GSA Webinar Series

The Art of Engaging Older Adults in Research

SUPPORTED BY THE GSA INNOVATION FUND: THE GENERATIVITY EFFECT

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Clarifying Questions?

- We will not be using the “raise hand” feature today
- Please use the “questions” feature accessible on the right side of your screen
- Speakers will not see questions until the end of the presentation
- If we do not get to all of the questions today, we will email responses after the webinar
Webinar Panel

Amy Eisenstein, PhD
Program Officer
The Retirement Research Foundation

Carol Geary, PhD, MBA, RN
Assistant Professor
University of Nebraska Medical Center

Erin McGaffigan, PhD, MSW, MS
Policy and Research Fellow
LeadingAge LTSS Center
University of Massachusetts Boston

Gyasi Moscou-Jackson PhD MHS RN
Nurse Scientist
University of Maryland Medical Center

Agenda

- Introduction and overview
- Moderated discussion with representatives from two Research Advisory Boards
  - Overview of model for engagement
  - Highlighted experiences and lessons learned
  - Next steps
- Wrap up
Introduction to Engagement

- The Patient-Centered Outcomes Research Institute (PCORI) Engagement Rubric:
  - Reciprocal relationships
  - Co-learning
  - Partnership
  - Trust, transparency, and honesty

Greater Understanding of Engagement ➔ Stronger Engagement in Proposals ➔ Strong Engagement in Research

Stakeholder Engagement in Research on Aging

**Purpose:**
To bring together those typically excluded from research, with the aim to learn about and discuss research concepts in order to provide voice to the direction, design, and implementation of national research on aging.

**Persons with Lived Expertise should be:**
- Defining the research problem
- Contributing to design and practicality of the intervention
- Reviewing materials (including proposals, IRB, questionnaires, reports, and dissemination)
- Aiding in interpretation of the findings
Models of Engagement in Gerontology

- The Bureau of Sages
  - Lieberman Center for Health and Rehabilitation at CJE SeniorLife in Skokie, Illinois*
  - Virtual Senior Center Bureau in Chicago and New York City*
  - Mesulam Sages at the Mesulam Center for Cognitive Neurology and Alzheimer’s Disease at Northwestern Medicine in Chicago, Illinois
  - Vancrest Research Advisory Group at Vancrest Health Care Center in Van Wert, Ohio*
  - JHEP Bureau of Sages at the Jewish Home of Eastern Pennsylvania in Scranton, Pennsylvania*
  - In Development: A Massachusetts Bureau of Sages*

- Rural Patient and Stakeholder Engagement in Research, University of Nebraska Medical Center (PCORI Eugene Washington Award EAIN-10693)

*Rural Patient & Stakeholder Engagement in Research projects were funded through Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Awards (PCORI Engagement Award #2640-CJE and #7206-CJE)

Rural Patient & Stakeholder Engagement in Research

- Engagement capacity building project lead by:
  - Paul Estabrooks, PhD (Research)
  - James McClay, MD (Clinical)
  - June Eilers, PhD (Patient)
  - Carol Geary, PhD (Business)

This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EAIN-10693).
Rural Engagement

- Research Teams
  - 10 Teams
- Steering Committee
  - Patient
  - Stakeholder
  - Researcher
- Co-Leads

Engagement Process

- Identification of Partners
- Summit Planning & Coordination
- Introduction of Concepts & Tools
- Development of Teams & Project Management
- Engagement Evaluation
Just-in-Time Engagement

- 10 Research Teams
- Patient & Stakeholders with project-specific lived experience
- “Summit” approach to initial connection

Key Lessons: Organizational

- Ethical Access
- IRB
- HIPAA
- Payment
- Other?
Key Lessons: Researcher

- Research Project
- Topic
- Scope
- Timing
- Research Team
- Research Stage
- Researcher Team Science Experience
- Goals for Engagement

Key Lessons: Partners

- Needed Partners
- Number
- Specific requirements?
- Trusted point of access
- Situations related to lived experience
Next Steps

- Evaluation of engagement within the 10 projects
- Dissemination

- Ongoing just-in-time connections between researchers and partners
  - Existing groups and relationships
  - New needs

Stakeholder Engagement to Inform Research

- Jewish Home of Eastern Pennsylvania (JHEP) Bureau of Sages (Scranton)
- Hebrew SeniorLife Bureau of Sages (Boston, MA)
- Sages’ Symposium to Expand Researcher Readiness Steering Committee (National)
Bureau of Sages Research Advisory Boards

Key Elements

- Small group of consistent older adults
- Community or facility based
- Initial and ongoing research training
- Meet routinely
- Inform a wide range of research topics
- Have facilitator and staff support

