

# What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a 'one-stop shop' for pragmatic research:

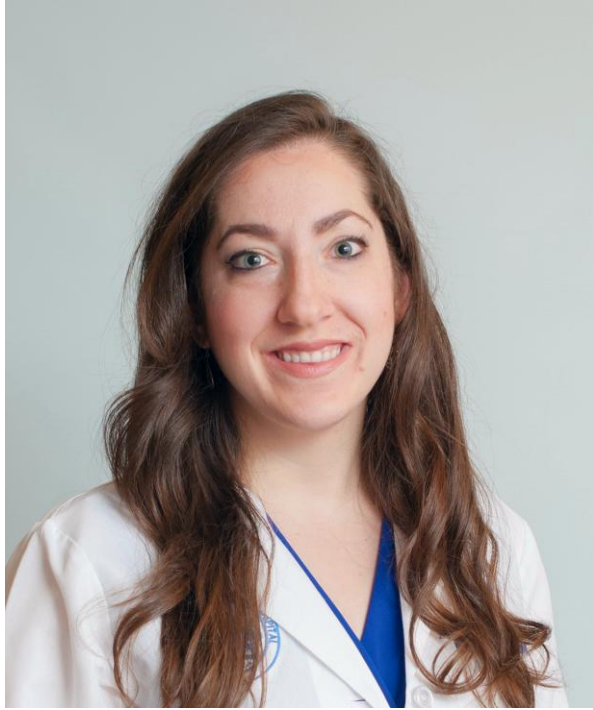
- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally



# ACCORDS Upcoming Events – mark your calendars!

January	<ul style="list-style-type: none"><li>• January 15 – D&amp;I Science Graduate Certificate application launch</li><li>• January 28 – ACCORDS/CCTSI Community Engagement Forum – <i>Engaging Community in Data Analysis and Interpretation</i></li></ul>
May 20-21, 2026	<p>Colorado Pragmatic Research in Health Conference <i>Pragmatic Research: Methods, Tools, and Technology for Rapidly Changing Contexts</i></p> <p>Registration is live! Visit <a href="https://coprhcon.com">coprhcon.com</a> for more info.</p> <p><b><u>*New to COPRH Con*</u></b> Pre-conference workshops:</p> <ul style="list-style-type: none"><li>• Pragmatic Research Planning</li><li>• Planning for a Competitive Career Development Award: A Roadmap for Health Services Researchers</li><li>• Mixed Methods Design &amp; Integration Training for Health Services Research</li><li>• Design for Innovation: Practical Use of User-Centered Design</li><li>• AI Essentials for Health Services Researchers: Balancing Increased Productivity with Responsible Use</li><li>• Elevating Research Project Management Practice</li><li>• Dissemination in the Age of AI: Design Tools at Your Fingertip</li></ul>





## **Draping the Star Quilt: Developing a Palliative Care Community Health Worker Intervention in American Indian Reservation Communities**

**Bethany-Rose Daubman, MD**  
Co-Director, Global Palliative Care  
Program at Massachusetts  
General Hospital





# Draping the Star Quilt: Lessons Learned from an American Indian Palliative Care (PC) Community Health Worker Program

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# Objectives

Use a case-based example to discuss how community-based participatory research can be a powerful tool to advance care in disenfranchised communities

Consider inclusion of a wider team than is traditionally represented in research/clinical care when developing care in disenfranchised communities such as American Indians

# Acknowledgements

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- JR LaPlante, JD
- Sara Purvis, MPH





