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Whose citizenship in "citizen science"? Tribal identity, civic dislocation, and environmental health research

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Introduction: Citizen science

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 for the achievement of environmental justice (Shepard 2002; Cohen and Ottinger 2011; Wylie et al. 2014). Citizen science (CS) is broadly defined as partnerships between scientists and laypeople (non-scientists) in which data is collected, analyzed, and shared (Irwin 1995; Jordan et al. 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 focused 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 citizens, better contributing members of society (Jordan et al. 2012; Riesch et al. 2013).

At the other end of the spectrum, "street science" (Corburn 2005) and "popular epidemiology" (Brown 1992) are approaches utilized in community-driven projects in which laypeople 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, 655).

Communities sometimes use street science to initiate more formal research partnerships in CBPR (community-based participatory research) projects, or what Woolley et al. (2016) have called "extreme citizen science." These projects are co-created between community members and professional scientists, a process in which power should be shared between both parties in all aspects of the research process, and study outcomes benefit the community via interventions and policy change (Brown et al. 2011; Ramirez-Andreotta et al. 2014). 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, 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. In the Native American community of Akwesasne, which I will describe below, participatory research that stipulated the collection of scientific data by tribal members was utilized to determine the health impacts of environmental contamination. The series of environmental health research projects conducted in this community faced a number of challenges as a result of the need for collaboration between parties with very different backgrounds and knowledge experiences, but also benefited both the scientists and the community members who took part.

But who constitutes the "citizen" in citizen science has generally not been considered critically. "Citizens" have been conflated with volunteers, amateurs, or "members of the general public."[1] Ostensibly, this is anyone who is not a scientist. The noble intention behind many citizen science projects is to create a nation with a more educated citizenry, which will then in turn support scientific principles and projects.

In writing about how the citizen in CS can be theorized, Leach and Scoones (2005, 16) note that we need to "embrace a more fluid, decentered and

experience-based notion of both citizenship and expertise, but without losing sight of the historical, political and institutional structures that shape often highly contrasting forms of engagement." They cite differing perspectives from which the role of the citizen can be defined, starting with the "liberal perspective," which sees the state as the benevolent protector of individuals, protecting them against major risks, utilizing science to guarantee their safety through food safety regulations and pollution risk management. "Liberal understandings of citizenship thus hold faith in the modern state's expertise, and science has become its core currency in the technology arena" (Leach and Scoones 2005, 22). But as we will see below in the case of the Mohawk community of Akwesasne, the state – as exemplified by New York state and US federal entities – bases standards and enforcement on what is economically beneficial for industry, rather than the protection of Indigenous people, thus not guaranteeing their safety. Participatory development attempted within this framing usually entails individuals choosing among an array of options and services, without playing a major role in setting policy agendas. The "communitarian perspective" centers on the notion of the socially embedded citizen and membership of a community, in which individual identity is subsumed to that of the group, and the common good is prioritized over individual interests, with the state appearing more distantly if at all. Communities are often seen as bounded and homogeneous with people acting toward a common goal (Leach and Scoones 2005, 23). And the "civic republican perspective" bridges the liberal and communitarian perspectives, situating individuals as part of collectives that press for claims in the political realm. Leach and Scoones (2005, 24) note that people will factionalize based on interests, and so citizenship is thus related to a common civic identity based on common public culture, and individual obligations to participate in communal affairs. "Civic republican thought generally assumes that nation-states provide the organizing frameworks for political dialogues, and by implication the epistemological basis for such interactions" (Leach and Scoones 2005, 25). In the case of the collaborative research at Akwesasne, the organizing framework of the dominant nation-state occasionally came up against that of the tribal government, as well as that set by the community organization Akwesasne Task Force on the Environment (ATFE), as tribal citizens often took diametrically opposing views to clean-up solutions from those of their non-Native neighbors.

