

A Partnership Study of PCBs and the Health of Mohawk Youth: Lessons from Our Past and Guidelines for Our Future

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This paper describes a research partnership between the people of Akwesasne and researchers from the State University of New York at Albany for the study of polychlorinated biphenyls and the health of Mohawk youth. The study is distinctive because its goals have been set by the scientists and the community members and is being conducted jointly by these groups. The research partnership recognizes the history of relationships between native and nonnative peoples, particularly scientists, and seeks not only to fulfill certain scientific goals but to further community ones as well. The relationship is based on three principles: mutual respect, mutual equity, and mutual empowerment. These principles guided every aspect of the research process. The project goals were determined jointly to maximize data quality and minimize the intrusion of research activities into the lives of community members. Data collection is performed by research assistants who received extensive and ongoing training in data collection methods, and who are members of the community. Feedback procedures were designed by community members and scientists jointly to maximize understanding. Feedback regarding individuals' pollutant levels and assessments of growth and development are provided to each individual. Information about community pollutant levels are provided to the community. Hypothesis testing is carried out by research scientists, and the results presented first at a community meeting. Research conducted in this way—as a partnership—requires more communication, discussion, and travel, but the result is mutual satisfaction and growth. — *Environ Health Perspect* 106(Suppl 3): 833–840 (1998). <http://ehpnet1.niehs.nih.gov/docs/1998/Suppl-3/833-840schell/abstract.html>

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Currently, the health of minority communities is substantially poorer than that of the general U.S. population (1). Improving the health of minority community members is essential for the United States to meet Healthy People 2000 objectives (1). Children of minority communities are especially at risk for environmental health problems (2,3). To improve the health of children, additional research is necessary in minority group communities (4). This

paper describes a partnership between the Akwesasne Task Force on the Environment (ATFE), representing the Mohawk community at Akwesasne, and a research team at the University at Albany, State University of New York (SUNY) for the study of polychlorinated biphenyls (PCBs) and the well-being of Mohawk youth. This paper reviews the history of the development of this project, highlighting features of each partner's background, and describes specific

concrete steps that have been taken to facilitate an equal partnership that will produce constructive results for the scientific and host communities. These specific action steps may serve as a framework for partnerships between other scientists and other minority communities.

The paper is not written in the usual scientific style in which there is a single and perspective-free voice. Instead it is written to represent two distinct voices: the community partner's and the scientist's. The intention is to give full representation to two voices in the same way that the partnership research project itself provides representation of both the scientific and the minority communities.

Brief History of the Mohawk Nation at Akwesasne

The Mohawk Nation at Akwesasne is part of the Haudenosaunee Confederacy, most often referred to as the Iroquois. Akwesasne straddles the U.S.-Canadian border between northern New York, eastern Ontario, and western Quebec. It covers about 28,000 acres and has a population of approximately 10,000. There are three main rivers that traverse the land: the St. Lawrence, St. Regis, and Raquette. The St. Lawrence River is a major shipping channel that connects the Great Lakes to the Atlantic Ocean, and it is contaminated with numerous pollutants from the Great Lakes and from local sources (5–8). The waterways play an important role in this community's life, not only as an economic source for the dwindling fishing industry, but also as a major source of recreation.

Akwesasne is a community that has three main political factions within its territory: one implemented and recognized by the U.S. government (St. Regis Mohawk Tribe), one implemented and recognized by the Canadian government (Mohawk Council of Akwesasne), and one that has always existed and is recognized by the Traditional Longhouse and Haudenosaunee Confederacy. Each of the three political factions has its own regulations and guidelines within Akwesasne, which adds to the complexity of this tiny community, where many residents are citizens of the United States and Canada as well as the Mohawk Nation. Akwesasne has been the home for many generations of Mohawk people and to some of the finest craftspeople, best ironworkers, and greatest storytellers in the world.

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Abbreviations used: ATFE, Akwesasne Task Force on the Environment; FERP, First Environment Research Projects; NYSDEC, New York State Department of Environmental Conservation; PCBs, polychlorinated biphenyls; PI, principal investigator; RAC, Research Advisory Committee; SUNY, State University of New York.

