Together Overcoming Diabetes: An Intergenerational and Culturally Grounded Diabetes Intervention

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CENTER FOR
INDIGENOUS HEALTH

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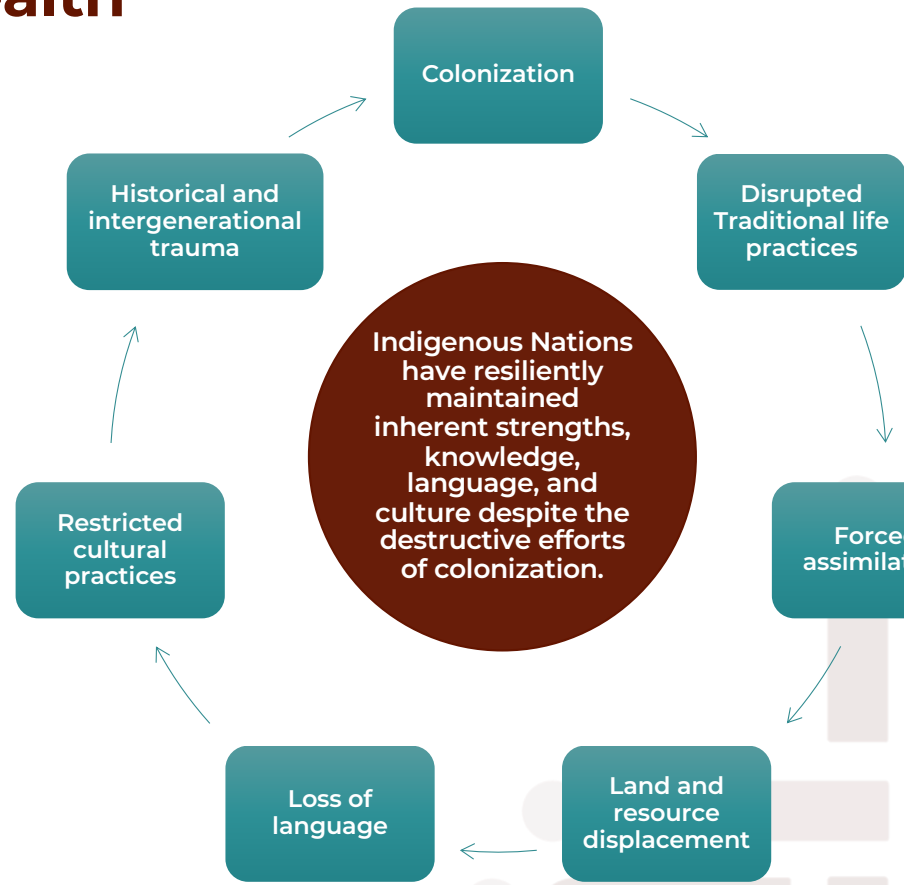
Agenda

- Background – Type 2 Diabetes Among Indigenous Populations
- Current Study – Together Overcoming Diabetes
- Lakota-specific Cultural Adaptation
- Next Steps

Influences on Indigenous Health

Prior to varying experiences of colonization

Many Indigenous Peoples consistently consumed nutritious, low glycemic, traditional foods and practiced ways of life that inherently protect against disease.

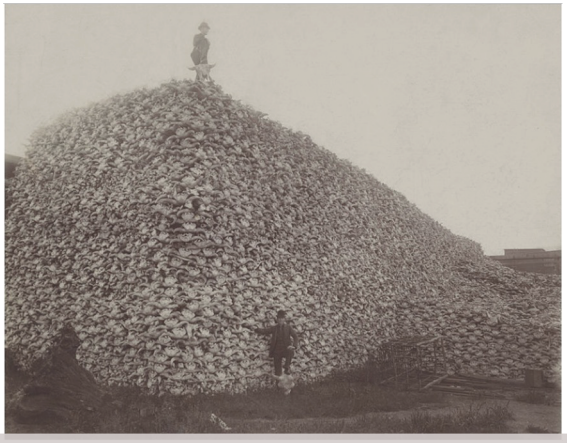


Historical Influences on American Indian/Alaska Native (AI/AN) Health

Ongoing impacts of colonization

Traditional food systems themselves were also disrupted by forced removal and relocation of AI/ANs

