Paper Presentations: Full Author Lists & Abstracts

1. Perspectives on Aging, Dementia, and the Good Life among Traditional Knowledge Keepers (TKK) in the Great Lakes Region in USA & Canada

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The Indigenous Cultural Understandings of Alzheimer's Disease and Related Dementias – Research & Engagement (ICARE) project (NIH5R56-AG62307-2) explores the impact of ADRD in Indigenous populations across four diverse sites in Canada and the United States. Traditional Knowledge Keepers (TKK) were interviewed and asked to share their understandings and teachings on living a Good Life, aging, and dementia. The majority of the interviews included stories or teachings related to the circle of life, including the unique roles and responsibilities used to navigate distinct stages from childhood to elderhood. Interviews were conducted with TKKs (n=19) in Manitoulin Island, Ontario, Grand Portage and Red Lake Nations in Minnesota, and Oneida, Wisconsin. All interviews were audio recorded and transcribed. Any interviews that were conducted in the Indigenous language were translated and member checked with participants. Coding and analysis involved a grounded Two-Eyed Seeing approach utilizing an Indigenous and Western lens, while prioritizing an Indigenous framework. The TKKs shared teachings of how each person comes into this life with a purpose and intended lifepath. They reflected on their own cultural teachings and upbringing, including any disruptions throughout their life stemming from colonial impacts, intergenerational trauma, and grief, that may have caused them to live out of balance with their intended lifepath. They described loss of language, cultural practices, visiting, and community values as contributing to various illnesses including cognitive decline in later life. The TKKs shared how revitalizing cultural values and practices can serve as a protective measure to help people get back to their intended lifepath and living a Good Life. Embracing cultural activities, language preservation, staying busy, promoting social cohesion, and reclaiming traditional diets are all seen as cognitive protective factors. Efforts to address dementia

2. Ka Niigaanwidoon: The Use of an Asset Map Activity in Successful Data Gathering Through Visual Storytelling to Determine Indigenous Communities' Strengths in Supports and Resources for People Living with Dementia and Multiple Chronic Conditions

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Ka Niigaanwidoon, an Indigenous-led research project grounded in Community-Based Participatory Action Research (CBPAR) and Indigenous Research Methodologies (IRM), addresses service gaps for older individuals with multiple chronic conditions (MCC) in Anishinaabek communities on the North Shore and Manitoulin Island. With a scarcity of research on MCC in First Nation people, the project emphasizes cultural connectedness and community capacity building through participatory action research, aiming for a collaborative identification of services, resources, and support to foster a culturally inclusive health care approach. The project seeks to develop culturally grounded strategies to mitigate the higher risk of chronic comorbidities among Indigenous Peoples, enhancing well-being in these communities. One data-gathering exercise employed was Asset Mapping; the activity identifies and leverages resources, strengths, and capacities within Indigenous communities, going beyond traditional needs assessments. This approach actively engages stakeholders to unveil hidden or underutilized resources for positive community development. The research explores the intersection of Indigenous methodologies and artistic expression, highlighting art's role in enriching cultural understanding. Art becomes a powerful tool for Indigenous researchers, contributing to the decolonization and revitalization of knowledge systems. It fosters cultural resilience, reclaims narratives, and forges meaningful connections within and beyond Indigenous communities. Incorporating art aligns with its deeply rooted place in Indigenous culture, serving as a conduit for transmitting history, spirituality, and traditions. Art in Indigenous research challenges colonial knowledge systems, disrupting Eurocentric frameworks and centering Indigenous perspectives. Through art, Indigenous researchers assert intellectual sovereignty, reshaping research into a collaborative, reciprocal process honoring community wisdom. This research underscores the transformative potential of art in Indigenous research, advocating for its continued integration to enhance understanding, foster resilience, and promote inclusive collaboration. Art in Indigenous research and art-incorporated asset mapping offer pathways for holistic well-being, community empowerment, and cultural preservation, amplifying Indigenous voices in research paradigms.

3. Ngiinda wala ngarraangiyay ngaya-ndi biyagay ngarraanggu, Gala nganyundiyu muya-wunba-tu biyagay ganyjaarriw (You may think that I don't remember, But my Spirit will never forget)

<u>Lindy Moffatt, Kylie Sullivan</u>, Dr Kylie Radford, Ellen Finlay, Dr Louise Lavrencic

Neuroscience Research Australia, Sydney, Australia

The title means, while we may not completely be able to prevent serious illnesses in our life, we can build spiritual strength and resilience to manage these conditions, to be able to live longer, and age well. In line with the theme of the conference Growing Knowledge, we describe some of the work we do with our Elders in communities, using preventative and protective factors to make clear that even when someone's mind or body is unwell, people can still be strong. We will present a storyline demonstrating Aboriginal life in Australia. This includes showing

ways that the impacts of exposure to different traumas across the life course put our mob at risk of developing later life illnesses, such as Dementia. We will also highlight the strengths of older Aboriginal people, including showing how ancient cultural traditions that kept our people well pre-colonisation, are being revived to inform practices for our continued survival and wellbeing. One example of how we are reviving old cultural practices supporting Elders' wellbeing is through the mindfulness program *Ngarraanga Giinganay*. In this program, local languages are used to connect us to our Ancestors, traditional medicines heal and keep us strong, we use dance, storytelling and yarning circles for healing – all to enable Elders manage stress and feel well. Through our research we hope to further the understanding of what links trauma with later life health issues but also show how protective factors like keeping strong connections to culture, family and community are being used by Elders. In this way we show what it takes to create supportive wellbeing environments for Elders and ultimately all community with a range of health abilities.

- 4. Culturally relevant protective factors for dementia in Australian Aboriginal communities: Moving away from deficits-based perspectives <u>Louise Lavrencic</u>^{1,2,3}, <u>Kylie Sullivan</u>¹, Holly Mack⁴, Adrienne Withall², Kylie Radford^{1,2,3}
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Older Aboriginal and Torres Strait Islander peoples play vital leadership, knowledge transfer, and care roles in their communities. Yet, Aboriginal people experience dementia at rates 3-5 times higher than the broader Australian population. The current focus on modifiable biomedical risk factors at the individual level (e.g., high blood pressure, diabetes, smoking, alcohol use) maintains "a settler state fixation on the Indigene as the problem" (Walter, 2022, University of Queensland). It does not adequately address the brain health landscape by recognising the "dynamic interconnectedness" between culture, spirituality, family and community. It is well established that accumulation of protective factors across the lifespan, known as 'cognitive reserve' (CR), is important for understanding cognitive outcomes and dementia onset, whilst also acknowledging the influence of risk factors and how these factors interact. However, the appropriateness of many conventional CR measures for Aboriginal and Torres Strait Islander peoples remains unclear, including the role of culturally specific protective factors in CR. To address this gap, we developed and are validating a culturally relevant CR measure focussing on life course protective factors, including known related measures (e.g., education, unskilled work), and cultural factors. Extensive community stakeholder consultation occurred as part of the development phase and pilot testing of the questionnaire has been carried out with older Aboriginal people aged 50+ years (n=27), which has been acceptable to participants. We are currently further refining the measure and continuing to administer to participants, in conjunction with measures of brain and cognitive health. We will examine patterns of engagement in culturally relevant factors that are likely to contribute to CR, and relationships between life course CR and cognitive impairment/decline assessed at annual follow-up.

5. A Comprehensive Review of the Kimberley Indigenous Cognitive Assessment (KICA)

Roslyn Malay¹, Lyn Yappo¹, <u>Betty Saqiqi</u>², Elise Alexander¹, Aaron Basile¹,³, Chenoa Wapau⁴, Carmela Pestell³, Harry Douglas⁵, Dawn Bessarab¹, Kate Bradley⁵, Zoë Hyde¹,⁵,⁶, Dina LoGiudice⁵,⁷, Leon Flicker⁶, Sarah Russell⁴,⁶, Rachel Quigley⁴,⁶, Edward Strivens⁴,⁶, Gwenda Darling⁶, Shelley Kneebone¹⁰, Jesse Zanker⁵, Makarena Dudley¹¹, Jennifer Walker¹²,¹³, Robyn Smith⁵, Osvaldo Almeida⁶, Huong Nguyen⁵,³,⁷, Daniel Hunt¹⁴, <u>Kate</u> Smith¹

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Background: The Kimberley Indigenous Cognitive Assessment (KICA) was co-developed with local Kimberley communities and health services to address the lack of a valid dementia screen for Aboriginal and Torres Strait Islander Peoples. Since implementation in 2003, evolving clinical, digital, and cultural needs warrant a KICA review. This first study phase aimed to comprehensively review the current KICA instruments and assessment processes. Methods: This study applied a mixed methods design, informed by a Participatory Action Research approach, collaborative co-design, and Indigenous research methodologies. Ethics approvals were gained on a state and national level. Learnings were derived through a scoping review of international literature on cognitive assessment for First Nations Peoples; yarning circles with older Aboriginal and Torres Strait Islander Peoples and caregivers; online surveys completed by clinicians; shared learnings explored with assessment research teams in other settings; and item response theory analysis of KICA-Cog de-identified data from studies nationally. Elders Governance Group members and service and research partners informed the process and reviewed findings. Results: The methodologies applied resulted in a holistic review of the KICA toolkit. Preliminary findings confirm the cultural acceptability and psychometric robustness of the KICA, with scope to improve its ability to detect mild forms of cognitive impairment, and KICA clinical guidelines. There is an identified need for defined Indigenous research methods for cognitive assessment development and adaptation. All review findings will be presented, indicating any changes needed to KICA items and assessment guidelines to improve utility and ability to detect early cognitive change. Discussion: Study findings will inform stage two of the broader project, including if and what adaptations are needed to encompass cultural and clinical needs, while preserving the psychometric robustness of the tool. This work is critical for the timely assessment and best practice care of Aboriginal and Torres Strait Islander Peoples with dementia.

- 6. Cognitive Assessment Tool Efficacy in Native Hawaiians and Pacific Islanders: Preliminary Findings from the Ike Kupuna Clinical Trial J. Ke'alohilani Worthington Antonio^{1,2}, Joel Steele², Adrienne Dillard³, B Puni Kekauoha³, Sheryl R Yoshimura⁴, Malia Purdy⁵, Chantal Keliihoomalu⁶, Richard F MacLehose⁷, Joseph Keawe'aimoku Kaholokula¹
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Background: Native Hawaiians and Pacific Islanders (NHPIs) exhibit a higher prevalence of early-onset Alzheimer's disease and related dementias (ADRD) compared to Whites, Asians, and African Americans. The increased prevalence of hypertension, obesity, diabetes, and dyslipidemia among NHPIs elevates their risk of ADRD. Early intervention opportunities exist in the stages of mild cognitive impairment (MCI) and subjective cognitive impairment (SCI). Most validated cognitive assessment tools are developed and tested predominantly on non-NHPI populations, potentially compromising their accuracy and efficacy for NHPIs. There are no cognitive assessment tools validated specifically for NHPIs. Objective: This study aims to evaluate the applicability and accuracy of existing cognitive assessment tools in diagnosing MCI and SCI among NHPIs. Methods: The Natives Engaged in Alzheimer's Research: Ike Kupuna Project, an NIH-funded clinical trial, employs four cognitive assessment tools: (1) Quick Dementia Rating Scale, (2) Cognitive Change Index, (3) Number Symbol Coding Test, and (4) Cognivue. All participants are self-identified NHPIs, aged 50-75. A preliminary quantitative analysis was conducted midway through the trial, comparing the scores from NHPIs to standard population benchmarks. Results: Results have yet to be analyzed due to final data collection occurring. It is predicted that preliminary analysis will show significant variations in how NHPIs scored on these cognitive assessments compared to the standard population. These findings are expected to suggest potential cultural and demographic biases in the existing tools when applied to NHPIs. Conclusion: This study underscores the need for cognitive assessment tools validated specifically for NHPIs to ensure accurate diagnosis and appropriate intervention strategies. Further research is necessary to develop and validate such tools, facilitating better clinical outcomes for NHPIs at risk of ADRD.

