Impacts of NINR-funded Advance Care Planning Research with Alaska Native Peoples

Jennifer Shaw, Ph.D. , Research Associate Professor
Center for Alaska Native Health Research, Institute of Arctic Biology
University of Alaska Fairbanks

NINR National Advisory Council Meeting
September 9, 2025

Funding and Disclaimers

Overview

- Need for Advance Care Planning (ACP) Research with US Indigenous Populations

- A Research Program to Implement and Evaluate an ACP Communication Intervention in an Alaska Native Health (AN) System

- Building Capacity for ACP Research with AN Populations, Communities, and Health Systems

Advance Care Planning (ACP)

- Identifies your wishes for care if you become seriously ill or hurt

- Occurs through conversations to identify your values, goals, and priorities

- Ideally, results in an advance directive that:
  - ✓ Names your health care agent (Medical Power of Attorney)
  - ✓ Give instructions for medical treatment you do/do not want in certain conditions (Living Will)
  - ✓ Is documented in an electronic health record

ACP in Alaska Native/American Indian (AN/AI) communities

- High need, low utilization
- Cultural "barriers" – reality or myth?
- ACP in AN/AI (and all) communities must be timely, acceptable, accessible, & understandable

Alaska Native Health System

Facts

229 Federally Recognized
Tribes (Villages)

SCF:
Primary care services
in Anchorage,
Matanuska-Susitna Valley and
the Anchorage Service Unit

ANHB:
Statewide health
advocate voice

ANTHC:
Statewide specialty and
tertiary health care

Regional Native Corporations

- Arctic Slope Regional Corp.
- NANA Regional Corp.
- Bering Straits Native Corp.
- Doyon Ltd.
- Calista Corp.
- CIRI
- Sealaska Corp.
- Ahtna Inc.
- The Aleut Corp.
- Bristol Bay Native Corp.
- Koniag Inc.
- Chugach Alaska Corp.

Key

★ SCF Services Hub

★ Regional Health Hub

Southcentral Foundation/
Anchorage Service Unit

1. Also serves Native Village of Eklutna,
   Ninilchik Village Traditional Council, Seldovia
   Village Tribe, Chickaloon Village Traditional Council,
   Knik Tribal Council, and Native Village of Tyonek.

2. ANMC jointly owned and comanaged
   by SCF and ANTHC.

Map labels: Sammuel Simmonds Memorial Hospital; Arctic Slope Native Association; Maniilaq Association; Maniilaq Health Center; Tanana Chiefs Conference; Norton Sound Health Corp.; Norton Sound Regional Hospital; Chief Andrew Isaac Health Center; Yukon-Kuskokwim Health Corp.; Yukon-Kuskokwim Delta Regional Hospital; McGrath Regional Health Center; Copper River Native Association; Valley Native Primary Care Center; Robert Marshall Clinic; Alaska Native Medical Center; Southcentral Foundation; Chugachmiut; Dena'ina Wellness Center; Seward; Bristol Bay Area Health Corp.; Kanakanak Hospital; Nilavena Subregional Clinic; St. Paul Health Center; Kodiak Area Native Association Medical Clinic; Kodiak Area Native Association; Eastern Aleutian Tribes; SouthEast Alaska Regional Health Clinic; SouthEast Alaska Regional Health Consortium; Metlakatla Health Center; Metlakatla Indian Community; Oonalaska Wellness Center; Aleutian/Pribilof Islands Association

REFERRALS FROM:
- ○ HOSPITALS
- ○ MD HEALTH CENTERS
- ○ PA/NP HEALTH CENTERS
- ○ CHA CLINICS

ACP in the Alaska Tribal Health System

2015-2016: Palliative care program established; Alaska Native-centered ACP materials developed; YCYC piloted → Patients aged 40+ with documented ACP increased from 2% to >30% (nat'l average); NINR funds R21 project to tailor and pilot Jumpstart, a patient-centered ACP communication tool

2017-2020: Provider ACP training modules developed and rolled out in all primary care clinics, along with YCYC → overall increases in ACP documentation

2020-2023: ACP documentation decreases due to SARS-CoV-2 pandemic, NINR funds R01 project to implement and evaluate comparative effectiveness of Jumpstart AN/AI

"One must be wise in knowing what to prepare for and equally wise in being prepared for the unknowable."
Always Getting Ready/ Upterrlainarluta by James H. and Robin Barker

YOUR CARE, YOUR CHOICES

Advance Care Planning

Jumpstart Communication Tool

Identify…

…individual ACP preferences and barriers.

- **Collect** brief form from patient (ICSI-Q)

Integrate…

…ICSI-Q answers with ACP tips using algorithm.

