

## Article

# Frontiers of Bio-Decolonization: Indigenous Data Sovereignty as a Possible Model for Community-Based Participatory Genomic Health Research for Racialized Peoples in Postgenomic Canada

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**Abstract:** This paper explores the manners in which Indigenous and allied non-Indigenous researchers, medical directors, and knowledge-keepers (among others) extend the ethical precepts and social justice commitments that are inherent in community-based participatory research (CBPR) approaches to genomics. By means of a genealogical analysis of bioethical discourses, I examine the problem in which genomic science claims to offer potentially beneficial genetic screening tools to Indigenous and racialized peoples who have and continue to struggle with historical health inequity, exploitation, and exclusion by the very biomedical institutions which would be charged with the task of ethically introducing these biomedical tools. This investigation focuses on Indigenous data sovereignty (IDS) as an approach established by Indigenous communities and scientists to gain access to the benefits of genomic health which, if the field's promises are true, aims to counter the historical neglect or exploitation by biomedical researchers and institutions. I chart the role of CBPR principals as it pertains to collective efforts by both Indigenous communities and non-Indigenous allies to create the social, biomedical, and institutional conditions to improve Indigenous health equity in the context of genomic science in two specific studies: the Silent Genome initiative (British Columbia) and the Aotearoa Variome (Aotearoa/New Zealand). This investigation contributes insights to social science literatures in health equity for racialized communities, biomedical ethics, Indigenous Science and Technology Studies, and decolonial biomedical and technoscience histories.

**Keywords:** indigenous data sovereignty; community-based participatory research; health equity; genomics; precision medicine; race; Canada



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## 1. Introduction

In the 1940s, “participatory action research” sought to promote inquiries that were both relevant to and focused on facilitating concrete and beneficial socio-material interventions for subjects involved. What was especially novel was that this mode of inquiry sought to empower participants through scholarly investigation as an intrinsic part of the research enterprise (Minkler and Wallerstein 2010). The fruition of independence struggles in Latin America, Africa, and Asia in the 1970s imbued *participatory action research* with an additional, and an indispensable, meaning, which spoke to concerns of emancipation for those who had been previously exploited or marginalized (Rebecca 1997). Though genealogically related, *community-based participatory research* (CBPR below) is somewhat different because it has come to also incorporate important concerns for self-determination and sovereignty particularly as the method has been incorporated into research involving Indigenous communities in Canada (Masuzumi and Quirk 1993; Macaulay et al. 1998; Minkler and Wallerstein 2010).

Comprised within CBPR approaches are the possibilities of conducting research that is attuned to social justice and anti-racist commitments which, in the Canadian context,

are relevant not only to First Nations but also racialized communities more broadly. As an emergent product of the equitable and collaborative process whose orientation, principles, and protocols I thematize below, it is important not to think about CBPR as a template of ethical research protocols that is generically applied to all community-based research. Indeed, projects incorporating the ethical commitments of CBPR vary significantly between them, not only for reasons of contextual difference and community priorities but also because a given research undertaking may also be the site of political and cultural contestation within communities (Cornwall and Pratt 2010; Weijer and Emanuel 2000).<sup>1</sup>

In practice, it is incumbent on the involved researchers to remain vigilant to the history of exploitation and dispossession for which colonial science has been, and continues to be, responsible. In the context of health research with Indigenous communities, the point of departure for CBPR starts with community members and researchers co-defining a health or research problem taking into account Indigenous forms of knowledge, culture, and values (Chambers 1997).<sup>2</sup> The priorities of the community participating in the research and its socio-material development are paramount to the design of CBPR, and it characterizes the ethos that enables it (elaborated below). There must be mutual respect between researchers, government officials, health directors, and the community, and the latter must be continually involved such that Indigenous peoples are not only afforded the benefits of the research but are also given opportunities for forms of training in order to advance their human capital development (Tsosie et al. 2021b; Nickels et al. 2007). Similarly, ensuring that all the stakeholder groups *within* communities are represented serves to recognize the social (and to be sure, political) diversity within Indigenous nations (Kaufert et al. 1999). In contrast to all-too-common previous practices of convenient data or biological sample gathering by institution-based researchers, sometimes referred to as “helicopter” or “vampire research”, all participants must be open to knowledge-sharing, in multiple directions, throughout the various phases of the research project (Garrison et al. 2019b, p. 498). Under the auspices of research partnerships with Indigenous communities, consent has tended to be conceived in radically different ways than in conventional research. In particular, such partnerships have striven to balance the rights of individual participants with communities as a whole; this balance is a vital component of the processual and collaborative tenor of designing CBPR (Kaufert et al. 1999). The results of research and often permission to publish manuscripts are part of the process of reporting back to the participating community, which ought to be undertaken regularly as the project progresses (Nickels et al. 2007; Ritchie et al. 2013).

The introduction of genomic science to clinical practice and health research introduces both possibilities and challenges to address health inequities which Indigenous and racialized communities encounter in ways that are significant and institutional. Over the past decade, genomic science has produced novel tools for preventative screening particularly as it concerns chronic diseases, such as rheumatoid arthritis, gout, diabetes, a limited number of cardiac events, and adverse reactions to anesthetic (among others), many of which can be prevalent in some, but certainly not all, Indigenous and racialized communities in Canada (Fowler-Woods et al. 2021; Crowshoe et al. 2019; Nakatsuka et al. 2017). However promising these tools claim to be, the exploitation of biological and genetic data of Indigenous communities in particular since the 1980s (and continuing to the present) makes First Nations rightfully weary of participating in conventional genetic screening studies. Coupled with this kind of caution, the explosive interest in genetically mapping the genomes of racialized communities, notably South Asians who constitute a group that has been of disproportionate interest to contemporary genomic scientists, for example, introduces concerns regarding consent, genetic data access, data ownership, and stewardship which parallel those already articulated by Indigenous communities (Nakatsuka et al. 2017; Durbin et al. 2010; Basu et al. 2003)<sup>3</sup>.

