

# Community-Based Participatory Research in Indian Country

## Improving Health Through Water Quality Research and Awareness

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Water has always been held in high respect by the Apsáalooke (Crow) people of Montana. Tribal members questioned the health of the rivers and well water because of visible water quality deterioration and potential connections to illnesses in the community. Community members initiated collaboration among local organizations, the tribe, and academic partners, resulting in genuine community-based participatory research. The article shares what we have learned as tribal members and researchers about working together to examine surface and groundwater contaminants, assess routes of exposure, and use our data to bring about improved health of our people and our waters. **Key words:** *community-based participatory research, health disparities, Native American, water quality*

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**E**NVIRONMENTAL HEALTH concerns of Native Americans and Canadian First Nations' people are increasingly being addressed through community-based participatory research (CBPR) partnerships among tribal communities, university researchers, and others.<sup>1-6</sup> A frequently cited review of *community-based research in public health* defines it as “[A] collaborative approach to research that equitably involves, for example, community members, organizational representatives and researchers in all aspects of the research process.”<sup>7(p177)</sup> A number of health researcher teams conducting CBPR have shared their experiences in working with Native communities,<sup>8-14</sup> and in some cases the lead authors have been Native researchers.<sup>15-18</sup> However, rarely have Native American community members written about their perception of the value of the CBPR process to their community, why they would participate in such research, and how research should be conducted in their home community.<sup>15,19</sup> A better understanding of how to work with communities has been identified as a critical need in risk-assessment research in particular.<sup>20</sup>

As members of the Apsaálooke (Crow) tribe in south central Montana, we identified deteriorating water quality as a critical environmental health issue in our community and recruited academic partners to help us conduct a local risk assessment of exposure to contaminants via water sources.<sup>21-29</sup> Data gathered in our collaborative efforts are quantifying our water quality problems, providing useful information to tribal members, and being successfully used to raise funds to improve water and wastewater-treatment infrastructure in our community. We hope to also improve risk-assessment modeling and methodology for Native American communities, in general. We meet monthly as a steering committee to work with our staff and academic partners to guide our collaborative work. Tribal members who are science majors at our local tribal college conduct most of the fieldwork and community surveys; these students have been motivated to continue on in

pursuing bachelor's degrees in environmental health and related fields and several are now in graduate school or in the process of applying.

In this article, we describe how our project began, how our partnership with academic researchers developed, and what we have learned and gained in the process. We hope that sharing our experiences will be helpful to other reservation communities and possibly other minority communities who are faced with environmental health challenges, as well as to university researchers partnering with communities to conduct community-based research in environmental health.

#### **STATEMENT OF THE PROBLEM: BATTLING FOR HEALTHY WATER IN CROW INDIAN COUNTRY**

When the First Maker created the people who eventually became the Apsaálooke or Crow, he asked a duck to dive down in the water and bring up some earth. From this wet earth he sculpted the first Crow man and woman and breathed life into them (Harry Bull Shows, Crow Tribal member, deceased, personal communication to Urban Bear Don't Walk). This creation story instills in the Crows a respect for the animals and for the earth; the earth is one of the 3 mothers of the Crows.

Like respect for the animals and mother earth, a fundamental tenet of the Crows is to respect water. Water comes in many forms (snow, ice, sleet, hail, rain, and mist) and is powerful. Water has sustained the Crow people since their creation. Past and contemporary Crows grew up along the rivers, where they learned to swim, fish, and hunt—it was a way of life for us. Rivers provided sustenance to us and were our major source of home drinking water until the 1960s.

From the very beginning of the creation of the Crows to present, Crows have faced many adversities. One incident involved an attempt by enemy tribes to join forces and wipe out the Crows. A pitched battle took place along Arrow Creek. The Crows were losing

and facing certain annihilation because they were vastly outnumbered until some of the Crow warriors sought spiritual guidance (Ray Bear Don't Walk, Sr, Crow Tribal member, deceased, personal communication to Urban Bear Don't Walk). Obviously, the Crows survived, but whom or what came to help them is reserved for later in this article.

Currently, the Crows, about 13 000 enrolled members, are faced with another insidious and ominous enemy: contamination and degradation of the Little Big Horn and other rivers that flow through the tribe's 2.2 million acre reservation located in south central Montana. As early as the 1950s, tribal members started filtering and boiling river water before drinking it. The river used to clear up after spring runoff, but by the mid-1960s it remained impaired and was aesthetically unpleasant (turbid, odiferous) throughout the summer. Although we no longer collect our drinking water directly from the rivers, the rivers continue to be essential to the maintenance of the Crow culture. Water from rivers and springs is used for spiritual ceremonies that are vital to the Crow people. Tribal members continue the traditional practice of feeding the river for protection and to show appreciation. For instance, after a successful hunt, a small portion of the raw meat is thrown into the river as an offering. The rivers are the municipal water source for the 2 largest communities in the area. Groundwater sources are also impacted by contamination. Many rural residents obtain their water from wells that were drilled only to the first aquifer or "first water" to reduce costs. These wells are subject to overflow from agricultural practices and are likely to be influenced by water drawn in from the nearby river. Another issue is the potential presence of radionuclides in water and air, since one reservation watershed has numerous abandoned uranium mines.

