

Paper Presentations:

Full Author Lists & Scientific Abstracts

1. Power and Precarity: Indigenous Dementia Prevalence and Associated Factors in the All of Us Study

Cliff Whetung, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Kyle Conniff, University of Wisconsin, Madison, USA

Indigenous peoples in the United States face persistent, lifelong socioeconomic and healthcare disparities that elevate their risk for dementia, yet they remain severely underrepresented in longitudinal aging research. While Large-Scale Volunteer Databases like the National Institutes of Health's All of Us research program offer unprecedented statistical power, their utility and validity for studying dementia prevalence and risk factors in marginalized, heterogeneous populations remain largely unexamined. We used Version 8 of the All of Us controlled data tier (released February 2025) linked to electronic health record data to calculate age-adjusted dementia prevalence estimates across racial and ethnic groups, benchmarked against the 2017 American Indian and Alaska Native population distribution. Additionally, descriptive characteristics of Indigenous participants aged 50+ in All of Us (N = 3,130) were compared with an Indigenous cohort from the nationally representative Health and Retirement Study (HRS) (N = 383). The age-standardized dementia prevalence among Indigenous respondents in All of Us was 1.77%, which was significantly higher than the rates observed for Asian (0.88%) and Black (1.29%) respondents, but did not differ significantly from White respondents (1.59%). Compared to the HRS, the All of Us Indigenous cohort was younger, reported lower household incomes, exhibited lower crude dementia prevalence, and had higher rates of type 2 diabetes and depression. Although All of Us resolves critical statistical power issues for underrepresented groups, volunteer selection biases and the redaction of geospatial identifiers limit its external validity and immediate community application. Enhancing data infrastructure with restricted geospatial oversight is vital to improving the translational potential of these large-scale datasets into actionable insights for diverse Indigenous communities.

2. He Rapunga Hauora mo te Mate Wareware: A Prevalence Study Protocol

Meikyla Mason, Centre for Brain Research, University of Auckland, Auckland, New Zealand

Nick Garrett, Biostatistics and Epidemiology, Auckland University of Technology, Auckland, New Zealand

Oliver Menzies, Te Whatu Ora - Te Toka Tūmī, Auckland, New Zealand

Braden Te Ao, Health Systems, School of Population Health, University of Auckland, Auckland, New Zealand

Claudia Rivera-Rodriguez, Department of Statistics, University of Auckland, Auckland, New Zealand

Matthew Croucher, Te Whatu Ora - Waitaha Canterbury, Christchurch, New Zealand

Suzanne Purdy, School of Psychology, University of Auckland, Auckland, New Zealand

Lynette Tippett, School of Psychology, University of Auckland, Auckland, New Zealand

Adrian Ruiz-Martinez, Department of Psychological Medicine, The University of Auckland, Auckland, New Zealand

Waiona Port, Centre for Brain Research, The University of Auckland, Auckland, New Zealand

Richard L.M. Faull, Centre for Brain Research, University of Auckland, Auckland, New Zealand

Makarena Dudley, School of Psychology, University of Auckland, Auckland, New Zealand

Accurate, population-based data regarding the prevalence of mate wareware (dementia) among Indigenous Māori in Aotearoa New Zealand is critically lacking. To address systemic health inequities and support evidence-based healthcare planning, comprehensive, culturally grounded epidemiological data are urgently needed. This research describes the methodological protocol for a population-based mate wareware prevalence study within a community-dwelling sample of Māori aged 65 and older. This is the first epidemiological study investigating the true incidence and lived impact of mate wareware within the Māori population of Aotearoa New Zealand. The study utilises a cross-sectional, population-based design. To ensure robust international and domestic benchmarking, the protocol implements the validated 10/66 Dementia Research Group diagnostic framework and Wairua component of the Māori Assessment of Neuropsychological Abilities (MANA) tool. This study operates in parallel with an independent prevalence study across European, Chinese, and Indian/Fijian-Indian communities in Aotearoa New

Zealand. Utilising identical 10/66 protocols allows for valid, equitable comparisons between Māori and non-Māori cohorts. Structurally, the protocol is underpinned by Māori Data Sovereignty principles, ensuring that data collection, ownership, storage, and dissemination are entirely governed by Māori, for Māori, safeguarding indigenous knowledge and privacy. This study will quantitatively measure the prevalence of dementia in Māori and investigate the impact of mate wareware on individuals, whānau, hapū, and iwi across Aotearoa New Zealand. The justification for a comprehensive, bicultural prevalence study across Aotearoa New Zealand's major ethnic groups is firmly established. Collectively, the results of this study will serve as a gold-standard, research-based data platform to aid in the development of future mate wareware services for Māori in Aotearoa New Zealand. Ultimately, this foundational research provides the necessary framework to drive culturally appropriate, responsive services, work toward eliminating health inequities, and reduce the profound social and economic costs borne by indigenous communities.

3. Estimating Mate Wareware (Dementia) Prevalence Among Māori: Preliminary Findings and Research Challenges

Nick Garrett, *Auckland University of Technology (AUT), Auckland, New Zealand*

Makarena Dudley, *University of Auckland, Auckland, New Zealand*

Ariana Athy, *University of Auckland, Auckland, New Zealand*

Oliver Menzies, *Health New Zealand, Auckland, New Zealand*

Braden Te Ao, *University of Auckland, Auckland, New Zealand*

Claudia Rivera-Rodriguez, *University of Auckland, Auckland, New Zealand*

Background

The well-being of Māori kaumātua (elders) is under threat, with higher exposure to known risk factors for mate wareware (dementia) and earlier onset. Understanding the impact of mate wareware on whānau (families) requires accurate estimates of its prevalence. A national prevalence study is currently underway in Aotearoa New Zealand. The study aims to:

- * estimate the prevalence of mate wareware among Māori
- * examine the extent and costs of kaitiakitanga (care-giving)
- * identify risk factors and psychosocial outcomes
- * explore impacts on the oranga (well-being) of individuals and their whānau

Methods

This study uses a multi-phase sampling design across five regions of Aotearoa New Zealand to capture major iwi.

- * Census area units (approximately suburb-level) were selected proportional to the estimated Māori population aged 65+
- * Within selected areas, meshblocks (~100 people) were randomly sampled
- * Households were approached through door-to-door recruitment
- * Participants included Māori aged 65 years and older with a target of 550 participants

The 10/66 dementia diagnostic schedule, adapted for Māori, was used as the primary assessment tool.

Results

Recruitment of kaumātua has been challenging, particularly in urban areas such as Auckland. Training and retention of Māori field staff - critical for culturally appropriate, face-to-face engagement - has also been difficult.

The preliminary age-adjusted prevalence of mate wareware is estimated at 17%, suggesting a substantial burden.

Caregivers and participants living with mate wareware:

- * reported similar caregiving expenses to those without mate wareware
- * had fewer GP visits
- * used less medication
- * caregivers reduce or give up employment

Conclusions

Preliminary findings indicate a high prevalence of mate wareware among Māori. The lower levels of healthcare utilisation among those affected are concerning and suggest possible unmet needs or barriers to access.

Additionally, the study highlights challenges in applying quantitative tools to capture culturally grounded concepts of care-giving, suggesting the need for more culturally responsive measurement approaches.

4. **Supporting Tribal Communities in the Great Lakes Region Through Community-Engaged Brain Health Programming**

Michael Davis, Great Lakes Inter-Tribal Council, Lac du Flambeau, USA

Kianna DuFault, Great Lakes Inter-Tribal Council, Lac du Flambeau, USA

Amber Hoon, Great Lakes Inter-Tribal Council, Lac du Flambeau, USA

Christina Alaniz, Great Lakes Inter-Tribal Council, Lac Du Flambeau, USA

Jeni Edwards, Great Lakes Inter-Tribal Council, Lac du Flambeau, USA

Kade Lenz, Great Lakes Inter-Tribal Council, Lac du Flambeau, USA

Background

GLITEC serves 34 federally recognized Tribes and four Urban Indian communities across Michigan, Minnesota, Wisconsin, and Chicago, Illinois. GLITEC's Together Strong: Brain Health Program delivers evidence based, culturally relevant dementia education tailored to Tribes.

Methods

GLITEC offers the Virtual Dementia Tour (VDT) and Savvy Caregiver in Indian Country (SCIC) trainings, along with facilitator trainings that build local capacity for Tribes to lead their own programming. Through technical assistance requests, the program also supports Tribes nationwide. Community engagement is foundational, with input shaping training design, delivery, and evaluation. In addition to quantitative metrics, the program collects qualitative feedback to center caregiver experiences and community knowledge.

Results

In FY26, GLITEC received 51 brain health and aging related technical assistance requests. The program trained 11 Tribal staff to deliver VDT and 19 to deliver SCIC. As of May 2026, 267 individuals, including Elders, Tribal leaders, youth, and health staff, have participated in trainings. Recent expansion into Michigan and Minnesota has further increased regional reach and capacity.

Conclusion

GLITEC's Brain Health Program continues to grow through community driven engagement and capacity building. By equipping caregivers, families, and communities with culturally relevant knowledge and tools, the program strengthens long term support for brain health in Native Populations.

5. **Respectful Engagement with Indigenous Communities: Best Practices**

Marvina Chavez, International Association for Indigenous Aging, Silver Springs, USA

Ron Epps, International Association for Indigenous Aging, Silver Springs, USA

This paper presents best practices for respectful engagement with Indigenous communities. Effective engagement requires recognizing indigenous communities as sovereign governments, honoring cultural values and protocols, and fostering long-term relationships grounded in trust, transparency, and mutual respect. The paper emphasizes the importance of government-to-government engagement, obtaining free, prior, and informed consent, and following natural laws, leadership structures, and community protocols throughout all phases of collaboration.

The paper also highlights the need to understand the historical and contemporary experiences of Indigenous communities, including the impacts of colonization, historical trauma, and ongoing inequities, while recognizing the resilience, strengths, and contributions of Indigenous Peoples. Respect for Indigenous knowledge systems, cultural practices, languages, and data sovereignty is identified as essential to ethical and effective partnership.

Key recommendations include engaging Elders and youth, partnering with Indigenous-led organizations, communicating openly and consistently, and involving communities in shared decision-making from project inception through implementation and evaluation. The paper encourages organizations and researchers to support community-driven priorities, invest in long-term capacity building, and promote cultural and language revitalization efforts.

Finally, the paper emphasizes accountability, humility, and responsiveness as foundational principles of engagement. By adopting these practices, organizations and partners can strengthen relationships with Indigenous communities and contribute to more equitable, collaborative, and sustainable outcomes.

6. **Rooted in Relationship: Gathering, Growing, and Sharing Food, Memory, and Care**

Adrianne Lickers Xavier, McMaster University, Hamilton, Canada

Kitty RLynn, McMaster University, Hamilton, Canada

Lori Davis Hill, McMaster University, Hamilton, Canada

This presentation explores the deep interconnections between food, memory, and well-being through an Indigenous, relationship-centered lens. Grounded in the understanding that food systems are not merely sites of nutrition but of knowledge, care, and connection, it positions the practices of gathering, growing, and sharing food as foundational to individual and collective health.

Within Indigenous contexts, food is inseparable from land, identity, and community. The act of gathering and growing food engages the body and mind through movement, observation, and sensory experience, while also strengthening relationships with the land. These practices cultivate attentiveness, reduce stress, and support cognitive well-being. Equally, the preparation and sharing of food are embedded in systems of teaching and reciprocity, where memory is enacted and passed on through doing—through stories, skills, and time spent together.

Food, in this sense, holds and carries memory. It connects generations, linking past, present, and future through lived practice. Sharing food within families and communities reinforces social bonds and creates spaces of care, belonging, and mutual support—conditions that are essential to mental and emotional wellness.

By centering relationship as the foundation of food systems, this presentation invites a broader understanding of health that moves beyond individualistic and nutrient-based frameworks. It highlights how Indigenous food practices sustain not only the body, but also memory, identity, and community well-being. In doing so, it offers a pathway for rethinking brain health as something cultivated through connection—to land, to food, and to one another.

