USING THE BUREAU OF SAGES MANUAL

This manual was developed specifically for the purpose of operating the Bureau of Sages at CJE SeniorLife as an ongoing research advisory board. We provide it as one example of how to structure and operate an advisory board of nursing home residents and older adults living with frailty at home. The procedures and processes for sustaining the Bureau at CJE SeniorLife may help others develop their own Bureau or similar advisory board. Others can use this manual to identify basic principles, guidelines, or types of activities that have worked for us, while making adjustments and adaptations to fit the unique features of and conditions in the setting, as well as the needs of the target population.

Please reference this manual as follows, if used or cited:


This project was funded by the Patient Centered Outcomes Research Institute through a Eugene Washington PCORI Engagement Award (2640-CJE).
A MANUAL FOR RESEARCH COACHES AND CJE STAFF
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INTRODUCTION

The Bureau of Sages is a research advisory board made up of Lieberman Center Community residents and older adults staying at home with assistance, with participation from guest clinicians and researchers. Participants share experiences, build knowledge, and develop skills for working tougher to provide voice to the direction, design, and implementation of research on aging.

Purpose of the Manual

This manual is for staff and volunteers at CJE SeniorLife who coordinate and facilitate the day to activities of the Bureau of Sages. The manual includes descriptions of the history, purpose, roles, responsibilities, guidelines and procedures of the Bureau. This manual serves as:

1. A guide for sustaining the Bureau as a permanent entity at CJE SeniorLife
2. An orientation for Research Coaches or staff who are new to the Bureau.

The manual is intended for use specifically at CJE SeniorLife, as certain aspects of the Bureau are likely to be unique to this setting. Please contact Dr. Amy Eisenstein for more information about how to use the Bureau of Sages as a model, if you are interested in developing a similar advisory group of older adults in another setting.

History

Starting in January 2016, the Leonard Schanfield Research Institute developed the Bureau of Sages over a two-year period, with funding from the Patient-Centered Outcomes Research Institution (PCORI) Eugene Washington PCORI Engagement Award (2640-CJE). In Year 1, older adult members received training on basic research concepts that enabled them to talk about research and interact with researchers. Clinicians and researchers were included in the development phase of the Bureau to foster communication and collaboration among Research Stakeholders that would empower Sages to contribute their voice. The project team also developed tools and tips for researchers regarding how to seek input from Sages. In Year 2, Sages experienced developing their own research proposal, and presented that experience to the community and at a local aging conference. In collaboration with Research Stakeholders, they prepared guidelines and procedures and guidelines for sustaining the Bureau of Sages as a permanent research advisory board at CJE SeniorLife.

Structure of the Bureau

The Bureau convenes two types of meetings, as shown below. Lieberman Community Sages and the Virtual Senior Center Sages meet separately in “Sage Meetings”. Both groups come together quarterly for “Advisory Group Meetings” with Research Stakeholders, where they serve as experiential advisors to researchers.
Research Advisory Services

Since its initiation, the Bureau has provided feedback on research topics, proposal ideas, data collection strategies, 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.

The Bureau of Sages serves as:

- An advisory bureau to CJE SeniorLife’s internal research department
- An advisory bureau for local and national researchers who wish to conduct Patient-Centered Outcomes or Comparative Effectiveness Research
- A connection to opportunities for individual Sages to participate in larger Patient-Powered Research Networks or patient-centered research collaboratives
- A vehicle for Sages to serve as champions and role models for other older people in their situation, by advocating for including their voice in research

For examples of research topics that Sages have provided their input on and a list of Desired Health Outcomes that Sages feel should drive research priorities, please refer to Appendices A & B.

Participant Roles and Responsibilities

The Sages are older adults living with frailty who serve as the members of the Bureau. There are two groups of Sages: those who live in the Lieberman Community and those who live at home and connect through the Virtual Senior Center. Biosketches of current Sages are available on Bureau of Sages website at https://www.cje.net/research-education/bureau-sages .. Requirements and procedures for joining the Bureau as a Sage are described in the section “Sage Recruitment, Orientation and Training.”
**Research Coaches** are volunteers, interns or CJE staff members who facilitate all Bureau meetings and events, document notes or minutes, and assist with preparing the products of the Bureau. They play a critical role in the successful engagement of Sages, because they will be most familiar with individual’s preferences, capacities and needs for support in their role as a Sage. They also help Sages develop positive group dynamics that enable meaningful interactions with Research Stakeholders. The application and orientation process for Research Coaches is described in the section “Becoming a Research Coach.”

**Research Stakeholders** engage with the Bureau of Sages in discussions and feedback regarding their research. Their role is integral in helping to improve rapport between older adults and researchers/clinicians. Through their participation, they seek Sages input on research and share their research knowledge on topics that matter to older adults. Research Stakeholders can include anyone who has vested interest in the direction, design, implementation, and dissemination of research on aging. In the past, meetings have been attended by researchers, clinicians, and care staff at CJE. Researchers or other professionals have also been asked to participate in discussion of research topics or other education at Sage Meetings. Expectations and procedures for seeking input from the Bureau of Sages are described in the section “Researcher Stakeholder Engagement.”

CJE staff also play a role in sustaining the Bureau and assisting with its activities. The **Leonard Schanfield Research Institute** (CJE’s Research Department) supports Bureau activities in the following ways:

- Reaching out and marketing to Research Stakeholders, through contacts with universities, professional organizations, and at conferences.
- Identifying qualified Research Stakeholders to seek input at an Advisory Group Meeting.
- Identifying qualified Research Stakeholders to participate in a Sage Meeting.
- Providing orientation materials and any required forms to Research Stakeholders before they attend any Bureau meetings.
- Recruiting, orienting and supervising Research Coaches by providing them with this manual.
- Orienting and supervising incoming CJE staff involved with the Bureau by providing them with this manual and sharing the manual with CJE staff who provide staff orientations.
- Co-facilitate Advisory Group Meetings with Research Coaches and staff.
- Attending any events, presentations or publications that showcase the Bureau of Sages.
- Monitoring feedback from Sages, Research Coaches, Research Stakeholders and CJE Staff to improve Bureau activities.
- Conducting continuous quality improvement on all activities of the Bureau.

**Lieberman Center** designates a staff person to be responsible for assisting with recruitment of Sages, informing floor staff of the Bureau of Sages schedule, ensuring that Sages are brought to their meetings and events, and attending or co-facilitating Sage meetings.
Mission, Vision and Values

During Year 1 of the project, Sages collaborated with Research Stakeholders, Research Coaches and project staff to develop 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 research

**Values**

- Speaking Our Language
- Compassion
- Mutual Understanding and Respect
- Unity Through Teamwork
- Listening
- Sharing Perspectives through Open Dialogue
- Sharing Perspectives through Open Dialogue
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.
BECOMING A RESEARCH COACH

Qualifications

CJE’s research department identifies Research Coaches through university internship or practicum programs, through CJE’s Volunteer Department or via other volunteer programs. Volunteers may contact CJE if they are interested in becoming a Research Coach.

Research Coaches qualifications can include, but are not limited to:
- Training or experience with research
- Education, experience or interests related to aging
- Prior experience communicating or working with older adults living with chronic illnesses, impairments, or disabilities
- Demonstrated commitment to understanding the perspectives of nursing home residents or older people living with chronic conditions or disabilities
- Commitment to person-centered long term care or patient-centered healthcare
- Desire to learn about Patient Reported Outcomes and Comparative Effectiveness Research

Expectations and Responsibilities

Research Coaches facilitate the activities of the Bureau of Sages and are expected to:
- Collaborate with Sages as an “equal”
- Listen to, understand, and respect the perspectives of Sages and Research Stakeholders
- Adhere to CJE volunteer policies
- Be willing to serve as Research Coach for one year (important for building rapport with Sages and maintaining continuity in facilitation of Bureau meetings)
- Sign a Contract of Commitment to the Bureau of Sages
- Prepare a Bureau of Sages biosketch, using the same format at Research Stakeholders (see below)

Research Coaches responsibilities are to:
- Facilitate or co-facilitate all meetings with Sages
- Assist Sages and CJE staff with scheduling Sages’ meetings and other Bureau events
- Assist with recruiting new Sages
- Orient new Sages and facilitate refresher training at Sage Meetings
- Support Sages’ abilities to communicate and interact, including those who have hearing, vision or other impairments.
- Assist professional presenters in communicating with Sages.
- Document Sages discussion or other work via notes or minutes
- Prepare any products of the Bureau, in collaboration with Sages.
- Orient potential Sages and train new Sages in basic research knowledge.
- Assist with coordinating logistics for meetings and events.
• Provide ongoing feedback to improve Bureau activities.

Orientation Procedure

This manual serves as an orientation and guide for Research Coaches, and includes materials for working with Sages (see Appendices). General guidelines for orienting and training Sages, as well as facilitating training and meetings are summarized in the next section of this manual. CJE staff member(s) provide supervision and support for Research Coaches.

The orientation procedure for volunteer or intern Research Coach is as follows:
• Initial interview with the Director of Research
• Upon offer and acceptance of position as Research Coach, review this manual; and meet with Director of Research to discuss any questions
• Complete all CJE required volunteer procedures, orientation and forms
• Observe a current Research Coach or CJE staff member facilitate two Sage Meetings
• Facilitate a Sage meeting under supervision of an existing Research Coach or CJE staff member
• Report to/meet with supervisory staff member, as required by them (at least monthly)

When discontinuing the role of Research Coach, we ask that he/she complete an exit questionnaire to help us improve the program.
SAGE RECRUITMENT, TRAINING AND FACILITATION

To become a Sage, an older adult must be either a resident of Lieberman Center or living at home and a participant of Self Help Community Services’ Virtual Senior Center. They must be comfortable participating in online interactions and discussion.