A Native Community Perspective

Recent History of Research with Native Communities

In the past few decades, research with Native-American communities typically progressed in a manner that ultimately had greater benefits for those performing the research—the scientists. The target community usually did not profit from this type of work either economically or otherwise. The Mohawk community of Akwesasne has dealt with this type of research for many years with many different researchers. Previously, the typical native/scientist relationship consisted of very little trust. A probable scenario of how some of this research took place might have been as follows: The scientists would enter a community with a preconceived notion of what the community's problems were and with no notion at all of what the community was like. The scientists would then proceed with their research and collect their data. When they finished, they would pack up and leave the community. Very seldom would the community hear from the researchers again. The researchers' work would eventually appear in the literature or media in one form or another.

How Such Relationships Were Not Effective in the Past

In retrospect, this type of research was not very beneficial from the community's point of view. Jobs or opportunities for community members were rarely created; there was no equity. The community's input was rarely included in anything. The community was seldom perceived to have any credibility; there was no empowerment. The community members were rarely recognized as people with a distinct culture; there was no respect. Hence, this type of relationship was not one that fostered trust in a research scientist. The negativity that was created from this kind of relationship was, and is, difficult to overcome. Even today, some people at Akwesasne are hesitant to participate in research because of the negativity they feel toward the scientific community.

When research is conducted in a community, some community members may view it as an economic or educational opportunity. In most instances this was not the case, as there was very little equity involved in this type of relationship. The research team would come to the community fully staffed with no room or need for anyone else. Occasionally, a few members

of the community may have been involved. This was probably the most common oversight among researchers doing work at the community level. When entering a community, most researchers have overlooked the wealth of information and knowledge that members of the community hold. This knowledge base could range from speaking the native language to knowing who the researchers should contact first to further the study. Having community members as part of the research team is one way to enhance the effectiveness of the work being done. Community members are more capable of gathering information or data from their people than someone who is not from the community. They know how to communicate with the people and how to introduce the research project in their own terms. This is one of the most important skills to have, especially when working on human health studies that are based on interviewing participants. Creating jobs and training community members in this type of work is one of the ideal benefits that could be gained from a good research relationship. It would also be beneficial for communities with few economic opportunities.

It would be uncommon to find a past research study where the researchers encouraged the community to be involved in the development of the study project. Research scientists usually entered communities with study projects already designed. Community input was practically unheard of. Members of the community usually did not have the opportunity to make suggestions or recommendations as to how the project should be designed, how it should proceed, or if it should proceed. A misconception of some researchers is assuming the community wants research to be conducted in their community. Without any input from the community, the research may be viewed by the community as worthless. With assistance, a research study could be designed that is better suited for a particular community. In turn, the members of the community may support a study if they feel it is addressing problems as they perceive them.

Especially in Native-American communities, researchers may not realize the differences in the way a particular population views things. There are many things to consider when designing a research study in a Native-American community, such as their culture, language, values, belief systems, and the current political situation. When developing a research study, each of these must be incorporated and considered

throughout the entire process. This is why community input and involvement is so valuable; you will not find this type of information in any textbook. This information must come from the people—the community's most valuable resource. Along with the input from the community comes recognition for their valuable and valid knowledge. Several times this has gone without credit and unnoticed, which illustrates a lack of credibility given to community members.

Many research projects are directed toward minority communities because of their location, proximity to local industries, point sources of pollution, or their lower socioeconomic status. Whatever the reason, researchers must always contend with that particular community's cultural identity. Each community is unique and special in its own way. Even populations of the same ethnic group may differ. For example, there are many different native communities across the Americas and Canada, but each is unique. One cannot assume that all native communities across the United States are the same. The fact that they are all natives is not enough to make such an assumption. This is true for other minority communities. In the past many researchers have not taken the time to get to know the community before beginning their research there. Not knowing even a little about their culture may be interpreted as not having an interest in it. This may appear to be a lack of respect on the researchers' part. Not understanding part of the culture in a minority community could cause the scientists to make misinterpretations of the data that would misrepresent the community. It is this kind of action that could later have a negative impact on the community.

