Comment

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Indigenous sovereignty and the limits of the Canadian Precision Health Initiative

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Launched in 2024, the Canadian Precision Health Initiative will amass Canada's largest human genomic dataset, including genomes of Indigenous peoples. Our analysis reveals how its structure and governance constrain Indigenous sovereignties within Canadian genomics and precision health efforts.

In October 2024, Genome Canada, a leading funder of genomics research in Canada, launched a call for Letters of Intent (LOIs) for the first pillar of its Canadian Precision Health Initiative (CPHI). The CPHI is a $200 million national effort aimed at transforming health care by generating and mobilizing large-scale, diverse genomic data to enable equitable, personalized health interventions for Canadians, including Indigenous peoples. Structured in four program pillars: data generation, mobilization, governance (including the ethical, environmental, economic, legal, and social implications of genomics (GE3LS)), and alliance-building, the initiative aims to sequence over 100,000 genomes, prioritize Indigenous data sovereignty, and foster health research innovation. As stated in the CPHI call for research proposals, the initiative aims to "advance research outcomes and clinical impact for patients" while ensuring that the resulting national genomic database will "reflect the diversity of Canada's population". Phase 1 of the project involves the collection of large-scale genomic data. In Phase 2, after research projects are selected and data production begins, issues regarding the uses of genomic data, data governance, and GE3LS will be considered. By design, this project therefore seeks to generate genomic data prior to its ethical considerations and before establishing more meaningful Indigenous governance over the work, raising familiar problems and risks for Indigenous peoples in relation to genome research historically. The CPHI project phases are structured in a way that is therefore not aligned with emerging global best practices for research involving Indigenous peoples whom this initiative seeks to include[1–3]. Indigenous research contexts often require that project and data governance agreements and details be developed *prior* to the commencement of data production, lest the resulting project outcomes be out of alignment with Indigenous interests and benefits. Greater attention to numerous pre-existing guidelines regarding Indigenous sovereignty, genomics, and precision health research might have revealed the inconsistencies between Genome Canada's CPHI model and its stated intention of supporting Indigenous peoples' sovereignty and control over their genomic data. As it currently exists, the CPHI's model is incommensurate with the meaningful exercise of Indigenous governance which it claims to support.

The program positions equity as being central to generating diverse human genomic datasets, prioritizing projects involving underrepresented populations, including Indigenous peoples and rural communities. Genome Canada asserts its commitment to Indigenous data sovereignty, rights, and self-determination citing various national and international policies (i.e., Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada, First Nations principles of ownership, control, access and possession (OCAP®), Truth and Reconciliation Commission's Calls to Action, and United Nations Declaration on the Rights of Indigenous People). However, in effect, Genome Canada's approach may result in the extraction of participation and the genomic data of Indigenous peoples, while constraining the possibility that Indigenous expertise, leadership, and governance are able to shape the foundation, development, scope, and outcomes of their precision health initiative.

Genomics, colonialism, and Indigenous critique

It is important to understand that disrupting or decentering Indigenous peoples' decision-making powers, including in how scientific projects involving Indigenous peoples are produced and governed today, is related to Canada's ongoing colonial history. In Canada, colonialism has and still does involve the dispossession of Indigenous peoples from their lands, life/ways, and decision-making powers over matters concerning their communities. Colonial dispossession, therefore, includes anything that removes or restricts the ability of Indigenous peoples to govern and form knowledge about their own bodies, peoples, and/or territories. Indeed, colonial dispossession involves the forced transfer of such powers from Indigenous peoples to colonial nation-states and their institutions, which continue to possess and exert authority over the peoples and resources within their boundaries[4]. Public institutions related to health, education, child welfare, and criminal justice have historically reinforced colonizing forms of control. For example, the racist treatment of Indigenous peoples in Canadian healthcare and health research is well-documented, as is Indigenous people's resulting distrust of much biomedical research and healthcare[5–9]. Health research, therefore, has not existed separately from colonialism. By not including Indigenous peoples from the beginning of the initiative, the CPHI risks similar outcomes. Further, the relative lack of representation of Indigenous populations in genomic reference databases is not simply a result of having been historically excluded from research but having had resisted inclusion on terms that are/were not their own. Their absence, therefore, may not be rectified if, and when the exercise of Indigenous sovereignty over the research is back ended.

