



Empowering Partnerships

*Preparing People with Dementia
to Partner with Researchers*

Peer/Stakeholder Recruitment Plan

LiveWell

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Executive Summary:

This project will demonstrate how a stakeholder supported, peer-driven network can effectively recruit and engage individuals impacted by dementia in Patient Centered Outcomes Research/Comparative Effectiveness Research (PCOR/CER) and create a multi-stakeholder community that continuously builds its capacity and infrastructure. The Peer/Stakeholder Action Team is tasked to create an awareness and recruitment plan that expands the reach of the Dementia Peer Coalition (DPC) across the North Central and South Central regions in Connecticut. The outreach in these regions to individuals and multi-stakeholder organizations will be anchored and supported by LiveWell Alliance, Inc. and the research programs of collaborative partners Yale School of Medicine and University of Connecticut Health Center. This comprehensive plan will build project momentum and address the recruitment of peers living with dementia (PLWD), care partners (CP), researchers, as well as additional multi-stakeholder partners dedicated to sustaining a PCOR/CER community and the Dementia Peer Coalition.

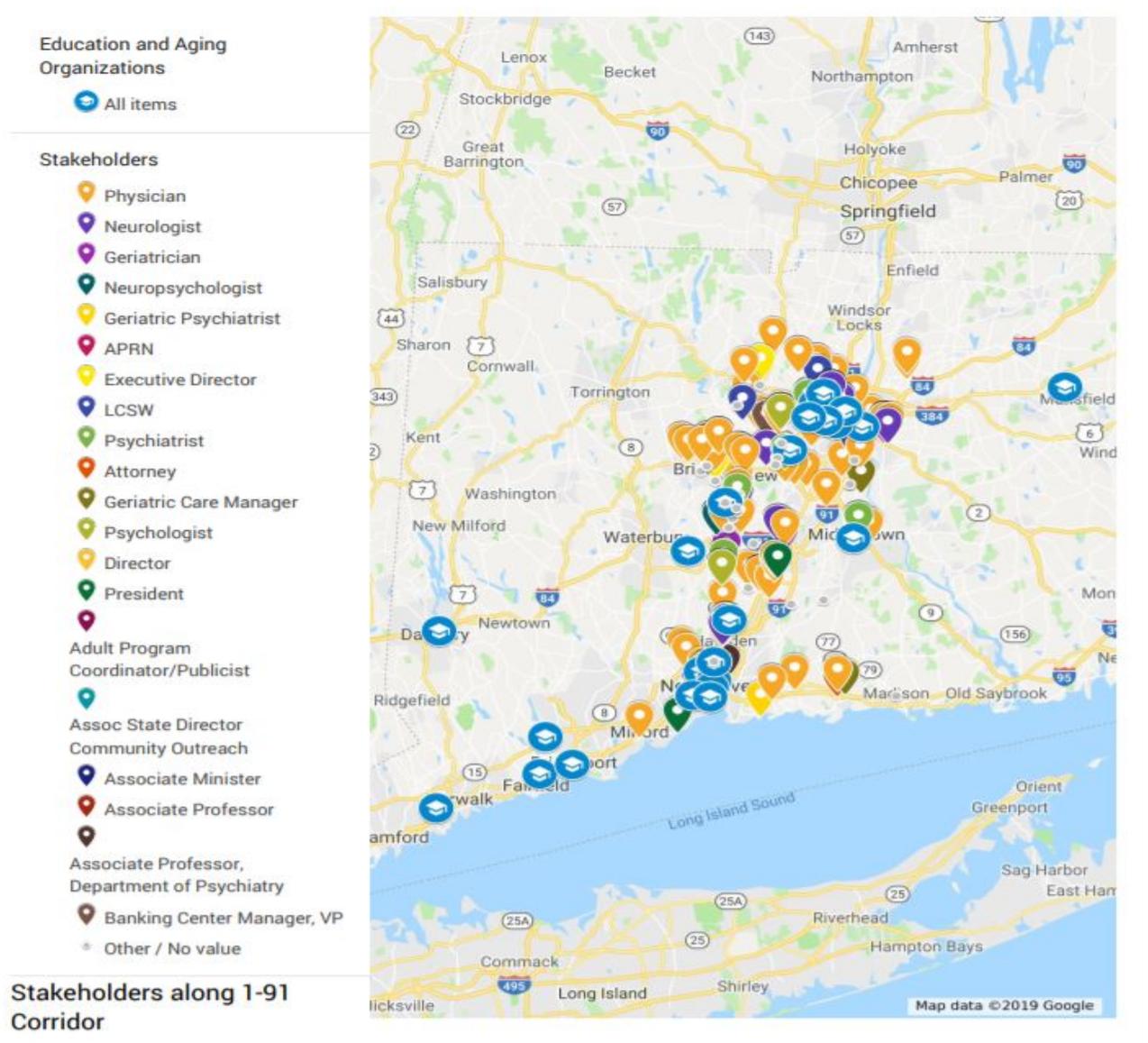
The Dementia Peer Coalition aims to create an independent 501(c)3 that will be supported by LiveWell, along with partnering stakeholders. As a neutral entity, the DPC Board of Directors seeks to ensure that the Coalition is sustained and led by those impacted by dementia. The Board will work to secure funding and partners that will propel the initiatives that matter most to people living with dementia, including an on-going research agenda, advocacy campaigns, opportunities for peer support, volunteerism, and community education.

