

# Implementation Process for the Canadian Indigenous Cognitive Assessment

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## Abstract

As Canada's population ages, the number of individuals living with dementia is expected to increase. Between April 2020 and March 2021, nearly 477,000 people above age 65 were living with diagnosed dementia in Canada. It is thought that there were likely many more undiagnosed cases within the population (Public Health Agency of Canada, 2024), indicating a need to better screen for and diagnose dementia. In North America, some Indigenous populations show a higher prevalence of dementia than non-Indigenous populations (Jacklin, Walker, and Shawande, 2013; Mayeda et al., 2016). Specifically, dementia prevalence in First Nations people in Alberta is higher than in non-First Nations populations and increasing more rapidly (Jacklin, Walker, and Shawande, 2013). Current widely used cognitive assessments do not account for culture, colonization, or health and social inequalities (Jacklin et al., 2020). This highlights the need for a culturally appropriate cognitive assessment, hence the creation of the Canadian Indigenous Cognitive Assessment (CICA), modeled after the Kimberley Indigenous Cognitive Assessment (KICA) from Australia (LoGiudice et al., 2006; Jacklin et al., 2020; Walker et al., 2021; Marsh et al., 2023).

The goal of this paper is to highlight key considerations realized during the implementation process of the CICA and what future work is required for its successful use in communities. Work was done through Dr. Walker's research team that is partnered with the Anishinabek Nation and Za-Geh-Do-Win Information Clearinghouse. Results were informed by the Indigenous Dementia Research Conference on January 29 - February 1, 2024, where many First Nations community members came together to discuss the impacts of dementia and CICA implementation.

The results of this research can provide guidance on the opportunities and challenges when implementing a culturally appropriate tool in First Nations communities in Ontario. This paper also highlights what future steps and research might be needed to better support Indigenous people living with dementia and their communities.

## Self-Location of Author

Clara Austrins (she/her) is a White settler of European ancestry and a cisgender woman. She lives and works on A Dish with One Spoon Treaty Territory. She is thankful for the Haudenosaunee and Anishinaabe Peoples who traditionally live on the land she currently resides upon as an uninvited guest. Clara has been working under the supervision of Dr. Jennifer Walker since December 2023 on projects related to Indigenous wellbeing, biomedical research, and Indigenous data sovereignty. She is working in this field as she finds it incredibly enlightening to learn and listen to Indigenous ways of knowing. She also finds Indigenous ways of wellbeing to be beautifully holistic and hopes to reflect this in future aspirations related to healthcare. Clara recognizes the daily impacts of colonization upon Indigenous Peoples and hopes to contribute to literature reducing the deficit-based approach to Indigenous research. She is learning from Dr. Walker to reduce the stereotyping and marginalization of Indigenous Peoples in research that is founded in communities' needs and results in action. She is grateful to have learned from meetings with Dr. Jennifer Walker, Julia Rowat, Niki Naponse with Za-Geh-Do-Win Information Clearinghouse and First Nations community members at the Indigenous Dementia Research Conference.

## Background Information

As Canada's population ages, the number of individuals living with dementia is expected to increase. Between April 2020 and March 2021, nearly 477,000 people above age 65 were living with diagnosed dementia in Canada. It is thought that there were likely many more undiagnosed cases within the population (Public Health Agency of Canada, 2024), indicating a need to diagnose dementia properly. In North America, some Indigenous populations show a higher prevalence of dementia than non-Indigenous populations (Jacklin, Walker, and Shawande, 2013; Mayeda et al., 2016). Specifically, dementia prevalence in First Nations people in Alberta was higher than in non-First Nations populations and was increasing more rapidly from 1998 to 2009. This study also showed that First Nations men were at a disproportionately greater risk of dementia than non-First Nations men and First Nations individuals had a greater likelihood of earlier onset dementia than non-First Nations people (Jacklin, Walker, and Shawande, 2013). In a study with the Anishinabek Nation, the Institute for Clinical Evaluative Sciences (ICES) health data was analyzed and found that from 2009 to 2019 the prevalence of dementia increased in Anishinabek First Nations people over the age of 40. By 2018, this prevalence was 1.7% and 318 people were living with dementia. There were no significant trends in the incidence of dementia in this population over time. In 2018, the incidence of dementia in Anishinabek First Nations people aged 40 and older was 2.4 per 1000. These statistics likely undercount the number of Anishinabek First Nations people living with dementia as data from provincially funded Aboriginal Health Access Centers and the Federal Non-Insured Health Benefits (NIHB) program were not included (Mecredy, 2024).

