

Two Day Training
October 9 & 10, 2019



Empowering Partnerships

*Preparing People with Dementia
to Partner with Researchers*

Day 1: October 9th
8:30am-5:00pm

Time	Activity/Agenda
8:30-9:15	Breakfast
9:15-10:05	Introductions – Heidi Gil, Stephani Shivers Strengths & Preferences Shared Values Creating an Inclusive Environment
10:05-11:00	Thoughts on Empowerment, Fears & Excitement – Geri Taylor, Bob Savage, Jim Taylor, Joan Monin, Maria O’Connell, Erica DeFrancesco Reviewing Expectations for Working Together – Erica DeFrancesco
11:00-11:15	Break
11:15-12:15	Plan for 2 days – Stephani Shivers Moving from Ideas to Project Design Research Engagement and Concepts
12:15-1:15	Lunch
1:15 – 2:30	Determining Research Priorities – Teresa Webb
2:30-2:40	Break
2:40-3:15	Determining Research Priorities (continued) Coming to Consensus Drawing Group Priorities
3:15-4:00	Sharing Priorities
4:00	Voting on Priorities & Networking
4:30	Priorities Revealed
4:30-5:00	Choose Working Group Continue Social Hour Networking

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Day 2: October 10th
8:30am-5:00pm

Time	Activity/Agenda
8:30-9:00	Breakfast
9:00-9:30	New Beginnings, Checking In, Meeting Expectations? – Erica DeFrancesco
9:30-10:15	Plan for Day: Refining the Study Working Sessions Understanding the Research Enterprise – Rick Fortinsky Intro to Non-Pharmacological Interventions/Strategies, PCOR & CER Introduction to Outcomes Crafting Good Research Questions - Maria O’Connell
10:15-12:15 (take break when group wants)	Activity 1: Determining a good research question Activity 2: Determining Interventions and Study Design Activity 3: Determining Measurable Outcomes
12:15-2:00	Lunch (includes presentations below)
12:45-2:00	What’s next? How can we get involved? Opportunities for engaging in research: Clinical Trials – Jim Taylor, Geri Taylor, Susan Good What’s Next? How can we get involved? – Bob Savage, Dan Belonick Opportunities for engaging in research. Introduction to Personal Action Plans Intro to Visual Representations – Heidi Gil
2:00-3:15 (take break as you need)	Activity 4: Collecting Data Determining Measurable Outcomes, Collecting Data Activity 5: Reviewing Funding Criteria Activity 6: Building a Visual Representation of Group Project
3:15-4:00	Group Reporting – Erica DeFrancesco, Dan Belonick
4:00-4:30	Next Steps Complete Personal Action Plans Sign Up for Continued Dialogue
4:30-5:00	Closing Reflections – Circle with 1 word to express feeling for 2 days Complete Post-Training Evaluation

Who's in the room?



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Activity 1 (10 minutes): Introductions

Please have everyone at your table take 1 minute to share their answers to the following questions:

- *What is your name?*
- *What perspective are you bringing to this training? Are you a Person living with dementia, a Carepartner or a Researcher?*
- *Why did you decide to participate in this training?*

Activity 2 (10 minutes): Strengths & Preferences

Please take a look at your profile in your binder:

- *What are your Strengths? Preferences?*

When one of your strengths is identified, please stand up at your seat

Activity 3 (10 minutes): Shared Values

Find someone at your table who has one of the same values as you have listed on your profile. In 1-2 minutes share:

- *Why is this value is important to you?*
- *Please share an example of that value from your personal experience.*

Thoughts on Empowerment



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Activity 1 (15 minutes): Purpose, Pride, Participation

Identify someone in the group to take notes on people responses.

Please have everyone at your table take 1-2 minutes to share their answers to the following questions:

- *Describe something that gives you a sense of purpose.*

Activity 2 (10 minutes):

After everyone at your table shares, we will share out the table's answers to the larger group.

Determining Research Priorities



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Activity 1: Determining Priorities. Knowing that we are ultimately going to be identifying research priorities and going through the process of moving from an idea to researchable project, we'd like you to answer the following questions. The goal of this exercise is to identify themes/areas/priorities that could be researched. Please take 10-15 minutes to think through your answers and jot down notes below. You will then have 5-6 minutes to share out your answers to the group. A scribe will gather your responses and help identify potential areas of research.