FEATURES OF DEMENTIA PEER COALITION	BENEFITS FOR PCOR/CER
<ul style="list-style-type: none"> ● Coalition for and by PLWD ● Access to opportunities for peer support, advocacy, volunteerism, community education, and research ● Opportunities for PLWD to support and empower one another, including mentorship, shared roles, responsibilities and opportunities ● Elicited feelings of purpose, usefulness, empowerment and inclusion ● Connections to local and statewide peers via in person and virtual group meetings ● Active public speaking engagements and awareness raising events to change attitudes and embed lived experiences in educational opportunities ● Advocacy efforts that focus on human and disability rights, social justice, reduction of stigma, and improvement of dementia related services 	<ul style="list-style-type: none"> ● Recognition for PLWD as empowered experts on their own lived experiences ● Acknowledgement that PLWD are equals and valued contributors ● Network of PLWD ready to engage in PCOR/CER ● Provision of a safe space to share experiences ● Improved capacity of researchers to co-partner with PLWD and CP in research ● Advancement of dementia research in alignment with 2018 Research Summit on Dementia Care recommendations

Target Market/Audience:

LiveWell will leverage existing relationships and contacts as noted below on this Asset Map reflecting current and potential stakeholders for PCOR/CER efforts. The Asset Map is indicative of the wide array of stakeholders including healthcare providers, community supporters, and education hubs built through LiveWell outreach and activity. These stakeholders possess knowledge and expertise from different sectors along the target area of North and South Central Connecticut.

