


# Culturally Appropriate Resources for Indigenous People with Dementia

Karen Pitawanakwat & Melissa Blind  
Dementia Care 2019  
Winnipeg, MB  
March 4-5, 2019



*Addressing the need for culturally appropriate  
dementia specific practice tools to use with  
Indigenous populations in Canada: The  
development of PIECES of my Relationships*

Available at <https://www.i-caare.ca/practicetools>

# Acknowledgements

## Investigators , contributors, and staff

- Kristen Jacklin
- Melissa Blind
- Karen Pitawanakwat
- Louise Jones
- Rhonda Trudeau
- Wayne Warry
- Jerry Otowadjiwan
- Monica Bretzlaff
- Emily Piraino
- Roxanne Makela
- Bob Spicer

## Advisory Group Members

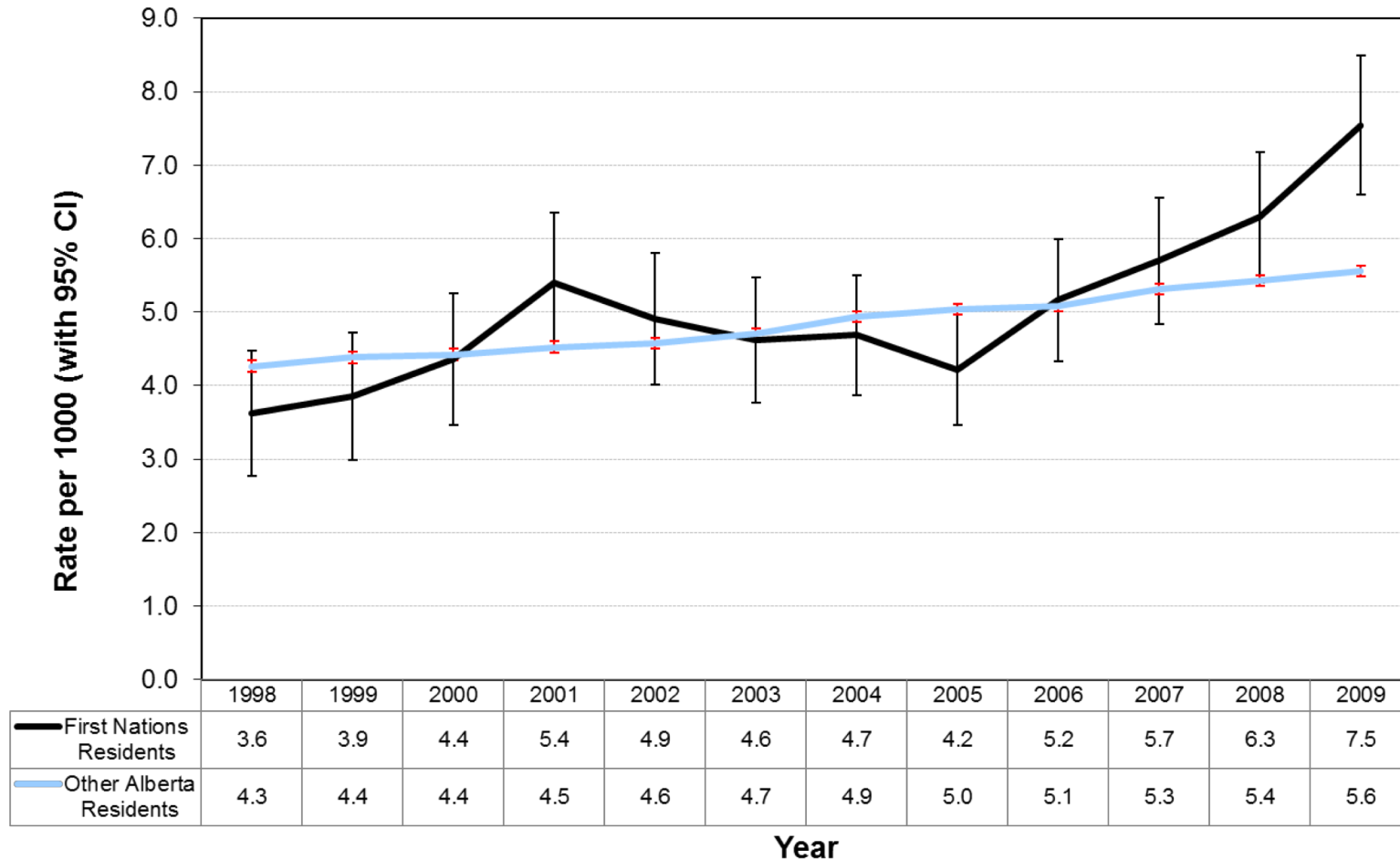
- Isaac Trudeau
- Rose Shawanda
- Monica Pheasant
- Jules Osawamick
- Yvette Corbiere
- Roseanne Debassige
- Bonita Bebamash
- Bill Antoine
- Jean McGregor-Andrews
- Anna Griggle