Generally, scientists appear to have gained more from research than has the community. Many times research studies are done for academic advancement. Researchers conduct their studies and end up with their advanced academic degrees, while the community simply acts as a stepping stone. Those researchers who already have their degrees may have done their work as a way to apply for larger grants to obtain more funding for their respective universities. Meanwhile, the community gains no economic or academic advancements whatsoever.

The Process—What Brought Us Together

The previous description is fairly typical of how research was done at Akwesasne. One communitywide study was conducted at

Akwesasne in the late 1970s and early 1980s by a university medical school to assess the health status of the people of the St. Regis Reserve (Akwesasne) in relationship to their estimated degree of exposure to fluorides, methylmercury, PCBs, and mirex. The senior investigator is now deceased and the name of the study is not as important as are the feelings that it created at Akwesasne. It was a large intensive health study that left many of its participants feeling like guinea pigs. At the completion of that project, the research team left. No public presentation was made to the community regarding the results and only the participants with a serious medical condition received feedback. Unless they were directly involved with this particular study, not many people really understood what the study was about. From the community's point of view, the results of this study were not useful and it seemed to create more problems than it solved. The majority of residents at Akwesasne regarded this study as doing more harm than good. Many people have expressed feelings of rejection from this study and their present feelings toward research reflect this. Poorly done studies can greatly impact future research. This is what the field staff working on a current research project at Akwesasne faces. Time and time again, when a prospective participant for the current projects is approached, the field staff encounters the same resentment (9). Resentment was not the only outcome created from that kind of research relationship. Feelings of mistrust, suspicion, and a general lack of confidence were also created. These are the types of reactions we deal with as a result of a research study gone bad. Residents involved in past studies will not forget how they were treated or how they were made to feel.

Development of the Akwesasne Task Force on the Environment

All of this started to change in the mid-1980s. An organization within our community, the ATFE, saw the need to become active in the actual process of any research project done at Akwesasne. The ATFE is a community based organization founded to conserve, preserve, protect, and restore the environment and natural and cultural resources within the territory of Akwesasne. The ATFE is comprised of community members who reside in all regions of Akwesasne. The objectives of the ATFE include serving the people of Akwesasne by acting as environmental representatives to external agencies, and acting to establish partnerships with educational

and environmental organizations to assist the community in developing and implementing strategies for environmental protection (10). It was also the wisdom and foresight of a Mohawk midwife, K. Cook, a native of Akwesasne, that initiated the human health research we are part of today. Cook was instrumental in urging the research at Akwesasne. She contacted the New York State Department of Environmental Conservation (NYSDEC) and the Wadsworth Center for Labs and Research at the New York State Department of Health for help (11). This began a full-range study at Akwesasne that included the analysis of fish, wildlife, and human breast milk. From that point on, our community became more aware of and more involved in the actual research process.

The research progressed in conjunction with the ATFE and employed Akwesasne residents as field staff to collect the data and samples. The field staff at Akwesasne represented an organization founded by Cook—the First Environment Projects. The name derives from Cook's belief that women are the first environment. Women's bodies sustain life and give nourishment. Their bodies are the first environment in which we exist as infants. The field staff at Akwesasne still proudly represent the First Environment Research Projects (FERP) as part of our current research studies.

Development of the Research Guidelines

In 1995, the ATFE established a research advisory committee (RAC) as a result of an increasing number of research projects being proposed by scientists. The role of the RAC is to review and comment on all proposals to be conducted at Akwesasne. With a large influx of proposals, the RAC realized the need to develop guidelines to standardize the review process. The resulting set of guidelines was titled *Protocol for Review of Environmental and Scientific Research Proposals* (10).

