

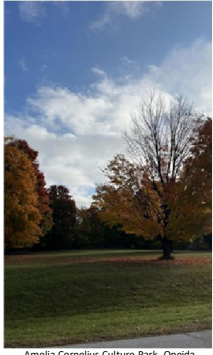


Inspiring Hope in Dementia Research:
The American Indigenous Cognitive Assessment (AMICA)

Addressing Alzheimer's Disease and Related Dementias Disparities

Alzheimer's Association Annual Wisconsin State Conference
Kalahari Resort, Wisconsin Dells, WI
May 6th, 2024

Amelia Cornelius Culture Park, Oneida

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Oneida AMICA Team



Cassandra Thomas- Community Researcher


Dr. Kala Kimberly Cornelius- Nurse Practitioner


Carrie Trojanczyk- Project Coordinator



Dr. Carey Gleason- Principal Investigator


Dr. Nickolas Lambrou- Research Scientist


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Learning Objectives

- Acknowledge the history and background of Indigenous peoples' participation in Alzheimer's Disease and Related Dementias (ADRD) research.
- Recognize the partnerships needed for successful relationships with local tribes and community experts.
- Gain insight on the project methodology utilized in Community-Based Participatory Research (CBPR).
- Understand the goals and impacts of the AMICA tool and potential applications in diverse tribal communities.



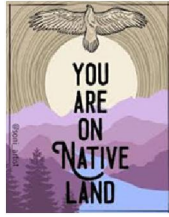
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Land Acknowledgement

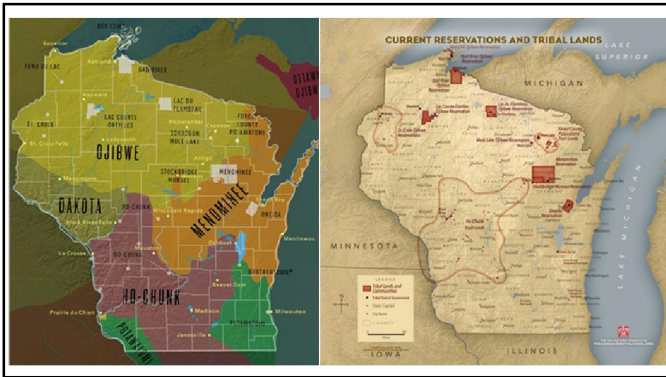
The Wisconsin ADRC respectfully acknowledges that the University of Wisconsin–Madison occupies ancestral Ho-Chunk land, a place their nation has called Teejop (day-JOPE) since time immemorial. In an 1832 treaty, the Ho-Chunk were forced to cede this territory. Decades of ethnic cleansing followed when both the federal and state government repeatedly, but unsuccessfully, sought to forcibly remove the Ho-Chunk from Wisconsin.

We acknowledge the circumstances that led to the forced removal of the Ho-Chunk people, and honor their legacy of resistance and resilience. This history of colonization informs our work and vision for a collaborative future. We recognize and respect the inherent sovereignty of the Ho-Chunk Nation and the other 11 Native Nations within the boundaries of the state of Wisconsin.

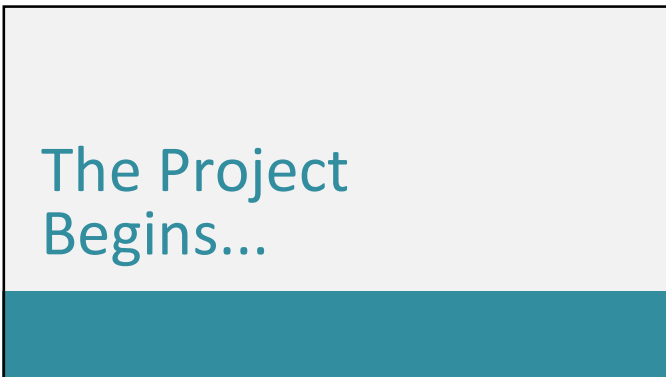
We recognize the region served by our outreach and research teams in Oneida exists upon lands ceded from the Menominee Tribe to the Oneida Nation. We acknowledge this land we stand upon today as sacred, historical, and significant to the Menominee and Oneida Nation, as are the lands of all First Nations People.



