



Empowering Partnerships

*Preparing People with Dementia
to Partner with Researchers*

PROJECT TOOLKIT

Ignited by a Eugene Washington PCORI Engagement Award
#10644-LWA

September 2018 – November 2020

LiveWell
I N S T I T U T E

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“We can speak up and we will speak up.”

—Geri Taylor, person living with dementia

The Empowering Partnerships Project was partially funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (10644-LWA).



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Toolkit Introduction

“I’m happy I have Alzheimer’s, because I would never have been able to have this experience otherwise.” - Gail, a person living with dementia

a statement made to one of the project team members
at the conclusion of LiveWell’s Empowering Partnerships workshop in October 2019

It has been a privilege to dream up, design, and implement a two day Empowering Partnerships workshop – bringing together people living with dementia, care partners, and researchers to learn about the importance of doing research differently and actually go through the process of engaging in co-research together. Through our initial workshop in October 2019 and future workshops we are collectively accomplishing our *goal*:

*To enhance the participation and engagement
of people living with dementia in all aspects of research
through the training of people with dementia, care partners and researchers*

This toolkit offers information and resources from all phases of our project to guide future replication efforts, so that you too can inspire people living with dementia (PLWD), care partners (CP), and researchers to look at research through a more inclusive lens, offering PLWD and their CP more robust roles in all stages of research. The toolkit contains a combination of documents, audio podcasts, videos, and recorded webinars. Feel free to contact us if there is something else from our project you would like to access.



Information on our Empowering Partnerships project can be found at:
<https://livewell.org/empoweringpartners/>

The full project toolkit can be found at:
<https://livewell.org/empoweringpartners-toolkit/>

Throughout this narrative guide you will see various items with the toolkit icon above in front of them. This icon indicates there is a corresponding resource in the toolkit.

The Empowering Partnerships project was championed between September 2018 – November 2020 by the LiveWell Institute, a division of LiveWell Alliance. LiveWell Alliance, Inc. is a not-for-profit organization formerly known as the Alzheimer’s Resource Center. Since 1990, LiveWell has been a national leader in the field of dementia services and its 30+ year history includes pioneering work in residential, community, education, and consulting services.

The LiveWell Institute formally houses the thought leadership of the organization as a research and policy hub and leads LiveWell’s important work of engaging PLWD in all aspects of research. This project is clearly aligned with the Institute’s mission to advance thought leadership, education, research, and advocacy to transform how we age.

Project Overview Media

This toolkit contains this narrative guide, a podcast and two deep dive videos to give you an in-depth understanding of our project activities and insights.

Introductory Podcast

Our “Creating Energy, Shared Purpose, and Momentum to Doing Research Differently” podcast introduces the Empowering Partnerships project, briefly describes the process of preparing researchers, PLWD, and CP to collaborate on research, and highlights outputs and outcomes of the program, including prototype study designs that meaningfully address topics prioritized by PLWD, and changes in knowledge and attitudes about co-research among program participants. The podcast foreword highlights the importance of engaging PLWD in patient-centered outcomes research, comparative effectiveness research, and embedded pragmatic clinical trials of treatments and interventions for PLWD.



[Podcast: Creating Energy, Shared Purpose, and Momentum to Doing Research Differently](#)

Empowering Partnerships Two-Part Video Series

The video series provides a detailed review of key components of the Empowering Partnerships project, including expanding the Dementia Peer Coalition and developing and delivering the two-day Empowering Partnerships workshop.



[Video 1: Building a Partnership Network](#)

This video introduces the Dementia Peer Coalition, a group led by and for PLWD, with an aim to engage in research. It describes how the Dementia Peer Coalition was developed and the key resources available in the Toolkit.



[Video 2: LiveWell’s Empowering Partnerships Training Experience](#)

This video introduces the two-day Empowering Partnerships workshop, including the processes to prepare for and facilitate the workshop. It introduces several workshop resources that are available in the Toolkit.

