



Empowering Partnerships

*Preparing People with Dementia
to Partner with Researchers*

Introductory Kick-Off

LiveWell

DEMENTIA
PEER
COALITION



Who are we?

- ▶ Heidi Gil, Project Lead
- ▶ Stephani Shivers, Project Co-Lead
- ▶ Bob Savage, Person living with dementia, Design Team
- ▶ Erica DeFrancesco, Key Personnel
- ▶ Maria O'Connell, Key Personnel

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H P G
HoodenPyleGil

DEMENTIA PEER



COALITION

RESEARCH



What Matters Most to You?

Values Matter

- ▶ Our core values largely determine how we answer “what matters most?”
- ▶ Our core values highlight what we stand for and guide our behaviors, decisions, and actions
- ▶ We can best identify our core values when thinking about what brings us meaning, joy, and fulfillment

Welcome

- ▶ Think about something right now that is meaningful to you or a positive experience that you've had in the past few months.
- ▶ What values are related to that experience? Circle 3-5
- ▶ Pair with someone new and share your work



RESEARCH



“Persons living with dementia maintain ability to communicate values and preferences long after their decision-making abilities are affected by cognitive changes. Research within the past 13 years indicates that participants can reliably report their core values and preference, well-being, and quality of life through moderate to severe dementia.”

► *Research Article:*

Shared decision-making in dementia: A review of patient and family carer involvement

Miller, Whitlatch, and Lyons



- ▶ Founded in 1990 as the Alzheimer's Resource Center
- ▶ Established history as thought leaders and pioneers in dementia services seeking to positively transform the way people living with dementia (PLWD) are viewed, engaged and supported
- ▶ Campus in Southington, CT home to 133 people living with dementia (skilled nursing and assisted living communities)





- ▶ Suite of community services including day services, support groups for PLWD and carepartners (CPs), community education, dementia care navigation
- ▶ LiveWell Therapy and Medical Specialists - new transdisciplinary outpatient group practice (OT, PT, SLP, Counseling, Geriatrician, Palliative Care MD, APRN)
- ▶ LiveWell Institute: Transforming communities through education, thought leadership and advocacy to advance the wellbeing and inclusion of people as they age

DEMENTIA PEER



COALITION

“A group of resilient people living well with the changes attributed to various forms of dementia who are joining together into a local peer coalition run by and for people with dementia.”

FOCUS AREAS

Peer Support, Advocacy,
Community Education & Research

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proudly supports the DPC

WWW.DPC-CT.ORG

DPC - Support Groups & REACH

- ▶ Peer Support Groups

- ▶ Southington, Bristol, Farmington, Hamden, Zoom Video Conference

- ▶ *REACH Meeting*

(Research, Education, Advocacy, Community Happening)

- ▶ Research Opportunities
 - ▶ Community Education & Public Awareness events
 - ▶ Advocacy Opportunities
 - ▶ Social Events - upcoming memory cafes, etc.





Empowering Partnerships

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Eugene Washington PCORI Engagement Award

September 2018 - August 2020

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Who is PCORI?

Patient Centered Outcomes Research Institute

<https://www.pcori.org>

Mission:

*PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from **research guided by patients, caregivers, and the broader healthcare community.***

PCORI is funded through the Patient-Centered Outcomes Research Trust Fund (PCOR Trust Fund), which was established by Congress through the Patient Protection and Affordable Care Act of 2010.

PCORI Engagement Principles

- ▶ Reciprocal relationships
- ▶ Co-learning
- ▶ Partnership
- ▶ Transparency, honest, and trust



