



Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

PCORI Empowering Partnerships Program Recap

Empowering Partnerships program participants—including people living with dementia, care partners, and professional/academic researchers—prioritized four domains for research and designed a study prototype to address each domain during the two-day workshop (**Table 1**).

Table 1. Domains prioritized and study prototypes developed by people living with dementia, care partners, and professional/academic researchers in the Empowering Partnerships program

Domain	Study Prototype
Impacts of Social Engagement	Comparative Effectiveness of Peer Support Group Modalities for Persons Living with Cognitive Change
Social and Close Relationships	Identifying and Comparing the Effectiveness of Couples Activities for Protecting Relationship Quality among Couples Impacted by Dementia
Independence	Supporting People Living with Dementia to Ask Family Members for Assistance: Help-seeking Intervention Evaluation
Stigma	Public Engagement in Social Programs with People Living with Dementia: Impacts on Dementia Stigma

Brief summaries of all four study prototypes are provided on the following pages. These summaries were developed by combining notes from the workshop with post-workshop notes captured by workshop participants. The prototype summaries provide a brief background for the study, clarify the primary research question and specific aims to be addressed, describe the study design, and note points of significance and innovation of the study.

Comparative Effectiveness of Peer Support Group Modalities for Persons Living with Cognitive Change

Domain: Impacts of Social Engagement

Background: To date, no studies have addressed the improvement of mood and social connectivity of those living with dementia through use of peer-led support group models.

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

Primary Objective and Specific Aims: Determine the comparative effectiveness of In-person vs. virtual peer-led support groups for improving the mood, perceived social support, and hope of people living with dementia

Study Design: This project will be a comparative effectiveness study to identify similarities and differences between these two models of peer-led support (In-person vs virtual), looking at variables including mood, perceived social support, and hope. We will utilize a pre-test/post-test model for quantitative data (using the PHQ-9, MOSS-SS, AHS, and LSIA assessment tools), and also pursue qualitative interviews to gather further data. Assessment will be given to three groups: 1) Control (no intervention) 2) Group A (In-Person Support Group) 3) Group B (Virtual Group) prior to beginning the study, at the conclusion of the intervention, and 6 months following completion. The peer-led groups will use the model of support group as established by the Dementia Peer Coalition. The control group will be given literature on well-being.

Significance and Innovation: The study is significant in addressing the prevalent rates of decreased mood and increased social isolation among persons living with dementia, and innovative through the use of technological solutions to address variables.

Identifying and Comparing the Effectiveness of Couples Activities for Protecting Relationship Quality among Couples Impacted by Dementia

Domain: Social and Close Relationships

Background: To our knowledge, no past research has examined what daily activities romantic couples engage in that protect their relationship quality over time when one couple member is living with cognitive change.

Primary Research Question: What are daily individual and shared activities that preserve relationship quality in romantic couples in which one person is living with cognitive change?

Primary Objective and Specific Aims: Identify the shared social, emotional, cognitive, and physical activities engaged in by couples who are living with dementia and determine the comparative effectiveness of different activities for protecting relationship quality.

Study Design: This will be a longitudinal, observational, mixed methods study to examine the shared social, emotional, cognitive, and physical activities in which couples engage and whether certain activities protect relationship quality more than others. We will use validated measures assessing leisure activities (e.g. Jopp & Hertzog, 2010) and adapt to include questions about the extent to which the activities are shared. We will measure multiple aspects of relationship quality, such as intimacy, perceived responsiveness, conflict, and attachment security using validated quantitative measures. We will also conduct open-ended interviews asking about couples' engagement in activities and their relationship quality. Questionnaires and qualitative interviews will be completed with the help of a trained interviewer in couples' homes at a baseline visit, and couples will be followed every 6 months for two years with home visits. Both the person with cognitive change and the spouse will complete these assessments separately and privately to the extent to which they are able at each visit.

Significance and Innovation: The study is significant in addressing the health of the romantic relationship between persons with cognitive change and their partners/spouses to inform support services for families. It is innovative in following couples over time and using quantitative validated scales of leisure activities and multiple aspects of relationship quality.

Supporting People Living with Dementia to Ask Family Members for Assistance: Help-seeking Intervention Evaluation

Domain: Independence

Background: Persons in our group were voicing that it is often difficult to ask for help from family members, so we explored an intervention to facilitate asking for help from family members and friends via a letter or phone call.

Primary Research Question: What is the comparative effectiveness of an intervention that facilitates asking for help relative to a non-intervention control group?

Primary Objective and Specific Aims: Determine the impact of an intervention designed to support people living with dementia to ask for help from family members on the social functioning and mood of persons living with dementia

Study Design: Our study would select an intervention to facilitate asking for help and compare the group who asked for help using a structured format to a group that did utilize this intervention. The group wanted to use pre and posttests. Our group found an instrument called the Social Functioning in Dementia Scale that we had hoped to further explore to potentially use at baseline and then again at 3- or 6-months post intervention. We also wanted to explore additional scales such that would look at mood to determine if there might be a change in mood if additional help were to be received.

Public Engagement in Social Programs with People Living with Dementia: Impacts on Dementia Stigma

Domain: Stigma

Background: Studies regarding the stigma of dementia have focused primarily on asking participants questions about their understanding of dementia or asking participants to reply to stigma questionnaires after reading a vignette describing a person with dementia. To our knowledge, only one previous study has considered the effect that exposure to people living with dementia has on those who have limited experience with dementia.

Primary Research Question: When the general public joins people living with dementia and their care partners in a collaborative social program, is stigma around dementia substantially reduced?

Primary Objective and Specific Aims: Engage the general public in a collaborative social program with people living with dementia and care partners and assess the impact of participation on dementia stigma.

Study Design: Four social programs (e.g., dance, theater, a walking group, and softball game) will each occur over three months, with each group meeting about 10-12 times. Participants in each program will include roughly equal numbers of people living with dementia and care partners (recruited via LiveWell and LiveWell-affiliated dementia support groups) and the general public (consisting primarily of undergraduate students recruited from university partners). Interviews and questionnaires will be conducted with participants to assess perceptions of stigma and to determine how perceptions of dementia change with participation in the programs. Interviews will be open-ended and include themes such as awareness of dementia and willingness to help people with dementia. The questionnaire will be informed by existing instruments, such as the Social Distance Scale, and will focus on participants' impressions of individuals living with dementia, including perceived competence and willingness to interact socially with persons with dementia. Interviews will last approximately 15-20 minutes and will be conducted before the intervention, mid-way through the intervention, immediately after the intervention, and six months post-intervention.

Significance and Innovation: Patient-centered and community based participatory research principles will be used to engage all team members in decision making.

Research team: The research team is collaborative, integrating academic researchers, people living with dementia, and care-partners of people living with dementia.