Sages in Every Setting

CJE SeniorLife

Overview of the Bureau of Sages Model

Contents

This document describes how the Bureau of Sages was originally developed. This document can be used to help conceptualize or plan the creation of new research advisory boards. The document may be helpful for partners, researchers, or other stakeholders interested in learning about the Bureau of Sages model.

This project was funded by the Patient Centered Outcomes Research Institute through a Eugene Washington PCORI Engagement Award (2606-CJE).

History

Researchers at the Leonard Schanfield Research Institute of CJE SeniorLife developed the Bureau of Sages with funding from the Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (2640-CJE). Older adult members received training on basic research concepts that enabled them to talk about research and interact with researchers, while researchers and clinicians gained experience working with Bureau members as equals.

Over the course of two years, a team of staff and volunteers facilitated meetings and sought real-time feedback from all participants in the development experience. Project staff and research coaches supported members and participating researchers/clinicians in a collaborative process to develop materials and procedures for sustaining the Bureau of Sages as a permanent research advisory board at CJE SeniorLife. In Year 2 of the project, guest researchers joined some retreats or meetings to seek feedback on their projects or to join discussions.

The Bureau of Sages was originally made up of older adults receiving Long Term Services and Supports (LTSS) in a nursing home or while staying at home, research stakeholders, and research coaches, who met for half day quarterly retreats for research learning activities. Older adult members also attended training meetings in between retreats. Those members who were stay-at-home later became part of their own Bureau of Sages which meets virtually. During Year 1 of the project, members collaborated with research stakeholders, research coaches and project staff to develop the mission, vision and value statements, listed below:

Mission

Empowering nursing home community members and stay-at-home elders to learn and collaborate with researchers to advocate for timely, useful studies that matter to them.

Vision

Improved lives for older adults as the result of patient-centered

Values

1. **Speaking Our Language** – Using communication strategies that enable older adults to understand researchers and other professionals.
2. **Listening** – Fostering the art of listening so that older adults "feel heard."
3. **Compassion** – Taking the time to feel or empathize with what older adults feel.
4. **Mutual Understanding and Respect** – Actively reaching out to understand each other in respectful ways.
5. **Sharing Perspectives through Open Dialogue** –Fostering conversations that result in a meeting of the minds through the sharing of diverse views and concerns from all participants on the Bureau.
6. **Unity through Teamwork** –Working together as patients and professionals to achieve shared goals and outcomes.

Roles and Responsibilities

Researchers from the Leonard Schanfield Research Institute at CJE SeniorLife served and continue to serve as the **Research Partner**. They have been responsible for reaching out and marketing to researchers, and providing them with materials and guidance on how to present their work to the Bureau of Sages for input. They also train and support Research Coaches and coordinate meeting logistics with Provider staff.

The Lieberman Center for Health and Rehabilitation of CJE SeniorLife serves as the **Provider Partner**. They designate one or more staff members to be responsible for assisting with member recruitment, informing floor staff of the Bureau meeting schedule, ensuring that members come to their meetings and events. Sometimes staff will also observe meetings.

The Bureau of Sages used to use the term **Research Coach** to describe the person who facilitates training and discussions with members. Research Coaches have included volunteers, interns or provider staff members. They facilitate all advisory board training, meetings and events, document notes or minutes, and assist with preparing materials and products. They play a critical role in the successful engagement of members, because they are familiar with individual's preferences, capacities and needs for support. They also help develop positive group dynamics that enable meaningful interactions with researchers. Some research coaches were also familiar with research so that they were able to "translate" between participating stakeholders from both worlds.

Recruiting and Training Research Coaches

Potential Research Coaches are interviewed by a research staff member, and complete all requirements of our volunteer department. A research staff member or existing Research Coach provides an orientation to facilitation resources and members, after which they typically observe a meeting and then lead or co-lead a meeting and debrief with a research staff member or other Research Coach. Research Coaches are asked to provide a biosketch as an introduction to Bureau members.

Research Coaches are expected to:

- Create positive conditions for co-learning and engagement by fostering a welcoming atmosphere of mutual understanding and respect in an unintimidating environment
- Collaborate with members as equals; including preparing a biosketch
- Listen to, understand, and respect the perspectives of members and researchers
- Be willing to serve as research coach for three months to one year (important for building rapport with members and maintaining continuity in facilitation of meetings – timing is up to the individual advisory board)
- Adhere to any volunteer policies

Recruiting and Training Advisory Board Members

Members were initially recruited in collaboration with Provider staff members, who helped to identify individuals with potential interest and ability to participate in group discussions of research. Members received orientation and training over the course of the two year Bureau of Sages project, and quarterly retreats with researchers were designed to foster co-learning.