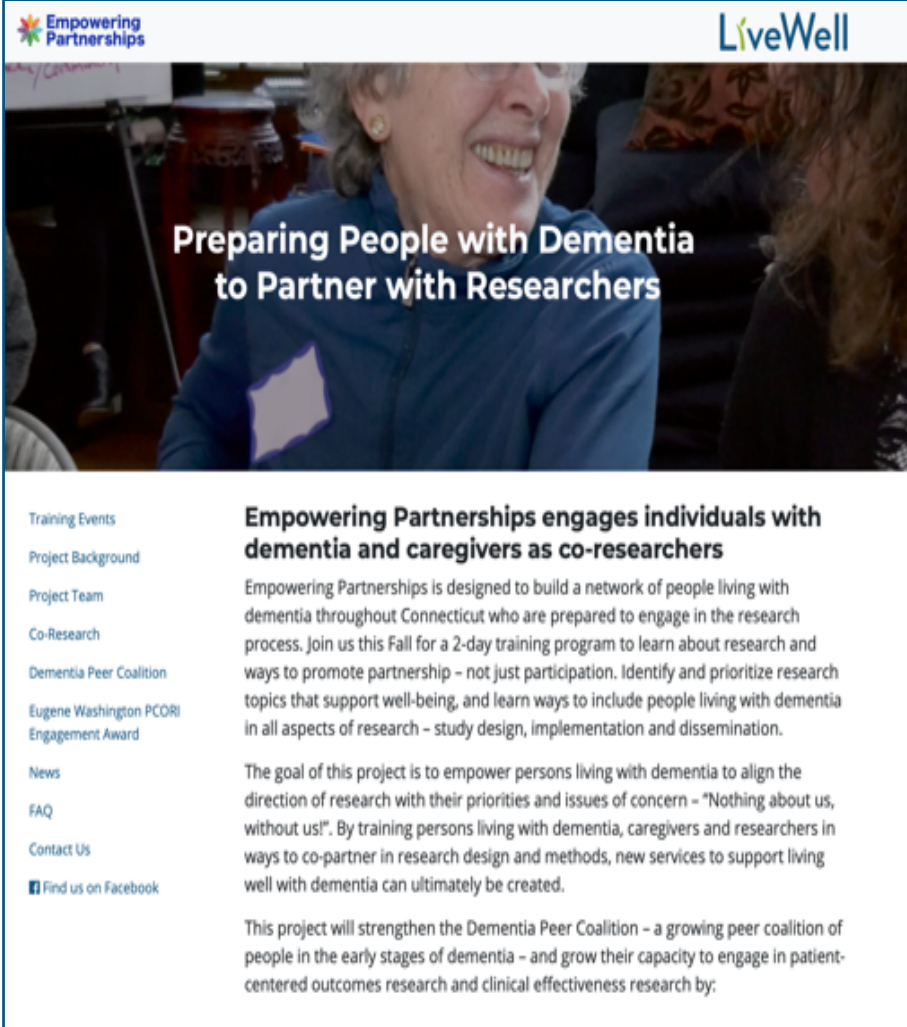
**Empowering
Partnerships**

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Our 2-year project

GOAL:

Enhance participation and engagement of people living with dementia in all aspects of research through the training of people with dementia, carepartners and Researchers



The screenshot shows the website for Empowering Partnerships, a project by LiveWell. The top navigation bar includes the 'Empowering Partnerships' logo on the left and the 'LiveWell' logo on the right. Below the navigation bar is a large hero image of an elderly woman smiling, with the text 'Preparing People with Dementia to Partner with Researchers' overlaid. To the left of the main content area is a vertical sidebar menu with links: 'Training Events', 'Project Background', 'Project Team', 'Co-Research', 'Dementia Peer Coalition', 'Eugene Washington PCORI Engagement Award', 'News', 'FAQ', 'Contact Us', and 'Find us on Facebook'. The main content area features a heading 'Empowering Partnerships engages individuals with dementia and caregivers as co-researchers' followed by two paragraphs of text. The first paragraph describes the project's goal to build a network of people living with dementia throughout Connecticut who are prepared to engage in the research process. The second paragraph explains the goal of the project to empower persons living with dementia to align the direction of research with their priorities and issues of concern. The third paragraph states that the project will strengthen the Dementia Peer Coalition, a growing peer coalition of people in the early stages of dementia, and grow their capacity to engage in patient-centered outcomes research and clinical effectiveness research by:

Empowering Partnerships engages individuals with dementia and caregivers as co-researchers

