

The AMICA project: a community-based approach to adapting a culturally safe dementia screening toolkit across three sites.

Melissa Blind, PhD

IHS 2026



# Acknowledgements

## Minnesota

Dr. Kristen Jacklin, PI

- Dr. Wayne Warry, Co-I
- Dr. Melissa Blind, Project Coordinator overall
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- Dr. Nancy Pandhi, Co-I
- Blake Boursaw, Sr Research Scientist
- Debra Garcia, Administrative Operations Director
- Rebecca Owl Morgan, Community Based Researcher
- Erik Kakuska, Research Scientist

## Community Partners

Red Lake Nation

Oneida Nation

First Nations Community

HealthSource

## Consultants

Karen Pitawanakwat, RN,

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Dr. Melissa Castro, Neuropsychologist

Dr. Megan O'Connell, R.D. Psych,

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Dr. Kate Smith, PhD

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I have no disclosures to declare

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# Memory Keepers Medical Discovery Team (MK-MDT)

## MISSION

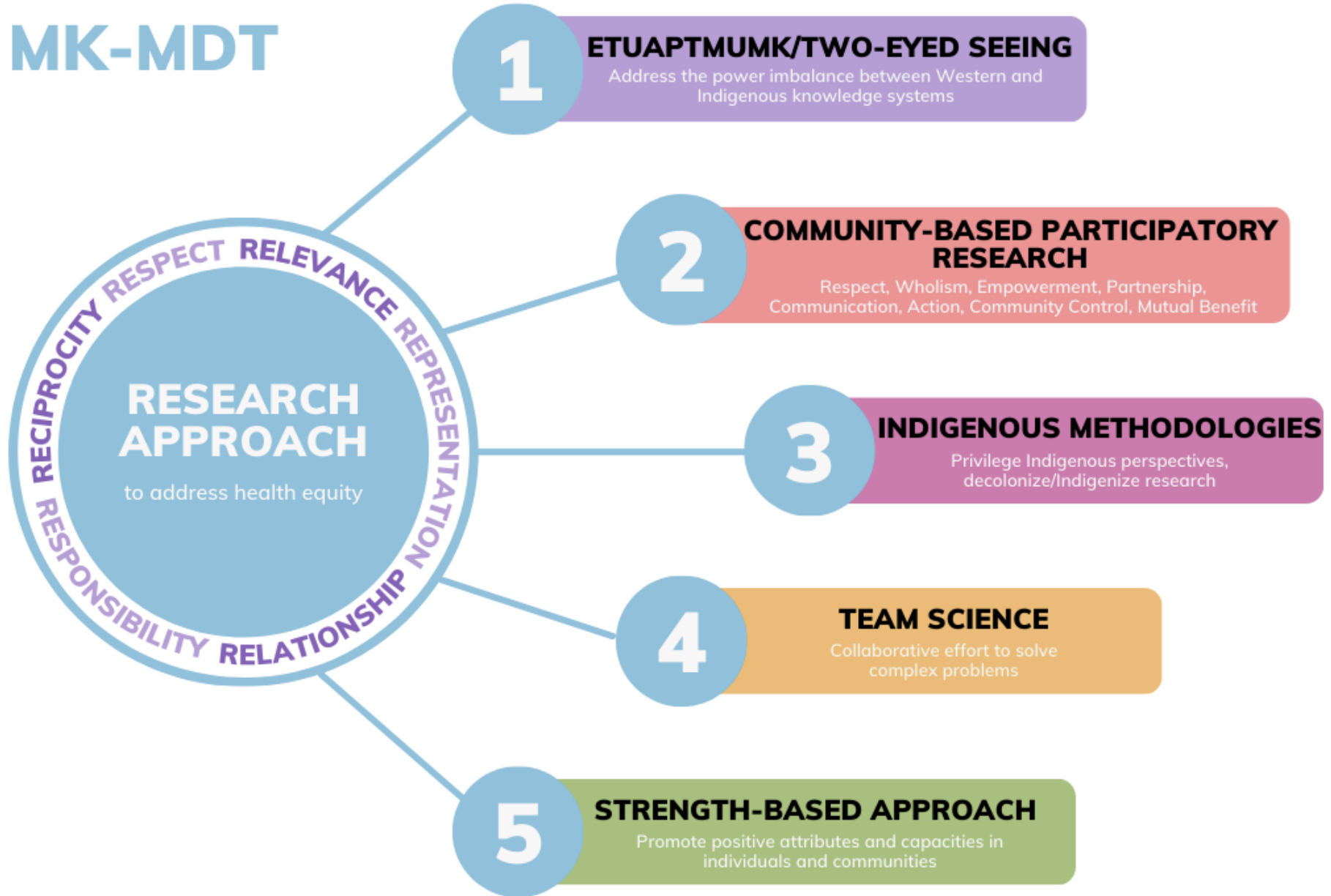
Our MISSION is to engage Indigenous and rural communities in culturally meaningful research to improve dementia and brain health outcomes for all.

