

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



Gary Epstein-Lubow, MD
Presenter



Heidi Gil
Presenter



Ula Hwang, MD, MPH
Panelist



Michael Lepore, PhD
Panelist



Joan Monin, PhD
Panelist

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

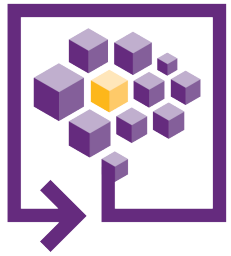
<https://www.linkedin.com/company/65346172>



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



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COLLABORATORY
TRANSFORMING DEMENTIA CARE

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
 - Lori Frank, Emily Shubeck, Melanie Schicker, Teresa Webb, Katie Maslow, Laura Gitlin, Cynthia Huling Hummel, Edward K Kaplan, Brian LeBlanc, Myriam Marquez, Brenda P Nicholson, Greg O'Brien, Louise Phillips, Brian Van Buren, Gary Epstein-Lubow
 - 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>

Quality Measures

Gary Epstein-Lubow, MD

Louise Phillips, MD, MBA

In Collaboration with









Brenda Nicholson, MD

Persons Living with Dementia
Stakeholder Group

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.

Review of Stakeholder Engagement: contact us...

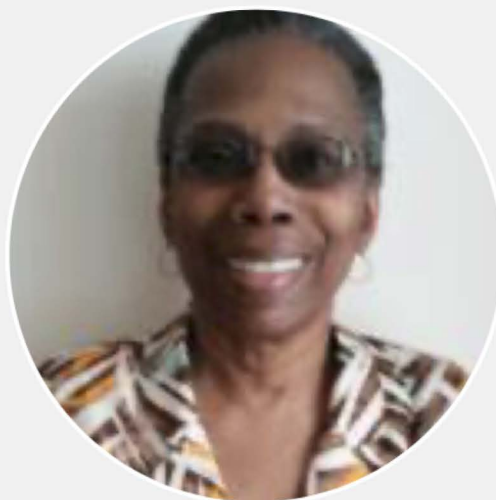
<input type="checkbox"/>	 Name	 Type	 Country	 Year	 Organization	 Main Ideas	 Main Themes
1	A map of resources for co-producing research in health and social care, Version 1.2	Guidance	UK	2020	National Institute for Health Research (NIHR) ARC We...	<ul style="list-style-type: none">A guide for researchers, members of the public and	Evaluation Dissemination During COVID-19 Pandemic
2	A Researcher's Guide to Patient and Public Involvement	Guidance	UK		NIHR Oxford Biomedical Research Centre	<ul style="list-style-type: none">Comprehensive guide to PPI for researchers	Dissemination Evaluation Developing Research Questions Stakeholder Recruitment Training Study Design
3	Appendix 2: Patient Engagement Monitoring and Evaluation Framework	Framework	Based in European Union	2021	PARADIGM (Patients Active in Research and Dialogue...	<ul style="list-style-type: none">This excel file consist of three sheets: 1) framework	Evaluation
4	Best video conferencing apps and software for accessibility	Webpage		2020	The Big Hack and Business Disability Forum	<ul style="list-style-type: none">Alphabetical list of the most commonly used apps ...	Virtual Engagement
5	Briefing notes for researchers - public involvement in NHS, health and social care research	Guidance	UK	2021	National Institute for Health Research	<ul style="list-style-type: none">This guidance is for researchers new to public ...	Stakeholder Recruitment Evaluation
6	Dementia Peer Coalition	Website	USA		Dementia Peer Coalition	<ul style="list-style-type: none">The DPC is a group of people living well with the changes	Working w/ PLWD
7	Different experiences: A framework for considering who might be involved in research	Guidance	UK		INVOLVE (a national advisory group), National ...	<p>Key guidance:</p> <ul style="list-style-type: none">Be clear about the purpose of	Stakeholder Recruitment
8	EMPOWERING PARTNERSHIPS PROJECT TOOLKIT RESOURCES	Toolkit	USA		Live Well	<ul style="list-style-type: none">Toolkit offers information and resources from all phases of	Working w/ PLWD Engagement Activities
9	Ensuring Your Trial is Designed for All Who Could Benefit	Worksheet	UK		National Institute for Health Research	<ul style="list-style-type: none">The key questions are designed to prompt trial	Health Equity Challenges Stakeholder Recruitment Consent Process
10	Evaluating public involvement in research	Guidance	UK	2018	University of the West of England (UWE) Bristol	<ul style="list-style-type: none">This guidance is for researchers, and it discusses	Evaluation
11	Evaluation: Practical Guidelines A guide for evaluating public engagement activities	Guidance	UK		National Co-ordinating Centre for Public ...	<ul style="list-style-type: none">This guide is for researchers seeking to engage general	Evaluation
12	Guidance on co-producing a research project	Guidance	UK	2021	National Institute for Health Research	<ul style="list-style-type: none">Explains what co-producing a research project means	Principles Challenges
13	How do I hold a PPI meeting using virtual tools?	Webpage	UK	2020	NIHR School for Primary Care Research	<ul style="list-style-type: none">12 tips and tricks for researchers on holding virtu...	Virtual Engagement
14	How to evaluate public engagement projects and programmes	Guidance	UK	2017	National Co-ordinating Centre for Public ...	<ul style="list-style-type: none">Shares some of the ways people have used evaluation	Evaluation Reporting
15	Online Engagement: A guide to creating and running virtual meetings and events	Guidance	UK		National Co-ordinating Centre for Public ...	<ul style="list-style-type: none">This guide focuses on designing and delivering	Planning Virtual Engagement
<input type="checkbox"/>	 Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive ...	Report	Based in Europe	2019	Alzheimer Europe	<ul style="list-style-type: none">Discusses ethical challenges linked to 1) public ...	Working w/ PLWD Consent Process Stakeholder Recruitment