## 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

# Background: Dementia in Indigenous Peoples in Canada

Age-adjusted treated prevalence of Alzheimer's disease and dementia, Alberta, 1998 to 2009



Prevalence 34% higher in First Nations

Average age of onset 10 years younger

Greater proportion of males diagnosed

Dementia increasing at a faster rate in First Nations

Source: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0

## Adapting PIECES of my PERSONHOOD

- Partnership between North East BSO, CCNA Team 20, and Maamwesying – North Shore Community Health Services
  - NEBSO Indigenous Engagement Strategy – ongoing partnerships since 2014
- Adaptation work on PIECES of my PERSONHOOD tool began in 2015 – 2018



Initial Kazien working group, June 12, 2015

# PERSONHOOD in Dementia Care



**PIECES of my PERSONHOOD** (Version 12/12/12)

Name (First & Last):		Age:	Dominant Hand: Left	Right
Interviewer(First & Last):		Date:	Form #	of
		d/m/y		
PERSONHOOD	PAST	PRESENT		
Preferred Name				
Preferred Language				
I Am Most Proud to be Known As/For...				
Spirituality/Religion/Traditions				
Significant Persons in Life/Relationship				
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“It is more important to know what kind of person has a disease, than what kind of disease a person has.”  
– Sir William Osler

# North East LIHN – where the adaptation took place



- Geographic area is ~400,000 KM<sup>2</sup>
- Population of ~560,000
- 11% NELHIN are Indigenous
- 41 First Nations, mainly in rural/remote areas
- Highest population >65 years of all LHINS (i.e. 16.3% vs. 13.5%)

# Adaptation process



Working group meeting  
July 12, 2016

- Initial review of the tool with the Kaizen recommendations
- Review and recommendations by CCNA Team 20 Community Advisory Group and Elder Jerry Otowadjiwan
- Review of key concepts and translation by CCNA Team 20 Expert Language Group



