

Which Values Will Guide Us?



Indigenous peoples have always had their own traditional ways of relating to the natural world and creating knowledge. Similarly, Indigenous peoples have also defined values that guide how they relate to outsiders seeking knowledge about their people. As sovereign governments, tribes have the right to regulate research on their lands. Defining a research regulation process can be a challenging task. Tribes may wish to begin with examining which values will drive their process of research regulation. Similarly, in deciding how to relate to genetics research, tribes may find it helpful first to decide which values will guide their decision making. In this section we

will discuss community values related to research in general. There is also a guide for [making decisions specifically about genetics research](#).

One way to begin thinking about your community's values is to look at examples from other communities. The Akwesasne Community of the Mohawk Nation is an example of a community that has defined its own values for research. This community formed the Akwesasne Task Force on the Environment (ATFE) to oversee research conducted in the community. In its Protocol for Review of Environmental and Scientific Research Proposals, the ATFE includes its Guiding Principles for research. The values are:

1. skennen (peace)
2. kariwio (good mind)
3. kasastensera (strength)

These are the central ethical values to which both the ATFE and researchers must adhere when working in Akwesasne. The [ATFE Protocol](#), developed by and for members of the Akwesasne Mohawk Community, sets out a comprehensive vision of how ethical research should be conducted at Akwesasne. This vision is based on traditional cultural values of the tribe.

The federal government offers another useful example. The federal government uses the three ethical principles in the [Belmont Report](#) to guide its oversight of research involving human research participants. These principles are:

1. Respect for Persons: This principle emphasizes the concept that individuals are "autonomous agents" capable of "self-determination." It also means that individuals should not be coerced into participating in research, and their decisions regarding research participation should be respected.
2. Beneficence: This principle means that researchers have the "obligation" to not harm research volunteers and to maximize possible benefits while minimizing possible harms of the research.
3. Justice: This principle states that the burdens of research should be equally distributed amongst different groups, including individuals of different racial and socioeconomic backgrounds. The fairness demanded by this principle also means that "research supported by public funds" must ensure that the benefits of the research, such as new drugs or diagnostic tests, are equally available to all individuals, even those considered socially disadvantaged in any way.

These values are also used by Institutional Review Boards (IRBs) at universities around the nation. IRBs are committees which review research proposals involving human research volunteers to make sure that research participants are protected. Some tribes have also created their own IRBs. Other tribes have created research review boards or committees with a different structure from an IRB.

AI/AN communities may find it helpful to consider what values they hold dear that should apply to research. Communities could involve elders, religious and spiritual leaders, youth, and other stakeholders in discussions about which values should guide research. Communities vary widely in what "tradition" and "knowledge" mean to them. We encourage communities to decide what values matter to them related to research. This might mean adapting existing sets of ethical principles, like the Belmont Report, or defining a unique set of values for the community. Some questions that could be asked in community discussions are:

1. What are our most important cultural values as a community? What are some key values that guide us in everyday life and decision-making in our community?
2. If the tribe's Native language is widely spoken, what are some key concepts expressed in the tribe's traditional language that come up often in everyday life?
3. Are there cultural ceremonies practiced in the community? Why are these ceremonies important to us? What values are we trying to keep alive and pass down through these ceremonies?
4. What are some key concepts we consider sacred in the community?
5. How might these values apply to the way research is done in the community?

Here is a sample of how these answers might help a community to define their values related to research. This sample is not from a real community, but just an example of possible responses.

1. *What are our most important cultural values as a community? What are some key values that guide us in everyday life and decision-making in our community?*

[View answer](#)

2. *If the tribe's Native language is widely spoken, what are some key concepts expressed in the tribe's traditional language that come up often in everyday life?*

[View answer](#)

3. *Are there cultural ceremonies practiced in the community? Why are these ceremonies important to us? What values are we trying to keep alive and pass down through these ceremonies?*

[View answer](#)

4. *What are some key things we consider sacred in the community?*

[View answer](#)

5. *How might these community values and concepts apply to research?*

[View answer 1](#)

[View answer 2](#)

[View answer 3](#)

[View answer 4](#)

In conclusion, community values can be incorporated into many aspects of research such as:

- The topics that are studied
 - The way researchers are asked to engage with the community and specific groups like youth or elders
 - The process for review of research proposals, data collection, and publication of results
 - Consideration of the benefits and risks of a research study to the community
 - Decisions about whether a researcher would be a good partner for the community
 - Agreements researchers sign
 - Tribal research codes or protocols
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