

#### Researcher Bio

Nanibaa' Garrison (Diné) is from Tsegi, Arizona on the Navajo Nation. She holds a B.S. from the University of Arizona and a Ph.D. from Stanford University. She is working in the area of biomedical ethics and is concerned with issues around justice, equity, and respect for indigenous peoples, particularly in research about genetics.

Dr. Garrison's past work focused on the harms and impact of the Havasupai tribe's lawsuit over misuse of genetic material. She is a contributing author to NCAI's Genetics Resource Center at http://genetics.ncai.org.

#### Contact us

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UW Medicine SCHOOL OF MEDICINE

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# Genomics and Native Communities:

Perspectives, Ethics, and Engagement

Tribal Nations

Advisory

Genetics

Research

Leaders

Participation

Governance

**Ethics** 

Policy Community

Data

Sovereignty

Privacy

#### **Project Goals**

To understand your views and opinions on genetic research

To identify strategies for tribes to participate and engage in ethically sound genetic research

To develop policies and guidelines that will be made publicly available for tribes to use

# Genomics and Native Communities project Perspectives, Ethics, and Engagement

### How will the research findings be used?

We will identify the major themes from the interviews to develop a survey for tribal leaders, health professionals, and policy makers.

We will engage stakeholders on these topics and work to develop guidelines that tribes can use to govern research within their communities.

The findings will be used in presentations and publications. No identifiers (name, tribe, job title, etc.) will be revealed.

The study investigator will work with the National Congress of American Indians Policy Research Center to develop policies and share information.

#### **Eligibility includes:**

- 18 years of age or older
- A leader in your community, health professional, or policy maker who has a view on genetic research
- Have previously written or spoken publicly about your views on genetics

#### What does the study involve?

If you take part in this project, we would meet in person or by phone for a 1-hour interview. We will ask you questions about your thoughts related to genetics research in American Indian and Alaska Native communities.

The interview will be audio recorded. These audio files will be transcribed for data analysis purposes and the files will be stored securely.

#### What is in it for you?

You will receive a gift card or a coffee mug to thank you for your time and expertise. You may request a copy of any publications.

In the future, we may contact you again to follow up and to share information from this study.

## What are your rights as a participant?

- Decline to be audio recorded
- Decline to answer any questions
- Stop the interview at any time
- Ask to have the audio file destroyed