Manitoulin First Nations Language Advisors January 2016

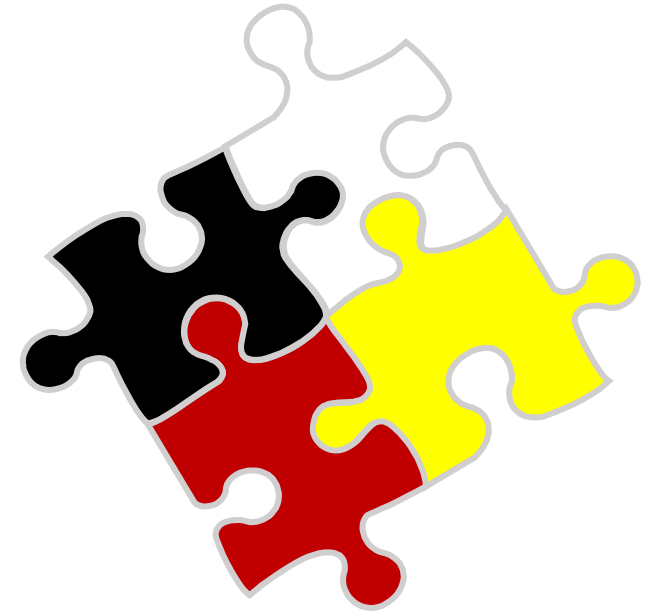


Manitoulin First Nations Advisory Group,  
Feb 2016



# Utilizing Community Based Participatory Research and Indigenous Research Methods

- A commitment to equitable partnerships throughout the research process.
- Community engaged research and action of benefit to all partners, and which is scalable across diverse communities.
- Adhering to the 4 R's of research (Kirkness and Barnhardt 1991; Wilson 2008; Kovach 2009, 2015; Absolon, 2010; Tuhiwai Smith 2012)
  - Respect
  - Relevance
  - Reciprocity
  - Responsibility



