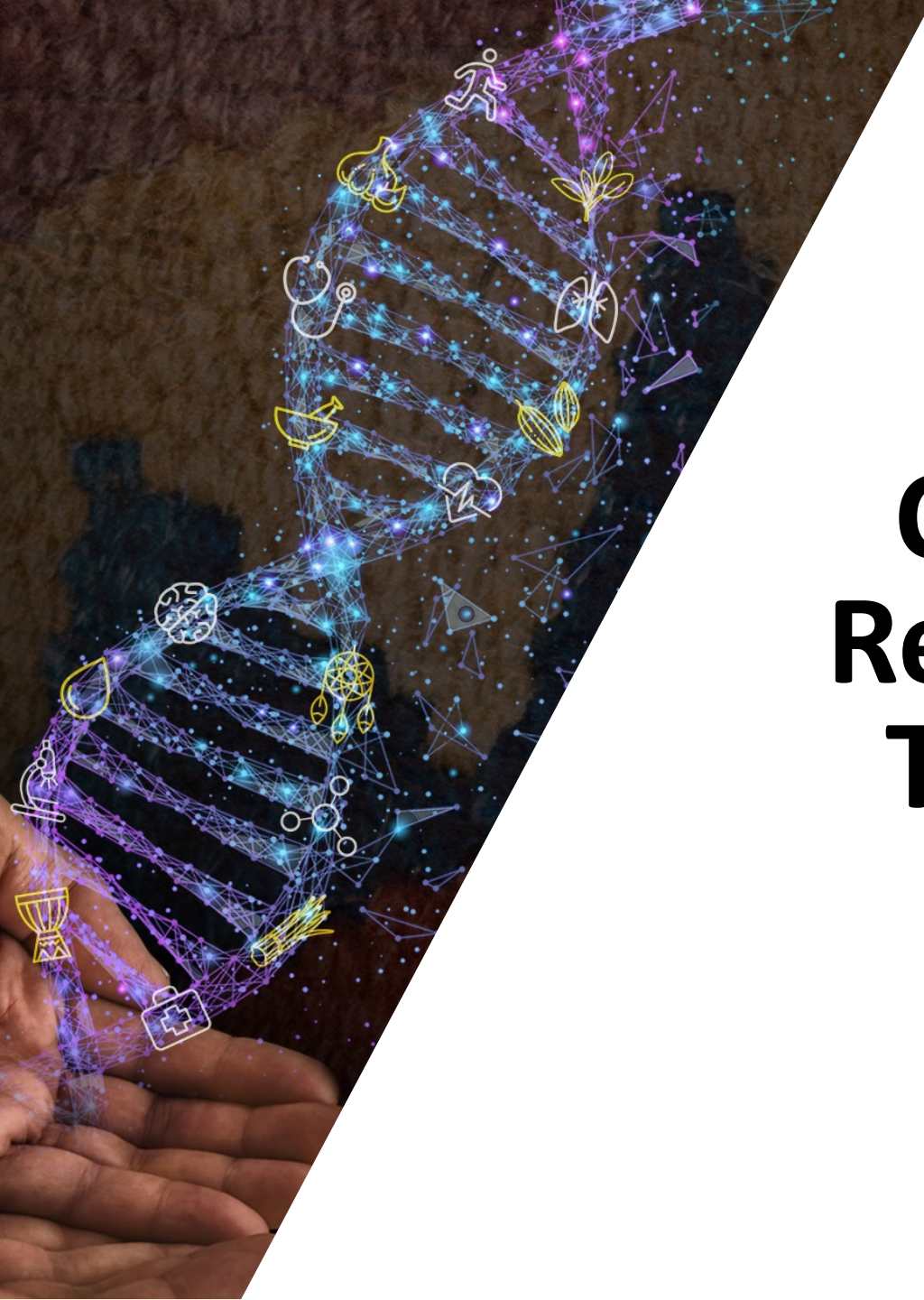
