Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

October 9 & 10, 2019

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This project was partially funded through a Patient- Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (10644-LWA).

Who are we?

- Heidi Gil, Project Lead
- Stephani Shivers, Project Co-Lead
- Geri & Jim Taylor, Design Team
- Bob Savage, Design Team
- Erica DeFrancesco, Key Personnel
- Maria O’Connell, Key Personnel
- Dan Belonick, Key Personnel
- Brian Connolly, Key Personnel
- Patty Richards, Key Personnel

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HPG
HoodenPyleGil

DEMENTIA PEER
COALITION

Who’s in the room? Activity 1

Please have everyone at your table take 1 minute to share their answers to the following questions:

- What is your name?
- What perspective are you bringing to this training? Are you a Person living with dementia, a Carepartner or a Researcher?
- Why did you decide to participate in this training?

Strengths & Preferences: Activity 2

Find your profile in your binder:

- *What are your Strengths? Preferences?*

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Shared Values: Activity 3

Find someone at your table who has one of the same values as you have listed on your profile. In 1-2 minutes share:

- *Why is this value is important to you?*
- *Please share an example of that value from your personal experience*

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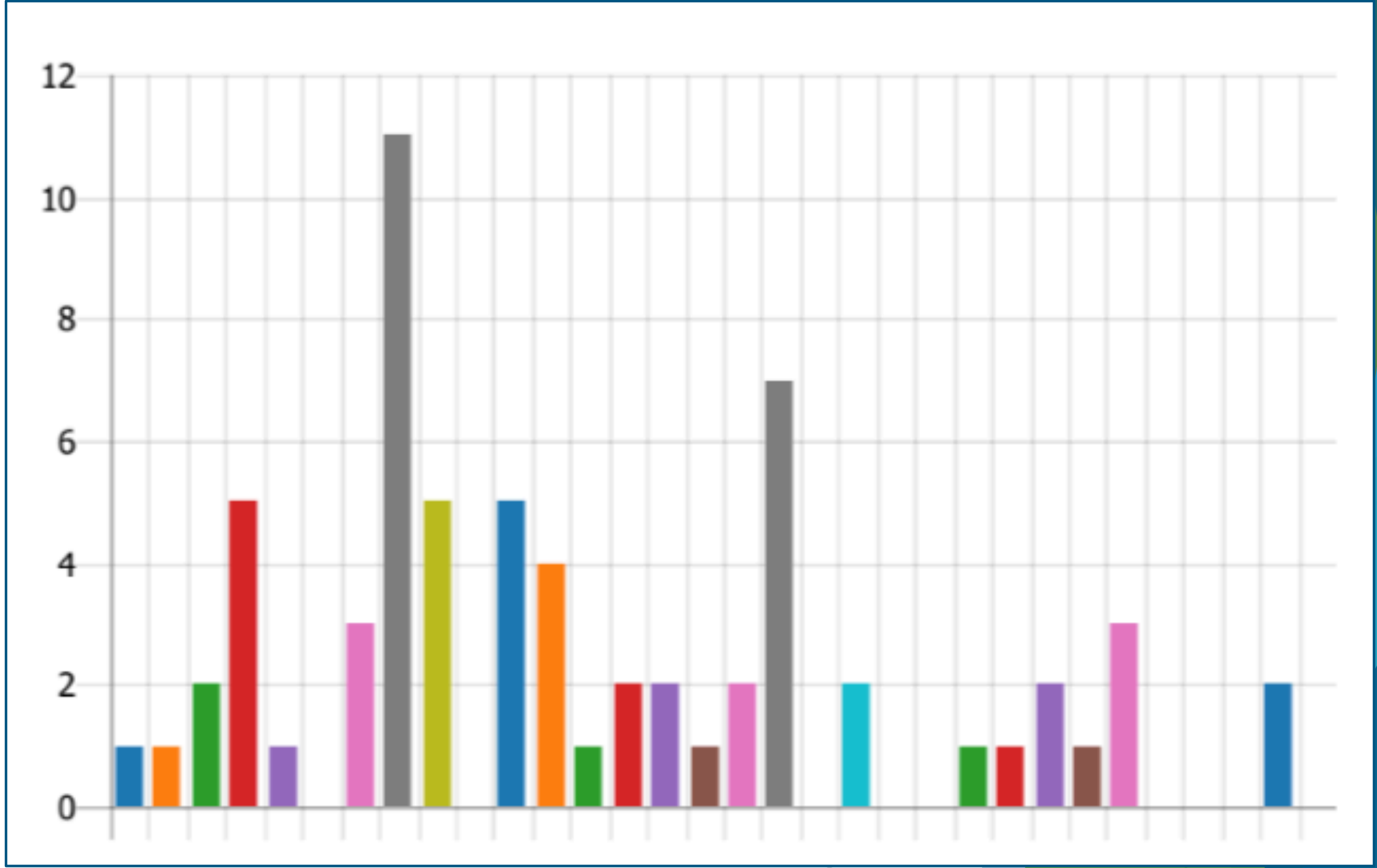
Top Values: Persons living with dementia & Carepartners

- Family
- Love
- Compassion, Friendships, Happiness



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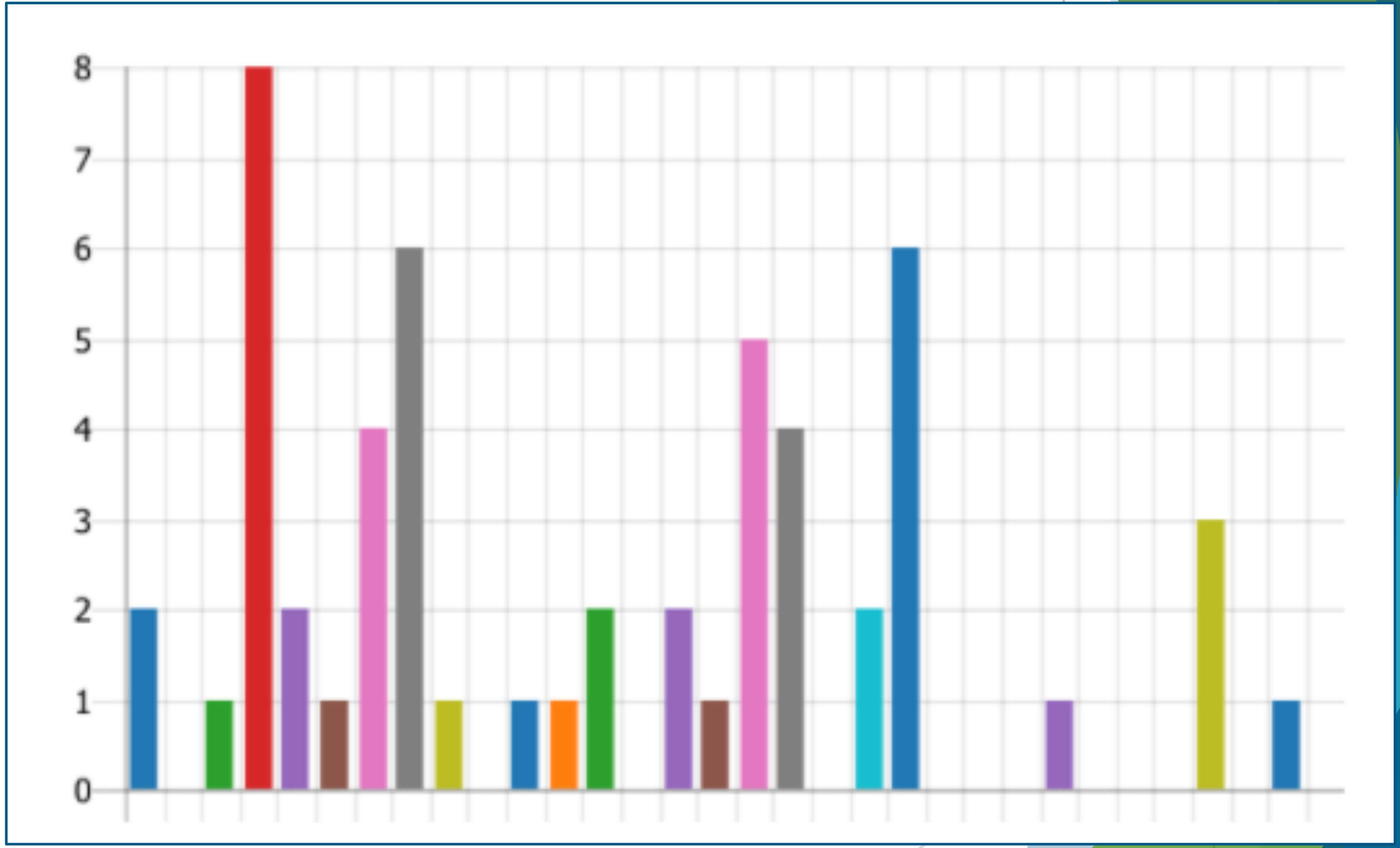
Top Values: Project Team & Researchers

- Compassion
- Family, Meaningful Work
- Learning



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PCORI Engagement Principles

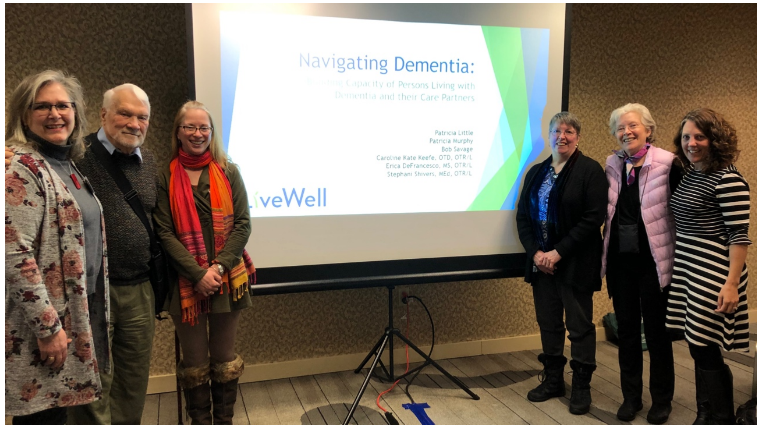
- Reciprocal relationships
- Co-learning
- Partnership
- Transparency, honest, and trust

Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

Creating an Inclusive Environment

- Geri Taylor
- Bob Savage
- Jim Taylor
- Joan Monin



Expectations for Working Together

- Empower the person with dementia to respond first
- Give time for the person living with dementia to respond (20-90 seconds)
- One person should speak at a time
- Be clear
- Project your voice
- Don’t speak too fast

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Thoughts on Empowerment

Identify someone in the group to take notes on people responses.