# Two things to note...

- Definition of palliative care
- Stories vs data



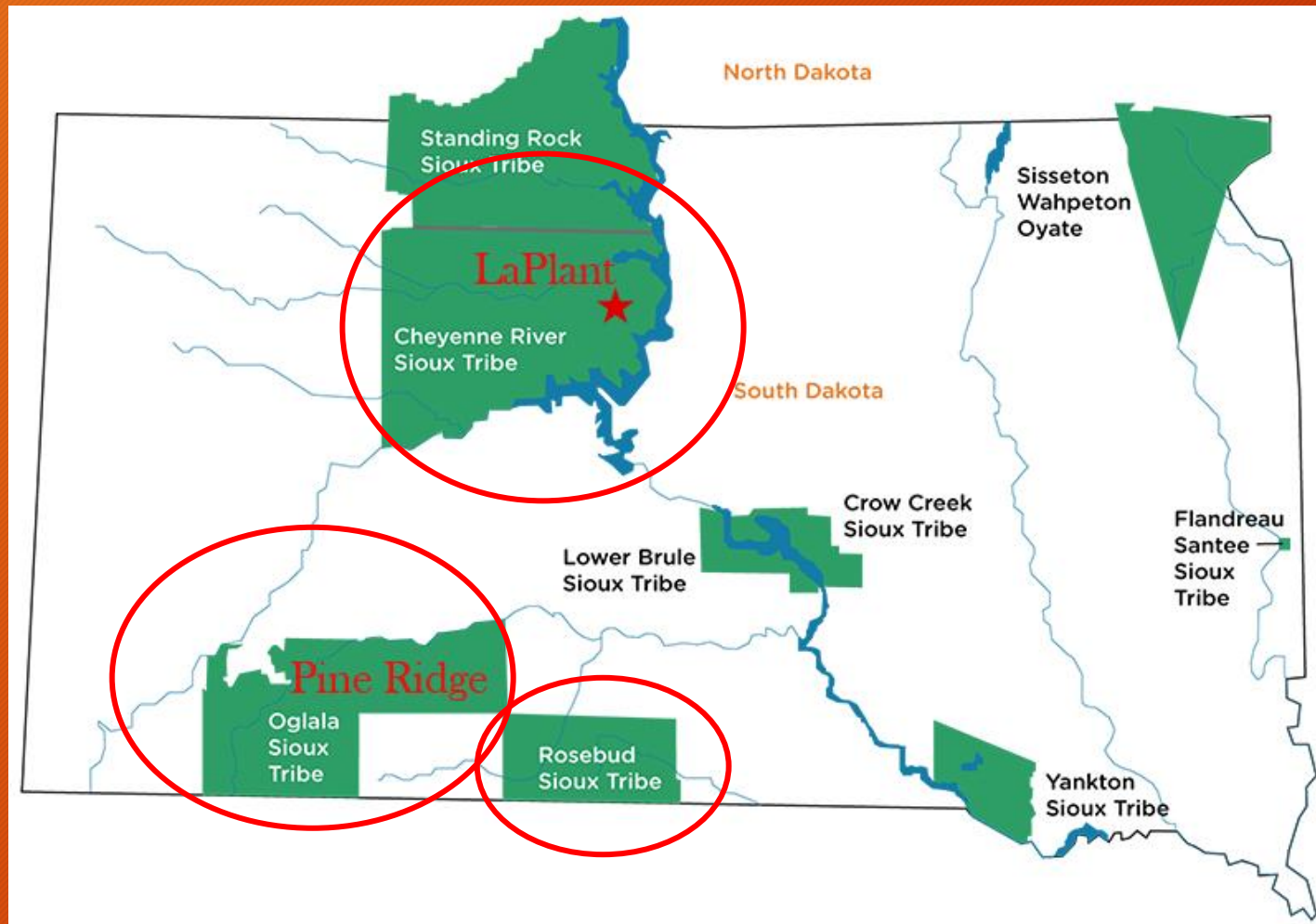
Lakota artist Derek "Focus" Smith



# Lakota Nation









# Palliative Care Access

- Does it exist?
- Is it accessible?
- Is it culturally responsive?





# American Indian Health Outcomes

- Higher rates of many cancers
  - Diagnosed at more advanced stages
  - Higher mortality rates
- Greater incidence of heart, kidney, and liver disease
- Less access to high-quality care
- Geographic challenges to accessing care
- Poverty
- Lack of culturally responsive healthcare
- Historical and ongoing trauma

















# Exploring Palliative Care Program Implementation for American Indian and Alaska Natives throughout the US

**Table 2.** Interviewee Role, Palliative Care Delivery Model, and Entity Involved in Palliative Care Program Administration

Interviewee role	PC delivery models <sup>a</sup>	Entity involved in PC <sup>a</sup>
Physician ( <i>n</i> = 7)	HBC ( <i>n</i> = 5)	Tribally owned hospital/org ( <i>n</i> = 6)
Administrator ( <i>n</i> = 3)	IS ( <i>n</i> = 4)	IHS hospital ( <i>n</i> = 3)
Social worker ( <i>n</i> = 1)	OC ( <i>n</i> = 2)	Nontribal PC agency ( <i>n</i> = 1)
Nurse practitioner ( <i>n</i> = 1)	HS ( <i>n</i> = 2)	Academic medical center ( <i>n</i> = 1)

<sup>a</sup> Several of the nine programs utilized more than one model and entity to deliver PC services; numbers do not add up to nine.