### Health disparities

Tribal members are concerned that the occurrence of disease seems greater on the reser-

vation than in other communities. A lack of Indian Health Service (IHS) funding for intervention and prevention has left the community with a sense of hopelessness. Health disparity data specific to the Crow tribe are not readily available; however, individuals noticed clusters of cancers and other ailments. Although most tribal members receive their healthcare at the local IHS hospital, some receive benefits through Medicaid or Medicare and are able to seek healthcare at off-reservation clinics. Others have private health insurance; thus, there is not a single source for tribal health statistics. This compounds the difficulty in collecting accurate health disparity data. Data from the Billings IHS area office include 8 Indian reservations (7 in Montana and 1 in Wyoming) and are aggregated into a "Northern Plains Indian" group rather than by tribe or reservation. For example, a recent report by the Montana Central Tumor Registry indicates that American Indian residents in Montana have incidence rates of lung/bronchial cancer 1.6-fold higher and of stomach cancer 2.3-fold higher than White residents.<sup>30</sup> While smoking is believed to cause about 90% of lung cancer cases, radon exposure is responsible for about 10% and is the leading cause of lung cancer for nonsmokers. The reservation is in a high-risk zone for radon but little is known about home air radon levels. Stomach cancer is also a concern; among Native Americans in Montana, *Helicobacter pylori* was associated with half of the cases of a specific stomach cancer, while this was one-third for White Montanans.<sup>30</sup> As with home radon levels, little is known about exposure to *H pylori*. Consequently, health disparities that are the focus of our efforts are lung and stomach cancers and gastrointestinal illness.

The community began to suspect that increases in these diseases were associated with several environmental factors but primarily water. Additional changes in our rivers were noted in the early 1970s. The sewage lagoon at Crow Agency was leaking onto surrounding lands and into the river. Two community members went directly to the Bureau of

Indian Affairs' facilities manager to report their observations, but their concerns were summarily dismissed. One recalls the response he received from the facilities manager was that "the Navy" (probably meaning the Army Corps of Engineers) "approved the discharge of the raw sewage and if you don't want to drink the water, you shouldn't have been born." Another red flag was raised when we began catching fish with lesions, clearly unfit for consumption. Frog, crawfish, and clam populations were declining. Children contracted shigellosis in the summer, apparently from swimming in the rivers, which resulted in bloody diarrhea, fever, and stomach cramps. The community members' concerns were ignored by those who controlled the municipal water and wastewater systems.

As time passed, it became apparent that no one else was going to take steps to clean up the rivers; thus, 2 community members were compelled to organize and move forward with these issues. One had become a county commissioner and the other a respected construction manager; both had gained skills in voicing concerns. They began a campaign to improve the health of the rivers and the municipal water system. In 2000, these 2 men and others were appointed to the newly established Apsáálooke Water and Wastewater Authority (the "Authority"). This group was successful in acquiring Bureau of Indian Affairs funding for a preliminary engineering report on the municipal water and wastewater systems serving Crow Agency. Public recognition that the problems existed was finally confirmed.

The tribal health educator began sharing her concerns about health disparities related to the water with a local tribal college's (Little Big Horn College, LBHC) science faculty member while in the sweat lodge. The previously mentioned construction manager also started talking about local water quality issues with this same faculty member. She in turn sought assistance from the Indian Country Environmental Health Assessment Program to provide training for the community. This initial 5-day training involved participants from a broad range of community agencies and included

a reservation-wide environmental health assessment. The assessment documented that water quality was the highest-ranking environmental health issue. Some of the participants joined forces with the Authority and formed our working group, now known as the Crow Environmental Health Steering Committee (CEHSC). The Crow Water Project was on its way.

### **Need for data**

The Authority needed water quality data to submit grant applications for water and wastewater infrastructure improvements. The tribe had neither the necessary data nor the capacity to generate it, but LBHC was already involved in local water quality monitoring. Data on the reservation's rivers, collected by LBHC science majors with supervision from LBHC and Montana State University (MSU) faculty and staff and guidance from the CEHSC, have recently been used successfully by the Authority to attain grants. The data documents community concerns about water quality and its potential impact on our health. We now recognize that the pollution problems are worse than suspected.

