



W UNIVERSITY of WASHINGTON



COMMUNITY ADVISORY BOARD MEMBERSHIP MANUAL

University of Washington Alzheimer's Disease Research Center

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Introduction

Purpose

The purpose of this manual is to provide guidance on the addition of new members to the University of Washington Alzheimer's Disease Research Center (UW ADRC) Community Advisory Board (CAB). In doing so, this document will outline the processes for recruiting, inviting, selecting, and welcoming prospective UW ADRC CAB members.

Please note, this manual does not provide guidance on the initial creation of the ADRC CAB, only the addition of new members.

What is the University of Washington Alzheimer's Disease Research Center?

The University of Washington Alzheimer's Disease Research Center (UW ADRC) is a research component of the UW Memory & Brain Wellness Center (MBWC). The UW ADRC was established in 1985 and is one of the nationwide network of 35 research centers funded by the National Institute on Aging. ADRCs are major sources of discovery into characterizing the causes and characteristics of Alzheimer's disease and related dementias, and into the development of more effective approaches for prevention, care, and treatment. The UW ADRC contributes to the development of shared resources that support dementia-relevant education and research, and coordinates research efforts with other investigators both locally and nationally. The UW ADRC has seven "Cores" which work together to facilitate research efforts. These Cores include: Administrative; Clinical; Data Management & Statistics; Imaging and Biomarker; Native Research & Resources; Outreach, Recruitment, & Engagement; and Precision Neuropathology. The UW ADRC also has a Research Education Component (REC), which mentors and trains early career researchers in the interdisciplinary perspectives needed for a career focused on Alzheimer's Disease research.



For more information about the UW ADRC and its Cores, please visit our website: www.uwadrc.org.

Quick Reference: Acronym Glossary

- **ADRC:** Alzheimer's Disease Research Center
- **CAB:** Community Advisory Board
- **MBWC:** Memory and Brain Wellness Center
- **NIA:** National Institute on Aging
- **ORE:** Outreach, Recruitment, and Engagement Core
- **RC:** Research Coordinator
- **RS:** Research Scientist
- **UW:** University of Washington



What is the UW ADRC Community Advisory Board (CAB)?

The ADRC Community Advisory Board (CAB) is a critical connection between the UW ADRC and the communities the UW ADRC partners with. The CAB supports and guides the development of relevant, resources, programs and events. Members act as a sounding board and as community liaisons, while guiding the prioritization of goals and development strategies related to resources, programs and events, including identifying and reducing barriers.

UW ADRC CAB Mission Statement:

The mission of the UW ADRC CAB is to serve as the voice and representative perspective of the community to the UW ADRC with the goal of improving the health and well-being of patients with Alzheimer's disease and their caregivers through the development of treatments, programs, and therapies addressing Alzheimer's disease and related dementias

Who is on the UW ADRC CAB?

The UW ADRC CAB is a group of individuals comprised of individuals from the community with interest in healthy aging as well as Alzheimer's disease and related dementias, including persons living with memory loss (documented diagnosis of early stage Alzheimer's, Mild Cognitive impairment, or other early stage dementia) associated with UW ADRC or the UW Memory Brain and Wellness Center, care partners, and representatives from community programs. Representative could mean that CAB members share characteristics (e.g., language, culture, geography) and/or experiences with the community of interest.

UW ADRC CAB Roles and Responsibilities

Although individual CAB members may hold specific roles (e.g., co-chair), which are defined below, all CAB members must adhere to the following overarching CAB roles:

1. **Interest in or actively working** towards advancing care for Alzheimer's disease and related dementias
2. **Ability to attend** all (or most) meetings or send an alternate representative
3. **Ability to inform community** members about the UW ADRC process and decisions that are made during CAB meetings
4. **Commitment to collaborating** with all CAB members, drawing on strengths and experiences for the betterment of the community health and research projects
5. **Understanding of and/or representative of community** and the ability to represent the community in research and project-related discussions
6. **Interest in or actively working** towards advancing science for Alzheimer's disease and related dementias



CAB ROLES SUMMARY



Engage in both short and long-term planning of projects



Contribute to discussions on planning and implementation



Review and assess project performance



Inform the community about the projects, focusing on short- and long-term solutions

Current CAB Members:

These individuals are existing members of the CAB. They provide community insight and expertise to the UW ADRC and research agenda. Each CAB member will be asked to serve a two-year term of service with the possibility of extension. A two-year term aligns with common practices¹ and will allow CAB members to gain familiarity with the ADRC projects and provide sustained guidance and community perspective. Furthermore, it will allow CAB members to reassess their priorities, availability and alignment with the larger ADRC and CAB mission, current scope of work and project funding cycles.

