Table of Contents

Moving Mountains to Address HIV/AIDS in Northern BC through Community Based Research

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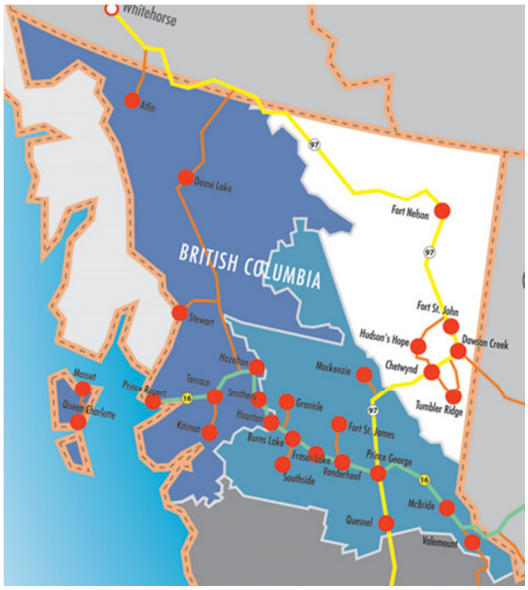
INTRODUCTION

The traditional territory of the Lheidli T'enneh First Nation in the community of Prince George, British Columbia (BC) was the site of the *Moving Mountains: HIV/AIDS Community Based Research Conference* on June 17-19, 2014. This three-day event saw researchers, academics, leaders in Aboriginal HIV research and services, and peers explore community-based research (CBR) in HIV/AIDS in Northern BC. It was the first step in what is hoped will be a long-term process to support the development of intersectoral, cross-disciplinary community-driven HIV/AIDS research in the region.

Context: HIV/AIDS in Northern British Columbia



Northern BC is a region that comprises more than half the province – at approximately 500,000 km sq., it is larger than California or Japan and twice the size of the United Kingdom (Figure 1). The Northern Health Authority (NHA), the northernmost regional health authority in BC, provides healthcare services to a total population of 285,300 residents (Government of British Columbia, 2014). There are three distinct Health Service Delivery Areas (HSDAs), which are the geographic operating divisions that make up the region, including: Northern Interior (light blue),

Figure 1. Northern Health Authority Region (Northern Health Authority, 2014a)

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Northwest (dark blue), and Northeast (white) as seen in Figure 1. As of the most recent demographic statistics in 2012, the population of each area is: 141,700 in the Northern Interior, 73,103 in the Northwest and 68,102 in the Northeast (Government of British Columbia, 2014).

It is important to distinguish between each of these HSDAs. Although they share many similarities; they also host many demographic and socio-economic differences. The Northeast HSDA, for example, is a temporary home to many migratory oil and gas workers who have helped transform the rural and urban landscape, as the result of a resource boom (Markey, Halseth, & Manson, 2009). Similar booms have changed areas in the Northern Interior and Northwest, but not with the same regional effect over a similar period of time. One similarity in the entire NHA region, however, is the large proportion of Aboriginal peoples who represent 17% of the total population (Northern Health Authority, 2014b).

In terms of HIV/AIDS, the Northern Interior and Northwest HSDAs, had the second and third highest rate of new positive HIV tests in BC in 2012, at 5.5 and 5.3 per 100,000 population, respectively, compared to the provincial rate of 5.1 (British Columbia Centre for Disease Control, 2012). Further, from 1995 to 2012 there have been 210 cases of HIV reported in the Northern Interior, 87 in the Northwest, and 21 in the Northeast (Northern Health Authority, 2013). Accompanying these rates are worrying trends among the populations at greater risk for HIV/AIDS, most prominently including Aboriginal peoples, people who use illicit drugs, and sex trade workers. These groups are party to unique regional trends, including mobility between home communities and larger urban centres (Callaghan, Tavares, & Taylor, 2007) and between urban centres, such as Prince George and Vancouver's DTES (Spittal, Craib, Teegee, Baylis, Christian, Moniruzzaman, & Schechter, 2007). As in other parts of the country, the numerous Aboriginal communities in Northern BC face unique and persistent challenges in shouldering the impact of HIV/AIDS (Duncan, Reading, Borwein, Murray, Palmer, Michelow, . . . Hogg, 2011).

