OLDER ADULTS' ENGAGEMENT

Engaging People Living with Dementia |Barriers & Facilitators |Solutions & Tips

AGE-WELL

A federally-funded Network of Centers of Excellence (NCE), established in 2015 to help older Canadians maintain their health, quality of life and independence by accelerating social and policy innovation, supporting world-class research in technologies and aging, training future professionals and innovators.

OA-INVOLVE

A core AGE-WELL project researching the practices and experiences of older adults' engagement in technology projects, promoting their active and meaningful engagement in the entirety of the research process, and facilitating their engagement by developing practical guides for effective participatory research and development (R&D) of technologies. OA-INVOLVE has established a cross-national Older Adult Research Partner Group that is engaged in the research process in an advisory and decision-making capacity. OA-INVOLVE Project is lead by Dr. Susan Kirkland.

Participatory work engaging older adults with dementia

Participatory approaches in research and development of technologies for older adults are characterized by the active involvement of older adults themselves. These approaches are based on the principles of justice, whereby all people should have an equal opportunity to participate in research, and on the principles of democracy and reciprocity. These approaches recognize abilities, skills, and expertise of all involved. Participatory approaches have been successful in engaging and empowering older adults living with dementia, decreasing stigma, increasing their autonomy, and improving the products developed including their usability and effectiveness.

Engaging older adults living with dementia in technology projects

The question is not 'Should we do it?' but 'How can we afford not to?'

Technology has the potential to enhance the quality of life of people living with dementia. Older peoples' input to the design, development, and testing of technologies improves the products as well as their acceptance and use. Although there may be a growing interest amongst researchers to involve people living with dementia in technology projects, there continues to be a lack of practical guidance to enhance the necessary skills to involve people living with dementia in research and development projects (Alzheimer Europe 2011). The lack of expertise in engaging people living with dementia, along with a tendency to overemphasize challenges can deter research teams from creating engagement opportunities for people living with dementia. This is a missed opportunity for all. This brief will support AGE-WELL projects to successfully engage people living with dementia in various aspects of the research and development process. It is important that we acknowledge that people living with dementia are capable of taking part in research projects as participants, advisors and decision-makers. But we do need to think carefully about how to meaningfully involve them and make and necessary accommodations.

Practical tips for engaging older adults living with dementia in the research process

Recruitment, Safe Space & Timeline

❖ Support the person's autonomy but invite a family member (caregiver) to the meetings if that is requested by the older person.

❖ Consider connecting with community-based organizations (e.g. dementia care services), faith groups, memory clinics, and caregiver support groups to assist with recruiting people living with dementia.

❖ Devise safe spaces for all involved. Establish what a safe space means for people living with dementia and their caregivers during initial project planning activities, then verify it during subsequent meetings.

Resources

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❖ When introducing your project to people living with dementia do so in their familiar surroundings or have familiar persons present. The place should be agreed upon with all individuals involved.

❖ Support the wellbeing of the people living with dementia, ask them (or their caregivers) how best to ensure their comfort during the process; ensure they get home safely from meetings; have emergency contact information at hand.

❖ Prepare project information packages to take home. Keep information short and clear. Encourage everyone to ask questions and consult about the research opportunity with friends and family if they choose.

❖ Ethical clearance and attracting volunteers might take considerable time. Keep the process open so that new members can be brought into the project if attrition occurs.

Ethical Principles, Terms of Reference & Roles

❖ Follow ethical principles, even if you are not formally required to obtain approval from an Ethics Board for the engagement of people living with dementia (e.g. as Advisory Board members).

❖ Obtain consent before each session or research stage. Watch for verbal and non-verbal cues indicating discomfort or desire to discontinue participation in a meeting; those should be treated as signs of consent withdrawal for that session. Train the research team to identify the signs.

❖ Draft Terms of Reference with the individuals involved and/or their carers/family members (e.g. expectations, roles, purpose) at the beginning of the process, and update as needed (an example of Terms of Reference document is available here: www.oa-involve-agewell.ca/our-reports.html).

❖ Ask the people living with dementia how they want to be involved in the research project, including specific aspects of the research process and in what roles. Do this at several points during the project duration to ensure ongoing interest and consent.

❖ Plan flexible engagement that builds on each person's capacities to maximize their involvement in planning and other aspects of the research process (e.g. as co-designers)

Training & Communication

❖ Provide appropriate training to people living with dementia about your research approaches and activities to facilitate their full participation. Build in repetition to ensure understanding.

❖ Encourage researchers to spend time in partner organizations that support people with dementia to become more aware of experiences living with dementia. Ensure that the research team has the required mix of skills and desired attributes to support people living with dementia to participate to the fullest extent.

Resources

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❖ Provide project information in accessible, jargon-free language.

❖ Discuss preferences for how to receive project information (e.g. electronic, paper copy, telephone, in-person).

❖ Keep the individuals who wish to be involved regularly informed about research news, plans, opportunities for further engagement, and how their contribution is being incorporated in the project.

❖ Ensure written information is culturally appropriate, does not stigmatize people living with dementia in any way, and is accessible and engaging.

Facilitating Participation

❖ Dedicate meeting time to get to know all individuals involved and let them get to know you. Informal chat during breaks is important for building trust and making sessions enjoyable. Dedicate time for social activities during regular breaks.

❖ Facilitate engagement by providing ample time for each person to complete tasks. Active listening is key to supporting engagement by improving a sense of security and understanding. Pair older persons with an assistant to work one-on-one if needed, offer support, training, and regular follow-up.

❖ Negotiate house rules for group meetings.

❖ Encourage people to participate but ensure that you are not putting pressure or unintentionally coercing participation (allow them to complete planned activities to the degree they wish to). Do not extend meeting time beyond the initially agreed on duration even if the meeting is going well – running overtime might coerce some people to stay longer than they wished.

Facilitating Learning & Conceptualization

❖ All involved need to know what is required of them and understand the activities and timelines, they do not necessarily need to know all technical aspects of the research and technology development in order to meaningfully contribute to the project. Provide information as necessary.

❖ It is useful to use illustrative examples and analogies from daily lives to explain research-related activities. This can help to promote understanding.

❖ Use language that resonates with the group: create a common terminology by using vocabulary used and understood by the group. Explain terms each time they are used and refrain from using abbreviations and acronyms. Provide glossaries and activity guides to take home.

Acknowledgements

❖ Use creative approaches to help with conceptualization and visualization of project tasks and goals (e.g. scenarios, videos, role play) and avoid using abstract concepts.

❖ Small group sessions can promote a sense of togetherness and group learning. Each person in the group should be supported by a research assistant. This is an effective way of working to gain genuine involvement of people with dementia.

Valuing the Engagement of People with Dementia & Providing Feedback

❖ Provide regular feedback about how the advisors' contributions have influenced the research or technology. Acknowledge both personal and collective contributions.

❖ Allow ample time for all members to express their thoughts and ideas and address any questions they may have. Build time into the research or meeting schedule for this.

❖ Celebrate achieving project goals or milestones. Thank everyone for their time and contributions.