

Adapting and Validating a culturally appropriate cognitive assessment tool: The Canadian Indigenous Cognitive Assessment (CICA)

Presenters: Melissa Blind PhD. Karen Pitawanakwat RN.,
CCNA Team 20



Dementia Care 2019
Winnipeg, MB
March 4-5, 2019



CCNA
Canadian Consortium
on Neurodegeneration
in Aging



CCNV
Consortium canadien en
neurodégénérescence
associée au vieillissement



CRaNHR
Centre for Rural and Northern
Health Research



Northern Ontario
School of Medicine
École de médecine
du Nord de l'Ontario
ᐅ·ᐅᐅᐅ ᐅᐅᐅᐅ
L'ᐅᐅᐅ ᐅ ᐅᐅᐅᐅᐅ

Acknowledgements

CCNA Team 20 - Focus Area 2 Investigators , contributors, and staff

- Kristen Jacklin PhD (Team 20 ON lead)
- Carrie Bourassa (Team 20 SK lead)
- Megan O'Connell PhD,
- Wayne Warry PhD,
- Jennifer Walker PhD,
- Brock Pitawanakwat PhD,
- Laura Warren PhD student
- Kate Smith PhD,
- Dina LoGiudice MBBS PhD,
- Leon Flicker MBBS PhD,
- Elder Jerry Otowadjiwan (ON)
- Elder Betty McKenna (SK)
- Louise Jones MSW,
- Rhonda Trudeau
- Jody Tverdal

Community Partners

- Wikwemikong Unceded Territory
- Noojmowin Teg Health Access Center
- Mnaamodzawin Health Services (on behalf of Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River, Zhiibaahaasing)
- M'Chigeeng First Nation

Advisory Group Members

- Isaac Trudeau
- Rose Shawanda
- Monica Pheasant
- Jules Osawamick
- Yvette Corbiere
- Roseanne Debassige
- Bonita Bebamash
- Bill Antoine
- Jean McGregor-Andrews
- Anna Griggle

Language Group Members

- Late Thecla Pheasant
- Late Isaac Pitawanakwat
- Malcolm Simon
- Rosella Kinoshameg
- Edward Osawamick
- Joe and Roselinda Peltier
- Evelyn Roy
- Marion McGregor
- Bill Antoine
- Jean McGregor-Andrews

Health Expert Panel

- Marilyn Proulx
- Dr. Roy Jeffery
- Grace King
- Tamara Beam
- Martina Pitawanakwat
- Darlene Maracle
- Linda Trudeau

CICA in context: An overview of CCNA Team 20 and the Validation project

The Canadian Consortium on Neurodegeneration in Ageing (CCNA) is a five-year national networking initiative supported by CIHR. The CCNA started in 2014 and connects research teams looking at dementia, Alzheimer's Disease and other types of neurodegenerative conditions.

Within the CCNA, Drs. Kristen Jacklin (ON) and Carrie Bourassa (SK) have co-led Team 20, a team of researchers specifically exploring dementia in Indigenous populations, in partnership with communities.

The CICA Validation project is one of several projects connected to CCNA.