As the first advisory board of its kind, it was difficult to explain the purpose of the advisory board and the role of members. Research Coaches first explained to members they would learn something about research, share their care or health experiences, and learn how to talk to and understand researchers. They found creative ways to carefully revisit the purpose of an advisory board and expectations for members on many occasions. Early on in the development process, research coaches tried to set realistic expectations among members by giving examples of how long things can take (e.g., a year or two to develop an advisory board, six months to come up with a mission, and months for a researcher to develop a proposal).

Training was largely discussion-based and hands on. We found that asking members to share “thoughts” or “ideas” (as opposed to more personal views or opinions) was most productive. Members sometime brought up problems in the their care setting, thinking that the advisory board could do something to improve care at their facility. As members became more familiar with their role, we could remind them that personal concerns could be addressed in other ways. Research coaches would prompt discussions that encouraged members to recognize how others living in similar situations also had these experiences and how the purpose of the advisory board was to advocate for them as well.

Meeting Structure

Currently the Bureau of Sages at CJE SeniorLife holds regular meetings at the nursing home twice a month for one hour. In between advisory sessions with researchers, members review research concepts and discuss research articles and topics, as part of their ongoing training. Meetings with researchers are held either in person or virtually.

The Virtual Bureau of Sages meets virtually twice a month for an hour as a separate advisory board and has since expanded to include older adults living in New York City. During the project period, CJE partnered with the SelfHelp Home's Virtual Senior Center, or VSC, to host the Virtual Bureau. The VSC has a user-friendly interface and the ability to video chat with a group or access email. All members had been using the VSC for at least a year before joining the Virtual Bureau, so they had already received affordable access to all needed technology, personalized set up in their home, training on how to use the platform features, and ongoing support from tech "buddies." Members understood that there can be interruptions in service or other technological challenges that require patience. A volunteer Research Coach continues to facilitate their meetings on this platform.

Research Advisory Services

The Bureau of Sages serves as:

- An advisory board to CJE SeniorLife's internal research department
- An advisory board for local and national researchers who wish to conduct Patient-Centered Outcomes Research or Comparative Effectiveness Research (PCOR/CER)
- A connection to opportunities for individual members to participate in larger patient-powered research networks or patient-centered research collaboratives
- A vehicle for members to serve as champions and role models for other older people in their situation, by advocating for including their voice in research

Since its inception, the Bureau of Sages has provided feedback on research topics or priorities, proposal ideas, recruitment and data collection strategies, interpretation of results, and methods for disseminating results. They have also provided input on priorities for research and policy regarding the needs of older adults and their caregivers.

Research Advisory Meetings

In the Bureau of Sages, engagement sessions are most effective when researcher presentations are limited to 10-20 minutes, followed by a 40-50 minute facilitated discussion that allows members to express their experiences and views. Researchers typically come with 2-4 questions for members to discuss. The Bureau of Sages provides researchers with templates for a one page lay biosketch and a simple public summary of their research, along with tips for communicating with members and other facilitation resources. After receiving input from members, the Bureau of Sages asks researchers to complete a satisfaction questionnaire, and let members know how their input was used to shape priorities, revised recruitment strategies, interventions or methods. Researchers are encouraged to inform members on the results or impact of their study and to seek input on dissemination strategies for nonresearch audiences.

Researchers who seek input from or participate in the Bureau of Sages have experience with or interest in aging research, understanding perspectives of older adults, person-centered care, patient-centered outcomes, and/or comparative effectiveness research. To effectively engage advisory board members, researchers should be familiar with common strategies for patient engagement and accommodating the needs and preferences of older adult learners. They are expected to:

- Communicate research ideas and concepts in everyday language
- Collaborate with members as equals
- Listen to, understand, and respect diverse perspectives
- Engage in mutual learning

We also encourage researchers to advocate for patient-centered research by sharing learning from members through professional presentations, publications, etc.

Adapting Resources from the Bureau of Sages Model

CJE Seniorlife provides online resources for creating research advisory boards, which include samples of materials used by the Bureau of Sages or other research advisory groups created through the Sages in Every Setting project. Each advisory board can and should adapt these materials to address the unique characteristics of LTSS recipients that make up the advisory board or conditions in the setting. If Bureau of Sages materials are not easily adapted to fit the setting, then advisory boards should develop their own materials.

The resource page also provides a sample orientation brochure in a separate document, which gives an overview of the Bureau of Sages. This can be edited to include the advisory board's own by mission, vision, recruitment language and other details.

The core elements of research training for Bureau members are provided in "Facilitation Guides, Agendas, and Tools," which includes examples of agendas, talking points, learning activities and slides. That document includes tips on how to amend this set of guides for an 8-week training program, as well as some sample agendas from the earlier retreat events. Facilitators of advisory boards can and should tailor the design of specific activities, timeframes, contents, formats, and procedures to meet the needs of their members.