

Partnering With Northern British Columbia First Nations in the Spectrum of Biobanking and Genomic Research: Moving Beyond the Disparities

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Biobanking, genomic research, and their potential for clinical applications are playing a primary role in the evolution of cancer care in Canada and around the world. Although this is having an impact on everything from screening and diagnosis to treatment and the foundational understanding of disease, its success has become a potential driver of persisting health inequities in Canada. Although Canada plays a prominent role in oncogenomic research, it should be noted that this is primarily localized to metropolitan centers that have the associated academic institutions, genomic laboratories, human resources, and research budgets to permit this. Northern, rural, and Indigenous populations are at best minimally represented and at worst actively excluded from this research and its beneficial effects downstream. It is anticipated that addressing this broadening gap—often termed the “genomic health divide”¹—will be necessary to prevent an untenable growth in the inequities of cancer care and outcomes.

In 2010, a patient in northern British Columbia asked her physician, “Why does our postal code dictate who has the choice to be part of research and who does not?” She asked this question 2 days after she discovered that her cancer, which had been treated 3 years earlier, had recurred. Her new headaches translated into lesions that were identified on a computed tomography scan of her head. She asked this question with gut-wrenching emotion. However, there was no answer that could explain why living in northern British Columbia marginalized so many people from the empowerment of applying the hardship of disease toward scientific discovery through research participation. There was no acceptable explanation regarding the inequitable access to opportunities to be part of knowledge generation. She summarized this succinctly, yet tragically, by stating, “All I can give my daughters now is a first-degree relative with cancer.”


The Northern Biobank Initiative (NBI) was introduced to create a research platform to start addressing this genomic divide in northern British Columbia, where no biobank or process for inclusion existed. This was

particularly evident with the most marginalized—the First Nations peoples (ie, Indigenous peoples whose ancestors have inhabited this land since time immemorial). Canada’s population is more sparsely dispersed in northern and rural communities. Two-thirds of the country’s population is nestled within 100 km of the southern border with the United States,² and only 20% live in rural areas.³ For British Columbia, there is a starker north–south discrepancy. Using the northernmost geographic health authority in the province as a definition of “northern British Columbia” in this context, the Northern Health Authority consists of approximately 600,000 km² (approximately two-thirds of the provincial landmass), but holds less than 10% of its population.⁴ Moving north in British Columbia, one finds a higher percentage of people who live in rural and remote communities,⁴ and the percentage of First Nations becomes more prominent in this demographic group. According to the 2011 National Household Survey⁵ in southern British Columbia, First Nations made up 3.6% of the total population, whereas First Nations represented just over 14% of the total population in northern British Columbia. Partnering with the First Nations communities to explore the potential of a northern British Columbia First Nations biobank will address this disparity in research and require unique, but non-negotiable, steps in consultation to establish a culturally relevant, safe, and respectful biobank.

A biobank is a research tool that systematically stores and databases biospecimens (eg, malignant tumors and blood samples, with annotated clinical data) for the purpose of future research. There are established protocols in biobanking for the procurement, processing, storage, handling, and dissemination of specimens. However, it must be recognized that a population-based biobank should be led by First Nations, because First Nations would embed cultural perspectives into its creation and utilization. This biobank requires many scientific concepts to be redefined within a unique First Nations framework, thus reflecting their vision, challenges, goals and ways to attain them.

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From its inception, the NBI concept and progress to date has recognized the need for partnership with the First Nations peoples who would potentially participate in and/or benefit from a First Nations biobank embedded within the NBI, should it come to fruition. To be honored with this partnership would require bringing the Western scientific concept of genomics and biobanking into conversations centered on First Nations values, cultures, protocols, and ways of knowing. Initial steps to explore this potential First Nations component of the NBI included discussion with provincial First Nations leaders, a workshop with northern First Nations community members and elders, and input from colleagues with experience in the field of genomic research with Indigenous peoples. Feedback from these discussions established that there exists fundamental and optimistic support regarding the concept of a northern British Columbia First Nations biobank. Furthermore, this preliminary dialogue to permit dialogue⁶ initiated the relationships and laid the groundwork for developing proposed project plans and grant applications to make the next step of formal consultations with First Nations regarding this concept a reality. Approaching this process in the reverse order—funding first, followed by discussions—would have been inappropriate, culturally insensitive, and impossible.

Our primary partners with respect to a northern British Columbia First Nations biobank are the British Columbia First Nations Health Authority (FNHA) and the Northern Health Authority. Although the concept of a biobank was supported, consultations were required to obtain input from northern First Nations leaders and community members regarding governance, cultural protocols, and First Nations' perspectives on ethical standards for this potential First Nations biobank. After funding was obtained for these consultations,⁷ significant guidance was provided by the FNHA northern regional leaders. Since June 2016, the NBI team and FNHA have worked in partnership to plan and perform extensive community consultations with northern British Columbia First Nations via the well-established processes of the FNHA. Northern First Nations chiefs (who are elected to leadership roles by their communities) passed a resolution to support this qualitative research by the NBI team to ascertain how to establish a culturally relevant northern British Columbia First Nations biobank. The chiefs requested continued support from the FNHA northern team as well as creation of the subsequent Northern First Nations Biobank Advisory Committee (NFBAC) to help guide the NBI team.