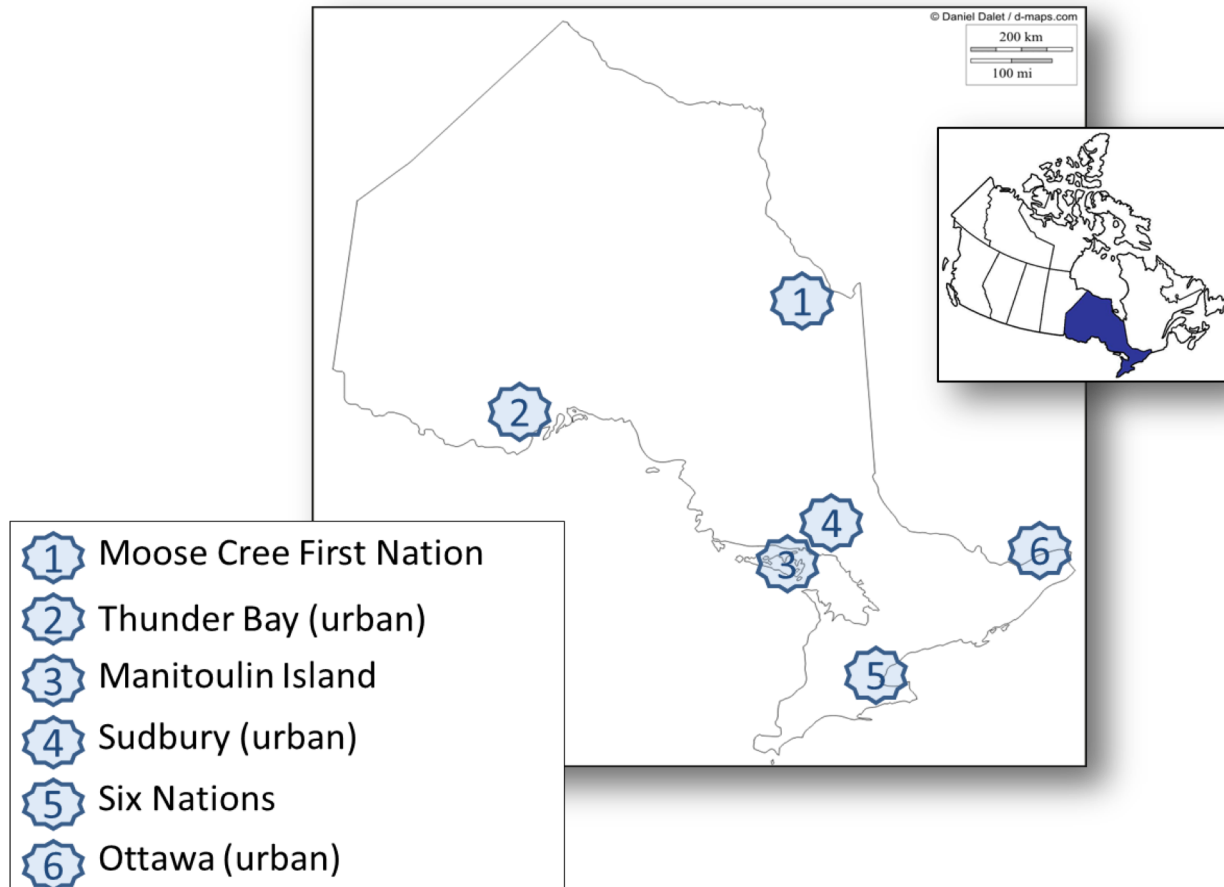


Karen Pitawanakwat, (CCNA T20 ON community researcher) and Kristen Jacklin, (Co-PI