To aid in dementia diagnosis, the Mini-Mental State Examination (MMSE) was developed in 1975 for global assessment of cognitive status. Another test, the Montreal Cognitive Assessment (MoCA), has been shown to be less susceptible to educational and cultural artifacts than the MMSE (Gluhm et al., 2013). These mental status screenings are used alongside a patient's history, physical exams, and diagnostic imaging and tests to inform a diagnosis of dementia (Gonzalez Kelso and Tadi, 2024). However, neither the MMSE nor the MoCA truly accounts for culture, colonization, education, or health and social inequalities (Jacklin et al., 2020). Therefore, there is a need for cognitive assessments that address cross-cultural assessment fairness (Walker et al., 2021).

In 2006, Australian researchers worked with Indigenous communities to create the Kimberley Indigenous Cognitive Assessment (KICA), a culturally appropriate cognitive screening tool, to use within Indigenous communities in the Kimberley area of Western Australia (LoGiudice et al., 2006; Marsh et al., 2023). Since then, the KICA has been adapted for other regions in Australia (Almeida et al., 2014; Radford et al., 2015; Smith et al., 2009), Iranian adults (Ebrahimi et al., 2015), and Brazilian Indigenous Peoples (De Carvalho, 2016). A similar process to the KICA has been undertaken with Māori people, the Indigenous Peoples of New Zealand, resulting in another tool called the Māori Assessment of Neuropsychological Abilities (MANA) (Dudley, 2020). The KICA was used as a model to develop a culturally appropriate cognitive screening tool for Indigenous Peoples in Canada, specifically created with the Anishinaabe population on Manitoulin Island, Ontario (Jacklin et al., 2020).

To create the Canadian Indigenous Cognitive Assessment (CICA), a Community Based Participatory Research (CBPR) study grounded in a Two-Eyed Seeing approach began in 2015 (Jacklin et al., 2020). This process was used to create an Ethical Space looking at multiple worldviews (Ermine, 2007). The Two-Eyed Seeing approach is a guiding principle brought to academia in 2004 by Mi'kmaq Elders Albert and Murdena Marshall and Dr. Cheryl Bartlett (Roher et al., 2021). The name comes from the Mi'kmaq word for "the

gift of multiple perspectives,” *Etuaptmumk*, which can be translated to “Two-Eyed Seeing.” The Two-Eyed Seeing approach supports partnerships and learning between Indigenous and Western knowledge, so that there is a convergence of understanding (Liberda et al., 2022). The Two-Eyed Seeing approach is a general way of conducting research, contrasted with specific research methods like CBPR that use defined guidelines to ensure equitable power distribution occurs amongst the researchers and community (Liberda et al., 2022). The Two-Eyed Seeing approach must be used in an authentic and holistic way, ensuring that interactions between Indigenous knowledge and Western views are respectful and collaborative. There is a lack of consistency in where it has been applied in literature as researchers have used it as ethical protocols, guiding principles, or frameworks beyond its roots in the Mi’kmaq worldview (Wright et al., 2019). Some have questioned the usefulness of the Two-Eyed Seeing approach in research when Indigenous perspectives are denied in policy decisions for Indigenous communities (Forbes et al., 2020).

The CICA was created to have a culturally safe cognitive assessment (Jacklin et al., 2020), which requires respect for the individuals, consideration of institutional discrimination, reflection upon one’s beliefs and assumptions, and a creation of space where individuals feel safe (Government of Canada; Publications, 2002). The Government of Canada writes that “in a culturally safe environment, non-Aboriginal people recognize and acknowledge that they too will learn and gain competency from their relationships with Aboriginal people” (2002). A culturally safe environment is defined by the participants, and health care professionals are responsible for fulfilling these requirements (Smylie, Olding and Ziegler, 2014).

Researchers recruited members for a Community Advisory Council (CAC) who had either professional or lived experience with dementia and lived in any of the seven First Nations communities on Manitoulin Island. The CAC advised the research team to ensure community participation, specifically recommending that an expert Anishinaabe language group (EALG) be formed. On the EALG, there were 11 older Anishinaabe adults from the seven First Nations communities. These members needed to know traditional and contemporary changes to Anishinaabemwin, be able to communicate in English and Anishinaabemwin, and have respected community standing. Together, the CAC, EALG, researchers (including clinicians), and Elder Jerry Otowadjiwan adapted the KICA into the CICA (Jacklin et al., 2020).

Overarching modifications made to adapt the KICA into the CICA included increasing the clarity and specificity of question wording in both English and Anishinaabemwin, softening the tone of questions, and changing some actions to be culturally appropriate (e.g., respecting the sacredness of hair in the Anishinaabe culture by replacing a hair combing activity). The original KICA was proven to be an ideal assessment for dementia screening among Indigenous people in Australia in remote and rural areas due to its high specificity (88.6%) and sensitivity (95.6%) (LoGiudice et al., 2011). The CICA was tested for inter-rater reliability and validity in Anishinaabe communities on Manitoulin Island, achieving similar specificity (85%) and sensitivity (100%) results in identifying cognitive impairment (Walker et al., 2021).