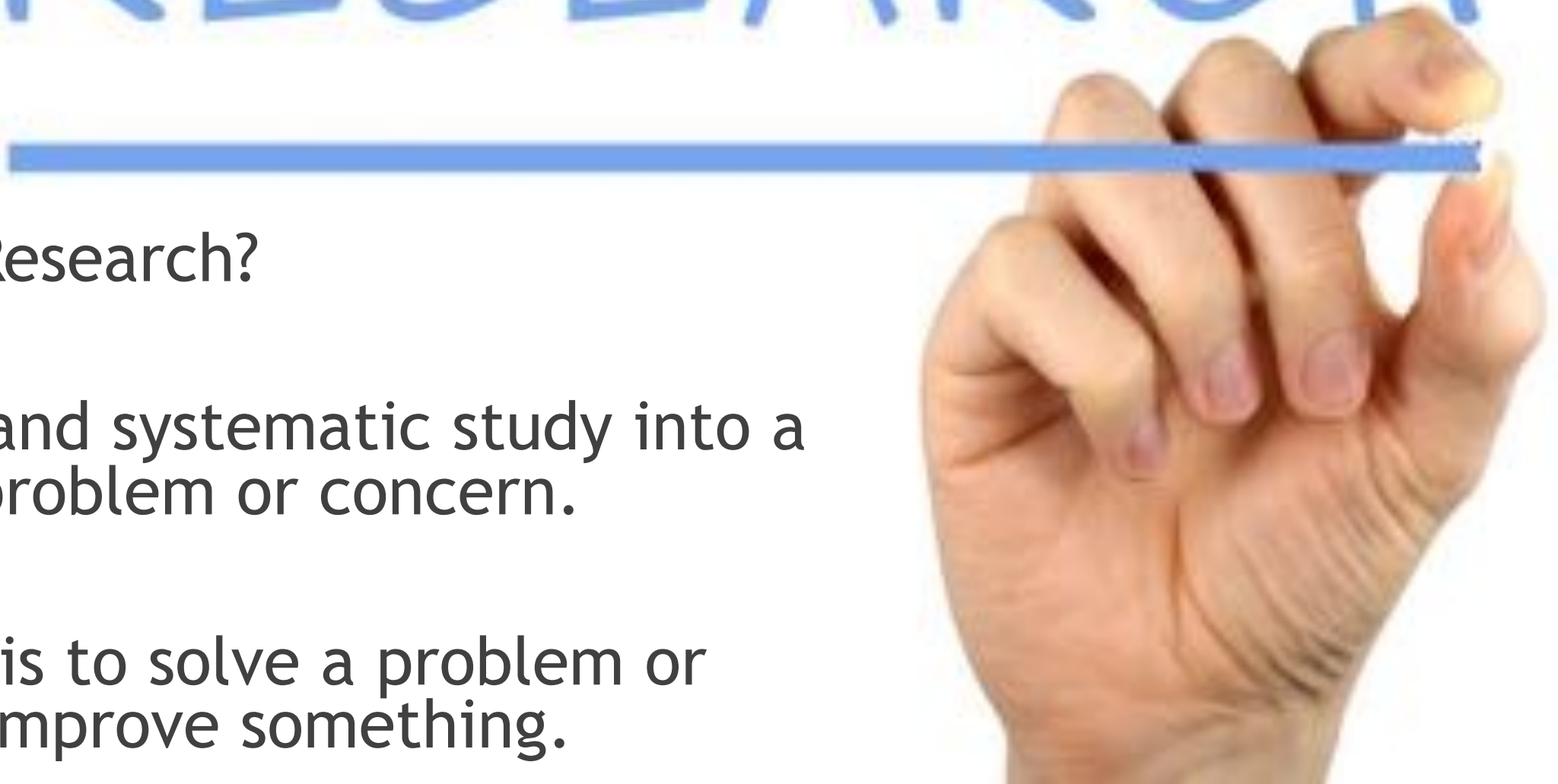
Empowering Partnerships is designed to build a network of people living with dementia throughout Connecticut who are prepared to engage in the research process. Join us this Fall for a 2-day training program to learn about research and ways to promote partnership – not just participation. Identify and prioritize research topics that support well-being, and learn ways to include people living with dementia in all aspects of research – study design, implementation and dissemination.

The goal of this project is to empower persons living with dementia to align the direction of research with their priorities and issues of concern – “Nothing about us, without us!”. By training persons living with dementia, caregivers and researchers in ways to co-partner in research design and methods, new services to support living well with dementia can ultimately be created.