CJE staff or other professionals can identify potential Sages, using the criteria listed below. Older adults may also nominate themselves to become a Sage, if they meet the qualifications and expectations listed below.

Qualifications

In order to serve as a Sage, older adults are expected to demonstrate a commitment in one or more of the following areas:

- Have a desire to “give back” or “make a difference”
- Be interested in learning about research.
- Make a commitment to try their best to attend meetings and stay actively engaged.

Expectations and Responsibilities

New Sages are expected to sign a Contract of Commitment in which they agree to:

- Participate in orientation to the Bureau and training about engaging with researchers (as described below).
- Participate in Sage Meetings and Advisory Group Meetings for a two year period or as able.
- Engage in interactive activities and group discussions without undue burden or stress.
- Express their thoughts and ideas.
- Listen to, understand, and respect the perspectives of others.
- Respect any group rules for discussions.
- Be willing to share information about their participation in Bureau activities in presentations and publications
- Provide ongoing feedback to improve Bureau activities and participate in evaluations.
Orientation Procedure

Once a potential Sage has been identified:

1. The Research Coach provides an orientation to the Bureau of Sages, in a small group format or one on one, using the Orientation Slides (Appendix C), and provides each person with the Bureau of Sages Pamphlet as a take away (Appendix D).

2. The Sage then decides if he/she wishes to join the Bureau and signs a Sage Contract of Commitment.

3. The Research Coach then meets with the Sage a one on one to interview them for purposes of creating a biosketch (Appendix E) and eliciting a brief story about a positive experience related to health or care.

4. In a second one on one meeting, the Research Coach and Sage work collaboratively to finalize the biosketch and review the story themes for accuracy.

5. The Sage can then begin attending Sage Meetings for research training; new and existing Sages jointly participate in 4-6 “refresher” training sessions.

6. New Sages may also participate in Advisory Group Meetings.

Research Coaches have some flexibility in how they choose to use orientation materials. In general, the Research Coach determines how much information to share with potential Sages, depending on their attention spans, learning styles and sensory impairments. For instance, the pamphlet can be disseminated as a take away at recruitment events or to individuals who have been identified as potential Sages. The orientation slides can be used in different ways, depending on the needs of the older adult audience: 1) as a slide presentation either in person or online or as a printed handout, 2) as a printed orientation packet to go over with an individual, one on one, 3) or as a guide for the Research Coach to use in any way that best fits the situation. In the latter instance, the Research Coach may decide to present fewer slides to Sages, but use the full packet to guide their presentation or conversation with a Sage. Please note that the slides include notes with talking points or additional information for the Research Coach; these can be printed in the notes format within PowerPoint. Orientation can be done over more than one session, in the event potential Sages need more time to process the information. Additionally, any or all of the orientation can be repeated at a Sage Meeting, when new Sages come on board, as a refresher for everyone.

Facilitating Research Training and Meetings

New Sages are trained alongside existing Sages, during regular Sage Meetings. Research Coaches are provided with facilitation tips (Appendix F) as well as facilitation guides, references materials and handouts for Sages, for each training activity (Appendix G). There are six training topics or activities, designed to be repeated whenever new Sages join the Bureau. Research Coaches can determine the best timing for refresher training. The recommended order (Appendix I) is designed to build and reinforce learning for both new and existing Sages over a 2 to 3 month period. We recommend that each Sage Meeting be co-facilitated by a research
coach and staff member. Research Coaches also assist Research Staff with preparing Sages for Advisory Group meetings and co-facilitation.
RESEARCH STAKEHOLDER ENGAGEMENTS

Researchers and other professionals who wish to seek input from the Bureau of Sages must first contact the Director of CJE’s research department, the Leonard Schanfield Research Institute. If a researcher approaches a Research Coach or CJE staff member directly, please refer them to the Research Director, Dr. Amy Eisenstein (amy.eisenstein@cje.net or 773-508-1040 first.

Expectations

Researchers who seek input from or participate in the Bureau of Sages are expected to:

- Have experience with or interest in aging research
- Be committed to any of the following:
  - Understanding the perspectives of nursing home residents and other older people living with frailty
  - Person-centered long term care or patient-centered healthcare
  - Patient Reported Outcomes for older people
  - Comparative Effectiveness Research involving older people
- Collaborate with Sages as an “equal” and actively engage in mutual learning.
- Communicate research ideas and concepts in everyday language
- Listen to, understand, and respect the perspectives of Sages and other research stakeholders
- Advocate for patient-centered research by sharing learning through professional presentations, publications, etc.

Research Review Procedure for Advisory Group Meetings

Research Stakeholders can present a research topic, proposal, project or specific method to the Bureau of Sages Advisory Group Meeting for review and input from Sages. Before the meeting, Research Stakeholders responsibilities are to:

- Submit a one page Biosketch, using the Bureau of Sages template (Appendix H)
- Be familiar with the Guidelines for Engaging Sages (Appendix I and Tips for Communicating with Older Adults (Appendix J)
- Review any other recommended readings or materials provided by the Bureau
- Complete a Public Summary for the research presentation, using the Bureau of Sages template (Appendix K)
- Be prepared to briefly define key research concepts or terms in everyday language

After receiving input from Sages, we ask that Research Stakeholders:

- Complete a satisfaction questionnaire (Appendix L)
- Let Sages know how their input was used
- Sages especially appreciate hearing about any or all of the following:
  - How their input shaped research priorities or an aspect of the reviewed project
  - A summary of results from a study that was reviewed by the Bureau of Sages
- How a reviewed study may eventually benefit other people in their situation
- How their input was shared with other researchers or students and/or its potential impact on making research more patient-centered

**Participating in Sage Meetings**

A Research Stakeholder may also attend a Sage Meeting as a guest. They can join a discussion, collaborate with Sages in their work, or provide education on a research-related topic.
APPENDICES
A. EXAMPLES OF RESEARCH CONTRIBUTIONS

Robyn Stone, PhD, Senior Vice President for Research and Executive Director, LeadingAge

“The Bureau of Sages is probably one of the most important projects I’ve been a part of for the past few years. It really puts the nursing home resident and participants of the virtual senior center in the driver’s seat in terms of research, and really for too long these two groups have been dismissed in terms of thinking that they actually couldn’t have anything to say about the research process. What’s wonderful about this program is it really makes them the Sages, they are the ones who actually tell us what is important about research, why we should do research, what questions we really should be asking, and as important, also gets them educated about the research process. I love it as a researcher, because for the first time I actually have insights from populations who have never been asked before and I think not only are they Sages, but this has also empowered them tremendously.”

Project Description:

<table>
<thead>
<tr>
<th>Topic/Condition:</th>
<th>To test a model for services and supports in low income housing that enable older adults to stay in their apartment longer with a good quality of life.</th>
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</thead>
<tbody>
<tr>
<td>Methods:</td>
<td>Incorporate a service coordinator and wellness nurse team into housing for older adults. Residents voluntarily work with this team to build a healthy living plan and wellness goals.</td>
</tr>
<tr>
<td>Population:</td>
<td>Low income older adults living in the community</td>
</tr>
<tr>
<td>Outcomes of Interest:</td>
<td>Health, hospital visits, ER visits, social relationships with peers, ability to manage health problems</td>
</tr>
</tbody>
</table>
Sages Contributions:

- Researchers need to listen more; not assume we know what an older person thinks is a concern or a priority.
- We must overcome the notion that it will be too difficult to get information from older people with various health conditions.
- It is important to realize that even when we think we are including older adults, we may not be.
- Exploring what research means to an older adult as a person (as opposed to just an age group being studied) could change the outcomes.
- The heterogeneity of the population underscores the importance to talk with people of a variety of ages and in a variety of situations.
- There are options to work virtually when we can’t meet with people face-to-face.
Margaret Danilovich, PT, DPT, PhD, Assistant Professor of Physical Therapy and Human Movement Sciences Feinberg School of Medicine, Northwestern University

“The advice and feedback from the Bureau of Sages is invaluable to researchers. This opportunity is unlike any other experience I have had as a researcher by allowing me to share my ideas with the patient population I will be working with to get feedback in the formative stage. For example, selecting outcomes for a research study is commonly driven by what clinicians or researchers view as important. My time with the Bureau positively influenced the selection of measurement outcomes for my research study. Bureau members identified important concepts to assess that I had not considered. Further, during our time together, Bureau members helped problem solve solutions to strengthening a weaker aspect of my grant proposal. In the dissemination plan, Bureau members identified specific strategies to share results with older adults, family members, patient advocacy groups, and policy makers.”

Project Description:

**Topic/Condition:** We are studying a walking intervention for frail and pre-frail older adults

**Methods:** We will conduct 12, 30 minute 1:1 walking sessions and measure outcomes at the beginning, end, and 6 months later.

**Population:** Older adults in the adult day center

**Outcomes of Interest:** frailty, walking endurance, walking speed, balance, fall risk, strength, and quality of life
Sage Contributions:

- Fear of falling
  - There is a measure for risk factors for falls, but fears need to be considered as well, very important to this population.

- There are multiple dimensions to consider for something that seems as simple as walking exercise, these need to be taken into consideration in the research:
  - External/environmental safety
  - Physical barriers, including personal barriers such as wearing supplemental oxygen
  - Financial barriers – Medicare doesn’t cover additional PT
Amy Eisenstein, PhD, Director, Leonard Schanfield Research Institute
CJE SeniorLife, Adjunct Assistant Professor, Department of Medical Social Sciences
Northwestern University, Feinberg School of Medicine

“The opportunity to work with and learn from the Sages has been one of the greatest benefits of my work here at CJE SeniorLife. As a researcher in the field of Aging, I feel it is imperative for me to receive input from older adults into the direction and design of the work that I do. After all, neither I nor any of my colleagues have experienced growing into our 80’s or 90’s, living in a nursing home, or having chronic limited mobility due to a medical condition. Without that experiential knowledge, we are limited in our ability to determine what should be our highest priority research topics, the methodologies that will be most effective and meaningful outcomes. The Sages have provided insights which have greatly benefited my work and have led to research being funded. I am confident that this effort will ultimately help provide dignity and quality of life to future generations of older adults.”

