



Stakeholder Perspectives:

Engaging and Working Effectively with Individuals Living with Dementia as Stakeholder Advisors and Research Partners

About the Stakeholders



Brenda Nicholson, MD (pictured left), and **Louise Phillips, MD, MBA** (pictured right), are retired physicians who are living with dementia. Both have participated as stakeholder advisors and research partners for important research-related initiatives on dementia care and services. Currently, they

are members of the Executive Committee for the [Stakeholder Engagement Team](#) in the National Institute on Aging's [IMPACT Collaboratory](#).

Dr. Nicholson and Dr. Phillips were members of the Persons Living with Dementia Stakeholder Group for the first National Research Summit on Care, Services, and Supports for People with Dementia and their Caregivers held in 2017. Dr. Phillips spoke at that summit, and Dr. Nicholson helped to plan the presentation. Dr. Nicholson is also a member of the Stakeholder Advisory Committee for D-CARE, a multi-site pragmatic clinical trial that is comparing the effectiveness and cost of a health system-based versus a community-based dementia care program.

Dr. Nicholson was a practicing oncologist before she developed symptoms of dementia. Dr. Phillips was a practicing physician and Medical Director at a community-based long-term care facility in New York City. They are both familiar with research and research methods and understand the importance of evidence-based clinical care. Their professional education and experiences are advantages for them as they participate in dementia research initiatives. Their many interactions with other people living with dementia and their awareness of their own dementia-related symptoms are also advantages, allowing them to provide valuable insights about the experience of living with dementia and the needs of people with the condition. At the same time, their own dementia-related symptoms mean that various kinds of adaptations are needed to support their effective participation as stakeholder advisors and research partners.

Why Participation as Stakeholder Advisors is Important

Dr. Nicholson and Dr. Phillips give 3 reasons for their ongoing commitment to participate as stakeholder advisors and research partners in dementia care research:

1

They hope to encourage more research on topics that are important and relevant for the well-being of people living with dementia and their families.

2

They hope their participation will help to convince researchers that it is valuable to include people living with dementia as research partners in their dementia care studies; so, in a sense, to “break through the glass ceiling” in this research area.

3

They hope their involvement as research partners will be a clear and present reminder to research team members of the real human needs of people living with dementia which are sometimes lost in the strong focus on research procedures and challenges.

Based on their own experiences, Dr. Nicholson and Dr. Phillips offer the tips below for researchers who want to engage and work effectively with people living with dementia as stakeholder advisors and research partners. They emphasize, however, that every individual living with dementia has a unique background and current symptoms and lived experiences of dementia that result in different, but valuable perspectives and insights, as well as different needs for adaptations to support their participation in research. With that caveat in mind, they suggest that researchers should consider adaptations in the following areas as they plan their studies:

Deciding how stakeholder group and research team meetings will be conducted

For people living with dementia, there are pros and cons to meetings and communications that are conducted in-person, by telephone, by Zoom or another video conferencing method, or by email.





Traveling to an in-person meeting can be difficult for many reasons, but despite the difficulty, individuals living with dementia often appreciate being able to meet in-person and interact with other members of the group or team.



Meeting by **telephone** is familiar and easy, but individuals living with dementia may have difficulty recognizing who the other call participants are and getting their own ideas heard in a telephone call.



Zoom and other **video conferencing** methods are less familiar and can be technologically difficult, at least at first, but many individuals living with dementia appreciate being able to see and “get to know” other participants on these calls, even though the calls are not in-person.



Individual and group **emails** are an important way to communicate between meetings and can be read at the convenience of the person living with dementia, but emails can be difficult to organize and may get lost and have to be requested and resent.

Considering these pros and cons, Dr. Nicholson suggests organizing an in-person stakeholder group or research team meeting early in the study process, if feasible. An early in-person meeting can allow the group or team members, including those living with dementia, to get to know one another. Feeling comfortable with other meeting participants makes it easier for individuals living with dementia to overcome insecurities, ask questions, and share ideas. Because travel is costly and challenging for many people living with dementia, Dr. Nicholson suggests that subsequent and frequently held meetings should be conducted by Zoom or other video conferencing methods, and perhaps one or a few additional in-person meetings, depending on the duration of the project.



