



Indigenous Ways of Knowing: Implications for Participatory Research and Community

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Researchers have a responsibility to cause no harm, but research has been a source of distress for indigenous people because of inappropriate methods and practices.

The way researchers acquire knowledge in indigenous communities may be as critical for eliminating health disparities as the actual knowledge that is gained about a particular health problem. Researchers working with indigenous communities must continue to resolve conflict between the values of the academic setting and those of the community. It is important to consider the ways of knowing that exist in indigenous communities when developing research methods.

Challenges to research partnerships include how to distribute the benefits of the research findings when academic or external needs contrast with the need to protect indigenous knowledge. (*Am J Public Health*. 2008;98:22–27. doi:10.2105/AJPH.2006.093641)

ACCORDING TO AN ALASKA

Native saying, “Researchers are like mosquitoes; they suck your blood and leave.” This saying reflects the fact that an extensive body of health-related research has been conducted about indigenous populations around the world, but appears to have had

little impact on their overall well-being.^{1–6} To improve this situation, it is important to ask why so much research has produced so few solutions.

Why are researchers viewed with skepticism by many indigenous peoples? Participatory research has often been proposed as a solution to this skepticism because it engages participants in the research process at all stages. Participatory research has been described as a

collective self-reflective enquiry undertaken by participants in social situations in order to improve . . . their own social practices.^{7(p5)}

Thus, participatory research simultaneously contributes to basic knowledge in social science and social action in everyday life. Although a full discussion of participatory research cannot be presented here, even this model of research, as it is typically practiced, does not prevent the risk that indigenous ways of knowing are marginalized by the scientific and academic community.^{2–5,8–10} Participatory researchers need to consider the power that indigenous methods can bring to research design and to the entire research process.

We first provide a brief overview of the problems associated with research partnerships in the

past to provide a context for the concerns we raise. We then describe some examples of successful research partnerships and developments in participatory research. We provide specific examples of indigenous ways of knowing that have educated us regarding the possibilities of research design. Finally, we discuss one of the continuing challenges for participatory research: how the benefits of research can be managed and distributed fairly.

THE NEED FOR PARTICIPATORY RESEARCH

Recent progress has been made through the incorporation of participatory research procedures in indigenous communities.^{5,11} However, it is important to consider and understand the reasons indigenous people might object to the idea of partnerships with researchers—why communities are wary or apprehensive at times even when the proposed research will address an important health issue.⁶ Historically, research conducted on indigenous people has been inappropriate because it has often served to advance the “politics of colonial control.”^{2,12} For instance, in the early years of colonization in Australia, research

was preoccupied with “classifying and labeling” in an attempt to “manage” Aboriginal people.¹²

Although unethical research that carries risks to the health and welfare of indigenous participants has generally ceased, this early approach to research led to significant distrust of researchers.² Unfortunately, some types of inappropriate research practices have continued, largely through the use of culturally insensitive research designs and methodologies that fail to match the needs, customs, and standards of indigenous people and communities.^{5,6,8–10,13} Researchers have a

responsibility to cause no harm, but even well-intentioned research has been a source of distress for indigenous people because of its implications, methods,² and lack of responsiveness to the community and its concerns.⁶

The most significant impact of insensitive research is the perpetuation of the myth that indigenous people represent a “problem” to be solved and that they are passive “objects” that require assistance from external experts.³ Too often, health research documents significant issues and problems using inappropriate methods of identifying those problems, with a resulting overstatement of the negative aspects of these communities. It is no surprise that



individuals and communities feel stigmatized when this research is published. No community wants to have the reputation of having the most alcoholics or the most people with mental disorders.

One example of the type of violations of trust perpetrated by researchers in indigenous communities is the recent Havasupai medical genetics case in Arizona.¹⁴ In the Havasupai study, blood was collected by researchers under the guise of an investigation into the genetics of diabetes. It is understood that because diabetes was a major concern to the Havasupai tribe, they granted approval for years of ongoing blood collection.

