INTRODUCTION

AGE-WELL Network supports the development of solutions that will help older Canadians maintain their independence, health and quality of life. AGE-WELL does this by promoting research and innovation within the areas of technology and aging that will positively impact current and future generations of older adults and their caregivers.

Engaging older adults in technology research and development projects has several benefits including addressing older adults’ needs (1), and improved early adoption and diffusion of the products and increased functionality, usability and quality of the products (2), which have been recognized by the management and researchers affiliated with the AGE-WELL network. As such, older adults’ involvement is a cornerstone of the AGE-WELL network. Our success depends on the active engagement and participation of the people who will use the technologies and services developed through our research.

THE OA-INOLVE PROJECT

OA-INOLVE stands for Older Adults’ Active Involvement in Aging and Technology Research and Development. The OA-INOLVE project is one of the core AGE-WELL research projects with the aim to develop best practices to support the active involvement of older adults in AGE-WELL projects. The project focuses on understanding the ways in which older adults are involved in every stage of technology research and the development process.

AGE-WELL PROJECTS SURVEY

In 2017 OA-INOLVE conducted a second survey of AGE-WELL members focused on gathering information about basic aspects of older adults’ engagement in their work. The first survey created a snapshot of baseline practices of older adults’ engagement (Survey 1), while the current survey (Survey 2), in addition to documenting the status of older adults’ engagement across the Network affords a longitudinal perspective.

SURVEY PROCESS

A custom online survey tool was used. Invitations to participation were emailed to AGE-WELL leads in July 2017. Sixty groups were contacted, including the leads or co-leads, the crosscutting activities leads (N=4), core projects (N=51), stand-alone projects (N=4) and the AGE-WELL Network management office (N=1). Email auto replies required follow-up (e.g. vacation, long term leave, out of office, conference attendance, email address corrections, employment change, no email access, sabbatical leave, personal travel, parental leave). Follow-up emails were sent out three times on July 24, August 2, September 5. Final phone call follow-up occurred in Sept/Oct. Two surveys were completed in person in October 2017 at the AGE-WELL conference.
SURVEY PARTICIPATION
Sixty respondent groups were invited to participate in the current survey, indicating that 21 more projects were supported by AGE-WELL since the previous year (NEW, OLD, Fig.1). The Survey 2 was completed by 46 respondent groups amounting to 77% response rate, as compared to 100% in Survey 1. Fifteen of the NEW groups (71%) completed the Survey 2 and out of 39 OLD groups 31(79%) completed the survey. Thirty groups responded to both, Survey 1 and 2 - this subset will be analysed separately for longitudinal change (Figure 1).

WHERE IS AGE-WELL RESEARCH TAKING PLACE?
AGE-WELL projects are conducted in 8 Canadian provinces and 3 other countries (Denmark, UK, USA). Again this year, the majority of the respondents (N=25, 54%) said their studies take place in Ontario, followed by British Columbia (N=7, 15%) and Quebec (N=6, 13%). In Survey 2, the following new project locations were reported: Manitoba, New Brunswick, and international cities (Figure 2). At the time of the survey no research activities involving older adults were reported in NL, PEI, and the Territories.

4328 OLDER ADULTS ARE NOW CONTRIBUTING TO AGE-WELL PROJECTS, AN INCREASE OF 2246 FROM LAST YEAR WHEN 2082 OLDER ADULTS PARTICIPATED

OLDER ADULTS’ INVOLVEMENT IN AGE-WELL
Survey 2 respondents reported 4328 older adults’ engagement. This is more than a two-fold increase since last year (2082, Survey 1). Most of the groups engage between 1 and 50 older adults (Figure 4). The majority of engagement falls within the ‘participant’ role, with significantly less in advisory and decision-making roles (Figure 3). The percentage breakdown by engagement role is as follows:
- 80% participants
- 10% advisors
- 10% decision-makers (See definitions: p.3)

This percentage breakdown is similar to Survey 1 (82%, 11%, 7%, respectively).

Some projects involve older adults in more than one role during the project’s course.

The majority of AGE-WELL teams engage older adults in their projects. OA-INOLVE will support research teams to move along the involvement continuum towards greater engagement of older adults in the advisory and decision-making roles.
THE MAJORITY OF PROJECTS OFFER MULTIPLE ENGAGEMENT ROLES

Typically when older adults are engaged in a single role, it is the participant role (97% cases). Therefore, reporting engagement in multiple roles sheds light on the opportunities for active engagement (e.g. advisor, decision-making roles). In Survey 2, there is a 19% increase in groups reporting multiple engagement roles when compared to Survey 1; that is 67% of groups report older people engaging in multiple roles. Most importantly, 40% of the groups reported the engagement of older adults in all three roles (Figure 5). However, when asked about their future engagement plans, respondents reported an expected decrease in future older adults’ involvement in all 3 roles. This answer does not specify whether this means lower enrolment of additional older adults (e.g. in addition to current status) or the projected total numbers of older adults in the future.

