Planning and enabling meaningful public and patient involvement in research

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Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

Dementia Prevention Research Clinic

Christchurch
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Dementia Prevention Research Clinics

Recruit a large *cohort* of individuals from Aotearoa New Zealand with:

- ***mild cognitive impairment (MCI)***
- **the *earliest stage of Alzheimer's disease***
- ***healthy older adults***

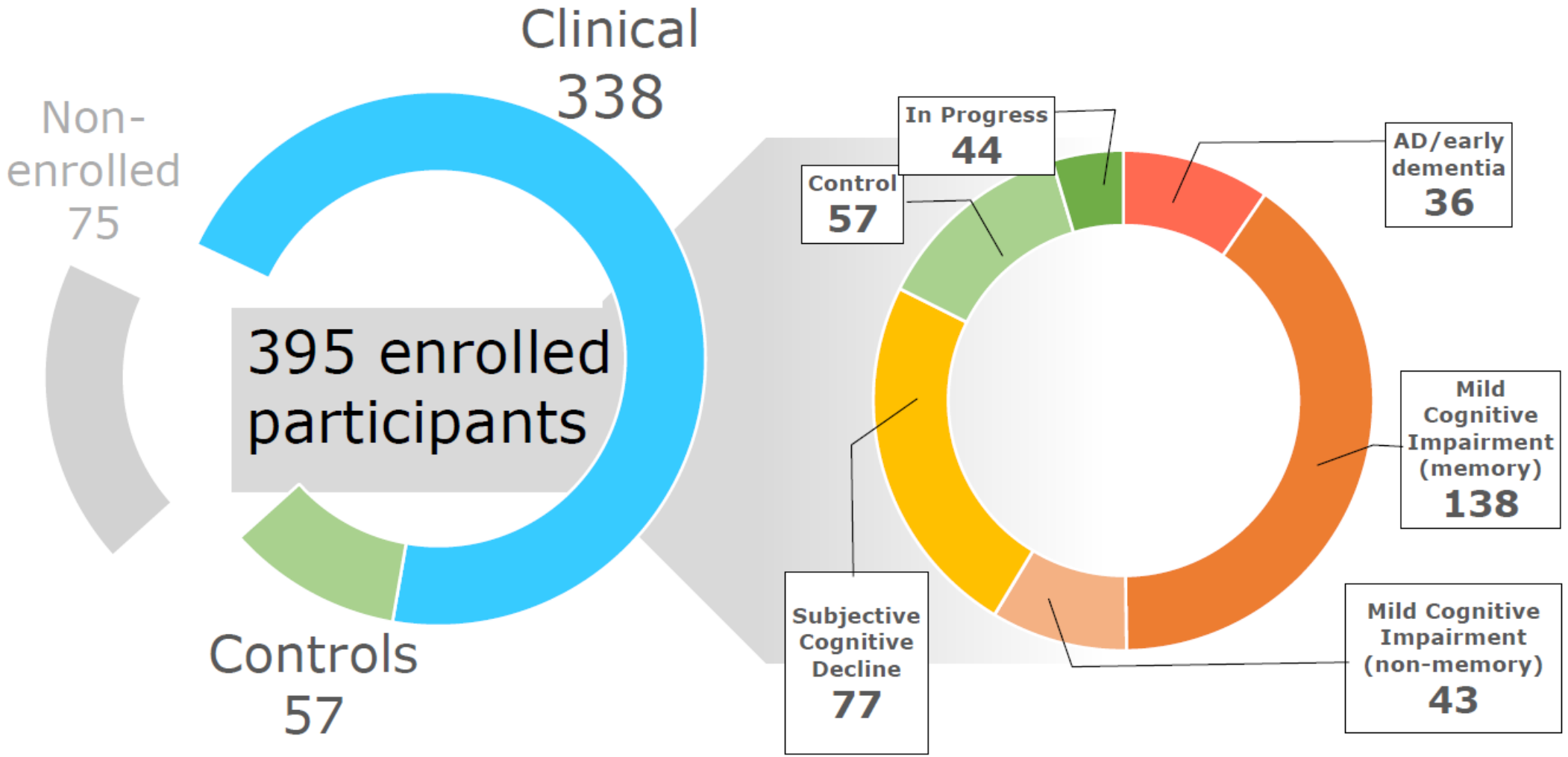
to be involved in longitudinal study (10 years)

