ESTABLISHING AND COORDINATING AN OLDER ADULT ADVISORY GROUP

A PRACTICAL GUIDE

Acknowledgments
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Prepared by OA-INVOLVE 2018
Establishing and coordinating an older adult advisory group

This brief guide outlines the processes and steps in establishing and coordinating an older adult advisory group, based on the experiences of the OA-INVOLVE project.

“I think it is important for researchers to remember that the essence of success for any relationship and perhaps especially with older adult volunteers, regardless of whether they are or are not scientifically/computer oriented or otherwise, is communication. If they want to gain the most value they can from the volunteers they involve in their project and, in turn, have the volunteers feel they have added something to the work of the researchers and are valued then they need to recognize that from the very beginning and keep it going throughout the process/project (...) I think it cannot be emphasized enough starting with recruitment of volunteers and onward.”

/Bessie Harris, OA-INVOLVE, OARPG Member/

“Consider location and ease of access. Meeting at a University Campus involves uncertain parking availability (I once went to 4 sites before finding parking); walking relatively long distances; sometimes stairs (difficult if using a walker). Consider a more central community place where seniors are more apt to meet, and book a room e.g. at a library or a seniors centre. “

/Janet Fowler, OA-INVOLVE, OARPG Member/

“I think it is important to emphasize that older adults are looking for meaningful activities. Therefore, it is desirable for assignments to be time-bound and to have clear purpose, and the results of assignments to be clearly reflected to the group.”

/Ian Goldman, OA-INVOLVE, OARPG Member/

OA-INVOLVE is a core project in the AGE-WELL Network, a Network of Centres of Excellence funded by government, industry and not-for-profit organizations. Our mission is to promote the active involvement of older adults in technology research and development projects to develop better technologies, products and services that are useful, acceptable, and “fit for purpose”. To this end, OA-INVOLVE is developing practical involvement guides that are tailored toward working with diverse older populations.

Authors:
Susan Kirkland, OA-INVOLVE Co-Lead, Dalhousie University
Judith Sixsmith, OA-INVOLVE Co-Lead, The University of Dundee
Pia Kontos, Investigator, Toronto Rehabilitation Institute – University Health Network
Kieran O’Doherty, Investigator, University of Guelph
Izabela Panek, Jennifer Diep, Kristie Serota, Oriana Vaccarino, Romeo Colobong, Tanya Crawford
OARPG members: Bessie Harris, Ian Goldman, Janet Fowler

For more information contact: Izabela.panek@dal.ca or visit www.oa-involve-agewell.ca
Steps to consider when establishing and coordinating an older adult advisory group

Planning

What are the project goals and objectives?
Discussion about project goals and objectives is a good starting point for planning an Advisory Group. Working in partnership with older adults is a two-way avenue, where both parties benefit from the partnership and add value to common goals. The benefits will vary depending on the project, the motivations of the older adults, and the researchers guiding the partnership. To begin, determine what the project has to offer to the older adults and what the needs of the projects are.

What is the purpose(s) of the group?
It is important to consider what the purpose of the group is and what roles the older adults will/can take on. They might contribute as informants, participants, testing prototypes, or informing the project as part of needs gathering (e.g. via surveys). It is recommended that older adults be actively involved in the projects, meaningfully contributing to the project’s phases and helping to shape the project’s directions as advisors, co-researchers, or co-designers because of the value and expertise that they bring.

Will you need Research Ethics Board (REB) approval?
Establishing the roles OAs might take and what you will do with the information collected during the work will determine whether or not you will need Research Ethics Board (REB) clearance for the involvement of older adults.

If the plan is to collect data and publish findings in which the older adults are participants in the study as study subjects, ethics approval is required. If older adults are involved as co-researchers and you do not collect data from them, but rather work with them in a collaborative manner, where their feedback is used to inform the project or improve the quality of collaboration, ethics approval is generally not required. However, it is a good practice to confirm this with the institutions that will be involved in the study and institutions involved in older adults’ recruitment. If ethics approval is required for your project, and it is a multi-institutional project, staggering the filing of the applications by submitting to the primary investigator’s institution first might help to expedite the process. Any changes requested to the protocol and related materials (e.g. consent forms) in one REB must be approved by the REBs in each institution.