CCNA Team 20, lead for Ontario)



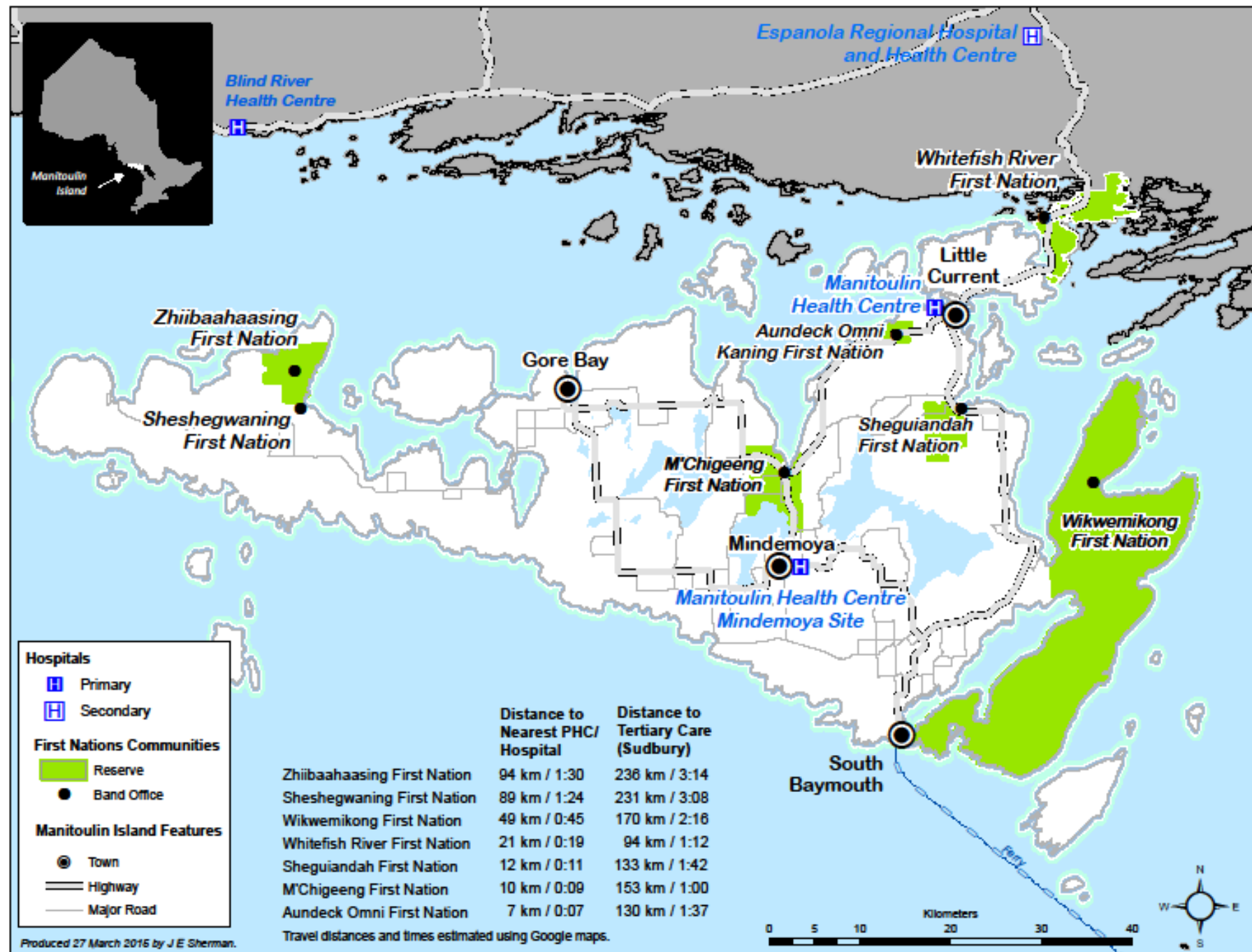
Jennifer Walker (PI) CIHR Validation grant

