Canadian Indigenous Cognitive Assessment (CICA)

Guidebook

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The CICA was adapted from the Kimberly Indigenous Cognitive Assessment (KICA). The adaptation process in Ontario was guided by Project Elder, Jerry Otowadjiwan, a Community Advisory Council, an Expert Anishinaabemwin Language Group, an expert panel of health care providers, and the authors of the KICA. The validation was completed with assistance from Dr. Christopher Patterson, Dr. Cheryl Allaby, and Rosanna Petrangeli. The work is supported by the local First Nations Health Authorities and Chief and Council. Our community partners include: Wikwemikong Unceded Territory; Noojmowin Teg Health Access Center; Mnaamodzawin Health Services (on behalf of Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River, Zhiibaahaasing); and M'Chigeeng First Nation.

Technically, the CICA is a case-finding tool to facilitate the assessment of mild cognitive impairment and dementia in Indigenous people. However, we also refer to the CICA as a 'screening tool' for dementia in recognition that these terms are sometimes used interchangeably.

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1.1 Introduction and Background

Dementia is a growing public health issue in older Indigenous people. Based on our previous research (Perceptions of Alzheimer's Disease and Related Dementia Among Aboriginal Peoples in Ontario 2009-2014), we found that current cognitive assessment tools are not culturally appropriate. Current screening tools that assess dementia such as the Mini-Mental State Examination (MMSE) or the Montreal Cognitive Assessment (MoCA) do not pay enough attention to culture, education or health inequalities in their assessment process; so, those tools often lead to misdiagnosis and may mistakenly say that people have cognitive impairment when they are actually cognitively well. Because many Indigenous older people are not properly assessed, their cognitive concerns are less likely to be recognized by health care professionals.

Our research partners and advisory boards stressed the importance of having a culturally appropriate and safe screening and assessment tool to use with Indigenous people in Canada. After examining a number of cognitive assessment tools, we decided to take a closer look at the Kimberly Indigenous Cognitive Assessment (KICA) (Western Australia Centre for Health and Aging, 2019).

Adapting the KICA was a multistep process involving a group of expert language speakers, an adaptation working group consisting of researchers, physicians, geriatricians and a neuropsychologist, focus groups with health care professionals working with older Indigenous adults, and ongoing consultations with the principal authors of the KICA. The adapted tool was piloted, tested for reliability, and validated for use by health care professionals with Anishinaabe people ages 45 and older on Manitoulin Island, in northern Ontario (The CICA Tool is available on the I-CAARE website www.i-caare.ca).

The resulting instrument, the Canadian Indigenous Cognitive Assessment (CICA), is a case-finding tool, where a score of 34/39 and below may indicate possible dementia. Those with a CICA score of 34 or lower should be referred to a doctor/nurse practitioner or to their local health centre for further medical testing to rule out any other causes of cognitive impairment. There may be different reasons for a low test score, such as depression, delirium, urinary tract infections, or other treatable conditions.

1.1 Key Terms

Throughout this guide and the adapted tool, we will be using consistent language. Some key terms you might encounter include:

1.1.1 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 Indigenous partners have expressed that this term is appropriate for use in Indigenous 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. The term has been used in lieu of “patient” or “client” throughout the CICA, this guide, and the accompanying training. 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.

1.1.2 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 is 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)*

1.1.3 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.

2.0 The need for culturally safe dementia care and tools

2.1 What is cultural safety?

Cultural safety, a concept originally defined by New Zealand Maori nurse educators, addresses structural inequalities and power relationships between health care providers and patients that influence equitable access to care and create inappropriate health care encounters (Ramsden, 1990). Cultural safety retains, and also expands upon the cultural domains previously associated with cultural competence and cultural sensitivity allowing for a more critical awareness of the residual structural violence in our health care systems; that is, the way health institutions may harm people by preventing them from attaining appropriate, safe health care, and positive health outcomes (Bailey et al., 2017; Farmer, 2004). Cultural safety and culturally safe care are approaches that have emerged as strategies to address disparities in Indigenous peoples' health and health care. Appropriate delivery of dementia care in a culturally safe way, requires that care providers receive cultural sensitivity training that includes Indigenous explanatory models of dementia, appropriate approaches to the clinical encounter, dementia prevention and care, and how to reduce barriers and improve access to appropriate care and support (Jacklin, Warry, Pitawanakwat, & Blind, 2016).

