



The Center for Aging
Research and Education
SCHOOL OF NURSING
UNIVERSITY OF WISCONSIN-MADISON

We have what they don't have":

Engaging older adult
community members as
advisors on health research



A TOOLKIT

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SECTION 1

Why involve older adults in health research?

What older adults say

Members of the two Boards of Older Adult Advisors (BOAA) make strong arguments for engaging older people in health research:

"I want researchers to know we may not have the education they do, but we have what they don't have: the knowledge and wisdom that comes from living our lives."

"You see the color of my skin. You see my gender. You see my age. And you think you know something. But that is disrespectful. You need to ask and listen."

"It is wonderful when we are included. It lets us know that someone cares about us and that our voice matters."

"Aging is not just one thing. Everybody ages differently. Don't assume everyone experiences or approaches it the same way."

"Do not talk down to older citizens. So many people do that. We still have a brain and feelings about what is and what was. Listen to us."

"Aging and health issues change life's choices and limit our options. But we must adapt and learn new ways to stay healthy and active. ... I want researchers to know that aging requires that adaptability. But the system can make things better for aging people too."

Health and aging in the U.S.

Supporting healthy aging becomes even more important as the U.S. population grows older. The number of people age 65 and older will reach nearly 81 million by 2040, more than twice as many people as in 2000.¹ The older population is becoming more racially and ethnically diverse. From 2019 to 2040, the number of white non-Hispanic older people is projected to increase by nearly 30 percent, compared to 115 percent for older people of color.²

Yet older adults are often underrepresented in health research, even among studies on issues that most often affect them.³ This is particularly concerning given that older people represent a significant percentage of all people who take medications and use healthcare services. More than 60 percent of older adults are managing multiple chronic conditions.⁴ Some older people experience the cumulative health impacts of life-long disparities.

Older adults are the experts on their own bodies, lives, needs, and strengths. Engaging older people as research advisors has been shown to increase the relevance of research questions, improve study design, increase the number of older study participants, and improve the generalizability of research findings.⁵ Community advisors are essential to patient-centered outcomes research and comparative effectiveness research, which focus on what's meaningful to patients and what people need to make informed healthcare decisions.⁶

Older adults benefit from collaborating with researchers. Older people report feeling empowered that they can contribute to health research,⁷ shape public policy⁸, and give back to their communities.⁹

About this toolkit

This toolkit shares materials that were created and insights gained during a two-year project to develop two community advisory groups of older people, the Boards of Older Adult Advisors (BOAAs), rooted in different Wisconsin communities. In addition to this written material, there are video interviews with BOAA members and researchers who brought questions to them, at:

<https://care.nursing.wisc.edu/board-of-older-adult-advisors/>

This toolkit is intended for health researchers who are curious about, interested in, or already conducting community-engaged research. We hope these materials, examples, and lessons learned will lead to increased engagement of older people throughout the research process, including for patient-centered outcomes research and comparative effectiveness research.

This work was carried out by the Center for Aging Research and Education (CARE) (care.nursing.wisc.edu) with assistance from the Wisconsin Network for Research Support (WINRS) (winrs.nursing.wisc.edu), both housed at the University of Wisconsin–Madison School of Nursing. The two-year project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (#EACB-22560).

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SECTION 2

Project overview

Our goals, strengths, and limitations

The primary objective of our work with the Boards of Older Adult Advisors (BOAAs) is to increase health researchers' engagement of older adults, including people from communities at higher risk of health disparities. Engaging older people throughout the research process facilitates patient-centered outcomes research and comparative effectiveness research, which compares the benefits and harms of different healthcare approaches. Our long-term goals include improving healthcare for diverse older populations, identifying the outcomes most important to older people, reducing disparities, and supporting healthy aging.

As we began this project, we benefited from having:

- Project team members with community engagement expertise
- Strong partnerships with organizations in different Wisconsin communities
- A network of university researchers focused on older adult health and well-being
- Growing interest in community-engaged research across University of Wisconsin (UW)-Madison campus

Additional strengths include the trusted organizations in each community that partnered with us, and especially the wonderful people who joined the two BOAAs. BOAA members have a wide range of perspectives and experiences and are highly motivated to improve research and care for older people.

We acknowledge limitations in our approach. With ten members of each BOAA, it is not possible to reflect the full diversity of older Wisconsinites. Madison BOAA members predominantly identify as Black, with diverse personal and professional backgrounds. Rural BOAA members all identify as white, and include military veterans, farmers, and residents of under-resourced communities.

Why two BOAAs?

We formed two BOAAs—one comprised of residents of Wisconsin’s capital city, Madison, and the other including residents of rural Southwest Wisconsin—to reflect more of the heterogeneity in the older population than would be possible with one group. We specifically recruited people from communities at higher risk of health disparities: under-resourced rural areas and communities of color. However, we did not limit participation to people who fit those descriptions.

Having two BOAAs allows for comparison and contrast. Each group’s priorities and personalities are reflected in their mission statements and community agreements (see section 4). Some researchers bring the same questions to both BOAAs, to see if and how their input differs.

Discussions with the BOAAs often reflect the intersecting identities represented in each group. Madison BOAA members consider how health issues impact Black people and older adults. Rural BOAA members speak to the experiences of older people and rural residents.

Towards the end of the initial project period, we brought the Rural and Madison BOAAs together for two meetings. People enjoyed the opportunity to get to know each other, to reflect on their experiences with the BOAAs, and to give advice to researchers. However, at least one BOAA member was relieved that there wouldn’t be joint Madison-Rural BOAA research meetings, as that might leave too little time for the researchers to talk!

Paying community advisors

The time, perspectives, and lived experiences of community advisors are valuable. The expertise of community advisors—who become skilled at providing feedback—needs to be valued, as is the expertise of academic researchers with advanced degrees and professional titles.

We show how we value BOAA members’ contributions in numerous ways, including by paying them \$100 for each 90-minute meeting. We navigate university systems to pay BOAA members promptly and offer them options for how they are compensated: by app, check, or gift card. We asked our university what total payment per year leads them to report the income as taxable. We know that some BOAA members prefer to stay below this total, to ensure the payments will not affect benefits they may receive.