Crow tribal members, like members of other tribes, are sensitive about participating in research because we repeatedly have been the subjects of research with little or no benefit to the tribe. This experience was different because tribal members initiated the work, the data are useful to us, and we are solving the problems we have identified. The fact that the impetus for this research originated with the community continues to be the single most important factor in the overall success of our Crow Water Project.

Research has expanded beyond the initial efforts. Currently tribal and MSU researchers are addressing community concerns about perceived cancer clusters by conducting a community-based risk assessment of exposure to contaminants via water sources and select subsistence foods. This includes conducting community member surveys and comprehensive chemical and pathogen testing of

drinking water sources. We focus on home well water, but we are also examining river water sources used for traditional activities and for municipal water systems.

### **IMPLEMENTATION OF CBPR IN A NATIVE COMMUNITY**

The critical element in making CBPR work is clear, unbiased, and empowering communication between the university researchers and tribal community members. It is important for key players to have a full comprehension of CBPR and how it impacts the community. Outreach to a broad spectrum of tribal members is important in developing the CBPR concept. Cultural sensitivity training for the university research team members—in the day-to-day life of Native communities—in hands-on and in real life.

Our CBPR design is a creative, collaborative process that respects and takes the following into consideration: (a) the community's extensive knowledge of the local environment, environmental degradation, and potentially related human health issues; (b) the community's traditional respect for and relationship to the land and rivers; (c) the community's need for data to answer local questions; (d) Western scientific knowledge of environmental health and of risk-assessment methodology; (e) legal considerations; and (f) what research is valuable to other rural or minority communities and therefore worthy of outside funding. Community knowledge about cancer cases and historical and current sources of contamination has been invaluable in designing the research. Steering Committee members understand the scientific method and are able to connect it with tribal consciousness and knowledge.

Political support is critical to our ability to work together successfully. Since 2006, key officials of the Crow tribe, LBHC, and MSU have consistently supported our efforts and together signed a memorandum of understanding detailing conditions of the collaboration. The diversity of tribal community members (age, gender, cultural and professional

expertise, and agencies represented) on our Steering Committee helps tremendously.

The CBPR concept pervades the organization of the research. We have a "flat hierarchy" for the CEHSC. Rather than elect a president, meeting facilitation is rotated through members of the Steering Committee. We share the responsibility of presenting our work, whether at local, state, or national levels. Three Steering Committee members have traveled with LBHC project staff to copresent posters at national conferences. For the past 3 years, our group has given a panel presentation annually at the statewide IDeA Network for Biomedical Research Excellence conference. This structure extends to our university partners and project principal investigators.

Much of the progress of the Crow Water Project has been accomplished on sheer people power. However, there was also a need for funding. After acquiring the initial data and working collaboratively, we have developed solid CBPR proposals. Community involvement was essential in every aspect, from the initial planning to the writing of the proposals; collaboration was essential to express the community's initiative and commitment to and partnership in the research effort. Our partnership has grown from small projects to a much broader collaboration with IDeA Network for Biomedical Research Excellence funding from the National Center for Research Resources at the National Institutes of Health. The funding enhanced science education at the tribal college, including science faculty development and research capacity building. Funding has also come from the National Center for Minority Health and Health Disparities.

### **THE PROJECT AS A MODEL FOR A CBPR METHOD**

From the researcher's perspective, the process was developed to move the water-related work forward and serves as a model for how to develop a positive, functioning partnership between a community with health- and environment-based research needs and university researchers. The learning experience

is particularly helpful to those working with other reservations but is also applicable to other minority communities who are faced with environmental health challenges. The processes and insights are viewed by the US Environmental Protection Agency as a contribution to their initiative to incorporate community knowledge and insight into risk assessment. In particular, there is a growing need to manage risk in a community-specific, culturally appropriate way that takes into account social, cultural, and other nonchemical factors.

Our journey has also uncovered many of the challenges that are part of a community-based effort. It is clear that the community has more trust if the research is driven by people in that community and when the main point of contact is a community member. Our project has been successful because the person who is conducting surveys and collecting samples on the reservation is fluent in Crow language and can communicate with those who value and routinely use their native language. Having students and staff from LBHC involved also demonstrates that the community is engaged in the work, rather than having it done by someone who is not local. It has been critical to know that cultural issues such as strong family ties will influence the pace of the work. Because there are many critical needs in the community, the work must continue to be relevant so that it retains its importance and focus. To serve this purpose, it is essential that the community knows that the work is important and is yielding valuable information for them and not just the researcher. These are just a few of the lessons that we have learned in the process of developing, funding, and accomplishing the work that we collectively believe will improve the health of the environment and the people.

