Centre for Co-Created Ageing Research

Vanessa Burholt, Ngaire Kerse, Jo Hikaka, Tia Reihana
Karakia and welcome

Tutawa mai I runga
Tutawa mai I raro
Tutawa mai I roto
Tutawa mai I waho
Kia tau ai, te Mauri tu
Te Mauri ora, ki te katoa
Haumi e, Hui e, Taiki e.

Come forth from above, below, within and from the environment.
Vitality and well-being for all. Strength in Unity.
Waiata – Te Aroha

Te aroha
Te whakapono
Me te rangimarie
Tätou, tätou e.

Kia kaha ra
Kia manawanui
Kia u, Kia Maia
Tatou, tätou e.

Love,
Hope,
Peace,
For us all.

Be strong.
Be Patient.
Be Strong minded.
Be Brave.
All of us together!
# Plan for the day

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Facilitator</th>
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<tbody>
<tr>
<td>10.00</td>
<td>Karakia and welcome</td>
<td>Ngaire</td>
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<tr>
<td>10.20</td>
<td>• CCREATE-AGE - who we are and our story (Ngaire)</td>
<td>Tamika</td>
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<td></td>
<td>• Getting to know each other (All)</td>
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<td>• Sharing aspirations (All)</td>
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<tr>
<td>11.20</td>
<td>PRESENTATIONS:</td>
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<tr>
<td>11.20</td>
<td>How CCREATE-AGE is set up</td>
<td>Jo</td>
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<td>11.30</td>
<td>Intro to Co-Creation and what it means in practice</td>
<td>Ngaire</td>
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<td>11.50</td>
<td>Research Development Groups (RDGs)</td>
<td>Ness</td>
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<td>12.10</td>
<td>LUNCH</td>
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<td>12.40</td>
<td>CCREATE-AGE Groups</td>
<td>Tamika &amp; Rosie</td>
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<td>1.00</td>
<td>PANEL</td>
<td>Tamika</td>
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<tr>
<td>1.40</td>
<td>Next steps and upcoming events</td>
<td>Tamika</td>
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<td>1.50</td>
<td>Closing remarks and karakia</td>
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Co-creator community - Getting to know each other

Ko wai katou (Who are you – the whānau/network/group/organisation you are bringing to this hui?)

No hea koutou (Where are your rōpū from?)

I tautoko ana I te Kaupapa (How do your aspirations of your rōpū align to the CCREATE-AGE pūrākau (story) and the aspirations/themes/focus areas on projection? What do bring today to the co-creation setting?)
Areas and Aspirations

- Older people
- Equal partnerships
- Community-up process
- Transform ageism
- Equity and justice
- Research by community

- Impact for community
- Research about:
  - Place & Community
  - Health & Wellbeing
  - Work, ‘Retirement’ & Income
  - Equity
  - Architecture & Design
  - Technology, Engineering, Digital economy
How CCREATE-AGE is set up and run - Jo

- Research: Our primary function
  - Priorities identified by communities ('listening events')
  - Themes and theme leaders
- Structure
- Financial stability: Base funded for 5 years (Transdisciplinary Centre)
- Fund raising e.g., Daily Living research space; Aged Care Consortium
Older people as co-creators

INvolvement
Research carried out with and/or by older people

Engagement
Mutual transfer of resources and knowledge

Participation
Recruiting older people to participate in projects
Working groups

Involvement and engagement
Help us develop written material (e.g. leaflets, adverts)
Assist with public engagement activities or tend stands at public events

Publicity and communications
Work with a range of media (e.g. our website and printed materials)

Knowledge and impact
Develop ways to keep track of the knowledge co-created and the impact it has had on people and society

Research and development
You would be provided with training: to assist in identifying questions, designing research projects, or conducting research
CCREATE-AGE people and collaboration

- Community of Co-Creators (you all)
- Working Groups (some of you)
- Operational Management Group and Directorate (Co-Directors and team (in the shirts))
- Leadership & Governance Groups ("quadruple helix" collaboration)
Research themes & Theme leaders

- Rebecca Sharp (Becks), Snr Lecturer, Psychology
- Rubina Bogati, Professional Teaching Fellow, Nursing
- Alan Wang, Associate Professor, Bioengineering Institute
Bringing funding and more

Rachel Hopkins
- Commercial Engagement
- Experience in Aged Care
- Apologies from Europe (visiting whānau)

Akerei Maresala-Thomson
- Commercial Engagement
- Maori & Pacific
- Connecting with Franklin
- Hosting us at Pasifika Digital Knowledge Bank, Pukekohe
- Apologies for today
Introduction to cocreation – Ngaire
The aim of the conversations was to explore what was meaningful for them to live a good life in care

Methods that created ways of communication:
- Pictures of home references
- Cup of tea and food contributions
- Sculptures
- Smell
- Drawings made by them

“Just ask people. Well, what do you feel about the way you are living? Robert
"we feel happy to remember the old things"

“this was smelling very nice... my nose is very sharp... and my ears are very sharp to hear”
"you suffer the loss of your own soul"

"At this stage of life, where you are now in the sunset of life. You wouldn't like to be argumentative"

“but there are some some very good caregivers and other staff also very good so you feel homely when they are there."