A contemporary manifestation of this dispossession in genome research includes preventing Indigenous peoples from control and decision-making over genetic/genomic data generated about and affecting them. Indigenous peoples' critical engagement with

genomics therefore has a long history. There was a surge of critical Indigenous activism and scholarship following the launch of the Human Genome Diversity Project (HGDP) in the late 1990s and early 2000s that firmly identified resistance to the extractive and exploitative research approach of the HGDP as part of a much longer defense against colonialism[10,11]. More recently, Indigenous peoples have developed policies, methods, and guidelines to govern the genome sciences affecting them[12–15]. Adding to these studies are calls for capacity and infrastructure-building in genomics among and by Indigenous scholars and communities and assertions of the collective rights of Indigenous nations in and through research. Indigenous critique has always impacted genomic research, and some have argued that it has had the most profound impacts on changing the ethical terrain of the field[16].

Similar large-scale population genomics initiatives that precede the CPHI have exemplified extractive relationships with Indigenous communities, eroding Indigenous self-determination and sovereignty[10,17,18]. The All of Us Research Program in the United States has, for example, been critiqued by Indigenous researchers for emphasizing individual over collective consent procedures and lacking protections against the commodification of Indigenous peoples' DNA[19]. These critiques have argued that when precision health initiatives fail to support Indigenous expertise, leadership, and governance, the consequences for Indigenous peoples are profound. These failures perpetuate a legacy of extractive research, where Indigenous peoples' genomic data may be used in ways that do not return meaningful benefits to Indigenous peoples or address issues that are of concern to them. As Tsosie and colleagues have argued, without Indigenous governance, such programs can bypass Indigenous sovereignty by recruiting individuals outside of their communities through individual consent models, ignoring the group-level risks and benefits posed by re-identification and data mis/use[20]. In light of prior large-scale, national genomic health projects, we argue that the CPHI ought to have been shaped by Indigenous leadership from the ground up.

As Genome Canada proceeds with its own national-scale genome project, it does so in full view of Indigenous peoples' critiques of such projects elsewhere in the world—precedents which might have informed Genome Canada's own precision health ambitions beyond the rhetoric of equity, reconciliation, and data sovereignty. Given this history, we anticipate significant critical engagement with the CPHI from Indigenous researchers and communities. Indigenous nations have already begun to critique the CPHI's approach. At the 2025 Assembly of First Nations annual general meeting, Chiefs Sheldon Kent and Blaine Fiddler moved and seconded a draft resolution opposing the CPHI, including the Pan-Canadian Genome Library, based on its failure to adequately respect First Nations' collaboration, governance, consent, and inherent right to sovereignty[21]. The resolution was passed.

Further considerations for the CPHI

The power of funding agencies to shape research is significant. They can strategically craft grant opportunities in ways that uphold or transform status quo power dynamics in research. In the case of the CPHI, Genome Canada has strategically deployed the language of equity, diversity, inclusion, and reconciliation to signal that the organization is moving away from "under-recogniz[ing], under-valu[ing], [and] under-fund[ing]" research "done with Indigenous communities, on Indigenous lands, and/or incorporating Indigenous knowledge" (Genome Canada 2024,11). Building on our analysis of the structure and governance of the CPHI project phases above, we consider four additional limitations in the CPHI's phase one call for proposals, including what Genome Canada refers to as Timeline, Project Eligibility, Participant Inclusion Criteria, and Project Selection that further undermine Indigenous partnership-building and its stated commitment to Indigenous sovereignty.

Timeline. Researchers had less than 1 month to submit LOIs, with successful teams given under 1 month to submit full applications. Quick turnaround times are common in funding opportunities but often serve as profound obstacles to Indigenous-led and Indigenous-partnered research. Indigenous-led partnerships take time. While there are examples of pre-existing Indigenous-led and Indigenous-centered genome research projects in Canada and elsewhere in North America, most researchers in medical genetics are not Indigenous and do not have pre-established relationships with Indigenous colleagues and communities. This timeline did not allow them to make and sustain those relationships in a meaningful way (if willing) and ensure that Indigenous expertise, leadership, and community stakes and interests in genomics drive the work. Moving forward, funding institutions might provide earlier and greater investments in relationship and partnership-building in advance of their major research funding initiatives, which would help reduce problems of timeline constraints downstream when drafting Indigenous-led project details like data and benefit sharing agreements.