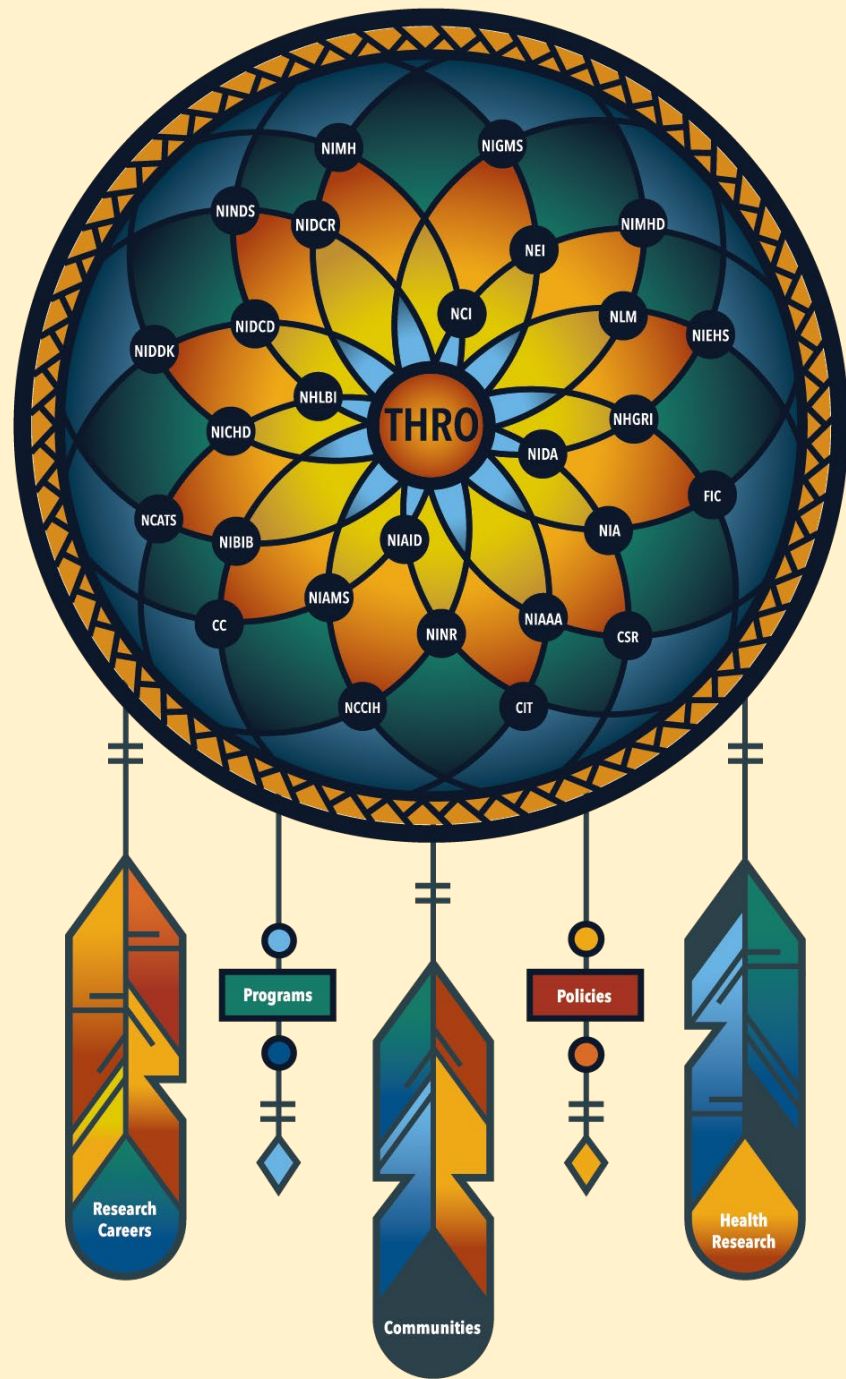