7. Culturally Safe and Clinically Sound: Adapting the American Indigenous Cognitive Assessment (AMICA)

Sheamus Cavanaugh, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Melissa Blind, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

January Johnson, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Alexis Mason, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Cassandra Thomas, University of Wisconsin – Madison, Madison, USA

Rebecca Owl Morgan, University of New Mexico Health Sciences, Albuquerque, USA

Nickolas Lambrou, University of Wisconsin – Madison, Madison, USA

Carrie Trojanczyk, University of Wisconsin – Madison, Madison, USA

Kala Cornelius, University of Wisconsin – Madison, Madison, USA

Blake Boursaw, University of New Mexico Health Sciences, Albuquerque, USA

Amy Otto, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Lysie Radovich, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Sierra Skenandore, University of Wisconsin – Madison, Madison, USA

Erik Kakuska, University of New Mexico Health Sciences, Albuquerque, USA

Jonathan Bryan, University of Wisconsin – Madison, Madison, USA

Reanne Dwyer, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Megan Zuelsdorff, University of Wisconsin – Madison, Madison, USA

Terry Mangin, University of Wisconsin – Madison, Madison, USA

Melissa Castro, MCC Medical and Forensic Neuropsychology, Kamloops, Canada

Megan O'Connell, University of Saskatchewan, Saskatoon, Canada

Jennifer Walker, McMaster University, Hamilton, Canada

Karen Pitawanakwat, Wikwemikong Health Center, Wikwemikong, Canada
Blythe Winchester, Cherokee Indian Hospital Authority, Cherokee, USA
Nancy Pandhi, University of New Mexico Health Sciences, Albuquerque, USA
Wayne Warry, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Tassy Parker, University of New Mexico Health Sciences, Albuquerque, USA
Caret Gleason, University of Wisconsin – Madison, Madison, USA
Kristen Jacklin, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Existing cognitive assessments have largely been created for use with Westernized populations. Recognition that these tools and their implementation are not appropriate or culturally safe has resulted in efforts to adapt and validate dementia screening tools for use with Indigenous populations. The American Indigenous Cognitive Assessment (AMICA) project aims to develop a culturally safe and appropriate dementia screening toolkit. AMICA partners include University of Minnesota Medical School Duluth Campus, University of Wisconsin Madison, and the University of New Mexico, in partnership with the Red Lake Nation, Minnesota; the Oneida nation, Wisconsin; and First Nations Community HealthSource, including an urban Indigenous population in Albuquerque, New Mexico.

Grounded in Community-Based Participatory Research, each site convened an Indigenous Knowledge Advisory Group (IKAG) to adapt the Canadian Indigenous Cognitive Assessment (CICA). They then nominated two members to the National IKAG (NIKAG) to reach consensus on an intercultural AMICA toolkit. The NIKAG adaptations were brought to an Assessment Expert Panel (AEP) to ensure the adapted assessments were clinically sound. The NIKAG and AEP worked iteratively to arrive at consensus on the toolkit.

We offer preliminary results on the AMICA adaptation and present two themes: cultural adaptations and question construction.

Cultural adaptations included consideration of seasonal cultural activities for acceptable answers to questions about orientation to time. Changes were also made to assessor training, with a goal to honor respectful assessment delivery based on prior healthcare experiences of IKAG members attending cognitive screenings for their families.

Adaptations to question construction focused on cultural communication preferences including clarity, specificity, and using more conversational language. These adaptations include omitting certain phrases that detracted from clarity or specificity, or adding additional language to clarify what is being asked.

The adapted AMICA toolkit will next be piloted to determine cultural safety and relevance and then validated against standard cognitive assessments.

8. The American Indigenous Cognitive Assessment (AMICA) Toolkit: Insights, Preparation and Community-driven Implementation with the Oneida Nation of Wisconsin

Kala Cornelius, University of Wisconsin-Madison, Madison, USA
Sierra Skenandore, University of Wisconsin-Madison, Madison, USA
Cassandra Thomas, University of Wisconsin-Madison, Madison, USA
Carrie Trojanczyk, University of Wisconsin-Madison, Madison, USA
Jonathan Bryan, University of Wisconsin-Madison, Madison, USA
Nickolas Lambrou, University of Wisconsin-Madison, Madison, USA
January Johnson, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Alexis Mason, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Rebecca Owl Morgan, University of New Mexico, Albuquerque, USA
Melissa Blind, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Sheamus Cavanaugh, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Blake Boursaw, University of New Mexico, Albuquerque, USA

Lynsie Radovich, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Amy Otto, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Erik Kakuska, University of New Mexico, Albuquerque, USA
Reanne Dwyer, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Megan Zuelsdorff, University of Wisconsin-Madison, Madison, USA
Terry Mangin, University of Wisconsin-Madison, Madison, USA
Melissa Castro, Minneapolis Clinic of Neurology, Golden Valley, USA
Megan O'Connell, University of Saskatchewan, Saskatoon, Saskatchewan, Canada
Jennifer Walker, McMaster University, Hamilton, Ontario, Canada
Karen Pitawanakwat, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Blyth Winchester, Cherokee Indian Hospital, Cherokee, USA
Nancy Pandhi, University of New Mexico, Albuquerque, USA
Wayne Warry, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA
Terry Parker, University of New Mexico, Albuquerque, USA
Carey Gleason, University of Wisconsin-Madison, Madison, USA
Kristen Jacklin, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth campus, Duluth, USA

Estimated dementia incidence in Indigenous populations is disproportionately high. Roughly 1 in 3 Indigenous Elders aged 65+ will develop dementia, with a 10 year earlier onset, compared to 1 in 9 in the white population. However, current dementia assessment tools are not validated for use with Indigenous populations in the United States, limiting access to accurate and appropriate dementia-related services. The AMICA project aims to validate a culturally safe dementia evaluation toolkit for use with Indigenous populations in the United States.

AMICA uses a community-based participatory research approach and is a multi-site collaboration of community partners in Red Lake Nation, Minnesota, an urban Indigenous population in Albuquerque, New Mexico, and the Oneida Nation in Wisconsin. Indigenous Knowledge Advisory Groups (IKAGs) have been established at each site to develop, review and adapt a screening toolkit for relevance and cultural safety. In collaboration with IKAGs, an interdisciplinary Assessment Panel consisting of experts in fields such as medical anthropology, neuropsychology, and geriatric medicine works to ensure the adapted tools are psychometrically valid. This iterative process has yielded the first version of the AMICA Toolkit, which will be piloted with each partnering community site.

While commonalities in adaptations exist across sites, implementation may vary given distinctions in culture, context, and resources between Tribal communities. Therefore, it is important to understand similarities and distinctions across partnering Tribal communities to ensure effective implementation of the AMICA Toolkit. This presentation will highlight the adaptation process as it unfolded in Oneida, drawing upon first-hand experiences with members of the Oneida, WI research team in collaboration with the Oneida community. It will explore preparations, adaptations, frequently asked questions, and prospective applications of the AMICA toolkit in clinical and community settings specific to the Oneida Nation.

9. **Culturally Grounded Adaptation of the Age-Friendly Health Systems 4Ms: A Tree-Based Framework Rooted in Indigenous Knowledge to Support Holistic Well-Being of Indigenous Elders**

Marvina Chavez, International Association for Indigenous Aging, Silver Springs, USA
Megan Dicken, International Association for Indigenous Aging, Silver Springs, USA
Ron Epps, International Association for Indigenous Aging, Silver Springs, USA

Indigenous elders are the knowledge keepers, language carriers, and cultural anchors of their communities. Supporting their health and well-being requires approaches that extend beyond clinical care to honor culture, traditions, history, community, sovereignty, land, language, and Indigenous knowledge systems. While the Age-

Friendly Health Systems “4Ms” framework—What Matters Most, Medicine, Memory, Mood, and Thinking, and Movement—offers an evidence-based model for improving elder care, it must be culturally grounded to be fully effective in indigenous communities.

This session introduces the International Association for Indigenous Aging (IA²) culturally adapted 4Ms of Age-Friendly Care resource, represented through a tree diagram. In this model, the roots symbolize Indigenous knowledge systems, including culture, traditions, history, land, language, sovereignty, and community—foundational elements that sustain elder well-being. The trunk and branches represent the 4Ms, illustrating how care practices must grow from and remain connected to these roots.

Participants will explore how each of the 4Ms can be applied through an Indigenous lens. “What Matters Most” is centered on cultural identity, roles, and community responsibilities. “Medicine” considers how clinical care can align with traditional practices and avoid disrupting cultural ways of being. “Memory, Mood, & Thinking” is supported through language, storytelling, history, and intergenerational knowledge. “Movement” is promoted through culturally meaningful activities that sustain independence, purpose, and connection to land.

Presenters will share lessons learned from developing this resource, emphasizing visual storytelling, community voice, and culturally grounded frameworks. Participants will gain practical strategies for integrating the adapted 4Ms into Indigenous health systems, community programs, and elder services.

This interactive workshop equips attendees with tools to implement age-friendly care that honors Indigenous sovereignty, strengthens cultural continuity, and supports holistic elder wellness in AI/AN communities.

10. Neekokaabjigan and Dignified Care: Growing a Place-Based Analysis of Indigenous Dementia Caregiving

Chantelle Richmond, Western University, London, Canada

Sharlene Webkamigad, Laurentian University, Sudbury, Canada

Liz Webkamigad, Algoma University, Sault Ste. Marie, Canada

Place-based analyses of Indigenous dementia care remain rare. Existing work touches on connection to Country, traditional food and memory in care settings, language and kinship continuity, and community-based relational care, but rarely theorizes the relationship between physical locations and the relational spaces that give them meaning.

Drawing on Indigenous health geographies, we examine how place (the discrete physical locations where care unfolds) and space (the relational and cultural territories where care becomes meaningful or harmful) can shape the dignity of Elders living with dementia and those who care for them. As daughters, knowledge keepers, nurses, and researchers, our work focuses on the places where our Elders live, including care homes, family homes, and clinical corridors. Our positioning within the lived realities of dementia forms the epistemological foundation of this analysis.

Connected through the New Frontiers in Research Fund Transformation project on Indigenous dementia assessment, we each share one relational example: moments that taught us how dignity — including the continuation of language, role, and cultural belonging — is cultivated, protected, or lost in the places where our Elders live. We anchor our analysis in the concept of neekokaabjigan, “the string that binds us” — an Anishinaabe framework of relational accountability and collective care for how we understand dementia, and our roles as researchers.

We offer these reflections to open into a larger program of work: a synthesis of existing evidence on the needs of Indigenous older adults and Elders; a scoping review of Indigenous understandings of care community; and an analysis of Indigenous concepts shaping dementia research and care. We invite this audience into that conversation, and into the question that drives it: how do we dignify dementia care in all the places we find ourselves?

11. Navigating Advanced Dementia: Insights into Family Caregiving Across Diverse Indigenous Communities in the Great Lakes Region of North America

Dana Ketcher, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Collette Pederson, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Alexis Mason, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

January Johnson, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Rhonda Trudeau, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Karen Pitawanakwat, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Marlene Summers, University of Wisconsin School of Medicine and Public Health, Madison, USA

Lois Strong, University of Wisconsin School of Medicine and Public Health, Madison, USA

Melissa Blind, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Nickolas Lambrou, University of Wisconsin School of Medicine and Public Health, Madison, USA

Carey E. Gleason, University of Wisconsin School of Medicine and Public Health, Madison, USA

Megan Zuelsdorff, University of Wisconsin School of Medicine and Public Health, Madison, USA

Wayne Warry, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Kristen Jacklin, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

While Alzheimer's disease and related dementias (ADRD) pose public health challenges globally, the experiences of Indigenous family caregivers remain critically underrepresented. This paper examines post-interview reflections from Indigenous community-based researchers (CBRs) to understand the nuanced dynamics of family caregiving for Indigenous Elders navigating late-stage ADRD.

A qualitative thematic analysis was conducted on CBR post-interview summaries (N=48) documenting the lived experiences of family caregivers across four Indigenous communities: Miskwaagamiiwi-Zaagaiganing / Red Lake Nation (n=17), Gichi-Onigaming / Grand Portage (n=10), Oneida (US sites) (n=11), and Manitoulin Island First Nations (Canada) (n=10). Data were synthesized to describe overarching themes related to caregiver experiences, systemic barriers, and cultural facilitators.

Findings reveal that caregiving across all communities is arranged as a multi-generational, collective family responsibility, and that late-stage dementia was characterized by several, sometimes severe, health changes, both physically (e.g., comorbidities, mobility limitations) and cognitively (e.g., reversion to first-language for bilingual Elders). Cross-community differences emerged regarding barriers and facilitators. For instance, Oneida caregivers mentioned jurisdictional and eligibility barriers for non-Native spouses. In Grand Portage, which faces geographic isolation issues, caregivers rely heavily on existing community safety nets and neighbor monitoring. Across communities, there was a repeated call for community-wide education targeting a broad swath of the community, from youth to healthcare providers, to mitigate issues faced by family caregivers.

