



ALBERTA COMMUNITY-BASED RESEARCH REGIONAL PRIORITY CONSULTATION REPORT

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About the Consultation

The most recent REACH community-based research (CBR) priority consultation in Alberta was held in 2013, and the context of the epidemic has shifted significantly since then. Among other changes, the provincial government announced [universal coverage for PrEP](#) and [several cities in Alberta will be operating supervised consumption sites](#) by the end of 2019. Because of this significant progress, many of the areas that emerged from the 2013 consultation no longer match the concerns and needs of people living with HIV and community stakeholders. Renewed input from stakeholders was necessary for REACH to move forward on new CBR projects in Alberta that are responsive to the present context of the epidemic. The Alberta region required updated information on the priorities of community members and an opportunity to gather to build capacity and develop collaborative relationships with the Alberta CBR REACH team.

To address these issues, the Alberta CBR Collaborative held a regional consultation to better understand the current research priorities of people living with HIV and community agencies, while also facilitating a networking opportunity for stakeholders. The objectives of the consultation were to:

1. Facilitate a consultation to develop regional CBR priorities that are grounded in community realities and represent the current concerns of stakeholders.
2. Strengthen CBR capacity in the region by developing collaborative relationships to stimulate new, community-led research projects related to HIV/AIDS.
3. Increase awareness about the purpose and activities of the Centre for REACH and the CBR Collaborative Centre in Alberta.

Methods

The consultation involved three components: 1) An online pre-consultation survey, 2) a one-day stakeholder meeting, and 3) an online post-consultation survey. This section outlines how each component was conducted and the ‘Findings’ section combines results from the three components.

1. Pre-Consultation Survey

An online pre-consultation survey was sent to Alberta CBR stakeholders via SurveyMonkey to gather preliminary ideas about research priority areas and capacity building needs. The survey link was disseminated through direct email invitations sent by the REACH CBR Regional Coordinator and by Alberta Community Council on HIV (ACCH)’s Executive Director. The survey was open from February 22 to March 4, and two reminder emails were sent during that period.

A total of 23 stakeholders responded to the survey with a 79% completion rate. Of survey participants, the majority (65%, n=15) identified as representatives from AIDS service organizations, front-line organizations, or community-based organizations. Fewer participants identified as students or trainees (22%, n=5), health services employees (22%, n=5), peer

researchers (13%, n=3), academics (8.7%, n=2) or other stakeholder groups (8.7%, n=2).¹ Survey participants primarily worked in southern (39%, n=9) or central (35%, n=8) Alberta, with fewer respondents from northern Alberta (8.7%, n=2) or working provincially (13%, n=3).¹ Survey questions that received >15 responses are summarized in Appendix I, and are integrated into the ‘Findings’ section below.

2. Stakeholder Meeting

A one-day, in-person stakeholder meeting was held on March 6, 2019 in Calgary, Alberta. The REACH CBR Regional Coordinator and ACCH’s Executive Director disseminated 34 invitations via email. The event was held as an ancillary meeting to ACCH’s Annual Member Meeting, allowing for greater representation from organizations not directly linked to REACH or the CBR Collaborative Centre.

The in-person consultation had 23 attendees from across the province. Stakeholders were affiliated with 11 different community-based organizations, two universities, and Alberta Health Services. Attendees represented a diverse range of HIV stakeholders in Alberta including people living with HIV and individuals working with gay, bisexual, and other men who have sex with men, African, Caribbean, and Black communities, Indigenous communities, and people with injection drug use. While the majority of participants were from Calgary or Edmonton, there were participants whose organizations serve smaller cities, rural communities, and Northern Alberta.

The meeting’s agenda is included in Appendix II. Briefly, the day was structured as follows:

- A brainstorming activity on important characteristics or qualities of CBR.
- A presentation to familiarize stakeholders with the objectives of the Centre for REACH and the CBR Collaborative Centre. The presentation also included a summary of results from the pre-consultation survey.
- Small group discussions to elicit the research areas and gaps that impact people’s lives and/or work related to HIV, and the capacity-building needs across the province. Small group facilitators reported back a list of priority areas and capacity needs that were generated in the discussions, and a master list was developed for a voting activity.
- A voting activity where stakeholders allocated up to three votes to priority areas they deemed most important, and unlimited votes to capacity-building activities in which they were interested.

3. Post-Consultation Survey

The post-consultation survey aimed to narrow the priority areas generated in the discussions, as well as gain feedback on the in-person event. The survey was disseminated via SurveyMonkey to the 34 stakeholders that were invited to the in-person meeting, and stakeholders were asked to complete the first portion of the survey (priority areas) even if they were not able to attend the

¹ Total >100% because participants checked all boxes that applied.

meeting. The survey was open from March 14 to 29, and two reminder emails were sent during that period.

