



BC ASSEMBLY OF FIRST NATIONS

1992 Landooz Road
Prince George, BC V2K 5S3
Website: www.bcafn.ca

BCAFN ANNUAL GENERAL MEETING
October 28, 29 & 30, 2025
Hybrid - In person & online via Zoom

Resolution 34/2025

**SUBJECT: FIRST NATIONS DATA SOVEREIGNTY AND GOVERNANCE IN THE CANADIAN
PRECISION HEALTH INITIATIVE**

Moved BY: CHIEF WILF ADAM, LAKE BABINE FIRST NATION

SECONDED BY: CHIEF DONALD SAM, ʔAKISQ̓NUK FIRST NATION

DECISION: CARRIED

WHEREAS:

- A. Precision medicine, which uses genomic health research to tailor prevention and treatment for each individual, is transforming healthcare but when segments of the population do not participate, it will leave such communities behind and widen existing health gaps and given its benefits for those populations already involved, genomic research and affiliated healthcare is poised to widen disparities without First Nations participation.
- B. In October 2023, the Government of Canada announced a \$15 million investment over five years to create a federated Pan-Canadian Genome Library (PCGL), a national genomic database aiming to coordinate genomic data management and sharing across the country, developed through partnerships including the Canadian Institutes of Health Research, Genome Canada, the Digital Research Alliance of Canada, and Canada's National Platform for Genome Sequencing and analysis (CGEn);
- C. In March 2025, Genome Canada launched the Canadian Precision Health Initiative (CPHI) to assemble Canada's largest-ever collection of human genomic data, over 100,000 genomes

Certified copy of a resolution adopted on the 30th day of October 2025

Terry Teegee, BC Regional Chief

representing the diversity of Canada's population, funded by an initial \$81 million federal investment with an anticipated total investment of \$200 million through partnerships;

- D. *The United Nations Declaration on the Rights of Indigenous Peoples* (UN Declaration) affirms that Indigenous peoples have the right to participate in decision-making in matters which would affect their rights (Article 18), the right to free, prior, and informed consent before adopting legislative or administrative measures that may affect them (Article 19), and the right to maintain, control, protect and develop their cultural heritage, traditional knowledge, human and genetic resources, and intellectual property (Article 31);
- E. The Truth and Reconciliation Commission's Call to Action #18 calls upon federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous colonial government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties;
- F. 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; and
- G. The stewardship 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 First Nations genomic information by third parties, in ways that contravene First Nations laws, values, and interests.

THEREFORE, BE IT RESOLVED THAT:

- 1. The BCAFN Chiefs-in-Assembly direct the Regional Chief to request that each Canadian Precision Health Initiative (CPHI) project involving First Nations participants ensure that First Nation participants have the ability to consent to Indigenous data governance both in the CPHI and the subsequent Pan-Canadian Genome Library, and to ensure that it proceeds with meaningful consultation or consent with First Nations (communities and/or individuals as appropriate to the project) and adherence to OCAP principles and the *United Nations Declaration on the Rights of Indigenous Peoples* (UN Declaration);
- 2. The BCAFN Chiefs-in-Assembly direct the Regional Chief and BCAFN to offer to collaborate with the First Nations Information Governance Centre to identify and assess existing Indigenous-

Certified copy of a resolution adopted on the 30th day of October 2025

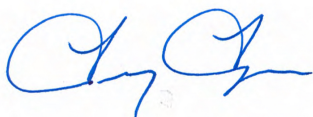


Terry Teegee, BC Regional Chief

controlled genomic data libraries or governance frameworks that uphold First Nations' data sovereignty, reflect OCAP principles, and align with First Nations cultural values and protocols;

3. The BCAFN Chiefs-in-Assembly call on the Government of Canada to immediately pause the transfer of First Nations genomic data from the CPHIs and related projects to the Pan-Canadian Genome Library (PCGL) until meaningful consultation with First Nations is conducted, formal mechanisms for First Nations governance, consent, and accountability are established and/or the Silent Genomes Governance structure is adopted as the established First Nations genomic data governance framework for First Nations participants in any CPHI project involving data transfer; and
4. The BCAFN Chiefs-in-Assembly require 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 the UN Declaration, and to support the development and implementation of Indigenous-led data governance structures both nationally and globally.

Certified copy of a resolution adopted on the 30th day of October 2025



Terry Teegee, BC Regional Chief