

Indigenizing our research: indigenous community leadership in HIV epidemiology research

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Abstract

The use of data intensive health research has allowed for greater understandings of population health. When conducting data intensive health research, engaging and involving the community is essential for conducting meaningful research that is responsive to the public's needs. Particularly, when engaging Indigenous communities in research, there is a need to understand historical and ongoing impacts of colonialism and recognize the strengths in Indigenous Peoples' knowledges and experiences while supporting Indigenous leadership and self-determination in research.

This article describes the approach our research team/organization used to engage and involve Indigenous people living with HIV in three research projects using large, linked datasets and looking at HIV outcomes of Indigenous populations in Canada. The foundation of these projects was simultaneously: 1) supporting Indigenous people living with HIV to be involved as research team members, 2) developing research questions to answer with available datasets, and 3) integrating Indigenous and Western ways of knowing.

We have identified important considerations and suggestions for engaging and involving Indigenous communities and individuals in the generation of research ideas and analysis of linked data using community-based participatory research approaches through our work. These include engaging stakeholders at the start of the project and involving them throughout the research process, honouring Indigenous ways of knowing, the land, and local protocols and traditions, prioritizing Indigenous voices, promoting co-learning and building capacity, and focusing on developing longitudinal relationships. We describe keys to success and learnings that emerged. Importantly, the methodology practiced and presented in this manuscript is not a qualitative study design whereby research *subjects* are surveyed about their experiences or beliefs. Rather, the study approach described herein is about engaging people with living experience to co-lead as *researchers*. Our approach supported Indigenous people to share research that addresses their research priorities and responds to issues relevant to Indigenous Peoples and communities.

keywords

HIV; community-based; indigenous; cultural safety; epidemiology; two-eyed seeing; medicines of the land

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Introduction

Over the past decades, the field of public and population health has been revolutionized by data-driven approaches to research. Data intensive health research is a term commonly described as a conglomeration of large and linked datasets which include a variety of routinely collected data elements that are often interconnected and rapidly evolving [1–4]. The evolution of data intensive health research has created many opportunities to better understand population health and its determinants; however, increased use of large linked datasets raises important ethical questions around the processes of doing research for or with impacted communities [2, 5, 7]. Recent literature illustrates why the public is an essential player in informing the use of data in a way that drives innovation and efficiency in research [4, 8, 9]. However, additional literature on how to operationalize public involvement data intensive research is needed.

When engaging Indigenous communities in data intensive health research, researchers must understand the colonial history of Indigenous Peoples and the settler state, the ongoing impacts of colonialism on the communities they work with, and the ways in which health research carried out by non-Indigenous researchers has harmed Indigenous communities [10–12]. Indigenous Peoples in Canada have a long and complicated history with data-intensive health research [13–16]. They are often underrepresented in conventional statistical studies and existing statistical portrayals are often stigmatizing and centered around disparity, deprivation, disadvantage, dysfunction, and difference [17]. As part of a path towards reconciliation, non-Indigenous researchers must support Indigenous self-determination in research and actively work towards achieving Indigenous data sovereignty [18]. They must recognize and acknowledge the strengths and knowledge of Indigenous peoples, including those with living experience of health issues.

To highlight the importance of honouring Indigenous knowledge, our research team has asked me, Valerie Nicholson, to share the history of our work with you. I carry many names: the one the eagles watch over, No de Wen da (wolf eyes), Auntie (Torres Straight Islanders). I am a mother and grandmother. I am Mi'Kmaq, Haida, Gypsy and UK Islander decent. I am living with HIV. Although I do not hold a research degree, my path has led me to become a researcher. I represent members of the public, patient partners, and peers, depending on the terminology you choose. I prefer to identify as Elder Valerie. Throughout this manuscript, I call upon my Indigenous and allied colleagues to weave their voices in with mine. You will notice different writing styles throughout this manuscript. Although this practice is not common in academic literature, we feel this best embodies our use of Etuaptmuk also referred to as the Two-Eyed Seeing guiding principle [19].

