

REMOTE CONTROL

BUILDING ON CAPACITY TO IMPLEMENT COMMUNITY-BASED RESEARCH
IN RURAL, NORTHERN, AND REMOTE COMMUNITIES IN MANITOBA

WE WOULD LIKE TO THANK AND ACKNOWLEDGE THE TREATY SIGNATORIES OF TREATY 1 TERRITORY AND THE MÉTIS NATION FOR WELCOMING US TO THEIR TRADITIONAL LAND.

ABOUT REMOTE CONTROL

In Manitoba, incident HIV rates are consistently higher than national averages¹. When compared to the national data, women and people who self-identify as Aboriginal are significantly over-represented in new HIV cases in Manitoba, and heterosexual transmission continues to be the primary mode of transmission². Late presentation to care is an alarming reality in Manitoba with 66% of new patients presenting to care having CD4 counts < 350 cells/mm³ at the time of diagnosis².

The challenges relating to HIV are unique to our province and in some ways magnified in rural, northern, and remote communities in Manitoba. All HIV specific care services are located in Winnipeg and yet about 20 – 30% of incident HIV cases are reported outside of the capital city². Of immediate importance are recent cluster outbreaks of HIV in three remote northern communities, accounting for at least thirteen new cases in the Prairie Mountain and Northern Health Regions in 2013³. The specificity of the situation calls for the development of locally tailored solutions to confront the epidemic and care appropriately for those living with and affected by HIV. It is essential to expand research outside of the geographic scope of Winnipeg in order to engage with priority communities throughout the province of Manitoba to explore outbreaks and gaps in services, and to make policy recommendations to address the unique contexts of these communities to ultimately work to improve earlier diagnoses and HIV outcomes for everyone in Manitoba.

It is the acute awareness of these urgent needs that prompted a group of community-based organizations, people living with HIV, researchers, and healthcare professionals to get together, under the leadership of the 595 Prevention Team*, to build the foundations of a community-based research (CBR) initiative within three communities in Northern and rural Manitoba. As a first step, Remote Control, a two-day capacity building training and discussion with key stakeholders was held in Winnipeg, Manitoba on June 18 and 19, 2015. The

event was meant to engage in dialogue with these communities, to introduce key stakeholders to the concept of CBR and to allow them to network and create relationships with one another, to discuss HIV/AIDS related issues and priorities in their communities, and to develop a plan to implement a CBR project in each respective community through a collaborative grant proposal development process. We understood that this was crucial to reinforcing existing capacities and to catalyze the emergence of solutions. The Remote Control event was envisioned as one component of a larger plan that we hope will be a long-term process to develop HIV/AIDS research strategies that are intersectoral, inter-disciplinary and community-driven. Individuals from three distinct locations in Manitoba came together along with Winnipeg-based people to build on their CBR capacities and to provide an opportunity to network amongst themselves and with researchers and health care professionals. The three communities: Thompson, Flin Flon, and Swan River, were selected due to individuals or organizations expressing an interest in HIV CBR, paired with their geographic proximity to priority populations.

Remote Control was attended by 25 individuals from local and national community-based organizations, community members affected by HIV, health care professionals, researchers, faculty members, and graduate students from University of Manitoba and the University College of the North. This event was made possible because of funding from the Canadian Institutes of Health Research and the Aboriginal HIV and AIDS CBR Collaborative Centre.

* The 595 Prevention Team is a Manitoba-wide organization that works with Peers, network members, policy makers, community leaders, and academics to make recommendations about the development, implementation, and evaluation of prevention initiatives focused on sexually transmitted and blood borne infections (STBBI). The 595's work is largely steered by the Peers – a group of 20 individuals who identify as members of a community affected by HIV and/or HCV, and who are actively involved in reducing the transmission of STBBIs.



THE FIRST DAY OF THE CONFERENCE WAS SPENT ESTABLISHING THE BASIS OF WHAT CBR IS, AND HOW IT WORKS BEST, BASED ON PARTICIPANTS' EXPERIENCES WITH CBR.