Issues of informed consent provide essential context for considering this case and the subsequent violation of tribal trust. The blood samples, understood to be collected in order to determine genetic precursors of diabetes, were used in a series of additional studies to examine the genetics of schizophrenia, among other topics. Blood samples were distributed nationally to other researchers and used in tribally unauthorized research, resulting in the advance of academic careers through, for instance, dissertations and scholarly publications. For the Havasupai, however, their trust in researchers—who had been invited to assist in the process of redressing the epidemic and debilitating impact of diabetes on an American Indian community—was broken.

A similar example involves the Canadian Nuu-chah-nulth people, whose blood was ostensibly

drawn for health research on arthritis and was used instead to establish ancestry.⁸ This deception has led to intense suspicion of research among the Nuu-chah-nulth people and a reluctance to engage in further research, even when it may be beneficial.

It is not surprising, given these examples, that the indigenous experience of research has been predominantly negative, both in terms of its processes and outcomes. Experiences such as these have compounded the negative attitude of indigenous peoples toward research and have reduced their willingness to participate in the research process.

RESEARCH PARTNERSHIPS AND INDIGENOUS WAYS OF KNOWING

It is clear from these examples of inappropriate indigenous research that *how we go* about acquiring knowledge in indigenous communities is just as critical for the elimination of health disparities—if not more so—as the actual knowledge that is gained about a particular health problem. An important negative impact of inappropriate research methods, no matter how laudable the intent of the researchers, is that they can reduce the validity and reliability of research findings,¹⁵ thus minimizing the utility of the conclusions and wasting the time of participants.

According to Maori researcher Linda Tuhiwai Smith,³ academic knowledge is organized according to disciplines and fields of knowledge that are grounded in

Western “ways of knowing” and are therefore inherently culturally insensitive. Western research simply interprets indigenous knowledge from a Western framework, effectively distorting reality. In Australia, indigenous researchers have claimed that Western research has

led to a continuing oppression and subordination of Indigenous Australians in every facet of Australian society to the point that there is no where that we can stand that is free of racism.^{4(p113)}

Too frequently, the definition of what constitutes acceptable research design rests with academic researchers, for whom methods that do not conform to the “gold standard” of experimental design can be considered questionable in terms of rigor and value. To solve this problem from a statistical perspective, practitioners and researchers have recommended strategies such as oversampling and pooling of data.^{16,17} Although we support these recommendations, remedies also need to be sought at the level of conceptualization and research design. Researchers must begin to expose the underlying assumptions of Western research and the ways in which this research maintains oppression.¹⁸

Researchers in health and human services have recently been advised to give greater consideration to the influence of culture on their science.¹⁹ As Gergen et al. have written,

To what degree and with what effects is psychological science itself a cultural manifestation? . . . It is immediately apparent that the science is largely a

byproduct of the Western cultural tradition at a particular time in its historical development. Suppositions about the nature of knowledge, the character of objectivity, the place of value in the knowledge generating process, and the nature of linguistic representation, for example all carry the stamp of a unique cultural tradition.^{20(p497)}

From various fields of study, challenges are now arising as to how science is defined and the nature of science itself as a “cultural manifestation.” Du Bois, for example, initiated her exploration of science by stating that

Science is *not* “value-free”; it cannot be. Science is made by scientists, and both we and our science-making are shaped by our culture.^{21(p105)}

Indeed, as Harding has argued, those who refuse to question the way science is practiced are avoiding the “scrutiny that science recommends for all other regularities of . . . life.”^{22(p56)}

Given the negative impact of inappropriate research with indigenous communities, there is an urgent need for an ethical research approach based on consultation, strong community participation, and methods that acknowledge indigenous ways of knowing.^{5,9,10} Ensuring that the research used by researchers who work in indigenous communities is both culturally appropriate and rigorous in design is essential for (1) obtaining new knowledge and understanding in regard to health disparities and (2) evaluating interventions to eliminate these disparities. To date, much of the nonindigenous



response to calls for appropriate indigenous research has been at the level of process and methodology. The participation of indigenous people has often been mere token inclusion. Further, one might assume that in applying qualitative methods, researchers will address cultural insensitivity by using methods of data collection that are in line with traditional cultures. However, questions about appropriate research methods and indigenous communities go beyond the “quantitative versus qualitative” debate and focus on the root issue of how we go about knowing.