Map of Potential Stakeholders



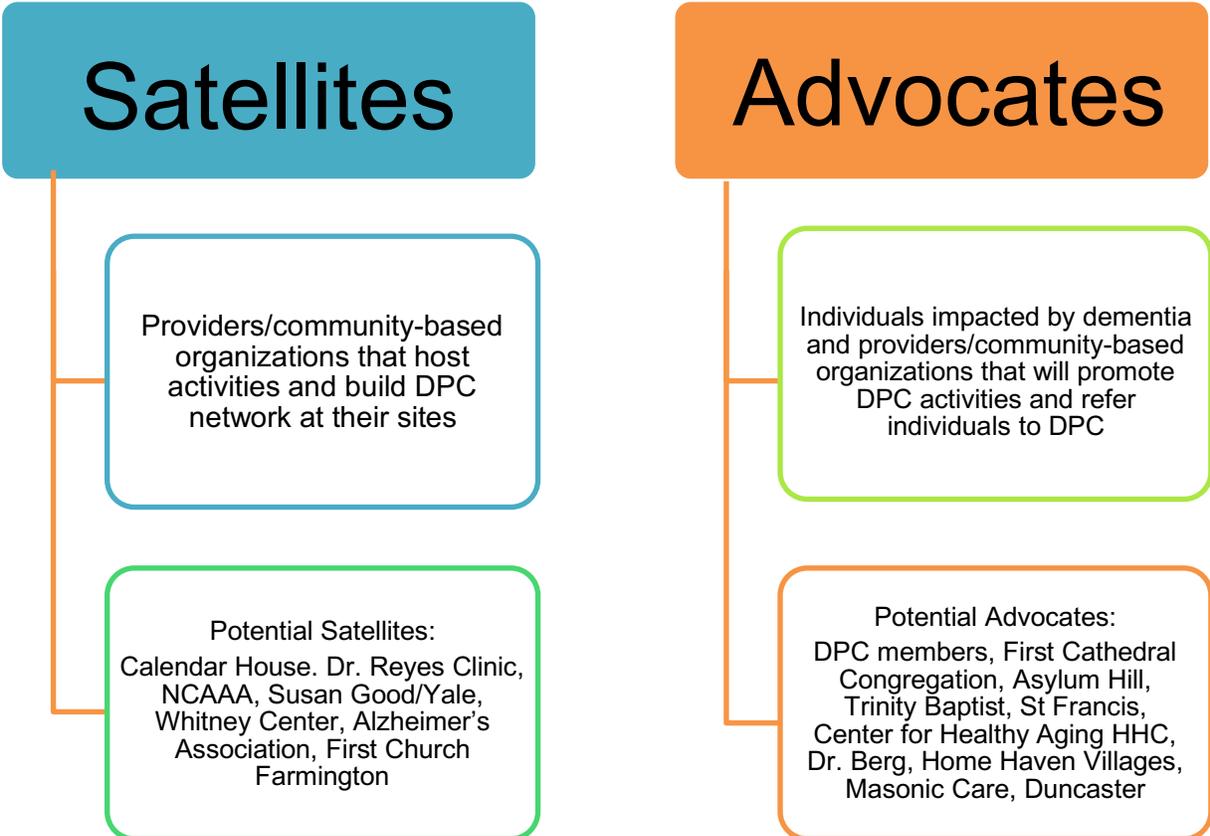
Deployment Approach:

WORKFLOW

The workflow will be both dynamic and multilevel with components that will be branded and on message for consistency and reinforcement. The overall approach will be an individualized and peer-centered outreach program engaging our healthcare and community partners to leverage their networks to disseminate information and engage people living with dementia and their care partners. Using a grassroots marketing strategy will allow us to engage in a more personal manner and to better develop the relationships we need to instill comfort and confidence in all participants. To do this, it's necessary that DPC members engage personally with each individual on some level be it by letter, email, phone call or in-person. Additionally, using social and digital media allows us to more easily disseminate information and keep everyone engaged and on the same page.

