Vampire Projects or Long Ago Person Found? A History of Genetic Research in First Nations Communities

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Genetic research of Indigenous populations has been fruitful for scientists and the wider public, but has it benefited Indigenous communities themselves? We explore past (ab)uses of genetic research in Canadian First Nations communities through case studies. Although early projects were largely researcher-driven, the Human Genome Diversity Project of the 1990s catalysed a change towards participatory, community-controlled genetic research in Canadian Aboriginal communities.

Introduction

Indigenous* peoples have often been subjects for biomedical research, and the benefits to mainstream society include improved vaccines and better understanding of type 2 diabetes pathophysiology. Genetic studies of Aboriginal populations have yielded dissertations and scholarly articles on subjects ranging from rheumatoid arthritis, to breast cancer, to evolution and migration of human populations. But to what extent have Indigenous communities themselves benefited from this research? Through selected case studies, we explore the history of genetic research in Canadian First Nations communities, with a particular emphasis on the degree of community control.

Why Community Control?

In the late 1960s, Vine Deloria (Standing Rock Sioux) drew attention to research in Aboriginal communities that was driven more by researchers’ interests than by “the needs of the people.” Given that these communities are often struggling for survival against the political, economic, and social consequences of colonialism, Deloria condemns “pure research” of Indigenous peoples that benefits only the researcher: “We should not be objects of observation for those who do nothing to help us.” Indeed, power disparities between a community and outside researchers can make the research process into a form of exploitation, undermining Aboriginal knowledge and sovereignty: “The Indian explanation is always cast aside as a superstition,” Deloria observes, “Indians must simply take whatever status they have been granted by scientists.”

Furthermore, research ethics in North America have traditionally focussed on individual rights, neglecting collective rights of groups. Yet many Indigenous communities consider information about the group to be communal property. Even something considered so individualistic, at least in mainstream Canadian society, as DNA may be seen as a common resource, as Debra Harry (Northern Paiute) describes: “We’re talking about something that has existed collectively. It doesn’t belong to the present generation.” Outsider researchers may lack the knowledge to negotiate these political, cultural, and ethical complexities, and so the long-term distribution of benefits and harms from a project will be influenced by the degree of community control.

* We use “Indigenous” and “Aboriginal” interchangeably. In a Canadian context, “Aboriginal peoples” include First Nations, Metis, and Inuit populations.
“He Used Us like Guinea Pigs”: Two Cases of Genetic Research

In 1989, the Havasupai people of Arizona gave blood to researchers from Arizona State University, seeking to understand the high prevalence of diabetes in their community. In the early 2000s they realised the blood had also been used for unrelated studies by several researchers.11 Of particular concern to some donors was the use of their DNA in population evolution studies that contradicted their oral history; Havasupai Chairwoman Carletta Tilousi explains, “They challenged our identity and our origins with our own blood without telling us what we were doing.”7 Anishinaabe scholar Winona LaDuke argues that such studies have political, as well as cultural, significance. Governments or others with interest in Aboriginal peoples’ traditional lands, she suggests, may use the authority of “genetic evidence” to portray Indigenous groups as migratory “settlers” with no higher claim to land rights.7 The Havasupai Tribal Council and several community members have filed multi-million-dollar lawsuits against the researchers and their university.12

Members of Nuu-chah-nulth First Nations in British Columbia gave their blood to Ryk Ward, a geneticist at the University of British Columbia (UBC), in the mid-1980s, hoping to uncover the reason for their community’s high rates of inflammatory arthritis.13 They heard nothing more until 2000, when the Nuu-chah-nulth learned that Ward failed to find significant results in his arthritis study and had taken their blood with him to new appointments at Utah State University and Oxford University.13 Nuu-chah-nulth people, led by Larry Baird, one of the blood donors, have successfully lobbied for the return of the blood, and it is now stored at UBC.14 Baird explained his efforts to retrieve the blood from Ward in a Nuu-chah-nulth-run newspaper: “He profited at our expense. He published over 200 papers and became top guru in his field because he was carrying our blood around with him. He used us like cheap guinea pigs.”14

Note the diversity of communities’ responses. Baird objected to a researcher profiting from his community without reciprocity; Havasupai donors protest the use of their DNA in population studies that contradict their oral history; others, such as members of the Amazonian Yanomami people, have cultural beliefs against the preservation of blood;15 and different groups within communities may have conflicting responses to the secondary use of their samples.8

