Faculty of Health | Te Kaupeka Oranga
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Consumer Workshop/Wānanga – Co-Developing a Digitally Enabled Care Framework for the Community Healthcare Sector: A Participatory Research Approach
Information Sheet for Participants

Kia ora,

This sheet has information about a research project called **Co-Developing a Digitally Enabled Care Framework for the Community Healthcare Sector: A Participatory Research Approach.**

You can ask a support person, carer or another adult who you trust if you need help to read and understand this sheet.

Who is doing the project?

My name is Laurie McLay.

I'm a professor and researcher at the University of Canterbury (UC)

I'm working with Professor Elsamari Botha, Dr Ruth Monk, Professor Ann-Marie Kennedy, Dr Kylie Short, and Associate Professor Cathy Andrew. They also work at UC.

I'm also working with Professor Stacy Wood, Professor Kevin Schulman, and Professor Brian Bollinger. These researchers live in the United States.

Stacy works at North Carolina University, Kevin works at Stanford University (in California), and Brian works at Dartmouth College (in New Hampshire).

Stacy, Kevin, and Brian will travel to Aotearoa New Zealand to do parts of this research.

What is the research about?

We're working on a project to make healthcare better for New Zealanders.

To do this, we're creating a digitally-enabled care framework (DECF). This means using online tools to help doctors to share information with you before, during and after your appointments, check your health, find out what might be wrong, explain health information clearly, and keep track of how you're doing.

The goal of the DECF is to improve Aotearoa New Zealand's community healthcare system (e.g., GPs, district nurses, pharmacies) and make it easier to access for all New Zealanders.

We want to hear from Autistic adults who've used community healthcare (e.g., GPs). You can help by attending a wānanga (workshop).

In the wānanga, we'll share an example of a DECF and some digital health tools. We'll ask for your thoughts and talk together about things like:

- What you like and dislike about each digital tool
- What you would like to change about each digital tool to make it better meet the needs of Autistic people
- Where the tool would fit in the DECF (e.g., pre-, during-, or post-appointment stages, or all of these stages)
- What your ideal digital platform would look like

We've also done a wānanga with health professionals.

The ideas from all the wānanga will help us to create a draft DECF specifically focused on community healthcare for Autistic people. This draft will show what the DECF should include at each step of a community care appointment. It will also highlight what's needed to make sure that the DECF is inclusive, culturally appropriate, and the right fit for Aotearoa New Zealand's healthcare system.

Who can take part in the research?

You can take part in the research if you:

1. Are Autistic (self-identify or formally diagnosed)
2. Are aged 18 years or above
3. Live in Aotearoa New Zealand

What will happen to me if I take part?

If you take part, you'll join a wānanga with up to 19 other Autistic people.

Wānanga will run for 3 1/2 hours. There will be regular breaks.

Wānanga will take place in-person in Wellington and Christchurch. If you would like, you can join the Christchurch wānanga online via Microsoft Teams. Just let Laurie know on the consent form, and she will send you a Teams link closer to the time.

Here's what we will do:

- We'll share some examples of a DECF and digital health tools
- We'll ask for your feedback on each tool (likes, dislikes, changes)
- We'll look at what a DECF should include before, during, and after appointments
- We'll talk about what your ideal DECF would look like

You can share your ideas at any time and in the way that feels best for you. This might include written feedback, drawings, or sharing your ideas verbally. You can share your ideas in a small group or own your own.

Will I be recorded?

Yes, the wānanga will be audio-recorded (and video-recorded for online sessions). Online wānanga will be audio- and video-recorded using Microsoft Teams. In-person wānanga will be recorded using a recording app (Apple Voice Memos). Doing this means that the researchers won't be distracted by trying to remember what you said.

The recordings will be used to make a transcript (a written version of the things we talk about during the wānanga). We will use an AI tool (such as Teams' built-in transcription or Contented) to create the transcript for online wānanga. In-person wānanga will be transcribed from the audio-recording.

Do I have to take part?

You only have to take part if you want to:

- It is your choice, and you can say no
- No one will be angry or upset if you say no
- Even if you say yes, you can change your mind later and stop taking part for any reason
- To do this, you can leave the wānanga at any time (including exiting the online session)

If you decide later that you don't want to take part anymore, you can email Laurie after the wānanga has finished to let her know.

Please note: We can't fully remove your data. This is because what you share may shape what the group talk about. If you do withdraw, any direct quotes from you will not be used in reports.

What will happen to my information?

Here is how we'll keep your information safe:

- Your information, the recordings and notes will be stored securely on university computers with a password
- Only me and the other researchers listed above will know the password
- We'll use the recordings and notes to write up what we talked about
- Once we've written everything down, we'll delete the recordings and notes
- Your information will be kept for 10 years after we write reports, then it will be deleted

We will keep your information private – we'll never share your name or contact details. Instead, we'll replace your name with a code number so no one will know you took part.

Your privacy is important to us. Let us know if you have any questions

How will the research results be used?

The results of this research will be published in academic journals.

Some of the findings might also be shared at conferences and seminars with professionals and researchers. They might also be published in a Masters thesis (a written copy of the project) and shared with the public through the University of Canterbury's library website.

Don't worry - your identity will stay private. If we use any quotes from what you say in the wānanga, they will not have your name, only your code number to keep things confidential.

If you'd like, I can send you a summary of the research when the study is finished. Just let me know, and I'll email it to you. Your email will not be linked to anything you say in the interview.

Will taking part be good or bad for me?

By taking part in a wānanga, you'll help us design a framework to make community healthcare easier to access and use.

Your lived experiences of using community healthcare matter. Sharing your stories and ideas will guide us to create a DCF that better meets people's needs.

This will support the health and wellbeing of everyone in Aotearoa New Zealand – especially communities who are not well supported by the current system.

At the same time, we understand that some things we talk about might be sensitive or bring up difficult emotions.

If you ever feel upset or distressed, you can leave the wānanga at any time. You don't have to tell anyone why if you don't want to.

If you need extra support, you can also reach out to the support agencies listed below:

Hotlines	Contact Information
1737 free confidential emotional support (24/7 service)	To talk to a trained counsellor, ring OR Text: 1737 (freephone) Digital hub with self-help tools and information available at: https://www.1737.org.nz/
Healthline (24/7 service)	To get help from a registered nurse, ring: 0800 611 116 (freephone)

Websites	Contact Information
Mental Health Foundation Crisis Directory	To find contact information for your local mental health crisis team (available 24/7), please visit the following link and select your region: https://mentalhealth.org.nz/help
Te Hiringa Mahara – Mental Health and Wellbeing Commission: Where to Get Support	To find contact information for more helplines, please visit: https://www.mhwc.govt.nz/where-to-get-support/

If you are in immediate danger, please call 111. You can also go to your nearest hospital emergency department.

Who can I get in touch with if I have any questions or concerns about the research?

If you have any questions or concerns about the research, please contact Laurie McLay by email at: laurie.mclay@canterbury.ac.nz

If you'd like, Laurie can meet with you online to chat about what the wānanga will be like and answer any questions you have. Just send her an email and she'll set up a time to meet and send you a Microsoft Teams link.

This study has been reviewed and approved by the University of Canterbury Human Research Ethics Committee (HREC). If you have any concerns or if you want to complain about the research you can contact the HREC by email at: human-ethics@canterbury.ac.nz.

What happens next?

Please complete the survey on the next page.