Incorporating Patient Voice into Meaningful Research:
Lessons learned from a Eugene Washington Engagement Award

Clinical Directors Network, Inc. Webcast
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Disclosures

We have no relevant commercial relationships to disclose.

Acknowledgements

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Agenda

1. Introduction: What’s it all about?
   • Engagement/PCORI Engagement Awards
   • Development of a Research Advisory Board
   • Case Example: Bureau of Sages

2. Lessons learned on Engagement

3. Engaging Stakeholders in all aspects of Research

4. Q & A
Eugene Washington Awards

- Provides a platform to expand the role of all stakeholders in research to support PCORI’s engagement priorities
- Awards up to 2 years, $250,000

- Knowledge, training and development dissemination awards
- PCOR/CER Meeting and Conference Support
- Dissemination and Implementation activities of the PCORI pilot projects
PCORI Engagement Rubric

- Reciprocal relationships
- Co-learning
- Partnership
- Trust, transparency, and honesty
Continuum of Stakeholder Engagement in Research

*Contents adapted from Wilkins CH et al. 2015*
Bureau of Sages

Development of a Research Advisory Board

A PCORI Engagement Project
What is the Bureau of Sages?

The Purpose of the Bureau is to bring together a variety of stakeholders to learn about and discuss research concepts in order to provide voice to the direction, design, and implementation of national research on aging.

Members will learn from one another through activities and discussion.

- *Lieberman Community and Virtual Senior Center Members* will gain experiences in expressing their expertise as patients and users of healthcare.
- *Clinicians and researchers* will gain experiences in listening for and identifying meaningful outcomes that matter to users of the health care system.
Long Term Objectives of the Bureau

To prepare a diverse group of Stakeholders with information, knowledge, and training on ‘Patient-Centered Outcomes Research’ and ‘Comparative Effectiveness Research’ in order for them to:

1) Serve as an advisory bureau to CJE SeniorLife’s internal research department.

2) Serve as an advisory bureau to local and national researchers wishing to conduct Comparative Effectiveness Research or Patient-Centered Outcomes Research.

3) Serve as individual advisors to larger Patient-Powered Research Networks.

4) Serve as champions and role models for incorporating the voice of diverse patient populations into research.
What is the Bureau of Sages?

The Bureau of Sages project is supported by a contract from PCORI (Patient-Centered Outcomes Research Institute). PCORI is an independent, nonprofit, nongovernmental organization authorized by Congress in 2010.

PCORI recognizes that patients are the DRIVING force in improving care, and must be involved in the research process.

None of this amounts to anything if REAL CHANGE does not happen.

Director: Mary Ana

When they say they’re going to do something they need to follow through. We want to talk about the things that really matter to us. Keep supplies stocked. We get sick. When the powers that be need to take a long look at themselves and treat us like we count. "Power to the people." - Ariella

When they say we don’t treat us like we don’t count. "It’s about time we get some acknowledgement." - Ariella

Our involvement is not just to give our ideas. We want to see it through.

Drawing credit to Katharine Houpt

The Bureau of Sages:
Empowers nursing home community members and stay-at-home elders to learn about research and collaborate with researchers to advocate for timely, useful research that matters to them.
Strategies for Engagement

• 4 Formal retreats a year for all Bureau Members
• Monthly informal meetings for Lieberman Community Members and Virtual Senior Center Members
• Periodic activities and assignments for Bureau members to participate in, between formal retreats. These activities are intended to enrich learning experiences.
• 1 annual event for each Membership group to share their findings and experiences with the broader community.
Accommodation Considerations

Ask what people need... Seek ongoing feedback!

- Information
- Communication
- Support
- Setting
- Getting There
- Time & Expenses
Margaret Danilow, PT, DPT, PhD
Northwestern University, Personal Pastimes
CJE SeniorLife
Leonard Scherff Research Institute

Rebecca Berman, Ph.D.
Project Manager

Relevant Experience
I am an applied researcher, program evaluator, and educator who has worked in the field of aging for over 25 years. I have always been interested in gathering different points of view, understanding everyday experiences, and thinking about aging from different disciplinary perspectives. I hope that my work contributes to making a difference in people’s lives and helping social service agencies improve their work.