Stakeholder Perspectives:

Engaging and Working Effectively with Individuals Living with Dementia as Stakeholder Advisors and Research Partners

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



- 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



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Empowering Partnerships:

Fueling the Research Enterprise with Shared Purpose and Hope



Heidi Gil

Chief Strategy Officer, LiveWell Alliance, Inc.

OUR MISSION



*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**



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Empowering Partnerships

*Preparing People with Dementia
to Partner with Researchers*



**A Eugene Washington
PCORI Engagement Award**

LiveWell



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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

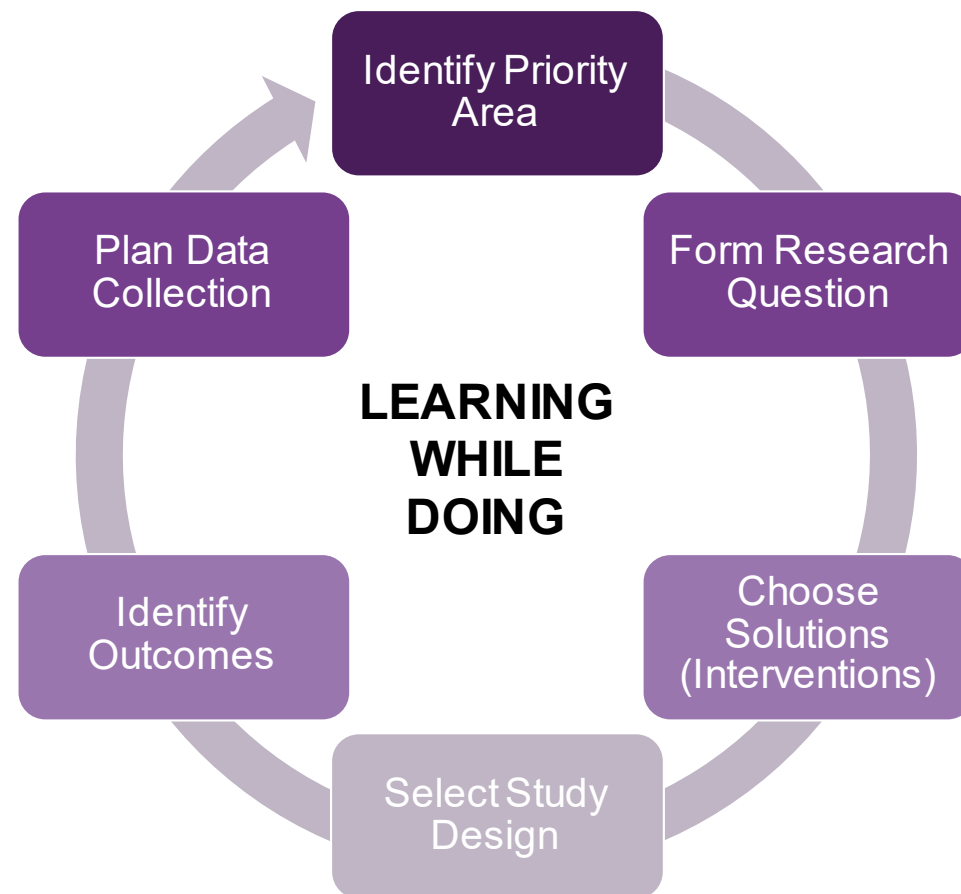
Specific aims:

- 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

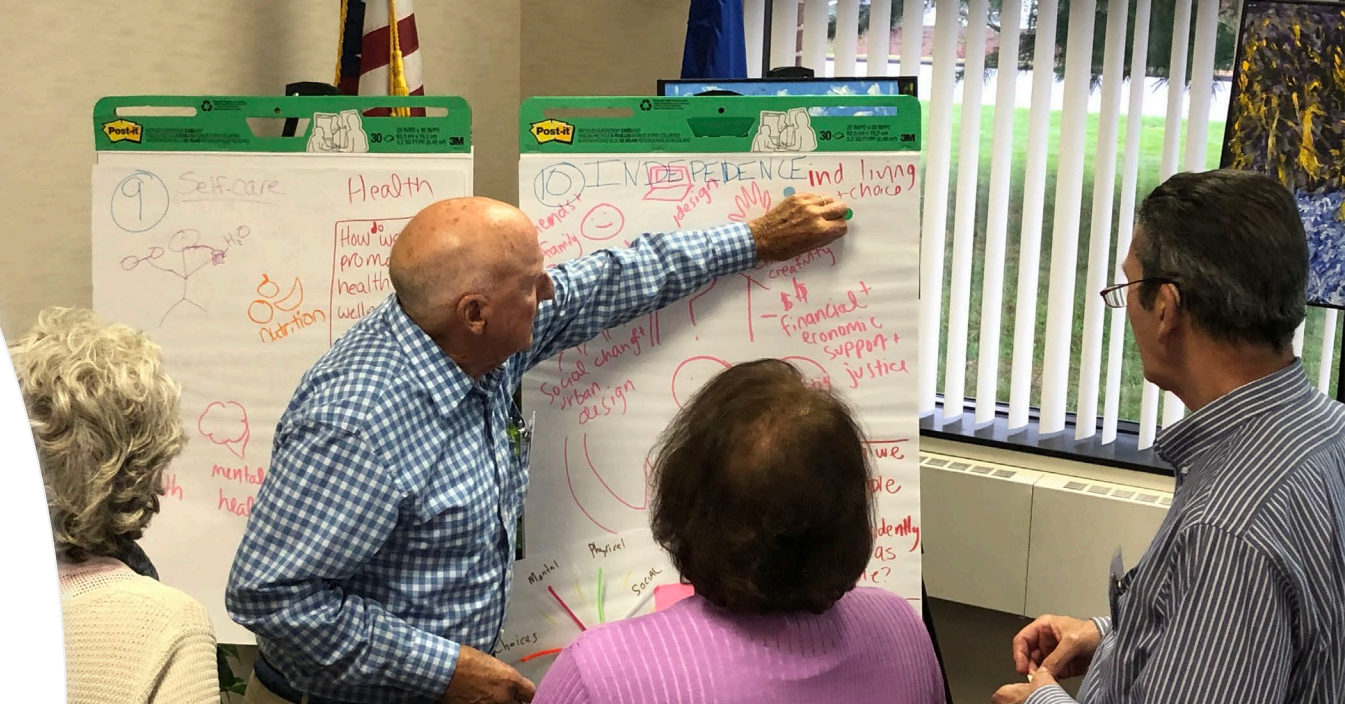
Participants Identified and Co-Designed Research Priorities and Projects:

- 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/>



EMPOWERING PARTNERSHIPS

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. In Oct 2019 we hosted the first of its kind 2-day training event with people living with dementia, researchers and care partners learning together on ways to promote partnership – not just participation. Over the 2 days we identified and prioritized research topics that support well-being, and learned ways to include people living with dementia as partners in all aspects of research – from study design, to implementation and dissemination.

What is one word that describes your experience with Empowering Partnerships?