When we found out that one BOAA member doesn’t reliably receive her mail, we began hand delivering her meeting packets and payments. These visits offer additional opportunities to check in about the group and the issues that matter to her.

Community organizations

We worked with two well-known community organizations in each area to determine recruiting strategies, recruit BOAA members, and develop materials for the initial BOAA meetings. All four organizations saw our project as aligned with their work to serve older community members. Each organization remained involved throughout the two-year funded project, during which they received compensation for their time and effort. The organizations' networks and insights were crucial to forming and launching the two BOAAs.

In Madison, our organizational partners are:

- Lussier Community Education Center, which offers programs in low-resourced neighborhoods on the west side of the city
- NewBridge Madison, an agency serving older adults with extensive outreach to the African American, Latinx, and Hmong communities

In rural Southwest Wisconsin, our organizational partners are:

- Aging and Disability Resource Center of Southwest Wisconsin, which provides services and resources to keep older adults and people with disabilities living well and independently
- Iowa County Veterans Service Office, which provides information and resources to more than 1,000 veterans across the county

Researchers

So far, we have found no shortage of health researchers who want to meet with one or both BOAAs. We benefit from UW–Madison's extensive research community, including the CARE Network of faculty, staff, and graduate students focused on older adult health and well-being; the UW–Madison Institute for Clinical and Translational Research; Center for Health Disparities Research; Institute on Aging; Center for Demography of Health and Aging; Wisconsin Alzheimer's Disease Research Center; and Morgridge Center for Public Service, which promotes community-engaged research, scholarship, and learning.

During the two-year PCORI-funded project period, researchers could bring their questions to one or both BOAAs for free. To support the BOAAs' continued operations—and to meet the strong interest from researchers and BOAA members alike—we are transitioning to a fee for service model.

For more on our plans to sustain the BOAAs beyond the funded project period, see section 6. Our approach to recruiting and working with researchers is detailed in section 5.



SECTION 3

Recruiting members

Recruiting strategies

In consultation with the four community organizations and four older adult consultants, we developed strategies and materials to recruit BOAA members.

In Madison, the two organizations publicly posted flyers about the BOAAs and shared a BOAA job description with anyone who expressed interest. The organizations' staff also approached individuals who they thought might be interested, encouraging them to consider participating. Staff relayed the names and contact details of potential BOAA members to our project team.

In rural Southwest Wisconsin, the two organizations included BOAA flyers in newsletters mailed out to their contacts. The organizations' staff also made announcements about the opportunity during meetings of their advisory boards or regional offices. Staff relayed the names and contact details of potential BOAA members, though most individuals contacted our team directly.

Recruiting materials

MADISON FLYER



School of Nursing
UNIVERSITY OF WISCONSIN-MADISON

Older Adult Advisory Board Members Needed

Are you at least 65 years old?

Are you interested in health topics?

The Center for Aging Research and Education at the University of Wisconsin-Madison is looking for interested older adults to join a new Board of Older Adult Advisors (BOAA). People who identify as African American or Latinx are encouraged to join.



What will being a BOAA member involve?

- BOAA meetings will be held online every 4 to 8 weeks
- Meeting day and time will be decided by BOAA members
- BOAA members will be paid \$100 per meeting
- BOAA members will offer advice to researchers on projects designed to benefit the health of older adults
- No previous Board experience required

To learn more, please contact:



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Diane Farsetta
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MADISON JOB DESCRIPTION

Job description: Board of Older Adult Advisors (BOAA)

Are you interested in health topics? Do you enjoy talking and learning with others? If so, you could be one of ten members of the Board of Older Adult Advisors (BOAA).

The UW–Madison School of Nursing’s Center for Aging Research and Education (CARE) believes that health research should include the views and experiences of older adults. Working together, older adults and researchers at the University of Wisconsin can find creative ways to improve people’s health and well-being as they age.

You could be a BOAA member if you are:

- 65 years old or older
- Interested in health topics
- Willing to share your thoughts and listen to others
- Able to commit to serving as a BOAA member for two years

People who identify as African American or Latinx are encouraged to join the BOAA.

BOAA members will be asked to:

At the start

- Set meeting day and time
- Attend orientation
- Develop meeting structure

Ongoing

- RSVP for each meeting
- Attend 90-minute meetings, held every 4 to 8 weeks
- Participate in discussions of health research ideas

BOAA meetings will start in June 2022. Members will be paid \$100 for each meeting they attend.

Currently, we plan to meet online to keep everyone healthy and safe. The Center for Aging Research and Education (CARE) will provide tablets, wireless connections, and technical support as requested. When it is safe to meet in person, BOAA members will select a meeting location.

CARE will send out reminders and materials before each meeting. CARE will ask for feedback on how to improve meetings.

If you have questions, please contact ...

RURAL FLYER



School of Nursing
UNIVERSITY OF WISCONSIN-MADISON

Older Adult Advisory Board Members Needed

Are you at least 65 years old?

Are you interested in health topics?

The Center for Aging Research and Education at the University of Wisconsin-Madison is looking for interested older adults to join a new Board of Older Adult Advisors (BOAA). People who live in rural areas, including Veterans and people living on lower incomes, are encouraged to join.



What will being a BOAA member involve?

- BOAA meetings will be held every 4 to 8 weeks
- BOAA members will decide meeting day, time, and location
- BOAA members will be paid \$100 per meeting
- BOAA members will offer advice to researchers on projects designed to benefit the health of older adults
- No previous Board experience is required

To learn more, please contact:



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Diane Farsetta

Senior Outreach Specialist

UW-Madison School of Nursing

RURAL JOB DESCRIPTION

Job description: Board of Older Adult Advisors (BOAA) from rural Southwest Wisconsin

Are you interested in health topics? Do you enjoy talking and learning with others? If so, you could be one of ten members of the Board of Older Adult Advisors (BOAA).