The post-consultation survey received nine (9) responses with a completion rate of 78%. Closed-ended question results are reported in the ‘Objectives and Outcomes’ section of this report (Table 3).

Findings

Important Characteristics of CBR

In the stakeholder meeting, participants were asked to write down what they considered the three most important characteristics or qualities of CBR. Figure 1 uses a word cloud to depict the main qualities generated by the group. Qualities mentioned frequently by the group included GIPA/MIPA, engagement, collaboration, relationships, equity, and filling gaps in knowledge. These characteristics are consistent with the [REACH CBR Collaborative Centre’s ‘Principles of CBR’](#), and the activity served as a reminder to reflect on how the centre is supporting these characteristics in day-to-day work and in Alberta-based initiatives moving forward.



Figure 1. Stakeholder-identified important CBR characteristics and qualities.

Research Priority Areas

The small group discussions generated 34 research priority areas. These priorities largely mirrored the responses to the pre-consultation survey (Appendix I). Table 1 lists priority areas in the order of support received during the voting activity. Where applicable, research priorities were aggregated into larger categories. The areas that received the most support in the voting

activity included stigma and discrimination, prevention, medical education or screening guidelines, knowledge synthesis, and testing.

Table 1. Research priorities generated by group discussions. Organized according to support received during the voting activity at the stakeholder meeting.

| Category | Research Priority Area | Votes |
|---|---|-------|
| Stigma and discrimination (9) | Stigma | 4 |
| | Unconscious bias in service provision | 4 |
| | Racism and homophobia: Impact on access | 1 |
| Prevention (9) | Perceptions of PrEP | 4 |
| | PrEP access and implementation | 3 |
| | PrEP in ACB populations | 1 |
| | Knowledge and awareness of HIV in specific communities | 1 |
| | Critical analysis of prevention messaging | - |
| Medical and nursing education or screening guidelines (7) | Evidence to support HIV screening guidelines for Alberta clinicians (ASaP Maneuver) | 4 |
| | Curriculum and training in medical and nursing education | 3 |
| Knowledge synthesis (6) | Service mapping/Environmental scan | 3 |
| | Synthesis of Alberta-specific evidence | 3 |
| Testing (6) | Access to testing and barriers to uptake for new technology (POCT) | 5 |
| | Access to services and testing in rural communities (barriers) | 1 |
| Issues related to injection drug use (3) | Intersection of HIV, mental health, and addiction | 2 |
| | Vulnerability and risk in women with injection drug use | 1 |
| | Impact of supervised consumption services on HIV incidence | - |
| Access to services (2) | Access to care and experiences of ACB communities in health services | 2 |
| | Access to care, treatment, and support in Northern Alberta | - |
| | Telemedicine | - |
| Tools (1) | Developing storytelling tools for KTE | 1 |
| | Developing shared outcome tools | - |
| Surveillance (1) | Key population based surveillance data | 1 |
| | Epidemiology and pathways to care | - |
| Experiences of ACB populations (1) | Experiences of ACB women living with HIV | 1 |
| | ACB youth and immigration | - |
| Other | Critical analysis of indigenous strategies in mainstream services | 2 |
| | Issues around individuals who are incarcerated | 1 |
| | Training needs for peer supporters | - |
| | Regional Sex Now! survey data for service providers | - |
| | Syphilis co-infection | - |
| | Cascade of care | - |
| | HIV and aging | - |

In addition to the priority areas identified above, stakeholders noted several concerns about the Alberta CBR landscape in the pre-consultation survey (Appendix I) and during the small group discussions. Notably, stakeholders raised concerns over the lack of time and personnel resources

available for research, especially in harm reduction organizations responding to the opioid crisis. Concerns were also voiced related to equity in CBR, as some stakeholders felt that historically there has been under-representation of key populations in CBR in Alberta. Concerns included the amount of research, support, and resources allocated to certain populations over others, as well as a perceived lack of diversity in the peer researchers and participants involved in CBR projects. CBR initiatives in Alberta should consider how they are supporting community needs, rather than straining existing resources, and how they are incorporating principles of equity in project design and implementation.