CICA in Context: a brief background



- 2007 Dementia identified as a community priority
 - Round table organized by the First Nations Health Authorities on Manitoulin Island
- 2009 secured funding to carry out research
“Alzheimer’s Disease and Related Dementias Among Aboriginal Peoples in Ontario”
 - 2009-2013 worked with 9 First Nations communities & 4 urban Aboriginal organizations to produce 6 community reports

Manitoulin Island



Need for culturally appropriate and relevant assessment tools

Patient

Yah, and then he asked me the last one he asked me (laughter) something start with the letter "F". He said to me say, give me 10 words, I couldn't even come up with one word (laughter), but you know what come into my head right away "F" off, "F" word. I said no, I don't know anything, no, there's lots of things, you know, fun, farm and all of that. I couldn't even come up with one word that begin with an "F". (KP Manitoulin Island Person with Dementia 03)

Specialist

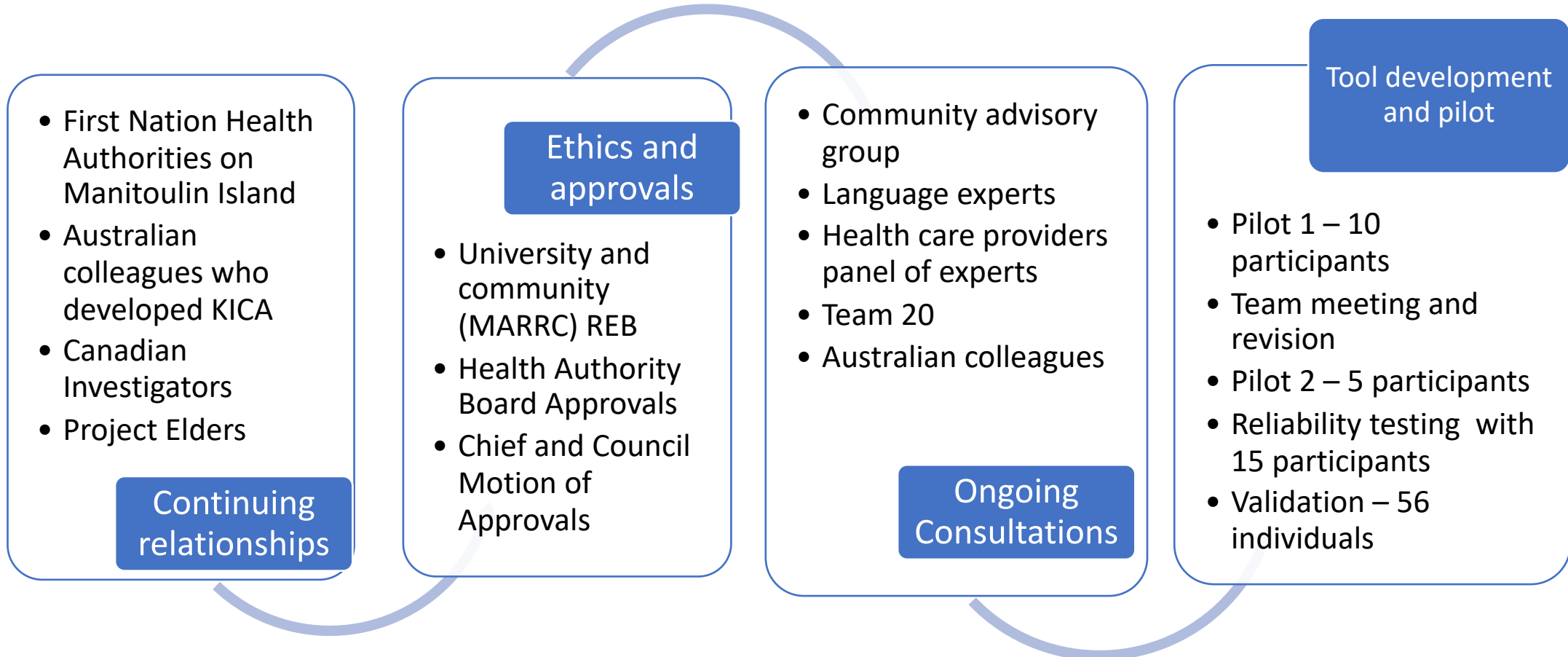
They're usually quite irrelevant. They don't work. In fact, when we first went up there we realized that the traditional screening tools were useless. And we, um, we tried to use tools that were transcultural and were not very successful, so for the most part we're relying on the staff of the nursing home to interpret the behaviours and inform us about the uh, the, uh cognitive deficit. (WW Manitoulin Island Specialist 01)

Planning, Relationship Development, and Research

- Review cognitive assessments deemed appropriate for Indigenous populations
- Identify candidate assessments to adapt
- Settled on the KICA which was developed to address the lack of culturally appropriate assessment tools for older Indigenous people living in Australia
- Held feasibility meetings with Australian researchers (CIHR and IHRDP Planning grants 2012-2014)



Adapting the KICA for use with Anishinaabe people



Iterative process to produce a culturally relevant cognitive assessment tool



Language group working meeting April 4, 2016



Health Care Provider Expert panel May 13, 2016

Refining the tool & fostering relationships



- * AAIC Conference Toronto 2016;
 - * Team Meetings on Manitoulin Island July 29 – August 3, 2016
- * LEGS meeting – “Creating and Adapting a Culturally Sensitive Cognitive Assessment Tool to use with Indigenous People”
 - Presentations given by Leon Flicker, Dina LoGiudice, and CCNA Team 20
- * Group meeting with Advisory group, Language group, Focus 2 members
- * IAGG conference San Francisco 2017