The UW–Madison School of Nursing’s Center for Aging Research and Education (CARE) believes that health research should include the views and experiences of older adults. Working together, older adults and researchers at the University of Wisconsin can find creative ways to improve people’s health and well-being as they age.

You could be a BOAA member if you are:

- 65 years old or older
- Interested in rural health topics
- Willing to share your thoughts and listen to others
- Able to commit to serving as a BOAA member for two years

People living in rural areas, including those who are Veterans or living on lower incomes, are encouraged to join.

BOAA members will be asked to:

At the start

- Set meeting day, time, and location
- Decide if you will participate in person or online
- Attend orientation
- Develop meeting structure

Ongoing

- RSVP for each meeting
- Attend 90-minute meetings, held every 4 to 8 weeks
- Participate in discussions of health research ideas

BOAA meetings will start September 2022. Members will be paid \$100 for each meeting they attend.

We will prioritize keeping everyone healthy and safe. BOAA members will discuss whether meetings will be in person, online, or a combination of the two. The Center for Aging Research and Education (CARE) will provide tablets, wireless connections, and technical support as requested.

CARE will send out reminders and materials before each meeting. CARE will ask for feedback on how to improve meetings.

If you have questions, please contact ...

Interviewing potential BOAA members

Two members of our project team interviewed people interested in becoming BOAA members, either by phone or video call. We started the interviews by introducing ourselves and reviewing the BOAA job description, answering any questions. Since community advisory boards generally aren't well known, we wanted to make sure that the role and responsibilities were clear before interviewing the person.

Interview questions were developed with input from the four community organizations. The interview questions were largely the same between the two BOAAs. The following questions were asked of potential Madison BOAA members:

1. What made you interested in joining the BOAA?
2. Would you prefer to attend meetings online or in person?
3. If you are attending in person, where is a convenient location for you?
4. Have you joined online meetings before? Is there anything that would help you join online meetings of the BOAA – a tablet, wireless connection, tech help, etc.?
5. Do you think you will be able to participate in the BOAA for two years?
6. What is one thing that you want health researchers to know about aging or older adults?
7. One of the goals of the BOAA is to increase the range of voices included in health research. Because of that, we are asking everyone a few questions about their identity and background. For any of these questions, you can say you prefer not to answer.
 - a. Are you at least 65 years old?
 - b. How would you describe your race and ethnicity?
 - c. How would you describe your gender?
 - d. Is there anything else about yourself you would like to share?
8. Do you have any questions for us?

Rural BOAA members were asked the same questions, plus the following as part of number 7:

- e. Do you live in a rural area?
- f. Would you say you are living on a lower income?
- g. Do you identify as a veteran of the U.S. military?

The interviews were wonderful opportunities to start to get a sense of people's personalities and motivations for wanting to join the BOAA. Generally, by the end of the conversation, the two project team members were able to decide whether to officially welcome the person as a BOAA member. Months later, some BOAA members commented on how much they had enjoyed the interview process.

The Madison Board of Older Adult Advisors brings a range of perspectives + first-hand knowledge about aging to health researchers, providing insight on how to support older adult health, well-being + independence. BOAA members learn from each other + from researchers about healthy aging, for themselves + their families.

SECTION 4

Initial meetings: Orientation and shared decision making

Why shared decision making?

Shared decision making or co-creation of group processes and foundational documents deeply involves members in defining their group. By sharing control and working in partnership, our team demonstrated our respect for BOAA members right from the beginning. This approach encourages members to feel ownership and actively engage. It aligns how the group functions with the preferences, norms, and personalities of its members.

We explained to BOAA members that the basic outlines of the project—for example, the focus on health research and the number of meetings over the first two years—were set and non-negotiable. However, within such broad outlines, each of the BOAAs has the power to decide how their group operates.

Foundational materials

The following documents are the result of shared decision making or co-creation with BOAA members. Most were developed over the initial three meetings of each BOAA, which are described in more detail below.

Mission statements

During the third meeting of each BOAA, we introduced the concept of mission statements. We discussed how organizations develop mission statements to describe what they do and why, and to highlight how they are unique. We explained that mission statements briefly describe things like:

- Why an organization exists
- Who the organization works with
- What the organization does
- How the organization does it

As examples, we shared mission statements from organizations that BOAA members are familiar with, including the local community organizations collaborating with us.

In between the third and fourth meetings, we talked with each BOAA member individually about what they wanted in their group's mission statement. We combined their ideas in a draft mission statement, which was presented at the fourth meeting. Over the next one to two months, the Rural and Madison BOAAs revised and finalized their mission statements.

RURAL MISSION

The Rural Board of Older Adult Advisors (BOAA) collaborates with researchers, fostering understanding of health experiences from rural and aging perspectives. The Rural BOAA provides candid, constructive feedback to help research be more kind, open, and innovative, and to improve care, especially for people whose needs are not being met.

MADISON MISSION

The Madison Board of Older Adult Advisors (BOAA) offers a range of perspectives and first-hand knowledge about aging to health researchers by providing insight on how to support older adult health, well-being, and independence. BOAA members and researchers have a mutual responsibility to listen, learn, and challenge to make research meet the needs of older adults and their families.

Community agreements

During the second meeting of each BOAA, we formed community agreements describing each group's expectations for their time together. We first asked people to think about a group or a meeting that they really enjoyed being part of. We discussed what made those meetings or groups work well. Keeping those things in mind, we then developed community agreements for the BOAA.

We take a few minutes at the beginning of every meeting to read the BOAA's community agreements out loud. BOAA members find this to be a positive and effective way to ground their meetings in their shared values.