Take 1-2 minutes to share with your group:

- *Describe something that gives you a sense of purpose.*

Fears & Excitement – Persons living with dementia

FEARS

- 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

EXCITEMENT

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

Fears & Excitement – Researchers

FEARS

- Not knowing how to communicate with persons living well with dementia at various stages of dementia
- Not being able to speak about research in a health literate manner

EXCITEMENT

- Learning about what matters 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

Fears & Excitement – Carepartners

FEARS

- Unintentionally taking over or speaking for my loved one with dementia
- Not knowing my own role in the Empowering Partnerships experience

EXCITEMENT

- Watching my loved be empowered to have a voice and to have that voice be heard, valued, and acted upon
- Learning about the research process and opportunities through which my partner and I can become involved

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Take a break! Introduce yourselves!

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Image by Steve Cliff from Pixabay

Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

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

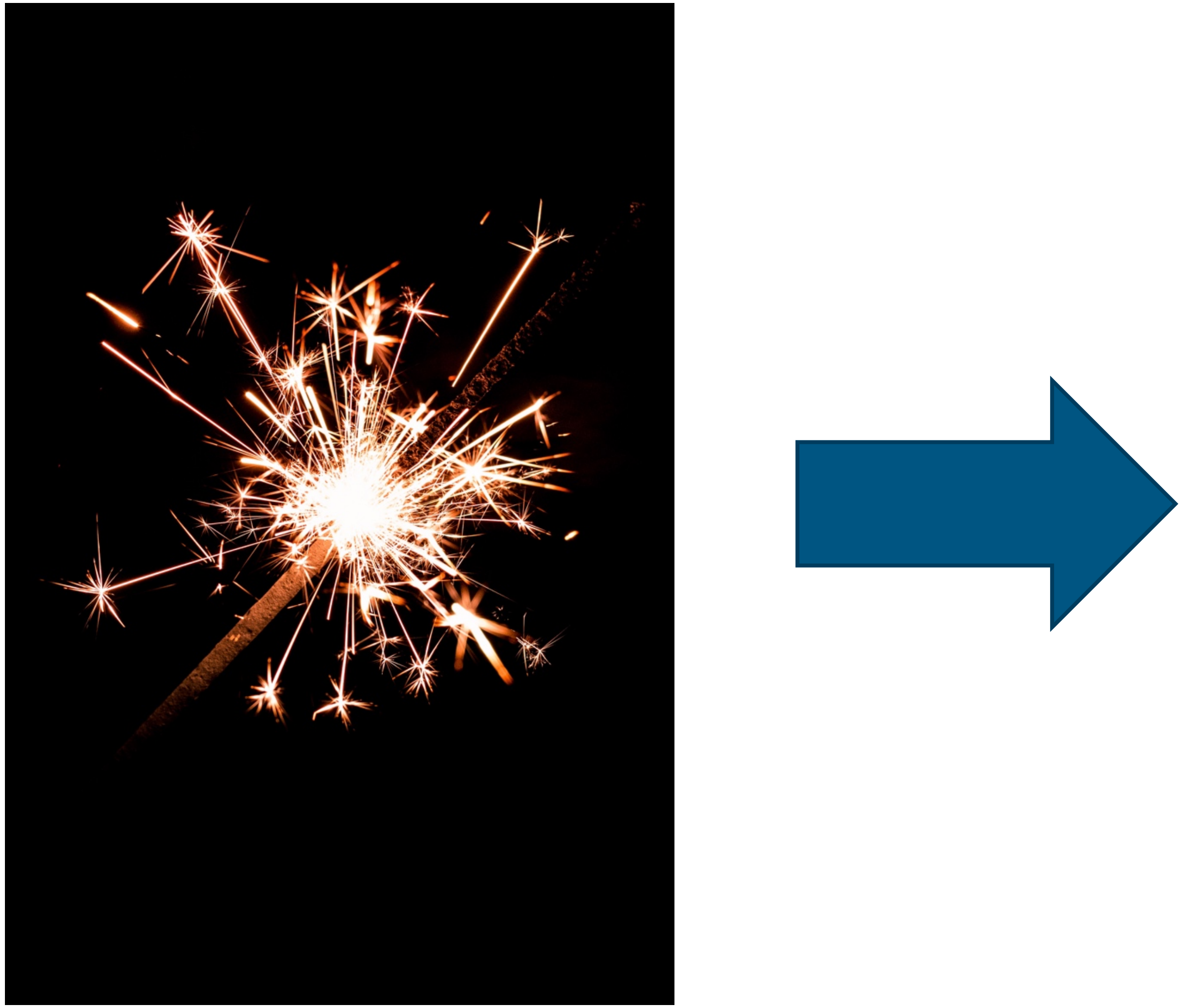
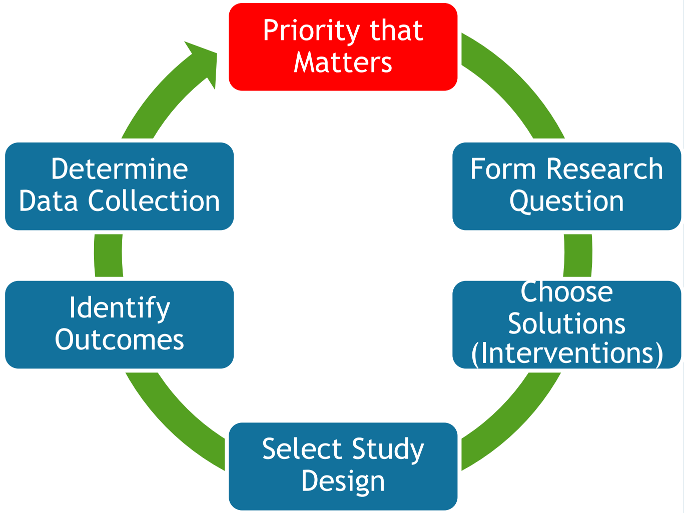


Photo by Jez Timms on Unsplash

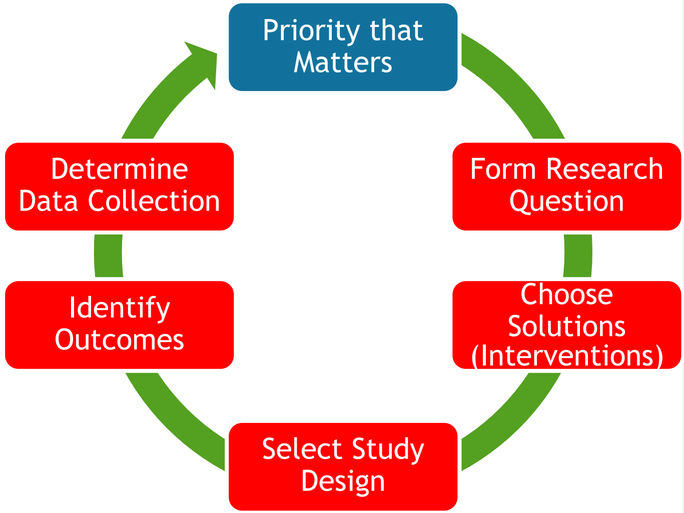
Photo by SpaceX on Unsplash

Learn By Doing: Practicing Partnering



- Reflect and share your priorities – What matters most
- Small group work at tables – Activities in binder. Identify themes/priority areas.
- Come to consensus on 1-3 themes/priorities per table
- Share with large group
- Full group will vote to identify 3 priorities to use to design a study

Day 2: Practicing Partnering



- Join workgroup on priority area of your choosing
- Go through a series of activities to walk through the process of determining and refining a research study idea
- Share study ideas with large group
- Consider personal action steps to get more involved in research

Who is PCORI?

Patient Centered Outcomes Research Institute

https://www.pcori.org

PCORI ® is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continually seeking input from a broad range of stakeholder to guide its work.