Project Introduction

“We can speak up and we will speak up.”—Geri Taylor, person living with dementia

In a roomful of well-intended researchers and clinicians speaking for and about PLWD, Geri Taylor chimed in, “Speak with me, not for me.” And in that pivotal moment, Geri delivered a call to arms for PLWD to have their voices included in research partnerships. Despite the demand and recent proliferation of efforts to meaningfully engage PLWD and their CP (i.e. PCORI’s “patient partners”) in research partnerships, the voices of PLWD as co-researchers and participants have been noticeably absent. Presumptions of incapacity, stigma, and a lack of

innovative methods to facilitate participation have contributed to the silence. This project set out to change all of that.

Project Goal and Aims

The Dementia Peer Coalition (DPC), LiveWell, and project partners co-designed the Empowering Partnerships project with the goal to enhance the participation and engagement of PLWD in all aspects of the research the process.

We had specific aims to:

- Expand and strengthen a peer network of individuals living with dementia
- Offer a training workshop on research concepts, methods, and participation as co-researchers
- Create and prioritize a list of research topics
- Produce and disseminate an Implementation Toolkit for workshop replication

Listen to Bob Savage, a PLWD and a key member of the project team, talk about the meaning of the project.



[Why is the Empowering Partnerships Project important? A Video with Bob Savage - A Person Living Well with Dementia](#)

Eugene Washington PCORI Engagement Award

This project was ignited by a Eugene Washington PCORI Engagement Award from the Patient Centered Outcomes Research Institute (PCORI)(#10644-LWA). These awards are designed to support projects that increase the engagement of patients and other non-traditional stakeholders (with firsthand experience of the health conditions being studied) in all aspects of the research process. PCORI is a unique funding organization, because all their research is guided by patients, caregivers, and the broader healthcare community. You can learn more about this organization and these Engagement Awards on the PCORI website: www.pcori.org.

PCORI Principles

At the foundation of the Empowering Partnerships project were PCORI's Six Engagement Principles. Signs with these engagement principles were prominently displayed in the training space to highlight their importance.

Reciprocal Learning

This principle is exemplified when the roles and decision-making authority of all research partners are defined collaboratively and clearly stated.

Co-learning

This principle is exemplified by helping PLWD and their CP understand the research process, while also helping the research team learn about person-centeredness and

strategies for engagement and encouraging the team to incorporate them into the research process.

Partnerships

This principle is exemplified when the time and contributions of all stakeholders are valued and demonstrated in fair financial compensation as well as in thoughtful and reasonable requests for time commitment by patient and stakeholder partners. Further, the research team is committed to diversity across all project activities with consideration of cultural competency, including disability accommodations when appropriate.

Transparency, Honesty, and Trust

These principles are exemplified when major decisions are made inclusively, and information is shared readily with all research partners. All are committed to open and honest communication with one another.

This PCORI Engagement Rubric for Applicants was used as a guide when submitting our application for the award as well as when designing the two day workshop.

 [PCORI Engagement Rubric for Applicants](#)

Project Team and Advisory Councils

Our project team was comprised of PLWD, CP, researchers, and healthcare professionals, all of whom had varying levels of experience engaging in co-partnerships in research (see page 21 for a complete list of team members). Additionally, we had an Advisory Council and three overlapping Action Teams comprised of national and statewide stakeholders supportive of the project to join efforts on recruitment, training, and dissemination. A Memorandum of Understanding was signed by all council and team members and all received the same stipend compensation.

 [Advisory Council Memorandum of Understanding](#)

Key Project Personnel

- Heidi Gil (Project Lead) Chief Strategy Officer, LiveWell
- Stephani Shivers (Project Co-Lead) Chief Operating Officer-Community Services, LiveWell
- Bob Savage, Co-founder of the Dementia Peer Coalition and PLWD
- Erica DeFrancesco, Director of Community Education, LiveWell
- Dan Belonick, Director of Counseling Services, LiveWell
- Anne Kenny, Geriatrician, Palliative Care Physician
- Maria O'Connell, Associate Professor of Psychiatry and Director of Research and Evaluation at the Yale Program for Recovery and Community Health
- Richard Fortinsky, Professor, Center on Aging, School of Medicine, UConn Health

For our two day training we prepared a ‘Bio-sketch’ for each participant. Check out the bio-sketches of some of our project team members.