Whom to invite to the advisory group?
Unless the project’s objective is to focus on a specific population of older adults, it is advisable to work with a diverse group of older adults to ensure that project outcomes are applicable to as many older adults as possible. Key considerations include gender, age, ethnicity, socioeconomic status, health status, and (dis)abilities. To minimize attrition, and depending on the project’s scope, one might consider initial brief interview with candidates to ascertain what interests them or that they have the desired level of familiarity with the technology.

Resources planning
Resources available to the research team and advisory group for the duration of the project must be carefully considered in terms of human resources, time, and financial resources.
The number of members in the advisory group will reflect the balance of achieving the best member diversity and expertise given available resources. Academic literature on public and patient involvement indicates that working with older adult groups can be resource intensive. For instance, substantial training might be required or one-on-one support work between the older adults and researchers to enable members to understand and contribute to meetings. Researchers may also require training to work with an advisory group. Preparing individualized materials that are given well in advance, allowing for flexible scheduling, and accommodating unique needs and preferences of the older adults (all of which are paramount for creating lasting and meaningful partnerships) can require extensive time, expertise and funding. It is also good practice to reimburse members for any costs related to participating in the advisory group such as transportation, parking, respite for carers, or long distance calls. Also, consider the provision of compensation for their time and contributions.

What kind of training is needed?
Successful work with an older adult advisory group might require providing specific training to both the researchers and older adults. Training should start during recruitment and continue on an ongoing basis.

• Researchers might require training in participatory work, or training required on inclusiveness and sensitivity (e.g. working with people with dementia – being able to recognize non-verbal cues for the withdrawal of consent to participate).
• Older adults might require training in research methods, processes, or to familiarize themselves with the project and its requirements.

What kind of communication is needed?
Planning the work with an older adults’ advisory group needs to include planning for effective communication via a variety of means: electronic, phone, or in person. The means for preferred communication is usually negotiated early with the members. Some older adults prefer phone over email communication; however, it is not safe to assume that all older adults are not comfortable with technologies such as videoconferencing, smartphones and other electronic means of communication. If possible, having a toll-free line removes the cost barrier and a direct line helps with reaching team members without the hassle of university switchboards. Simplifying the steps is particularly important when working with people living with dementia.

Other tips for communication include:

• Provide enough information without being overwhelming. Use plain language. Repeat key points. Provide information in a format, medium, and frequency preferred by the older adults.
• Establish the best ways to share information (e.g. email, hard copy) and provide information in a variety of formats (e.g. detailed instructions, lay summaries, glossaries for technical terms).
• Establish a comfortable and flexible level of engagement in the research and planning.
• Ensure written information is culturally appropriate and accessible across levels of literacy, and also visually engaging (consider potential vision limitations), and delivered timely, with mutually agreed upon frequency of delivery.

Drafting a Terms of Reference document
A Terms of Reference (ToR) document serves as the main document for outlining the definitions, requirements, and commitments for participating in an advisory group. It helps to manage expectations and incorporates steps to achieve improvement in the quality of the collaboration. Typical sections of ToR include: name of group, purpose/role of group, training, ways of working, membership, review, sharing of information and resources. The ways of exiting the project and opportunities for engagement following the end of the project should be also discussed with the members.

With the OA-INVOLVE project, the initial ToR draft was negotiated with and agreed upon by each member of the group. During these conversations we were frank about the expectations. For instance, we shared that the later stages of the project depended on the outcomes of preceding stages, which limited the information about actual tasks and activities we could provide in advance. We ensured that the members were aware that their participation could be very flexible; they could commit their time and share their expertise at the level they were comfortable with, and they could change their degree of commitment at any time.
Doing - Working with the group

Recruitment of older adults
Depending on the nature of the project and particular circumstances, various recruitment methods can be considered. Perhaps most frequently, older adults are invited to participate via partner organizations working with older adults (e.g. long term care facilities, recreational centres for seniors, associations). A well-crafted poster (see Appendix B) can be placed in these partner organizations or posted online. Examples from the literature also include recruitment through personal connections, pools of volunteers from previous studies, or snowball recruitment (using initial participants to identify others). Other examples are the use of media advertising or newsletters. The team might also consider the effect of self-selection of the members and the benefit of reaching out to people who do not usually volunteer, or who live in isolation, or have no access to the advertisement.