Community Based Research with AI/AN Tribes and Villages

David R. Wilson, Ph.D.
Director of the Tribal Health Research Office





Established in 2015, the Tribal Health Research Office is located in *the Division of Program Coordination, Planning, and Strategic Initiatives* in the Office of the Director (OD), NIH.

The office was created in recognition of the importance of ensuring meaningful input from and collaboration with tribal Nations on NIH programs and policies.



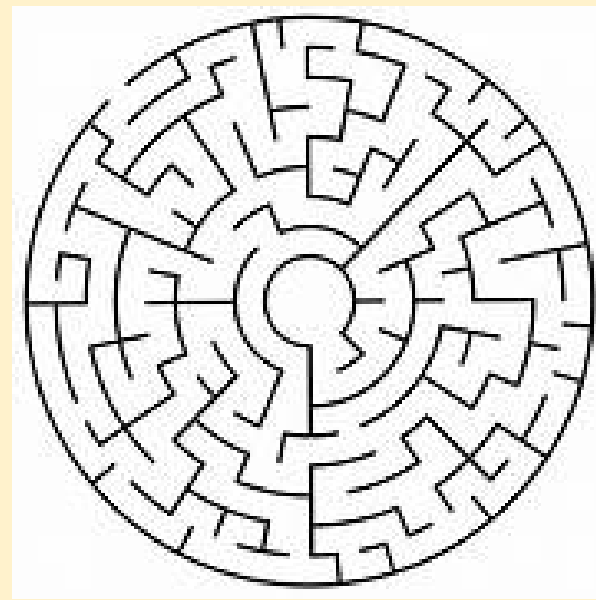
8 principles to ethical research*

- Collaborative partnership
- Respect for recruited participants and study communities
- Social Value
- Favorable risk-benefit ratio
- *Fair selection of study population*
- Scientific validity
- Independent review
- Informed consent

*Ezekiel J Emanuel, David Wendler, Jack Killen, and Christine Grady, What Makes Clinical Research in Developing Countries Ethical? The Benchmarks of Ethical Research, JID 2004; 189:930-7

Minimizing Exploitation of Communities and Individuals

1. Collaborative partnerships



Isolating DNA with NN Genetic Research Policy Group



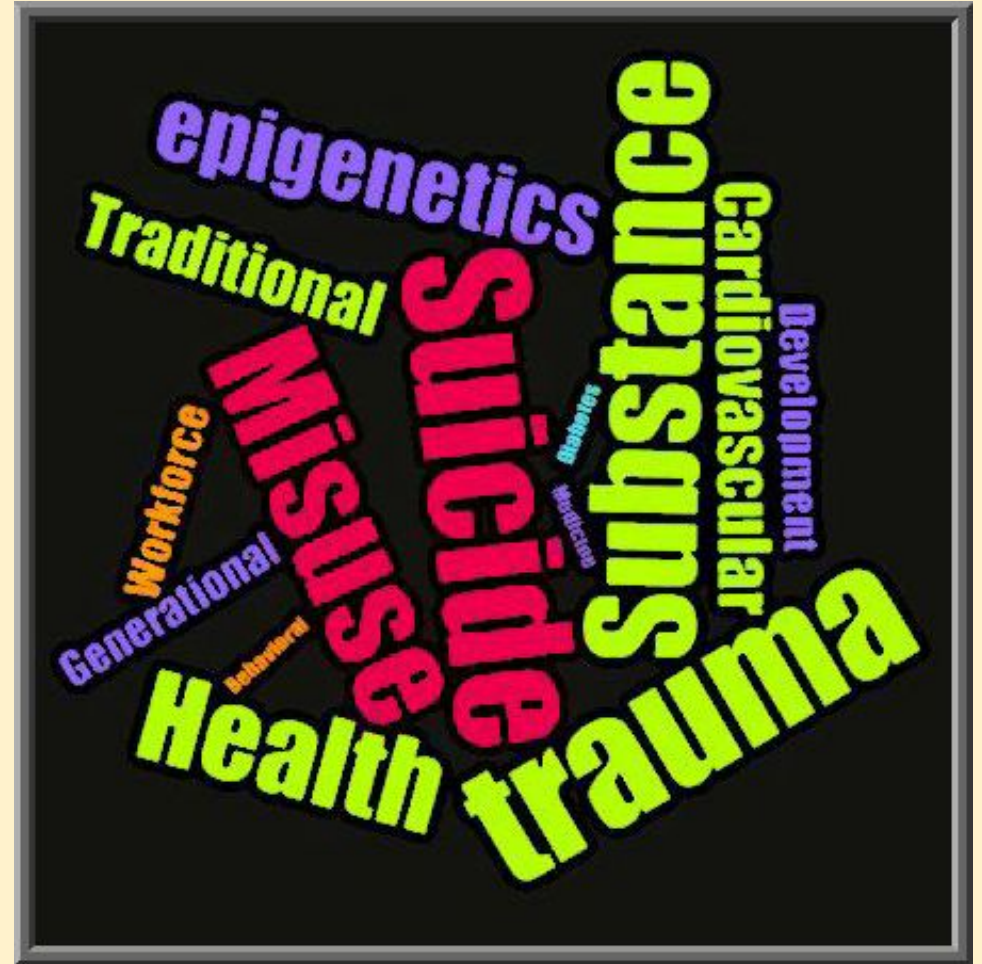
2. Respect for recruited participants and study communities