[Project Team Bio-sketches](#)

Background Resources

In 2017, the U.S. Department of Health and Human Services (HHS) sponsored the first National Research Summit on Dementia Care which brought together PLWD, CP, researchers, and other key stakeholders to identify knowledge and gaps to improve quality of care and the “lived experience of persons with dementia and their caregivers.” Summit recommendations included “funding more research on how people living with dementia and their caregivers can be partners with researchers”. However, noted throughout Summit materials was the critical knowledge gap that remains in how to guide PLWD, CP, and researchers into co-research partnerships. Four key recommendations from Theme 5 of the Summit *Engaging Persons Living with Dementia and Caregivers as Members of the Research Team* formed the inspiration for this project:

- 1) Engage persons living with dementia and care partners as part of research teams; and
- 2) Develop and evaluate promising practices for increasing the engagement.
- 3) Evaluate the impact of research engagement of persons living with dementia and their caregivers on the validity, value, and credibility of the research findings, and
- 4) Encourage the use of engaged research models in studies of dementia care, services, and supports

Below, are links to the HHS Summit final report, the final recommendations from the Summit’s Persons Living with Dementia stakeholder workgroup, and a video from Teresa Webb – one of the PLWD who was Co-Chair of that workgroup. Teresa shares about her powerful experience of being a part of this group. We shared this video during our workshop.



[HHS Summit Final Report](#)



[Final Recommendations from HHS Persons with Dementia Stakeholder Workgroup](#)



[Teresa Webb video on HHS Experience](#)

Coalescing Stakeholders and Learning from Others’ Experiences

Leveraging Others’ Experiences

In the initial phase of our project, the design team completed a thorough literature review and interviewed several researchers, nationally and internationally, both with and without experiences in co-partnerships in research. We also interviewed members of our Advisory Council and Action Teams which included PLWD, CP, researchers, as well as healthcare providers, physicians, and aging service providers. These interviews involved the sharing of

lessons learned from their work and recommendations to guide LiveWell in the design of the two day training experience.

Additionally, the design team interviewed PLWD (and 1 CP on the design team) to discuss their experiences with and perceptions of co-research. Many PLWD shared both positive and negative experiences with research, and LiveWell strove to learn from the work of others. Themes from these interviews were compiled. One theme involved PLWD reporting that despite participating in research studies, they rarely heard from the researchers after participating in this research. They reported feeling abandoned and were left uncertain as to how their contributions helped others, if at all. Learning about this lived experience encouraged the LiveWell design team to emphasize the importance of reciprocal relationships and communication. Our initial literature review and summary documents from our interviews can be accessed below.



[Literature Review \(12/31/2018\)](#)



[EP Interview Questions](#)



[Researchers Interviews on Training](#)



[PLWD and CP Interview Themes](#)

Training Tips

Several training tips emerged from the interviews. The following considerations were offered and we have included recommendations based upon our workshop experience:

- Offer several breaks throughout the day.
- Pause at different points throughout the day to offer check-ins. Gauge how the group is doing and determine whether any adaptations need to be made.
- Provide a separate, relaxing space for people to go to in the event of overstimulation or need to decompress, away from the group.
- Offer more cognitively taxing learning opportunities in the morning, so that fatigue in the afternoon does not interfere with ability to participate.
- Provide material ahead of time, so that PLWD can familiarize themselves with questions to be posed and content to be addressed.
- Be cognizant of volume of materials given, so as not to overwhelm PLWD.
- Provide separate rooms for break out groups and small group work.
- Have visors, ear plugs, headsets available for sensory relief/assistance.

Growing and Activating a Sustainable Network Ready for Co-Research

A deep dive video on this portion of our project has been prepared to go along with this section of the toolkit.







[Video 1: Building a Partnership Network](#)

This video introduces the Dementia Peer Coalition, a group led by and for PLWD, with an aim to engage in research. It describes how the Dementia Peer Coalition was developed and the key resources available in the Toolkit.






To grow a sustainable network ready for co-research in Connecticut, we took a systematic approach to coalesce a supportive stakeholder network to support the emerging Dementia Peer Coalition (DPC) – an independent organization comprised of PLWD focused on peer support, advocacy, community education, and research (www.dpc-ct.org). Robert Savage is a PLWD and is the Co-Founder of the DPC along with Stephani Shivers and Dan Belonick. All three Co-Founders of the DPC were involved in the Empowering Partnerships project.

