

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



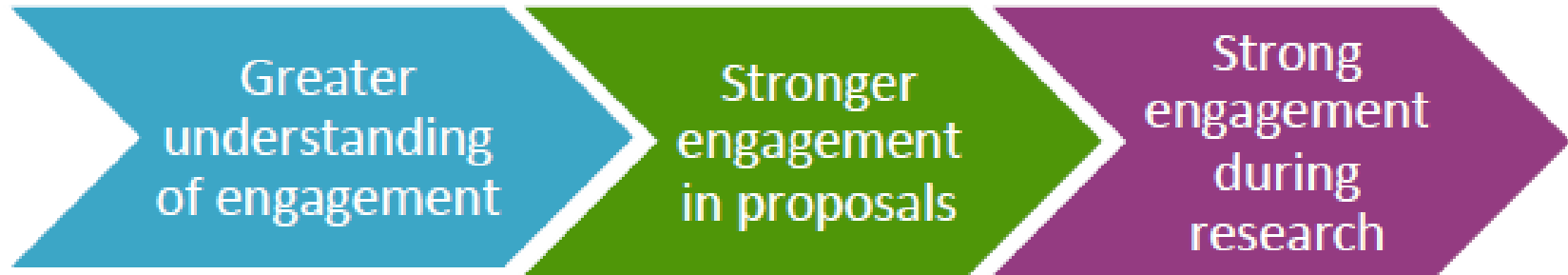
- PCOR/CER Meeting and Conference Support



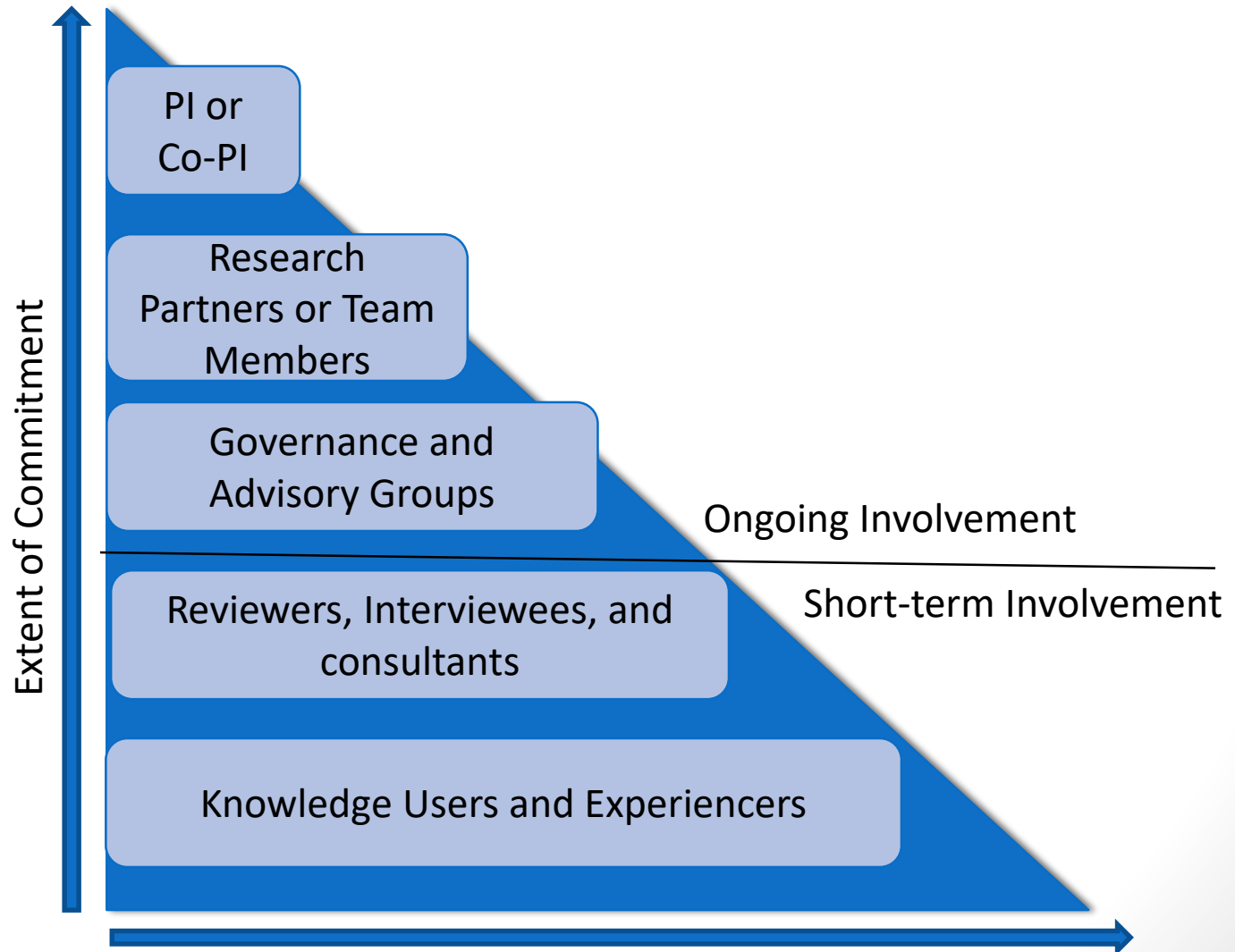
- Dissemination and Implementation activities of the PCORI pilot projects