Amy, the Director of the Leonard Schanfield Research Institute (LSRI) at CJE SeniorLife, presented to the Bureau of Sages members during one of their Sage Meetings to get feedback on the CJE SeniorLife Research Agenda.

After reviewing the Mission and Vision of the Leonard Schanfield Research Institute, Sages discussed various research projects under consideration by LSRI.

Research Project 1: Aging With Disability - Community Health Workers to provide peer support to persons aging with disability

Research Project 2: Friendly Caller - Creating a volunteer panel of friendly callers to help reduce isolation in the community

Research Project 3: Quality of Life in a Nursing Home - How do we assess and understand how quality of life is impacted by living in a nursing home?

Research Project 4: Engaging Older Adults in Research - how do we expand and enhance the Bureau of Sages project?
Sages Contributions:

- Sages discussed and made recommendations to enhance each research project. Some examples include:
  - Adding a component of cognitive activity to the menu of options that community health workers could work with older adults on.
  - Needing to schedule extra time for interviews on quality of life with older adults in order to develop rapport and get truthful responses.
  - Expanding opportunities for self-advocacy among older adults, and creating additional Bureau’s across the country for the Bureau of Sages to network with. Being heard and acknowledged as an older adult not only has the potential to impact future generations, but also increases quality of life and satisfaction of the person being heard. All of these things should be measured and recorded.
  - The need for increased opportunities for social connection such as writing groups and discussion groups to learn about each other
  - Interactions with staff could greatly improve quality of life, and staff must be considered in any research being conducted (staff at a nursing home and in a care relationship at home).
  - Older adults need to be treated and written about as persons who is ‘able’

Suggestions for new directions for the department to consider from the Sages:

- “Living in our shoes” as part of a field training for nursing home care staff
- Using Amazon Echo technology to address issues of loneliness, check vitals, and gain independence through purchasing power for nursing home residents
- Wheel chair topics
  - Ageism and perceptions – how people are treated differently when they are in a wheel chair, etc.
  - Getting attention of people when you are not eye to eye
  - New technology possibilities, for example stand-up wheelchairs
Hailee Gibbons, PhD candidate, Disability Studies, University of Illinois at Chicago & Research Coach for the Bureau of Sages

“Presenting my dissertation proposal to the Bureau of Sages was an invaluable experience. My interest in dementia is grounded in my personal experiences volunteering in dementia units of nursing homes since I was 16 years old. However, as a young adult, I have yet to experience old age or care in an institution. After my presentation, the Bureau of Sages assured me that my project was significant and innovative. As a young researcher and emerging scholar, receiving feedback from the Bureau of Sages was encouraging and affirming, but also pushed me to examine my study more holistically and incorporate factors I had not previously considered.”

Project Description:

<table>
<thead>
<tr>
<th>Topic/Condition:</th>
<th>Explore the lived experiences of old women with dementia and the women who care for them in an Alzheimer's Special Care Unit in a nursing home in the Chicagoland area</th>
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<tbody>
<tr>
<td>Methods:</td>
<td>Ethnography - explore how these social locations intersect to influence interactive moments, relationships, and acts of care in an institutional context</td>
</tr>
<tr>
<td>Population:</td>
<td>Two multiply marginalized groups in American society: old women with dementia living in special care units in nursing homes, and the women who are employed to care for them, many of whom are low-income immigrant women of color</td>
</tr>
<tr>
<td>Outcomes of Interest:</td>
<td>How disability, age, gender, race, ethnicity, class, and immigrant status are constructed and coconstructed within dementia care</td>
</tr>
</tbody>
</table>
Sage Contributions:

- This project is important and relevant – the “day in the life” of a nursing home resident is not well understood.
- Focusing on how people living with dementia are treated will help to understand how to improve in care could be made, and outcomes will be improved.
- Inclusion of Family members
  - How will they be involved in the study? It is important for Hailee to consider the role that family members play in the nursing home.
B. SAGES’ DESIRED HEALTH OUTCOMES

This list was developed based on Sages personal experiences with successfully getting attention for a health or care issue. Themes from their stories are listed under each outcome.

Outcome 1: Maximized independence in care settings

- Feeling a sense of “freedom” or independence regardless of physical abilities
- Figuring out how to do everyday things despite your limitations (e.g., transportation, adjusting to limits, getting a hospital bed with heat/massage, walking, getting places, etc.)
- Care staff helping me do what I need assistance with
- Having the ability to self-advocate, communicate with clinician, and do your own research on health issues; in nursing homes, a clear, direct process to advocate for ourselves

Outcome 2: Feeling cared for and heard by care providers

- Having care providers that think outside the box, do something creative, try different solutions, and don’t give up
- Having care providers who listen, are responsive, authentic, caring, comforting, and attentive
- Getting attention for concerns and needs; getting an immediate response (e.g., timely response to call lights and verbal requests for help)
- Having someone advocate for you
- Feeling taken care of (with authenticity); gratitude
- Resolution of a terrifying or difficult moment due to unexpected or caring assistance from others
- Having a coordinated “team” of care providers

Outcome 3: Opportunities for social connections

- Being able to communicate (be verbal) with others
- Being able to connect with other people; opportunities for socialization
- Being able to give back, being able to help others

Outcome 4: Well-managed chronic symptoms

- Reduced pain, fatigue, discomfort or other symptoms
- Having distractions from symptoms or concerns (e.g. activities that you enjoy)

Outcome 5: Opportunities for feeling positive

- Having feelings of hope or positive attitude
- Being able to see life as a journey and a moving target, acceptance
- Feeling better in the moment
C. BUREAU OF SAGES ORIENTATION SLIDES AND FACILITATION NOTES

Bureau of Sages

Becoming a Sage
(Orientation Session)

What is the Bureau of Sages?
An advisory group of older people committed to
improving research on aging

Talking points:
- An advisory board to researchers
- A partnership with research stakeholders
• Who are research stakeholders?—researchers and professionals who use research in their work such as clinicians, service providers, care providers

What does research mean to you?

Words to describe your feelings about research:

(There are no right or wrong answers.)

Talking points:
• [goal is to explore perceptions of research, good or bad]
• What are some words to describe your feelings about “research”? (There are no right or wrong answers)
• [Elicit at least 3 words from participants; Briefly comment on any negative or positive connotations of those words. If needed, use a few of the following examples]
  • Negative: Intimidating…Confusing…Contradictory…Misuses…Not believable…
  • Somewhat Neutral: Technical…Evidence…Experimental…Hypotheses…Knowledge
  • Positive: Fascinating…Important…Improvement…. Innovation…Useful]

Research is part of human nature…everyday we explore and process information, create categories, compare things, synthesize, and learn

OPTION: Provide one “ordinary” example of an activity that is like research: How is a gardener like a researcher? A gardener builds on prior knowledge and then…
• Determines purpose of the garden
• Makes a plan—design, location, types of plants, when to plant, etc.
• Plants and tends the garden
• Shares results with others (e.g., beauty, produce)
• Learns from results or challenges and tries again!
Example is based on brainstorming sessions with service providers in a research and evaluation training provided by ASSERT at Northwestern University, a program developed and led by Madelyn Iris & Rebecca Berman

**RESEARCH**

**Definition:** Systematic documentation of information for a specific purpose that produces credible evidence to build knowledge.

Talking points:
Research process should always start by reviewing what is known and not known and always end with using results, to either do more research or, ideally, to make a difference in people’s lives based on something we learned

1. Ask a question that matters (relevant, important, etc.)
2. Make a detailed plan for how to answer that question
   - All the methods, procedures, tools, etc,
   - But also accounting for factors that might affect the findings (potential bias)
   - And having a plan for how to protect participants from potential risks of the study procedures
3. Systematically gather, record, analyze and interpret data
4. Report results honestly, including any limitations, biases, negative results

There are Many Types of Research

A few examples in the field of health:
• Describing something—e.g., prevalence of health conditions.
• Developing or testing theories—e.g., theories about what causes aging.
• Testing treatments—e.g., clinical trial of a medication.
• Assessing programs—e.g., evaluation of a health education program.

Wrap Up/Transition to next slide on Purpose of Bureau
Researchers are not necessarily good at translating what they do for everyday audiences
They may not know how to incorporate the voices of those being studied, especially if they don’t understand their day to day lives
That is one of reasons we formed the Bureau of Sages! They help researchers learn how to talk with older people!
This will help them make sure that research about older people (or aging) reflects their needs and concerns
What is the Bureau’s purpose?

- Promote relevant research about aging, health and care.
- Advise researchers at CJE SeniorLife, locally and nationally.
- Promote some specific types of research:
  - Patient-Center Outcomes Research.
  - Comparative Effectiveness Research.
- Connect Sages with other ways to be involved in research.

How was the Bureau developed?

CJE SeniorLife Research Department worked with Sages to develop the Bureau (2015 to 2017).*

- Trained Sages about basic research concepts, so they could talk with researchers.
- Oriented researchers how to talk with Sages about research in everyday language.
- Gave Sages the experience of developing an idea for research (a research proposal).
- Developed a structure and procedures for how to operate as an ongoing advisory board.

*Funded by the Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (2640-CJE).