Indigenous communities and scientists posit that the protocols aligned with Indigenous Data Sovereignty (IDS below) can provide safeguards for ethical genomic research. This is the case, in part, due to the fact that IDS is grounded in community-based partici-

patory research methods which are anti-racist and anti-oppressive in nature (Caron et al. 2020; Tsosie et al. 2021b). While the genealogy I undertake below traces the emergence and evolution of genomics-related IDS, its introduction to the fields of health and the life sciences has been framed by the struggles of Indigenous communities and researchers to regain full control over their demographic, territorial, and biostatistical data (among other kinds) as an indispensable tool of sovereign self-government (Kukutai and Taylor 2016). How CBPR precepts and protocols are translated for ethical biomedical research in the context of genomics seems to be a vital question regarding the purchase of adopting genomic tools as part of the enterprise of striving to attain health equity for both Indigenous and racialized communities in Canada.

This article explores the manners in which Indigenous communities, knowledge-keepers, medical directors, researchers, and their allied non-Indigenous counterparts extend the ethical precepts and social justice commitments that are inherent in CBPR to contemporary genomics in Canada. Specifically, this exploration traces the manners in which IDS strives to empower Indigenous communities, medical professionals, and scientists to gain access to the benefits of genomic health countering a history of neglect or exploitation by biomedical researchers and institutions. I explore the possibilities that IDS can serve as a model not only for First Nations in Canada but also racialized communities, both of whom encounter some parallel challenges regarding achieving more equitable and culturally safe health services (while acknowledging historical, socio-economic, and cultural differences between Indigenous and racialized settler groups, of course).

This analysis of the manner in which the commitments as well as protocols of CBPR have been extended to genomic science is organized in the following manner. First, I review the prospects that advocates of genomic science suggest the field offers to extant genetic screening practices which could be consequential for Indigenous and racialized peoples. Here, I trace the struggles that Indigenous communities in Canada have historically encountered particularly as they concern university-based, non-Indigenous researchers conducting genetic screening studies, without incorporating CBPR protocols, in British Columbia in the 1980s. Next, I discuss the concept of *DNA On Loan*, which advanced the first vision of IDS, built as it was on established protocols of CBPR in the late 1990s and early 2000s. In the third section, I discuss problematic premises of the Human Genome Diversity Project, referred to by scholars as a form of “salvage genomics”, focusing on the critical responses by Indigenous communities and decolonial scholars who underscore how such initiatives are linked to various legacies of colonial science and biomedicine (TallBear 2013, pp. 149–51; Abu El-Haj 2012, p. 27). In the section that follows, I chart the role of CBPR principals as it pertains to collective efforts by both Indigenous communities and non-Indigenous allies to co-create the social, biomedical, and institutional conditions to improve Indigenous health equity in the context of applying the tools of genomic science to genetic screening in two specific studies: The Silent Genome initiative (British Columbia) and the Aotearoa Variome (Aotearoa/New Zealand). I describe the role of Indigenous forms of knowledge and the unique solutions to data governance that advocates of IDS have proposed and enacted in both studies. By way of a conclusion, I outline how approaches aligned with the tenets of IDS demand participating scholars to accommodate diverse research methods and ethics especially as it concerns the organization of genetic data and its governance. I also explore how ethical research based on IDS protocols, and commitments to health equity that inhere the approach, might align with pledges to promote more equitable health access for both Indigenous and racialized communities. I underscore some of the hazards that persist with contemporary studies aiming to complete a “more inclusive” map of human genomes, at the center of which is the objective to fully map out the genomes of Indigenous and racialized peoples.

## 2. Genealogical Methods of Technoscientific Objects

This account does not follow conventional methodological protocols of an inquiry that the reader might encounter in the history of science or medicine, or Indigenous or

decolonial history, in which scholars have tended to examine events that may have occurred at least thirty years ago (if not more). In many ways, this is because of the context of the study of Indigenous and racialized peoples' experiences with biomedicine as it intersects with the introduction of genomics, which is constituted by novel bioinformatics and computational technologies, to clinical medicine (referred to as *precision medicine* or *precision health*). (Precision medicine is defined as involving, for example, individual genomic mapping to ascertain disease predisposition.) As such, the genealogy I seek to trace is informed by the observation of technology studies scholar Paul-Brian McInerney (2014), who suggests that an entire era can pass in a mere decade when historicizing information and computer technologies (McInerney 2014). As such, the genealogy which I explore here concentrates on Indigenous data sovereignty, which comprises institutional practices that emerged approximately fifteen years ago.

Evidence on which this inquiry is based include published oral testimony in addition to the interpretation of a variety of documentary sources which, together, form the archive of this investigation. I constructed this archive in the following manner. First, I collected articles published in journals exploring biomedicine, bioethics which discuss Indigenous data sovereignty in Canada and its comparisons with parallel initiatives in Aotearoa/New Zealand, Australia, and the United States; I began with articles in which Indigenous researchers were the authors or coauthors. I supplemented these documentary sources with institutional statements and various media publications (each in print, radio, and video) that discuss Indigenous data sovereignty and genetic screening studies undertaken among First Nations communities in Canada, the United States, Aotearoa/New Zealand, and Australia, including instances of exploitative research practices and efforts undertaken to address such abuses. I also consulted the published testimonies of residential school survivors published under the auspices of the Truth and Reconciliation in Canada, in addition to those included in volumes focusing on the history of residential schools and the survivors' testimonies documented in these texts. Because it is directly relevant to the emergence of the field of genomics and precision health, I also collected critiques articulated by Indigenous health advocates and Indigenous scholars regarding the Human Genome Diversity Project (HGDP, below), which has been expanded and amalgamated into the 1000 Genomes project maintained by The International Genome Sample Resource (IGSR) (<https://www.internationalgenome.org/home>, accessed on 7 June 2022).

Themes that emerged from my interpretation of archival evidence included experiences with abuses and ongoing exploitation of colonial medicine, residential schools, social determinant of health, sovereignty and self-determination, community-based participatory research and training, the field of medical genetics and genetic screening, disease prevalence, the *omics* family of screening technologies, resistance to human genome mapping projects, research ethics concerning Indigenous and racialized communities, Indigenous health and data sovereignty, biobanking stewardship of biological samples, biological data access and governance, genomic databases, and Indigenous knowledge and wellness.