MADISON COMMUNITY AGREEMENTS

- Show up on time
- Be ready to participate
- Be understanding, respectful, and care for each other
 - Support each other, have each other's back
 - Take care of ourselves
- Have fun
- Tension is fine, acknowledge it, be honest and be yourself
 - Consider other points of view
 - Ask questions to understand
- Call people in if something doesn't sit well
- Have space for all to share ideas
 - Step up, step back
 - Try not to interrupt others, raise hand
 - Practice active listening
- Commit to learning and sharing

RURAL COMMUNITY AGREEMENTS

- All voices included – more quiet people are encouraged to speak
- Facilitation is active, good, shared
- Discussions / decisions are meaningful
- There's compromise – hear others, be flexible
- New voices come in over time
- Have a clear plan, goals – written agenda
- People's time is respected
- People arrive on time (if possible), come prepared
- Have respect for each other, good intentions
- There's time for informal interactions

Research meeting agendas

During the third meeting of each BOAA, we discussed the structure of research meetings. Our project team suggested the following for 90-minute meetings with health researchers:

- Welcome and ice breaker question – 13 minutes
- Review community agreements – 2 minutes
- Researcher introduces themselves (responding to the questions: How did you choose your work? Why is it important to you?) – 5 minutes
- Discussion of questions / materials brought by researcher – 65 minutes
 - Setting the stage: Overview of the who, what, why, where, and when of the research; and clarifying questions
 - Questions for discussion (often three to four questions)
- Closing / meeting feedback – 5 minutes

The Rural BOAA decided to adopt the above meeting structure as is. The Madison BOAA made a minor change, taking five minutes from the research discussion to make sure they had time to ask the researcher questions. In practice, members of both BOAAs ask questions throughout meetings.

We also discussed what information BOAA members want to receive before and after meetings. At least one week before meetings, the BOAAs receive mailed meeting packets that include the meeting agenda and a biographical sketch of the researcher (see below). Usually, the packets also include a plain language description of the research or flyers or other materials that will be discussed. (The Rural BOAA likes to prepare for meetings by reading more detailed information, once happily digesting a 10-page overview of a study with diagrams!)

Following our debrief meeting with the researchers (see section 5), we prepare a written report for BOAA members that includes a brief description of the research, the researcher's questions, a summary of BOAA members' responses, and how the researcher plans to act on their input. We generally include this in the packet for the next meeting. BOAA members value this feedback. It has helped convince some BOAA members that the researchers really are listening to them.

After each BOAA held four meetings with researchers, we revisited the meeting structure. BOAA members feel that the agendas, along with the co-facilitators, keep their discussions on track. They want researchers' specific questions for them to be listed in the written agenda.

Some BOAA members would like more immediate feedback from researchers. That led to an idea for a potential change: including a few minutes at the end of the meeting for researchers to summarize what they heard from BOAA members. Doing so could also help ensure that what researchers hear accurately reflects what BOAA members mean.

BOAA biographical sketches

During the second meeting of each BOAA, we talked with BOAA members about interviewing them to develop one-page biographical sketches. We share these BOAA bios with researchers before the meeting. BOAA members receive a similar bio for the researcher before the meeting. The idea of exchanging similar researcher and community member bios was inspired by the Bureau of Sages, research advisory boards comprised of Chicago-based nursing home residents and homebound older adults¹⁰

Following the second meeting, one of us interviewed each BOAA member and drafted their one-page bio. Each BOAA member reviewed their draft bio, suggesting changes that we incorporated before finalizing and formatting the bios.

Each BOAA member was asked the following four interview questions, which were shared with them in writing beforehand:

- What are your hobbies or pastimes?
- What do you want researchers to know about aging?
- What are you interested in learning more about on the BOAA?
- What are your thoughts or perspectives on health and wellbeing as you age?

With permission, we shared bios with all members of the same BOAA. This helped members get to know the others in their group. Later, in the weeks before the first joint meeting of the Madison and Rural BOAAs, we shared the bios with the members of the other BOAA.

BOAA members agree that having the bios helped them to find things to talk about with others. They hope that when researchers read their bios before the meeting, it helps challenge any assumptions the researchers might have about aging and older people.

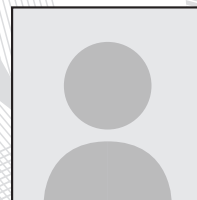
Roughly a year later, some BOAA members expressed an interest in updating their bios or doing a “deeper dive” interview, saying they would share more about themselves now that they knew the group. Some BOAA members think it might be helpful to add information to the bios about the person’s relationship status and employment background.

References:

10. Bureau of Sages. CJE SeniorLife. <https://www.cje.net/bureauofsages>. Accessed October 30, 2023.

Sample BOAA bio

Board of Older Adult Advisors Name



Hobbies and Pastimes

"If you get a chance to dance, dance! If I get an opportunity, I like to take it."

- I enjoy **cooking**, reading recipes and **baking**. My grandkids know I will always bring cookies. I also enjoy eating! I have a group of friends that visit different WI supper clubs together.
- I am on the ADRC and library boards and am the "Chief Election Inspector" for my county. I open the polls and authenticate the election. I **volunteer** as a way to give back—it is my turn.
- I play **Mahjong** with friends every week.
- I used to love to walk in nature but have arthritis in my feet. I stay physically active now by **swimming** and doing **water aerobics**.
- I love to read, particularly spiritual authors. I do daily spiritual study and enjoy going on retreat.

What I want researchers to know about aging

"I want researchers to know we may not have the education they do, but we have what they don't have: the knowledge and wisdom that comes from living our lives."

Everyone does things for a reason, they have their own context and motivation. You may not understand me and I may not understand you, but let's talk. If we are not so set in our ways, we can understand different situations and viewpoints. Generally, I think we find we are more alike than different—we all want safety, a good education, to be loved... We can talk out our differences. That is what I want the world to be like.

Perspectives on health and wellbeing as I age

"I am way less prone to depression when I am physically active. Physically doing something increases my level of confidence. I have no idea about human brain chemistry, but I'm sure that what I'm doing is making myself happy."

I understand and accept that I'm 68 years old and it's not a race. It's no longer important for me to do a four-minute mile. It's important for me to do a mile. I don't have to bench press 125 pounds, curl 35 pounds.

It's easier to age gracefully if you can put your pants on by yourself.

