

**SILENT GENOMES INDIGENOUS BACKGROUND VARIANT LIBRARY GOVERNANCE
COMMITTEE (SG-IBVL GOVERNANCE COMMITTEE)**

TERMS OF REFERENCE

Version 1.5

January 24, 2025

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Silent Genomes Indigenous Background Variant Library Governance Committee (SG-IBVL Governance Committee) Mission Statement: Established to provide cultural oversight, strategic advice and decisions in support of the collaborative expansion and utilization of the Indigenous Background Variant Library (IBVL) including respectful, culturally safe policies regarding access to data for clinical diagnoses and related research, while engaging future generations of Indigenous scholars and community members.

Terms of Reference, SG-IBVL Governance Committee

This document is the Terms of Reference (TOR) for the SG-IBVL Governance Committee. It contains the purpose and structures of the Committee, describes the membership of the Committee, and contains details related to oversight, operating guidelines, conflict resolution and sustainability. This document has been developed through an Indigenous lens with care to highlight sovereignty in the process. It is vital that Indigenous Data Sovereignty (IDS)¹ rights are protected, empowering Indigenous Peoples to challenge dominant colonial data and power dynamic discourses. A culturally safe environment will be upheld where Indigenous peoples can then make decisions and actively harness their ways of knowing to effectively govern.

Introduction

The Indigenous Background Variant Library (IBVL) and its infrastructure is situated at the BC Children's Hospital Research Institute (BCCHR), which stewards genomic variant data from consenting Indigenous participants across Canada. The main purpose of the IBVL is to provide Indigenous representation of genomic variant data, which are currently lacking in population databases that hold genomic reference data. The goal is to improve diagnostic success for Indigenous patients and their families with genetic disorders and thereby address the 'genomic gap', reflecting increasing health care inequity due to limited access to precision genomic diagnosis. Such data indicates the DNA letters (A, C, G, or T) and their frequency that are present in the DNA of Indigenous people at each position of the genome, some of which will be different compared to the letters and frequencies observed in other populations. Knowledge of such information allows clinicians to determine if a DNA letter observed in a patient is common, or uncommon, or novel, and therefore less or more likely to cause severe disease. The IBVL is primarily a tool to enhance clinical diagnosis, but research that is relevant to Indigenous health may be requested.

In order for this committee to effectively carry out its work, it needs to be updated with current technologies and Indigenous perspectives that are relevant to the IBVL. The Silent Genomes team will provide the committee with updates and opportunities to discuss such issues.

The SG-IBVL Governance Committee will work alongside the Silent Genomes team in consultation and partnership with Indigenous communities and leaders as the IBVL expands.

Participating Indigenous individuals, families and communities will:

- Expect their genomic data may benefit their Peoples but also expect that it is protected from culturally insensitive and unethical uses such as uses that go beyond the scope of the consent.

- Expect the highest level of data security available within the Provincial Health Services Authority.
- Expect that Free, Prior, and Informed (FPI) Consent for individual participation has been or will be obtained as well as community approval when communities or Nations are involved ([TCPS2- Chapter 9](#), 2022)².
- Expect that principles that are relevant to participating Indigenous persons of Canada, such as OCAP® for First Nations³, Principles of Ethical Métis Research⁴, or National Inuit Strategy on Research⁵ are upheld to support Indigenous Data Sovereignty.
- Expect transparency and accountability to address breaches of security or misappropriation of data.
- Expect that processes will be in place by the Silent Genomes Project team in conjunction with the data steward (the BC Children’s Hospital Research Institute (BCCHR)/Provincial Health Services Authority (PHSA)) and the SG-IBVL Governance Committee to protect the data, as agreed upon throughout the existence of the IBVL, and also in the circumstance that the IBVL is dissolved.