The reader should take note of the following three qualifiers. First, this investigation does not strive to make a comprehensive presentation on genomic research as it intersects with health priorities of Indigenous and racialized peoples everywhere. Indeed, many of the examples regarding the participatory role of Indigenous communities in health research included in this article reflect the history and governance structures of health research in Canada.<sup>4</sup> However, I do touch on issues of Indigenous health in many points by amplifying the views of First Nations communities and scholars as it pertains to population genomics and Indigenous understandings of wellness. Second, it is not my intention to represent Indigenous data sovereignty studies as a panacea to the many forms of inequality confronting Indigenous and racialized communities or issues of structural racism within health institutions. Last, the reader should not get the impression that I am the first to articulate the social-justice aims of IDS in the context of community-based participatory research in biomedicine. As I hope the reader will remember, the claims of authors working on Indigenous data sovereignty initiatives echo—and are aligned with—many of the findings

of scholars working outside of genomics on, for example, diabetes, health services research, and health sciences education. These scholars articulate calls for health equity for Indigenous and racialized peoples by also underlining the awareness that is requisite regarding social and cultural factors of disease occurring across these communities (Crowshoe et al. 2019; Fullwiley 2011; Ahmed et al. 2016; Savulescu and Kerin 1999; Duster 2003; Henderson et al. 2018; Barnabe 2021). It is my hope that the genealogy advanced in this inquiry supports, amplifies, and is allied with their findings, their prescriptions, and initiatives.

### 3. The Human Genome Project, Genetic Screening and Racialized Peoples

Genomic science emerged as a significant field after the initiation of the Human Genome Project in the 1990s, which sought to map out the entire human genome with the aim to identify disease-causing genes (Rajan 2006). Though a draft mapping of the human genome was completed in 2000, the Project failed because it became more widely recognized that the presentation of disease was correlated with complex epigenetic factors and could not be causally reduced to the presence of a specific gene variation (as was originally hypothesized). Still, the advances in bioinformatics analysis on which the Project depended initiated a veritable explosion in new methodologies and diagnostics to conduct screening which include proteomics, transcriptomics, lipidomics, and metabolomics (among others). These screening technologies require the analysis of different aspects of blood and tissue, but they are also similar in their reliance on the computational analysis of genetic data, so I will refer to them generally as genomics for the reader's ease of reference.<sup>5</sup>

Existing screening diagnostics predate the HGP, and they might have been very effective tools for the practice of preventative health within Indigenous communities. Indeed, Cheryl Barnabe's (2021) findings on health care systems serving First Nations suggest that these communities tend to be treated for acute illnesses rather than being able to access preventative care (Barnabe 2021). Rheumatoid arthritis, diabetes, a limited number of cardiac events, and adverse reactions to anesthetics might be prevalent in some, but not all, Canadian First Nations and racialized communities, particularly South Asians (Fowler-Woods et al. 2021; Crowshoe et al. 2019; Nakatsuka et al. 2017). Some Indigenous communities have distinguished themselves in rightfully and deliberately expressing their reluctance to participate in genetic screening studies owing, at least most recently in western Canada, to a scandal involving the exploitation of blood samples taken from the Nooka (Nuuth-chah-nulth) community in the 1980s in northern BC. At the time, it was University of British Columbia researcher Ryk Ward with whom the community had agreed to provide biological samples for the purpose of investigating if there existed a genetic marker for rheumatoid arthritis within the group. Ward failed to find one within the community; however, he reused the samples and the data derived from them without permission to study the ancestry and incidence of retrovirus, referred to as secondary research, when he was subsequently appointed at the University of Utah and then Oxford University (Dalton 2002). The case prompted the creation of federal guidelines for medical research concerning Indigenous communities in Canada, specifically, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, *Guidelines for Health Research Involving Aboriginal People* and the *Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People*.<sup>6</sup> Despite the publication of these policy statements and guidelines, the experience of the Nuuth-chah-nulth has pushed a number of communities in Canada to be weary of participating in genetic screening studies.

Ward's exploitation of Indigenous biology echoes the historical experience of many Indigenous communities with medical treatment more generally. Of the heartbreaking litany of examples that we are still discovering, one can hear Sara Saimaiyuk's story about her incarceration for tuberculosis exposure in the Charles Camsell Indian Hospital in Edmonton in the 1950s. She recounts:

When I got to the hospital, all my clothes were taken away from me, maybe because I was more infected than the others. I never thought I was that sick. All this time there were no interpreters . . . At the time I was just a young girl



and unmarried. I didn't want to go home because I got to like some Inuit in the hospital and I didn't want to leave them. I was in the hospital for three years (Meijer Drees 2013, p. 81).

This story describes a context in which Indian Health Services hoped to control the bodies of Indigenous children who exhibited symptoms of TB by removing them from residential schools and confining them to sanatoria for extended periods of time that were located in central Alberta, as in this case, but also southern Saskatchewan and central and southern Manitoba (Hackett 2008; Komarnisky et al. 2016). There, Indigenous children might have struggled with isolation, being located far from their families who might reside near their residential school, in addition to boredom and ennui.

While one could recount many more stories, unfortunately, this examination is aligned with novel insights from Indigenous Science and Technology Studies and decolonial studies that shift the focus from the important (and continuing research) of racialized peoples' health experiences under the theme of coloniality toward also asking questions falling under the rubric of *sovereignty* (Bastien 2004; Venkat 2021; Banerjee 2020; Fullwiley 2011; Cajete 2000; Kolopenuk 2020a; Munsterhjelm 2014; TallBear 2013). The latter-mentioned intellectual currents follow the novel explorations which emerged over the past decade by Indigenous communities, Elders, and scientists who seek to rethink the ethical, methodological, and clinical purchase of contemporary biomedicine to which I also connect genetic screening studies under the rubric of IDS.