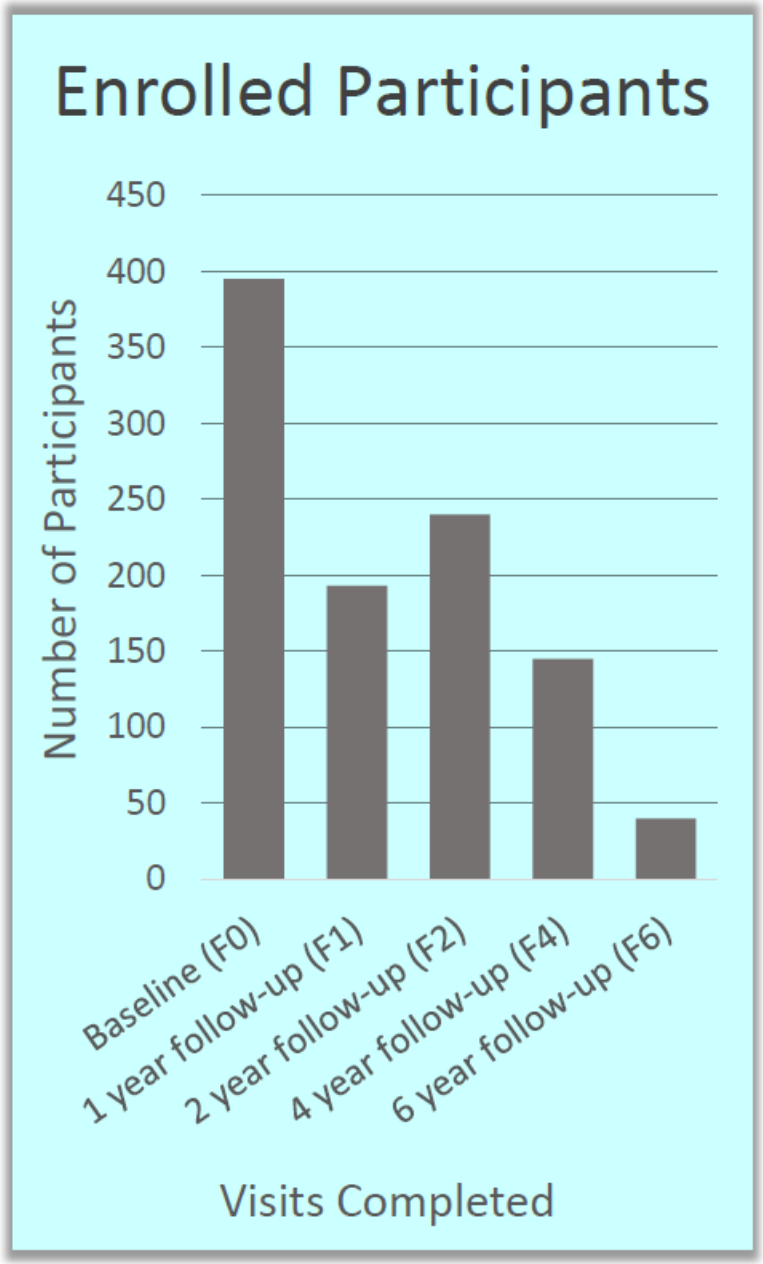
Dementia Prevention Research Clinic: Aims

1. To identify a 'biomarker signature', or pattern, that predicts progression from MCI to AD, and that affects rate of progression in a NZ cohort
2. To understand the experiences of individuals and their whānau living with mild cognitive impairment and dementia
3. To investigate and identify mechanisms underlying the development of these conditions