Dependence on foods offered by United States (US) government nutrition programs was ensured by:



- Restricting access to traditional foods and hunting capabilities, and
- Removing AI/AN children from their families and homelands to often violent boarding school environments[1,2]
- Nearly eradicating primary food sources (e.g., government-sanctioned buffalo eradication in the 1800s)

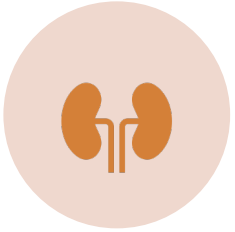
Historical Influences on AI/AN Health

Introduction to low quality foods

Labeled instructions on corn syrup to "use in baby formula[2]."

Leading to diets with poor nutritional value.[3,5]

Stark difference to the biodiverse, whole traditional foods known to be critical drivers in preventing chronic disease.[7]



Many of the foods are linked to nutrition-related chronic diseases prevalent among AI/AN populations today:

Type 2 diabetes, cancer, and heart disease.[2,4,6]

Government food programs have since improved their food offerings and FDPIR sometimes includes traditional foods in food packages.

Type 2 Diabetes Among AI/AN Populations in South Dakota

AI/ANs in South Dakota (SD) are 80% more likely to be diagnosed with diabetes than non-AI/AN residents[11]

Diabetes is the 8th leading cause of death in SD [12],

Among AI/ANs it is the 2nd leading cause of death[13]

“Indigenous populations who have very low type 2 diabetes prevalence appear to be those who have managed to retain or reclaim cultural practices, language, ceremonies and traditional food systems [14, 165, 166]. This finding is also supported by evidence that even a short-term return to traditional lifestyles improves weight and glucose tolerance [167].”[14]

Diabetologia
https://doi.org/10.1007/s00125-025-06624-y

SYSTEMATIC REVIEW

Prevalence of type 2 diabetes among global Indigenous adult populations: a systematic review

Courtney Claussen[1,2] · Emily Papadimos[3,4] · Dianna J. Magliano[5,6] · Cheri Hotu[7] · Hiliary Monteith[8] · Baiju Shah[9] · Louise Maple-Brown[3,10] · Alex Brown[11] · Odette Pearson[12,13] · Donald Warne[14] · Melanie Nadeau[15] · Elizabeth L. M. Barr[3,5] · Anthony J. Hanley[16,17]

Received: 20 March 2025 / Accepted: 2 September 2025

Abstract

Aims/hypothesis Despite evidence documenting high prevalence of type 2 diabetes among several Indigenous populations, a comprehensive systematic review of type 2 diabetes among global Indigenous Peoples has not been recently conducted. Our aim was to report region-, time-, age- and sex-specific type 2 diabetes prevalence among Indigenous adult populations globally.

Diabetologia
https://doi.org/10.1007/s00125-025-06556-7

ARTICLE

Prevalence of youth type 2 diabetes in global Indigenous populations: a systematic review

Emily R. Papadimos[1,2] · Courtney Claussen[3,4] · Dianna J. Magliano[5,6] · Cheri Hotu[7] · Alex Brown[8,9] · Odette Pearson[10,11] · Donald Warne[12] · Louise Maple-Brown[1,13] · Baiju R. Shah[14] · Hiliary Monteith[15] · Louise A. Baur[16] · Andrew Cotterill[2] · Anthony J. Hanley[15,17,18] · Elizabeth L. M. Barr[1,5]

Received: 20 March 2025 / Accepted: 27 June 2025

Abstract

Aims/hypothesis We aimed to synthesise global prevalence estimates of type 2 diabetes among Indigenous youth aged under 25 years, and examine age- and gender-specific differences and secular trends.

Current Study

GREAT PLAINS
Together Overcoming Diabetes
SKÚYA WAYAZAN PI KIN
PTÁYELA KAPHÁ PI KTE

CENTER FOR INDIGENOUS HEALTH
GREAT PLAINS HUB

National Institutes of Health Community Engagement Alliance (NIHCEAL)

American Indian, Alaska Native, Native Hawaiian, and Pacific Islander Enrichment Initiative

This research is funded by the National Institutes of Health (NIH), Agreement OT2HL158287.