# Adapting a culturally safe tool across the NE LIHN

## Focus groups across 3 sites

- Serpent River
- Sudbury
- Cochrane

Communities chosen for linguistic, geographic, and cultural diversity

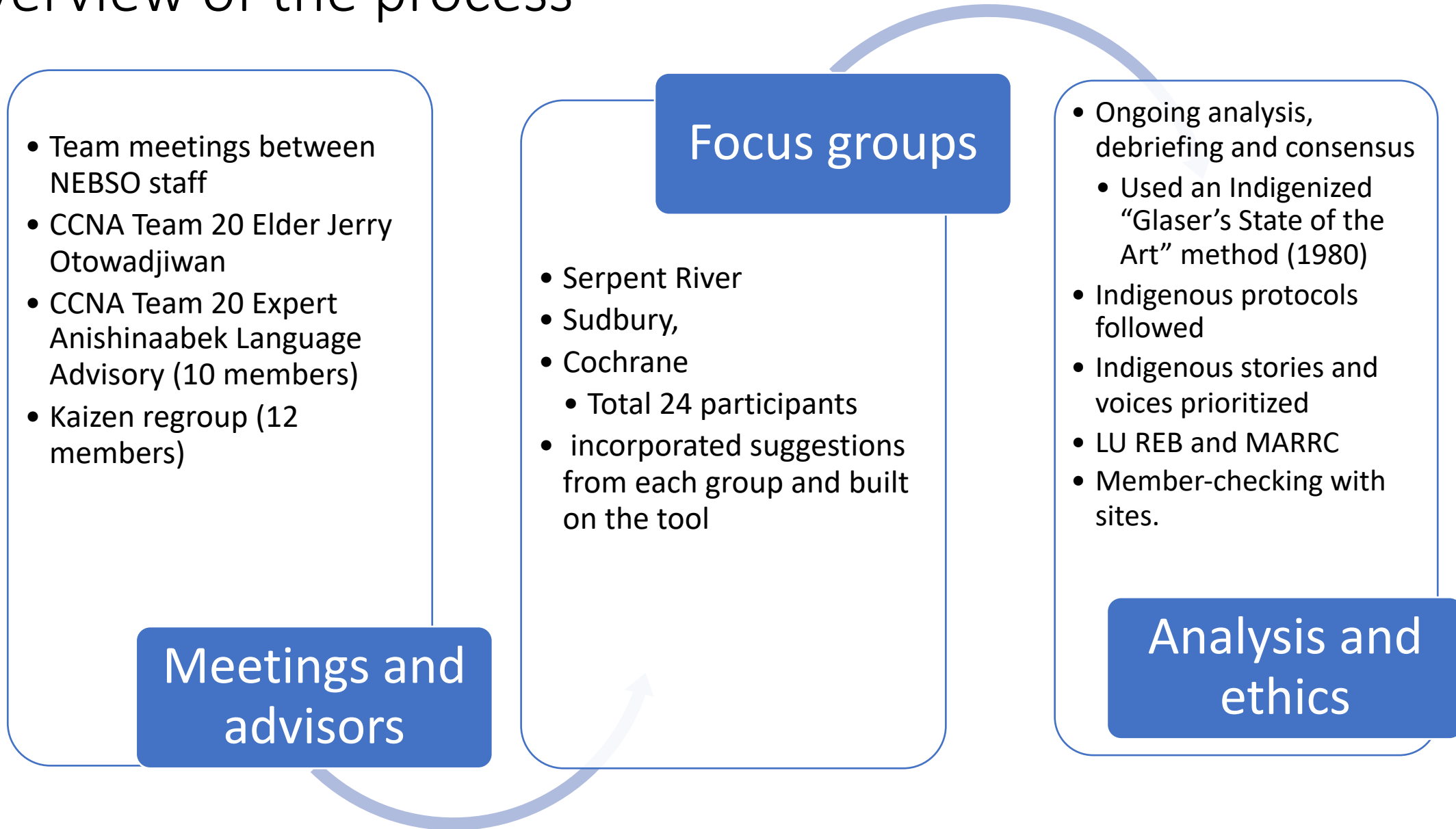


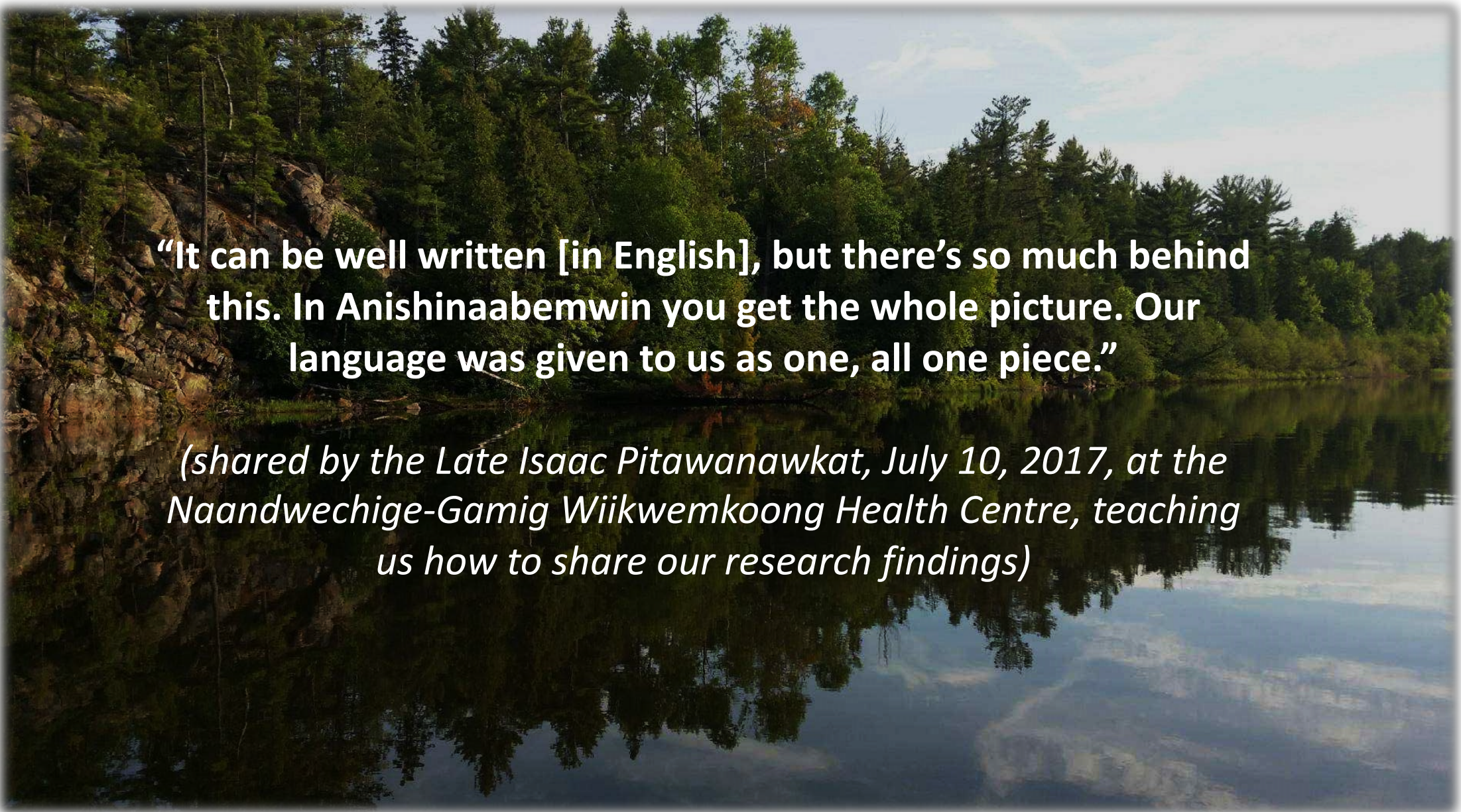
# Community engagement and relationship building