A marketing and outreach plan guided our recruitment phase of the project to cultivate ‘satellites’ and ‘advocates’. An advocate could be an individual or a provider that would refer PLWD/CP to the DPC, promote its values and activities and help in other ways as able. A satellite is a provider or community-based organization that actually hosts DPC activities and is building out the DPC network at their site. We wanted these providers and community partners to connect PLWD/CP directly to members of the DPC for two reasons. First, because all the key personnel on the project have current or past roles in direct dementia service provision and we know that connecting PLWD to others with shared experience is a very helpful and powerful thing to do from a quality of life perspective. Secondly, based on our literature review and interviews with researchers who had engaged in co-research, we believed that the best way to get people involved in this project was using a peer-to-peer recruitment strategy.

You can learn more about DPC, its activation and supporting stakeholders via these resources:

-  [Marketing & Outreach Plan](#)
-  [Satellite/Advocate Opt-In checklist](#)
-  [DPC Advocate Pledge](#)
-  [Video: Why Join the DPC?](#) And the DPC website: www.dpc-ct.org

Two peer-to-peer meetings were created and implemented during this project. A ‘Getting Connected’ information session was held in different parts of the state to recruit new members to the DPC and to introduce the concept of co-partnerships in research. For those interested in learning more about co-research, an ‘Introductory Kick-off’ to the Empowering Partnerships Workshop was co-facilitated by researchers, PLWD, and members of the project team. This session was designed to introduce people to the training and give them a ‘feel’ for the workshop through some experiential exercises.

-  [Getting Connected: An Introduction to the Dementia Peer Coalition slide deck](#)
-  [Empowering Partnerships Introductory Kickoff Session slide deck](#)
-  [Values Activity Worksheet from Kick off session](#)
-  [Research Design slide Bureau of Sages](#)
-  [Invitation to Training & Next Steps flyer](#)

Developing and Guiding the Two Day Workshop Experience

A deep dive video on this portion of our project has been prepared to go along with this section of the toolkit.



Video 2: LiveWell's Empowering Partnerships Training Experience

This video introduces the two-day Empowering Partnerships workshop, including the processes to prepare for and facilitate the workshop. It introduces several workshop resources that are available in the Toolkit.

A Strengths-Based Approach: Experiences, Strengths, and Preferences Inventory

Knowing that issues of capacity, stigma and the general lack of knowledge on how to maximize the retained abilities of PLWD are barriers to co-research, we knew going into this project that we wanted to leverage our team's expertise in strengths-based approaches to develop substantive materials that could make a contribution beyond our training workshop. We also knew that we were fostering 'co-research relationships' which is a relationship of partnership. This is different than a researcher – subject relationship and so the concept of 'capacity' is not actually an issue. Finally, we knew that we wanted to foster an atmosphere of comfort, trust and reciprocity. To do this, we needed everyone to be seen as a valuable human, with a unique and important perspective to share.

Before the training workshop all the program participants completed the Experiences, Strengths and Preferences Inventory (ESP) which the project team created specifically for this project. The ESP draws from the Myers-Briggs Type Indicator® personality inventory, various learning style inventories, values clarification tools, and group process roles. It also includes information on life and work experiences such as family, significant others, friends, home life, work/career history, cultural influences, hobbies and leisure activities. The ESP focuses on people's strengths and uses tools for the general population (vs. assessment tools for someone with dementia). The ESP was completed in advance by all participants attending the two-day training, and the results were crafted into a personalized bio-sketch that was shared with all participants in the workshop binder. Data elements from the survey were also captured on nametags and table nameplates for various activities. The ESP was designed to identify and capture values and strengths (which could be referenced on the bio-sketch), promote enhanced self-awareness, underscore commonalities and differences as 'people' based on 'normal things' like life, personality, learning, values, interests, culture, work history, etc. vs. being identified by a disease which is typically the case when one is diagnosed with dementia.

Prior to the workshop, a project team member conducted an interview with all potential workshop participants who were living with dementia to go over the ESP. An interview guide was created following a format similar to the *MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR)*. We did not use this interview to establish 'capacity' for participation (which is the intention of the MacCAT-CR). Rather, the purpose of the interview was to ensure that all PLWD understood the project and were comfortable sharing information

about their lived experience with dementia as they would be identified with that experience at the workshop and in a co-research partnership.