All communities shared core values of collective family caregiving, yet the operationalization of family caregiving is shaped by each place's unique geography, resource availability, and socioeconomic contexts. Health systems, communities, and policymakers cannot rely on a "one-size-fits-all" approach. Rather, CBR post-interview summaries highlight the importance of uplifting local culturally tailored resources, and financially and structurally supporting the important dementia caregiving work that Indigenous families are currently practicing.

12. A culturally grounded approach to understanding and improving Alzheimer's disease and related dementia knowledge, attitudes, and behaviors for American Samoan family caregivers

Danielle Eakins, American Samoa Community Cancer Coalition, Tafuna, American Samoa; Seven Directions, Indigenous Public Health Institute, University of Washington, Seattle, USA

Va'atausili Tofaeono, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

Jessica Williams-Nguyen, Washington State University, Seattle, USA

Nancy Schoenberg, University of Kentucky, Lexington, USA

Toaiva Hall, American Samoa Community Cancer Coalition, Tafuna, American Samoa

Anatalita Auau, American Samoa Community Cancer Coalition, Tafuna, American Samoa

Alzheimer's disease and related dementias (ADRD) are progressive neurodegenerative disorders with devastating impacts on individuals and their families. Native Hawaiians and Pacific Islanders (NHPs) are among the fastest growing racial groups in the United States, and Samoans are the second largest NHP subpopulation. In American Samoa — a U.S. territory where 90% of residents identify as Samoan — there is pressing concern about ADRD due to

a growing older adult population disproportionately burdened by risk factors including obesity, hypertension, and type 2 diabetes.

Family caregivers navigate significant challenges including limited health literacy and restricted access to formal support services. At the same time, deep cultural values of filial duty and collective family responsibility represent meaningful strengths. Despite their critical role as often the first and only line of care, little is known about Samoan caregivers' experiences — a gap forestalling culturally appropriate ADRD interventions.

This study employed an explanatory sequential mixed methods design guided by a Samoan Socio-ecological model and a culturally grounded knowledge, attitudes, and behaviors (KAB) framework. First, we administered a battery of established Westernized KAB tools to 66 Samoan caregivers. Caregivers demonstrated moderate-to-good ADRD knowledge and generally positive dementia attitudes, with positive caregiving appraisals exceeding negative ones. Greater knowledge was associated with more negative appraisals — perhaps reflecting anticipatory burden among more informed caregivers — while positive appraisals predicted greater instrumental caregiving, consistent with Samoan cultural values. Focus groups with 36 caregivers elucidated Samoan epistemologies, cultural norms, and social determinants of health, revealing a strong sense of duty alongside feeling overwhelmed by limited formal resources. Together, these findings are informing development of a preliminary Samoan caregiver ADRD KAB measurement tool. We will discuss integration of quantitative and qualitative insights and next steps engaging a Samoan community expert panel to establish consensus and assess validity.

13. Indigenous Dementia Diagnostic Biomarker (InDX) Workflow Project: An Oneida Tribal Effort to Ensure Accessible and Indigenous-Centered Dementia Diagnostics

Cary Waubanasum, University of North Dakota, Grand Forks, USA

Rachael Wilson, University of Wisconsin, Madison, USA

Carey E. Gleason, University of Wisconsin, Madison, USA; University of Minnesota, Minneapolis, USA

Debra J. Danforth, Oneida Comprehensive Health Division, Oneida, USA

Henrik Zetterberg, University of Wisconsin, Madison, USA; University of Gothenburg, Gothenburg, Sweden

Kala Cornelius, University of Wisconsin, Madison, USA

Julie Beans, Southcentral Foundation, Anchorage, USA

Sidney J. White, Oneida Comprehensive Health Division, Oneida, USA

Carrie J. Blohowiak, Oneida Comprehensive Health Division, Oneida, USA

Lauren W.Y. McLester-Davis, University of Wisconsin, Madison, USA

Kyle Conniff, University of Wisconsin, Madison, USA

Megan Zuelsdorff, University of Wisconsin, Madison, USA

Nickolas Lambrou, University of Wisconsin, Madison, USA

Carrie Trojanczyk, University of Wisconsin, Madison, USA

Cassandra Thomas, University of Wisconsin, Madison, USA

Background:

Blood-based biomarkers, particularly plasma p-tau217, accurately identify brain amyloid across the Alzheimer's Disease (AD) clinicopathologic continuum. However, Tribes have limited access to these diagnostic options. As AD and AD Related Dementia (AD/ADRD) diagnostics advance, parallel efforts to Indigenize science are emerging, emphasizing approaches that humanize participants and center Indigenous worldviews alongside Western scientific paradigms.

Centered at the intersection of these initiatives, the Indigenous Dementia Diagnostic Biomarker (InDX) Workflow Project aims to establish a community-based AD/ADRD biomarker testing infrastructure.

Methods:

During the planning phase, we will (1) Establish a Community Advisory Group (CAG) and develop culturally relevant education materials and Community Research Forums to foster community dialogue; (2) Develop laboratory workflows and billing processes to implement plasma AD/ADRD biomarker assays within the Tribe's Health Division; (3) Build data and biospecimen management protocols aligned with Tribal sovereignty and research ethics; (4) Create a replication toolkit for adaptation in other Tribal communities.

During the implementation phase, we will (1) Assess feasibility, acceptability, sustainability, and perceived benefits using mixed-methods approaches; (2) Evaluate analytic validity and reliability of plasma biomarker data compared

with an academic laboratory; (3) Pilot a data and biospecimen management system that upholds sovereignty principles and Tribal law; (4) Refine and disseminate the InDX Toolkit in at least one additional Tribal community.

Results:

The InDX project would establish community-led aging research infrastructure that expands access to AD/ADRD diagnostic research and clinical services. To sustain the initiative, the project will build a platform for billable diagnostic testing that can generate revenue and support Tribal economic growth.

Conclusions:

The proposed InDX Workflow will co-create a local dementia biomarker testing infrastructure that is replicable, sustainable, and Tribally-owned. Beyond dementia, the workflow provides a scalable framework for advancing locally led aging research, addressing persistent underrepresentation in aging research among Tribal communities.

14. Biomarker Participation among American Indian and Alaska Native Participants in the National Alzheimer's Coordinating Center Uniform Data Set

Kyle Conniff, *University of Wisconsin-Madison, Madison, USA*

Tia Petratos, *University of Wisconsin-Madison, Madison, USA*

Carey Gleason, *University of Wisconsin-Madison, Madison, USA*

Joshua Grill, *University of California-Irvine, Irvine, USA*

Daniel Gillen, *University of California-Irvine, Irvine, USA*

Background:

Biomarker studies are essential for advancing our understanding of the disease, diagnosis, and treatment of Alzheimer's disease and related dementias (ADRD). However, most biomarker research disproportionately represents non-Hispanic White (NHW) populations. As a result, we lack the data needed to interpret biomarker patterns in American Indian and Alaska Native (AI/AN) populations, limiting diagnostic accuracy and clinical trial inclusion for these groups.

Methods:

We used the National Alzheimer's Coordinating Center Uniform Data Set (NACC UDS) to evaluate disparities in participation across biomarker modalities (i.e. neuroimaging, cerebrospinal fluid analysis (CSF), and autopsy), comparing AI/AN and NHW participants. Analyses included unadjusted Chi-squared tests for small sample size modalities (CSF and autopsy) and logistic regression with adjustment for age, sex, education, and cognitive status for neuroimaging and a composite outcome.

Results:

AI/AN participants have significantly lower odds of participating in all modalities compared to NHW participants. Just 5% of AI/AN participants have CSF data compared to 18% of NHW (uOR: 0.238 (0.12, 0.42); $p < 0.001$). Among those known to have passed, autopsy rates are similarly different with 36% AI/AN participation vs 62% NHW (uOR: 0.343 (0.13, 0.83); $p = 0.01$). For adjusted results, AI/AN participants have 56% lower odds of having neuroimaging data than NHW participants (aOR: 0.440 (0.34, 0.57); $p < 0.001$).

Conclusions:

Gaps in sample representativeness threaten the generalizability of biomarker-based diagnostic tools and risk assessments. AI/AN participants had significantly lower odds of participation in each of the modalities compared to NHW participants. Overall, AI/AN participants were markedly less represented in the biomarker subsample, raising concerns about the generalizability of biomarker-derived findings to Indigenous populations. More inclusive research is essential for improving diagnostic validity, initiating earlier treatment, and ensuring equitable access to emerging dementia interventions.

15. Reevaluating Modifiable Dementia Risk Factors in Indigenous Populations: An Analysis of American Indian and Alaska Native Participants in the All of Us Research Program

Carina Campbell, *University of California-Riverside, Riverside, USA; University of Wisconsin-Madison, Madison, USA*

Kyle Conniff, *University of Wisconsin-Madison, Madison, USA*

Cliff Whetung, *University of Minnesota-Duluth, Duluth, USA*

Carey Gleason, *University of Wisconsin-Madison, USA*

Background: The 2024 Lancet Commission identified fourteen potentially modifiable risk factors associated with dementia prevention. Although these factors are well established in the general population, their applicability to Indigenous populations remains understudied.

Objective: To evaluate the prevalence and contribution of Lancet Commission dementia risk factors among Indigenous participants diagnosed with dementia in the All of Us Research Program.

Methods: We conducted a cross-sectional analysis of demographic and health data from 126 self-identified Indigenous participants with dementia enrolled in the All of Us Research Program, a nationwide U.S. biomedical research cohort. Thirteen of the fourteen Lancet Commission risk factors were assessed using available survey and electronic health record data; environmental toxin exposure was unavailable. Weighted population attributable fractions (PAFs) were calculated to estimate the relative contribution of each risk factor.

Results: Up to 37.4% of dementia cases in this cohort may be attributable to modifiable risk factors with positive weighted PAFs. Low educational attainment and traumatic brain injury emerged as the leading contributors, accounting for an estimated 5.7% and 5.2% of dementia cases, respectively. Several established dementia risk factors demonstrated minimal or negative weighted contributions, findings that may reflect survivor bias, differential misclassification, selection effects, or limitations in risk factor measurement within this population.

Conclusions: The Lancet Commission framework provides a useful foundation for dementia prevention research; however, its applicability to Indigenous populations may be limited. The prominence of traumatic brain injury and the differing contribution of several established risk factors suggest that community-specific risk profiles may not be fully captured by existing models. Future research should incorporate culturally responsive methodologies and Indigenous-centered frameworks to better understand dementia risk and prevention in American Indian and Alaska Native communities.

16. **Data as Medicine: Examining Indigenous Social Determinants of Health, Stress Embodiment Pathways, and Cultural Protection in Cognitive Vulnerability Among American Indian Adults**

***Laura Sawney**, Rising REZilience, LLC, Broken Arrow, USA; University of North Dakota Indigenous Health Doctoral Program, Grand Forks, USA; University of Oklahoma Health Sciences Center (PLAN Lab), Tulsa, USA*

American Indian communities experience disproportionate exposure to historical trauma, structural inequities, chronic stress, substance misuse, and barriers to culturally grounded health services. While growing evidence links chronic stress exposure to cognitive decline and Alzheimer's disease and related dementias (ADRD), Indigenous populations remain underrepresented in cognitive health surveillance, embodiment research, and dementia prevention efforts. Existing models frequently isolate cognition from mental health, coping behaviors, cultural connectedness, and the broader Indigenous Social Determinants of Health (ISDoH).

This presentation introduces Data as Medicine, a sovereignty-centered mixed-methods research initiative and emerging dissertation framework designed to examine how colonial disruption, ISDoH, stress embodiment pathways, and cultural protection interact in relation to cognitive vulnerability among American Indian adults in Northeastern Oklahoma. Guided by Indigenous research methodologies, Indigenous data sovereignty principles, and community governance, the project conceptualizes cognitive wellness as a relational process shaped by mind, body, spirit, kinship, culture, and community rather than as an isolated neurological outcome.

The project employs an explanatory sequential mixed-methods design consisting of a data landscape assessment, community survey, Talking Circles, community interpretation sessions, and an exploratory wearable feasibility component examining sleep stability, autonomic regulation, and metabolic variability. Central to the framework is the hypothesis that historical and contemporary stressors influence cognitive vulnerability through behavioral and physiological pathways, while cultural connectedness, relational belonging, and Indigenous protective factors function as regulatory mechanisms that promote resilience and well-being.

