

Increasing Participation in Gene Therapy Clinical Trials and Research in Tribal and Urban Indigenous Communities

Investigators

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Project Summary

This project leverages community-based participatory research and will engage American Indian communities, stakeholders, and researchers in understanding knowledge, concerns, and beliefs of participating in gene therapy clinical trials. Findings will be derived from focus group discussions representative of reservation, urban, and rural American Indian communities and will weave in traditional teachings of four cultural core values comprised of relationships, responsibility, reciprocity, and redistribution. By understanding community perceptions and creating opportunities for dialogue across the multiple collaborative partners, this project seeks to understand community hesitancy for enrollment and strategies to increase participation in gene therapy clinical trials.

Populations Served: American Indian or Alaska Native

Goals/Aims:

- Partner with local tribal colleges to assess American Indian community knowledge, concerns, and beliefs about gene therapy clinical trials within the Northern Plains using a mixed methods approach.
- Identify barriers to and strategies for enrolling participants in gene therapy clinical trials among American Indian communities within the Northern Plains region by collecting qualitative data from American Indian providers, researchers, and public health experts.

Publications/Abstracts/Posters, etc.

- Manuscript in preparation.