But how might one proceed to consider genomic innovations critically in the context of the health priorities and histories of racialized peoples? The positions articulated by Indigenous communities regarding these innovations might indeed be instructive to the efforts to achieve health equality from colonial biomedical institutions, which confront all Indigenous and racialized peoples. Jessica Kolopenuck's observations are noteworthy when she remarks:

the study of DNA has been ascending as the fields of science, politics, economy, and law continue to be defined by colonial imbalances in which Indigenous peoples are too often dispossessed from their authority to govern the policies and knowledge output that affect them. (Kolopenuk 2020b, p. 27)

Biomedicine, from which colonial medicine is inseparable, has not only been cruel, uneven, or inadequate in addressing health challenges among First Nations, it has also been dispossessing.

In the manner that Indigenous communities critically rethink the benefits of biomedical innovations, such as genomics, I pose a question as to whether sufficient safeguards exist to prevent exploitation, which genomic-based screening for racialized peoples might also introduce. One of the first sites in which to rethink genomic and genetic research in this respect concerns the treatment of DNA.

#### 4. Beginnings: DNA on Loan

As I have suggested so far, genomic science seeks to advance new tools to Indigenous and racialized peoples in the form of genetic screening studies for conditions that are prevalent in these communities. If such tools can in fact be ethically put in the service of these communities, they would gain valuable access to preventative care, which heretofore has largely been inaccessible and/or denied to them. Paradoxically, biomedical institutions have historically exploited the genetic samples and data of Indigenous and racialized peoples, thus making them rightfully weary of participating in such biomedical studies. Whether and how DNA, and the data derived from it, will be ethically used and accessed, or whether it will be exploited again as did Ryk Ward, lies at the heart of the skepticism articulated by these communities toward genetic screening studies.

As one response to Ward's abuses, Indigenous and non-Indigenous geneticists, data scientists, and bioethicists in Canada have proposed IDS as an approach that safeguards

Indigenous interests, taking from broader efforts to safeguard the data of First Peoples. This includes the

rights and interests of Indigenous peoples relating to the collection, ownership, and application of data about their people, lifeways and territories ([Kukutai and Taylor 2016](#), p. 2).

In many ways, IDS can be viewed as a contemporary movement within and outside biomedicine with multiple and different initiatives launched in Canada, Aotearoa/New Zealand, Australia, and the United States. Indigenous claims on data, which have been historically collected, coveted, and often used against community interests by colonial governments, have been viewed as being indispensable to sovereign governance generally ([Taylor and Kukutai 2015](#)). The explicit articulation of the movement and its principles in the field of health came after its first practices were undertaken. Instances of the application of “DNA on loan” approaches took place among communities in western Canada in the early 2000s with Laura Arbour and Doris Cook, respectively, a non-Indigenous geneticist at the University of British Columbia and a senior health analyst from the Mohawk Nation (and residing on the reserve) ([Arbour and Cook 2006](#), p. 155). At the time, they opposed the prevailing view within the field of genetics invoking the writing of Frank Dukapoo, the noted geneticist from the Hopi nation. He stated:

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. (Dukapoo, quoted in [Arbour and Cook 2006](#), p. 155)

Parallel to health-focused CBPR, which begins with the forms of understanding and knowledge of the participating Indigenous community in Canada, the meaning of DNA and related biological samples are not merely material, they carry spiritual, metaphysical—and in the context of medical research—significant ethical connotations that medical researchers and professionals must consider. This view on bodily fluids and tissues thus proposes significant different protocols for the handling of biological samples compared with conventional science, hence the focus on the *data sovereignty* of Indigenous communities (about which I elaborate below).

In many ways, principals of *DNA on loan* emerged out of the institutionalization of CBPR in Canada. It incorporated principals of the empowerment of communities participating in research at the center of which was the struggle for self-determination ([Arbour and Cook 2006](#), p. 155). This enterprise was undertaken in the context of the establishment of guidelines between 1993 to 2001 which defined ethical research involving Indigenous communities along the model of community-based participatory research that include specific protocols for working with Dene/Metis communities, Inuit, Kahnawake, Akwesasne, and Cree communities in Canada. In the context of research with Indigenous communities, Arbour and Cook distilled some of principles, beginning first that it had to prioritize the development needs of the communities participating in the research, and the point of departure for its framing began with the knowledge of these communities, their culture, and traditions.<sup>7</sup>

With Arbour and Cook on the foreground, DNA on loan is premised on respecting the sovereignty of Indigenous communities through every aspect of a research project. They note:

Aboriginal peoples, First Nations, Metis, and Inuit, comprise nearly 4% of the total Canadian population. The historical, political, and cultural structure of these First Peoples of North America requires special consideration in research ethics, i.e., one that respects the notion of ‘self-determination’ unlike in most other non-aboriginal communities . . . 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 [*sic*] (Arbour and Cook 2006, p. 154).

Unlike conventional research then, medical research with Indigenous communities cannot be undertaken for the purpose of contributing to scholarly knowledge alone. The needs of the participating community are intrinsic to the development of the research enterprise from the moment the research question is being constructed, and research results are therefore also reported back to the community. The location of the community and their governance structure reveal how the practice of DNA on loan is varied. For example, permission to conduct research in the United States with Tribal nations requires permission from its Tribal Institutional Review Board. Departing from the Canadian guidelines, urban indigenous communities in the United States can require partnerships and permission from a local Native organization(s).

In this iteration of CBPR, then, unique approaches concerning the ownership of the data have tended to be generated from the research project. At the time of the publication of “DNA On Loan”, two arrangements were proposed for the ownership of biological samples and data: they could either be shared between the community and the researcher or the latter would be committed to data stewardship. Regardless of the arrangement, Arbour and Cook proposed that blood and tissue samples be considered to be the perpetual property of the donors and the community involved, that it is on loan to the researcher (hence the term *DNA on loan*). To address previous abuses of reusing the samples or data generated from them without permission (as Ward had done), the project would adopt a “stepwise consent” structure in which additional research would be proposed to the community for their consideration as it emerged to be relevant (Arbour and Cook 2006, p. 155).

More generally, DNA on loan has been embedded in an iterative process of collaboration, which privileges the knowledge, priorities, and cultural understandings of the community. Within this frame, researchers and communities, perhaps forming a separate review board with Elders and professionals, would address: how genetic information would be used, issues of privacy and confidentiality, discussions of potential stigmatization which might arise from discovery of genetic variations associated with specific diseases, psychological impact, reproductive issues, education and standards of quality and control, and any impact of commercialization. They also noted that issues concerning stigmatization, psychological impact and reproductive issues must be considered by the research team in the appropriate cultural setting and recognizing the historical context of cultural repression and reduced standards of health care availability in Indigenous communities.

