Partnering with People Living with Dementia and Care Partners in Embedded Pragmatic Clinical Trials
Housekeeping

• All participants will be muted

• Enter all questions in the Zoom Q&A/chat box and send to All Panelists and Attendees

• Moderator will review questions from chat box and ask them at the end

• Want to continue the discussion? Associated podcast released about 2 weeks after Grand Rounds

• Visit impactcollaboratory.org

• Follow us on Twitter & LinkedIn:
  
  @IMPACTcollab1
  
  https://www.linkedin.com/company/65346172
Learning Objectives

Upon completion of this Grand Rounds, you should be able to:

• Understand the need/benefits of engaging persons living with dementia and care partners in every aspect of dementia care research

• Identify how all stakeholders can be empowered and engaged as co-partners in research

• Explore lessons learned and resources available to conduct research differently

• Discover the value of skilled stakeholder engagement support and facilitation
Focus on Collaboration:
Including people with lived experiences as partners in research.

Gary Epstein-Lubow, MD
Associate Professor of Psychiatry and Human Behavior
Associate Professor of Medical Science, Alpert Medical School of Brown University
Associate Professor of Health Services, Policy and Practice, Brown University School of Public Health
In Memoriam...

Robert E. Lubow, MD
11/29/1939 – 11/19/2021
Contributions of Persons Living with Dementia to Scientific Research Meetings

- Invite Participation
- Develop Communication
- Establish Shared Goals
- Confirm Deliverable Products

- Contributions of Persons Living With Dementia to Scientific Research Meetings. Results From the National Research Summit on Care, Services, and Supports for Persons With Dementia and Their Caregivers

- The Experiences of Persons Living with Dementia Planning for a Dementia Research Meeting. Lessons Learned From the National Research Summit on Care, Services, and Supports for Persons With Dementia and Their Caregivers


- Amer J Geriatric Psychiatry. 2020 April

2017 National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers

https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-additional-information/napa-caregiver-summit/2017-national-caregiver-summit
Stakeholder Engagement Team

- Jill Harrison
- Linda Elam
- Laurie Herndon
- Katie Maslow
- Brenda Nicholson
- Ellen Tambor

- **Guides and, supports investigators** conducting ePCTs among people living with dementia and their care partners in stakeholder engagement activities.

- **Develops and disseminates guidance and training materials** about engaging stakeholders in the conduct of ePCTs among people living with dementia and their care partners with health care systems.

