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SPECIAL ISSUE: CITIZEN SCIENCE, PART I

“We’re not going to be guinea pigs;” Citizen Science and Environmental Health in a Native American Community

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Abstract

Determined to learn the extent to which a local contaminated site was impacting community health, the Native American community of Akwesasne reached out to a research university, eventually partnering on the first large-scale environmental health community based participatory research project (CBPR). Based on interviews with scientists, community fieldworkers, and study participants, this article examines the ways in which collaborating on these studies was beneficial for all parties — especially in the context of citizen science goals of education and capacity building — as well as the challenges they faced, including communicating the limits of what scientific studies could accomplish for the community.

Keywords Citizen science; Community action; Health communication

Citizen Science and CBPR

After decades of traditional health and environmental studies which left many communities — especially low-income and communities of color — feeling disempowered, community involvement in the production of science is being heralded as necessary in the achievement of environmental justice [Wylie et al., 2014; Shepard, 2002; Ottinger and Cohen, 2011]. Citizen science (CS) is broadly defined as partnerships between scientists and lay people (non-scientists) in which data is collected, analyzed, and shared [Irwin, 1995; Jordan, Ballard and Phillips, 2012]. Under the broader umbrella of citizen science, there are varying levels of public involvement in the initiation of the research project, research design, data collection and analysis, and dissemination of results.

In science-education-based CS projects, the public is invited to play a contributory role, taking part in the data collection for environmental or ecologically based projects commonly based out of a university setting [Bonney et al., 2009; Havens and Henderson, 2013]. By involving the public directly in the production of scientific knowledge, this type of CS is intended to help enhance the public understanding of scientific processes — including knowledge gained from the study outcomes as well as data collection and other practical skills utilized by scientists, that will help participants become better contributing members of society [Jordan, Ballard and Phillips, 2012; Riesch, Potter and Davies, 2013].

On the other end of the spectrum, “street science” [Corburn, 2005] and “popular epidemiology” [Brown, 1992] are approaches utilized in community-driven projects in which lay people utilize scientific methods to answer questions about, or draw attention to issues in their communities, often working independent of research institutions. These approaches reverse the order of the traditional contributory CS model and resemble more of a co-created CS project, entailing "community initiation of investigations, gathering of scientific knowledge, and if necessary, recruiting of scientific professionals" [Ramirez-Andreotta et al., 2014, p. 655].

Communities sometimes use street science to initiate more formal research partnerships in CBPR projects — which are co-created between community members and professional scientists, in which power is shared between both parties in all aspects of the research process, and study outcomes benefit the community via interventions and policy change [Ramirez-Andreotta et al., 2014; Brown et al., 2011]. CBPR "begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities" [Minkler and Wallerstein, 2008, p. 7]. In recent years, community/academic partnerships using a CBPR approach have played an important role in bringing attention to, and addressing situations of, environmental injustice [Shepard, 2002].

Unlike the broad-scale nature of many education-based CS projects, CBPR projects are often rooted in a localized issue. Below I will explore how the Mohawk community of Akwesasne utilized popular epidemiology and CBPR to determine the health impacts of environmental contamination on their tribal members; the benefits and challenges to this research; and ultimately what is still to be gained.

Context: Akwesasne

Akwesasne is a Mohawk community of about 15,000 people that shares a border with New York, Ontario, and Quebec. The community is bisected by the St. Lawrence River, which was developed into the St. Lawrence Seaway in 1954. The project included the construction of hydroelectric dams, which brought industry to the area; General Motors (GM), Alcoa, and Reynolds,[1] all of which are just upstream of Akwesasne.

In 1981 two dormant sludge pits filled with polychlorinated biphenyls (PCBs) were discovered behind the GM plant, adjacent to Akwesasne. Until they were banned in 1978, GM utilized PCB-laced hydraulic fluids that were periodically flushed from the plant and disposed of in reclamation lagoons, which were periodically drained and the sludge buried onsite. The lagoons were found to have flooded several times, contaminating the riverbeds of the St. Lawrence River, Raquette River, and Turtle Creek, as well as groundwater [Grinde, Johansen and Zinn, 1995]. The entire 270-acre site was placed on the National Priorities List as a Superfund site in 1984.

That same year, a Mohawk midwife from Akwesasne, Katsi Cook, invited New York State Department of Environmental Conservation (NYSDEC) Wildlife Epidemiologist Ward Stone to Akwesasne to test fish and wildlife in the vicinity of the GM plant. In 1985 he began announcing his results, which he immediately made public, much to the chagrin of the NYSDEC that demanded he follow protocol and have his results approved by the agency before making them broadly

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[1] Alcoa acquired Reynolds in 2000, renaming the site Alcoa East.

available [Anon, 1989]. His tests revealed levels above what was safe to consume;[2] 190 ppm PCBs in a duck, 11 ppm in a sturgeon, and 3,067 ppm in a male snapping turtle. According to Jim Ransom, who worked for the Tribe's Environment Division at the time, "Without Ward, we'd still be thinking groundwater was the major concern. It's not. It's the wildlife and the fish. And the food chain. Stopping the pollution becomes even more urgent " [Andrews, 1989Ruin on the Reservation].

