
DNA on Loan: Issues to Consider when Carrying Out Genetic Research with Aboriginal Families and Communities

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Key Words

Canadian aboriginals · First Nations communities · DNA on loan · Research ethics · Community-based participatory research

Abstract

In the current research milieu where genetic etiology is considered a critical component in the discovery of pathogenesis, aboriginal families and communities affected with genetic conditions may be considered as research participants. However, because of concerns about the impact of genetic information and historical harmful research practices, some aboriginal communities have considerable unease when faced with this prospect. Therefore, in the circumstance that genetics is considered an important part of research inquiry by aboriginal families and communities, there needs to be assurance that the research will be carried out according to mutual expectations. A research relationship that respects aboriginal individuals and communities within their culture and is in keeping with their values is essential. This respect extends to the use of biological samples, considering the DNA to be 'on loan' to the researcher for the purpose of the research for which consent was obtained.

This paper will explore practical ways of maintaining a respectful research relationship when genetics research with aboriginal people is undertaken.

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Introduction

Genetic studies in aboriginal populations have been widely criticized by the communities targeted. Not limited to the large-scale proposal of the Human Genome Diversity Project, critics have cited lack of involvement of the community in the planning of the project, insensitivity to cultural beliefs around the condition, potential stigma of research results, lack of feed-back to the community once a project is completed, commercial ownership of DNA, and overall impressions of exploitation of the communities as particular concerns [1–6]. Serious concern over the potential uses of stored DNA and cell lines of aboriginal groups for unauthorized research has been raised by high-profile aboriginal organizations [7, 8]. Of Canadian relevance, it was brought to international attention that blood destined for health research from a First Nations group in British Columbia was instead used to establish ancestry. Blood sampling of more than 800

people of Nuu-chah-nulth origin (about 45% of the targeted population) was carried out by a research team to explore the high rate of arthritis in that group [9]. The blood was used instead to isolate mitochondrial DNA and carry out research to determine the origins of the Nuu-chah-nulth people [10–12]. This case and others prompted public discussion, workshops¹ [1, 2] and plans to develop national guidelines for carrying out health research with Canadian aboriginal communities. Internationally, similar cases have exemplified the importance of understanding the issues that are important to aboriginal people when genetic research is carried out with them and in their communities [13, 14]. This paper will address the issues and approaches to consider when information to be derived from genetic research is considered important by aboriginal families and communities. It is written from the viewpoints of a Canadian non-aboriginal investigator (L.A.) who carries out genetic research with aboriginal communities and a Canadian aboriginal woman (Mohawk Indian) who lives on reserve and has had a career as a senior health policy analyst (D.C.) of a national health organization. She currently heads the Canadian Institutes of Health Research [15] Aboriginal Ethics Working Group which is establishing long awaited national guidelines for health research carried out with Canadian aboriginal people.

Respect for Aboriginal Communities

Aboriginal peoples, First Nations, Metis and Inuit, comprise nearly 4% of the total Canadian population [16]. The historical, political and cultural structure of these First Peoples of North America requires special consideration in research ethics [17, 18], i.e. one that respects the notion of ‘self-determination’ unlike in most other non-aboriginal communities [19]. As with other indigenous populations around the world [20], discussions have occurred [21] and guidelines have been established for research in some communities and populations (table 1) [22–25]. The guidelines are largely based on the model of ‘participatory action research’, a methodology acknowledged under that name since the 1980s, promot-

¹ Two workshops were funded by the Canadian Institute for Health Research, Institute for Aboriginal Peoples Health, to explore culturally appropriate ways to carry out genetic research, including the handling and storage of DNA. These were entitled ‘An exploratory workshop on a tribal controlled DNA bank, part 1 and part 2’, held in Vancouver and Tofino, British Columbia, in August 2001 and January 2002.