Our work focuses on Indigenous people living with HIV in Canada. The term Indigenous in Canada is inclusive of many different peoples from three distinct groups: First Nations, Métis, and Inuit [20]. In Canada, Indigenous people are overrepresented in the HIV pandemic, representing 11.3% of new HIV infections in 2016, yet only 4.6% of the total population [21]. In addition, Indigenous people in Canada often have poorer HIV-related health outcomes compared to

non-Indigenous people living with HIV [22]. Historical and ongoing colonization, racism and marginalization of Indigenous Peoples in Canada has eroded the trust between many Indigenous communities and settler health services [23, 24].

The research tradition introduced in this discourse is not a form of qualitative data collection. While valid, we seek to differentiate ourselves from qualitative research methods that involve addressing a specific—and often pre-determined—research question through examining experiences and beliefs of a research *subject*. Instead, we wish to honour *researchers* with living experience by empowering the knowledge keepers to steer us on our research path. We believe it is of fundamental importance to include those with whom the research is about in all levels of study design. This means that researchers with living experience are to decide which questions to ask. This approach is in accordance with the principles of Greater Involvement of People living with HIV and/or AIDS (GIPA) and Meaningful Engagement of People living with HIV and/or AIDS (MEPA): “Nothing about us without us”. We honour all people that are represented in our data and recognize that the people are the spirit of the number and the experience behind the statistic.

Our manuscript describes how our research team and the BC Centre for Excellence in HIV/AIDS (BC-CfE) approach Indigenous public engagement in HIV research using large linked datasets. While a valuable consideration, our paper does not focus on the data linkage process itself. Rather, our work focuses on the generation of meaningful research questions, as well as the analysis of datasets that have already been linked. The BC-CfE is Canada’s largest HIV/AIDS research, treatment, and education centre. It is home to the provincial Drug Treatment Program (DTP), [25] BC’s centralized system of antiretroviral therapy dispensation, providing a well-designed platform for data collection on HIV-related clinical variables.

Approach

Indigenous public involvement and engagement in HIV research at the BC-CfE began in 2014 and continues to grow. We describe three projects that focused on empowering with Indigenous Elders, scholars, and community members to identify meaningful research priorities. Research questions that could be addressed using existing cohorts or data linkages were formulated together, and team members worked cooperatively with both Indigenous and Western ways of knowing throughout the research process. To allow for sufficient discussion, we focused our paper on the project entitled, *Building More Bridges* (project 2 described below) and briefly describe two related projects (projects 1 and 3).

The 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 [26]. In a good way is to do no harm and do the work with courage, truth, respect, honesty, love, and humility.

Two-eyed seeing

Our work is grounded in Two-Eyed Seeing guiding principles, as articulated by Mi'kmaw Elder, Albert Marshall, who lives in the Eskasoni Community in Nova Scotia, Canada. Elder Marshall describes Two-Eyed seeing as "learn[ing] to see from your one eye with the best or the strengths in the Indigenous knowledges and ways of knowing... and learn[ing] to see from your other eye with the best or the strengths in the mainstream (Western or Eurocentric) knowledges and ways of knowing... but most importantly, learn[ing] to see with both these eyes together, for the benefit of all" [27]. Indigenous and settler ways of knowing have distinct ontologies, epistemologies and axiologies that influence methodologies used in knowledge generation [27]. Each of these ways of knowing are valid and there is no hierarchy that places one above another and it is difficult to adapt one to accommodate the other. Two-Eyed Seeing enables both Indigenous and settler ways of knowing to co-exist in an ongoing journey and practice of reciprocal learning and teaching that allows both knowledges to contribute and draw on their respective strengths. Our team achieved this by inviting members with experience in Indigenous ways of knowing and settler scientific ways of knowing. All team members were treated as equal, and it was recognized that everyone had something to teach and something to learn.

