



Guidelines and Advice for Older Adults who are Interested in Becoming Involved or are Currently Involved in Research Projects

Get involved in research. Your life experience can contribute to research and your voice matters. You may have a general interest in learning and research or you may be motivated to help in the development of technologies that can assist older adults. This includes giving consideration to the ease of use and affordability of technology. There are many potential benefits of getting involved in research. Your role may be as a participant, advisor, decision-maker or other. Older adults with cognitive or physical impairments can be involved in research. Those living in remote areas can also be involved in research through technology like video conferencing. The following guidelines will help to ensure that you enjoy the benefits of being involved in research and that you feel comfortable and informed throughout the research process.

Potential Benefits of Being Involved in Research

1. Discuss with the researcher(s) how this research project may be of mutual benefit (e.g., social reward, monetary compensation, access to and assistance with technology).
2. Use the opportunity to provide feedback based on your lived experience to influence the direction of research that will help older adults.
3. Look upon your participation as an interesting and fun experience! If you're not enjoying yourself, you may want to re-think your involvement.
4. Enjoy the opportunity to work with people of diverse backgrounds and skills.
5. Get involved with group work, writing blogs, giving presentations, attending conferences, and fully participating in all aspects of the research experience.
6. Ask the researcher(s) for feedback about the value of your participation, how it has contributed to the research, and what benefit or difference it has made.

7. Being involved in a research project provides you the opportunity to learn what is being done to help yourself and other older people to achieve a better quality of life. It also helps to keep you active and provides a learning and social experience by interacting with the researcher(s) and others in the research project.

Seeking Clarification from the Researcher(s)

1. Ask the researcher(s) to avoid technical jargon and communicate with you using clear words and accessible language as needed. Ask for clarification at any point, including any informed consent that may be required, during the research process.
2. Make sure you are clear about the commitments, expectations, and expected research outcomes. Ask for a document to clarify the purpose of the research, project activities, and possible roles for you (e.g. consent form or Terms of Reference). For an example of a Terms of Reference see http://www.oa-involve-agewell.ca/uploads/1/2/7/2/12729928/oa-involve_terms_of_reference-2019.pdf
3. Continue to clarify with the researcher(s) your role at various stages of the project and the expectations for that role.
4. Make sure your opinions are heard and request feedback from the researcher(s).
5. Ask for periodic updates on the progress and challenges of the project.
6. Seek support and feedback on tasks that you are asked to perform especially if you have any reservations.

Ways to Feel Comfortable at All Stages of the Research Process

1. Let the researcher(s) know your concerns if you become uncomfortable at any stage of the research process.
2. Persons with cognitive or physical impairments may wish to attend meetings with a support person. With or without a support person, make sure your voice is heard. Make the researcher(s) aware of any of your special needs.

3. Ensure that you are comfortable in meetings and focus groups including that the time frame is not too long and that your surroundings and the group size meet your needs (e.g., support chair, comfort level).
4. Let the researcher(s) know what technology and related training you require to fully participate in the research project (e.g., tablet, cell phone, training to use handheld devices).
5. Take the opportunity to ask questions and talk with other participants. If you would like to meet with one or more of the other participants in your research group, ask the researcher(s) to arrange a meeting.
6. Share with the researcher(s) what your needs are on an ongoing basis because your needs may change. Ensure that the location and transportation options meet your needs.
7. Ask the researcher(s) to increase the size of font, graphs, colour contrast, etc. on documents if they are too difficult to read.
8. Talk to the researcher(s) if you are concerned about privacy or anonymity.

Prepared by Members of the OA-INVOLVE Older Adult Research Partner Group

Janet Fowler
Ian Goldman
Bessie Harris
Anne Kerr

For more information contact the Project Coordinator at ajenki02@uoguelph.ca or OARPG Lead at romeo.colobong@uhn.ca. Please visit us at oa-involve-agewell.ca