Disclaimer

The views and statements presented in this training are solely the responsibility of the project team and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

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PCORI’s Focus: Patient Engagement

What Real Patient Engagement in Research Should Be

Libby Hoy
Founder and CEO
Patient and Family Centered Care Partners

https://www.pcori.org/video/what-real-patient-engagement-research-should-be

RESEARCH PROCESS

1. Ask a question ?
2. Make a detailed plan
3. Gather & analyze data
4. Share results
5. Build knowledge & use results!

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

Health/Care **Interventions**
(non-pharmacological interventions)

Strategy to improve health, well-being or care.

Can be standardized and repeated to get the same effect.

Has positive effect on dementia symptoms or relevant outcomes

Sample Interventions

- Opening Minds through Art (OMA), pg. 33
- Care of Persons in their Environment (COPE), pg. 6
- Timeslips, pg. 39
- Tailored Activities Program, pg. 8
- Tai-Chi, Yoga
- MIND Diet
- FINGER Study

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Understanding Outcomes:

What is impact of intervention? What difference does intervention make?

Increase in positive factors

- Quality of life, function, safety, engagement

Decrease in negative factors

- Hospitalization, Insurance claims, emergency room visits, 911 calls, falls

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Clinical Effectiveness Research

Compares different interventions

<u>Research questions:</u>

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

Clinical Effectiveness Research Example

Which is better?

Professional led support group?

Peer led support group?

What areas of research are important to you? What are your priorities?

Examples: Priorities, Themes, Focus Areas

- Care strategies
- Early diagnosis, Improved diagnosis
- Caregiver support
- End of life issues
- Environmental design in housing
- Long term care needs: institutional or home
- Meaningful engagement
- Managing symptoms, behavioral expressions

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RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

National Research Summit on Care, Services and Supports
for Persons with Dementia and Their Caregivers

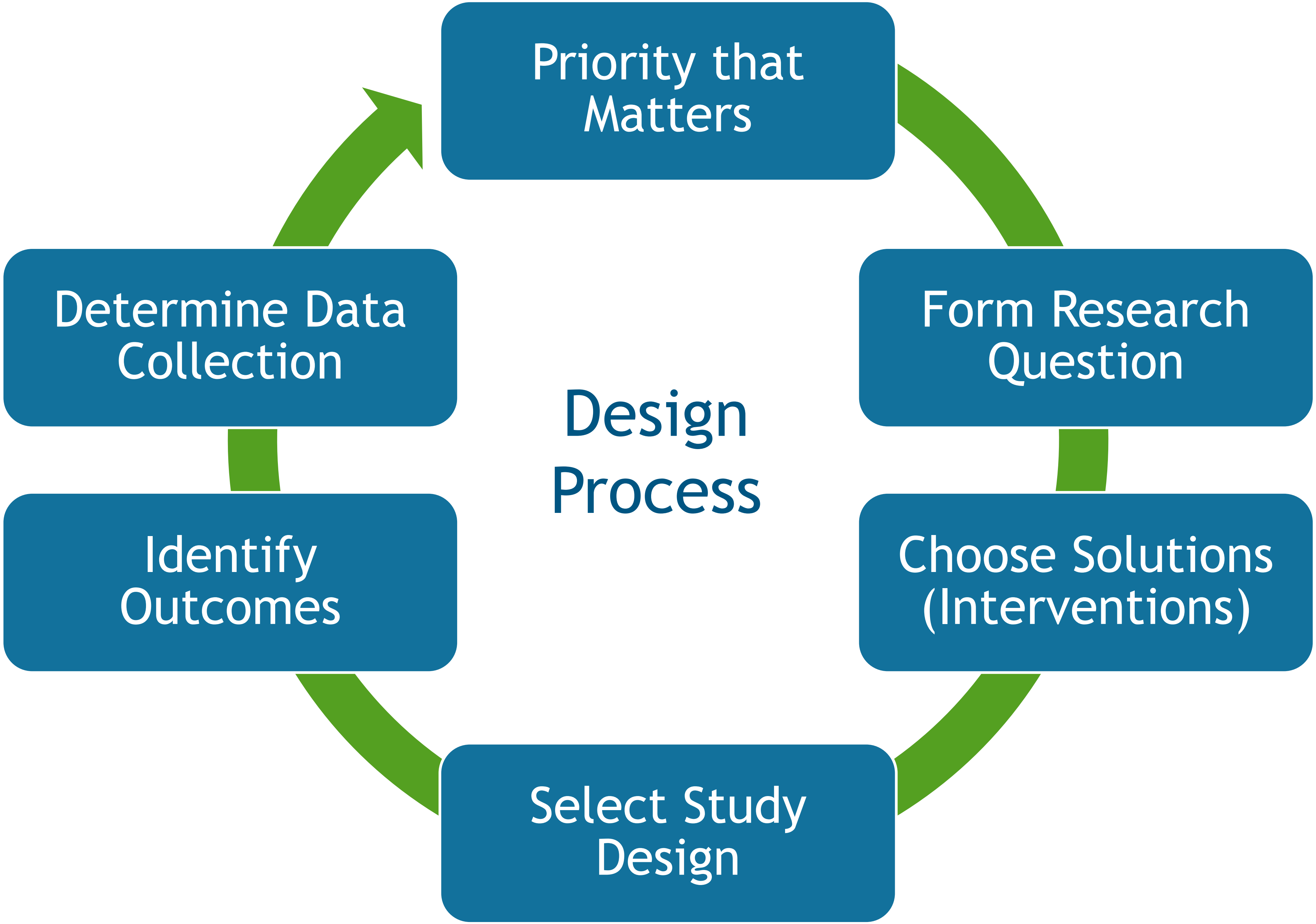
NIH Campus, Natcher Building #45 | 45 Center Drive | Bethesda, Maryland

October 16-17, 2017

Teresa Webb, Co-Chair Persons with Dementia Stakeholder Workgroup

PLWD Stakeholder Workgroup: Research agenda themes

1. Care practices and behavioral strategies to address symptoms, and challenges.
2. Assessment and care planning
3. Culturally sensitive and accessible resources and coordinated care
4. Terminology of “cognitive impairment” or “cognitive disorder” instead of “dementia”
5. Impact of having one general term such as “dementia” or “Alzheimer’s.”
6. Impact of financial burden



Priority that Matters

Form Research Question

Choose Solutions (Interventions)

Select Study Design

Identify Outcomes

Determine Data Collection

Design Process

Criteria for a good study

- Is the topic **significant**?
- Is the study **innovative**?
- Does the study raise any **ethical** issues?
- Is this study **feasible**?

- Is it **fundable**?

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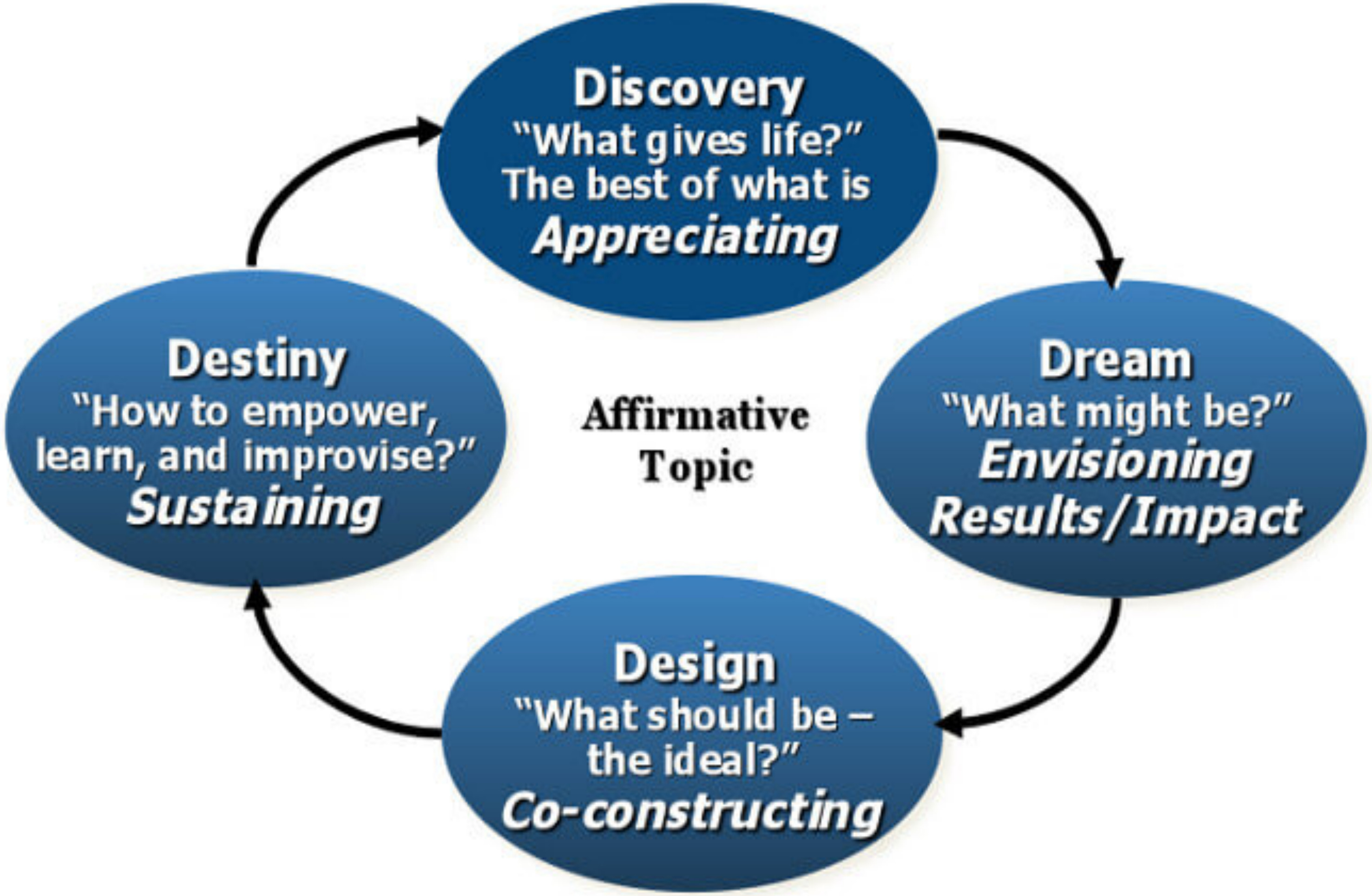
Lunch