Project 1: Building bridges – describing a process for indigenous engagement in epidemiology

The project 1 manuscript builds from our earlier work carried out by members of this research team. Project 1, entitled Building Bridges, saw the creation of two community research teams (one in Vancouver, British Columbia and one in Toronto, Ontario) of Indigenous people living with HIV, Indigenous researchers, and non-Indigenous researchers. These teams met for a series of gatherings to discuss issues and research priorities for Indigenous people living with HIV in Canada, learn about cohort data analysis and develop research questions important to Indigenous communities. In Vancouver, the team named their gatherings, *Voices of Wisdom* gatherings, and in Toronto, the team referred to their gatherings as *Sharing Circles* aligned with their use of an Indigenous methodology [28]. Importantly, the *Voices of Wisdom* and *Sharing Circles* gatherings were not interviews where people living with HIV were researched. Instead, these gatherings were of researchers coming together from diverse epistemological backgrounds to pose questions and shape research priorities together.

The research questions developed by the research teams were used to complete data request forms and submitted to the Canadian Observational HIV Cohort (CANOC). CANOC is a large and heterogeneous dataset housed at the BC-CfE. This dataset is a national study that includes 11 linked datasets across 5 provinces in Canada, and includes demographic, laboratory and clinical data on people living with HIV over the

age of 18 [29]. The linked datasets in CANOC are described in Table 1.

Similar to the Western scientific convention, the community-based research teams were engaged throughout the research process. For example, researchers were engaged in refining, defining, and deriving the variables of interest. The findings were then discussed as a team and the suitable next steps emerged. Final analyses were discussed again as a community of researchers and together we developed manuscripts, conference abstracts and community knowledge sharing products. This work resulted in four peer-reviewed publications (three data papers and one process paper) with strong community engagement (Table 2).

Building Bridges led to a process for Indigenous engagement in epidemiology [33]. Indigenous people living with HIV were involved as researchers throughout all phases of the research including research question development, data analysis, interpretation of data, and knowledge translation. Our process honoured Indigenous ways of knowing, was guided by Elders, and included ceremony. Our team prioritized Indigenous voices and relationality and continuously aimed to create safer research spaces for all team members. This process, while not meant to be prescriptive, provided guidance to engage the public in health research using pre-existing cohorts or databases.

Project 2: Building more bridges

Listening to our peers who are living with HIV was the foundation of our work in Saskatchewan. Building on our knowledge from the Building Bridges framework and our prior work in Ontario and British Columbia, we joined together to work with our brothers and sisters in Saskatoon. Building More Bridges took place over 3 days in October 2019 in Saskatoon, Saskatchewan, Canada, with the goal of bringing community researchers (Indigenous people living with HIV, $n=8$) and non-Indigenous researchers ($n=6$) to the table in partnership. Together, we developed research questions to investigate using CANOC that were important to Indigenous people living with HIV in Saskatchewan. Each morning we had a smudge, an opening circle and prayers. We feasted together and honored the foods of the lands. We recognized our full agenda and the importance of being mindful of everyone's energies so we acknowledged that we might not get through everything and set expectations up front.

Day 1: Building connections

As the study's Elder, I began our work on the first day with an Opening Ceremony and Welcome to the Territory. Each subsequent morning was started in a good way involving an acknowledgement of our ancestral lands and honouring our ancestors who walked before us. On the first day, we received teachings from an Elder living with HIV who shared his knowledge about medicines of his land and his relatives' teachings. We define an Elder as someone that has accepted the responsibility to mentor, teach and witness others' journey in HIV. Our team then created medicine pouches fashioned from elk leather and filled them with Indigenous medicines (e.g., tobacco, sage, lavender). Through ceremony we thanked the animal that gave its life, giving prayers for the animal,

Table 1: CANOC data structure and linkages

Province	Site	Linkages
British Columbia	BC-CfE	BC-CfE lab database with multiple linkages, BC-CfE being the repository and data steward.
Saskatchewan	Southern Saskatchewan HIV Cohort Saskatoon HIV/AIDS Research Endeavour	Site related data derived from each cohort
Ontario	Ontario HIV Treatment Network Toronto General Hospital Maple Leaf Medical Clinic Ottawa Hospital	Site related data derived from each cohort
Quebec	Clinique Medicale L'Actuel McGill University Health Centre Quartier Latin	Site related data derived from each cohort
Newfoundland	Memorial University of NFLD	Site related data derived from each cohort

Abbreviations: CANOC: The Canadian HIV Observational Cohort; BC-CfE: British Columbia Center for Excellence in HIV/AIDS.