Remote Control participants included (everyone on this list consented to being included):

- Brenda Dawyduk, RN, NP, MSc, University College of the North
- Carrie Pockett, Play It Safer Network Coordinator, The 595 Prevention Team
- Claudyne Chevrier, Ph.D candidate, Center for Global Public Health, Community Health Sciences, University of Manitoba
- Ethan West, The 595 Peer Working Group
- Javier Mignone, Associate Professor, Community Health Sciences, Faculty of Health Sciences, University of Manitoba
- Joanne Roberts RN, MN, Faculty of Nursing, The Pas Campus, University College of the North
- Kellee Hodge, Manitoba Coordinator, CIHR CBR Collaborative: A Program of REACH
- Marissa Becker, Centre for Global Public Health, University of Manitoba and Manitoba HIV Program
- Marleny M. Bonnycastle M.A, Ph.D., Assistant Professor, Faculty of Social Work, University of Manitoba
- Marni Amirault, AHA Centre Community-Based Research Manager
- Paula Migliardi, Sexuality Education Resource Centre
- Sherri Pooyak, Community Based Research Manager, Canadian Aboriginal AIDS Network/ Aboriginal HIV & AIDS CBR Collaborative Centre
- Shohan Illsley, Executive Director, The 595 Prevention Team
- Sonia Gaudry, CIHR Centre for REACH in HIV/AIDS
- Stasie McKinnon, HIV Educator, Cree Nation Tribal Health
- Tammy Reimer, Director of Allied Care and Health Promotion, Nine Circles Community Health Centre
- Tracey Prentice, University of Ottawa
- Veda Koncan, The 595 Prevention Team

The first day of the conference was spent establishing the basis of what CBR is and how it works best, based on participants' experiences with CBR. After a very useful and informative session on Thursday morning that brought us all to level on the status of HIV in Manitoba, we moved right on to brainstorming about

what makes community-base research different from other research. The following presentation related the information that came out of the brainstorming to the guiding principles of CBR research. The afternoon sessions were case studies of exemplary CBR research projects and examples of how to "make good research". These were the presentation topics:

- Strategies to Indigenize research to "make good research" and to do it in a good way from CAAN's perspective and experiences.
- Experience with the very successful and transformative Visioning Health research project and working in a strength-based approach.
- Collaborative research and prevention programs organized by Anas Wayuu in La Guajira, Colombia. An important highlight from that example was the diploma that community members were able to receive as part of the research/program.
- Vibrant example from a project from University of Manitoba of the use of photovoice for a project with men and women in situation of homelessness in Thompson to allow community members to represent their realities for themselves.
- Concrete examples of CAAN research projects Family Matters and Stable Homes Strong Families.
- Example from the 595 successful project It felt good from the beginning.

The second day was mostly dedicated to the Community Café exercise, led by Dr. Marleny M. Bonnycastle, as will be detailed below. Tracey Prentice from CAAN presented on Aboriginal HIV CBR Research Strategy in the morning. The afternoon sessions had a practical focus on grant-writing skills and an overview of the current research projects taking place in Manitoba. The topics were:

- Glossary of applying for grants
- Demystifying grant-writing, 'what to expect when you're submitting'
- Lessons Learned in applying for funding
- How to formulate a research question, and how to move those questions into action
- Current HIV research in Manitoba
- Manitoba Northern Health Research Network



THIS METHOD ALSO PERMITTED PARTICIPANTS' KNOWLEDGE AND EXPERTISE TO BE HEARD AND VALUED EQUALLY, BE IT EXPERIENTIAL KNOWLEDGE, INDIGENOUS KNOWLEDGE, COMMUNITY KNOWLEDGE OR ACADEMIC KNOWLEDGE.

COMMUNITY CAFÉ AND RESEARCH DIRECTIONS

The most important session of the event was the Community Café session led by Dr. Bonnycastle, on the first half of the second day. The goal of this exercise was to advance out plans for potential grant proposal development. A Community Café is a collaborative knowledge creation method that builds on the shared knowledge and expertise of the participants. In this process, the participants were separated in 4 groups, 3 of which circulated between tables and one that stayed at the same table for the duration of the activity. In short 10 minute sessions, participants were given a topic to discuss. That same topic was discussed 3 times at each of the tables, which allowed all the participants to speak to each other about it. A series of 5 topics were discussed in this manner. During the discussions, a note taker at each of the tables recorded the ideas discussed on sticky notes that were passed on to the Community Café facilitators at the end of each session. The sticky notes were then organized and grouped into themes that quickly created a knowledge map.

