

**International Indigenous Genomics Advisory Committee**  
***Silent Genomes Project***  
**TERMS OF REFERENCE**

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## **ABOUT SILENT GENOMES**

Genome Canada, with Genome BC, in partnership with the Canadian Institutes for Health Research, Michael Smith Foundation for Health Research, BC Children's Hospital Research Institute, UBC Faculty of Medicine, Provincial Health Services Authority, and LifeLabs have provided funding for the *Silent Genomes Project*<sup>1</sup> which aims to reduce health care disparities and improve diagnostic success for children with genetic diseases from Indigenous populations within Canada.

The Silent Genomes Project will address health care disparities and reduce access barriers to diagnosis of genetic disease in Indigenous children by:

- Establishing processes, through an Indigenous lens, for safe governance of biological samples and genome data in the Silent Genomes project, which will lead to broader policy.
- Addressing barriers to accessing genetic/genomic health care and bring genomic testing to at least 200 Indigenous children with suspected genetic disorders.
- Developing an Indigenous Background Variant Library (IBVL) of genetic variation from a diverse group of 1500 FN Canadians and assess improvement in diagnosis for referred children.

Assessing effectiveness of the IBVL to lower health care costs and plan for long term use of IBVL for Canadian Indigenous children and adults needing genetic/genomic health care.

## **ROLE AND PURPOSE OF IIGAC**

The IIGAC is a committee of international Indigenous experts and scholars who provide the *Silent Genomes Research Team* with external guidance, insight and strategic advice on the projects' goals and deliverables, international best practices, and independent advice on:

- 1) safe governance through an Indigenous lens of biological samples and genome data policy in the *Silent Genomes project*;
- 2) identification and address of barriers to accessing genetic/genomic health care;
- 3) development of an *Indigenous Background Variant Library (IBVL)* aimed at improving diagnostic assessments;

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<sup>1</sup> <https://www.bcchr.ca/silent-genomes-project>.

- 4) efficacy of the IBVL to lower health care costs and plan for long term use of IBVL for Canadian Indigenous children and adults needing genetic/genomic health care;
- 5) contributions to relevant genetic and genomic research reports, articles and manuscripts for publication; and,
- 6) collaborate on an internationally relevant policy framework/best practices for to guide future Indigenous genetic and genomic research practices and equitable health care.

## **MEMBERSHIP**

The International Indigenous Genomic Advisory Committee represents international Indigenous perspectives that can foster collaboration with both national and international stakeholders, and foster best practices dialogue. IIGAC members provide Indigenous perspectives from Canada, the United States (including Hawaii), Australia and Aotearoa New Zealand.

## **OPERATING GUIDELINES**

The IIGAC:

- interacts with the *Silent Genomes Project Team*;
- is chaired by an IIGAC member;
- will be consulted on key issues raised by the *Silent Genomes Project* team and meet via teleconference/virtual meeting/webinar when necessary;
- agrees on recommendations that can be made public on the *Silent Genomes* website;
- meet face-to-face four (4) times throughout the project duration as outlined in the research proposal;
- arrange meeting locations in various regions reflective of the members;
- invite new members to join the IIGAC in consultation with existing members; and,
- advise the development of collaborative scholarly publication(s) arising from discussions that provide international Indigenous perspectives on best practices in genetic/genomic health care and research.

## **CONDUCT**

- IIGAC members will not receive honorariums in conjunction with the *Silent Genomes Project*;
- Reimbursement of travel and accommodation expenses for attending annual meetings in person may be provided if booked according to *Project* guidelines, and funds are available;
- Resignation of membership can be requested by the *Silent Genomes Project Team*, in writing or via email, at any time;

- Members shall respect the confidential nature of certain discussions and research findings; and,
- Members shall respect the nature of non-conflict of interest to the *Silent Genomes Project*.

### **Appendix – Consensus model for decision-making**

The simplest and most basic definition of consensus is, ‘general agreement about something’ (Soannes, C. and Hawker, S., ed., *The Compact Oxford English Dictionary of Current English*. 3<sup>rd</sup> ed. Oxford University Press, 2005).

In this approach, people are not simply for or against a decision, but have the option to situate themselves on a scale that lets them express their individual option more clearly. This model is usually used with a round, so that everyone in the meeting is given the opportunity to state where they are according to the following six levels:

1. Full support
2. Acceptable
3. Support with reservations
4. I am not thrilled with it, but I can live with it and will not block it
5. Need more information or more discussion
6. Cannot support it and cannot accept it

If everyone is at level #4 or above (3, 2 or 1), then by definition, consensus has been reached.

If someone is at level, 2, 3 or 4, they have the option of explaining their reservations. These can be addressed by the meeting, if the group wishes to. This is not absolutely necessary for achieving consensus if everyone is already at 4 or higher, but it usually improves the recommendation or suggestions being discussed.

If someone is at level 5, they have the obligation to explain what information or discussion they require from the group. If someone is at level 6, it is important for them to try and offer a solution that can accommodate their needs and the needs of the rest of the group.

In addressing someone’s reservation, it is important to:

- a) Ask everyone for possible solutions (the person expressing the concern and the rest of the group have the responsibility to find solutions).
- b) Ask people to suggest improvements as alternatives that meet the objectives of the entire group.