- Indigenous knowledge and voices prioritized
- Indigenous protocols for each area followed
- Creating a safe environment to share experiences
- Follow up with participants and organizations

*I interviewed some Elders on it [the original tool] and they were happy about it [the adaptation], when I told them about it. They're thankful because that way they are looking to help [others like] them to be safe in an environment like that [institutional care setting] when they leave their home. They're thankful.  
(Cochrane focus group participant)*

# Overview of the process





**“It can be well written [in English], but there’s so much behind this. In Anishinaabemwin you get the whole picture. Our language was given to us as one, all one piece.”**

*(shared by the Late Isaac Pitawanawkat, July 10, 2017, at the Naandwechige-Gamig Wiikwemkoong Health Centre, teaching us how to share our research findings)*

# Use of terminology: Loving and Giving

You will notice that instead of “person with dementia” we use **loved one**. Throughout this work, we spent time with Elder Jerry Otowadjiwan to make sure that work was done in a good way. Elder Jerry shared teachings about love with us. He shared that a person with dementia is someone who needs a lot of love and will need to be reminded that they are loved. And whether or not their caregiver is someone who loves them, the act of providing care is a loving act, and somebody, somewhere loves this person. Using the term **loved one** reminds us of how we should be treating and respecting the person with dementia.

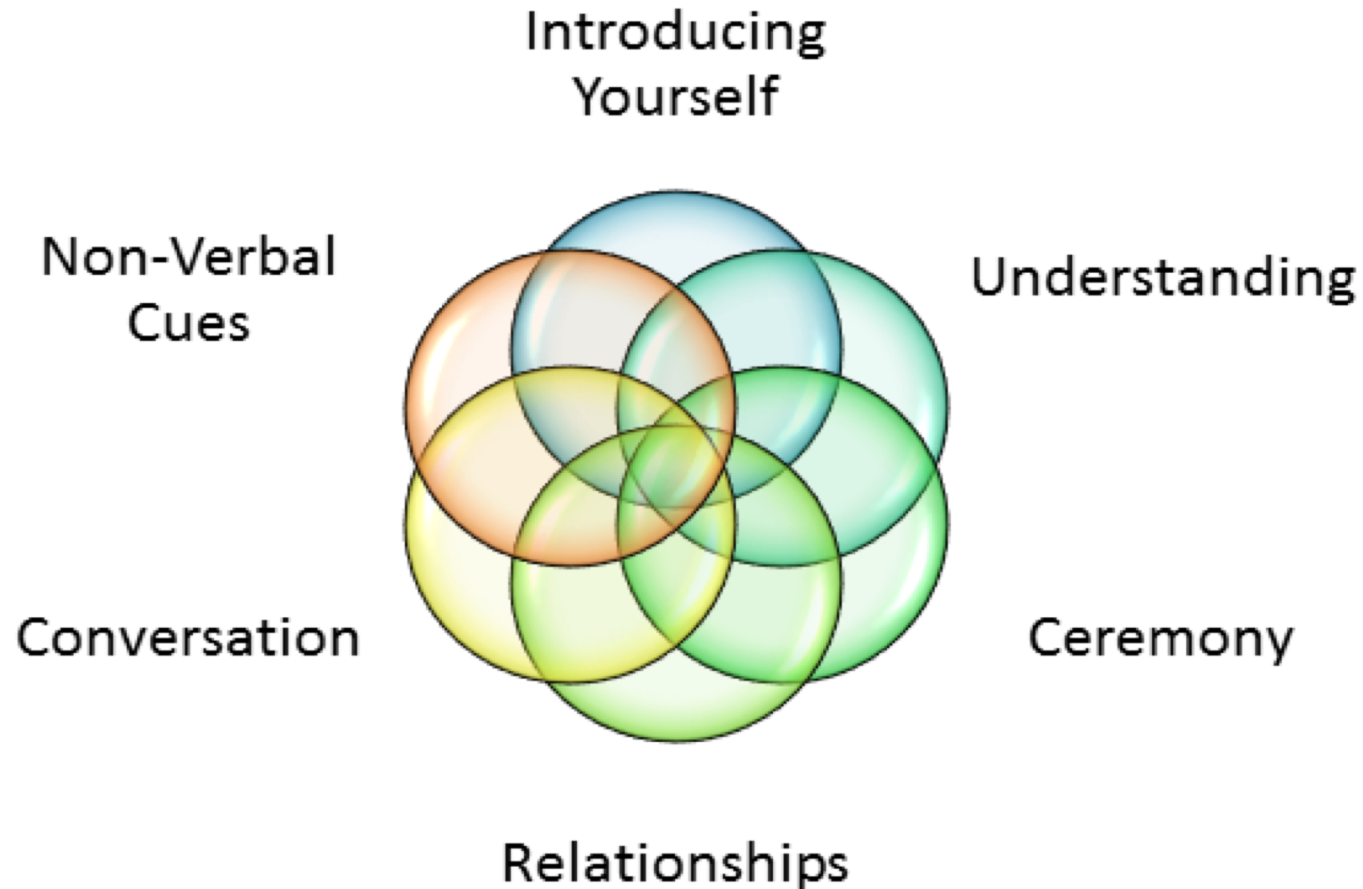
Community advisory groups, participants in studies, and community partners all reacted well to **loved one** and found it appropriate in an Indigenous context.

We also use the term **caregiver** instead of the more recent “care partner.” This is because to provide care is to offer a valued gift to another. **Caregiver** was also preferred by all of the community stakeholders and participants in the research.

## Results

### Emphasis on approach & relationship building

*An interconnected approach to PIECES of my RELATIONSHIPS.*



*“There is a difference between a paper question and a question from the heart.”  
(Serpent River Focus Group)*

## *Results*

### Trauma informed approach to care is needed

- We recognize that older Indigenous adults may carry fear of health care and social service professionals.
- Project Elder Jerry, the Language Advisory, and the focus groups agreed that knowing a loved one's triggers (i.e. dislikes and fears) was appropriate, but asking for their trauma story was not.