Instruments such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP, 2007)⁶ and the CARE Principles (Collective Benefit, Authority to Control, Responsibility and Ethics Principles, 2019)⁷ provide a universal framework perspective on data governance for Indigenous Peoples. In the context of UNDRIP⁶, CARE Principles⁷ and the Truth and Reconciliation Commission of Canada (TRC, 2015)⁸, the SG-IBVL Governance Committee is committed to supporting Indigenous Peoples within their Indigenous knowledge systems in their assertion of self-determination. Through this TOR (but not solely through this TOR) the SG-IBVL Governance Committee will support moving these commitments forward.

The 1st phase of the IBVL utilized samples from consenting First Nation Canadian Alliance for Healthy Hearts and Minds (CAHHM) communities [Appendix 2]; Alliance representatives are key members of the SG-IBVL Governance Committee. In addition, a representative of the SGP attends the CAHHM - National First Nations Working group monthly meetings to report on the SG Governance Committee activities, and progress on the expansion of the IBVL.

It is acknowledged that the oversight of IBVL is Indigenous, and consultations for the expansion are ongoing. We respect the path of our Indigenous partners in the process, as many are at a different place and yet to decide regarding participation. The Terms of Reference (TOR) therefore apply to this SG-IBVL Governance Committee comprised of Indigenous partners/participants who are working with the Silent Genomes team that will engage in the process of expanding the IBVL within its governance framework, while respecting the preferences of our Indigenous partners for inclusion.

Ethical or legal challenges. It is difficult to anticipate which ethical or legal challenges may present: the SG-IBVL Governance Committee may from time to time need to obtain independent advice and/or to invite experts with relevant knowledge to its meetings. Any costs associated with this will require approval by the co-leads with reference to Silent Genomes budget. Any advice will need committee consideration and approval before acceptance.

Membership

SG-IBVL Governance Committee will be Indigenous-led and Indigenous-operationalized with the support of the Silent Genomes Team.

The SG-IBVL Governance Committee membership (8-12 people) will reflect the following:

- Knowledge Carrier/Elder member(s) from the territory surrounding the BC Children's Hospital.
- 1-3 members each from FN, Metis, Inuit. These include Indigenous member(s) with connection to genetic conditions (These members may be suggested for consideration by community leaders, genetic counsellors, geneticists or self-nomination). 1-2 Indigenous scholars (academic Indigenous members).
- Member(s) connected to communities of the Canadian Alliance for Healthy Hearts and Minds (reporting structure to participating Alliance representatives and communities will be developed by them).
- Inclusion of youth and emerging Indigenous scholars and leaders. Engaging younger generations ensures sustainability and continuity of the governance process⁹.

*Members may fulfill more than one membership criterion, for example, a member connected to the communities of CAHHM may also be an Indigenous scholar. An Indigenous scholar may also have connection to genetic conditions.

Participation *ad hoc*:

- Participation from other Indigenous organizations (members or organizations, e.g. ITK, FNHA, and regional, national and/or other organizations as relevant to the communities they serve/agenda for the meeting requested).
- Others as needed (e.g. with knowledge of genomics/ genetics/ SG/ governance/ policy/ other specialists).

Roles and responsibilities

- To develop a reasonable/fully informed understanding of the Silent Genomes IBVL.
- To be decision-makers for issues related to the collaborative expansion and utilization of the IBVL including respectful, culturally safe policies regarding access to data for clinical diagnoses and related research.
- To consider issues raised and provide guidance as pertinent to the governance of the IBVL, its safety and security of the data, its ethical use, and its role in improving the chance of diagnosis of genetic conditions.
- To consider issues raised and provide guidance as pertinent to the governance of the IBVL, its safety and security of the data, its ethical use, and its role in understanding the genetic component of rare and common conditions through research.
- To support and provide advice to the sustainability of the IBVL.
- Vetting potential new committee members following a defined process.

The SG-IBVL Governance Committee will work with key members of the Silent Genomes team, including those with previous experience working with Indigenous communities, as well as those with expertise in medical sciences, genomic sciences, data security, among others; all of whom who are open to learning from the SG-IBVL Governance Committee and other Indigenous partners and working in full partnership and collaboration.