Research at the community level is a learning process, not only for testing hypotheses, but also for learning how to work together. The protocol for research by the RAC was developed by three main guiding principles. It is an understanding that both sides of the research team, community and academia, accept and believe in these principles. The three main principles are taken from the Mohawk language, and translations have been made to the closest possible interpretation of their true meanings. The principles of peace, good

mind, and strength are the basis for this document (11). Since the beginning of time our people have been told to strive for peace—inner peace as well as peace among others. To strive for peace in every sense of the word (spiritually, socially, and politically) will help one to develop a good mind and a good way of thinking. A good mind comes from the concept of one using the purest and most unselfish mind to realize that all creatures are equal and no one is better or more deserving than anyone else. When we work for peace and a good mind, we develop strength. Strength is the inner force of good will in humans to work towards peace, justice, and unity.

It is the emerging behaviors that flow from these three main guiding principles that serve as the criteria of the research process. From peace comes respect, from a good mind comes equity, and from strength comes empowerment. When respect, equity, and empowerment are achieved by all parties involved, a good research agreement will result.

Researchers and the community must generate respect for each other by understanding the other's social, political, and cultural structures. Communication must work both ways for a good research agreement to be generated. Cultural sensitivity training for the researchers and community awareness presentations help to develop a mutual understanding of the research process.

Equity is defined as a sharing of resources. Both the researchers and the community must bring equity to the agreement. Money is only one form of equity. Community knowledge, networks, personnel, and political and social power are other forms of equity useful to the project. Each of these commodities has value and must be shared between the researchers and the community if a good research agreement is to be formulated.

Empowerment is defined as a sharing of power and the result of a good research agreement developed by both the community and the researcher. Each participant must feel that his or her needs are being met and that their credibility is increasing. Partnership and responsibility continue to grow as more and more respect and equity enter the agreement. Empowerment also means that authorship must be shared between the community and the researcher. Although this is sometimes difficult, the increase in empowerment and credibility is beneficial to a good research agreement, which is the goal of the research guidelines.

A good research agreement is developed when it promotes collaboration within a framework of mutual trust and cooperation. This agreement will result in shared power, shared resources, and mutual understanding and will ensure that studies proceed in a manner that is both culturally sensitive, relevant, and beneficial to the participants and community.

Although these concepts are not new ones, it may be difficult for some researchers to incorporate them into a study at the community level. In the past, a typical research agreement did not follow this train of thought. Times are changing: Communities are becoming more aware of their actions and the impact that these actions ultimately have on their future.

In 1995 another group of research projects began. The Superfund Basic Research Program, through the National Institute of Environmental Health Sciences, funded a 5-year interdisciplinary research, training, and community outreach project to investigate the effects of PCBs and other known toxic substances on human health and to develop ways to clean up these hazardous wastes. Ten individual research projects and five core support projects make up this large program sponsored by the School of Public Health, University at Albany, SUNY, and the ATFE. Of these projects, three are human health studies that are currently underway at Akwesasne, including one on PCBs and Mohawk youth.

The staff of the FERP works in unison with the staff at SUNY Albany on the human health studies to help improve each project. The staff has assisted in the implementation of the study through comments and recommendations. Many times this feedback was incorporated to improve areas of the studies. This type of relationship has been most beneficial to both the community and the researchers. Not only are staff of FERP and members of the ATFE asked for comments, they are also invited to take part in the quarterly Superfund meetings. At these meetings, they have the opportunity to discuss any problems or concerns; it is a true partnership at almost every level.

A Scientist's Perspective

Pollutants at Akwesasne

Approximately 40 years ago when the St. Lawrence seaway and Moses Saunders Power Dam, Massena, NY, opened, the river became an attractive site for industries. The General Motors Corporation Central Foundry Division is located on the St.

Lawrence River and is less than 100 ft from the western border of Akwesasne Reserve. The division casts molten aluminum into automotive engine parts by a high-pressure process. PCBs used in the casting process have leaked into the surrounding soils, groundwater, and into the St. Lawrence River itself (12). The site is a designated Superfund site on the U.S. Environmental Protection Agency National Priority List (13). It is believed that groundwater flows eastward from the site to Akwesasne. Groundwater has been the principal source of drinking water on the reservation.