What works for the community and how can that be incorporated into research?



3. Social Value





Navajo



Alaska



Pacific Northwest



Arizona

Social Value



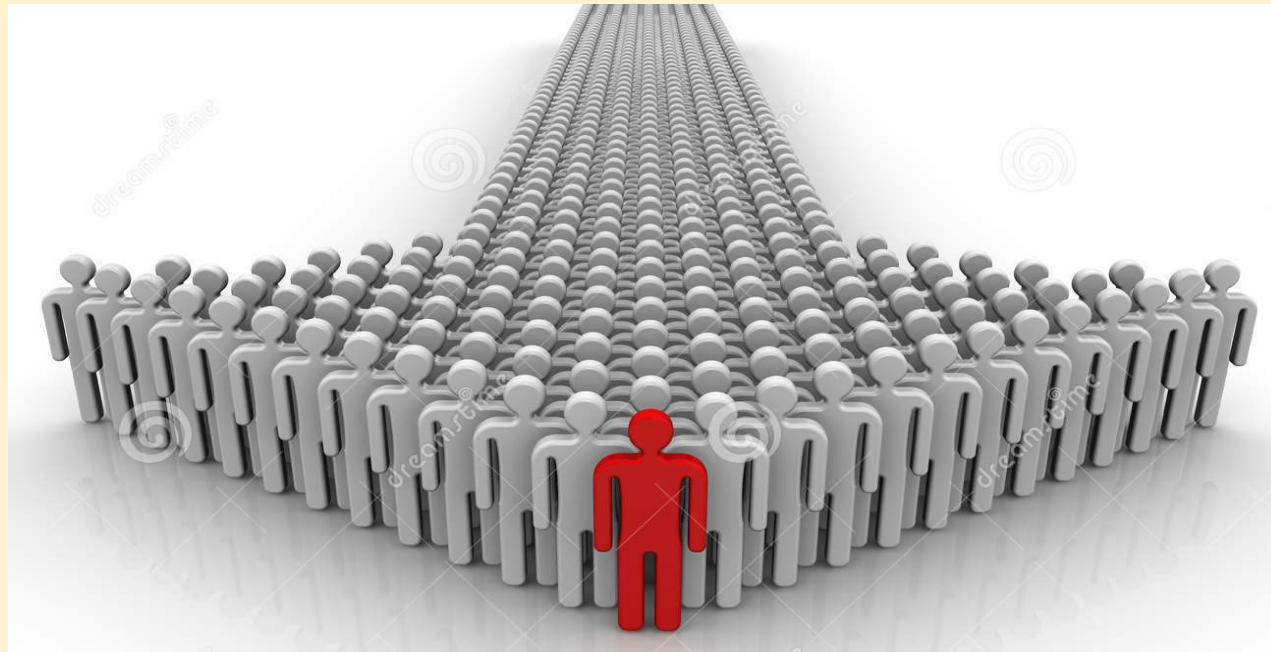
Oglala Sioux Health Division in Pine Ridge, SD



