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We honour the voices of all people living with HIV who have passed on before us. We have no conflicts of interest to disclose.

# Indigenizing our Research: Indigenous Community Leadership in HIV Epidemiology Research

Valerie Nicholson<sup>1</sup>, Andreea Bratu<sup>1</sup>, Alison McClean<sup>1,3</sup>, Simran Jawanda<sup>4</sup>, Niloufar Aran<sup>1</sup>, Knighton Hillstron<sup>5</sup>, Claudette Cardinal<sup>1</sup>, Elizabeth Benson<sup>5</sup>, Kerrigan Beaver<sup>5</sup>, Anita Benoit<sup>7</sup>, Robert Hogg<sup>1,4</sup>, Denise Jaworsky<sup>1,7,8</sup>



1. British Columbia Centre for Excellence in HIV/AIDS, Vancouver BC, Canada; 2. AIDS Vancouver, Vancouver, BC, Canada; 3. University of British Columbia, Vancouver, BC, Canada; 4. Simon Fraser University, Burnaby, BC, Canada; 5. Canadian Aboriginal AIDS Network, Vancouver, BC, Canada; 6. Saskatchewan Health Authority, Saskatoon, Saskatchewan, Canada; 7. University of Toronto, Toronto ON, Canada; 8. University of British Columbia, Prince George, BC, Canada.

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# Background

- When using large linked datasets for health research, it is crucial to engage communities in the research process in order to meaningfully address the public's needs.
- This is particularly important when engaging Indigenous communities, seeing that:
  - There is a need to understand the historical and ongoing impacts of colonialism,
  - It is crucial to acknowledge the strengths in Indigenous Peoples' **knowledges and experiences** while advocating for Indigenous leadership and self-determination in research.

**Aim:** to describe an **allyship-based approach** to community-based participatory research that was used to engage and involve Indigenous peoples living with HIV in three data-intensive research projects exploring HIV outcomes of Indigenous populations in Canada.

**Goals:**

- 1) To support Indigenous peoples living with HIV to actively participate in the research process
- 2) To generate research questions that can be answered with the available datasets
- 3) To integrate Indigenous and non-Indigenous ways of knowing throughout the research process.



# Approach

- We describe three projects that focused on empowering with Indigenous Elders, scholars, and community members to identify meaningful research priorities:

## 1. Building Bridges - Describing a Process for Indigenous Engagement in Epidemiology

The project created two community research teams (in Vancouver and Toronto) of Indigenous people living with HIV, Indigenous and non-Indigenous researchers. These teams met for a series of gatherings to learn about cohort data analysis and develop research questions important to Indigenous communities.

## 2. Building More Bridges

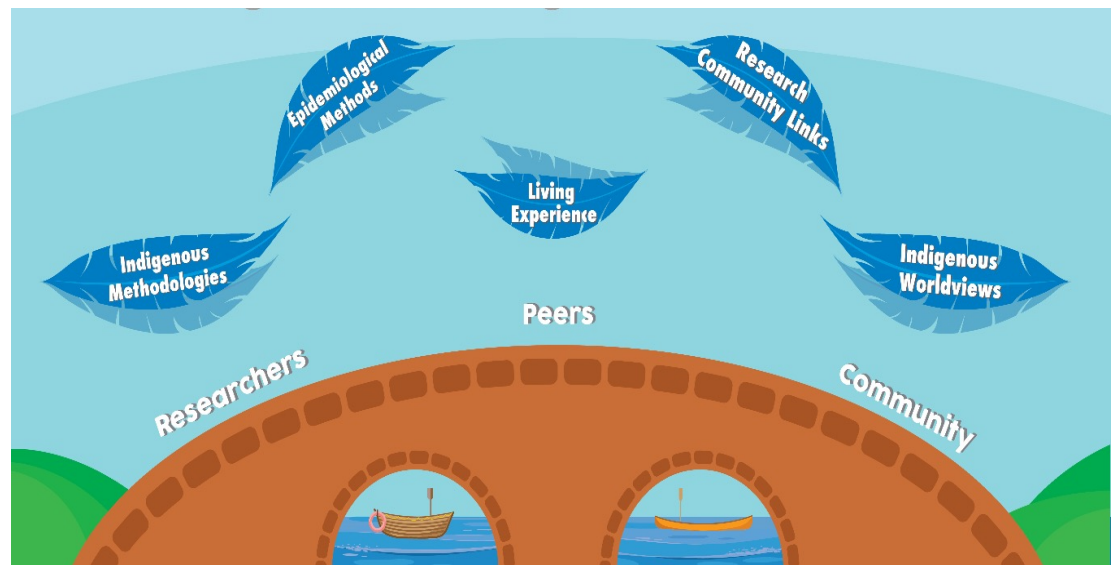
Building on the knowledge from the Building Bridges framework, the previous two teams were joined by a third team in Saskatoon, where the teams developed research questions to investigate using data from the Canadian HIV Observational Cohort (CANOC) study that were important to Indigenous people living with HIV in Saskatchewan.

## 3. Indigenous Circles through the Black Box of Big Data

Through the Comparative Outcomes and Service Utilization Trends (COAST) study, the introducing additional layers of ethical considerations. COAST is a population-based cohort that includes longitudinal linked data on all people living with HIV in British Columbia (BC), Canada and a 10% random sample of BC's adult general population from 1992-2020.

- All three projects were guided by principles of **Two-Eyed Seeing** and conducting research “in a good way”, which is defined by the Canadian Aboriginal AIDS Network as:

*‘following principles of relationality and relational accountability; being community-controlled; addressing a need identified by the community; bringing positive change to the community; creating opportunities for the community; valuing the role of Elders; doing no harm to the community; honoring the physical, spiritual, mental, and emotional aspects of all people involved; valuing all ways of knowing; and more.’<sup>1</sup>*





# Learnings & Discussions

- Reflecting on our work, we share the following **key considerations and suggestions** for engaging Indigenous Communities and people living with HIV in population data research:
  1. Engage relevant stakeholders at the start of the project.
  2. Focus on developing relationships throughout the research process.
  3. Honour Indigenous ways of knowing and local protocol, lands, and traditions throughout the research process.
  4. Prioritize Indigenous voices and priorities.
  5. Promote co-learning and capacity building.
  6. Involve Indigenous research team members in data analyses and interpretation and knowledge translation.
  7. Honour relationships after research is completed.



# Conclusions

- The success of our work has been supported by the leadership, voices, and knowledges of Peer Indigenous Co-Researchers: Indigenous People Living with HIV who bring living experience of HIV, along with experience in epidemiological research.
- We were able to “**bridge**” Indigenous knowledges and worldviews and conventional research practices, thus connecting community and researchers.
- This paper is timely and will enable community-driven research to facilitate scientific breakthroughs, social movements, activism, and human rights shifts relevant to HIV in the era of data intensive research.

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