Cook then began to set the stage for scientific studies to demonstrate whether the PCB contamination found in their food source was impacting the health of mothers and their infants. While Cook acknowledges she did not have the credentials of most researchers, she recognized the importance of her position in the community for bringing women's issues to the fore; "I don't have an engineering, environmental engineering degree, I don't have anything like that, but what I do have as a midwife and as a Mohawk woman moving through the small world webs of the community, I would hear this one had a miscarriage, that one over here is sick with this" [Cook, 2008]. Because of this "situated knowledge," [Haraway, 1988] Cook ultimately proved to be one of the "champions" who emerged "to design innovative public participation processes" [Gallagher, 2009, p. 914]. One of Cook's main concerns was whether she should be encouraging mothers to breast feed their babies, as milk concentrates lipophilic pollutants. Mothers had contacted her asking, " 'Gee, Katsi, these scientists are coming to my home taking samples of everything but me. Is it safe to breastfeed?' And I said, 'You know what? I don't really know. I wish I did' " [Cook, 2005].

To answer some of these questions, Cook contacted a chemist at the New York State Department of Health (NYSDOH) about conducting a breast milk study. In 1985 Cook embarked on what she terms "barefoot epidemiology," personally collecting samples of milk from ten nursing Mohawk mothers, and sending them to a private lab in Wisconsin, in addition to the NSYDOH lab, because she did not initially trust the State to give her accurate results.[3] The samples contained PCBs, Mirex, and hexachlorobenzene at levels that the NYSDOH did not think were dangerously high, but warranted further investigation. This initial "street science" study led to a health risk assessment [Fitzgerald et al., 1992], and then two Superfund Basic Research Program (SBRP) grants[4] that supported several research studies designed and carried out in collaboration between the State University of New York (SUNY) Albany and the grassroots organization Akwesasne Task Force on the Environment (ATFE), the first such community based participatory research project of its kind with an indigenous community.

As opposed to traditional health studies in which professional researchers or graduate students collect samples, the Mohawk community insisted that SUNY Albany hire and train local residents for the project. As Cook described, "At the very outset, I demanded that the only way we're going to work with Mohawk women in the precious intimacy of Mohawk mothers' milk is to ensure the mothers

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[2] Chicken containing more than 3 ppm of PCBs is considered unfit for human consumption, and over 50 ppm qualifies as toxic waste.

[3] The two labs returned similar results, and future samples were processed in Albany.

[4] The National Institutes of Environmental Health Sciences (NIEHS) Superfund Research Program (SRP) (prior to a name change in 2009, the program was called Superfund Basic Research Program), funds university-based multidisciplinary teams to conduct research on human health and environmental issues related to hazardous substances [National Institute of Environmental Health Sciences (NIEHS), n.d.].

that they are co-investigators in this study… we're not going to be guinea pigs" [Cook, 2005]. Cook began the First Environment Research Project (FERP) as a means of organizing Mohawk women fieldworkers, and coordinating the data for the health studies. FERP employees collected blood and breast milk samples, and for some studies conducted cognitive assessments, body measurements, and nutritional surveys. The data was sent to Albany for analysis, and in time, a letter was sent back to the participant explaining their individual results [Schell et al., 2007]. Periodically, the SUNY researchers would also host retreats at Akwesasne, where they would present the progress of the studies to the community.

Studies conducted through the first SBRP grant connected levels of PCBs in participants' breast milk and blood to fish consumption [Fitzgerald et al., 1992; Fitzgerald et al., 1998], which decreased as community members began heeding fish advisories published by the Tribal government [Tarbell and Arquette, 2000; Hoover, 2013]. This decrease in fish consumption proved a complex trade-off, as community members and scientists would later cite how the substitution of affordable foods for fish has contributed to other health problems [Schell, Gallo and Cook, 2012].

SUNY Albany and Akwesasne acquired a second SBRP grant (1996–2000), which enabled them to conduct studies that began to document health impacts in community members with higher PCB body burdens. These impacts include abnormal thyroid functioning in adolescents [Schell et al., 2004; Schell et al., 2008; Schell et al., 2009; Schell and Gallo, 2010]; earlier menarche in adolescent girls [Denham et al., 2005]; a greater propensity for diabetes [Codru et al., 2007]; higher levels of total serum lipids, which contribute to heart disease [Goncharov et al., 2008]; affected cognitive function in adolescents [Newman et al., 2006; Newman et al., 2009; Newman et al., 2014]; affected cognitive function in older adults[Haase et al., 2009]; and reduced testosterone levels in men [Goncharov et al., 2009] as well as adolescent boys [Schell et al., 2014]. While data collection ended a decade ago, data analysis has been ongoing, and papers continue to be published.