Talking Points:
- Trained Sages
  - focused on basic principles and key terms
  - because we need to be able to “speak basic research language” in order to talk with researchers
• Oriented researchers
  o focused on how to listen and communicate and how to explain key terms or concepts...
  o Because they need to translate or “speak our language” as well
• Experienced developing research proposal
  o to learn how complicated that process can be
  o Because we need to understand what researchers have to think about and plan for
  o Did this in consultation with researchers (getting their input and feedback)
• The overall strategies for developing the Bureau
  o Foster two way communication
  o Hear each other
  o Expand our views
  o ...a TEAM EFFORT!
• What is PCORI?
  o An independent, nonprofit organization authorized by Congress in 2010.
  o Their Mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions.

Talking points:
• Our end goal...our vision
Talking points:

- What does the Bureau do to make this vision happen?...Our mission

Examples of research that has been discussed or reviewed by the Bureau of Sages:

- Understanding the role of resilience when aging with a disability
- Testing an exercise program for persons with physical limitations
- Testing a federal demonstration project to connect senior housing residents to care and services in their own buildings
- Using poetry as a tool for patients to communicate what they are feeling with their physicians
- The Bureau will also review research that compare two different strategies for addressing a problem to see what works better—an example might be comparing different ways to manage pain such as 1) medications only VS. 2) medications along with meditation
Who participates?

- Sages (members of the Bureau):
  - Older adults living at Lieberman (6-8).
  - Older adults who receive care in their home (3-7).
- Research Stakeholders:
  - Researchers and clinicians.
  - Who else could participate?
    Anyone with a vested interest in research on aging, quality of care, quality of life for older adults.
  - Examples?

Examples of other possible research stakeholders...can either ask for some or list a few

- Nurses and care assistants
- Nutritionist
- Health care education specialists
- Family caregivers

How Does the Bureau Work?

SAGE MEETINGS
(Sages meet in separate groups)
Lieberman Community
Virtual Senior Center

Twice a month, for 1 hour
Weekly, for 1 hour

ADVISORY GROUP MEETINGS
(All Sages meet with 1 or 2 researchers)
Quarterly, for 3 hours
Talking Points:

Purpose of Sage Meetings—
- Receive ongoing research training and practice in how to talk to researchers
- Discuss research topics and ideas
- Review our priorities for research
- Discuss the “health outcomes” we want researchers to focus on
- Have guest Research Stakeholders come to either provider training or participate in our discussions

Purpose of Advisory Group Meetings
- Hear from 1-2 researchers about their projects and give them feedback
- The Research Department will get requests from researchers to get our input; they will screen those researchers and prepare them to talk with us
- The Research Department will come to us for input on research they are doing here at CJE

Full Values Statement:
In order to fulfill our mission and realize our vision for research driven by older adults, the Bureau of Sages aspires to a set of core values to guide our work. [go over the definitions below]

- **Speaking Our Language** – Using communication strategies that enable older adults to understand researchers and other professionals.
- **Listening** – Fostering the art of listening so that older adults “feel heard.”
- **Compassion** – Taking the time to feel or empathize with what older adults feel.
- **Mutual Understanding and Respect** – Actively reaching out to understand each other in respectful ways.
• **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.

• **Unity through Teamwork** – Working together as patients and professionals to achieve shared goals and outcomes.

Talking points:
- Annual Event to showcase the work of the Bureau
- Possible participation in presentations or videos
What makes a Sage?

1. Desire to “give back” or “make a difference.”
2. Interest in learning about research.
3. Any of the following:
   - Personal experience as a patient or care recipient.
   - Interest in advocating for older adults.
   - Prior work health care or long term care.
   - Prior experience with any kind of research, as a subject or researcher.

Responsibilities of a Sage

- Work as a team and learn together.
  - Participate in group discussions.
  - Express thoughts, share ideas, and ask questions.
  - Respect the views of others.
- Interact with researchers/professionals.
  - Hear about studies.
  - Provide constructive feedback on research.
  - Advocate for research that matters to older people.
- Represent the voice of other older adults in living in similar situations.
Expectations

- Serve on a voluntary basis, for two years.
- Participate in one on one and small group training in how to talk with researchers.
- Participate in Bureau meetings.
- Be willing to share information about their participation in Bureau activities in annual events, videos, presentations or publications.

What can you bring to the table?

- Share your health and care experiences with researchers and others.
- Serve as champions and role models for other older adults living in similar situations.
- Help improve the direction, design and implementation of research on aging!

Any questions?
D. BUREAU OF SAGES ORIENTATION PAMPHLET

The Bureau of Sages was developed by the Leonard Schanfield Research Institute at CJE SeniorLife as part of a two year project. This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (2640-CJE).

**Sages** serve as champions and role models for incorporating the voice of diverse older patients into research.

*Sages and Research Stakeholders* share experiences, build knowledge and develop skills for hearing from each other and working together.

**Our Vision**
Improved lives for older adults as the result of Patient-Centered research.
What is the Bureau of Sages?

The Bureau of Sages brings research stakeholders together to learn about and discuss research ideas. Sages work together to provide a voice for older adults in the direction, design, and implementation of research on aging.

The purpose of the Bureau is to:
1) Advise researchers at CJE SeniorLife, in the Chicago area and nationally.
2) Promote Patient-Centered Outcomes Research and Comparative Effectiveness Research.

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.

Participants

Sages are older adults who receive care in a nursing home or in their own homes. The Bureau includes two groups: Lieberman Community Sages and Virtual Senior Center Sages.

Research Stakeholders include researchers, clinicians and others who promote the health and quality of life of older adults.

Bureau Activities

Sage Meetings: Each group of Sages meets separately several times a month to receive education about research, discuss research ideas, and design the work of the Bureau. Research stakeholders may participate as a guest.

Advisory Group Meetings: All Sages meet together on a quarterly basis to hear from and give feedback to researchers.

Special Events: Sages plan and host an annual event to showcase the work of the Bureau. They may participate in presentations or videos.

Becoming a Sage

- Attend an orientation to learn more about expectations for Sages.
- Make a commitment to become a Sage.
- Receive training on how to talk with researchers.
E. SAGE BIOSKETCH TEMPLATE

SEE NEXT PAGE
Role

Stakeholder—[Lieberman Community Sage or Virtual Senior Center Sage]

Instructions: Have a one on one conversation with each Sage, using the suggested questions below; keep detailed notes. Then draft a written summary of the Sage’s responses under each heading below. In a second visit, work with the Sage to approve a final version of the biosketch. Option: Compile a separate document, listing themes across Sages’ stories about positive health experiences for discussion at a Sage meeting.]

Relevant Experience

1. Have a conversation:
   - Did you ever conduct any kind of research? What kind?
   - Have you ever been involved in a research study? Tell me a little about that.
   - Have you worked or volunteered in health care? Tell me a little about that.
   - What do health care professionals need to know about the experience of being a “patient”? What else would you like me to know about you? (background, experience, profession)
2. Draft 1-3 sentences here, summarizing responses to the conversation prompts (use Verdana 14 font)

Perspective on Aging & Health

1. Have a conversation:
   - What are some words or phrases that come to mind when you think about getting older?
   - What does quality of life mean to you?
   - What does “healthy aging” mean for you?
2. Ask for a story about a good health experience (required): “Please tell me about a time when you got the right attention for a health issue, or when someone did something right, and you felt positively and/or appreciated it.” (Prompt for details: What happened? Where were you? Who was involved? What improved/what was a positive result?)
3. Draft 1-3 sentences here, summarizing responses to the conversation prompts (use Verdana 14 font)
F. FACILITATION TIPS FOR RESEARCH COACHES

Research Coaches play a critical role in facilitating the capacity of Sages to provide their voice to research stakeholders, whether one on one or in group settings. Coaches should strive to create a welcoming atmosphere that fosters mutual understanding and respect, as well as an unintimidating environment that builds Sages’ confidence in their ability to interact with researchers. Research Coaches need to be familiar with facilitation and communication strategies that enable Sages to understand and discuss core research concepts, respect each other’s diverse views, make basic decisions about research issues, and express themselves when they are engaging in dialogue with researchers and clinicians.

These facilitation tips are designed to orient Research Coaches to the unique aspects of group facilitation with nursing home residents and other older adults living with frailty or chronic conditions that affect their abilities to engage. Many of the techniques are based on literature regarding group facilitation in general, but have been adapted for use with the Bureau of Sages.

This tip sheet includes four sections:

I. Facilitating Group Activities with Sages
II. Using the Training Materials with Sages
III. Facilitating Discussion between Sages and Research Stakeholders
IV. Resources/References

I. Facilitating Group Activities with Sages

This section addresses general facilitation techniques, managing group dynamics, as well as issues specific to working with older adults with functional or sensory limitations.

1. Be sensitive to perceptions of research and/or health care* such as:
   - Mistrust of health care providers and/or health care research.
   - Negative experiences with health care/research.
   - Lack of confidence in their ability to talk with researchers (e.g., due to lack of research expertise, no personal experience with research, confusion about what they can contribute, etc.).
   - Not speaking up or feeling intimidated around researchers/clinicians.
   - Cynicism about the likelihood of change in research or practice.
   *Especially for those who are new to the Bureau.

2. Gently reiterate or “review” the Bureau of Sage’s purpose, goals, and roles* as there is likely to be:
   - Confusion about the goals of the Bureau of Sages or misunderstanding of the goals of specific activities.
   - Perceptions of the Bureau as a venue for discussing personal issues, health concerns or frustrations with care services or the facility they live in.
   - Impatience regarding the long term impact of Bureau activities, such as questioning “Where this is all going?” or “Will this actually change anything?”
o Strong opinions about what the Bureau “should” be that are not relevant to its intended outcomes.
*Especially for those who are new to the Bureau or who have memory impairments.