Findings will contribute to the development of culturally grounded indicators, Indigenous-led cognitive health surveillance approaches, and future research exploring the intersections of stress embodiment, substance misuse, cognitive wellness, and Indigenous resilience across the life course.

17. **Interaction Between Diabetes Status and Intraindividual Cognitive Variability in Predicting Brain Atrophy and Cognitive Decline in American Indians**

***Lihui Tu**, The Krieger Klein Alzheimer's Research Center, Brain Health Institute, New Brunswick, USA*

Michal Beeri, The Krieger Klein Alzheimer's Research Center, Brain Health Institute, New Brunswick, USA
Naomi Chaytor, Washington State University, Spokane, USA
Dedra Buchwald, University of Washington, Seattle, USA
James Galvin, University of Miami Miller School of Medicine, Miami, USA
Maureen Schmitter-Edgemcombe, Washington State University, Pullman, USA
Astrid Suchy-Dicey, Boston University Slone Epidemiology Center, Boston, USA
Luciana Fonseca, The Krieger Klein Alzheimer's Research Center, Brain Health Institute, New Brunswick, USA,
University of São Paulo School of Medicine, São Paulo, Brazil

Background: Intraindividual cognitive variability (IICV) refers to variability in an individual's performance across cognitive measures assessed at a single timepoint or over a short period and has been proposed as a noninvasive marker of dementia, with higher variability generally predicting poorer cognitive trajectories. However, it remains unclear how concurrent metabolic conditions, such as diabetes, may modify this association.

Objective: To examine whether diabetes status modify the associations of IICV with cognitive decline and structural brain atrophy in American Indians, a population with high burden of diabetes and increased risk of dementia.
Methods: We analyzed 375 Strong Heart Study participants (71.3 ± 4.8 years) with complete longitudinal cognitive and neuroimaging data (mean follow-up: 6.7 years). Domain-specific IICV (memory, executive function [EF]/processing speed, multidomain), and annualized brain volume changes were calculated from FreeSurfer-estimated brain regions. Cognitive decline was defined as the baseline-adjusted longitudinal slope of Modified Mini-Mental State scores. Regression models adjusting for baseline variables evaluated the interaction effects of IICV and diabetes on cognitive decline and structural brain outcomes, with false discovery rate (FDR) correction for multiple testing.

Results: Participants with diabetes exhibited lower EF (verbal fluency) scores and greater brain atrophy ($P < 0.05$). Analyses revealed an interaction ($P < 0.05$) of IICV (particularly EF) with diabetes on the association with global cognitive decline and brain atrophy; lower IICV was associated with greater cognitive deterioration, hippocampal loss, and cortical thinning in those with diabetes.

Conclusions: The informative utility of IICV may depend on diabetes status. Although greater cognitive variability has been associated with neurodegeneration in people without diabetes, lower IICV is associated with greater brain atrophy and cognitive decline in people with diabetes in this sample. These findings suggest that metabolic status may be an important consideration when evaluating cognitive variability as a clinical biomarker.

18. **Walking Together on a Dementia Journey: Four Decades of Community Care Evolving towards Community-Led and Culturally Grounded Brain Health Care at Six Nations of the Grand River**

Lori Davis Hill, McMaster University, Hamilton, Canada; Six Nations of the Grand River, Ohsweken, Canada

Jacqueline Powless, Six Nations of the Grand River, Ohsweken, Canada

Jill Monture, Six Nations of the Grand River, Ohsweken, Canada

Semiah Smith, McMaster University, Hamilton, Canada; Six Nations of the Grand River, Ohsweken, Canada

Joanne Osborn, Six Nations of the Grand River, Ohsweken, Canada

Andrea Smith, Six Nations of the Grand River, Ohsweken, Canada

Kitty RLynn Lickers, McMaster University, Hamilton, Canada; Six Nations of the Grand River, Ohsweken, Canada

Six Nations of the Grand River (SNGR) is a partner site in the Wholistic Brain Health Assessment Bundle project, a multi-site initiative focused on advancing culturally grounded approaches to dementia screening, assessment, and care. This presentation reflects on over four decades of dementia-related experiences at SNGR, situating current efforts within a historical continuum of community-based care, evolving service delivery, and shifting relationships with external health systems. Drawing on collective knowledge from community healthcare providers within the Department of Wellbeing, this work examines early reliance on mainstream Western medical models for identification and diagnosis, often situated outside the community and lacking cultural safety.

Over time, SNGR has witnessed significant growth in local services, transitioning from externally driven care toward community-led, culturally rooted systems. This transformation includes the development of the Senior Support Hub and its dedicated Dementia Care team, which provides ongoing support to individuals and families navigating the complexities of a progressive condition. Despite these advancements, care providers identify persistent challenges,

including resistance among community members to formal assessment and diagnosis—experiences shaped by historical mistrust, stigma, and misalignment with Indigenous ways of knowing and being.

Engagement in the Wholistic Brain Health Assessment Bundle project creates a critical opportunity to address these gaps by co-developing culturally safe screening and assessment tools, enhancing community awareness, and reducing stigma associated with dementia. This presentation shares insights from past and present work to illuminate pathways toward a decolonized model of care. It highlights the importance of grounding dementia services in Haudenosaunee values, relationships, and community leadership.

Ultimately, this work represents both a reflection and a forward-looking vision, emphasizing self-determination in health research and practice. By sharing SNGR's dementia journey, the presentation contributes to broader Indigenous-led efforts to reimagine brain health assessment, intervention, and care in ways that honour culture, community, and lived experience.

19. Beyond geography: A qualitative yarning study of Place in dementia diagnosis and care with Aboriginal and Torres Strait Islander peoples

Antonia Clarke, Monash University, Melbourne, Australia; The University of Sydney, Sydney, Australia

John Towney, University of New South Wales, Randwick, Australia

Cammi Murrup-Stewart, Monash University, Clayton, Australia

Cheryl Swinton, The University of Sydney, Dubbo, Australia

Patricia Bates-Canty, Western NSW Local Health District, Bourke, Australia

Judith McGuinness, Neuroscience Research Australia, Randwick, Australia

Louise Lavrenic, Neuroscience Research Australia, Randwick, Australia

Kylie Radford, University of New South Wales, Randwick, Australia

Adrienne Withall, University of New South Wales, Randwick, Australia

Amy Brodtmann, Monash University, Melbourne, Australia

Aboriginal and Torres Strait Islander communities hold longstanding strengths in family, cultural continuity, and community-led approaches to caring, articulated through the Social and Emotional Wellbeing (SEWB) framework. Yet Aboriginal and Torres Strait Islander peoples continue to experience significant inequities in dementia diagnosis and care, more so in rural and remote areas of Australia. Current health and aged-care approaches are largely informed by biomedical models of care, which may inadequately account for the influence of Indigenous conceptualisations of Place on dementia experiences and service engagement. We aimed to explore how Place influences care preferences, decision-making, and health system navigation beyond conventional geographic classifications. We employed yarning as an Indigenous qualitative research methodology across eight urban, regional and rural/remote sites in Australia. Data were analysed using a reflexive deductive–inductive approach, with deductive coding guided by the SEWB framework and inductive analysis centring Aboriginal perspectives. Thirteen research yarns were held with 121 participants from 6 ACCHOs and 7 community groups between March 2024 and April 2025. Participants described trust, cultural continuity, historical contexts, service accessibility, and connection to Country and community as foundational to dementia diagnosis and care. Shared themes across sites included the stigma surrounding dementia, difficulties accessing timely diagnosis, and the central role of family and community caregivers. Place-oriented findings highlighted how cultural obligations, SEWB, and experiences of institutional mistrust influenced engagement with health and aged-care services. Participants emphasised the importance of culturally safe, relationship-based care that supported time on Country and community participation. Workforce shortages, metropolitan-designed service models, and fragmented systems were identified as barriers to implementing locally responsive dementia care. Best-practice dementia diagnosis and care for Aboriginal and Torres Strait Islander peoples must be Place-based. Place-responsive approaches require policy and service models that are locally determined and grounded in community priorities and SEWB.

20. Reflections on guiding culturally safe care in a mainstream residential care community in Australia

Lyn Goldberg, University of Tasmania, Launceston, Australia

Kylie Sullivan, Neuroscience Research Australia, Sydney, Australia

Yasmin Abdullah, University of Western Australia, Perth, Australia

Clair Andersen, University of Tasmania, Hobart, Australia

Dianne Baldock, University of Tasmania, Hobart, Australia
Leslie Dick, University of Tasmania, Launceston, Australia
Terence Donovan, University of Tasmania, Kempsey, Australia
Harry Douglas, Victorian Aboriginal Health Services, Melbourne, Australia
Dawn Gilchrist, University of Western Australia, Perth, Australia
Darren Holten, Booroongen Djugun, Kempsey, Australia
Daniel Kelly, University of Tasmania, Mildura, Australia
Lindy Moffatt, University of Tasmania, Brisbane, Australia

Aboriginal and Torres Strait Islander peoples needing dementia-related care frequently receive services from mainstream organisations and non-Indigenous care providers unfamiliar with or unsure about providing care that is culturally respectful and safe. This presentation shares reflections of Aboriginal Elders who initiated an innovative series of podcasts and complementary vodcasts to educate non-Indigenous staff about culturally safe care in a rural mainstream residential care community in Trouwerner/Lutruwita (Tasmania).

Currently, the project is ongoing but will be completed in June. This will enable us to report complete data.

Elders' reflections from initiating the project (baseline data) identified six themes: 1) Importance of truth telling, (2) Value of staff interest, (3) Impact of the Smoking Ceremony, (4) Appreciation of the care environment; (5) Lack of Acknowledgement and understanding, and (6) Contribution of an Elder-in-Residence program. Elders' experiences from their initial visit to this rural mainstream residential care community confirmed the need for staff education about culturally safe care and how to implement such care. Aboriginal people were in residence but appeared unknown to staff. The environment was calm and supportive but not culturally welcoming. There was no Aboriginal flag outside the residence, no acknowledgement of the land of the local Aboriginal community, and no artwork or cultural items indicating respect for Aboriginal culture. An Elder commented, "Lots of photos celebrating colonial times, not our culture...I tried to picture myself here – it was just that sort of sterile, clinical kind of environment. I would feel very culturally isolated living here."

Elders' reflections provided valuable insight into the need for their innovative series of podcasts and complementary vodcasts focused on culturally safe care. We hope the impact of the podcasts and vodcasts will be positive and look forward to sharing how they guided culturally safe care for Aboriginal people in this mainstream community.

21. Toward Culturally Safe Dementia-Friendly First Nation Communities in Northwestern Ontario: Identifying Key Components

Brittany Skov, Lakehead University, Thunder Bay, Canada
Dilico Anishinabek Family Care Community Advisory Committee, Dilico Anishinabek Family Care, Thunder Bay, Canada
Jennifer Walker, McMaster University, Hamilton, Canada
Christopher Mushquash, Lakehead University, Thunderbay, Canada

Background: The number of Indigenous Peoples in Canada (i.e., First Nations, Metis, and Inuit) living with dementia is projected to greatly increase over the next 25 years. Efforts to increase access to culturally safe dementia post-diagnosis care are needed, as culture influences approaches to caregiving, health guidance needs, and treatment preferences. One approach to supporting post-diagnosis care is through dementia-friendly communities, where people living with dementia feel respected, supported, and included. These communities rely on accessible health communication and guidance, training, programming, and transportation, among other components. However, there is limited research on the specific needs and perspectives related to culturally safe dementia care among First Nations communities in Canada, particularly in ways that can inform culturally safe dementia-friendly communities.

Method: In partnership with Dilico Anishinabek Family Care, we examined the needs for culturally safe dementia post-diagnosis care among community-dwelling First Nations people living in Northwestern Ontario. We conducted interviews and knowledge gathering circles with 41 predominantly First Nation adults (18+) residing in a large urban city (>100,000), a small town (<1,000), two road-connected rural communities, and one community adjacent to a large urban city. Community members included those with personal or professional experience or interest related to dementia. Data were analyzed using reflexive thematic analysis.

Results: Five themes describing culturally safe post-diagnosis dementia care were developed: 1) Wraparound care and aging in place; 2) Culturally safe dementia healthcare; 3) Caring for care partners; 4) Honouring wise practices and expanding knowledge; and 5) Kinship networks.

Impact: This research identifies key components of culturally safe dementia-friendly communities and a need for culturally grounded, multi-modal health guidance to support First Nations individuals and families navigating post-diagnosis dementia care. Addressing this gap may strengthen the development and implementation of dementia-friendly communities in Northwestern Ontario and similar contexts.