But as political scientist Sarah Marie Wiebe (2016, 60) notes, "Western liberal notions of citizenship that separate land from life and that blame individual citizens for their health and well-being" diverge from Indigenous values and beliefs. Notions of citizenship have always marked the threshold between inside and outside of political life. Wiebe calls for an intersectional interpretation of citizenship, that moves beyond binaries and rethinks citizenship as

inherently ecological, based on reciprocal relationships between human and more-than-human worlds. Along these lines, she describes ecological citizenship as illuminating the inherent deep-seated interconnection between human and more-than-human life. In her work with the Anishinaabe of Aamjiwnaang, an Indigenous community faced with an abundance of petrochemical pollution, Wiebe (2016, 121) explains that an Indigenous approach to "ecological citizenship" can be understood through the words, actions, and practices of citizens trying to maintain their Indigenous way of life. For Native people, she notes, "citizenship is corporeal, territorial, and practiced. It cannot be separated from consideration of land, treaties and the environment" (Wiebe 2016, 124).

Each of these theories conceptualizes "citizen" as a category of participation. But what does it mean to be a "citizen," as distinct from a professional scientist, and what about when Indigenous citizen scientists do not necessarily feel they share nationhood and citizenship with the scientists with whom they are working? The case study of Akwesasne explored below gives us the opportunity to consider how environmental justice differs for tribal communities as opposed to other ethnic or racial minority communities, and what "citizen science" means for citizens of a tribal nation, where participants are contending with citizenship identities across tribal, state, and federal governments.

Environmental justice and research in Indian country

In the United States, Native communities live in close proximity to approximately 600 Superfund sites, and environmental mitigation for these communities lags significantly behind that for non-tribal communities (United States Environmental Protection Agency 2004). Sites ranging from industrial plants to mines to military bases – as well as places affected by the release of pesticides and other agricultural by-products – have negative effects not only on their surrounding environments but also on the health and cultures of the Indigenous communities they border (LaDuke 2005). But although Indigenous people have made important contributions to the environmental justice (EJ) movement, when the study of EJ is applied to a tribal context, environmental issues cannot be contemplated apart from a recognition of American Indian tribes' unique cultural, historical, political, and legal circumstances (Ranco et al. 2011). As Potawatomi philosopher Kyle Whyte (2017) notes, settler colonialism actively works to disrupt Indigenous abilities to maintain relationships with other-than-human communities, destroys Indigenous food systems, and overall denies Indigenous communities the ability to maintain an adaptive capacity in their homelands. On a legal and political level, geographer Ryan Holifield notes,

"Environmental justice in Indian country is intimately bound up in the complex matter of tribal sovereignty," which differentiates EJ cases in these communities from those in other racial or ethnic communities (Holifield 2012).

Mohawk midwife Katsi Cook highlighted this important difference between American Indians and other EJ groups in a keynote speech she delivered to environmental health researchers in 2015:

> It's important to understand that North American Indigenous are not a racial or ethnic minority, but are one of three sovereignties in the United States. These are the federal, state and tribal levels of government. And so our traditional cultural property is protected by whole body of case law and Supreme Court decisions, treaty rights, and has significance for the work that's being done to recover our community from this historic moment of the post-WWII economic boom and the development of the St Lawrence Seaway. (Cook 2015)

Any consideration of environmental issues in Indian country needs to take into account the unique colonial history of Native Americans and the relationship that tribes have with the United States. A tribe is not simply another ethnic minority group; tribes are also sovereign nations, with their own governments, courts, laws, healthcare systems, and citizenship rules. In many Native communities, tribal police enforce tribal laws and patrol borders. Healthcare for tribal nations is generally delivered through tribal clinics, primarily funded by the Indian Health Service, or by traditional healers. Tribal enrollment offices keep citizenship records, determining eligibility based on each individual tribe's stipulations that may include a specific blood quantum, lineal descent from a particular tribal register, and/or clan membership, or any combination of the above. Tribal institutional review boards determine whether or not research can be conducted in some Native communities. Recognizing that CBPR cannot be conducted in exactly the same way in tribal communities as in other communities, researchers in the fields of cancer research, public health, psychology, and environmental health have laid out key principles for conducting CBPR in Native communities (Schell and Tarbell 1998; Fisher and Ball 2003; Burhansstipanov et al. 2005; LaVeaux and Christopher 2009). Researchers must also consider these communities' particular contexts and histories.