3. **Build confidence in and trust among Sages:**
o Validate Sages’ diverse views; restate them if needed so that everyone hears and understands those views.
o Reassure Sages that they will continue to learn more about how to communicate with researchers over time.
o Make research less intimidating by framing learning activities as “introducing,” “practicing,” “imagining,” and “reviewing” key concepts and skills.
o Provide examples of or invite speakers from other patient-centered projects (e.g., CDRN’s, PPRNs, PCOR studies, etc.).
o Provide examples of how the Bureau’s input or feedback has been used by researchers (e.g., thank you letters from researchers).
o Give concrete examples of how patients’ perspectives have made a difference in other patient-centered projects.
o Remind them that having an impact on research takes time and that “we are in this together, with researchers”; give examples of the challenges that researchers face.

4. **Limit or manage “off task” dialogue:**
o Remind Sages of the purpose of the Bureau of Sages.
o Set up basic operating rules for the group about speaking, listening, respect, etc.
o Clearly state the goals of each meeting or activity (refer to Facilitator Guides).
o Remind Sages of those goals during the meeting, if needed.
o Acknowledge the importance of personal concerns and then provide Sages with alternative venues for addressing those concerns (e.g. Resident’s Council).
o Use complaints or negative experiences as learning tools; reframe them in a positive way by:
  ▪ Identifying potential solutions or desired outcomes that address that experience.
  ▪ Discussing hopes for future research that can benefit other older adults or society.
o Stay in your role as facilitator; be conscious of your own body language or behavior and avoid defensiveness.

5. **Use strategies suited for older adult learners:**
o Foster a positive group dynamic that encourages participants to interact and learn from each other as equals who each have valued experience or expertise.
o Maximize discussion-based or experiential learning; avoid lecturing.
o Use lay language or familiar examples to introduce key research concepts and then explain how researchers talk about that concept; avoid using research terms (jargon) before having such conversations.
o Maximize reiterative learning by:
- Introducing and “practicing” using key terms, concepts and skills.
- Reminding Sages of what they have discussed previously.
- Reviewing their previous work or products.
  o Avoid asking Sages to recall prior activities or remember what they learned so as to minimize performance pressure or cognitive burden.
  o Provide information in multiple ways, such as visual and audio formats; be sure these materials are accessible (see below); if possible, provide visual or audio aids before and/or after sessions.

6. Adapt to Sages’ capacities and challenges (physical, sensory or cognitive):
  - Facilitate each Sage’s ability to hear, understand and contribute via any or all of the following strategies for increased accessibility:
    ▪ Use hearing aids, microphones, speakers with no feedback.
    ▪ Ensure all visuals are in large print and written in accessible and concise language.
    ▪ Show videos with captions.
    ▪ Use visual or online technology that maximizes ability to see and hear.
    ▪ Use online platforms that are user friendly for those with communication or physical challenges.
    ▪ Support an individual’s ability to express his/her ideas; carefully listen to and restate his/her comments, as needed.
    ▪ Restate the comments of those who cannot speak loudly or clearly enough to be heard.
  - Provide a physical space that is comfortable, without excessive background noise or interruptions.
  - Test all adaptive devices, technologies or techniques before meetings.
  - Avoid detailed decision making.
  - Support the group’s ability to make decisions by summarizing consensus.

II. Using the Training Materials with Sages

This section provides tips for using Facilitator Guides, Facilitator References and Sage materials. Again, the Research Coach should use these materials to promote an unintimidating, conversational tone that fosters rapport, builds confidence, and reinforces teamwork among Sages.

1. Before each session:
   - Review the Facilitator Guide, References (for the Research Coach only) and/or Sage materials.
   - Be prepared to adapt the content стрategies to different capacities and needs of Sages (e.g., how much information will be covered, whether to print handouts or have slide for Sages).

2. During each session:
   - Provide the group with discussion ground rules, if needed.
   - Paraphrase talking points on the Facilitator Guide; do not read aloud as a script.
Use any or all of the discussion prompts/questions.
Adjust scope and depth of content to the capacities of the group or individuals.
Be attentive to suggested timeframes; help the group stay on task.
Watch body language and check in on participant’s understanding and engagement.
Be flexible and adapt your communication style to maximize Sage engagement.
Assign a staff or Research Coach note-taker to document Sages’ ideas, responses, reactions and/or products.

3. Materials for Sages:
Only provide materials that will complement or clarify tasks and concepts.
Be responsive to Sages’ needs for large print or alternative visual formats.
Keep it simple; avoid providing information materials that could confuse or distract Sages from the task at hand (e.g., excessive text; overly complex diagrams or tables, numerous pages of information, packets that are stapled and/or printed on both sides).
If Sages request printed materials or additional information, it should be provided after the session.

4. After each session:
Prepare a summary of discussion topics, key issues, and/or decisions made during the session.
Note any challenges and successful strategies with facilitating the session.
Thank everyone for their contributions.

III. Facilitating Discussions between Sages and Research Stakeholders
This section addresses issues specific to facilitating guest research presentations and feedback sessions or other research activities in which Sages and researchers, clinicians or other professionals engage with each other. The Leonard Schanfield Research Institute (CJE’s Research Department) will orient researchers and other professional presenters or guest who participates in Sage Meetings or Advisory Group Meetings. Prior to attending a meeting, they will be provided with Bureau of Sages Tips for Communicating with Older Adults, as articles related to communicating with older adults, age-sensitive principles for presenting information, interviewing older patients, etc. The will also be asked to prepare a Research Project Public Summary and a Bureau of Sages Biosketch. Representatives from the Research will also participate in Advisory Group Meetings.

1. Model techniques for communicating with Sages:
While introducing the session and any guest speakers, demonstrate positive facilitation and communication techniques (listed above).
Clearly state the goals for both the researcher and the group.
Demonstrate how to ask Sages short, direct questions that can help clarify the meaning of what they said or are trying to say.
Encourage Research Stakeholders to define key terms in plain language (e.g., use the Speaking Our Language activity in the Sage Refresher Training Guide)
2. **Support Research Stakholders’ abilities to communicate with and listen to Sages:**
   - Restate any comments from Sages if Research Stakeholders have difficulty understanding their thoughts, speech or gestures.
   - Check in with the Sage to ensure you accurately represented their point; if you are unsure what the Sage was attempting to communicate, ask clarifying questions or encourage the Sage to say more.
   - Assist Research Stakeholders with expressing complex thoughts by suggesting alternative lay language, if needed.
   - Periodically recap the discussion and ask for additional reactions or thoughts from Research Stakeholders and/or Sages.

3. **Reiterate mutual learning at the end of the session:**
   - Reiterate key issues or topics and highlight how those could be framed as suggestions for researchers.
   - Ask Research Stakeholders what they learned for Sages and how they might use that information.
   - Ask Sages what they learned from the Research Stakeholder(s).

4. **Ask researchers/professionals to convey the impact of Sages’ input on their work** so they know how their input is being used:
   - Encourage Research Stakeholders to share subsequent changes in their research (specific or general) at a later date (e.g., via a thank you letter or another presentation).
   - Encourage Research Stakeholders to come back and share an update on their research or results.

### IV. Resources/References

Below are a list of additional resources related to facilitation, group dynamics, communicating with and presenting to older adults, and examples of positive engagement of nursing home residents or patients. These sources were also used to develop this tip sheet.

**Group Facilitation:**
Communicating with and Presenting Information to Older Adults:


Example of Positive Ways to Engage Nursing Home Residents/Patients:


## G. SAGE REFRESHER TRAINING MATERIALS

The sessions listed below should be repeated during regular Sage Meetings as refresher training, whenever new Sages join the Bureau. The recommended order is designed to build and reinforce learning for both new and existing Sages over a 2 to 3 month period.

<table>
<thead>
<tr>
<th>Topic &amp; Materials</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong> REVIEW DESIRED HEALTH OUTCOMES</td>
<td>Provides new and existing Sages with an opportunity to update outcomes, themes, or priorities.</td>
</tr>
<tr>
<td>Facilitation Guide</td>
<td></td>
</tr>
<tr>
<td>Sages Desired Health Outcomes</td>
<td></td>
</tr>
<tr>
<td>Slide-Definition of PRO</td>
<td></td>
</tr>
<tr>
<td>DISCUSS RESEARCH TOPICS</td>
<td>Reviews the concepts of “Comparative Effectiveness Research (CER)” and “Health Intervention.” Facilitates a general discussion of 1-2 examples of CER topics that are relevant for older adults.</td>
</tr>
<tr>
<td>Facilitation Guide</td>
<td></td>
</tr>
<tr>
<td>Slides-Research Definitions</td>
<td></td>
</tr>
<tr>
<td>Reference- CER Topics</td>
<td></td>
</tr>
<tr>
<td>PRACTICE REVIEWING RESEARCH</td>
<td>Gives Sages practice reviewing a research topic or project. This format can also be used for TELL ME ABOUT YOUR RESEARCH, when Research Stakeholders chose to informally present research issues at a Sage meeting. It can be used for discussion of a research article (&quot;Journal Club&quot;).</td>
</tr>
<tr>
<td>Facilitation Guide</td>
<td></td>
</tr>
<tr>
<td>Sages Review Criteria</td>
<td></td>
</tr>
<tr>
<td>Slides-2 study examples (using public summary template)</td>
<td></td>
</tr>
<tr>
<td>LEARN ABOUT RESEARCH NETWORKS</td>
<td>Prepares Sages for any guests from PPRNs or CDRNs. A guest from a Research Network may attend this session or Sages can have a general discussion about examples of research networks. Optional: Include discussion of research participant roles, such as participating in a clinical trial or an controlled trial intervention study.</td>
</tr>
<tr>
<td>Facilitation Guide</td>
<td></td>
</tr>
<tr>
<td>Slides-Research Networks</td>
<td></td>
</tr>
<tr>
<td>TELL ME ABOUT YOUR RESEARCH EXPERIENCE</td>
<td>A brief exercise for meetings or one on ones with a guest researcher. Provides an opportunity to engage in more personal, informal conversations with a researcher.</td>
</tr>
<tr>
<td>Facilitation Guide</td>
<td></td>
</tr>
<tr>
<td>SPEAKING OUR LANGUAGE</td>
<td>A brief exercise for meetings that include guest researchers. Orient researchers/clinicians about how to communicate research concepts in an understandable manner. Empowers Sages to ask researchers/clinicians to clarify and explain.</td>
</tr>
<tr>
<td>Facilitation Guide</td>
<td></td>
</tr>
</tbody>
</table>
Purpose

When first joining the Bureau, you were asked to share a positive experience related to successfully dealing with a health or care issue. The Bureau uses Sages’ stories to explore what matters to older people in our situation. It helps us identify desired health or care experiences. In research, these are called “Patient Reported Outcomes.” [Handout or post slide]

Today we will review the Bureau’s list of desired health outcomes. We can also discuss any new issues we may want to include and revisit our priorities for research.