Capacity-Building Needs

Table 2 lists the capacity-building needs generated in the small group discussions, which were similar to the needs identified in the pre-consultation survey (Appendix I). The area that received the most votes was peer support and training. Stakeholders have raised this issue in the past, expressing the need for a formalized peer researcher network that links peers to training resources and opportunities. Stakeholders also discussed the need to link various peer groups together, and to share training resources across groups. Several organizations and initiatives are utilizing peer-based models in programs and in research. Yet, no centralized peer network exists in Alberta. Other capacity-building ideas that received support were funding for community-driven research, hosting KTE conferences and program exchanges, and providing evidence to support program implementation in community-based organizations. It is clear there are several pathways to further develop CBR capacity in the region.

Table 2. Capacity-building ideas generated by the group and voted on during the consultation.

| Capacity Needs | Votes |
|---|-------|
| Peer support and training | 9 |
| Funding for community-driven research | 7 |
| KTE conferences and opportunities to discuss program results and success | 6 |
| Evidence support for implementing programs | 6 |
| Access to data and evidence | 5 |
| Support for ethics applications | 3 |
| Connecting citizen research to resources (i.e. research not led by academics) | 2 |
| Gathering key stakeholders | 2 |
| Coordination and capacity building | 1 |
| Program evaluation: Needs and tools | 1 |
| Funding and support for students | 1 |

Objectives and Outcomes

The stakeholder consultation had three main objectives:

1. Facilitate a consultation to develop regional CBR priorities that are grounded in community realities and represent the current concerns of stakeholders.
2. Strengthen CBR capacity in the region by developing collaborative relationships to stimulate new, community-led research projects related to HIV/AIDS.

3. Increase awareness about the purpose and activities of the Centre for REACH and the CBR Collaborative Centre in Alberta.

The outcomes reported by participants and listed in Table 3 indicate the consultation was successful in achieving goals. In particular, participants in the post-consultation survey agreed that the consultation provided opportunities to participate in discussions about CBR priorities, to meet new people involved in CBR, and to learn about the CBR Collaborative Centre and the Centre for REACH.

Table 3. Objectives and outcomes for the consultation event. Left column lists the event’s expected outcomes; right column indicates whether the outcome was achieved.

| | |
|--|--|
| Objective 1: Facilitate a consultation to develop regional CBR priorities that are grounded in community realities and represent the current concerns of stakeholders. | |
| <p>Outcome 1.1 Engage up to 30 stakeholders in developing a list of CBR priorities for Alberta. By establishing the priorities of community members, we will ultimately produce research with greater potential to benefit the health outcomes of people living with HIV and other STBBI.</p> | <ul style="list-style-type: none"> Engaged 23 stakeholders to develop lists (Table 1, Table 2) of CBR priorities for Alberta, with a relative ranking attached to each item. The organizations and sectors represented in the meeting were diverse, and this was the largest priority consultation ever conducted by REACH in this region. All post-consultation survey respondents (n=7) strongly agreed with the statement “Everyone had an opportunity to participate in the discussions”, and either strongly agreed (n=3) or agreed (n=4) with the statement “I was able to provide input regarding the CBR research and capacity building priorities for Alberta”, indicating discussions were inclusive and stakeholders felt their priorities were heard. |
| Objective 2: Strengthen CBR capacity in the region by developing collaborative relationships to stimulate new, community-led research projects related to HIV/AIDS. | |
| <p>Outcome 2.1 Have at least 40% of participants report meeting at least one new person involved in CBR in Alberta.</p> | <ul style="list-style-type: none"> Of survey respondents (n=7), six (6) strongly agreed and one (1) agreed with the statement “I met at least one new person involved in CBR in Alberta at the meeting.” |
| <p>Outcome 2.2 Submit a community-grounded CIHR operating grant to the Fall 2019 call for proposals.</p> | <ul style="list-style-type: none"> At the time of writing, this outcome was in-progress and on track. Proposal updates will be circulated in the Alberta CBR Collaborative’s monthly newsletter. |
| Objective 3: Increase awareness about the purpose and activities of the Centre for REACH and the CBR Collaborative Centre in Alberta. | |

| | |
|---|--|
| <p>Outcome 3.1 Have at least 50% of participants report a better understanding of the Centre for REACH and the CBR Collaborative Centre after the meeting.</p> | <ul style="list-style-type: none"> • During the stakeholder consultation, NH presented on the goals and objectives of the Centre for REACH and the CBR Collaborative Centre, and on past work supported by REACH in Alberta. • Of post-consultation survey respondents (n=7), five (5) strongly agreed and two (2) agreed with the statement “I now have a better understanding of the Centre for REACH and the CBR Collaborative Centre.” |
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Conclusions & Next Steps

This consultation allowed Alberta HIV stakeholders to provide input on CBR priority areas for the region. While many priority areas were identified, there was some consensus across stakeholder groups around the areas of stigma and discrimination, prevention (including issues related to PrEP), medical and nursing education or health service procedures, knowledge synthesis, and access to testing. Further, stakeholders identified a need for collaborative research that is inclusive across sectors and populations, and does not place excess burden on community. Future CBR Collaborative projects in Alberta will aim to address these community-identified priorities.