# Results

## Creation of new tools and guides

The adaptation process resulted in the creation of 4 documents:

- PIECES of my RELATIONSHIPS tool
- PIECES of RELATIONSHIPS family supplemental tool
- Quick guide on Approach
- Guidebook on the adaptation process and how to use the tool

The image displays four overlapping document thumbnails. The top-left thumbnail is titled "P.I.E.C.E.S. of my Relationships Family supplement" and contains questions such as "What keeps your loved one going", "What kinds of things is your loved one good or gifted at?", and "How is your loved one still giving back?". The top-right thumbnail is titled "P.I.E.C.E.S. of my Relationships" and includes sections for "Who I am" and "Where are you from?". The bottom-left thumbnail is titled "Introducing Yourself" and features a central Venn diagram with four overlapping circles labeled "Non-Verbal Cues", "Understanding", "Conversation", and "Ceremony". Below the diagram is a section titled "Relationships" and a flowchart at the bottom showing the progression from "Cultural Awareness: Acknowledgement" to "Cultural Sensitivity: Knowledge", "Cultural Competency: Knowledge & Skills", and finally "Cultural Safety: Addressing Inequality". The bottom-right thumbnail is titled "Guidelines for PIECES of my RELATIONSHIPS" and includes a quote: "It's about belonging to a community." - Elder Jerry Otowadjiwan.



# “Who I Am”

## Personhood (before)

- Name/Preferred Name
- Family Background
- Pets/Animals
- Significant Persons in Life and Relationships

## Relationship (After)

- Who I Am

*“Our names are very sacred. So if you’re going to ask that question, make sure you’re going to be really attentive to what they say and everything, because that’s really important because of the sacredness.” (North Shore Focus Group)*

## Rational for asking questions in a certain way...

*"I went to residential school. My mother went to residential school. My grandmother went to residential school. If I was asked where were you raised... When I went back to school... one of my assignments was about residential school. I was to interview somebody about residential school. So I chose my mom. One of the questions was 'How many years did you actually live with your mom and dad?' And then she said 'In my family I'm the only one that went to residential school. I was the well educated one.' That short period that she was in there had a great impact on her life. And it showed, it showed in my mom. I know she had a hard time in life. But she loved her mom and her dad, but the relationship was broken when she was young. Thirteen years old. When she was in her early teens, with those that age, she was in residential school... By the time she came out...*

*And, you know that, from the questions I was asking her, she had a hard time answering, so when I see this, 'Where you were raised...' if you're looking for the specific place you were raised... I was raised in residential school, away from my parents. I did my own. How many years I was away from my parents and how many years I was actually raised by my parents. I went into residential school at the age of six. I became a mother at the age of 19. I was in residential school for seven years for ten months out of a year. Summertime was the only time I saw my parents. Sometimes Christmas if we were allowed to go... Anyways, I calculated how many months, how many years I was actually raised by my parents from age six to age 19. When I started high school I had to leave [the James Bay coast]. There was no high school. I went to high school [in southern Ontario]. So I included those, from which I became a mother at 19. I had my first child at 19.*

*When I calculated how many years I was actually with my parents, it was only 39 months. From age six to age 19, I don't know how many years that is... I only actually lived with my parents 39 months." (Cochrane Focus Group)*



# “A day in my life”

## PIECES of my Personhood

- Mealtime preferences
- Sleeping and waking preferences
- Socialization preference

## PIECES of my Relationships

- A day in my life

*“Simple things like the man liked country music, and here the PSW is putting on rock music and wondering why the man is getting upset.”  
(Sudbury)*

## Section 2: A day in my life...

*“Some Aboriginal people like a smudge. It might help them if they are used to having a smudge every morning, or in the evening, or whenever. The first thing I do every morning when I come into work is I lay a smudge downstairs and the staff smudge there... that’s what I do. So if I did have that Alzheimer’s, that would help. I might not remember to do it, but as soon as I started I would know the feeling.” (Sudbury)*



# “What keeps me going”

## PIECES of my Personhood


- I am most proud to be known as/for
- Interests and hobbies
- Significant high points in life
- Sources of hope, comfort and favourite things

## PIECES of my Relationships

- What keeps me going

ziibaakdukeh  
giiew seh in nibowatchidying  
weh si ik  
niimiding  
laughing making maple syrup bopying  
hunting dancing  
binoji ik children  
animals visiting  
making goose down blankets

# What keeps me going?

 **P.I.E.C.E.S. of my Relationships**  
*Family supplement*

What keeps your loved one going

What kinds of things is your loved one good or gifted at?