We are very enthusiastic about the ESP and resultant Bio-sketch as a product of this project and for future work to foster co-research partnerships. It is a valuable tool to showcase a wealth of relevant information about a person, showcases relevant strengths, provides opportunities for participants to see similarities and find connecting points on retained abilities, values, and life experiences. These connections can be used to build relationships that foster transparency, honesty and trust – three of the PCORI engagement principles necessary for co-partnership.

 [Experiences, Strengths, and Preferences Inventory](#)


 [ESP Inventory Interview](#)

 [Empowering Partnerships Bio-sketch Examples](#)

Prior to attending the two day workshop, all participants – and specifically researchers - were invited to watch a webinar created by LiveWell, “Learning to Partner with People Living with Dementia—A Primer”. They were also provided with these additional resources which we believe to be relevant for those partnering with PLWD.

 [“Learning to Partner with People Living with Dementia – A Primer” Webinar](#)

 [DEEP Guide: Dementia Words Matter](#)

 [“Supporting and Accommodating People with Dementia at Professional Conferences and Other Events”, Dementia Alliance International](#)

Appreciative Inquiry Framework

On October 9 & 10, 2019, LiveWell hosted our two day Empowering Partnerships workshop. Our workshop followed an Appreciative Inquiry framework and was intentionally designed to be 80% experiential, 20% didactic learning with a balance of both large and small group work. Our slide deck below guided the agenda, the education portions of the workshop, and the Appreciative Inquiry process.

 [Empowering Partnerships Workshop slide decks](#)

 [Appreciative Inquiry Slide](#)

The 4-D Appreciative Inquiry process includes the four steps of discover, dream, design, and destiny. In the ‘discover’ step, our goal was to make sure that each person was seen and valued as a human first without titles/roles or a diagnosis. We wanted to discover and underscore the individual and collective strengths in the room. With the ‘dream’ step, we focused on envisioning research priorities. Participants worked in small groups to identify what matters most through their values and life experiences. With the ‘design’ step, we focused on learning while doing. We learned how to partner in research by designing research study prototypes together. And finally, in the last step of ‘destiny’, we focused on the creation of personal action plans to ensure that all participants internalized the momentum of co-partnership and engagement in research. We had 42 participants join our training workshop:

12 PLWD, 9 CP, 15 researchers (including researchers from Brown University, Georgia Tech, University of Massachusetts - Amherst, Yale School of Medicine, Yale School of Public Health, Quinnipiac University, and others).

Expectations for Working Together

The two day training commenced with a discussion on creating an inclusive environment that best promotes the participation of and empowers PLWD. The stage was set FOR inclusion BY inclusion. Two members of the original design team who are both living with dementia addressed the group, followed by a CP and a researcher. You can access the scripts from Geri and Jim Taylor, and Bob Savage below.



[Opening thoughts from Geri and Jim Taylor](#)



[Bob Savage thoughts on Resilience](#)

From this conversation, a list of expectations was created that would ultimately serve to inform the two day training. The list was iterative, with people adding to it throughout the two days. Recommendations provided by PLWD included:

- Empowering the person with dementia to respond first
- Resisting the urge to speak on behalf of people living with dementia
- Giving people living with dementia extra time to process and respond to questions (20-90 seconds)
- Ensuring that when someone was speaking, that there not be side conversations
- Speaking clearly and projecting one's voice
- Paying attention to the speed with which people speak

Respect Rocks

Small rocks were distributed to participants with the word RESPECT written on them. These served as tangible symbols of the shared respect for people living with dementia in the room. People not living with dementia who had the urge to speak first or on behalf of people living with dementia were asked to hold the rocks and use the two days as an opportunity to resist these urges.

Empowering Partnerships Activity Worksheets

At the start of the two day workshop, all individuals were presented with a binder that included an agenda, activity worksheets, bio-sketches from all the participants, and additional resources that would help to inform some of the workshop activities. We have included this binder here:



[Empowering Partnerships Activities Binder](#)



[Empowering Partnerships Workshop slide deck](#)

Throughout the training workshop, participants engaged in experiential activities that often involved reflecting upon some questions in writing, discussing responses in small groups, and

then returning to the larger group for further discussion. For example, one exercise was to identify themes/areas/priorities that could be researched. Sample questions included:

- PLWD: Since being diagnosed, what things can you identify that have been going well? What has contributed to these positive experiences?
- CP: As you think about the future of your loved one, what experiences are you hopeful for?
- Researchers: As a researcher, what positive experiences have you had with your current or past work?