- **Convenes a Stakeholder Advisory Committee** that advises the IMPACT Collaboratory about stakeholder engagement activities, strategies to assist investigators with stakeholder engagement, and priority topics for the development of guidance materials.
<table>
<thead>
<tr>
<th>Name</th>
<th>Type</th>
<th>Country</th>
<th>Year</th>
<th>Organization</th>
<th>Main Ideas</th>
<th>Main Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>A map of resources for co-producing research in health and social care, Version 1.2</td>
<td>Guidance</td>
<td>UK</td>
<td>2020</td>
<td>National Institute for Health Research</td>
<td>• A guide for researchers, members of the public and</td>
<td>Evaluation, Dissemination, During COVID-19 Pandemic</td>
</tr>
<tr>
<td>A Researcher’s Guide to Patient and Public Involvement</td>
<td>Guidance</td>
<td>UK</td>
<td>2020</td>
<td>NIHR Oxford Biomedical Research Centre</td>
<td>• Comprehensive guide to PPI for researchers</td>
<td>Dissemination, Evaluation, Developing Research Questions, Stakeholder Recruitment, Training, Study Design</td>
</tr>
<tr>
<td>Appendix 2: Patient Engagement Monitoring and Evaluation Framework</td>
<td>Framework</td>
<td>Based in European Union</td>
<td>2021</td>
<td>PARADIGM (Patients Active in Research and Dialogue) Framework</td>
<td>• This excel file consist of three sheets: 1) framework</td>
<td>Evaluation</td>
</tr>
<tr>
<td>Best video conferencing apps and software for accessibility</td>
<td>Webpage</td>
<td></td>
<td>2020</td>
<td>The Big Hack and Business Dialogue Forum</td>
<td>• Alphabetical list of the most commonly used apps</td>
<td>Virtual Engagement</td>
</tr>
<tr>
<td>Briefing notes for researchers - public involvement in NHS, health and social care research</td>
<td>Guidance</td>
<td>UK</td>
<td>2021</td>
<td>National Institute for Health Research</td>
<td>• This guidance is for researchers new to public ...</td>
<td>Stakeholder Recruitment, Evaluation</td>
</tr>
<tr>
<td>Dementia Peer Coalition</td>
<td>Website</td>
<td>USA</td>
<td></td>
<td>Dementia Peer Coalition</td>
<td>• The DPC is a group of people living well with the changes</td>
<td>Working w/ PLWD</td>
</tr>
<tr>
<td>Different experiences: A framework for considering who might be involved in research</td>
<td>Guidance</td>
<td>UK</td>
<td></td>
<td>INVOLVE (a national advisory group), National ...</td>
<td>Key guidance:  • Be clear about the purpose of ...</td>
<td>Stakeholder Recruitment</td>
</tr>
<tr>
<td>EMPOWERING PARTNERSHIPS PROJECT TOOLKIT RESOURCES</td>
<td>Toolkit</td>
<td>USA</td>
<td></td>
<td>Live Well</td>
<td>• Toolkit offers information and resources from all phases of ...</td>
<td>Working w/ PLWD, Engagement Activities</td>
</tr>
<tr>
<td>Ensuring Your Trial Is Designed for All Who Could Benefit</td>
<td>Worksheet</td>
<td>UK</td>
<td></td>
<td>National Institute for Health Research</td>
<td>• The key questions are designed to prompt trial</td>
<td>Health Equity, Challenges, Stakeholder Recruitment, Consent Process</td>
</tr>
<tr>
<td>Evaluating public involvement in research</td>
<td>Guidance</td>
<td>UK</td>
<td>2018</td>
<td>University of the West of England (UWE) Bristol</td>
<td>• This guidance is for researchers, and it discusses</td>
<td>Evaluation</td>
</tr>
<tr>
<td>Evaluation: Practical Guidelines A guide for evaluating public engagement activities</td>
<td>Guidance</td>
<td>UK</td>
<td></td>
<td>National Co-ordinating Centre for Public ...</td>
<td>• This guide is for researchers seeking to engage general</td>
<td>Evaluation, Consent Process</td>
</tr>
<tr>
<td>Guidance on co-producing a research project</td>
<td>Guidance</td>
<td>UK</td>
<td>2021</td>
<td>National Institute for Health Research</td>
<td>• Explains what co-producing a research project means</td>
<td>Principles, Challenges</td>
</tr>
<tr>
<td>How do I hold a PPI meeting using virtual tools?</td>
<td>Webpage</td>
<td>UK</td>
<td>2020</td>
<td>NIHR School for Primary Care Research</td>
<td>• 12 tips and tricks for researchers on holding virtu...</td>
<td>Virtual Engagement</td>
</tr>
<tr>
<td>How to evaluate public engagement projects and programmes</td>
<td>Guidance</td>
<td>UK</td>
<td>2017</td>
<td>National Co-ordinating Centre for Public ...</td>
<td>• Shares some of the ways people have used evaluation</td>
<td>Evaluation, Reporting</td>
</tr>
<tr>
<td>Online Engagement: A guide to creating and running virtual meetings and events</td>
<td>Guidance</td>
<td>UK</td>
<td></td>
<td>National Co-ordinating Centre for Public ...</td>
<td>• This guide focuses on designing and delivering</td>
<td>Planning, Virtual Engagement</td>
</tr>
<tr>
<td>Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive participation</td>
<td>Report</td>
<td>Based in Europe</td>
<td>2019</td>
<td>Alzheimer Europe</td>
<td>• Discusses ethical challenges linked to 7) public ...</td>
<td>Stakeholder Recruitment, Consent Process</td>
</tr>
</tbody>
</table>
About the Stakeholders

Brenda Nicholson, MD (pictured left), and Louise Phillips, MD, MBA (pictured right), are retired physicians who are living with dementia. Both have participated as stakeholder advisors and research partners for important research-related initiatives on dementia care and services. Currently, they are members of the Executive Committee for the Stakeholder Engagement Team in the National Institute on Aging’s IMPACT Collaboratory.
Lived Experience Panel

