
Community Action Board

National Institute on Minority Health and Health Disparities

Center of Excellence in American Indian and Alaska Native Health Disparities

April 2020 Update



This Center of Excellence is a collaboration between the University of Colorado Denver and Washington State University (WSU). We collaborate with private, tribal, and public groups to create a culturally informed, patient-centered program that conducts high quality research on cognitive impairment and dementia in Native communities.

Halito (*hello*) Community Action Board Members

The Precision Medicine for Alzheimer's disease and Related Dementias Center of Excellence for American Indians and Alaska Natives thanks you for taking the time to help guide our efforts in 2020. It has been an unusual year, and we hope and pray you all are well. We'd like to provide you with an update on our progress and share some future plans in 2020.

As a reminder, our center is composed of an Administrative Core, a Community Outreach and Education Core, as well as two research projects.

Overview of CAB Efforts

During our February 2020 meeting, the Community Action Board (CAB) was updated on the progress being made at each community site regarding the AD8 screener. The CAB also heard from the leads of the research projects.

As you may recall, the AD8 is an eight-item screener that can be completed by an individual or administered by a provider. During our February 2019 meeting, CAB members guided us through a process of culturally adapting the AD8 screener. CAB members discussed and revised aspects of the screener, recommending small modifications to language and sentence structure in order to ground this tool in our common cultural knowledge and ensure its cultural relevance in capturing potential memory loss.

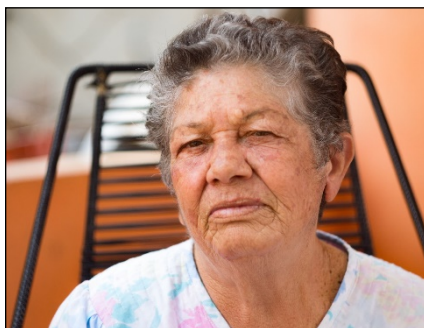
One of the important things learned from the February CAB meeting is that this CAB wants to have more regular engagement, perhaps on a quarterly basis. To that end, we have organized our next CAB meeting:

Wednesday, May 13, 2020 at 10AM MT/9AM PT

An agenda and Zoom meeting details will be sent to CAB members before the meeting.

In March this year, the CAB met to review infographics developed by AARP. CAB members were asked to provide feedback about the infographics and suggest changes to make them more useful for their communities. In depth recommendations were discussed during the meeting and CAB members provided further feedback through a web-based survey. CAB member recommendations to tailor the infographics for our American Indian and Alaska Native communities were compiled and provided to the AARP leadership team for further review and consideration.

We are currently working to schedule a follow-up meeting between the CAB and the AARP leadership for further discussion on tailoring the infographics for broader use in Native communities.



Research Updates

Our Center of Excellence has 5 Satellite Centers located around the country, all led by Native researchers. The purpose of the Satellite Centers is to ensure Native people in all parts of the U.S. are represented in our work. The Satellite Centers also make sure information on cognitive impairment and dementia is distributed to local communities. Here are some highlights from each of the Satellite Centers:

Northeast

Northeast Satellite Center staff has completed their collection of AD8 surveys with both rural and urban American Indians at several events attended by Native elders. The data has been compiled and analyzed by the project team. The Northeast Satellite Center team is working closely with several local organizations to find opportunities to share the information learned through the survey data. They are scheduled to participate in a panel discussion through the University of Minnesota Wisdom Steps program in June.

Southwest

The research protocol to collect 75 surveys from urban American Indians at First Nations Community HealthSource clinics in Albuquerque and the All Nations Wellness & Healing Center (ANWHC) in Albuquerque was approved on April 27. The protocol includes modifications to collect data remotely using Zoom/telephone due to COVID-19. The exact launch date for this part of the project is unknown at this time, but will likely be in May 2020.

Dr. Tassy Parker and Nathania Tsosie met with tribal leadership from an Albuquerque-area Pueblo to discuss collecting 75 surveys to complete the rural sample. The leader expressed support and recommended submitting a research protocol through the ABQ Area Indian Health Board IRB. The meeting was held prior to COVID-19 and further discussions have since been put off until further notice. We are hopeful that we can navigate the regulatory and research process with minimal disruption to the community and their tribal members.

Rocky Mountain

In October 2019, team members conducted the AD8 Survey with 75 rural American Indians at the Black Hills Powwow in Rapid City, South Dakota, over a three-day event. In November, the team traveled to the Four Corners region to work with Ute Mountain Ute and administer the AD8 survey to 75 rural American Indians over two days. The team attended two health fairs in two communities, one in Utah

and one in Towaoc, Colorado. In December 2019, the team administered the AD8 survey to 75 Urban American Indians at the Annual Elder's Dinner at the Denver Indian Center. This annual event draws over 200 attendees 55+ years of age. The elders were treated to a fun night full of food and gifts for the holidays. After the holidays the team began preparation to administer the AD8 at the Annual Denver March Powwow normally held the third week of March. After several months of preparation, the Denver March Powwow was postponed due to the Covid-19 pandemic. Focus now is looking at methods to disseminate the data, and staff is working towards a symposium in the later part of the summer or early fall with some key stakeholders and the community. The team is also continuing to collaborate with the local Alzheimer's Associations Diversity and Inclusion Committee to develop ways to support the local American Indian community.