This project will strengthen the Dementia Peer Coalition – a growing peer coalition of people in the early stages of dementia – and grow their capacity to engage in patient-centered outcomes research and clinical effectiveness research by:

www.empoweringpartnerships.livewell.org

RESEARCH



What is Research?

Careful and systematic study into a problem or concern.

Goal is to solve a problem or improve something.



1. Ask a
question
?



2. Make a
detailed
plan



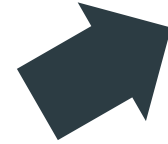
3. Gather &
analyze data



4. Share
results



5. Build
knowledge &
use results!



**RESEARCH
PROCESS**



RESEARCH

Are there different types?

Clinical Trials

RESEARCH



About TrialMatch

Alzheimer's Association TrialMatch® is a free, easy-to-use clinical studies matching service.

[Get Started](#)



What Are Clinical Trials?

[Learn More](#)



How Clinical Trials Work

[Learn More](#)



Why Participate in a Clinical Trial?

[Learn More](#)



Talk to Your Doctor

[Learn More](#)

Health/Care Intervention Research



Tests a strategy to improving health, well-being or care.



Examples:

- Education and training
- New services and supports
- Environmental design



Clinical Effectiveness Research

Compares different strategies for improving health, well-being or care.



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Research questions:

- Which works better?
- What are the benefits and risks of each?

RESEARCH

What is a research outcome?

Outcomes

Results of trial, strategy, or intervention

Clinical Outcomes - measured by tests

- Increase/decrease in something clinical - eg. Cholesterol, amyloid protein

Patient/Person Reported Outcomes- measured by asking people

- Ability to do everyday tasks
- Quality of life
- Quality of care



RESEARCH



Ask Me!

Research ‘Partnerships’