Additional Resources

These additional resources were also made available to help guide choices on evidence-based interventions and outcomes.



[Evaluating Dementia Services and Supports: Instrument Resource List](#)



[Outcomes of the James Lind Alliance Dementia Priority Setting Alliance](#)



[Grantee-Implemented Evidence-Based and Evidence-Informed Dementia Interventions](#)



[Non-Pharmacological Therapies in Alzheimer's disease: A Systematic Review](#)

Action Plans

At the culmination of the two day training experience, participants wanted to know, “What’s next?” Armed with new knowledge about how they could participate in all phases of the research process, they were eager to learn about how they could become more involved. Action plans were distributed that provided participants with a multitude of options about how they could actively participate in co-partnerships in research. All participants checked off at least one action they were inspired to take as a result of having attended the training.



[Empowering Partnerships Action Plan](#)

Post-Workshop Results & Co-Research Reflections

5 Groups – 16 Priorities – 4 Top Priorities

During our workshop we started our time together in 5 initial working groups. Each group identified their top 2-4 priorities which produced this list of **16 priorities** when compiled together. All participants then voted for their top 3 priorities which produced our 4 top priorities to move into our study design phase on the second day of the workshop.

1. Support: Peer, Community, Caregiver
2. Communication: Verbal and Non-Verbal
3. Education: For self and others
4. Relationships

5. Social Interaction: Family, Friends, Community, Faith Community
6. How to plan and communicate for the future
7. Independence: Social, Physical, Mental, Expanding Choices
8. Diagnosis: What to Expect, Improving Happy/Positive Expectations, Dealing with Reality and Making Decisions
9. Stigma
10. Health: Nutrition, H2O, Mental Health, Physical Health, Well-Being
11. Independent Living & Choices: Dealing with Social Changes, Financial/Economic Support, Justice, Culture
12. Communication: Speech/Language Group to improve external communication and understanding, and also for PLWD to be more comfortable
13. Close Relationships: Improving close-partner relationships
14. Impact of Social Activities: Autonomy & Self-Determination vs Challenge to Engage PLWD
15. Clinical Trials: Managing Expectations, Communication, and Understanding
16. Stigma: Navigating Terms to reduce stigma

The **4 Top Priorities** were:

1. Stigma
2. Independence
3. Relationships: Social & Close
4. Impact of Social Activity

5 Study Designs

Participants self-selected the top priority they wanted to work on, and a large group chose the priority of “Relationships”, so two teams were created to work on that priority making a total of five study design teams. Below is a summary of the priority areas and a brief write up of the study designs.



[Summary of Empowering Partnerships Priorities](#)



[Research Project Summaries](#)

Here are photos of our five teams and the five research questions that were co-designed.

Research Area: Stigma

- ⇒ Research Question: How substantially does participation in a collaborative program - including dance, theater, walking group or sports activities with people living with dementia and care partners by younger persons without dementia reduce stigma?



Research Area: Independence

- ⇒ Research Question: How would the use of adaptive technology toolkits enhance adherence to an evidenced-based health promotion care management program aimed to decrease Emergency Room visits for urinary tract infections?



Research Area: Impact of Social Relationships

- ⇒ Research Question: What effects do personal relationships with extended family have on persons living with dementia and carepartners?



Research Area: Impact of Social Relationships

- ⇒ Research Question: What are the day to day activities or practices that preserve relationship qualities in which one person is living with cognitive change?



Research Area: Impact of Social Activity

- ⇒ Research Question: What is the impact of a Virtual vs. In-Person Peer Support Group for persons living with cognitive change?



Workshop Evaluation

Participants in the Empowering Partnerships two day workshop completed pre/post workshop surveys including the Dementia Attitudes Scale and questions targeting the interpersonal interactions between the participants. We had positive attitude changes and positive

interpersonal interaction responses for PLWD, CP and researchers after our workshop. You can find the full data set in the evaluation report.

