

Assembly of First Nations

50 O'Connor Street, Suite 200
Ottawa, Ontario K1P 6L2
Telephone: (613) 241-6789 Fax: (613) 241-5808
www.afn.ca



Assemblée des Premières Nations

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Ottawa, Ontario K1P 6L2
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ANNUAL GENERAL ASSEMBLY
September 3-4-5, 2025, Winnipeg, MB

Resolution no. 16/2025

TITLE:	Opposition to the Canadian Precision Health Initiative
SUBJECT:	Health, Genomics, Data Governance
MOVED BY:	Chief Derek Nepinak, Minegozibe Anishinabe First Nation, MB
SECONDED BY:	Andre Bear, Proxy, Little Black Bear First Nation, SK
DECISION	Carried; 5 Opposition; 5 Abstention

A. The *United Nations Declaration on the Rights of Indigenous Peoples* (UN Declaration) states:

- i. Article 18: Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions.
- ii. Article 19: States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free, prior, and informed consent before adopting and implementing legislative or administrative measures that may affect them.
- iii. Article 31(1): Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

B. The Truth and Reconciliation Commission's Call to Action #18 states:

- i. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-

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Cindy Woodhouse

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care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

- C. The First Nations principles of OCAP® (Ownership, Control, Access, and Possession) assert that First Nations have the right to own, control, access and possess information about their nations, which is fundamental to First Nations Inherent right to self-determination and data sovereignty.
- D. In October 2023, the Government of Canada announced a \$15 million investment over five years to create a Pan-Canadian Genome Library (PCGL). The first-of-its-kind national genomic database aiming to centralize genomic data management and sharing across the country. The PCGL is being developed through partnerships, including the Canadian Institutes of Health Research, Genome Canada, the Digital Research Alliance of Canada, and CGEn (Canada's National Platform for Genome Sequencing and Analysis).
- E. In February 2025, the Government of Canada announced the Canadian Genomics Strategy, backed by \$175.1 million in federal funding over seven years (starting in 2024-25). This Strategy is intended to strengthen Canada's global leadership in genomics by accelerating the translation of research into real-world applications in health (e.g., personalized medicine, rare disease treatments), agriculture, and environmental sustainability.
- F. In March 2025, Genome Canada (with support from the Government of Canada) launched the Canadian Precision Health Initiative (CPHI) to assemble Canada's largest-ever collection of human genomic data: over 100,000 genomes representing the diversity of Canada's population. The CPHI is funded by an initial \$81 million federal investment, anticipating a total investment of \$200 million through partnerships. The initiative has goals to enhance health care through precision medicine.
- G. The centralization and sharing of genomic data without explicit First Nations governance and consent risks violating First Nations data sovereignty and repeating colonial patterns of data extraction. Without mechanisms for First Nations oversight or accountability, the current initiatives may enable misuse, misrepresentations, and/or unauthorized access to Indigenous genomic information by third parties, in ways that contravene to First Nations laws, values, and interests.

THEREFORE BE IT RESOLVED that the First Nations-in-Assembly:

- 1. Direct the Assembly of First Nations (AFN) to formally oppose the inclusion, collection, and use of First Nations genomic data within the current structure and implementation of the Canadian Precision Health Initiative (CPHI), including the Pan-Canadian Genome Library, where it has proceeded without meaningful consultation or consent with First Nations and lack of adherence to OCAP® principles (ownership, control, access and possession) and the *United Nations Declaration on the Rights of Indigenous Peoples* (UN Declaration).
- 2. Direct the AFN to collaborate with the First Nations Information Governance Centre to identify and assess existing Indigenous-controlled genomic data libraries or governance frameworks that upholds First Nations' data sovereignty, reflect OCAP® principles, and aligns with First Nations cultural values and protocols.

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3. Call upon the Government of Canada to immediately pause the collection and use of First Nations genomic data within the CPHI and related projects until meaningful consultation with First Nations is conducted, and formal mechanisms for First Nations governance, consent, and accountability are established. This resolution does not preclude First Nations from choosing to partner with such initiatives on their own terms.
4. Urge all federal agencies and partners involved in genomic data initiatives to recognize and respect First Nations' Inherent rights to their genomic data, as affirmed by UN Declaration, and to support the development and implementation of First Nations-led data governance structures both nationally and globally.

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