Methods

In March of 2008, I traveled to SUNY Albany and the NYSDOH to interview seven scientists who had worked directly with the community while conducting health studies at Akwesasne from 1986–2003. I spoke with each of them about their experiences in organizing the study, in working directly with Akwesasne community members, and their ideas about how the studies could have been conducted. From June-November 2008, I interviewed 64 Akwesasne community members, 32 who had been involved in environmental health studies in some capacity. Five of these interviewees worked as FERP fieldworkers, six consulted with SUNY as members of the Akwesasne Task Force on the Environment (ATFE), and the remainder were study participants. The interviews lasted between 45–120 minutes, and pertained to the health studies, perceptions of change in the health and environment of the community, and participants' suggestions for how to improve future environmental health studies. Interviews with scientists and Akwesasne community members were transcribed and then uploaded to two separate NVivo8 files, and coded for themes. Below I have included the names of interviewees who allowed me to do so, and designated those who wished to remain confidential with a number.

Results

Akwesasne community members and scientists came to take part in these studies with slightly different motivations: members of the ATFE and FERP wanted to gather the necessary data to determine the health impacts of neighboring industries, force the industries to clean up, and acquire financial compensation for damages. Researchers at SUNY Albany took part in these studies to not only further their own professional careers, but also help the Mohawk people and other communities affected by PCB contamination better understand the potential health impacts of exposure. The outcome was 47 peer-reviewed publications (which have collectively been cited 863 times)[5] that contributed to the broader scientific understanding of the impact of PCBs on human health. Below I will discuss the benefits accrued to, and challenges faced by, both parties taking part in this project, including issues around understanding and communicating the limitations on the types of answers the research process could provide.

Benefits for the community

The community benefitted from information gained through the research, the education and job skills gained by the FERP fieldworkers, and the grant money spent in the community. This is in part because of the intentions of the academic partners, but also due to stipulations of The Good Mind Research Protocol, an Internal Review Board (IRB) document created by the ATFE Research Advisory Committee that must be adhered to by researchers working in Akwesasne [Akwesasne Task Force on the Environment 1996]. Based on Mohawk cultural teachings, this agreement stipulates that Respect, Equity, Empowerment will be ensured for both parties, which includes practicing cultural sensitivity, sharing of resources, returning information to the community, and including community members as co-authors on publications.

Because of the stipulation that results be reported back to participants, they benefitted from the information they received about the levels of contaminants in their bodies. Many of the study participants (n=10) I spoke with remember being surprised when they received their results, expecting that they would contain higher levels, and pleased when they did not. For example one participant (#14)[6] who had her breast milk tested remembered: “I was thinking it was going to be horrible, but it wasn’t. So I was really happy about that.” Many of these participants described limiting their fish consumption after fish advisories were issued, and before these tests were done, which in all likelihood helped to ensure that their levels were not elevated [Hoover, 2013].[7]

The SBRP grant provided tangible benefits for the community, through the full-time employment and benefits for ten community members, and SUNY purchasing everything locally for their conferences. In addition, SUNY offered two classes on research methods and testing measurements, so FERP employees received college credit while training for their jobs. The training they received in phlebotomy and the administration of various tests were skills that could potentially help

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[5] Citations were found in Web of Science.

[6] All interviewees signed an informed consent form asking if they wanted their names to be utilized in publications, or if they preferred to remain confidential. Interviewees who chose the latter are identified here by number.

[7] 37 out of 50 interviewees who were asked about rates of fish consumption mentioned decreasing it due to fish advisories.

fieldworkers acquire jobs in hospitals. One of the fieldworkers, Agnes, who is now a community health worker, gained her first practical experience in this field through working at FERP. She expressed that she “got a lot out of it. I was in the community, I had a job, I felt I was doing something.”

Beyond these concrete skills, and in line with the broader principles of CS, Dr. Schell from SUNY noted that “a lot of people involved in the Task Force did get some greater exposure to science, to the industry of science, how papers are produced and so on, and to methods of analysis and questions that scientists have.” In addition to just *understanding* science, Schell also described a desire for the community to be *empowered* by these skills: one of the goals of the researchers “was that people in the community would have skills for research methods so that when other researchers would come in and they would be able to say ‘we have expertise too.’ That was kind of the goal.”

There are many research needs identified by indigenous communities — environmental degradation, epidemic health threats, and culturally appropriate economic development to name a few [Castellano, 2004]. Akwesasne Mohawk scholars highlight that “the need for better site- and Nation- specific data emphasizes an important area of research for Native Nations” [Arquette et al., 2002, p. 261]. What is necessary for communities to be able to embark on the research that they see as necessary is the capacity for the community to be able to carry out that research. For the FERP employees who received training to work on these studies, for the ATFE members who consulted on these studies, and for the study participants and community members who learned from the study process and results, this was a step toward that capacity building; “the cultivation and use of transferable knowledge, skills, systems, and resources that affect community and individual level changes consistent with public health related goals and objectives” [Goodman et al., 1998, p. 259]. One participant, Randi, expressed that she now has a greater awareness of chemicals that affect the ecosystem and her body. Being a participant in the health studies and a resident of Akwesasne during this pivotal time in its environmental history has given her the vocabulary to both understand and speak about environmental contamination in a different way than a community who had not been exposed to this form of education. In recent years, Akwesasne has had a number of tribal members return with college educations in the sciences, contributing to an active Tribal Environment Division, and to the health services in the community.