Table 2: Summary of building bridges and building more bridges research questions and applicable main results

Research paper	Research question	Main results
Building Bridges		
Benoit et al. 2017 [30]	Are there differences in experiencing (1) virologic suppression and (2) virologic rebound between Indigenous and non-Indigenous people living with HIV?	(1) Indigenous people were less likely to achieve viral suppression compared to white people (aHR 0.58, 95% CI 0.50, 0.68) (2) There was no statistically significant difference between Indigenous and non-Indigenous people experiencing virologic rebound (aHR 1.03, 95% CI 0.84, 1.27)
Benoit et al. 2017 [31]	Are there differences in all-cause mortality between Indigenous and non-Indigenous people living with HIV?	There was an increased risk of death for Indigenous people compared to white people. (aHR 3.73, 95% CI 2.95–4.71).
Jaworsky et al. 2018 [32]	Are there differences in HIV treatment interruptions between Indigenous and non-Indigenous people?	Indigenous ethnicity was a significant predictor of antiretroviral treatment interruption (aHR 1.43, 95% CI 1.21, 1.70).
Building More Bridges		
<i>In progress</i>	How does distance from an HIV care provider or from a community with visiting HIV services impact markers of quality of HIV care?	
<i>In progress</i>	How do peer networks and connection to culture impact HIV treatment outcomes	

Abbreviations: aHR: adjusted hazard ratio; CI: confidence interval.

and smudging of the hide—as it is the responsibility we hold to the medicines that we put in the pouch. We wore these around our necks to honour our ancestors and their teachings. Medicine pouches are personal, and many will put a rock from the lands, a feather, or personal items and their prayers in with the medicines. I also shared an important teaching that a medicine pouch is not to be opened by anyone except the one who made it.

Shortly thereafter, the team was (re-)introduced to the Two-Eyed Seeing guiding principle and how to create safer spaces by practicing respect, embracing wisdom, and acting with courage, honesty, truth, humility, and love. Researchers discussed Indigenous and settler worldviews and the importance of recognizing everyone as both teachers and learners.

To cultivate a connection with the lands, our team travelled to Wanuskewin, a sacred place for the Peoples of the Northern Plains for over 6000 years. We walked the lands of the Buffalo

and the first Peoples to feel the histories and to be witness to their ceremonies. At Wanuskewin, the group participated in a Tipi raising and hoop dancing, learned about medicines growing from the land, and cooked bannock over a campfire. Through these activities, our team reinforced connections within themselves, between one another and with the land. We walked where our ancestors had once walked and felt the energy and knowledge of the land; it connected us all.

Day 2: Learning about epidemiology

These deep connections were called upon on the second day when researchers learned about epidemiology and working within the data-confines of CANOC. Research priorities were identified through a Sharing Circle and included the importance of studying all people living with HIV not just those with stigmatized characteristics, the need for increased community HIV education, and the importance of reducing

and eliminating HIV stigma. Conversations began to center around the need for HIV research in the Canadian prairies and the impact of geographical distance and availability of peer support on HIV and health outcomes. Researchers emphasized the importance of strength-based analysis in place of the more common deficit-based approach to health outcomes research.

Our work went smoothly. It was as if our ancestors were guiding us with their knowledge and keeping us safe. Taking the time to honor the lands and traditions of many nations, brought by our team members, all while keeping our hands busy—we were amazed that our work was done ahead of schedule. We had little ones and youth join us in all our activities, as this is the way of our ancestors. While drinking teas from local leaves and fruits, the team worked on our rattles made from deer hide and sinew which were filled with beans and decorated with feathers, leather, beads, and paint. Shortly after, everyone went on a guided walk, led by team member, Knighton, to learn about plants found along the river in Saskatoon that held significance to the local Indigenous community and their ancestors as medicine, food, materials and use in ceremony.

