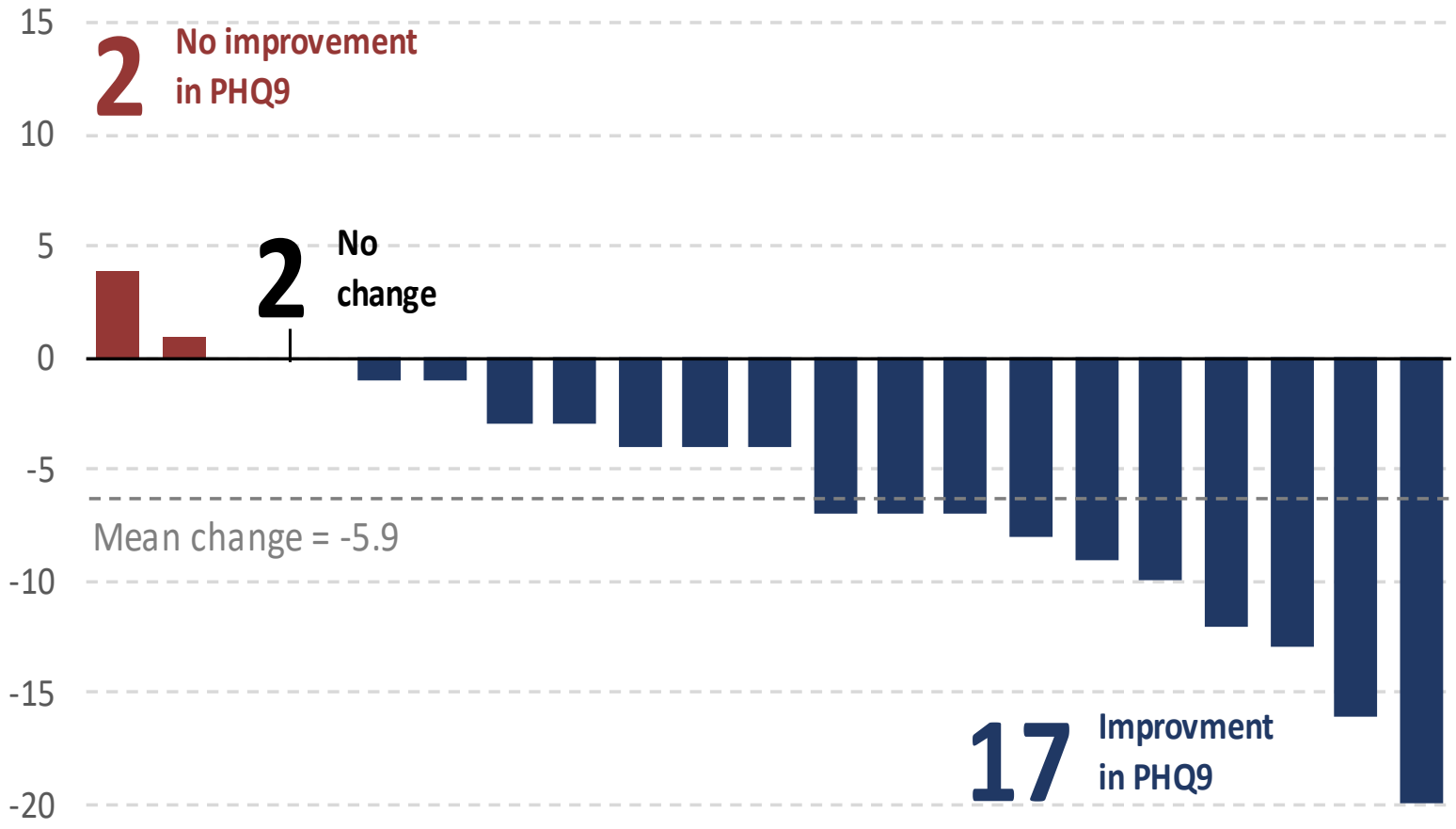
Who received an intervention

- 156 people recorded in the database – 52 from Manaia practices and 104 from Te Tai Tokerau practices
- 67 had an intervention recorded – 27 (52%) from Manaia and 40 (38%) from Te Tai Tokerau
    - 58% Māori, most aged over 40 with 57% over 60 years, 60% male and 40% female