Questions for Persons living with dementia

- *Since being diagnosed, what things can you identify that have been going well? What has contributed to those positive experiences?*

- *Since being diagnosed, what has been challenging? What would make your experience better?*

- *As you think about the future, what are your priorities?*

Determining Research Priorities



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Questions for Carepartners

- *As a Carepartner, what things have you noticed that have been positive experiences for your loved one? What has contributed to those positive experiences?*
- *What experiences could have been/could be better for them?*
- *As you think about the future of your loved one, what experiences are you hopeful for?*
- *What Carepartnering experiences have been positive for you? What experiences could have been/could be better for you?*
- *As you think about Carepartnering in the future, what experiences are you hopeful for?*

Determining Research Priorities



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Questions for Researcher

- *As a researcher, what positive experiences have you had with your current or past work?*

- *What has made those experiences positive?*

- *As you think about your future research endeavors, what will make your experiences better?*

If you are the scribe/notetaker for your group, please mirror back what you hear and clarify with the speaker the researchable theme/focus area/priority associated with their answer. Write examples and themes on flip chart.

Determining Research Priorities (continued)



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Activity 2 (10-15 minutes): Additional Priorities

Given the outcomes that matter and the priorities you have just heard, the experiences we have discussed today, and your own priorities and values:

- *Are their additional topics that matter to you for us to consider as priorities for research? What are they?* Discuss your answers in your small group.

Activity 3 (10 minutes): Consensus

Given the experiences you have discussed today, and all the themes/focus areas you have identified on your flipcharts, please partner together to come to consensus in identifying 3-4 priority areas that you would like the larger group to focus on for our remaining training exercises. We will vote on these topics at the end of the day.

- Priority 1:

- Priority 2:

- Priority 3:

Activity 4 (20-25 minutes): Drawing your priorities

Create a drawing to represent each of your priority areas on a flip chart. When you finish your group should have 3-4 drawings which illustrate (in some manner) your priority areas. When you are finished, you will share your drawings (2 minutes for each priority) with the larger group.

Determining Research Priorities (continued)



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Activity 5 (5-6 minutes each table): Sharing Priorities

- Please share your group's top 3-4 priorities with the larger group (1-2 minutes on each drawing).
- Listen to each presentation and determine which 3 priorities are most important to you. After all presentations have been made, you will be given the opportunity to vote for 3 priorities for the larger group to focus on during our training exercises tomorrow.

Activity 6: Voting on Priorities & Networking

- Each person has been given sticky dots to use during voting. The dots are color coded by role (Person with dementia-yellow, Carepartner-green, Researcher-blue). Select the top 3 priorities that are most important to you. Go to the drawing that represents that topic and cast your vote by placing your sticky dot on that drawing. Drawings with the most sticky dots will be identified after voting, and used during our training exercises tomorrow.
- While the program staff are tallying votes, enjoy a drink and some snacks. Use this opportunity to meet new people, identify potential collaborations, and discuss your insights from the day.

Activity 7: Priorities announced. Choose working group.

- Please chose your Primary Priority area and sign up for that workgroup. Place a 1 next to your name.
- Please chose your Secondary Priority and sign up for that workgroup. Place a 2 next to your name.
- If you are a Carepartner, please consider working on a different priority from your loved one.

Day 2: New Beginnings



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Activity 1: Checking In (15 minutes)

Take a few minutes to answer the questions below. Please have everyone at your table take 1 minute to share out their answers.

- *What was your time like yesterday? What makes you excited? Feel useful? What was meaningful?*

Activity 2: Meeting Expectations? (15 minutes)

Please share your thoughts on the following questions with the whole group.

- *How are we doing with the expectations we established yesterday for working together? Is there anything we need to add?*
- *What expectation or strategy that we have spoke about yesterday morning did you use?*

Activity 3: What's Next? Introduction to Personal Action Plans

- Locate the Personal Action Plan in your binder.
- By the end of the day, please identify 1-2 action steps you will take to increase your engagement in research.

Refining the Study



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Activity 1: Determining a Good Research Question (60 minutes)

Identify someone in the group to take notes on people responses.

Answer the following questions for your Priority Area. The goal of this activity is to determine a good research question.

- What is the research area/priority?
- What research has already been done? (Have your researcher do a quick literature review on topic)
- Who is affected? Who will be included in the study? i.e. what population? Where?
- What are some solutions/interventions?
- How will the interventions affect the participants? i.e. What are the expected outcomes? From the overall research project?
- What is the ultimate research question?