- **Create** personalized 1-page conversation tip sheet

Induce…

…an ACP conversation.

- **Give** tip sheet to patient & clinician

Study #1: Exploring Palliative Care Communication with ANAI People at Two Primary Care Sites

- ## Culturally **adapted** Jumpstart
  - Focus with 25 Tribal health system stakeholders in New Mexico & Alaska to gather feedback to tailor the tool
  - Cognitive interviews with 8 patients to assess usability & acceptability of the adapted tool

- ## Adapted Jumpstart **assessed** for feasibility and acceptability
  - Group-randomized pilot trial of Jumpstart ANAI with Alaska Native adults with serious illness and their primary care providers

Do you have experience with a serious illness?

Seeking Volunteers for a research study

Call (907) 729-8623 or email SCFJUMPStudy@southcentralfoundation.com and mention the JUMP study.

Culturally Adapting an Advance Care Planning Communication Intervention With American Indian and Alaska Native People in Primary Care
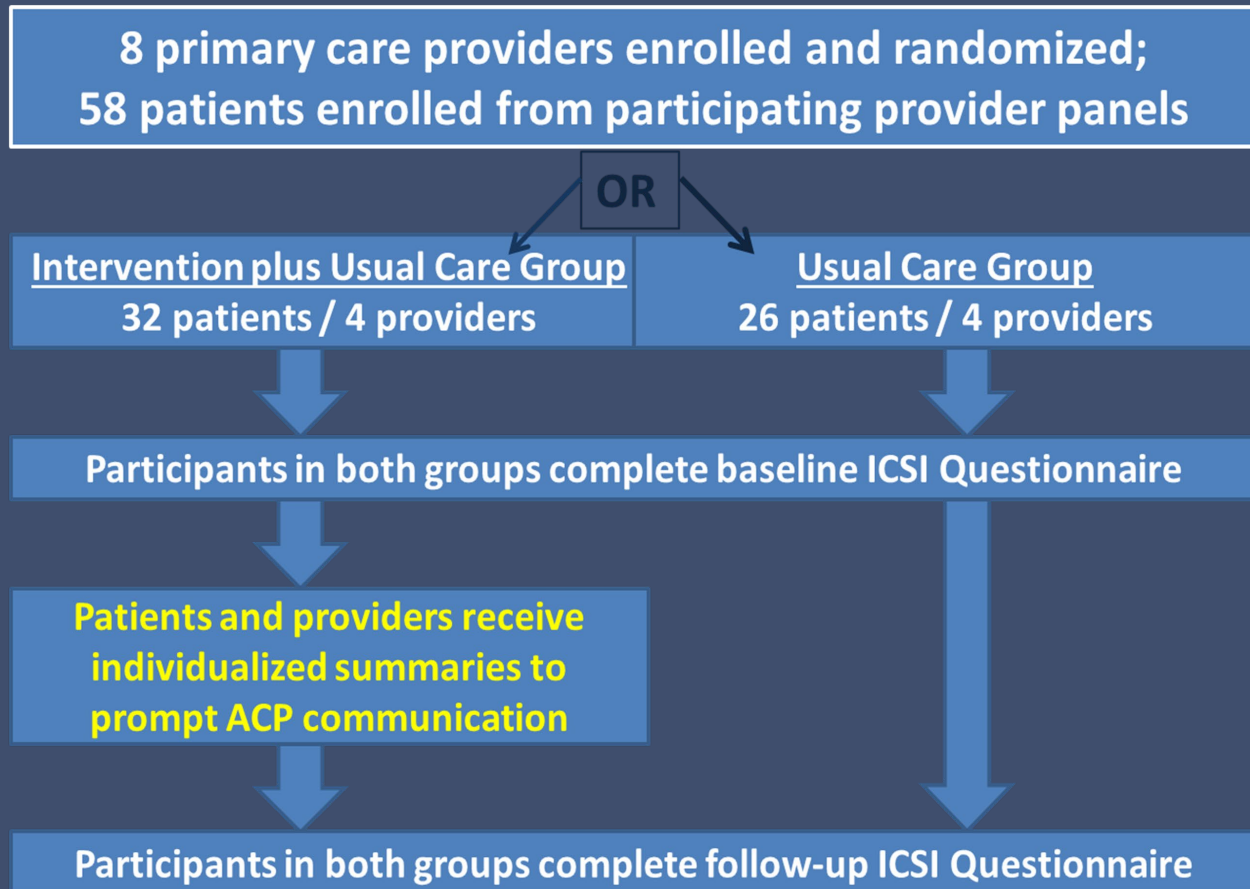
Kate M. Lillie, PhD[1] ⑩, Lisa G. Dirks, MLIS, MAdm[1],
J. Randall Curtis, MD, MPH[2], Carey Candrian, PhD[3],
Jean S. Kutner, MD, MSPH[3], and Jennifer L. Shaw, PhD[1]