## VISION

Our VISION is transformative research for brain health equity.



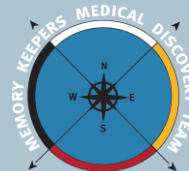
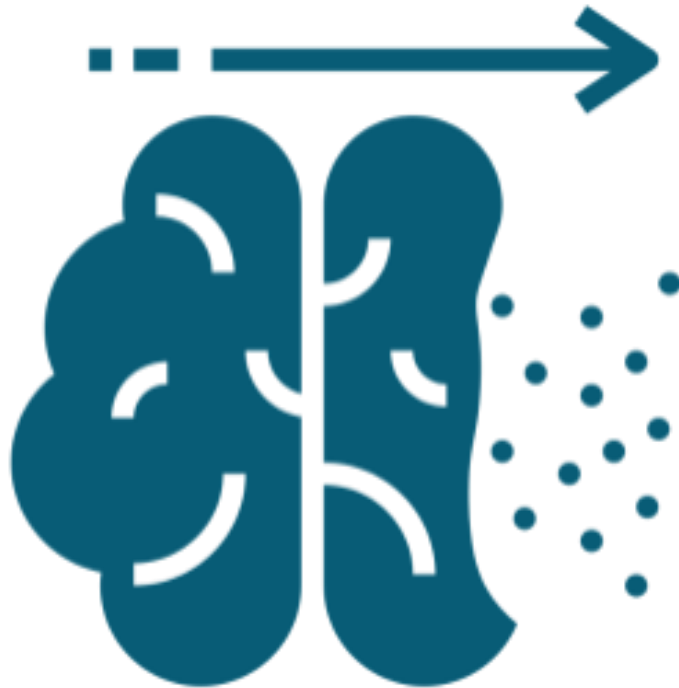
# MK-MDT



# Alzheimer's Disease /Alzheimer's Disease and Related Dementias (AD/ADRD) in American Indians/Alaska Natives (AI/AN)

## What we do know

- **1 in 3** AI/ANs aged 65+ years are at risk of developing dementia.
- **1 in 6** AI/ANs aged 45+ report memory loss/cognitive decline that impacts their daily life.
- Current cognitive assessments may not be culturally relevant and can lead to misdiagnosis or under diagnosis



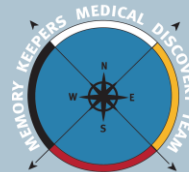
# Benefits of an early diagnosis

## For the person experiencing memory issues / has a diagnosis

- Planning ahead
  - Maximize time with family / loved ones
  - Express wishes about any legal, financial, medical, and end of life decisions
  - Access resources and support programs
- Discuss treatment options that can help slow progression

## For the family and caregivers

- Knowing your loved one's wishes
- Learn about the progression of the disease
- Connect with supportive programs and services
- Involve family / friends in the care and respite planning