Meet the 2021 Panelists

2021 Lived Experience Panel

• 4 people with diagnosis of dementia
• 3 care partners
• 4 care partners representing people with advanced disease

• Areas of Focus:
- Identification of research topics
- Selection of outcomes measures
- Considerations about study design

NIA IMPACT COLLABORATORY
TRANSFORMING DEMENTIA CARE
Empowering Partnerships: Fueling the Research Enterprise with Shared Purpose and Hope

Heidi Gil
Chief Strategy Officer, LiveWell Alliance, Inc.
Lead transformation in self and society by re-imagining and changing how we age

Pioneer services and experiences that empower people impacted by dementia

Advance thought leadership, education, research, and advocacy to transform how we age
Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

A Eugene Washington PCORI Engagement Award

LiveWell
Overall Goal:

*Enhance participation and engagement of people living with dementia in all aspects of research through the training of people with dementia, care partners and researchers*

Specific aims:

1) Expand and strengthen a peer network of individuals living with dementia
2) Offer a training workshop on research concepts, methods, and participation as co-researchers
3) Create and prioritize a list of research topics
4) Produce and disseminate an Implementation Toolkit for project replication
The Empowering Partnerships Two-Day Training Experience: An Appreciative Inquiry Summit

Participants Identified and Co-Designed Research Priorities and Projects:

- 12 Persons Living with Dementia
- 9 Care Partners
- 15 Researchers
  - Albertus Magnus
  - Brown University
  - Georgia Tech
  - Quinnipiac University
  - University of Connecticut
  - University of Massachusetts
  - Yale School of Medicine
  - Yale School of Public Health
5 Top Priorities and Study Designs that Matter Most

- Reduce Stigma
- Maximize Independence
- Foster Close Relationships
- Increase Social Activity
- Improve the Diagnosis Experience
The Empowering Partnership Toolkit:

✓ Easy to Use Narrative Guide with Links to Resources

✓ Introductory Podcast: “Creating Energy, Shared Purpose, and Momentum to Doing Research Differently”

✓ Webinar 1: “Building a Partnership Network”

✓ Webinar 2: “Empowering Partnership Training”

✓ Video: “The Empowering Partnership Experience”

https://livewell.org/empoweringpartners-toolkit/
What is one word that describes your experience with Empowering Partnerships?

- Exhilarated
- Ground-breaking
- Exciting
- Galvanizing
- Inspired
- Fantastic
- Collaboration
LiveWell is activating the **Empowering Partnerships Network**, a diverse, peer network of individuals living with dementia, care partners, and multi-stakeholders that are engaged to transform care, services, and experiences with and for people impacted by dementia. Collaborative activities include the following:

- **Research**
  - Co-partnership of PLWD/CP with Researchers
  - Study Design, Implementation, Evaluation, Dissemination

- **Policy**
  - Advocacy
  - Community Awareness
  - Policy and Social Change

- **Practice**
  - Program Development/Implementation
  - Workforce Development (informal/formal)
Empowering Partnerships Network
“A Neutral Broker”

SUPPORT FOR THE RESEARCH ENTERPRISE/PROJECTS INCLUDES:

- Identification Stakeholder Engagement Needs
- Recruitment of Diverse Stakeholders (including peer to peer methods)
- Research Project Planning and Request for Application Processes
- Stakeholder Engagement and Training
- Project Implementation/Technical Assistance
- Creation and Implementation of a “Peer-Based Community of Practice”
- Facilitation of Summits for Project Planning/Dissemination
- Continued Evolution of Tools/Resources and Access to Best Practices
Panelists

Joan Monin, PhD
Yale School of Public Health

Michael Lepore, PhD
LiveWell Alliance

Ula Hwang, MD, MPH
Yale School of Medicine
“From a researcher’s point of view, I’m really excited to share all that I’ve been working on for a really long time with people who really care about what I’m actually talking about. That’s really exciting!”
Dr. Joan Monin