In addition to the General Motors Foundry, there are two other aluminum plants nearby, operated by Reynolds and Alcoa, located within 1 and 3 miles upstream from the General Motors site, respectively. The NYSDEC has declared these to be inactive hazardous waste sites (12). Both sites contribute PCBs and polychlorinated dibenzofurans. The latter can be found at greater concentrations near the Reynolds site than at the General Motors site (14).

Wildlife near the reservation is contaminated with PCBs and other toxicants from local sources and the Great Lakes. Surveys by the NYSDEC have determined that fish and waterfowl nearby have elevated levels of PCBs (6). Studies of native mussels (*Elliptio complanata* and *Lampsilis radiata radiata*) from the St. Lawrence River show that the number of different PCB congeners is twice as great in the area near the reservation as it is in the upper river (7). Even far downriver from Akwesasne, river contamination persists. Necropsy of beached beluga whales in the St. Lawrence River estuary revealed high levels of organochlorines, heavy metals, and benzo[*a*]pyrene exposure (8).

Traditional Mohawk subsistence involves consumption of local fish, wildlife, and plants. Many Akwesasne residents have obtained food locally from their own gardens and by fishing, hunting, and trapping. This increases dietary exposure to local contaminants. Recreation and religious ceremonies also involve close interaction with the local environment.

Contamination of water, soil, fish, and fowl at Akwesasne is a source of tremendous concern to the people at Akwesasne. Traditional Mohawk culture emphasizes the unity of people, animals, plants, land, and water. Curtis (15) analyzed the consequences of contamination of their lands for Native-American groups, and elucidates three major areas of adverse impact. Tribal

identity may be weakened because this identity often depends on ties to specific locations. Religious values are weakened when tribal lands and resources are no longer available for traditional activities. A reduced quality of life (i.e., loss of morale, reduced subjective well-being) may result from the loss of tribal identity and the destruction of religious values. When quality of life is severely reduced, social and psychologic pathologies can increase, and demographic declines through outmigration, incarceration, and death may result. The combination of these adverse impacts can promote cultural extinction. Thus, for the Mohawk at Akwesasne, the contamination affects not only their choices of food, but also their religion, sense of tradition, and their very way of life.

Understanding of the Community's Perspective

The history of scientists and government officers working with Native-American communities has produced a legacy of abuse and mistrust. The history of governmental abuse of Native Americans is too long to review in detail (16,17), but certain key points are relevant and not widely appreciated by scientists. Native Americans living within the United States may exist as members of federally recognized or unrecognized tribes. A group can lose its federally recognized status and may experience severe declines in health, economic status, and general welfare as a result (18). The process of rerecognition is long and bureaucratically intricate and places Native Americans in a dependent position to reobtain federal recognition and certain rights as members of a federally recognized tribe. American Indians are citizens of the United States and are wards of the U.S. federal government as well (19-21). As wards, Native Americans are subject to extraordinary interventions by the U.S. government in their daily lives. For example, beginning in the late 19th century and continuing well into the 20th century, the U.S. government forced the education of Native-American children at boarding schools far from their family homes (22). Not until 1904 were federal agents required to obtain parental consent for removal of children to schools, and on some occasions food rations to families were withheld to enforce compliance with attendance policies. Religious education at such schools was mandatory. The forced removal of children to federal schools and their forced religious education is well

within the memory of contemporary Native Americans on and off U.S. reservations (23). Thus, governmental intervention with Native-Americans' lives is not merely a subject for history books but is experienced in the lives of Native Americans every day and unfortunately is the starting point for research collaborations with native people.