# Need for earlier recognition and diagnosis

- Um, sometimes if, like, the family is caring for, for a resident or a patient with Alzheimer's, it, **it doesn't really get diagnosed, as soon as others that are being cared for in a facility** or whatever. We just, um, pretty much go with it as being elderly, (laughs) like, you know? Like, I know, like from my experience and taking care of my grandfather, we knew ... he was getting forgetful and stuff like that, but he wasn't, um, you know, **he wasn't diagnosed until after he was in the nursing home** and everything. (ICARE MN02 SFG 01)
- Doctors have traditionally thought they were really good at figuring it out without doing anything specific to find it out, but the studies have shown that **when left to our own devices, we don't diagnose it very early**. It's usually middle to late that we get around to diagnosing it. (ICARE MN01 PR04)

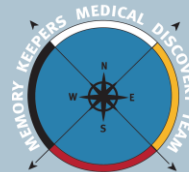
ICARE funded through NIH1R56AG062307-01/5R01AG062307-03



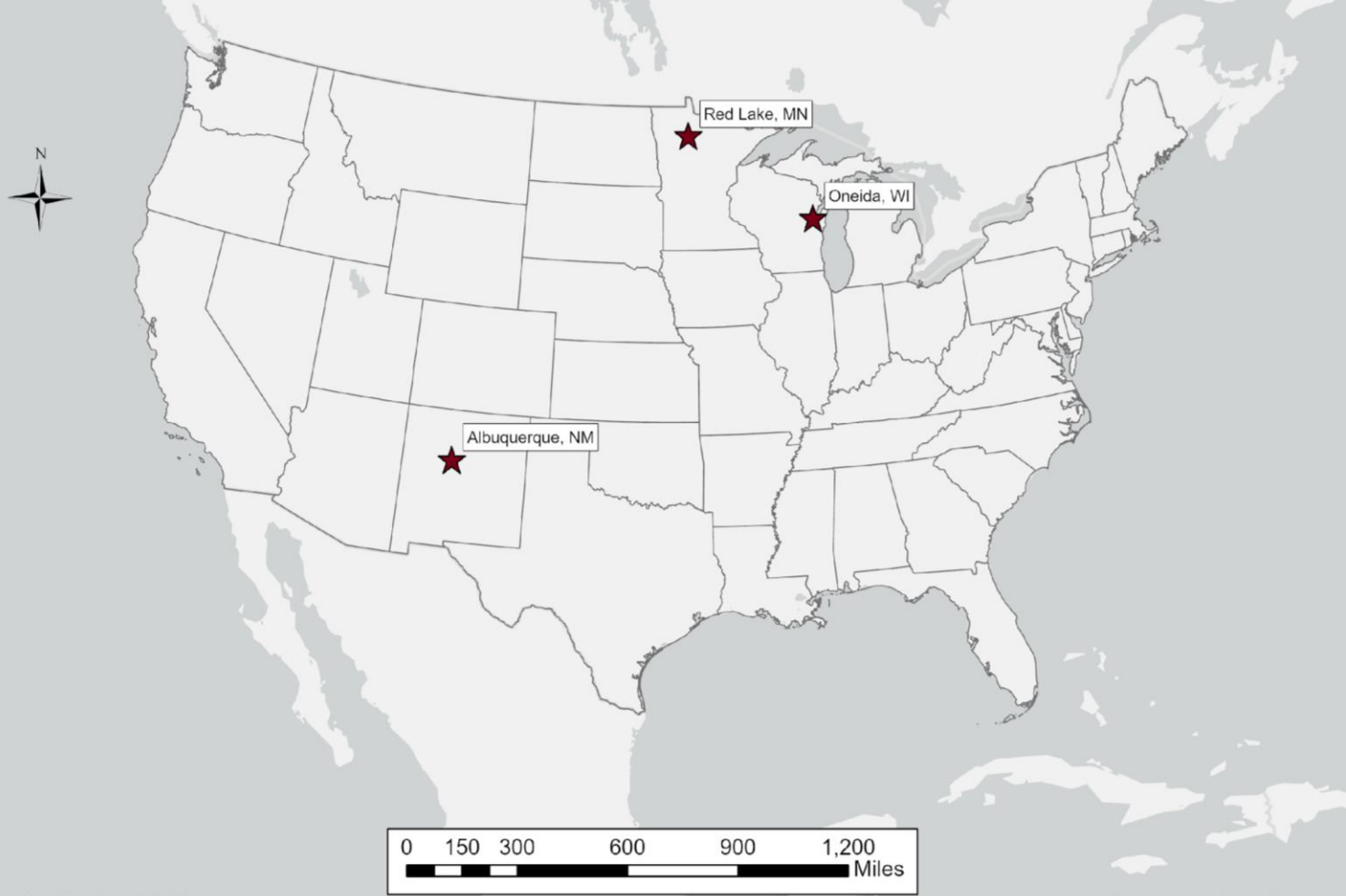
# Need for culturally appropriate cognitive assessment tools