SATELLITES & ADVOCATES

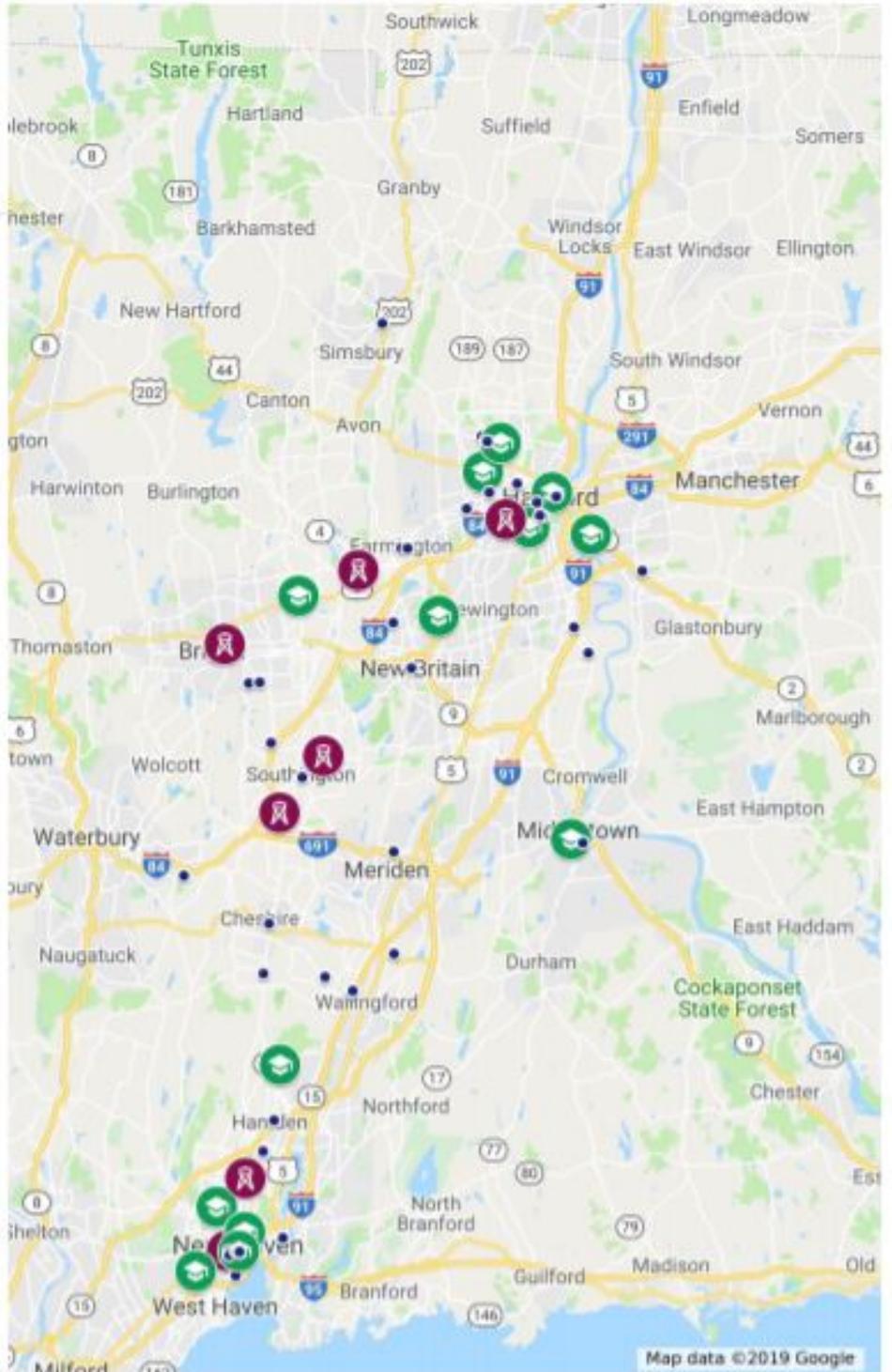
Two types of partner stakeholder relationships will support the project efforts including Satellites and Advocates (see below for an operationalization of these terms, potential partners, and map of satellite/advocate locations).



Map of Potential Satellites and Advocates

Satellites and Advocates

- Advocate
- 🎓 Research
- 📡 Satellite



An MOU/MOA will be created with partners with specific opt-in activities/commitments for Satellites and Advocates. For examples of activities/commitments see chart below.

Sample Opt-in Activities/Commitments	Satellite	Advocate
Assist with managing referrals on behalf of the DPC	✓	
Host support groups on a regular basis	✓	
Host Information and/or Welcoming/Orientation Sessions	✓	
Provide meeting space when needed for activities/events	✓	
Promote activities/events on behalf of the DPC	✓	
Promote DPC information on web-site and other communication channels as identified	✓	✓
Work to identify champions living with dementia to serve on the DPC Board of Directors and support recruitment activities for the DPC	✓	✓
Organize volunteers to support DPC activities	✓	✓
Provide administrative support to DPC members (calendars, email assistance, video conferencing, printing materials)	✓	
Communicate with other DPC Satellites to coordinate efforts, share learning, etc.	✓	✓
Volunteer time/space on ad hoc basis		✓
May serve on Advisory Council to DPC	✓	✓
May provide transportation support as needed for DPC members	✓	✓

THREE WAVE APPROACH

Utilizing the Asset Map, stakeholders in the North and South Central regions are identified and prioritized; these key referral sources include associations/community-based organizations (ACB), physicians and clinicians (PC), healthcare providers (HP), and faith-based organizations (FBO). The identified referral sources may also serve as Dementia Peer Coalition “Satellite” locations. Recruitment will occur in three waves; below are the targeted stakeholders in the recruitment plan and the waves in which they be engaged.