Johns Hopkins Center for Indigenous Health

- **Founded:** 1991 at Johns Hopkins Bloomberg School of Public Health in the Department of International Health.
- **Mission:** We work in partnership with communities to advance Indigenous well- being and health leadership to the highest level.
- **Vision:** Thriving Indigenous communities worldwide

Together Overcoming Diabetes

Johns Hopkins University
TOGETHER ON DIABETES
Center for American Indian Health

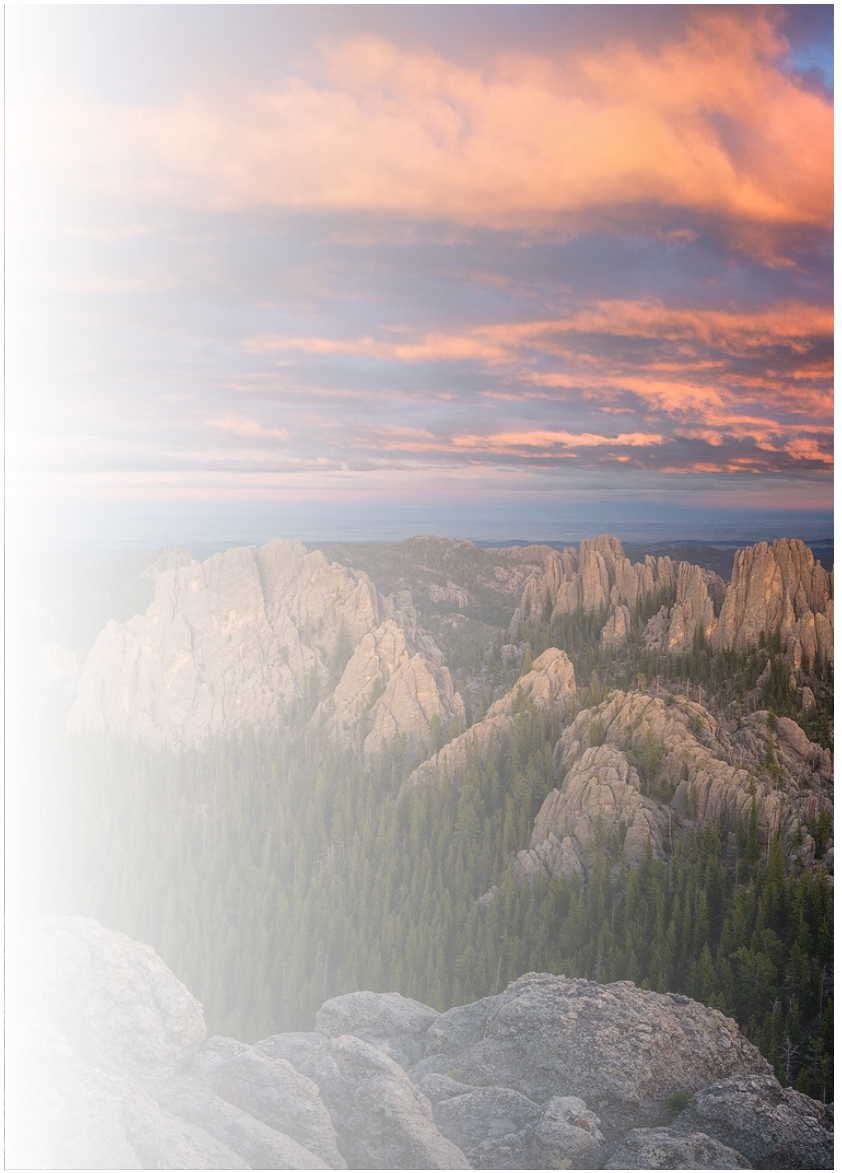
Niwii-shaagoojitoomin izhi-maamawi
Great Lakes
Together Overcoming Diabetes

GREAT PLAINS
Together Overcoming Diabetes
Skúya wayazan pi kin
Ptáyela kaphá pi kte

- Family-based, culturally grounded intervention
- Designed with AI/AN communities to improve type 2 diabetes management among adult caregivers and prevent type 2 diabetes among youth
- This is the second rigorous, scientific evaluation of the TOD program and the first version of the program that is Lakota-specific

Project Summary

To culturally adapt, pilot, implement, and further evaluate a validated diabetes intervention, ***Together Overcoming Diabetes*** (TOD), an 8-lesson, paraprofessional (Family Health Coach) - delivered curriculum that addresses the unique underlying risk and protective factors and social determinants of diabetes among American Indian populations in South Dakota.