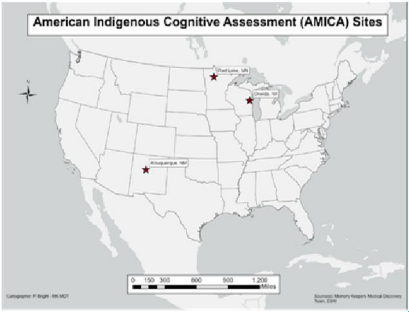
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American Indigenous Cognitive Assessment (AMICA) Sites

University of Minnesota and the Red Lake Nation

University of Wisconsin- Madison and the Oneida Nation of Wisconsin

University of New Mexico and First Nations Community Health Source in Albuquerque

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AMICA Full Team

<p>*Wisconsin</p> <ul style="list-style-type: none"> Dr. Carey Gleason, MPI Dr. Megan Zuelsdorff, Co-I Dr. Nickolas Lambrou, Research Scientist Carrie Ann Trojanczyk, Project Manager for Oneida site Dr. Kala Cornelius, Coordinator & Advanced Practitioner Provider Cassandra Thomas, Community Based Researcher Derek Norton, Biostatistician Carola Ferrer Simo, Research Specialist 	<p>Minnesota</p> <ul style="list-style-type: none"> Dr. Kristen Jacklin, PI Dr. Wayne Warty, Co-I Dr. Melissa Blind, Project Coordinator overall January Johnson, Community Based Researcher Alexis Mason, Community Based Researcher Dr. Sung Han Rhew, Post-Doc Dr. Lynsie Radovich, Research Manager Dr. Antonio Paniagua, Guzman, Post-doc Brooke Metz, Communications Coordinator 	<p>Albuquerque</p> <ul style="list-style-type: none"> Dr. Tassy Parker, MPI Dr. Nancy Pandhi, Co-I Nathania Tsosie, Research Scientist Sherry MacFarlane, Project Coordinator Kandyce Garda, Research Specialist 	<p>Community Partners</p> <ul style="list-style-type: none"> Red Lake Nation Oneida Nation First Nations Community HealthSource <p>Consultants</p> <ul style="list-style-type: none"> Karen Pitawanakwat, RN, Dr. Jennifer Walker, PhD, Dr. Melissa Castro, Neuropsychologist Dr. Megan O'Connell, R.D. Psych, Dr. Blythe Winchester, M.D., Dr. Kate Smith, PhD
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The AMICA project is a five-year (2022-2027) grant awarded by the National Institutes of Health (NIH) with funding through the National Institute on Aging (NIA) (R01AG074231)

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An Ongoing Partnership

- Collaboration began in 2015 after members of the Oneida Nation Commission on Aging (ONCOA) sought to learn more about Alzheimer's disease
- In 2016 the Oneida Nation Alzheimer's Disease Community Advisory Board (Oneida CAB) was formed.



<https://www.adrc.wisc.edu/oneida>



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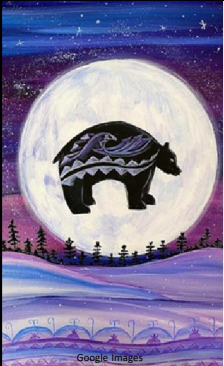
What Does Dementia Look like in Indigenous Communities?

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Rates and Disparities

- **1 in 3** Indigenous elders 65+ are projected to develop dementia (compared with 1 in 9 from the general population)
- **1 in 6** American Indians and Alaska Native people 45 and older report problems with their memory that have gotten worse in the last year

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Underrepresented in ADRC Research

- As of March 1st 2024, of the 50,962 people included in the National Alzheimer's Coordinating Center (NACC) Dataset, **~326 identified as American Indian or Alaska Native (AI/AN)**
 - 0.63 %
- In the Wisconsin Alzheimer's Disease Research Center (ADRC), there are **~70 enrolled participants who identified as (AI/AN)**
 - ____ %

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Barriers to Access



"Perseverance", by Leland Bell

Practice Based Experts have found:

- Transportation and availability to medical care is more difficult in some parts of the country
- Many reservations are rurally located
- Lack of culturally sensitive and safe providers and educational materials with people seeking to manage dementia care
- Lack of resources, support, or referrals for caring for Indigenous elders at home

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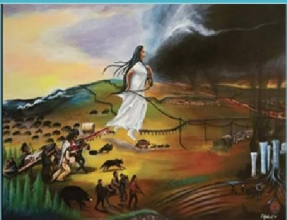
Data Sovereignty

- Data sovereignty is the right to have jurisdiction over any data that is gathered and created in any sovereign entity, and sovereign entities should use that data as they see fit
- Researchers who work with Indigenous communities have a responsibility to respect and facilitate a community's right to oversee and own their data
- Tribal IRBs are being initiated
- Protects cultural integrity and culturally sensitive knowledge



Google Images

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Hilliard, C. 2021. American Progress. Indian Land Tenure Foundation.



Croft, G.A. (ca. 1873). American Progress ca. 1873 [Photograph].