Exhilarated



Galvanizing



Hope

Inspired



Ground-breaking



Fantastic



Collaboration

Exciting



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Empowering Partnership Network

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

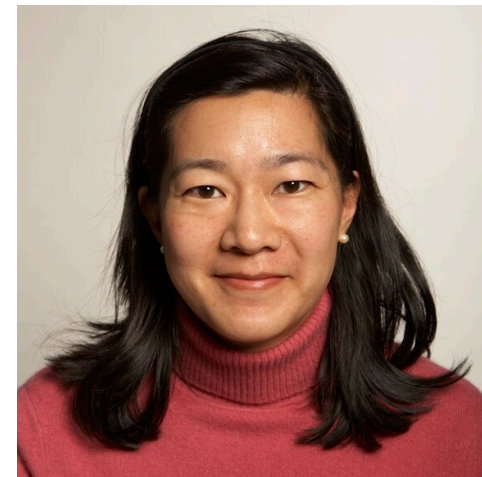
Panelists



Joan Monin, PhD
Yale School of Public Health



Michael Lepore, PhD
LiveWell Alliance



Ula Hwang, MD, MPH
Yale School of Medicine

Dr. Joan Monin



"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



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**Empowering
Partnerships**
*Preparing People with Dementia
to Partner with Researchers*

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.”

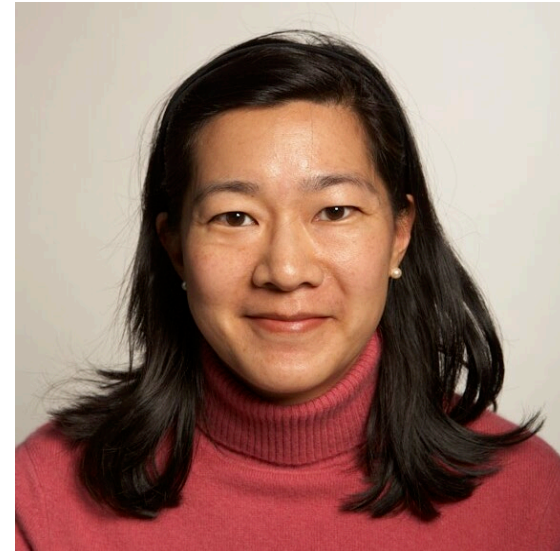
Stakeholder engagement in pragmatic trial planning



Stakeholder engagement in 1-year pragmatic trial

	Pre	1	2	3	4	5	6	7	8	9	10	11	12
Stakeholder Engagement	X	X	X	X	X	X	X	X	X	X	X	X	X
Pilot wave (1 group)					X	X							
Refine processes						X	X						
Wave 1 (3 groups)								X	X				
Wave 2 (3 groups)										X	X		
Analysis							X	X	X	X	X	X	X

Ula Hwang, MD, MPH



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
Geriatric Emergency care
Applied Research