Abstract

Introduction: Advance care planning (ACP) is a process in which patients, families, and providers discuss and plan for desired treatment goals. American Indian and Alaska Native people (AI/AN) have higher prevalence of many serious, life-limiting illnesses compared with the general population; yet AI/ANs use ACP considerably less than the overall population. **Method:** We conducted a qualitative study to culturally adapt an existing ACP intervention for AI/ANs in two primary care settings. **Results:** We found that it is important to incorporate patients' cultural values and priorities into ACP, determine who the patient wants involved in ACP conversations, and consider the culturally and locally relevant barriers and facilitators when developing an ACP intervention with AI/AN communities. **Discussion:** At the core, ACP interventions should be clear and understandable across populations and tailored to facilitate culturally appropriate and meaningful patient–provider communication. Our results and methodology of culturally adapting an intervention may be applicable to other underrepresented populations.

Theme/subtheme	Example quote
Culture/role in ACP communication	"Can you add maybe like a suggestion, of adding the word culture, I know you have the religious and spirituality but maybe putting cultural beliefs, I think some people might register that more.
Talking about health care/ identifying key people	"Sometimes it's the CMA that's taking your blood pressure that has a better rapport with the patient, than the care provider . . . it doesn't necessarily have to be the person that had the "MD" behind their name, or their BSN. It's really [about] who's the person that best can speak with the patient, because they're part of the team, too."
What makes talking about care harder or easier/provider-initiated communication	" . . . when you're scared about something and you don't really want to talk about it, you're going to avoid if . . . And if your provider doesn't bring it up, then you're gonna get out of that appointment and think, 'Whew, I didn't have to touch that, this time.'"

Jumpstart ANAI Pilot Trial

8 primary care providers enrolled and randomized;
58 patients enrolled from participating provider panels

OR

Intervention plus Usual Care Group
32 patients / 4 providers

Usual Care Group
26 patients / 4 providers

Participants in both groups complete baseline ICSI Questionnaire

Patients and providers receive individualized summaries to prompt ACP communication

Participants in both groups complete follow-up ICSI Questionnaire

Feasible

- Recruited 97% of the target sample
- Retained >75% (n=44) at follow-up

Acceptable

- At follow-up 95% reported that Jumpstart facilitated ACP conversations with primary care providers, **even if they had these conversations previously.**

Signs of effectiveness

- New ACP conversations 4x as likely in Jumpstart group.
- New ADs 3.5 times higher in the Jumpstart group.

Study #2: Jumpstarting Culturally Informed Advance Care Planning with ANAI People in Primary Care

Specific Aims

Aim 1

Tailor an implementation plan to integrate Jumpstart AN/AI into routine primary care

Aim 2

Conduct cluster-randomized controlled trial to evaluate Jumpstart AN/AI as compared to usual care

Aim 3

Complete rigorous, mixed-methods process evaluation of Jumpstart implementation using the Consolidated Framework for Implementation Research

Aim 1: Implementation Planning

Community Engagement

| Semi-structured interviews with health system customer-owners & staff | Primary care leadership |

Implementation Workgroup

Health care improvement specialists, clinical experts, and researchers, developed E.H.R. build, workflows, communication plans, and protocols for Jumpstart implementation

Aims 2 & 3

- Cluster randomized type 1 hybrid trial & evaluation of Jumpstart implementation
- *N*=450 patients
- Brief Jumpstart vs. Full Jumpstart vs. Usual Care
- Implementation planning completed in June 2025
- Trial enrollment began in July 2025

Alaska Native
HEALTH CAMPUS
← EMERGENCY
H

KNIK · TRIBAL · COUNCIL
EST. 1989

SOUTHCENTRAL FOUNDATION ANCHORAGE, ALASKA

ATHABASCAN NATION
CHICKALOON VILLAGE

AyiK

EXIT

We Changed Everything

Qaĝaasakung
Aleut

Quyanaa
Alutiiq

Quyanaq
Inupiaq

AwA'ahdah
Eyak

Mahsi'
Gwich'in Athabascan

Igamsiqanaghalek
Siberian Yupik

Háw'aa
Haida

Quyana
Yup'ik

T'oyaxsm
Tsimshian

Gunalchéesh
Tlingit

Tsin'aen
Ahtna Athabascan

Chin'an
Dena'ina Athabascan

Thank you!