Prince George, the largest urban centre in Northern BC, is home to many of the services for HIV prevention, treatment and care, including those for people living in marginalizing circumstances due to intersecting disadvantages, such as poverty, historical trauma, discrimination, stigma, and violence. However, available services do vary for priority populations and by region, throughout Northern BC. For example, Prince George in the Northern Interior and Smithers in the Northwest host a primary or receiving needle exchange site, as well as accessible satellite or secondary sites, yet similar services are difficult to locate in larger communities in the Northeast, such as Dawson Creek and Fort Nelson (Northern Health Authority, 2013, 2014a). In addition, Prince George hosts a number of HIV specific non-profit Community Based Organisations (CBOs), such as Positive Living North: No khēyoh t'sih'en t'sehena Society, the Northern BC Aboriginal HIV/AIDS Coalition, and the Northern HIV and Health Education Society. All CBOs have regional capacities, but are located in a central community in the region. Access to HIV treatment is also available through select providers in various locations, such as through the Central Interior Native Health Society, also in Prince George, and has been increased through the

provincial STOP HIV/AIDS and *From Hope to Health: Towards an AIDS-Free Generation* (2012) strategies. General delivery of harm reduction services, including HIV testing and counselling, condom distribution, prevention and treatment of STIs, hepatitis C, and TB, and sexual health and HIV education are available on a wider basis throughout Northern BC.

The challenges associated with healthcare intervention delivery within such an expansive and diverse geographic area are multiple. Beyond the capacity of healthcare providers, additional barriers such as travel distances and costs, limited human resources, diversity in health intervention delivery and access, lack of culturally appropriate care, stigma and discrimination, and the limited number of healthcare professionals working on HIV/AIDS in BC's North pose unique challenges.

The Planning Phase of Moving Mountains

Sometimes addressing significant issues, such as HIV/AIDS, in such a large, diverse region can feel insurmountable – like scaling a high mountain. Community-based research (CBR) can be a tool for identifying what kind of information is needed in each community, and for bringing diverse stakeholders together to develop shared agendas and move research to action (Minkler, 2005). The *Moving Mountains HIV/AIDS CBR Conference*, and ancillary activities, was born out of this desire to bring Aboriginal and non-Aboriginal people together to review research underway, build the capacity to participate in CBR, and to identify gaps in information and priorities for future research – all with the goal of strengthening the local response to HIV/AIDS.

Bringing a range of people together, some for the first time, to build relationships and to collaboratively develop research priorities was seen as an essential step in building the capacity to engage in research that might be fruitful in reinforcing assets and catalyzing solutions. Through the dedicated work of a research collaborative consisting of researchers from the University of Northern British Columbia (UNBC), a CBR specialist from the Pacific AIDS Network and the CBR Collaborative Centre (a program of the CIHR Centre for REACH in HIV/AIDS) and a community organization representative, funding for this vision was obtained through the Canadian Institutes for Health Research (CIHR) HIV/AIDS Community-Based Research Planning Grants. As part of this process, the team interacted with other several interested community representatives and a Peer Research Associate (PRA), who all provided letters of support for the initiative. In addition to CIHR funds, the Canadian Association of HIV/AIDS Research (CAHR) sponsored the event as part of their workshop series.

Once funding was secured, an Advisory Committee (AC) was formed that brought together both Aboriginal and non-Aboriginal members. Most of the AC members had provided letters of support for the initiative. Invited AC participants was made up of members from national, provincial and regional, Northern BC non-profit organizations, municipal government, academics, including trainees, health professionals, peer researchers and interested community

members. Members of the AC were proficient in a diverse range of fields including, for example, public health, nursing, frontline service provision, politics, research, and education. Participation in the designing and planning of the process was in itself an opportunity for AC members to build relationships, and therefore trust, with one another, another key element of successful CBR (Christopher, Watts, McCormick, & Young, 2008).