- 7. Development of a prototype rapid screen of cognitive impairment for Aboriginal and Torres Strait Islander peoples in primary care Huong Nguyen¹, Zoe Hyde^{1,2,3}, Kate Smith², Roslyn Malay³, Leon Flicker³, Jo-anne Hughson¹, Kylie Radford^{4,5,6}, Sarah Russell^{7,8}, Rachel Quigley^{7,8}, Edward Strivens⁷, Brian Draper^{9,10}, Louise Lavrencic^{4,5,6}, Adrienne Whithall^{5,6}, Kim Delbaere^{9,11}, Robert Cumming¹², Bridgette McNamara^{13,14}, Dina LoGiudice¹
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Background: Rates of cognitive impairment and dementia are three to five times higher in Aboriginal and Torres Strait Islander peoples compared to non-Indigenous Australians in cohort studies, but clients attending primary care often remain underdiagnosed. The aim of this project is to develop a rapid screen for dementia for use in primary care through psychometric analysis of the 16-item Kimberley Indigenous Cognitive Assessment (KICA), a validated tool for the assessment of dementia in Aboriginal and Torres Strait Islander peoples.

Methods/design: We harmonised three cohort studies with KICA assessments of Aboriginal and Torres Strait Islander peoples aged ≥45 years. Logistic regression was used to evaluate the cross-sectional association between individual components of the KICA and presence of dementia by independent consensus diagnoses, in order to identify candidate items for a short scale. Sensitivity, specificity and optimal cut-off scores were calculated through receiver operating characteristic curve (ROC) analysis. A resulting prototype short scale was then validated in a separate cohort of Aboriginal and Torres Strait Islander peoples. Results: In the combined cohort, 80 (9.9%) out of 808 participants had a consensus clinical diagnosis of dementia (mean age 64±9.8 years; 61.3% female). A combination of 4 items in the KICA (orientation to time, orientation to place, naming and recall) had high sensitivity (0.83), specificity (0.83), and area under the curve (AUC 0.83). Validation of this 4-item scale in a separate cohort of 83 individuals yielded good sensitivity (0.80), specificity (0.83), and discriminatory value for dementia (AUC 0.82) at the same cut-off point. Discussion: This 4-item prototype tool based on the KICA may be useful in general practice to enable rapid cognitive screening as part of routine health assessments and promotion. However, further testing, validation, and consultation with Elders governance groups is required prior to implementation in clinical practice.

8. Assessing Alzheimer's Disease and Related Dementias prevalence using the Kimberley Indigenous Cognitive Assessment Tool in American Samoa

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Introduction: Native Hawaiian and Pacific Islanders (NHPI) are amongst the fastest growing minority groups in the U.S. Previous studies assessing ADRD prevalence have not reported disaggregated results between NHPI subpopulations and Asian Americans. There are variations between these groups that could lead to better understanding of how to eliminate health disparities. However, there is a paucity of studies on Alzheimer's Disease and Related Dementias (ADRD) prevalence in NHPI populations including Samoans. Methods: We administered the Kimberley Indigenous Cognitive Assessment (KICA) tool to a sample of 150 adults aged 50. The KICA was developed for the Aborigine population in the Kimberley region of Australia when Westernized tools identified dementia was four times higher compared to the non-indigenous population. The questions assess cognitive function on a scoring range from 0 to 39. A score of ≤ 33 indicates increasing possible dementia. Results: Respond driven sampling recruited 218 eligible adults (45.9% male; 54.1% female) between August 25, 2021 and November 18, 2021. The median age of the sample was 58 with the lowest age of 50 and the highest of 91. We discovered 15.1% scored within the possible dementia range and 84.9% were controls. Statistical associations were found between education and age. Validity could not be realized as confirmatory factor analysis revealed fit within only one out of five indices, but internal consistency was above the minimum with an α of 0.84. Conclusions: Our study aimed to address the significant gap in the literature regarding Alzheimer's Disease and Related Dementia (ADRD) prevalence within the Native Hawaiian and Pacific Islander (NHPI) populations, specifically focusing on Samoans in American Samoa. Future studies should continue to explore ADRD prevalence and associated factors within NHPI communities, employing comprehensive and culturally sensitive approaches.

9. Optimizing best-practice care for Aboriginal and Torres Strait Islander people with cognitive impairment and dementia attending primary care: study findings of a stepped-wedge cluster RCT

Jo-anne Hughson¹, Zoë Hyde², Kate Bradley¹, Roslyn Malay², Harold Douglas¹, Sadia Rind³, Rachel Quigley⁴, Sarah Russell⁴, Diane Cadet-Janes⁴, Valda Wallace⁴, Bonnie Giles⁵, Kylie Sullivan⁶, Wendy Allan⁶, Bridget Allen⁶, Lauren Poulos⁶, Kate Fulford², Dawn Bessarab², Leon Flicker², Kylie Radford⁶, Kate Smith², Edward Strivens⁴, Mark Wenitong⁴, Mary Belfrage⁷, Robyn Smith¹, Louise Lavrencic⁶, Sandra Thompson², David Atkinson², Irene Blackberry⁵, Sharon Wall⁶, Juliette Ciaccia¹, <u>Dina LoGiudice^{1,8}</u>

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Background: This study was developed in response to the high prevalence and low detection rates of dementia seen in Aboriginal and Torres Strait Islander communities. The study implemented and evaluated a culturally responsive best-practice model of primary care aiming to optimize the detection and management of people with cognitive impairment and/or dementia. The best-practice model of care delivered health professional education and co-developed and customized practice changes, such as: changes to Aboriginal and Torres Strait Islander annual health check templates; establishing geriatrician clinics in health services; and clinical resource provision. Methods: We conducted a stepped-wedge cluster randomized controlled trial with 12 co-researching Aboriginal Community Controlled Health Service partners across 4 states in Australia. Six-monthly health record file audits of a patient sample aged ≥50 years tracked study progress. Two co-primary outcomes were measured: 1) rates of detection of dementia and cognitive impairment; 2) documentation of management strategies relating to detection, measured as presence of ≥2 of cognitive assessment, dementia blood screening, neuroimaging and/or referral to specialist services for patients with cognitive concerns. Data were analyzed with mixed effects complementary log-log regression. Results: We found no effect of the intervention on the first co-primary outcome: HR = 1.53 (95% CI 0.64-3.65), p=0.337). An effect was found for the intervention on the second co-primary outcome: HR = 2.34 (95% CI 1.05-5.25), p=0.039. Intention-to-treat analyses (which followed the original protocol specifications exactly) yielded similar results; for the first co-primary outcome: HR = 1.40 (95% CI 0.56-3.51), p=0.468; for the second coprimary outcome: HR = 2.57 (95% CI 1.11-5.96), p=0.027. Conclusions: The implementation program significantly increased activities relating to the diagnostic pathway for dementia. The co-developed best-practice model of dementia care for Aboriginal and Torres Strait Islander people attending primary care holds promise for scaling up to improve health outcomes nationally.

10. The successes and challenges of implementing an Aboriginal Health Practitioner-led dementia prevention trial in Western Australia: The Kaat Koort Aboriginal Brain Health Study

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Rates of dementia among Australia's Indigenous peoples (Aboriginal and Torres Strait Islanders) are markedly higher (3-5 times) than the general population. This is attributed, in part, to the high prevalence of known risk factors for dementia and cognitive decline in older Indigenous Australians. These factors include lifestyle-related risk factors such as physical inactivity, tobacco use, unhealthy dietary patterns and harmful use of alcohol, along with chronic conditions like hypertension, diabetes, hypercholesterolemia, obesity, and depression. Our study aims to test the effectiveness of an Aboriginal-specific, Aboriginal Health Practitioner (AHP)-led heart health program to improve cardiometabolic and cognitive health—the Kaat Koort Aboriginal Brain Health Study. Kaat Koort is a pragmatic Randomized Controlled Trial

(RCT) conducted in Perth and Bunbury, Western Australia since August 2021. Aboriginal participants aged 35-60 years with selected risk factors were recruited and randomly assigned to either an AHP-led program focusing on cardiovascular risk management and lifestyle modifications (which included regular appointments with dietitians and exercise physiologists), or usual care. The primary outcome is the reduction of blood pressure at 12 months. This presentation will provide an overview of the design and methods of Kaat Koort, as well as insights into the challenges, pitfalls, and achievements encountered during the conduct of this complex, multi-intervention trial. This will include issues of design, recruitment, implementation, and data collection.

11. Social connectedness and cognitive health in an Indigenous cohort: Preliminary findings on emotional support, loneliness, and cognitive resilience to Alzheimer's disease pathology

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Background: Growing evidence suggests that social connectedness reduces risk for clinical onset of Alzheimer's disease (AD) and related dementia (ADRD). Plausible protective mechanisms include direct influence on AD pathology, or indirect influence on cognition through building cognitive reserve. Inclusive resilience-focused research will accelerate equitable translation into communities facing high ADRD burden. In research supported by a partnership with the Oneida Nation of Wisconsin, we explored (a) associations between key facets of connectedness and cognition, and (b) moderation of those relationships by AD pathology, in an expanding cohort of American Indian/Alaska Native (AI/AN) Elders. Method: Self-identified AI/AN participants (N=56) in the Wisconsin Alzheimer's Disease Research Center Clinical Core provided neuropsychological, psychosocial, and blood-based biomarker data. Key predictors in cross-sectional, multivariable linear regression models were NIH Emotion Toolbox T-scores for Emotional Support and Loneliness scales. Cognitive outcomes included performance on tests of speed and flexibility and episodic memory. Cognitive reserve mechanisms were assessed by interacting psychosocial variables with plasma p-tau217 levels to predict cognition. Results: In this sample [78.6% female, mean (SD) age 68.9 (9.2) years], emotional support positively associated with cognitive test performance across both domains, but not with p-tau217 levels. There were observable interactions between Emotional Support T-scores and plasma p-tau217; specifically, positive relationships between support and mental flexibility were strongest in the presence of accumulated AD pathology. No main effects for loneliness were observed although elevated plasma p-tau217 and loneliness synergistically predicted poorer mental flexibility. Conclusions: Perceived availability of a community-salient resource, emotional support, predicted better cognitive health. Importantly, associations of support with mental flexibility were strongest in participants with elevated AD pathology. Future studies in larger Indigenous samples are needed, but we provide preliminary evidence that facilitating Elders' social connectedness is a promising strategy for maintaining cognitive abilities in later life.

12. Developing a Māori Model of Support for Kaiāwhina of Whānau with Mate Wareware

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Mate wareware (dementia) affects over 44 million globally, with higher prevalence in indigenous communities such as in Māori communities in New Zealand. Colonisation exacerbates risks, with an estimated 4,500 affected Māori by 2026, necessitating culturally appropriate care. Informal care, mainly from whānau (family), is predominant but leads to psychological strain for kaiāwhina (caregivers). Western-centric approaches overlook crucial Māori health aspects, hindering adequate care for kaiāwhina looking after kaumātua (elders) with mate wareware. A Kaupapa Māori (Māori ideological) approach rooted in Māori worldview and values is crucial, integrating Mātauranga Māori (Māori knowledge) and tikanga (Māori systems) to enhance well-being for kaiāwhina. This approach recognizes mate wareware's impact on wairua (spirit) and emphasizes collaboration with whānau. While some Mātauranga Māori-based frameworks for kaumātua living with mate wareware exist, there's a need for Kaupapa Māori-based kaiāwhina support programs. A comprehensive and culturally sensitive approach, guided by Kaupapa Māori Theory, is essential to empower Māori communities and bridge existing care gaps for kaiāwhina caring for kaumātua with mate wareware. This research aims to develop a culturally responsive mate wareware carer support program, establish a community-based group for kaiāwhina and whānau affected by mate wareware, and create a Māori model of support for kaiāwhina and whānau living with mate wareware. The research will use Qualitative and Kaupapa Māori Theory methodology. Participants will fill out the Zarit caregiver burden questionnaire at three different time points and discuss their experiences of caring for a whānau member with mate wareware at hui (focus groups) throughout the duration of the program. This research is currently being undertaken. Data collection will conclude at the end of July/start of August.