Duties

1. Guide in the ongoing principles for Data Governance.
2. Advise and update protocols for release of variant information for clinical diagnosis, research requests and manuscript review to ensure the cultural safety of the data held in the IBVL.
 - * Review and give feedback on the utilization of data in the IBVL for clinical and for approved related research purposes.
3. Provide input for external communications regarding use of data in the IBVL.
4. Provide guidance in the situation of complaints during the Silent Genomes project involving expansion and use of the IBVL.
5. Provide guidance in conflict resolution as needed during the expansion and utilization of the IBVL.
6. Provide strategic guidance to Silent Genomes team and the leadership of BCCHR/PHSA about maintaining the utility and usefulness of the IBVL into the future.
7. Provide strategic guidance to Silent Genomes team and the leadership of the BCCHR/PHSA about changes in stewardship, and/or data disposition if there is reason to dissolve the IBVL.
8. The planning of the meetings, approving the agenda, and reviewing the minutes before distribution is the responsibility of a designated member with the support of the SG team facilitator.
9. The membership will decide on the structure of the leadership within the SG-IBVL Governance Committee.
10. Collaborate with other Indigenous-led governance bodies, research ethics boards, and international initiatives to share best practices and lessons learned.

Operating Guidelines

Confidentiality

All members will respect the privacy of individual, family, and community stories. Personal information and stories shared amongst the group will not be disclosed without permission.

Conflict of Interest

Members will be required to declare any interests they might have in any issues arising at the meeting that might conflict with the Silent Genomes project and/or the IBVL. These issues may be temporary or for a single matter, and the member will be required to step away for the duration of the conflicting issue.

Independent Advice

The Governance Committee may from time to time need to obtain independent advice and/or to invite experts with relevant experience to its meetings. Any costs associated with this will require approval by the co-leads with reference to Silent Genomes budget.

Attendance

Attendance by Members: The lead or co-lead of the Governance Committee will use their best endeavours to attend all scheduled meetings. If the lead or co-lead is unable to attend, they will appoint a proxy as a member of the committee. Other group members should attend a minimum of 50% of all meetings.

Frequency

Governance Committee meetings will be held quarterly via video link/teleconference and/or in person and may require more frequent meetings.

Review of Terms of Reference

The SG-IBVL Governance Committee will review its TOR on an annual basis or more often if needed. This will be a “living document”.

Support

1. Members of the SG-IBVL Governance Committee shall be offered an honorarium. These payments reflect commitments to:
 - 1.1 Attend meetings and any specific work required outside meetings.
 - 1.2 Expenses related to travel will be covered (if travel required).
2. Administration support will be provided by Silent Genomes project members. They will:
 - 2.1 Record and distribute the minutes, agenda and relevant information to members of the SG-IBVL Governance Committee prior to meetings.
 - 2.2 Arrange venue and/or videoconference and teleconference information for meetings.
 - 2.3 Organize travel and accommodation arrangements where required.
 - 2.4 Arrange to pay fees and any reimbursements to members of the Steering Committee in a timely manner.
 - 2.5 Record decisions and obtain approval from the SG-IBVL Governance Committee before communicating them more widely.

Duration

While the IBVL is in existence, the duration of the terms contained herein shall be from the date of the adoption of the TOR and will be reviewed yearly thereby requiring ongoing Indigenous Governance.

Conflict Resolution

The SG-IBVL Governance Committee shall work in partnership and with respect under these terms and any conflict between the parties shall be resolved with integrity:

1. By working toward majority agreement whilst addressing the basis of conflict. A progress plan will be based on a process focused towards achieving common ground, mutually beneficial outcomes and foster an environment that delivers best practice.

2. By advice and support from independent third parties where applicable. Independent advice will be objectively considered on structural aspects, events and behavioral/attitudinal patterns and not on individual personalities.