22. Simulated Based Dementia Training: Health Professionals, and Community Members Gain an Increased Awareness and Understanding of Dementia

***Iris Walking Eagle**, Spirit Lake Senior Services, Fort Totten, USA*

***Loretta Heuer**, North Dakota State University School of Nursing, Fargo, USA; Spirit Lake Senior Services, Fort Totten, USA*

***Shaylynn Demarrias**, Spirit Lake Senior Services, Fort Totten, USA*

***Marilyn G. Klug**, University of North Dakota, Grand Forks, USA*

Background: In 2023, the Alzheimer's Association estimated 13,700 people of 123,840 North Dakota residents over the age of 65 had Alzheimer's (Stacker, 2024). With the increasing prevalence of dementia, there is the need for education and awareness programs that target the public, people at-risk, providers and caregivers. The purpose of this study was to evaluate the awareness and perceptions of health care professionals and community members.

Method: A quasi-experimental pre-post design used the Healthcare and Community Pre/Post Surveys. Trained facilitators implemented the 60-minute Virtual Dementia Tour intervention at sites on a rural reservation and surrounding towns. Paired t-tests and means ($<.001$) analyzed pre/post changes.

Results: There were 135 health care respondents. Most (69%) were 30 to 59 years old. Seventy-three percent identified as Caucasian and 18% as American Indian. Healthcare respondents had significant increases between the pre/post-tests. From a physical standpoint, how capable did you feel carrying out simple tasks ($M = 1.94$, $SD = 1.30$), current state of relaxation ($M = 1.02$, $SD = 1.17$), how easy is it for a person with dementia to get through a day ($M = 0.52$, $SD = 0.64$), and do people with dementia get the needed care ($M = 0.56$, $SD = 1.11$). Fifty respondents completed the community survey and 80% identified as American Indian. After the intervention, 52% did not feel capable of carrying out simple tasks, 38% were not relaxed, and 4% did not think people with dementia get the needed care. Respondents shared the dementia characteristics that increased were negative thoughts, following others, pacing, searching for lost items, talking to self, and having difficulty with directions. The number of community respondents with one or more characteristics increased from 42% to 90%.

Conclusion: Overall, respondents had significant changes in awareness and perceptions of dementia and related care.

23. Questions to Ask Your Doctor About Memory Loss + Symptom Tracker for Indigenous Individuals, Families, and Caregivers

***Marvina Chavez**, International Association for Indigenous Aging, Silver Springs, USA*

***Ron Epps**, Interactional Association for Indigenous Aging, Silver Springs, USA*

The IA² "Questions to Ask Your Doctor About Memory Loss" materials were developed to support Indigenous individuals, families, and caregivers in recognizing, tracking, and discussing changes in memory, thinking, and behavior with healthcare providers. Rooted in the understanding that memory and wisdom are sacred within Indigenous communities, these culturally grounded resources encourage respectful, informed, and compassionate conversations about memory loss and dementia.

The materials include a practical guide of questions individuals and caregivers can bring to medical appointments, addressing topics such as when memory changes may be concerning, available testing and assessment options, possible causes of symptoms, lifestyle changes, safety planning, community resources, and preparation for disease progression. The guide also prepares families for questions healthcare providers may ask about symptoms, medications, stress, illness, injury, and life changes. In addition, the materials emphasize the importance of symptom tracking to help individuals and caregivers document patterns of forgetfulness, confusion, or difficulties with daily activities over time.

The resources also acknowledge that memory loss may result from causes other than dementia, including anxiety, depression, sleep disorders, thyroid conditions, vitamin deficiencies, infections, dehydration, medications, or head injuries. By promoting early conversations and culturally respectful care, the materials aim to reduce stigma, improve communication between families and healthcare providers, and support timely access to diagnosis, services, and community-based supports. These tools are intended to empower Indigenous communities with knowledge and practical strategies while honoring the dignity, wisdom, and lived experiences of Elders and those experiencing memory changes.

24. Building capacity of Alzheimer Society Staff and volunteers to co-design support groups with members of Indigenous communities

Megan O'Connell, University of Saskatchewan, Saskatoon, Canada

Jennifer Walker, McMaster University, Hamilton, Canada

Edith Mercieca, Maamwesying, Cutler, Canada

Terry Caprossoi, Alzheimer Society of Sault Ste. Marie and Algoma, Sault Ste. Marie, Canada

Clara Austrins, McMaster University, Hamilton, Canada

Shoshana Green, University of Saskatchewan, Saskatoon, Canada

Heather Dash, Alzheimer Society of SK, Regina, Canada

Chelsea Grimard, Maamwesying, Cutler, Canada

Ngozi Iroanyah, Alzheimer society of ON, Toronto, Canada

Claire Jimmison, Alzheimer Nova Scotia, Annapolis Valley, Canada

Jody MacDonald, Alzheimer Nova Scotia, Victoria, Canada

Christine McWilliam, Alzheimer Society of AB and NWT, Red Deer, Canada

Emily Piranio, Maamwesying, Cutler, Canada

Marie Christine, Le Bourdais, Societe Alzheimer de Montreal, Montreal, Canada

Lavina Gignac, Senior PAC, Cutler, Canada

Mary Hill, Senior PAC, Cutler, Canada

Marie Pine, Senior PAC, Cutler, Canada

Willard Pine, Senior PAC, Cutler, Canada

Marella Schofield, Senior PAC, Cutler, Canada

Mary Simon, Senior PAC, Cutler, Canada

Lulubelle Tessier, Senior PAC, Cutler, Canada

Delores Trudeau, Senior PAC, Cutler, Canada

Millie Young, Senior PAC, Cutler, Canada

Caregiver support groups that are co-designed with caregivers, and offered in partnership with Indigenous organizations, provide meaningful and effective support for Indigenous families living with dementia. One barrier to this co-creation is the capacity of Alzheimer Society staff and volunteers to work in culturally-safe and trauma-informed partnerships to develop Indigenous dementia supports. In response, we have been working with staff and leadership from Alzheimer Societies from across Canada along with settler researcher clinicians, Indigenous researchers, and leaders of Indigenous community organizations to co-design an educational resource to enhance their Alzheimer Society capacity to deliver Indigenous dementia care. The steering committee included support group facilitators, First Link Coordinators, and Directors of various levels including Executive Directors from several regional Alzheimer Societies and Alzheimer Society of Canada to support the building of the tool. The resulting educational tool was hosted on the Learning Management Platform of the Alzheimer Society of ON. We began considering adaptation of an existing resource created for researchers, the Indigenous Cognitive Health Pathway, but we quickly decided that more foundational knowledge was required. A draft module was co-created on how to create meaningful relationships with Indigenous communities, and this was presented to a community-based patient advisory group comprised of First Nations Elders. In an attempt to maintain a strengths-based focus, we had removed some of the information in the Indigenous Cognitive Health Pathway on residential schools. The Elders' advisory council wanted us to put this back in and told us "this is our story" and they wanted learners to "not just know it but feel it." This co-design process will be used to develop a further two modules to support capacity building within Alzheimer societies that will enhance their ability and willingness to work with a local Indigenous community to co-design culturally safer caregiver support groups.

25. Remember when...? Poetry, Culture, and Wellbeing in Indigenous Dementia Care

Antonio Paniagua Guzmán, *Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA*

Roger Smith, Sr., *Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA*

Person-centered, art-based behavioral interventions have been successfully developed to support people living with dementia (PLWD) and their caregivers. Among these, music and visual arts have been the most extensively studied in dementia research. However, there has been increasing interest in language-based art forms, including poetry. Previous research suggests that engaging in poetry can enhance emotional health, cognition, and communication between PLWD and their caregivers. Despite the development of several meaningful poetry-based interventions, none have been specifically tailored to Indigenous communities in the United States using culturally safe approaches. Guided by a community-based participatory research framework and Indigenous methodologies, our study to develop an Indigenous poetry intervention for PLWD and their caregivers was conducted in partnership with the Fond du Lac Band of Lake Superior Chippewa Tribe in Minnesota. During the summer of 2025, ten poetry sessions were held, each involving an average of 12 participants, including PLWD and their caregivers, and led by two community facilitators. In each session, participants recited and co-authored poems closely tied to the Anishinaabe culture. At the request of participants, all poems co-authored during the program were compiled into an anthology titled *Giminjimendaan ina gaa-inakamigak? (Remember When...?)*, which has been distributed within the community and shared with other communities. Interviews before and after the intervention were conducted with participants who provided consent and we gathered observational data throughout the sessions. Findings of this research suggest that the program had a positive impact on participants' well-being across four key areas: (1) emotional release and healing, (2) preservation and sharing of knowledge, (3) honoring of culture and heritage, and (4) mutual support among families affected by dementia.

26. Identifying and analyzing Indigenous & Two-Spirit Persons in the Canadian Longitudinal Study on Aging

Skye Wilson, *The Community-based Research Centre, Vancouver, Canada*

KD King, *University of Alberta, Edmonton, Canada*

Megan O'Connell, *University of Saskatchewan, Saskatoon, Canada*

Jennifer Walker, *McMaster University, Hamilton, Canada*

Letebrhan Ferrow, *McMaster University, Hamilton, Canada*

Jessy Dame, *The Community-based Research Centre, Vancouver, Canada*

Lane Bonertz, *The Community-based Research Centre, Montreal, Canada*

There is little known about the experiences of Indigenous Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Intersex, or other diverse sexual and gender identities (2SLGBTQIA+) and aging. To address this gap, a diverse group of Indigenous, Two-Spirit, and allied community and academic researchers turned to the Canadian Longitudinal Study on Aging (CLSA), a nationwide cohort study that tracks aging experiences. We found that there are issues with identifying Indigenous and 2SLGBTQIA+ people within the data. There was no CLSA category for Two-Spirit individuals. Using an iterative, Indigenous and Two-Spirit led approach, we were able to determine a cohort of Indigenous and Two-Spirit people based on individual responses in the tracking or comprehensive cohort reporting being lesbian, gay, bisexual, or identified with an orientation or gender identity that doesn't match the existing codes, or identified as genderqueer at baseline or follow-up (N = 17; M age 58.7 years). These records were compared with the non-Two-Spirit Indigenous sample (N = 522; M age = 59.6 years). The Two-Spirit group was more likely to own a home and be single (never married or never living with a partner). They were also more likely to report being diagnosed with diabetes. The Two-Spirit sample reported less social support, as measured by the Medical Outcomes Social Support Survey, with effect sizes ranging from small for tangible social support (d = .267) to large for overall support (d = .804) and affection (d = 1.095). Differences in all other comparisons were not statistically significant. We identified opportunities to develop more specific and inclusive questions in CLSA data collection to improve understanding of Indigenous 2SLGBTQIA+ people, and to explore purposive sampling in future longitudinal research to increase their representation. The findings illustrate potential sites for intervention to prevent diabetes and to increase social supports for our 2SLGBTQIA+ relatives.

27. **Puipui Malu Manatu (Protecting Memories): Building the First Longitudinal Dementia Cohort in American Samoa**

Va'atusili Tofaeono, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

Tulimalefoi Vaofanua, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

Grace Tuato'o, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

Jueta McCutchan-Tofaeono, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

Robin Faumuina-Vasai, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

James Galvin, University of Miami, Bacon Raton, USA

Background: Native Hawaiian and Pacific Islander (NHPI) populations remain among the most underrepresented groups in Alzheimer's disease and related dementias (ADRD) research despite experiencing a high burden of vascular and metabolic risk factors associated with cognitive decline. To address this gap, the PMM study was established in American Samoa as the first comprehensive ADRD research initiative in the territory. This presentation shares lessons learned from building a culturally grounded dementia research platform and discusses implications for other Indigenous communities seeking to develop sustainable brain health research programs.

Methods: PMM employed a community-engaged, culturally responsive approach grounded in Fa'aSamoa (the Samoan way) and principles of respect, reciprocity, and collective responsibility. Research instruments were translated, culturally adapted, and validated through consensus translation, back-translation, cognitive interviewing, and pilot testing. Infrastructure development included workforce training, biospecimen collection and shipping systems, implementation of culturally adapted cognitive assessments, and establishment of the first MRI capability in American Samoa.