2.2 Previous and associated research in building the framework for Indigenous specific dementia tools

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.

3.0 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 experience, thoughts, knowledge, and initial testing results with each other on every question within the original KICA. Following the adaptation, the revised assessment was pilot tested in two consecutive studies. The conclusion of that study is that the adaptation of the Australian KICA to the Anishinaabe context in Ontario was successful, with the results being the creation of the Canadian Indigenous Cognitive Assessment (CICA), in both English and in Anishinaabemwin.

3.1 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 also 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. For more information on the detailed results from this study, please contact Drs. Jacklin and/or Walker (Walker et al., validation study in development).

Together these pieces of evidence support the CICA ON as a valid and reliable test for cognitive impairment for use in North American First Nations and Indigenous persons.

4.0 Conducting the assessment

The CICA can be used by formal and informal caregivers, health care providers, and allied health staff in the loved one's home, community, or health care setting. It can be used whenever there is a change in cognitive function or health status, or where cognitive impairment is suspected. The CICA is ideal for Indigenous older adults, it is a gentle and culturally safe test that might help to mitigate anxiety, and it can be administered in different languages or through translation. At this point, we do not know how the CICA scores relate to clinical changes over time, so it should not be used to track cognitive function over time for clinical purposes.

4.1 Key considerations in approach and non-verbal communication (cultural safety)

The Project Elder, along with the Community Advisory Council and the Expert Anishinaabemwin Language Group all stressed the importance of approaching older Indigenous adults in the right way. The assessor or assessment team will need to allow ample time to build trust and develop the relationship in a gentle way. This may include sharing information about yourself with the loved one such as who you are, who your parents are, where you are from, and what you do. The assessor will then need to explain the purpose of what the assessment is and why they are going to ask these questions.

We have worked with language experts and a Community Advisory Council to ensure the wording is appropriate to use with Anishinaabe older adults. Both groups stressed the importance of softening the tone of the language used and making the questions more specific but less direct. Please read the question as stated. If the loved one needs further clarification, you can rephrase the question at that time. For example, you may be asked why these questions are being asked. In response, you might want to gently acknowledge this by responding to the loved on being assessed by saying, “this assessment is being done so that we can understand your memory today”.

4.2 Training and using the CICA

4.2.1 Training videos

There are four versions of the CICA training video; English only, Anishinaabemwin only, English to Anishinaabemwin using a translator, and American Sign Language. These videos can be found online at www.i-caare.ca.

4.2.2 Translation

If the loved one indicates that they are more comfortable speaking Anishinaabemwin or a language other than English, 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 on makes a mistake may be as important as whether or not they have made a mistake. The interpreter should translate all mistakes made by the patient with as much detail as possible.

4.2.3 Specific instructions to using the assessment

Use clear, simple, and easy to understand instructions to start the assessment. We used the following instructions during the pilot, reliability and validity testing of the CICA. This section provides chapter-by-chapter instructions. Wherever possible, specific considerations or instructions are highlighted for individual questions. This information is highlighted in **bolded text**.

I would like to ask you a few questions about your memory. Some will be easy or simple. Answer as best you can.

Chapter one - Orientation: (Section out of /3)

1) What time of day is it right now? /1

Acceptable answers include, exact time of day, as well as, "morning", "breakfast time", "afternoon", or "lunch time" are acceptable plus or minus within 1 hour of that time.

2) What time are we in right now; is it spring, summer, fall or winter? /1

Make note of the answer given; in between seasons is acceptable. For example, if it is October, but there is snow on the ground, winter would be an acceptable answer.

3) Do you know where you are right now, what is this place? /1

Check with interpreter or family member if answers are correct.