Wave 1: [NCAAA](#), CT Alzheimer’s Association, [Calendar House](#)
Wave 2: [Center for Health Aging](#)
Wave 3: Home Haven Villages

Wave 1: [Dr. Reyes](#), [Dr. Berg](#), [Dr. Van Dyke & Susan Good \(Yale\)](#)
Wave 2: [St. Francis Healthcare Partners and Neurology](#)
Wave 3: Pro-Health Physicians

Wave 1: [North Central CCRC](#), [Whitney Center](#)
Wave 2: Masonicare, Duncaster
Wave 3: Mary Wade

Wave 1: [First Congregational Church, Southington](#)
Wave 2: [Trinity Baptist Congregation](#), [Asylum Hill Congregation](#)
Wave 3: [First Church/St. Patrick, Farmington](#), N.H. Faith Community

*Satellites (actual or potential) are **underlined and in bold***

Advocates (actual or potential) are in plain text

- ❖ [Stakeholders in blue represent those in the North Central Region](#)
- ❖ **Stakeholders in black are located in the Southern Region**

REFERRAL PROCESS

LiveWell will leverage existing partnerships in conjunction with a diverse range of marketing and engagement strategies to identify and sustain members for the DPC. LiveWell will address key operating practices and partnership expectations for Satellites and Advocates through an MOU/MOA in an effort to build and sustain a committed community in patient-centered research. Referrals will be streamlined through a faxable referral form, electronic referral, and/or TigerText. Potential members identified through providers or marketing materials will receive personal contact from DPC members and LiveWell staff via phone, email, or mail. Potential members will receive an overview of DPC activities, with direct attention and invitations towards engagement in the Empowering Partners training. New members will receive a welcoming packet providing a highlevel overview of the DPC and its involvement in PCOR/CER. Updates on DPC and PCOR/CER activities will stream through social media as well as web-pages and email newsletters, with membership information being maintained through a secure customer relations management system.

Potential members will also be invited to participate in one of two Information Sessions to learn more about the DPC and the Empowering Partners training opportunity. Content for the Information Session will include:

OUTLINE FOR INFORMATION SESSIONS

- Welcome by DPC Member and LiveWell Staff
 - Personal Narrative by DPC Member
 - Share Marketing Video
- Introduction to Peer Coalition
 - Context from Scottish Working Group, ADI, DAI, and DAA (LW Staff)
 - History of Development of DPC (LW Staff)
 - Group Values and Mission (DPC Member)
 - Core Areas of Focus (DPC Member)
- Describe Why DPC is Important
 - Unique Nature of Group Composition/Leadership (LW Staff)
 - Combating Stigma (DPC Member)
 - How Groups are Run (DPC Member)
- Transition to Why Research is Important
 - Empowerment of PLWD (LW Staff)
 - “Nothing About us Without Us” (DPC Member)
 - Investment of Researchers to Issues of Concern for PLWD (LW Staff)
 - Introduction to Values Based Survey
 - Introduction to the A-Lists
- Invitation to Empowering Partners Training

- Personal Narratives about Empowerment (Pat & John) (LW Staff)
- Open Possibilities for Research based on Summit Recommendations (DPC Member)
 - Improving Participation in Research
 - Identifying Research Priorities
 - Expanding Areas of Research in Quality of Life
- Q&A

The Empowering Partners training opportunity and information on the DPC will also be shared at LiveWell’s community education and public awareness events and through 1:1 meetings with members of the DPC in order to expand the reach of the opportunity.