[Handout, post or write down the outcomes from the Facilitator Reference Bureau of Sages Desired Health Outcomes & Story Themes. If participants want or need more information for discussion, include the examples of themes from positive health stories under each outcome. If there are new Sages, briefly share a few general themes from new Sages’ positive health experience stories, but do not provide details about personal experiences or health conditions.]

Discuss the List of Desired Health Outcomes [open discussion]

Discussion prompts:

- Does the list capture what is important for a variety of older adults living in similar situations or who have similar health issues?
- Are there other desired outcomes that we should add?
- Which of these issues should be of highest priority for research?
- Is there anything we would like to focus on this year? (A topic for our annual event? A research project idea we would like to share with researchers?)
Wrap Up/Next Steps

- Research Coaches will update this list, based on today’s discussion.
- We will review our list of desired outcomes at least once a year (or when new Sages come on board and share their stories).
- We will post the updated list on the Bureau webpage and also share it with researchers who come to the Bureau for advice.
Sages Desired Health Outcomes
Reference Guide

[Option: Large print version can be shared with Sages.]

This list was developed based on Sages personal experiences with successfully getting attention for a health or care issue. Themes from their stories are listed under each outcome. The list should be updated as the Bureau develops new interests and priorities, or when new Sages join the Bureau and share their experiences.

Outcome 1: Maximized independence in care settings
- Feeling a sense of “freedom” or independence regardless of physical abilities
- Figuring out how to do everyday things despite your limitations (e.g., transportation, adjusting to limits, getting a hospital bed with heat/massage, walking, getting places, etc.)
- Care staff helping me do what I need assistance with
- Having the ability to self-advocate, communicate with clinician, and do your own research on health issues; in nursing homes, a clear, direct process to advocate for ourselves

Outcome 2: Feeling cared for and heard by care providers
- Having care providers that think outside the box, do something creative, try different solutions, and don’t give up
- Having care providers who listen, are responsive, authentic, caring, comforting, and attentive
- Getting attention for concerns and needs; getting an immediate response (e.g., timely response to call lights and verbal requests for help)
- Having someone advocate for you
- Feeling taken care of (with authenticity); gratitude
- Resolution of a terrifying or difficult moment due to unexpected or caring assistance from others
- Having a coordinated “team” of care providers

Outcome 3: Opportunities for social connections
- Being able to communicate (be verbal) with others
- Being able to connect with other people; opportunities for socialization
- Being able to give back, being able to help others

Outcome 4: Well-managed chronic symptoms
- Reduced pain, fatigue, discomfort or other symptoms
- Having distractions from symptoms or concerns (e.g. activities that you enjoy)

Outcome 5: Opportunities for feeling positive
- Having feelings of hope or positive attitude
• Being able to see life as a journey and a moving target, acceptance
• Feeling better in the moment
2-DISCUS RESEARCH TOPICS
Facilitation Guide

[Focus on Comparative Effectiveness Research Topics]

Purpose

[Paraphrase all text below, using a conversational style.]
To keep up to date on our research knowledge, we periodically review research topics that researchers feel are important. Let’s first review what research is:

**Definition:** Systematic documentation of information for a specific purpose that produces credible evidence to build knowledge.
Optional Talking Points:
- Before planning a study, researchers review what is known and not known
- After a study is complete researchers use results to plan more research
- Ideally, they also use the results to make a difference
- Build knowledge and theory
- Apply new knowledge to address a problem

The basic research process:
1. Ask a question that matters (relevant, important, etc.)
2. Make a detailed plan for how to answer that question
   Recruitment, data collection methods, procedures, tools, etc.
   Account for factors that might affect the findings (potential bias)
   Plan for how to protect participants from potential risks of the study procedures
3. Systematically gather, record, analyze and interpret data
4. Report results honestly, including any limitations, biases, negative results

One important type of research is called “Comparative Effectiveness Research (CER).” Let’s review what this means

**Comparative Effectiveness Research**

**Definition:** Compares different strategies for improving health, well-being or care.

**Research questions:**
- Which works better?
- What are the benefits and risks of each?

The compared strategies are called “interventions.” This type of research is based on existing evidence that each intervention has benefits.

BRIEF EXAMPLES [Include 2-3 hypothetical topics here—refer to Comparative Effectiveness Research Topics for other ideas]
- Compare exercise programs vs. medical treatments to see which is better at preventing falls
- Compare home care vs. nursing homes to see which has better health outcomes or quality of life outcomes for older people living with physical limitations
- What do researchers mean when they talk about health interventions? [review next slide]
Optional discussion prompt: What do you think of the term “intervention”?

Discuss Research Topics
Today we will discuss some topics that researchers have suggested are important for Comparative Effectiveness Research. Each topic includes comparison of at least two strategies or types of interventions. [Discuss 1-3 topics from the list provided in the Facilitator Reference “Comparative Effectiveness Research Topics”.

Discussion prompts:
- Is this topic important for older people? Why or why not?
- What would be the desired outcome for patients?
- How could research on this topic make a difference for older people?
- Could research on this topic be helpful for clinicians or others who care for older people? How so?

Wrap Up/Next Steps
- The Bureau will discuss emerging research topics or studies, from time to time.
- It will help us learn about current research and priorities!
## Comparative Effectiveness Research Topics

**Reference Guide**

*For Facilitator Only*

Topics below were based on a list of priority CER topics provided by the Institute of Medicine (IOM) of the National Academies of Sciences, Engineering and Medicine. (June 2009).

| TOPIC | COMPARE STRATEGIES | VS. |
|-------|--------------------|-----|----------------|
| 1     | Most effective way to prevent falls | Exercise programs with balance training | A combination of medications, supplements, vitamins and vision correction |
| 2     | Best living arrangement for providing care and services to older people who have limitations | Home care | Nursing homes or group homes |
| 3     | Best way to help older adults with complex care needs after hospital discharge | Social services that help the patient adjust to a going back home and taking care of themselves | A team approach to health care |
| 4     | Best way to help people with dementia | Provide social and family support | Medications |
| 5     | Best way to help people with Alzheimer’s Disease | Alternative approaches such as music, arts, etc. | Medications |
| 6     | Better treatment of anxiety, depression, pain, and other experiences that are related to having chronic diseases | “Mindfulness” interventions: yoga, meditation, deep breathing | Usual medical care |
| 7     | Better treatment of diabetic retinopathy, macular degeneration, and retinal vein occlusion | Laser therapy | Medications such as steroids |
| 8     | Better treatment of depression after a stroke | Psychotherapy or antidepressants | Combination of the same treatments, along with counselling |

The Research Coach can instead choose a topic from the sources below, but he/she will need to create a summary in plain language (as demonstrated above):

**IOM priority topics:**

**PCORI CER research questions** (elicited from public and approved for refinement):
http://www.pcori.org/research-results/about-our-research/how-we-select-research-topics/generation-and-prioritization
3-PRACTICE REVIEWING RESEARCH
Facilitation Guide

Purpose
To keep up with our research feedback skills, we periodically review examples of real or hypothetical research projects. [If there are new Sages present] If you are new to the Bureau, this will help you become familiar with how researchers present their research to the Bureau Advisory Group meetings. You will also learn about the Bureau’s review criteria. We can all benefit from a little practice now and then!

Mock Research Presentation
Research Coach presents a research project/study using the slides for **one** of the following sample projects:
- Stress Management and Cardiovascular Disease
- Resilience in Aging with a Disability
- Alternatively, the Research Coach can prepare a presentation based on a research article or abstract using the Public Summary Template,

Mock Review Session: Discussion and Feedback
We use four general criteria to give researchers feedback on their projects or studies: Significance, Innovation, Ethics, and Feasibility. Let’s start with significance…

Discussion Prompts:
[Not all prompts are relevant for every study. If participants desire or would benefit, you may print or post a large print version (see sample Bureau Review Criteria handout.)]

**Is the topic significant? [about 10 Minutes]**
- Is the study needed?
- For CER studies...Are the intervention(s) appropriate for older adults?
- Does it clearly describe benefits or outcomes that are important to older adults?
- Is it clear who will use results or make decisions & how it will improve care?
- Could other older adults benefit from the results (besides those in the study)?

**Is the study innovative? [about 10 Minutes]**
- What ideas or methods are novel or interesting?
- Can you suggest any other “outside of the box” ideas for this study?

**Does the study raise any ethical issues? [about 10 Minutes]**
- Does the study leave out an important group? Who else should be included?
- Do you have any concerns for participants in this study? (Re: data collection, protection of privacy, risks, compensation, etc.)

**Is this study feasible? [about 10 Minutes]**
- What might make it hard to recruit participants?
- What might make it hard to get the right information from participants?
Are the right stakeholders involved in order to effectively carry out the study? Are older adults/patients sufficiently engaged in shaping the study?