As Bernal indicated, there is a distinction between methodology and epistemology that has not always been recognized.²³ Epistemology is the understanding of knowledge that one adopts and the philosophy with which research is approached. This issue cannot be disentangled from history or from the social position one holds within society as a result of that history. Knowledge reflects the values and interests of those who generate it, and it is these values that then determine the methods that are used and the conclusions that are drawn. These values and worldviews can lead majority cultures to disregard knowledge that is gained through another set of values and worldviews.

A long-standing and favorite example is exemplified by the Inuit whalers, who detect the presence of whales by listening for the sound of their breathing.²⁴ In contrast to this method, the “scientific count” conducted by the International Whaling

Commission included only those whales that could be seen passing from the edge of the ice. Although the Inuit methods had been criticized as being inaccurate because their counts did not match those of the International Whaling Commission, their estimates of whale numbers, based on listening to the whales’ breathing, “were verified by successive aerial surveys.”^{24(p28)} Another good example is found in the navigational expertise of the Native Hawaiian ocean voyagers, who had perfected knowledge about sailing long before Europeans had done so.²⁵ Native Hawaiian voyagers collected knowledge from swell patterns; currents; moon phases; surface water quality; bird migration; star, planet, and sun positions; and cloud shapes. Multiple examples exist in which indigenous knowledge and the use of indigenous ways of knowing within a specific context have produced more extensive understanding than might be obtained through Western knowledge and scientific methods.

The health sector might also benefit from better understanding and appreciation of indigenous ways of knowing. Working in partnership with individuals who have indigenous knowledge, skills, and abilities in the area of health might help us to minimize rates of chronic conditions or disabilities and to ensure equitable access to appropriate health and rehabilitation services.

The Alaska Native Science Commission (ANSC), which serves as a model for promoting participatory research and the use of indigenous knowledge,

was created to bring together research and science in partnership with Native communities and to serve as a clearinghouse, information base, and archive of research involving Alaska Native communities.²⁶ The genesis of the ANSC was the Arctic Contamination Conference held in Anchorage in 1993, where a position paper was prepared that stated the desire of the Alaska Native community to become actively involved in scientific research, to become aware and informed of science investigating Native lives and environment, and to ensure that when science is performed in Alaska, it is with the knowledge, cooperation, and understanding of the Native community.²⁷

Importantly, the ANSC is concerned with addressing factors related to chronic illness, which can result in disability. In one example of participatory research conducted by the ANSC, residents became alarmed by high rates of cancer in their region and perceived a relationship between these rates and the presence of local military sites. They found that people’s diets increasingly included store-bought foods, soft drinks or soda water, and improperly stored canned and frozen foods. It seemed that, over the same time period, more people were dying from stomach cancer, ulcers, and other cancers.²⁸

Although the community could not make causal attributions, this knowledge provided them with the capacity to take action. They were awarded grant funding to engage in research about food sampling, preservation, storage,

and nutritional benefits and to clean up some of the military sites. The project clearly demonstrates how beneficial collaborative research can be for the people who are the focus of the research. The principles and practices of the ANSC highlight how researchers can no longer expect indigenous communities to be “compliant” with university-based research efforts and should be aware of the concerns, rights, and research protocols established by communities.