Photo by Jennifer Schmidt on Unsplash

Appreciative Inquiry 4-D Framework:



Discovery
"What gives life?"
The best of what is
Appreciating

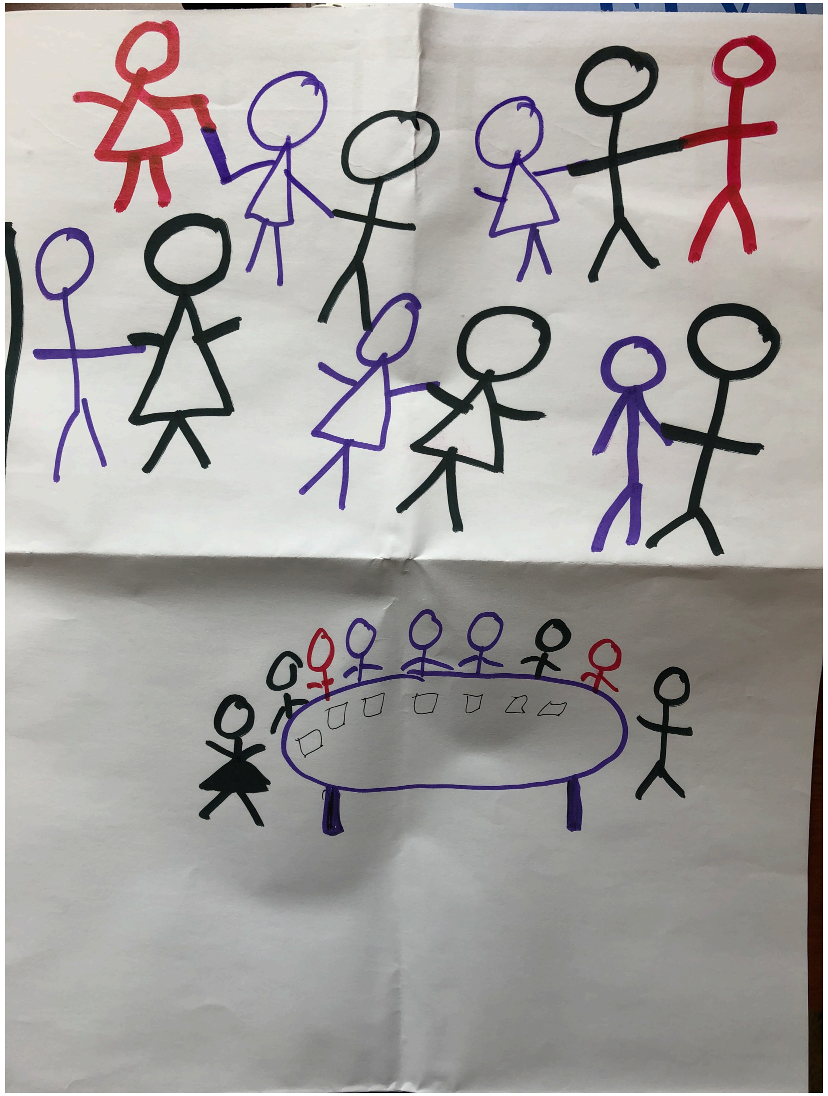
Dream
"What might be?"
Envisioning
Results/Impact

Design
"What should be –
the ideal?"
Co-constructing

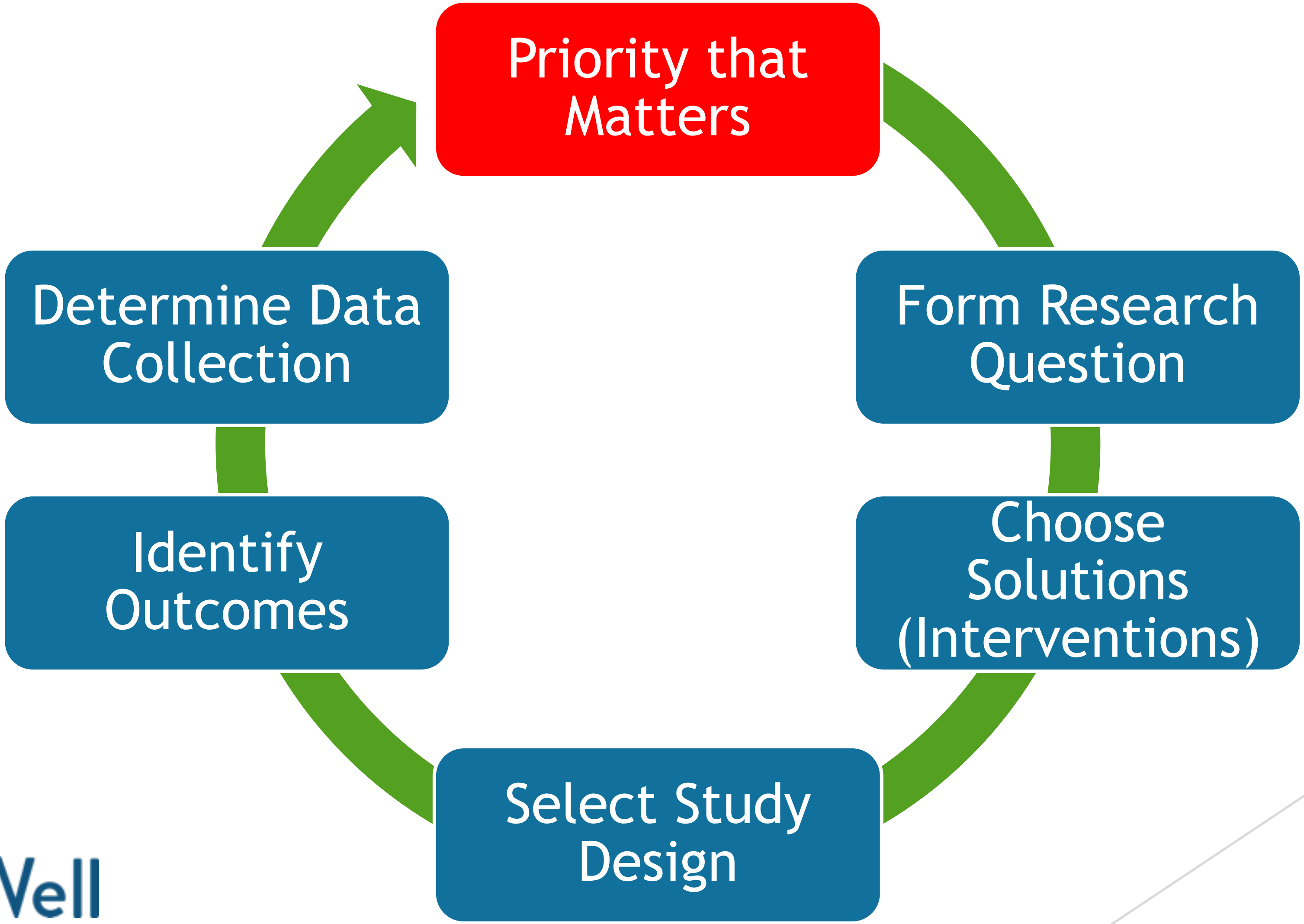
Destiny
"How to empower,
learn, and improvise?"
Sustaining

Affirmative
Topic

Dream Realized – Stephani’s example



Determining Research Priorities: Activity 1



Priority that Matters

Form Research Question

Choose Solutions (Interventions)

Select Study Design

Identify Outcomes

Determine Data Collection

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Determining Research Priorities: Activity 1

Activity Goal – Identify themes, focus areas, priorities that can be researched

- Find questions in your binder. Take 10-15 minutes to think through your answers, jot notes.
- Everyone share their responses with the group (5-6 minutes)
- Choose a scribe to record answers on flipchart

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NIH Stakeholders Research Agenda priorities

1. Psychosocial care practices and behavioral strategies to address neuropsychiatric symptoms including hallucinations, emotional issues (depression, anger), and information processing challenges (i.e. noisy environments) as well as other problematic symptoms such as incontinence and impaired motor control affecting balance and risk for falls.

2. Person-centered approaches to assessment and care planning that thoroughly address the individual preferences and quality of life needs of a person living with dementia.

NIH Stakeholders Research Agenda priorities

3. Resources and models of coordinated care after a diagnosis that are tailored to the person’s culture and language, and accessible regardless of geographic location.