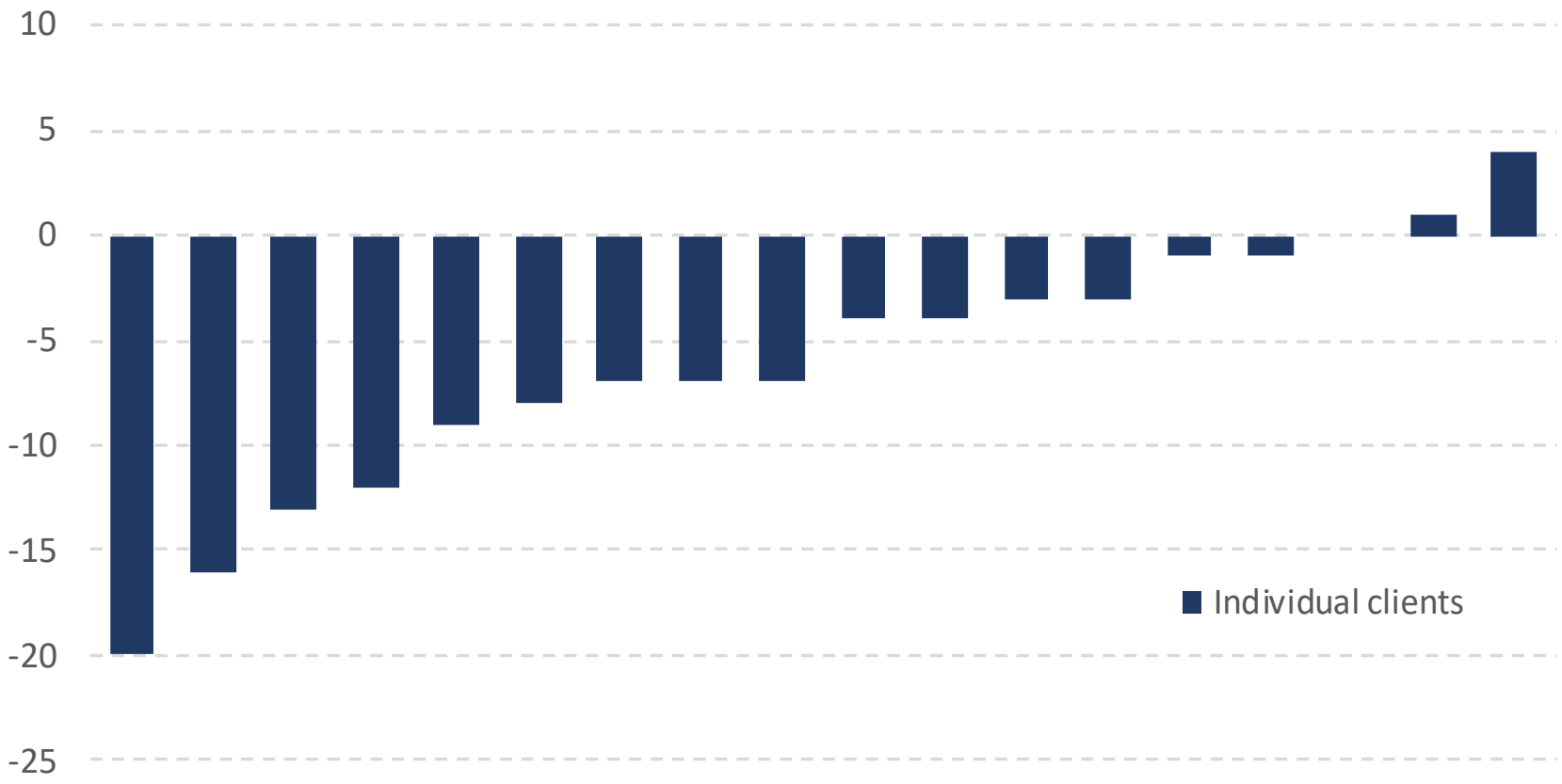
Changes in pre- and post-HbA1c measures for Northland adults (n=22)



Changes in PHQ-9 scores before and after participation in Northland's adult diabetes programme (n=21)



Northland – adult whaiora – changes in PHQ-9



- Available for 18 people – consistent improvements
- Numbers too small to compare types of interventions and changes in HbA1c

Northland – what worked

- Home visits by the Kaupapa Māori community nurse – getting to know whaiora and whānau
- Use of the three tools to support holistic assessment: Whānau Tahi, Hua Oranga, Whakaahua
- Group sessions – whaiora learning and supporting each other
- Use of technology – online tools and GP consultations by Skype
- Flexi-fund – used but lack of detail about what it was used for e.g travel, hair and beauty, groceries, entertainment, bills.

Northland – what did not work

For whaiora

- Remote, rural location
- Feeling that they were left alone
- Lack of rapport
- Lack of rapport with health services

For providers

- Remote, rural locations
- Limited resources
- Patchy wifi access – limits the use of apps
- Interventions too complex and not accessible in some locations
- Lack of confidence in interventions – reluctance to share

What did we learn about improving outcomes for people with diabetes

- **Prevention** - connecting with whaiora pre-diabetes
- **At diagnosis** – time to fully explain diabetes and diabetes care for as many sessions as it takes
- **Ongoing support:**
  - Strengths-based
  - It's about holistic wellbeing not just mental health
  - Outreach support where required to identify and address barriers to change and bridge the gap to clinical support
  - Flexi-fund (putia) helps address barriers to improving wellbeing

What did we learn about changing practice

- **Time** – an excuse or a lack of prioritisation in models of care.
- **Attitude changes** – Replacing ’horror-stories’ with recognition of strengths-based approaches, whaiora and whānau goal setting, reduction in ‘victim-blaming’.
- **Health literacy** – interviews with whaiora/whānau demonstrated incomplete understanding of diabetes. Health literacy is the health providers responsibility. Kaiawhina can bridge the gap.
- **Mental health** – lack of confidence in having discussions about mental health and knowledge of approaches.
- **Partnerships are important** – kaiawhina and clinical partners, integration between primary and secondary care, and between primary care and community providers.

What did we learn about design

- Flexibility
- Co-design of service delivery
- Keep it simple
- Alignment
- Sustainability

Thank you from the Malatest team

Dr Debbie McLeod

Director

Debbie.mcleod@Malatest-intl.com

021 872 573

Dr Tania Slater

Senior evaluator

Tania.slater@Malatest-intl.com

021 181 0344