Benefits for scientists

The benefits to the scientists involved in this CBPR project included access to a community that will no longer allow research to be conducted without their input, and better recruitment than they likely would have obtained without the help of Mohawk fieldworkers. As one of the fieldworkers, Trudy, noted, “I believe that’s why our projects were so successful. It’s because they took somebody from here that knows everybody and they sent them out.” FERP employees and ATFE members worked with the SUNY team to ensure that surveys issued in the community were appropriate — to ensure maximum participation and to try to avoid offending people. Dr. Schell expressed that CBPR-framed studies provided better results for the scientist. “I really believe that it worked better when it involves a community, it's better scientific work. And one reason why it is, is because you often get better interviews and of course you're probably going to get more cooperation in terms of people wanting to be in the study, if they're being asked by someone they know and hopefully trust." This idea of "better scientific" work because of community involvement goes beyond the education-based CS goals of increasing "public understanding of science" — scholars like Ottinger argue that science conducted in communities is "likely to be deficient if the insights of the public are not incorporated" [Ottinger, 2013, p. 17].

In addition to the community becoming more educated about science, scientists received an education in working with the community members. Dr. Schell told me that he learned a lot from working on this project, and when I asked for specifics, he included, that among many other things, he learned to listen more, to talk when necessary, and how to communicate better. Another researcher (SS02) who was in the room remarked, "They taught me a lot about their culture and taught me how to look at and perceive things in a different light, in a different point of view." This two-way education was highlighted in an article co-written by Schell and FERP director Alice Tarbell that described the university-community partnership as "an opportunity for researchers to learn as well as teach" [Schell and Tarbell, 1998, p. 838].

Similar to community members gaining greater capacity to take part in and conduct future scientific research, this project increased the capacity of SUNY researchers for community research. For example, Dr. Schell, who led two adolescent studies, went on to conduct an additional study on reproductive health in Mohawk women. David Carpenter, who worked on both SBRP grants, went on to conduct CBPR research with the Yupik on St. Lawrence Island in Alaska [Miller et al., 2013]. At a conference organized by Cook that brought together indigenous communities impacted by environmental contamination [Hoover et al., 2012], the Yupik women present thanked the Mohawk women for "training David so well," on how to work with Native communities. The skills gained in working in Akwesasne will be important in conducting future research with indigenous communities. As Schell notes, "In the future, it seems likely that community willingness to participate in research may not be assumed. Many communities and populations that human biologists want to work with… are politically galvanized and expect more from research that is conducted in their backyards" [Schell et al., 2007, p. 513].

In addition to these beneficial aspects of the collaboration, there were also difficulties that the two parties worked to overcome, including the amount of time each party thought aspects of the study should take, issues of control over what data was collected and how, and how aspects of the study should have been communicated. These are common challenges in CBPR work [Minkler and Wallerstein, 2008; Israel et al., 1998], but with some challenges specific to working in an indigenous community wary of researchers.

Challenge I: time

Both researchers and community members took issue with the amount of time it took to accomplish various aspects of the project. Because this was collaborative — with community input required every step of the way, including in the authorship and approval of research projects — SUNY researchers noted that this project took more time than others they had worked on. Dr. Newman stated that the project took quite a while because it was important "that we work with the community to develop it rather than do what the scientists think we should do. Which was a different focus and it takes a little longer to put together a project that way." She noted that the deadlines she was faced with often came up against the schedules of community meetings, and as a result "output from the study in terms of publications and presentations has been slower than it might be from another population." Dr. Schymura expressed that even though they had better recruitment because of Mohawk fieldworkers, the process was still much slower than other projects she had worked on.

FERP staff mentioned problems with the amount of time it took to return study results to participants. Three interviewees mentioned that the participants they worked with complained about waiting for their results, which for many subjects were meaningless by the time they were returned. As Trudy noted, "they want answers, but like within a month, they don't want to wait for three years down the road to get the answers." Because of difficulties setting up a lab that was certified to return results to participants, some of the samples were held up for participants in the first few years of the SBRP grant. Alice, the FERP director described how "Sometimes it was years before people got their results back, and it was embarrassing... They're [results] irrelevant, and it was embarrassing to us. We would go to the post office, we would go to the supermarket and people would run into us and say, 'where's my results?' Our hands were tied." This was due in part to the newness of this type of report back: labs that were finally certified to return PCB results were now additionally having to run clinical measures like cholesterol tests, which took time. For another study, there were several labs involved in the analyses, and so the results came in pieces, with one of the labs holding out until they received more money to run the tests. When I relayed this information to FERP employees, they suggested that future studies get their labs in order before collecting samples from individuals.[8] In this particular situation, the clock was already running on the time frame designated by that grant for data collection, and so putting off the collection of study results could have led to other time issues. But for future studies, both parties will be aware of the necessary lab specifications at the inception of the study.