Day 3: Weaving it all together

On the third day, our team summarized the research priorities and worked together to refine these into research questions. We arrived at a consensus and two research questions were finalized: (1) how does distance from health services impact the quality of HIV care in Saskatchewan? and (2) how do peer networks and culture impact HIV outcomes? Throughout the Building More Bridges retreat, participants used Two-eyed Seeing to draw on the strengths of Indigenous ways of knowing and Western ways of knowing to bring both ‘eyes’ together to benefit everyone. Indigenous team members were actively engaged in reciprocal knowledge exchange that highlighted the areas of research that were meaningful to them and their communities. Just as the retreat began, it ended, in a good way with a Closing Ceremony where everyone came together, on even ground, with their rattles, a smudge, and a prayer.

Following the retreat, we continued to strengthen our relationships and collaborate as a team through virtual meetings. We further refined our research questions and made a plan to continue our work and we continue this research journey together.

Project 3: Indigenous circles through the black box of big data

The Comparative Outcomes and Service Utilization Trends (COAST) study [34] is a population-based cohort that includes longitudinal linked data on all known adults living with HIV in British Columbia (BC), Canada and a 10% random sample of BC’s adult general population from 1992-2018. In addition to administrative health data, COAST contains linked laboratory and treatment data, as well as data on behavior and social determinants of health. We have described the COAST data structure and data linkages in Table 3.

Through COAST, we are currently adopting the Building Bridges and Building More Bridges processes described earlier to a larger population data setting, which introduces additional layers of ethical considerations (Figure 1). Although many

of the processes that we have used to engage the public in large HIV cohort research can be applied to population data, there is a need to better articulate ethical principles for this work. Funded by the Canadian Institutes for Health Research, our ongoing work aims to: 1) develop an ethical framework and best practice recommendations for data-intensive research involving Indigenous communities 2) identify ethical ways to make large linked datasets accessible to Indigenous communities; and 3) expand on research models bridging epidemiological methods and Indigenous worldviews.

The *Indigenous Circles through the Black Box of Big Data* project will unfold in two stages. Firstly, we will engage the current Building More Bridges team members and create new partnerships with stakeholders with expertise in data-intensive research and policymaking. Secondly, this interdisciplinary team will come together in a ‘Voices of Wisdom Gathering’. The Gathering aims to facilitate discussion around how Indigenous data sovereignty, Indigenous self-determination, and justice for Indigenous Peoples should guide data-intensive research, as well as the inherent challenges of achieving these goals. Additionally, we will develop best practice recommendations for stakeholders engaging in data-intensive research with Indigenous communities.

Learnings and discussion

Reflecting on our work, we share important considerations and suggestions for engaging Indigenous communities and people living with HIV in population data research (Table 4). We share these with the readers and acknowledge that this builds from previous work in the original Building Bridges (project 1) [45].

Key to success: Honouring ancestors and the land enabled co-learning

As teachers we are learners. The first teachers of this land were our Ancestors, and they were taught by the land itself. Our teachings show us that we do not create or own ideas or concepts. Instead, they have always been there for us to pick up, learn from, and teach about. In all our work, we first acknowledged the land that we are working on which was the territory of the Niitsitpiis-stahkoi (Blackfoot), Očeti Šakówiŋ (Sioux), Michif Piyii (Métis) and Cree. When we honour the land and the teachings of the land, the land will guide us in our work. We honoured our ancestors through ceremony. This enabled us to do our work in a good way and to ground all members of the team so that we were ready to learn and teach together. Whether it was knowledge about the land or about epidemiology concepts, knowledge was shared, and not owned. As Shawn Wilson puts it, “[research] is a ceremony for improving your relationship with an idea” [45]. After receiving and acknowledging all the teachings, our work became clear and we knew the questions that we would research.