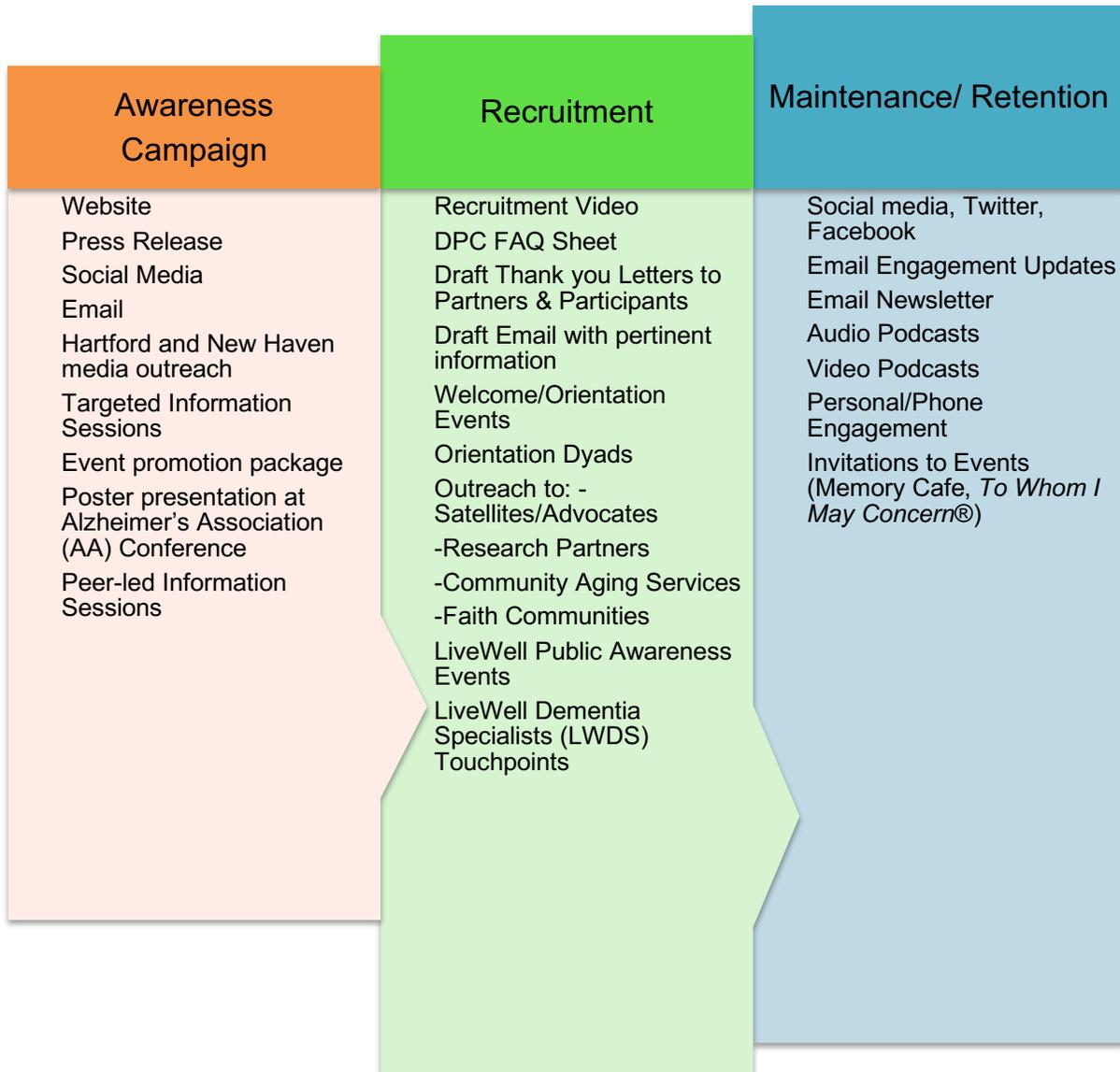
Once a PLWD has expressed interest in the training opportunity, a strengths-based functional capacity and the social supports screening will be conducted to ensure this training opportunity is an appropriate match for the person living with dementia’s retained skills.

