



Data collection with people living with dementia Information Sheet

Introduction and Purpose

There is a lot of variability in dementia. Skills and abilities vary across individuals and over time as dementia progresses. Therefore, traditional data collection methods (e.g., focus groups, surveys, interviews) may be appropriate for some people living with dementia but not for others. Further, sometimes it may take someone with dementia longer to take in a question and determine their response. It's important to consider how research activities can be made more inclusive for people with dementia. The purpose of this information sheet is to provide a high-level overview of some of the ways that we, as project staff, volunteers, and researchers, can support persons with dementia to share their experience, knowledge, and expertise!

Interviews

When interviewing people with dementia, remember that there are a lot of steps in responding to a question (hearing the question, processing it, thinking of a response, deciding on a response, etc.). Sometimes persons with dementia may need longer to take in a question and determine their response. When interviewing, the following consideration may be helpful:

- Provide response options on a laminated piece of paper that participants can refer to.
- Provide the questions ahead of time to give participants more time to review the questions and think about their responses.

Surveys and Questionnaires

Scales (e.g., 5-point scale – poor, fair, good, very good, or excellent) can provide too many options for some people with dementia. The above considerations work for scales as well! Here is an example of a scale that may be challenging for some people living with dementia:

On a scale from 1 to 5, how would you rate your satisfaction with this program?

- a. 1 - not satisfied
- b. 2
- c. 3
- d. 4
- e. 5 - fully satisfied

How can we make this more accessible for persons living with dementia?

- Break down the scale and starting with a dichotomous response. For example, you could ask “overall, were you satisfied with this program? yes or no?” Then, follow-up to get a more specific response. For example, if the person said “no” ask if they are not satisfied at all or just somewhat unsatisfied?
- Use alternate labels for scales other than traditional numeric labels. Examples include smiley face emojis, colour gradients, and thumbs up or down. For example, consider how this scale can be altered with the use of emojis:

In general, would you say your health is...?

- Excellent
- Very good
- Good
- Fair
- Poor

In general, would you say your health is...?

- Excellent 
- Very good 
- Good 
- Fair 
- Poor 

Let’s explore another example of how a scale be altered with the use of a coloured gradient.

How would you describe your sense of belonging to your local community?

- Very weak
- Somewhat weak
- Somewhat strong
- Very strong

How would you describe your sense of belonging to your local community?



Focus Groups

Focus group guidelines for engaging persons with dementia suggest that 3-6 participants is ideal. When conducting focus groups, consider having a conversation or topic guide with the list of questions you want to ask, or topics that will be covered. ^{Dementia Enquirers 2019} Another consideration for conducting focus groups with persons living with dementia is to give participants a sign that says, “I would like to speak”. ^{Dementia Enquirers 2019} This may promote equal opportunity to participate. The SIIP backbone team has a series of speaking cards available to project teams (see image below) that may be useful during focus groups.



Additional Research and Communication Tips

Here are some general considerations that can be used across various forms of data collection (e.g., focus groups, surveys, interviews) to support the comfort and engagement of persons with dementia in sharing their expertise and experiences:

- Consider having the persons who are collecting the data wear informal name tags, displaying their name in big and clear font.
- Face the person and speak clearly. People who are older may have vision or hearing difficulties, therefore additional aids may be necessary to optimize their participation (e.g., Pocket Talker). The volume and tone of your voice is important, try to find the volume level at which the person can hear you clearly and maintain that volume.
- Ensure all written material provided to participants are in an accessible font and increased font size (e.g., Arial size 14 font for printed documents).
- Ease into the conversation. Include time for a non-research activity, such as a chat to get to know each other or a cup of tea or coffee. Starting with an informal exchange by asking everyday questions (e.g., how are you?) can help to relax the participant and build rapport.
- Ensure that messaging to persons with dementia before starting any data collection that there are no right or wrong answers.
 - o Reassure the participant that the onus is on the program. For example, stating that “we want to make sure that we are doing a good job of providing the program so your input, regardless of it’s good or bad, will help to make it better!”

- Ask a question at the beginning to ensure they are thinking of the correct program (e.g., why were you referred to this program?).
 - o Try to give some additional cues to the participant (e.g., your name, specifically identify the activity and program being discussed).
 - o You may not be able to collect data from an individual if they aren't talking about the correct program – if it is clear in the data that they were not, do not include or remove that data.
- Consider grouping questions into themes or topics that follow a logical sequence, although you can move back and forth between questions or topic areas that make sense with the natural flow of the interview or focus group. Highlight and prepare the person when you are switching to a new topic.
- Where possible, be flexible to a persons preferred time of day and location for data collection. For example, some people may feel more comfortable being interviewed in their home or another familiar location. Try to ensure that the data collection location is as free of distractions as possible.
- Consider the length of time you are asking for from persons living with dementia and ensure there are breaks given and refreshments are provided.
- Remember that some people have more to say than others! It is important to not probe repeatedly for details or contradict participants.

The Alzheimer's Society provides strategies for supporting communication and participation which are transferable to research activities. These include: being close enough to the person with dementia so that they can see your expressions and gestures, using short and simple sentences, using closed-ended questions, and including the person in conversations with others.

Additional resources:

1. Dementia Enquirers - DEEP Dementia Engagement and Empowerment Project – UK wide network, a team of around 80 groups of people with dementia – wide range of resources on engaging people with dementia
<https://www.dementiavoices.org.uk/deep-resources/involving-people-with-dementia/>
2. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-methods-review_MR022.pdf
3. <https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/communicating-people-living-dementia>



The Schlegel-UW Research Institute for Aging (RIA) is a charitable, non-profit organization tackling some of the biggest issues facing an aging population. We push the envelope to find and share solutions that make a difference to benefit older adults everywhere.