Table 1. Canadian guidelines defining ethical research in aboriginal communities

Dene tracking: a participatory research process for Dene/Metis communities (1993)
Inuit Tapirisat background paper on negotiating relationships in the North (1994)
Kahnawake code of research ethics (1997)
Akwesasne research code of ethics (1996)
Cree Board of Health and Social Services of James Bay code of research ethics (2001)
Protocols and principles for conducting research in an indigenous context (Uvic)

ing relevance and an action agenda which also serves to empower those involved. Although the term ‘participatory action research’ was first used in the 1980s, the term ‘action research’ can be traced to the 1940s in the United States [26] where it was initially used in a somewhat different context, promoting research involvement especially for stakeholders in education and other organizational settings (sometimes referred to as the ‘Northern tradition’). By the 1970s, an expanded methodology was integrated as an ‘emancipatory’ approach. Developed more in the southern hemisphere in regions such as Latin America, Asia and Africa [26], the emphasis is on empowerment and an action agenda particularly for those who have been previously marginalized or exploited [27–29]. The term continues to evolve and is now referred to, especially in the context of research involving aboriginal communities, as ‘community-based participatory research’ [26, 30], and although empowerment is an important aspect, it also recognizes the importance of self-determination. Thus, in the context of participatory action research or community-based participatory action research as promoted by Canadian aboriginal communities [22–25, 27], research inquiry is not sufficient, but a participatory agenda which focuses on the needs of the community and their development is crucial to the process. The research *must* reflect the needs of the community and must be considered, by the community and researcher, an appropriate research problem to explore. Respect for aboriginal culture, knowledge, tradition and values are fundamental to the development of culturally competent research. Respect is developed through an understanding of aboriginal social, political and cultural structures. The community needs to be involved with the development of the research from the time the research question is asked. The research must offer something to the commu-

nity, such as the opportunity to develop research skills. Research results are reported back (ideally generated together), and the data are considered in some cases to be mutually owned by the community and researcher, and in other cases, owned by the community having agreed upon data stewardship, which is generally held by the researcher. This arrangement enables the community to act on the results as they see fit. To carry out research in this manner, the researcher recognizes that his or her beliefs, as well as the methods of inquiry, goals, and objectives of the research, may not be reflective of the beliefs of the community, and therefore, must be respectful of the differences. The opportunity for learning is mutual. The advantage of these methodologies is that the researcher learns through the participation of the community in the planning, implementation and analysis of the research, and similarly, the community is provided with the opportunity to learn as well [28].

Although variations on community-based research methodology have been well known in the social science domain, and have been extended to and found to be effective [30] in various forms of health research, such as public health and epidemiology [31–33], the methodology is infrequently applied to biomedical research, including health-related genetic research, where a basic science or medical component is the primary focus or integrated with the research program. In general, biomedical research is hypothesis driven in the analysis of ‘causes that influence outcome’. The purpose of the research is ultimately to add to the body of scientific knowledge without focusing on the needs of a specific community. In general, subjects are recruited, considered necessary to provide data, and rarely involved in the research development. Although the importance of recruitment is recognized in that the research subjects are necessary to carry out the research, the subjects are generally not part of the research development or implementation. Results are expected to be published, but biomedical research results are not usually returned to participants. In keeping with general research ethics guidelines, much emphasis is placed on anonymity of subjects, and incentives that would provide benefit are discouraged since there is reasonable concern that participation may then be considered coerced. Thus, although there is a significant international movement encouraging benefit sharing when research is carried out [19, 34], genetic researchers (and other biomedical researchers) may not yet be implementing this approach. A statement by the Human Genome Organization in 2000 explains ‘that undue inducement through compensation for individual participants, fami-

lies and populations should be prohibited. This prohibition does not include agreements with individuals, families, groups, communities or populations that foresee technology transfer, local training, joint ventures, provision of health care or of information, infrastructures, reimbursement of costs, or the possible use of a percentage of any royalties for humanitarian purposes’ [35].

Although participatory research guidelines developed in Canadian aboriginal communities are intended to include all types of research, also biomedical/genetic research, methods of how biological samples should be collected, stored and subsequently used are not generally addressed in research guidelines [22, 23, 25]. Thus, even when research is performed in a participatory manner, the issue as to how the management of biological samples is carried out may not be discussed. In this respect, research expectations between aboriginal communities and researchers may be at a divide. Indeed, the researcher who may be familiar with the common practice of obtaining samples, maintaining the samples to obtain quality results [36], carrying out research, removing individual identifiers, and proceeding with relevant secondary research² might have been surprised to find the usage of de-identified samples in secondary research considered offensive by some [11–13].

