



Research Priority Setting

Results of Group Mapping Session

June 17, 2014

The culminating session of Moving Mountains worked to set research priorities for Northern BC. The session brought conference participants together in groups to discuss their (or those of the organization they represent) HIV/AIDS-related research priorities and needs. The groups then worked to build a consensus on which research priorities should be highlighted for future work. Part of this discussion involved identifying which areas or populations participants felt were underserved and underrepresented.

The methodology used for this process was ‘concept-mapping,’ a process used with small groups to engage them in a facilitated activity to brainstorm, share ideas, and collaborate on bringing these together into a diagram or map to link related concepts (see example in Figure 2). During the Moving Mountains session, groups discussed their map, and came to consensus on 3 to 5 leading priorities to share back with the group.

Group A:

Group-established Priority Themes and Participant-Identified Research Priorities:

- Economics/Funding
 - Migration related to resource development
 - “Fly-over-effect”
- Knowledge Bank
 - Peer support committees – how to secure funding
 - Accountability
 - Ageism
 - Centralized location knowing which research/funding/workshops are taking place
- Policy
 - How to improve access to services for First Nations communities
 - Research why government has a hard time giving funds for obvious needs or why it takes them so long → research government and their policy

- Education
 - Collaboration between government, people living in community, local organizations (universities, NGO's), and international organizations
 - Invalidation of the person and their identity
 - Training for health care
 - Education to reduce stigma
 - Help doctors, nurses, and front line workers understand residential schools and intergenerational trauma
 - Education around residential schools and historical trauma
 - Stigma
 - Find out why some bands will not acknowledge there is HIV/AIDS in their territory – too much denial
 - Find out why HIV/AIDS is not as “loud” as it used to be
- Socio-Cultural
 - Research how many Aboriginal people do die because of HIV – too many dying of “cancer,” we need the truth to fight this
 - Translation beyond simply words
 - Stigma, cultural sensitivity, and ageism
 - Respect and cultural safety
 - Have more HIV+ people to speak to funders and let them see the impact on a personal level

Identified Research Priorities:

1. Stigma – Silence on reserve, training for service workers, education
2. Cultural Safety – translation using other modes of language, education
3. Best ways to secure funding to implement change – projects, research, services, economic development and access to services

Group B

Group Established Priority Themes and Participant-Identified Research Priorities:

- Research in Northern BC
 - More research in small and rural areas – not just Prince George
 - Smaller and more rural communities means a need for different research
- Health and Behaviors
 - Drugs and sex
 - Sex, sexuality, sexual health, sex positivity
 - Illicit drug use in small communities
 - Harm reduction
- Broadening Our Lens
 - Look at all populations
 - Different diseases (HCV, HBV, STI's) grouped together
 - Getting education about sexual health into remote areas
 - How to fully access across age/generation, income, etc. and not just research those who are “typically” researched

- How do we best translate knowledge to the communities/people most at risk?
- What are the needs of multicultural clients?
- Uptick in testing – will that skew research?
- In what format should information be provided to seniors?
- Criminalization
 - Support services and disclosure
- Stigma
 - How do we decrease stigma around testing?
- Youth
 - How do we meet the needs of the youth?
 - Youth outreach – engage youth and get their questions and needs
 - How do “gay” (LGBTQ) youth get their education information or tools
- Community Input into Priorities
 - What question do we ask when we don’t know the question to ask?
 - Community buy in outside the ASO world
 - Community readiness
 - In order to identify gaps we need to complete community readiness/environmental scan
- Resilience
 - Assets based resilience focus
- Adherence
 - Factors that interfere with adherence
 - Impact of mental health and addictions in treatment, life satisfaction, adherence
 - Testing/drug adherence – once a day drug versus once a month, buy in on testing
- Migration
 - Work camps and housing implications
 - Socioeconomic impact and economic drivers
 - Migration for testing, services, licit and illicit drugs
- Peer Research Associates
 - Northern BC peer researchers – recruit, what is the best way to compensate/thank?
 - I’d like to see the inclusion of a program that focuses on emotional needs of persons with HIV for peers and see this researched
 - Training up PRA’s – education
 - What’s next once I do one project?
 - Honoraria – should it be cash or something else that is decided on?
 - Stretched resources, limited staff knowledge