4. Implications for use of the term “cognitive impairment” or “cognitive disorder” instead of “dementia” for persons living with illness, family members and public health.

NIH Stakeholders Research Agenda priorities

5. Implications on advocacy, stigma and reported prevalence rates as a result of consolidating the disease names of all memory disorders under one general term such as “dementia” or “Alzheimer’s.”
6. Implications of financial burden on diagnosis, treatment and research participation.

Priorities that Matter – James Lind

- Survey in 2013 in United Kingdom designed to collect people's questions on the prevention, diagnosis, treatment and care of dementia.
- Over 4000 responses, collated down to 146 questions
- Questions sent to over 250 people living with dementia and caregivers, 36+ organizations, health and social care professionals
- Identified 25 priorities
- Workgroup of PLWD, CPs, professionals determined Top 10 (in your binder)

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Priorities that Matter – Activity 2

Are their additional topics that matter to you for us to consider as priorities for research? What are they?

- Discuss your answers in your small group.
- Scribe to add additional topics to table's list of areas/priorities

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Take a break! Introduce yourselves!

Image by Steve Cliff from Pixabay

Determining Research Priorities: Activity 3: Consensus

Given the experiences you have discussed today, and all the themes/focus areas you have identified on your flipcharts:

- *Identify 3-4 priority areas that you would like the larger group to focus on for our remaining training exercises.*

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Draw your priorities

Photo by Taru Huhkio on Unsplash

Share your priorities

5-6 minutes each group

Photo by Júnior Ferreira on Unsplash

Vote & Network

Meet new people

Identify potential collaborators

Discuss insights from the day.

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Join a workgroup

Choose your 1st and 2nd choice

Photo by Nicholas Swanson on Unsplash

Empowering Partnerships

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New Beginnings

Share at your tables – 1 minute each

What was your time like yesterday?
What makes you excited? Feel useful?
What was meaningful?

Meeting Expectations?

How are we doing with the expectations we established yesterday for working together? Anything to add?

What expectation or strategy that we have spoke about yesterday morning did you use?

What’s Next? How can you get involved?

- Participants
- Knowledge Users and Experiencers
- Reviewers, Interviewers, and Consultants
- Governance and Advisory Groups
- Research Partners or Team Members
- Co-Investigators or Investigators

DPC – *REACH*

Research, Education, Advocacy, Community Happenings

- Bi-Monthly Meeting: 1st Friday November, January, March, May, July, September, 11:00-12:30 pm LiveWell, 1261 S. Main St. Plantsville, CT and via Zoom
- Focuses on opportunities in:
  - Research
  - Community Education & Public Awareness
  - Advocacy
  - Social Events – upcoming memory cafes, etc.

DEMENTIA PEER

COALITION

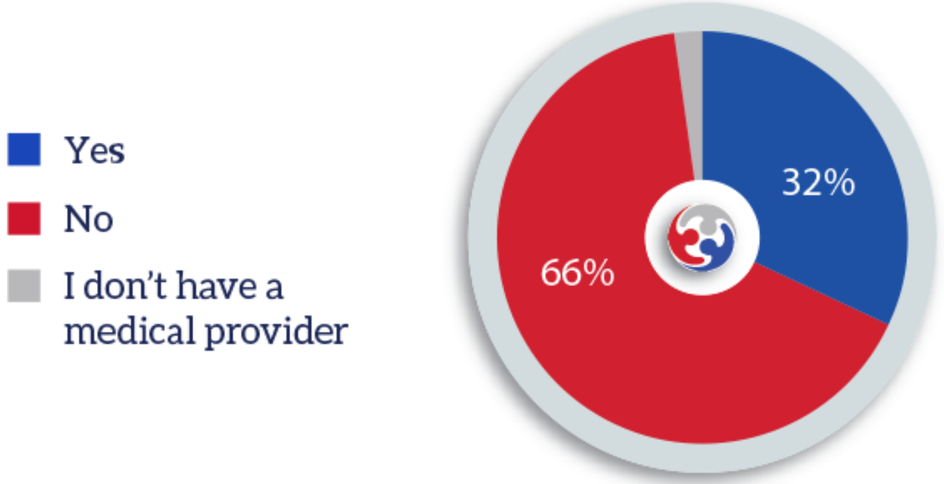
CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The **A-LIST** is a growing cohort of more than 6,000 individuals living with Alzheimer's or other dementias and caregivers, who believe it is time for researchers, regulators and payers to understand "What Matters Most" to them

A-LIST

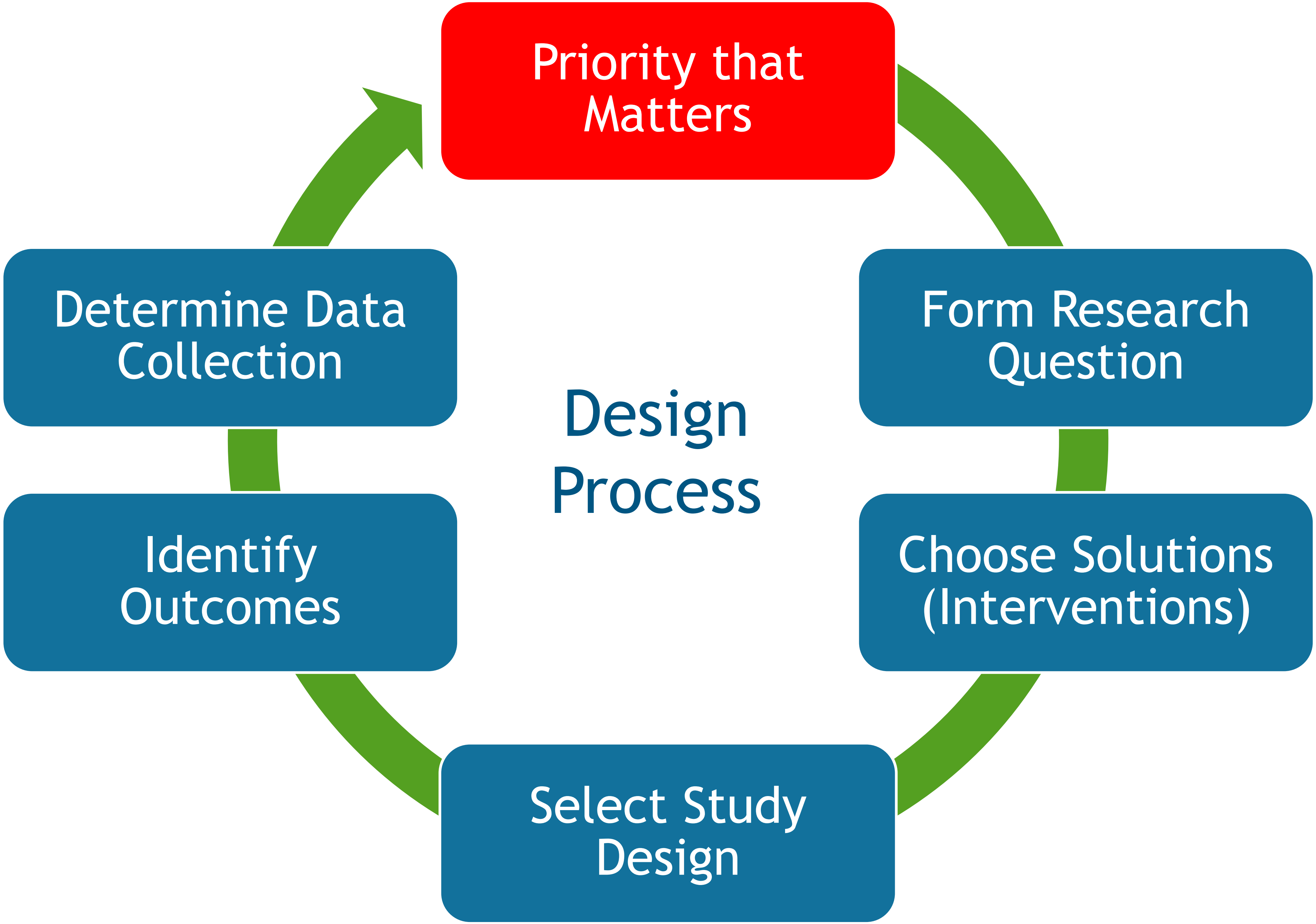
Patients and families
transforming Alzheimer's research

HAVE YOU HAD A DISCUSSION WITH YOUR MEDICAL PROVIDER ABOUT EARLY ASSESSMENT OF COGNITIVE IMPAIRMENT?



KEY FINDINGS:

- Approximately two-thirds (66%) of **A-LIST** respondents have not discussed early cognitive assessment with a medical provider



Design Process

Priority that Matters

Form Research Question

Choose Solutions (Interventions)

Select Study Design

Identify Outcomes

Determine Data Collection

Understanding the Research Enterprise

- Is the topic **significant**?
- Is the study **innovative**?
- Does the study raise any **ethical** issues?
- Is this study **feasible**?

- Is it **fundable**?
- Is it **researchable**?

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Health/Care **Interventions** (non-pharmacological interventions)

Strategy to improve health, well-being or care.

Can be standardized and repeated to get the same effect.