What I want to learn on the BOAA

I want to learn more about the human body, about the mind and how the brain works in aging, in particular. We are all going to age. But some people age better than others.

I have so many questions! What causes the difference in how we age? What feeds the brain? What causes dementia? Is it about genetics or are there things we can do to prevent it? Are there things the scientists know that could help caregivers and families help their loved ones?

Questions for researcher biographical sketches

Working with the members of each BOAA, we developed interview questions for the researchers' one-page biographical sketches. We ask these questions of researchers during a planning meeting, held four to six weeks prior to their meeting with the BOAA.

There are three questions that both the Madison and Rural BOAAs include in the researcher bios:

- What are your hobbies and pastimes?
- What do you want people to know about aging?
- What do you want to learn from community members?

The following questions are specific to researcher bios for the Madison BOAA:

- How would you briefly describe your research?
- What is your "ask" of the BOAAs?

The following questions are specific to researcher bios for the Rural BOAA:

- Where are you from?
- What experience do you have with rural communities?
- Where are you in the research process with this project? Do you have data yet?
- What do you want to get out of meeting with the BOAA? What would success look like?

Members of both BOAAs agree that the exchange of researcher and BOAA bios before meetings "eliminates a top-down" dynamic between researchers and community members. They see the bio as an introduction to the researcher, which they can build on during the meeting.

After participating in several research meetings, some BOAA members said they would like to learn more about the researcher. Questions they would like to ask researchers include:

- What experience do you have with older adults?
- What have you done beyond formal education to understand your research question from a lived experience (or community member) perspective?
- How has your research program evolved over time?

Sample researcher bio



Madison Board of Older Adult Advisors: Meet researcher Dr. Barb King!

My hobbies and pastimes

I like doing anything creative. I'm making quilts for my grandchildren. I love to knit, sew, and bake, too. I have a garden and grow enough vegetables to share with everyone in my neighborhood.



What I want people to know about aging

No one ages in the same way. The older adult population has more variation in it than any other age group. A forty-year-old can be in worse physical shape than a ninety-year-old elite athlete. We lump people age 65 and older together because of Social Security, but that can lead to stereotypes about aging.

What I want to learn from community members

I want my research to be based in the real world, not just something I come up with or read about. I want to know how older people think about mobility and base my work on those thoughts and experiences. I want to ask research questions that apply to people's lives and inform other researchers. Then we can figure out how to address the issues that actually affect older people.

About my research

My research is focused on improving how older adults are cared for during a hospital stay. Often, older adults enter the hospital being able to take care of their own daily needs, like bathing, dressing, toileting, eating, and walking. But by the time they are discharged from the hospital, they have trouble doing one or more of those tasks by themselves.

I and other researchers found that not walking during a hospital stay is the number one cause for older adults having difficulty taking care of themselves. I'm a nurse. I worked with Dr. Linsey Steege, a Human Factors Engineer, to design a model of care that increases how often and how much older adults walk during their hospital stay. We are currently spreading our model of care to hospitals in Wisconsin, to support older adult health and independence.

My "ask" for the Madison BOAA

I'm just starting to think about a new study to understand how older adults recover after a hospital stay. I'm asking the BOAAs for your feedback on the language I use to describe this. I want to know how to compensate people for participating in the study. I also want to hear what full recovery after a hospital stay would look like for you.

Soliciting BOAA member feedback

Shared decision making or co-creation is an iterative process. We frequently ask BOAA members for their feedback. Whenever possible, we make changes in response and tell BOAA members how we incorporated their suggestions. If there is disagreement among BOAA members, we consider how best to honor the feedback and the opinion held by most people.

Towards the end of each meeting, we ask BOAA members:

- What about today's meeting went well?
- What didn't go well?
- How could we improve?

We also ask for feedback in post-meeting emails, texts, and phone calls. Many people prefer to have time to reflect before offering feedback.

Over their first year, we surveyed BOAA members three times about their experiences with the group and with researchers, using the initial evaluation survey, interim evaluation survey, and follow-up evaluation and satisfaction survey from the Bureau of Sages project.¹¹

After each BOAA's fourth meeting with researchers, we conducted a focus group interview to collect additional feedback. Different members of our team led the focus groups than the people who co-facilitate BOAA meetings, to encourage constructive criticism of BOAA meetings.

The focus group interviews included the following questions:

- What has it been like for you to be a Board of Older Adult Advisors member?
- Is being a BOAA member what you hoped it would be? Why or why not?
- What specifically about the BOAA reflects your input or preferences?
- What was it like for you when researchers listened to you and used your input?
- If someone in another community wanted to start their own BOAA, what would you tell them to do differently?
- If you could make one change to this BOAA, what would it be?
- If we set up training for researchers on how to engage older adults, what should we include?
- What gets in the way of older adults being willing to join a group like the BOAA?

References:

11. Resources: Suggested Evaluation Materials. CJE SeniorLife. <https://www.cje.net/research-education/lrri/creating-research-advisory-boards/resources>. Accessed October 30, 2023.

Meeting outlines

Below are outlines of the first three meetings of each BOAA, which were devoted to orienting members to the project and health research, and to engaging them in shared decision-making or co-creation of meeting processes. Each meeting was roughly 90 minutes long.