Dr. Walker’s research team is working with communities from the Anishinabek Nation to implement the CICA. The Anishinabek Nation passed a resolution in June 2019 to enter a research relationship with her at Laurentian University. A collaboration agreement was then signed in June 2023 when Dr. Walker’s team moved to McMaster University. The team, along with the Anishinabek Nation and Za-Geh-Do-Win Information Clearinghouse, developed a research conference to invite Anishinabek Nation community representatives to gather and gain more information regarding dementia and its impact on Indigenous Peoples to build the communities’ capacity for response. Planning for the conference began in the

summer of 2023 and the conference lasted from January 29 until February 1, 2024, in the Chippewas of Rama First Nation territory.

## Purpose

This paper attempts to show the process and important considerations in implementing the CICA, a culturally safe cognitive assessment, by First Nations communities and the health services supporting First Nations people. As Anishinabek communities move toward the implementation of the CICA, there are a lot of questions and considerations that need to be discussed. Based on my learnings from research literature, discussions with community members, and attending the Indigenous Dementia Research Conference, I will highlight key considerations for Dr. Walker's research team and their community partners.

## Approach

To write this paper, I consulted the broader literature on Indigenous dementia research and standardized cognitive screening. I attended the Indigenous Dementia Research Conference (see appendix), Bi-wiji-naanaagdawendaming (let's come together and think), where many considerations and conversations arose that are discussed in this work. During the conference, there was a meeting with three Anishinabek First Nations community health directors with Dr. Walker's research team regarding implementation of the CICA in their communities. I actively consulted Dr. Walker's research team to encapsulate the broader picture of this project and explore five key considerations.

## Discussion

### Key Consideration 1 – Balancing the standardization of the CICA with community relevance

Any standardized cognitive assessment will have some subjectivity in the administration of the exam. It has therefore been shown that leniency in assessment administration can have negative impacts on assessment sensitivity (Gonzalez Kelso and Tadi, 2024). Many standardized assessments try to provide clear instructions and tutorials on the administration and scoring of the assessment to lessen administrator bias. Since a cognitive assessment is only one piece of a potential diagnosis, it is imperative that the administrator exercises clinical judgement as each patient has unique contexts (Gonzalez Kelso and Tadi, 2024).

As adaptations to the CICA occur, it will be important to re-test for reliability and validity. The CICA was made with and for Anishinabek First Nations communities but is beginning to be used in other populations. Based on consultations with community members, clinicians, and researchers, Dr. Walker's research team is looking to balance the requirements of the CICA being a standardized tool versus its need to be a community relevant tool.

The CICA has been tested for inter-rater reliability in Anishinaabe communities on Manitoulin Island (Walker et al., 2021) but could now be tested for alternate-forms reliability which is testing the consistency of scores in many forms of an assessment (Committee on Psychological Testing, Populations and Medicine, 2015), such as adaptations for different Indigenous populations. The CICA was also tested for criterion-related evidence of validity as geriatricians blinded to the CICA scores assessed participants

and the researchers found that CICA results matched well to geriatricians' outcomes (Committee on Psychological Testing, Populations and Medicine, 2015; Walker et al., 2021). The goal to have a community relevant tool can be captured in researching cultural validity which tests for the content and procedures of the assessment to reflect the sociocultural context of patients (Committee on Psychological Testing, Populations and Medicine, 2015). As CICA scores are standardized and the cutoff score of 34/39 was found in Anishinabek First Nations on Manitoulin Island (Walker et al., 2021), it is important to ensure this cutoff is still correct in other populations. The norm group should be representative of the test population, and if this is not the case, then inaccurate scores and misinterpretations can occur (Committee on Psychological Testing, Populations and Medicine, 2015).

The use of the CICA is expanding in different populations. This provides a unique opportunity to further test reliability and validity in different populations. Currently, Dr. Megan O'Connell uses the CICA to assess cognitive status in rural Saskatchewan with patients of diverse backgrounds (O'Connell, 2024). In her Rural and Remote memory clinic, she used the CICA with a majority of Eurocentric patients and found the CICA to have high accuracy identifying cognitive impairment. Her preliminary results show that the CICA can be used effectively in patients with a range of cultural backgrounds (O'Connell et al., 2020).