TOD Project Phases

Phase I (18 months)

- Tailoring of TOD curriculum to Lakota context with focus group and community feedback
- Waitlist Clinical Control Trial with 40 caregiver/youth dyads in Mni Luzahan (Rapid City)
- Intervention = Months 13-18

Phase II (3 years)

- Expand the intervention to 130 adult/youth dyads across Mni Luzahan (Rapid City) + 2 reservation communities (Cheyenne River and Pine Ridge)
- Further implement and evaluate intervention

Study Oversight

Johns Hopkins Center for Indigenous Health - Great Plains Hub

Collaboration with the Special Diabetes Program for Indians, Oyate Health Center, Great Plains Tribal Leaders Health Board

Community Research Council

Data Safety Monitoring Board

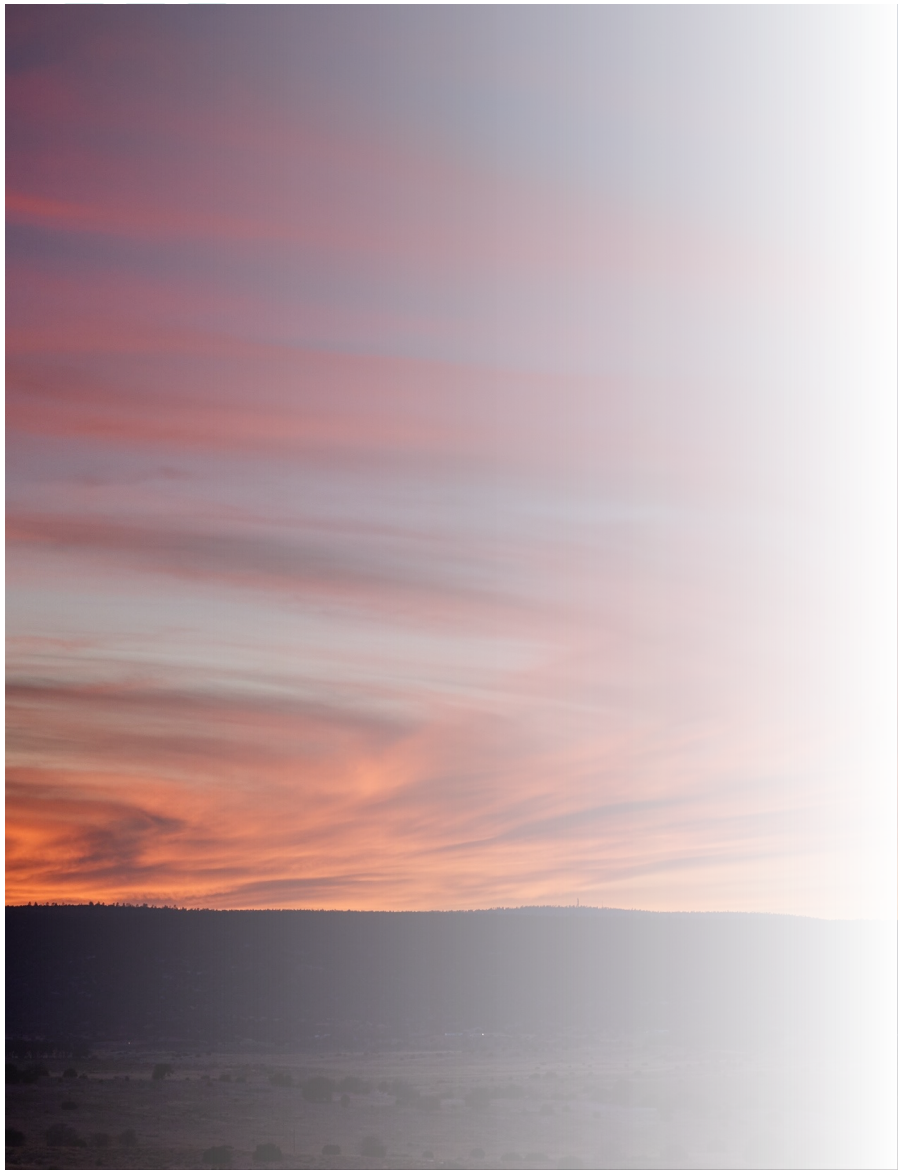
Together Overcoming Diabetes Intervention