HBC, home-based care; HS, hospice; IHS, Indian Health Service; IS, inpatient services; OC, outpatient clinic; PC, palliative care.



# Exploring Palliative Care Program Implementation for American Indian and Alaska Natives throughout the US

- Facilitators of implementation included:

- a high tension for change
- effort of champions
- use of existing resources
- engaging community
- consideration of cultural values
- and the presence of Native staff

- Barriers to sustainability included:

- administrative leadership support
- dependence on champions
- and high cost

Program aggregate	Innovation characteristics		Outer setting	Inner setting			
	Cost	Culturally tailored design	Knowledge of needs+resources	Tension for change	Compatibility with culture	Relative priority	Leadership engagement
Sustained (n = 5)	+	++	++	++	++	++	++
Not sustained (n = 4)	-	++	++	++	++	--	--







# Exploring Factors Influencing Palliative Care Access for Great Plains American Indians

- Qualitative study interviewing 38 individuals working at 5 regional cancer centers (specialty clinicians) and 3 IHS service units (primary clinicians) in the Great Plains
- Broad themes identified included:
  - Healthcare system operations
  - Geography
  - Workforce elements
  - Historical trauma and racism





# R01 Talking Circles and Interviews

Daubman BR, Duran T, Johnson G, Soltoff A, Purvis SJ, LaPlante LJR, Jackson S, Petereit D, Tobey M, Armstrong K, Isaacson MJ. **"Are They Just Experimenting With All of Us?" Cultural Considerations for Clinicians Caring for Seriously Ill Great Plains American Indians.** Am J Hosp Palliat Care. 2025 Mar 14:10499091251327404.

Isaacson MJ, Duran T, Johnson GR, Soltoff A, Jackson SM, Purvis SJ, Sargent M, LaPlante JR, Petereit DG, Armstrong K, Daubman BR. **Great Plains American Indians' Perspectives on Patient and Family Needs Throughout the Cancer Journey.** Oncol Nurs Forum. 2023 Apr 21;50(3):279-289.

Isaacson MJ, Duran T, Johnson G, Soltoff A, Jackson S, Petereit D, Armstrong K, Daubman BR. **"Calling the Spirit Back:" Spiritual Needs Among Great Plains American Indians.** J Pain Symptom Manage. 2022 May 23:S0885-3924(22)00718-7.

Daubman BR, Duran T, Johnson G, Soltoff A, Purvis S, Sargent M, LaPlante JR, Petereit D, Armstrong K, Isaacson MJ. **"You Can't Record That!" Engaging American Indian Traditional Healers in Qualitative Research.** J Pain Symptom Manage. 2023 Jan 20:S0885-3924(23)00033-7.





# Overarching Themes

- Native-led
- Involving accompaniment for both patient and caregiver
- Adapted to fit the needs of each reservation
- Incorporating traditional spiritual practices

"Lakota Women" by Linda Haukaas





# JR LaPlante, JD R01 Co-Investigator



# Community-Based Participatory Research Focus

- Interviews with American Indian/Alaska Native PC Leaders Nationally
- IHS and Specialty Provider Interviews
- Talking Circles
- Traditional Healer Interviews
- Tribal Leader Interviews
- Lakota Community Advisory Boards
- Meeting with Community Health Workers (CHWs)
- Developing a CHW PC Training Curriculum
- CHW PC Clinical Trial







Palliative Care: the  
origin  
PALLIARE (LATIN): “TO CLOAK”





# Strength in Partnerships

- Interdisciplinary R01 team (clinicians and researchers)
- Native and non-Native partners
- Community Advisory Boards
- Tribal leaders
- Traditional healers
- A judge





# Adding to the team....

- Community Health Workers, or **Wawokiya** Health Advocates

**Wa-** something good, natural, and pure

**Wo-** doing something collectively

**Ki-** with

**Ya-** a journey



Ledger art by Evans Flammond, Sr.