Fieldworkers and participants were also hoping to gain information about what everyone's results actually meant in terms of health trends in a much more timely fashion. When it came to analyzing the data, Alice noted that they had five years to collect the data, and then at the end of five years, the funding ran out. The researchers still needed to analyze the data, but this was done at a slower pace, because the money was gone and scientists took on other funded projects. As a result, the analysis "wasn't happening as fast as the collection period was," with the result that some community members were "waiting and waiting and waiting and waiting," as Alice described it, to see what would come out of all of the data. Even though data collection for most of the studies ended in 2000, and the Young Adult data collection ended in 2003, papers linking the community's PCB levels with potential health effects were not published until after 2005, with others still being written.

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[8] Scientists, upon hearing this suggestion, have expressed that while this is a worthwhile goal, research teams will not have the money to "get the lab in order" until the project starts.

One of the researchers, Dr. Newman, addressed this, recognizing that the research process takes longer than most people realize, with often a delay of years between when the data is collected and the reports are produced. While this, and many other communities engaged in CBPR research, insisted on the importance of the community seeing the results before publication, Newman felt that the scientific peer review was important in ensuring that the results and analyses they were giving back to the community were sound and valid:

> The way in science that you accept that something is valid is you go through the peer review process and you have experts review what you have written and say 'okay your conclusions are warranted.' The whole process is incredibly long and not to mention that you have to do your analysis and write it up and submit it and resubmit it and such… it wasn't that we wanted to keep it from them. We wanted to not be just giving, you know, things that were going to be proven invalid because we knew people's lives were impacted. So it was long, so I'm sure they must have felt at some point, and maybe still do, that we didn't give them all the results back, we are still doing that, I have still got students analyzing the stuff and writing it up and I am doing it so it is still coming and it is eleven years later. So I don't see how they could understand that, you know, not being part of the professional community, the academic community. So I hope they don't feel that we've done that.

From this scientist's perspective, delays in study feed back to the community are part of the reality of the scientific peer review process, and reflect the importance of this process in assessing the validity of results. Scientists did not want to return results to the community until they knew they would stand up to scrutiny — to learn there was something wrong with the results and then have to retract them would have negatively impacted the community. However, from the community's perspective, this was too long to wait for information about their health.

Issues of 'ownership' by researchers over particular data can also slow down the rate at which the papers are published. Dr. Schymura described to me how none of the adult thyroid data had been analyzed or published, because one particular graduate student was working on it for his doctorate in Public Health, and "we wanted to wait until he was done so I am envisioning some papers coming out of that." Dr. Carpenter also noted his regret that he as the PI allowed individual research projects to hold on to "their little pots of data" for too long, in an effort to respect their concerns about authorship. "Everybody's always going to write the paper and analyze the data tomorrow. Well, I waited six years… but the problem is, of course, when the funding ends people get other jobs," and then it is even more difficult for them to publish on the data. He regrets that he now has less money to employ students to look at the data, but feels that he has an obligation to the community to learn all that he can from it.

At the same time, ATFE saw value in the production of articles about their case. Schell and colleagues describe that at the inception of the adolescent study they discussed with the community what the product of the research would be, and "we agreed that peer-reviewed publication would be of value to the community. A part of the community's interest focused on the utility of such publications in furthering legal attempts to redress the impact of pollutants in the community" [Schell et al., 2007, p. 521]. Attempts at litigation against GM to date have not been successful because lawyers for the community were not able to prove an absolute link between the contamination and community health. With some of the more recent publications, some community members are again taking up the issue. If further connections between PCB levels and health are determined as additional data is analyzed, this too could be potentially helpful in this cause.

Challenge II: control over data, and distrust of its use

Another area of contention between the research partners was deciding what data would be collected, by whom, and how. Although understood as necessary, it was difficult, and contrary to their training, for the scientists to give equal control over the data to the community. The anthropologist/epidemiologist I spoke with described how field staff would go and collect all of the data. "It was very unlike anthropology, having someone else do your data collection. Would you have someone do your interviews?. . . We had to do that. . . It's a kind of letting go. You can't be a control freak. You have to really channel that control." Even beyond relinquishing control of the data collection, the Good Mind Research Protocol states that if the community feels that harmful data is being collected, they reserve the right to retrieve it and bring it back to the community. This happened to some of the surveys, a Cultural Affiliation Scale, that one of the research projects collected. Although the scale was used without issue in an earlier study, when other community members found about its use for another SUNY study, they became uncomfortable with the scale, demanded that its use cease, and that all data collected with this scale be returned to the community. One woman (26C) remembers it as eight questions, and from these "they could determine how Indian you were, and we didn't like that at all (sarcastic laugh). We made them return them all, and I think they were destroyed. . . We didn't think it was their place to determine peoples' heritage. And that kind of thing could be used against you. It just didn't serve a good purpose."