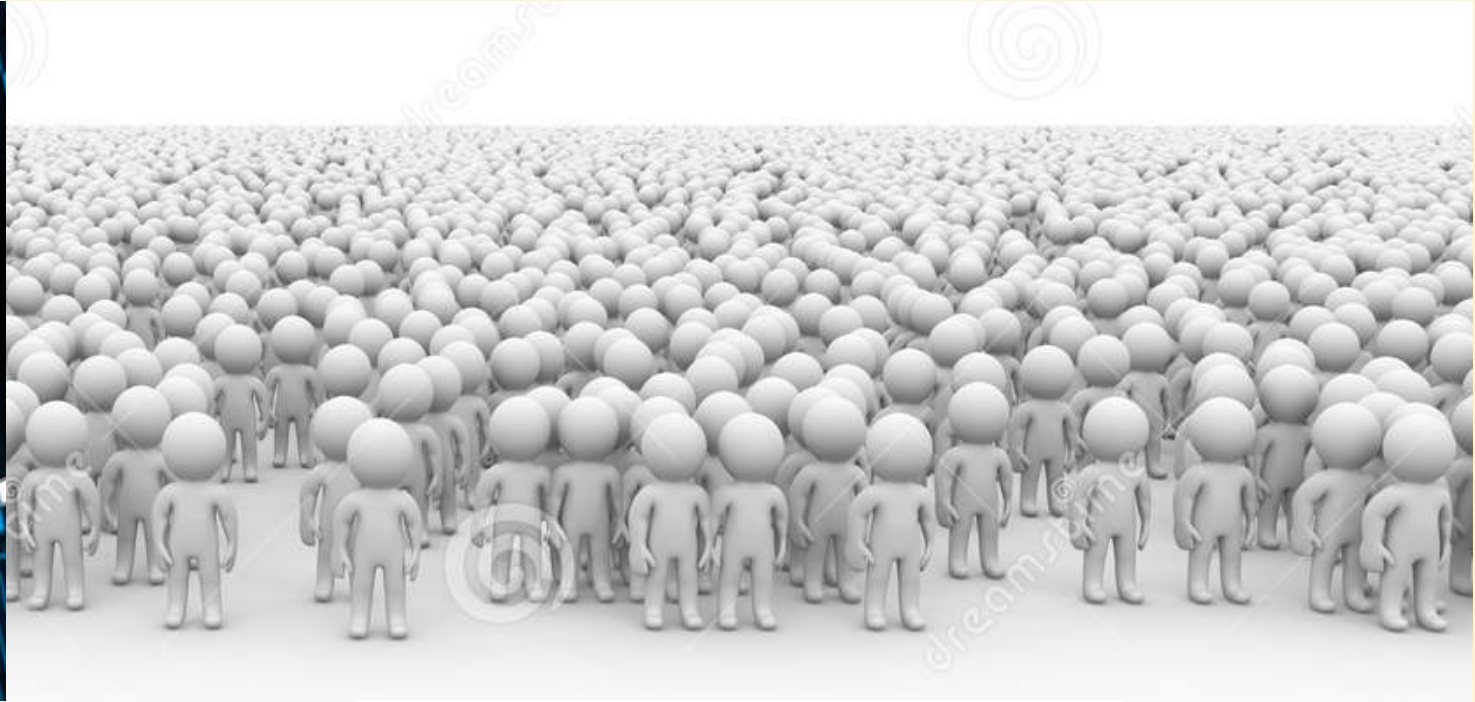
Dr. Nora Volkow, Director, NIDA, and Dr. Eliseo J. Pérez-Stable, Director, NIMHD, at 2018 consultation on the Opioid Epidemic and American Indian/Alaska Native Communities.