Dr. Lynden Crowshoe is adapting the CICA with urban Indigenous populations in Calgary and is currently testing its reliability. Large changes were made to the original CICA to be applicable to this population. There is a plan to test this adaptation's validity later (Walker, 2024b). The CICA has also been adapted for Nakoda First Nations in Carry the Kettle Nakoda Nation Saskatchewan, Canada (Rowat et al., 2024). Similar processes in the CICA creation were implemented in the adaptation, including an advisory group consisting of Elders and community members. The Nakoda advisory group suggested several changes to the original CICA, with one being implemented (a tea towel to be folded instead of a piece of paper) and many remaining the same to keep the integrity of the assessment intact. As such a small change was made, it was determined that the CICA should have similar reliability and validity. It also showed that there are only minor changes needed to implement the CICA in some other First Nations contexts while keeping the assessment standardized. Translation of the English CICA to the Nakoda language was not completed as there were few community members whose first language was Nakoda. In future, it is important to see if an accurate translation can be made and if it is needed for better access in different First Nations communities (Rowat et al., 2024). If larger changes were made, it would be ideal to retest reliability and validity to explore alternate-forms reliability and cultural validity, potentially demonstrating more strengths of the CICA.

Dr. Walker's research team has found that the most common adaptation request amongst different Indigenous communities is in changing the pictures associated with the CICA (Walker, 2024b). In doing this change, it is imperative to ensure the images shown have a word associated with the same semantic frequency as the original images, so it is not easier nor more difficult to name the object. This ensures the assessment holds its same validity and reliability (Walker, 2024b). In cognitive assessments for semantic verbal fluency, it is important to assess word production of both living and non-living categories (i.e birds and articles of furniture) to screen for cognitive impairments (Quaranta et al., 2016). Thus, researchers adapting the CICA must be careful to replace images that hold the same place in people's minds.

Drawing on knowledge from the use of the MoCA, differences have been found in participants with different sociodemographic backgrounds, including many studies suggesting the need to add "correction point(s)" to accommodate for years and quality of education. People with fewer years of education or

lesser quality learning generally score unfairly lower on the MoCA (Bruijnen et al., 2020). To know with more certainty whether the CICA is applicable more broadly, studying reliability and validity for adaptations is a logical step to take.

### Key Consideration 2 – Potential for educational bias in the CICA

As explored in Key Consideration 1, further research can be done as researchers adapt the CICA and apply it to more populations. This is a good opportunity to retest the specificity and sensitivity of the CICA to account for the participants' education. When adapting the KICA into the CICA with Manitoulin Island First Nations participants, the question of level of education was purposefully omitted. Level of education is a complex question to ask as a Western count of formal education does not include traditional Indigenous knowledge (Walker, 2024a). Indigenous knowledge is passed through generations in experiences and storytelling by Elders or family members whose teachings cannot be counted by grade levels (Hansen, 2022). Level of formal education would count time in residential schools, a traumatic period of assimilation with the poorest quality of education (National Centre for Truth and Reconciliation, 2020). Residential schools were formed to oppress Indigenous ways of knowing and this schooling was genocidal in its attempts to erase Indigenous Peoples as people (Hansen, 2022). It is imperative to recognize the traumas of colonization and understand level of education is an inappropriate and harmful question to ask Indigenous Peoples to test for the CICA's specificity and sensitivity. Therefore, as the CICA is applied to White populations, education bias could be answered soon.

It is known that the MMSE and MoCA both have education bias, but we have no data on whether the CICA has any education bias (Jacklin et al., 2020). We can again use knowledge of the MoCA for what future studies can be done to the CICA. As specificity and sensitivity are calculated based on false and true negatives and positives, and cut-off scores are decided based on attempting to make specificity and sensitivity closest to 100%, educational bias can greatly affect what we believe is a good assessment. False negatives were found in the MoCA with patients that had a high educational level (Dautzenberg, Lijmer and Beekman, 2020). False positives were found in the MoCA with patients that had a low educational level (Wong et al., 2015). It is important to know if the CICA has any educational bias because our assessment of it being a good test could change. Dr. Walker's research team would then be able to correct educational bias, if present, to improve the CICA. Some adaptations of the MOCA to mitigate educational bias include a domain-based approach, adapting the cut-off score, or adding "correction point(s)."

The MoCA was studied in adults aged 60 years and older in Colombia, where it was found that the mean MoCA score increased proportionally to the participants years of schooling. This study showed that patients with a higher educational level had lower odds of incorrect answers in the visuospatial, executive function, confrontation naming, phonemic fluency, and orientation sections of the MoCA as well as short memory-recall task but to a lesser extent (a 7% decrease compared to 13%-20% decreases in incorrect answers in the other domains) (Borda et al., 2019). It would be ideal to analyze each section of the CICA and how education may bias certain cognitive domains differently. If education bias is found, the CICA could, as Borda et al. suggested for the MoCA, screen with a domain-based approach, lessening education bias (2019).

