



# ETHICS

## Ethics Training for Health in Indigenous Communities Study

ETHICS is supported by funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (1R01HD082181; 9/2014 – 8/2018)

### Ethics Training for Health in Indigenous Communities Study (ETHICS) Specific Aims

Despite **glaring health disparities among AIAN compared to non-indigenous U.S. populations**, AIAN-specific **research lags behind** other racial and ethnic data in addressing AIAN's own health concerns. A major impediment to research and population health across Indian Country is distrust of the scientific establishment based on **over 100 years of experience with culturally insensitive AIAN research** resulting in tribal stigmatization, unethical research, and data failing to adequately inform prevention and treatment services.

In response, the National Institutes of Health endorses **community-engaged research (CEnR) as a valid and necessary strategy to increase research with AIAN communities and ameliorate health disparities**. However, a significant barrier to CEnR across Indian Country is the absence of culturally relevant research ethics education for community partners. Currently, online ethics training modules for federally funded research are not written for community research partners, nor do they address ethical issues unique to AIAN cultural contexts. The Collaborative IRB Training Initiative (CITI) offers a potential gateway into ethical and respectful CEnR partnership in Indian Country. However, there are still critical gaps in CITI's research ethics training pertinent to AIANs:

- (1) Ethics topics and examples are not relevant to AIAN populations
- (2) Clear, simple language is needed
- (3) Lack of community-level oversight, and risk and benefit concerns.

ETHICS addresses the urgent need to develop and empirically evaluate a culturally relevant CITI training module to increase AIAN community participation in federally funded research conducted in Indian Country. The **overarching goal of the proposed research is to strengthen research capacity and increase AIAN community involvement in NIH funded research** by developing and validating a CITI module that is relevant, passable and accessible.

Using an innovative CEnR approach, this project aims to:

- (1) Identify language, formatting and research examples in the current CITI training module that require cultural adaptation for AIAN community researchers. Aim 1 will be achieved by drawing on expertise of AIAN community leaders, researchers, policy analysts, and ethicists with a wide range of experience in AIAN research.
- (2) Develop and validate a CITI research ethics curriculum that will increase AIAN community members' involvement in research through increased research ethics knowledge, research efficacy, and trust. Aim 2 will be achieved through preliminary beta testing and a subsequent large scale two-arm randomized control trial among a national sample of AIAN potential





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research collaborators testing regional tribal differences and national Indian Country generalizability.

- (3) Translate the findings into policy and practice guidelines. Aim 3 will be achieved by disseminating the training **for immediate use** through the CITI, National Congress of American Indians, and American Indian Higher Education Consortium.

Using a multi-level national CEnR approach, this **innovative study** will address ethical challenges in conducting AIAN-based research **by increasing informed community involvement in research oversight**, design, implementation, and dissemination. Its **significance** lies in its potential to **increase AIAN participation** in federally funded research through culturally adapted online research ethics training and by doing so enhance the responsible conduct of research in Indian Country.



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