“you gave us something to think and ponder about... I enjoyed the conversation everybody you're respected one another they spoke the minds off the other listen ”

“I can tell you one thing, that this cake was made with love and affection”

"I think health is not just about the physical. It's also I about the holistic, and the effect that has on your life."
Expectations to prepare for their future pathways of care

Interactions with respect, kindness because it influences their mood

Opportunities to maintain activities that are valuable for people in their homes. For example:
• Cooking foods from their cultural backgrounds and personal preferences
• Gardening
• Going in and out with ‘freedom’
• Having quality of interactions with staff and residents – greetings, courtesy,
• Animal company

Room and equipment for everyday life activities

Challenges in getting used to the new routines (e.g. ‘timing regime’)
“You can’t sit in your office and know what the community is going through. You got to get down there to ‘ground-zero’ and find out from ‘ground-zero’ what is happening down at ‘ground-zero’. What we are doing today and asking the questions of what is happening from people who are currently living that sort of situation – that’s a good place to start”.

Vaihola Tangi – Senior Entrepreneur
CCCREATE-AGE Groups - Tamika

• Research Development Groups (RDGs) – Ness

• Impact [Knowledge for Positive Change] Group - Ness

• Involvement and Engagement - Tamika

• Communications and Publicity - Rosie
CENTRE FOR
CO-CREATED AGEING RESEARCH
CCREATE-AGE

RESEARCH DEVELOPMENT GROUPS
(RDGs)
To support CCREATE-AGE in its vision to stimulate co-created ageing research, we will fund Research Development Groups (RDGs) up to $10,000 per group to support a transdisciplinary group of people who are interested in **co-creating a research proposal**.

Research proposals should address a single research question or comprise a programme of research work related to **priorities identified by communities through our listening events**.

As a result of the award, the RDGs are expected to apply for at least one substantial research grant application or funding opportunity.
MEMBERSHIP OF RDG

The RDG should

- Include at least two experienced researchers at UoA
- Have a chair who will convene the RDG meetings, report progress and maintain communication with CCREATE-AGE project manager.
- Be transdisciplinary, which means:
  - Cover at least two academic disciplines;
  - Involve older people
  - Involve collaborators from at least one sector other than academia i.e., private, public or civic society. For example, practitioners, local council, and voluntary sector representatives and community groups with an interest in the research topic may be useful partners.
The expected outputs of the RDG will be:

• At least one co-created research proposal with an outcome that will benefit older people in Aotearoa.
• A public seminar at a CCREATE-AGE forum to describe the work of the RDG.
• Progress report to CCREATE-AGE.

Information on the RDGs will be included on the CCREATE-AGE website.
CCREATE-AGE SUPPORT FOR RDGs

All RDGs will receive an introduction session on the Principles of Co-creation.

RDGs can request research support through CCREATE-AGE including:

• A training session with an introduction for RDG members who haven’t been involved in research before.
• Research assistant support with organising and supporting meetings.
• Research assistant support with reviewing literature.
• Research artist support.
• Advice on proposal content from Senior Academics.
RDG: CO-CREATING A CRITICAL REVIEW WITH PEOPLE LIVING WITH DEMENTIA

The cover image is based on the Special Issue Review A research agenda for promoting continence for people living with dementia in the community: Recommendations based on a critical review and expert-by-experience opinion by Vanessa Burholt et al., https://doi.org/10.1111/jocn.15537. Image Credit: Silin Cyfyngedig. Photographer: Barry Davies.
HRC PROJECT - PROMOTING CONTINENCE AND MANAGING INCONTINENCE FOR PEOPLE LIVING WITH DEMENTIA IN THE COMMUNITY IN AOTEAROA

Phase One
Months 1 - 12

Prevalence and incidence of incontinence for PLWD in the community
- Cohort study from standardised home care interRAI assessments

Phase Two
Months 1 - 12

Continence management for PLWD in the community
- Review of clinical policies & guidance from all DHB continence services
- Qualitative focus group interviews