ADRC Investigator (PI):

Investigator from the UW ADRC scientific research program. This role may be held by the Lead of the Outreach, Recruitment, and Engagement (ORE) Core. They are responsible for serving as a scientific liaison between the CAB and the UW ADRC.²

ADRC Research Coordinator or Research Scientist (RC/RS):

The RC/RS is a member of the UW ADRC research team. The RC/RS is the individual overseeing daily management and coordination of the project. They are often a liaison between the larger project team, project leadership, and sponsor/funding agencies. The RC/RS works closely with the UW ADRC Investigator on all aspects of the project from development and data collection to dissemination of results. This individual is also the *administrative lead* for the CAB and is responsible for co-creating meeting agendas with the CAB co-chairs (if the administrative lead is not already serving as a co-chair) and larger UW ADRC CAB events (e.g., strategic meetings, retreats, etc.), as well as coordinating CAB meetings.

ADRC Research Coordinator #2 (RC):

An additional research coordinator may assist the UW ADRC CAB co-chairs by providing administrative support. This may include drafting and sending meeting agendas prior to CAB meetings, as well as taking detailed notes during the CAB meeting and sending all notes or relevant materials and documents discussed to all CAB members after the meeting.

ADRC CAB Co-Chairs:



Two CAB members can serve as the ADRC CAB co-chairs. Co-chairs will collaborate to: 1) create and review meeting agendas, 2) co-lead CAB meetings, 3) represent the CAB at UW ADRC Steering Committee and External Advisory Board (EAB) meetings, and 4) make decisions on behalf of the CAB for decisions that are time constrained, and 5) sign any CAB letter(s) of support on behalf of the CAB. UW ADRC CAB co-chairs can be elected, nominated, or volunteered positions, and will serve a one-year term with the possibility of renewal. Co-chairs should represent the community and research teams by appointing one member from each group to serve respectively. This will help dismantle research hierarchy and elevate the voice and opinion of both groups equally.

Prospective CAB Member:

A prospective CAB member is an individual who is interested in serving on the ADRC CAB but has not yet formally joined. As with other CAB members, the prospective CAB member should share characteristics (e.g., language, culture, geography) and/or experiences with the community of interest. This will allow them to better understand, advocate for, and serve as a liaison of the community when discussing the project with research staff. For more information about the prospective CAB member process, please see the next section, “New or Prospective CAB Members.”



New or Prospective CAB Members

Identifying Prospective CAB Members

New ADRC CAB members may be needed to fill a UW ADRC CAB vacancy, or to strengthen or supplement the current CAB with a new area of expertise and/or perspective to better reflect the community and serve the UW ADRC project. Both scenarios are outlined respectively below. New members may be commonly sourced from current CAB member referral, through community networking, or through past CAB partnerships/participation.¹

CAB Vacancy

A UW ADRC CAB member may leave the CAB for a variety of reasons. For example, a CAB member may leave when the predesignated term of service ends or if the CAB member's interests or availability changes. A CAB member may also resign or retire from the community based organization (CBO) they were representing on the CAB. All vacating members can recommend another member from their organization to serve in their place and continue representing the community.

It is important to note that a CAB member may resign or retire from their CBO but still be interested in continuing to serve on the UW ADRC CAB. If this is the case, current CAB members can discuss maintaining the individual CAB member in a non-CBO affiliated role; however, a new member to represent the former CBO will still need to be identified.

Strengthen or Supplement Current CAB

It may become apparent that there is a gap in CAB representation. For example, gaps may be reflective of a missing organization, community perspective, or lived experience. These gaps may be identified by asking the question *"Whose voice is not represented currently within our CAB?"*

When considering prospective CAB members to fill an existing vacancy or strengthen/supplement current CAB members, it may be helpful to review the roles and responsibilities (prior section, "UW ADRC CAB Roles and Responsibilities"). The CAB administrative lead should also share these roles and responsibilities with the interested or prospective CAB members to review and assess whether they are interested in joining.