Project eligibility. For projects to be eligible for funding through this program, whole genome sequencing must happen at a limited number of Genome Canada–approved sequencing centers. The resulting sequence data and metadata must be deposited in a national databank through the Pan-Canadian Genome Library. While these requirements align with prevailing research norms for publicly funded genome research, they limit the sovereignty of Indigenous communities to determine where their data will be stored. These data deposition requirements may also limit the sovereignty of Indigenous peoples to determine how and by whom such data will be used. In the existing structure of the call for LOIs, it is not clear to what extent Indigenous peoples will be able to govern the future access and use of their data. Even if Indigenous peoples' data standards are integrated at some point during this process, best practice for all such considerations should involve partnership with Indigenous peoples prior to the beginning of research and data production, not after the fact. There is a clear tension between the CPHI project eligibility requirements and national and international principles of Indigenous data sovereignty, including the principles of Ownership, Control, Access, and Possession (OCAP™) and Collective Benefit, Authority to Control, Responsibility, and Ethics (CARE).

Participant inclusion criteria. In the CPHI's call for LOIs, participant eligibility requires consent to the deposition and sharing (with unspecified national, international, academic, and industry partners) of personal health information; metadata like race, ethnicity, and ancestry; along with their genome sequences, for an indefinite time. The expectation that Indigenous peoples will share this data and metadata, possibly with little or no control, carries potential risks of coercion and data dispossession. Presuming open data before Phase II GE3LS research and as a universal requirement, operates against at least some Indigenous peoples' sovereignty. The rigidity of participant eligibility requirements inhibits Indigenous researchers, leaders, and

partners from foundational involvement in configuring alternative and Indigenous-led models of consent, data governance, and direct benefit sharing based on communities' stakes and interests. Again, these elements of a given research project should be determined before any research takes place and will differ depending on local Indigenous decisions and priorities, and over time.

Project selection. It was unclear if experts in Indigenous-led research and the politics/ethics/science of genomics would review the applications involving Indigenous peoples and communities. Given the current shortage of such experts and existing demands on their time, it is implausible that there would be enough of them/us to (1) serve in leadership roles on projects funded through this opportunity and (2) serve as possible application reviewers. The shortfall in expertise needed for a rigorous review of the CPHI applications involving or affecting Indigenous peoples indicates the ongoing need to properly value specialized experience and expertise in the area. In March 2025, the 12 sequencing projects funded through the CPHI were announced. Of the 53 project leads, only 2 individuals self-identify as Indigenous and both are Métis. The lack of Indigenous leadership, inclusive of also First Nations and Inuit peoples in Pillar 1 is a serious problem given the initiative's staunch dedication to Indigenous sovereignty, self-determination, and inclusive participation.

Conclusion

In offering this analysis, we are not prescribing a standardized way forward. Nor are we presuming to identify Genome Canada's intentions behind the inclusion of Indigenous peoples into the CPHI while compromising Indigenous peoples' sovereignty in its design. Doing so would be antithetical to our key point that locally specific Indigenous expertise, leadership, and governance ought to drive whether and how the CPHI is of value to Indigenous nations, communities, and families. Our goal, rather, has been to identify structural limitations of the CPHI's program design to date, which currently restrict the possibilities for this (the exercise of Indigenous sovereignty in research) to meaningfully happen, and to provide insights that might inform future genomic and precision health funding initiatives. To date, Genome Canada's CPHI has laid bare the ongoing distance between ethical pronouncements and meaningful structural change, between policies of health equity and the transformative application of them in relation to Indigenous peoples. Its recent call has also shown that Indigenous sovereignty remains decentered in the CPHI's effort to shape new directions in large-scale genomics and precision health. In turn, the program will likely ensure the prepotency of non-Indigenous researchers, methodologies, institutions, and data and benefit sharing models. It could also exacerbate Indigenous health inequities and research and training capacities in the science and politics of genomics. The structure of this initiative means that Indigenous peoples may remain subject to, rather than leaders of, genome research in Canada. The approach joins a history of dispossessive national genome projects elsewhere in the world which have and may continue to diminish Indigenous peoples' participation in, and clinical benefits from, the Canadian Precision Health Initiative.