Other tips for recruitment include:
• Use a variety of strategies and methods for recruitment to ensure that a diverse group is involved, recognizing that each older adult is unique and cannot represent all older adults.
• Keep the recruitment process open so that new older adult members can be brought into the project if there is attrition. Although introducing new members into an existing group can be challenging, the potential contributions made by new members can be worth the effort.
• Include in the timeline a period to phase out or transition older adult involvement in the research. Present other opportunities (e.g. joining a university panel of community participants in research) for older adults to stay engaged in research if they wish.
• Do not assume that a particular group (e.g. those with dementia) cannot participate because of their personal situation; be prepared to make needed accommodations.

Negotiating the Terms of Reference (ToR)
The success of ongoing work with an older adult advisory group, which often extends over a number of years of the project, will depend on setting clear expectations and defining clear roles. The ToR should be revisited with the members either in a group setting or individually as the group gains experience working together. New observations and experiences might necessitate changes to the document. Every member should have a paper copy of the negotiated ToR document and should feel free to propose amendments to it at any time. All members should agree to any amendments before implementation. Scheduled annual review is also advised.

Annual engagement plan
Older adults often have very busy lives. Drafting an annual engagement plan can help with setting up meeting dates and assessing the time commitments required. The engagement plan is not to be considered as set in stone, but rather should be treated as a road map. Plan for choice and flexibility of involvement; individual members might choose to participate in certain aspects of the project, and that could signal the need for ongoing recruitment of additional older adult members during certain phases of the project. Involve older adults actively in all aspects of the research process in accordance to their preferences (e.g. as co-designers), and not just as experimental subjects or interviewees.

Advisory Group meetings
The way of working with older adults might vary, depending on the individuals involved and the project needs. It is usually agreed upon during initial meetings, but could change when working on particular tasks. It is also important to get to know members’ interests and life experiences. Work with individuals or sub-committees might be effective when working on specific activities (e.g. conference presentation planning) or when specific members signal an interest in contributing beyond regular group meeting times. Other tips for facilitating participation include:
• Have face-to-face meetings early in the process to help break down barriers, foster rapport and “togetherness”.
• Develop an Annual Engagement Plan: having the dates and times planned well in advance is helpful for the older adults.
• Build into the proposal the financial resources required to facilitate engagement (e.g. travel, group meeting space, hospitality, etc.).
• Secure accessible, comfortable & safe space for meetings (close availability of washrooms, regular breaks, dietary restrictions and assistance). Meet in social places that are not just university meeting rooms; provide
directions as needed.

- Agree on ways to contribute from home (e.g. by Skype, phone, personal visit).
- Maintain regular contact. Establish a regular means of open communication throughout the research process.
- Facilitating learning within technology research is important but can also be challenging. It is important to use lay language, especially when introducing and discussing technology. It can also be helpful to provide workshop type activities, as well as repeated opportunities for hands-on interaction and reflection with technology.
- Arrange experiences that support conceptualization (e.g. visit smart home exhibition of rehabilitation research facility).
- Provide scenarios that are relevant to those involved. Draw on their own experiences to help link the project’s points with their own lives (e.g. provide scenarios of everyday life when technology might be used, avoid abstract concepts, use art, videos, written pieces, drama).
- Even if older adults are comfortable with basic technology, many are not so comfortable with video conferencing. It is a bit of a learning curve. There may be uncertainty about speaking up, issues of hearing clearly, not really knowing the others, and simply “lack of air time” if 16 or more people wish to say something. The time allotted for the meetings should be sufficient to allow each person to speak, carry out the group discussion and allow “bonding” time.

OA-INVOLVE works both with local groups, and collectively in a national group, and also with individual members on different aspects of the project. National groups are essential in creating the unity of the group, discussing information, and sharing updates and progress. In-person work with the local groups stimulates discussions and it is more feasible when working on detailed tasks. It can be less intimidating for some members who are not comfortable speaking on camera.