Key to success: Research needs ceremony

Throughout our work, we honoured the protocols of the territory. We started our day with a smudge, prayers and

Table 3: COAST data structure and linkages

Name of dataset	Data repository	Data stewardship	Description
Population-level cohort data			
Drug Treatment Program [35]	BC-CfE	BC-CfE	Longitudinal data on ART use, clinical outcomes, viral load, resistance testing
LISA [36]	BC-CfE	BC-CfE	Questionnaire-based data on a cohort of PLHIV, includes demographic, socioeconomic, substance, and health data
Momentum Health Study [37]	BC-CfE	BC-CfE	Questionnaire-based data collected among HIV-positive and HIV-negative gay, bisexual, and other MSM in Vancouver, includes sociodemographic and HIV prevention data
Administrative health data			
Consolidation File [38]	PopData	BC-MoH	Basic demographics such as age and sex, residence, and registration data
Discharge Abstracts Database [39]	PopData	BC-MoH	Records of discharges, transfers and deaths from BC hospitals
Medical Services Plan [40]	PopData	BC-MoH	Diagnosis codes, laboratory and diagnostic procedures
PharmaNet [41]	PopData	BC-MoH	Drug identifiers, costs, prescription date and length, dosages
Vital Statistics Deaths [42]	PopData	BC Vital Statistics	Records of all deaths in BC; includes date, place and cause of death
BC Cancer Registry [43]	PopData	BC Cancer	Records of all cancers reported to the BC Cancer Registry
Mental Health Services [44]	PopData	BC-MoH	Diagnostic codes, care episodes, and service events

Abbreviations: BC: British Columbia; UBC: University of British Columbia; MoH: Ministry of Health; BC-CfE: British Columbia Centre for Excellence in HIV/AIDS; LISA: Longitudinal Investigation into Supportive and Ancillary Health Service; PopData: Population Data BC; CANUE: Canadian Urban Environmental Health Research Consortium.

acknowledgement of the land we were on. We opened and ended our day in a good way. Ceremony guided our work, and this was essential to creating a safer space for research. Indigenous team members of many nations and non-Indigenous team members participated in ceremony together. This strengthened relationships and facilitated team building.

Key to success: Strength comes from the team

When I look at our team, we each brought our strengths and wisdoms. Our team is very diverse in age, gender, and cultural backgrounds. Like a braid of sweetgrass, we braided our cultures together, giving our team a unique strength. According to the sweetgrass teaching from my Grandfather, “when we look at a single strand of sweetgrass and if we pull on it, it will break. When you look at the braided sweetgrass and you pull on it, it has much strength. When we learn to work together, ask for help, and involve others, we are stronger and will not break easily.”

In Indigenous cultures across Turtle Island we believe we are all related. We are all connected in this web of life and everything we do is affected by each other and nature. This is one of our first teachings and is the foundation of our existence, this is why we say all my relations. When I was

diagnosed with HIV, I was angry. I got very sick and did harm to my body with addiction to crack and crystal meth. When I accepted myself and connected back to my roots, ceremony, and nature, I started my healing journey. Without all my relations, and finding that connection, I know that I would not be writing this today. It is this connection that brought our team together.

Our team came together to do our work in a circle where no one is above or below anyone else. We would see each other's faces, honour all voices, and learn together. In the circle, we are to be humble and honour the wisdom and experiences of the older ones, the knowledge keepers, and the energy of the young ones. Respecting the circle connects us all.

Key to success: Acknowledge and celebrate strengths

The peers on our team each bring their living experience of HIV and this was essential to our work. Someone that is not living with HIV can never fully understand or feel what that is like. We bring the living knowledge to help others understand. We are not just a statistic or a line on a graph. We are life in action, loving, learning, sharing, teaching, moving, and

Figure 1: Building more bridges in big data indigenous health epidemiology approach