Another example of a participatory model that builds on indigenous knowledge is found in the work of the Canadian Institutes of Health Research (CIHR). One of the 13 founding institutes of the CIHR, the Institute of Aboriginal Peoples’ Health (IAPH), is dedicated to leading an advanced research agenda in Canadian aboriginal health. The profile of the IAPH includes support and promotion of health research that has a positive impact on the mental, physical, emotional, and spiritual health of aboriginal people at all life stages. The IAPH is the only national aboriginal or indigenous health institute in the world that is devoted to the advancement of holistic and multidisciplinary health research for indigenous people. Canada decided in 2000 to establish such an institute not only because of its own domestic health disparities but also because of the United Nations’ call for improvements in the health of indigenous peoples. In the long term, CIHR-funded health research is expected to improve the health of Canadian aboriginal people



through the active participation and involvement of aboriginal communities in setting their own research agenda and through the development of research guidelines that ensure culturally competent research that is protective of the health, safety, and human rights of aboriginal people.

Australia has recently moved one step closer to the ideal situation in which indigenous knowledge and participation are integral to the conduct of indigenous research. In the most recent revision of the National Health and Medical Research Council's guidelines for the conduct of indigenous research,²⁹ researchers are required to submit only research proposals that are ethically defensible against an indigenous value base rather than against Western research ethics. The document clearly outlines 6 values that have been generated by Australian aboriginal and Torres Strait Islander communities: (1) spirit and integrity, (2) reciprocity, (3) respect, (4) equality, (5) survival and protection, and (6) responsibility. Thus, depending on the views of the particular community, it may be critical that indigenous ways of knowing are fully integrated into the research design and that the research is both participatory and beneficial to the community.

DECIDING WHO BENEFITS FROM INDIGENOUS KNOWLEDGE

Partnerships between academic researchers and indigenous communities must be clear regarding what, and for whom,

the expected benefits are to be. For the academic researcher, there are university requirements for faculty retention or promotion; these requirements usually include professional presentations, grant proposals, books, and articles. For many who work in indigenous communities, there is the sense of contributing to the social good, community well-being, and social justice through their research. Yet there is also the conflicting sense that knowledge that has been uncovered, revealed, or shared must be protected and that the different purposes and values of community research participants must be both acknowledged and accommodated to the extent possible.³⁰

A key issue that continues to damage the concept of research in the minds of many indigenous people is the area of intellectual and cultural property rights. Who gets credit for the knowledge that is gained from research conducted in indigenous communities? A full body of research and scholarly activity is being devoted to issues of indigenous cultural and intellectual property rights; we can but touch on this important topic here. For this discussion, however, it is important to understand that knowledge gained from indigenous communities is both local and specific to a given research effort, but it is also global in terms of history and potential impact.

Who "owns" the knowledge and has the right to patents or copyrights? What is the responsibility of researchers to advise indigenous people about how to protect the knowledge they

have—knowledge that might benefit the larger community? A useful example comes from a Mixe local coordinator of a research project in Oaxaca, Mexico. In a published report, he revealed knowledge about a local herbal remedy for prevention of kidney stones. He stated:

There are some herbs, for example . . . I've been in a wheelchair for 17 years and, thanks be to God, I don't have any kidney problems—no stones, no infections and that's entirely due to the herbs. As you can see, if we think about what we have at hand, it can really serve us well. Because otherwise we'd always be thinking about antibiotics, about operations for gall stones.^{31(p109)}

C. A. M. was later contacted by researchers who wanted to further explore the herbs in question. She stated that there would be a need to discuss intellectual and indigenous property rights with the Mixe owners of the knowledge. The researchers were never heard from again. However, an American Indian colleague who visited the Mixe community also recommended that the medicinal herbs should be further investigated so that people with spinal cord injuries and secondary conditions associated with kidney problems could benefit from them. Beyond those whose health might directly benefit from the herbs, it is unclear who would benefit from further investigation and who would hold the rights to the knowledge.

