



**For Researchers:
How to Conduct Research in
American Indian and Alaska Native (AI/AN) Communities**
June 16-17, 2005
Fort Yates, North Dakota

Hosted by:
Northern Plains Tribal Epidemiology Center

Sponsored by:
Indian Health Service
Spirit of Eagles
University of Nebraska Medical Center

TRAINING AGENDA

This training will provide tools to help researchers better conduct effective and culturally competent research in American Indian and Alaska Native (AI/AN) communities. The Institutional Review Boards (IRB) and federal guidelines address protections for the individual; this training will address research benefits and harms to both individuals and their communities. The process of community consultation, an element of community-based participatory research, will be discussed as a method to increase: effectiveness of the research; acceptability of the research to AI/AN communities; research protections to communities and individuals; and benefits to communities and individuals. This training will include useful tools and approaches that researchers will be able to apply in their work.

DAY 1: Thursday, June 16

- 7:00am Registration
- 8:30am Welcome and Introductions
Francine Romero, PhD, MPH, Director, Northern Plains Tribal Epidemiology Center
Standing Rock Sioux Tribe
- 9:00am Keynote Address: What is Culturally Competent Research?
Laura Arbour, MD, University of British Columbia
- 10:15am Break (light refreshments provided)
- 10:45 am Participant experiences with working in AI/AN communities
- 11:15am Introduction
Purpose of this training; overview of topics to be covered; what participants can expect to gain; review of materials

- 11:30am History of Research in AI/AN Communities
William Freeman, MD, MPH, Director of Tribal Community Health Programs & Human Protections Administrator, Northwest Indian College
The historical culture of research in AI/AN communities must be examined to understand where we are today in relation to research ethics. Human subjects protections in conventional terms of individuals have not always prevented harms to entire communities. This session will explore the concepts of individual and community research protections through the timeline of research events in AI/AN communities and other 'vulnerable' groups.
- 12:30pm Lunch (provided)
- 1:30pm Definitions of Research
Elyse Summers, JD, Public Health Analyst
Division of Education and Development, Office for Human Research Protections
This session will identify elements that constitute "research" as defined by federal regulations, researchers, and community.
- 2:15pm Types of Community Harms
Connie Garcia, Administrative Officer
Albuquerque Area Indian Health Board
The session will define some of the more common forms of community harms and how they may be identified.
- 3:00pm Break (light refreshments provided)
- 3:30pm Breakout 1: Potential individual and community harms in research scenarios.
- 4:30pm Group Discussion
- 5:30pm Adjourn

Day 2: Friday, June 17

- 8:00am The Validity of Informed Consent is Dependent Upon the Process, Not the Document
Ernest Prentice, PhD, IRB Chair
University of Nebraska Medical Center
This session will begin with an overview of the history of Informed Consent, and then it will focus on the process of consent using a brief case study approach.
- 8:45am Introduction to community consultation as a way to address harms and benefits in an AI/AN community
Connie Garcia, Administrative Officer
Albuquerque Area Indian Health Board
This session will provide an overview of the community consultation process.

- 9:15am Community Consultation Process in Detail
William Freeman, MD, MPH, Director of Tribal Community Health Programs & Human Protections Administrator, Northwest Indian College
Rick Strickland, MA, Director, North Central Spirit of EAGLES: AI/AN Leadership Initiative on Cancer, University of Wisconsin Comprehensive Cancer Center
Francine Romero, PhD, MPH, Director
Northern Plains Tribal Epidemiology Center
Community consultation, a process of community-based participatory research, will be described as a method to ensure research protections for individuals and communities. This session will begin with the current basic process for proposing and conducting research in tribal communities, followed by an assessment of how community consultation can be incorporated into the research design.
- 10:15am break (light refreshments provided)
- 10:45am Breakout Session 2: Modify a protocol to incorporate community consultation
- 11:45am Group Discussion
- 12:45am Q&A
- 1:00am Adjourn

ACKNOWLEDGEMENTS

The Northern Plains Tribal Epidemiology Center would like to thank everyone involved for their time and effort in planning and implementing this training.

Special Thank You

Standing Rock Sioux Tribe

Sponsored by

Indian Health Service
Spirit of E.A.G.L.E.S.-Mayo Clinic NCI 86098-05
University of Nebraska Medical Center

Planning Advisory Committee

Dewey Ertz, MD

Co-Chair, Institutional Review Board
Aberdeen Area Indian Health Service

Ernie Prentice, PhD

Chair, Institutional Review Board
University of Nebraska Medical Center

William L. Freeman, MD, MPH, CIP

Director of Tribal Community Health Programs
& Human Protections Administrator
Northwest Indian College

Rick Strickland, MA

Director, North Central Spirit of EAGLES:
AI/AN Leadership Initiative on Cancer
University of Wisconsin Comprehensive Cancer Center

Marianna Kennedy, MSW, MPA, MPH

Executive Director
Albuquerque Area Indian Health Board

Timothy L. Taylor, PhD, MPH

Director, Division of Planning, Evaluation & Research
Indian Health Service

Terry J M Powell

Administrator, Institutional Review Board
Alaska Area Indian Health Service

Guest Speakers

Laura Arbour, MD

Assistant Professor
Department of Medical Genetics
University of British Columbia

Elyse I. Summers, J.D.

Public Health Analyst
Division of Education and Development
Office for Human Research Protections

Presenters and Moderators

Laura Arbour, MD

Assistant Professor
Department of Medical Genetics
University of British Columbia

Sayaka Kanade

Academic Liaison
Northern Plains Tribal Epidemiology Center
Aberdeen Area Tribal Chairmen's Health Board

William L. Freeman, MD, MPH, CIP

Director of Tribal Community Health Programs
& Human Protections Administrator
Northwest Indian College

Ernie Prentice, PhD

Chair, Institutional Review Board
University of Nebraska Medical Center

Connie Garcia

Administrative Officer
Albuquerque Area Indian Health Board

Francine Romero, PhD, MPH

Director, Northern Plains Tribal Epidemiology Center
Aberdeen Area Tribal Chairmen's Health Board