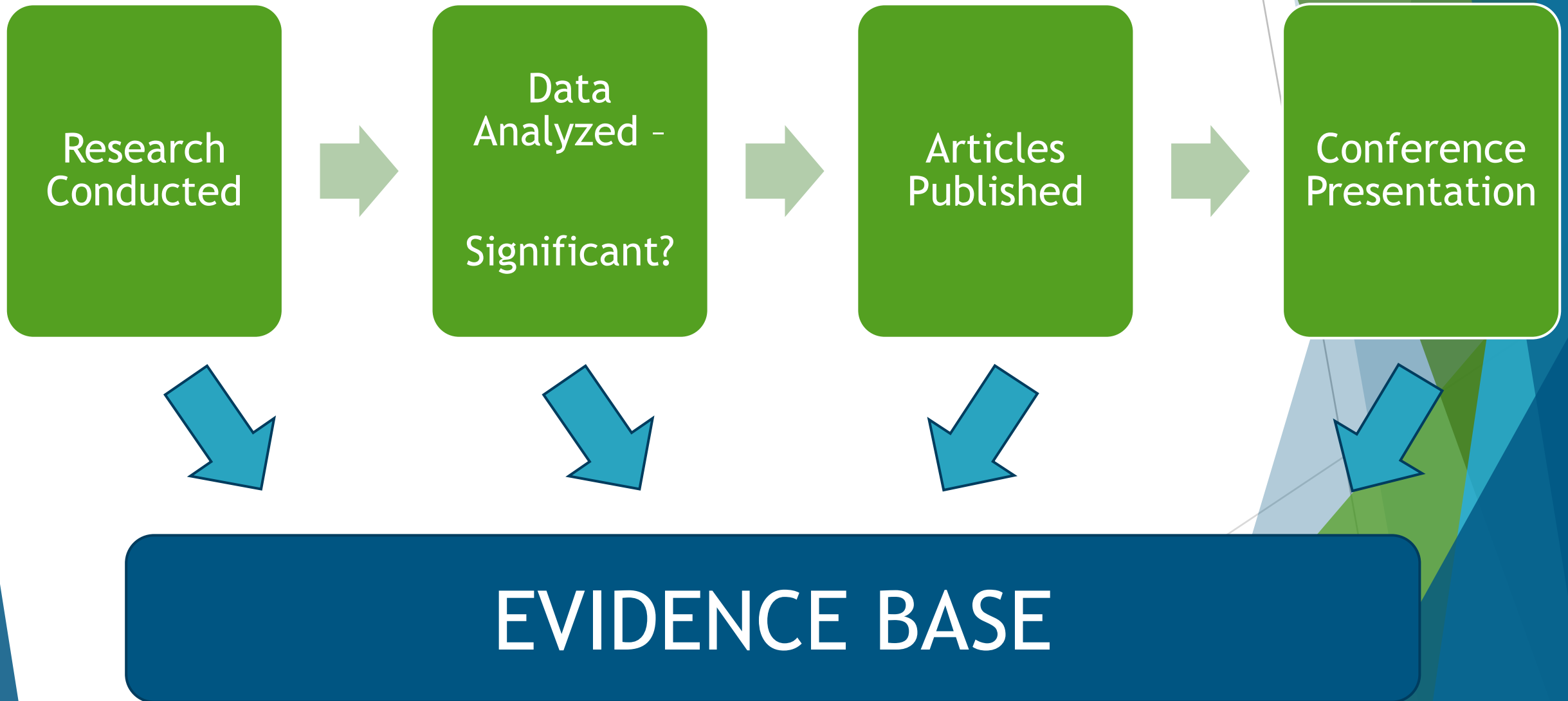
Traditional Research

- ▶ Persons with dementia are the subjects of research

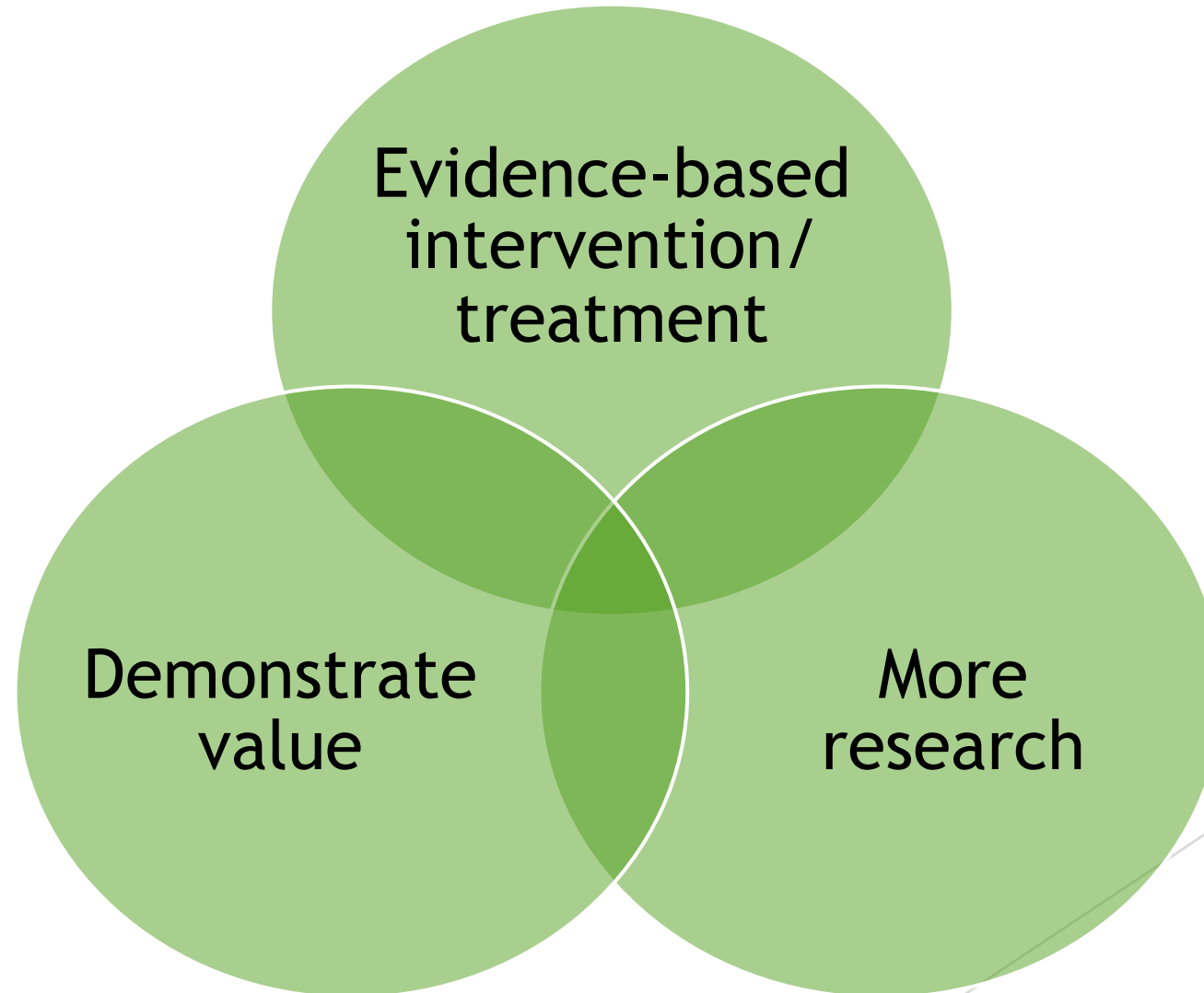
Research Partnerships

- ▶ Persons with dementia are viewed as experts with ‘lived experience’ who can participate in all aspects of research including:
 - ▶ Planning studies
 - ▶ Conducting studies
 - ▶ Sharing the results of studies

What happens with research information?



How is research used?



Successful Partnerships

PARTNERSHIP

- ▶ Think about a “successful” partnership (current or past). This does NOT have to be related to research.
- ▶ What is it about this partnership that makes it successful? (ex., mutual respect)
- ▶ Talk about this in pairs, and write down some notes. You will be asked to voluntarily share your responses.

Common Fears/Concerns



Researchers. . .

- ▶ Fear inability to convey value and contribution persons living well with dementia can have on research
- ▶ Fear not knowing how to communicate with persons living well with dementia at various stages of dementia

Persons Living Well with Dementia

- ▶ Research may be intimidating
- ▶ Limited communication; participating but not knowing the results or outcomes
- ▶ Stigma will impact the way that researchers communicate with persons living with dementia

I'm EXCITED about....

Researchers

- ▶ Learning about priorities that matter to persons living with dementia
- ▶ Getting to the right questions by talking directly to persons living well with dementia
- ▶ Improving the way research is done

Persons Living with Dementia

- ▶ Having researchers take me seriously
- ▶ Making a difference/impact/contribution
- ▶ Breaking down barriers/stigma

What is dementia friendly research?

- ▶ Equal partnerships
- ▶ Inclusive, involving persons living well with dementia at all stages of the research
- ▶ Development of trust, understanding, and respect