13. Four Considerations for Implementation Science in Indigenous Dementia Research

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Indigenous populations have been disproportionately impacted by Alzheimer's disease and related dementias (ADRD) around the world. Communities and researchers have made important efforts to address existing patterns by developing and implementing research and interventions aimed at improving ADRD outcomes in Indigenous populations in diverse contexts. The IIDRN Special Interest Group 3 - Implementation/Intervention/ Programs is mindful of the need to keep developing and implementing successful and culturally appropriate

projects that positively impact Indigenous people living with dementia, their caregivers, and communities. In response, we have collaboratively identified four critical aspects to consider when implementing interventions, research projects, and programs aimed at improving ADRD outcomes and address existing inequalities in collaboration with Indigenous communities around the globe. Drawing on ongoing and previous projects, as well as experience and knowledge of community members and Elders, the group will elaborate on: (1) the importance and significance of Elder advisory councils and Reservation/community IRBs; (2) community and Traditional Knowledge Keepers; (3) clinical and policy considerations; and (4) knowledge on universal best practices and culturally appropriate research. The analysis and exemplification of the above considerations with existing projects attempts to serve as a supporting guide for future interventions, research projects, and programs, primarily developed using a community-based participatory research approach.

14. Wisdom in Action: The Pesa Sooname Advisory Group's Journey in Fostering Dementia-Friendly and Inclusive Communities at Pyramid Lake Casey Acklin¹, Carla Eben²

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The Pyramid Lake Paiute Tribe has embarked on a transformative journey to foster dementia-friendly and inclusive communities on their reservation. As part of the broader Dementia Friendly Nevada initiative, the tribe formed the Pesa Sooname Advisory Group, bringing community members, tribal staff, and researchers together for a collaborative effort to support the well-being of tribal elders living with dementia and their care partners. "Pesa Sooname" means "good thought" or "good think" in Northern Paiute, and this reflects the group's mission to promote good thoughts toward elders living with dementia and to protect good thinking through proactive brain-healthy living practices. This presentation delves into the participatory action research project undertaken by the tribe, highlighting the Pesa Sooname Advisory Group's innovative and culturally resonant approaches. Key group activities include: (1) Organizing statewide "Nevada Tribal Summits on Brain Health and Dementia" to engage tribes from across the state, sharing strategies for brain health and care partnership within a Native context. (2) Supporting the launch and utilization of the CDC Healthy Brain Initiative Road Map for Indian Country through action-oriented wisdom circles. (3) Contributing to the development of Dementia Friends for American Indian and Alaska Native Communities and continuing to lead implementation of that program across Nevada. (4) Developing a research-driven documentary film exploring aspects of traditional culture that support the well-being of tribal elders and their care partners. The presentation will close with a dedicated discussion about how to foster a successful community-academic partnership within the context of dementia-friendly and inclusive initiatives in Indian Country. Through sharing the Pyramid Lake Paiute Tribe's learnings, this presentation aims to inspire indigenous communities to adopt participatory approaches to becoming more dementia-friendly and inclusive. Attendees will leave having gained valuable insights into the power of culturally tailored, community-driven research and its potential to create lasting, positive change.

15. Te Ōranga Ō Te Roro: kaumātua perspectives on the development of a mobile app for mate wareware (dementia) awareness

<u>Makarena Dudley</u>¹, Sharon Olsen², Cherry Reihana¹, Marcus King¹, Hohepa Spooner², Sarah Cullum¹, Alexandr Merkin², Edgar Ramirez-Rodriguez³, Bobby Nepia⁴, Adrian Martinez¹, Diana Siew¹, Kahu Pou¹

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Aim: Mate wareware (dementia) presents a significant social and economic burden for Māori in Aotearoa New Zealand. Previous literature has highlighted the need to improve health literacy for Māori regarding the causes and management of mate wareware, yet there is a lack of Māori-centred educational resources. It was determined that a mobile phone application (app) could meet this need and that early consultation with Māori was required to ensure the digital solution would be culturally safe and relevant. Method: This study explored the perspectives of kaumātua (Māori elders) regarding how to cater the mate wareware mobile app to Māori. Through a qualitative approach based on Kaupapa Māori principles, two focus groups were held with 15 kaumātua. Focus group data were thematically analysed. Results: The analysis identified four themes related to the content of the proposed app and its design features. "Information about mate wareware" and "Caregiver support" were prominent themes that kaumātua prioritised for inclusion in the proposed app. To ensure uptake, kaumātua emphasised that the "Access" and "Appeal" of the proposed app should be considered. Conclusion: The findings have informed the design of the Mate Wareware app and should be considered when developing other digital health interventions for Māori.

16. International learnings and recommendations for Indigenous specific cognitive assessment development and validation: the KICA roundtable

<u>Elise Alexander</u>¹, Aaron Basile¹, Dawn Bessarab¹, Jennifer Walker², <u>Makarena Dudley</u>³, Kristen Jacklin⁴, Juliana Souza-Talarico⁵, Leon Flicker¹, Melissa Blind⁴, Sarah Russell⁶, Robyn Smith⁷, Dina LoGiudice⁷, Megan O'Connell⁸, Julia Rowat², Rachel Quigley⁶, Edward Strivens⁶, Carey Gleason⁹, Chenoa Wapau⁶, Lyn Yappo¹, Camila C Bezerra¹⁰, Kate Smith¹, Indigenous Cognitive Assessment Collaborative¹

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Culturally developed and validated cognitive assessments support the timely detection and diagnosis of dementia and mild neurocognitive disorder (MND) in older Indigenous peoples globally. In 2003, the first Indigenous specific comprehensive dementia screen, the Kimberley

Indigenous Cognitive Assessment (KICA) was co-developed and validated by researchers, Elders and local services in the Kimberley region of Western Australia. The KICA has since been adapted and validated in other regions of Australia, and informed cognitive assessment development with Indigenous peoples internationally, applying research methodologies sensitive to respective cultures and languages. The inaugural International Indigenous Dementia Research Network (IIDRN) conference held in Hawaii in 2023 provided an opportunity for Elders, researchers and service partners from Australia, Canada, New Zealand, America, and Brazil to share learnings from common experiences in developing KICA-informed culturally specific cognitive assessments for Indigenous peoples. With this objective, a focused round table discussion and café style deep dive was held comprising 37 people from various disciplines (e.g., allied health, medicine, medical anthropology, nursing) grounded by the Knowledge of Indigenous Elders. As an Indigenous Cognitive Assessment Collaborative we collectively present a summary of the learnings and considerations for co-developing and validating Indigenous specific cognitive assessments, and ensuring translation into policy and practice. Preliminary outcomes indicate: the use of community participatory principles to better identify, prioritize and address community recognized cognitive health priorities; the importance of applying Indigenous Research Methodologies to accurately reflect culturally safe ways of knowing, being, and doing, and promoting the self-determination and sovereignty of Indigenous peoples in assessment development; and the necessity of culturally informed, co-designed assessment training and resource development. Furthermore, the need and opportunity to collectively develop a research roadmap for international Indigenous specific assessment development, validation and translation to embed, guide and uphold culturally appropriate, robust research practices.

17. [withdrawn]

18. Caregiver experiences of Māori whānau (families) living with dementia

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Introduction: As the number of individuals with dementia increases over the coming years, the number of whānau (family) members acting as unpaid informal caregivers will increase too. For Māori, the Indigenous people of New Zealand, informal caregiving is considered the preferential way to care for their elders with dementia compared to services such as aged residential care. Prior research has found that there are both positive and negative experiences associated with caregiving that are unique to Māori whanāu. However, there is limited research examining the experiences of whānau caregivers who are caring for Māori with dementia. Furthermore, there is no research examining the cost of caregiving for Māori and how it may differ compared to non-Māori. Method: This study will use a mixed-methods, Māori-centred approach to explore how caregiving is experienced for whānau caregivers caring for Māori with dementia. Using quantitative methods, we first plan to establish the economic and psychosocial impact of caregiving for Māori whānau and compare this between dementia and non-dementia groups ($N \approx 220$). Using qualitative methods, we will conduct follow-up interviews with ten whānau caregivers caring for Māori with dementia to explore how caregiving is understood and experienced for those caregivers. This research will provide important data on the economic and psychosocial outcomes of caregiving for dementia in Māori whānau. Such data would identify the needs of Māori whānau to help design culturally appropriate care. Results: Preliminary results and discussion will be presented.

19. Community review of the adapted Savvy Caregiver Program: 'Auamo Ke Kuleana O Nā Ma'i Poina

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As caregiving roles and responsibilities are rooted in culture, we aimed to adapt the Savvy Caregiver Program (SCP), an evidence-based caregiving intervention, with a Native Hawaiian community in Hawai'i. A community action board (CAB) and research team tailored the curriculum to include Hawaiian values, language, proverbs and culturally relevant examples while maintaining the core components of the program. After developing the adapted program, titled 'Auamo Kuleana O Nā Ma'i Poina ('Auamo Kuleana), we invited six members of the Native Hawaiian community to participate in a 7-week pilot test. Only one participant was actively providing care and five participants were interested in proactive training to support or give back to the community. When the pilot concluded, participants were asked to complete a brief survey and join a focus group or interview to 1) share their experiences with caregiving and 2) provide feedback about 'Auamo Kuleana. The CAB and research team analyzed the qualitative data using thematic analysis. Caring as a community was a primary theme with two subthemes: shared knowledge and including cultural practices. Participants shared positive feedback about 'Auamo Kuleana; most participants attended all sessions, read the caregiver manual, and preferred to meet in-person. Participants suggested including all family members in the program to be in alignment as a 'ohana (family) and to include information about planning for their own care. As these changes would modify SCP core components, we did not include these revisions and proceeded with additional testing. We suggest future Native Hawaiian-focused caregiving interventions consider incorporating participants' desire to learn about caregiving proactively, care as a community, provide family-centered caregiving (rather than dyadic caregiving), and engage in advanced care planning.

20. Indigenous-centered Dementia Care: A framework to improve culturally safe dementia care

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Background: Rates of dementia are increasing in the overall Canadian population and although there is little reported data on incidence and prevalence of dementia for Indigenous populations in Canada, these populations experience increased rates of diagnosed dementia and are at higher risk of developing dementia. The current dementia care system does not address the unique needs of Indigenous populations and could be more effective in supporting, treating, and caring for both Indigenous Peoples living with dementia and their care partners. The purpose of this project was to understand what concepts are required to ensure dementia care is Indigenous-centered and culturally safe. Methods: Through community-based participatory research, we used a qualitative approach that was grounded in Indigenous worldviews and the Métis theoretical way of knowing of Keeoukaywin (The Visiting Way). We conducted one-on-one interviews with 12 participants throughout Alberta including Indigenous Peoples living with dementia, care partners, and community members. The interviews were recorded, transcribed, and coded using thematic analysis. Results: Our results highlighted three overarching themes in relation to culturally safe dementia care for Indigenous Peoples: Relationality, Being Well, and Safety. Each theme included subthemes related to social, cultural, and physical characteristics informed by participant experiences. Discussion: An Indigenous-centered dementia care approach must consider the domains of Relationality, Being well, and Safety, recognize the interconnectedness of these domains, and acknowledge the harmful implications when they are not considered. Each domain exists within several spheres including social, physical, and cultural, and dementia care must be cognizant of the interplay between these spheres. This research highlights the need for health interventions and policies to ensure dementia care is Indigenous-centered and culturally safe and suggests a framework to address the unique needs of Indigenous populations with dementia.