#### **THE IMPORTANCE OF CROW COLLEGE STUDENT INVOLVEMENT**

Our projects are giving Crow science majors at LBHC and MSU the opportunity to participate in research in their home commu-

nity on issues that are relevant and meaningful to them and to our tribe as a whole. LBHC, like the majority of the 30+ tribal colleges around the country, offers associates degrees and therefore student research experience is a relatively new addition to our educational programs. The CBPR work has provided a unique opportunity to develop research capacity at LBHC while also providing a meaningful research opportunity for the students. For the current research projects, fieldwork, laboratory work, community-based surveys and community education work is being conducted on the reservation and at LBHC, while genetic analyses of organisms in water samples are being carried out at MSU. This provides Crow students with an opportunity to participate in research as freshmen and sophomores, without having to leave home. When they transfer to MSU, they can continue to stay involved as juniors and seniors and mentor LBHC student interns. At least 15 Crow students have participated in our Water Quality Project, at LBHC or MSU or both; most have completed their bachelor's degrees or are still in school in various science disciplines. One will finish her master's degree this fall in science education, another will begin a master's degree in community health this fall, and others are now considering graduate school. For those of us who teach and mentor these students, it has been rewarding to see how much they are learning and how committed they are to the research.

The students contribute substantially to research in the community and in the university research laboratories. One intern commented that she sees her role, and that of other students, as helping to connect the community and the academic researchers. In the Crow community, the term *researcher* has long had the connotation of "intruder." The survey and well water-sampling work done by the research team simply could not be done by non-community members working alone. The interns and our project coordinator are tribal members; they can translate the scientific language of water contamination into terms that make sense to other tribal members, thus

increasing community knowledge of water quality and health-related issues. Educating the community to protect our surface and groundwater can only be done effectively in person, for instance, by showing them potential problems with their wellhead. Distributing printed materials alone is not very effective.

Our current community project coordinator began her involvement as a student intern and went on to complete her bachelor's degree in environmental science. She initially heard about the water quality project from other LBHC interns and applied to participate. Once she began her internship, she realized how polluted the rivers were, raising her awareness of the degradation of this resource. For example, as a child, her family drank the river water untreated and swam in the river in the summer months without becoming ill. This is no longer the case, and as stated earlier, the water is sufficiently polluted that now it cannot safely be consumed without treatment. At LBHC, she gained experience in baseline water quality monitoring. When she transferred to MSU for her bachelor's degree, she was accepted to work in our project's microbiology laboratory. There she was able to see what happened to the water samples when they got to the laboratory, and gained experience in molecular biology (polymerase chain reaction) techniques for identifying the isolated bacteria. This experience helped her in some of her other classes. Upon completing her bachelor's degree, she was hired as our environmental health project coordinator at LBHC, where she is able to train, supervise, and mentor the water quality interns. She finds that the students are eager to learn the protocols of water collecting and want to do the best job; they gain an appreciation for the importance of accuracy and precision in data collecting. The interns realize that their role in the research project is important, both to the community and to the university researchers.

Another former project intern went on to complete a bachelor's degree in hydrogeology and has been hired for a 1-year math/science

teaching position at LBHC. From MSU side, a non-Native microbiology doctoral student who has worked with the project since being an undergraduate has also found the experience invaluable. She has gained a greater understanding of how to conduct research and outreach in a Native American community. On a reservation where "research" has a toxic legacy, the increased success of our students in pursuing careers in environmental science and health and especially their interest in graduate school is simply transformative.

## CONCLUSION

Earlier in this article, a survival story of the Crow was shared with a promise to tell what saved the Crows from certain annihilation. A warrior appeared seemingly from nowhere on the battlefield. He was invisible to the Crows, but the enemy said he was riding a beautiful pinto horse and wore a war bonnet with trailing extensions that nearly touched the ground. The Crows saw the enemy retreating, but they only learned of the appearance of this warrior upon parleying with the enemy years later. The enemy asked who the warrior was and the Crows did not immediately say, but after considerable discussion and thought, concluded that this must have been Isáahkawattee, a key character in Crow oral history who not only plays tricks on them but is also willing to come to their rescue in times of great need (Ray Bear Don't Walk Sr, Crow Tribal member, deceased, personal communication to Urban Bear Don't Walk). This begs the question: Is Isáahkawattee in some way involved in this community-based effort regarding the sacred waters and lands that Crow ancestors had bargained for in treaties and had set aside for future generations for as long as the grass shall grow and the rivers shall flow?

After years of inaction, indifference, and/or the lack of resources to address our water quality, water infrastructure, and related health-disparity concerns, we have found that we can successfully take on these problems,

identify the necessary researchers, and effectively collaborate with them on mutually acceptable terms. We want to restore the health of our rivers and of our community. We realize it will take a broad-based, grassroots effort to make this change. Passion, tenacity, persistence, mutual support, and not letting one

another quit are making this process work. We continue to learn more about health issues and how to facilitate change so that we can improve the well-being of our Native community. We now feel empowered to take on other environmental health issues that affect our community.

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