Other studies have looked at lowering the cut-off scores for patients with less years of schooling (Milani et al., 2018). If the cut-off is too high, a proportion of people will incorrectly be classified as cognitively



impaired. Data from the National Alzheimer’s Coordinating Center in the United States was analyzed looking at non-Hispanic White, non-Hispanic Black, and Hispanic participants and found the original cut-off score of 26 for the MoCA was too high when stratified by race/ethnicity, so optimal cut-offs were 25 for non-Hispanic Whites, 23 for non-Hispanic Blacks, and 24 for Hispanics. These cut-offs had different optimality depending on years of education, see table 1 (Milani et al., 2018).

Table 1: Optimal MoCA cut-offs depending on years of education  $\leq 12$  years of education (high school or less), 12-16 years of education (college), or  $>16$  years of education (more than college) and race/ethnicity (Milani et al., 2018).

	$\leq 12$ years of education	12-16 years of education	$>16$ years of education
Non-Hispanic Whites	22	24	25
Non-Hispanic Blacks	19	23	23
Hispanics	23	24	24

In a study with 407 African Americans, higher perceived discrimination was associated with worse global cognition and performance on episodic memory and perceptual speed when accounting for age, sex, and education (Barnes et al., 2012). Racial discrimination is likely a contributor to neurodegeneration due to it being a consistent source of stress (Coogan et al., 2020). As mainstream cognitive assessments were generally standardized on White male populations, there are cultural biases present, but adjusting cut-off scores on the basis of race has been a criticized practice (Mirza, Waheed and Waheed, 2022). Using race to determine disease prevalence in medicine oversimplifies the complexity of health issues and perpetuates race-based disparities in health. The use of race in clinical determinations can reinforce racial prejudices and stereotypes due to historical and societal biases healthcare providers may carry. As race is accepted to be a social construct, it is not a good determiner for biological differences amongst individuals. Racial categories are not standardized among researchers and data sets, thus it is ambiguous to use race for clinical algorithms (Visweswaran et al., 2023). In short, the study by Milani et al. highlights the cultural and educational biases in common cognitive assessments like the MoCA. If considerations are not made to account for these biases, then people will be wrongly screened with cognitive impairments. Although Milani et al. account for both race/ethnicity and educational level, as well as their intersection, this practice has been criticized. The CICA was created to be a culturally relevant tool (Walker et al., 2021), so it accounts for potential cultural bias. Suggestions that the MoCA could implement varying optimal cut-offs based on race/ethnicity can be partially attributed to a lack of cultural equivalence in assessment items (Milani et al., 2018), but this has been accounted for in the CICA. Missing now is the lack of knowledge on potential educational bias in the CICA. Once this is understood, it will be crucial for CICA researchers to not perpetuate race-based disparities in health, thus changing cut-off scores based on race is likely not the best path to potential mitigation.

Some studies suggest adding “correction point(s)” to accommodate for less education. The MoCA assessment suggests adding 1 point for patients with  $\leq 12$  years of education to account for education bias, but this adjustment value has not been thoroughly studied (Milani et al., 2018). A population of

Spanish-speaking Hispanics aged 51-90 at the Easton Center for Alzheimer's Disease Research in California, United States were evaluated with the MoCA. This data suggested that patients with a lower level of education (<6 years) required a correction of 3-4 additional points to account for educational bias (Zhou et al., 2015). It would be a complex decision to use "correction point(s)" for the CICA as too much correction could cause false positives, but too little correction will cause false negatives. As the question of education would not be asked of Indigenous participants, "correction point(s)" would be difficult to apply during assessment administration.

Dr. Walker's research team has many routes to explore the potential educational bias in the CICA either at the cognitive domain level or standardized scoring level. If adaptations are required, studies can focus on delivering the CICA with a domain-based approach, adapting the cut-off score, or adding "correction point(s)." There would be intricacies to applying any of these options, and it seems the most feasible would be a domain-based approach as the question of education level should not be asked. Understandably, this work has not occurred yet due to the inappropriate and harmful nature of asking level of education from Indigenous Peoples. This work will have to be explored in other populations or work with Indigenous advisory groups could attempt to find an equivalent, culturally appropriate, and relevant way to ask about education. It would also be imperative to ensure researchers do not perpetuate disparities when using data found in non-Indigenous people and potentially apply findings to work with Indigenous communities. If an education bias is found, great care will be required in adapting the CICA to lessen the gap without stereotyping entire populations.

### Key Consideration 3 – Screening versus case finding use of the CICA in communities

The conference allowed for open conversation amongst health directors in the Anishinabek Nation communities and Dr. Walker's research team. Initially, many communities requested widespread screening to gain their community's cognitive baseline, yet Dr. Christopher Patterson discussed the complications with widespread screening during his presentation. Dr. Patterson warned that this goes against expert recommendations and may bring about results a community will be unprepared for (Patterson, 2024).