Additionally, for aboriginal communities and individuals, research with biological samples may hold traditional and spiritual significance. For example, in the words of Dr. Frank Dukupoo, a Native American geneticist: ‘To us, any part of ourselves is sacred. Scientists say it’s just DNA. For an Indian, it’s not just DNA, it’s part of a person, it is sacred, with deep religious significance. It is part of the essence of a person’ [37]. Thus, from a cultural perspective, it can be seen that the respect accorded to communities should also be extended to the handling and use of the biological samples derived from the community. Therefore, in keeping with cultural perspectives and the principles of participatory action research, it is proposed that unless otherwise stipulated, all blood and tissues accepted for research in aboriginal communities must be considered the continued property of the donor/community involved, that is ‘*on loan*’ to the researcher. In this way, the individual and the community (or their designates) retain the ability to determine the future handling

² Although previous common practice was to remove identifiers and proceed with relevant research after the original project was complete, a stepwise consent process is now encouraged where the research participant has a choice to allow samples to be used in a limited fashion (only for research consented to) and in an expanded fashion for future research.

and use of biological samples. Thus, the idea of 'DNA on loan' becomes an important concept for both the researcher and the aboriginal community. The researcher now becomes the steward, holding the DNA (or other biological samples) for the purpose of the research that has been consented to. The ownership remains with the participant or community, as has been designated. This concept leaves no room for misunderstanding. The researcher is not at liberty to use the sample without consent of the individual, community or designated party, even if the personal identifiers are removed. Although the aboriginal community may wish to waive the 'ownership' for anonymous research, the fall-back position is that the sample is 'on-loan', and only if otherwise specified will it be considered differently. Although there is currently no governing body which enforces such a concept, written consent stipulating that the DNA is on loan requires legal adherence. Although seemingly restrictive compared with previous common practice of removing personal identifiers and carrying out secondary unrelated research, extending the participatory process to biological sample use serves to protect both research subjects from research that may not reflect priorities or needs, and researchers from misinterpretations of limitations of the use of samples for scientific inquiry. Importantly, as in all aspects of participatory research, a continued relationship must be maintained with the community. Because the researcher is 'the steward' and not the 'owner' of the samples, if, for example, 10 years after the initial research has been carried out, new genes for the condition initially under research are revealed (or new techniques to reveal known genes are discovered), the researcher is then bound to report back to the community. Whether individual consent is sought or possible will then be determined by the circumstances, with the input of the governing body for the community (or family). The concept of 'DNA on loan' enables research to be carried out, but protects the interests of the individuals, families and communities involved and assures that research is carried out in keeping with mutual expectations (participants and researchers). This concept does not exclude the eventual possibility of a development of repositories for biological samples derived from aboriginal groups, where storage, handling, and future use are controlled by advisory groups of aboriginal people, as in 'a tribal controlled DNA bank'.

Thus, 'respect for the aboriginal community' [38, 39] involves consideration of the desire of a community to exercise self-determination in the research process, including the use of research samples. Thus, (1) research carried out must reflect the needs and priorities of the

community; (2) the community needs to be involved and informed in all stages of research; (3) the community must have the opportunity to benefit from the research (capacity development, diagnostics and treatment, access to new products, equipment, health care programs, information, education); (4) results will be returned to the community for their own use and for use in partnership with the researcher; (5) biological samples such as DNA, serum, and solid tissue must be handled with respect in accordance of the wishes of the individuals and the community; (6) unless otherwise stipulated, blood and tissues accepted for research should be considered the property of the donor/community involved and will be considered 'on loan' to the researcher.

Other Issues Involving Genetic Research with Aboriginal Families and Communities

If genetic research is considered a priority for the community and there are plans for initiation, the same ethical concerns for any culture or population undergoing genetic research or testing should be taken into consideration [40]. Some of these issues include fairness in the use of genetic information, privacy and confidentiality, potential stigmatization, psychological impact, reproductive issues, education, standards, as well as quality control and impact of commercialization [41]. The research process needs to consider all of these issues in a cultural context when establishing a community relationship that will determine how the research is carried out [42]. Indeed, issues such as the potential of stigmatization may be more of a concern to a community amidst a historical context of cultural repression and reduced standards of health care availability [43, 44]. The protection of the research participant from physical, social and psychological harm prevails whether the participant is an individual or represents a community [20].