- TOD expands beyond other lifestyle interventions by focusing on:
  - Modifiable lifestyle changes—such as diet and physical activity—in communities where healthy foods and safe recreational spaces are limited.
  - Reducing stress and promoting coping resources, as prior research conducted by the Center for Indigenous Health has demonstrated stress is a key factor in AI/AN diabetes inequities.
  - Promoting overall quality of life and wellness through local Indigenous cultural and spiritual assets.

Two-Generation Approach

The TOD program is implemented with adult caregivers with type 2 diabetes (T2D) and a youth support person aged 10–25. This structure taps into motivational reciprocity between both generations.

While parents direct the necessary resources to create and maintain healthy family environments, youth can provide key motivation for family-based behavior change.



Project Goal

Our goal is to improve diabetes management/control and clinical outcomes (HbA1c levels were our primary outcome measure) among adults with T2D; to promote protective and resilience factors among participants; and to reduce diabetes risk among their 10-to-25-year-old youth family members

Anticipated Outcomes

Caregivers with Diabetes

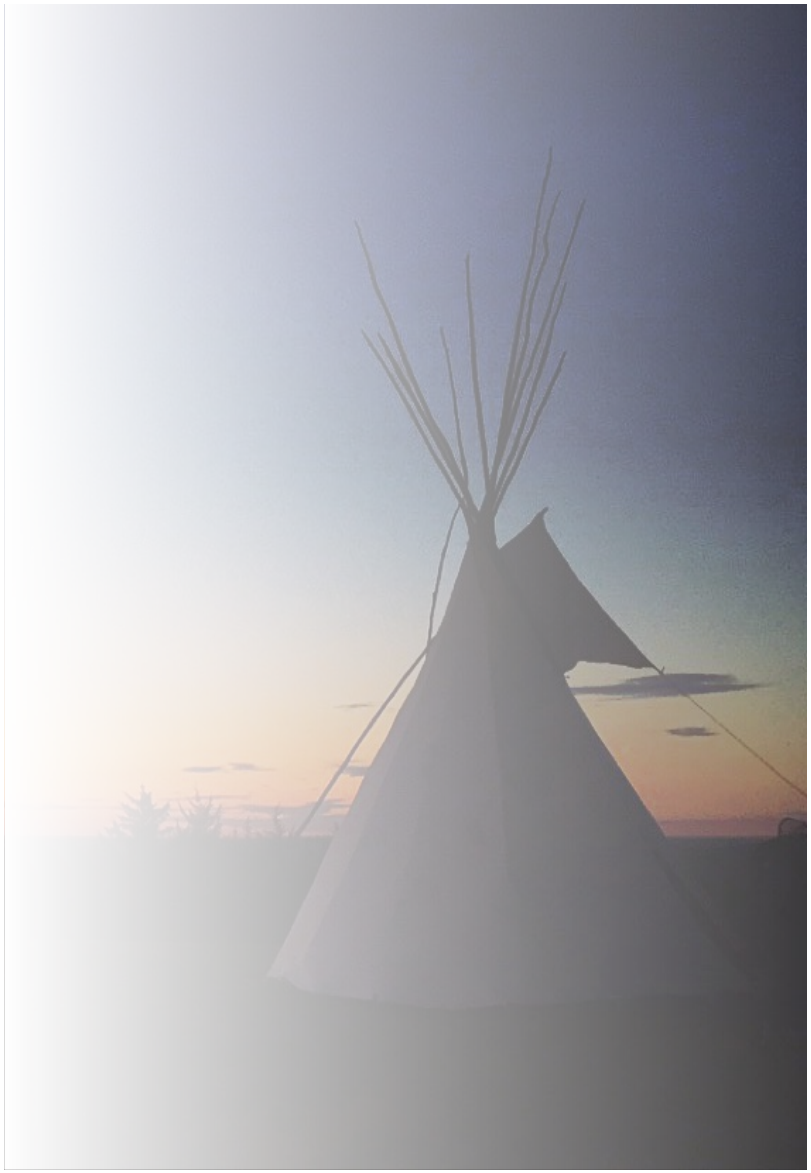
- Physiological: Improved HbA1c levels (primary outcome), weight status, waist circumference, and blood pressure.
- Psychosocial: Improved diabetes self-efficacy, quality of life, and reduced stress and depression.
- Behavioral: Adherence to medication plan, provider visits, reduced sugar consumption, and increased physical activity.