Chapter two - Recognition and naming: (Section out of /6)

1) What is the name of this: *hold up spoon* (1)
2) What is the name of this: *hold up cup* (1)
3) What is the name of these: *hold up matches* (1)

If the loved one has poor vision, put each item in their hand and ask them to recognize it. If unable to identify the items, name each item and place it in their hand.

For the below questions in Chapter Two, hold up each item as you ask the respondent:

4) What is the purpose of this? *Hold up spoon* (1)
5) What is the purpose of this? *Hold up cup* (1)
6) What is the purpose of these? *Hold up matches* (1)

If the loved one has poor vision, put each item in their hand and ask them what the purpose of the item is for.

After the loved one describes the purpose of the object the assessor will then hide the objects around themselves and state:

I AM GOING TO PLACE THESE THINGS AROUND ME. TRY TO REMEMBER WHERE I PUT THEM. I WILL ASK AGAIN LATER ON.

The assessor will then place each object around their personal space and out of the direct eyesight of the loved one. Do not get up and place them around the room as this may upset the loved one.

Simply place the items around you. For example: placing the spoon under a piece of paper on a table, placing the cup in a handbag next to a chair, and putting the matches in a jacket pocket. It is important to verbalize where you are putting each item. Hold up each object and say, "I'm going to place this one here" and then place the object around yourself.

Chapter three – Registration: (Section out of /3)

1) Okay, now tell what those things were?

Give one point for each correct item the loved one remembers.

Chapter four - Verbal comprehension: (Section out of /3)

1) Pick up this paper, fold it once, and give it to me

For this question, you must ask the loved one to complete the three-step task all at once. Do not prompt. Score one point for each step completed

Chapter five - Verbal fluency: (Section out of a maximum of /3)

1) Next, I (we) will ask you to name as many animals as you can in one-minute, wild animals or domesticated animals. Start (or please start now)

Time for 1 minute. If needed, prompt after 15 seconds of silence: How about birds? How about fish?

How to score:

Response	**Score**
1-4 animals	**1 point**
5-8 animals	**2 points**
9 or more animals	**3 points**

In this chapter, you will need to time the loved one for one minute. For timing, a watch or a stopwatch is preferred. Cell phones were distracting and concerning for loved ones

during the piloting of the CICA. For example, loved ones worried that they were being recorded or that assessors were not paying attention to them. This distracted them from the task and made them uncomfortable.

If the loved one is silent for 15 seconds, you may prompt them. If they appear to be really enjoying naming animals, you may let them continue past the one-minute mark, but stop counting animals at that point. Animals that are named both in Anishinaabemwin and in English only count as one animal for scoring purposes.

Chapter six – Recall: (Section out of /3)

1) Where did I put the spoon?
2) Where did I put the matches?
3) Where did I put the cup?

Score one point for each object that is correctly located. The location must be specific, and could either be verbally described or motioned towards.

Chapter seven - Visual naming: (Section out of /5)

1) I will show you some drawings, like this leaf (*Point to example drawing*). Tell me what is drawn. Your task is to remember these, I will ask you one other time.

Show the leaf drawing first, using it as an example, but don't count it in the score. Tell them that they have to say what the drawing is and remember all of the drawings for later on. Once they understand this continue with the rest of the drawings.

Open book/printed copies and point to each drawing, one at a time. Ask: "What is drawn here?" for each drawing.

In translation, be aware of all of the possible names of black birds (i.e. raven, crow) and trees (i.e. spruce and pine), as these are all considered correct.

Remember to remind the loved one that you will ask them about these pictures one other time (e.g., "Remember, I will ask you about these ones another time").

Chapter eight - Frontal/Executive function: (Section out of /1)

Show alternating crosses and circles – XOXOXXOO

1) Copy these letters that you see here (*show or point*) on this piece of paper (*show or point*).

The aim of this exercise is to have the loved one copy the Xs and Os in the correct order on the blank piece of paper. Neatness and size are not scored.