For a number of racial and ethnic minority groups in the United States, mistrust of research is rooted in a general mistrust of mainstream society, where exploitative or unethical treatment remains a serious problem (Lex and Norris 1999; Epstein 2007). Historically, research conducted on Indigenous peoples has served to advance "the politics of colonial control," which is often obsessed with classifying and labeling Indigenous peoples in an attempt to "manage" them (Cochran et al. 2008). Research studies conducted on Native Americans have

often been exploitative and have not contributed to community empowerment. In many cases, researchers have entered with pre-developed projects, failed to ask for community input, pressured people into taking part, treated Native people as subjects or informants and not as colleagues, sensationalized problems in the communities in their publications, and used Native people's blood samples for unauthorized projects (Schnarch 2004). Among the negative views that community members have expressed are that researchers receive career advancement from their studies of tribal communities, while the communities themselves get poorer; that researchers are disrespectful of cultural practices; that research studies are actually designed to harm Indians; that participation in disease studies may cause the disease to manifest in one's family or the community; and that the benefits of studies rarely reach tribal members. Many complain that results are not shared with the tribal community, or, if they are, they are presented in a way that is too technical to understand (Morton et al. 2013; Burhansstipanov et al. 2005). Overcoming this legacy of past research projects is one of the difficulties that researchers now face when they embark on studies to explore and address community problems. It is for this reason that CBPR research specifically, which actively engages tribal community members, is the only type of research that some communities will allow.

Akwesasne

Akwesasne is a Mohawk community of about 15,000 people that shares a border with New York, Ontario, and Quebec. Because of the myriad borders that crisscross Akwesasne, residents must contend with two federal, three state/provincial, and three tribal governments, along with all of their accompanying agencies. If they step off either end of the reservation, they are also dealing with two different New York counties, Franklin County and Saint Lawrence County. Children in Akwesasne have the option of attending public schools on either side of the international border (or the community-based Akwesasne Freedom School), and many have dual US and Canadian citizenship in addition to their tribal citizenship.

The southern portion of the community is governed by the St Regis Mohawk Tribe (SRMT), the elected tribal government recognized by the US federal government. The Mohawk Council of Akwesasne (MCA), the elected tribal government recognized by the Canadian government, governs the northern half of the community. A third governing body, the traditional clan-based government empowered by the Haudenosaunee Confederacy, the Mohawk Nation Council of Chiefs, considers the entire territory of Akwesasne as its jurisdiction,

although it is not recognized by either the US or the Canadian federal governments. Each of these tribal governments maintains separate tribal registers, and their affiliated citizens carry membership identity cards. Most Native American communities are jurisdictionally challenging, but Akwesasne is exceptionally so.

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[2] – all of which are just upstream of Akwesasne. While it is the responsibility of state and federal agencies, as well as the industries themselves, to monitor these industrial plants to ensure they are not harming the local environment, this was often not the case. Over the years since the GM foundry was established directly adjacent to the Raquette Point portion of Akwesasne, Mohawk people attempted to report issues related to the plant to the New York State Department of Environmental Conservation (NYSDEC). But rather than holding GM responsible, the state often wrongly blamed Mohawks for the problems. In the early 1970s, when the open dumps at the GM site spontaneously combusted, state agencies blamed Akwesasro:non (people of Akwesasne) for setting the fires. In 1972, a nurse at Akwesasne's medical clinic reported to regional environmental officers that open dumping and burning were taking place at the GM site, within 450 feet (137 meters) of Mohawk homes. The district health department director's comment was that "Indians did all the burning at the dumpsite," which angered community members that Mohawks were being blamed for the reactions of chemicals dumped by GM (Cook and Nelson 1986, 6). The slowness of response from state agencies led someone to call the US Environmental Protection Agency (EPA), which acknowledged GM's illegal dumping (Cook and Nelson 1986). Even as NYSDEC acknowledged that GM was operating a landfill in violation of New York law, the director of the state's Division of Solid and Hazardous Waste conceded that it was only one of 300 illegal landfills in New York at the time (Andrews 1989). The GM landfill remained open, without a permit, for another six years after NYSDEC discovered the problem, and continued to contaminate the environment.