The June 2014 *Moving Mountains* conference was one component of what is hoped will be a long-term process to support the development of intersectoral, cross-disciplinary community-driven HIV/AIDS research in communities throughout Northern BC. Event participants included those interested in and committed to this development. A targeted invitation list was developed by the research planning team with input and suggestions from the AC, with the goal of using a personalized approach to drawing in a diverse group of participants. In addition to these invites, the conference was open to anyone of the general public who wished to attend, and promotions were made through local networks and email lists, as well as through mainstream media (Fondahl, 2014; Hinzmann, 2014; Jan, 2014; O'Connor, 2014). The sole qualifying factor that limited participation was the availability of individual financial support to travel to the conference, although travel assistance was made available upon request.

Both the planning and event phases of this project were rooted in the CBR principles of being community driven, having community relevance, promoting equitable partnerships, incorporating capacity building, attending to process, and having action-oriented outcomes (Christopher, Watts, McCormick, & Young, 2008; Minkler, 2005). The principles of the Greater/Meaningful Involvement of People Living with HIV/AIDS (GIPA/MIPA) and the Tri-Council Policy Statement, Chapter 9 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010) – research involving the First Nations, Inuit, and Métis peoples of Canada, which underscores the collaborative process in working with Aboriginal communities – guided this project through active participation and involvement of both people living with HIV/AIDS and Aboriginal peoples whenever possible, throughout all phases of planning, implementation and analysis. It is notable that, despite the involvement of one person living with HIV/AIDS in the grant-writing phase, the AC did not succeed in recruiting a replacement for participation in the event planning – a shortcoming that became an important point of discussion.

Community agency representatives on the AC spoke to barriers to involvement that people with lived experience face when getting involved in research, including the lack of supports to facilitate involvement, the isolation faced by some peers working as Peer Research Associates in the region, and how HIV-related stigma keeps people from disclosing in such a "public" way. In light of these challenges, the AC put specific attentions towards creating an event that would be accessible and interesting to people with lived experience. The AC felt this would be achieved by hosting the Moving Mountains event downtown instead of at UNBC, for example. Additionally,

a session by and for peer researchers was included in the program, and arts-based and visual methods were used in the priority setting activity. APHAs were also offered honoraria for attending.

The AC and a smaller Logistics Planning Committee (which met more frequently) developed the conference to include a specific orientation. As this was the first time that many of the participants were meeting to discuss HIV/AIDS CBR in Northern BC, it was determined that the conference should include the following components: a public event with music and food; findings from research underway or recently completed be "brought back" to community; a peer-focused session, and; an interactive session that would engage participants in sharing their thoughts on what priorities for future research should be. Following the conference it would then be the work of the research team, with the continued support from the AC, to report on the activities and further develop the key priorities.