Chapter nine - Free recall: (Section out of /5)

1) Do you remember those drawings I showed you? In any order, tell me what was drawn? *(Show example (e.g., the leaf) as a prompt, don't count in the final score).*

If they get all the answers correct (5/5), automatically give a free recall score of 5/5

Points are given if the loved one's response is generally correct (e.g., "bird" instead of "crow" and "tree" instead of "pine tree"). The example drawings used to demonstrate understanding of the task, the leaf, does not count towards points.

If the loved one remembers all five drawings, skip Chapter 10 and proceed directly to Chapter 11. If they do not remember all five pictures, complete Chapter 10.

Chapter ten - Cued recall: (Section out of /5)

1) Choose the one I showed you at first. *(one of three drawings on a page; repeat with all 5 items)*

Use the leaf page as an example only (don't count in the score). Continue when they understand to point to only one object out of the three shown on the page. In Anishinaabemwin, there is a difference when asking an animate or inanimate question.

Chapter eleven – Praxis: (Section out of /2)

1) I have already loosened this small bottle. Pour however much you want into the small cup.

Make sure to loosen the cap on bottle. If the loved one still has trouble taking the cap off, undo it and set the cap on top of the bottle and ask them to take it off and pour the contents into the cup. For loved ones who are experiencing issues with hand strength or joint pain, you may consider using a bottle that is only half or a quarter full as it will be lighter for them to pick up.

2) Show me how to use this spoon. **Do not prompt or give an example.**

Modifications for Poor Vision

Chapter 2: Recognition and naming: Place each object in the loved one's hand and ask them what it is and what it is used for. Ask them to remember the objects for later on.

Chapter 6: Recall: Ask them "tell me those 3 things I showed you."

Chapter 7: Visual naming: Name pictures for them to remember.

Chapter 8: Frontal executive function: Write **XOXOXXOO** in larger letters for them to copy. If they have significant visual impairment, omit this question.

Chapter 10: Cued recall: Tell them the 3 options that they can choose from. For example, "Which one did I tell you to remember: item, item, or item?"

5.0 After the Assessment

5.1 Interpreting the results

The CICA is scored out of 39 possible points. A score of 34/39 or less indicates possible dementia. A loved one scoring 34 or less should be referred to a doctor/nurse practitioner or to the local health centre for a full dementia medical assessment to rule out any other causes of cognitive impairment. There may be different reasons for a low test score, such as depression, delirium, or other treatable conditions.

Seeking help from your health care provider as early as possible is important. Forgetting things and having confusion may have many causes such as: medication side effects, drug interactions, and complications of infections or other diseases. This emphasizes the importance of seeking an accurate diagnosis of dementia. Early diagnosis will help your loved one & family access the best treatment, support, and information on the illness.

To seek an accurate diagnosis, please contact your health care provider and share the results of the CICA with them. It will be very helpful for them to have a copy of your loved one's assessment, so please keep it in a safe place until your loved one is on their way to see a health care provider.

This assessment may lead you to have many questions. Our team has created several resources that may help you understand what dementia is. These fact sheets may also help you identify signs and symptoms of dementia, how to prevent dementia by aging well, and what to expect after a diagnosis. Additional resources can be found on the internet at www.i-caare.ca/factsheets. When you are on the website, you can find the factsheet "Signs and Symptoms of Dementia: An Indigenous Guide" (© I-CAARE, 2015). These resources can help you think of other ways memory loss may be affecting your loved one. You are always encouraged to speak with your health care provider when these signs and symptoms are worrisome and have daily impacts.

5.2 Need for Additional Support

A diagnosis of dementia can be scary for the loved one and their family. This is why there is a circle of care ready to support them. It is also very important for those family and friends who surround a loved one diagnosed with dementia to get the help they need. Family members, friends, neighbors, and community members naturally play a caregiving role in some communities. It will be important to ensure they are also supported and know what services are available to help. Please share information with your local health care providers as appropriate.

The next section provides some resources that might help you get started.

