



Getting to Know Us: Our Project – What you should know

This interview guide was created to be delivered in an interview format similar to the *MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR)*.¹ All participants in the Empowering Partnerships training can be interviewed using this guide including Persons Living with Dementia (PLWD), Carepartners (CP), and Researchers (R). The purpose of this interview is ensure that all participants have an understanding of the project and are comfortable sharing information about their experience – this is particularly important for PLWD. We are not using this interview to establish capacity for participation which is the intention of the MacCAT-CR. Capacity is NOT a requirement for research partnerships.

With the ultimate goal of the Empowering Partnerships project to increase the participation of PLWD in all aspects of research, we do hope that PLWD will also join research studies as participants. Given this aspiration, the project team felt obliged to provide some level of preparation for a capacity interview. This is our attempt at that aim.

To conduct the interview, the participant should have a printed copy of the “Getting to Know Us: Our Project” Information Sheet (see Appendix). This information is including at the beginning of the *Experiences, Strengths, and Preferences Inventory*. The Interviewer should read the prompts below in italics under each section heading. The headings in the yellow sections are references to the MacCAT-CR. At the end of each section there are questions and the interviewer is listening for specific responses - noted in bold with checkboxes. If the participant does not provide the listed response, there are additional probe questions. If the participant does not provide the response after the probe, move on to the next question.

Interview Guide

Understanding

U1 Disclosure (Nature of project):

“You have been invited to join a training that brings together researchers, persons living with dementia (PLWD) and family caregivers (CG). The purpose of the training is to prepare PLWD, Caregivers and researchers to partner together on research initiatives. This training is the first of its kind and lasts for 2 days.

¹ (2011) MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR). In: Kreutzer J.S., DeLuca J., Caplan B. (eds) Encyclopedia of Clinical Neuropsychology. Springer, New York, NY. https://doi.org/10.1007/978-0-387-79948-3_4894

During the training you will learn about the research process, hear from people living with dementia and hear from researchers. You will hear lectures, watch videos, read/review materials, and participate in group discussions.

We are asking you to join the training, because [select the correct choice]:

- *You have Alzheimer’s or another form of dementia, and this training is specifically designed for people with these diseases who are interested in engaging in research initiatives*
- *You are a carepartner of someone with Alzheimer’s or dementia, and you are interested in supporting people living with dementia to be engaged in research initiatives*
- *You are a researcher interested in partnering with people living with dementia in research initiatives*

During the training, you will also be asked to answer questions and share your opinions as a _____ [PLWD, CP or Researcher].

Your participation in the training is completely voluntary. After the 2-day training, we are hopeful that participants will be interested in engaging in some type of research project. However, you will not be required to participate in any further project.

“Do you have any questions about what I just said?”

“To make sure I am being clear, can you tell me what you have understood about the training?”

- Purpose of project** - prepare PLWD, Caregivers and researchers to partner together on research initiatives
 - [If subject fails to mention spontaneously, ask: “What is the purpose of the project I just described to you?”]
- Duration of the training (procedural element 1)** – 2 days
 - [If subject fails to mention spontaneously, ask: “How long will the training last?”]
- Activities of Training:** Hear lectures, watch videos, read/review materials, and participate in group discussions (procedural 2)
 - [If subject fails to mention spontaneously, ask: “What sorts of things will participants be doing in the 2 days?”]
- Participation in training (procedural element 3)** - answer questions and share your opinions
 - [If subject fails to mention spontaneously, ask: “What will be expected of you during the training?”]

U-2 Disclosure (Primary purpose is exploratory, not individualized)

Historically, researchers have only engaged with PLWD as research subjects. Our hope is to see if we can change the way research is developed. This training is bringing together 3 groups of people: PLWD, CPs and Researchers. Over the course of the 2 days, researchers will hear directly from PLWD about their priorities and goals for research. And PLWD and CPs will learn about how research is designed, funded and conducted. By talking and working together, we hope to see Researchers and PLWD working in partnership to develop research initiatives.

“Do you have any questions about what I just said?”

“To make sure I am being clear, can you tell me what you have understood about the purpose of the training?”

- Primary purpose** – *change way research is developed. Work in partnership.*
 - [If subject fails to mention spontaneously, ask: “What is the purpose of the training I just described to you?”]

U-3 Disclosure (Effect of training on individual)

U-4a Disclosure (Benefits of participation)

As we have shared before, this is the first time we are offering the Empowering Partnerships Training Program. This is a pilot program. We have based the training on other successful programs, and we hope it will be useful and beneficial to all participants. Before and after the training, we will ask participants to complete surveys to help us determine the impact and benefit of the training.

