



## Interview Questions:

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

### Categories of interviewees with interview candidates

- A) Persons living with dementia WITHOUT experience co-partnering with research
- B) Person living with dementia WITH experience co-partnering with research
- C) Care partner WITH experience co-partnering with research
- D) Care partner WITHOUT experience co-partnering in research
- E) Researcher WITHOUT experience co-partnering in research
- F) Researcher WITH experience co-partnering in research
- G) Healthcare Professional

### Use corresponding question set below:

#### A) Persons living with dementia WITHOUT experience co-partnering with research

- Describe any experiences you have with research. Were these positive or negative experiences?
- Describe any educational or training programs you have participated in? In particular, what was positive about these experiences? Negative?
- When thinking about partnering with researchers, what thoughts come to mind? What fears/ concerns do you have? What excites you about such an opportunity?
- How do you think partnering persons living with dementia with researchers can be helpful for:
  - Researchers?
  - Persons living with dementia?
- What challenges/barriers exist that might prevent you from partnering with researchers? From attending a 2 day training?
- What are some of the reasons persons living with dementia might want to partner with researchers?
- What do you most want researchers to know about persons living with dementia?

- How do you best learn?
- What would help to create an environment in which you felt comfortable sharing?
- As we are planning this 2-day training, what do you believe are important considerations (ie. space, breaks, handouts, etc.)? What adaptations might need to be made to help persons living with dementia successfully participate in a training?

## **B) Person living with dementia WITH experience co-partnering with research**

- Describe your experience co-partnering with researchers. What did you most enjoy? Least enjoy?
- What were your reasons for wanting to participate in this experience? Why would you encourage persons living with dementia to get involved in co-research? Researchers?
- What were your thoughts about co-partnering in research before you became involved in this process? How was this experience similar to/different from what you anticipated/thought it would be like? What surprised you?
- What did you gain/learn from participating in co-research? What do you think researchers gained from partnering with you?
- What were some of the challenges or barriers that you encountered during your experience?
- Describe your relationship with your co-researchers? What helped to build this relationship?
- Was your research partnership successful? How did you know this?
- What advice do you have for persons living with dementia:
  - who want to participate in research?
  - who are reluctant or afraid to co-partner in research?
- How do you best learn?
- As we are in the planning phases of the training program, what do you think are the most important considerations?
  - What do you think we should be certain to include? To avoid?
  - What adaptations do you feel are necessary to consider when planning a training program?
- Would you be willing to create a short video about your experience(s) that could be included in our training?
- If invited, would you be willing to speak at the training summit we are planning about your co-research experiences (either via Skype or in-person)?

## **C) Care partner WITH experience co-partnering with research**

- Describe your experience co-partnering with researchers.
  - What did you gain/learn from the experience?

- Most valuable takeaways?
- What did you most enjoy about your experience co-partnering in research?  
Least enjoy?
- What were your reasons for wanting to participate in this experience? Why would you encourage care partners to get involved in co-research?
- What were your thoughts about co-partnering in research before becoming in co-research? How did these initial thoughts compare/contrast with your actual experience? What were your fears/concerns about participating in this experience? Did these fears/concerns become a reality when partnering in research?
- What were some of the challenges or barriers that you encountered during your experience?
- Describe your relationship with your co-researchers? What helped to build this relationship?
- Was your research partnership successful? How did you know this? What do you think researchers gained from partnering with you?
- How do you best learn?
- What advice do you have for care partners of persons living with dementia:
  - who want to participate in research?
  - who are reluctant or afraid to co-partner in research?
- As we are in the planning phases of the training program, what do you think are the most important considerations?
  - What do you think we should be certain to include? To avoid?
  - What adaptations do you feel are necessary to consider when planning a training program?
- Would you be willing to create a short video about your experience(s) that could be included in our training?
- If invited, would you be willing to speak at the training summit we are planning about your co-research experiences (either via Skype or in-person)?