Genetic research may be introduced into a community in a variety of ways. For example, community members may have become aware of a single gene or complex condition disproportionately affecting them, the understanding of which could have a positive health care impact. The community itself may recognize a need for research and seek a competent research team to work with them to solve the question [45, 46]. On the other hand, a clinician may recognize a condition in an individual that affects an extended number of related or unrelated members of a community and approach the family or community about the potential of research [47]. Finally, a re-

searcher with a particular disease interest may suspect that a certain condition may be more prevalent in a particular nation, tribe or geographic location that affects more than one defined community [48].

In all situations, it is the researcher's responsibility to learn about the social and political structure of the community or communities at the onset. Early relationship building is essential to an ongoing process that aims to take into consideration the cultural, social and political perspectives of the community and assures ongoing integrated governance of the research. For those conditions affecting more than one family within a community, a formal liaison with the community, either with the tribal, municipal council and/or research review committee will be needed. Increasingly, Canadian aboriginal communities are designating research review committees to establish research guidelines for their community, review research requests, determine if the needs of the community are reflected in the research question, and decide on behalf of the community whether the research question and methods fit with their current and projected goals for health inquiry. Thus, the governing council may be designated to consent to the establishment of the research process for the community. This is often necessary before obtaining an institution/university-based research ethics review [49] and will be necessary prior to recruiting individual participants who will retain the individual right to participate or not.

However, in some communities, the governance structure may not have the mandate to provide 'community consent', or the health problem being researched may not allow for a unified community governance approach. Nonetheless, in all cases, a respectful research relationship and a research contract with aboriginal participants is necessary to maintain. When establishing a research contract that will be legally bound to the signed consent, issues to discuss include: (1) provision of culturally appropriate counseling when genetic information is revealed, (2) possibility of stigma as a result of the research, (3) use, storage and disposal of biological materials, (4) regular reports of research progress and return of the results, and (5) commercialization potential, data sharing and ownership, publication review, authorship and use of the particular aboriginal or tribal affiliation.

Examples of successful approaches to genetic research exist but do not get the same degree of attention as when research goes wrong. For example, diabetes disproportionately affects aboriginal people from around the world. Great efforts are being undertaken to understand the biological basis of the condition, to control the environmen-

tal determinants (such as diet and exercise) and to mitigate the complications which lead to significant morbidity and early mortality. Model approaches for carrying out research, addressing the needs of the community, as well as exploring the biological basis of the condition have been implemented and shown to be welcome by the communities affected. An example of respectful engagement and collaboration with a community is the Sandy Lake Health and Diabetes Project started in 1991 as a partnership between the community and diabetes researchers [24, 50, 51]. With community involvement, intervention programs were integrated into the research including education, exercise, home visits and a store program to assure that healthy foods are provided. Additionally, research has been successful at identifying genetic factors that predispose these community members to diabetes, leading to a better understanding of the pathogenesis of the disease [52, 53]. For this and other successful participatory programs of research [45, 54], the community has been involved from the onset, the research/community relationship is sustained, and benefits to the community are apparent.

However, not all genetic research lends itself to a community program that is so apparently beneficial. In addition, in some cases, it is difficult to determine where the boundaries of the community lie, and who speaks for the community. This is particularly difficult when a condition is prevalent in a geographic region inhabited by more than one community, where there are a minimal number of affected individuals in any one defined community, but collectively there is an impact on health.

An example for this is given in the case of primary biliary cirrhosis, an autoimmune liver disease which is the leading indication for liver transplantation in First Nations people of the west coast of Canada [55]. There are no public health efforts known that can prevent the condition from developing. Indeed, the greatest public health benefit for this condition, sometimes misdiagnosed as alcoholic cirrhosis, is raising the awareness of the high prevalence in the population to promote early, accurate diagnosis. The aim was to initiate early effective treatment to mitigate the progression of the condition which ultimately leads to liver failure, transplantation and death of the relatively young women affected. In this case example, the condition was recognized by a community physician and family members of one extended family of First Nations descent. To initiate contact, the researcher (L.A.) was invited to a wedding celebration being carried out in the form of a traditional Potlatch. Subsequently, a meeting with a senior branch of the family was