Professional background/work

Involvement with the Empowering Partnership project

My experience in the Empowering Partnership Training workshop and the impact on my research

What is needed to engage PLWD/CP and what are the future implications for doing research in this way
Stakeholder engagement informs intervention selection

Reduce Stigma
Maximize Independence
Foster Close Relationships
Increase Social Activity
Improve the Diagnosis Experience
Cognitive Stimulation Therapy for Mild to Moderate Dementia

Principal Investigator: Michael Lepore, PhD
LiveWell Alliance

Health Care Systems:
- The Center for Geriatric and Family Psychiatry, Inc.
- University of Connecticut Health Center
- Yale Memory Center

“Engaging people living with dementia in stimulating online group activities has the potential to reduce cognitive decline without the risks of in-person gathering.”
Stakeholder engagement in COVID-era feasibility trial

- **Cognitive Stimulation Therapy (CST)**
  - Evidence-based group therapy

- **Virtual CST (V-CST) test**
  - 11/2020 to 1/2021

- **Acceptable to PLWD**
  - 99% attendance

- **Themes verified by participants**
  - 3/5 participated

---

**Themes from V-CST pilot group**

**Enjoyable experience despite dementia**

“Enjoyed the time to socialize but I have difficulty remembering the specifics of the activities.”

**Confidence building**

“I have delightfully noticed that I am more comfortable speaking to others.”

**Inclusive activities and group dynamics**

“The agenda was perfect. Everyone had a chance to talk so all of us got to share our thoughts and memories.”

**Appreciation of current affairs discussions**

“Today was great. The discussion on the morning after pill was interesting.”

---

Lepore et al. (in press). Virtual Cognitive Stimulation Therapy (V-CST) for mild to moderate dementia. *Gerontology, Geriatrics, & Aging.*
Stakeholder engagement in pragmatic trial planning

Identify target stakeholders
- People living with dementia
- Care partners
- CST experience
- Racial diversity
- <6 to ensure all have time to contribute

Recruit stakeholders
- Invite Participants in community programs and in Empowering Partnerships workshop
- Describe study and commitment

Engage stakeholders
- Monthly Zoom meetings
- Email messages
- Collect verbal and written input
- Report on updates (e.g., revisions to patient-facing information)
# Stakeholder engagement in 1-year pragmatic trial

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stakeholder Engagement</strong></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td><strong>Pilot wave (1 group)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Refine processes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Wave 1 (3 groups)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Wave 2 (3 groups)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Professional Background/Work:

- Professor, Vice Chair for Research, Department of Emergency Medicine, Yale School of Medicine

- MPI (Hwang/Shah) Geriatric Emergency care Applied Research (GEAR) Network 2.0 – Advancing Dementia Care (R61 AG069822)

- [IMPACT Pilot funding, Round 1]
The Geriatric Emergency care Applied Research Network 2.0 Advancing Dementia Care (GEAR 2.0 – ADC)

Mission: Advance the science supporting emergency medical care for people with cognitive impairment (CI) or dementia (ADRD) by engaging with a wide variety of stakeholders, with emphasis on people with dementia and their care partners.

R61: Identify and prioritize research gaps (Care Transitions, Communication & Shared Decision Making, Detection, ED Practices) in emergency care for people who have CI or ADRD (Phase 1, Yr 1-2).

R33: Support and grow research(ers) to improve emergency care for people who have CI or ADRD (Phase 2, Yr 3-5) by awarding $1.1 million in partnered research funding support.
How did GEAR 2.0 engage Person Living With Dementia (PLWD) / Care Partners (CP)?

1) Participated on GEAR 2.0 Task Force
   • Workgroup participants
   • Health Equity Advisory Board

2) Participant at GEAR 2.0 Consensus Conference

3) Reviewers for GEAR 2.0 pilot proposals
GEAR 2.0 Consensus Conference
September 9-10, 2021
Virtual via Zoom
GEAR 2.0 Consensus Conference 2021
Considerations & Preparatory work

- Could PLWD participate?
  - Retention, comprehension, pace

- Separate meetings
  - Explaining goals process of workgroups, consensus conference
  - Sessions for feedback, answering questions