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References

1. Karabin, J. et al. A conjunctural analysis of the origins of 'embedded ELSI' in U.S. genomic medicine. *J. Responsible Innov.* **11**, 2413698 (2024).
2. Claw, K. G. et al. A framework for enhancing ethical genomic research with Indigenous communities. *Nat. Commun.* **9**, 2957 (2018).
3. Hudson, M. et al. Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data. *Nat. Rev. Genet.* **21**, 377–384 (2020).
4. Moreton-Robinson, A. *The White Possessive: Property, Power, and Indigenous Sovereignty* (Univ. Minnesota Press, 2015).
5. Roach, P. et al. Prevalence and characteristics of anti-Indigenous bias among Albertan physicians: a cross-sectional survey and framework analysis. *BMJ Open* **13**, e063178 (2023).
6. Barbo, G. & Alam, S. Indigenous people's experiences of primary health care in Canada: a qualitative systematic review. *Health Promot. Chron. Dis. Prev. Can.* **44**, 131–151 (2024).
7. Pilarinos, A. et al. A qualitative exploration of Indigenous patients' experiences of racism and perspectives on improving cultural safety within health care. *CMAJ Open* **11**, E404–E410 (2023).
8. Vogel, L. Broken trust drives native health disparities. *CMAJ* **187**, E9–E10 (2015).
9. McCallum, M. J. & Perry, A. *Structures of Indifference: An Indigenous Life and Death in a Canadian City* (Univ. Manitoba Press, 2018).
10. Barker, J. The Human Genome Diversity Project: 'peoples', 'populations', and the cultural politics of identification. *Cult. Stud.* **18**, 571–606 (2004).
11. Harry, D., Howard, S. & Shelton, B. L. *Indigenous People, Genes and Genetics: What Indigenous People Should Know About Biocolonialism* (Indigenous Peoples Council on Biocolonialism, 2000).
12. Kolopenuk, J. Rethinking the genomic diversity problem: rejecting inclusion in defense of Indigenous sovereignty. *Annu. Rev. Genomics Hum. Genet.* **26**, 479–487 (2025).
13. Garrison, N. A. et al. Genomic research through an Indigenous lens: understanding the expectations. *Annu. Rev. Genomics Hum. Genet.* **20**, 495–517 (2019).
14. Taniguchi, N. K. et al. A comparative analysis of Indigenous research guidelines to inform genomic research in Indigenous communities. *Int. Indig. Policy J.* **3**, 1–20 (2012).
15. Fong, M., Braun, K. L. & Chang, R. M. Native Hawaiian preferences for informed consent and disclosure of results from research using stored biological specimens. *Pac. Health Dialog.* **11**, 154–159 (2004).
16. Radin, J. Ethics in human biology: a historical perspective on present challenges. *Annu. Rev. Anthropol.* **47**, 263–278 (2018).
17. Tsosie, K. S. et al. We have "gifted" enough: Indigenous genomic data sovereignty in precision medicine. *Am. J. Bioeth.* **21**, 72–75 (2021).
18. TallBear, K. *Native American DNA: Tribal Belonging and the False Promise of Genetic Science* (Univ. Minnesota Press, 2013).
19. Fox, K. The illusion of inclusion in genomic medicine: the "All of Us" research program and Indigenous peoples' DNA. *N. Engl. J. Med.* **383**, 411–413 (2020).
20. Tsosie, K. S., Yracheta, J. M. & Dickenson, D. Overvaluing individual consent ignores risks to tribal participants. *Nat. Rev. Genet.* **20**, 497–498 (2019).
21. Kent, S. & Fiddler, B. *Opposition to the Canadian Precision Health Initiative*. Resolution no. 11/2025 (Assembly of First Nations, 2025).

Author contributions

J.K. conceptualized the manuscript, conducted the original analysis, and wrote the original draft. R.W.A.S added significant analyses, technical expertise, feedback, and edits. Both authors contributed to and approved the manuscript.

Competing interests

The authors declare no competing interests.

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