There are several benefits that we hope will result from the training. First, the training team will gain the insight from PLWD, CPs and researchers on what is important to them in this type of research training. Second, participants may learn ways to partner in research development. Third, participants attitudes about dementia, and those living with it may change.

“Do you have any questions about what I just said?”

“To make sure I am being clear, can you tell me what you have understood about the purpose of the training?”

- Effects of training** – *Unknown. Will do surveys.*
 - [If subject fails to mention spontaneously, ask: “Do we know what effects will the training have on participants? How will we find out the effects?”]
- Benefits of training** – *Insight into training. Learning to partner. Changing Attitudes.*

- [If subject fails to mention spontaneously, ask: “What are the potential benefits of the training?”]

U-4b Disclosure (Risks/Discomforts of participation)

U-5 disclosure (ability to withdraw)

A3 Subject believes that a personal decision to decline/withdraw will be honored.

During the training, we will be working to ensure that everyone has a positive experience. If you are a PLWD, we are particularly interested in hearing your opinions and priorities and we hope that you will be comfortable expressing yourself. Over the 2 days, other training participants may ask you about your thoughts and experiences living with dementia. There will also be some material which may be new or unfamiliar. If at any point during the training, you feel uncomfortable with an activity, you can stop or ask for help. Your participation is completely voluntary. No one has to be in the training. You can change your mind at any time, and your withdrawal will not have a negative impact on you now or in the future.

“Do you have any questions about what I just said?”

“Can you tell me your understanding of what I just said?”

Risks – *Hope it is positive experience. May be asked to share opinions. Exposure to new material.*

- [If subject fails to mention spontaneously, ask “In what way might PLWD be uncomfortable during the training?”]

Withdrawal – *Can stop anytime. Can ask for help. No negative impact.*

- [If subject fails to mention spontaneously, ask “What will happen if a person refuses to be in the project or decides to stop once it begins?”]

Since I’m involved in the training team for this project, I’d like to ask you a few questions about your participation.

Appreciation

A-1 Subject believes that his or her personal benefits are not the primary objective of this study.

“Do you believe that you have been asked to be in this training primarily for your personal benefit?”

- YES
- NO

“What makes you believe that?”

A-2 Subject believes that there is a reasonable possibility that being in the project may be less personally beneficial.

“Do you believe the you will receive as much benefit as the training team?”

- YES
- NO

“What makes you believe that?”

Expressing a Choice

“As you know, you have been invited to participate in the 2 day training for PLWD, CPs and Researchers.

Do you think you would:

- Like to participate?*
- Or Not participate?*

Reasoning

R1/R2 Consequential and comparative reasoning

Why do you think that is the best option? [Probe to explore reasoning process.]

Consequences

Comparative reasons

R3 Generating consequences

We discussed some of the possible benefits and discomforts of participating. What are some ways that you can see this training affecting your life?

Benefits

- [If subject fails to mention a consequence of either the benefit or risk/discomfort, ask “How might (restate benefit/risk) affect your everyday life?]

Risk/discomforts

Final Choice

A few minutes ago you told me that you would Like/Not Like to participate in the 2 day training for PLWD, CPs and Researchers. What do you think now that we have discussed everything? What do you want to do?

- Participate*
- Not participate?*

Reasoning

R4 (Logical consistency of choice)

[Interviewer records and explains presence or absence of logical consistency in subject’s choice]

- Logical Consistency**
- Absence of Logical Consistency**

APPENDIX



**Empowering
Partnerships**

*Preparing People with Dementia
to Partner with Researchers*

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We are asking you to join the training, because:

- 1. You have Alzheimer's or another form of dementia, and this training is specifically designed for people with these diseases who are interested in engaging in research initiatives. OR...*
- 2. You are a carepartner of someone with Alzheimer's or dementia, and you are interested in supporting people living with dementia to be engaged in research initiatives. OR...*
- 3. You are a researcher interested in partnering with people living with dementia in research initiatives*

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Do you have any questions about the above information? Feel free to contact:

<i>Erica DeFrancesco</i>	<u>edefrancesco@livewell.org</u>	<i>860-628-3012</i>
<i>Dan Belonick</i>	<u>dbelonick@livewell.org</u>	<i>860-628-3025</i>
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I have read and understood the above information and would like to participate in the Empowering Partnerships Training.

Name: _____ Date: _____