Results: PMM successfully enrolled and phenotyped the largest cohort of older Samoan adults studied to date (n=929), demonstrating the feasibility of conducting advanced ADRD research in a geographically isolated Indigenous community. Key lessons included the importance of prioritizing relationships before recruitment, adapting research methods rather than expecting communities to conform to existing models, investing in local workforce and infrastructure development, and integrating Indigenous knowledge systems with Western scientific approaches. These efforts resulted in culturally valid assessment tools, strong community participation, and for PMM 2.0.

Conclusions: The PMM experience demonstrates that Indigenous-led, culturally grounded dementia research is both feasible and sustainable when community priorities, local capacity building, and cultural values are central to study design. Lessons learned offer a scalable framework for other Indigenous and underserved populations seeking to advance brain health research, reduce disparities, and strengthen community-based approaches to healthy aging.

Poster Presentations:

Full Author Lists & Scientific Abstracts

1. A Community Empowered Approach to Telehealth Dementia Care in an Indigenous Community in the United States

Kala Cornelius, William S Middleton Memorial Veterans Hospital, Madison, USA
Sarah Punshon, William S Middleton Memorial Veterans Hospital, Madison, USA
Carrie Trojanczyk, William S Middleton Memorial Veterans Hospital, Madison, USA
Wes Martin, William S Middleton Memorial Veterans Hospital, Madison, USA
Jenna Woestman, William S Middleton Memorial Veterans Hospital, Madison, USA
Danielle Lennon, William S Middleton Memorial Veterans Hospital, Madison, USA
Joseph Perzynski, William S Middleton Memorial Veterans Hospital, Madison, USA
Steve Barczy, William S Middleton Memorial Veterans Hospital, Madison, USA

The American Indigenous (AI) population is aging rapidly and is disproportionately impacted by dementia. AI elders and their families, especially those in rural areas, face significant barriers to accessing dementia diagnosis, care, and management. Efforts to address these barriers through effective community collaborations are critical to support the health and well-being of elders. Our presentation will report on a partnership between the Oneida Nation (ON)-a midwest Tribal sovereign Nation in the United States, Veterans Affairs (VA), and the University of Wisconsin Madison (UW) to tailor and implement culturally relevant, evidence-based memory care telehealth services to Indigenous elders and support the community through education. To facilitate a community empowered approach, our interdisciplinary team includes members of the ON who are paid for their work, are involved in making all decisions about the research, are co-authors on poster and oral presentations, and will be co-authors on publications. We partner with the ON Veterans Group to provide community education events where ON Tribal member feedback is collected by quantitative surveys with opportunities for open-ended responses. The feedback collected guides topics for future education events. ON Tribal Clinic staff education needs were collected through a quantitative survey, and the results informed topics for staff education and training. Our approach to communication and reciprocal exchange of information includes the VA and UW project teams sharing the results of research data with the ON Tribal community. This work will be disseminated to additional Tribal Nations through the development of an implementation toolkit. In this descriptive presentation, we will share our community empowered research plan, data collected from community surveys to date, community and staff education provided, and results from qualitative interviews completed with staff to characterize memory care services offered at the Tribal Health Clinic.

2. Relationships First: Community Engagement in Indigenous Brain Health Research

Kara-Lyn Harrison, Maamwesying North Shore Community Health Services, Sault Ste. Marie, Canada
Edith Mercieca, Maamwesying North Shore Community Health Services, Cutler, Canada
Athena Moffatt, Maamwesying North Shore Community Health Services, Blind River, Canada
Kate Dunn, York University, Iron Bridge, Canada

Background:

Biomedical models for dementia and brain health assessments may not reflect Indigenous perspectives on aging, memory, and wellness. Culturally grounded awareness, engagement, and research are essential to developing relevant, respectful, relational processes and assessment tools reflecting community priorities.

Project Overview:

Long-term goals support the decolonization of brain health with Indigenous communities contributing to culturally connected Indigenous-centred brain health assessment, education, and training for healthcare providers. Maamwesying North Shore Community Health Services is one of five Indigenous partner sites and serves seven First Nation communities along the north shore of Lake Huron, providing accessible, quality, culturally safe, wholistic health services that support the wellness of individuals, families, and communities. Together with partner sites,

Maamwesying seeks to co-develop culturally relevant approaches to understanding and assessing and supporting brain health within Indigenous communities.

Relationship First Engagement:

Engagement with First Nation communities served by Maamwesying was intentionally approached as reciprocal rather than extractive. The first year of this six-year project focused on building relationships, learning and following community protocols, and participating in ceremonies to honour local traditions. Activities were designed to create safe spaces for dialogue about brain health, through attending community events, sharing information on brain wellness, and actively listening to community priorities. This relationship-centred approach ensures research begins in partnership with community rather than driven by external agendas.

Significance:

Relational engagement efforts have strengthened relationships, fostered trust, and created safe spaces for meaningful discussion about brain health within communities. These relationships will continue throughout the project and support active community participation to defining brain health and the components of a wholistic brain health assessment. Our goal is to co-develop a brain health assessment reflecting community-defined understandings of memory, aging and wellness and lived experience. This relationship centred approach honours Indigenous self-determination and provides a model for culturally grounded, community-led research partnerships.

3. Sustaining Community Engagement in Multi-Year Projects with Indigenous Communities Across Canada: A Scoping Review Protocol

Brittany Skov, Lakehead University, Thunder Bay, Canada

Kara-Lyn Harrison, Maamwesying Northshore Community Health Services, Sault Ste. Marie, Canada

Kayla Kubinec, Lakehead University, Thunder Bay, Canada

Sophie Ella Watson, McMaster University, Hamilton, Canada

Kate Dunn, York University, Toronto, Canada

Naponse Niki, Za-geh-do-win Information Clearinghouse, Sault Ste. Marie, Canada

Bobbie O'Donnell, Laurentian University, Sudbury, Canada

Megan O'Connell, University of Saskatchewan, Saskatoon, Canada

Roger Pilon, Queens University, Kingston, Canada

Chantelle Richmond, Western University, London, Canada

Jennifer Walker, McMaster University, Hamilton, Canada

Elizabeth Webkamigad, Wholistic Brain Health Assessment Bundle Study, Sault Ste. Marie, Canada

Sharlene Webkamigad, Laurentian University, Sudbury, Canada

Mushquash Christopher, Lakehead University, Thunder Bay, Canada

Background: In response to past harmful research conducted with Indigenous communities, guidelines and principles have been developed to ensure relational, respectful, relevant, reciprocal, responsible, and ethical research. Several challenges exist in practicing respectful community engagement, including navigating distinct remote, rural, and urban community needs and the need to extend engagement to marginalized voices in communities. Moreover, sustaining community engagement in multi-year projects with Indigenous communities presents unique challenges and opportunities, including shifting priorities, interests, leadership, and attrition over time. These challenges require approaches that help to ensure the research process and outcome remain flexible and responsive. There is a need to synthesize existing research on methods, strategies, and practices for sustaining community engagement among community members and leadership in multi-year projects.

Method: We will use the 2020 Joanna Briggs Institute methodology for scoping reviews, complemented by an Indigenous-informed approach. We will systematically search PsycINFO, Web of Science, PubMed, ERIC, CINAHL, and gray literature databases to identify relevant qualitative and quantitative studies. Reviewers will assess titles, abstracts, and full-text articles for inclusion. We will chart and synthesize data to summarize methods, strategies, and practices for sustaining community engagement in multi-year projects.

Results: Results will be shared with community members and organizations for feedback. Reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews guidelines.

Impact: This work will offer practical methods for sustaining community engagement with Indigenous community leaders and members throughout multi-year projects, ensuring that research remains relational, relevant, respectful, responsible, responsive, and reciprocal.

4. Pathways to community engagement in regional and multi-site dementia research with First Nation communities in Northwestern Ontario, Canada

Brittany Skov, Lakehead University, Thunder Bay, Canada

Kayla Kubinec, Lakehead University, Thunder Bay, Canada

Katlynn Gustafson, Dilico Anishinabek Family Care, Thunder Bay, Canada

Jennifer Walker, McMaster University, Hamilton, Canada

Dilico Anishinabek Family Care Community Advisory Committee NA, Dilico Anishinabek Family Care, Thunder Bay, Canada

Christopher Mushquash, Lakehead University, Thunder Bay, Canada

Background: Community-engaged Indigenous dementia research supports self-determination, addresses community needs, and integrates cultural perspectives, protocols, and approaches. Yet, this approach involves multiple complexities. This work involves multiple complexities, including navigating accountabilities to Indigenous leadership, community members outside leadership roles, and service providers (e.g., healthcare professionals) who may help implement the work. These challenges are amplified in regional and multi-site contexts, where engagement spans diverse communities and geographies. Yet, practical guidance on sustaining meaningful engagement in such contexts and understanding its impact on research processes remains limited.

Method: In partnership with Dilico Anishinabek Family Care, we co-developed and implemented a pathway to guide community engagement across a large region of Northwestern Ontario, including an urban center, small towns, and rural First Nation communities. The pathway ensures responsiveness to community leadership and members' priorities.

Results: The community engagement pathway includes community-based discussions within rural First Nations communities, a monthly urban brain health promotion program, behaviour-change theory-informed health guidance, games, social media, newsletters, and meetings with Dilico Anishinabek Family Care. This approach has facilitated the identification of additional research priorities and culturally meaningful methods for gathering and sharing community stories.

Impact: This work offers a practical model for regional, multi-site community engagement that can help researchers, communities, and health organizations ensure that research with and for Indigenous communities remains relevant, respectful, responsible, and reciprocal.

5. Coalition Building Across Distance: Establishing a Community Advisory Board for Dementia Support from 5,000 Miles Away

Marika Humber, Department of Veterans Affairs, Palo Alto, USA

Leah Haverhals, Department of Veterans Affairs, Denver, USA

Marisa-Francesca Lindsey, Department of Veterans Affairs, Palo Alto, USA

Lynsay Paiko, Department of Veterans Affairs, Palo Alto, USA

Nainwant Singh, Department of Veterans Affairs, Reno, USA

Christine Gould, Department of Veterans Affairs, Palo Alto, USA

Community advisory boards (CAB) are vital for driving culturally informed care delivery. Our team sought to identify culturally responsive strategies as part of an evaluation of virtual dementia services provided by the Department of Veterans Affairs (VA) to Veterans in Guam. Dementia is a debilitating, progressive disease affecting older Veterans due to military-related risk factors such as traumatic brain injuries. Access to dementia care is particularly difficult in underresourced areas. As part of the evaluation, we conducted phone and in-person interviews with VA leadership, clinicians, staff, and Veterans/caregivers to gather perspectives on local conditions and dementia care needs. We worked to build a coalition by establishing a CAB of dementia caregivers and support staff to describe Veterans' care needs and enhance brain health and dementia management services. Starting in October 2025, we recruited for our CAB using phone, email, digital flyers, and mailed thank you notes for participating in previous interviews. We

contacted 19 individuals and organizations. Most were contacted multiple times. In phone calls and emails, we described the evaluation and CAB goals, provided our contact information, and asked contacts to distribute flyers within their networks. Most outreach attempts yielded no follow-ups, with some phone numbers inactive and others requiring transfer to another individual who did not follow up. We conducted the first CAB meeting in March 2026 with three caregivers: two adult children and one adult grandchild. Two joined after receiving the thank you note, and one saw the digital flyer in the VA's newsletter. We transcribed meeting notes in a matrix based on the He Pikinga Waiora framework. A local aging support service representative was recruited by phone and will join the next meeting. Our experiences highlight the challenges of conducting outreach from afar and the necessity of personal connections and physical presence for successful outreach.