Most important, Arbour and Cook did not suggest a single method or paradigm but underscored instead a complex of issues and concerns that could be dialogically addressed to generate a unique research plan, enshrined in a research contract, to which all parties were willing signatories. It is in this particular domain that DNA on loan can become an interdisciplinary undertaking in that social scientists might play a role in interfacing between community and researchers to facilitate this ongoing dialogue, translating cultural understandings and social and institutional priorities from the community in addition to their responses to the issues outlined above. One issue this seminal publication did not explicitly address is the place and role of the Indigenous scientists, though the provision of training is certainly mentioned. A second wave of the IDS movement takes this up (and which I explore in subsequent sections).

I should contrast Arbour and Cook’s approach with what had, and often still continues to, prevail with conventional research projects. Previously, identifiers on blood and tissue samples might have been removed after which secondary research could be undertaken. In many ways, the entire enterprise of DNA on loan and community-based participatory research departed from the existing research methodologies that prevailed in much biomedical research including genetic health research at the time. The authors note that many of the principals of community-based participatory research which I outlined above were incorporated into social science research but were implemented unevenly in health research at the time of press (2006), with epidemiology and public health leading the way, but less



so in biomedicine generally, especially in genetic research. The authors note that prevailing biomedical research methodologies have been hypothesis-driven, focused on discovering cause and effect relationships. As opposed to prioritizing the needs of communities, the purpose of biomedical research was to contribute to knowledge within the field. While conventional human subjects' protections governed how participants were recruited, they were rarely included in research development with the results expected to be published but not returned to the participants. Similarly, conventional research ethics place an emphasis on the anonymity of subjects, and the safeguarding of participants has tended to focus on inducements to ensure that participation has not been coerced. Reflecting the prevailing norms of its publication in 2006, Arbour and Cook indicated that DNA on loan does not preclude the establishment of a "tribal controlled DNA bank"; however, this aspect was not fully developed until almost a decade later by a cohort of Indigenous scientists and social scientists (Arbour and Cook 2006, p. 156).

### 5. CBPR, Population "Isolates" and IDS

Between the publication of DNA on loan protocols in 2006 and 2019, initiatives to establish background variant databases were undertaken in Canada, Aotearoa/New Zealand, Australia, and the United States. Simultaneously, several statistical surveys of Indigenous communities, based on the principals of IDS, were also undertaken globally. Notably, and as a fillip to these efforts, the United Nations Declaration on the Rights of Indigenous People was adopted in 2007 and it informed the agendas of these data sovereignty projects in subsequent workshops that were held in these countries in 2015 by an international group of scholars, representatives of Indigenous organizations and government personnel from Canada, Australia, Aotearoa/New Zealand, and the United States (also sometimes referred to as CANZUS) (Kukutai and Taylor 2016). Particularly relevant to the Canadian context, the report of the Truth and Reconciliation Commission in Canada was also published in this period. Two of the Commission's *Calls to Action* demand that "the gaps in health outcomes between Aboriginal and non-Aboriginal communities" be closed and for the value of "Aboriginal healing practices" to be recognized and used "in the treatment of Aboriginal patients", among other Calls pertaining to improving Indigenous health (Truth and Reconciliation Commission of Canada (TRC) 2015, pp. 2–3).

Within medical genetics, the science of genomics advanced the field significantly in this period of time with the introduction of the concept of precision health. This has comprised the comparative analysis of individual patient genomes to a database cataloging genetic variations (referred to as a background variant database) as a new diagnostic tool for preventative health.<sup>8</sup> As I discuss below, the issue over the control, analysis, and access to the genetic data of Indigenous and people of colour was, and remains, a vexing issue when it pertains to sharing the possible benefits of genomic and precision health with these communities.

Genomics also came to be associated with another controversy in the 1990s, namely, the Human Genome Diversity Project (HGDP, below) for which specific Indigenous communities globally became of significant because it was incorrectly presumed by physical anthropologists and geneticists participating in the Project that these communities possessed unique genomes because of continuous practices of endogamous marriage (i.e., marriage within ethnic, caste or "tribal" groups). The HGDP aimed to make up a deficit in the mapping of human genomes in that the HGP depended on primarily European genomes (and only those of eleven persons at that (Khamsi 2022, p. 3)). According to proponents of the HGDP, genomes from specific communities identified in Africa, western Canada, the United States, the Amazon, the South Pacific, India, central America, Siberia, Spain, and Taiwan were thought to be isolated and "relatively unmixed descendants of ancestral populations". Erroneously, it was assumed that members of these communities were untouched by European ancestry, whose genomes might be a record of humanity's genetic heritage documenting the "prehistoric migrations, natural selection, the social structure of populations and the frequency and types of mutations" the human species

might have experienced (Cavalli-Sforza et al. 1991, p. 490). Of interest to the study of genomics in western Canada, the Tsuut'ina and Stoney Nakoda were two communities on a list of 722 who were targeted by the HGDP. No Indigenous scholars, Elders, or representatives were included in these meetings and, as analyzed by anthropologist Joanne Barker, the HGDP was rightly excoriated by Indigenous groups and scholars globally for its racist assumptions, the exclusion of Indigenous communities from its proceedings, and the intention to store the cell lines in repositories and gene banks controlled exclusively by scientists and the institutions at which they were appointed.