- And I think when **we're looking at like, screeners**, like the depression scale or the geriatric anxiety index. **I don't really know that it's culturally sensitive**. Like, I sometimes ask those questions ... and one, I never do it in my initial visits, I usually wait at least ... And I've learned that you wait until you build rapport, and that person knows you. But a lot of the questions they don't even [understand] like, because that might not be a word they use in language. (ICARE ON AD01)
- I think **there's a language barrier sometimes**. Some of my older patients, uh, you know, at one point, especially with the MoCA, you have to look at a camel, a hippopotamus. I can't remember the lion, like there's animals. I find that there's often, um ... Most, most people recognize the lion, but like a hippopotamus or something. I find that sometimes... **I don't think it's a dementia issue, I just think that the word doesn't come because the, either it's a language issue or why, why would they have thought of a hippopotamus recently?** Like, you know, I just don't, I'm not too sure. (ICARE ON PR03)

ICARE funded through NIH1R56AG062307-01/5R01AG062307-03



## American Indigenous Cognitive Assessment (AMICA) Sites



Cartographer: P. Bright - MK-MDT

Source(s): Memory Keepers-Medical Discovery Team, ESRI

University of Minnesota  
and the Red Lake  
Nation

University of  
Wisconsin- Madison  
and the Oneida Nation  
of Wisconsin

University of New  
Mexico and First  
Nations Community  
HealthSource in  
Albuquerque

# AMICA Objectives

- Develop a culturally appropriate dementia evaluation **toolkit** to be used in American Indigenous communities
- Improve Indigenous brain health in present and **future generations**



A Cognitive Assessment



Caregiver Interview of Symptoms of Dementia



Evaluation of Depression Symptoms



Inventory of Changes in Activities of Daily Living

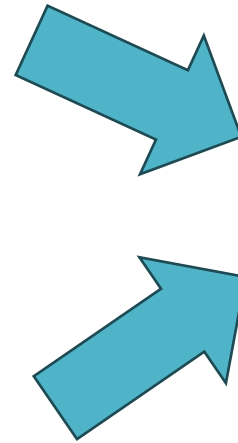
# Canadian Indigenous Cognitive Assessment (CICA)

Cognitive Assessment Screening Tool

*KICA*



*Kimberley Indigenous  
Cognitive Assessment*



# Phase 1

Identify Minnesota, Wisconsin & New Mexico Advisory Groups (IKAGS)