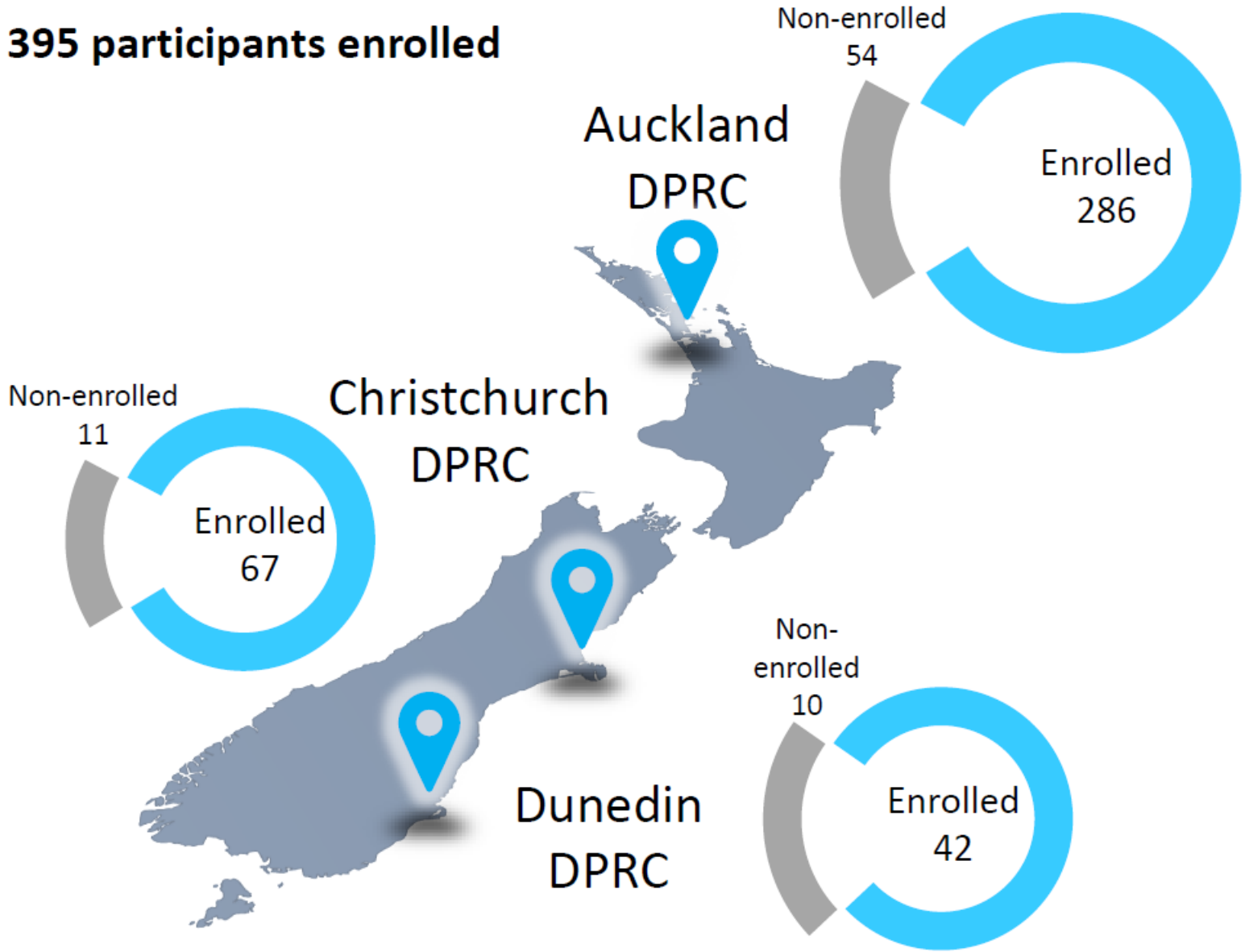
Tippett et al., 2022

470 participants assessed





395 participants enrolled



Benefits of involving participants in dementia prevention research

- Empowerment
- Insight and perspective
- Increased trust
- Improved participation
- Better understanding of participant journey

Feb 2023
Brief introduction of the idea in participant information event

April/May 2023
Email to invite participants for a workshop

1st Workshop in June 2023

- 24 Study Participants
  - ✓Control
  - ✓SCD
  - ✓MCI
  - ✓Dementia
- 11 Study Partners