Several of these priority areas align with ongoing REACH and CBR Collaborative Centre projects, and with the work of other stakeholders in Alberta. In the area of stigma and discrimination, CBR Collaborative partners and staff will continue working on the HIV Stigma Index project, providing more information on the stigma experienced by people living with HIV and residing in Alberta. Additionally, the application to renew REACH funding (‘REACH 3.0’) lists stigma, prevention, and testing as focal areas for the centre. If the application is successful, there may be funding available for new projects related to these priorities.

Several capacity-building initiatives were proposed by stakeholders to support a responsive CBR agenda. Initiatives included peer support and training, funding for community-driven research, KTE conferences and program exchanges, and providing evidence to support program implementation in community-based organizations. These initiatives are within the scope of the CBR Collaborative, and we will incorporate these priorities in planning capacity-building activities for the region.

The CBR priorities identified in this document serve as a roadmap for developing future projects in the region, and the CBR Collaborative’s staff, infrastructure, and resources will support initiatives that align with identified community priorities. We may be able to support stakeholders advancing projects in these areas by assisting with network mobilization, proposal writing, coordination, dissemination, and training/workshops. Please contact Natasha Hoehn, CBR Regional Coordinator, at nhoehn@mtroyal.ca for more information.

Appendix I. Pre-Consultation Survey Results

Table 2.1 CBR resources available in Alberta (n=17).

| Resources Listed | n |
|---|----------|
| None, no resources, or none that I am aware of | 6 |
| Specific organizations (ACCH, HIV Community Link, Centre for Sexuality, etc.) | 3 |
| Alberta Universities | 2 |
| STBBI OSAP Working Groups | 2 |
| Collaborative relationships between sectors (CBO – CBO, CBO – Researcher, etc.) | 2 |
| AIDS Service Organization Programs (peer, prevention, advocacy, testing) | 2 |
| Universities without Walls | 1 |

Table 2.2 CBR limiting factors in Alberta (n=18).

| Limiting Factors Listed | n |
|--|----------|
| Resources (time, funding, infrastructure) | 12 |
| Stigma | 4 |
| Research seen as a lower priority (especially in light of the opioid epidemic) | 3 |
| Lack of tangible, action-oriented work and KTE | 3 |
| Lack of knowledge about CBR | 2 |
| Lack of interest or willingness (either in community or among academics) | 2 |
| Distrust between sectors | 1 |
| Marginalization of key populations | 1 |

Table 2.3 Current and emerging issues, trends and challenges related to HIV and other STBBIs that impact survey participants or their work (n=17).

| Issues, Trends, and Challenges | n |
|---|----------|
| Stigma (including intersection of stigma with drug use, sexual orientation, gender identity, and immigrant or refugee status) | 8 |
| PrEP access and uptake | 3 |
| Need to increase testing | 3 |
| Lack of education (among healthcare providers and more generally) | 3 |
| Co-morbidities (including mental health) | 2 |
| Racism | 2 |
| Funding | 2 |
| Rural transportation and access | 1 |

Table 2.4 Gaps in evidence or information that impede the work of survey participants (n=16).

| Gaps Identified | n |
|--|----------|
| Lack of population-specific data and/or marginalization of particular groups (Indigenous populations, ACB populations) | 4 |
| PrEP uptake, access, and perception (among target population and healthcare providers) | 2 |
| How to overcome stigma or isolation | 2 |
| Lack of education | 2 |
| How to reduce barriers to testing | 2 |

Appendix II. Agenda for Stakeholder Meeting

9:00 - 9:30

- Breakfast and Registration

9:30 - 10:00

- Welcome
- Land Acknowledgement
- Introductions

10:00 - 10:30

- Brainstorming activity
- Background on REACH and the CBR Collaborative Centre

10:30 - 11:00

- Coffee Break

11:00 - 11:30

- Pre-consultation survey results

11:30 - 12:15

- Small Group Discussions
 - Priority areas for research
 - Skills and support needed for CBR engagement

12:15 - 1:00

- Lunch

1:00 - 1:30

- Report back from small discussions to larger group

1:30 - 2:00

- Ranking Activity
- Wrap-up