21. Indigenous Participants' Preliminary Measurements of Tau, Amyloid, and Amyloid Onset Age from the Wisconsin Alzheimer's Disease Research Center Studies

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The amyloid cascade hypothesis of Alzheimer's disease (AD) centers the brain's accumulation of pathological amyloid and accumulation of tau neurofibrillary tangles in leading to cognitive decline. Identifying the age of onset of amyloid accumulation may aid in optimizing AD interventions. Recent advances have enabled measurement of amyloid burden-through positron emission tomography imaging (PET) of Pittsburgh compound B (PiB) or blood plasma phosphorylated tau 217 measurement (pTau217). The utility of these biomarkers to capture preclinical amyloid onset is unknown for Indigenous (self-identifying American Indian, Alaska Native, Native Hawaiian) participants in AD research. Here we describe preliminary analyses of plasma pTau217 concentrations (n=49), amyloid PET PiB+ (n=32), and estimated amyloid onset ages for Indigenous participants at the Wisconsin Alzheimer's Disease Research Center. Forty-nine Indigenous participants had a plasma pTau217 measurement (~53% had >1 sample; 81% female; mean±SD age was 68.6±9.9). At baseline, mean±SD pTau217 was 0.428±0.330 pg/mL; 63.3%, 22.5%, and 14.3% were in the presumed PiB negative, intermediate/indeterminate, and PET PiB positive range respectively, per previously published cut-offs. Median(Q1-Q3) plasma-based, sampled-iterative-local-approximation (SILA)-estimated amyloid onset in the latter two categories was 68 (54-77) years old. Ten (35.7%) Indigenous participants who had a PET scan were PiB+ using a previously published threshold (95% CI: 18.6%-55.9%). In the non-Indigenous participants, 234/852 (27.5%) were PiB+ (95% CI: 24.5%-30.6%). More sampling is required to understand if this trend of higher PiB+ in Indigenous populations is widespread. Median (Q1-Q3) PiB-based, SILA-estimated amyloid onset for those with PiB distribution volume ratios greater than 1.13 was 62 (56-69) years old. Mixed models examining amyloid burden's associations with longitudinal cognition were inconsistent and a larger sample is needed. These preliminary findings support investigation of pTau217, PiB+, and estimations of amyloid onset age for non-invasively measuring time to implement AD therapeutic medications for Indigenous populations.

22. A Preliminary Report on the Performance of the p-Tau217 Blood-Based Alzheimer's Disease Biomarker in an Indigenous Cohort

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Background: For groups excluded from medical research, blood-based Alzheimer's disease (AD) biomarkers can help increase access to tests clarifying the clinical impact of AD-specific amyloid and tau pathologies. One promising blood-based biomarker is tau, phosphorylated at threonine 217 (p-tau217). We present preliminary p-tau217 data from a sample of Indigenous participants enrolled in University of Wisconsin's Alzheimer's Disease Biomarker Program. Methods: A community-engaged partnership with the Oneida Nation (Wisconsin) supported research with N=68 participants self-identifying as Indigenous. The Oneida Business Committee, and Oneida Alzheimer's Community Advisory Board approved the research, involving collection of blood, cognitive, and neuroimaging data. N=26(38%) completed both amyloid (PiB index) and tau (meta-temporal ROI) PET. P-tau217 was measured using ALZpath Single molecule array assay. PET and ptau217 amyloid (A) and tau (T) positivity status (A-/T-, A+/T-, and A+/T+) was determined separately based on thresholds published for each method (Ashton et al., 2024). Nonparametric Kruskal-Wallis tested whether p-tau217 and PET (amyloid and tau) means differed, respectively, according to PET and p-tau217 A/T positivity status. Mixed effects models tested if p-tau217 A+/T+ (relative to A-/T-) status associated with worse age-related cognitive decline on memory and executive function outcomes (RAVLT immediate/delayed recall; Trail Making Test). Results: At baseline participants were 62.6 years (SD=9.9), n=8 had mild cognitive impairment by end of observation. Individuals with PET A+/T+ (n=4) status demonstrated significantly higher p-tau217 versus A-/T-status (n=15). Amyloid and tau PET were significantly higher for ptau217 A+/T+ versus A-/T-status. P-tau217 A+/T+status (n=12) demonstrated higher initial memory performance and significantly more memory decline (versus A-/T- [n=48]). Discussion: In a small sample of individuals identifying as Indigenous, the p-tau217 biomarker shows promise for AD-proteinopathy detection. Research including larger samples is needed to validate blood-based AD biomarkers within Indigenous populations.

23. Perceived Discrimination, Allostatic Load, and Cognition Among Indigenous Older Adults: What are biomarkers telling us? <u>Cliff Whetung</u>

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The number of Indigenous older adults will more than double in the next thirty years, and they are at high risk of cognitive inequities in later life. Despite this, there are many potential risk factors associated with cognitive decline among Indigenous older adults that remain unexplored. This study examines whether associations between perceived discrimination experiences (everyday discrimination, major lifetime discrimination) and cognition are mediated by allostatic load, a measure of physiological stress. This study used eight years (2008-2016) of restricted Health and Retirement Study (N = 363) data to examine cognitive trajectories among Indigenous older adults with mixed effect growth curve models. Models were adjusted for relevant covariates, and allostatic load was tested as a mediator of discrimination experiences and cognitive trajectories. We found that everyday discrimination experiences were negatively associated with cognition at baseline and over time. Major lifetime discrimination experiences were associated with lower baseline cognition scores and positively with cognitive change over time. While allostatic load partially mediated the relationship between discriminatory experiences and cognition in unadjusted models, this relationship lost statistical significance in fully adjusted models. Indigenous older adults have a unique profile that places them at elevated risk for cognitive pathology in later life, and structural inequities are powerfully associated with many of these risk factors. While these risk factors were associated with higher allostatic load, our algorithm of allostatic load did mediate the association between these risk factors and cognition. This finding conflicts with existing minority stress hypotheses but may be the product of fundamental flaws in the operationalization of allostatic load writ large. Dementia research integrating measures of allostatic load requires additional transparency on the sensitivity and reliability of the construct.

24. Updating the Good Spirit, Good Life tool for use in Australian health and aged care services - a quality of life tool for older Aboriginal and Torres Strait Islander peoples

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Background: The Aboriginal and Torres Strait Islander worldview of having a good life is centred around the essence of spirit. This has been captured in the Good Spirit, Good Life (GSGL) quality of life framework which describes the quality of life needs of older Aboriginal and Torres Strait Islander peoples in Australia. For health and aged care services to be culturally responsive and address the aged-related quality of life needs of older Aboriginal and Torres Strait Islander peoples, accurate and meaningful assessment is needed. Aims: The aim of this study was to adapt and validate the GSGL tool for use in remote settings. Methods: Applying a co-design methodology, we conducted yarning groups in 5 communities in 2 remote regions of Australia with older Aboriginal and Torres Strait Islander people aged ≥45 years to explore the acceptability and validity of the existing GSGL tool. Suggestions for adaptation were presented to an Elders Governance Group in each region to confirm acceptability. Translation/back translation of the tool was completed prior to pilot-testing in the participating communities. Findings: Due to vernacular differences, minor adaptations to the wording of tool items were recommended (eg. younger mob to younger people). Additionally, culturally-specific examples were explored to improve clarity (eg. weaving, dancing). The results of this research and implications for policy and practice will be presented. An updated version of the tool will soon be available for use by health services. Discussion: Preliminary results indicate that the adapted GSGL tool is a culturally-appropriate, culturally-acceptable, validated tool for older Aboriginal and Torres Strait Islander Australians living in urban, regional, and remote settings. Health and aged care services should use the updated version of the tool to effectively assess the well-being of Aboriginal and Torres Strait Islander Australians using their services, and to guide improvements to service delivery.

25. Assessing Alzheimer's Disease and Related Dementia risk in American Samoa using the Talanoa research framework Va'atausili Tofaeono¹, Jueta McCutchan-Tofaeono², Robin Faumuina-Vasai², Tuilimalefoi Mauga¹, Salalau Tuifono-Blocker¹, James Galvin³

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Background: The American Samoa population has high prevalence of Alzheimer's Disease and Related Dementia (ADRD) risk factors (e.g. tobacco use, obesity, hypertension, and diabetes), however, ADRD risk has not been defined or assessed. The Puipui Malu Manutu (PMM) Study (RF1AG075904) is accomplishing this by assessing knowledge, health literacy, readiness, and resiliency and vulnerability factors using culturally adapted instruments in a sample of 1098 adults aged 50 and above. Additionally, Indigenous populations have unique worldview perspectives and epistemologies that have not been widely accepted in mainstream academia. Therefore, we decolonized Westernized research approaches by incorporating the Talanoa framework into the discussion and decision-making of the ADRD risk profile each participant. Talanoa is culturally grounded in four unique perspectives: alofa (love between the participant and researcher), fa'aaloalo (respect), tautau (service to the community), and malamalama (knowledge gained for the community). Methods: We established a Consensus Group (CG) comprised of the PMM study staff, a Samoan clinical Psychologist, and a Samoan Medical Doctor to define ADRD risk. The Talanoa framework guided the CG, with the PMM study staff and ADRD risk definition, to openly discuss and decide ADRD risk in participants in a culturally safe manner. Results: First, a definition of ADRD risk using cut-offs and ranges of subjective and objective data gathered by various cognitive assessment tools was created. Second, preliminary results of 26 participants have shown 61.5% are at high risk. Diet and lack of physical activity are contributing risk factors. Further results will be made available at the time of presentation. Conclusions: Determining ADRD risk will assist public health programs to prioritize risk factors in education and awareness efforts. Decolonizing concepts and paradigms of ADRD research is a first step to ensuring Indigenous values are recognized to achieve a culturally safe environment and build trust for research in our community.

26. Indigenous approaches in Developing an Indigenous Functional Assessment tool: Findings from a Community-Based Study

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Dementia rates are rising significantly among Indigenous populations in Canada. Standard assessment tools help in the timely diagnosis of dementia; however, their reliability and validity across cultures are challenging. The Canadian Indigenous Cognitive Assessment (CICA) tool was adapted and validated in collaboration with the First Nations communities on Manitoulin Island to address this. While validating the tool, the community advisory council and the physicians involved recognized the need for an informant-based Indigenous Functional Assessment tool. During the decline in the functional abilities of an individual, Instrumental Activities of Daily Living (IADLs) is the first to decline in the early stage of dementia. The existing IADLs are mainly developed for the English- speaking White population and may be culturally inappropriate for use in an Indigenous context. Thus, to address this, we conducted preliminary community-based research to inform the development of an Indigenous Functional Assessment tool. In partnership with Maamwesying North Shore Community Health Services, we conducted focus groups with Indigenous and non-Indigenous health professionals involved in assessing Indigenous people's cognitive and functional decline. The aim was to understand their experiences and perspectives and explore the approaches and domains of developing a culturally relevant and appropriate functional assessment tool. A Community Advisory Group, including an Elder, was formed to guide the research process. Thematic analysis was used to analyze the qualitative data. The thematic analysis identified six themes and eleven subthemes. These themes included Indigenous understanding of dementia, late diagnosis and disease progression, challenges faced by health professionals, barriers to accessing health services, approaches to potential Functional Assessment tools and domains of a new tool. Furthermore, the community-based study was the first to understand the health professionals' perspectives regarding culturally grounded and appropriate functional assessment tools and paved a path for Maamwesying to prepare for research and development of functional assessment tools.

27. Is a clock enough? The Clock Drawing Test versus the Kimberley Indigenous Cognitive Assessment tool for detecting cognitive impairment in older Aboriginal and Torres Strait Islander adults

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Aims: To explore performance of the Kimberley Indigenous Cognitive Assessment (KICA) and Clock Drawing Test (CDT) in people with dementia or other cognitive impairment (CI) and functional impairment (FI) in the national Let's CHAT Dementia cohort. *Methods:* In a nested case control study, Aboriginal and Torres Strait Islander older adults completed Comprehensive Geriatric Assessments (CGA). Demographic, health and function histories/assessments and cognitive assessments (KICA and CDT) were recorded in REDCap, along with participants' history of cognitive impairment. Logistic regression and Receiver Operating Characteristic (ROC) curve analyses were performed. *Results:* Eighty-six adults aged (median [interquartile range]) 74 [65-78] years were assessed, of which 47 (54.7%) were women. People with CI were older, had more comorbidities and were more likely to have completed schooling, but not significantly (p>0.05). People with CI, or CI and FI combined, performed worse on the KICA (p<0.001 and p=0.002, respectively), but not the CDT (p>0.05). KICA and CDT performance were not associated with FI alone (p>0.05). KICA performance was negatively associated with CI in both unadjusted and fully adjusted models (adjusted odds ratio [OR]=0.71; 95% confidence interval 0.59-0.85). CDT performance was not significantly associated with CI in both models (p>0.05).

Used alone, the KICA was superior to the CDT for detecting cognitive impairment (area under the curve [AUC]=0.79 (95% confidence interval 0.67-0.91) and 0.57 (0.41-0.73), respectively; p=0.001). However, in full risk factor models incorporating age, gender, education, and medical comorbidity, a model with the KICA was not significantly different to a model with the CDT (AUC 0.82 [0.69-0.94] vs. 0.75 [0.62-0.88]; p=0.151). *Conclusions:* KICA is a superior predictor to CDT for CI when considered in isolation. This difference is diminished when demographic factors are included. This suggests cognitive screening performance should be considered in the context of other factors in this population.