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 in the unlined landfill. The use of the lagoons was intended to prevent the direct contamination of the rivers, but the waste overflowed into the St Lawrence at least seven times between January and September 1982 alone, contaminating the beds of the St Lawrence River, the Raquette River, and Turtle Creek (Grinde et al. 1995). GM also had an outfall that discharged into the St Lawrence River that led to sediment contamination, especially in Turtle Creek ("Superfund" 12).

In addition to the lagoons, in December 1981, NYSDEC found the groundwater on the GM property to be contaminated with PCBs (polychlorinated biphenyls), heavy metals, chromium, mercury, and cadmium. A month later, tests found PCBs in the 220-foot-deep private well of Raquette Point residents Tony and Ella Cole. Rather than hearing directly from regulators, Mohawks found out about these tests through articles in the local newspaper. NYSDEC blamed the breakdown in communication on the fact that although the GM plant is adjacent to Akwesasne, the plant is in Saint Lawrence County, which is in NYSDEC Region 6, while Akwesasne is in Franklin County, in NYSDEC Region 5. This failure of both industry and regulatory agencies to communicate with the community, coupled with a general distrust of many of the institutions that were tasked with ensuring the environmental health and safety of people in the region, led to the development of the community organization Mohawks Agree on Safe Health (MASH), which was founded in an attempt to ensure that health-related information was reaching residents and that their needs were properly represented.

The 270-acre General Motors site was nominated to the National Priorities List as a Superfund site in the fall of 1983 and was placed on the list in early 1984. That same year, a Mohawk midwife from Akwesasne, Katsi Cook, invited 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, revealing levels above what was safe to consume:[3] 190 ppm (parts per million) PCBs in a duck, 11 ppm in a sturgeon, and 3,067 ppm in a male snapping turtle (Andrews 1989).

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, 914). One of Cook's main concerns was whether she should be encouraging mothers to breastfeed 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 10 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.[4] The samples contained PCBs, Mirex, and hexachlorobenzene at levels that the NYSDOH did not think were dangerously high, but that 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[5] 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 the study is designed entirely by outside scientists, and professional researchers or graduate students collect samples, the Mohawk community insisted from the beginning of this research that they be included as equal partners, and 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 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.

In 1987 MASH merged with a new group, the Akwesasne Task Force on the Environment. The purpose of ATFE, which is still active today and has become well known as an Indigenous grassroots environmental organization, is to bring together representatives from all three tribal governments in the community of Akwesasne, as well as any community members who want to attend meetings and be involved. The New York state and US federal governments had procedures in place for working with the federally recognized St Regis Mohawk Tribe (SRMT), but in a politically complicated community like Akwesasne, this meant that a number of stakeholder voices were not being formally included.

ATFE was developed to reach across these different political lines to create a united front, a unified community voice, that would represent the best interests of all Akwesasro:non. Because ATFE is removed from the political process, it can both advocate for community-based solutions to environmental issues and ensure that researchers do not "take advantage of intra-tribal differences" (Akwesasne Task Force on the Environment 1996, 95).

ATFE also established a Research Advisory Committee and developed the Good Mind Research Protocol to ensure that any research conducted in Akwesasne is to the benefit of the residents there. The goal of the advisory committee is to help ensure that the proposed research will benefit the whole community, give the people of Akwesasne opportunities to be involved in decision-making processes during the research, and empower those involved through education, training, and/or authorship.

As detailed in the Good Mind Research Protocol, a research team must begin working with ATFE in the earliest stages of study planning, so that community members have sufficient time to thoroughly review and understand all aspects of the proposed research. The research team must submit a synopsis of the project that includes information about the methods that will be employed, how the project results will benefit or harm the community, how confidentiality will be protected, how data will be stored, and how study participants and the community at large will be fairly compensated through grant money and shared authorship.

While the community was coalescing to develop grassroots organizations that could operate outside the political system, the SRMT government was also working to improve its own capacity to deal with the environmental situation. The SRMT Environment Division grew out of a single position sponsored by the federal Indian Health Service, which then developed over the years into a large division with departments devoted to air quality, brownfields, solid waste management, water resources management, wetlands protection, Natural Resource Damages Assessment, hazardous materials, and Superfund oversight.