The importance of conflict awareness and timely management is acknowledged as this has the potential to not only generate better solutions with new practices and processes but also to foster trust, increase motivation, morale, performance and productivity. Following clarification of pertinent issues from any conflict, the solution(s) agreed upon and responsibilities of each party going forward would be acknowledged. The net effect of resolution would be to ensure all opinions are thoroughly considered and addressed, and, when possible, resolved with consensus, or if not possible, with majority agreement (voting procedures to be established).

Register of Interests Declaration

A register of interests relating to other roles of members of the SG-IBVL Governance Committee will be established, maintained and updated as needed by the SG-IBVL team members. This will follow standard Conflicts of Interest guidelines established by the University of British Columbia (refer to appendix 4). Real, potential or perceived conflicts of interest will be obtained and updated annually and as needed.

References

1. Hudson M, Garrison NA, Sterling R, Caron NR, Fox K, Yracheta J, et al. Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data. *Nat Rev Genet.* 2020. doi: 10.1038/s41576-020-0228-x. [cited 2025 Jan 30];21(6):377–84.
2. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2022), Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada. Government of Canada; 2022 [cited 2025 Jan 30]. Available from: https://ethics.gc.ca/eng/tcps2-eptc2_2022_chapter9-chapitre9.html
3. First Nations Information Governance Centre. Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance. 2014 [cited 2025 Jan 30]. Available from: https://fnigc.ca/wp-content/uploads/2020/09/5776c4ee9387f966e6771aa93a04f389_ocap_path_to_fn_information_governance_en_final.pdf
4. ACHH Initiative. Guide to ethics in health research with Indigenous Peoples. NAHO Métis Centre; 2018 [cited 2025 Jan 30]. Available from: https://achh.ca/wp-content/uploads/2018/07/Guide_Ethics_NAHOMetisCentre.pdf
5. Inuit Tapiriit Kanatami. National Inuit Strategy on Research - Implementation Plan. 2018 [cited 2025 Jan 30]. Available from: <https://www.itk.ca/national-inuit-strategy-on-research/>
6. United Nations. United Nations Declaration on the Rights of Indigenous Peoples. 2007 [cited 2025 Jan 30]. Available from: https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf
7. Global Indigenous Data Alliance. CARE Principles of Indigenous Data Governance. 2019 [cited 2025 Jan 30]. Available from: <https://www.gida-global.org/care>
8. Truth and Reconciliation Commission of Canada. Truth and Reconciliation Commission: Calls to Action. 2015 [cited 2025 Jan 30]. Available from: https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf
9. Anand SS, Yusuf S, Jacobs R, Davis AD, Yi Q, Gerstein H, et al. Canadian Alliance for Healthy Hearts and Minds: First Nations Cohort Study Rationale and Design. *Prog Community Health Partnersh.* 2018 [cited 2025 Jan 30];12(1):55–64. Available from: 10.1353/cpr.2018.0006
10. University Counsel, University of British Columbia. Understanding conflicts. [date unknown] [cited 2025 Jan 30]. Available from: <https://universitycounsel.ubc.ca/subject-areas/coi/coi-overview/>

APPENDICES:

1. Glossary

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| BCCHRI/BCCHR | BC Children’s Hospital Research Institute |
| CAHHM | Canadian Alliance for Health Hearts and Minds [Alliance] |
| CARE | Collective Benefit, Authority to Control, Responsibility, and Ethics |
| FNHA | First Nations Health Authority |
| IBVL | Indigenous Background Variant Library |
| IDS | Indigenous Data Sovereignty |
| NFNWG | National First Nations Alliance Working Group |
| OCAP | Ownership, Control, Access, and Possession |
| PHSA | Provincial Health Services Authority |
| S-GIRDD | Silent Genomes Indigenous Rare Disease Diagnosis |
| TCPS2, Chapter 9 | Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada |
| TOR | Terms of Reference |
| TRC | Truth and Reconciliation Commission of Canada |
| UNDRIP | United Nations Declaration on the Rights of Indigenous Peoples |