**Wrap Up/Next Steps** *(about 10 Minutes)*
- Overall, is the study patient-centered? How so?
- Any suggestions for sharing results with patients or the public? (How, where, when, etc.)
- Any final comments or suggestions?
Sages Review Criteria

Do you feel the topic or question is significant?

Consider if the topic is important and needed, if it addresses an important problem or intervention, and if it is relevant to older people’s lives. You might also think about who could use the result or how it could benefit older adults in general.

Do you think the study is innovative?

Consider what is unique about the study, if it takes a new approach, if it explores a new idea, or if the results could change something (like knowledge or practice). You can also suggest other “out of the box” ideas.

What ethical issues need to be considered?

First, consider if the study includes the right groups and will serve their interests and society as a whole. Second, think about how participants are protected in the way the research is conducted. Consider how people will be told about the study, if the study could hurt or bother someone in some way, if participants’ privacy will be protected, and if they will receive anything for participating. Identify potential problems.
Is this study feasible?

When evaluating if the study is feasible, consider if there are any foreseeable difficulties with recruiting participants or collecting the data. Or, another way to think about feasibility is to consider if the study has involved the right stakeholders (including older adults) so that it could be accomplished.

Overall:
Any comments on how the study is “patient-centered”? Any suggestions for sharing results with patients or the public?
Purpose

[Paraphrase all text below, using a conversational style.]
Joining the Bureau of Sages is one way to advocate for research that matters to older adults. Today we will talk about a different approach called “research networks.”

What are Research Networks?

Talking points:
- Research networks involve more people and organizations than the Bureau of Sages
- Each network focuses on specific areas of research or specific conditions
- Research networks are designed to...
  - Answer more research questions more efficiently
  - Address questions that “matter” for patients, caregivers, families, etc.
  - Produce more useful results

Patient Powered Research Networks

[Hand out or post slides]

Talking points [use as needed]:
- PATIENTS directly provide health information for research
- Operated by patients and partners (see examples on slide)
- Large...can include thousands of patients, as many as 75,000+
- Each network focuses on a topic or condition... Examples: arthritis, cardiovascular disease, Chronic Obstructive Pulmonary Disease (COPD), Alzheimer’s disease, dementia & brain health
Examples of what patient networks do...
- Online tools or mobile phone apps connect patients with researchers
- Patients answer health questions or complete health assessments
- Patients turn personal health experiences into research questions
- Patients are involved in developing studies and disseminating results
- Researchers communicate with patients about opportunities to be in studies
- Patients more easily enroll in studies
- Study participants/patients get access to their own data to facilitate health care decisions or health education
- Researchers track patient health status over time

Discussion prompts:
- What do you think of this way of connecting patients with researchers?
- How do you feel about patients providing their health information online?
- What topic would you want a patient network to focus on?

Clinical Data Research Networks

Talking points [use as needed]:
- Operated by health systems that have clinical data (routine patient care data)
- DATA is shared, electronically, across existing health systems...creating a larger pool of data
- Networks of healthcare and data systems (examples in slide)
- Each network usually focuses on more than one condition...Examples:
- In Chicago “CAPriCORN- the Chicago Area Patient-Centered Outcomes Research Network” focuses on anemia, obesity, asthma, sickle cell disease, recurrent Clostridium difficile colitis
• AT Harvard a similar data network focuses on osteoarthritis, obesity, pulmonary arterial hypertension, suicide prevention, autism, essential hypertension, prevention of cardiovascular disease
• Examples of what data networks do...
• Create secure data storage and sharing systems with privacy protections
• Analyze and learn from the data to improve health care systems
• Set up a system for reviewing and approving research studies
• Make the data pool available for researchers to study

Discussion prompts:
- What do you think about creating large pools of clinical data about patients?
- Do you have any concerns?
- What do you think patients might want to know about this? Patient permission and understanding—what do patients need to know?

PCORnet

Talking points [use as needed]:
• The Patient Centered Outcomes Research Institute (PCORI) has funded many of research networks (see map)
• Circles are the Patient networks (PPRNs)
• Triangles are the data networks (CDRNs)
• Numbers inside are how many networks in each state
• PCORI also funds an organization that coordinates these networks (called PCORnet), which is like a “network of networks” across the nation
Wrap Up/Next Steps

- Bureau of Sages is small group of people trying to promote research that matters for patients
- Research networks are larger and take on bigger tasks to promote research that matters
- Explain that members of the Bureau of Sages could choose to participate in a PPRN that focuses on their condition [Provide information about how to find Research Networks on PCORI’s web site, if there is interest. Examples of PCORI research networks can be found at http://www.pcori.org/research-results/pcornet-national-patient-centered-clinical-research-network/clinical-data-and-o ]
Note: This can be used as a small group or one on one exercise at any time, whenever there are researchers present at a meeting with Sages. Professional guest(s) can be partnered with 1-2 older adult members of the Bureau to have conversations with each other, using the prompts as guides, or a guest can have a conversation with the full group. Alternatively this activity may be especially helpful for a New Sage to become more comfortable talking with research, if there is an opportunity for them to meet with a research one on one.

**Purpose:**
[Paraphrase all text below, using a conversational style.]
Get to know a researcher on a more personal basis.

**Conversation About Research Experiences**

Conversation Prompts [Not all prompts will be appropriate for all situations; select those that will be most useful. Alternatively, participants’ biosketches can serve as a conversation starter.]

- How would you describe your career overall? What do you tell people you do?
- How have you been involved in research? Background? Skills? Roles? Topics?
- What health or aging issues are you interested in?
- What is one of the best research experiences you have had?
- What else do you want to share about yourself?

Option: Refer to Sages Desired Health Outcomes from positive health experience stories. Do any of these issues spark an idea for research?

[If Sages are partnered with Research Stakeholders in one on one’s or small groups, allow time to switch roles so Sages can share their research experiences]  
[If the activity was done in pairs or small groups, facilitator asks for 1 or 2 learnings from each group]
Note: This can be used as a brief activity any time there are researchers present at a meeting with Sages (including Advisory Group Meetings). It can be used as a warm up activity, as a tool for asking questions during a presentation or during discussion after a presentation. Ideally the guest should be asked to come prepared with definitions of 1-3 key terms related to their research or presentation.

Ask presenter to share definitions (as suggested above)
Please give us a brief explanation of any important research terms you will be using (or the term just used)
Please define each term in everyday language.

Elicit feedback on levels of understanding (in part to educate the presenter)
[Check in with Sages to see if there are questions or a need for further clarification; use prompts, if needed]
- What this explanation helpful?
- Does it makes sense? [option-show of hands]
- What did you think about the terminology he/she used?
- Is this explanation confusing in anyway?
- What else might need to be explained?
- Any other comments about communicating with the Bureau of Sages?

[Encourage Sages to ask for clarification; if necessary facilitator can ask for further explanation, to model how to interact with researchers in a way that helps them “speak our language.”]
H. RESEARCH STAKEHOLDER BIOSKETCH TEMPLATE

SEE NEXT PAGE
Role

Stakeholder: insert “Researcher” “Health Care Professional” or some other role

Relevant Experience

Write 2-4 sentences on your research interests or background relevant to aging, health care, etc.

Perspective on Aging

Write 2-4 sentences about your view of aging, healthy aging, quality of life as people grow older, etc. Picture is optional (example below)
I. GUIDELINES FOR ENGAGING THE BUREAU OF SAGES

The Bureau of Sages is an advisory board made up of older adults who have received training on ‘Patient-Centered Outcomes Research’ and ‘Comparative Effectiveness Research’ (PCOR/CER). They serve as experiential advisors to researchers in the field of aging, PCOR/CER researchers and other Research Stakeholders.

The “Sages” are nursing home community members and stay-at-home elders. Sages have experience living with a variety of health conditions in partnership with caregivers who assist them in maintaining their independence. As members of the Bureau, they provide their voice to the direction, design, and implementation of research on aging.

The Bureau of Sages advises CJE SeniorLife’s internal research department and local or national researchers wishing to conduct research in aging, PCOR or CER. Individual Sages may also choose to participate in Patient-Powered Research Networks and other patient-centered research networks. Thought these activities, Sages serve as champions and role models for incorporating the voice of diverse patient populations into Research. Biosketches of all Bureau of Sage members & staff are available on Bureau of Sages website at https://www.cje.net/research-education/bureau-sages

To gain meaningful feedback from Sages, the Bureau expects researchers who seek input from Sages to be ready to actively engage them in discussion. Researchers and other professionals who participate in meetings with Sages should prepare to accommodate older adult learners, including those with sensory limitations. The Bureau requires researchers to use the following tools to maximize the value of engaging with Sages:

- Bureau of Sages Research Stakeholder Biosketch (submit before the meeting)
- Tips for Communicating with Older Adults
- Researcher Public Summary Template (use for presenting a research project)
- Bureau of Sages Review Criteria Questions (see below)

Presentations should be around 20 minutes. The Bureau provides at least one Research Coach per session to facilitate communication and interaction with Research Stakeholders. Research Coaches support Sages in expressing their experiences and views and may refer to the Review Criteria Questions to stimulate discussion and input as needed. Sages are most productive if the discussion time is limited to 20-30 minutes, focusing on some but not all of the review Criteria. Therefore, the Bureau encourages researchers to select a few review criteria and/or question prompts that are most relevant for discussion.
J. TIPS FOR COMMUNICATING WITH OLDER ADULTS

We have consolidated information from a variety of sources (listed at the end of this document) regarding how to communicate effectively with older adults under a variety of circumstances.

**In General**

**Reflect on your own assumptions.** Assess your own views of aging and older people and be conscious of how you use language when in the presence of older people. Avoid patronizing language.