Providing assistance with travel

A person living with dementia may have significant difficulty or be unable to manage the necessary planning and arrangements to travel to an in-person meeting and back home. Before and during the trip, the person may feel anxious about getting to the meeting location, finding his or her hotel room, the meeting room, and restrooms. Many people living with dementia need a travel companion to help with these activities and may feel vulnerable and/or afraid of getting lost without such a companion. Feelings of anxiety, vulnerability, and fear of getting lost can later interfere with the person’s capacity to participate effectively in the meeting.



To promote a more positive experience, researchers should plan to provide assistance with travel as needed. Someone from the project should be available to make travel arrangements for the person and a travel companion. Clear instructions should be provided about the travel arrangements and how to get to the hotel, if needed, and the meeting location. The person living with dementia and the travel companion should have the name and phone number for a contact person from the project who will be able to help with problems that arise during the trip. In thinking about a recent travel experience, Dr. Nicholson says:



"I can't follow directions, so thankfully, I arrived with others who could help when we had to maneuver our way to the conference room. So, keeping in mind how easy it is for a person living with dementia to get lost in unfamiliar places, making sure someone is looking out for us getting to meetings would be helpful. This speaks to another role a 'point of contact' person might help with. When it was time to return to the hotel, someone helped me call for a cab, and I followed the pack to find my way. But if I had departed at a separate time from others, I could not have managed on my own."

Dr. Phillips suggests that the procedures followed in assisting stakeholders living with dementia who participated in the 2017 National Research Summit provide a good model for meeting planners. For the summit, stakeholders living with dementia convened in the meeting hotel. Transportation was provided to the meeting location, where the stakeholders were met, led to the meeting room, and shown where bathrooms were located. At the end of the meeting, the onsite contact walked out with Dr. Phillips and helped her get a taxi.

Dr. Nicholson and Dr. Phillips emphasize that even with accommodation, traveling takes a lot out of them and that it probably takes a lot out of many other people who are living with dementia. They have to rest in preparation for a trip and often need several days to recover. Nevertheless, they are almost always glad they went, feel that they made a contribution to the meeting, and enjoyed talking and being with other meeting participants.

Helping the person living with dementia to prepare for a stakeholder group or research partner meeting

Dr. Nicholson says that she feels more capable of making a contribution to meetings, whether in-person or by telephone or Zoom, if she knows ahead of time what will be discussed in the



meeting and if possible, what the meeting leader and research team want her to address. When she has this information, she often makes notes for herself about ideas and questions she wants to raise. For the meeting leader and research team, making sure that this information is communicated ahead of time to participants living with dementia is likely to increase the relevance and value of those participants' ideas and suggestions.

Structuring the meeting to optimize the environment, experience, and contributions of stakeholder group and research partners living with dementia

To support stakeholder group and research team members who are living with dementia, meetings should start with a clearly stated purpose and structure, and the planned structure should be maintained to the extent possible. This is important because a person living with dementia may become confused if changes are made quickly, especially if they are made without explanation.

Dr. Nicholson points out that:



"Crowded meetings can be very difficult environments for individuals living with dementia. This is especially true if the location is unfamiliar and many people are standing around visiting at once. A person living with dementia can feel overwhelmed and get overstimulated easily, making it difficult to stay self-possessed and maintain composure. As a person's dementia worsens over time, such situations become more difficult to navigate."

With respect to her own case, Dr. Nicholson says:

"When I begin to feel overwhelmed in a meeting, it becomes difficult to compensate for my dementia-related symptoms. If I decompensate, my Pseudobulbar Affect is triggered, making the situation even worse. Although I have learned to hide most of my symptoms and discomfort from people who don't know me well, I function better when in a comfortable and welcoming environment."

To help meeting participants who are living with dementia feel comfortable and welcome, the meeting leader should greet and acknowledge them when they arrive. These participants will



feel more comfortable if they recognize one or more other participants they have met previously. For an in-person meeting, the meeting leader or another designated group or team member should “re-introduce” participants living with dementia to other individuals they have met before.

When the meeting begins, ask all participants to introduce themselves, whether it is an in-person, Zoom or telephone meeting. For telephone meetings, ask all participants to identify themselves before they begin to speak.

Helping group or team members living with dementia to get their ideas heard

Whether the meeting is in person or by telephone or Zoom, participants who are living with dementia often have difficulty getting their ideas and suggestions heard and then feel frustrated about not being able to break in. This is especially likely to occur in fast-paced discussions when several people are speaking at once. Although many meeting participants who are not living with dementia probably also experience frustration about not being able to break in during fast-paced discussions, it is important for researchers and meeting leaders to be aware of specific dementia-related problems that increases the difficulty and level of frustration and worsen its consequences for those living with dementia.