- ▶ Use of a common language
- ▶ Acknowledgement of persons living well with dementia as experts
- ▶ Acknowledgement of strengths of persons living well with dementia, while also providing accommodations as necessary



Practical Tips for Dementia Friendly Research

- ▶ **A:** Avoid assumptions
- ▶ **S:** Support the person to do the best
- ▶ **K:** Knowledge needs to be put into action and acknowledged
- ▶ **M:** Meet regularly and early
- ▶ **E:** Ethical sensitivity and responsibility



How to be involved in research

Participants

Knowledge
Users and
Experiencers

Reviewers,
Interviewers,
and Consultants

Governance and
Advisory Groups

Research
Partners or
Team Members

Co-Investigators
or Investigators



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Join Us!
October 9 & 10

2-Day Training



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WHO?

- ▶ Persons living with dementia
- ▶ Caregivers/carepartners
- ▶ Researchers

WHEN?

- ▶ October 9 & 10, 9:00 am - 5:00 pm (breakfast available from 8:30 am)

WHERE?

- ▶ Connecticut Hospital Association/LeadingAge
- ▶ 100 Barnes Rd., Wallingford, CT 06492

WHAT ELSE?

- ▶ Participants will receive \$50 stipend per day
- ▶ Meals are included (breakfast & lunch)
- ▶ Transportation will be provided if needed
- ▶ Travel within Connecticut will be reimbursed

Empowering Partnerships Training



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NEXT STEPS?

- ▶ Register today or via email/phone
- ▶ Schedule a 1:1 meeting to complete the project's *Strengths, Preferences and Experiences Inventory* and discuss any questions
- ▶ Optional: Join/Watch webinar on *Understanding Dementia* on Wednesday, September 25, 12:30-1:30pm
- ▶ Read/watch assigned short videos and materials

Contact Us!



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QUESTIONS:

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