MEETING ONE

- Ice breaker: What is one thing friends or family would say you are good at?
- Overview of the Board of Older Adult Advisors project
 - Project goals
 - People and groups involved
 - Make-up of the Rural and Madison BOAAs
 - Project timeline
- Introduction to health research
 - Health inequities / disparities
 - What does research mean to you?
 - The research process
 - Types of research
- Shared decision making
 - Meetings – where, when, and how
 - Community agreements
 - Mission
 - Plan for researcher meetings
 - Making decisions by consensus
- Team building / get to know you exercise – “True colors” activity
- Meeting feedback and closing

MEETING TWO

- Ice breaker: If someone was writing your biography, what would be the title (or a section or highlight)?
- Shared decision making: Community agreements
 - Think about a meeting or group you really enjoyed being part of. What were you feeling? What were people doing? Write down 3 or 4 things you really liked.
 - Share with the whole group
 - Considering these qualities, what agreements do we want to have for our time together?
- Positive health stories
 - Split into pairs and share a story about a positive experience related to your health care or well-being
 - Summarize your partner's story in one sentence to the whole group
 - What can we learn from these stories about what matters to us?
- Shared decision making: Mission statement
 - Consider community agreements, positive health stories, mission statement examples
 - Process by which we will develop a BOAA mission: one-on-one conversations, drafting a mission statement, then revising and finalizing it
- BOAA biographical sketches
 - Why and how we will use them
 - Four interview questions
 - Process by which we will develop bios: one-on-one conversations, drafting bios for your review, revising and finalizing, then sharing with all members of this BOAA and with researchers before you meet with them
- Meeting feedback and closing

MEETING THREE

- Ice breaker: What is something that you've recently asked for feedback on (or who do you ask for feedback)?
- Read and affirm community agreements
- Offering feedback to researchers
 - How do you like to receive feedback on something you have worked on and care about?
 - Example: How the City of Madison asked for community input on the format of wayfinding signs
 - Exercise 1: Giving feedback on a project idea – the Board of Older Adult Advisors
 - » What are some possible benefits?
 - » What are some possible concerns or downsides?
 - » How could we address the concerns you have raised?
 - Exercise 2: Giving feedback on a recruiting flyer
 - » What jumps out to you?
 - » Is there anything you particularly like? Don't like?
 - » Is it inviting? Do you want to read the flyer?
 - » Are the images compelling? Anything you would suggest or change?
 - » Read the heading. Does it make sense? Is it clear and easy to understand? Anything you would suggest or change?
 - » Read the text underneath. Does it make sense? Is it clear and easy to understand? Anything you would suggest or change?
- Shared decision making: Research meeting process
 - What information do you want before meetings?
 - Review draft meeting agenda. What reactions do you have? What changes do you want to make?
 - What information do you want after meetings?
- Meeting feedback and closing



SECTION 5

Working with researchers

Recruiting materials

Over the initial project period, we quickly filled the available research meeting slots. Below are a newsletter announcement and flyer we developed to announce the opportunity to health researchers across disciplines at UW–Madison.

NEWSLETTER ANNOUNCEMENT

Do you study aging and health? The Center for Aging Research and Education (CARE) and Wisconsin Network for Research Support (WINRS) announce the formation of two new standing community advisory groups to provide feedback to researchers working with older adults.

The Madison Board of Older Adults will be comprised of individuals 65 and older who identify as Black, Latinx, or living in under-resourced neighborhoods. The Rural Board of Older Adults will be comprised of individuals 65 and older living in rural areas of Wisconsin. Beginning next fall, both groups will be available to meet with researchers. If you have a project you would like to bring to one of the groups, please contact ...

FLYER



School of Nursing
UNIVERSITY OF WISCONSIN-MADISON

Want a simple (and effective) way to engage older adults in your research?

There are now two Board of Older Adult Advisors (BOAAs) to assist researchers. One BOAA includes veterans and other residents of rural southwest WI; the other BOAA includes Black older adults and other Madison residents.



How can the BOAAs help you?

- Give input on research questions and design
- Offer recommendations on recruitment strategies, study activities, and dissemination to engage people typically under-represented in health research
- Provide plain-language editing of public-facing materials

To learn more, please contact:

✉ farsetta@wisc.edu
☎ (608) 265-9542



Diane Farsetta

Center for Aging Research and Education
UW-Madison School of Nursing

Process for researchers

We meet with researchers four to six weeks before their meeting with the BOAA. We discuss what information they hope to get from BOAA members and the meeting structure (see section 4). We ask researchers questions to develop a bio for them and encourage them to read BOAA members' bios before the meeting.

Two of our team members co-facilitate BOAA meetings, translating the researcher's needs into the BOAA's framework. Researchers have five minutes to introduce themselves early in the meeting. We encourage researchers to talk about why their work is important to them. We present an overview of their study, with the researchers responding to clarifying questions from BOAA members.

We share the following with researchers before the planning meeting, to clarify our respective roles and the BOAA meeting process and timeline:

	Our team	Research team
<i>Preparation</i>	<ul style="list-style-type: none"> • Adds you to the BOAA meeting schedule • Meets with you to discuss your research materials and goals for the BOAA meeting • Creates an agenda for the BOAA meeting, research bio to introduce you to the BOAA members, and any other meeting materials • Sends you short bios for the BOAA members • Handles all meeting logistics 	<ul style="list-style-type: none"> • Provides all research materials relevant to your questions for the BOAAs <i>at least 3 – 4 weeks in advance</i> of the BOAA meeting • Meets with our team at least 4 weeks in advance of the BOAA meeting • Reads the BOAA members' bios
<i>During the meeting</i>	<ul style="list-style-type: none"> • Facilitates discussion • Records discussion and takes notes • Enjoys and learns 	<ul style="list-style-type: none"> • Briefly introduces team • Answers clarifying questions • Enjoys and learns
<i>After the meeting</i>	<ul style="list-style-type: none"> • Shares meeting recording • Sends written summary of BOAA members' input • Meets with you to discuss your experience of the BOAA meeting and your plans to respond to their input • Shares back with BOAA members your feedback and plans 	<ul style="list-style-type: none"> • Decides how to respond to BOAA members' input • Meets with our team <i>within one month</i> of the BOAA meeting to debrief • Shares with our team posters, workshop abstracts, publications, or other deliverables that make use of BOAA members' input

Debriefing with researchers

We follow up with researchers within one month of their meeting with the BOAA to hear their impressions and reactions to BOAA members' input. Prior to the debriefing, we send them a brief written summary of the discussion with BOAA members.

We ask researchers the following questions during the debriefing:

- How was your experience meeting with the BOAA?
- Did you find their input to be valuable and applicable to your work?
- Will you incorporate their feedback into your work? If so, how?
- Did the experience change how you think about engaging older adults in research?
- Any feedback on the written meeting summary?