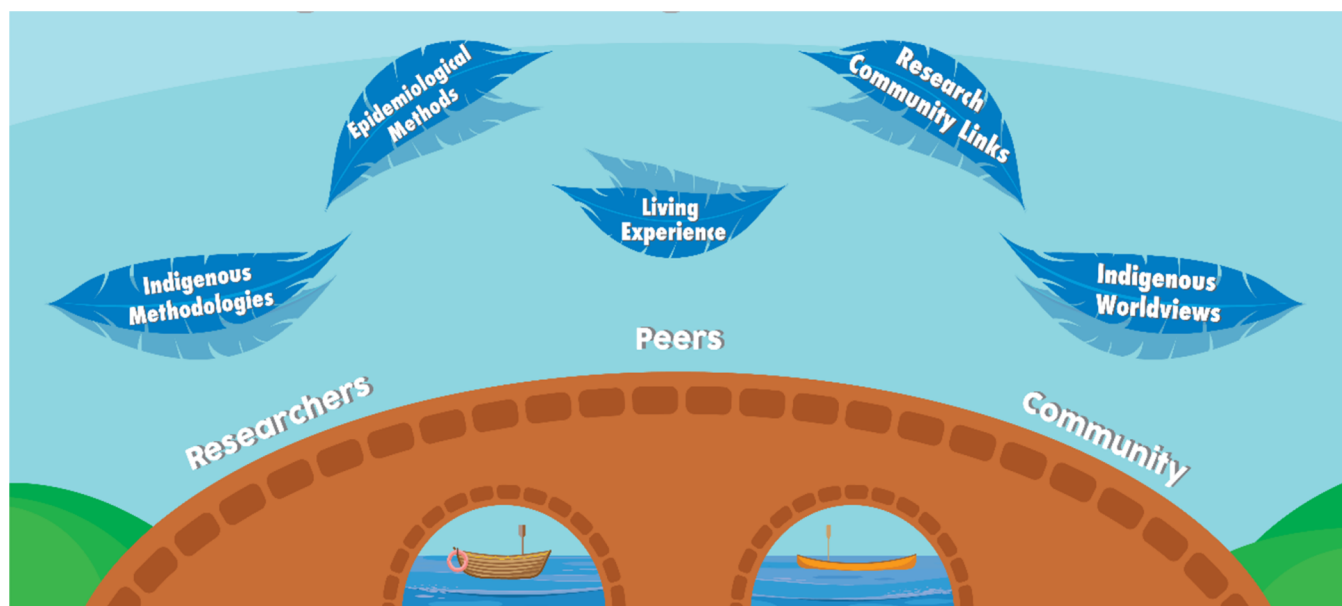


Table 4: Key considerations and suggestions for engaging Indigenous communities in population data research

Engage relevant stakeholders at the start of the project

Engage Indigenous persons and communities at the beginning of the project as research team members in project planning and direction setting. Be receptive to making changes to meet the needs and priorities of Indigenous persons and communities.

Focus on developing relationships throughout the research process.

Dedicate time and resources to developing meaningful and trusting relationships throughout the research process.

Honour Indigenous ways of knowing and local protocol, lands, and traditions throughout the research process.

Involve Elder(s) and/or Knowledge Keepers to guide the work.

Be inclusive of Indigenous ways of knowing and incorporate them into the research. Recognize there may be diverse beliefs among Indigenous research team members and ensure these perspectives are represented.

Acknowledge the ancestral traditional land on which the research is being completed.

Incorporate ceremony led by an Elder, connection to the land, and traditional teachings in research and gatherings, as determined appropriate by Indigenous Peoples and communities.

Prioritize Indigenous voices and priorities

Research questions should be determined based on community-identified needs and priorities. Efforts should be made to create welcoming and safer spaces where Indigenous people can share their experiences and priorities and are supported in developing these priorities into research questions.

Promote co-learning and capacity building

Create space and opportunity for co-learning between Indigenous people and allied researchers, where everyone is a teacher and learner and share their respective strengths and expertise.

Provide training to Indigenous people to increase understanding of cohort and data intensive research methods and strengthen their capacity to conduct future research.

Involve Indigenous research team members in data analyses and interpretation and knowledge translation.

Findings from analyses should be brought to Indigenous research team members to refine and interpret. Findings should be shared with Indigenous communities and stakeholders as determined by Indigenous research team members.

Honour relationships after research is completed

Once the research project is completed, it is vital to continue to honour the relationships developed during the research

growing. We speak for ourselves and for those that cannot speak for themselves.

Someone who practices allyship does so every day and is gifted the name of an ally. They join us in our work. They

do not pretend to know how someone living with HIV feels. Instead, they listen and show empathy. They ask when they don't know and above all, understand that all learnings do not come from a book [45].

