

## **Appendix A:**

Supplementary Information on the  
Development of the CICA with  
Anishinaabe Communities on Manitoulin  
Island, Ontario.

## Introduction & Background

The CICA was developed using a community based participatory research (CBPR) approach, which began in 2009 with focus groups and interviews in collaboration with Indigenous Communities from 6 regions of Ontario, Canada. That work was conducted in partnership with communities meaning that local Community Advisory Council and Elders worked with university researchers in mutual respect and cooperation. Together they conceptualized the research question, guided the development of the research protocol, analyzed the data and shared the results both locally and internationally. They used interviews with patients suspected to have dementia, family caregivers, professional health care providers, Elders and traditional healers to characterize how diverse First Nations people in Ontario understood and experienced memory impairment and assessments. That work shows that key factors influence the process of diagnosis and that cultural understandings influence the perception of symptoms. It also describes the systemic, structural, and access-related barriers in existing Canadian healthcare. One conclusion of this research is that existing screening measures are not culturally safe nor acceptable to the communities. A different approach for clarifying the presence or absence of dementia in Indigenous persons is needed.

## Development of the CICA

### **Adaptation to Validation**

The positive results from the initial CBPR work in the communities was followed by an extensive qualitative study to adapt an existing Australian screening tool called the Kimberly Indigenous Cognitive Assessment (KICA) for use with Canadian Indigenous older adults (Pitawanakwat et al., 2017). A Community Advisory Council, expert Anishinaabe language speakers, and the research team worked together by sharing experiences, thoughts, knowledge, and initial testing results with each other on every question of the original KICA. Following the adaptation, the revised assessment was piloted in two consecutive studies. The conclusion of that study is that the adaptation of the Australian KICA to the Anishinaabe context on Manitoulin Island, Ontario was successful, with the results being the creation of the Canadian Indigenous Cognitive Assessment (CICA), in both English and in Anishinaabemwin. For more information on the adaptation process see Jacklin et al. 2020.

### **Reliability Testing and Validation**

The CICA was next tested for reliability and validity. Reliability is demonstrated when assessors come to similar conclusions no matter who administers the test. To test this, we used two different assessors who administered the CICA to 15 community members twice within the same day. This test showed very good inter-rater reliability. Next, we undertook a validation study. A valid test would be one that accurately identifies dementia in people who are assessed. This is measured using the concepts of sensitivity (it can identify dementia when the

loved one really has it) and specificity (it will mislabel the loved one who does not have dementia). To test this, we assessed people with the CICA and by a geriatrician to see if our new tool agreed with the geriatrician's assessment. This helped us to determine that the best cut-off for the CICA was 34/39 points (a CICA score of less than 35 indicates possible dementia, and medical review required) where the CICA could tell the difference between patients with dementia or no dementia very well. Together these pieces of evidence support the CICA as a valid and reliable test for cognitive impairment for use in North American First Nations and Indigenous persons.

## Key Terms

**Loved one:** The term “loved one” is used to describe the individual who is being assessed for dementia. Although mainstream practice and current recommendations suggest steering away from using the term “loved one”, our Anishinaabe partners on Manitoulin Island have expressed that this term is appropriate for use with Anishinaabe people in their communities. The term “loved one” was adopted after consultation with Elder Jerry Otowadjiwan, who indicated that the term “loved one” was appropriate to describe a person with memory loss or a person receiving care in the Anishinaabe context. Elder Jerry Otowadjiwan teaches that the person who is having difficulties with their cognition needs a lot of love at that point in their lives. They are also loved by someone, whether that person is the caregiver or not. Using the term “loved one” serves as a reminder of how care providers should be treating and respecting the older person who is being assessed for dementia.

**Second Childhood and Coming Full Circle:** The terms “second childhood” and “coming full circle” are Anishinaabe culturally rooted descriptions of cognitive impairment in later life. They do not come from an insulting place and are not considered ‘infantilizing’. In fact, age-related cognitive impairment is most often considered a natural process and is accepted by families and communities. In the Perceptions of Alzheimer’s Disease and Related Dementias among Aboriginal Peoples in Ontario project, these terms came up often:

“Well, for me it is a natural process. I think that if you, you know, like again, back to being a child as you get older as we get older to the point of as, so as, like a child.

“We have to, a child has to learn to walk so how to, you know, it’s a, you forget how to... going back to being a child, like an infant so it’s like I said. We finished our circle of life, you know?” (Senior, Manitoulin Island, Perceptions Project)

“The older people they always refer to that term of going back into their childhood, but they use the Anishnawbe word for that, and that term is “keewayabinoocheeaway.” That’s returning back to childhood.” (Senior, Thunder Bay, Perceptions Project)

“He has or she has back to her childhood again. Like the person has lost all her memories in her future life and she was going backwards into her childhood. I remember that.” (Person with Dementia, Sudbury, Perceptions Project)

**Covered or Buried Memories:** Ni-ngoshkaani wi gaa gkendang “Covered” or “buried” memories are another way of describing the onset of memory loss. This perspective is rooted in the Anishinaabemwin language, and memories are not viewed as “lost.” Rather, they are buried, and inaccessible to the loved one at this time. This way, their identity, roles, and knowledge remain with them, but are covered for the time being. Memories that are covered might be brought to the surface again by sounds, smells, or other stimuli. This is particularly the case with important, cherished childhood memories.

### Translating the CICA

If the loved one indicates that they are more comfortable speaking Anishinaabemwin, the test should be conducted by either a fluent language speaker or with the assistance of an interpreter, using the Anishinaabemwin version of the tool. The interpreter should follow the questions as closely as possible, changing as little phrasing as possible to ensure continued reliability and validity of the tool. The interpreter must read the training materials and watch the training videos. When testing memory, how a loved one makes a mistake may be as important as whether they have made a mistake. The interpreter should translate all mistakes made by the patient with as much detail as possible.

### References

Jacklin, K., Warry, W. and Blind, M. Perceptions of Alzheimer’s Disease and Related Dementias in Aboriginal Peoples in Ontario: Sudbury Community Report (64 pages). Submitted to: Sudbury-Manitoulin Alzheimer’s Society; N’Swakamok Indian Friendship Centre.

Jacklin, K., Warry, W. and Dietrich, D. Perceptions of Alzheimer’s Disease and Related Dementias in Aboriginal Peoples in Ontario: Thunder Bay Community Report (51 pages). Submitted to: Thunder Bay Indian Friendship Centre and Anishinaabe Mushkiki Health Centre.

Pitawanakwat, K., Jacklin, K., Blind, M., O’Connell, M. E., Warry, W., Walker, J., ... & Flicker, L. (2016). Adapting the Kimberly indigenous cognitive assessment for use with indigenous older adults in Canada. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 12(7), P311.