Data Control Options for American Indian/Alaska Native Communities

This information sheet presents options for American Indian/Alaska Native (AI/AN) communities for controlling data collected in research or program evaluations. AI/AN communities often face questions about data access and control, such as:
- Who owns data?
- Who should be able to access data?
- Should data be shared, and if so, with whom?
- What requirements do funders have for data sharing?
- What strategies can AI/AN communities use to restrict access to sensitive data?

Researchers sometimes share data to:
- Help one another with their research by building on the findings of previous studies
- Make the best use of existing data and limited grant funds
- Avoid replicating another researcher’s work
- Make comparisons across AI/AN communities
- Meet requirements of funding agencies (e.g., NIH)

Tribes may also receive requests for data from funders who provide grants for local programs (e.g., health promotion or disease prevention efforts). Funders use these data to evaluate activities supported by their grants.

Some concerns AI/AN communities have expressed about data sharing include:
- Breaches in confidentiality for the tribe or individual community members
- Stigmatization of the tribe or individual community members
- Dissemination or misuse of sensitive information
- Data ownership and intellectual property rights

Communities may be able to negotiate with researchers and funders for restrictions on data sharing. Some options for restricted data use include:
- A data enclave, in which only specific individuals can access the original data, but will provide data analysis results to interested outsiders1
- Negotiate with funders to provide aggregate data for the community as a whole rather than the raw data for individual community members
- Develop a written contract or Memorandum of Understanding (MOU) with researchers or funders that sets out specific terms for data sharing2

Communities might also choose to share data without restrictions if potential benefits outweigh risks. For example, some communities may view data sharing as an acceptable requirement of

grants that support important programs. However, in other cases, communities might reject research proposals or grants because of concerns about the risks of data sharing.

For more information about data control and AI/AN communities, please see the NCAI PRC research regulation papers at: http://www.ncaiprc.org/research-regulation-papers.