Sharing researchers' feedback with BOAA members

There are two advantages to debriefing with researchers within a month of their meeting with the BOAA: researchers' memories are still fresh, and we can report back to BOAA members in a timely manner. Generally, the mailed meeting packet includes a summary of the last meeting, including the researcher's plans for responding to BOAA members' input.

The written meeting summary we develop for researchers includes their questions for the BOAA, followed by BOAA members' responses to each question, and an overall summary. We adapt this for the report back to the BOAAs, adding in how the researcher plans to incorporate the BOAA's guidance into their work.

BOAA members' impact on research

Every researcher who has met with one or both BOAAs found their input to be valuable and actionable. The following quotes are from researcher debrief meetings:

"It struck me how engaged they were as a group. ... Their answers were thoughtful, relating the topic to their own experiences. They considered the needs of the researchers, too."

"People brought up lots of good points that I hadn't considered. It was very helpful to get their perspectives."

"We got great feedback. I felt they were honest and appreciated their suggestions for carrying the work forward. ... We gave them a hard task in focusing on process and they did a nice job."

"What a positive experience it was to meet with both groups. The experiences and perspectives of individuals and the groups as a whole were distinct. ... It was particularly valuable to see the differences between the groups."

"We asked tough questions. It was obvious they were digging in, making the time count. It was helpful to see them disagree with each other. We all have our own preferences, and that's valuable feedback."

"They are so knowledgeable about their community, which really helped us gain a better idea of what to include and not include on our flyer."

"As a researcher, I find so much value in including the voices from different experiences and backgrounds. I wish we had done it earlier in the process."

The following table summarizes how BOAA members' input informed researchers' plans:

Meeting	Researcher plans to incorporate BOAA members' input by:
<i>Madison #1</i>	<ul style="list-style-type: none"> • Using clearer language with campus and community audiences to describe the topic • Looking for validated instruments that measure outcomes that are important to older people • Increasing incentives for study participants
<i>Rural #1</i>	<ul style="list-style-type: none"> • Using some quotes (with permission) in infographics and publications • Validating themes identified in interviews with other groups
<i>Madison #2</i>	<ul style="list-style-type: none"> • Changing language in study materials and adding schematics to clarify study procedures • Highlighting participant experiences and voices in study materials • Talking with colleagues about sharing data across studies to avoid participants undergoing duplicative testing • Looking for funding to increase engagement of groups underrepresented in research
<i>Rural #2</i>	<ul style="list-style-type: none"> • Revising recruiting flyer, adding photos that show a broader range of people and activities • Adapting language to make it more accessible
<i>Madison #3</i>	<ul style="list-style-type: none"> • Using some quotes (with permission) in infographics and publications • Rethinking how to reimburse study participants, to make more accessible (not tied to a certain store that not everyone can get to)
<i>Rural #3</i>	<ul style="list-style-type: none"> • Incorporating their ideas into the design of the next study • Following up with community organizations that BOAA members recommended as recruiting partners • Thinking differently about messages targeted to rural audiences
<i>Madison #4</i>	<ul style="list-style-type: none"> • Revising recruiting flyer • Planning more community presentations to give back by sharing information
<i>Rural #4</i>	<ul style="list-style-type: none"> • Including their ideas in a funding proposal • Following up with community groups that BOAA members suggested as partners • Considering how to include more context when describing interventions to potential study participants



SECTION 6

Starting your own older adult advisory board

BOAA members' advice

Members of the Rural and Madison BOAAs join us in hoping that this toolkit will inspire and assist you in developing older adult advisory boards to ground your work in the lived experiences of older people.

Be clear with yourself and others about why you're forming a new group, advises one BOAA member: *"Have a really good reason why [you] want to do this."*

It helps to bring together older adults who share some experiences, while including people with a range of perspectives and backgrounds, say the BOAAs. The motivation of the people involved is crucial:

"Get people who have a desire to do something good, to make a difference."

"You have to pick people who, in fact, are interested in what the subject is. ... You desperately have to find people who care and are willing to speak up, even if it's something that you don't want to hear."

Not just anyone can run a meeting, the BOAAs caution. Work with skilled facilitators or seek training in meeting facilitation so that your older adult advisory board can reach its potential:

"There's too many things that need to be kept on track in this kind of a board—focus on the research, focus on time, you know. And then looking ahead and also looking back. I mean, we require strong direction. And there are some people like me who go off on tangents."

BOAA members want others to learn from their experiences, while making clear that new groups should co-create their own goals, priorities, and processes:

"Depending on where you live, your particular situation will be different. ... So you've got to look at your group, and then you determine where you're going to go with it."

"If you can get a sample of what co-creating is with [the BOAAs], then think about how it can be used. They can take the recipe, so to speak, and modify it. ... It's that [new] group that has to think about, 'What are our needs? What are our goals?' and go from there."

What we learned

As with all community-engaged work, success depends upon building trust and fostering relationships.

Communities of color and other groups under-represented in health research have historically been exploited and harmed by researchers. People in these communities are more likely to have negative healthcare experiences, as we heard during interviews with potential BOAA members. It is not a small thing to ask people to share their perspectives and experiences with researchers, and to have faith that good will come of it.

Some BOAA members were skeptical at first—especially in the Madison BOAA, whose members predominantly identify as Black. Madison BOAA members asked for an opportunity to get to know the researchers as people before responding to their questions. We organized a social gathering, where members of three research teams briefly described their work and chatted with Madison BOAA members over refreshments.

Happily, the major trend that we saw across the three BOAA member surveys was a growing trust that researchers will listen to them and use their input. As one BOAA member said:

"Our points of view are really taken, and that really surprised me. ... They [researchers] all seem to really welcome our input. And they're happy to be here, and they seem to actually follow it, which is what surprised me."