A prospective CAB member will be invited to complete the UW ADRC CAB interest form (Appendix C), accompanied by the UW ADRC CAB Overview handout (Appendix D). The interest form will provide information to existing CAB members regarding the prospective member's advisory board experience and interests in serving on the ADRC CAB. The UW ADRC CAB Overview handout will serve as an informative resource on the purpose of the CAB while considering potential membership to the CAB.

A note on CAB membership size: The number of CAB members may depend on the purpose of the CAB, and the diversity of voices and experiences needed to adequately represent the community and guide the different areas of ADRC research. CABs may range from 5-20 members^{3,4} or may chose not to set a



threshold for membership. The ADRC CAB will continue to add members as needed (identified by current CAB), until the CAB reaches a total of 20 active members, at which point the threshold of 20 will be reassessed based on current need and capacity.

Sharing Prospective CAB Member Information

The CAB administrative lead (RC/RS) will compile all prospective member information into a single document, including CAB member interest form and a short paragraph detailing how the prospective CAB member could contribute to the UW ADRC CAB. Once compiled, the CAB administrative lead will disseminate the document to all existing CAB members and request that they review it prior to the scheduled Community Conversation with Prospective CAB members, as well as prior to the next CAB meeting. Additionally, prospective member materials should be sent with the meeting agenda to re-prompt all members to review the material prior to the next meeting.

Community Conversation with Prospective CAB Members

Once the prospective CAB member has completed the UW ADRC CAB interest form (Appendix C), they will be invited to an informal 45-minute Community Conversation held over Zoom*. The informal Community Conversation is a chance for current CAB members to dialogue with the prospective CAB member. Bidirectional conversation between the prospective and current members will help reiterate the CAB mission and values, as well as allow for current members to better understand the prospective members' interest in joining the CAB.

**A note about scheduling: out of respect for everyone's time, the administrative lead will send out a doodle poll of available times to the current CAB members. Doodle poll times will be representative of times that the prospective CAB member was available to meet for 45-minutes.*

Selecting Prospective CAB Members

The process for selecting new members should take into account the opinions of the entire CAB. After reviewing the prospective member materials and recommendations, and having the opportunity to attend the Community Conversation with the prospective CAB member, the administrative lead will facilitate a discussion on the new prospective CAB member at the next CAB meeting. During this time, they will review the prospective CAB member's interest form, present a short summary of why the prospective CAB member would be a good fit for the CAB and open the floor for current CAB member reflections from the Community Conversation. At this time, all CAB members in attendance will have the opportunity to ask questions or provide feedback on prospective CAB members.

Voting on Prospective CAB Members

Once the CAB has completed discussing prospective CAB members, current CAB members will have the opportunity to vote on the addition of prospective members to the CAB through an online survey. The survey will be administered through REDCap. All CAB members will be able to vote anonymously or abstain from the vote.



There are three possible outcomes of the vote: (1) selected, (2) needs more discussion, and (3) not selected. A majority “selected” vote will confirm that the prospective member is selected and will be invited to join the CAB. A majority “not selected” vote will confirm that the prospective member will not be joining the CAB. If the decision is “not selected,” the CAB will have to provide a rationale or statement explaining their decision. If there are any “needs more discussion” votes, the administrative lead will add an agenda item for continued discussion of the prospective candidate at the next UW ADRC CAB meeting. Once a decision has been made, the administrative lead (RC/RS) will communicate the collective CAB decision(s) to the prospective member.

Orientation and Training

Once a prospective CAB member has been offered an ADRC CAB position and accepted, the RC/RS will share orientation and training documents with the new member including the ADRC CAB Overview Handout (Appendix D) – this sheet contains general information on the UW ADRC and the CAB. Depending on a member’s prior CAB (or similar) experience, they may require additional orientation and/or information (e.g., research ethics).

Leaving the CAB

If a CAB member is leaving their position on the CAB, they should inform the administrative lead (RC/RS) of their departure as soon as possible. If the departing CAB member is representing an organization on the CAB, the administrative lead will ask for suggestions of organization employees who can transition into the departing CAB member’s position. This will allow the CAB to promptly fill the vacancy as needed.