held to discuss the aims of research. A project was developed, funding was obtained, and the initial phases of the research started. At that time, there was no formal structure for health research review in the community. It soon became apparent that the condition did not only affect this one family, but other members of the same community, as well as those adjoining in a common geographic area. Thus, the research team who had initiated the project began to study the genetic and environmental determinants of this condition in the larger population [56]. Inquiry led to the discovery of an overriding research consultation process (but no 'consent' process) led by the First Nations' Summit Chief's Health Committee (FNCHC) [57] that primarily promotes health programs within communities and generally oversees health research carried out in the majority of First Nations communities of British Columbia – there are about 40 different First Nations divided into about 200 bands or distinct communities [58]. Consequently, further relationships with individuals and communities developed, leading to several community meetings initiated by local health professionals and affected individuals. Articles were published in the FNCHC newsletter and in a provincial First Nations news paper allowing the information to be disseminated in forums likely to be read by aboriginal people. Information pamphlets were developed with input from the research participants and distributed. Undergraduate First Nations students were recruited as research assistants. With research still in progress, regular research updates are sent to the participants. Relationships are formed with the various involved research committees and the local health units, as well as with the individual research participants and their families. Papers that are written for publication are sent to the FNCHC and other involved research committees for review prior to publication [59]. The research samples are considered 'on loan' to the research team. All members of the research team are in support of the concept. DNA and serum is stored in one designated secure lab and is only sent to other labs for experiments related to the specific research project. Thus, although the community is not well defined by geographical borders and does not have a single governing structure, an approach consistent with the above guidelines can be undertaken.

The third case example considers an aboriginal family whose genetic condition does not seem to affect the community at large. To provide clinical genetic services in some cases, for example prenatal diagnosis or cancer screening, a form of research needs to take place. In this example, a special referral for a chromosome abnormal-

ity was revealed as an unusual situation where young women gave birth to chromosomally abnormal infants. A family meeting was held in their northern health center, attended by several young women, their spouses and the grandmothers of affected individuals, all from the same First Nations community. The possibility of research to delineate the chromosome abnormality on a molecular level was discussed. The research had two aims: to understand the mechanism of the unusual chromosome abnormality and to provide information to the family members regarding their individual risk. Some family members were interested in prenatal diagnosis, others were not. In this case, the family felt that the condition was limited to their family and needed to go no further to a community-structured consent process. Therefore, a more private research process ensued in contrast with the high-profile research discussed in the two previous examples. Although this family's unusual condition has become the subject of an intense research project that may bring mechanistic insights into a rare presentation of a genetic condition, the family is kept up to date with research progress, and the blood samples drawn are considered 'on loan' for this project only. In publications, there is no designation that this is a First Nations family, and their particular band or nation is not revealed. Health care and counseling for the family is provided on a more informed basis, individual autonomy is respected, and as part of the research contract, cultural respect is integrated. As to whether the designation of First Nations is ever used to raise public health awareness will be determined by the community and the family within the context of their own governance structure. Thus, the potential of stigmatization, depending on the condition in question, would be balanced against the public health advantage of increasing awareness of the condition if found to eventually affect more than one family.

The above examples are only a few approaches to genetic research that can be respectfully carried out with Canadian aboriginal families and communities. Although the examples illustrated are in reference to genetic research in First Nations communities, the principles of respecting aboriginal culture, social and political structure are relevant for Inuit and Metis in communities, as well as those aboriginal people who are living away from defined aboriginal communities. These examples, integrating consultation, education, ongoing communication and return of results to participants may also be relevant for genetic studies with families and other communities who are not aboriginal.

Conclusion

When research priorities of aboriginal people include a genetic component, there are several issues that need to be considered. In many Canadian communities, there will be a well-established governance structure in place to review and determine the merit of the research for the community and consider 'community consent'. Even when the community does not have an established structure, or the research does not lend itself to a community approach, the researcher's commitment to an ongoing research relationship is essential in providing integrated accountable governance of the research, with the provision of benefit for the participants and community involved. The overriding principles include respect for aboriginal individuals, families and communities within the cultural, social and political milieu in which they live. Respect for the accepted method of the participatory aboriginal research process that dictates ongoing involvement of research participants and includes respect for the biological samples ('DNA on loan') is integral to the ultimate success of the project.

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