Refining the Study



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Activity 2: Determining Interventions and Study Design (15 minutes)

Identify someone in the group to take notes on people's responses. In your workgroup, answer the following questions:

- Based on our discussion so far, are there two interventions/solutions that we can compare?
- How will each of the interventions/solutions happen?
- What will partners/participants do or learn?
- Who will partner/participate?
- Will we compare different groups?
- When, how often, or how long will the intervention/solution be?

Refining the Study



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Activity 3: Identify Measurable Outcomes (15 minutes)

Identify someone in the group to take notes on people's responses.

In your workgroup, answer the following questions:

- What outcomes could we measure?
- When could we expect to see these outcomes in participants? How long would it take?
- Are our outcomes likely to be due to the interventions? Or are there other influencing factors?
- Are they realistic?

Activity 4: Collecting Data (15 minutes)

In your workgroup, answer the following questions:

- How could we collect data on outcomes?
- What methods will be most appropriate for participants?
 - Interviews, journals, surveys, group discussions, tests, assessments, records, observations, videos, etc.
- When will we collect the information? Before and after? How long after? (when do we expect the result to happen)

Study Review: Meeting Criteria



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Activity 5: Reviewing Funding Criteria (15 minutes)

As our research question and study design are shaping up, we need to determine if they will meet certain standards established by funding agencies. The criteria below are based on the National Institutes of Health review criteria and PCORI's review criteria for patient advisory groups. Review the questions below to determine if your question is answerable? Or if you need to narrow/adjust your study in any way?

- **Is the topic significant?**
 - Is the study needed? Or are these the right intervention(s)?
 - Does it clearly describe benefits or outcomes that are important?
 - Is it clear who will use results or make decisions & how it will improve care?

- **Is the study innovative?**
 - What ideas or methods are novel or interesting?
 - Can you suggest any other “outside of the box” ideas for this study?

- **Does the study raise any ethical issues?**
 - Does the study leave out an important group? Who else should be included?
 - Do you have any concerns for participants in this study? (Re: data collection, protection of privacy, risks, compensation, etc.)

- **Is this study feasible?**
 - How might we recruit partners and participants? What are ways to generate interest?
 - How might we get the right information from partners and participants?
 - Have we identified the right stakeholders to be involved in order to effectively carry out the study?
 - How do we continue to sufficiently engage the right stakeholders in shaping the study?

Visualizing Your Project



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Activity 6: Building a Visual Representation of your project (30 minutes)

Using the supplies on your table (and anything else you would like), your group will build a visual representation of your project. Use your creativity to express your idea in whatever way your group would like.

When you are finished, you will share your project with the larger group.

Determine a spokesperson for your group to share the details of your project. Others are welcome to chime in. You will have 5-6 minutes to share.

Personal Action Plan



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After participating in *Empowering Partnerships*, I plan to...

- Sign the Dementia Peer Coalition Advocate Pledge to support DPC activities
- Attend Dementia Peer Coalition REACH Meetings (*for persons living with dementia and care partners*) to learn about research opportunities
- Lend my voice to research about ME by being willing to be contacted by researchers (*for persons living with dementia and care partners*)
- Contact people living with dementia and/or care partners to collaborate and partner on research projects (*for researchers*)
- Continue to empower persons living with dementia to actively engage research
- Stay updated on *Empowering Partnerships* opportunities and spread the word
- Join the A-List
 - <https://www.usagainstalzheimers.org/networks/A-LIST>
- Sign up for Clinical Trial
 - <https://medicine.yale.edu/psychiatry/alzheimers/clinical/>
 - <https://trialmatch.alz.org/find-clinical-trials#createaccount>
 - <https://www.nia.nih.gov/alzheimers/clinical-trials>
- Other _____
- Other _____

Signed _____ Date _____

Stipend & Travel Reimbursement



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Thank you for participating in the *Empowering Partnerships* 2-Day training program. Please provide the information below so we can process your stipends and any qualifying travel expenses.

Stipend Information

In alignment with PCORI principles, all participants will be reimbursed the same \$50 stipend per day. Please check the boxes below for the days you were in attendance.

- I participated in Day 1 training on Oct. 9, 2019
- I participated in Day 2 training Oct. 10, 2019.
- I decline my stipend

Travel Information

In addition to providing a daily stipend, we can also reimburse mileage expenses within Connecticut.

- I provided my own transportation on Oct. 9, 2019.
- I provided my own transportation on Oct. 10, 2019.
- Calculate my mileage reimbursement based on the address below.
- I decline my travel reimbursement.

Name: _____

Address: _____

City: _____ State: _____ ZIP Code: _____

Email: _____ Phone number: _____