4. Favorable Risk-Benefit Ratio

7 generations of sustainability



Risk Vs. Benefit

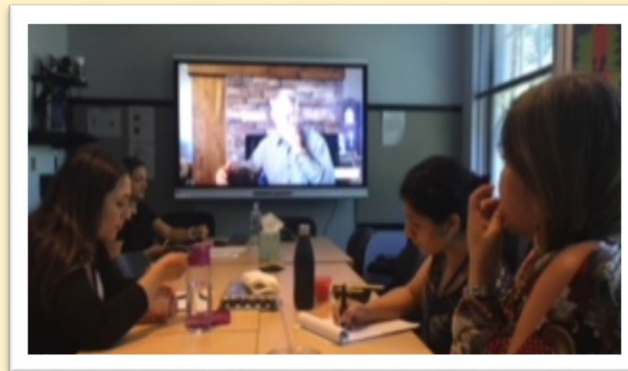
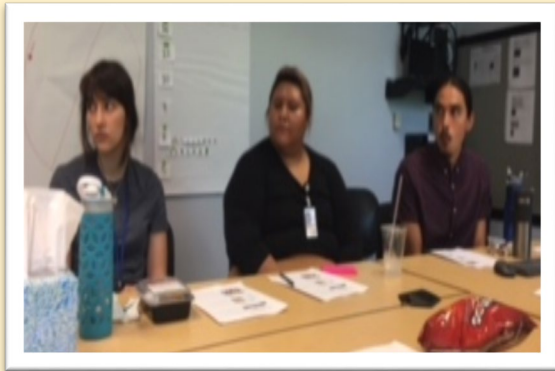
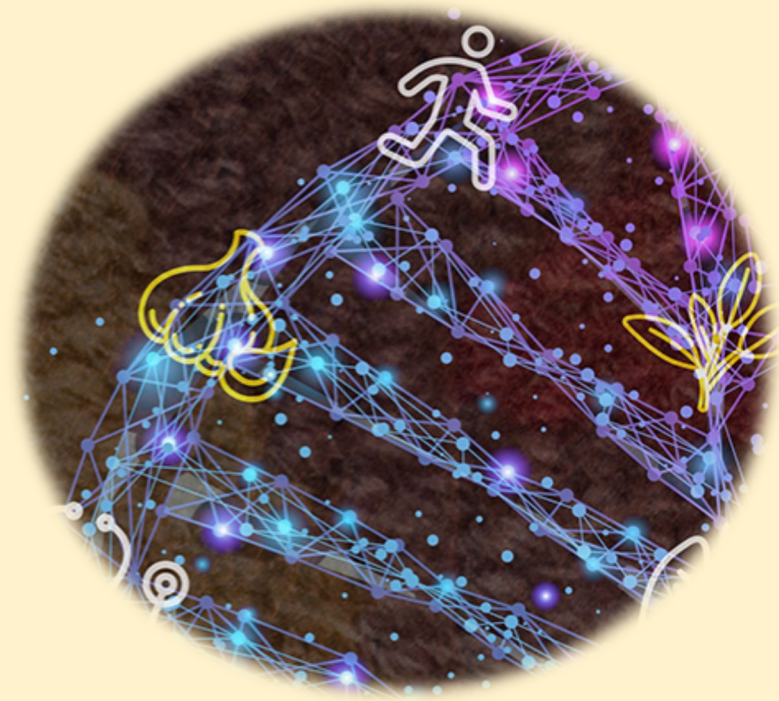


5. Independent Review



Tribal Institutional
Review Boards

6. Scientific validity





7. Informed Consent

Informed consent is usually defined as a process that functions to respect individual autonomy.

When working with tribes, informed consent should be a process that respects tribal sovereignty.

Individual vs. Community consent

- Validating the scientific process



National Institutes of Health

Thank You!

David R. Wilson, Ph.D., Director
Tribal Health Research Office, NIH

TRIBAL HEALTH RESEARCH OFFICE



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