In another example, an Australian aboriginal woman advised us that her community knew through "bush medicine" how to cure cervical cancer. Who should

and could benefit from this knowledge? If the knowledge became the property of research facilities, including those associated with universities, the benefit would most likely accrue to pharmaceutical companies via patents and profits; however, others in need might also benefit. What about the women in Appalachia, where cervical cancer is epidemic? Or should that particular aboriginal community that holds the knowledge be the only ones to benefit? How should their discovery be adequately recognized and protected without preventing the widespread use of a beneficial health product? This challenge is not insignificant, and the extent to which it can be resolved may influence the willingness of both indigenous communities and nonindigenous researchers to engage in partnership research in the future.

CONCLUSIONS AND RECOMMENDATIONS

Some would say that indigenous communities have been "researched to death," that researchers only take and give back nothing; there is good justification for this perception. Ultimately, those of us who serve as researchers with indigenous communities must resolve the conflict—or at least our sense of conflict—between the values of the academic setting and those of the community. We must continue to participate in conversations and seek guidance on how to deal with individual instances of intellectual and cultural property rights, indigenous rights, and



academic or professional responsibilities. We need to continue to explore our understanding of knowledge, what constitutes valuable knowledge, and how it is gathered and how it is shared.

Acceptance of indigenous ways of knowing by nonindigenous researchers will bring with it time-consuming and fundamental changes in research methods. A major challenge to researchers who wish to work in indigenous communities is the collaborative identification of research methods, inclusive of indigenous ways of knowing, that lead to sustainable, efficacious services that redress health disparities among indigenous people without violating their rights.

There are no easy solutions to the challenges raised in this essay. We have reported on the efforts of work groups, symposia, summits, and institutes that are attempting to address these issues. We know that the work of local institutional review boards and community research groups produces a wealth of unpublished but critical conversations that tackle these same concerns. In the spirit of sharing what has influenced us after decades of conducting participatory research in indigenous communities, we offer the following recommendations as topics in need of further attention by those engaged in participatory research activities.

1. Academic researchers, and the institutions that sustain them, may have to relinquish their hold on the role of “principal investigator” to facilitate truly collaborative research, seeing themselves primarily in a service role, accepting community direction regarding priorities for research, considering indigenous ways of knowing in research methods, and sharing or giving up entirely—depending on community needs and desires—the dissemination of research findings (including where, how, and if research results are published, as well as who speaks for the research team in a standard 10-minute conference presentation).
2. Research sponsors must require participatory research procedures in indigenous communities and support such work through the funding of community-based positions that enable communities to be engaged in a discussion of research methods at the design table.
3. Participatory researchers in indigenous communities need to look globally for a range of useful operational models and practices; for instance, Australia, Canada, and New Zealand have been actively addressing culturally appropriate research design in indigenous communities over the last few decades.
4. Research sponsors who value participatory research—and, in particular, community-based participatory research—must understand that the Western-style empiricism to which they are accustomed may not be the research method of choice in indigenous communities. Research sponsors will need to view as valid—and support through funding—participatory research that uses alternative ways of knowing as a foundation.
5. Using indigenous ways of knowing in research methods is different from using or benefiting from indigenous or cultural knowledge per se. Nonetheless, the use of indigenous ways of knowing to better understand a topic—to make an impact on eliminating health disparities, for instance—may lead to the exposure of indigenous knowledge and the challenges we have raised in this essay.
6. Participatory research in indigenous communities may also involve capacity-building, which will require additional funding. Asking local community members and indigenous service providers in indigenous communities to serve on a research design development committee means removing them from their substantive roles and services. Researchers are typically funded to carry out participatory research; community participants in participatory research are typically not funded—the funding stream may need to be shared more equitably. Even though there are examples of capacity-building in participatory research (T.E. Downing, University of Arizona, unpublished data, 1995), the question remains, whose capacity needs to be built if indigenous ways of knowing are to be incorporated into the research design?

Finding ways to maintain trust, increase institutional support, and redefine partnership roles—but continue moving forward in participatory research—is a challenge we embrace, and we encourage others with interest in indigenous communities to accept it. ■

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C.A. Marshall and E. Kendall led the writing of the essay. All authors contributed to the conceptualization of this work, participated in the review process, and assisted in editing the essay.

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