

## Supplement 1

The Empowering Partnerships workshop agenda and worksheets for determining research priorities employed during the workshop follow below:

**Two Day Training**  
October 9 & 10, 2019



**Day 1: October 9<sup>th</sup>**  
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

**Two Day Training**  
October 9 & 10, 2019



**Empowering  
Partnerships**

*Preparing People with Dementia  
to Partner with Researchers*

**Day 2: October 10<sup>th</sup>**

8:30am-5:00pm

Time	Activity/Agenda
8:30-9:00	Breakfast
9:00-9:30	New Beginnings, Checking In, Meeting Expectations? – Erica DeFrancesco
9:30-10:00	What's Next? How can we get involved? – Bob Savage, Dan Belonick Opportunities for engaging in research. Introduction to Personal Action Plans
10:00-10:30	Plan for Day: Refining the Study Working Sessions Understanding the Research Enterprise – Rick Fortinsky
10:30-11:00	Intro to Non-Pharmacological Interventions/Strategies, PCOR & CER Introduction to Outcomes Crafting Good Research Questions - Maria O'Connell
11:00-11:15	Break
11:15-12:15	Determining a Good Research Question
12:15-1:30	Lunch (includes presentations below)
12:45-1:30	What's next? How can we get involved? Opportunities for engaging in research: Clinical Trials – Jim Taylor, Geri Taylor, Susan Good
1:30-1:45	Intro to Visual Representations – Heidi Gil
1:45 -3:15 (take break as you need)	Determining Interventions and Study Design Determining Measurable Outcomes, Collecting Data Reviewing Funding Criteria 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

## ***Determining Research Priorities***



**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?*

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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?*

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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.

## Supplement 2

The following are additional details regarding our analytical process (see the section titled “Empowering Partnerships Workshop”): All three authors were active participants and contributors to both the Empowering Partnerships workshop and subsequent events; our qualitative synthesis is best described as participant observation. Participant observation has increasingly been recognized as a valid methodology in psychology research (see Griffin & Bengry-Howell, 2008 and Robey & Taylor, 2018) and this team included an anthropologist (author EG) with participant observation fieldwork experience with people living with ADRD in Mexico and the US (Griffith, 2023). In addition to our firsthand experiences and notes, materials produced included full group notes taken by facilitators during the Empowering Partnerships workshop on large white boards, notes from breakout groups at the workshop, materials/correspondence from a mock grant application focusing on proposed stigma reduction methods written after the workshop, various e-mail correspondence coordinating post-workshop activities, and minutes from all post-workshop meetings. With the exception of meetings between the three authors to prep the manuscript, all activities included at least one person living with ADRD.

## References

- Griffin, C., & Andrew Bengry-Howell, A. B.-H. (2008). Ethnography. In C. Willig & W. Stainton-Rogers, *The SAGE Handbook of Qualitative Research in Psychology* (pp. 15–31). SAGE Publications Ltd. <https://doi.org/10.4135/9781848607927.n2>
- Griffith, E.E. (2023). “Recruiting Participants for Dementia Research Without Saying ‘Dementia’: A Site Study in Central Mexico.” In: BM Howell & RP Harrod, *Anthropological Perspectives on Aging*, (pp. 298-313). University of Florida Press.

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Robey, D., & Taylor, W. (2018). Engaged Participant Observation: An Integrative Approach to Qualitative Field Research for Practitioner-Scholars. *Engaged Management ReView*, 2(1), 1-13. <https://doi.org/10.28953/2375-8643.1028>