ACTION STEPS

Referral Process		
Create Referral Form	Dan	2/15/2019
Create FAQ for Satellites and Advocates	Dan, Brian	2/15/2019
Create talking points for potential members/project participants	Bob, Dan, Brian	2/15/2019
Create Welcome Packets	Brian, Nash	2/15/2019
Identify sites, dates, and speakers for Information Sessions	Dan, Erica	2/22/2019
Create MOU for Satellite and Advocates	Stephani, Dan	3/1/2019

Multi-Component Marketing and Engagement Campaign:

Three interconnected campaigns comprise the marketing and engagement plan, including awareness, recruitment, and maintenance/retention campaigns.



CONTENT DEVELOPMENT

The campaigns begin with the creation of websites, the media kit, social media sites and slide decks for Information Sessions.

ACTION STEPS

Content Development		
Develop event promotion package (Flyer for each event, MailChimp template, Email template, Eventbrite event, SM post)	Brian	2/15/2019
Create Empowering Partners Website	Brian	2/15/2019
Update DPC Website	Brian	2/15/2019
Create slide deck for Empowering Partners opportunity to be used in Information Sessions	Erica	2/28/2019
Create slide deck for DPC for Information Sessions	Erica	2/28/2019
Create DPC FAQ Sheet	Dan	2/28/2019
Create FAQ for Empowering Partners opportunity	Dan	2/28/2019
Draft Press Release	Brian	2/28/2019
Create Twitter site, monthly posts	Brian	2/28/2019
Create Facebook site, monthly posts	Brian	2/28/2019
Create list of events including dates and target numbers	Brian	2/28/2019
Create Email template (EP Overview with CTA for all)	Brian	2/28/2019
Develop Talking Points and Scripts for Information Sessions	Bob, Erica, Dan	2/28/2019
Complete Recruitment Video	Brian	2/28/2019
Draft Thank you Ltrs Satellite/Participant	Stephani, Nash	2/28/2019
Draft Emails w/pertinent information to 3 stakeholder types (Peers, Partner, Researcher)	Brian	2/28/2019
Develop media kit (includes press release, pitch sheet, FAQ, Contact resources, quotes, images)	Brian	2/28/2019
Create MOU for project partners	Stephani	3/4/2019
Create Audio and Video Podcast topics, outlines and production schedule	Brian	3/15/2019

AWARENESS CAMPAIGN

The Awareness Campaign is designed to promote interest and ignite action to join the DPC and learn about the Empowering Partners opportunity. Media efforts will highlight bi-monthly public events of the DPC including two primary Information Sessions led by DPC peers--one in the North Central region and one in the South Central region.

- Website: the website will be a repository for curated content for all constituents and the location to find up-to-date information and to promote the upcoming events.
- Publicity: A press release will be developed to enhance awareness of our project and provide benefits for all parties with an opportunity to engage.
- Social Media: We will also use social media such as Twitter and Facebook to create awareness, drive our audience to the website for additional information where they can also engage with us through various calls-to-action to engage with several events. These posts can also be shared virally with our audience, increasing our reach and creating a groundswell of interest.
- Email: We'll create an email template that can be updated and sent directly to our partners and to our asset map targets bi-monthly. It will be constructed in away that it can easily be shared with their individual networks, thus increasing our reach to a greater targeted audience.
- Audio and Video Podcasts: Branded viral media, meant to be shared electronically, will be created on topics vetted by our partners living with dementia and will include content provided by all partners. These podcasts will include links and appropriate calls-to action and will inform, inspire, engage audiences and promote our message of empowering partners.
- Events: Through our established events, and through the events that our partners and asset map targets have established, we'll encourage promotion and engagement with the project to garner further awareness and reach. In particular LiveWell will showcase the DPC and Empowering Partners opportunity during Dementia Friendly events, monthly Memory Cafes, *To Whom I May Concern*® (TWIMC) performances, carepartner support groups, and community talks.