The post-workshop survey also included quality questions regarding what participants enjoyed most about the Empowering Partnerships workshop experience, what they would change, and asked for any additional suggestions/comments. Responses were assessed from 32 participants (9 PLWD, 11 CP, and 11 researchers), common responses were grouped together, and thematic statements were generated to summarize the evaluation content. Four themes were identified and are summarized below with sample responses from workshop evaluations.

- **Theme 1. Participants found the workshop both substantively and socially fulfilling.** This theme reinforces the importance of attending to the whole person, and creating opportunities for intellectual engagement and interpersonal interactions, in workshop design and facilitation. For example, a PLWD said “It was social, it was informative, all rolled together, everyone’s ideas were heard and put in as part of the process”, and a researcher stated “I have never experienced something like this before - the trust, generosity and enthusiasm were remarkable. This is such a valuable model for future research (and I will use it!!)”
- **Theme 2. Workshop facilitation is important for supporting participants to effectively communicate.** This theme reinforces the workshop facilitation practices, such as the establishment of expectations that the views of PLWD would be consistently prioritized and given time for communication. For example, a CP reported, “Anyone who had anything to say at any time was given the opportunity to be heard”, and a researcher explained, “I enjoyed being an information seeker and learning from both people living with dementia and their care partners about what matters most to them.”
- **Theme 3. Environmental factors impact the workshop experience.** This theme reflects the consistent importance of environmental factors, especially with regard to minimizing distractions, in workshop planning and preparation as well as in workshop facilitation. For example, a CP said, “The only thing I would change is announce to participants to try to hold down the noise since I am hard of hearing and background noise makes it hard to concentrate”.
- **Theme 4. Workshop agenda adjustments.** PLWD did not recommend adjustments to the workshop agenda, but agenda adjustment recommendations were made by care partners and researchers. For example, a researcher described wanting, “A bit more time for development of research questions”, and a CP advised, “As important and well-deserved as the information on clinical trials was at lunch time on Day 2, the amount of time inhibited my ‘getting going’”.

We captured various moments throughout the two days and compiled them into a short video. At the conclusion of the workshop, we stopped participants on the way out to capture a few reflections on the experience. We think they provide the best evaluation of the experience!



[Pre/Post Training Workshop Survey](#)



[Dementia Attitudes Scale](#)



[Empowering Partners Workshop Evaluation](#)



[Empowering Partnerships Workshop Video: What one word would describe your experience?](#)

Lessons Learned

The key lesson learned in this project is that bringing together people with dementia, carepartners and researchers to learn how to partner together in research initiatives CAN be done! Below is a list of some other key learnings that came out of our project team's analysis of the two day training.

- The majority of our stakeholders (including the researchers) were very clear that they did not just want our training to focus exclusively on research methods, article reviews, etc. They asked for activities designed to develop trust and build relationships amongst all participants. They wanted the majority of the training to be interactive learning experiences. This was a slightly different format that we had originally envisioned.
- Through the Experiences, Strengths and Personality Inventories, we developed comprehensive bio-sketches for each participant. We'd recommend circulating those to participants in advance so they can learn about the others. And if we predetermine small groups, noting who would be in the group would be a benefit.
- We started our training with brief presentations by a person living with dementia, a carepartner, and a researcher. This set the stage for equality and reciprocal relationships. This is a best practice for future projects.
- We did not do formal introductions of all participants. People had copies of everyone's bio-sketch and wore nametags with colored dots to designate if they were a PLWD, CP, or researcher. About 3 hours into the first day a PLWD made a comment about needing some good researchers to help work on a particular problem. At that point we asked the researchers to stand and introduce themselves and their institution. It was an amazing moment to witness the impact of that moment of support and solidarity. I'm not sure how to recreate that experience, but it would be worth looking for the opportunity to make those introductions at an opportune time – (vs. just a convenient one).
- One of the important things we did during the training, was to establish ground rules for interacting with one another. These were posted around the room and were used as reminders when we needed them. A key ground rule was to give people living with dementia the opportunity to speak/respond to questions first. Their ideas drove the direction of the projects.
- One of the challenges we anticipated and pretty successfully thwarted, was carepartners 'taking over' or speaking out too much. The carepartner (Jim Taylor) who spoke at the beginning our session spoke directly to this issue, and we continually reminded the groups to make sure people living with dementia were sharing their ideas and opinions first during the discussions.