Working with community organizations active in the geographic areas and with the communities we hoped to recruit from was essential. With our partners—community organizations, individual older adult consultants, and BOAA members—we showed how we valued them and their contributions by:

- Asking for their input early, listening carefully, and adapting our plans in response whenever possible
- Pointing out how their input strengthened the project and giving them credit
- Compensating them well for their time and expertise
- Asking how people prefer to be contacted and how they prefer to receive payment, when we were able to offer payment options
- Communicating the intent of any meeting, being prepared for meetings, and following up as promised
- Checking in one-on-one if something was unclear, unexpected, or potentially amiss
- Being open to negative as well as positive feedback
- Acknowledging our perspectives, limitations, and constraints
- Meeting where and when people prefer and bringing refreshments they enjoy

Challenges

Sadly, one BOAA member died after attending the three initial meetings. We did not anticipate needing to be prepared for a loss that soon. As her health declined, we shared updates as we were able and, with the agreement of other BOAA members, sent her a card and flowers from everyone in the group.

As a palliative care social worker reminded us, older people may experience multiple losses among family and friends. This can make any additional loss especially difficult. Making space to talk about feelings, to support each other, and to do something together in honor of the person can help people process their grief.

Another BOAA member left the group after attending the three initial meetings because she did not feel respected during a discussion. We followed up and offered to meet her to talk about what happened, but she declined. At the next meeting, we informed the group of her decision. While we didn't agree with her interpretation of events, we respected her decision and understood how some of the language in that discussion was unintentionally divisive.

Less serious challenges include the perennial temptation to include more on an agenda than can be discussed during a 90-minute meeting. Both BOAAs are frustrated when they can't get through the full agenda.

We have found that less is often more. We have gotten better at "right sizing" agendas, though we occasionally ask if people are able and willing to stay an extra five or ten minutes. We have decided against asking to regularly hold two-hour meetings, because the energy of the group tends to wane by the 90-minute mark.

A related challenge is finding a balance between the time for group process versus research discussions. Based on our experience, we suggest devoting at least three and maybe four meetings to the initial orientation and shared decision making.

A different and long-established community advisory board also facilitated by the School of Nursing has a steering committee that makes decisions about group processes. Any board member can participate in steering committee meetings, which are separate from research meetings. However, there is no compensation for steering committee meetings.

Because the BOAAs were formed and launched as COVID levels fluctuated in 2022 and 2023—and because it's sometimes not a good idea to drive during Wisconsin winters—we meet in person in local community spaces set up to facilitate video conferencing. Most people who join by video call fully engage in discussions, though we have had to clarify expectations for participation by remote participants. Some people who attend in person dislike the hybrid meeting format, but we feel the benefits of increased accessibility outweigh the challenges.

Sustainability

The BOAAs started meeting a little over a year before we developed this toolkit. So far, we have considered sustainability with regards to people and funding.

Sustainability with people involves supporting, listening to, and generally valuing current BOAA members, so that they want to stay involved. In addition to the “What we learned” points above, this means our commitment to shared decision making and co-creation did not end after the initial meetings. We asked BOAA members if they wanted to continue past the funded project period—and received many enthusiastic yeses! We surveyed BOAA members about their preferences and hopes for the future of their group, and shared and discussed the responses with them.

A year after the groups began meeting, BOAA members said the camaraderie and “casual respect” make them want to keep participating. They value open communication and the opportunity to learn from researchers and hear other BOAA members’ opinions. BOAA members appreciate that all the meeting details are taken care of. Some think of the meetings as providing social interactions that are good for their brain health. One person shared how supported she felt by other BOAA members when she was dealing with health issues.

Another aspect of sustainability with people is recruiting and onboarding new BOAA members when people need or choose to step down. We have not added new BOAA members since the initial three meetings. Current BOAA members suggest doing the following when we add people:

- Interviewing prospective members, as we did initially
- Sharing the BOAA’s mission statement and community agreements with prospective members
- Inviting prospective members to observe a BOAA research meeting

Current BOAA members noted that they will need to be welcoming of new members, as it can be challenging to enter an established group. They hope to create an environment where everyone feels safe and supported in sharing their stories.

Sustainability with funding involves finding a way to cover costs including BOAA member payments; meeting expenses such as space, refreshments, and travel; and staff time to recruit and prepare researchers, engage BOAA members, and prepare for, facilitate, and report on meetings. As mentioned in section two, we are transitioning from project funding to a fee for service model. We are fortunate to have a sizable research community at UW-Madison that values community engagement.



SECTION 7

Closing

We hope that this toolkit provides inspiration and useful information to researchers, whether you are just beginning to think about whether or how to engage older people or have experience in community-engaged scholarship.

The Patient Centered Outcomes Research Institute (PCORI) is an independent, nonprofit research organization that supports and drives initiatives to make U.S. health research more patient-centered. This includes funding comparative clinical effectiveness research, which compares the harms and benefits of different healthcare approaches to help patients make informed healthcare decisions.

PCORI resources include:

- Building Effective Multi-Stakeholder Research Teams, a website for research team members
- Research Fundamentals: Preparing You to Successfully Contribute to Research, a self-paced training for people new to research
- Engagement Tool and Resource Repository for Patient-Centered Outcomes Research, a peer-to-peer repository of engagement tools

The above and other PCORI resources can be found at:
<https://www.pcori.org/engagement/engagement-resources>

Additional resources

- About the Bureau of Sages research advisory board of nursing home community members and homebound older adults: <https://www.cje.net/bureauofsages>
- Wisconsin Network for Research Support toolkits on recruiting and retaining patient stakeholders and orienting patient advisory committees: <https://winrs.nursing.wisc.edu/resources/toolkits/>
- Anti-oppressive facilitation: <https://www.fammed.wisc.edu/files/webfm-uploads/documents/diversity/AO%20Resources.pdf>
- Additional facilitation guides: <https://winrs.nursing.wisc.edu/resources/articles/facilitation/>
- Grieving a friend: <https://www.ourhouse-grief.org/grief-pages/death-of-a-friend/>
- Grieving a co-worker: <https://www.ourhouse-grief.org/grief-pages/death-of-a-co-worker/>



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