Alternatively, a CAB member may leave the organization they were representing while serving on the CAB. If this is the case, they should still inform the administrative lead (RC/RS) of their departure as soon as possible. If amenable, they can recommend another colleague who is still working at that agency to serve on the CAB. The CAB member can also remain part of the CAB representing their new agency if they perceive that the goal of the new agency aligns with the ADRC mission.



APPENDIX A: Email Templates

A.1. Email template (Administrative Lead): Invitation to learn about ADRC CAB

The following email template can be used by the CAB administrative lead to establish contact with a prospective CAB member.

*****TEMPLATE*****

Hello _____,

My name is [INSERT NAME] and I work with the University of Washington Alzheimer's Disease Research Center (ADRC) Community Advisory Board (CAB). We are currently looking to invite new community members to become part of the CAB!

We thought that you might be interested in joining our CAB given your [INSERT: expertise, your connections to the community, etc.; alternatively recommended by...]. If you are interested and would like to learn more about the UW ADRC CAB mission as well as the roles and responsibilities of the CAB, please let me know and I would be happy to provide additional information or meet with you.

Sincerely,
[INSERT NAME AND SIGNATURE]

A.2. Email template (Current CAB Member): Invitation to learn about ADRC CAB

The following email template can be used by a current CAB member to establish contact with a prospective CAB member.

*****TEMPLATE*****

Hello _____,

My name is [INSERT NAME] and I collaborate with the University of Washington Alzheimer's Disease Research Center (ADRC) as a member of the Community Advisory Board (CAB). We are currently looking to invite new community members to become part of the CAB!

We thought that you might be interested in joining our CAB given your [INSERT: expertise, your connections to the community, etc.; alternatively recommended by...]. If you are interested and would like to learn more about the UW ADRC CAB mission as well as the roles and responsibilities of the CAB, please let me know and I would be happy to provide additional information or meet with you.

Sincerely,
[INSERT NAME AND SIGNATURE]



APPENDIX B

Email template: Invitation to Join

The following email template can be used to invite a prospective CAB member to join the CAB.

Hello [INSERT PROSPECTIVE CAB MEMBER NAME],

Thank you for your interest in and willingness to serve on the University of Washington Alzheimer's Disease Research Center Community Advisory Board (CAB).

I am excited to formally invite you to join our CAB effective [INSERT DATE]. Our next CAB meeting will take place on [INSERT DAY AND TIME] and will be held [ZOOM OR IN PERSON]. Prior to the meeting, we will send an agenda and a quick introductory message welcoming you to our team.

We are looking forward to working with you. Please respond to this email indicating your acceptance or decline of this position. If we can provide any additional information to aid in your decision, or answer any questions, please let us know.

Sincerely,

[INSERT NAME AND SIGNATURE]



APPENDIX C

ADRC CAB Interest Form¹

Contact Information

First name:		Last name:	
City:		Zip code:	
Phone number:		Phone type:	
Email:			
General availability:	☐ Weekdays – mornings (9am-12pm) ☐ Weekdays – afternoons (12-6pm) ☐ Weekends – mornings (9am-12pm) ☐ Weekends – afternoons (12-6pm) ☐ Other:		

Demographic Information

Age range:	☐ 21-30	☐ 31-50	☐ 51-70	☐ 71+
Gender:	☐ Female	☐ Male	Other:	
Race/ethnicity: <i>Select all that apply.</i>	☐ Hispanic/Latino		☐ African American/Black	
	☐ American Indian/Alaska Native		☐ Asian	
	☐ Native Hawaiian/Other Pacific Islander		☐ White/Caucasian	
	☐ Other:			

Advisory Board Experience and Interest

The next set of questions will ask you about prior service and/or collaboration with community advisory boards. Additionally, they will ask you about your current interests.

1. Have you advised a research project or served as a members of a community advisory board before?
☐ Yes ☐ No ☐ Not sure
2. If yes, please describe your prior experience advising a research project or serving as a member of a community advisory board.

Community Experience and Interest

This final set of questions will ask you about your lived experience and interest in the community.

¹ INTERNAL NOTE: This interest form was modeled off several CAB applications available online. These included: 1) the Community Advisory Boards Resources Packet by the Collaborative Research Center for American Indian Health⁵ and the University of Minnesota Center for Healthy Aging and Innovation (CHAI) Community Advisory Board Application.⁶ Although this CAB interest form was modeled off existing CAB applications, we would like to reiterate that *this form is an interest form and not an application*.