PCORI Engagement Rubric

- Reciprocal relationships
- Co-learning
- Partnership
- Trust, transparency, and honesty



Continuum of Stakeholder Engagement in Research



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.



Drawing credit to Katharine Houpt

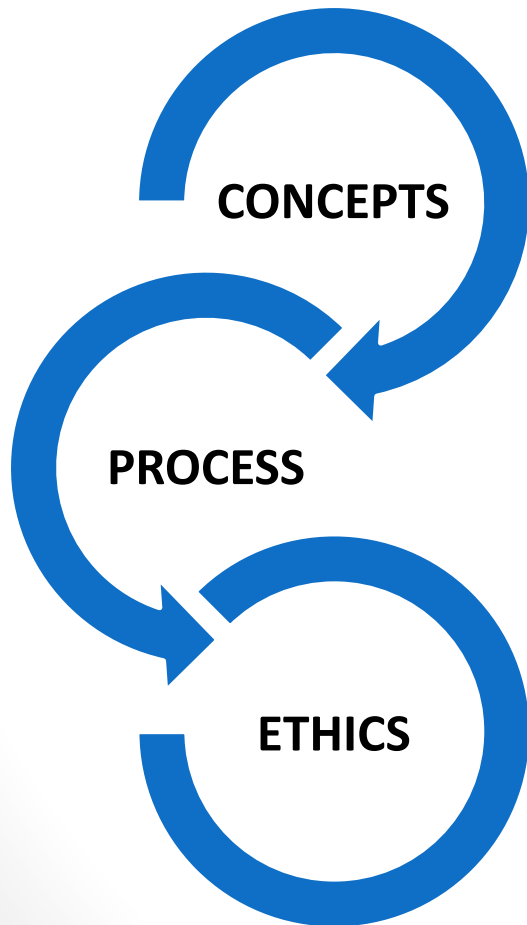
The Bureau of Sages:

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

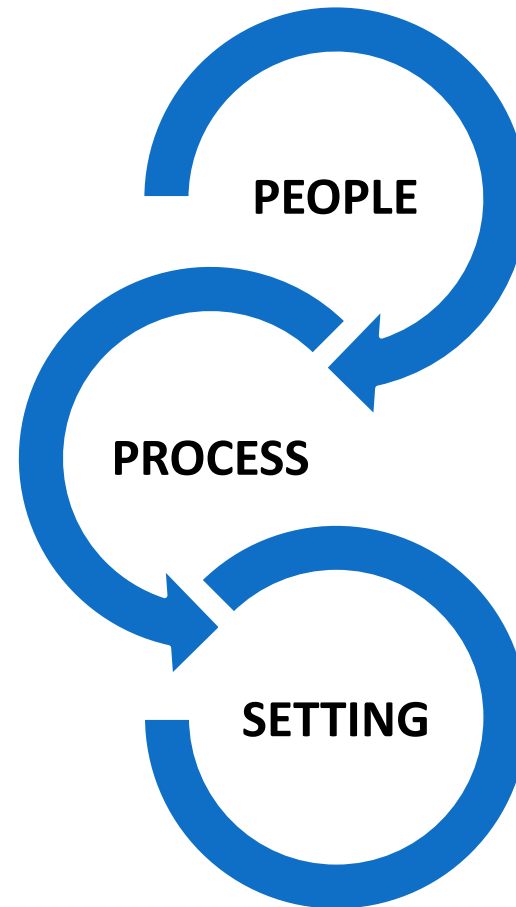
Strategies for Engagement

- 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.

PREPARING SAGES



PREPARING RESEARCHERS



Accommodation Considerations

Ask what people need... Seek ongoing feedback!



- Information



- Communication



- Support



- Setting



- Getting There



- Time & Expenses

Guest Researcher

Margaret Danilov
PT, DPT, PhD



Northwestern
Personal

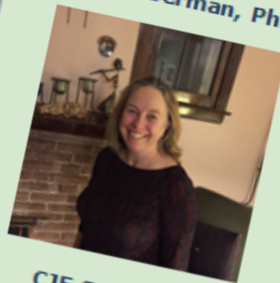


Television

Playing Words

Bureau of Sages Biosketch

Rebecca Berman, Ph.D.



CJE SeniorLife
Leonard Schanfield
Research Institute

Personal Pastimes

Being active outdoors



Ballroom and social
dancing



Role

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 lives and helping social service agencies improve their work.

Perspective on Aging

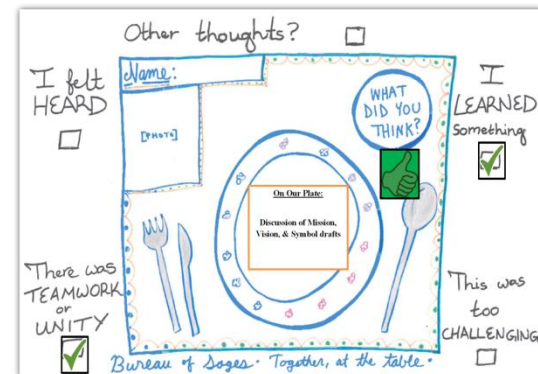
I have learned from research, family and friends that there are many different ways to adapt to change over a lifetime. Even the concepts of 'age' and 'aging' can be perceived quite differently, depending on one's vantage point. As a result, I find it difficult to generalize the 'experience' of aging. 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

Selfhelp's Virtual Senior

Secure | https://vsc.selfhelp.net

Selfhelp

Welcome Back, Bureau Of Sages
Wednesday May 24 2017

Home

Calendar

Skype™

Internet

Gmail

Games

Class Info

Photos

Home

←

→

Zoom In

Zoom Out

HELP

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; cchessen@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