Informed by both the hazards of the HGDP and previous scandals of the unauthorized use of Indigenous genetic samples and data by biomedical scientists, two initiatives in Canada and Aotearoa/New Zealand have sought to adapt the protocols of IDS, which had originally started to be explored in relation to demographic survey data pertaining to Indigenous communities. These ongoing initiatives have sought to explore the possibilities of creating Indigenous-controlled databases that would store genetic information based on biological samples collected from eight communities that are also participating in the Canadian Alliance for Healthy Hearts and Minds cohort study. The Silent Genomes study (SG below) has been conducted in northern BC, and the Aotearoa Variome study (AV below) has been conducted in Aotearoa New Zealand. Co-PIs of each study have sought to bridge what geneticist Nadine Rena Caron calls “the genomic divide” (Caron et al. 2020, p. 111). As Caron et al. (2020) indicates, such a divide exacerbates already-existing disparities in health arising from an historical lack of access to safe, respectful, and effective health services to which she and her coauthors add genetic knowledge. Specifically, they note that existing genomic databases, i.e., the Genome Aggregation Database, largely omit genomes from First Nations peoples, thereby excluding them from the possible benefits of being able to preventatively screen Indigenous peoples for genetic variations associated with specific diseases.<sup>9</sup>

Both SG and AV have adopted the DNA on loan protocols to establish Indigenous-led and -designed databases of genomic data. As Caron and her coauthors (2020) describe, both studies begin with Indigenous ethical frameworks. The AV, for example, interprets DNA on loan as *takoha* or a gift of responsibilities, which obliges whomever uses the data to deliver outcomes that are useful to the community and require research to be conducted in a culturally appropriate manner (Caron et al. 2020, p. 4). Reflecting a demographic change in the field in which many more Indigenous scientists are active in the life sciences, these databases are co-designed by scientists and community members, and the studies are co-led to benefit the participating communities as a way to enact “Good Actions/Actors” versus insights that might be of mere intellectual curiosity (i.e., evolution or migration) (Caron et al. 2020, p. 5).

Probably central to the ethical grounding of these studies is the structuring of Indigenous governance over data. In the case of the AV, a leadership group, consisting of Maori professionals and researchers, provide project oversight and direction in addition to assisting with the development of governance policies and community engagement. Indigenous partners are consulted and collaborate in the Silent Genomes study and, at the time of writing, continue to explore the possibility of creating an Indigenous genomic database, implementing and sustaining it as a clinical tool. Most important, Silent Genomes has established an International Indigenous Genomics Advisory Council that develops a governance structure for the database and policy guidelines that establish best practice models for the oversight of biological samples and genomic data. As an overarching goal, Indigenous self-determination and ownership are central in order to enable communities to realize control of their own destiny, which, the authors describe, is an Indigenous articulation of their communities being worthy recipients of health services.

The following practices exemplify the creation and management of these samples and data. Samples are stored in a biobank or repatriated for disposal in a culturally appropriate manner. In the words of the legal scholar and bioethicist David Winickoff, these studies seek to shift the focus of genomic research from only involving benefit sharing to also

devise “power sharing”. Here, I want to direct the reader’s attention to the manner in which such practices contrast with more conventional approaches to data governance. As Maui Hudson and their coauthors (2020) stress, relatively recent calls to embrace “open data” and “data sharing” protocols regarding genomic data introduce the same hazards of exploiting Indigenous communities for their biological data as in the past (Hudson et al. 2020). Krystal Tsosie and her coauthors issue a parallel caution in the context of the hasty embrace of “open data” practices in biological anthropology where it concerns biological and physical data belonging to Indigenous communities (Tsosie et al. 2021b). These authors underline the consensus that the uncritical adoption of open data practices would be an anathema to the ethos community-based participatory research in the current postgenomic era, which situates the participating community’s health priorities at the center of a project out of which research questions, methods, findings, and treatments are generated. In contrast, open data places Indigenous biological data in the service of academic exploration and curiosity for which there is no explicit consent by the communities being represented and researched (Tsosie et al. 2021b). It is inspiring and noteworthy, then, to note that Indigenous institutions in Canada appear to have led the way in the field of First Nations data governance through the creation of the OCAP® trademark and protocol, representing the Ownership, Control, Access and Possession of data concerning Indigenous communities (FNIGC 2016). The trademark is held by the First Nations Information Governance Centre (FNIGC 2016), which came into being when a comprehensive health survey of and by Indigenous communities was undertaken in the late 1990s, with the data kept within the Centre (FNIGC 2016).

## 6. Indigenous Knowledge, Data Governance, and Training

Indigenous forms of knowledge are indispensable to the organization of the data which are generated from blood and tissues samples that the respective teams of both the SG and AV have collected. Through the support and direct participation of Maori *whakapa*, who are genealogy keepers, the AV project incorporates traditional knowledge of genealogy, based on oral histories and Maori tribal affiliations, as genealogical indicators/guides of the collected samples. As a consequence, the study ensures that a diversity of participants and genealogical groups are represented in the project. Additionally, members of the AV research team have approached communities who participated in previous studies in which full genome sequencing was not undertaken to explore if there exists an interest in having their genetic data entered into a database. In the context of the SV project, eight communities, which are also participating in the Canadian Alliance for Healthy Hearts and Minds cohort study, will decide if they want to participate in the planned database construction weighing if diagnosing a single-gene disorder is relevant and beneficial to the collective health of their respective communities. For the SG project, genetic diseases occurring among Indigenous children have come to be the focus of the study’s clinical application. If the participating communities consent to its creation, this database will catalog variants observed in Indigenous communities to support future genomic analysis (as per the stepwise protocol, described above).

Biological anthropologist Krystal Tsosie and her coauthors Joseph Yracheta, Jessica Kolopenuk, and Rick Smith discuss health and genomics-related IDS initiatives in New Zealand, Canada, Australia and the United States more broadly. They note that Indigenous research review boards (RRBs) can replace or work with university-based Internal Review Boards (IRB), the latter of which is the only body typically charged with the task of reviewing the research ethics of biomedical studies (Tsosie et al. 2021a). The principles of IDS which I have outlined so far may also be enshrined at the outset at the stage in which IRB takes place and take the form of the establishment of a relationship between institutions and Indigenous nations and the forms of collaboration which characterized the tenets of DNA on Loan (Marley 2021). All the studies I discussed above also acknowledge the need for flexible understandings of research ethics and compliance for biomedical studies involving Indigenous communities compared with those which do not. For example, Tsosie

and her coauthors point out that consent may be defined across communities in different ways and may require community-wide or an arrangement of co-consent, depending on the context (Tsosie et al. 2021a). In all situations, the context and frameworks of Indigenous knowledge ought to define each IDS undertaking with the understanding that there is no single Indigenous perspective, framework, or model partnership (Arbour and Cook (2006) also stress this). Enthusiasm for a given project on behalf of community members may be variable, and this may also shape the structure of how access to the data is governed. The approaches that Tsosie and her coauthors describe, which are based on their experiences, would thus have to be tailored for each research initiative (Tsosie et al. 2021a).

