Engaging Older Adults in Research: The OA-INVOLVE Experience

Amanda Jenkins, PhD
Dalhousie University

Team: Susan Kirkland, Pia Kontos, Kieran O’Doherty, Romeo Colobong, Ashley-Ann Marcotte, Alexis Fabricius, Chester Sun, Older Adult Research Partner Group

APPTA Conference
December 2020
The aim of OA-INVOLVE is to develop best practices to support the active involvement of older adults in technology research and development projects.

We focus on understanding how to best incorporate the experience and insight of older adults throughout the research and development process in order to make a positive impact on project outputs and outcomes.

Ensures that products and services produced are fit for purpose, accessible and effective in improving the health, wellbeing and quality of life of older people.

Technologies developed “with” rather than “for” older adults.
OLDER ADULTS’ INVOLVEMENT

ADVANCING THE ENGAGEMENT CONTINUUM

DECISION-MAKERS

ADVISORS

PARTICIPANTS

RESEARCH & DEVELOPMENT PROCESS

Concept

Prototype

Plan

Product

Use
Older Adult Research Partner Group

- National group established in four sites across Canada – Vancouver, Toronto, Guelph, Halifax
- Take part in all aspects of the research project – idea development, decision making, study design, data collection, analysis, interpretation, knowledge translation and dissemination
OA-INVOLVE Case Studies

• Document existing practices of engaging older adults within selected AGE-WELL projects.

• Develop an in-depth understanding of the issues teams and projects face with respect to involving older adults across the engagement continuum.

• Identify barriers and facilitators for involving and engaging older adults in technology research and development.

• Work with teams to identify solutions, move along the engagement continuum.
**AGE-WELL NETWORK**

### 8 Workpackages:

- WP 1
- WP 2
- WP 3
- WP 4
- WP 5
- WP 6
- WP 7
- WP 8

### 35 Projects:

- WP 1.1
- WP 1.2
- WP 1.3
- WP 1.4
- WP 2.1
- WP 2.2
- WP 2.3
- WP 2.4
- WP 2.5
- WP 2.6
- WP 3.1
- WP 3.2
- WP 3.3
- WP 3.4
- WP 4.1
- WP 4.2
- WP 4.3
- WP 4.4
- WP 4.5
- WP 5.1
- WP 5.2
- WP 5.3
- WP 5.4
- WP 5.5
- WP 6.1
- WP 6.2
- WP 6.3
- WP 6.4
- WP 7.1
- WP 7.2
- WP 7.3
- WP 7.4
- WP 8.1
- WP 8.2
- WP 8.3

### Interest Themes:

- Needs Older Adults
- Needs Caregivers
- Technology for Functional Autonomy & Independence
- Technology for Active Participation in Society
- Technology for Prevention & Reduction of Disease & Disability
- Technology for Maintaining Good Mental & Cognitive Health
- Health System Practice Policy & Regulatory Issues
- Ethical, Cultural & Social Aspects of Technology

- NEEDS-OA
- NEEDS-CG
- TECH-FAI
- TECH-APS
- TECH-DD
- TECH-MCH
- TECH-POLICY
- TECH-ETHICS
Case Study Approach

**Phase 1:** One on one interviews with 8 selected AGE-WELL project leads, researchers, and older adults – Focus on understanding needs. (Research Coordinator)

**Phase 2:** Small group interactive workshop with project leads – Focus on SWOT analysis, developing solutions. (Project Leads)

**Phase 3:** Follow up interviews with project leads – Focus on what worked. (OARPG Members)
# Example of Themes Identified Across Phases

<table>
<thead>
<tr>
<th>Categories</th>
<th>Themes</th>
<th>Sub Themes</th>
</tr>
</thead>
</table>
| **Individual Level Facilitators** | Relationships                   | Reciprocity  
Trust  
Managing Older Adult Expectations |
| **Individual Level Barriers**   | Underestimating Older Adults     | Capabilities, Knowledge and Cognitive Functioning of Older Adults |
| **Structural Level Barriers** | Costs, Time and Resources       | Funding Models  
Time Commitments |
|                              | Gatekeepers of Older Adults     | Caregivers Restricting Access  
Institutions Restricting Access (long-term care homes, hospitals) |
Structural and Administrative Barriers

Ethics
- The academic ethics process precludes early involvement and is too formalized.

Funding
- Funding submission deadlines often make it difficult to begin involvement with older adults at the ideas generation and proposal writing stages.

Gatekeepers
- Some institutions such as long-term care homes were viewed as a blockage in accessing, recruiting and working with older adults.
Individual Level Barriers

Lack of Training in Participatory Methods

• Researchers had not worked in these ways in the past, lacked knowledge and skills.

• "I think the overarching barrier is that when you read about participatory design, it is heavy on the goals and the values of participatory design and it is light on the specifics on how you make it work". (Phase 1 Transcript 4)
Changes to Institutional Policies to Support Older Adult Engagement in Research

• Modifications to ethic review processes for participatory research methods

• Flexible funding models for participatory research

• Partnerships between research institutions and long-term care homes across Canada

• Resources made available to researchers to support older adult engagement.
Why is this Important for Policy Work?

a) Aging-in Place policies

b) Canada’s Strategy for Patient Oriented Research (SPOR)

c) Policies on Decreasing Digital Divide in Canada
Thank you!

Amanda.Jenkins@dal.ca
Susan.Kirkland@dal.ca

http://www.oa-involve-agewell.ca/

Twitter: @OA_INVOLVE