How is your loved one still giving back?

Relationships

Was your loved one always loved?

Were they ever treated poorly by someone close to them?

Adapted by Jacklin, Pitawanakwat, Blind, Otowadjiwan, Jones, Rowe, and NE BSO, 2016

1

*These ancient people I use to hear of, they were exceptionally good at wood boats even sail boats. They're stories are shared sometimes. How did those boats look that used to take our ancient ones around? Not like the sail boats today, I had the privilege of seeing one, it had a hole in the middle, there was a machine in that hole and it made a putt putt sound. It was named after this sound: **medwewebdehing**, which is a moving sound in the heart. It was a sail at the same time. He was from Wiikwemkoong a very well-known boat builder. His name was **Kuknaangwe**. He lived on an island, the island beside the island where they blow up the rock. He made many of these kinds of boats. He even had the ability to build – for the wind blowing the snow over the ice in the winter. This ancient one made a sail that is blown over the ice. He was that gifted, that wise. The island where he lived is named after him. His name describes small particles moving over one and other by wind, these particles being small parts of a base of the same particles, like sand dunes, but it can also be snow. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*



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How to keep me safe

Someone who has trauma experiences a tear up of every essence of who they were, so much that the pieces could not be put back together to be any kind of whole being ever again. (Anishinaabeg Language Expert Advisory)



What memories do you carry in your heart?

*It's so different for us when we are given a gift. You know I will never forget for my family there were ten of us - seven sisters and three brothers. My cousin came to our home, my mom and dad could not buy us toys because there was too many of us. She gave to us, and I never forgot that. Me and my sister were the oldest, we got coloring books and crayons. And while they were visiting we went behind the stove and laid down on the floor and we were coloring our coloring books. We never, I never forgot that. That was a big gift that she gave us. (Sudbury Focus Group)*



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# How to care for my whole being



*He was smudging...  
his fear was  
relieved.  
(Anishinaabeg  
Language Expert  
Advisory member)*

Photo credit: Joseph Pitawanakwat

# Caring for my whole being

*The way we understand as Anishinaabeg the old ones and those who are preparing to leave for the spirit world, when this is not understood it gets very difficult to prepare. The one that is leaving is actually being stopped held back from continuing to walk their life the way it was meant to be. There are some who fear leaving and they need to be visited about how happy it is where they are going. They need to get to the place where they give up their life and believe they are ready. Sometimes they show this by refusing medication. Uncle Ben's niece told the nursing home staff he was preparing to go, and just to keep him comfortable. He slept for four days and four nights. When he woke up he asked for tea and complained of feeling hungry. They gave him left over soup and tea. "Well, I am leaving soon," he announced. He travelled there, he told her. He saw it. "It is of the most beautiful place anyone could ever imagine," he said, "they sing so well/the melody on the other side." There let it be he ended, not yet he announced but it's going to happen anytime I will leave, he was gone in a month's time. Grandfather was different (before I understood this), he said he was leaving soon, I asked where he was going? where you have ever after happiness, where the dead go he replied. How do you know? he was asked. My father came to me he said, at first he was far away and now he is closer he is coming to get me anytime. He came to him to prepare himself, he told me to prepare ahead of time. To set his clothes he's to wear and moccasins not shoes. (Translated from Anishinaabemwin – Anishinaabeg Language Expert Group)*

# Key Takeaways

- Adapting culturally safe care tools
  - Takes time - Need to work closely WITH people the tools are meant for
    - Outreach and relationship building, ongoing feedback
  - Requires self reflection (personal, professional, organizational level)
  - Acknowledges and seeks to address the some of the inequities in health care

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# 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*  
Wikwemikong Health Centre,  
Wikwemikong, ON

Kpitawanakwat@wikyhealth.ca

[www.I-CAARE.ca](http://www.I-CAARE.ca)

Twitter: @I\_CAARE