6.0 Additional Resources

Indigenous specific Dementia factsheets can be found at https://www.icaare.ca/factsheets.

In addition to resources at www.i-caare.ca, a number of resources can be found at the following websites:

- Indigenous Inuit Home and Community Care www.hc-sc.gc.ca
- Alzheimer's Society of Canada www.alzheimer.ca
- Alzheimer's Association https://www.alz.org/
- Government of Canada www.seniors.gc.ca
- End-of-Life Care in Indigenous Communities http://eolfn.lakeheadu.ca/
- Overcoming barriers to culturally safe and appropriate dementia care services and supports for Indigenous peoples in Canada - https://www.nccah-ccnsa.ca/docs/emerging/RPT-Culturally-Safe-Dementia-Care-Halseth-EN.pdf
- Wellness in Early Onset Familial Alzheimer Disease: Experiences of the Tahltan First Nation http://med-fom-neuroethics.sites.olt.ubc.ca/files/2015/08/GTP-Wellness-in-EOFAD-s.pdf
- RaDAR Resources for Dementia Care https://cchsaccssma.usask.ca/ruraldementiacare/Resources.php

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8.0 Appendix

CANADIAN INDIGENOUS COGNITIVE ASSESSMENT (CICA – ON)

Date:_____

Assessor:_____

Participant:_____

I would like to ask you a few questions about your memory. Some will be easy or simple. Answer as best you can.

CHAPTER 1: ORIENTATION (__ / 3)

What time of day is it right now? (1)	
What time are we in right now; is it spring, summer, fall or winter? (1)	
Do you know where you are right now? What is this place? (1)	

CHAPTER 2: RECOGNITION AND NAMING (__ / 6)

Hold up each item in turn and ask:

What is the name of this: *Hold up* ***spoon*** (1)	
What is the name of this: *Hold up* ***cup*** (1)	
What is the name of these: *Hold up* ***matches*** (1)	

Hold up each item in turn and ask:

What is the purpose of this? *Hold up* ***Spoon*** (1)	
What is the purpose of this? *Hold up* ***Cup*** (1)	
What is the purpose of these? *Hold up* ***Matches*** (1)	

CHAPTER 3: REGISTRATION (__ / 3)

I am going to place these things around me. Try to remember where I put them. I will ask again later on.

Okay, now tell what those things were? (3)	

CHAPTER 4: VERBAL COMPREHENSION (__ / 3)

Pick up this piece of paper, fold it once, and give it back to me.	

CHAPTER 5: VERBAL FLUENCY (__ / 3)

Next I (we) will ask you to name as many animals as you can in one minute, wild animals or domesticated animals. Start (or please start now).

Time for 1 minute. If needed, prompt after 15 seconds of silence:

How about birds? How about fish?

1-4 animals (1), 5-8 animals (2), 9 or more animals (3)	

CHAPTER 6: RECALL (__ / 3)

Where did I put the spoon? (1)	
Where did I put the matches? (1)	
Where did I put the cup? (1)	

CHAPTER 7: VISUAL NAMING (__ / 5)

I will show you some drawings, like this leaf. (*Point to example drawing*). Tell me what is drawn. Your task is to remember these. I will ask one other time.

Open book and point to drawings What is drawn here?

Number of drawings correct	

Remember, I will ask about these one other time.

CHAPTER 8: FRONTAL/EXECUTIVE FUNCTION (__ / 1)

Copy these letters that you see here (*show or point*) on this piece of paper (*show or point*).	

CHAPTER 9: FREE RECALL (__ / 5)

Do you remember those drawings I showed you? In any order, tell me what was drawn.

Number of drawings correct	

CHAPTER 10: CUED RECALL (__ / 5)

Choose the one I showed you first, like the leaf.

Point to example drawing.

Number of drawings correct	

CHAPTER 11: PRAXIS (__ / 2)

I have already loosened this small bottle. Pour however much you want into the small cup. (1)	
Show me how to use this spoon. (1)	

TOTAL: __ / 39

CICA drawings

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