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,

You are invited to take part in a research study that aims to co-develop a digitally enabled care framework (DECF) for Aotearoa New Zealand's community healthcare system. The DECF will consider how digital tools, including Artificial Intelligence (AI), can be used in community-based care settings to help with things like screening, assessments, diagnosing health conditions, patient education, and monitoring. The goal of the DECF is to make community healthcare more effective and to improve access to healthcare for all New Zealanders. The research team includes Professor Laurie McLay from the University of Canterbury | Te Whare Wānanga o Waitaha (UC; Project Lead); Associate Professor Elsamari Botha (UC), Associate Professor Cathy Andrew (UC), Dr Kylie Short (UC), Dr Ruth Monk (UC), Professor Ann-Marie Kennedy (UC), Professor Stacy Wood (North Carolina State University), Professor Kevin Schulman (Stanford University) and Professor Bryan Bollinger (Dartmouth College).

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

What is the purpose of this research?

This research aims to co-develop a DECF for Aotearoa New Zealand's community healthcare system that is specifically designed to support Autistic people's access to, and engagement, and benefit from community healthcare. To do this, we will partner with potential end-users of the DECF (stakeholders). Stakeholders include healthcare professionals, like GPs, nurses, healthcare leaders and managers, and policy makers, as well as Autistic people, who often face the greatest barriers to getting the healthcare that they need.

To help develop the DECF, we will share an existing DECF to understand which components would be most helpful in supporting access to care. This will include focused discussion and feedback on the pre-, during-, and post-appointment stages. During the workshop, we will also share examples of existing digital tools – including AI technology – that could help make community healthcare more accessible, efficient and effective for Autistic people. We will be seeking your feedback on these tools. These might include things like electronic health records, tools to support pre-appointment information sharing, AI tools that support screening or diagnosing health conditions, ways to monitor health remotely like smartphones or smartwatches, and ways to share post-appointment guidance.

What we learn from this study will help us to create a draft version of the co-developed DECF. This will outline what the DECF should include throughout all stages of the community care appointment journey. It will also include components that will help to ensure that the DECF is inclusive, culturally appropriate, and suitable for Aotearoa New Zealand's community healthcare system.

Together, the findings from these studies will allow us to co-develop a DECF that can guide how decisions are made, and how health services are planned and delivered in Aotearoa.

If put into practice, the co-developed DECF could help remove some of the barriers people face when seeking healthcare and support fairer outcomes for everyone in Aotearoa – especially for communities that have often missed out on receiving the care that they need to stay healthy.

Why have you received this invitation?

You are invited to participate in this research because you identify as Autistic, and (1) you have responded to a request for participants, or (2) other people shared information about this study with you because they thought you might be interested in participating.

Your participation is voluntary (your choice). If you decide not to participate or to withdraw, there are no consequences. Your decision will not affect your relationship with me, UC, or any member of the research team.

What is involved in participating?

If you choose to take part in this research, you will be asked to attend a co-design wānanga (workshop). This will be a half-day session with up to 19 other Autistic people, where you will be supported to share your thoughts about what a DECF for Aotearoa New Zealand's community healthcare system should look like and types of digital tools that can support access to healthcare and healthcare outcomes for Autistic people. You are welcome to invite a support person to attend the workshop, should you wish to do so. We have also conducted a separate wānanga with healthcare professionals.

Wānanga will take place in-person in Wellington and Christchurch. Christchurch wānanga will also have an online attendance option (via Microsoft Teams). Professor Laurie McLay will share a Teams link with all consenting participants before the wānanga starts. You are also welcome to bring a support person with you to the wānanga.

The wānanga will involve the researchers introducing ourselves and other members of the research team. We will explain how the wānanga will work and answer any questions you may have. Then, we will facilitate a group discussion. The discussion will focus on developing a DECF for the community healthcare system in Aotearoa, and what this should look like across the pre- to post-appointment phases of community care visits. We will share some examples of existing digital tools and discuss the things that you like and dislike about these tools, and any areas for improvement. You can choose to share your ideas verbally and/or by writing things down. The wānanga will run for 3 1/2 hours. Regular breaks will be scheduled throughout.

Will the wānanga (workshop) be recorded?