28. Potentially Preventable Dementia in Australia and within First Nations Australians

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Background: Dementia is the second leading cause of disease burden in Australia and three-to-five times more common in First Nations Australians. We aimed to calculate the population attributable fractions (PAFs) of dementia attributable to 11 of 12 previously identified potentially modifiable health and social risk factors (less education, hearing loss, hypertension, obesity, smoking, depression, social isolation, physical inactivity, diabetes, alcohol excess, air pollution), for Australians overall and three population groups (First Nations, and those of European and Asian ancestry). Methods: We calculated the prevalence of dementia risk factors (excluding traumatic brain injury) and PAFs, adjusted for communality, from multiple national surveys conducted by the Australian Bureau of Statistics. Findings: A large proportion (38·2%, 95% CI 37·2–39·2) of dementia in Australia was theoretically attributable to the 11 risk factors; 44·9% (43·1–46·7) for First Nations Australians, 36·4% (34·8–38·1) for European ancestry, and 33·6% (30·1–37·2) for Asian ancestry. Physical inactivity (8·3%, 7·5–9·2), hearing loss (7·0%, 6·4–7·6), and obesity (6·6%, 6·0–7·3) accounted for approximately half of the total PAF estimates across Australia, and for all three population groups. Interpretation: Our PAF estimates indicate a substantial proportion of dementia in Australia is potentially preventable, which is broadly consistent with global trends. The highest potential for dementia prevention was among First Nations Australians, reflecting the enduring effect of upstream social, political, environmental, and economic disadvantage, leading to greater life-course exposure to dementia risk factors. Although there were common dementia risk factors across different population groups, prevention strategies should be informed by community consultation and be culturally and linguistically appropriate.

29. Including intersectional Two-Spirit perspectives on dementia in a national aging cohort study in Canada

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The significance of understanding the aging experiences of Two-Spirit community members is underscored by the limited research and resources available to support this community. Two-Spirit is a term that came to be in the 1990s, but the concept has existed within Indigenous communities since the dawn of time. The concept may include one's sex, gender and sexual orientation, but it is not limited to these intersecting factors, rather connected to the roles and responsibilities within community. Through an environmental scan examining the intersection of Two-Spirit Peoples and dementia care, we found a significant gap in research that adequately considers intersections of Indigeneity, sex, gender identity, and sexual orientation. To address these gaps, we brought together a working group of leaders from Two-Spirit organizations from across Canada with a Two-Spirit centred research team and other Indigenous and non-Indigenous academic researchers analyze data from the Canadian Longitudinal Study on Aging (CLSA). We sought to explore the adequacy of the CLSA for addressing intersectional Two-Spirit dementia and aging research. Working under the guidance of the Two-Spirit Working Group, we applied for and received CLSA baseline (2011-2015) and follow up (2015-2018) data. The Two-Spirit Working Group reviewed the data and provided guidance to the research team and to the CLSA overall for meaningful changes that promote greater inclusivity and accuracy in data collection. The primary outcome of this phase of the project is a set of revised interview questions that will be implemented in the next phase of the longitudinal CLSA data collection. In addition, an Indigenous-specific module is being developed to better understand the aging experiences of Indigenous participants and a new Indigenous cohort is being explored.

30. Process evaluation of an Aboriginal Health Practitioner-led dementia risk management program (DAMPAA)

<u>Nakita Little</u>¹, <u>Elders Governance Group</u>¹, Alex Lalovic², Athira Rohit², Lynette Yappo², Glennette Dowden², Leon Flicker^{3,2}, Dina LoGiudice⁴, Kay Cox^{2,3}, Osvaldo Almeida^{3,2}, Keith Hill⁵, Deborah Woods⁶, Paula Edgill⁷, Carmel Kickett⁸, Sandra Thompson^{9,2}, Christopher Etherton-Beer^{3,2}, Ivan Lin^{9,2}, Julie Ratcliffe¹⁰, Rachel Milte¹⁰, Carmela Pestell², Dawn Bessarab², Kate Smith²

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Background/Aim: Dementia is a key health issue for Aboriginal and Torres Strait Islander peoples. A co-designed, Aboriginal Health Practitioner (AHP) led dementia risk management program (DAMPAA) was implemented in 2021-2024 for Aboriginal Australians aged 45 years and over. Key characteristics of DAMPAA included group walking and yarning sessions incorporating health and wellbeing education twice a week, and a home program for 6 months. A parallel process evaluation assessed enablers and barriers and recommendations for future implementation. Methods: A Theory of Change framework underpinned the process evaluation and was developed in partnership with Aboriginal Community

Controlled Health Services (ACCHS) and an Elders Governance Group in Western Australia. Qualitative data was collected from i) Elders through yarning circles and exit interviews, and ii) staff through semi-structured interviews. *Results:* Key program enablers highlighted by Elders and staff were i) need for a brain health program tailored for Elders, ii) supported connection to country, and iii) flexible, culturally sensitive program delivery. Program gaps discussed by participants included 1) a lack of variety and 2) lack of dedicated education sessions. Barriers to program recruitment included i) impact of COVID, ii) DAMPAA being a randomised controlled trial, iii) Elders' family commitments iv) staff resources. Recommendations for program translation include an ACCHS based program, integrate program delivery with existing ACCHS services, and delivery by qualified, local AHPs. *Conclusions:* Based on the learnings and recommendations from the process evaluation, DAMPAA program will be implemented as a community program for Elders by one of our ACCHS partners by mid-2024.

31. [withdrawn]

Poster Presentations: Full Author Lists & Abstracts

1. [withdrawn]

2. Research Side Effects in Community: Raising Dementia Awareness through Community-Based Participatory Research with the Grand Portage Lake Superior Chippewa, USA

<u>Collette Pederson</u>¹, Melissa Blind¹, January Johnson¹, Rhonda Trudeau¹, Karen Pitawanakwat¹, Lois Strong², Marlene Summers², Nickolas H. Lambrou², Dana Ketcher¹, Melinda Dertinger¹, Wesley Martin², Jordan P. Lewis¹, Wayne Warry¹, Megan Zuelsdorff², Carey Gleason², Jennifer Sorenson³, Becky Deschampe³, John Morrin³, Emma Carlson³, Patty Winchell Dahl³, Mary Harrelson³, Shirley Stevens³, Kristen Jacklin¹

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This poster highlights dementia specific research and community activities of the Grand Portage Band of Lake Superior Chippewa, a small community located in northeastern Minnesota, USA. Grand Portage is one of four sites in the Indigenous Cultural Understandings of Alzheimer's Disease and Related Dementias – Research & Engagement (ICARE) project (NIH 5R56-AG-62307-2; R01-AG-62307-2) since 2019. The research uses a Community-Based Participatory Research (CBPR) approach. A community-based researcher (CR) is involved in all aspects of the research and works closely with a Community Advisory Group (CAG) who provides guidance on research activities, recruitment, analysis, and dissemination. The presence of the CR and CAG has greatly increased dementia awareness and fostered important service relationships at the community, county, and state level. Dementia awareness was raised, in part, through data collection with Key Informant Interviews (n=35) and Sequential Focus Groups (n=5). Dissemination of research activities and findings are shared through community newsletters, presentations, and a community report. As a part of the recruitment strategy, the CR and CAG conducted outreach activities including dementia awareness walks, informational booths at community events, and community listening sessions. Beyond the research mandate, at the Tribal level, the CR and CAG advocated for a Tribal Council Resolution to partner with the Alzheimer's Association to implement dementia friendly training for all Tribal businesses, managers, and staff. A dementia caregiver support group was also started. The research and outreach efforts have garnered attention from county and non-profit organizations, and helped foster relationships resulting in additional services and supports for Grand Portage. Increasing dementia awareness at the community level cannot be done by research alone. The flexibility in awareness strategies in Grand Portage and the dedication of the CR and CAG to increasing dementia knowledge and awareness has resulted in important dementia partnerships that will continue to support the community long term.

3. Voices of our Elders: Adapting Community Based Dementia Research and Practices for Wabanaki Elders

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The Wabanaki Center for Research, Knowledge and Innovation is conducting Voices of Our Elders (VOE), an epidemiologic study assessing health and lifestyle risk factors for Alzheimer's disease and Alzheimer's disease related dementia (AD/ADRD) and cognitive decline, in addition to screening for the prevalence of AD/ADRD and mild cognitive impairment among Tribal members 55 years and older. A division within Wabanaki Public Health and Wellness, a Tribally operated public health district in the state of Maine, the Wabanaki Research Center for Health is partnering on this NIH funded study with two academic partners, Washington State University and the University of Miami on VOE. Wabanaki Public Health and Wellness serves the four federally recognized Tribes in Maine. Through collaborative efforts, we aim to enhance support systems, promote cultural continuity, and improve the overall well-being of Wabanaki Elders living with dementia. From the perspective(s) of a Tribal public health district (and academic partners) in this presentation, our objectives are to: Describe and explore the process of developing, adapting, and Indigenizing research methodologies of a dementia study, to better serve the needs and perspectives of Wabanaki Elders, incorporating community-based practices with Indigenous understanding. Through the VOE study, we have engaged directly with Wabanaki Elders to understand prevalence of ADRD and Alzheimer's. Describe and reflect upon on the engagement and interactions with academic institutional review boards, additional aspects of the process of developing a dementia study; and strengths and learning lessons from community and academic perspectives.

4. Alzheimer's Disease Among Native People – Building the Biospecimen Repository for American Indian Nations (BRAIN) to Address Gaps in Alzheimer's Disease and Related Dementias Research (ADRD) in American Indian and Alaska Native (AI/AN) Communities

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In this presentation we describe a project to raise awareness of ADRD, understand participants' knowledge of and attitudes towards participation in ADRD-related research, and determine the optimal methods to maximize recruitment (NIH U54MD00050). The project was implemented by the South Dakota-based Missouri Breaks Industries Research, Inc. (MBIRI), an Indian-owned business that maintains strong relationships with local Tribes. MBIRI recruited AI/ANs ages 40 years and older living in the Rapid City area. Eligibility criteria were 1) self-identification as AI/AN; 2) ability to speak, read, and understand English; and 3) possessing cognitive and decisional capacity to consent. Participants were recruited through flyers posted in public spaces, word of mouth, radio and newspaper announcements, and community events. Eligible and interested individuals were randomized into one of 3 arms of a trial that offered the same educational content on ADRD but used different delivery methods. The arms comprised a 1) culturally-tailored brochure and video; 2) culturally tailored brochure; and 3) non-tailored brochure. Participants completed baseline questionnaires that included information on demographics, health history, traumatic

brain injury, healthcare access/use, ADRD-related screening measures and knowledge, psychosocial factors, health literacy, and cultural identity. Biospecimens (serum, urine, saliva) were collected, and data is available derived from the problem list in participants' medical records. After completing the baseline assessment, participants were asked to enroll in a research repository – BRAIN – for future research on ADRD among Al/ANs. Enrollment in BRAIN was the primary outcome of this randomized controlled trial. A total of 1,307 Al/ANs were screened and 1,150 (88%) enrolled; of these, 1007 (88%) joined BRAIN. We will describe our methods, measures, recruitment materials, baseline participant characteristics, and the partnerships foundational to the project. Data and biospecimens are available for analysis with appropriate approvals. MBIRI maintains BRAIN through regular newsletters, retention events, and annual follow-up assessments.