**Pay attention to yourself.** Monitor your own reactions and control your nonverbal behaviors.

**Communicating One on One**

**Face the individual.** Place yourself at their level (for instance if they are seated) and turn towards the person.

**Minimize distractions.** Reduce background noise and interruptions that make it difficult for both parties to hear and understand each other.

**Use clear sentence structures.** Avoid long convoluted sentences or questions that contain multiple or confusing ideas, but use normal vocabulary (do not talk down).

**Listen carefully and intentionally.** Convey your interest and attention in what they have to say.

**Adjusting to Hearing Loss**

**Get the person's attention.** Say the person’s name before beginning a conversation or, if needed, touch the listener's hand, arm, or shoulder lightly. If the person can hear better in one ear, move to that side.

**Speak naturally.** Speak distinctly at a normal rate without exaggeration or shouting. If needed, adjust your pace to needs of the person you are speaking to. Use pauses to give the person time to process speech.

**Maintain eye contact.** Face the person with hearing loss and make eye contact to maximize nonverbal communication through facial expressions and body language. Keep your hands and other objects (e.g. papers) away from your face while talking. For those who may need to lip read, do not chew gum or eat. Be aware that beards or moustaches may impede lip reading. Avoid trying to exaggerate your mouth shape while talking.
Rephrase rather than repeat. If the listener has difficulty understanding a particular phrase or word, find a different way of saying it.

Modify the environment. Ask the person if you could turn off the radio or television. Move to a quiet space, if needed. Converse where there is good lighting so that your face can be more easily seen. Avoid strong lighting coming from behind you, such as through a window.

**Adjusting to Vision Loss**

Ask what they need. Ask if they want assistance with anything and, if so, how you can help. It may help to research vision aids, such as magnifiers, so that you can understand how they help people.

Use clear, verbal cues. Introduce yourself; introduce others in the room. Give specific directions to indicate where you, others or objects are. If you need to touch the person or something nearby, let the person know what you are doing before you do it. Indicate when you are leaving.

Speak at a normal volume. Avoid speaking more loudly to explain something (a common urge when talking to someone with vision problems).

Provide easy to see printed information. Effective materials have a simple design with sharp contrast between text and background. In printed materials use a large font size, such as 16- or 18-point, with 1-inch margins and at least 1 1/2 blank spaces between lines of text. When using a table, make it simple and easy to follow.

**Conducting Open-Ended Interviews with Older People**

Ask one question at a time. Keep each question relatively brief and clear. If the person doesn’t hear or understand the question, repeat the question and/or substitute words with similar meaning.

Wait for a response. Allow for periods of silence or pauses. Someone may need time to formulate ideas or to decide how to respond to a negative experience.

Notice nonverbal cues. Silence accompanied by other behaviors can indicate that a person is uncomfortable with a question or a topic. If the person becomes uncomfortable or emotional, accept their response, validate its significant and show empathy. Wait to see if they want to continue.

Restate when needed. If you are not sure you fully understood what the person said, restate what the person said to validate what you heard. If needed, then ask a follow-up question to clarify meaning, instead of assuming you know what they mean.
Respect the need or desire to not share. Someone may choose to avoid topics or deny problems. Focus on what they want you to know and learn from that.

Redirect to the topic at hand. If the person brings up what appears to be an unrelated subject matter, respectfully ask for clarification of how that example or issue relates to the topic of the interview.

Presenting to Older Audiences

Be aware of your communication style with older people. Reflect on your initial reactions and attitudes towards older people or how you might shift your language or tone when talking with older people. Avoid “elder speak” or talking down to older people.

Face your audience. Limit movement around the room as you talk to maximize eye contact, particularly if members of the audience have hearing difficulties.

Minimize distractions. Eliminate background noise or music and choose a location free from interruptions to accommodate those who have difficulty hearing. They may need to work harder to understand speech or decode information.

Lower your pitch. Lower your pitch without lowering your volume to accommodate those with hearing difficulties.

Speak clearly. Enunciate clearly and use pauses judiciously. Be conscious of your normal pace of speaking. If you tend to speak quickly, slow down.

Use simple sentence structures. Use simply constructed sentences without simplifying your vocabulary to accommodate potential age-associated changes in working memory.

Ask your audience for feedback. Early in the presentation ask if your audience can hear you. Tell them to give you a signal (e.g. raised hand) if they cannot hear you so that you can make adjustments throughout your presentation.

Repeat any questions so the whole audience can hear. If you receive a question from the audience, repeat it before answering it so the whole audience can hear it.

Use large visual aids such as diagrams or pictures. Visual aids reduce the need for complex verbal descriptions. Point to them as you are discussing them. Make them large and easy to see.

Keep the organization and design simple. Avoid busy backgrounds. Use clear short titles. Minimize the amount of text or bullets (5-7). Limit the number of photos or graphics to one per slide. Avoid layering pictures and text.
Make text easy to read. Maximize contrast. Avoid special effects such as shadowing or word art. Use easy to read fonts such as Arial or Tahoma with a minimum size of 24 points.

Use PowerPoint as an outline. Do not read word for word from the screen.

Describe key visuals. Verbally describe any important ideas that are conveyed in a graph, chart or photo to accommodate people with visual challenges.

Make handouts of key visuals. Large printed versions of key slides may be helpful (full page size).

Provide auditory cues for key transitions. If you are moving on to a new slide or topics, announce the transition clearly. For slides, you may include a sound cue (such as a “click” or “whoosh”) for people with severely limited vision.

Consider lighting needs. Provide room lighting that is appropriate for the presentation or activity (allows the audience to clearly see images on a screen vs. see a handout in front of them)

Preparing a Research Presentation for the Bureau of Sages

Complete the Bureau’s Research Summary Template at least 1 ½ weeks before your presentation so that it can be shared with Sages. The Bureau provides a PowerPoint template that includes the following information:

- Topic, problem or condition
- Central question or aim and main objectives of the study
- The primary outcomes of interest (i.e., the desired benefits for older patients)
- A non-technical description of methods (i.e., how the question or aim will be addressed)
- For a Comparative Effectiveness Research study, the interventions being compared
- Population and setting

Sages request that you end any bullets with a period.

Familiarize yourself with best practices for writing lay summaries. Resources for writing lay summaries are listed below and some general guidelines include:

- Write in active language
- Use person-centered language that does not objectify the study population
- Aim for 5 to 5 ½ inch lines and 15 to 20 words per sentence

Actively engage in dialogue with Sages. The Bureau provides a trained facilitator or “Research Coach” who is familiar with the Sages. Researchers can assist the facilitator by providing concise verbal explanations that include concrete, everyday examples that explain key elements of your study.
Sources

Communicating, Interviewing & Presenting


Preparing a Research Summary


Diabetes UK. Writing a Good Lay Summary. 2017. Available at: https://www.diabetes.org.uk/Research/For-researchers/Apply-for-a-grant/General-guidelines-for-grant-applicants/Tips-on-writing-a-lay-summary/

U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services. TOOLKIT for Making Written Material Clear and Effective. CMS Product No. 11476 September 2010

Section 4: Special topics for writing and design, Part 9: Things to know if your written material is for older adults Available at: https://www.cms.gov/outreach-and-education/outreach/writtenmaterialstoolkit/downloads/toolkitpart09.pdf


Examples of lay summaries can be found at:
Chrohns and colitis Foundation of America Patient Powered Research Network https://ccfa.med.unc.edu/research_completed_research
Mid South Clinical Data Research Network https://midsouthcdrn.mc.vanderbilt.edu/research/
K. RESEARCH PUBLIC SUMMARY TEMPLATE

Bureau of Sages

Public Summary Template

Insert Brief Research Question

Insert title of project

Research (or CER) Question

What is the question or problem this research will be addressing (in everyday language)?

What are the major objectives? (in everyday language)
Other Important Study Details:

- Optional
L. RESEARCHER SATISFACTION SURVEY

Evaluation of Advisory Board Meeting

Dear Researcher,

Thank you for coming to talk to the Bureau of Sages about your research, we feel it is so important to get the experiential voice of older adults into research, during all phases of the work. We are glad you took the time to come talk to us and hope that the feedback we provided has been helpful. In order to make sure we are attending to your needs as a researcher, please complete the following questions and feel free to provide any additional feedback. This information will also be helpful to give back to the Sages. Thank you again and best of luck on your research! Please don’t forget to keep us informed about this work you are doing.

Thank you.

1) What phase of research is your project in?
   - Initial topic/concept/idea development
   - Proposal development
   - Recently funded, beginning implementation
   - Mid-implementation/on-going
   - Analyzing results/findings
   - Dissemination
   - Other

2) If there was a specific component of your research that you came seeking feedback on, what was it? (check all that apply)
   - I was not looking for specific feedback, I came to discuss my research in general terms / general advising
   - Input on topic selection/defining the importance of the topic
   - Feedback on quantitative surveys
   - Feedback on qualitative surveys or interview/focus group guides
   - Recruitment methods
   - Understanding the findings
   - Development of the intervention

3) Did this session meet your expectations?
   - Yes, very much
   - Yes, a little
   - No, not really
   - No, not at all
4) Why or why not? ____________________________________________

5) What was the most helpful aspect of the advisory session? (Provide an example of what you gained or learned): __________________________

6) How do you plan to use the feedback you received from the Sages? __________________________

7) Please provide us with any other feedback or a testimonial: ______________

8) If you are willing to allow us to use your testimonial on our website, please include your name here: ______________ (You may write “anonymous” if it is alright for us to use your testimonial, but you would prefer not to have your name appear with the testimonial.)

   If you would like to discuss your experience, or have further feedback, please don’t hesitate to contact Amy Eisenstein: amy.eisenstein@cje.net, or 773-508-1040.