Dementia Assessment Expert Panel



Interactive process between IKAGS & Expert Panel



Site Adaptations



Iterative process between National IKAG & AEP



National IKAG negotiates consensus AMICA Toolkit for all sites



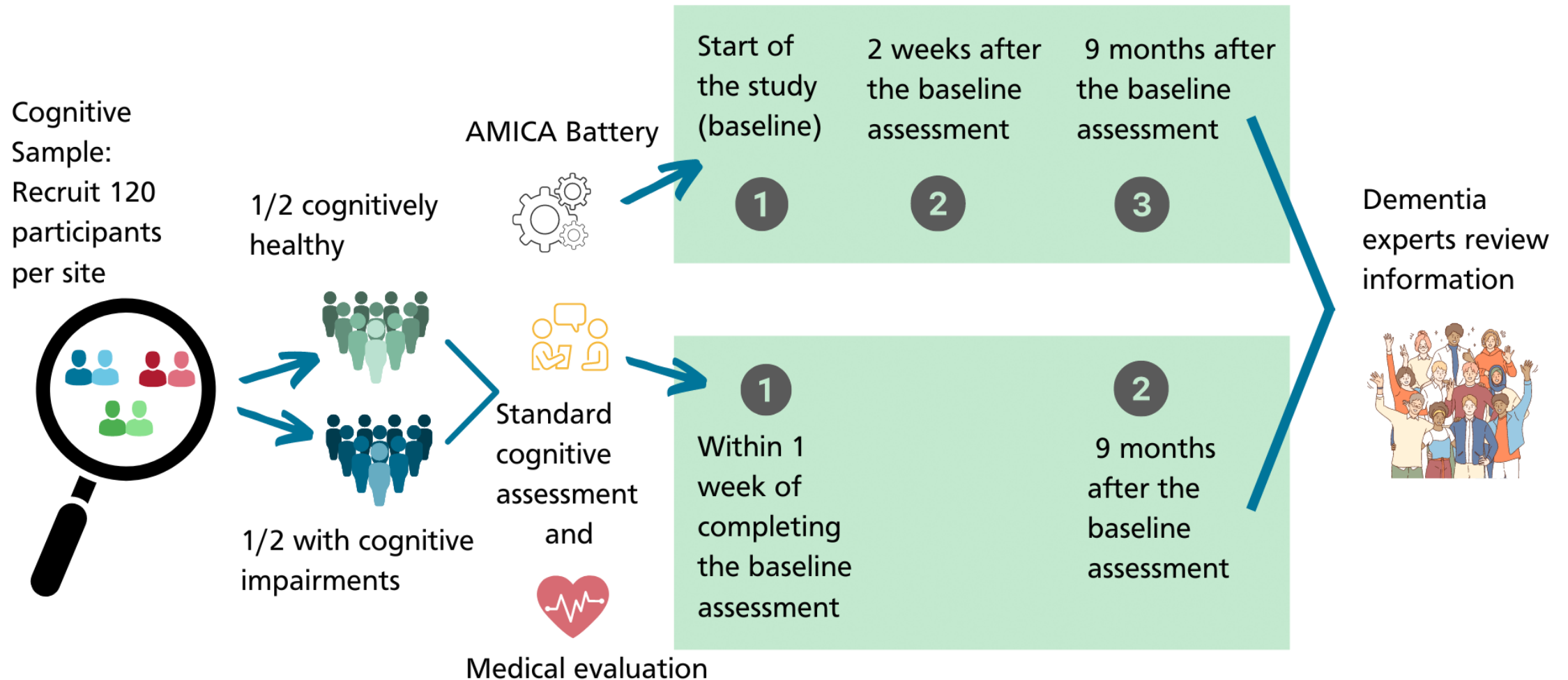
Pilot test tools with 10 dyads per site



AMICA tools ready for validity and reliability testing



# Phase 2 pilot and validation 2025



Adapting an intercultural  
assessment tool kit across 3  
sites

# Multi-site Approach



Community Advisory Groups



Local Indigenous Community-Based Researchers



Site-specific Coordinators



Approval and Updates to Tribal Leadership



Indigenous Knowledge Advisory Groups (IKAGs)



Assessment Expert Panel (AEP)

# Coordinated research strategy across all sites

- Initial team building retreat
  - *site coordinators, community researchers, and senior staff members*
  - *Consensus development of project facilitation guides, meeting summary templates, consistent documentation practices*
- Regular meetings and check-ins
  - *MPIs, coordinators, community researchers, large team meetings, assessment expert group*



# Working with IKAG members across each site



- Each site has 5-8 respected members of their community who have an understanding their culture and language
  - Red Lake, MN – Ojibwe
  - Oneida, WI - Haudenosaunee
  - Albuquerque, NM – urban Indigenous population
- Review and examine current assessments (CICA / KICA)
- Discuss adaptations needed to make tools culturally safe and appropriate to use with Indigenous older adults