Recommendations were released in 2020 for the fifth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD) whose guidelines apply to Canadian clinicians and researchers. They did not recommend cognitive screening in asymptomatic adults, including those with risk factors like family history or vascular risk factors. They also stated that a practice of routine screening asymptomatic individuals is not founded in evidence (Ismail et al., 2020).

The Canadian Task Force on Preventative Health Care published similar findings in 2016 with a strong recommendation to not screen community-dwelling asymptomatic older adults ( $\geq 65$  years) for cognitive impairment. This decision was based on low-quality evidence as there were no trials examining cognitive impairment screening effectiveness on patient outcomes, family and care partner outcomes, or societal outcomes. Their conclusion was that screening asymptomatic patients would most likely yield mild cognitive impairment, not dementia results. Then, looking at the outcomes for individuals with mild cognitive impairment, it was found that there are no clinically effective treatments for these patients. Thus, the task force strongly recommended against asymptomatic screening due to a lack of evidence on

the efficacy of screening and treatments for mild cognitive impairment (Canadian Task Force on Preventive Health Care et al., 2016). During the Indigenous Dementia Research Conference, Dr. Laura Middleton discussed how lifestyle factors like exercise and diet can be changed to support someone with normal cognitive function as well as during a time of mild cognitive impairment and after a dementia diagnosis. She highlighted that preventative actions are possible to reduce dementia risk, delay symptom onset, and improve function if a person gets dementia (Middleton, 2024). Dr. Middleton's findings contradict the Canadian Task Force on Preventive Health Care's results that there are no clinically effective treatments to mitigate cognitive impairment.

The US Preventive Services Task Force (USPSTF) also found that there is no empirical evidence to suggest screening for cognitive impairment improves patient or care partner outcomes nor causes harm. USPSTF said it is unknown if interventions for patients with cognitive impairment or their care partners clinically benefit from earlier detection. This publication also explored the harms of screening including diagnostic inaccuracy or stigma surrounding a diagnosis. Their recommendation is that there is insufficient evidence to understand the benefits or harms of cognitive impairment screening in asymptomatic community-dwelling adults aged  $\geq 65$  years have, so more research is required (Patnode et al., 2020).

There will need to be sufficient support in communities if widespread screening were to occur. If someone receives a low CICA score, they will need further clinical evaluations to determine the cause of their cognitive impairment. To diagnose someone with dementia, after a cognitive assessment is taken, they may undergo blood tests, vital sign assessments, brain scans (i.e CT, MRI, PET), and other evaluations. A team of specialists may be required including neurologists, psychiatrists, and geriatricians (National Institute on Aging, 2022). A community will need to be prepared for a potential large influx of patients requiring these services upon widespread screening.

Stigmatization of dementia is another issue patients are facing, and communities must overcome. Stigma has been seen to decrease quality of life for individuals living with dementia and cause people to seek less support and medical advice (Rewerska-Juško and Rejdak, 2020). Feelings of shame are attached to internal sources of stigma for patients with dementia. Many people experiencing stigma feel negatively labeled as "spoiled" and often face a loss of power and/or status (Swaffer, 2014). The stigma surrounding dementia also often causes discrimination and social exclusion (Phinney et al., 2023).

To support people living with dementia, we must reduce the stigma associated with dementia in our societies. Using preferred terms and creating dementia-friendly communities are steps toward normalizing dementia. Ensuring language surrounding people with dementia keeps their dignity and self-esteem intact instead of using terms like "suffering" and "victim" which perpetuate helplessness. Creating dementia-friendly communities would include people living with dementia in planning dementia-friendly projects and empowering them to live their pre-diagnosis lives as long as possible (Swaffer, 2014). Education-based stigma reduction includes spreading facts about dementia in an accessible and culturally relevant format. Contact interventions include displaying people living with dementia's achievements and ability to live active lives. It is also important for relationships to be built amongst people living with dementia and the broader community (Bacsu et al., 2022).

A diagnosis is clearly just the first step in a community's need to provide resources. Future research and projects are working toward ensuring culturally relevant support for people living with dementia and care partners of people living with dementia. This includes Mina Nindamowin, a project by Maamwesying, North Shore Community Health Services (Mercieca, 2024). Many branches of the Alzheimer's Society in Canada do not have the capacity to support Indigenous-specific resources, but capacity is being built as attention is drawn to this issue (Iroanyah, 2024). Care partners of those living with dementia can experience ambiguous loss and grief. Being a care partner can be an extremely challenging role, especially if care partners experienced intergenerational trauma (Restoule, 2024). Therefore, care is imperative to provide to care partners, as a supported care partner can provide a higher quality of care to the person with dementia (O'Connell, 2024). Communities must also actively engage in projects aimed at reducing stigma related to dementia. Overall, there is much more work required to support all Indigenous people affected by dementia.