6. Pōmai and Her Papa: An Animated Story About Dementia

Kalilinoe Detwiler, University of Hawai'i at Mānoa, Honolulu, USA

Jena Funakoshi, University of Hawai'i at Mānoa, Honolulu, USA

Shelley Muneoka, University of Hawai'i at Mānoa, Honolulu, USA

Justin Kepo'o Keli'ipa'akaua, University of Hawai'i at Mānoa, Honolulu, USA

Miquela Ibrao, University of Hawai'i at Mānoa, Honolulu, USA

Kathryn Braun, University of Hawai'i at Mānoa, Honolulu, USA

Native Hawaiians are at a high risk for dementia, with Alzheimer's disease being the sixth leading cause of death for Hawaiian and other Pacific Islanders at age 65+. Many Native Hawaiian elders reside with families, including youth, in multigenerational housing for cultural, economic, and health reasons, and as such Native Hawaiian families often provide the majority of care to loved ones with dementia. Yet, few educational materials are available for Native Hawaiian youth in accessible formats, and few are specific to the Hawai'i context. This presentation focuses on the animation of a research-driven storybook titled Pōmai and her Papa (2021) for Native Hawaiian youth who may be encountering dementia in their families. The original storybook Pōmai and Her Papa was developed by Hā Kūpuna, a Native Hawaiian serving organization, using community-engaged approaches for feedback and dissemination. The process of developing the book was presented at the 2023 IIDRN Conference, along with a separate presentation on the translation into 'ōlelo Hawai'i (Hawaiian language), titled Pōmai Laua 'o Papa, to address the knowledge, needs, and accessibility of Hawaiian-speaking audiences. In 2025, we completed and published online the animation, Pōmai and Her Papa, to further enhance accessibility for all audiences. This year, we will provide a brief overview of the 2023 presentations and will focus largely on the challenges and insights of adapting the storybook to an audio-visual form. This presentation may aid others endeavoring to translate health communications into new media for their communities. We also discuss how culturally grounded dementia education through storytelling increases the accessibility of dementia research, fosters cultural identity, and encourages relationships across generations. This project underscores the importance of creative, community-serving health education strategies that contribute to Native Hawaiian wellbeing.

7. Enhancing food sovereignty and promoting healthy aging for Indigenous older adults through culturally responsive food programming in long-term care homes

Anik Obomsawin, Toronto Metropolitan University, Toronto, Canada

Krystal Kehoe MacLeod, Bruyere Research Institute, Ottawa, Canada

Victoria Wicks, Bruyere Research Institute, Ottawa, Canada

Kaitlyn Patterson, Queen's University, Kingston, Canada

Billie Julian, Millbrook First Nation, Millbrook, Canada

Gerald D. Gloade, Millbrook First Nation, Millbrook, Canada

Sarah Funnell, Queen's University, Kingston, Canada

The rate of dementia for Indigenous Peoples is approximately 34% higher than for non-Indigenous Peoples. Many older adults living with dementia receive care in institutional settings such as long-term care homes, where daily practices, including food, play an important role in quality of life. For many Indigenous communities, food is not only a source of nutrition but is deeply connected to culture, relationships, and connections to land. However, institutional food environments often fail to reflect these values. Advancing Indigenous food sovereignty in later life,

therefore, requires protecting access to Indigenous foods in the community and also ensuring that long-term care settings move beyond basic nutrition toward culturally meaningful, relational, and self-determined food practices. To work towards this goal, our intersectoral and interdisciplinary team collaborated with Indigenous community leaders in three First Nations communities across Canada to understand the role that institutions can play in promoting food sovereignty and preferences for food-focused reform in long-term care. This presentation focuses on findings from sharing circles with Elders, food leaders, and Chief and Council in Millbrook First Nation. Thematic analysis revealed three overarching themes: (1) community-defined meanings and values of food sovereignty, (2) institutional and systemic constraints, and (3) practices of reclamation and resistance. Findings highlight how community leaders envision food sovereignty being upheld in long-term care, the structural barriers that limit its realization, and the existing community-led initiatives and networks that support culturally grounded food practices. These insights underscore the need for institutional change that centers Indigenous self-determination, cultural identity, and relational approaches to food in later life care, including dementia care contexts.

8. Exploring the Ethical Space Between Haudenosaunee and Western Biomedical Knowledge to Inform Culturally Safe Dementia Care in Six Nations

Maya Lalji, McMaster University, Hamilton, Canada

Jacqui Powless, Six Nations of the Grand River, Six Nations, Canada

Lori Davis-Hill, McMaster University, Hamilton, Canada

Jill Monture, Six Nations of the Grand River, Six Nations, Canada

Semiah Smith, McMaster University, Hamilton, Canada

Jennifer Walker, McMaster University, Hamilton, Canada

Bonnie Marie Freeman, McMaster University, Hamilton, Canada

Dementia is an emerging and unprecedented public health concern for Indigenous Peoples in Canada. Increasing rates of dementia are complicated given that Indigenous perspectives of dementia are diverse and often differ from biomedical perspectives of dementia, resulting in barriers in the provision of culturally appropriate and relevant care from mainstream health care services. This project addresses gaps in community-specific research on dementia with a focus on the Six Nations community by investigating the following research questions: 1) What are cultural understandings of dementia from a Six Nations perspective? 2) How can Six Nations cultural understandings of dementia be bridged together with Western biomedical understandings to improve culturally safe dementia care from health care providers for people in and from Six Nations?

To answer these questions, this project involves collaboration with the Brain Health Research Team at Six Nations to explore the perspectives of community members from Six Nations, including people living with dementia, caregivers, and Knowledge Keepers, and Indigenous and non-Indigenous health care providers who serve this population. Data analysis is guided by principles of the Two Row Wampum and the Haudenosaunee principle of the Good Mind to inform how different knowledge systems can support one another in a way that is collaborative, mutually supportive, and grounded in ethics of peace, friendship, and respect. By bridging Six Nations and Western biomedical understandings together through this framework, the research explores the ethical space between these knowledge systems in order to inform and improve culturally safe care and reduce barriers to care within mainstream health care services.

9. Defining Success and Effectiveness in Community Advisory Boards: Insights from Community Members and Research Staff

Alexis Nelson, University of Wisconsin-Madison, Madison, USA

Tracy Smith, University of Wisconsin-Madison, Madison, USA

Terry Hetzel, Oneida CAB, Oneida, USA

Marlene Summers, Oneida CAB, Oneida, USA

Lois Strong, Oneida CAB, Oneida, USA

Florence Petri, Oneida CAB, Oneida, USA

John Breuninger, Oneida CAB, Oneida, USA

Kyle Conniff, University of Wisconsin-Madison, Madison, USA

Nickolas Lambrou, University of Wisconsin-Madison, Madison, USA

Cassandra Thomas, University of Wisconsin-Madison, Madison, USA

Carrie Trojanczyk, University of Wisconsin-Madison, Madison, USA

Carey Gleason, University of Wisconsin-Madison, Madison, USA

Background:

Community Advisory Boards (CABs) are increasingly used as a strategy to increase inclusion, enhance project relevance, and build trust. As researchers and community members build these collaborative advisory groups, it is crucial to identify key elements for success as defined by both the community and research staff perspectives. This is especially important to consider when working with Indigenous communities who have experienced a long history of mistreatment and under-inclusion in research settings.

Current studies have largely focused on CABs' contributions to the research process with less attention to how success is achieved or defined by community and research staff who support and sustain these partnerships. In this study, we will center research staff and community perspectives to clarify key elements that sustain an effective longstanding collaboration.

Methods:

The Oneida Nation CAB was founded in 2017 to address Alzheimer's disease outcomes for the Nation and to enhance the research engagement with the Wisconsin Alzheimer's Disease Research Center. This study will discuss our experience organizing and managing communications and meetings as UW research staff, offering insight into CAB operations. We will administer semi-structured interviews and surveys to Oneida CAB members, community collaborators, and the staff providing key support for the partnership. We will also analyze meeting notes, Business Committee Resolutions, and grant submissions.

Results:

This study will identify what success looks like from the community and research staff perspective and the key elements that contribute to the effectiveness of the Oneida CAB.

Conclusion:

Incorporating research staff and community voice in defining what makes a CAB successful is essential for advancing research partnerships with Indigenous communities. These findings have potential to inform other Indigenous communities looking to develop an effective and community driven advisory group.

10. Medicine Wheel: The Circle of Life

Iris Walking Eagle, Spirit Lake Senior Services, Fort Totten, USA

Shaylynn DeMarrias, Spirit Lake Senior Services, Fort Totten, USA

Loretta Heuer, North Dakota State University, Fargo, USA

This presentation was developed to offer our community a supportive, culturally relevant introduction to dementia and memory loss. By utilizing the Medicine Wheel, we connect the challenges of dementia to the interconnected elements of mind, body, emotion, and spirit. We will explore how this condition affects individuals across the entire circle of life, examining its distinct impacts on the four stages of growth: child, adolescent, adult, and elder.

11. Sex-Specific Pathways to Cognitive Health Among Indigenous Amazonian Older Adults: A Structural Equation Modeling Analysis

Arantxa Sanchez Boluarte, Universidad Peruana Cayetano Heredia, Lima, Peru

Ronald Castillo-Blanco, Universidad Peruana de Ciencias Aplicadas, Lima, Peru

Monica Diaz, University of North Carolina at Chapel Hill, Chapel Hill, USA

Alicia Boluarte Carbajal, Universidad Cesar Vallejo, Lima, Peru

Background: Indigenous populations remain underrepresented in global dementia research. This study examined sex-specific pathways linking social determinants of health (SDOH), clinical factors, and functional performance to cognitive health among older adults in an Indigenous Peruvian Amazonian population.

Methods: We analyzed cross-sectional data from 401 Shawi adults aged 50. Cognitive health was measured using a culturally adapted Peruvian Rowland Universal Dementia Assessment Scale (RUDAS-PE). Structural Equation

Modeling (SEM) evaluated theoretically-driven predictors of functionality and cognitive health across the total sample and sex-stratified subsamples.

Results: About 54% of participants were females, with a median age of 59. The total sample model demonstrated adequate fit ($\chi^2(37)=59.77$, $p=.010$, CFI=.937, RMSEA=.039, SRMR=.034). Age ($\beta=-.24$, $p<.001$), sex ($\beta=.34$, $p<.001$), and bilingualism ($\beta=.11$, $p=.010$) predicted functionality, while functionality ($\beta=.23$, $p=.025$) and education ($\beta=.12$, $p=.029$) directly predicted cognitive health. Sex-stratified models required respecification. In females ($\chi^2(30)=45.86$, $p=.031$, CFI=.909, RMSEA=.050, SRMR=.041), age ($\beta=-.26$, $p<.001$) and bilingualism ($\beta=.14$, $p=.032$) predicted functionality; however, direct predictors of cognitive health lacked statistical significance. In males ($\chi^2(32)=39.97$, $p=.157$, CFI=.941, RMSEA=.036, SRMR=.045), age ($\beta=-.22$, $p=.003$) and household size ($\beta=-.13$, $p=.047$) predicted functionality, while functionality ($\beta=.31$, $p=.018$) and education ($\beta=.24$, $p=.002$) directly predicted cognitive health.

Conclusion: Pathways to cognitive health diverge significantly by sex among Indigenous Amazonian older adults. While functionality and education directly drive cognitive outcomes in males, female cognitive pathways appear more complex. These findings underscore the necessity of sex-stratified, culturally grounded models to understand cognitive aging in the Global South.

12. Advancing Inclusive Health Research with Indigenous Populations: Findings from a Systematic Literature Review

Amanda Boyd, Washington State University, Pullman, USA

Louise Hsu, University of Idaho, Moscow, USA

Magdalena Haakenstad, University of Washington, Seattle, USA

Jocelyn Kruger, Oxford, Oxford, United Kingdom

Diversity in research is essential for advancing health equity, strengthening scientific rigor, and ensuring findings are applicable to broad populations. Historically, clinical trials have underrepresented racial and ethnic minority groups, women, and older adults, resulting in significant gaps in knowledge regarding the safety and effectiveness of medical interventions. Indigenous populations, in particular, have been excluded or underrepresented in clinical and public health research, limiting the relevance of research findings and contributing to ongoing health disparities. Despite growing attention to inclusion in research, limited understanding exists regarding the barriers and facilitators influencing participation in health research among Indigenous populations, particularly in Alzheimer's disease research.

Using PRISMA guidelines, we conducted a systematic literature review examining Indigenous participation in health research in the United States and Canada. The search identified 10,562 potential articles, of which 27 manuscripts met the inclusion criteria. Articles were analyzed to examine: (1) characteristics of studies focused on participation in health research; (2) factors influencing willingness to participate; and (3) barriers and incentives affecting recruitment and engagement.

Findings indicate that participation is strengthened when research is relevant and meaningful to Indigenous communities and provides tangible community benefits beyond academic or institutional goals. Trust emerged as a central factor, highlighting the importance of credible researchers who demonstrate genuine commitment to community well-being. Transparent, culturally appropriate, and understandable consent processes were also critical to informed participation. In addition, research approaches must be accessible, inclusive, and responsive to community priorities to effectively engage Indigenous populations.

Results from this review provide recommendations for developing more inclusive and community-engaged research practices with Indigenous populations and identify directions for future research aimed at improving participation and promoting health equity.