Youth Support Person

- Psychosocial: Improved quality of life and wellness and reduced stress and depression (primary outcomes).
- Behavioral: Reduced consumption of sugar-sweetened beverages and improved physical activity.
- Physiological: Improved zBMI and blood pressure outcomes.

Project Aims

1. Identify Lakota family and community attitudes, beliefs, and practices that are facilitators or barriers to family-based diabetes management among AI/AN caregivers with type 2 diabetes and their youth and tailor TOD to local contexts.
2. Produce pilot evidence of TOD's impact on parent/caregiver and youth diabetes-related outcomes.
3. Apply lessons from Phase 1 to design and implement a larger, longer trial in Phase 2



Focus Group Discussions to Identify Facilitators or Barriers to Family-based Diabetes Management

Figure 10. Sunburst chart of all subthemes, with Health Impacts of Trauma and Healing the most prominent subtheme, followed by Providing Options (for activity and exercise) and Incorporating Holistic Healing Practices.

Participants were asked to list words or feelings that come to mind when thinking about diabetes:

Participants were asked to list words or feelings that come to mind when thinking about what it means to be healthy:

Key Adaptations to the Curriculum

- Adapted from 14 to 8 lessons based on input about optimal dosage from prior studies, focus group discussions, & Community Research Council input
- Integration of Lakota cultural practices and language
  - We engaged fluent Lakota language speakers to translate key phrases, affirmations, and curriculum titles for participants
  - The Wicozani concept of wellbeing and validated instrument for participant health surveys
- Engagement by and with Lakota Peoples
  - Community Research Council and Lakota Research Team

Together Overcoming Diabetes Curriculum

GREAT PLAINS
Together Overcoming Diabetes
Skúya wayazan pi kin ptáyela kaphá pi kte

1. Diabetes 101 and Goal Setting	Skuya Wayázan na Taku Glustan Pi
2. Building Positivity and Problem Solving	Taku Wašté Kaga Pi Nahan Woyustan
3. Stress and Diabetes	Čante Ikamepi/Puskičat'a na Skuya Wayázan
4. Historical Trauma and Healing	Ehanni Takusiča Akhiphapí na Woašni/Apiciyapi
5. Nutrition Knowledge: Not All Foods are Created Equal	Apíičiyapi Wasloyupi na Woyute Hena Íthoca
6. Putting Nutrition Knowledge into Practice and Mindful Eating	Apíičiyapi Wounspe na Ícunpí Iwang Wotapí
7. Exercise Effects and Safety, Let's Get Moving!	Tangluškehan na Okhóphesniyan un Škan Škan Pi Kte!
8. Communication and Focus on Family and Community	Oyanke, Tiospaye, Tiwahe na Hena Onah'un/Woglakapi Kte
Supplementary Materials and Handouts	Isakib Wowapi Icupí na Wičakupi

Lakota Language Integration

Wópila tánka, we extend gratitude to Gerald Yellowhawk, Manny and Renee Iron Hawk, for translating key lesson phrases and titles to Lakota. Pilámayapi for keeping the Lakota language alive.

Variations of the Lakota language may exist in your community and the phrases and terms below are presented with sometimes two variations. Kiksúya (Remember) that the Lakota language is descriptive, there isn't always one way to communicate what you mean. We encourage you to reach out to the Lakota language speakers in your community if you are interested in learning more.