#### Key Consideration 4 – Policy changes in NIHB

The Non-Insured Health Benefits (NIHB) program covers eligible First Nations and Inuit people with health benefits that are not covered by social programs or private, provincial, or territorial health insurance (Government of Canada; Indigenous Services, 2019). Currently, the NIHB requires the MoCA to be administered as a cognitive assessment. When communities use the CICA currently they must also administer the MoCA (Mercieca, 2024). During the Indigenous Dementia Research Conference, community health directors called for policy changes in the NIHB to recognize the CICA as a valid cognitive assessment. Future work should be done to request the Government of Canada to switch the standard cognitive assessment required to be the CICA instead of the MoCA as it was made to be culturally relevant. Research to support crosswalks between the MoCA and CICA scores in non-Indigenous populations may help support this change.

#### Key Consideration 5 – Integrating the CICA into Information Systems

The CICA was created to be scored on paper and allow communities to input results in whichever system they require. During the Indigenous Dementia Research Conference, community health directors voiced that if the CICA could be integrated into their electronic medical record (EMR) systems, there would be a greater ease of administering the assessment and an immediate upload of results. Future work should be done to adapt the paper scoring into communities' EMRs.

## Conclusion

The key considerations explored in this paper were informed by research literature and influenced by conversations at the Indigenous Dementia Research Conference. As the CICA is a novel culturally fair cognitive assessment for First Nations in Canada (Walker et al., 2021) conversations have only just started regarding the intricacies of its implementation. Many more key considerations may appear in the coming years as the CICA is used in Anishinabek First Nations communities and other diverse populations. As found in the five key considerations addressed here, more research is required to assess the CICA's quality of assessment in diverse Indigenous communities in Canada. It is also crucial to adapt as research continues to improve the CICA's applicability. We are at the beginning of finding the ways in which the CICA can grow and become a useful tool for many Indigenous communities.

As this research continues, it is important to note that despite what some may say, Indigenous research does not move slowly. Instead, it moves at the pace of the community. When a community has time to provide attention to these projects, the work moves quickly. The timeline for communities may be slow in the world of grants and funding from academia, and might not fit well into these models, but if a want for research that benefits their communities is there, then the research will be done. As work continues with the CICA, it will be critical for academia and funding to better match communities' timelines to continue in a mutually beneficial and respectful manner.

# INDIGENOUS *Dementia* CONFERENCE

JAN 30-31, FEB 1

2024



**LOCATION:**

*Casino Rama*



**Bi-wiiji-naanaagdawendaming**

**“Let’s Come Together and Think”**

# INDIGENOUS Dementia CONFERENCE

**Bi-wiiji-naanaagdawendaming**

“Let’s Come Together and Think”

## AGENDA

Pre-Conference One Day Training Session  
Monday, January 29th

1:00 PM - Canadian Indigenous Cognitive Assessment Tool - Training Session  
4:00 PM Co-Presenting: Dr. Jennifer Walker, Dr. Megan E. O’Connell & Julia Rowat

Day One  
Tuesday, January 30th

7:30 AM Breakfast - Silvernightingale Ballroom

8:30 AM Opening

- Master of Ceremony: Dr. Pamela Williamson
- Welcoming Prayer and Song
  - Nookmis & Mishomis

- Welcoming Address
  - Chief Ted Williams, Chippewas of Rama First Nation
  - Jimbob Minomaazo Marsden, SE Regional Deputy Grand Chief
  - Reginald Kaawingai Niganobe, Anishinabek Nation Grand Council Chief

9:00 AM Plenary A

- Dr. Samir K. Sinha, MD, DPhil, FRCPC, FCAHS, AGSF Peter and Shelagh Godsoe Chair in Geriatrics and Director of Geriatrics Sinai Health System and the University Health Network
  - A Report card: Review on Ontario’s Dementia Strategy and its impact on Ontario First Nations



## Day One - Continued

**10:30 AM Wellness Break**

**10:45 AM Plenary B**

- **Dr. Laura Middleton** - Associate Professor & Schlegel Research Chair in Dementia and Active Living Department of Kinesiology & Health Sciences, University of Waterloo Schlegel-UW Research Institute for Aging
  - *How physical activity and healthy eating can impact dementia outcomes.*

**12:00 PM Lunch**

**1:00 PM Plenary C**

- **Dr. Lynden Crowshoe**, Associate Professor of Medicine and Assistant Dean Indigenous Health at the University of Calgary (UC) Cumming School of Medicine (CSM)
  - "Type 3 Diabetes" - the Impact of Diabetes on Brain Health

**3:00 PM Wellness Break**

**3:15PM Plenary D**

- **Dr. Brenda Restoule**, CEO, First Peoples Wellness Circle
  - Helping Families Manage the Grief of Dementia