13. Centering Indigenous voices to transform public health research practice: A cross-study qualitative synthesis

Amanda Boyd, Washington State University, Pullman, USA

Marija Bogic, Washington State University, Pullman, USA

Lucas Gillespie, Washington State University, Pullman, USA

Erin Morgan, Washington State University, Pullman, USA

Denise Dillard, Washington State University, Pullman, USA

Background

American Indian and Alaska Native (AI/AN) communities remain underrepresented in health research due to longstanding structural inequities, historical harms, and research practices that often fail to reflect Indigenous priorities. This study synthesized community perspectives to identify community-defined principles for improving public health research engagement.

Methods

We conducted a cross-study thematic synthesis of qualitative interviews and focus groups from two community-engaged projects examining AI/AN perspectives on clinical research. Participants included AI/AN clinical trial participants, clinical trial recruiters, and AI/AN community members discussing Alzheimer's disease and related dementias (ADRD) clinical trials. Findings were synthesized across studies and stakeholder groups to identify overarching principles for equitable research engagement.

Results

Five cross-cutting principles emerged. First, participants emphasized that research should be relational rather than transactional, prioritizing sustained relationships, reciprocity, and trust over episodic recruitment. Second, participants called for shared governance throughout the research lifecycle, including study design, implementation, dissemination, and stewardship of findings. Third, transparency about research partnerships, funding, biospecimen use, and data ownership was considered essential to culturally safe research. Fourth, participation was motivated primarily by collective benefit—including improving health for families, communities, and future generations—rather than individual incentives. Finally, returning research results was viewed as an ethical responsibility that can strengthen trust, support community ownership of knowledge, and promote future engagement.

Discussion

Centering Indigenous voices reframes research participation as a public health partnership rather than a recruitment challenge. Community-defined principles identified across stakeholder groups provide actionable guidance for researchers and policymakers seeking to strengthen equitable engagement and community-centered public health research.

14. Black American Perspectives on Cultural Safety in Research: Physical, Emotional, and Interpersonal Safety

Hector Salazar, University of Pittsburgh, Pittsburgh, USA

Lilcelia Williams, University of Pittsburgh, Pittsburgh, USA

Kelly Tan, University of Pittsburgh, Pittsburgh, USA

Elizabeth Shaaban, University of Pittsburgh, Pittsburgh, USA

Heidi Donovan, University of Pittsburgh, Pittsburgh, USA

Jennifer Lingler, University of California Davis, Davis, USA

Background: Black Americans (BA) face twice the likelihood of developing dementia, higher rates of late stage-diagnosis, and underuse of FDA-approved treatments, yet remain underrepresented in research. Cultural safety (CS), a Māori Indigenous concept, offers a promising approach to close gaps by guiding researchers to affirm the cultural identities, values, traditions, and lived experiences of minoritized persons. However, the concept of CS has not been adapted to the experiences of BA. Thus, it is critical that persons identifying as BA define what CS means to them, including what makes them feel safe or seen, and what experiences left them feeling unsafe or unseen, in order to translate CS principles into research practices.

Methods: We conducted a qualitative descriptive study to understand what CS means to Black-identifying participants from Southwestern Pennsylvania enrolled in the Brain Cognitive HHealth Campaign-Allegheny County (U01NS141777) study. Preliminary analysis was conducted using inductive thematic analysis.

Results: More than half (57.1%) of participants (N=14) identify as female (n=8), with advanced degrees (50%) and a mean age of 61.58 years. When prompted to define CS, participants made references to physical safety (freedom from violence or threat), emotional safety (feeling seen, heard, and without judgement), and interpersonal safety (feeling that someone relates to you and understands you). For example, one participant stated, “I actually shed a tear after the meeting...they don’t listen through my lens,” reflecting emotional and interpersonal safety. Another participant expressed interpersonal safety as “somethings that no one can experience if you’re not in our skin”. Describing physical safety, a participant stated, “my grandsons driving while Black...getting hurt, going to jail, or losing their life”.

Conclusion: Physical, emotional, and interpersonal safety are key elements of cultural safety in research settings among BA. This highlights a critical point: researchers must first establish these conditions before engaging BA participants.

15. Reimagining Dementia Prevention Through Lā'au Lapa'au: A Kānaka 'Ōiwi Framework for Brain Health
Makoa Miura, University of Hawai'i at Mānoa, Honolulu, USA

Kānaka 'Ōiwi kūpuna experience disproportionately high rates of Alzheimer's disease and many of its modifiable risk factors, including cardiovascular disease, diabetes, chronic stress, and socioeconomic inequities. Although public health increasingly recognizes the importance of culturally responsive dementia care, Indigenous healing practices remain largely absent from prevention strategies despite their longstanding role in promoting holistic wellbeing. This review explores how lā'au lapa'au may be implemented as a culturally grounded component of dementia prevention for Kānaka 'Ōiwi kūpuna by synthesizing 'ike kūpuna with emerging evidence on brain health.

Peer-reviewed literature, Kānaka 'Ōiwi resources, and public health reports were reviewed to examine Alzheimer's disease risk factors among Kānaka 'Ōiwi, the traditional foundations of lā'au lapa'au, current evidence regarding māmaki (*Pipturus albidus*), and community models that integrate Indigenous healing into health promotion. Implementation opportunities were examined through the lenses of cultural relevance and community engagement rather than clinical efficacy alone.

The literature suggests several pathways through which lā'au lapa'au may contribute to dementia prevention. Māmaki demonstrates antioxidant, anti-inflammatory, and neuroprotective properties in preclinical studies and supports cardiovascular and metabolic health, both of which are associated with reduced dementia risk. Equally important, lā'au lapa'au emphasizes relationships among 'āina and community, creating opportunities to address psychosocial determinants of brain health that are frequently overlooked in biomedical prevention models. Existing Kānaka 'Ōiwi health organizations demonstrate that culturally grounded healing can be integrated alongside conventional care through community-based programming and traditional healing services.

Implementing lā'au lapa'au within dementia prevention should be understood not simply as introducing traditional medicine into clinical practice but as strengthening Indigenous systems of wellness. Future research should evaluate community-led implementation models that respect Indigenous knowledge and support cultural continuity to advance brain health among Kānaka 'Ōiwi kūpuna.

16. Strengthening Retention of Native Hawaiian and Pacific Islander Participants Through Community Partnership: Early Lessons from the CARE NHPI Working Group

Va'atausili Tofaeono, American Samoa Community Cancer Coalition, Pago Pago, American Samoa

Justina Tavana, Brigham Young University, Provo, USA

Christy Nishita, University of Hawaii, Manoa, USA

Van Park, University of California San Francisco, San Francisco, USA

Background: Native Hawaiian and Pacific Islander (NHPI) populations remain substantially understudied in Alzheimer's disease and related dementias (ADRD) research despite experiencing persistent disparities in research. Within the Collaborative Approach for Asian Americans, Native Hawaiians, and Pacific Islanders Research and Education (CARE) Registry, the NHPI Working Group was established as a community-engaged implementation strategy to adapt recruitment and retention activities through culturally responsive communication, participant navigation, translation of study materials, and partnerships with trusted community organizations.

Methods: Guided by community-based participatory research and NHPI values, the NHPI Working Group developed culturally grounded retention approaches emphasizing relationship building, bilingual communication, participant navigation, translation of study materials, and continuous community feedback. These strategies build upon longstanding partnerships and are integrated into CARE-wide retention activities across American Samoa and the continental United States.

Preliminary Findings: The CARE Registry included 18,012 participants, including 782 participants from American Samoa and 1,252 participants identifying as NHPI (5.9%). Since the CARE 2.0 launch, 898 new NHPI participants have enrolled. CARE partners conducted 445 outreach and retention activities, with nearly 70% delivered through in-person or hybrid community engagement, reflecting the program's emphasis on trusted relationships and culturally responsive implementation. CARE-wide retention outcomes indicate that 69.0% of participants remain actively engaged, while only 0.2% have been lost to follow-up. These findings suggest that sustained community partnerships, culturally adapted communication, and Indigenous-led engagement strategies are feasible approaches for strengthening long-term participation among historically understudied populations.

Conclusions: The NHPI Working Group represents a scalable, community-engaged implementation strategy for improving recruitment and retention of historically underrepresented populations in AD/DR research. By integrating Indigenous and community-informed approaches into registry operations, the Working Group provides a model for adapting participant engagement strategies across diverse NHPI communities. Ongoing analyses will evaluate NHPI-specific retention outcomes and implementation effectiveness, with additional findings available at the time of presentation.

17. Addressing Alzheimer's Disease and Related Dementias Needs in Indigenous Populations: The Indigenous Behavioral and Cognitive Symptoms (IBACS) Checklists Project

Kristen Jacklin, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Melissa Blind, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Sheamus Cavanaugh, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Amy Otto, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Lynsie Radovich, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Dana Ketcher, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

January Johnson, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Alexis Mason, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Paul Dressen, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Karen Pitawanakwat, NAANDWECHIGE-GAMIG Wikwemikong Health Centre, Wiikwemkoong Unceded Territory, Ontario, Canada

Rhonda Trudeau, NAANDWECHIGE-GAMIG Wikwemikong Health Centre, Wiikwemkoong Unceded Territory, Ontario, Canada

Cliff Whetung, Memory Keepers Medical Discovery Team, University of Minnesota Medical School, Duluth, USA

Cassandra Thomas, University of Wisconsin-Madison, Madison, USA

Carrie Trojanczyk, University of Wisconsin-Madison, Madison, USA

Kala Cornelius, University of Wisconsin-Madison, Madison, USA

Sierra Skenandore, University of Wisconsin-Madison, Madison, USA

Nickolas Lambrous, University of Wisconsin-Madison, Madison, USA

Kyle Conniff, University of Wisconsin-Madison, Madison, USA

Lauren Yowelunh McLester-Davis, University of Wisconsin-Madison, Madison, USA

Megan Zuelsdorff, University of Wisconsin-Madison, Madison, USA

Joseph Keawe'aimoku Kaholokula, University of Hawai'i at Mānoa, John A. Burns School of Medicine, Honolulu, USA

Zahinoor Ismail, University of Calgary, Hotchkiss Brain Institute and O'Brien School of Public Health, Calgary, Canada

Laura Rabin, Brooklyn College, New York, USA

Rebecca Owl Morgan, University of New Mexico Health Sciences Center, Center for Native American Health, Albuquerque, USA

Erik Kakuska, University of New Mexico Health Sciences Center, Center for Native American Health, Albuquerque, USA

Blake Boursaw, University of New Mexico Health Sciences Center, Center for Native American Health, Albuquerque, USA

Blythe Winchester, Cherokee Indian Hospital, Cherokee, USA

Melissa Castro, MCC Medical & Forensic Neuropsychology, Kamloops, Canada

Tassy Parker, University of New Mexico Health Sciences Center, Center for Native American Health, Albuquerque, USA

Carey Gleason, University of Minnesota Medical School, Minneapolis, USA

Rates of Alzheimer's disease and related dementias among Indigenous populations are approximately 3 times higher, with a 10-year earlier age of onset, compared to majority populations. Mild behavioral impairment (MBI) and subjective cognitive decline (SCD) are important predictors of dementia onset and help to identify the earliest symptoms of potential cognitive impairment. Existing clinical tools that are used to assess MBI and SCD have never been validated for use with Indigenous populations, which can contribute to misdiagnosis. The IBACS project (NIH R01AG100759) aims to develop culturally appropriate tools to identify the earliest symptoms of potential cognitive impairment in Indigenous older adults.

Using community-based participatory research and Two-Eyed Seeing, our team will adapt and validate the Mild Behavioral Impairment Checklist (MBI-C) and the Cognitive Change Index (CCI; used to measure SCD) for use with Indigenous populations in North America. This project includes three aims. Aim 1 will adapt these two tools with the Red Lake Nation and Dakota Tribal Nations in Minnesota, the Oneida Nation in Wisconsin, and seven First Nations on Manitoulin Island, Ontario, Canada. The adapted tools will be called the Indigenous-MBIC and the Indigenous-CCI, collectively called the IBACS Checklists. Aim 2 will pilot and validate the tools with community partners from Aim 1 and include partnerships with two additional culturally distinct regions: Native Hawaiian/Pacific Island communities in Honolulu, Hawai'i, and First Nations Community HealthSource working with an urban Indigenous population in Albuquerque, New Mexico. The IBACS Checklists will be validated with 300 dyads across all six partner communities. In Aim 3, the IBACS team will work with community partners across all sites to better understand existing community resources to support the implementation of the IBACS Checklists.

These tools can lead to more accurate identification of early symptoms of cognitive impairment and identify appropriate interventions and support.