5. Developing and implementing a successful research-informed outreach, recruitment, and engagement program to promote the participation of American Indian and Alaska Native elders in research at the University of Washington's Alzheimer's Disease Research Center

<u>Patrik Johansson</u>, <u>Gary Ferguson</u>, <u>Breanna Jones</u>, <u>Maddy Rantala</u>, <u>MichaeLynn Kanichi</u>, <u>Jolie Green</u> Washington State University, Seattle, USA

Background: The Indian Health Service predicts that the number of American Indian and Alaska Native (Al/AN) people aged 85 years and older is predicted to increase more than seven-fold by 2050, from 42,000 to 300,000. This finding raises concerns that the prevalence of Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) will increase among Al/AN people. In addition, Al/AN people experience a disproportionate burden of risk factors associated with AD/ADRD, yet this community is underrepresented in AD/ADRD research. We developed and implemented a research-informed outreach, recruitment, and engagement program to promote participation amongst Al/AN elders in the University of Washington Alzheimer's Disease Research Center's Clinical Core. Methods: Our research, outreach, recruitment, and engagement team developed: recruitment materials, presentations, outreach events, and a research protocol based on findings from focus groups and key informant interviews with national samples of Al/AN elders, Tribal health directors, and Tribal leaders, respectively. Strategies employed included cultural adaptation of materials, presentations, cultivating relationships with Native American serving organizations, outreach events to Al/AN audiences, having Al/AN representation on the recruitment team, and emphasizing options for level of participation in the Clinical Core, i.e., having the opportunity to opt in and out of different tests. Results: Using research-informed outreach, recruitment, and engagement strategies, we recruited 29 Al/AN elders into the University of Washington Alzheimer's Disease Research Center's Clinical Core in less than one year. Prior to the implementation of our strategies only 5 Al/AN people had been recruited into the Clinical Core. Conclusion: In reaching the recruitment goal for Al/AN elders to enroll into the University of Washington Alzheimer's Disease Research Center's Clinical Core, we used a research-informed and culturally attuned outreach, recruitment, and engagement progra

6. Warming the ground: Culturally safe and engaging online education to promote health and reduce dementia risk

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Technology-based communication has become a valuable way in which Aboriginal and Torres Strait Islander people can access and share health information in regional, rural, and remote locations. In addition to information provided through organizational websites, learning modules, and wearable apps, consumers can interact socially and advocate through media such as blogs, podcasts, Facebook, and WhatsApp groups. Ensuring that information is culturally safe, reliable, and accessible is essential. More formally presented online education, such as the nationally and internationally available and free Preventing Dementia Massive Open Online Course (PD MOOC), needs to be developed collaboratively with Aboriginal and Torres Strait Islander people to ensure the information is culturally safe, interactive, and engaging, and that learning is contextualized in cultural determinants of health. Our work has shown that Aboriginal people learn from the PD MOOC but do not see themselves or their culture in the information that is presented. Our review of current evidence relating to online health and dementia education highlights the critical need to work with communities for cultural fit, trust, and acceptability to ensure ongoing effectiveness. We use the metaphor *Warming the Ground* to convey the importance of Aboriginal and Torres Strait Islander community members, both young and older, coming together to share knowledge to promote health and wellbeing, and to guide the infusion of Western knowledge in culturally appropriate, effective, and sustainable online information to reduce dementia risk. In this novel 2-year project, Aboriginal and Torres Strait Islander communities across Australia will review the PD MOOC, contextualize the course content within a culturally appropriate, safe, strengths-based, and engaging framework that is adaptable to local contexts, and evaluate the effectiveness of this online approach to promote health and wellbeing and reduce dementia risk. The project will entail a pivotal whole-of-communit

7. Dementia Prevention and Risk Management Program for Aboriginal Australians (DAMPAA): A Co-Design of a Culturally Informed Program and Resources

<u>Alex Lalovic¹</u>, <u>Nakita Little²</u>, Zoë Hyde^{1,3}, Athira Rohit¹, Lynette Yappo¹, Glennette Dowden¹, Leon Flicker^{3,1}, Dina LoGiudice⁴, Kay Cox^{1,3}, Osvaldo Almeida^{3,1}, Keith Hill⁵, Deborah Woods⁶, Paula Edgill⁷, Carmel Kickett⁸, Sandra Thompson^{9,1}, Christopher Etherton-Beer^{3,1}, Ivan Lin^{9,1}, Julie Ratcliffe¹⁰, Rachel Milte¹⁰, Carmela Pestell¹, Dawn Bessarab¹, Elders Governance Group², Kate Smith¹

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Background: The brain health of older Aboriginal and Torres Strait Islander peoples is vital to the health and wellbeing of their communities. Several risk factors for dementia in this population are modifiable (e.g., head injury, hypertension, stroke and poor mobility). To address these factors, a comprehensive and culturally informed program with brain health education resources is required. Methods: In partnership with Aboriginal Community Controlled Health Services (ACCHS) and Elders in Western Australia, we co-designed an Aboriginal Health Practitioner-led health program (DAMPAA) and brain health education resources to target key dementia risk factors for Aboriginal people aged ≥45 years. Consenting participants underwent screening followed by further assessments and randomisation to the DAMPAA program or usual care. Participants in the DAMPAA program completed activities including a walking and yarning program and brain health education sessions in a culturally safe environment. Results: The seven new co-designed brain health resources are 5 tips to: i) be active, ii) good brain health, iii) eat healthy, iv) look after your heart and spirit, v) good medicine use for Elders, vi) protect your head from injury, and vii) stay connected. A training toolkit was developed for Moorditj Koort Aboriginal Corporation and other ACCHS's to implement DAMPAA as a community program for Elders. Two hundred and forty participants were screened using the Kimberley Indigenous Cognitive Assessment tool. A case series of participants completing the trial will be presented to illustrate how the program and resources can be used. We will explore trajectories of quantitative health measures over time. Discussion: The co-design approach to developing a brain health program and resources for Elders led to culturally responsive outcomes and timely translation into practice. Partner organisations have been empowered with tools for sustainable practice, enabling ACCHS to achieve the common goal of improving dementia risk management f

8. Indigenous Methods of Recruitment and Engagement – Updates on Lessons Learned from "Brain Trains" and Fostering Research Readiness with Community

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Background: The Recruitment and Engagement Core (REC) of the Natives Engaged in Alzheimer's Research Program Project is applying strategies recommended by the National Institutes on Aging for recruitment and retention of American Indian and Alaska Native (AIAN) and Native Hawaiian and Pacific Islander (NHPI) peoples in Alzheimer's Disease and related dementia (ADRD) research. We are committed to innovative as well as traditional methods to engage rural and urban AI/AN and NHPI peoples. Activities are led by AI/AN and NHPI investigators and staff representing a strong academic-community partnership. Method: The REC deploys a multi-pronged approach to increase "research readiness", a modifiable status along a continuum that can be applied to both individuals and communities. One highly successful event is "Brain Trains", which are novel hands-on educational workshops that utilize visual and interactive learning methods to cover ADRD knowledge, pathology, genetics, risk and resilience factors, and research participation. Participants are AIAN and NHPI Elders ages 50+ who visit 10 "stations" staffed mostly by AI/AN and NHPI researchers. Elders receive a "passport" that contains a record of their personal data to take home; copy is retained by the study team. The REC assesses "research readiness" for ADRD research via key informant interviews to identify resources and opportunities to address ADRD among partner communities. Result: The preliminary results of the REC will include a summary of the research readiness assessment which include 10 interviews from AI/AN and NHPI communities, respectively. Additionally, an update on catalog lessons learned and descriptive statistics from Brain Trains will be presented. Since 3/2023, 28 "Brain Trains" have been conducted with community partners from across the U.S. and its territories with over 1,200 participants engaged. An additional 9 sites are awaiting a Brain Trains. Conclusion: The REC is fostering new research-ready sites for ADRD community studies.

9. The Use of Poetry in Dementia Care: An Area of Opportunity for Indigenous Dementia Research

<u>Antonio Paniagua Guzman</u>¹, Amy Otto¹, Kristen Jacklin¹, Indira Galeeva¹, Sarah Brown²

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Art-based interventions for people living with dementia (PLWD) have been successful in improving diverse areas of well-being and quality of care. Within the spectrum of art-based interventions and research on the effects of art on ADRD outcomes, poetry has not been widely explored and used compared to other forms of art such as music or performing arts. However, some studies have suggested that the use of poetry in the ADRD context can improve communication, socialization, cognition, and regulation of behavioral outcomes of intervention participants. This research aims to investigate the ways researchers and communities have used poetry in interventions or programs for PLWD and their caregivers and the outcomes of such interventions/programs. Additionally, this research highlights important considerations for the design and implementation of poetry-based interventions for PLWD and their caregivers in the Indigenous context. This research draws on a scoping review focused on existing literature reporting poetry-based interventions for PLWD and their caregivers worldwide. Both completed and ongoing original research reporting intervention outcomes in peer-reviewed articles or certain types of gray literature were considered. This analysis looks at methodologies employed, participant demographics, format and form(s) of poetry used, and primary outcomes reported. After screening 1106 articles across multiple databases, 23 were included for full-text review, and 6 included in the final extraction. Findings show that while most extracted studies report positive outcomes on well-being and quality of care of PLWD and their caregivers, there are substantial field-based divergences in outcome reporting and evidence support among studies analyzed, which embodies a barrier

for multidisciplinary collaborations. Additionally, this research shows no existing poetry-based designed to serve Indigenous PLWD or their caregivers, which represents an opportunity for the field of Indigenous dementia research.

10. Trusting the process: Integrating cultural safety into dementia assessments with Indigenous Peoples

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Compared to non-Hispanic white populations, Indigenous rates of Alzheimer's disease and related dementias (ADRD) are estimated to be approximately 3 times higher with a 10-year earlier onset. However, prevalence and incidence estimates are likely unreliable given under and misdiagnosis. Inadequate and culturally unsafe dementia assessment tools contribute to diagnostic imprecision for Indigenous populations in the United States. The American Indigenous Cognitive Assessment (AMICA) project (NIH R01AG074231) aims to address these gaps by developing a culturally safe dementia evaluation toolkit. AMICA uses a Community Based Participatory Research (CBPR) approach, partnering with Red Lake Nation, MN, Oneida Nation, WI, and an urban Indigenous community in Albuquerque, NM, to adapt measures previously validated with Indigenous populations in Australia and Canada. Community collaborations build trust and allow for a Two-Eyed Seeing integrated consensus when developing culturally safe and relevant dementia tools. Working in tandem with an Expert Assessment Panel, Indigenous Knowledge Advisory Groups (IKAGs) are an integral part of this process. Preliminary analysis of qualitative data generated by IKAGs suggests the approach to administering the assessment is as important to outcomes as the tool itself. IKAGs across sites emphasized the critical need to create safe environments and trusting rapport prior to assessment. Suggestions included clearly explaining the assessment process, having loved ones nearby, offering gentle guidance and delivery, and orienting the assessor to cultural knowledge. Safety and respect carried throughout IKAGs' rationale for item adaptations, including word changes intended to increase comfort and foster rapport between the assessor, person with memory concerns, and loved ones. IKAG contributions reach far beyond the semantics of assessment items and suggest that relational aspects of respect, trust, and safety are foundational for accurate measurement. Preliminary findings demonstrate the value of a CBPR approach grounded in Indigenous knowledge combined with psychometric expertise in producing validated instruments.

11. [withdrawn]

12. Exploring Health Promotion Programs Targeting Modifiable Risk Factors for Dementia in Indigenous Populations: A Scoping Review of Reviews

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For many Indigenous people, ageing is viewed from a holistic perspective. It is often a time marked by wisdom, resilience, and participation in family and community life. The number of Indigenous older adults (>60) is projected to expand significantly, more than tripling in number by 2031. This welcome increase in the population of Indigenous older adults coincides with the understanding that ageing represents the most significant risk factor in the development of dementia. Moreover, approximately one third of the risk of developing dementia can be attributed to modifiable risk factors (e.g., cardiovascular disease, diabetes, smoking), which are disproportionately experienced by Indigenous populations. To promote the wellbeing of Indigenous older adults, interventions are needed to target modifiable risk factors known to impact the development of dementia. To date, most of the research on dementia focuses on risk at the individual level and fails to integrate knowledge of broader cultural and social determinants of health. Further, there is a lack of collaborative research that appropriately and adequately engages Indigenous Knowledge Holders, Community Members, and Elders within the knowledge synthesis process. To address these issues, we will establish an Indigenous Ageing Advisory Circle (i.e. Elders, Knowledge Keepers, and older Indigenous adults) to collaborate on the development, interpretation, and knowledge mobilization components of the project. We will use a mixed methods Western-Indigenous approach to collaboratively synthesize and contextualize what is known about health promotion programs targeting modifiable risk factors for dementia in Indigenous populations. This approach extends the JBI method by prioritizing consultation and community benefit through a decolonizing lens. Our scoping review process and preliminary insights from our advisory circle consultation will be discussed.