ACTION STEPS

Awareness		
Monthly Eblast for Upcoming Events	Brian	2/28/2019
Embed Information Sessions into LiveWell Public Awareness Events (Community talks, DFCT, TWIMC, Memory Cafe, etc.)	Bob, Erica, Shazia	3/1/2019
Host targeted Information Session in North Central region	Bob, Erica	4/1/2019
Poster presentation at Alzheimer's Association Conference	Dan, Bob	4/4/2019

Complete Hartford media outreach (includes press release, pitch sheet, FAQ, Contact resources, quotes, images)	Brian	4/15/2019
Complete New Haven media outreach (includes press release, pitch sheet, FAQ, Contact resources, quotes, images)	Brian	4/15/2019
Host targeted Information Session in South Central region	Bob, Erica	6/4/2019

RECRUITMENT

The Recruitment component of our strategy will embody a peer-led emphasis. Members of the DPC will target three specific audiences (peers, partners, and researchers) with custom information and benefits for each audience. Each audience has specific needs, and our project provides specific benefits for each of them. We will make clear that participation benefits both DPC members as well as partners and researchers. The dynamic component of our strategy allows information to be accessed in the way that is most comfortable for each of our partners. We will have engagement content prepared for each audience in a variety of components. We will deliver information via snail mail, email, phone call, and face to face where appropriate or necessary. We will provide these components for our peers for our partners and for our researchers. We will thank them for their engagement, update them with opportunities to join in our Welcome/Orientation sessions, networking opportunities, and in research.

There will be two Welcoming/Orientation sessions co-facilitated by PLWD, CP, and LiveWell staff. The purpose of this session is to welcome PLWD, begin engagement through relationship building, and to demystify and ignite inspiration for PCOR/CER. The key learning objectives will be:

- Internalizing personal strengths and values
- Personalizing why PCOR/CER matters
- Identifying personal and common goals desired to be achieved through PCOR/CER training and the DPC
- Understanding peer leadership and partnering skills that will impact engagement in PCOR/CER

ACTION STEPS

Recruitment		
Welcome/Orientation Dyad Meetings	Bob & ?	2/15/2019
First Wave outreach to potential Satellite/Advocates	Dan	2/18/2019
Send thank you letters to peers, partners and researchers as they are onboarded	Team	3/1/2019

Begin to disseminate MOU to project partners	Stephani	3/4/2019
Disseminate A-List Survey Tool	Dan, Bob	3/15/2019
Second Wave outreach to potential Satellite/Advocates	Dan	3/18/2019
Third Wave outreach to potential Satellite/Advocates	Dan	4/15/2019
Continue Outreach to Additional Partners	Dan	4/15/2019
Provide verbal introduction and FAQs to LWDS clients. Secure permission to have member of DPC contact clients when interested.	Dan	4/15/2019
Welcome/Orientation Event 1	Erica & Bob	5/15/2019
Welcome/Orientation Event 2	Erica & Bob	8/15/2019

MAINTENANCE/RETENTION

In the retention component of our strategy we will keep all partners updated in our accomplishments and the milestones reached so that they can be encouraged by the group's achievements.

To engage and retain our partners we will not only keep them updated through email newsletters, we'll keep them engaged using audio podcasts and video podcasts featuring our peers, partners and researchers so we can share their progress in their own words.

ACTION STEPS

Maintenance/Retention		
Personal/Phone Engagement	DPC champions	2/28/2019
Social media, Twitter, Facebook monthly updates	Brian	2/28/2019
Monthly Eblast for Upcoming Events	Brian	2/28/2019
Email Bi-monthly DPC Newsletter	Brian	4/15/2019
Identify and build capacity of DPC champions in each satellite	Bob, Erica	5/1/2019
Record and distribute quarterly audio podcasts	Brian	6/17/2019
Produce and distribute quarterly video podcasts	Brian	6/17/2019

PROJECTIONS

- ⇒ 5 peers involved in recruitment efforts
- ⇒ 5 Satellites, 15 Advocates signed MOU
- ⇒ 30 peers involved in the DPC
- ⇒ 40 participants in Information Sessions, 100 through other LiveWell Public Awareness Events
- ⇒ 35 participants in Welcoming Sessions