Canadian Indigenous Cognitive Assessment Domains

Orientation

Recognition
and naming

Registration

Verbal
comprehension

Verbal fluency

Recall

Visual naming

Frontal /
Executive
function

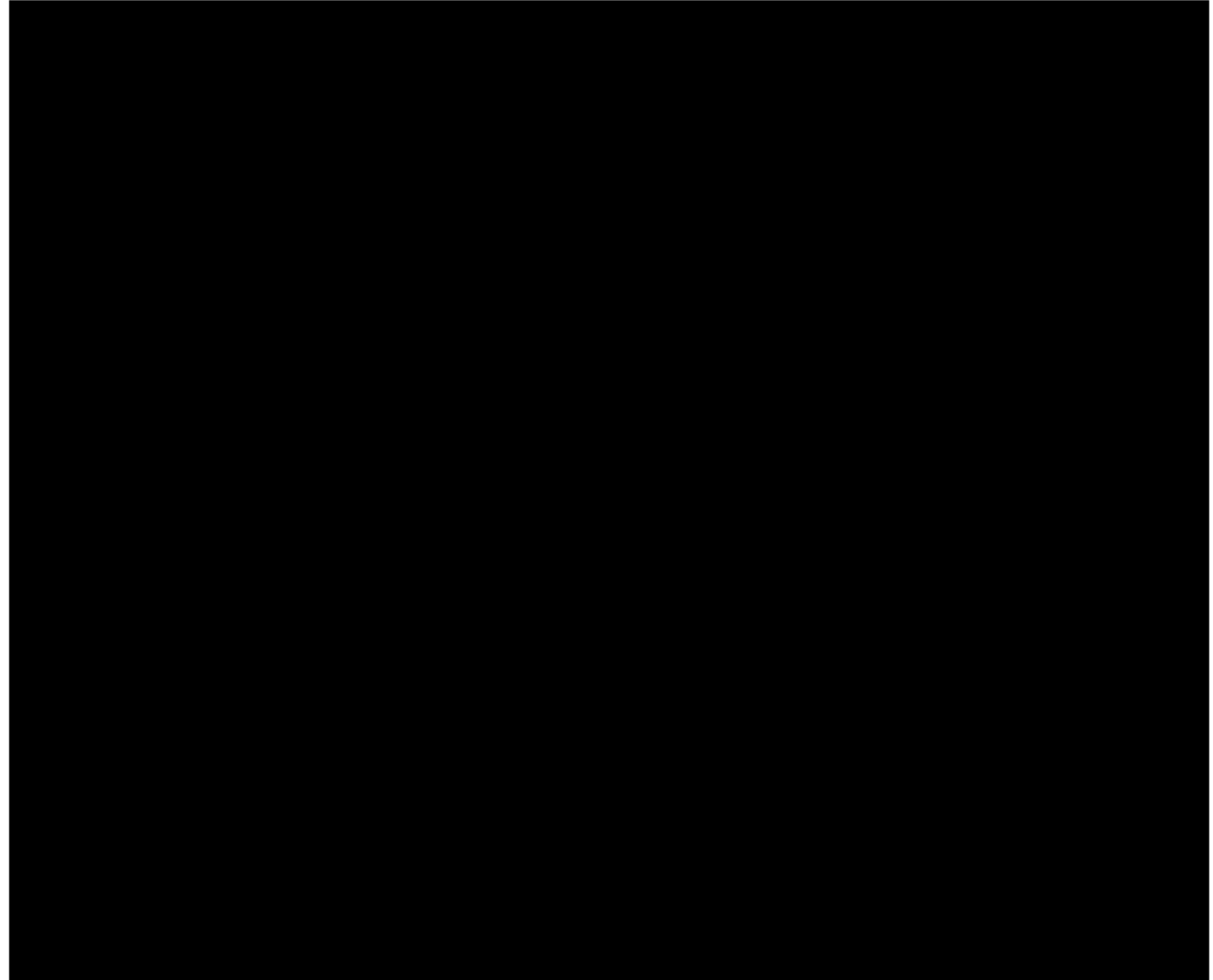
Cued Recall

Praxis

Possible score out
of /39

Translating each domain

KICA	Language group
<p>Chapter 1: Orientation Is this week pension / pay week? What time of year is it now? What is the name of the community / place?</p>	<p>Time How does it feel outside? Place Where you live now?</p>



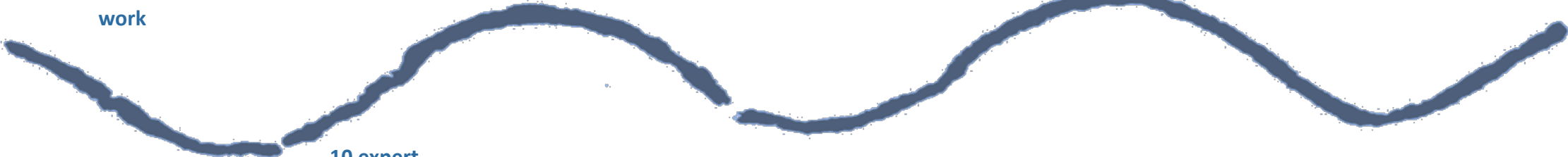
Pilot – Spring, 2017



Advisory group of Anishinaabeg from 7 communities direct the work



15 community members tried the CICA



10 expert Anishinaabemowin speakers translated the Kimberley Indigenous Cognitive Assessment from Australia and adapted it to the Manitoulin Anishinaabeg context

Pilot 1

10 participants

- 5 female
- 5 male
- 6 English speakers
- 4 Anishinaabemwin speakers
- 5 younger (45 – 60)
- 5 older – (61 – 80)

General comments

- Importance of approach
- *“I don’t think you can make this super cultural. The cultural part is understanding how to approach these people. Take the time rather than rushing through the process”* (Pilot 03).
- Use of humour important to all participants
- Setting – comfort level (home vs. office)