In 1980 and 1984, the EPA adopted official Indian policies that aimed to allocate more responsibility for the development of environmental standards to qualified tribes (Du Bey and Grijalva 1993–1994). These were then followed by amendments to federal legislation. In October 1986, the Superfund Amendments and Reauthorization Act added Section 126 to the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA), directing the EPA to treat qualifying tribal governments substantially the same as states for specified provisions of CERCLA. A qualifying tribal government is one that is federally recognized, has a governing body with authority to protect the health and welfare of tribal members and the environment, and has jurisdiction over

the site where CERCLA actions are contemplated.[6] Under this law, the SRMT now had authority over the contamination that had left the GM site and flowed onto tribal land (Du Bey and Grijalva 1993–1994). In 1987, amendments to the Clean Water Act allowed the EPA to delegate programs for establishing water quality standards to tribes, and 1990 amendments to the Clean Air Act allowed similar reallocation for air quality standards (Du Bey and Grijalva 1993–1994). Because of this series of amendments, when it comes to cleaning up Superfund contamination on tribal lands, tribal "applicable or relevant and appropriate requirements" (ARARs) are treated consistently with state requirements – meaning that if a tribe adopts standards that are stricter than those put in place by the federal government, the portion of clean-up that affects reservation land must meet the stricter standards.[7] In 1989, the SRMT developed ARARs for PCBs of 1 ppm for soil and 0.01 ppm for sediment, numbers far lower than the state and federal standards that were applied on land outside the Tribe's jurisdiction (1 ppm for sediment and 10 ppm for soil).[8] In reflecting on the process through which the Tribe chose the standard, Jim Ransom stated: "When we set the Tribal ARAR for PCBs, we recognized that it had to be scientifically and technically achievable. Our preference would have been zero. However, our lawyers advised that this would not meet technological requirements."[9] Because of the SRMT's status as a federally recognized tribe, and thereby a sovereign entity, the EPA was bound by law to follow the stricter standards for clean-up on Mohawk land.[10]

That the Mohawks were pushing for stricter standards than those applied to the general public was a recognition of the differences between the average American and the Mohawk tribal citizen. As members of the ATFE note, Akwesasne's cries for environmental justice were brushed aside by government agencies who stated that Akwesasne was not being treated any differently than any other community, ignoring that Mohawk people and culture are "unique." They write:

> Akwesasne, like many other Native communities, needs additional consideration and more stringent remediation. Standards and regulations have been tailored to meet the needs of industrialized society, not subsistence cultures and endangered peoples. These standards are often minimalist in nature and do not begin to address special tribal rights. Conventional risk assessments which drive remediation are severely limited in their application to Native peoples because they fail to adequately value cultural, social and religious factors as well as sovereignty, treaty rights and issues of self determination. (ATFE 1997, 272)

For this reason, the SRMT Environment Division worked to enforce stricter clean-up standards than the EPA would ordinarily impose.

Residents of the neighboring town of Massena and the Tribe had diametrically opposed positions on this clean-up. The tribe called for the landfill to be excavated to prevent any further exposure of Mohawk people in the future, and Massena residents called for it to be capped, concerned that too great a financial hardship would cause GM to lay off more workers. During a Public Meeting held in Massena on April 25, 1990, several Massena residents bristled at statements made by Akwesasro:non, and the descriptions given by EPA staff, arguing that their town should not be described as "an industrial wasteland," "a chemical wasteland," or "an environmental wasteland" ("Public Meeting," 1990, 38, 84). Instead, Frank Alguire, Director of the Massena Economic Development Council, called for a "factual, scientific and objective approach to the issues. We need to, if we can, separate emotion and politics from our task at hand," which he saw as remediating the site in the least economically detrimental way possible ("Public Meeting," 1990, 84). Since their culture and livelihood had not been disrupted to the same extent as their Mohawk neighbors downstream, but rather relied on the presence of employing industries in the area, Massena residents downplayed, and took offense at, the characterizations of environmental contamination, and thus advocated for very different clean-up strategies and results.