Modern scientists working with Native-American communities can further appreciate the native community's point of view by also becoming aware of the history of interactions between scientists and native peoples. Following the invasion of North America, naturalists and priests, who were united by their study of natural and divine order, sought to determine the very personhood of the inhabitants of America. After the humanity of Native Americans had been established, scientific interest shifted to questions of origins and affinities. By the 18th and early 19th centuries, scholars debated the origins of Native Americans and their relationship to earlier American civilizations. On one side were those Europeans who claimed that it was impossible for the ancestors of the Indians, who then were most often regarded as savages, to have built the large complex cities of Cahokia, Illinois, and Tenochtitlan, Mexico City, Mexico, or traded across thousands of miles. On the other side of the debate were those who sought empirically to determine whether there was cultural continuity between the ancient sites and the contemporary residents. North American anthropology and archaeology were born in the 19th century to answer this question and the larger questions of origins and affinities of all Native-American peoples (24). These questions were resolved not only by excavations but by studying cultural artifacts, religious and kinship forms, and the contemporary languages, as well as readily observable biologic characteristics among as many native groups as possible.

Scholars working on these scientific questions approached Native-American peoples with European orientation of thought. They brought with them all the intellectual baggage typical of the era, including racial typology and eurocentric hierarchies for classifying government, art, religion, technology, medicine, etc. (25). Asymmetric power relationships were the norm. To address issues of intergroup relationships and culture history, scientists took their knowledge about language and culture, as well as examples of clothing, pottery, basketwork, art, and ancestors' remains, and displayed them to their colleagues and the

interested public through museum displays and scientific publications. This has earned them the enmity of many contemporary native peoples. It is possible that any well trained, well motivated European in any discipline of science or scholarship working 100 years ago would have done the same. Indeed, more exploitation might have occurred if more naturalists and scientists had been interested in native peoples, but only a few were.

For their cooperation, the native people received little of value at the time. They were subjected, by greatly varying extents, to a eurocentric and often blatantly racist representation of themselves to the scientific world and indirectly to the public at large. The return to native peoples has included disease, decimation, and the destruction of language and culture (26).

In the 20th century asymmetric power relations persisted. Even within the past 20 years many types of scientists have continued to treat Native Americans and other minority persons as specimens for scientific study (27,28). Chavis et al. (29) use the term experimental colonialization to characterize the traditional relationship of scientists to many host communities, a relationship in which subjects can feel exploited and that little good will come from the research. Scientific study of Native Americans is not intended to be exploitative, and it is purportedly for the good of the native or minority communities themselves, or for benefits to science in general. However, to the subjects of the studies, the latter explanation may not appear much different from claims made for science by 18th and 19th century scholars.

Science is influenced by prevailing political forces and cultural mores (30,31). From the perspective of the nonscientist, scientists can be biased with respect to what is best for native and other minority communities, and may choose to emphasize activities of direct benefit to themselves. Conflicts can arise between scientific goals and moral principles (27), and the rights of subjects can be at risk (32). Statements on ethics, such as that of the American Society of Epidemiology (33), exist in part to promote behavior that does not exploit subjects and is responsive to society's will.

One role that native and minority communities can play is to provide additional force that may counterbalance scientists' own interests. Such communities can reflect self-serving bias by scientists and promote research that is considerate of local culture, community needs, and goals.

Implications of Community Principles for Human Health Research

At Akwesasne we have sought to equalize power relationships between researchers and the native community through adherence to the three principles of respect, equity, and empowerment. These terms have clear implications for scientists, specifically for the planning, budgeting, and day-to-day conduct of research.

Respect refers to the view we each take of the other. Scientists understand that the triad of operating principles comprise the Mohawk research protocol, and just as scientists follow their research protocol, so do we follow the community's research protocol. The scientists respect the native community's concern for the environment and listen and respond to requests for investigations. Thus, if there is community concern about fluoride in the environment, that question is a legitimate one. Scientists respect the concerns of the community for the community's own health, and are willing to investigate health outcomes of special interest. This is consistent with efforts to include participants in the selection of outcomes in other types of community based research (34). Respect even refers to respect for the subject's time and the disruption to their private lives and their culture that a research study would cause. It involves understanding their past experiences with scientific studies, and also understanding that being a partner in determining the health effects of environmental contaminants is different from being treated as a specimen, a passive object of scientific study. Respect also means consideration of the indigenous knowledge of the environment and the social system. The community also offers respect for the methods of science and the methods of laboratory and epidemiologic truth-seeking. It respects the long history of intellectual development that provided knowledge about the environment and human biology.