What these cases have in common are researchers who stored, shared, and re-used genetic samples without donors’ knowledge. Geneticists treated the samples much as biologists treat bacterial cultures: as scientific resources to be studied and shared. But individual donors did not consent to these uses; and since geneticists were naming a specific Indigenous community in their analyses, research was also being done on the community as a whole, without its consent. Perhaps for these researchers, operating relatively early in the genetic era, complex ethical reasoning had not yet caught up with scientific technique and curiosity. In an interview with Nature, Ward implies his secondary use of Nuu-chah-nulth samples was simply the “way people operated at the time... it didn’t cross anyone’s mind -- we didn’t mean to be evil, and we are more careful now.”13

“The Vampire Project”

The increasing vigilance of Indigenous communities, and corresponding tendency of geneticists to be “more careful now,” developed over the 1990s in the context of the Human Genome Diversity Project (HGDP) controversy. Conceived as a supplement to the Human Genome Project, the not-for-profit HGDP aimed to collect samples from genetically isolated Indigenous communities around the world, create immortalized cell lines, and make the DNA available to not-for-profit scientists. The initial goal was to facilitate study of population evolution and migration,16 although later representations of the project emphasised potential health research.17
An Indigenous resistance movement to the project developed very quickly. By 1993, the World Council of Indigenous Peoples had christened it “The Vampire Project” for the emphasis on retrieving blood, and the term stuck in North American Aboriginal newspapers.18-20 HGDP organizers attempted to mitigate criticism by forming a North American Regional Committee with two Aboriginal members, and by drafting a Model Ethical Protocol for collecting samples.21 Nevertheless, Canadian and American government agencies ultimately declined to fund the project, and it has stalled in North America.22

Why did a project considered innocuous by its originators22 generate such resistance? Representatives of Indigenous organizations from the Americas outlined common problems with the HGDP in 1995, including spiritual objections to immortalized cell lines, potential military or commercial abuses, and objectification of Indigenous peoples “to satisfy scientific curiosity” without benefit to the peoples themselves.23 Was true informed consent from individuals and communities possible, given linguistic and cultural barriers?24 Would genetic research support population migration theories that dismissed community origin stories and undermined struggles for land and sovereignty rights?25

One of the most frequent objections stemmed from the language of the HGDP’s draft project proposal; genetically distinctive Indigenous populations are referred to as “isolates of historical interest” whose genetic resources need to be collected immediately, before the populations die out or disappear.18,25-27 LaDuke explains many Aboriginal individuals’ outrage at the idea of salvaging genes instead of saving people: “Why would so many resources be involved in collecting the genetic materials from ‘vanishing populations’ rather than working to preserve those peoples and their cultures?”27

As evidenced by the presence of lawyer Catherine Twinn (Sawridge First Nation) and anthropologist Russell Thornton (Cherokee) on the HGDP’s North American Regional Committee, Indigenous opposition to the project has not been universal. Defences from Aboriginal persons in scholarly literature or the popular press, however, are difficult to find. The most prolific Indigenous writer on the HGDP in academia has been Frank Dukepoo, a Hopi/Lacuna geneticist. Citing the moral naiveté of the project’s originators, the real risks and uncertain benefits to Indigenous peoples, and the lack of community control inherent in open-ended gifts of genetic resources, he has generally argued against the project.28 Yet he asserts that not all Indigenous individuals and communities reject genetic research per se; the HGDP’s mistake, he suggests, is its “paternalistic” approach to conducting “research on rather than with indigenous people.”29

Participatory Research

Early in the 1990s, the people of Oji-Cree Sandy Lake First Nation (Ontario/Manitoba border) decided to address their community’s high prevalence of type 2 diabetes. They formed a partnership with two physician-researchers that “incorporates the principles of participatory research,” according to the project website.30 Community leaders and researchers established goals – determining community-specific prevalence and risk factors, implementing primary and secondary prevention programmes – and continue to discuss all aspects of the project, from protocol designs to dissemination of results.30 Protocols must be approved by the Band Council, and research is conducted by trained community members.30 Prevalence of type 2 diabetes was found to be five times the Canadian average, and a range of environmental and lifestyle risk factors were isolated; based on these findings, the project partners began to develop community-run, culturally-specific intervention programmes in 1995.31

The following year, the project organizers invited researchers from Robarts Research Institute at UWO to seek possible genetic components to diabetes in Sandy Lake First Nation.32 Analysis of DNA from 728 community members showed that a mutation unique to this community in gene HNF1A increased the risk of
developing type 2 diabetes by up to 15 times in homozygous individuals, compared with community members homozygous for the normal allele. The clinical applicability of testing for this mutation was examined as a means for directing enhanced prevention support to genetically susceptible individuals. The relative importance of genetic and environmental risk factors for early onset type 2 diabetes in community members was quantitatively assessed, with the conclusion that “changes in environment, at the level of lifestyle, could overturn genetic susceptibility, probably rapidly, and in a ‘low-tech’ manner.”