Pacific Northwest

In July 2019, 60 American Indians living in rural areas completed the AD8 at the Colville Elder Pow Wow. This data is in the process of being analyzed for the project. Data from urban American Indians will be collected from 75 urban elders in the Seattle area in partnership with Seattle Indian Health Board. The urban survey collection has been put on hold until the Covid-19 situation has stabilized, and it is safe to resume face-to-face data collection.

Alaska

In January and February, our Satellite Center staff recruited older Alaska Native and American Indian adults in the lobby of the primary care clinic in Anchorage, and 75 urban dwelling elders completed the AD8. Also in February, the staff started recruiting in a rural clinic and completed 9 AD8 surveys before stopping to help decrease the spread of coronavirus.

Staff Updates

Megan Jernigan, Pacific Northwest Satellite Center lead for the project, has left Washington State University for another opportunity in the Seattle area. Ms. Jernigan's role as Satellite Center lead has transitioned to Dr. Ka'imi Sinclair (Western Cherokee), Associate Professor and Co-Director of Partnerships for Native Health at Washington State University. We welcome Dr. Sinclair to the project!

Krista Schafer, Public Health Researcher, and Kelley Jansen (Aleut), Public Health Researcher, are both joining the project team from Southcentral Foundation in support of the Alaska Satellite Center's work. Welcome Krista and Kelley!

Research Project Updates

A Longitudinal Study of MRI, Clinical, and Genetic Biomarkers of Cognitive Impairment and Alzheimer's Disease in Elderly American Indians

Magnetic resonance images (MRIs) provide snapshots of the brain, including parts affected by Alzheimer's disease. This project uses data from a large group of 817 American Indians from 10 tribes in three states. Participants had MRI scans and did thinking and memory tests at two different times, 7 years apart. With partners at the Banner Alzheimer's Institute, we are carefully examining the MRIs from both time points using specialized software. We are looking for changes in the whole brain and

specific parts important in memory, concentration, and thinking. We will see whether a decrease in brain size is associated with problems with memory, concentration, and thinking and Alzheimer's disease. We are working on the analyses now and will write the full report in the coming months.

Addressing the Knowledge and Recruitment Gap in Alzheimer's Disease and Precision Medicine among Native People: An Innovative Randomized Controlled Trial

We will evaluate different ways to recruit American Indian and Alaska Native people into research studies. We will compare a brochure and video about problems with memory, concentration, and thinking and Alzheimer's disease. The brochure and video also describe precision medicine and how care can be tailored to individuals.

Participants at different clinical facilities will then randomly receive either the brochure or video. We will test if the brochure or video result in more American Indian people interested in joining research studies. We are working with American Indian people to create the brochure and hiring a Native-owned company to create the video. We are also looking for clinical facilities who want to test the brochure or the video.



Outreach and Dissemination Plans

An important part of the Center of Excellence's work is being able to disseminate, or distribute and share, the information that we collect during the project. Researchers will share this information with other researchers and Federal partners through scholarly articles, presentations, and speaking engagements. This is an important part of sharing the work of the Center and will help inform future project funding and policy at the Federal level.

Equally important is the sharing of the information collected through the center at the local and community level. Getting the information we learn through the project into the hands of clinicians, elders, families, and community members is a priority for us.

To that end, we will make time during our next Community Action Board Meeting to discuss outlets for sharing the information collected through this project on several levels: National, Regional, and Local.

Another important aspect of the Satellite Center work is the planning of local symposia annually in each region to raise awareness about Alzheimer's disease and related dementias. In 2020 the Rocky Mountain Satellite Center will partner with Denver-area clinical and community resource providers to host an event. If Covid-19 restrictions are lifted, then the event will happen in-person. Otherwise, the Rocky Mountain Leads will plan an engaging online event for this fall.

Finally, the Outreach, Engagement, and Dissemination Committee is working together across Satellite Centers to make a presentation to the National Indian Council on Aging (NICOA) at their semi-annual conference in Reno, Nevada in August. The presentation will describe the process of adapting and administering the culturally-tailored AD8 assessment with Native elders around the country.

Thank You!

Qaġaasakung <i>Aleut</i>	Quyanaq <i>Inupiaq</i>	'Awa'ahdah <i>Eyak</i>
Mahsi' <i>Cwich'in Athabaskan</i>	Igamsiqanaghalek <i>Siberian Yupik</i>	Háw'aa <i>Haida</i>
Quyana <i>Yup'ik</i>	T'oyaxsm <i>Tsimshian</i>	Gunalchéesh <i>Tlingit</i>
Tsin'aen <i>Ahtna Athabaskan</i>	Quyanaa <i>Alutiiq</i>	Chin'an <i>Dena'ina Athabaskan</i>



We raise our hands to our CAB for your guidance and dedication to Native elders.

For more information about this newsletter, please contact:
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