- Preparing support materials
  - Hardcopies of online materials
  - Instructions for everything (zoom, inserting backgrounds, polleverywhere,
  - Abbreviation list

- Ground rules for discussion
Sharing Stories
GEAR 2.0 Consensus Conference

DAY 1: Thursday, September 8, 2021 (all times EST)

SESSION 1 - Detection
10:00 - 10:15 am: Opening Remarks & Introductions
10:15 - 10:30 am: Summary of Findings - Identification
10:30 - 10:45 am: Roundtable Discussions & Questions
10:45 - 11:00 am: Break
11:00 - 11:15 am: Session 1 Closing

SESSION 2 - Communication & Shared Decision Making
11:30 - 12:15 pm: Overview of Session 2
12:15 - 1:00 pm: Roundtable Discussions & Questions
1:00 - 1:15 pm: Break
1:15 - 2:00 pm: Roundtable Discussions & Questions
2:00 - 2:15 pm: Session 2 Closing

DAY 2: Friday, September 9, 2021 (all times EST)

SESSION 3 - Care Transitions
9:00 - 9:15 am: Opening Remarks & Introductions
9:15 - 9:30 am: Overview of Session 3
9:30 - 10:00 am: Roundtable Discussions & Questions
10:00 - 10:15 am: Break
10:15 - 11:00 am: Roundtable Discussions & Questions
11:00 - 11:15 am: Session 3 Closing

SESSION 4 - ED Practices
11:30 am - 12:15 pm: Overview of Session 4
12:15 - 12:30 pm: Roundtable Discussions & Questions
12:30 - 12:45 pm: Break
12:45 - 1:30 pm: Roundtable Discussions & Questions
1:30 - 1:45 pm: Session 4 Closing
Research Priorities

GEAR 2.0

The Geriatric Emergency care Applied Research Network 2.0 (GEAR 2.0) aims to establish infrastructure to support collaborative, interdisciplinary research to improve care for older adults with dementia. Learn more below about dementia, and the implications on emergency department (ED) care for older adults, as well our specific Work Group topics designed to address these implications.
The GEAR Network aims to build a research infrastructure for interdisciplinary aging studies focused on geriatric care in the ED as well as advance the science supporting emergency medical care for people with cognitive impairment or dementia. To that end, GEAR offers funding opportunities to foster and support interdisciplinary research in key priority areas that have been acknowledged as research gaps. See below to learn more about the identified research priorities and funding opportunities.

Call for Proposals

GEAR 1.0 Funding

GEAR 1.0 Pilot Grant
GEAR Executive Committee and GEAR Advisory Board will review and select 3 proposals, each receiving up to $98,500 of total funding for this GEAR 1.0 Pilot Grant.

MORE INFORMATION »

GEAR 2.0 Funding (Dementia-Focused)

GEAR 2.0-ADC (NIA)/EMF/WHI Grant Information
GEAR 2.0-ADC has partnered with the Emergency Medicine Foundation and the West Health Institute to award four (4) pilot grants for the funding period July 2022-June 2023. The RFA can be accessed in two places: 1) the EMF Grants page and the GEAR Network page. The domains of specific interest for the pilot awards are: care transitions, emergency department practices, detection, and communication and decision making.
GEAR Network 2.0 Pilot funding (Deadline 2/4/22)

- https://www.emfoundation.org/grants/apply-for-a-grant/


- 12/14/21 4-5p EST Office Hours about GEAR 2.0 Pilot Request for Applications: GEAR 2.0 Request For Application (RFA) – GEAR (gearnetwork.org)
Next Steps

• Sharing lessons learned (this webinar)

• Disseminating Livewell Empowering Partnership Toolkit

• Lessons learned and prepping for PLWD as reviewers of pilot proposals (e.g., layperson summary with applications, prep meetings with PLWD and CP reviewers)

• Future webinars specifically around PLWD engagement in GEAR pilots – design considerations, recruitment considerations
Reflections & Feedback from PLWD & CP

- Standardizing terminology
- Providing links to websites and summaries
- Smaller group discussions appreciated
- Appreciated being heard, sharing their stories and experience
- Gratitude for being included to shape research priorities
- Model for future conferences
- Trust again
Questions?