13. Awareness of Actions to Reduce Dementia Risk Among First Nations People in File Hills Qu'Appelle Tribal Council: A Review of the Brain Health PRO Platform

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Background: The Brain Health PRO platform aims to reduce cognitive decline through online modules designed to educate older adults on preventative health measures for modifiable risk factors. The platform has not included First Nations perspectives in its program development,

and therefore does not reflect the needs of First Nations communities. Together with First Nations community members in File Hills Qu'Appelle Tribal Council (FHQTC), we reviewed Brain Health PRO content and approach. *Objective:* We aim to improve the existing Brain Health PRO platform and develop a guideline on creating a First Nations adaptation of the platform for FHQTC communities. *Methods:* Ten sequential focus groups were held with eleven community members to review Brain Health PRO content and approach, and to identify areas for improved cultural and contextual relevancy. *Results:* Community members highlighted the lack of relevancy of the content presented, such as the exclusion of Indigenous Traditional Knowledge and medicines, land-based teachings, and spirituality. Online program delivery was not the preferred method of sharing information for community members; instead, tangible educational materials and opportunities for in-person gatherings were recommended. *Limitations:* The knowledge shared in focus groups is intended to create a Brain Health PRO adaptation for FHQTC communities specifically; therefore, it may not be culturally relevant for other First Nations communities across Canada. *Conclusion:* Meaningful improvements to the cultural relevance of the Brain Health PRO Platform for FHQTC communities cannot be achieved with minor revisions; instead, larger foundational changes that reflect the interests, concerns, and worldviews of these First Nations communities are required.

14. Mina Nindamowin - Models of Indigenous Dementia (MInD) Care: Aging in place in First Nations Communities; a community-based approach to supporting older Indigenous people with Dementia

Sebastien Lefebvre¹, Michael-Ann MacLean², Jeanette McLeod¹, Mariette Sutherland¹, Geraldine McGregor², Sheila Coté-Meek³, Taima Moeke-Pickering⁴, Katherine McGilton⁵, Christianna Jones², <u>Edith Mercieca</u>¹, Jennifer Walker⁶, Gregory Ross^{7,8}

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Mina Nindamowin is an Indigenous-led research project seeking to find the gaps in services, resources, and supports available to Anishinaabek adults 45 and above experiencing cognitive decline within communities. There is a lack of understanding regarding the dementia care needs of diverse Anishinaabek 45+ adults and the challenge of creating culturally acceptable care. The focus is on enhancing community empowerment, understanding how dementia impacts lives, improving services, reducing caregiver burden, and enhancing caregiver well-being. The research seeks to identify gaps in the needs of Indigenous older adults with dementia from the caregiver's perspective.

Additionally, a survey of local communities and districts will be conducted to assess the services and resources available. The overarching goal is to provide Community Partners, Noojmowin Teg Health Centre, and Maamwesying North Shore Community Health Services, with insights for delivering adequate services to Indigenous adults with dementia. The project aims to develop culturally grounded, strength-based approaches to dementia care and health education within Anishinaabek communities, utilizing Indigenous Research Methodologies (IRMs). The research delves into the needs faced by Anishinaabek adults (45+) with dementia and their caregivers, the contextual factors influencing health issues and care barriers, and the existing services, resources, and supports in specific regions. One-on-one interviews will be conducted with 8-10 participants in each participating community. Further, an environmental scan will be conducted on services, resources, and supports available to Anishinaabek caregivers of people with dementia locally, provincially, and nationally, considering accessibility and eligibility. The research objectives aim to provide comprehensive insights for developing effective and culturally grounded dementia care strategies within Indigenous communities.

15. An Investigation of the Choice of Time Scale under Misspecification of Time

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Identifying factors associated with time-to-dementia-related outcomes relies on time-to-event statistical models, such as the Cox proportional hazards model. The Cox model estimates these relationships via comparing individuals who experience the outcome at time t with all individuals who are still at-risk of the outcome at time t. The definition of who is at-risk of the outcome at time t depends on the specification of a time scale. The two most common time scales used in practice are time-on-study and age. The age time scale is oftentimes used in studies with a dementia-related outcome due the strong relationship between age and dementia status. The time-on-study time scale is a natural choice in many application settings where there is a clear exposure time (e.g. clinical trials). These time scales have previously been assessed in simulation studies where one of the time scales is correctly specified. Results from this work have been mixed as to which may be the better time scale for epidemiological outcomes. Here, we assess the performance of the Cox model under settings where the true time scale is misspecified. That is, we specify a time T₀, at which the hazard of dementia changes and is unrelated to study conditions. Under the age time scale, our true time scale has a small hazard of dementia-onset prior to age T₀, after which the hazard of dementia-onset is simulated traditionally. Under the time-on-study time scale, our hazard of dementia is 0 up to age T₀ and is simulated traditionally afterwards. We simulate each combination of time scale (age/time-on-study) and relationship between the predictor-of-interest and the age-at-entry to study (correlated/uncorrelated). We observe that the time-on-study time scale is more robust to time scale misspecification. An application to Indian Health Services data highlights how these decisions may impact results/interpretations. Application pending Tribal review.

16. Using a Community Based Participatory Research Approach to Recruit American Samoans for Alzheimer's Disease and Related Dementia Research

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Background: Research hesitancy exists due to historical abuse of non-Indigenous researchers conducting studies that are not reflective of the community health needs. The *Puipui Malu Manatu* (PMM) study (RF1AG075904) deploys a community based participatory research (CBPR) approach utilizing diverse stakeholders in various levels of a study to ensure trust, respect, and reciprocity between the researchers and a community. Our previous studies have shown using CBPR approach with a cultural lens that shows *fa'aaloalo* (respect) have been effective in recruiting participants. *Methods:* We incorporated CBPR approaches that follow the *Fa'aSamoa* (Samoan way/culture) to promote awareness of the PMM objectives and recruit eligible participants. The adherence of cultural protocol was accomplished by presenting at the Office of Samoan Affairs (OSA). The OSA is comprised of the *Pulenu'u* (village mayor), led by an *Ali'I* (Paramount Chief), and is the cultural governance body for villages, essentially making them gatekeepers to eligible participants. The Secretary of Samoan Affairs provided a letter of support, granting the access to the villages via *Pulenu'u*. We implemented the "PMM on Wheels" in the remote village of Aoa in collaboration with the *Pulenu'u. Results:* The support from the OSA and *Pulenu'u* allowed for the first "PMM on Wheels" to be conducted. The staff recruited 10 eligible participants who would not be able to access the two study site locations. Furthermore, we were able to maintain randomization in our sampling strategy. All participants completed cognitive assessments and provided a blood sample. Future events are scheduled in the beginning of 2024. *Conclusion:* Negative reactions towards research studies in Indigenous populations have been supported by historical abuses by non-Indigenous researchers. Utilizing CBPR with a cultural lens in the American Samoa population has shown rebuild trust and *fa'aaloalo* to better the health outcomes of the community.

17. Characterizing Resiliency and Vulnerability Factors for Alzheimer's Disease and Related Dementias in American Samoa

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Introduction: Alzheimer's Disease and Related Dementias (ADRD) are progressive neurodegenerative disorders that include impairments in cognitive ability and overall functioning. Native Hawaiian and Pacific Islanders (NHPI) refers to persons having origins in the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. While NHPI life expectancies have increased over the past five decades, Samoans warrant particular attention due to a high prevalence of ADRD risk factors including obesity, hypertension, and type 2 diabetes. Despite these vulnerabilities, the current literature either aggregates across culturally dissimilar groups and/or lacks sufficient numbers of Samoans for meaningful insights about ADRD prevalence and potentially modifiable risk and protective factors. The current study was conducted by the Indigenous Samoan Partnership to Initiate Research Excellence (INSPIRE). INSPIRE parent project revealed that 15.1% of the sample of 150 American Samoan adults age 50 and above scored within the possible dementia range. In addition to ADRD prevalence data, there is a need for culturally adapted screening measures, illumination of risk and protective factors and holistic care grounded in Samoan knowledge and values. The current secondary data analysis examines relationships between cognitive functioning, emotional well-being, education, and smoking and alcohol use. Materials and methods: We administered the Kimberely Indigenous Cognitive Assessment (KICA) tool to a sample of 150 Samoan adults age 50 and above. Results: Results indicated that education was significantly associated with KICA cognitive score such that a higher reported educational attainment was associated with higher cognitive functioning. Results indicated that KICA emotional well-being was significantly associated with KICA cognitive score such that a higher reported emotional well-being was associated with higher cognitive functioning. Conclusions: We suggest utilizing emotional well-being findings to inform community prevention/intervention efforts. We also underscore the need to advocate for the reduction in structural inequities related to educational opportunities in American Samoa.

18. Creating a Digital Health Communication Campaign about Alzheimer's Disease Amanda Boyd

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Alzheimer's disease and related dementias (ADRD) affect approximately 5 million Americans 65 years of age or older. The number of people in the US with ADRD is expected to increase to approximately 14 million by 2050 unless preventive interventions and effective treatments are developed. Despite advances in ADRD research among non-Hispanic Whites, little is known about ADRD prevalence and risk factors for American Indian people. This is partly due to low participation of American Indians in ADRD research. To increase research participation, it is important to understand how best to communicate about ADRD to American Indians. In 2024 we conducted interviews with 50 American Indians aged 50 and older. Participants reported a preference for learning about ADRD from their doctor, other health professionals, brochures, the internet, and friends and relatives. Participants were asked about digital health communication preferences. Websites that included videos, pictures featuring American Indians, and clear messaging were preferred. In results we discuss factors that may contribute to and enhance ADRD research participation and improved digital health-risk messages about ADRD. Further study is needed to determine whether incorporating culturally relevant risk messaging improves ADRD awareness and increases participation in ADRD research.

19. [withdrawn]

20. Dementia Prevention for Métis Communities in Alberta: Reflections on Ethical Principles of Research

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Brain Health Pro is a web-based educational program designed to increase knowledge around dementia and help individuals make lifestyle changes to reduce the risk of dementia. The program is 45 weeks in length, includes lifestyle questionnaires and goal setting, and consists of eight topics including brain health, physical activity, cognitive engagement, nutrition, sleep, social & psychological health, vascular health, and vision & hearing. In partnership with the Métis Nation of Alberta, we are engaging in a series of focus groups to understand the cultural relevance of Brain Health Pro and find ways to make it more Métis-specific for communities in Alberta. Although this work is currently underway, the process of getting to this point has been difficult. Grounded in reflexivity, the purpose of this poster is to discuss the challenges

we encountered during the contractual and legal processes and share our lessons learned to help inform future research endeavours. Specifically, the objectives of this poster are to discuss the limitations of using standardized contracts for research with Métis communities, and the need for funders to recognize the importance of relationship building, local protocols, and honorariums. Following the six principles of Métis Health Research of reciprocity, respect, safe and inclusive environments, diversity, research outcomes, and Métis context, we can begin to understand why decolonization and decolonial strategies are required during the contractual process to ensure Métis research is funded in an ethical way. The ultimate goal of this research project is to ensure Métis people are supported in culturally appropriate ways to protect and enhance brain health and also when on an individual dementia journey; however, understanding the process of how we get there is extremely valuable for informing work going forward.

21. Comparing Vitamin B12 Levels, MoCA Score and Mediterranean-Low Salt Diet to Delay Neurodegeneration Associated with Alzheimer's Disease and Related Dementia in American Samoa

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Introduction: Alzheimer's Disease and Related Dementia (ADRD) affects over 5.7 million Americans and 35 million people globally (Alzheimer's Association, n.d.; World Health Organization, n.d.). Life expectancies in indigenous communities have increased significantly, leading to a three-fold increase in people over the age of 65 (National Institute on Aging, 2020). However, healthcare systems that serve these populations are underprepared for the patients and caregivers. Social determinants of health, diet, and lifestyle may play a critical role in the vulnerability of the American Samoa population to developing ADRD. Objective: To investigate the relationship between vitamin B12 levels with MIND Diet, and MoCA scores on the prevalence of Alzheimer's Disease in American Samoa. Materials and Methods: Blood samples for Vitamin B12 analysis were collected, centrifuged, and the plasma was pipetted into cryovials for immunoassay analysis. Data for Vitamin B12 levels, MoCA scores, and MIND diet adherence were analyzed by calculating the median, mean, and standard deviation. Associations between these variables were analyzed using R, including Pearson correlation to determine the relationship of MoCA scores. Result: The mean MoCA score is 13.7, with a median of 14 and a standard deviation of 4.02, out of a total score of 22. The MIND diet adherence had a mean of 9.22, a median of 9.5, and a standard deviation of 1.76, out of 15. The Pearson correlation coefficient is 0.06 (p-value: 0.21), showing no significant correlation between MIND diet and MoCA scores. Conclusion: There is no substantial evidence to support a correlation between MIND diet adherence and MoCA scores in the Samoan population. Vitamin B12 immunoassay analysis is pending the installation of the machine. The project is ongoing, and further data analysis and collection are in progress.