DEFINITIONS:
Participants: people passively engaged in the project, e.g. testing a prototype, research subjects, informants, interviewees.
Advisors: serve a consultative capacity throughout the research process, e.g. advisory board members, consultants in quality improvement initiatives.
Decision-makers: People whose input is required to make a decision about the project or its part, e.g. co-researchers, collaborators, partners in conducting research activities or in the technology development process.

OLDER ADULTS’ ENGAGEMENT: ANNUAL CHANGE

Thirty respondent groups completed both surveys. This subset of projects enables changes in participation to be documented from Year 1 (Survey 1) to Year 2 (Survey 2). In Year 1 (2016), the groups reported 1444 older adults’ involvement (including both current status and future planned engagement) in total. Interestingly, in 2017, the same respondents had significantly increased engagement of older adults to 3481, which is almost a 2.5-fold increase in what was reported previously.
SIGNIFICANTLY LARGER NUMBERS OF OLDER ADULTS WERE ENGAGED IN EACH ROLE IN 2017

In the 2017 survey, the groups engaged 1616 more participants; 147 more advisors and 274 more decision-makers, when compared to the previous year (Figure 6A). However, the percentage distribution of the roles did not change significantly over time. In both years, approximately ¾ of the total engagements were participants, and the remaining ¼ were both advisors and decision-makers (Figure 6B). In 2017, twenty of the projects increased older adults’ engagements in the participant role, 12 projects had more advisors, and 11 had more decision-makers. Seven projects had fewer participants, 9 fewer advisors, and 5 fewer advisors in comparison to Survey 1 (Figure 6C).

MULTI-ROLE ENGAGEMENT

Interestingly, in 2017, 71% of projects were engaging older adults in multiple roles. That is a 12% increase from the previous year (Figure 7). Note: only 22, and 28 of the total 30 groups that submitted the survey answered the question related to multiple engagement roles. The largest change was related to triple-role engagements, where all of the roles were reported by a single project. That is 50% of projects engaged older adults in triple-roles, up from 32% of projects in previous year.

REFERENCES

WHAT DID THE RESPONDENTS SAY

... about older adults’ involvement:
“Older adults have been providing extremely valuable input into our development of digital games.”
“WP(X) is focused primarily on employed caregivers and their employers. Few, if any, would be older adults.”
“All of our older adult participants serve the role of direct participant, advisor, and decision maker.”
“Value of having older adults involved in project for learning their day-to-day life experiences.”
“Contact dans les associations et résidences pour personnes âgées pour expérimenter les produits développés.”
“Out-reach activities may create opportunities to engage older adults in different capacities.”
“This project is for clinicians and decision makers.”
“Data collection is complete.”
“We are a team that is committed to the involvement of older people.”
“We believe that the target population is best at providing information about usability of ambient activity technologies, and at providing their comments and design recommendations as part of the evaluative research.”
“To date our work has focused on analysis of national survey data and an environmental scan for existing AT for caregivers. Consultations begin this year.”
“This specific project doesn’t meet your recruitment criteria. We are not involving older adults in these activities.”
“Older patients are involved in patient engagement committee as part of a consultative effort for peer-funding, including with the CIHR and FRQS (in Quebec).”
“Thus far, older adults have been involved in our project as volunteer beta testers and advisers.”
“Project is only in the beginning stages. Work with older adults not yet begun.”

... about their challenges with older adults involvement:
“This project involves significant community engagement to establish the iKT teams which initially slows down the research process...”
“[There is a] Finite amount of time to do things well; is (sic) a practicing physician while being team lead. WP lead, developing HUB while doing research project, difficult to do all things well, ensure older adults feel valuable making contributions.”
“We are unsure how much the group size will fluctuate in the coming year.”
“Data collection is not started.”
“We include older adults in our project to the level that they would like to be involved, it is therefore challenging to anticipate how many more of each role will be involved.”
“Hard to estimate future #s because these come directly from the Indigenous community.”

... about their future plans for older adults involvement:
“We hope to engage thousands of older adults, but exact numbers are highly dependent on our ability to engage sites as customers.”
“User study and field trials are being planned.”
“We are planning extensive product validation.”
“We will engage more end users in the development of our system once an initial prototype is developed this summer.”
“We plan to involve participants in more facilities (long term care homes).”
“We are doing a pilot RCT and in the future would plan to utilize older adults in an advisory capacity and as participants in a larger RCT. We will use our current study to help us do a power analysis and judge how many participants we would need in a subsequent trial.”
“We wish to expand this project to involve a larger number of first nations elders from more band areas.”
“We will be conducting two (possibly three) evaluation studies with caregivers of people living with dementia; many (likely most) will be older adults.”
“We would like to develop and test the concepts started by the workshop with carers, some of whom will be older adults.”
“Expect to engage [older adults] about wearable garments in development in focus groups, ~4-6.”
“We will involve different older adults in later projects.”
“We are currently recruiting more older participants, and will search for (older) advisors who could provide better perspective on our research affects this segment of the population.”

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