

COMMUNIQUÉ

SG-IBVL Governance Committee 2025 Year in Review

Prepared: March 26, 2026

1. The SG-IBVL Governance Committee was established with the launch of the Indigenous Background Variant Library (IBVL) in January 2025. It evolved from the S-GIRDD Steering Committee, an advisory body active between 2020 and 2024, into a formal Indigenous Governance body, developed in response to the need for Indigenous-led oversight in genomics. This transition reflects a shift from ‘steering’ to governance. Although both committees included an active role in decision-making related to how IBVL data are accessed, used, and protected, the processes to enable governance were built during the phase of the S-GIRDD Steering Committee. The IBVL Governance Committee maintains a focused role on governance, rather than building the process.

2. The SG-IBVL Governance Committee is Indigenous-led and Indigenous-operated. It works in conjunction with the Silent Genomes team and in relationship with Indigenous communities, partners, and leaders. Its membership brings together Knowledge Carriers, individuals with lived experience of genetic conditions, Indigenous scholars, and community members. Governance is understood not only as structure, but as relationship, accountability, and responsibility to people, communities, and future generations. The Committee’s membership in 2025 included Susan Dowan, Syexwaliya, Eduardo Vides, Bonnie Davis, Joe Keesickquayash, Lisa Mayotte, Julie Morrison, and Peter Hutchinson.

3. Indigenous governance in genomics remains essential consistent with Indigenous Data Sovereignty principles reflected in the United Nations Declaration of the Rights of Indigenous Peoples¹. This includes control over genetic resources (Article 31) The Silent Genomes Project supports the CARE Principles, (Collective benefit, Authority to control, Responsibility, and Ethics)². The IBVL Governance model formed with focus on the rights of Indigenous peoples. It ensures that decisions about data storage, access, current and future use are guided through Indigenous governance and remain aligned with free prior and informed consent, cultural perspectives, and Indigenous Data Sovereignty principles.

4. In 2025, the SG-IBVL Governance Committee held six regular meetings and two *ad hoc* meetings. These meetings aimed to determine how the Committee works in practice,

1. United Nations (2007). *United Nations Declaration on the Rights of Indigenous Peoples*. Available at: https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf

2. Global Indigenous Data Alliance (2019). *CARE Principles for Indigenous Data Governance*. Available at: <https://www.gida-global.org/care>

including development of Terms of Reference, membership structure, recruitment approaches, research review processes, and oversight of security and operations. The Committee received regular updates on the IBVL, including its security, use, and its perspective growth, addressing practical aspects of data governance. This included reviewing and discussing consenting documentation, decisions on using identifiers, and institutional efforts to maintain technical aspects of data security.

5. In addition to regular meetings, the Committee held three *ad hoc* review meetings to review one manuscript and two health research proposals involving IBVL data. These reviews required adherence to the first principle, that the research conducted or proposed was beneficial to the health of Indigenous people. There was attention to consent, collaboration, and accountability to participating communities/Indigenous participants. All three were approved following Committee review.

6. The Committee considered broader national developments in genomics, including the Canadian Precision Health Initiative (CPHI) and the Pan-Canadian Genome Library (PCGL). Across these discussions, a consistent position was maintained: participation of the SGP IBVL must not result in altering the Indigenous Governance framework in place. **The Committee supported approaches that ensure Indigenous participants can benefit from genomic medicine while retaining the processes adopted by the SGP IBVL GC, including Indigenous-led and operationalized oversight, review, and protection of their data.**

7. Members of the Committee and the Silent Genomes team contributed to a wide range of presentations, workshops, and discussions across clinical, academic, policy, and community settings. These presentations focused on several interconnected themes: development and implementation of the IBVL as an Indigenous-governed resource; Indigenous data sovereignty and governance in national genomic initiatives; clinical and research findings relevant to Indigenous communities, advancing equity in genetic and genomic diagnosis for Indigenous patients; engagement with communities, leadership, and national organizations on governance and participation. Committee members contributed directly to national and international discussions, including presentations at conferences, policy workshops, and governance forums.

8. Transparency and accessibility were also identified as priorities. The Committee discussed approaches to making its work more visible and understandable to communities, including communicate, newsletters, educational materials, and shared communications that reflect both the purpose of the IBVL and the governance behind it.

9. The SG-IBVL Governance Committee understands the IBVL as a long-term responsibility. Its purpose is not only to manage data, but to support a future in which Indigenous individuals and communities can access genomic diagnosis and benefit from advances in medicine without giving up authority over their data.