In-person and online wānanga will be audio-recorded (and video-recorded for online sessions). These recordings will be used to create a transcript (a written version of discussions). Online wānanga will be recorded using Microsoft Teams, which will also automatically transcribe the meeting. In-person wānanga will be audio-recorded using a digital audio recording application (Apple Voice Memos). Recordings will be deleted from the recording platform/application as soon as practicable after transcription. All recordings and transcripts will be securely stored on a password-protected University of Canterbury network drive and will only be accessible to the research team.

Another person [Taylor Scott; research assistant] will assist with transcription. They will sign a confidentiality agreement before listening to the recording.

Are there any potential benefits from taking part in this research?

By participating in this research, you will be helping us to design a framework that aims to make community healthcare easier for people to access and use. As someone who has experience using the healthcare system in Aotearoa, your views are really important. Sharing your stories and ideas will help us to develop a DECF that better meets the needs and preferences of consumers. In this way, the DECF will improve health and wellbeing for everyone in Aotearoa, especially for communities who haven't always been well supported by the current system.

Are there any potential risks involved in this research?

When you attend the wānanga, you may recognise other participants. If you identify others that you know at the wānanga and are uncomfortable with this, you may withdraw (please see below) without providing any reason.

Some things we talk about in the wānanga may involve sensitive topics, such as your past experiences with accessing and using community healthcare. Thinking about and sharing these experiences may cause some participants to become upset, distressed, or experience other negative emotions.

If you become upset or distressed, you can leave the wānanga at any time. You do not have to tell the researchers why if you do not want to. You might also want to contact 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 <u>immediate danger,</u> please call 111. You can also go to your nearest hospital emergency department.

What if you change your mind during or after the study?

You are free to withdraw at any time. To do this, please feel free to leave the wānanga at any point (including exiting the online session). You may also email Professor Laurie McLay after the wānanga has finished and say that you wish to withdraw and they will remove your data where possible.

Please note that the way wānanga work makes it difficult to remove data. Anything you say during the wānanga will affect what other participants talk about. Also, the researchers will not be able to "forget" what they heard during the wānanga. If you withdraw, it will not be possible to completely remove your data, but any direct quotes you make during the wānanga will not be mentioned in study results.

What will happen to the information you provide?

We will ask each participant to agree not to share information about the group with people who do not attend the wānanga. This includes sharing the names of others that attended the wānanga, any information shared by others, and sharing of information outside of the wānanga. If you are unable to agree to this, you will not be able to participate.

All of the researchers will keep all participants' identities, and the information they provide during the wānanga confidential (private). To make sure that your identity is not known to anyone outside the research team, we will store signed consent forms separately from the focus group transcript and notes. Your name will be changed to a code number wherever it appears in the transcript. We will store the file that links your real name and your code number individually on a password-protected, secure device.

All study data will be stored in password-protected files on UC's computer network or stored in lockable cabinets in lockable offices on the UC campus. All data will be destroyed 10 after completion of the study/publication of study findings. Professor Laurie McLay will be responsible for making sure that your data is only used by members of the research team for the purposes mentioned in this information sheet.

It is possible that additional academic researchers and postgraduate research students may be added to the research team at a later stage. If they do, they will have to sign a confidentiality agreement, or they will only be given access to anonymised data (meaning nothing that identifies you). Any additional research team members will be informed of all ethical requirements. If they are not prepared to comply with these, they will not be added to the research team.

How will the results of the study be published?

The results of this research will be published in peer-reviewed academic journals and a community report. Results may also be presented during conferences or seminars to wider professional and academic communities, or published in a Master's thesis (a written project). The thesis will be available to the general public through the UC library website.

You will not be able to be identified in any publication. Published results may include direct quotes you make during the wānanga. These will be presented alongside your anonymous code number to make sure that you cannot be identified.

If you would like, I will send a summary of the research to you at the end of the study. If you provide an email address for this purpose, it will not be linked to your wānanga contributions.

Who can you contact if you have any questions or concerns?

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

This study has been reviewed and approved by the University of Canterbury Human Research Ethics Committee (HREC). If you have a complaint about this research, please contact the Chair of the HREC at human-ethics@canterbury.ac.nz).

What happens next?

After reading this information sheet, you may choose to read the plain-language version on the next page, or skip it and go straight to the survey.