Has positive effect on dementia symptoms or relevant outcomes

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Resource Binders

UsAgainstAlzheimer's

Non-Pharmacological Therapies in Alzheimer's disease: A Systematic Review

INTRODUCTION

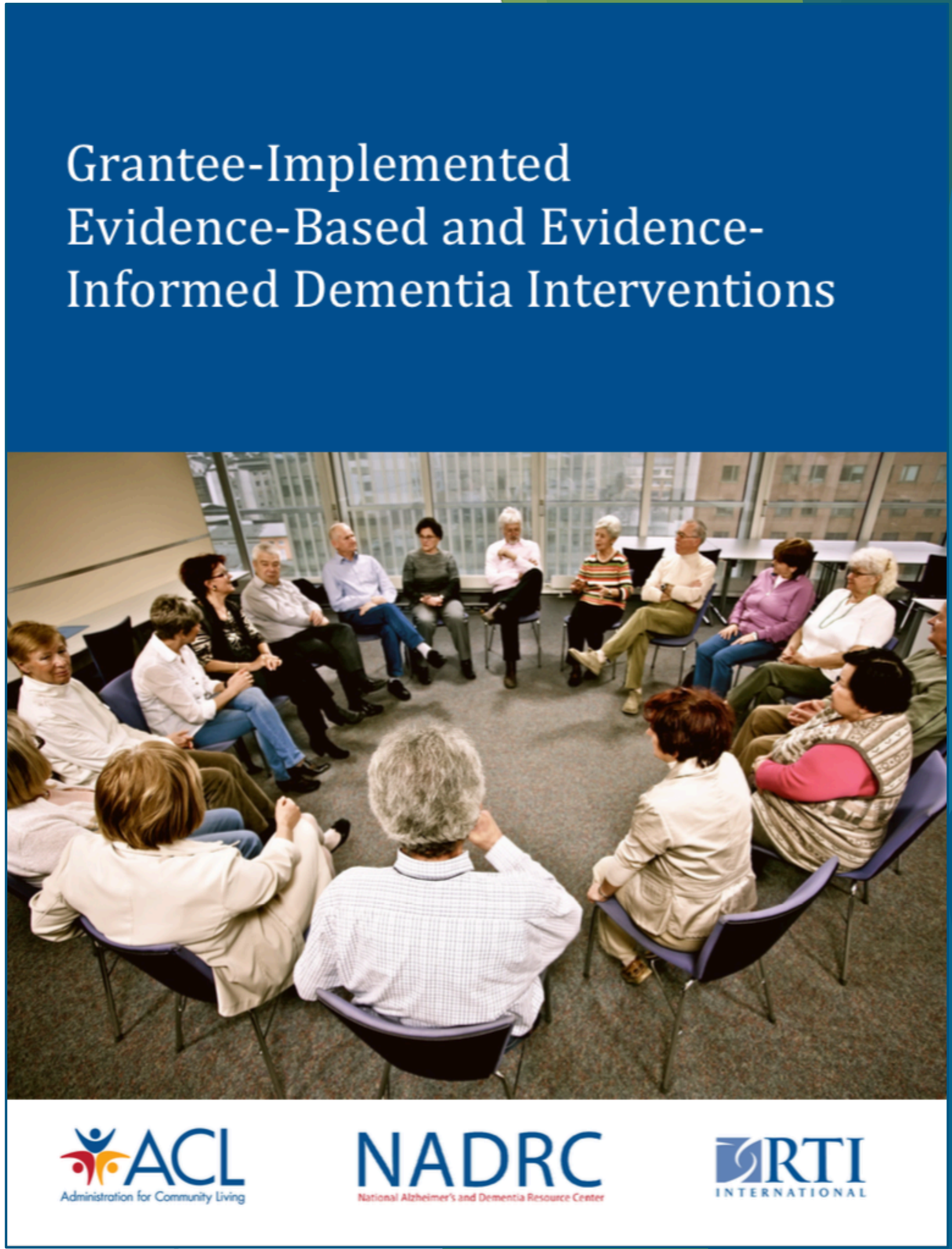
Alzheimer's disease (**AD**) is a degenerative neurological illness that is one of the most common causes of dementia and elderly disability in the United States. Recent reports suggest that, in 2018, almost 6 million Americans were living with AD. This figure is expected to increase to 14 million by 2050. AD is characterized by impaired short-term memory, altered communication, confusion, and behavioral changes. AD pathogenesis begins as much as two decades before overt symptoms appear. Early clinical evidence of cognitive decline without gross behavioral and/or physical dysfunction is diagnosed as Mild Cognitive Impairment (**MCI**). Later stages of dyscognition, neuropsychiatric symptoms, and loss of functional capacity is diagnosed as AD. Thus, MCI and AD are clinical stages within a spectrum of severity that encompass age-associated cognitive loss and functional decline.

Despite the tremendous financial investment into AD therapeutic discovery protocols, there are no known cures and there has not been a novel drug for AD introduced in about 15 years. The current crop of FDA approved drugs are limited to symptomatic relief and are not approved to treat the underlying disease process. In addition, recent late-stage Alzheimer's clinical trials have consistently produced negative results. This has led clinicians, researchers, and stakeholders to shift their focus towards interventional outcomes that aim to prevent or slow the progression of the disease earlier in the patient's lifespan. The growing number of diagnosed patients and subsequent economic burden makes AD one of the most pressing health and financial issues of our time.

The current dearth of pharmacological drug options highlights the need for additional prevention strategies and a robust evaluation of non-pharmacological treatments. In this report, we conducted an extensive search of non-pharmacological treatments assessed in AD, MCI, and normal aging. We identified 314 studies that met our inclusion criteria and subsequently organized them into various classifications.

We reviewed each therapy and identified important factors including market availability, stage of aging targeted, and expected post-treatment clinical outcomes, among others. We included published and peer-reviewed non-pharmacological therapies. General study categories included: pre-clinical (in-vitro and in-vivo), epidemiological/observational studies, active or completed non-randomized or randomized controlled trials (**RCT**), systematic/clinical reviews, and meta-analyses. To provide a measure of the quality and quantity of each non-pharmacological intervention, each therapy was rated on an ascending five-point scale known as the Level of Evidence (**LOE**) score. We did not conduct a meta-analysis for this specific review due to the extensive heterogeneity found among studies.

This report is not intended to assess the clinical meaningfulness or endorse any of the interventions discussed within it. Rather, the aim is to take stock of the most current literature on non-pharmacological therapies and identify potential opportunities for future research. In this report, we identified notable treatments (covered in detail within the "Case Studies" section), highlighted gaps in minority recruitment, and point to opportunities to bolster research efforts in low- and middle-income countries. In summary, this report builds upon previous findings by attempting to provide an up-to-date analysis of the current non-pharmacological research landscape and offer recommendations for future initiatives in Alzheimer's research.



Grantee-Implemented Evidence-Based and Evidence-Informed Dementia Interventions

ACL
Administration for Community Living

NADRC
National Alzheimer's and Dementia Resource Center

RTI
INTERNATIONAL

Understanding Outcomes:

What is the result or impact of the strategy or intervention? What difference does intervention make?

Increase in positive factors

- Quality of life, function, safety, engagement

Decrease in negative factors

- Hospitalization, Insurance claims, emergency room visits, 911 calls, falls

The Economic Impact of Dementia[4]

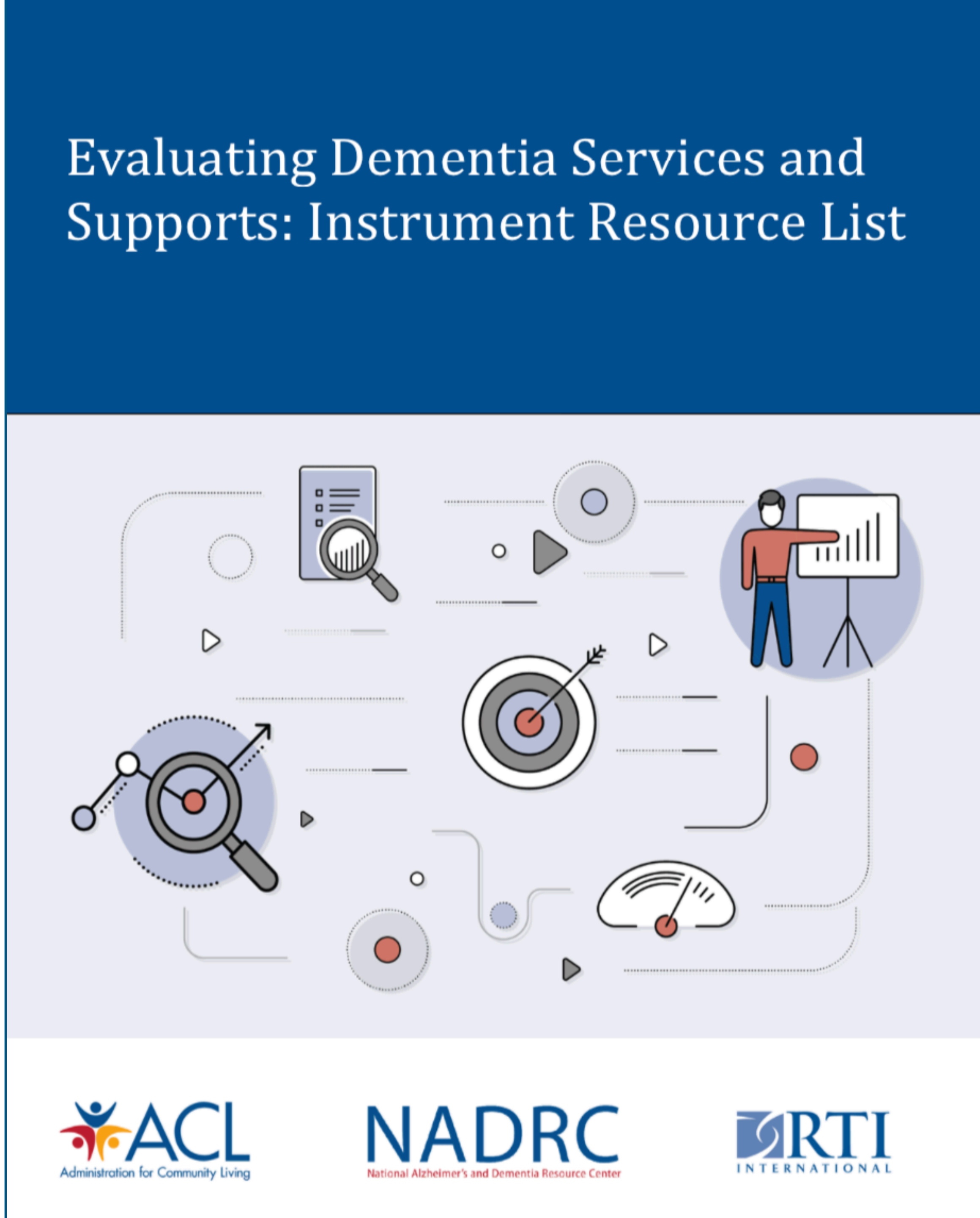
Source	Individuals Without Alzheimer's or other dementias	Individuals With Alzheimer's or other dementias
Medicaid	$358	$8,399
Inpatient Hospital	$3,509	$10,862
Nursing Home	$749	$15,463
Skills Nursing Facility	$462	$6,750
Hospice	$153	$2,017
Home Health Care	$367	$2,525
Medicare	$7,415	$24,122
Medical Provider	$3,569	$5,792
Prescription Medication	$2947	$3,436

