

Should We Participate in Genetics Research?

By Puneet Chawla Sahota, PhD

Some AI/AN communities have already taken a position on genetics research as is [discussed in the case studies](#) on how tribes are relating to genetics research. However, many communities have not yet determined where they stand on genetics research. Other communities are interested in genetics research participation, but need additional tools to engage confidently as partners in this type of research.

The questions and discussion guide below provide information and tools to communities with different views on genetics research, including those communities that have not yet solidified their position.

Within a community, individual tribal members may have different opinions about genetics research participation. There may be some issues the community can agree upon collectively, but other issues may be different for individual community members. For example, people may have different views on how they would like their biological specimens (blood, tissue, DNA, etc.) and resulting data handled in research. For example, some community members might want their specimens and data stored for use in future research studies. Other tribal members might want the specimens and data destroyed at the end of the original study. These kinds of differences in views can be accommodated through offering options to individual study participants on the informed consent form, which they sign to enroll in a study. More information about options and model language for informed consent forms is available [here](#).

In this section below, we will focus on how a community can develop a collective stance on genetics research. We offer several questions for your consideration. Please click on the answer choice that best describes your feelings or your community's perspective about research. You will then be provided with additional discussion and links to information specifically related to your answer.

Please note: your answers are not being recorded in any way. This website is a tool for you to consider your own views on genetics research.

Questions to Consider:

1. How do I/we feel about engaging in research in general?

- Want to participate
- Do not want to participate
- Want more information

2. How do I/we feel about participating in genetics research?

- Want to participate
- Do not want to participate
- Want more information to help guide our decisions about genetics research

3. What do we hope to gain from genetics research?

- A cure for disease or health issue facing our community

- Targeted prevention of disease
- Training opportunities for community members in science and research
- Other

4. What are our concerns about genetics research participation?

- Misuse of biological specimens (e.g., blood, skin cells) or genetic data
- Stigma or embarrassment for the tribe
- Ownership, patenting or intellectual property of biological specimens (e.g., blood, skin cells) and genetic data
- Concern about whether genetics research fits with traditional Native ways of knowing and living
- Other