Reflecting on our work

Checking in about experiences and valuing contributions and impacts

It is the duty of the researchers to provide a safe and comfortable place for all participants. Active participatory approaches to older adult involvement are a clear departure from researcher-centered work. The researcher position should be working with or for the older adult members, not the other way around. It is also important to illustrate how engagement in research can positively impact members’ lives, and the lives of others. Researchers obtain verbal ongoing consent before each session or research stage. Watch for nonverbal cues indicating discomfort or intent to discontinue the session. Address any concerns regarding privacy and sharing data openly.

Other tips for valuing older adults’ engagement and soliciting feedback:
- Clearly provide feedback on outcomes of individuals’ engagement and how it contributed to the research, processes and planning.
- Ensure that everybody’s voices are heard and valued.
- Reach out to and regularly communicate gratitude for invaluable contributions. Acknowledge participants’ collective efforts and contributions.
- Regularly seek feedback from the older adults including subjective evaluation of their experiences with their ongoing participation.

OA-INVOLVE has developed the practice of finishing each meeting by asking about the older adult members reflections about the meeting: what was good, what can we do better. Based on such informal feedback we were able to make improvements to our working together. For instance: sending out materials earlier, adding more practical tasks, and reformatting how we provided project updates (brief written documents rather than taking up precious time when we are face to face).

Adapting the practice

This point relates to the ‘Reflecting on your work’ above. Knowing about older adults’ experiences is not enough, and gathering feedback is also not enough to improve the quality and satisfaction of working together. It is important to act upon this knowledge and make changes based on this feedback whenever it is possible to do so. If it is not possible, discuss why not. Seeing that the members’ voices are heard and responded to are important factors in maintaining successful long-term relationships with older adult members of advisory groups.
APPENDIX A – Terms of Reference Examples of sections to include in the document (The font size and colors should be adjusted for proper print clarity).

Terms of Reference

Name of group: Older Adult Research Partner Group for OA-INOLVE Project (OARPG)

Purpose / role of the group: /Brief description of the purpose/

Membership:
• The OARPG will have 12-16 members in total; 3-4 in each geographic location (Guelph, Halifax, Toronto and Vancouver).
• OARPG membership will last for up to 3 years, or until the completion of the project. During this time, OARPG members may leave when they like, without repercussion.
• Membership will be re-affirmed on a continual basis.

Responsibilities:
The responsibilities and engagement plan will individualized according to member needs and abilities. OARPG members do not need to complete or participate in all of the responsibilities outlined; they will have the flexibility to determine and modify their level of engagement throughout the life of the project.
Responsibilities may include:
• Attendance at local face-to-face and/or videoconference meetings (approximately 5-6 per year).
• Provide advice and direction as appropriate on project plans, strategy and actions.
• Discuss and provide guidance on issues that affect the delivery of the project, the interpretation of study findings, dissemination and knowledge exchange strategies and actions.
• Decision-making in key aspects of the project.
• Help to guide the development of recommendations arising from their engagement.

Orientation and Training:
• Initial and ongoing review of details related to the project (e.g. objectives, concepts, methods) will be shared with any new members individually prior to a group meeting, and during the first meeting with the OARPG members.
• The training needs will be determined in collaboration with the group and individually with group members, and training will be provided on an individual and/or group basis as needed.

Ways of Working:
• Face to face meetings will be organized at locations agreed upon by all team members.
• The format of meetings may vary depending on the issues to be covered but will usually include discussions and presentations.
• National meetings will be organized via videoconferences facilitated by a group lead at each location
• Members of the OARPG will receive documentation, via preferred communication mechanism (e.g. a paper copy or electronic via email), a week before each meeting.
• Members may be contacted between meetings for advice should the need arise.

Resource Sharing:
• Information and resources will be shared across the group using email primarily but other ways (e.g. paper copy, telephone messages, personal visits) will be accommodated as necessary.

Review and Assessment:
• At the end of each year, all members will assess the relevance and value added by the OARPG.
• Continuous review of the terms of reference will also feature as part of OARPG work in order to achieve best results and positive experiences.

Conflict of Interest: /All members of the OARPG must declare current or potential conflicts of interest/.

Contact: /Provide name, phone, email of the contact person/.
APPENDIX B - Recruitment poster example
An example of a poster used to recruit members by OA-INVOLVE project – distributed during an event for older adults.

(Adapted from Lupin Battersby)