These genetic studies have not occurred in reductionist isolation, as all too often happens in basic science research, but rather are embedded in a community-controlled research project that includes problems, causes, and community-specific solutions in its scope of inquiry, and that requires results to be relevant and meaningful for all parties. Canadian Mohawk scholar Marlene Brant Castellano observes that this sort of collaboration makes for more effective research, and cites the Sandy Lake First Nation diabetes project as evidence that “Holistic awareness and highly focussed analysis are complementary, not contradictory.”

Long Ago Person Found

In 1999, the body of a young man who died hundreds of years ago was found preserved in a glacier on traditional Champagne Aishihik First Nations (CAFN) land (BC/Yukon border). The First Nations assumed responsibility for the remains, in keeping with a 1995 treaty affirming their control over cultural resources on their land. CAFN Elders named the remains Kwądąy Dän Ts’inchį (Long Ago Person Found) and together with the Band Council and other community members, decided to investigate his origins.

After consulting with neighbouring First Nations, the CAFN Band Council signed a management agreement with the BC government to allow for research on the remains. Researchers would not be able to own genetic or other materials gathered at the discovery site and would return all samples after analysis. The research included a comparison of mitochondrial DNA (mtDNA) in the remains to nearly 250 Aboriginal volunteers from the area. This genetic test suggested Long Ago Person Found has living relatives in CAFN and neighbouring Aboriginal communities. Since the relatives identified by maternally-inherited mtDNA are all members of the Wolf/Eagle clan, Elders concluded their ancestor likely was as well, given the matrilineal clan structure of their nations. This identification allowed for a memorial potlatch to be planned by Elders of the correct clan.

Symposia at the Royal BC Museum and the CAFN reserve in 2008 and 2009 made information gathered about the remains accessible to local Indigenous people and the general public. This included scientific and cultural talks, traditional accounts of lost travellers and trade routes to complement forensic analyses of clothing material and stomach contents, and local genealogies to fill in the gaps of high specificity/low sensitivity mtDNA testing. Requested by the community and contextualized with oral history and other studies, this DNA analysis demonstrates that community-controlled genetic research can sometimes support Aboriginal peoples’ psychosocial, as well as biomedical, well-being.

In this case, the community’s desire to know more about their ancestor coincided with outside researchers’ curiosity, and DNA testing was deemed acceptable by Band Council, Elders, and blood donors. Not all Aboriginal peoples will make similar decisions about remains found in their land, however, and interested geneticists must not suppose that DNA analysis will always be welcomed or acceptable in these situations.

Conclusions

In response to the increasing power and voice Indigenous peoples have negotiated for themselves about research in their communities, Canadian government funding agencies have begun requiring special ethical considerations, in
addition to usual practices, from those seeking grants for research with Aboriginal peoples. For example, the 2007 CIHR Guidelines for Health Research Involving Aboriginal People emphasises community/group consent, participatory research, ownership of biological specimens and data by the community, and new informed consent before any secondary use of samples and data, among other requirements.

Although these regulations apply only to CIHR-funded researchers, Canadian First Nations communities are beginning to establish their own codes of conduct and research ethics boards. These efforts flow from Canadian Aboriginal peoples’ constitutional right to self-government, according to a report by the National Aboriginal Health Organization (NAHO), and reflect the principles of “OCAP”: community ownership, control, access, and possession of research and biological samples.

When they learned how Ward had used their samples, the Nuu-chah-nulth Tribal Council formed a Research Ethics Committee chaired by Larry Baird, the community member most active in repatriating the blood. “We’re not closing the door on research,” Baird explains, noting that some Nuu-chah-nulth people are interested in renewing inquiry into the arthritis that still plagues their communities. But the “way people operated” when Ward took their blood in the 1980s will not be tolerated, Baird warns: “From now on our eyes are wide open.”

References