Engaged Research Take-Away:
Older Adults Want to Be Engaged

- Consider what older adult characteristics you are seeking to understand
- Determine where such individuals live and experience life
- Develop partnerships with community leaders, providers, and innovators
- Engage older adults where they live, enjoy life, and receive care and support
Engaged Research Take-Aways: Technology Can Bridge Divides

- Assess needs (who has a smart phone, camera, laptop, etc.)
- Provide small stipends (e.g., for cameras, assistance accessing technology)
- Provide 1:1 assistance to maneuver and troubleshoot technology
- Provide dedicated “champion” who is ready to invest time in the above
- Consider a combination process (in-person “book ends”)

Technology Samples
Engaged Research Take-Aways: Process Matters

Facilitation is an art!

- Identify a skilled, supportive facilitator
- Be ready to listen
- Take great notes; it will make sense later

Keep it simple!

- Simple materials are good for you and those you engage
- Few open-ended questions to inform discussion
- Share information ahead of time to support readiness

Engaged Research Take-Aways:

Process Matters

Bureau of Sages Tool
Our Next Steps: Plant Seeds and Help Them Grow

- Identify new researcher and research sites
- Keep older adults engaged and learning
- Support researchers’ readiness
- Identify ways to support self-sustainability
- Identify funders who support this concept or even require it

Helpful Tools

https://www.cje.net/research-education/lssi/creating-research-advisory-boards/resources

(You can also do an internet search for “Bureau of Sages”)
Supporting Researcher Readiness
Join Us In April 2020

- PCORI-Funded Sages’ Symposium to Support Researcher Readiness will occur in April 2020
- Chicago-based event to bring “Sages” together
- Assessing technology opportunities connect meeting attendees virtually
- Contact Missy@collectinsight.com to be added to a list for more information

Wrap-Up: The Difference Between...

“PATIENT-CENTEREDNESS”
The project aims to answer questions or examine outcomes that matter to patients within the context of patient preferences
Research questions and outcomes may also reflect what is important to caregivers

“PATIENT AND STAKEHOLDER ENGAGEMENT”
Patients are partners in research, not just “subjects”
How patients, caregivers, and “other” stakeholders will be involved is well thought out, active, and meaningful
Forms of Engagement

<table>
<thead>
<tr>
<th>Input</th>
<th>Consultation</th>
<th>Collaboration – Shared Leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholder partners provide information researchers use in defining agendas and making decisions</td>
<td>Stakeholder partners provide support or advise on specific study attributes</td>
<td>Stakeholder partners actively define agendas and make decisions</td>
</tr>
<tr>
<td>Information typically flows unidirectionally</td>
<td>Information flows both uni- and bidirectionally</td>
<td>Information flows bidirectionally</td>
</tr>
<tr>
<td>Partners do not have decision-making ability</td>
<td>Decision-making ability is limited to activities defined by the research team</td>
<td>Decision-making responsibility is shared</td>
</tr>
<tr>
<td>e.g. Focus Groups</td>
<td>e.g. Patient Advisory Committee</td>
<td>e.g. Patient Co-Investigator or Multi-Disciplinary Executive Committee</td>
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PCORI’s Engagement in Health Research Literature Explorer

- This searchable, catalogued resource for peer-reviewed literature can help identify publications about engagement.
- It contains over 1,000 articles that include:
  - Examples of engagement in health research
  - Evaluations of engagement in health research
  - Syntheses of engagement methods and impacts
  - Frameworks, editorials, and commentaries on engagement in health research
- Articles can be filtered by communities that were engaged, phase of research engagement (study design, recruitment, etc.), and publication year.

Link: Engagement in Health Research Literature Explorer: https://www.pcori.org/engagement/engagement-literature
PCORI’s Engagement Tool and Resource Repository

- This searchable peer-to-peer repository includes engagement-related tools and resources developed and used by PCORI awardees.
- These tools and resources can be used by the general public to inform and strengthen engagement in patient-centered outcomes research.
- Tools and resources can be filtered by resource focus, phase of research (implementation, recruitment, dissemination, etc.), health condition and population, and stakeholder group.


Thank You

GSA: Advancing Innovation in Aging
- The nation’s oldest and largest interdisciplinary organization devoted to research, education, and practice in the field of aging.
- 5,500+ interdisciplinary members around the world touching all facets of aging.

Mission
- Promote multi- and interdisciplinary research in aging.
- Translate and disseminate research findings.
- Promote/advocate for education/awareness on aging across disciplines.
- Foster application of research into policy development.

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Webinar Evaluation

*In an effort for continual improvement, we would like to hear your thoughts. Please provide feedback by clicking the survey link at the end of the webinar.*

*Thank you again and we hope you enjoyed the program!*