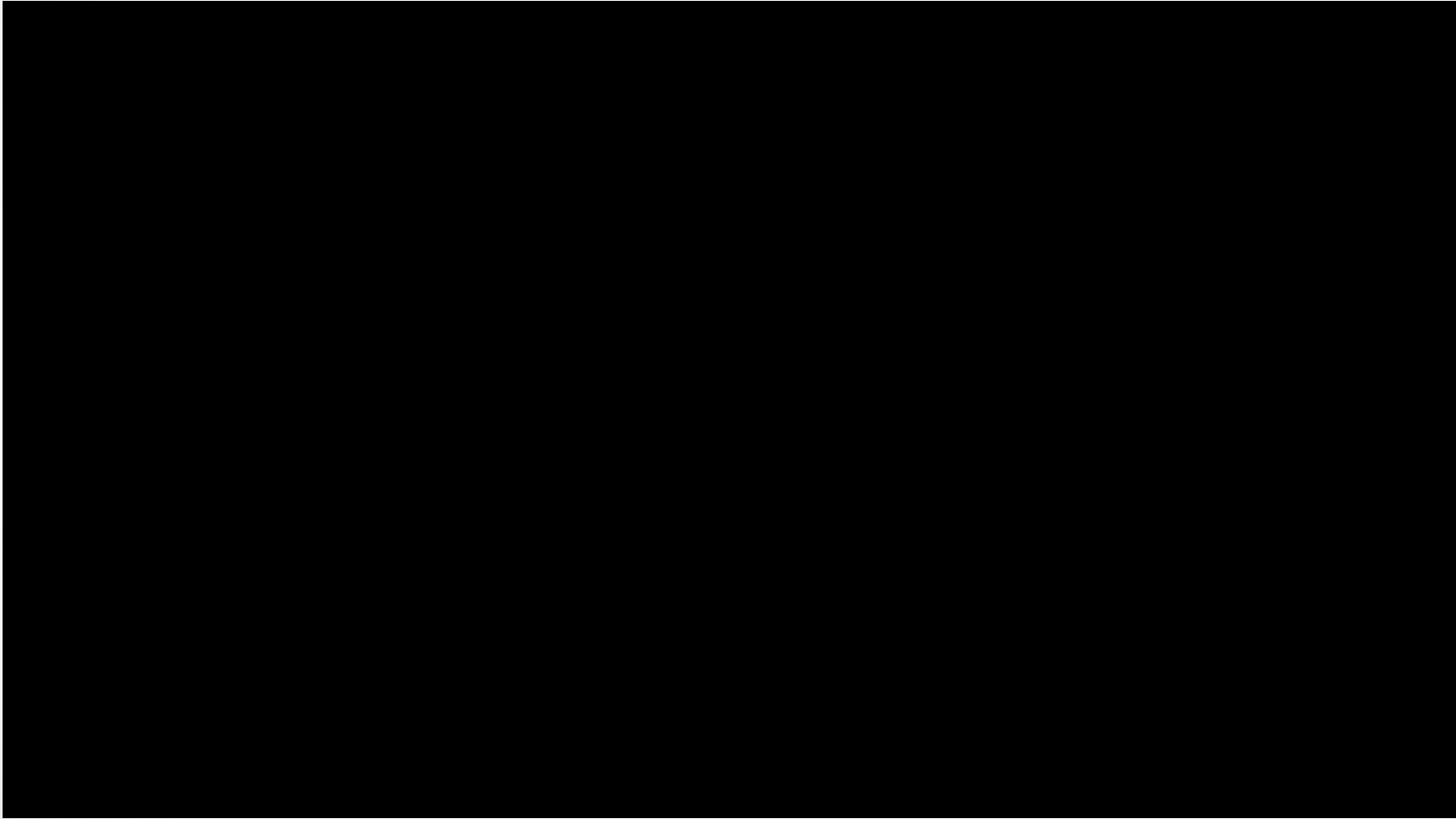
WEATHER

Today	Thursday	Friday
 Chance of Rain 55°	 Partly Cloudy 62°	 Overcast 67°

NEWS

- ▶ [Manchester, Pope Francis, Uber: Your Wednesday Briefing](#)
- ▶ [Duterte Suggests Martial Law Across Philippines, Citing Islamist](#)
- ▶ [Tom Cruise Confirms 'Top Gun' Sequel](#)
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- ▶ [Manchester Bombing Victims Include at Least 4 Parents Awaiting](#)
- ▶ [New York Today: New York Today: Roller Coasters Within Reach](#)