Participant Involvement: A Spectrum

Influencing study design

Collecting data

Analysing data

Interpreting data

Recruiting new participants

Disseminating research findings

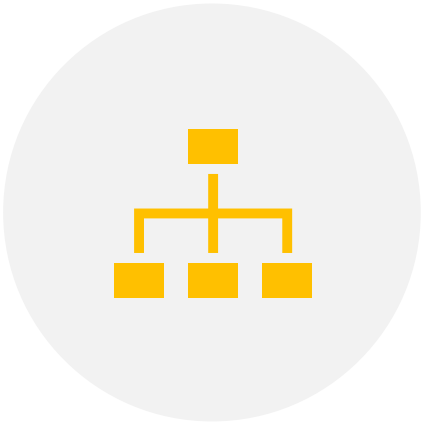
Which of these components would you like to be involved?

How can we ensure your voice is heard?

Participants told us…

THEY ARE INTERESTED IN OUR IDEA OF SETTING UP A PARTICIPANT ENGAGEMENT GROUP

“VARYING STAGES IN INVOLVEMENT, DEPENDING ON SKILLS AND CAN BE FLEXIBLE”



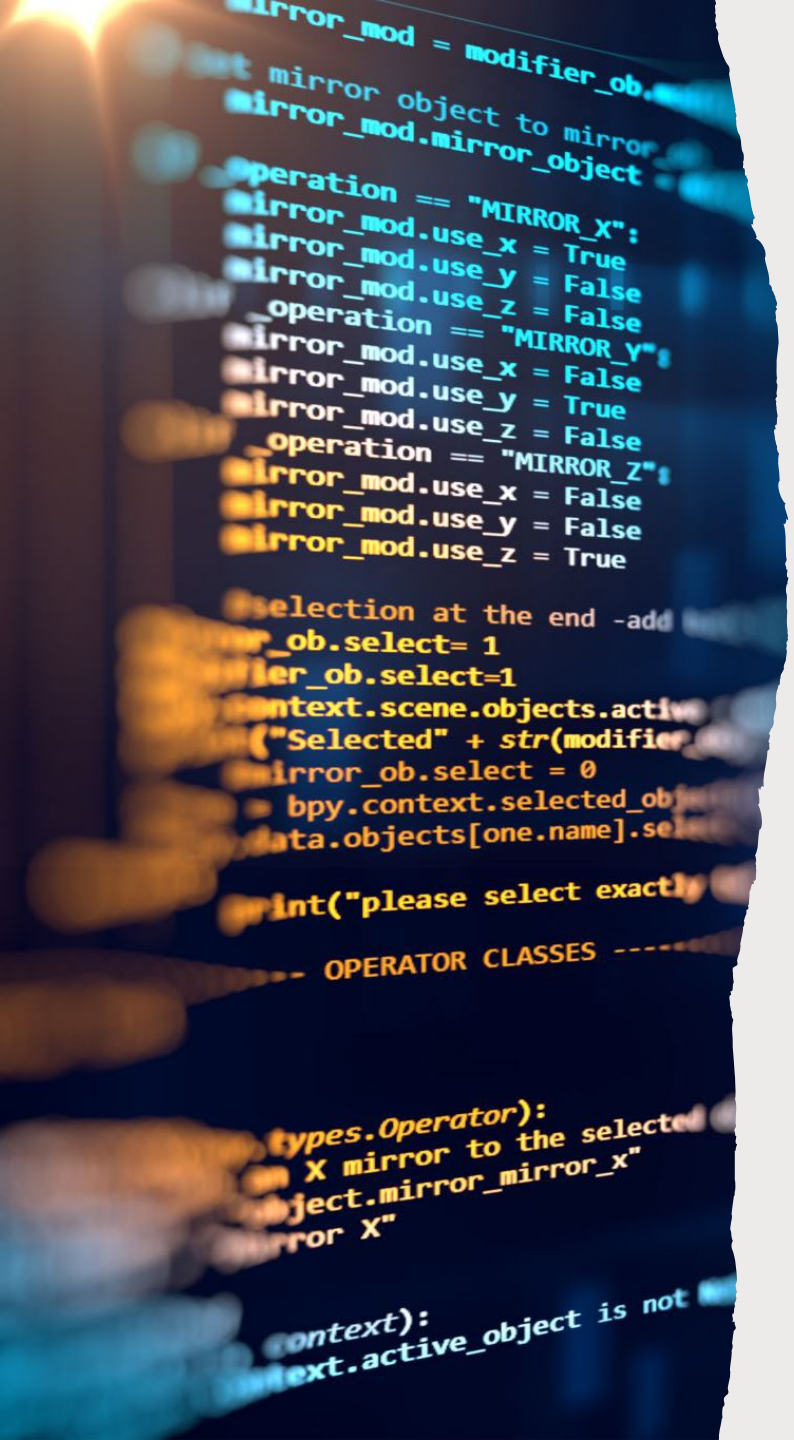
FURTHER DETAILS ON THE PURPOSES/FUNCTIONS OF THIS GROUP ARE NEEDED

What could be the purposes or functions?