# Wawokiya Health Advocate Training Modalities

Virtual Modules

In-Person 2 Day Training

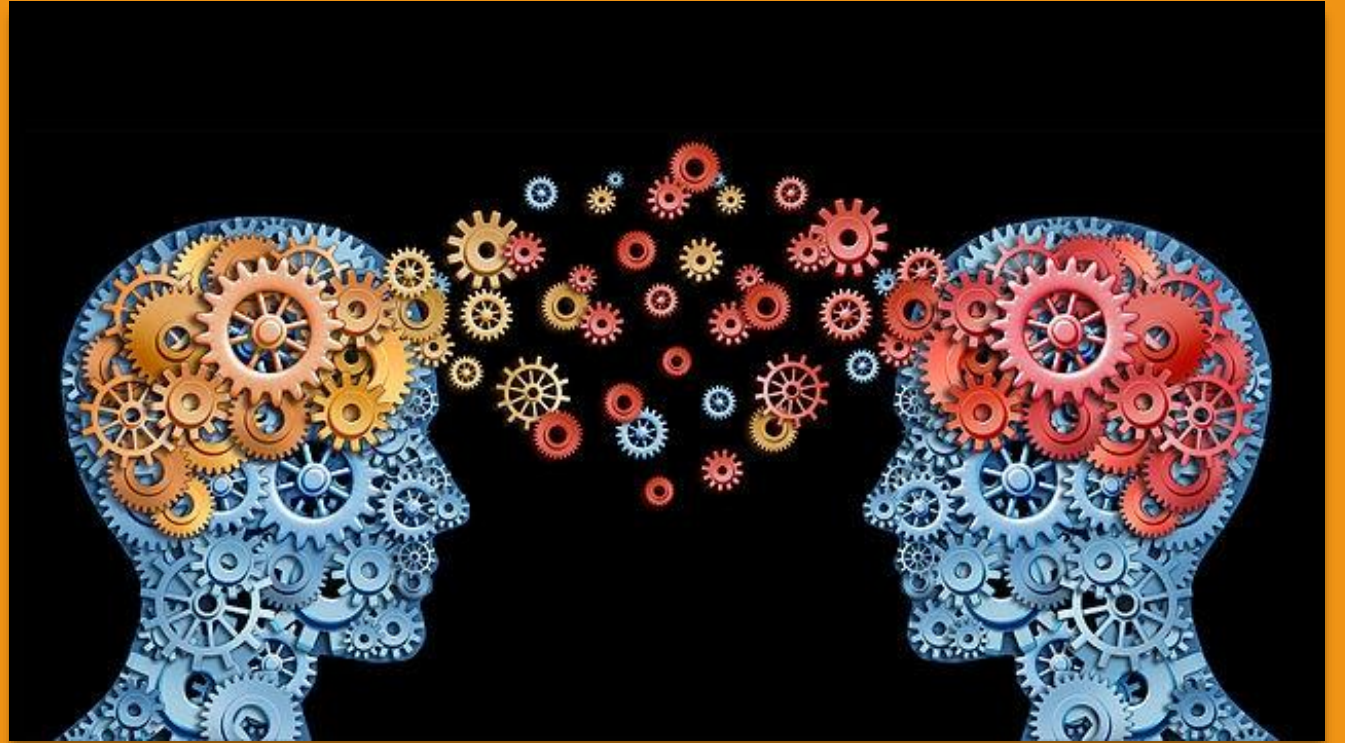
Shadowing Interdisciplinary Team in Palliative Care Clinic

Team Debrief

Weekly Case Conferences/Check-ins



Everyone  
Teaches,  
Everyone  
Learns



# Acknowledging Wakhuza

*Art by Genevieve Bluebird*





# Sharing Personal Experiences with Palliative Care

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For the hook, the audience's attention is getting ready to plummet to near zero. If something isn't done quickly, the students will end up in successively losing bouts of an effort to stay with me. What do they need? Not more information of the same type. Not more completely irrelevant cue that breaks them from the line of thought, making the information stream seem disjointed, unorganized, and polarizing. They need something so compelling that they break through the 10-minute barrier—something

# Virtual Modules

7 modules, completed asynchronously  
Roughly based on:

- Clinical Practice Guidelines for Quality Palliative Care (Ed4) <https://www.nationalcoalitionhpc.org/ncp/>
- Pallium India CHW training program

Everyone Teaches, Everyone Learns:

- Lakota elder co-teachers as well as MD and RN educators
- Reflection Questions and Case Exercises after each module

Module 1: What is Palliative Care?