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

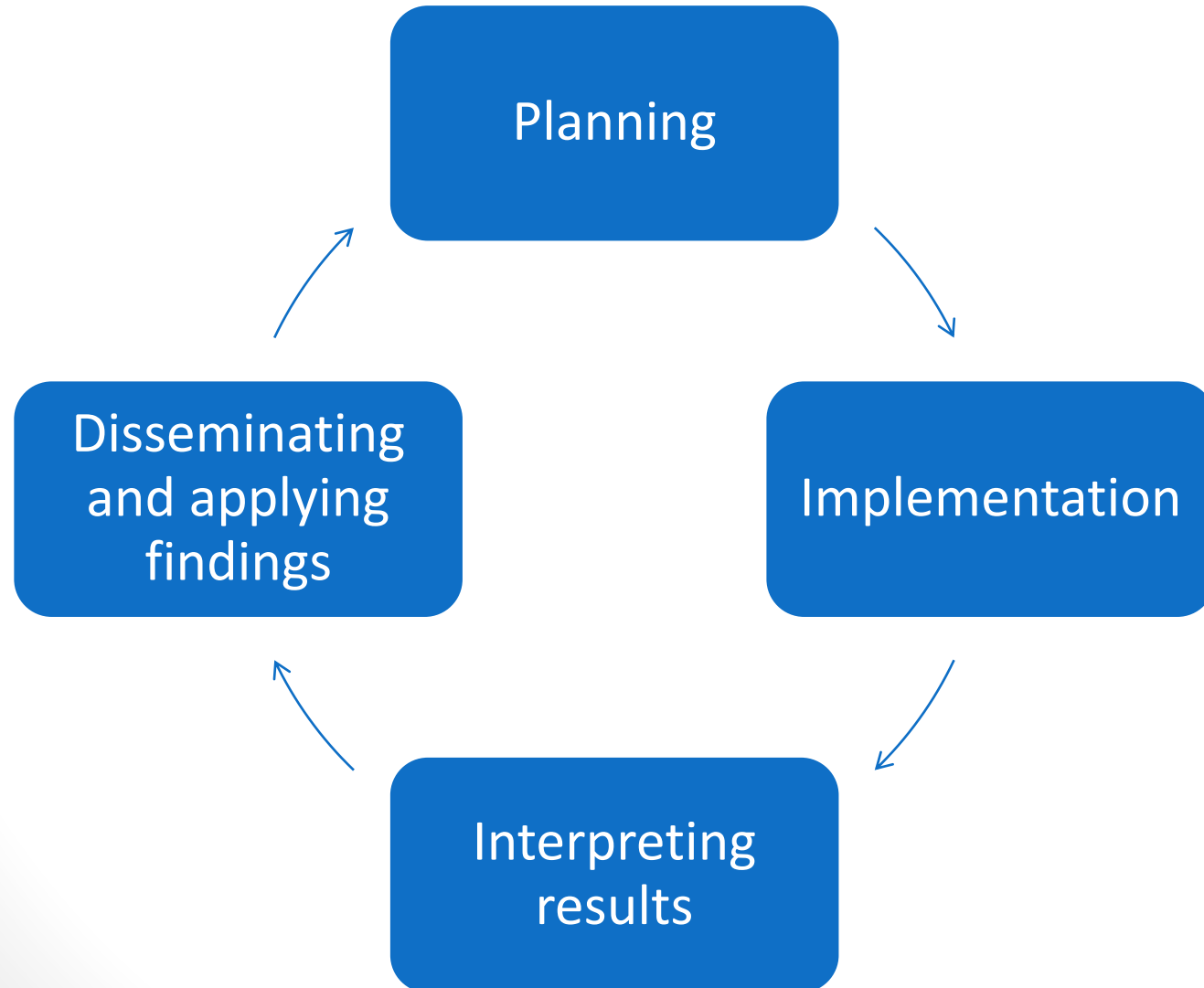
Sages:

- 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



Overcoming Barriers



Discussion



"Patients are our true north."

—Harlan Krumholz, MD
PCORI Board of Governors