[4] Average Annual Per-Person Payments for Health Care & Long-Term Care Services Provided to Medicare Beneficiaries Age 65 or Older, with and without Alzheimer's or Other Dementias in 2017 Dollars. Alzheimer's Facts and Figures 2017

Outcomes Measures

- Activities of Daily Living
- Attitudes
- Behavioral Symptoms
- Caregiver Competence, Stress
- Cognitive Functioning
- Coping
- Depression, Anxiety
- Falls
- Health
- Knowledge of dementia
- Quality of Life
- Safety
- Self-efficacy
- Social Functioning
- Stigma
- Stress
- Unmet needs

Resource Binders



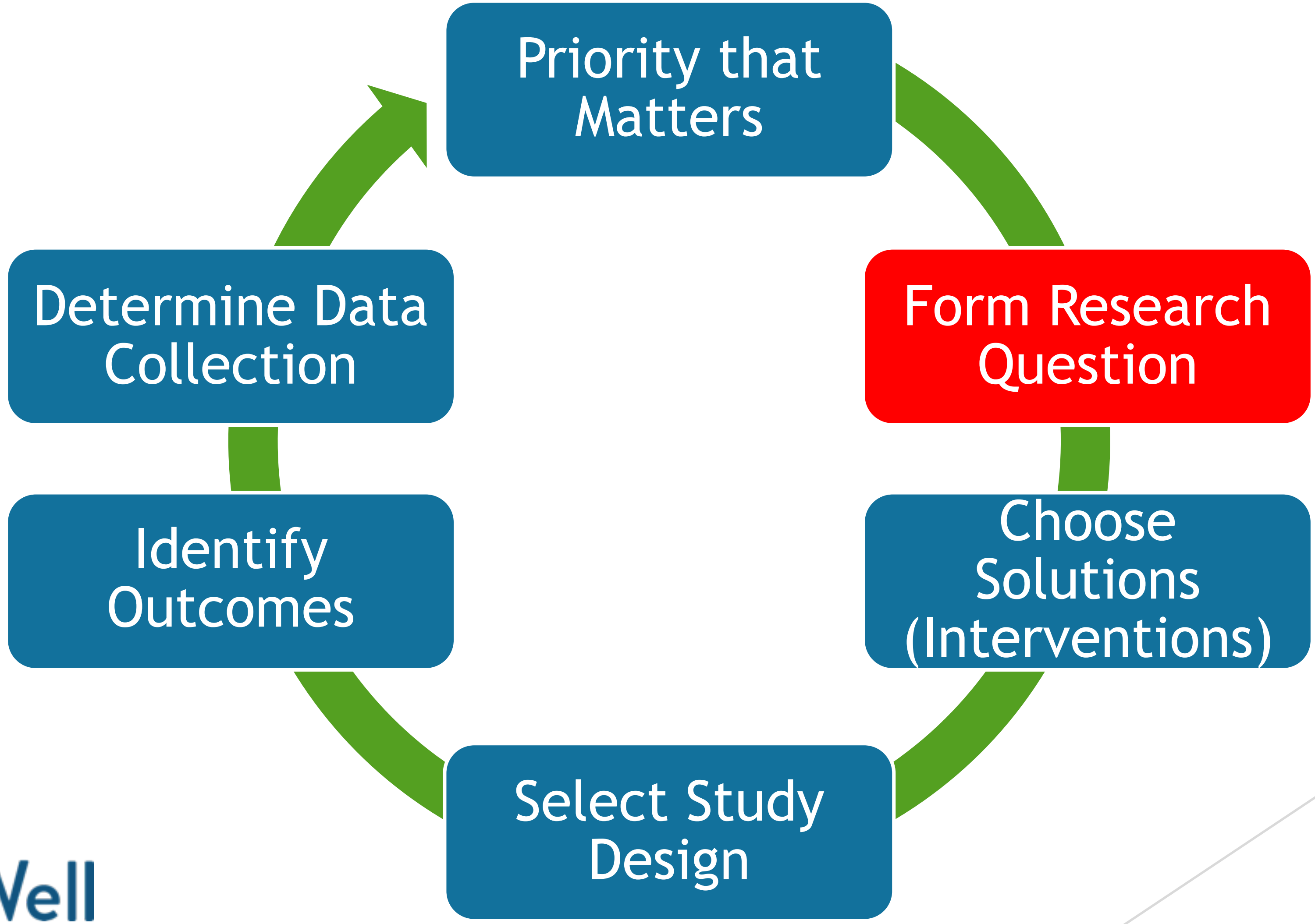
Evaluating Dementia Services and Supports: Instrument Resource List

ACL Administration for Community Living

NADRC National Alzheimer's and Dementia Resource Center

RTI INTERNATIONAL

Determining a Good Research Question



Priority that Matters

Form Research Question

Choose Solutions (Interventions)

Select Study Design

Identify Outcomes

Determine Data Collection

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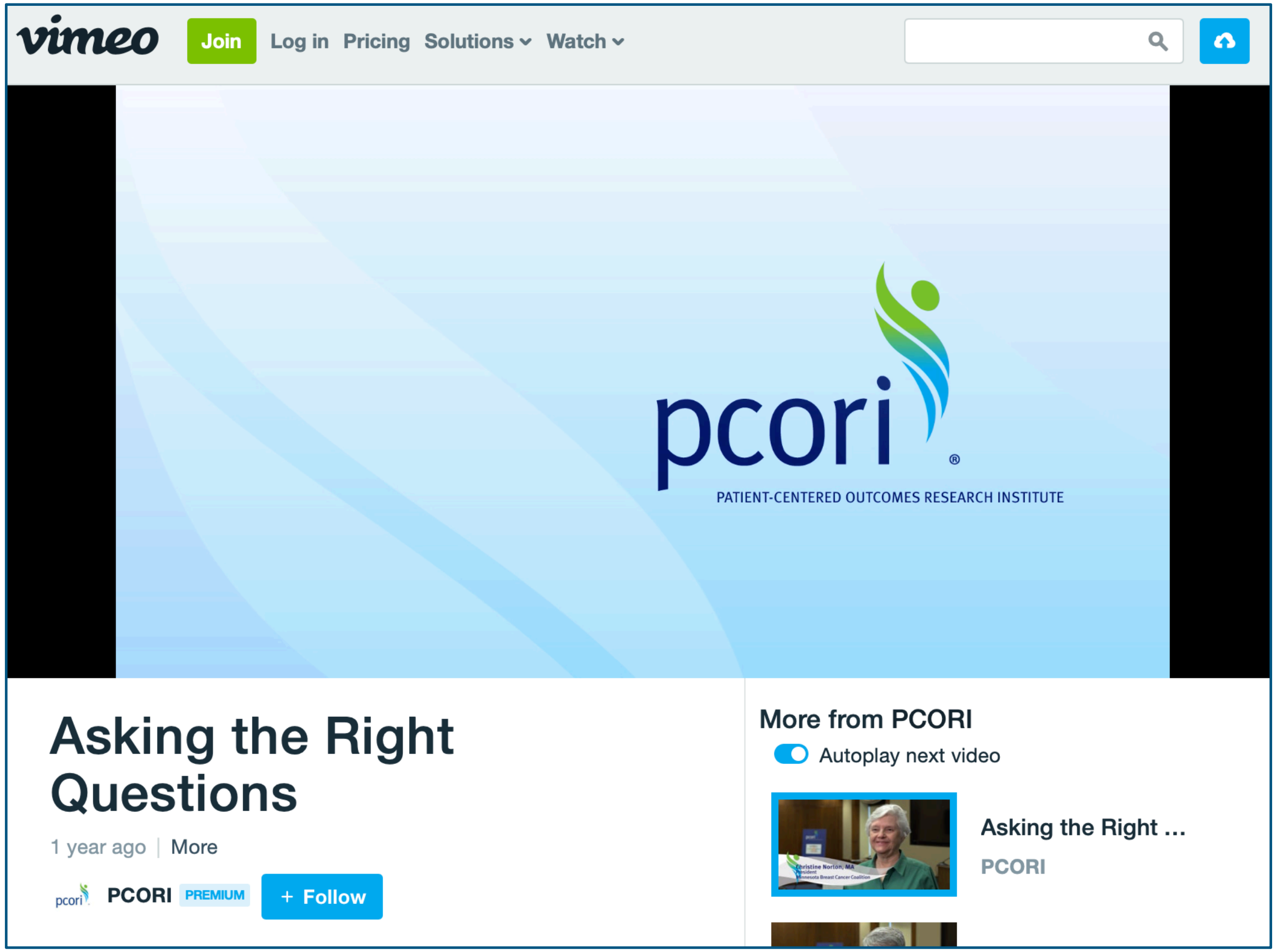
Asking the Right Questions