Module 2: Community Participation in Palliative Care & Role of the WHA

Module 3: Physical Needs in Palliative Care

Module 4: Emotional Needs in Palliative Care

Module 5: Spiritual & Religious Needs in Palliative Care

Module 6: Social Needs in Palliative Care

Module 7: Safety in the WHA Visits



Community Advisory  
Board Member  
Angela Stover  
Introducing  
Palliative Care



# 2 Day In-Person Workshop

Presentations, including co-teaching from Lakota elders via video

Group discussion

Role-play scenarios

Prayer

Flexibility in responding to community member's needs











# Next Steps in Training



Refresher Trainings



Team Debrief after Clinical Shadowing



Weekly Case Conferences/Check-ins



Wawokiya Health  
Advocate:  
Paige Fast Wolf



# Exploring Sustainability and Burnout in Palliative Care Wawokiya Health Advocates





# Exploring Sustainability and Burnout in Wawokiya Health Advocates

Weekly interdisciplinary calls with additional training

Offers of joint visits

Offers of referral to specialty palliative care

Surveys on burnout

Creative scheduling

Brainstorming solutions together





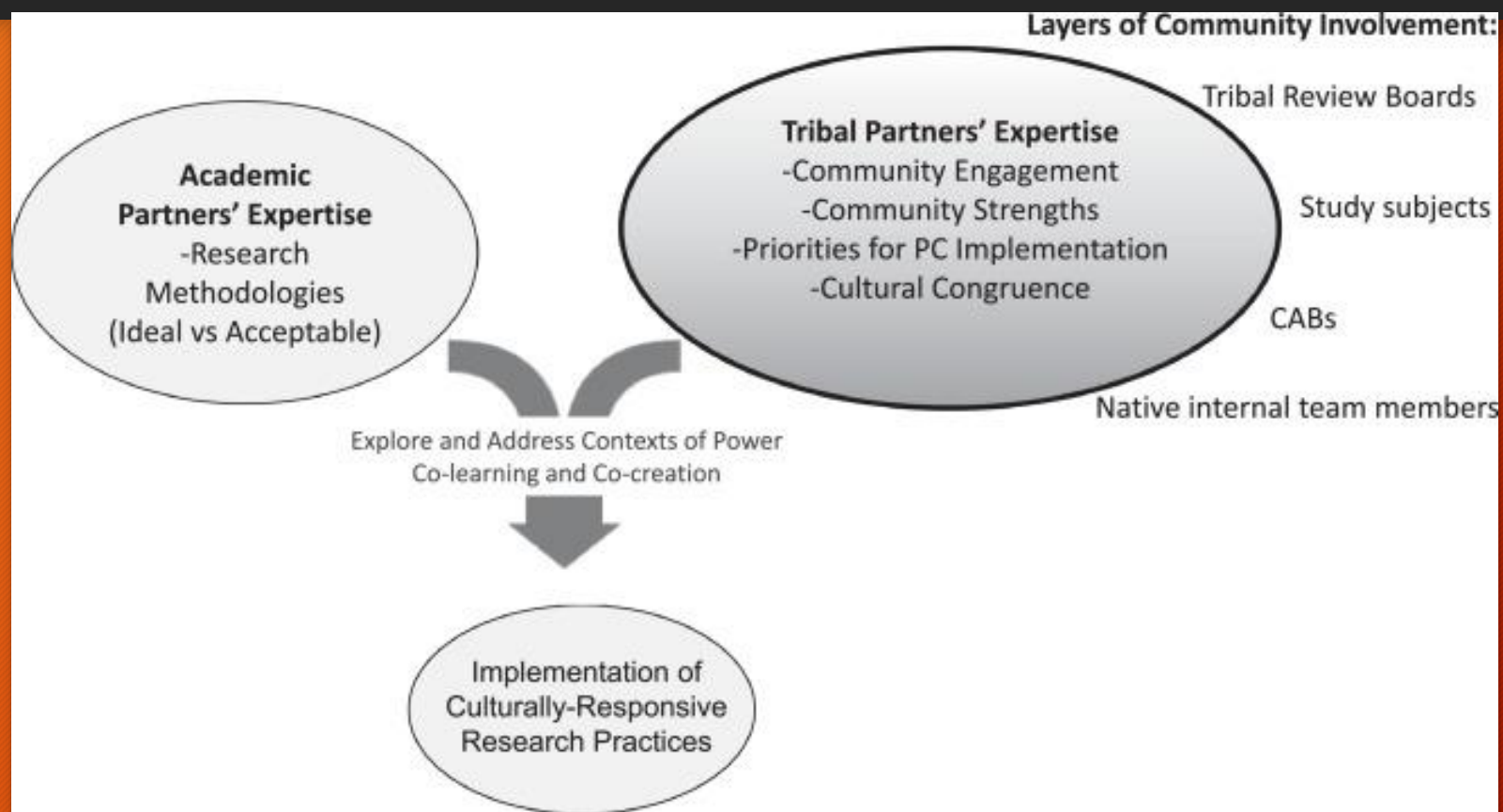
# Heal the Healers retreat

- Suggested by one of our Wawokiya Health Advocates
- Led by a Tribal leader who is a social worker and a Tribal elder
- Exploration of traditional healing practices, self-care, grief and bereavement practices





# Research processes development model for Tribal-academic research partnerships



Daubman BR, Duran T, Johnson G, et al. "You Can't Record That!" Engaging American Indian Traditional Healers in Qualitative Research. *J Pain Symptom Manage.* 2023;65(5):e507-e509. doi:1



# Patient Interviews at Study Conclusion



Has [WHA] been helpful  
to you?

Yes-7, No-0



Has [WHA] been helpful  
to your family?

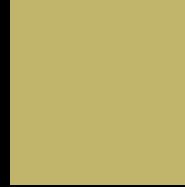
Yes- 6, No-1



How helpful? (Likert  
scale: Very unhelpful,  
somewhat unhelpful,  
neutral, somewhat  
helpful, very helpful)

All said Very  
Helpful