THEY ARE PARTICULARLY INTERESTED TO LEARN MORE ABOUT THEIR CONDITIONS SUCH AS DIAGNOSTIC GROUPS

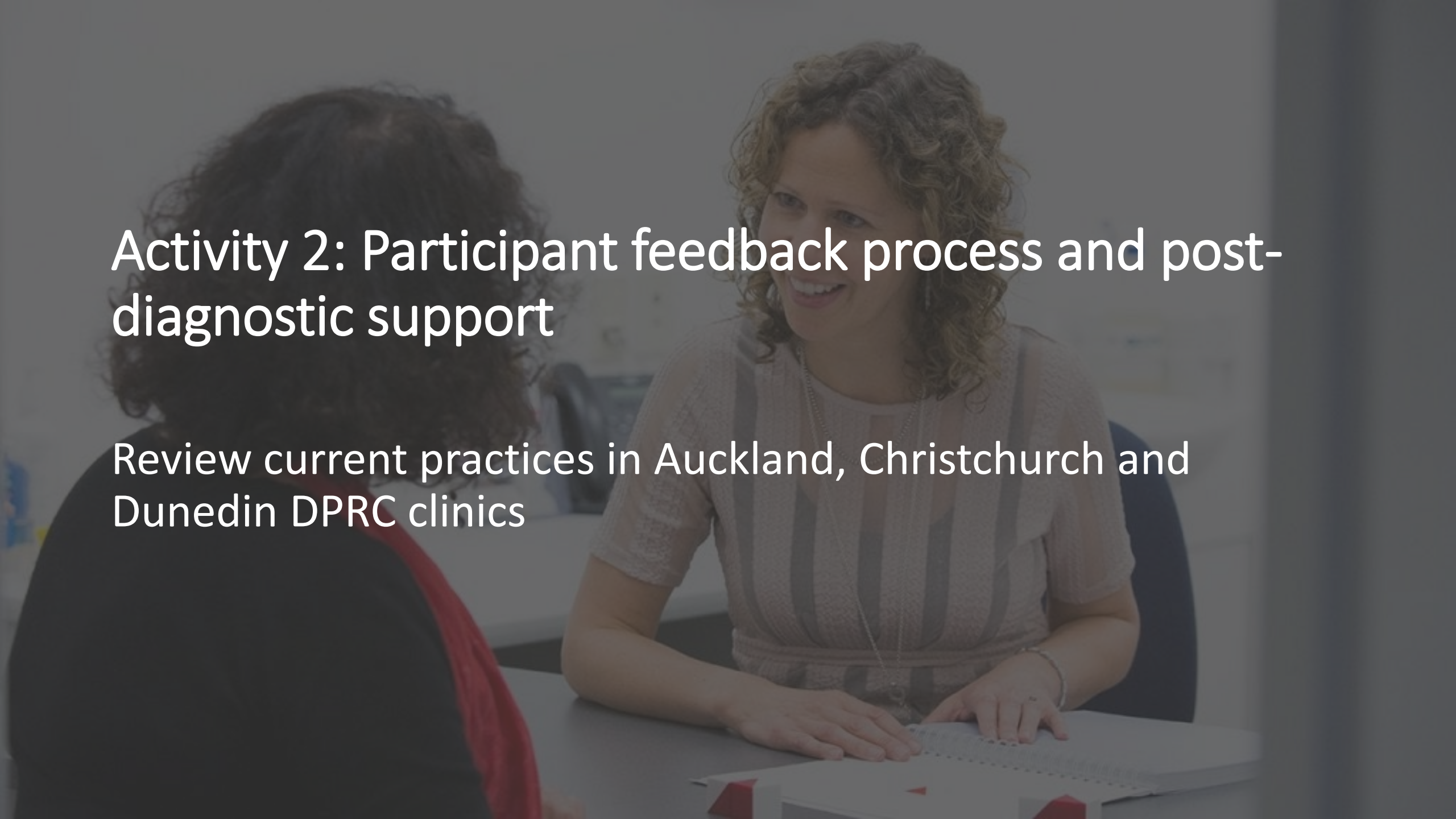
EDUCATION EXTENDS TO THE PUBLIC AND CULTURAL GROUPS

SUPPORT FOR BOTH STUDY PARTICIPANTS AND STUDY PARTNERS



Activity 1. Developing a national DPRC website

- This is a priority
- To include participants' suggestions on the website content
  - e.g. newsletter, research updates, videos of DPRC "ambassadors"
- The website is also for referrers and the public



Activity 2: Participant feedback process and post-diagnostic support

Review current practices in Auckland, Christchurch and Dunedin DPRC clinics

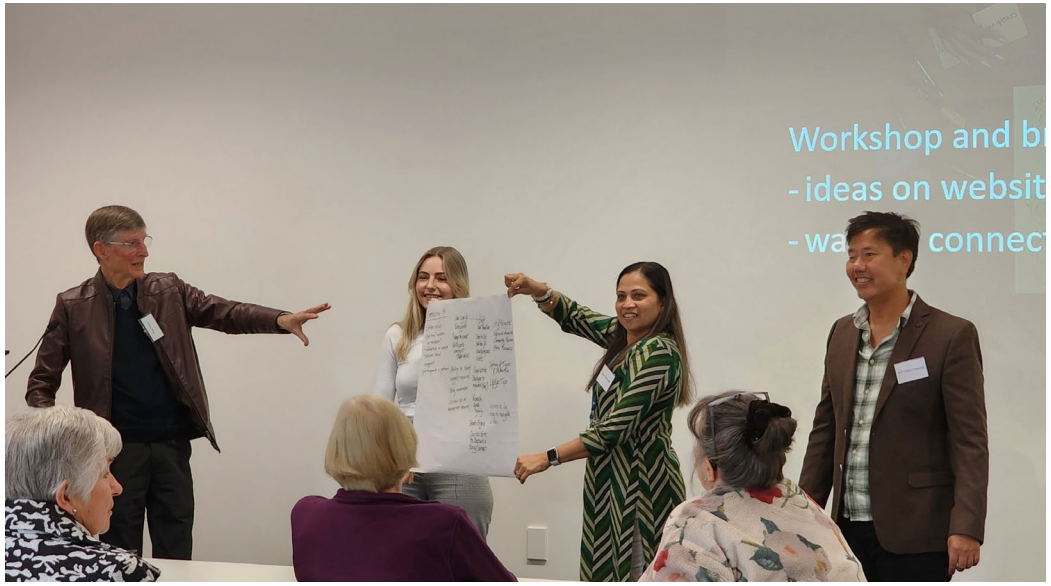
Activity 3. Māori participants focus group

- To create a safe space for Māori participants to reflect on their experiences and suggestions for improvement and recruiting Māori participants

2nd Workshop September 2023

- Workshop and brainstorm ideas on website content

- Ways to connect participants amongst themselves



3rd Workshop
December 2023

Goals for 2024

1) Ongoing DPRC website development
2) Māori participants focus group
3) Coffee group
4) Participant feedback process and post-diagnostic support
5) Further discuss community connection and support for participants/study partners at future PEG meetings.
6) Provide synopsis of PEG meetings in DPRC newsletters.