Tsosie and her coauthors also note that databases housed on Indigenous territories create institutional opportunities for Indigenous research and training to take place in addition to being able to curate and control the circulation of data (Tsosie et al. 2021a). Indeed, articulations of self-determination extend well beyond historical claims to land and material resources to also include data, research, and science, as foregrounded in early articulations of IDS that were not solely focused on health data (Kukutai and Taylor 2016; Taylor and Kukutai 2015). In Canada, some of the first claims to govern data and information pertaining to First Nations communities were embodied in Indigenous principles of Ownership, Control, Access and Possession (OCAP®), which has been trademarked and has been housed in the First Nations Information Governance Centre (FNIGC) since 2010 (FNIGC 2016; Walter and Carroll 2021; Kukutai and Taylor 2016). Relatedly, Nani-baa' A Garrison and her coauthors report that the control and ownership of digital data, including data-sharing agreements, are part of the Kahnawà:ke National Indigenous Data Centre established by the Mohawk community of Kahnawà:ke in Québec (Garrison et al. 2019b). Grand Chief Joseph Tokwirot Norton of the Mohawk Council of Kahnawà:ke has in fact stated, "We are leveraging our existing Kahnawà:ke Indigenous Data Sovereignty Centre and working closely with global software companies to become the global leader in Indigenous Cloud, software and secure data management." (quoted in, Garrison et al. 2019b, p. 509) Similarly, the Native Biodata Consortium located on sovereign lands of the Cheyenne River Sioux Tribe in Eagle Butte (South Dakota) strives to harness the analytical power of genomics to improve the health of Indigenous communities through the studies its teams of scientists conduct. In an attempt to integrate Indigenous ways of knowing, which emphasize relations between peoples, ideas, and land (among other things), the Consortium is running several studies including a study of Rheumatoid Arthritis, the Cultural, Ethical, Legal and Social Implications of Omics research, and two studies that are agriculturally focused (i.e., cell culture developing using gene editing and soil enhancement) (Tsosie et al. 2021a). In all these efforts, it has been vital that the epistemologies employed in these studies are deemed to be ethical using frameworks relevant to the Indigenous communities who are, ultimately, the beneficiaries of this research (West et al. 2020).

## 7. Genomic Health Equity for Indigenous and Racialized Peoples in an Era of Precision Medicine

In the beginning of this article, I indicated that this genealogical analysis would trace the manners in which IDS strives to translate the social justice commitments of CBPR to the application of genomic science in clinical medicine. I also aimed to reflect on the possibilities that IDS not only addressed some facets of structural health inequity that confront Indigenous peoples but also those parallel forms encountered by racialized communities. I specifically identified rheumatoid arthritis, diabetes, a limited number of cardiac events, and adverse reactions to anesthetics as examples of diseases that might be prevalent in some, but certainly not all, First Nations and racialized communities (Fowler-Woods et al. 2021; Crowshoe et al. 2019; Nakatsuka et al. 2017). As piloted by Indigenous communities and scientists in the SG and AV studies analyzed above, IDS strives to redefine if and how genomic tools might be incorporated into preventative genetic screen studies for diseases known to be mitigated if proactively monitored in advance. I am convinced that the principles of IDS, underpinned by social justice commitments as



they are, suggest a way to provide access to genomic-based preventative screening for both Indigenous *and* racialized peoples. I state this given the fact that Indigenous and racialized peoples are both, but not equally, structurally marginalized by colonial health institutions. As the current literature already confirms, without access to preventative care, Indigenous and racialized peoples consistently find themselves navigating a health crisis in acute care contexts for some of the conditions I mentioned (Barnabe 2021; Ahmed et al. 2016).

While the potential of genomic science might hold promise for addressing health inequities that confront Indigenous and racialized peoples, we currently also find ourselves in a moment in which competing teams of genomic scientists are striving to assemble lucrative databases of genetic markers. Such biotechnological tools will be indispensable to providing “enhanced” and “customized” health monitoring, which characterize precision medicine, based on individualized genome mapping, for which comparison with a rich library of genetic markers will be indispensable for the task of accurately identifying disease predispositions (Tsosie et al. 2021a; Garrison et al. 2019a; Hudson et al. 2020; Nakatsuka et al. 2017; Yin 2017; Sengupta et al. 2016; Altshuler et al. 2010).

The salvage genomics projects that I reviewed above (i.e., HDGP), in addition to novel ones currently underway, such as *1000 Genomes* and possibly the *Human Pangenome Project* (HPP, below), risk being complicit in the exploitation of genetic data belonging to Indigenous and racialized peoples who are specifically targeted for “inclusion” in their respective databases (Khamisi 2022, p. 4). As described in the context of the HPP specifically:

genome maps have improved, but still don’t adequately capture humanity’s vast diversity . . . [Therefore] the goal [of the Human Pangenome Project] is to do detailed, reference-quality genome sequencing of about 350 people from different backgrounds and to share those data as freely as possible (Khamisi 2022, p. 4)

While co-Principal Investigator Dr. Evan Eichler and his collaborators’ intentions may be driven by astute scientific observation about what is missing in the existing map of the entire human genome, and they may be committed to include the genomes of peoples excluded by the earlier genome mapping projects, the risks invited by projects seeking to “include” humanity’s genetic “diversity” are also significant and complex. First, the desire to include the genomes from racialized peoples is of strategic biomedical and financial importance rather than only being an effort that is altruistically inclusive in nature. This is the case because these previously excluded genomes provide data regarding genetic human variation that are currently absent in extant libraries of genomic markers. Do the goals of those scientists (and the entities with which they are affiliated) who are constructing this particular human genome map align with the health priorities and cultural understandings of wellness of those excluded and ‘diverse’ communities who have provided the biological samples necessary to fill in the gap in the human genome? Have these communities been fully informed of the data sharing protocols that are inherent in the construction of such a genome map and have they been fairly compensated if they choose to participate? Second, increasingly prevalent “open data” arrangements with genomic data re-introduce risks of biological exploitation for racialized communities discussed above. (In fact, they may introduce similar risks for a participant of any background also if one pauses to consider the issue carefully.) How have these risks been mitigated? Krystal Tsosie notes:

It is therefore a mistake to think about modern scientific advancements (including the bioethical and data sharing policies that regulate them) and colonialism as distinct entities, or as mutually exclusive possibilities, when they have long been one and the same. Therefore, the presumed decoloniality of increasing data access and data sharing is neither self-evident nor universal. (Tsosie et al. 2021b, p. 183)

Tsosie and her co-authors sound an important alarm as open-data communities emerge and expand in the field of genomics. Anticipating the possible abuses and flaws of open-data communities in the context of statistical data collected about First Nations, Indigenous communities, data scientists, and IDS scholars have also advocated for the adoption of “CARE Principles, in which the Collective benefit, Authority to control, Responsi-



bility and Ethics”, which reflect IDS data governance commitments that are linked to self-determination (Walter et al. 2021, p. 229).<sup>10</sup>

Permit me to extend Tsosie’s caution into a hypothetical scenario whose effects are indeed quite possible: One can imagine a biotech startup proceeds to appropriate Eichler and his collaborators’ publicly available human genome sequence to create a proprietary database. The advances of this new database, or its “value proposition”, to use the language of the startup world, is that it provides access to a fuller library of disease-associated genetic variations. The problem, however, which we have already encountered in the past as well, is that many of these variations have been taken from “diverse populations” without securing the permission for the secondary use of this data from them. In the frenetic and ultra-competitive world of biotech startups, the kind of unique genomic data which Eichler and his team might collect and publicly publish may inadvertently reify the forms of exploitation of biological data of Indigenous and/or racialized peoples that characterize the dispossessing inclinations of colonial biomedicine.

At various points in this article, I have suggested that IDS may propose productive arrangements for equitable and decolonial genomic data governance in the form of access agreements and stewardship, which are established at the outset of the design of a study. Approached in this manner, the CBPR and IDS principles that locate the knowledge, interests, and priorities of the participating community at the center of a biomedical research project might suggest a manner in which the tools of genomic science can be put in service—in a good way—for more equitable health outcomes for both Indigenous and racialized peoples.

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## Notes

- <sup>1</sup> Revealed in the context of applying CBPR protocols to non-Indigenous communities, the schematic offered below assumes the presence of enfranchised organization(s) which can legitimately represent the views of stakeholders within the community, something that might not always be present in the context of CBPR with non-Indigenous and racialized communities who might not possess elected and autonomous governance institutions (Weijer et al. 1999).
- <sup>2</sup> Below I employ the terms *First Nations* and *Indigenous* interchangeably in order to avoid repetition.
- <sup>3</sup> When relevant, I refer to examples among South Asians below. Based on presumptions that the following two sets of communities are genetic ‘isolates’, Canadian First Nations and South Asians are two peoples who have been of significant interest to life scientists in the twentieth and twenty-first centuries on the basis of now-invalidated and colonial-era anthropological assumptions of continuous practices of endogamous marriage within these communities. As such, a disproportionate amount of information regarding the genetic histories exists of these two sets of peoples and this continues in the current postgenomic era. It seems important, and analytically solidary, for this decolonial examination to therefore consider convergences between their experiences with biomedicine and genetics (while also recognizing their cultural, socio-medical, techno-material and political differences (Patel and Nath 2022; TallBear 2013)).
- <sup>4</sup> Similar to Canada, Tribal Institutional Review Boards grant permission, or engage in research partnerships, with Tribal nations in the United States. Urban Indigenous communities based in the United States can require partnerships and permission from a local Native organization which is a notable difference in human subjects protections for Indigenous communities based in the city.

- 5 The HGP contributed to the introduction of a new family of screening tests however amniocentesis, for example, was prior existing and it employed karyotyping and fluorescent in-situ hybridization (also referred to as *fish*) until chromosomal microarray analysis was introduced post-HGP.
- 6 A second well-known case regarding unauthorized secondary data use is that of the Havasupai tribe in Arizona which sued the Regents of Arizona State University when the geneticists who took the samples used DNA samples to study schizophrenia, migration and inbreeding after failing to find a genetic link to the incidence of diabetes in the community which was the proposed and agreed upon research focus (Garrison et al. 2019a).
- 7 In their research on innovation in Indigenous primary care, Lindsay Crowshoe, Anika Sehgal, Stephanie Montesanti, Cheryl Barnabe, Andrea Kennedy, Adam Murray, Pam Roach, Michael Gree, Carla Bablitz, Esther Tailfeathers and Rita Henderson refer to this as an this an “up and out” approach starting within Indigenous communities (Crowshoe et al. 2021, p. 729).
- 8 Adele Clarke and her coauthors (Clarke 2003), Nikolas Rose (2009), and Kaushik Sunder Rajan (Rajan and Leonelli 2013) examine, quite comprehensively, the important shifts involved in the introduction of biotechnology to primary care of which precision medicine, or precision health, is one important example (I employ both terms below to avoid repetition), is one example. These involve new emphases on preventative care based on risk versus diagnosis based on pathology, and the redeployment of biomedical innovations toward medical personalization, enhancement and customization. As these authors note, such interventions are increasingly driven by individual choices and perceptions of risk which consequently redefine the meaning of medical necessity.
- 9 The Aotearoa Variome is funded by two agencies promoting innovation and science of the New Zealand government. Silent Genomes is funded by CIHR, Genome Canada and BC, Provincial Health Services Authority, the Michael Smith Foundation and BC Hospital Foundation, with Life Labs funding a scholarship and Illumina providing in-kind support (Caron et al. 2020).
- 10 Discussed largely in the context of statistical data, which is not the focus of this article, data governance which underpins IDS, strives to reduce the dependency of Indigenous governments on colonial agencies for data, to decolonize conventional data which reify “non-Indigenous norms and priorities” and replace it with “Indigenous systems that define data, and inform how it is collected and used.” (Carroll et al. 2019).

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