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Partnering in Research: Guidance for Engagement with Indigenous Communities

Contents

Introduction 2
When This Guide Applies 3
What Genome BC Requires 3
Project Design Considerations 3
Community Engagement and Relationship 3
Relevance and Community Benefit 3
Indigenous Governance and Data Stewardship 4
Consent and Ongoing Participation 5
Potential for Group Harm 5
Research Team Considerations 5
Positionality 5
Experience and Readiness 6
Post-Award Expectations 6
Key Considerations Before You Apply 7

Introduction

This guide provides direction to applicants seeking funding for research that involves or affects Indigenous communities. This guide should be read alongside the specific requirements of each funding opportunity supported by Genome BC.

Genome BC supports genomics and life sciences research that generates health, environmental, social and economic benefits for British Columbia. Applicants are expected to demonstrate that research involving and affecting Indigenous communities is designed and conducted in alignment with the 6Rs of Indigenous Research: Respect, Relevance, Reciprocity, Responsibility Representation and Relationship[1]. Applying this framework to Indigenous research fosters respectful relationships, addresses relevant priorities identified by Indigenous partners, provides reciprocal benefits and supports Indigenous communities in exercising responsibility, self-determination and governance over matters that affect them. Applicants may also find value in reviewing the Í:westel qe tótel:exwtel (Teaching Each Other and Learning Together) Toolkit, developed under Genome BC's Societal Issues program, which documents the processes that the project team undertook to foster ethical, collaborative engagement with an Indigenous community.

[1] https://tribalcollegejournal.org/the-six-rs-of-indigenous-research/

When This Guide Applies

Applicants should use this guide when proposed research:

- Includes or affects Indigenous participants
- Includes Indigenous Nations, communities, or organizations as partners
- Uses Indigenous knowledge
- Collects biological specimens from Indigenous Peoples
- Generates genomic, proteomic, health, environmental, biodiversity, or other data connected to Indigenous communities
- May affect Indigenous lands, waters, species, or resources

If you are interested in engaging with an Indigenous Nation, community or organization and would like support, please contact a Genome BC Research and Innovation Manager, who can connect you with our Indigenous Engagement team.

What Genome BC Requires

Genome BC will evaluate the proposed Indigenous engagement strategy and its integration of Indigenous priorities. We will also assess the research team's positionality, experience working with Indigenous communities and overall readiness to undertake the project in a respectful, collaborative and culturally informed manner.

Project Design Considerations

Community Engagement and Relationship

Applications involving Indigenous communities should demonstrate that:

- Indigenous partners were engaged at the earliest stages of project development
- Research questions and objectives were co-created with Indigenous partners
- Project teams are committed to building and sustaining meaningful relationships with Indigenous communities
- Relationships are supported by evidence such as letters of support, agreements, resolutions or other community endorsements
- Community-specific protocols, customs and governance processes have been identified and will be respected
- Any Indigenous advisory group, reference group, steering committee or governance body supporting the project is described
- Processes are in place for review of major protocol changes with Indigenous partners

Applications that describe consultation only, without evidence of meaningful engagement or partnership, may not meet Genome BC expectations.

Relevance and Community Benefit

Applications involving Indigenous communities should demonstrate that:

- The proposed research addresses priorities identified by Indigenous partners

- The research results will be shared directly with involved or affected Indigenous communities, with a clear plan for how these results will be shared
- Benefits extend beyond academic outputs
- Communities will receive tangible benefits such as training, employment, mentorship, capacity-building, infrastructure, decision-support tools and results
- The project is not extractive in nature

Applicants should explain how they will address benefit-sharing and prevent inappropriate commercialization, patenting or use of findings without appropriate agreements and community involvement.

Indigenous Governance and Data Stewardship

Applications should demonstrate how Indigenous partners participate in governance throughout the research lifecycle. Alongside this guide, it is recommended to consult with the Genome BC Data Management and Sharing Policy.

Genome BC promotes scientific data management and stewardship using global, academic and industry standards. For data involving Indigenous people, these include the **First Nations Principles of OCAP®**[2], the **CARE Principles for Indigenous Data Governance**[3], the **Principles of Ethical Métis Research**[4] and the **Guidelines for Research Involving Inuit**[5] or the equivalent Indigenous community's framework. It is the Indigenous community's right to choose the data sovereignty framework they wish to assert and it is the responsibility of those working with these communities to respect their decisions.