Consultations in the form of focus groups with community members and key-informant interviews with chiefs and health directors commenced in April 2018 after approval by FNHA northern regional leaders, the NFBAC, and relevant research ethics boards. Focus groups in First Nations communities across northern British Columbia included associated community presentations to increase awareness of the NBI project, including biobanking concepts and the

potential of genomic research. These presentations included topics that the NBI team would pursue in more detail in our consultations, such as consent procedures, access to the proposed biobank, associated cultural protocols, and overall governance options. Since 2016, similar presentations have been given multiple times at FNHA leadership meetings, both at the northern regional and subregional levels, so that key-informant interview participants (ie, chiefs and health directors) were well informed and kept up to date on the NBI progress.

There is a growing movement for Indigenous peoples to have a place in the evolving field of genomic research and its clinical applications in Canada, as well as globally.⁸⁻¹² The dialogue that the NBI has sparked to date with First Nations leaders, elders, and community members has been fulsome and rewarding for the NBI team. Feedback from communities reflects increasing excitement about the creation of a northern British Columbia First Nations biobank and its future applications. On the basis of dialogue that the NBI team has participated in, it is anticipated that while a northern First Nations biobank would have documented processes and procedures for the acquisition and storage of tissue and annotated data such as those that standard Western medicine biobanks adhere to, it must also respect and support First Nations cultures and values. There must be cultural protocols in place that reflect the concept that a sample taken from a person's body is sacred and must be treated as such under the stewardship of the biobank team. The NBI team anticipates that, upon analysis of qualitative data from the consultations, adhering to the concepts of OCAP (Ownership, Control, Access, and Possession; an acronym that has come to represent the guiding principles of research with First Nations people in Canada¹³) will be highlighted as a common theme. For example, participating in the biobank may take on a perspective similar to that established by Arbour and Cook¹¹ as a process entitled "DNA on Loan," which highlights the fact that a donated biospecimen belongs not to the biobank or researchers, but to the person from whom it was obtained. Or perhaps it may reflect the concept documented by Hudson et al.⁸ Hudson was a Māori scholar who consulted with Māori communities in New Zealand to describe participation in a biobank as "Tākoha," ie, seeing the donation of a biologic sample—a part of a person—as a sacred gifting of the responsibility for stewardship vested in the team for the donated sample. The governance structure of this northern British Columbia-based biobank will be developed, with the First Nations voice directing this coveted resource and with associated capacity building embedded in this process. Although these dialogues took time and resources over the years, they are a necessary step to optimize the potential of this biobank. More importantly, these dialogues established critical relationships and laid the groundwork to sustain what Arbour refers to as the continuous conversation.¹⁴

At virtually all NBI meetings and conversations with First Nations in northern British Columbia, the concern about and priority of cancer emerged as requested targets for their biobank to focus on. This highlights the importance of the established governance to ensure that community priorities drive questions of access and use of the biobank. First Nations in Canada have endured inequity in access to participation or representation in cancer research in all pillars, including population health, health services, clinical trials, and basic science. A recent publication by McGahan et al¹⁵ was the first of its kind to study cancer in British Columbia First Nations compared with the rest of British Columbia; their study included incidence and survival data over 18 years (1993 to 2010). Disparities that were expected, but never documented, came to light. These included increased incidence of common malignancies (eg, colorectal and cervical cancers) and lower 1-year survival rates for most malignancies studied. The role of oncogenomics to explore these disparities, decrease cancer incidence, and improve cancer survival would, for many First Nations leaders, be a research focus to explore using their biobank. The scope of questions that may be asked and the role of northern British Columbia First Nations in cancer research may be significantly improved by creating

this research platform and increasing awareness of the role that research can play in this evolving field.

Canada's so-called universal health care system is not truly universal, nor is access to the research that so fundamentally shapes it. The NBI is a proposed significant step to addressing inequities in access to biomedical research and the impact on the health care spectrum that such research has.¹⁶ The rationale is on the basis of the fundamental concept of equity. With the increasing number of disease-based biobanks and the seemingly exponential impact that genomic research is making on the health care spectrum (eg, risk profiling, screening guidelines and technology, diagnostic tests, treatment options, and outcomes), how can we ensure that all Canadians have the choice to be part of it? How do we include First Nations peoples, whose expectations for biobanks, research protocols, and cultural safety surpass what most established biobanks in Canada can provide? How can we ensure that British Columbia-based First Nations lead their health care transformation into Canada's genomic space in cancer care and research? The NBI is a research platform that aims to be part of the solutions that get the bench to the bedside, while staying true to its pursuit of equity by striving to address the vital question: "What bed-sides are getting to the bench?"

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