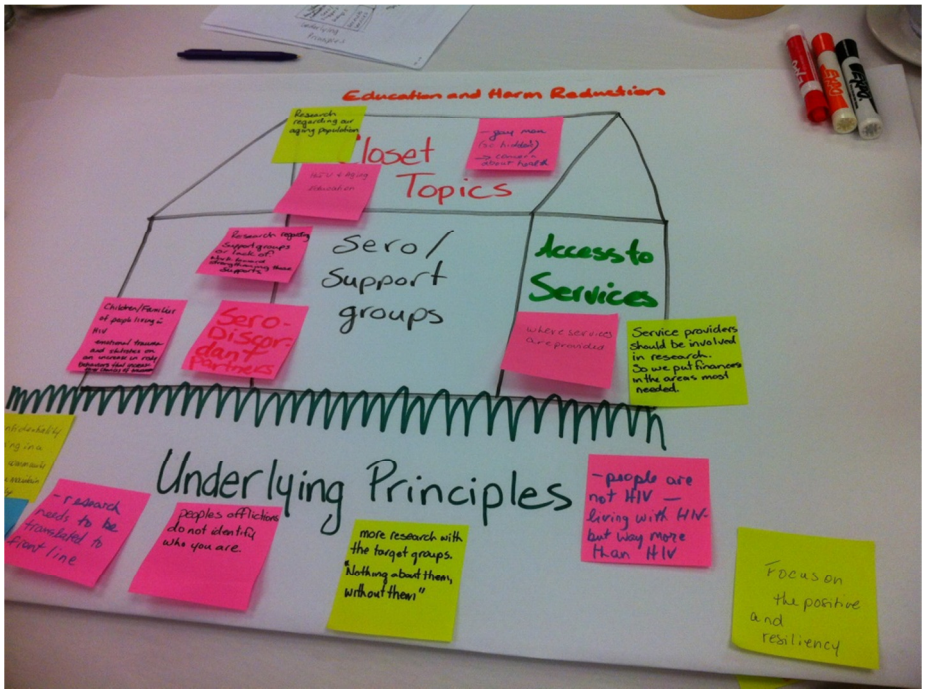
Bringing People together to Move Mountains

Marking the opening of the conference with a community event was very important to the *Moving Mountains* advisory committee. On the evening of June 17, 2014, the doors of the Power of Friendship Hall were opened wide at the Prince George Native Friendship Centre. Both conference attendees and interested members of the public gathered to share food, network, and to be welcomed by the Lheidli T'enneh Drummers, and join in song and dance. Keynote speaker Carrielynn Lund, a passionate and accomplished Métis health researcher from Alberta, set the tone for the conference with her opening talk entitled "Circle or Cycle?" She used stories to highlight important reflections on community readiness and process in CBR in northern, rural and/or remote areas.

The first day of conference, programming focused on setting the stage – bringing research findings back from recent or on-going studies, exploring key CBR concepts and methodologies (including Indigenous methodologies), and exploring how "no mountain can be moved" without peer involvement. The second and final day of the conference, focused on hands-on activities and engaging the group in activities to stimulate the identification of research priority areas, beginning with an arts-based workshop led by Virginia Russell and Dahne Harding, which had participants expressing research priorities and exploring meaningful collaboration in a tableaux-painting activity. The groups were then lead through a deliberative priority setting process to come to consensus in order to establish research priorities and identify information gaps. The methodology used was 'concept-mapping,' (Campbell, 2010) a process used with small groups to engage them in a facilitated activity to brainstorm, share ideas, and collaborate on bringing these ideas together into a diagram or map to link related concepts (see example in Figure 2). During the concept mapping session, groups created and discussed their maps, and came to consensus on 3 to 5 leading priorities to share back with the larger group of participants. The

entire list of ideas was captured on flip charts and would be shared back with participants following the event. Therefore, the priority lists were seen as "belonging" to the whole group.

Figure 2: Image of one of the concept maps created by participants.



The conference did not require the approval of a research ethics board. The information gathered throughout the conference (particularly during the above priority setting session) was collected as a group, and using general themes that were further developed by the Advisory Committee and research team; consensus was reached on releasing these publically. Permission to use photographs of individuals in knowledge mobilization products was collected prior to the onset of the conference.

An integral part of the *Moving Mountains* process was the commitment by organizers to write a community report (Reschny, Langlois, Daniels, & Duddy, 2014), which would include a synthesis of the generated priorities and articulation of next steps. Therefore, following the event all priorities generated through the concept maps were reviewed and analyzed by the research team according to concepts or themes. These themes were then divided into two distinct categories: research topical areas/themes and research needs. The topical areas/themes included areas identified for potential research projects; whereas the second group, research needs, included areas identified to support and encourage ongoing research in the region. Initial concepts and themes identified as priorities (1-3) and research needs (4) are as follows. However, it is important to note that these represent a starting point in this process and that further

discussions, activities, and processes may need to take place to add texture, and define points for action.