Applications should describe:

- Ownership of data, samples and Indigenous knowledge
- How control of data and information will be addressed to affirm a community's right to exercise decision-making authority over research that affects them. Describe community roles in oversight and decision-making throughout the data lifecycle, including but not limited to how Indigenous perspectives inform what data is collected, how it is collected and interpreted, disseminated, shared, stored and repatriated, as well as its secondary use.
- Access to data and results
- How possession of data, information and materials will be handled to preserve the Indigenous community's sovereignty over the data and information including the collected samples, hard copies; and digitized data, as well as stewardship and long-term management arrangements

[2] The First Nations Principles of OCAP® - The First Nations Information Governance Centre
[3] The CARE Principles for Indigenous Data Governance — Global Indigenous Data Alliance
[4] Guide_Ethics_NAHOMetisCentre.pdf
[5] Guide_Ethics_Inuit-Fact-Sheet.pdf

Consent and Ongoing Participation

Applications should demonstrate that consent processes are aligned with the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) FPIC, which is Indigenous peoples' rights to Free, Prior and Informed Consent, including:

- Culturally appropriate, developed with Indigenous partners and aligned with the community's protocols, values and expectations regarding consent
- Aligned with individual and community-level expectations
- Understandable and accessible
- Ongoing throughout the project where appropriate
- Clear disclosure regarding future use of samples, data and associated information
- The right of refusal, as consent, must be given voluntarily, without coercion, manipulation or undue influence

Potential for Group Harm

Applications involving Indigenous communities should assess and mitigate risks such as:

- Stigmatization of Indigenous communities
- Narratives that promote genetic determinism while ignoring historical, social, environmental and structural determinants
- Harm arising from interpretations of ancestry, origins, identity or community history
- Disclosure of sensitive familial, genealogical or relatedness information

Applications should describe how Indigenous partners will participate in reviewing and contextualizing findings prior to public dissemination.

Research Team Considerations

Positionality

Applications should describe the positionality of the research team and explain how team members understand their roles, relationships, responsibilities and connections to the Indigenous communities involved in the project. This helps applicants demonstrate awareness of their responsibilities, relationships and approach to conducting research involving Indigenous communities. Applicants are encouraged to include only information they consider relevant to the proposed research and may choose the level of detail they are comfortable providing. Individuals retain the right to include or omit any aspect of their identity and personal background in the positionality statements.

Information provided in this section will be shared with Genome BC's internal and external reviewers as part of the application package. All reviewers are contractually obligated to maintain the confidentiality of application materials.

A positionality statement may include:

- Relevant lived experience, community relationships and cultural connections
- Previous experience working with Indigenous communities

- Reflection on how individual and institutional perspectives and processes may influence the research
- Steps the team is taking to support cultural humility, reciprocal learning and respectful partnership
- The role of Indigenous team members, advisors, Elders, Knowledge Keepers and community representatives in project governance and decision-making

Experience and Readiness

Applications should describe the team's experience working with Indigenous communities and explain how that experience supports successful project delivery.

Applications may describe:

- Previous collaborative research projects
- Existing relationships with participating Indigenous partners
- Experience implementing Indigenous engagement plans
- Experience with community-led or co-developed research
- Experience with Indigenous data governance and stewardship
- Training related to Indigenous cultural safety, humility or ethical research practices
- Indigenous leadership within the research team, governance structure or advisory bodies.

Where teams have limited experience, applicants should describe how they will obtain appropriate education, guidance, mentorship and community support to ensure respectful and effective project delivery.

Post-Award Expectations

Where projects are funded, Genome BC expects researchers to maintain the commitments described in their application and continue meaningful engagement throughout the project lifecycle.

Genome BC is committed to supporting genomics research that advances Indigenous priorities as articulated by Indigenous communities, in a culturally safe way.

Applicants are encouraged to build strong partnerships based on trust, respect, transparency, shared decision-making and responsible stewardship of knowledge, data and biological materials.

Key Considerations Before You Apply

You may use the following to assess whether Indigenous engagement considerations have been addressed in your application. This is intended as a guide only and is not an exhaustive list of requirements. Applicants may address these considerations in different ways depending on the project, community and context. **Tip:** Hold Ctrl and then click on a heading to jump to the corresponding section in this guide.

Community Engagement and Relationship

- Indigenous partners were engaged at the earliest stages of project development
- Research questions and objectives were co-created with Indigenous partners
- Accountability to the Indigenous partners and the commitments established through project relationships will be maintained
- Evidence of support is provided such as letters of support, agreements, resolutions, etc.
- Indigenous community protocols and governance processes will be respected
- Indigenous advisory and governance structures supporting the project are described
- Processes for review of major protocol changes with Indigenous partners are described

Relevance and Community Benefit

- The proposed research addresses priorities identified by Indigenous partners
- Benefits extend beyond academic outputs
- Expected tangible benefits to Indigenous communities are clearly described
- The project is not extractive in nature

Indigenous Governance and Data Stewardship

- Management of Indigenous data, related results, samples and knowledge are aligned with the Indigenous community's chosen data sovereignty framework and applicable Indigenous data governance standards, for example OCAP®

Consent and Ongoing Participation

- Consent processes align with Free, Prior and Informed Consent (FPIC)
- Consent processes are culturally appropriate, aligned with individual and community-level expectations, understandable, accessible and ongoing where appropriate
- Future use of samples, genomic data and associated information is clearly disclosed
- Indigenous community's decision on how samples are stored, returned, destroyed and secondary usage is respected

Potential for Group Harm

- Potential risk that can result in group harm has been identified and mitigation strategies are in place
- Application describes how Indigenous partners will participate in reviewing and contextualizing findings prior to public dissemination

Team Readiness

- The research team's positionality is described
- Relevant experience working with Indigenous communities are described. Where experience is limited, plans are provided for education, guidance, mentorship, and community support.