#### **D) Care partner WITHOUT experience co-partnering in research**

- Describe any experiences you have with research. Were these positive or negative experiences?
- Describe any educational or training programs you have participated in? In particular, what was positive about these experiences? Negative?
- How do you think partnering with researchers can be helpful:
  - for care partners?
  - for researchers?
- What excites you about the potential opportunity to partner with researchers?
- What are your fears/concerns about partnering with researchers?

- What do you most want researchers to know about care partners of persons living with dementia? Persons living with dementia?
- How do you best learn?
- What barriers exist that might prevent you from participating in a 2-day training program? What about persons living with dementia?
- As we are planning this 2-day training, what do you believe are important considerations (ie. space, breaks, handouts, etc.)?
- What would help to create an environment in which you felt comfortable sharing? Persons living with dementia?

#### **E) Researcher WITHOUT experience co-partnering in research**

- Describe a positive moment or event you have experienced in your work as a researcher? What happened?
- What is your experience in partnering with primary stakeholders (i.e., persons with lived experience of your topic) in research, if any?
- When thinking about partnering with persons living with dementia in your research, what thoughts come to mind? What fears/concerns do you have? What excites you about such an opportunity?
- How do you think partnering with persons living with dementia can be helpful for:
  - Researchers?
  - Persons living with dementia
- How do you think your research would be different or change as a result of a co-partnership? What you think you would learn? How would your research be different?
- What challenges/barriers do you anticipate encountering as a co-partner in research?
- What do you think would compel researchers to co-partner in research?
- What would you most want persons living with dementia to know about research/researchers?
- What education might researchers with little to no experience in working with people with dementia need?
- As we are planning this 2-day training, what do you believe are important considerations? What adaptations might need to be made?

#### **F) Researcher WITH experience co-partnering in research**

- Describe your experience co-partnering in research with persons living with dementia? What were your valuable take-aways?
- Describe a positive moment or event you have experienced during your research co-partnership? What happened?

- What compelled you to become a co-partner in research? Why would you encourage other researchers to co-partner with persons living with dementia?
- What were your thoughts about co-partnership going into the experience and how did your experience compare/contrast with your thoughts about what it would be like? What concerns did you have going into the experience? What excited you about this opportunity?
- How do you think your research has changed as a result of co-partnership? How is your research different?
- What were some of the challenges/barriers you encountered as a co-partner in research?
- Describe your relationship with the persons living with dementia with whom you partnered? What helped to build this relationship?
- Was your research partnership successful? How did you know this?
- What advice do you have for researchers:
  - who want to co-partner with persons living with dementia in research?
  - who are hesitant to co-partner in research?
- What advice do you have for persons living with dementia:
  - who want to participate in research?
  - who are reluctant or afraid to co-partner in research?
- What education might researchers with little to no experience in working with people with dementia need?
- As we are in the planning phases of the training program, what do you think are the most important considerations?
  - What do you think we should be certain to include? To avoid?
  - Please list and describe between 3-5 important elements that you believe should be included in a training summit on co-research?
  - What adaptations might need to be made?
- Would you be willing to create a short video about your experience(s) that could be included in our training?
- If invited, would you be willing to speak at the training summit we are planning about your co-research experiences (either via Skype or in-person)?
- Please share with us any information you would like to add that was not addressed in this survey.

### **G) Healthcare Professional**

- Describe a positive moment or event you have experienced in your work as a healthcare professional? What happened?
- When thinking about partnering persons living with dementia with researchers, what thoughts come to mind? What fears/concerns do you have? What excites you this possibility?

- What do you anticipate can be gained from a co-partnership? From persons living with dementia, care partners, and/or researchers?
- What challenges/barriers do you believe will be encountered during the co-research process?
- If you have experience with persons living with dementia, what would you most want researchers to know about persons living with dementia?
- What education might researchers with little to no experience in working with people with dementia need?
- As we are planning this 2-day training, what do you believe are important considerations? What adaptations do you feel would help to create a positive experience for persons living with dementia during the 2-day training?
- Is there anything else you would like to share that we haven't covered?