For Tribes

This resource guide was developed to help American Indian/Alaska Native (AI/AN) tribal leaders and community members make informed decisions about genetics research participation. A number of tools and resources have been developed especially for AI/AN communities.

The main sections of this resource guide are:

Frequently Asked Questions: Quick overview of the resource guide, including key considerations in decision making around genetics research; research agreements; and the process of informed consent.



<u>Summary Tools</u>: Brief handouts and checklists for tribal leaders, including questions to consider in making decisions related to genetics research, options for control of data, increasing the number of Native scientists, and the use of genetic testing for tribal enrollment.

<u>The Basics of Genetics</u>: Stories and handouts for AI/AN communities about the basics of genetics, genetics research, and the relationship between genetics and health.

<u>Making Decisions about Genetics Research</u>: A guide to identifying community values to help you make decisions about research in your community, including an interactive set of reflection questions about genetics research.

<u>Cases of How Tribes are Relating to Genetics Research</u>: A set of interactive case studies about how tribes across the US have chosen to deal with genetics research, including both tribes that are participating in genetics studies and those that are not.

<u>Regulating Genetics Research in Your Community:</u> Templates and models for research contracts, informed consent forms, and tribal control of research data.

Enhancing Genomic Research through a Native Lens: A Native scholar's perspective on the field of genomics research, and a discussion of the need to increase the number of AI/AN scientists.

<u>Tribal Enrollment and Genetic Testing</u>: Information about the use of DNA testing in determining tribal citizenship or enrollment.

<u>People to Contact with Questions</u>: A list of the contributors to this resource guide and other individuals to contact who may be able to assist with questions about genetics research.

<u>For Researchers</u>: Information for researchers about how to partner effectively with tribes in genetics research studies.

<u>About Us</u>: Background and contact information for the National Congress of American Indians Policy Research Center.

<u>Download a PDF of the Guide</u>: All content found within the guide can be downloaded in one full document (PDF format).

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