# Assessment Expert Panel (AEP)



Adaptation and AEP working group meeting January 2024

AEP includes Indigenous and non-Indigenous experts

- geriatric and family medicine
- medical anthropology
- neurology
- epidemiology
- nursing
- neuropsychology
- bilingual competence and
- experts on the KICA / CICA adaptation process

- Provides clarification to any questions asked by the IKAGs
- Ensure adapted questions are psychometrically sound

# Building consensus across the groups

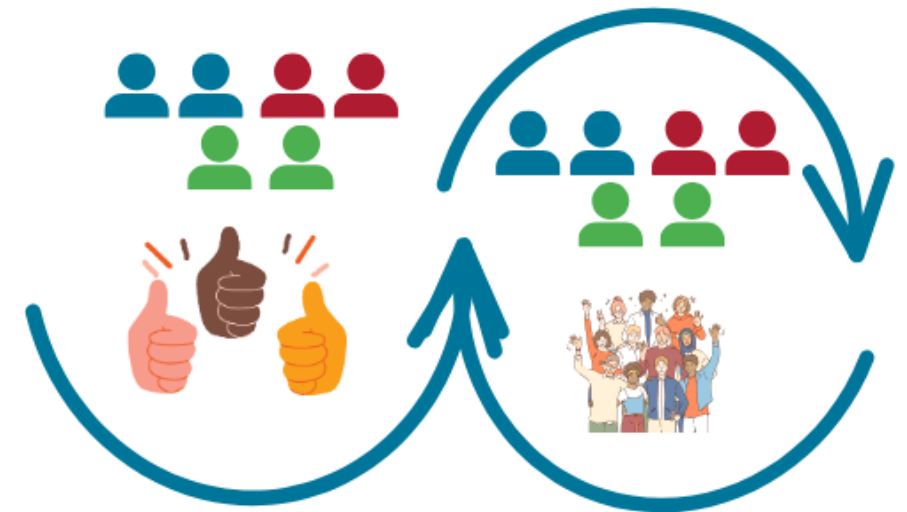


AMICA Team retreat with National IKAG Albuquerque, NM, Sept 9-13, 2024

Bringing together a National IKAG.

- 2 nominated IKAG members from each site.
- Purpose of meeting – Develop one common set of tools for all sites (if possible).
- Lots of time for discussion and consensus building.
- Two in person meetings, along with Zoom meetings.

Iterative process between National IKAG  
& AEP



National IKAG negotiates consensus  
AMICA Toolkit for all sites

# Preliminary Adaptation Outcomes

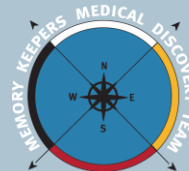
| Person being assessed      | Caregiver  |
|----------------------------|--|
| Cognitive Assessment       |  |
| Medical History            | Medical History of person being assessed             |
| Smoking / Alcohol History  | Smoking / Alcohol History of person being assessed   |
|                            | Cognitive Informant Report                           |
|                            | Behavioral Report                                    |
| Depression                 |  |
| Activities of Daily Living | Activities of Daily Living for person being assessed |

- 10 total tools
- 101 original questions adapted to 116 questions in AMICA Toolkit
- Additional questions and instructions added to:
  - Depression scale
  - ADLs
    - Cultural activities
  - Cognitive Informant Report
    - symptom start and trajectory