But for Akwesasne Mohawk people, there was no separating emotion and politics from the task of pursuing environmental remediation. At another public meeting a year later, Jim Ransom, who at the time was on the staff of the Tribe's environment division, and a member of the Akwesasne Task Force on the Environment, beseeched the EPA and GM staff to think of the land as a human relative suffering from cancer, describing the waste dumps as cancerous lumps in our earth mother's breasts that needed to be removed.[11] Mother Earth and her other-than-human children that Jim describes were not included in the agency's health risk assessment – most conventional risk assessment processes do not consider this extended system of non-human relatives. For this reason, the Akwesasne Task Force on the Environment (ATFE) has been critical of these processes, expressing that "all peoples, including plants, animals and the earth herself must be included in defining environmental justice" (ATFE 1997, 268; Tarbell and Arquette 2000, 95). Conventional risk assessments are severely limited in their application to Native peoples "because they fail to adequately value cultural, social, subsistence, economic, and spiritual factors" (Tarbell and Arquette 2000, 102). As Whyte's (2013) work in Indigenous communities highlights, this includes the way in which the relational responsibilities between these communities are not valued or taken into consideration when conducting these conventional assessments. This is the type of "ecological citizenship" described by Wiebe (2016) that is rooted in place and extends to other-than-human elements.

Studies conducted at Akwesasne through the first Superfund Basic Research Project grant connected levels of PCBs in participants' breast milk and blood to fish consumption, which decreased as community members began heeding fish advisories published by the tribal government. 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. 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; earlier menarche in adolescent girls; a greater propensity for diabetes; higher levels of total serum lipids, which contribute to heart disease; affected cognitive function in older adults; and reduced testosterone levels in men, as well as adolescent boys. While data collection ended a decade ago, data analysis has been ongoing, and papers continue to be published. (For full citations of all of the studies connected to each of these results, see chapter 2 in Hoover 2017a.)

Methods

As part of a broader project on environmental health research in Akwesasne (see Hoover 2017a), 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 to 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 to November 2008, I interviewed 64 Akwesasne community members, 32 of whom 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 and 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. This research culminated in a book (Hoover 2017a) and several articles (Hoover 2013, 2016, 2017b; Hoover et al. 2012, 2015). While these other publications

go into greater detail regarding the results of this research, this chapter details some of the challenges that came out of the environmental health citizen science research because tribal subjects and fieldworkers recognized that they held different cultural and citizenship affiliations from university and government researchers, as well as regulators.

Benefits and challenges

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 as of May 2014)[12] that contributed to the broader scientific understanding of the impact of PCBs on human health.

There were a number of benefits accrued by scientist researchers, community partners, and Mohawk fieldworkers (see Hoover 2016). For community members, this included information gained through the research, the education and job skills gained by the FERP fieldworkers, and the grant money spent in the community. Several participants were happy to receive their individual results and to find that their blood did not contain levels of contaminants that were as high as they thought they would be. Fieldworkers benefited from full-time employment and the classes they received on research methods and testing measurements, which resulted in some of the fieldworkers finding employment after the studies ended. The scientists benefited from being included in a project that allowed them access to a community that will no longer allow research to be conducted without their input. A greater number of participants were also likely included in the studies because of the role of Mohawk fieldworkers. Scientists also stated that they received an education about Indigenous communities as a result of being part of this study. At the conclusion of the SUNY SBRP studies, scientists have gone on to conduct research with Indigenous communities in Alaska (Miller et al. 2013), and continue to do research with Akwesasne Mohawk people (Gallo et al. 2016).

In addition to contributing to the capacity development of the scientists and community members who worked together on these health studies, environmental health research at Akwesasne also served to benefit the development

of science more broadly at a time when CBPR was just beginning to become a standard of community research. Science and technology studies scholars Cohen and Ottinger (2011) offer a theory of how science and engineering can change through "ruptures" in the routines of scientific practice. Because they are often viewed as static, scientific knowledge, institutions, and experts are sometimes excluded from accounts of the transformative nature of environmental justice work, but "environmental injustice is an important source of ruptures in technical practice, and thus a powerful force for the transformation of science" (Cohen and Ottinger 2011, 4). Creating a more dynamic research environment and relationship in which community members shape study design as well as data collection and analysis and continue to provide feedback and ask questions allows for "transformations" that "grow out of routine ruptures in everyday technical practices, where scientists and engineers have room to make new choices about how to do their work" (Cohen and Ottinger 2011, 4). By having members of the affected community contribute directly to study design and data collection, the Akwesasne SBRP studies altered the status quo of environmental health research. By refusing to remain on one side of the researcher/subject divide, Akwesasro:non brought environmental health research into discussions about tribal sovereignty, forever changing how this type of work will be done in this and other tribal communities.