This distrust towards the possible misuse of results extended to blood as well. Two of the SUNY scientists I spoke with described that when they began to develop a continuation plan for the Superfund project renewal grant, the Mohawks refused to allow for genetic study of any kind. Because the focus of many funding agencies had turned to genetic testing, and their renewal grant did not contain a genetic component, the SUNY team believes that this is why their grant was not renewed. The scientists respected that these were the wishes of the community, but never fully understood why the Mohawks were so opposed to genetic testing. When I interviewed the FERP employees, I asked them why they thought the community was so resistant to this form of study, especially after being party to so many other types of research. The answers were similar to the resistance to the Cultural Affiliation Scale: the government could and would distort and use any information gained from these measures to "prove" somehow that Akwesasne Mohawks are no longer Indians. Not because the community felt that this was true, but because past experiences, especially with the State government, have supported this concern.

One of the fieldworkers, Loralee, described the scenario in terms of government programs that non-Native people thought they no longer deserved on the basis of being a distinct population:

> The big concern among the staff is that there's always been this big push to prove that Mohawks aren't Indian any more. . . because the big thing that

> people would say is "oh, you're not anything special. You've been mixed up with all these other races for so long that there's no such thing as a Mohawk anymore."

She pointed out that it would be difficult to do any kind of genetic analysis on the data they collected anyway, because some of the people who took part in the study were not Mohawk by blood. Some couples included a non-Native, but if they had been living in the community for more than 20 years they were included, since they had been just as exposed as anyone else had. "We figured they are just as exposed as everybody else here. They're eating the same food, drinking the same water so we let them take part too."

Throughout the study, there was the concern that NY State would misappropriate the blood samples in some way. As described above, Cook initially sent the first blood samples to an outside lab, because she did not trust that the NYSDOH lab would give her accurate results. After the SBRP project began, the first batch of blood samples that were sent down to Albany to the Wadsworth Lab and were stored for an extended period of time but not analyzed, which made the community nervous. Alice described the concern in the community: "They weren't letting us have the blood samples, and there was a fear at the time that NY State, the Department of Health, Wadsworth Center is going to use those blood samples for genetic testing. At the time, the Human Genome Project was a big thing and they really wanted Native blood to look at." Because Wadsworth had been storing the samples without analyzing them, likely for reasons discussed above, the community became anxious and increasingly distrustful. FERP decided that the best thing to do would to bring the samples back to Akwesasne. The office had a -8 degree freezer to keep the samples preserved until a course of action around analysis could be set. Over 200 samples were stored there until an epic ice storm struck, during which they lost power, but Alice managed to secure a generator to keep the freezer operating. She was eight and a half months pregnant at the time, but she and another worker, Agnes, took turns going down to the office three or four times a day to make sure the generator had enough gasoline and oil. It was imperative to preserve these samples, because if they tried to go back and re-collect them, the samples would not match the interview data, and an incredible amount of time would be lost. They kept the generator going for five days before making an arrangement with SUNY researchers to meet them at a halfway point, where they handed off the samples and the chains of custody. Shortly after, the lab was able to begin processing the samples.

Once the samples began running, since the serum was the only part of the blood analyzed, Loralee explained that the Mohawks insisted anything left over be destroyed. "So somebody couldn't come in and say 'oh, well, you're not using these red blood cells, I'll just take them for my study,' " thereby conducting research with Mohawk blood that they might not approve of and could prove detrimental to them.[9]

The Mohawk's fear of having their blood misappropriated for unauthorized testing is not unfounded: the Havasupi tribe in Arizona took part in a study focused on diabetes, only to learn their blood samples had been used in research on

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[9] Saliva samples collected for the most recent study on reproductive health were returned to the tribal health center in 2014 for their disposal [Schell, 2015].

schizophrenia and consanguinity, as well as migration theories. The community felt deeply betrayed that they had allowed their blood to be collected for a project that was supposed to help them, and the samples were then used without their permission to conduct a study they did not agree with. Rather than punishing the scientists who had participated in this betrayal, the system rewarded them. The geneticist who was the key person responsible for the misuse of the blood samples was awarded the Presidential Award for Excellence in Science, Mathematics, and Engineer Mentoring, followed by a million dollar NIEHS grant [LaDuke, 2005; TallBear, 2013]. A similar betrayal happened to the Nuu-chah-nulth tribe, who agreed to a study on rheumatoid arthritis, but whose samples were then sent around the world, contributing to hundreds of academic papers on controversial topics such as the spread of lymphotrophic viruses by intravenous drug use, and research on human migrations [TallBear, 2013].