GEAR 2.0 Consensus Conference

September 9-10, 2021

Virtual via Zoom



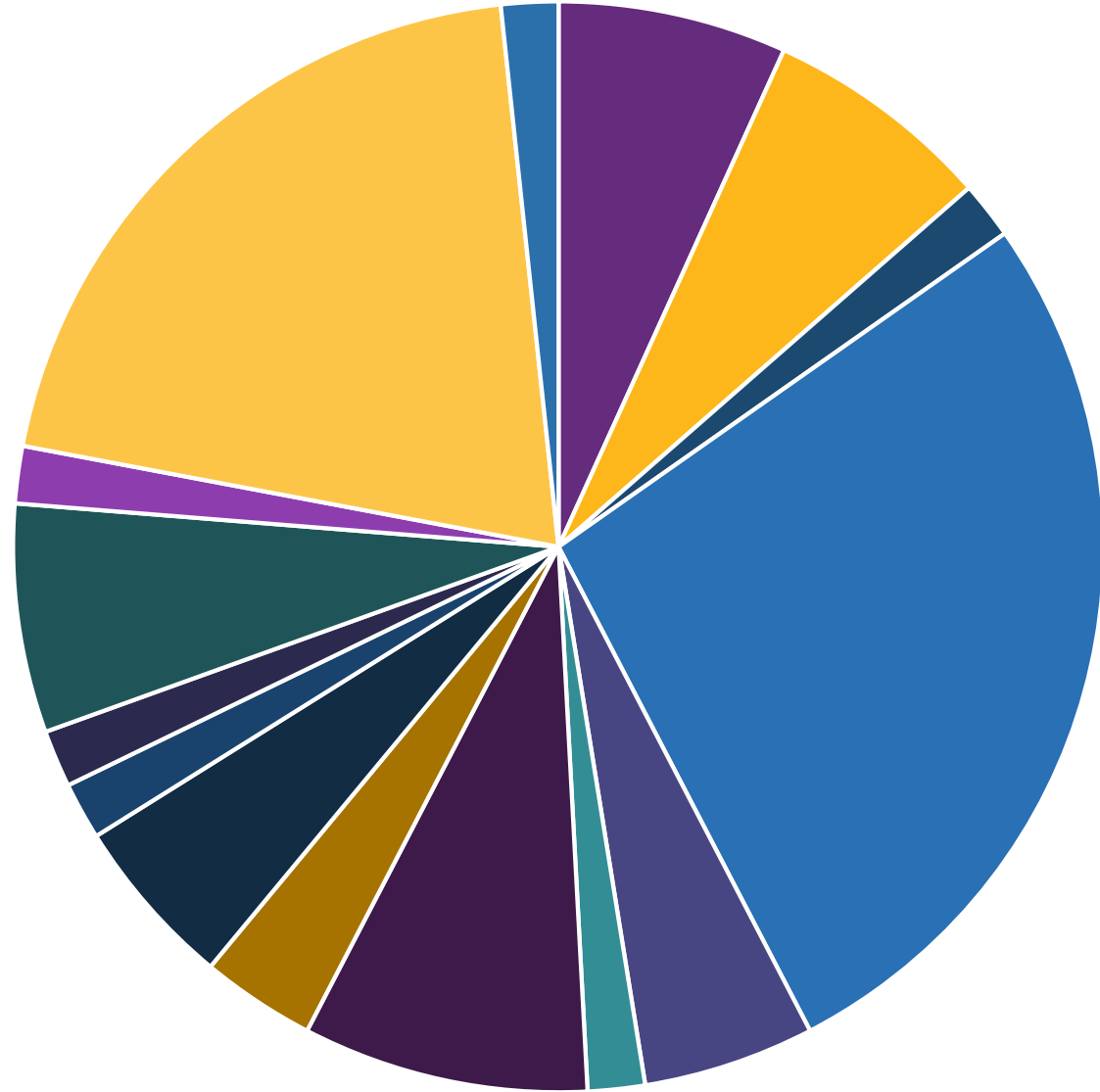
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GEAR 2.0 Consensus Conference 2021



GEAR 2.0 Stakeholder Attendees

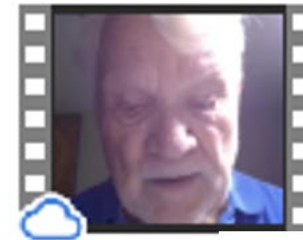
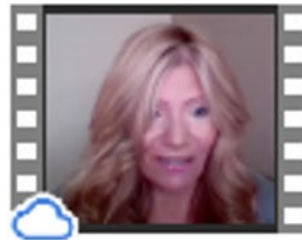
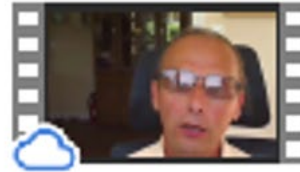
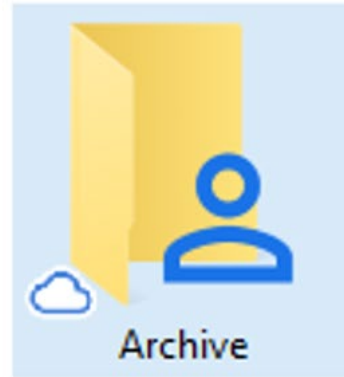
- Advocate
- Care Partner
- Educator
- Emergency Physician
- Funder
- Geriatric Psychiatrist
- Geriatrician
- Neuropsychologist
- Nursing
- Pharmacist
- Physical Therapist
- Person Living With Dementia
- Psychologist
- Researcher
- Student



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 9, 2021 (all times EST)

9:30 am – 10:00 am	CONFERENCE REGISTRATION
10:00 am – 10:25 am	WELCOME & OPENING

SESSION 1 – Detection

10:25 am – 10:45 am	SCOPING REVIEW OVERVIEW – Detection
10:45 am – 11:35 am	BREAKOUT DISCUSSIONS
11:35 am – 11:45 am	Break
11:45 am – 12:40 pm	DEBRIEF
12:40 pm – 1:15 pm	LUNCH / BREAKFAST
1:15 pm – 1:20 pm	Detection LIVE VOTING