Revisions after pilot 1

- Questions changed for following reasons
- Clarification
- Brought up past traumas, impacts of colonialism, trauma to land, including pollution and climate change
- Further account for cultural beliefs

Points of interest

- Use of language
 - Back translation to English not always clear
 - Anishinaabeg more descriptive
- Gender differences
 - Women's vs. men's roles in relation to recall
- Need to account for both culture and trauma
 - Cultural beliefs, values, and practices
 - Impacts of colonialism, residential schools, banning of cultural practices, intergenerational trauma

Pilot 2

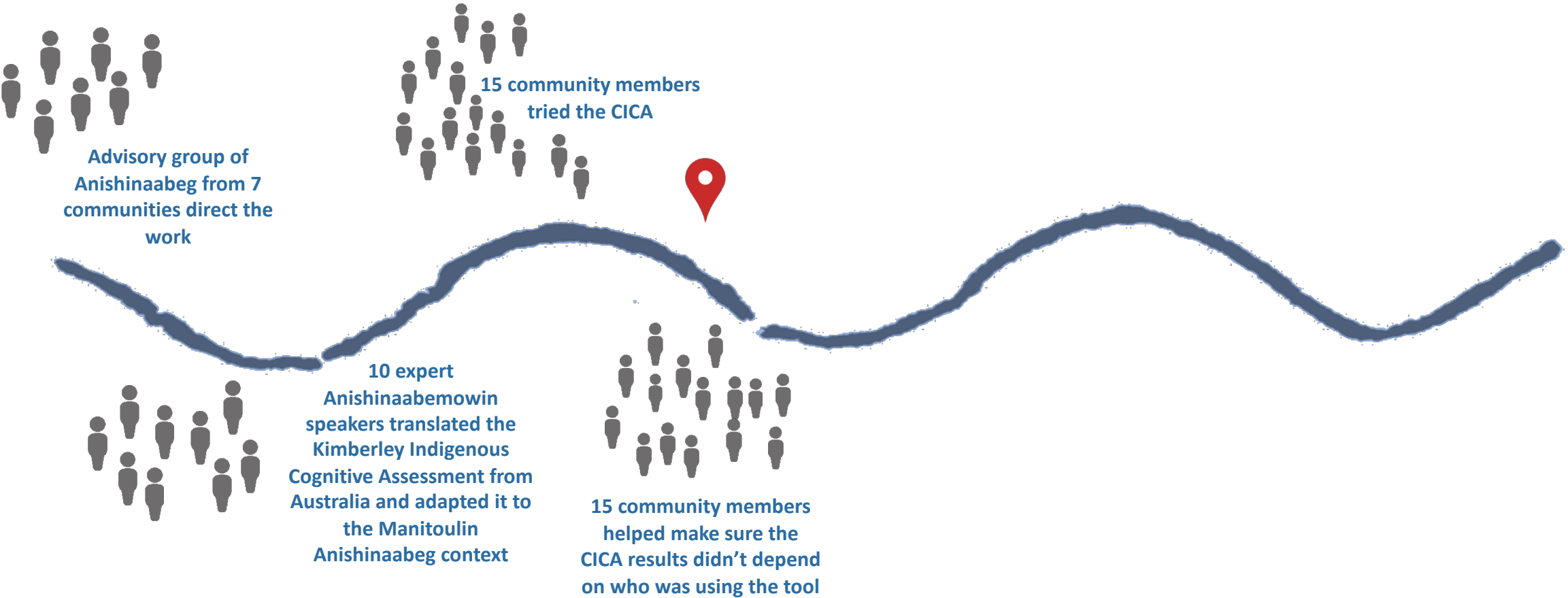
5 participants

- 3 males
- 2 females
- 2 English
- 2 both English and Anishinaabemwin
- 1 Anishinaabemwin

