



Persons Living with Dementia

Stakeholder Group Interviews

October 2017

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.



Interview with Persons Living with Dementia Stakeholder Group
Co-Chairs and Leadership Team: Lonni Schicker; Teresa Webb; Gary Epstein-Lubow;
Emily Shubeck; Cynthia Huling Hummel; Louise Phillips; Brian Van Buren
August 9, 2017, 2:00–3:00 pm ET

Interview questions

1. Can you talk about how you have chosen to manage your Stakeholder Group meetings? What approaches work well when communicating with the group? What does not work well?
2. What are the roles of the participants? What are the opportunities to contribute during meetings and outside of meetings? What feedback have group members provided that has guided this process?
3. Based on the discussions you've had already, what are some of the main concerns of the Persons with Dementia Stakeholder Group in relation to care and services for people with dementia and their caregivers?
4. What does it mean to live well with dementia? What kinds of care and support are most important to helping people live well with dementia?
5. What topics should researchers focus on that would most help persons with dementia?
6. How can researchers encourage people with dementia to be more involved in research?
7. What would the members of this group most like to see happen at the Dementia Care Summit? What would they like to see happen after the Summit?

Summary of Persons Living with Dementia Interview

1. Persons living with dementia want their voices to be heard

This group is concerned with making sure people living with dementia have the chance to participate actively in discussions about research, care, and services. They are the best source of information about their own experiences and what they need. Being part of this stakeholder group has been meaningful. Its members would like to see continued opportunities for people living with dementia to remain involved in discussions about services and supports and in all phases of project development, including development of initial concepts, intervention design, implementation of research or clinical programs, evaluation, and dissemination of effective new models.

There was some frustration expressed about not being taken seriously in the past. This summit is a chance to share their views and recommendations, and they are eager to see these recommendations disseminated and put into action. They want their voices to be heard at the summit and beyond.

The summit is a unique opportunity for researchers and people living with dementia to come together to make personal connections and to share ideas. The group has been working with co-chairs of the summit sessions to find opportunities for members of their group to speak and has also looked for other ways for its members to participate fully in the summit—for example, serving as a media liaison or providing input on session content.

The importance of having a voice extends beyond the summit. Members of the leadership team expressed the strong desire for people living with dementia to be able to determine their own care plans to the greatest extent possible. Often after a diagnosis, decisions are made by care partners or health care providers, with little or no input from the person living with dementia. Many members of this group have experienced this frustration. Having a voice means being able to decide for yourself what you want.

Because the people in this group are most familiar with issues related to the early stages of dementia, that has been the primary focus of their discussions. However, they expressed an interest in continuing their work together after the summit and discussing the issues that arise as dementia progresses.

2. How to support the involvement of persons with dementia in discussions about care and services

Approaches that have been successful

This stakeholder group has operated with a philosophy of enabling each group member to participate to their fullest ability. This entails getting to know each person, their skills, areas of interest, and the things that are most challenging to them. For example, some people may get “oversaturated” by long meetings, while for others, sorting through

multiple e-mails or long documents may be overwhelming. Checking in at the beginning or end of each meeting has provided an opportunity to hear how each member is doing and to adjust the approach if necessary. This has also helped build a strong spirit of caring and respect within the group.

Several strategies have helped accommodate group members' needs. For example, using web video-conferencing instead of a teleconference is preferred; members feel they can communicate more easily when they can all see each other. Emily Shubeck, at the national Alzheimer's Association, has also summarized meeting notes and has worked to limit the number of e-mails. She has organized all documents on Google Drive, which has made it easier for members to find information and to provide comments on documents. As the activity of the group has increased, having someone to help keep information condensed and organized has been important.

For each meeting, the group has selected a topic ahead of time and then invited a researcher to speak about that topic. The researcher often sends questions ahead of time for the group members to consider and to discuss on the call. This has helped members feel prepared before the meeting and to know what to expect.

Although there are two group co-chairs, Lonni Schicker and Teresa Webb, the decision was made to create a leadership group made up of 5 of the 12 members. This has helped keep the workload manageable for each member and has also enabled each person to take on specific roles and responsibilities that suits them, which also supports the goal of helping members participate fully. Areas of focus for this leadership group include communications and diversity.

Inclusivity

Several members of the leadership team expressed concerns about the lack of connection between researchers and the community. When there is not a strong connection between the two, research may not lead to interventions that are practical or sustainable in the community.

More specifically, researchers and service providers need to engage with underrepresented communities to learn about their values and priorities. For example, the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community has a shortage of support resources that are sensitive to their specific needs. Some general dementia support groups may be accepting of LGBTQ members and others may not. Sometimes LGBTQ people living with dementia do not have the same family support systems that can help with care, or with participation in a research study. People developing and implementing care and support services need to be aware of these needs. Other examples are a lack of connection between researchers and the African American community, rural settings, or senior centers that will not accept people with cognitive disorders.

3. Maximizing independence and living optimally with dementia

One of the key themes expressed by the leadership team of this stakeholder group is the importance of maximizing independence. This means being able to live on their own for as long as possible and doing as much as they can with the time and abilities they have. They want researchers to focus on ways to support this independence. Optimizing the experience of people living with dementia also means access to resources, including good medical care, a support system, and access to services and supports.

Living with dementia requires an ongoing process of adjustment to continual changes and figuring out how to best move forward. Finding ways to continue activities that bring joy and meaning is a priority, which may mean creatively adapting those activities, or sometimes finding a new interest that can bring enrichment. They acknowledged that there is a grieving process involved. “How do you move from ‘why me?’ to ‘what’s next?’”

4. Involving persons living with dementia as participants in research

This group wants persons living with dementia to have much greater access to research opportunities. Because of limitations, such as lack of a care partner or transportation challenges, many people have been unable to participate in research. Certain communities, such as African Americans or Latinos, have also been underrepresented in studies.

Several ideas for facilitating involvement have been suggested by the group, including use of videoconferencing; partnering with other clinics or hospitals so that some testing can be done locally; providing more accommodating scheduling options; paying for overnight accommodations or meals to enable people to travel; using a “bookmobile” approach to bring researchers to the community; partnering with faith communities to reach out to broader networks; and not excluding people living alone with dementia from studies.

5. Developing a common language and knowledge base

Lack of dementia awareness and education is a problem for the general public, health care professionals, care partners, and law enforcement. Terminology is not used consistently. Dementia may be called many different things even within the medical community, and people may use the same terms differently. This makes it very difficult to reach a common understanding of how to address needs and develop care plans. Lack of understanding also affects how people view dementia in general and how they treat people living with dementia.

Another key gap that the group identified is primary care physicians’ lack of knowledge about available resources. Many members received no information on supports and

services at the time of diagnosis. Doctors also need better tools for assessing the progression of dementia. Often, the same assessment tool is repeated over and over, but this provides little to no information on how the person is doing or how their needs might be changing.