Key to Success: Welcome children into the research space

In many Indigenous cultures it is the responsibility of the tribe or village to be part of raising children. Our research team decided to welcome children to our research gathering. It was our way of honouring the ways of our ancestors and bringing back traditions, which many have been taken away, or lost by colonization. Children are the carriers of old knowledge as they are closer to our ancestors. Allowing them at our gathering created a sense of being part of something much bigger than a research team – a tribe. It was an honour as an Elder, grandmother, and auntie to witness the change in the room that was brought about by the energy of the children. Instead of activating traumas of the settler state removing children from families and separating families, we honoured the bond between parents and children as an important part of our research environment.

Learnings (Challenges): Support team members even after the work is done

Upon returning to our home fires, some of us traveled by air. While crossing through airport security, two of our team members were stopped and searched. They both had their medicine pouches with them and were forced to open them. As you recall from the teachings above, this does not honour Indigenous teachings and ways. One team member was a youth who was learning his culture. He knew this violated Indigenous ways and this experience caused him confusion and distress. It was a form of trauma and a reminder of the ongoing colonial invasions into the lives and culture of Indigenous Peoples. From this experience, there are general learnings specific to public engagement in research.

The general learning was that we must stand up for our culture, traditions, and sacred items and include this in our teachings. When engaging public in research, we must ensure that we are able to support our team members even after the research work has ended. We must honour and remain accountable to the relationships we have built during the research process [45]. To support our team, I debriefed with team members, listening to their experience and teaching them not to carry anger from this experience – to not take it into our homes and leave it at the door. I shared teachings of using cedar boughs to brush off negativity.

Conclusion

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. For some, this experience in epidemiology research began with the training included in our work, while many joined the circle with prior epidemiology knowledge. 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. Our approach enables Indigenous people to co-lead research using large linked datasets, and we feel this is essential for health administrative data to be used in research ethically, meaningfully and in a good way. It also can be applied to similar approaches such as patient-oriented research in other disciplines. Our approach is based on a sustainable commitment to engage relevant stakeholders in every stage of the research process so that our research findings can be translated into efficient policy and practice. The current manuscript does not address ways in which Indigenous governance can be integrated in the process of linking large datasets. We acknowledge that this is an area of great importance and a focus for future exploration in our work.

By strengthening and supporting the capacity of Indigenous people's involvement and engagement with data intensive research using linked datasets, this project produces more rigorous research that responds to issues prioritized by the communities that we serve, work with and live in. We respect “nothing about us without us”. We were here before colonization therefore our teachings do not need decolonization. Instead, we are indigenizing research, and this was our approach to do so in the context of HIV epidemiology research. We indigenize research by standing up for our ways of knowing. We indigenize research by following the guidance of our ancestors and the lands.

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Statement on conflicts of interest

no conflicts of interest

Ethics statement

Ethics approval was granted for CANOC at participating sites and from the harmonized University of British Columbia-Simon Fraser University Research Ethics Board at Providence Health Care Research Institute (#H07-02684). The COAST study has received approval from the University of British Columbia/Providence Health Care Research Ethics Board (#H09-02905) and Simon Fraser University Office of Research

Ethics (#2013s0566). The study complies with the BC Freedom of Information and Protection of Privacy Act (FIPPA) and did not require informed consent as it is conducted retrospectively for research and statistical purposes only using anonymized data.

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Abbreviations

AIDS:	Acquired Immunodeficiency Syndrome
aHR:	Adjusted hazard ratio
BC:	British Columbia
BC-CfE:	British Columbia Centre for Excellence in HIV/AIDS
CANOC:	The Canadian Observational HIV Cohort
CBPR:	Community-based participatory research
CI:	Confidence Interval
COAST:	The Comparative Outcomes and Service Utilization Trends
DTP:	Drug Treatment Program
FIPPA:	Freedom of Information and Protection of Privacy Act
HIV:	Human Immunodeficiency Virus
PLHIV:	People Living with HIV
UK:	United Kingdom