Research Priorities

1. Bringing more research out of PG and into smaller communities, then do it differently
2. Broadening research focus
 - a. Community readiness and community identifying issues
 - b. Look at multiple things for efficiency
3. Supporting people who are positive to engage and adhere to treatment

4. Resilience

Group C

Group Established Priority Themes and Participant-Identified Research Priorities:

- Education and Harm Reduction
 - Research regarding our aging population
 - HIV & aging education
 - Concerns about gay men's health and are they hidden?
- Sero/Support Groups
 - Research regarding support groups or lack thereof – work toward strengthening those supports
 - Children and families of people living with HIV – emotional trauma and statistics on an increase in risky behaviors that increase their chances of transmission
 - Sero-discordant partners
 - PHA's and the workplace – concerns and supports, how does it affect their health?
 - GIPA (Greater Involvement of People Living with HIV/AIDS)
 - Sensitivity training for service providers, social workers, nurses, RCMP, and counselors
 - Pet therapy – PLHA's having pets and if it increases their health status
- Access to Services
 - Where services are provided
 - Service providers should be involved in research so that we put finances in the areas most needed
- Underlying Principles
 - Confidentiality associated with living in a small community, how do you maintain confidentiality
 - Disease is not person
 - People are not HIV, living with HIV but way more than HIV
 - Peoples afflictions do not identify who you are
 - Research needs to be translated to front line
 - More research with the target groups – “Nothing about them, without them”
 - Focus on the positive and resiliency

Leading Research Priorities

1. GiPA
2. Aging
3. Workplace supports for PHA's and kids – trauma and transmission, confidentiality in small communities, and translating research

Group D

Group Established Priority Themes and Participant-Identified Research Priorities

- Population Specific
 - Industry: contact, testing, HR

- Population specific chronic alcoholism, misuse – aim at northern communities, research, industry
- Research on relationships and how it impacts HIV transmission in rural or smaller centers
- How to include other communities without HIV organizations or HIV focused services
- Policy
 - Will this affect policy and if so, how?
 - Funding requirements vs. actual need
 - Services and policies may not encompass the needs of the people accessing our services
- Scope
 - Research collaboration horizontally with northern Canada communities, not vertical BC north-south
 - Community members want to know exact numbers in their towns, they stop listening when I don't know
 - Research capacity building in rural communities
- Ethics of aftercare
 - Support – community/service provider engagement
 - What services are working and not working
 - Peer led and based harm reduction
 - Youth self-esteem
 - Building relationships
 - People know their own bodies best
 - Learning a person's needs (home, life skills, doctor, spiritual, love, etc.) and requirements
 - After care
- To what end?

Research Priorities

1. To what end? How can we engage community without ASO's
2. Population specific alcohol, resource and industry, and relationship impact on HIV
3. Ethics of aftercare – care in research process and after in a rural and remote context
4. Benefit community relationships

Group E

Group Established Priority Themes and Participant-Identified Research Priorities

- Influence policy and funding with research
- Issues of funding for CBO's and non-profits
- LBGQT
- LBGQTeTS
- LBGQT and MSM
- True North gay and MSM

- Sexual education
- How/when is sex education delivered in schools?
- Intersectionality
- Power dynamics
- Community resilience
- Community attitudes and knowledge about transmission
- Operationalization
- Implementation
- Evaluation
- Feasibility of women's clinic
- Empathy (trauma, culture) training and health care professionals/community
- People over 50
- Migration – resource development and employment
- Industry intersection with chronic disease

Research Priorities

1. Implementation – action research
2. Migration and resource, industry, and impact of booms
3. Empathy training for health care providers and community – cultural shift
4. Intersectionality
5. Connections – moving out of PG, means working more broadly and looking at multiple factors