22. Enhancing Participation in Research for Asian American, Native Hawaiian and Pacific Islander Populations: The CARE Registry <u>Joshua Grill</u>¹, <u>Kenny Li</u>¹, Va'atausili Tofaeono², Poki'i Balaz³, Justina Tavanā⁴, Marian Tzuang⁵, Bora Nam⁵, <u>Janice Tsoh</u>⁵, Van Park⁵

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Introduction: Persons of AANHPI backgrounds are underrepresented in clinical research in general and in research focusing on aging, Alzheimer's disease and related dementias (ADRD), and caregiving. A query of the National Alzheimer's Coordinating Center reveals that among 51,836 participants, only 1448 (2.8%) were AANHPIs, including just 39 (0.07%) who self-identified as NHPI. AANHPI communities, encompassing diverse cultural histories, traditions, and languages, are heterogeneous in English proficiency, nativity, and socioeconomic status, which contribute to health and healthcare disparities and create barriers to research participation. As such, discovering tools and interventions to increase representation of AANHPIs in aging and ADRD clinical and caregiving research is imperative. Goal: The goal of CARE is to recruit individuals from AANHPI communities into a registry to connect them with potential research opportunities, thereby improving AANHPI representation in research. Methods: CARE is a national research recruitment registry that is free for researchers. CARE uses community based participatory research (CBPR) approaches to promote registry enrollment, and the enrollment survey is currently available in English and 5 AANHPI languages. Researchers who are interested in recruiting from CARE are required to follow a protocol that includes participant safeguards. Expected Results: Through strong partnerships with NHPI organizations and leaders, as well as community outreach using age-appropriate and culturally tailored media and materials, we plan to strategically expand enrollment in the CARE registry in the US with an emphasis on increasing the enrollment of AANHPI groups who are currently underrepresented in CARE. The inclusion of NHPI participants in research studies will ensure more representative data, ultimately leading to more informative and generalizable research outcomes. Research participation provides an opportunity to contribute meaningfully to advances in healthcare, gain access to important health information, and impact health for future generations.

23. Evaluating the Physical and Social Neighborhood Environment of Older American Samoan Adults and its Relation to Alzheimer's Disease and Related Dementias

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Introduction: Alzheimer's and related dementias (ADRD) affect over 55 million people worldwide (National Institute of Neurological Disorders and Stroke, n.d.). ADRD are the debilitating conditions that impair memory, thought processes, and functioning, primarily among older adults. The environment can play a large role in health and can expose communities to unhealthy foods and lower access to healthcare. There continues to be little research done on the environment and its role in neurocognitive disorders. There is no current research done in

American Samoa focusing on Alzheimer's and related dementias. With increasing life expectancies, there is a drastic increase in people over the age of 65. ADRD typically takes effect in a person in their mid-60s, but it can also develop before the age of 65, where it is then considered early-onset Alzheimer's (NIH, 2022). *Objective:* To determine any association between the Montreal Cognitive Assessment and the neighborhood questionnaire on the risk factors of Alzheimer's disease and related dementias. *Materials and Methods:* De-identified data through randomized ID numbers from the American Samoa Community Cancer Coalition's REDCap database system were collected. A data request will be made to access neighborhood questionnaire, Montreal Cognitive Assessment-Blind (MoCA-Blind), and cognitive scores. Data will be collected through a survey comprised of questions about built and social environment, cognitive abilities, and the Montreal Cognitive Assessment (MoCA-Blind). *Result:* The dependent variables MoCA (p=.0.427) and Cognivue (P=.294) were not found to be associated with Neighborhood questionnaire scores. Participants placed into low, medium, and high ranges for Alzheimer's and related diseases based on MoCA, Neighborhood questionnaire, and Cognivue scores, showed no association. *Conclusion:* There is no substantial evidence to support an association between MoCA, Cognivue, and neighborhood questionnaire.

24. Association between Alzheimer's and Related Dementias Risk and Demographics among Older Adults in American Samoa

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Background: Fifty five million people including 5.8 million Americans are affected by Alzheimer's disease and related dementias (ADRDs) worldwide. Alzheimer's disease is a progressive and irreversible degenerative brain disease characterized by memory loss and decline in cognitive function. Decreased cognitive impairment in older people has been linked to a greater risk for developing ADRD. There is still a large gap in the information available regarding ADRD risk and its associated risk factors among Indigenous populations, especially in American Samoa. This study will aid in increasing the knowledge about ADRD risk in American Samoa. Methods: This will be a retrospective cross-sectional study using de-identified data obtained from the American Samoa Community Cancer Coalition Puipui Malu Manatu study. Data includes demographics of American Samoan adults ages 50 and above, and Montreal Cognitive Assessment, Cognivue, and Number Symbol Coding Test scores to discover correlations between the participant demographics and ADRD risk. Analysis will be done in Statistical Package for Social Sciences (SPSS) through multivariate analysis, i.e., linear regression. Preliminary Results: This study shows that six variables were found to be associated with ADRD risk among older adults in American Samoa: age range, birthplace, primary language, highest degree earned, occupation type, and housing type. The next step in this project will be to analyze the demographic predictors of ADRD and correlation, results are pending. Conclusion: The identified associated variables from this study will build a necessary foundation for further research to be done in the American Samoan population. Pending results may also be expanded upon in further studies aiming to test effective prevention methods for ADRD. Findings may provide insight toward developing culturally tailored interventions for the Samoan community to address demographic associated ADRD risks.

25. Decolonizing Brain Health in American Samoa through a Culturally Grounded and Indigenous Perspective: A Framework for Trustworthiness in Community Qualitative Research

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BACKGROUND: There is no documented cultural understanding of brain health or Alzheimer's disease and related dementias (ADRD) within the Indigenous Samoan population. This study used a decolonization research framework to explore knowledge, beliefs, and experiences regarding brain health in American Samoa. METHODS: Three 90-minute focus groups were conducted in Samoan and English. Transcriptions were analyzed using an Indigenous research paradigm that incorporated ontology, epistemology, methodology, and axiology. The framework reflected a constructivist worldview and respected Samoan epistemological practices, such as oral traditions and storytelling, while combining Samoan culturally appropriate models with Western methods. The Samoan socio-ecological model, emphasizing collectivism at the individual, family, village, and community levels, guided this approach. RESULTS: Twenty participants (10 males and 10 females, aged 18-64) shared 101 stories categorized into five themes: faith-based, Fa'aSamoa, colonization, distrust in the medical system, and education/awareness. The decolonization framework highlighted cultural pride, resilience, and the lingering effects of colonization on health perceptions. DISCUSSION: Using a decolonized, culturally grounded methodology deepened connections with Samoan participants and allowed for organic discussions. The findings suggest that future brain health interventions in American Samoa should use culturally resonant approaches, prioritizing storytelling and building research capacity. The Samoan socio-ecological model offers a framework for addressing brain health in a culturally appropriate way that reinforces local leadership.

26. Kei tua i te pae o te mahara: Beyond the threshold of memory: A Kaitiaki approach to Alzheimer's/Dementia Hiraani Winikeri

Te Wananga o Aotearoa, Palmerston North, New Zealand

Addressing the challenges posed by Alzheimer's/Dementia requires innovative, transformative, and indigenous care approaches. This presentation explores a kaitiaki (spiritual guardian) approach to caregiving, guided by the whakatauākī (proverb) "Kei tua i te pae o te mahara" (Beyond the threshold of memory). This whakatauākī emphasises the importance of connection and care that transcend memory's limitations, offering a cultural and spiritual framework for Alzheimer's/Dementia care. The goal of this presentation is to illustrate how Māori bodies of knowledge can inform Alzheimer's/Dementia care. By examining the role of a kaitiaki and the significance of the whakatauākī, practical strategies will be presented for creating a supportive and spiritually enriching care model for whānau and their loved ones with Alzheimer's/Dementia. "Kei tua i te pae o te mahara" offers holistic solutions by transcending typical memory-focused approaches. The kaitiaki methodology, guided by the concept of connecting beyond the threshold of memory, emphasizes the importance of integrating cultural and spiritual dimensions into caregiving practices. This approach provides practical solutions to the challenges faced by Māori carers

and their loved ones with Alzheimer's/Dementia. Drawing on Māori bodies of knowledge as the methodology for caregiving, this principle-based model also addresses the needs of the carers themselves. Our people deserve transformative approaches to address disparities in the healthcare system. "Kei tua i te pae" can address such disparities. By adopting a kaitiaki approach, caring for a loved one with Alzheimer's/Dementia is purposeful and deliberate. It acknowledges a wairua (divine) element to one's practice that can enhance the overall well-being of both carers and those with Alzheimer's/Dementia.

27. Guidelines & Strategies to Implement an Inclusive Garden for People with Dementia

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Gardens have health and therapeutic benefits which include increased physical activity, decreased stress levels, connection to land, access to local foods, and more. Gardens are cultivated spaces for all types of vegetation, flowers, herbs, medicinal plants, grass, and trees. Gardens in both public and private locations can have many benefits for those who visit and interact with the environment. Persons with dementia and their caregivers can benefit from access to garden environments which can also promote a sense of security, relationship building, and provide access to sensory elements. While gardens have many benefits, there can be challenges in accessibility for persons with dementia to access gardens and engage with gardening activities. The purpose of this poster presentation is to identify strategies to remove barriers to inclusion at garden spaces for people with dementia and offer guidelines for creating inclusive, dementia-friendly garden environments. This research is aligned with the Ho'ōla 'Āina Pilipili Accessible School & Community Garden site, which ensures access to Native plants for food, tea, and medicine and provides a space to promote inclusion, relaxation, sensory engagement, and social interaction. Available resources include the 'Dementia-friendly' accessible garden checklist and the Ho'ōla 'Āina Pilipili Supply & Resource Guide. Ongoing research will focus on the implementation of 'dementia-friendly' gardens in Hawai'i. Learn more about Ho'ōla 'Āina Pilipili at https://go.hawaii.edu/ULk

32. The co-development of a suite of training modules to support the delivery of culturally safe and quality dementia care for older Indigenous Australians

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Rationale: Indigenous Australians experience high rates of age-related conditions, including dementia. The National Aboriginal and Torres Strait Islander Flexible Aged Care (NATSIFAC) program provides culturally appropriate aged care to Indigenous peoples in rural and remote regions of Australia. A lack of appropriate and standardized training options in these regions means aged care workers are often ill-equipped to deliver culturally safe and quality dementia care to older Indigenous peoples. Aim: To describe the process used to develop a suite of accredited Indigenous specific dementia care training modules for the NATSIFAC workforce to support the delivery of culturally safe and quality dementia care for older Indigenous Australians. Methods: This is a collaborative project between The Healthy Ageing Research Team, Remote Area Health Corps (RAHC), and NATSIFAC providers in Australia. A knowledge and skills working group, comprising aged care and dementia experts, NATSIFAC workforce representatives and Indigenous aged care and dementia advocates, worked together to identify key topics, guide module content, and co-develop learning materials. A review of existing Indigenous dementia education and training materials was undertaken to identify content. Where gaps in Indigenous material existed, non-Indigenous material was modified to be culturally appropriate. All contents were reviewed and approved by working group members. Training will be accredited by an approved training organization. Once complete, the free to access, nationally available modules will be hosted and maintained by RAHC. Conclusion: The codevelopment and expert-review of this suite of training modules will help to ensure content is high quality, culturally appropriate and relevant for the NATSIFAC workforce and clients. These modules will help to build and sustain a rural and remote aged care workforce competent and skilled in providing culturally safe and quality dementia care for older Indigenous Australians.