Lakótiya Wóglaka Po	Speak Lakota
Wóohitike (woah-oh-hee-tee-kay)	Bravery/courage
Wóikhuwa	Goal
Wóikigleğe	Accomplishment/achievement
Mazaní (maw-zaw-knee)	I am healthy
Skuya-woyazan / Skuye wayazan	Diabetes
Skuya-woyazan bluha Skuye wayazan imačeča	I have diabetes
Wakte owakihi Ohiwayan kte	I will defeat it

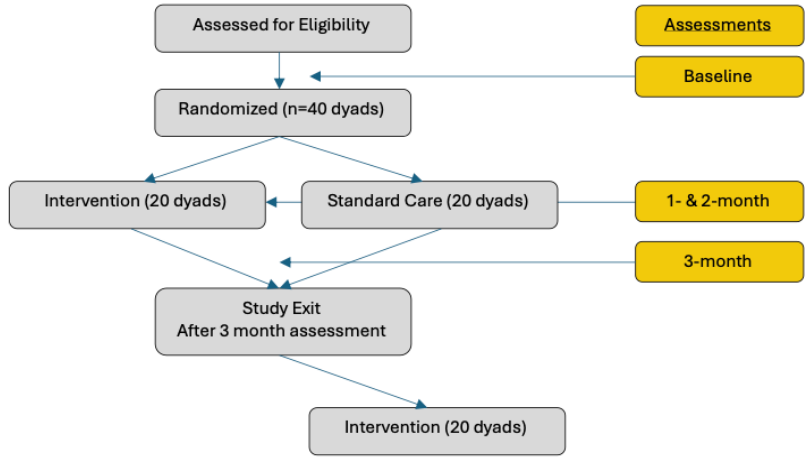
Together Overcoming Diabetes Study Team Members

- Donald Warne, MD, MPH – Principal Investigator
- Mary Cwik, PhD – Co-Principal Investigator
- Allison Barlow, PhD, MA – Co-Principal Investigator
- Courtney Claussen, PhD, MPH – Project Manager
- Loretta Grey Cloud – Operations Manager
- Dianne Amiotte-Seidel - Project Coordinator/Lead Independent Evaluator
- Arman Majidulla – Data Manager/Quantitative Data Analyst
- Katie Nelson, PhD, RN – Quantitative Data Analyst
- Anna Kihlström, MPH – Qualitative Data Analyst
- Kristin Masten, MPH – Curriculum Specialist
- Kevin Eagle Heart – Independent Evaluator
- Mateja Sitting Crow – Family Health Coach
- Bonita Bissonette – Family Health Coach

Together Overcoming Diabetes Phase I Study Design

- Waitlist Randomized Control Trial
  - Group A (Intervention)
  - Group B (Waitlist Control)
- 2 Lakota Independent Evaluators
  - To recruit, consent, and administer health checks with participants (physical measurements and health surveys) at **Baseline, 1, 2, and 3 months**
- 3 Lakota Family Health Coaches
  - To schedule with and deliver the 8-lesson curriculum to adult participant and youth support person dyads

Figure 1. Study Design



Phase I Findings

High participant retention ~95%

Statistically significant intervention group improvements for Adults:

- Interpersonal Diabetes Distress (0.041)
- Food Security (0.027)
- Depression (CESD-R-10) (0.02)
- Anxiety (GAD-7) (0.027)

Improvements for intervention group Youth:

- Food security, Depression, Anxiety, reduction in Sugar-Sweetened Beverage intake

Positive program satisfaction ratings for very helpful, just right, and supportiveness and effectiveness of facilitator

Phase I Findings

Positive health trends in the first few months of delivery are corroborated by previous Center for Indigenous Health study findings that have later led to significant physiological changes.

The study team is optimistic that with a larger sample, an extended timeline for lesson delivery, and longer follow-up windows in Phase II, we will see consistent improvements across many dimensions of health.

Current Progress/Next Steps

- Completed Phase I delivery of the intervention and health assessments with Group A and Group B
- Currently in Phase II to further implement and evaluate intervention delivery at the existing site + 2 additional Tribal community-based sites
- Longer trial with health assessments at baseline, 3-, 6-, and 12-months to assess the same health outcomes from Phase I

PILAMAYAPI

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