Minor changes

- Rewording of questions for clarity in both English and Anishinaabemwin

Reliability – Summer, 2017



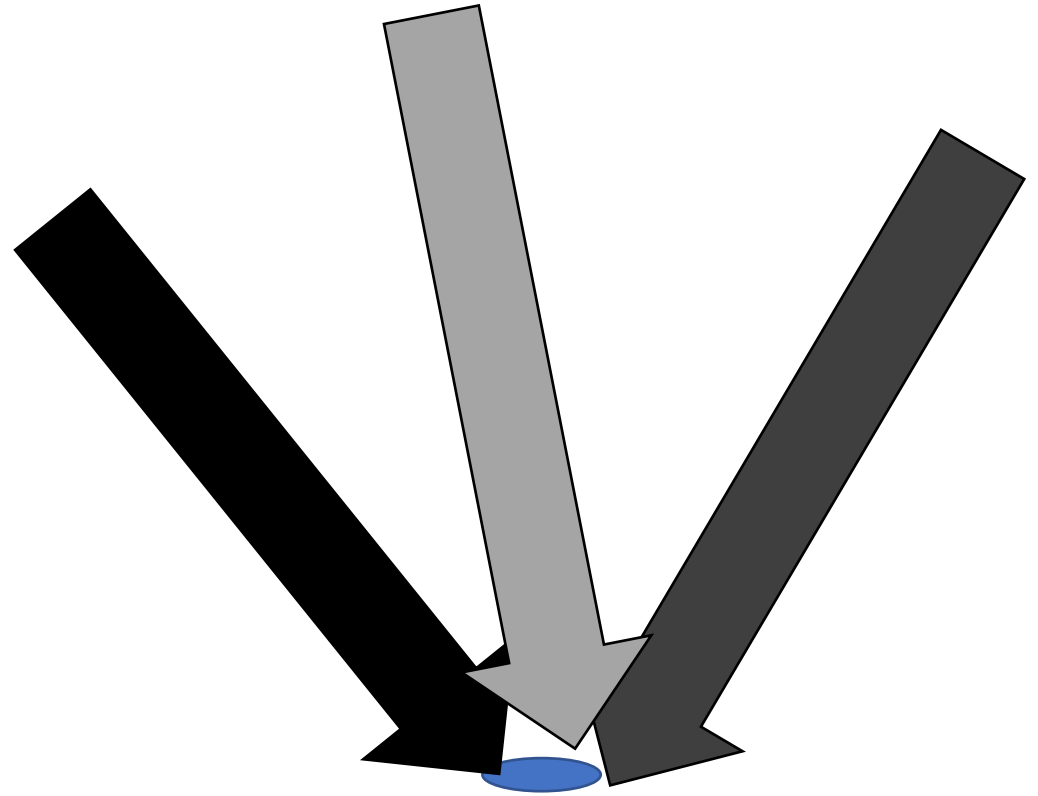
Reliability Methods

- 15 participants
 - 7 women, 8 men
 - 6 younger (45 – 65)
 - 9 older (66-96)
 - 9 living with memory issues
- Assessments conducted in morning and afternoon by two separate assessors



Reliability assessments conducted by:
Louise Jones, Karen Pitawanakwat, Melissa
Blind

What do the
results say
about the
CICA's
reliability?



Overall, the CICA is a **good** screening tool because two different assessors would give the same person a similar score!