For the researcher, equity refers to the equality of the partners in the research. Both bring to the project valuable resources that each partner must recognize for mutual benefit (29). Scientists have training and expertise in the conduct of scientific studies. They often have funds to conduct the collection and analysis of data. Although scientists recognize their own contributions, they are often recalcitrant in recognizing the contribution of the community. However, the community has

valid indigenous knowledge of the social system (35) and environment that may enhance, guide, or substitute for knowledge obtained through Western methods (36). Indeed, the concept and legality of intellectual property rights of indigenous peoples is based on the presence of this type of knowledge (37). The exchange of knowledge is a fundamental expression of equity. Researchers working with other Native-American groups have coined terms such as reciprocal learning (38) and reciprocal education (39) to describe this process of sharing knowledge. Finally, the concept of equity also recognizes that the community has political power that may impact the conduct of the research in the community and may position the project within the government's research priorities.

For the researcher, empowerment refers to one of the effects of the partnership. In addition to providing an answer to the specific research question that was the impetus to the partnership, the project should enhance the community in other ways as well. This is consistent with earlier statements by Chavis et al. (29), who advocated that scientists and community collaborators create linkages and partnerships in research that would help people help themselves. One goal for the Akwesasne community is self-sufficiency. Our research project is designed to empower the community in that direction. Community participation in the project trains community members in scientific methods of general epidemiologic research and in techniques of other related fields such as psychometrics and anthropometrics. This form of feedback to the community involves more than the return of study results, and it has the potential to build a community that is more knowledgeable about research methods and is more self-sufficient.

Partnership Studies

Research projects conducted in accord with these principles fit within the classification of epidemiologic or population biology studies that can be found in most epidemiology textbooks. As an observational study of humans, a partnership study has the usual ethical safeguards regarding participation, withdrawal, confidentiality, and informed consent. As a type of community study, investigators work with an organized self-identified group rather than with individuals, and consent comes on two levels: from the individual participants and from the community. However, in many community

studies the community may not be a full partner in the research (40).

Our partnership study is guided by the AFTE research protocol and by important mutual concerns: concern for the environment; concern for past, current, and future generations of people; and concern for good data to answer community concerns and promote scientific knowledge.

The research team includes community members, thus providing diversity of cultural backgrounds, histories, and professional orientations to consider and draw upon. Having community members on the research team allows for greater opportunity to hear community viewpoints and incorporate them in the research plan. Partnership is not a burden on the researcher's research agenda or a matter of paying dues, but is an opportunity for researchers to learn as well as teach.

One clear aspect of the partnership involves the choice of outcome measures in the study. In a partnership study, deciding which variables to measure depends on local community concerns and interests, national public health priorities, prior scientific research, and the availability of methods to measure each variable of interest that are both scientifically rigorous and acceptable to the community. Considering matters that are not purely scientific in selecting outcome measures may seem novel, but this aspect of partnership is consistent with earlier calls by experienced, community minded scientists for participants to take a variety of roles in research collaboration. Sherman and Sheldon (34) endorsed including participants in selecting research goals, methods, and outcomes.

In a partnership study, consent is sought from the community as well as from individual participants. To obtain these consents, community research partners are indispensable. The process usually involves expanding the network of contacts with community figures, providing more information, and collecting feedback through meetings with as wide a range of community members as is possible.

A critical aspect of the partnership is the return of information to the community and the participants from whom the data were collected (29). In our partnership study, the return of valuable information is paramount. It should be timely, as we have aroused participants' concerns by being there in the first place; it should be understandable to the participants rather than in technical language understandable to specialists only; and it should be valuable. Data

that is of no interest to the community is not wanted. Conversely, poor quality data is of little use. It is these last two interrelated points on which the partnership pivots. Scientists must work with people concerned about pollution and those people must work with scientists to get answers to their questions. Both partners have mutual interests.

