



Online Ethics Center
FOR ENGINEERING AND SCIENCE

Assessing the Bioethical Impacts of an Indigenous Scholars Network in Genomics

Year

2023

Description

Culturally congruent research that respects the values and norms of Indigenous communities is critically important to increase Indigenous peoples' representation and engagement with genomics research. The Summer internship for Indigenous peoples in Genomics (SING) short course offers training and tools for early career scientists to engage in the research process and for community members to guide their communities in interfacing with external research entities.

Body

Coincident with this training has been the production of ethical frameworks for the scientific community to reference when working with Indigenous communities and influential scholarship, for example, ancient human ancestry research focused on changing the practice of scientific collaboration with Indigenous communities as the core focus of research.

Recognizing that genomic research is inherent in future medical, scientific and translational research, the inclusion and involvement of Indigenous peoples is important and the role of SING to facilitate this engagement, unparalleled. We seek to objectively measure the impact of the SING program by eliciting the perceptions

and understandings of genomic science and ethics engagement of past SING participants and faculty members through focus groups, surveys, and social network analysis. These findings will inform in-person training to impact research approaches, scholarship, and public policy.

Our research aims are to:

- Elucidate Indigenous perspectives on genetic research and scholarship;
- Define SING interactions and influences on Indigenous genomics scholars; and
- Develop and deliver topic specific training to the general public and SING alumni.

Intellectual Merit

The proposed project will examine the intersection of ethics, culture, and professionalism for Indigenous geneticists, allies, and scientists who engage Indigenous peoples in research. A quantifiable analysis of impact on a training workshop such as SING has not been largely undertaken and will provide guidance as to the effectiveness of such programs and ways to increase their value by enhancing areas of strength and identifying those of weakness.

Broader Impacts

Indigenous peoples are the most underrepresented group in genomics research. While the numbers of Indigenous peoples with graduate-level training in geneticists and related fields is unknown, we have seen an increase in members in academia and in professional societies. The proposed project will explore relationships and networks created by Indigenous scientists, the impact of the SING program, and how these relationships have allowed us to explore and shape discussions of ethical genetic research practices with Indigenous peoples.

The OEC Project Pages are intended to cultivate a community of practice and allow ethics researchers, educators, and practitioners to more effectively disseminate their work. This Project Page provides a detailed overview and relevant resources for an on-going science or engineering ethics project. Once you've explored this project, visit the "Projects" section under "Resources" to see more ethics projects.

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