# Patient Interviews at Study Conclusion



Has [WHA] been able to connect you to any resources/people?

Yes-6, No-1



Were you connected to any resources that were not helpful?

No- 6, Yes-1



How satisfied have you been with your visits? (Likert scale: Very unsatisfied, somewhat unsatisfied, neutral, somewhat satisfied, very satisfied)

All said Very Satisfied



Themes from the  
interviews with  
representative quotes



# Wawokiyas helping with Resources

- “I mean, she’s not knowledgeable medically, but she’s knowledgeable with, like you said, trying to find resources for us. She’s knowledgeable with IHS, the Tribe’s help or stuff like that.”
- “..she’s helping me with my house, so that’s very helpful. Because I don’t have a job. So, the added help that she helped get for my money and for mileage and stuff, that helps my family as well because my parents were the ones who were paying for everything before.”
- “Even the gift certificates that I get from doing these surveys have really helped, especially in a time where we didn’t have no gas money or maybe it came in a time where I didn’t know how I was going to get supper that night. So, I mean, it has really helped in that way as well.”



# Wawokiyas helping with Advocacy and Education

- “She just sat us down, explained things to them about cancer patients.”
- “Yes, it was ‘cause they didn’t understand why I was always full of anxiety and stuff like that.”
- “She called the hospital for me one day.”

# Wawokiyas helping with Accompaniment

- “sometimes she’s the only person I see all day beyond my grandson... I’m pretty much a shut in because of my blood from the surgeries. It’s good to see her. She’s a nice person.”
- “.. it’s good to talk about things too. You don’t really have anybody to talk to about that kind of stuff.”
- “She listens whenever I'm having a bad day or if I don’t have anybody to talk to, she – she just checks on me. She would just call and is always asking if I'm okay and if I need anything that she can help me with.”