However, there were also distinct challenges faced by community and scientific partners as a result of working together in this study, including over what data would be collected, by whom, and what could then be done with that data. 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, to "citizens." 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 out 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 [sar-

castic 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 about the possible misuse of results extended to blood as well. Two of the SUNY scientists I spoke with described how, 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. Regardless of the citizenship rules applied by the tribal governments in Akwesasne, the concern was that outside government entities would work to discredit these affiliations – not because the community felt that this was true, or had any doubts about their own "Indianness," but because past experiences, especially with the state government, have supported a concern that outsiders would use any tools at their disposal to disenfranchise the community.

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. "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 New York state would misappropriate the blood samples in some way.

As described above, Cook initially sent the first blood samples to an outside laboratory, 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 were stored for an extended period of time but not analyzed, which made the community nervous. A FERP fieldworker named 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, the community became anxious and increasingly distrustful. FERP decided that the best thing to do would be 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 over the samples and the chains of custody. Shortly after, the lab was able to begin processing the samples.

Since the serum was the only part of the blood analyzed, once the samples began running, the Mohawks insisted anything left over be destroyed. The reason, Loralee explained, was "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 Mohawks might not approve of and that could prove detrimental to them.[13]

The Mohawk tribe'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 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 citizenship records with blood quantum requirements would show – "racially." But Akwesasne has a long-standing, well-founded distrust of New York 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.

Civic dislocation

Throughout the clean-up process, their interactions with the state and federal agencies reaffirmed for members of the Akwesasne community their impression that these entities were not working in their best interest. In many instances, Mohawks experienced what Sheila Jasanoff calls "civic dislocation," which she defines as

> a mismatch between what governmental institutions were supposed to do for the public, and what they did in reality. In the dislocated state, trust in government vanished and people looked to other institutions … for information and advice to restore their security. It was as if the gears of democracy had spun loose, causing citizens, at least temporarily, to disengage from the state. (Jasanoff 1997)

The dislocated state is characterized by a breakdown in communication between the government and its citizens, and doubt that the government is playing the role it should of protecting the public "against the complex uncertainties of the modern condition" (Jasanoff 1997, 223). Without the ability to assure the public of this protection, public institutions lose legitimacy, and other entities sometimes step in, or are created, to ensure safety. Akwesasro:non have had a contentious relationship with New York state and the US federal government for more than two centuries, and this was further compounded by the lack of support they felt they were receiving for the clean-up. Of the Akwesasne community members I interviewed, several articulated a general distrust of the state

and federal governments, and others took the view a step further with the belief that these entities were actively working to undermine Akwesasne.

Like other communities fighting for environmental justice, Akwesasne suffered through mitigation politics, fighting against a powerful corporation whose main goal was to protect its bottom line, and working both against and alongside state and federal agencies – agencies that were in many cases underfunded, understaffed, and mired in bureaucracy, and whose interests were sometimes influenced by industry. What made Akwesasne different from other communities fighting similar corporate powers was that, as a tribal nation, the Saint Regis Mohawk Tribe had federally ensured rights and powers to dictate clean-up levels on tribal land, and to have a seat at the table negotiating the site clean-up. Given the previous two and a half centuries of history in which Mohawks clashed with settler colonial powers regarding jurisdiction over and governance of the Akwesasne Mohawk community, that they were able to develop and assert their own environmental governance, and then collaborate with entities in New York state, is indeed impressive and important.