Perspective on Aging
I have learned from research, family, and friends that there are many different ways to adapt to change over a lifetime. Even the concepts of ‘age’ and ‘aging’ can be perceived quite differently, depending on one’s vantage point. As a result, I find it difficult to generalize the ‘experience’ of aging. Growing older is different for everyone and the context in which we age matters a great deal.
Innovative Solutions

In order to incorporate the voice of older adults typically left out of research, we relied on several approaches to improve and augment communication and collaboration between older adults and researchers/clinicians.

- The use of technology to incorporate the voice of Stay-at-Home Elders.
- Development of facilitator guides to assist with the challenges of leading discussions through multiple formats.
- Training and presentation templates for researchers and clinicians.
- Creation and implementation of hands-on evaluation method incorporating visual cues.
The Virtual Senior Center

Welcome Back, Bureau Of Sages
Wednesday May 24 2017

**WEDNESDAY 4PM:** Children’s lives in the Industrial Age w/Lee (NY Historical Society)

The Annual Wellness Visit is a preventative service covered at 100% by Medicare. This FREE visit includes vaccinations, screenings, falls risk assessments, and advice and referrals to stay healthy and strong. Call your doctor and ask for your Annual Wellness Visit. For more information about the Annual Wellness Visit Medicare benefit, please call the Medicare Rights Center Helpline 1-800-333-4114 or visit www.medicareinteractive.org.

VSC Staff (Mon.-Fri. 9am-5pm): Computer concerns including ZOOM class issues: Peter Gil or George Li at 718-559-4373 or vschelp@selfhelp.net; Classes/Facilitators: Carmella Chessen at 646-259-4987; cchesen@selfhelp.net; Client questions: Foon Tong: 718-559-4370 or ftong@selfhelp.net

**TODAY’S SCHEDULE**

9:00 AM Self Acceptance w/Dierdre

9:00 AM Meditation & Breath Work w/Fran (IBelong)

10:00 AM Ken w/Standards you love (Musicians on Call)

11:00 AM Where does the Dissent End & Inappropriate Behavior Begin?

12:00 PM Computer Skills w/John (Wed.)

1:00 PM Music w/Les

**WEATHER**

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**NEWS**

- Manchester, Pope Francis, Uber: Your Wednesday Briefing
- Duterte Suggests Martial Law Across Philippines, Citing Islamist
- Tom Cruise Confirms ‘Top Gun’ Sequel
- 3 Men Arrested In Investigation of Manchester Bombing
- Manchester Bombing Victims Include at Least 4 Parents Awaiting
Lieberman Community
Lessons Learned

Professionals need to be aware of the person they are treating’s attitude. They need to consider how a person feels towards their health and medical conditions, and how he or she will handle it.

~Bureau Older Adult Member

We’re focusing on identifying and treating illness, when they really want in non-pharmacological approaches for relieving pain. We emphasize their deficits when they’d like to make the most of their strengths.

~Bureau Professional Member
Lessons Learned

Sages:
• Confidence in ability to talk to researchers/clinicians
• Familiarity with research processes and concepts
• How to contribute meaningfully to research
• Capacity to engage with external researchers

Researchers/Clinicians:
• Capacity to design patient centered research
• Ability to draw on older adult experience
• Respect for the engagement process and continuation of engagement throughout the research cycle
Incorporating Voice into all Aspects of Research

Planning

Disseminating and applying findings

Implementation

Interpreting results
Overcoming Barriers

• Learn about assets and challenges, gain insight, volunteer

Community meetings & activities

• To play key roles, aid in finding funding, submitting IRB, improve recruitment and dissemination

Involving community partners

• Develop, revise, refine all study materials, refine findings

Tap advisory committees

Key informant interviews & focus groups

• Learn about community needs, inform problem statements
“Patients are our true north.”

—Harlan Krumholz, MD
PCORI Board of Governors