Phase Three
Months 1 - 36

Exploring experiences, strategies, impact and consequences of promoting continence and managing incontinence for PLWD in the community
- Secondary data analysis (months 1 – 12)
- Cross-sectional qualitative data collection (months 1 – 16)
- Longitudinal qualitative data collection (months 4 – 20)
- Preliminary analysis (months 1 – 24)
- Final analysis (month 36)

Phase Four
Months 25 - 36

Stage 1
- Face to Face meeting of Expert Panel: 5 caregivers and 11 professionals

Stage 2
- Online (and postal) survey with Expert Panel plus 25 health professionals

Stage 3
- Online (and postal) survey with Expert Panel plus 25 health professionals

Stage 1
- 2 x Face to Face wānanga/workshop: 5 Māori caregivers / 5 non-Māori caregivers

Stage 2
- Online and postal preference survey with 50 caregivers

Stage 3
- Consensus wānanga/workshop: 10 caregivers

Co-produced caregiver resources using a series of workshops/ wānanga
What will happen at each workshop?

**Session 1**: Topic: Introduction to research.

**Session 2**: Topic: The importance of sound in our lives.

**Session 3**: Topic: How could we capture sounds at home?

**Session 4**: Topic: Feedback on capturing sounds at home.

**Session 5**: Topic: Acoustics and hearing with your ears and brain.

**Session 6**: Topic: Feedback on capturing acoustics and hearing with your ears and brain.

**Session 7**: Topic: Desirable and undesirable sounds at home.

**Session 8**: Topic: What should we include in a research study on sounds at home for people living with dementia?
RuralWIDE: INVOLVING OLDER PEOPLE IN RESEARCH

University Staff:
Vanessa Burholt
Gill Windle
Dawn Naylor

Age Concern Ynys Môn:
John Clifford Jones
Carys Trenholme

Volunteers:
Barbara Jones
Roy Oades
Martin Riley
Delyth Kennedy
Evelyne Tebrock
Beryl Riley
Judy Oades
Carrie Humphries
Angela Jones
Sheila Carmody
Pauline Williams
Elaine Davies
Siw Wood
Mike Piercy
- Improved the knowledge and skills of older volunteers actively involved in the research process and pass skills and knowledge on to others
- Identified the long-term care needs and preferences of older people living in the most isolated rural communities
- Provided information that was used to develop, implement and extend services to older people in the most isolated rural communities

**Dissemination**

- British Society of Gerontology Annual Conference
- Local day conference
- British Geriatric Society
- ERA-AGE in Brussels
- Involving People Annual Conference
- Gerontological Society of America Annual Conference
CCREATE-AGE Groups - Tamika

- Research Development Groups (RDGs) – Ness
- Involvement and Engagement - Tamika
- Communications and Publicity – Rosie
- Impact [Knowledge for Positive Change] Group - Ness
GOVERNANCE AND ASSURANCE

Oversight Board

Advisory Group

Māori Kaitiaki Group

Directorate

Operational Management Group

Strategic Management Group

Research Development Groups

Involvement & Engagement Group

Communication & Publicity Group

Impact [Knowledge for Positive Change] Group

Working Groups

• Working Groups (some of you)
Involvement & Engagement Working Group - Tamika

• Calendar of events – review draft schedule

• Growing the Co-Creator community ("recruiting")

• Process to establish CCREATE Groups incl. Draft Kawa (Principles)

• "Collaboration model" – further design and rename
Co-creators community - recruiting

<table>
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<tr>
<th>Time</th>
<th>No.</th>
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<td>Nov 2022-June</td>
<td>41</td>
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<tr>
<td>July</td>
<td>10</td>
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<td>August</td>
<td>29</td>
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<td>September</td>
<td>28</td>
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<td>October</td>
<td>13</td>
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<td><strong>Total signed-up</strong></td>
<td><strong>121</strong></td>
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Communications & Publicity Group - Rosie

- Website development & Translations
- Brochure review & Translations
- Sign-up sheet review (suggestions from Prue Scott) & Translations
- Social media
Website for Working Group development

CCREATE-AGE (auckland.ac.nz)
Knowledge for Positive Change, Group - Ness

- Help develop a statement that says what change we want to make
- Develop ways to keep track of the knowledge produced by CCREATE-AGE
- Track and tell stories about the impact that our research has had on society
Help to ensure that our research has a real-world impact for older people, their families and whānau.
Next steps and upcoming events - Tamika

• Feedback from you about today please – All

• Feedback to you from today – Tamika and Rosie

• Contact Co-Creators for Working Groups – Tamika, Rosie, Ness

• Next Co-creators Forum proposed Tuesday 5th March (tbc by Involvement & Engagement Group – Tamika)