In particular, dementia-related problems with word-finding often make it difficult for meeting participants who are living with dementia to express and get their ideas heard in meetings. Likewise, dementia-related problems with processing new information in real time make it difficult for many participants living with dementia to express and get their ideas heard.

Dr. Phillips points out that:



“The best way to communicate with a person living with dementia depends on the specific needs of the individual. Some individuals living with dementia may have more difficulty with verbal communication, and others may have more difficulty with written or print communication.”

She adds that she has more difficulty with verbal communication and further explains:



"I hear the information, but it doesn't decode right away, especially if there is ongoing dialogue. The more detailed and specific the information, the more difficult it is to process, making me feel very lost in many meetings."

Dr. Nicholson and Dr. Phillips suggest that researchers should strive to be aware of the specific communication deficits of stakeholders they are working with and modify communication methods if necessary to accommodate individuals' needs. They recommend that meeting leaders should watch for problems in word-finding, processing time, and other dementia-related speech and language deficits that make it difficult for meeting participants to get their ideas heard; routinely ask those participants whether they have comments or questions, and try to ensure that the participants have time to process new information and respond.

Being encouraged to express their ideas and suggestions and receiving responses that show they were heard and understood will help individuals living with dementia participate effectively in research meetings. Over time, with successful experiences in project meetings, they will build trust in the meeting leaders, other meeting participants, and communication processes, and the likelihood of extreme frustration, anxiety, and fear of decompensation will be reduced, but meeting leaders and research teams still need to be aware of the risks.

Dr. Nicholson and Dr. Phillips suggest that for in-person meetings, participants living with dementia should be asked if they would like to have their travel companion sit beside them. It may also be appropriate to ask if they would like to sit near the exit so they can leave the meeting if they need some quiet. If the meeting lasts a full day or more, arrangements should be made for a quiet space the person living with dementia can escape to for a break.

Providing opportunities to submit additional ideas and comments after the meeting and staying involved over time

Individuals living with dementia want to contribute but may only think of some ideas and comments after the meeting. Meeting leader should encourage participants to send in questions and additional ideas later, and procedures should be in place for the research team to respond to these messages.

Some individuals living with dementia may want to have a recording of a meeting so they can listen to the discussions at a later time when they can better process the information. Researchers



and research teams should consider whether creating such a recording is feasible for their project.

Stakeholder advisors and research partners living with dementia sometimes say that their involvement in research-related activities makes them feel they are “living for something.” Dr. Nicholson suggests that researchers should keep in mind that these individuals may feel that they are participating against the backdrop of disease progression and increased cognitive losses.

She points out that:



“When collaborating with a person living with dementia, there is a silent and unspoken ‘deadline’ caused by disease progression which is unpredictable. So, if an investigator wants to collaborate with that person on a specific project, he or she might want to prioritize this project, because 6 months in the life of a person with dementia is a long time, but passes in an instant for a busy researcher.”

Avoiding the implication that the individual living with cognitive impairment and dementia is expected to represent all people living with dementia

Dr. Nicholson and Dr. Phillips know and talk with others who are living with dementia regularly, but they point out, as noted earlier, that each person living with dementia is unique. They emphasize that no single stakeholder group member or research partner should be asked or expected to represent all people living with dementia.

Evaluating the experience of individuals living with dementia who participate as stakeholder advisors and research partners in dementia care research

Dr. Nicholson and Dr. Phillips recommend ongoing (formal and informal) evaluation of the research-related experiences of individuals living with dementia who are participating as stakeholder advisors or research participants. They point out the importance of learning about both positive and negative research-related experiences and the potential for addressing problems in real time and improving procedures for effectively engaging individuals living with dementia in future studies.



Finally, Dr Nicholson and Dr. Phillips emphasize that individuals living with dementia want to contribute to research on dementia care and services:



"We want to do our best and to overcome our cognitive challenges in order to represent ourselves and the community of people living with dementia well. We want to learn new facts, understand concepts, process information, then vocalize our thoughts. At any place along this input/output pathway, however, we have deficiencies that challenge us, and there is often a hesitancy to ask for help or for adjustments to be made if we are struggling. We hope that researchers and others can learn from our experiences and that these tips are useful to them."

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