To some scientists, especially those convinced of their own ethics and good intentions, these fears may seem paranoid. Akwesasne is clearly a Native American community, culturally, ethnically, linguistically, politically, and as their membership records with blood quantum requirements would show, "racially." But Akwesasne has a long-standing well-founded distrust of NY State and the neighboring industrial plants. Episodes of direct conflict between Akwesasne Mohawks and the state government are still recent in the community memory, and so the possibility of being maltreated at the genetic level as well does not seem farfetched.

Challenge III: successfully communicating results and science

Study participants eventually received a letter in the mail with their personal results. Some participants expressed to me that they either did not understand the results that were sent back to them, or they expected a great deal more information to come from their results. This disconnect between what they expected to receive back and what they actually received was due in part to the need for additional education around basic science (or an additional level of editing the letters into more publically accessible language), and for others an expectation that the study would deliver information that was simply beyond the limits of science at the time.

Six of the study participants told me that they received their study results through a letter, but they did not really understand what those results meant. As Rob describes "there were a lot of words describing the toxins and stuff like that, levels that I didn't really understand." He was generally able to understand that his levels were not considered high. Joyce described how she received her daughter's results, but thought that the paper sent in the mail "doesn't really tell you very much. You know, they talk like co-genitors [sic] and things like that. I don't know if that was in particular to my daughter's blood sample. . . some of the concepts that they used were, you know, I misunderstood them until somebody took me aside and explained it to me." As a well-educated woman, she was concerned that if she had trouble understanding these results, other community members must have as well. Another woman (23C) got the results of her breast milk sample back but was angry because

> They didn't say 'this is what this means.'. . . I don't know what a triglyceride level is or whatever or this is really high. How do I know?. . . It made me feel

> worse. You get something and people don't help you, don't tell you about it. So it makes me feel bad because what you expect is that somebody is going to show this to you. You participate in this study and then they're going to say 'this is what this means, this is what you should do. This is our advice.'

Many of the individuals who did not understand their study results felt that in future studies, results could be better explained to participants, in a simpler language. One of the FERP fieldworkers who was herself in one of the earlier breast milk studies, felt that the level of clarity of the letters sent back to participants improved over time, as each successive study learned from the one before. In addition to letters, some participants suggested future studies include alternative forms of report back, like having the fieldworkers return to subjects' homes to present results in person, in order to be able to answer any questions about basic science. Funding structures and limitations would have to be expanded to allow for this type of report-back.

Some participants were expecting the report back letter to give them information that was not possible to present at the time — an assessment of their health, not just numbers that held no meaning on their own. Joyce kept mentioning that she was looking for the results to give her "an assessment, overall assessment of what does it mean? You know, what are the long term effects?. . . What's the impact long range on our family? Or, you know, our grandchildren?" Some of the scientists expressed to me that this was one of their greatest frustrations — that the community wanted them to be able to spell out what the contamination meant for the health of individuals and the community, and they could not.

Dr. Fitzgerald — who worked on the earlier studies — expressed to me an understanding of these frustrations in the community, noting that one of the most dissatisfying things about the science that came out of this work,

> . . . was our inability to really be able to determine scientifically and statistically the health impact of the PCB exposure on the community. . . I wasn't able to address what I think is their primary health, primary question which is you know 'how have these PCBs effected my health?' I think I have alluded to the primary problem there was that the Mohawk population is relatively small, so I'm just not going to be able to statistically demonstrate excesses of cancer, but even if you do, be able to relate it to PCB exposure, see that was the basic problem, and also those kinds of studies are very expensive too.

Alice, the director of FERP, expressed similar frustrations, noting that the studies "opened up a lot more concerns and questions without answering some of the basic things." Some of the concerns she mentioned included what level of cognitive delays could be attributed to PCBs, and potential impacts to people's metabolisms and reproductive systems. Unfortunately, with these kinds of questions "technology, at the time, couldn't answer them. I'm not sure we're really ready to be able to understand what that meant." This was frustrating to the community because the studies "raised more questions than we can even answer initially. It kind of shook my faith in the system. I really put my heart and soul into wanting this project to work and to mean something." Alice personally believes that people's health has been affected by the contamination, but

> How do you pinpoint exactly what caused it?. . . Yes, I think people's health is affected. But to what extent, we still can't prove it. You can't make that direct connection, and that's what people wanted to find out, how it's directly affecting themselves. The level of PCB or lead or whatever they had, if you have this then you should have this. I think that had a lot to do with the limitations of technology then. I don't know if they can even do that now or ever. But that was one of the limitations we really couldn't get around.

Little (2009) and the Health Investigations Communications Work Group (2004) both found similar issues among ATSDR scientists regarding the challenges they faced with the communities they were working with misinterpreting the actual ability of environmental health science to create "clean, useful, and evidence-based theories of causation" [Little, 2009, p. 100]. To avoid this disappointment, a

> Considerable amount of work is needed to help community residents understand what a health study can and cannot do, and this effort needs to occur during the planning phase. If this interaction does not occur, community residents may feel that they have been misled when the results and conclusions are presented [White et al., 2004, p. 487].

