Supporting Ethical Research Involving American Indian/Alaska Native Populations

VIRTUAL WORKSHOP

https://www.hhs.gov/ohrp/education-and-outreach/educational-collaboration-with-ohrp/workshops/ohrp-hosted-workshops-aug2021/index.html

August 26, 2021

Sponsored by the

Office for Human Research Protections (OHRP), Department of Health and Human Services (HHS)

References

Around Him, D, Aguilar, T, Frederick, A, Larsen, H, Seiber, M and Angal, J. (2019). Tribal IRBs: A framework for understanding research oversight in American Indian and Alaska Native communities. *American Indian and Alaska Native Mental Health Research, 26*, 71-95. http://dx.doi.org/10.5820/aian.2602.2019.71

Covey, S. Moving at the speed of trust. Franklin Covey. White paper published online: https://resources.franklincovey.com/resources/move-with-the-speed-of-trust

Dukes, K. A., Burd, L., Elliott, A. J., Fifer, W. P., Folkerth, R. D., Hankins, G. D., et. al. (2014). The Safe Passage study: Design, methods, recruitment, and follow-up approach. *Paediatric and perinatal epidemiology*, 28(5), 455–465. <u>https://doi.org/10.1111/ppe.12136</u>

Goins, R.T., Garroutte, E.M., Leading S., Geiger, S.D., Manson, S.M. (2011). Theory and practice in participatory research: Lessons from the Native Elder Care Study. *Geront*, *51*(3), 285-94. <u>https://pubmed.ncbi.nlm.nih.gov/21292753/</u>

Gratton, L. & Erickson, T.J. (2007). Eight ways to build collaborative teams. *Harvard Business Review*. November. <u>https://hbr.org/2007/11/eight-ways-to-build-collaborative-teams</u>

Norton, I.M. & Manson, S.M. (1996). Research in American Indian and Alaska Native communities: Navigating the cultural universe of values and process. *J Consult Clin Psychol.* 64(5), 856-860. <u>https://pubmed.ncbi.nlm.nih.gov/8916611/</u>

Manson, S.M., Garroutte, E.M., Goins R.T., Nez, H. P. (2004). Access, relevance and control in the research process: Lessons from Indian Country. *J Ag Health*, *16*(5S),58S-77S. https://journals.sagepub.com/doi/abs/10.1177/0898264304268149

Moreno-John G., Gachie, A., Fleming, C.M., Napoles-Springer, A., Mutran, E., Manson, S.M., Perez-Stable, E. (2004). Ethnic minority older adults participating in clinical research: Developing trust. *J Ag Health*, *16* (5S), 93S-123S. <u>https://journals.sagepub.com/doi/abs/10.1177/0898264304268151</u>

Noe, T.D., Manson, S.M., Croy, C., McGough, H., Henderson, J.A., Buchwald, D.S. (2007). The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. *Eth Dis.*, *17*, S1-14. https://pubmed.ncbi.nlm.nih.gov/17598311/

Parker, M., Pearson, C., Donald, D., Fisher, C. Beyond the Belmont principles: A communitybased approach to developing an indigenous ethics model and curriculum for training health researchers working with American Indian and Alaska Native communities. (2019). *Community Psychology*, 64(1-2): 9-20. <u>https://onlinelibrary.wiley.com/doi/abs/10.1002/ajcp.12360</u>

Pearson, C.R., Parker, C., Zhou, C., Fisher, D., Fisher, C.B., Fisher. A. (2019). Culturally tailored research ethics training curriculum for American Indian and Alaska Native communities: a randomized comparison trial. *Critical Public Health*, *29* (1), 27-39. https://www.tandfonline.com/doi/pdf/10.1080/09581596.2018.1434482

Resources

Indigenous Cultures Institute. https://indigenouscultures.org/

Indigenous Wellness Research Institute. Research templates: <u>http://iwri.org/resources/research-resources/research-templates/</u>

National Congress of American Indians.

Consultation Letters and Materials by Federal Agency: <u>https://www.ncai.org/resources/consultation-support/consultation-letters-and-materials-by-agency</u>

Consultation Support Center: https://www.ncai.org/resources/consultation-support

Research Ethics Training for Health in Indigenous Communities.

Free curriculum: https://redcap.iths.org/surveys/?s=R3EJPAYD4J

Training toolkit and license to distribute: <u>https://els2.comotion.uw.edu/product/rethics---</u>research-ethics-training-for-health-in-indigenous-communities

University of Arizona.

Tribal Consultation policy: <u>https://www.naair.arizona.edu/research-engagement-guidelines</u>

Urban Indian Health Institute. https://www.uihi.org/

Urban Indian Organizations listed by the Indian Health Service. https://www.ihs.gov/urban/urban-indian-organizations/