

MEMORANDUM OF UNDERSTANDING

LiveWell is pleased to have (X name, title, of organization) participate in the planning and execution of the Eugene Washington PCORI Engagement Award entitled: *Empowering Partners: Engaging Individuals with Dementia and Care Partners in Patient Centered Outcomes Research/Comparative Effectiveness Research (PCOR/CER).* This document will serve as a Memorandum of Understanding (MOU) between LiveWell Alliance, Inc. and (X name) to engage as a member of the project team over the course of the project's duration, September 2018 - August 31, 2020.

<u>Background</u>

The *Eugene Washington PCORI Engagement Award* funds projects that encourage active integration and engagement of patients, caregivers, clinicians, and other healthcare stakeholders as integral members of the patient-centered outcomes research/clinical effectiveness research (PCOR/CER) enterprise. Founded in 1990, LiveWell (formerly Alzheimer's Resource Center) has a history of, and reputation for, actively engaging and empowering people living with dementia (PLWD) in transformational change. Advancing this priority, LiveWell is helping to establish the innovative Dementia Peer Coalition (DPC), which aspires to be a statewide, peer-driven network led by PLWD, working in four priority areas: peer support, advocacy, education and research, and volunteerism. Partnering with members of the Dementia Peer Coalition, Project Lead Heidi Gil and Project Co-Lead Stephani Shivers of LiveWell have co-created the project design along with many notable partners.

Overall Project Aims:

This project's long-term objective is to increase engagement of PLWD and CP in all aspects of the PCOR/CER research process through a sustainable network of peers impacted by dementia.

Project partners have co-designed the following project aims:

- Expand the reach, diversity and membership of the DPC
- Build a sustainable PCOR/CER community of multi-stakeholder partnerships, motored by DPC awareness and recruitment strategies
- Develop a training program for PLWD, CP, and researchers to partner in research, including a guide to assess capacity to participate
- Implement the training program with a small number of diverse—including minority participants, and refine the program based on lessons learned
- Identify, prioritize, and disseminate research topics that matter
- Produce and disseminate a Program Implementation Toolkit for program replication

Guiding Principles and Project Infrastructure

All project activities will be guided through the following PCORI's six engagement principles including: Reciprocal Relationships, Co-learning, Partnerships, Transparency, Honesty, and Trust.

- LiveWell's key personnel will oversee and coordinate all activities
- An Advisory Council will provide overall project guidance, identify priorities for sustainability, monitor progress toward outputs/outcomes, and ensure alignment with applicable local/state/national efforts
- Three Action Teams will guide group productivity and key project aims: Peer/Stakeholder Recruitment, Training Program Development, Dissemination
- The Advisory Council and Action Teams will include PLWD, CPs and supportive multistakeholder partners including leading national/state/local visionaries, PCOR/CER qualified experts, and community-based stakeholders

Project Launch Webinar

An introductory webinar for all Advisory Council and Action Team members was held on **October 9**th, **2018 at 2:00pm-3:30pm ET.** A recording of the webinar is available through the project Dropbox folder with the expectation of previewing prior to the inaugural planning meeting(s).

Advisory Council and Action Team Meetings

Project members on the Advisory Council and each Action Team will attend *four meetings* (two - 4-hour in person meetings, and two - 2-hour video conferences) over the course of a *two-year period. Inaugural meetings:*

- Advisory Council: Wednesday, October 24th, 2018, 8:30am-12:00pm
- Peer/Stakeholder Recruitment Team: Tuesday, November 6th, 2018, 8:30am-12:00pm
- Training Program Development Team: Wednesday, November 7th, 2018, 8:30am-12:00pm
- o **Dissemination Team:** Thursday, November 8th, 2018, 8:30am-12:00pm

The meetings will be held at *LiveWell Farmington Valley, 729 Farmington Avenue, Farmington, CT, 06032* (unless otherwise notified). Details including agenda and preparation material will be sent *five* working days in advance of each meeting.

The additional dates/times for the meetings are provided in the following table and may be subject to change based on the project team's availability. If you are unable to participate in the meeting a minimum of a two weeks' notice is appreciated.

	Meeting 1	Meeting 2	Meeting 3	Meeting 4
Team	in person 8:30- 12:00pm ET	Zoom 2-4pm ET	In person 8:30- 12:00pm ET	Zoom, 2-4 pm ET
Advisory Council	10/24/2018	4/23/2019	10/16/2019	3/11/2020
Peer/Stakeholder Recruitment Team	11/6/2018	2/12/2019	6/4/2019	2/25/2020
Training Team	11/7/2018	2/13/2019	8/27/2019	2/26/2020
Dissemination Team	11/8/2018	2/14/2019	10/2/2019	2/27/2020

Tentative Schedule for All Meetings

Participant expectations for the project

Expectations for the Advisory Council and Action Team members include:

- Review comprehensive work plan, timeline, and other materials provided in preparation for meetings
- Participate as appropriate in project activities necessary to plan, conduct, and disseminate project (See Engagement Rubric below)
- Identify specific aspects of the project that may support and be aligned with your individual/organization's strengths, goals, and initiatives
- Recruit individuals and stakeholder organizations that can contribute in meaningful ways to project
- Promote project as appropriate for purposes of propelling deliverables and dissemination activities
- o Share materials and relevant exemplar practices occurring on a local, national, international
- Foster innovations and solutions to ensure effective program evaluation and sustainability



Stipend Compensation and Travel:

Acting in alignment with PCORI principles – all stakeholder participants (including people living with dementia, care partners, researchers, physicians) are reimbursed with the same stipend for the planning meetings:

- \$200 stipend for in person meetings inclusive of in-state travel
- \$100 stipend for video conferences

Stipend payments will be made by LiveWell Alliance within 30 days after a project meeting.

Accommodations will be made for out-of-state project members. Out of state travel expenses will be reimbursed upon completion of a reimbursement form, and/or can be arranged by the Project Assistant.

Any dietary restrictions and/or other meeting accommodations will be honored by the Project Assistant with appropriate notification.

Exhibits:

The following Exhibits are integrated as part of this MOU:

o PCORI Work Plan Attachment

This is an agreement made as of October 1, 2018, between

Name/Title/Organization

Stephani Shivers, COO - Community Services, LiveWell
Project Co-Lead and Administrative Officer

Heidi Gil, CEO, HPG Project Lead