



# Empowering Partnerships

*Preparing People with Dementia  
to Partner with Researchers*

## Summary of Responses from Researchers and Providers

May 30, 2019

LiveWell is designing a training program to prepare persons living with dementia and researchers to co-partner in research. Persons living with dementia can offer tremendous value to researchers. Persons living with dementia can certainly be participants in research studies, but there are so many different ways for persons living with dementia to partner that extend beyond being a participant. For example, persons living with dementia can help with designing and implementing the research questions, providing consultation on topics and interpretation of findings, dissemination of results, and planning for future research. We are interested in hearing from you about your experience with co-research partnerships and your views about what might facilitate such partnerships in the future.

Please review the questions below that apply to your experience with research and researchers. During our zoom videoconference, we will discuss the questions that are relevant to you! Thank you for your time and consideration!

### **Researchers and Providers With and Without Experience Co-Partnering with Persons Living with Dementia**

- Be intentional about creating opportunities to establish rapport; help all parties to learn about who is in the room (interests, backgrounds of persons living with dementia and researchers, experience with research for persons living with dementia, opportunities for researchers to share what led them to choose their profession as well as any connections to persons living with dementia) Provide opportunities for persons living with dementia and researchers to share their stories. Intentionally partner persons living with dementia and researchers.
- Help persons with dementia recognize the meaningfulness, usefulness of research. Connect research to persons with dementia on a personal level.
- Convey the value of co-partnership to all stakeholders (persons living with dementia can shape research priorities; persons with dementia need to have a voice, and their voice and experience should drive the development of research questions). Persons living with dementia have the ability to improve research and offer views of impact and innovation from a different lens. Persons living with dementia help with “grounding in reality”. Help persons with dementia to recognize the value that they offer!

- “People bring different expertise, but everybody’s expertise is really critical to the project working. Make sure persons don’t feel intimidated or reluctant to share if they don’t feel it is important.”
- Present information in user friendly format. Define the array of opportunities that exist for co-partnership. Health literacy was a common theme. Operationalize roles so that researchers and persons living with dementia can understand the different levels of partnership. What does this look like for basic scientists who may have little to no human interaction in the lab?
- Co-partnerships can help researchers to get to the right questions. It is important to talk with persons with lived experiences about the questions that are going to make a difference. Gathering input from persons with dementia can help researchers to ask the right question and develop solutions to authentic problems.
- Educate researchers about disease process, how to handle progression of disease when co-partnering. Additional education re: what kinds of scenarios may emerge and WHAT NOT TO ASSUME. Provide education about communication strategies; best practices re: communicating with persons living with dementia. Education should address basic knowledge about dementia and knowledge about how research can be enhanced by co-partnerships.
- Explore stereotypes, stigma that exists related to researchers and persons living with dementia; help persons with dementia recognize that “researchers are people too, with families”. Researchers are normal people who want to learn from persons with dementia. Even though they have may have very specific expertise at a high level, this does not mean they know enough. There are gaps in knowledge that can be filled by co-partnering with persons living with dementia.
- Adaptations/considerations: Make sure to speak common language, multiple breaks, varied teaching methodologies (graphics, reading, videos); giving equal time in the formal program to persons living with dementia and their care partners; have persons with dementia script what it is that they want to be researched and tell their stories. Find a dementia friendly environment for training. Provide refreshments.