**4:30 PM Day One Closing**

- **Master of Ceremony: Dr. Pamela Williamson**
  - Wrap Up & Draw

**6:00 PM-8:00 PM EVENING NETWORKING & CRAFT SOCIAL**

- **Lyndsay Taibossigai**
- *Intro Learning to Paint with Water Colours*





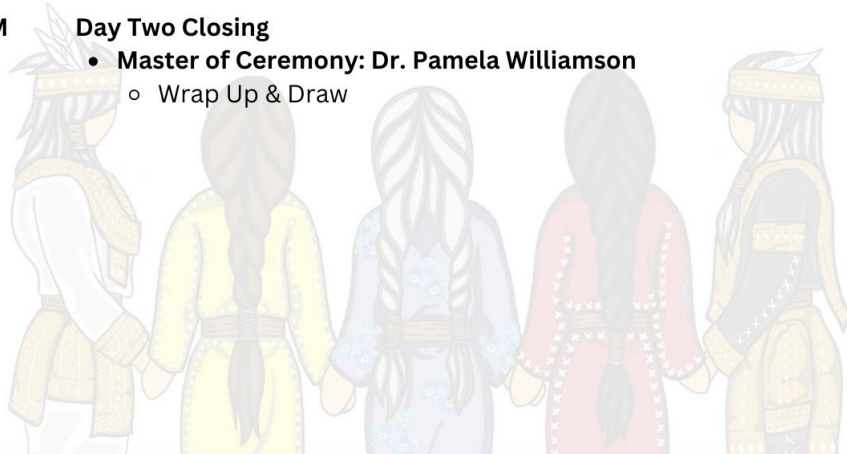
## Day Two Wednesday, January 31st

- 7:30 AM**      **Breakfast** -Silvernightingale Ballroom
- 8:30 AM**      **Welcoming Prayer and Song**
- Nookmis & Mishomis
- 8:50 AM**      **Recap of Day One**
- **Master of Ceremony: Dr. Pamela Williamson**
- 9:00 AM**      **Plenary E**
- **Dr. Jennifer Walker**, Associate Professor, Department of Health Research Methods, Evidence & Impact. McMaster University
    - Learning from First Nations' Aging and Dementia Research: Where to go from here?
- 10:15 AM**      **Wellness Break**
- 10:30 AM**      **Plenary F**
- **Dr. Megan E. O'Connell**, Ph.D., R.D.Psych. Co-Director of Clinical Training Professor, Department of Psychology & Health Studies, University of Saskatchewan
    - Supporting Indigenous Caregivers: Implementing culturally safer dementia caregiver support groups with Indigenous communities
- 12:00 PM**      **Lunch**



## Day Two - Continued

- 1:00 PM**      **Plenary G**
- **Dr. Anthea Innes** - McMaster University/Director, Gilbrea Centre for Studies in Aging /Faculty of Social Studies
    - *Social Inclusion for People living with Dementia*
- 2:45 PM**      **Wellness Break**
- 3:00 PM**      **Plenary H**  
**PANEL - Insights From The Frontline**
- Deborah Pegahmagabow - Health Director - Wasauksing First Nation
  - Peggy Dick - Home Care Supervisor - Algonquins of Pikwakanagan First Nation
  - Dr. Brenda Restoule - CEO - First Peoples Wellness Circle
  - Heather Nicholas - Councillor- Chippewas of the Thames
- 4:45 PM**      **Day Two Closing**
- **Master of Ceremony: Dr. Pamela Williamson**
    - Wrap Up & Draw



## Day Three Thursday, February 1st

- 7:30 AM**     **Breakfast** - Silvernightingale Ballroom
- 8:30 AM**     **Welcoming Prayer and Song**
- Nookmis & Mishomis
- 8:50 AM**     **Recap of Day Two**
- **Master of Ceremony: Dr. Pamela Williamson**
- 9:10 AM**     **Plenary I**
- **Louis Busch** - Centre for Addiction and Mental Health (CAMH)
    - *Honoring the Journey: Culturally-Responsive Behavioral Supports for First Nations Peoples with Dementia*
- 10:00 AM**     **Wellness Break**
- 10:15 AM**     **Plenary J**
- **Dr. Christopher Patterson** (Geriatrician)- McMaster University
    - *Early Interventions - What can be done right now?*
- 12:00 PM**     **Lunch**
- 12:45 PM**     **Quick Learn - Panel Presentations**
- Edith Mercieca, Maamwesying, North Shore Community Health Services
  - Marta Hajek, Elder Abuse Prevention Ontario
  - Graham Mecredy, ICES Indigenous Portfolio
  - Ngozi Iroanyah - Alzheimers Society of Ontario
- 3:00 PM**     **Wrap Up & Closing**
- **Master of Ceremony: Dr. Pamela Williamson**
    - Wrap Up & Draw

**Miigwetch for joining us and safe travel home**



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