Conclusion

What does it mean to be a "citizen," as distinct from a professional scientist, and what about when citizen scientists do not necessarily feel they share nationhood and citizenship with the scientists with whom they are working? As described above, citizenship at Akwesasne is complicated. Many of these citizen scientists are tribal citizens first. The Akwesasne Task Force on the Environment worked to bring together people from all of the various political entities in the community to form one grassroots organization that would govern research at Akwesasne. The Mohawks who founded this organization, which includes both professional scientists and amateur scientists, sought to work toward the broader goal of a healthier community and a cleaner environment. They fought against the distinctions of "citizen" and "scientist" – as noted above, Katsi insisted that women did not need to have degrees to be trained in data collection, and "there's not going to be any one of you researchers that stand taller than the Mohawk mothers." The binaries between citizen and scientist, between subject and researcher, were blurred through this research process (as Katsi insisted, "We're not going to be guinea pigs"). This is just one more way in which Akwesasne as a case study in CBPR and citizen science leads us to intentionally consider the social, cultural, and political processes that structure research in an Indigenous community.

Political scientist Kevin Bruyneel (2007) refers to this resistance to existing solely inside or outside the system as a "third space of sovereignty." Similar

to Indigenous nations that have for centuries demanded rights and resources from the settler state while also challenging its impositions on them, Mohawks resisted the binary of researcher/subject, citizen/scientist, to create a third space of sovereignty in the context of research, in which they refused the subjugated role to which communities under study are commonly relegated. Through the creation of the ATFE Research Advisory Committee (RAC), Akwesasne community members took a position of authority in the research process. They did not reject the institutions of science altogether, recognizing the need for this type of knowledge. But neither did they agree to a conventional research study. Instead, they created the ATFE RAC, a new community governance body, and developed a hybrid research model that has in recent years been emulated in increasing numbers of community-based research projects. Within this third space, Mohawks and SUNY researchers navigated the challenges of different identities, loyalties, and affiliations, and created room for a new research culture at the beginning of the CBPR movement.

But at the same time that Mohawks were fighting for this blurring of the lines between citizen and scientists, as well as for a recognition of the different experiences they held as citizens of a tribal nation, they were also fighting for a recognition of ecological citizenship, for a recognition that maintaining a Mohawk way of life requires reciprocal relationships with other-than-human elements to whom citizenship rights need to be extended as well. As ATFE members describe, "Conventional risk assessments are severely limited in their application to Native peoples because they fail to adequately value cultural, social, subsistence, economic, and spiritual factors" (Tarbell and Arquette 2000, 102). Mohawk philosophy espouses a precautionary approach, a paradigm of holistic, risk-based decision making, which is more protective of a wider range of "citizens" under an ecological citizenship mode.

Notes

1 OED Online, s.v. "citizen." www.oed.com (accessed February 21, 2017).
2 Alcoa acquired Reynolds in 2000, renaming the site Alcoa East.
3 Chicken containing more than 3 ppm of PCBs is considered unfit for human consumption, and over 50 ppm qualifies as toxic waste.
4 The two labs returned similar results, and future samples were processed in Albany.
5 The National Institute 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.).

6 H.R. 2005 Superfund Amendments and Reauthorization Act of 1986, https://www.congress.gov/bill/99th-congress/house-bill/2005. See also Du Bey and Grijalva (1993–1994).
7 US Environmental Protection Agency, "Applicable or Relevant and Appropriate Requirements (ARARs)," https://www.epa.gov/superfund.
8 Saint Regis Mohawk Tribal Council, Resolution No. 89-19, "A Resolution of the Saint Regis Mohawk Tribal Council Adopting Ambient Standards for PCBs on the Saint Regis Mohawk Reservation," 1989, cited in Lewis and DelVecchio (2007). As a side note, all of the land contaminated by GM is Mohawk territory and considered within the land claims territory. However, for legal purposes, the Tribe's standards for PCB clean-up could be applied only to land technically within the current boundaries of the reservation.
9 Jim Ransom, e-mail communication with author, June 9, 2015.
10 George Pavlou, associate director for New York programs for the EPA, stated at a public meeting held April 25, 1990, regarding the GM Central Foundry Division Superfund site in Massena: "Please bear in mind that EPA Regulations recognize that the Tribe is a sovereign state and require that we apply their standards for any cleanups that we undertake on Akwesasne lands. The law is very specific in requiring EPA to apply the more stringent requirements be it State or Federal for Superfund cleanups." See "Public Meeting" (1990, 6).
11 For full quote, see Hoover (2017b, 9).
12 Citations were found in Web of Science.
13 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).

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