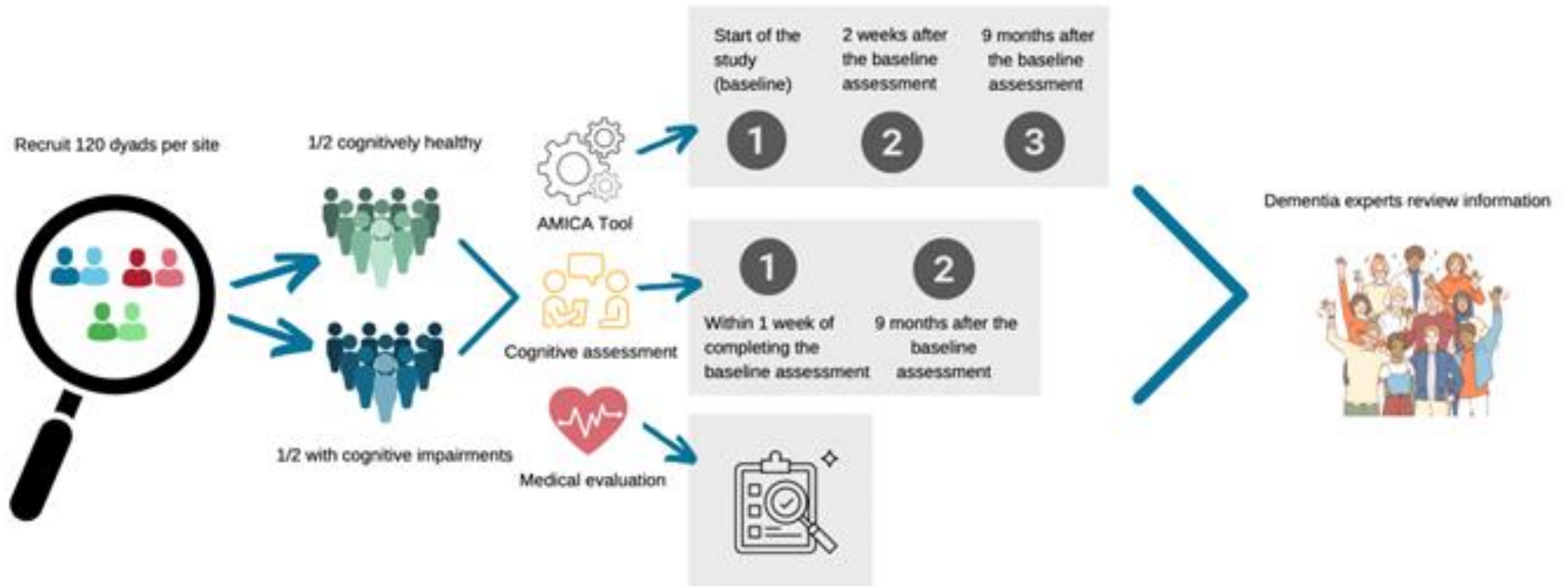
# Results: Draft Guidebook for using Toolkit

- Approach
  - Building trust
  - making the person being assessed comfortable
- Creating a safe environment
  - Purposeful explanations of why we are asking these questions
  - simplify language used to ask questions, be consistent
- Cultural Safety
  - Use a trauma informed approach

Importance of having a detailed guidebook for anyone using the toolkit



# Next Steps: AMICA Pilot and Phase 2: 2026-2027



# Implementing the toolkit in practice

## Who

- Community Health Workers
- Loved ones
- Caretakers
- Clinicians

## Where

- Community Health Centers
- Nursing homes
- In home
- Community gathering spaces



**AMICA**

Home

About Us

AMICA

Contact

# Addressing Alzheimer's Disease and Related Dementias Disparities

# AMICA

The American Indigenous  
Cognitive Assessment

More information about AMICA: [www.amicatoolkit.com](http://www.amicatoolkit.com)

# Miigwech, Thank you

Contact information

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Engagement Director

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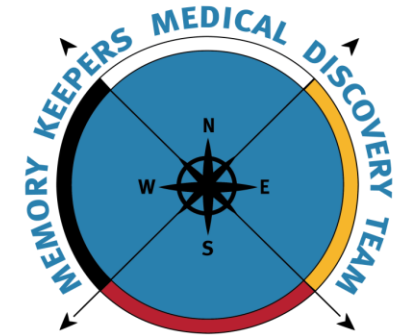
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MK MDT

website: <https://memorykeepersmdt.com/>

AMICA website:

<https://www.amicatoolkit.com>



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HEALTH SCIENCES  
CENTER FOR NATIVE AMERICAN HEALTH

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