- We noticed that different small groups worked on activities at different paces. On the second day, we ended up adjusting the schedule to give groups more flexibility to take the activities at their own pace. Flexibility in scheduling is important.
- As for the time and schedule of the training, we agreed that it would have been better to spread the sessions out over 3 days (half day, full day, half day). The schedule was very full, and it was difficult to incorporate the breaks that we wanted.
- Pay attention to the size of the room, noise, and glare. Be sure to have small rooms for all break out activities. You need to consider noise in the rooms.
- We realized that it would have been helpful to have done an orientation on some of the group activities with the table leaders and researchers prior to the training. This would have given them more time to think about pacing and facilitating the small group process.
- We also realized that we could have an introductory webinar for participants on the research concepts we were going to use during the training. We considered this, but we didn't think people would actually watch it. Now we believe we could garner enough interest through the video trailer that people would be more interested in coming to the training with a certain level of knowledge.
- We included a talk on clinical trials during the lunch break on the second day. Participants asked a number of questions (many of which were individualized for their particular situation) which demonstrated the value of the information, but the general consensus was the presentation was too long. In future trainings, we would shorten the presentation and shift it to a different time.
- We'd recommend having a tangible next step that invites participants to continue meeting together in some capacity on a regular basis.

Future Implications

The Empowering Partnership project was inspired by and aligns with the recommendations made from the 2017 National Research Summit on Dementia Care (2017) – and in particular those from Theme 5: *Engaging Persons Living with Dementia and Caregivers as Members of the Research Team*. Our project is specifically responsive to the first two recommendations:

- 1) Engage persons living with dementia and care partners as part of research teams; and
- 2) Develop and evaluate promising practices for increasing the engagement.

With a first of its kind training program and resources developed, we are eager to disseminate the Toolkit and provide additional workshops to persons living with dementia, care partners, and researchers. As one example we are in conversations with a funder to identify ways we can engage grant awardees in utilizing the Toolkit and participate in a workshop to bring co-partnership to all aspects of the research process. In the next phase of our work, we are eager to focus on the recommendation of:

- 3) Evaluate the impact of research engagement of persons living with dementia and their caregivers on the validity, value, and credibility of the research findings, and

- 4) Encourage the use of engaged research models in studies of dementia care, services, and supports

Project Replication and Assistance

The LiveWell Institute provides support to PLWD, CP, and Researchers to collaborate in any or all stages of research, from initial study design through data collection and analysis to final dissemination. Through the LiveWell Institute's ongoing Empowered Partnerships program, communities are supported in navigating all stages of co-research. If you have questions or would like more information on the Empowering Partnerships or the LiveWell Institute, please contact us:

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Thank You

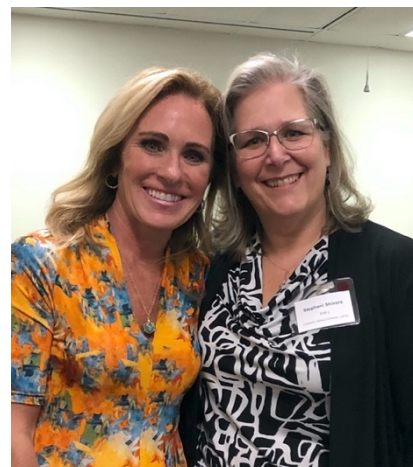
Co-leading this project has been one of the most powerful experiences in our personal and professional lives. We are grateful for the opportunity to have worked with such an amazing team of people to lay a different foundation for future research in dementia supports and services. To all our project partners and supporting stakeholders we say thank you, thank you, thank you for your support of this work. And to those of you considering how you might partner with people living with dementia in co-research, thank you for joining the tribe! Please let us know how we can help you in your efforts!

As Bob Savage – a person living 'well' with dementia – and our partner throughout this project has so aptly stated:

"I/We never dreamed that our group would become such a powerful *TEAM*! Join us in changing the research of the future!"

With great thanks,

Heidi Gil & Stephani Shivers – Project Lead & Co-Lead



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Empowering Partnerships

*Preparing People with Dementia
to Partner with Researchers*

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