Reflection Question

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AMICA Background



Rates of Alzheimer’s disease and related dementias (ADRC) among Indigenous populations are approximately 3 times higher, with a 10 year earlier onset compared to white populations



Current cognitive assessments may not be culturally relevant and can lead to misdiagnosis or under diagnosis



An accurate diagnosis of dementia is necessary to improve access to appropriate treatment and services and to support caregivers

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AMICA Goals

- Develop a culturally appropriate dementia evaluation **toolkit** to be used in American Indigenous communities



- Improve Indigenous brain health in present and **future generations**

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Project Methodology

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A slide titled "Community-Based Participatory Research" with a teal background on the right. On the left, there is a list of six items in light grey boxes with icons: "Community Advisory Groups" (group of people), "Local Indigenous Community-Based Researchers" (tribal symbols), "Site-specific Coordinators" (network), "Approval and Updates to Tribal Leadership" (checkmark), "Educational Community Briefs" (book), and "AMICA Website for Public Updates" (computer monitor).

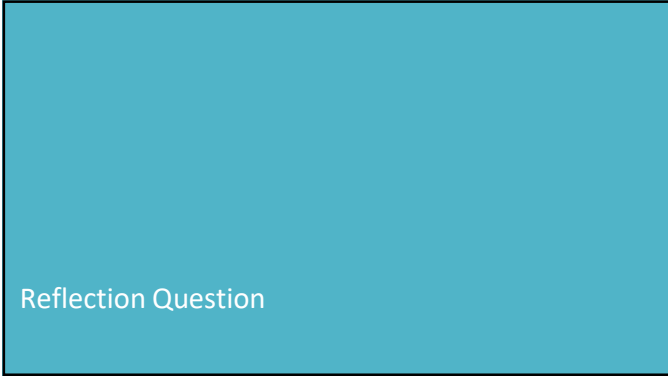
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A slide titled "Two-Eyed Seeing" with a teal background on the left. On the right, there is a list of four items in light green boxes with icons: "Indigenous Knowledge Advisory Group (IKAG)" (plant), "Respected members within the tribal communities" (tribal symbols), "Understand traditional ways and culture" (candle), and "Community-specific recruitment of members" (group of people).

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A slide titled "Indigenous Knowledge Advisory Group" with a light grey background. Below the title is a green horizontal bar. Underneath is a bulleted list of four items: "Review and examine current CICA/KICA assessments", "Discuss cultural and linguistic adaptations that may be needed for each tool", "Discuss with ADRD Assessment Expert Panel to clarify any issues identified on a tool-by-tool basis", and "Review of pilot testing data and refine questions where needed".

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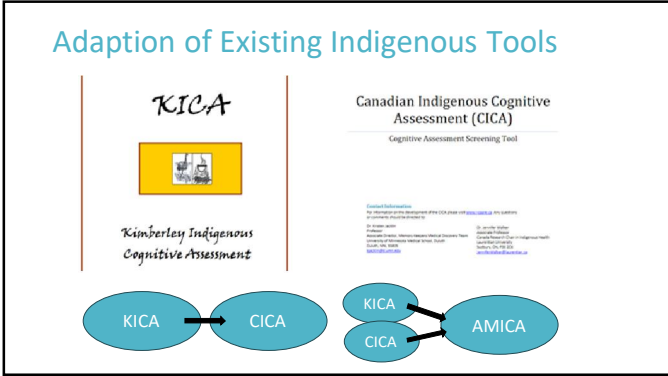
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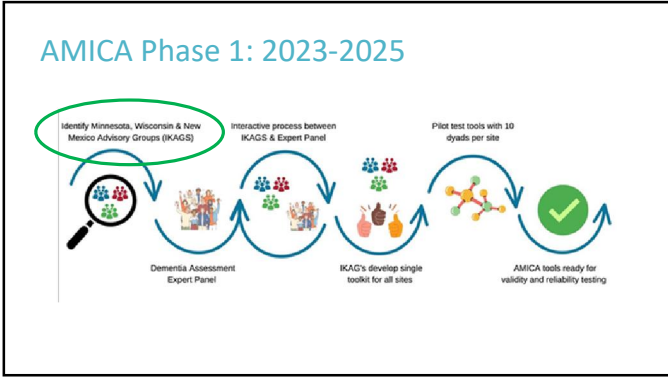
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Tools in Practice

Who

- Community Health Workers
- Loved ones
- Caretakers

Where

- Community Health Centers
- Nursing homes
- In home
- Community gathering spaces

Video: <https://www.i-caare.ca/anishnaabe-supplement>

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Reflection Question

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Next Steps...

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Our Hopes for the Future

- Earlier detection and enhanced access to culturally-safe, high-quality care for aging Indigenous adults with dementia
- Strengthening understanding of Alzheimer's disease and related dementias, co-creating knowledge and improving community health outcomes

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References

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