# Sub-theme: Emotional Support from Unexpected Sources- Study Paperwork

- “..I was really, really impressed with the manner in which the language, the Lakota language was implemented into the paperwork that they gave me. The - like the information. There was a lot of Lakota language incorporated into that. For me, it was really comforting and really special to see that. **It made it feel more spiritual in a sense because I know it's sacred and you feel it when you hear it spoken.**
- When you're going through things like that you get a lot of medical terminologies, jargons thrown at you. Then to see this program and you open up that folder that they give you and **there's this paperwork in there and it's in Lakota but it's talking about your cancer.** It's like, “Man, this feels good.” You know? So, I really, really appreciated that...
- With that cultural component with our people and our ways is that we always share that compassion with one another and ..people whenever they're going through difficult times and that was really helpful.”

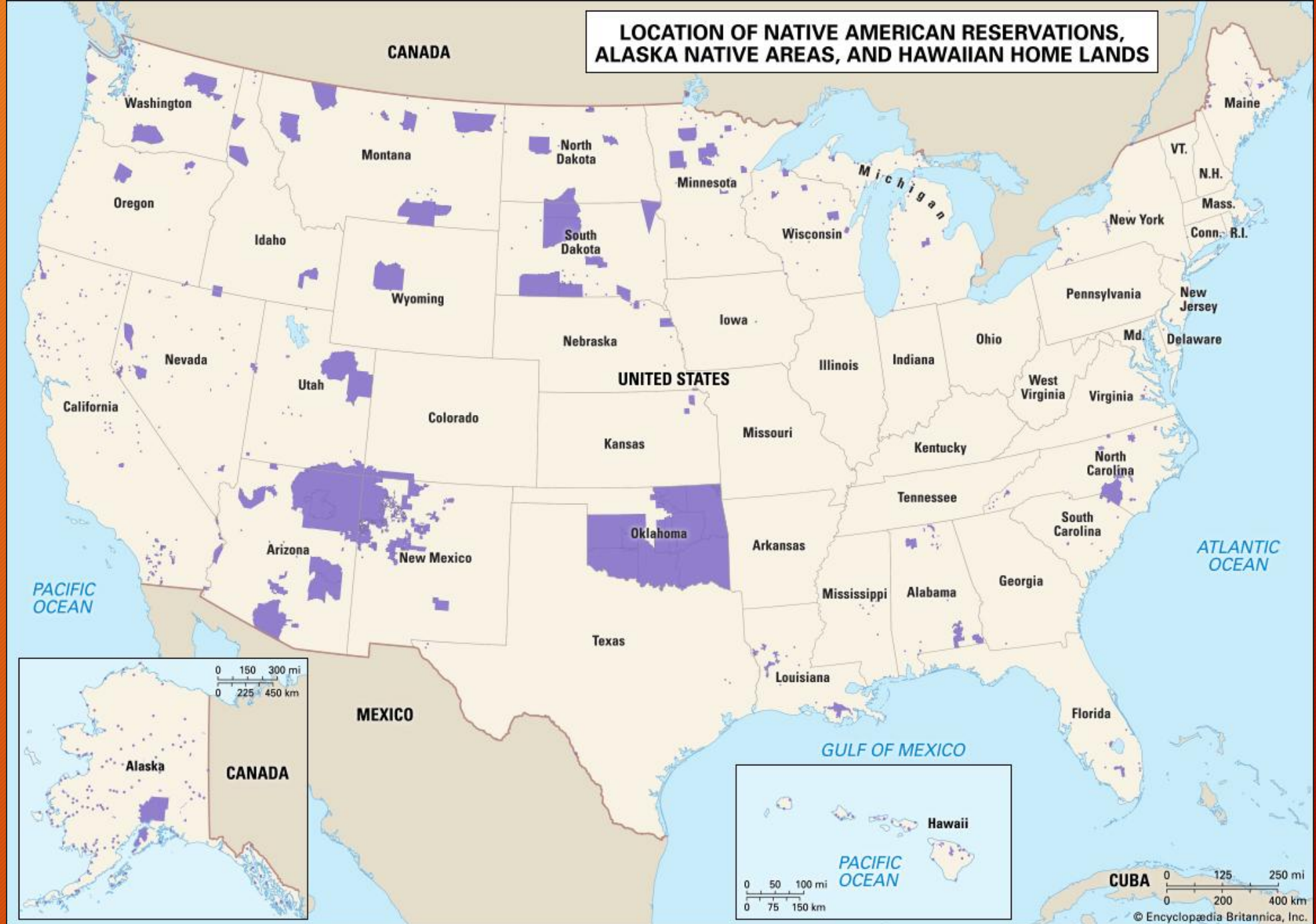


# Relevance of Community Health Worker Sustainability Beyond Tribal Communities

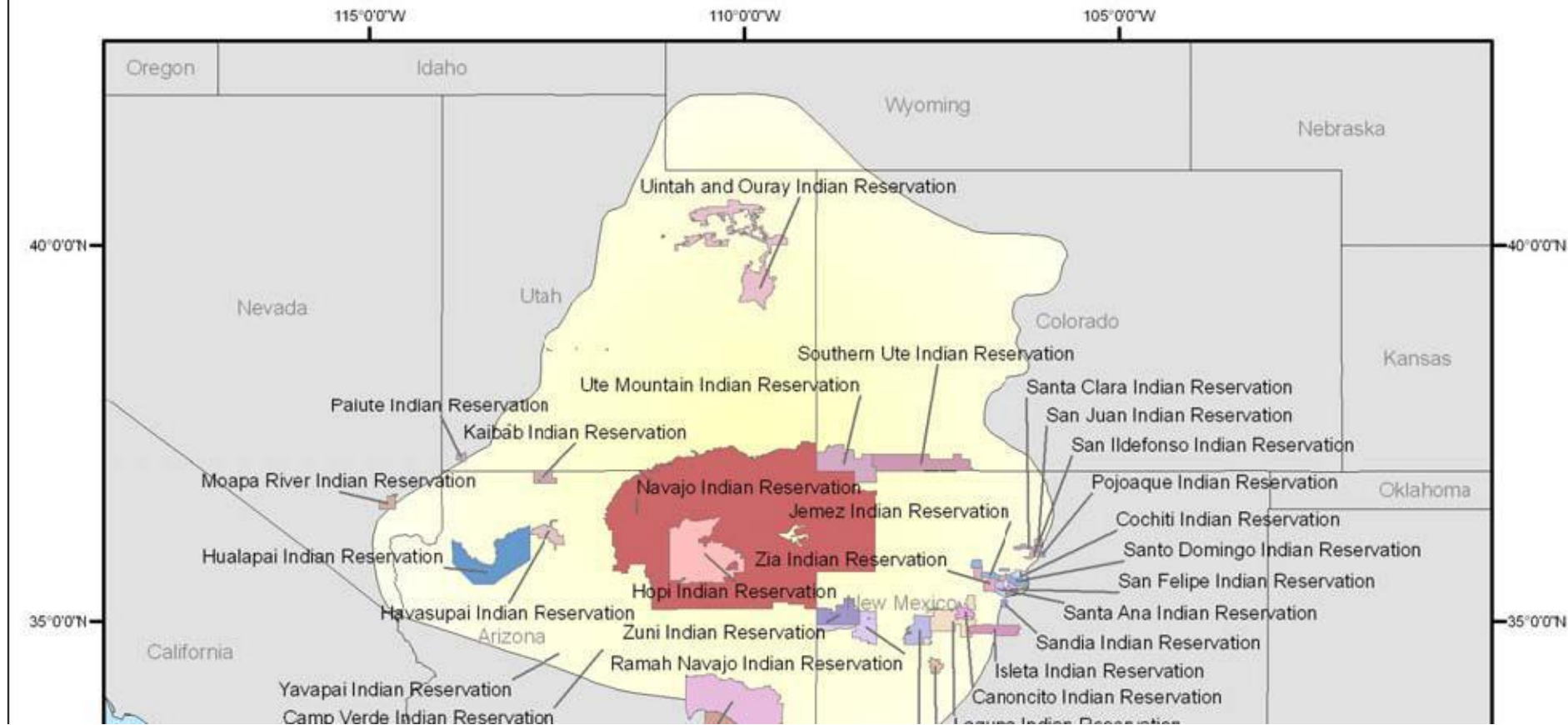




**LOCATION OF NATIVE AMERICAN RESERVATIONS,  
ALASKA NATIVE AREAS, AND HAWAIIAN HOME LANDS**



# Native American Reservations Located on the Colorado Plateau





# Draping the Star Quilt Together

- Community-based participatory research can be a powerful tool to advance palliative care in disenfranchised communities
- Consider inclusion of a wider team than is traditionally represented in research/clinical care when developing palliative care in disenfranchised communities



# Wopila Tanka (Thank you)

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