

# BUILDING BRIDGES: A MODEL FOR COMMUNITY ENGAGEMENT IN EPIDEMIOLOGY RESEARCH

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## Background

- There is a need to make cohort research data and findings more accessible and meaningful to individuals and communities.
- A process embedded with Indigenous methodology for using cohort data is lacking.
- **Building Bridges** was conceived to meaningfully engage First Nations, Métis and Inuit (collectively called Aboriginal in this project) leaders and peoples living with HIV (PHAs) in epidemiology research.

## What is Building Bridges?

- Building Bridges is a multi-site (Toronto and Vancouver) community-based research (CBR) project using data from the Canadian Observational Cohort (CANOC) collaboration.
- Building Bridges has six phases which aimed to follow CBR principles and Indigenous methodology.

## Building Bridges Objectives

1. Develop and pilot a model for meaningful engagement of Aboriginal peoples affected by HIV in epidemiology research.
2. Identify and answer epidemiology questions pertaining to HIV and Aboriginal peoples in Canada using CANOC data.
3. Create a team of Indigenous and allied scholars, service providers, and researchers that can collaborate on future projects.

## 1 Model Development

- Established an advisory committees of Aboriginal stakeholders to guide subsequent phases and inform the application of Indigenous methodology to epidemiology.
- Identified how to ...
  - Create culturally safe spaces. Fifteen statements were developed (e.g., Ceremony by Spiritual leader, meals).
  - Be inclusive of diverse ethnicities, identities, and cultures, persons with caretaking responsibilities, agency representatives, world views, foundational principles (OCAP, TCPS Chapter 9).
  - Incorporate Indigenous methods of knowledge generation in research and dissemination of research findings (e.g., epistemology and ontology, sharing circles, different worldviews, advisory committee, community and peer-driven dissemination), and in developing a recruitment strategy (e.g., hiring a peer research assistant, word of mouth).

## 2 & 3 Recruitment & Research Question Development

- Recruited Aboriginal PHAs to attend the meeting with the advisory committee and Building Bridges investigators to become the Building Bridges Research Team.
- Discussed how to create a safe space and use Indigenous methodology in research (Phase 1).
- Described Building Bridges and its objectives.
- Described what is epidemiology, statistics, and CANOC (i.e., database, participants, types of research questions, previous CANOC articles).
- Developed research questions.
- Circulated emails to refine research questions and a teleconference call was held to finalize questions.
- Research questions were submitted to the CANOC coordinator.

\*Recruited Aboriginal PHAs consented to participate for the duration of Building Bridges.

## 4 & 5 Data Analysis & Interpretation

- CANOC data analyzed by a CANOC statistical analyst
- Data analysis was an ongoing process.
- Presented and interpreted findings with meeting attendee(s).
- Efforts were made to present findings prior to the meeting for those unable to attend in order to obtain their feedback.

## 6 Knowledge Translation & Exchange

- Discussed conference abstracts and other dissemination activities (community presentations, manuscripts and research snapshots).
- Planned the final gathering and held the final gathering.
  - Several emails were circulated to plan the final gathering.
  - Meetings were held with the Spiritual Leader to determine ceremony to conduct at the gathering (i.e., feast, honoring ceremony for Aboriginal APHAs and the Spiritual leader, gift exchange between partner sites).
- Knowledge exchange was important throughout each phase of Building Bridges.

## Strengths

- Consistent, frequent and respectful engagement through in-person meetings and several emails and teleconferences facilitated team building.
- Identifying Indigenous leadership at community and research levels was pivotal to all phases.
- Team expertise in lived experiences, Indigenous culture, HIV research, epidemiology, services and support enabled multi-directional learning.
- Involvement of allied academic researchers facilitated meaningful relationships with community through the advisory committee structure.

## Please visit our other posters from our piloted Aboriginal Health Epidemiology Model

- CS02- "Differences in antiretroviral treatment interruption between Aboriginal Peoples and other ethnic groups in a multisite cohort of people living with HIV in Canada".
- CS55 - "Increased Mortality Among Aboriginal Persons in a Multisite Cohort of People Living with HIV in Canada".
- CS56 - "Differences in time to virologic suppression and rebound between Aboriginal Peoples and other ethnic groups among individuals initiating combination antiretroviral therapy in a multisite cohort of individuals living with HIV in Canada".

## Challenges

- Breaks in continuity during data analysis, recruitment, and limited email and phone access were challenges.
- Mitigating barriers and clear communication of roles and project duration was important for recruitment.

## Conclusions

- Building Bridges led to a collaborative **Aboriginal Health Epidemiology Model** and impactful research questions.
- Success hinged on ongoing engagement of Indigenous leaders, participants, service providers and researchers with diverse expertise and co-learning occurring among these groups.

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