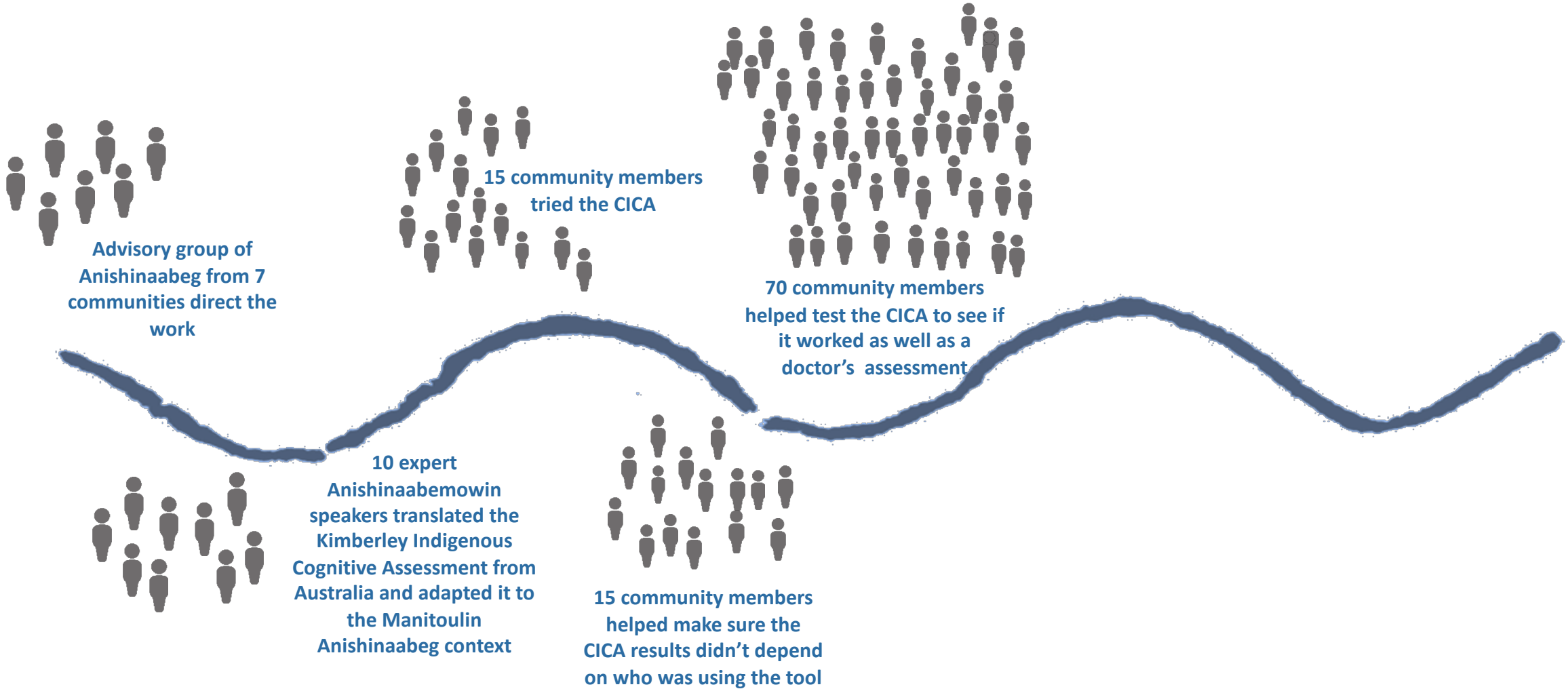
Participant Feedback

Participants said the following about the reliability testing:

- language speakers were very impressed with the quality of the translation (many said, "Good job, Karen!")
- People seemed relaxed throughout, and it was a quick process
- They were very excited to be helping with something that will support their communities. Some people mentioned that maybe the tool would be there for them if they ever needed to get tested.
- A lot of laughter!



Validation – Summer, 2018



Validating the CICA

Separate CIHR grant to see how well the CICA results match a clinical assessment by a geriatrician (Walker, Jacklin and Crowshoe 2016)



CICA validation team April 2018

- 56 participants assessed
 - CICA tool administered
 - Geriatric assessment
 - Clinical assessment
 - Caregiver corroborative interview
 - MOCA, MMSE
 - Vitals and medication review
 - No diagnosis given
 - Participants consented to a preliminary results being shared with their GP
- Honorarium - \$50

CICA screening tool

- We have validated the tool and are in the process of writing the results.
 - We found the CICA is a good screening tool for dementia because it has good sensitivity and specificity
 - Assessment generally takes between 8-12 minutes
- Updates will be posted on the i-caare website (www.i-caare.ca) and on twitter @i_caare

Next steps

- Adaptation and validation in two other provinces
 - Nakota version in Saskatchewan (piloted, reliability testing taking place within next 2-3 months)
 - Urban adaptation in Calgary will be piloted within next 2-3 months
- Training video and resources to support implementation will be released Spring / Summer 2019
- Implementation on Manitoulin Island to take place Spring/Summer 2019

Recap - CICA Process

Adaptation

Piloting (n=15)

Reliability (n=15)

Validity (n=56)

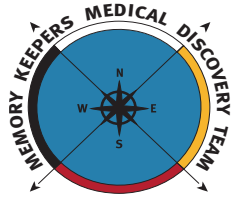
Implementation — 2019-2024

Key takeaway

Culturally Relevant tool that takes language, culture and trauma into account

May lead to earlier, more accurate diagnosis and improved health outcomes.

Identify supports for the person and the family and caregivers, the community



Miigwech! Thank you



Expert language speakers
Community Advisory Group members
Health Care Provider expert panel
Authors of the KICA



Pilot, reliability, & validation participants



Contact Information

Melissa Blind, PhD
Senior Research Associate
Memory Keepers Medical
Discovery Team
University of Minnesota
Medical School Duluth
mblind@d.umn.edu

Karen Pitawanakwat, RN
Community Researcher
Naandwechige-Gamig
Wiwemikong Health Centre,
Wiwemikong, ON
Kpitawanakwat@wikyhealth.ca

Updates and new releases will be posted to:

www.i-caare.ca

Twitter: @I_CAARE