2. Alliance background and governance outline on the project/communities

Background: CAHHM [Alliance] First Nations cohort study was part of the larger study on chronic disease in Canada which included 9700 non-Indigenous participants and 2000 Indigenous participants⁹. The First Nation participants were recruited from nine communities across Canada. The overarching objective of the CAHHM First Nations cohort was to investigate how the community-level environment is associated with individual health behaviors and the presence and progression of chronic disease risk factors and chronic diseases such as CVD and cancer. The specific objectives of the CAHHM-FN are to:

1. Determine the frequency of risk factors for CVD and cancer among First Nations people from diverse First Nations communities in Canada;
2. Characterize the availability and access to primary care screening, and management of chronic diseases and their risk factors;
3. Determine the burden of subclinical cerebrovascular and cardiac disease and ectopic adipose tissue using brain, heart, carotid, and abdomen MRI; and
4. Characterize the contextual factor profile of each community and understand how community-level environment is associated with individual health behaviors and risk factors.

In addition to the Alliance study, participants were invited to provide a blood samples for long term storage (biobanking) for use in future research studies. This was an optional and voluntary additional consent. The Silent Genomes team have partnered with the Alliance study and may be the first research study to access the biobank samples. The samples stored under ‘Biobanking for future research’ consents with the Alliance cohort project have been used for the development of the IBVL, with a return of the data generated to the Alliance study. Alliance Governance outline:

The Alliance First Nations Cohort's decision making is done at two levels:

1. Community level, by the Local Community Advisory Board (LCAB), and
2. National level, by the National First Nations Working Group (NFNWG).

Each First Nation community owns their data and works with their LCAB to decide how the study data may be used. Interim data are presented to the NFNWG showing all communities anonymously, and discussion is invited and reports modified as needed. The LCAB includes a minimum of three members made up of one community member, the director health services (or equivalent), and the local lead investigator. The volunteer community member is selected and mutually agreed on by the local lead investigator and health services director. This individual has interest and experience with research. The NFNWG is composed of at least one representative from the LCAB and the local lead investigator from each community. The mandate of the NFNWG is to oversee the storage and use of all blood samples and data.

The 1st phase of the IBVL utilized samples from consenting Alliance communities, and Alliance representatives are key members of the SG-IBVL Governance Committee. In addition, a representative of the SGP attends the NFNWG monthly meetings to report on the SG Governance Committee activities, and progress on the expansion of the IBVL.

3. SG-IBVL Governance Committee and Silent Genome Project members

Updated: December 2024

| | Governance Committee Members | | Silent Genome Project Members |
|----|-------------------------------------|--|--------------------------------------|
| 1. | Susan Dowan (Lead) | | Wyeth Wasserman |
| 2. | Syexwaliya Ann Whonnock (Elder) | | Nadine Caron |
| 3. | Eduardo Vides (Advisor) | | Laura Arbour |
| 4. | Bonnie Davis | | Emma Ewasiuk |
| 5. | Joe Keesickquayash | | Joanne Speakman |
| 6. | Lisa Mayotte | | Irina Manokhina |
| 7. | Julie Morrison | | |
| 8. | Peter Hutchinson | | |

4. UBC Conflict of Interest information/directions

Conflicts of Interest (COI) occur when an aspect of our private life influences or conflicts with the decisions we make on behalf of the Steering Committee or appears to do so.

Although the term Conflict of Interest has come to have a negative connotation, the mere existence of a conflict of interest does not necessarily indicate wrongdoing. In order to protect the integrity of the University and the Governance Committee, Conflicts of Interest must be disclosed and managed. Please refer to the UBC website [Understanding Conflicts](#)¹⁰ for more information on examples of conflicts and types of conflicts.

Each member of the Governance Committee will complete a COI and be responsible for changes during their time on the Committee.