Many of the papers from the second round of research, which are beginning to show possible connections between PCB levels and health issues, were only published very recently (several after I conducted these interviews). In addition, while they note trends, each of these research papers also cautions that they cannot definitively say that PCBs directly caused any of the illnesses studied, and cannot make predictions for anyone's individual health.

Report back

As demonstrated above, data management and report-back are some of the challenges facing CS and CBPR projects that entail the collection of personal information and biological samples [Quigley, 2006; Foster and Agzarian, 2006].

Reporting results has been controversial because researchers worry about giving back information with uncertain health or intervention implications; critics of report-back have understandable concerns about the emotional and psychological stress for participants who might receive data that does not paint a clear picture of the health implications or outcomes, or how to reduce exposures [Morello-Frosch et al., 2009]. For this reason, some university IRBs have been hesitant to grant approval for projects to report back individual results, as a means of trying to protect subjects from the stress of uncertainty [Brown et al., 2010]. Many IRBs have traditionally allowed aggregate reporting of study results, while discouraging the conveyance of individual information [Morello-Frosch et al., 2009]. For this reason, some researchers who support a "right to know ethic" have complained that there are few models for reporting personal exposures to study participants [Brody et al., 2009]. However, participants often want to know their results, and some researchers have argued that individuals have this right because it is "ethical to return information to the 'owner' of that information" [Quandt et al., 2004, p. 643]. Despite the concerns about stress associated with receiving ambiguous data, researchers who advocate for results report-back found no evidence of harm from participants receiving this information. On the contrary, they found that individual report-back contributed to environmental health education and stimulated behavior change and public involvement [Altman et al., 2008; Brown et al., 2011], and became a tool for public health advocacy [Morello-Frosch et al., 2009]. Knowledge is power, and thus the knowledge gained through research can be used by all partners involved to direct resources and influence policies that can benefit the community [deKoning and Martin, 1996]. As demonstrated above, while the process of reporting results back to participants was impacted by challenges like time, control over data, and issues of communication, ultimately having that information back in the community helped people to feel better informed about their condition and to advocate for further cleanup.

While the discussion about results report back has been ongoing among researchers working in environmental health and biomonitoring, ethical frameworks around informed consent and privacy are now also being developed for broader participant-led citizen science projects [Vayena and Tasioulas, 2013], and studies involving traditional ecological knowledge [Ballard, Trettevick and Collins, 2008; Huntington, 2000].

Conclusion

The GM Superfund site has been undergoing remediation for decades but may finally be nearing completion. After years of fighting with GM over cleanup methods and levels, the St. Lawrence River and Turtle Cove (renamed "Contaminant Cove") were dredged and capped, and the sludge from many of the wastewater lagoons on site was dredged and shipped to an offsite facility. The landfill, which Mohawks wanted excavated and removed, remained and was capped, although there are plans to pull the edge of the landfill back 150 feet from the shore of the St. Lawrence River and reservation boundary. The last of the general site cleanup and restoration activities, including a groundwater management system, will be completed by 2017 [US EPA, 2015].

Despite $49.5 billion in bailout money, GM declared bankruptcy in June 2009, and closed the plant. When it emerged from bankruptcy, GM was freed of responsibility for rehabilitating this and 88 additional toxic waste sites in 13 states where it had manufacturing plants. The new GM, freed of its old liabilities, has re-achieved success in the auto market, while the Mohawk are left living adjacent to an industrial landfill that they suspect will continue to pollute their environment. As long as the federal government sees institutional controls like fish advisories as an acceptable means of protecting humans from exposure to contaminants, the culture around environmental cleanup will focus on risk avoidance by residents, rather than risk reduction by industry [Hoover, 2013]. In the end, not even carefully crafted and conducted health studies pointing to connections between GM's contamination with health impacts in the community has been enough to counter the lack of political and economic will to fully remove the waste.

But, as noted above, despite the challenges that SUNY and the Mohawks faced in working collaboratively, in the end both parties developed greater capacity for future work. In addition, by having members of the impacted community contribute to study design and data collection, this series of studies altered the status quo of environmental health research, incorporating what Cohen and

Ottinger describe as “ruptures” in scientific practice that lead to a more dynamic science [Cohen and Ottinger, 2011]. In doing so, environmental health research at Akwesasne contributed to the development of science more broadly.

In moving citizen science forward, a number of lessons can be applied from this case study at Akwesasne. In many CS projects, the pool of participants is not as diverse as it should be [Pandya, 2012]. Members of underrepresented communities may not feel invested in, or welcome to the project, or may not have the financial means to take part [Evans et al., 2005]. Projects like the environmental health research studies at Akwesasne, in which the community was involved in nearly every step of the research process from inception to publication, fits a framework currently being developed in CS that focuses on inviting community members to be partners in defining research questions that advance both community priorities and scientific goals [Pandya, 2012]. Agreeing from the beginning on what types of research questions can answered, involving community members in the collection and processing of data, and then working together to select the most effective method of reporting that data back to the broader community will go a long way towards ensuring that both scientists and community members will benefit from research.

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