

Co-design Partners in Care case study

Engaging with adolescents who manage chronic health conditions (Bay of Plenty District Health Board)

Context

Adolescents with chronic health conditions need additional support to successfully access health care services at a time when they are also experiencing the vulnerabilities of being an adolescent.

We wanted to engage with those who have experienced disparities in accessing health care so we could design a service together that responds to their needs, enabling them to better self-manage their health and wellbeing.

The project was carried out in Tauranga by an Adolescent Diabetes Nurse Specialist and a community representative nurse.

Aim

To connect with teenagers who have chronic and potentially life-threatening health conditions, capture their perspectives, and design improvements enabling them to have better access to services.

Engage

We met with a range of senior leaders in their work places. We emailed and talked face-to-face with general practitioners, practice managers, school nurses, and public health nurses to try and widen engagement in the project. Initially we found it difficult to engage with general practices, until we started meeting with the line managers who support them.

We met with five teenage consumers with one or more chronic health conditions, to hear their stories and reflections on the services available to them. It was great to finally engage with them about the project and we encouraged them to take control of it, owning its design.

We also engaged with family/whānau to make sure they understood the aims of the project so they felt comfortable supporting the consumers, and in giving their own opinions. They showed commitment to the project by organising focus groups at venues they were able to access free of charge.

We found it challenging to engage with a broad cohort of consumers with chronic conditions, and it was disappointing that we could not engage with more. There was reluctance from health professionals to encourage consumers to take part in the project.

Our learning from this was to try and engage sooner, and to see if the teenagers themselves could recruit other consumers to join the project.

Capture

We met with five teenage consumers altogether. We met with three of them for the first time at a café. We made plans to stay in touch and meet again in a fortnight, at a place organised by one of

the consumers. They decided to include family/whānau in future discussions, so they could also share their experiences and observations as their teenager was diagnosed and treated.

The consumers connected with each other immediately and were very open in sharing their experiences. They were very motivated by the meeting and discussions about their journeys during and after their chronic health diagnosis and continued care, and how it never goes away.

They discussed the effect of the diagnosis on their relationships with peers and the continual misconceptions associated with other people's inability to understand the complexities of their health conditions. These included experiences with highly qualified health professionals whom they had assumed would have a better understanding of their health condition, and be more accepting of the unrelenting requirements needed for optimal management.

We facilitated focus groups with our consumers, inviting them to connect and discuss their experiences, and encouraged them to make the project their own work.

We used the structure of the 'experience questionnaire' as a basis for the consumers to develop categories of inquiry, to draw out experiences of the different phases of their health journey. These included:

- diagnosis
- first specialist appointment
- outpatient clinic
- future hospitalisations
- building a team of health care professionals
- seeing their GP
- adult service.

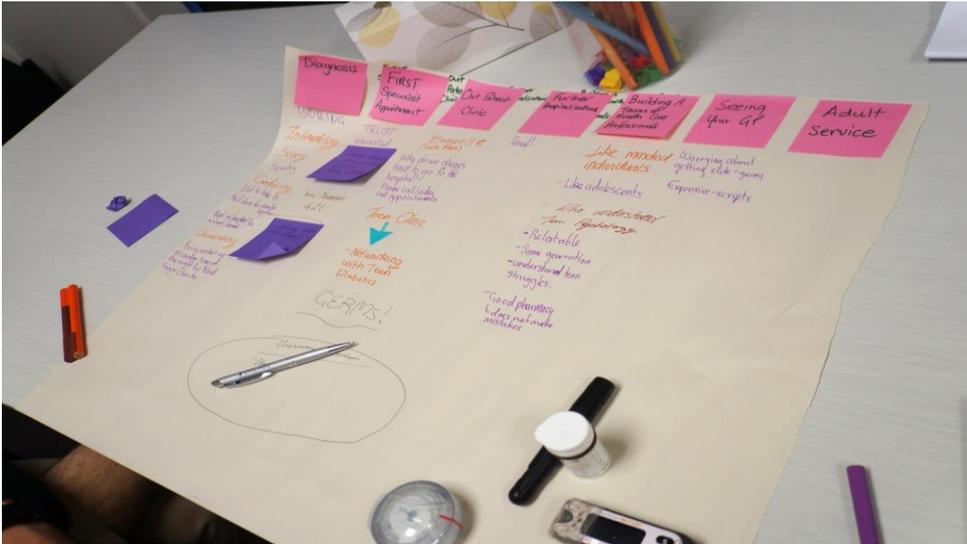
We collated the lived experiences of our consumers and of their family/whānau. From this, the consumers collated important topics and themes, and identified and prioritised the similarities.

