

# Indigenous Peoples and Genomics: Starting a Conversation

## PROJECT SUMMARY

The human genome is the name for the entire sequence of DNA that guides the development and functioning of our bodies. Technological advances in the last several years have made sequencing the entire genome an affordable task. Genomic sequencing is vastly superior to previous methods for diagnosing many medical conditions and sometimes pointing to a treatment.

Unfortunately, doctors are discovering that they are often unable to fully interpret genomic sequencing tests for Indigenous Canadians. The genomic sequence of the person being tested is compared to a public database, which contains anonymous sequences from people of multiple ancestries. Ancestry is like an extended family – our genomes are most similar to those we are most closely related to – so analysis relies on comparing the person being tested to genomes of similar ancestry. Unfortunately, Indigenous Canadians are under-represented in current databases, making it difficult to analyze their genomic sequences.

The goal of our project is to initiate preliminary conversations with individuals of Indigenous ancestries to raise awareness of their under-representation and to determine their perspectives, values, and concerns about this. In collaboration with participants, we will write a report and create a short film that describe the situation and share the diverse viewpoints of participants. The film and report could then be used to launch broader community-based participatory research on the issue via a more representative consultation with Indigenous communities across BC and Canada.

Ultimately, it is crucial to hold these consultations with the full representation of Indigenous communities, preferably in an Indigenous-led forum. Indigenous values and concerns must be forefront in guiding any attempts to address what the medical system perceives as disparities in translating genomic medicine equitably for all British Columbians. This is consistent with the Truth and Reconciliation Commission's call to identify and close the gaps between Indigenous and non-Indigenous Canadian's healthcare.

The project is jointly led by Jenny Morgan, Director of the Indigenous Health Program for Women and Families, BC Women's Hospital, and Patricia Birch, from the Department of Medical Genetics, UBC.

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