Asking the Right Questions

1 year ago | More

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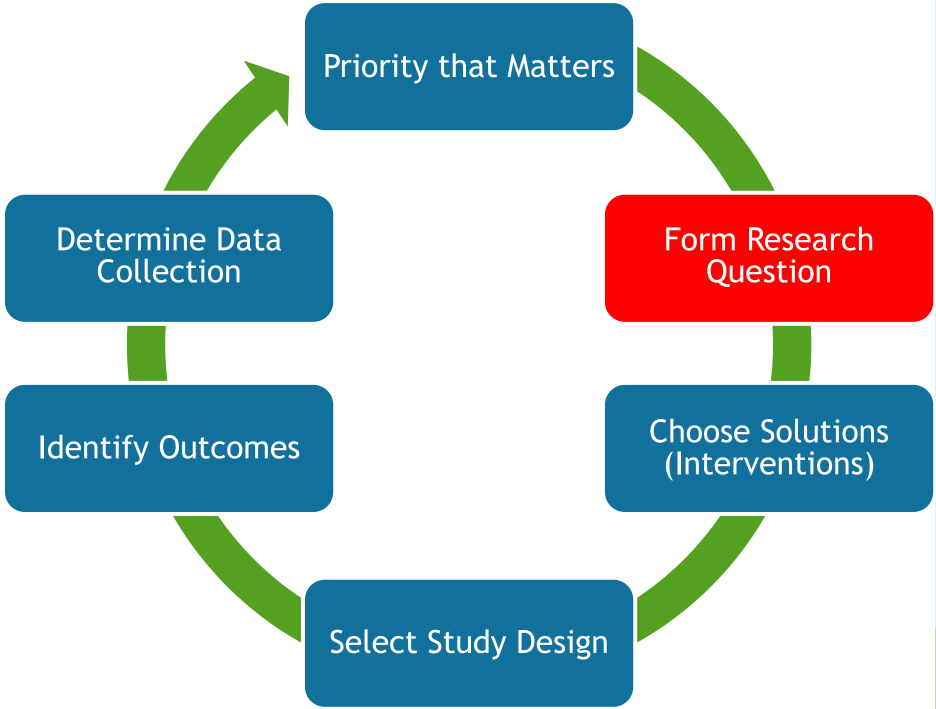
Asking the Right ...

PCORI

https://vimeo.com/260438480

Determining a Good Research Question: Activity 1

- Find your activity worksheet in your binder
- Work together to answer the questions
- Identify a scribe to take notes for the group on the flipchart
- 60 minutes


Priority that Matters

Form Research Question

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Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

Lunch

Photo by Jennifer Schmidt on Unsplash

Introduction to Clinical Trials

- Jim Taylor
- Geri Taylor
- Susan Good

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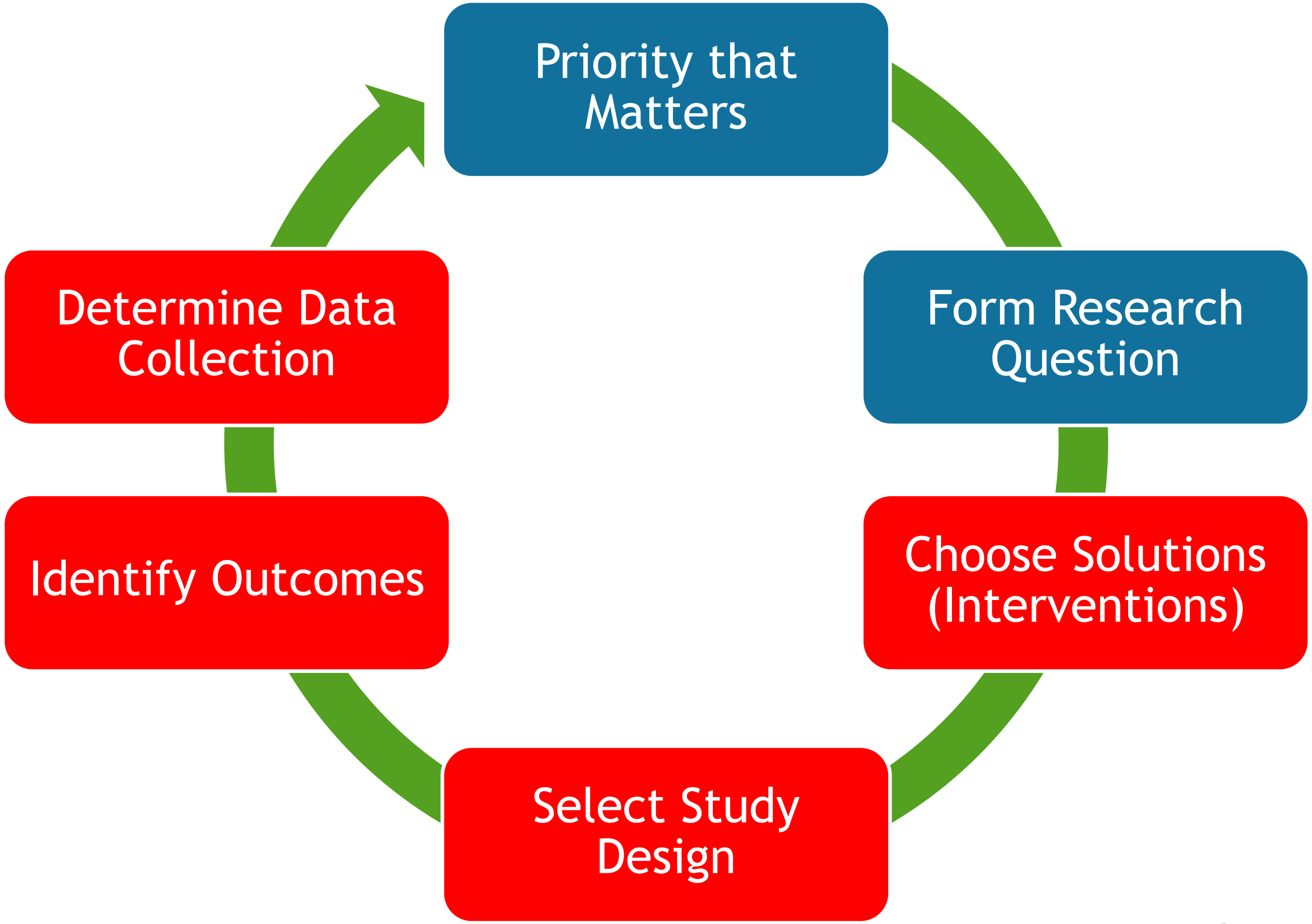
Refining the Study – 15 minute activities



Priority that Matters

Form Research Question

Choose Solutions (Interventions)

Select Study Design

Identify Outcomes

Determine Data Collection

NIH & PCORI Review Criteria

- Is the topic **significant**?
- Is the study **innovative**?
- Does the study raise any **ethical** issues?
- Is this study **feasible**?

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Share your projects

5-6 minutes each group

Photo by Júnior Ferreira on Unsplash

Next Steps

- Personal Action Plan
  - How can you get involved?
  - Write note to yourself with one action step.
  - Share your commitments
- Sign up for future projects
- Complete evaluation before leaving

With great thanks to…

- Geri & Jim Taylor
- Bob Savage
- Charles Michalak
- Pat Murphy
- Teresa Webb
- Erica DeFrancesco
- Dan Belonick
- Brian Connolly
- Patty Richards
- Michael Smith

- Anne Kenny
- Maria O'Connell
- Joan Monin
- Susan Good
- Rick Fortinsky
- Kate Keefe

- Advisory Council
- Action Teams
- Leading Age CT

Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

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Thank you!!

Heidi Gil
Project Lead
Heidi@hoodenpylegil.com
203-305-5735

Stephani Shivers
Project Co-Lead
sshivers@livewell.org
860-628-3020