As facilitators we were impressed and humbled by the impact of meeting and connecting the consumers, seeing them take control of the project, and the great resources and ideas they produced.

There were some challenges, such as keeping the group on track as their conversations diverted and they were distracted by technology and other factors in their lives. However, overall it appeared to be a very positive and cathartic experience for the consumers. It made us reflect on this as a self-healing process, and the pain and anguish family/whānau often have disguised.

Diabetes fatigue is a real issue, and Bay of Plenty District Health Board (BOP DHB) currently has no designated psychology or dietetic person assigned to support the adolescent and young adult service.

Understand



Themes that came out of the focus groups included:

- Youth as a culture – simply, that it is different to adult culture.
- Feelings at diagnosis – fearful, confusing, emotional, devastating, anger and sadness.
- The first specialist appointment – being able to choose who your doctor is, making it personal, knowing their personality.
- The outpatient clinic experience:
 - communication regarding the appointment
 - the waiting environment (cramped and noisy)
 - the act of waiting
 - arriving at an appointment
 - in the appointment (consultation with the clinician)
 - one size does not fit all.
- Hospital stays:
 - Adult ward stays
 - Paediatric ward stays (staff that you have come to know and trust).
- Admissions to hospital – why notes are accessed by allied health team members looking after consumers' diabetes, when the consumer had been admitted for another health condition.
- Transition to an adult service being patient centred (ie, being able to decide when to change to an adult service, given consumers had often built strong relationships with the people looking after them).
- Life with diabetes:
 - the environmentally-unfriendly packaging (a lesson was learnt that some equipment is biodegradable)
 - choice of a team: diabetes nurse, doctor, pharmacist, physiotherapist
 - choice of a group of people to be on the diabetes journey with them

Another meeting was planned with consumers sharing their stories, with some family/whānau involved as well. Key points consumers wanted family/whānau feedback on included:

- What allowance or financial supports are they accessing? How is this enabled, and is it a smooth process?
- What is the process for prescriptions and repeats, and how that is managed?
- What is it like living with diabetes?
- How do family/whānau feel about the transition to the adult service?

Improve

We learnt that teenage consumers and their families/whānau are navigating a pathway in the health care system which runs parallel to the service offered and this pathway doesn't always connect. Health care professionals can be under the illusion it is connecting all the time like a river and its tributaries; however we have learnt this is often not the case.

Examples of this include teenagers not being able to collect all their medication on their scripts at one time even when the script is 'Certified Exception Supply in Full', and teenagers being given the incorrect pump supply consumables when the script is presented to the pharmacy.

We will raise these issues with the Pharmacy Committee and highlight the difficulty for teenagers in not being allowed to pick up their supplies in full.

One consumer would like to make a video as a resource for other teenagers who are newly diagnosed with Type One Diabetes. We will look at how we can help make this happen, as well as other ways to provide more support to teenagers with chronic health conditions, such as building in a mentoring aspect to health care provider roles, or setting up a self-sustaining support group run by young leaders.

We would also like to find a way to sustain this consumer group, as it has proven so valuable.

Measure

We had hoped to have one or two pharmacies act as champions for insulin pump supplies for local areas, however after testing the idea, we found that this was not possible.

We are yet to test the remaining changes we hope to implement.

Working as a co-design team

We really enjoyed working on the project. We were surprised and delighted with the response from the teenage consumers, as they were so motivated, bright and cheerful, and eager to get along with anyone who listened to their story, and had great innovative ideas to contribute.



The project team

Name	Role	Email	Organisation
Zoe Woods	Consumer	zoelouisewoods@gmail.com	Consumer
Jaden White	Consumer	jadencharrington@gmail.com	Consumer
Makenzie McKay	Consumer	vholloway@xtra.co.nz	Consumer
Caela Adams	Consumer	gomez.adams@icloud.com	Consumer
Vanessa McKay	Consumer (parent)	v.holloway@xtra.co.nz	Parent
Niki Adams	Consumer (parent)	gomez.adams@icloud.com	Parent
Anne Woods	Consumer (parent)	woodzy99@xtra.co.nz	Parent
Emma Charrington	Consumer (parent)	emma_charrington@hotmail.com	Parent
Ellen Walker	Community Nursing Integration Project	Ellen.Walker@toiohomai.ac.nz	Primary Care: NP Whakatane
Rose Fifield	Adolescent Diabetes Nurse Specialist	rose.fifield@bopdhb.govt.nz	BOP DHB
Sandra Fielding	Clinical Services Manager (Project Sponsor)	sandra.fielding@bopdhb.govt.nz	BOP DHB