1) Improved HIV Prevention, Treatment and Care

A third research theme that participants identified was the need for ethical and culturally appropriate provision of services to those living with or affected by HIV/AIDS. This includes additional sub-themes such as: what people in the region would consider ethical support for people living with HIV/AIDS in rural areas and on reserve; or through greater involvement of people living with HIV/AIDS in research and; service development and provision. Specific issues relating to services were HIV/AIDS and aging, trauma and HIV prevention, engagement and adherence to treatment, community readiness, and resilience.

2) The impact of natural resource-development industries, worker migration and economic boom in the region on the HIV/AIDS epidemic

This research theme includes the impact of the natural resource-development boom on the HIV transmission, testing, and the provision of culturally appropriate services. Additional areas of research include, for example, factors that contribute to the further transmission of HIV in the region, such as increased alcohol and substance use or increased demand for sex trade workers.

3) Stigma and discrimination

At the conference, what was perceived as a growing regional apathy towards HIV and other blood borne viral infections among the general public featured prominently in discussions. This included indications that there is a need for implementation-research to focus on sexual health and basic HIV knowledge education in the regions. This concept was highlighted in stories of silence on some First Nation's reserves, as well as contrasting stories of both community and individual resilience.

4) Research models and approaches that are regionally responsive

Aside from the highlighted research topic priorities, many participants felt that additional discussions are needed with regards to how research is developed and carried out in the region. These potential discussion topics included, for example, the need for research to be done outside of urban centers; how to do research in a way that is ethical and takes into account what happens after projects end; how to conduct research that is responsive to cultural needs; and, how to move research to action, specifically within health and service programming. Due to the multiple issues selected for future research, the group also identified the need for the incorporation of an intersectionality framework, which is the study of inter-related phenomena including the health, social and structural inequities that may influence health outcomes (Hankivsky, 2012; Smye, Browne, Varcoe, & Josewski, 2011), and for research that is able to explore several overlapping

issues at once, for the sake of financial efficiency and to reduce possible research fatigue among individuals and communities.

Continuing the Journey

While the event was the first step in this journey, the research team has completed a community report which was shared with all participants and is available online http://pacificaidsnetwork.org/wp-content/uploads/2014/09/Moving-Mountains-Community-Report-2014-Final.pdf (Reschny, et al., 2014). The research team has also begun a systematic literature review, building off an environmental scan presented at the event (Jackson & Reschny, 2014), which focused on mapping out HIV/AIDS research in northern, rural and remote regions in Canada. This additional information will inform discussions around new research initiatives and capacity building activities, and the momentum will be used to provide opportunities for greater collaboration and partnering for researchers and communities. For example, the Pacific AIDS Network, the CBR Collaborative Centre (a program of the CIHR Centre for REACH), and the Aboriginal HIV and AIDS Community-based Research Collaborative Centre (AHA Centre), are already using the identified priorities to inform their future CBR strategies and endeavors.

Following the release of the report and final meeting of the AC for this project, the group decided to leverage the substantial interest generated by the event and sent an open call to participants of the conference to become part of a Research Working Group (RWG). The purpose of the RWG is to further develop a research project(s) based on one or more of the identified research priority themes listed in this article. At the time of publication, this group has since met by teleconference and is currently planning an in-person project development workshop in early 2015. The objective of this RWG will be to design, develop and submit a grant application or applications to continue this work on facilitating community-driven HIV/AIDS research in communities throughout Northern BC.

In community-based research, the development of research initiatives is a process; one that engages communities in developing research agendas by creating spaces in which all knowledge – experiential knowledge, Indigenous knowledge, community knowledge, and academic knowledge – are equally valued and can be shared. The *Moving Mountains* process was the first of its kind for the region – one that carries with it the promise of greater collaboration in the region and progress towards addressing HIV/AIDS through collective effort and the promise of research that is responsive to community needs.

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