SESSION 2 – Communication & Shared Decision Making

1:20 pm – 1:35 pm	SCOPING REVIEW OVERVIEW – Communication & Shared Decision Making
1:35 pm – 2:20 pm	BREAKOUT DISCUSSIONS
2:20 pm – 2:25 pm	Break
2:25 pm – 3:15 pm	DEBRIEF
3:15 pm – 3:40 pm	COFFEE-BIO / BREAK / ACTIVITY
3:40 pm – 3:45 pm	Communication & Shared Decision Making LIVE VOTING
3:45-4:00 pm	Day 1 Debrief / Day 2 Prep

DAY 2: Friday, September 10, 2021 (all times EST)

SESSION 3 – Care Transitions

10:00 am – 10:15 am	SCOPING REVIEW OVERVIEW – Care Transitions
10:15 am – 11:00 am	BREAKOUT DISCUSSION
11:00 am – 11:05 am	Break
11:05 am – 11:55 pm	DEBRIEF
11:55 am – 12:30 pm	LUNCH
12:30 pm – 12:40 pm	Care Transitions LIVE VOTING

SESSION 4 – ED Practices

12:40 pm – 12:55 pm	SCOPING REVIEW OVERVIEW – ED Practices
12:55 pm – 1:40 pm	BREAKOUT DISCUSSION
1:40 pm – 1:45 pm	Break
1:45 pm – 2:35 pm	DEBRIEF
2:35 pm – 3:00 pm	DESSERT / BIO BREAK / ACTIVITY
3:00 pm – 3:05 pm	ED Practices LIVE VOTING
3:05 pm – 3:30 pm	CLOSING

Presentation

PICO 1 Abstraction Table

PICO 2 Abstraction Table

Common Articles PICO 1&2

5

1

Session 1
Detection - Identification

1

2

Session 2
Communication & Shared
Decision Making

PICO 1 Abstraction Table

PICO 2 Abstraction Table

Common Articles PICO 1&2

3

Session 3
Care Transitions

4

Session 4
ED Practices

5

Conference Attendee
Bio Sheet

5



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.



Grants and Funding Opportunities

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 »](#)

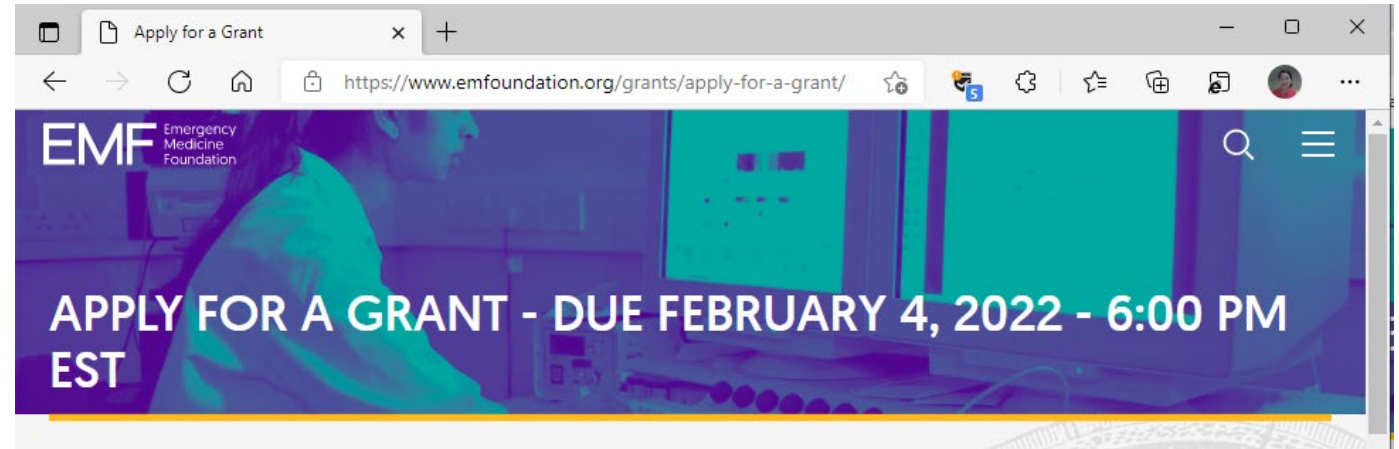
GEAR 2.0 Funding (Dementia-Focused)

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 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/>



- <https://www.emfoundation.org/globalassets/geriatric-emergency-care-applied-research-network-2.0--advancing-dementia-care-version-2.0.pdf>
- 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



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Questions?