

Protecting Small Groups: Lessons from Research in Native North America  
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Native communities are uniquely sensitized to the risks of health information and these concerns are longstanding. In their extensive analysis of the Barrow Alaska alcohol study in 1989, for example, Spero Manson and his colleagues reason from a case where a specific community suffered harm from research to come to a position on the need to protect the identity of groups, as well as individuals, in the research enterprise. This approach, which has been widely implemented in American Indian and Alaska Native health research since then, calls for community confidentiality, which has enabled significant research on stigmatizing conditions to proceed where it might not otherwise have happened at all.

But not all native communities have sought these protections. For example, publications on alcohol by Levy and Kunitz and their collaborators regularly refer not just to the Navajo Nation, but to specific communities within that Nation, some of which are notable for higher levels of alcohol consumption. And reports from the more recent program of research on Navajo healing in the context of psychiatric distress, led by Tom Csordas, now at the University of California San Diego, also consistently identify the tribe in the context of research on substance abuse and mental health.

And even where such protections are offered, informed consumers of the information can often make quite accurate educated guesses, especially when community collaborators are named or details of cultural form are necessary, for example, to understand risk or protective factors.

But perhaps most importantly, identification of specific communities is likely necessary if the information is to be of much or any use to them, either for advocacy or programming.

And this, I think, is the heart of the matter: More than anything, American Indian and Alaska Native communities need (and often currently lack) information that is useful.

In our community engagements with tribes, in the context of multiple different kinds of studies, including some explicitly focused on research ethics, the most consistent message we hear is that tribes want research and data that will matter for improving health and health care. Absent this kind of application, there is little need for the data at all. And I think it quite clear that useful data for a specific community inevitably entails some level of identification. Tribes cannot use data for advocacy and needs assessment, for example, without identifying that it is their data, running the risk that they will be stigmatized as an individual community.

Ironically, as well, concealing the identity of a specific community may simply create the possibility for higher-level discrimination and stereotyping, e.g., we may not be able to say that there are high levels of alcoholism in a particular tribe, but may instead end up suggesting that there are high levels of alcoholism in the northern plains more generally, which is hardly a better outcome.

Another key issue for tribes is control over access to the data. Tribal communities would likely be much less troubled by data repositories if they had control over who accessed the data and what they were using it for. Unfortunately this kind of control is not generally contemplated in public use resources. Indeed, these restrictions may run counter to the principles that govern such resources. But tribal communities may be quite sensitive to the abuse of publically available information about them, especially if it resides in biological materials that can be used for multiple additional inquiries that were not originally presented to participants. Certainly these concerns inform the actions taken by the Havasupai tribe

against Arizona State University. These issues obviously raise particular problems for biobanks and data sharing from genomic research. Fortunately, to date, the value of this information has been negligible, which reduces actual risks (just as it reduces actual benefits), but it is not likely that such research will move forward without recognizing some degree of tribal control over data use.

An option that my colleagues at the University of Colorado have been articulating positions an intermediary between the public and the data—in this case themselves—who can attempt to ensure that secondary use of the data conforms to tribal requirements, e.g., tribal review and or approval of publications. It is likely that national native organizations, or consortia of tribes, could assume similar responsibility for the management of tribal data, releasing data on specific communities for specific uses only with the authorization of the tribes. Such an effort could be built on nascent efforts to fund area epidemiological centers and Native American Research Centers for Health.

Of course making such a system work requires either levels of trust that are not in evidence (or warranted) or a substantial amount of retained legal expertise, which would require financial resources. It is obviously safer if the publically available data is less informative about specific communities or restricts information available to support unapproved analyses, but this is impossible to imagine in the case of biological materials and difficult to conceptualize in the case of biological information (although if we knew what a region coded for we could, conceivably, delete that from public data).

I will leave the issues of enforceable contracts for data use to the attorneys, but I do want to close by considering these other questions: questions of trust. I know that native

communities are not alone in their mistrust of researchers and policy makers and I think I side with Onora O'Neill in suspecting that formal contracts for data use or formal requirements in research training will not likely improve trust in public data repositories.

An alternative approach is to make the case for public data publically (and in specific tribal communities if that is the focus). As I said at the beginning, a major reason tribes don't want to participate in research is that it has proven meaningless to them. This is not to minimize the potential for harm that motivates this subcommittee's work, although that is likely exaggerated, but to suggest that a focus on the benefits of data might serve to promote not only public participation in science, but might also serve to promote better science and data collection as well.

Of course we often (usually) fail to realize the benefits of proposed studies, so it is important to be realistic in presenting these benefits, as we've come to appreciate in our deliberations about the microbiome in contexts marked by high levels of health problems and low levels of medical care. But a major component of outreach to tribal communities should be a sincere conversation about why this information matters. Absent that, we are certainly not likely to get very far in any institutional arrangement. Nor should we. On the other hand, once we are clear about why communities might want to participate, then we can probably have an extensive discussion about how that should happen.