Impact of Partnership Principles for Research Planning and Conduct

The principles of partnership studies entail specific action steps in the planning and conduct of the research, and these entail appropriate budgeting in applications for support of the research. Because funds for research are in demand for so many worthy projects, the expenditure of funds to promote partnerships between researchers and communities may be criticized as excessive. However, the actual expenditure may not be as large as might be feared. Many of the action steps below involve modest monetary expenditures but considerable effort to anticipate community concerns and desires as described previously. Partnership expenses may also be viewed as unwarranted. We argued that funds to enable a research partnership are budgetary items necessary for the immediate success of the specific research project and for the long-term success of health promotion in minority communities. Without community partners the research may not be performed at all, with loss of benefits to the community, science, and society at large. If the research is performed without partnership, it is more likely to be exploitative and not performed as well as it would have been with a community partnership. Ultimately, the use of funds to support partnerships will have to be evaluated after a sufficient number of trials with this form of research collaboration have been completed.

The following action steps specify likely expenditures of time and funds for partnership and involve virtually every step of the research process.

- Action step: Involve the community in research planning at the earliest stages. This planning would include choosing focal health outcomes and methods for assessing exposures and outcomes. Implication: Meetings with local health professionals and interest groups before the research plan is finalized, with the correlated expenditure of time and resources.

- Action step: Obtain consent from the community leaders and representatives as well as from individual participants. Implications: Again, additional meetings with community leaders and representatives to discuss the research project and solicit support, with the correlated expenditure of time and resources.
- Action step: Hire community members as field staff and train them to collect data rather than hire already trained personnel from outside the community. Implications: Data collectors must be blind to possible exposure status of participants. To ensure objective evaluation of exposure and outcomes, data collectors must be paired with participants with whom they have little contact or knowledge. Assessment of outcomes must precede assessment of exposure. Budgetarily this means including a data collection coordinator among the budgeted personnel. The coordinator will pair data collectors with participants appropriately to prevent bias in data collection. Second Implication: There must be more funds than usual for training. These would include greater funds for trainers, longer start-up and run-in periods, and more protocol adherence review meetings
- Action step: Keep the lines of communication open and communication flowing in both directions. Implications: The principal investigator (PI) should be in frequent contact with field staff to receive information as well as send it. If the PI is not available, a PI designate with full decision-making power should consistently act as surrogate. An unsatisfactory substitute for the PI would be someone who acts as a buffer between the PI and the field staff or community and who must have each action approved by the PI. Additionally, because face-to-face interactions are preferred by community partners, more frequent meetings would be required, and these involve correlated expenditure of resources.
- Action step: Involve community research partners in communication of research results to the participants. Implications: Meet with community research partners to craft a letter explaining the results in terms that are understandable to participants and in accord with community values and concerns. This may be the final and the most significant step in the research process from the community's perspective. Partnership in this process budgetarily means allowing more staff time for this important task, and more resources to host the requisite meetings.
- Action step: Inform the community, not just the study participants. Implication: Conduct public meetings to disseminate results. Have the community partners take the lead in this effort.
- Action step: Publish the research results for the larger community without deni-

grating the community in which the research was conducted. Share the authorship and work cooperatively in the publication of papers, press releases, and reports.

Implication: Because there are adverse effects of one's community being known as a site where research on an environmental hazard is taking place, include community research partners' contributions to the manuscript at the outset in the preparation stage, and do not seek community input when meaningful rewrites are impossible.

Conclusion

There are barriers to partnerships between communities and biomedical scientists. However, if one wishes to conduct research on important environmental health issues and ones that preferentially affect minority persons, a partnership effort has the ability to bear meaningful results across a range of socially and scientifically significant dimensions. Partnership does not mean abandoning scientific principles or abandoning community respect and integrity. It does mean planning to conduct research in a different way and budgeting for it appropriately. For our project we had more communication than usual, more meetings, more travel, more joint decision making (and a slower decision-making rate), more compromise and trust, and some original solutions to issues of quality control and confidentiality.

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