1. Do you have experience supporting individuals with or caring for individuals living with Alzheimer's Disease or related dementias, or memory loss?

☐ Yes ☐ No ☐ Not sure

2. If yes, please describe your prior experience.



APPENDIX D

ADRC CAB Overview Handout

UW Alzheimer's Disease Research Center (ADRC)

- Established in 1985, the UW ADRC is one of 35 research centers funded by the National Institute on Aging.
- Comprised of seven "Cores" and one "Research Education Component," which work together to conduct research efforts. All cores can be seen in purple box below.
- The UW ADRC CAB may collaborate with any of the seven Cores depending on project stage.
- The UW ADRC works on:
 - Examining the causes and characteristics of Alzheimer's disease and related dementias
 - Development of more effective approaches for prevention, care, and treatment
 - Development of shared resources that support dementia-relevant education and research
 - Coordination of research efforts with scientists both locally and nationally

UW ADRC Core Websites

- Administrative Core: <https://depts.washington.edu/mbwc/adrc/page/administrative-core>
- Clinical Core: <https://depts.washington.edu/mbwc/adrc/page/adrc-clinical-core>
- Data Management & Statistics Core: <https://depts.washington.edu/mbwc/adrc/page/data-management-statistics-dms-core>
- Imaging and Biomarker Core: <https://depts.washington.edu/mbwc/adrc/page/imaging-and-biomarker-core>
- Native Research & Resources Core: <https://depts.washington.edu/mbwc/adrc/page/nrrc>
- Outreach, Recruitment, & Engagement Core: <https://depts.washington.edu/mbwc/adrc/page/ore-core>
- Precision Neuropathology Core: <https://depts.washington.edu/mbwc/adrc/page/neuropathology>
- Research Education Component: <https://depts.washington.edu/mbwc/adrc/page/rec>

ADRC Community Advisory Board

Purpose

The ADRC Community Advisory Board (CAB) supports and guides the development of relevant, resources, programs and events. Members act as a sounding board and as community liaisons, while guiding the prioritization of goals and development strategies related to resources, programs and events, including identifying and reducing barriers.



Membership

The ADRC CAB is made up of individuals with interest in healthy aging as well as interest in Alzheimer's disease and related dementias, including persons living with memory loss (documented diagnosis of early stage Alzheimer's, Mild Cognitive Impairment, or other early stage dementia) associated with UW ADRC or the UW Memory Brain and Wellness Center, care partners, and representatives from community programs. The ADRC CAB will continue to add members as needed (identified by current CAB), until the CAB reaches a total of 20 active members, at which point the threshold of 20 will be reassessed based on current need and capacity.

Expectations

Members of the ADRC CAB commit to the following:

- Attend bi-monthly 1-hour advisory group meetings
- Provide input and guidance in prioritizing goals and developing strategies within the three categories outlined above
- Be available as able/desired for individual consultation in area of expertise
- Support programs and events as desired, by helping with program planning and implementation
- Spread the word about ADRC resources, programs and events
- Suggest community partnership opportunities

Members will have the opportunity to extend their commitment on a yearly basis, following an evaluation of the advisory group experience.

Benefits

Members of the UW ADRC CAB receive the following benefits:

- Learn more about current research, programs, treatments, and resources related to living well with memory loss
- Provide voices on how to increase diversity in research participation to ensure programming, treatments, and therapies benefit all communities
- Connect with a group of people interested in decreasing the stigma of dementia
- Leave your mark on the ADRC by advising this initiative

For more information about the UW ADRC and its cores, please visit our website: www.uwadrc.org.



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Partners

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- Chalin Pahn, CAB member, Asian Counseling and Referral Services
- Eleanor Lee, CAB member, Asian Counseling and Referral Services
- Eun Jung Lee, CAB member, Asian American Resource and Information Network (AARIN)
- Gail Li, CAB member, Asian Counseling and Referral Services
- Kelly Lewis, CAB member, Benton-Franklin Health District, Safe and Healthy Aging Coalition
- Raquel Garcia, CAB member, El Centro de la Raza
- Rosa Ortiz, CAB member, Yakima Farm Worker's Clinic



**Yakima Valley
Farm Workers Clinic**



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