The five topics that were discussed were:

Collaborative research and project experiences

- Underlying conditions that helped towards success
- Attitudes, behaviors and actions that helped towards success
- Information sharing among group members

Health research needs

- Most significant challenges, trends, events and development that are currently happening or that will happen soon
- What has worked in the past
- Possible consequences of not doing research

HIV concerns, issues

- Concerns in communities
- Possible consequences of not doing research in HIV
- Community-based Collaborative HIV research
- Imagine a community-based collaborative HIV research project taking place in Northern Manitoba

- How to ensure that it is both participatory and responds to local research needs?
- Who should be involved?

Future HIV Research Project

- Purpose and research questions
- Methodology
- Participants
- How would it involve people affected by HIV/AIDS?
- How would stigma be addressed?
- Who else needs to be involved?

This proved to be an extremely effective way of collaboratively discussing broad topics while allowing all the participants to talk to each other. This method also permitted participants' knowledge and expertise to be heard and valued equally, be it experiential knowledge, Indigenous knowledge, community knowledge or academic knowledge.

Through this exercise, the group decided on the following key research questions and potential methodologies.

What are the HIV care, treatment and support needs?

- People living with HIV
- People affected by HIV

What do people need in terms of access to stay their communities?

- What are the reasons why people stay in their communities?
- What are the reasons why people don't want to stay in their communities?

What other models of care exist in Manitoba that could inform an HIV strategy?

- How are other programs (ie Cancer) meeting the needs of their patients while the current structure of the HIV programs cannot?

What is the relationship between access to care and services and stigma in northern communities?



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WE CANNOT ASSUME THAT A COMMUNITY CAN BE EASILY
DEFINED OR IDENTIFIED AND RESEARCHERS AND
PRACTITIONERS MUST ALWAYS BE CAREFUL.

Methodology

- art-based, photovoice, digital story telling
- mapping of cascade / breakdown
 - epidemiology: demands of services outside of Winnipeg
 - movement of people
 - all the steps to access testing and treatment
 - Spatial analysis of distances: how it impacts outcomes to care

The discussion also included who should be involved in order to further explore and prioritize a research project.

Who should be at the table?

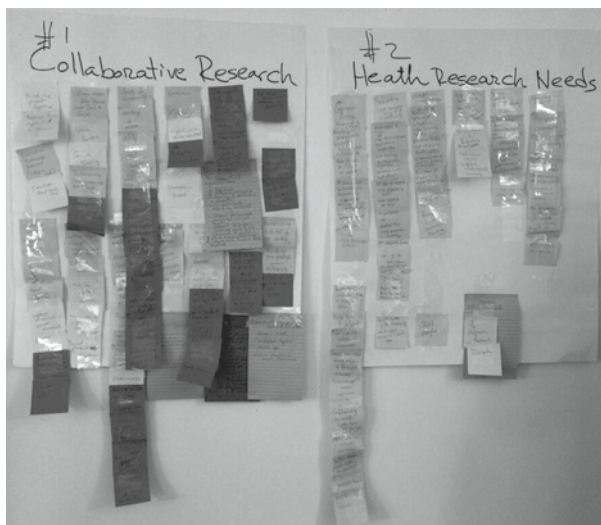
- Have local experts involved in Thomson, The Pas
- Chief and Council: especially council member in charge of health
- Cree Nation Tribal Health has experience with research and expertise with Harm Reduction Committees
- People who are impacted by HIV
- Health care providers: physicians, pharmacists, community health liaisons
- CDC and STI nurses, mental health workers, dieticians
- Laboratory
- Elders
- Representative from Child Family Services
- Social care
- Housing
- Researchers

Additional Research Needs, Priorities and Challenges

The Community café allowed the participants to share the most pressing issues that they recognized in their communities and/or in their relationships with individuals and groups that they work with. Some of the most important issues to be identified were:

- Move and stay away from “helicopter research”: research that comes in and out of a community without engagement or accountability, and that doesn’t benefit the community
- Jurisdictional issues
- The need for flexibility with where people receive treatment for HIV. Some want to stay in their communities and some want to leave.
- Lack of access to care and to treatment in communities.
- Confidentiality

Some of the original discussion on what CBR is also helped the Remote Control participants to identify what CBR should be, based on their past experiences. Participants agreed that the best CBR they have been involved with or have seen are transformational for participants as well as researchers because they engage in meaningful relationships where the community participants are first and where the community benefits from the research. CBR was also described as being, in its best uses, more culturally appropriate, has change at its heart, and is initiated or invited by community members instead of simply being consented to by the community. Finally, another highlight was a sustained discussion throughout the event about what “community” means. We cannot assume that a community can be easily defined or identified and researchers and practitioners must always be careful in the ways they use this concept.



HIGH LEVEL OF EXPERTISE OF PARTICIPANTS WAS EVIDENT THROUGHOUT AND ALLOWED DISCUSSIONS TO MOVE FORWARD TOWARDS BRAIN-STORMING RESEARCH NEEDS.

EVENT EVALUATION: FEEDBACK FROM THE PARTICIPANTS

Remote Control would not have been a success without the involvement of many people in its planning, including community members, staff, researchers, students, service providers, organizations and of all of the participants during the two-day event. Most of the participants involved worked towards achieving the project stated objectives:

1. Building Capacity for Community Based Research (CBR): The concepts and principles of CBR will be introduced and illustrated with practical examples of HIV/AIDS CBR initiatives from Manitoba. Participants will be encouraged to reflect on the challenges and advantages of implementing CBR projects in their community.
2. Identifying Challenges Related to HIV/AIDS: Participants will share issues from their communities related to HIV/AIDS. This may include trends, gaps in service access, and area-specific challenges.
3. Identifying Research Priorities: Participants will identify relevant research priorities to explore in their communities and work to formulate research questions, and identify key stakeholders including academics, students, community members, service providers, and those affected by HIV/AIDS.
4. Planning for Collaborative CBR: With facilitation from the 595, the group will develop a collaborative plan for a CBR initiative in their distinct communities. Further capacity building needs will be identified. A strategy will be developed to submit an application for a collaborative CIHR Operating Grant.

The participants to the two-day capacity building event were all invited to fill out a pre-questionnaire assessing their expertise and their expectations for the event. They were asked about their experience with community-based research, why they were interested in participating in a meeting about planning CBR related to HIV/AIDS in rural, northern, and remote Manitoba, about the main challenges

associated with HIV/AIDS in their communities and about specific topics or questions that they wanted to be addressed during the event. All the attendants who answered the questionnaire had some level of experience with CBR, ranging from being involved with research projects that used CBR strategies to teaching it at a university level, and with some members having extensive experience leading various CBR projects. During the event, the high level of expertise of participants was evident throughout and allowed discussions to move forward towards brain-storming research needs.

The participants were mostly interested in the two-day capacity building because the topics were relevant to their work or studies, and because of the networking and collaborations that they expected would come out of the event. One of the most common reasons named for why they were interested was also that they wanted to know more about the status of HIV/AIDS in Manitoba. Other participants also were interested in getting material for teaching, gaining skills to write grant applications and were interested in learning more about research participation.

Participants were also asked about the most important challenges relating to HIV/AIDS in the various communities that they are from. Stigma and discrimination was the most commonly identified challenge with seven participants identifying it. Participants frequently reported that lack of knowledge or awareness from community members, limited availability of treatment in communities and inadequate resources (people, time, financial) are very important challenges. Participants also identified challenges that can be broadly separated as relating to structural issues, challenges identified from patients' and communities' perspectives and relating to the health system, as detailed in Table 1. Many of these challenges ended up being the focus of our attention during the two-day event.



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PARTICIPANTS WERE ASKED A SERIES OF EIGHT QUESTIONS ABOUT HOW THE OBJECTIVES OF THE EVENT AND THEIR STATED EXPECTATIONS WERE MET.

Following the conclusion of the event, all of the participants who were present were invited to complete an evaluation form to explore the effectiveness of the event's design and delivery, and to assess the impact of participation for our participants. Overall, the evaluation form was interested in exploring participant's satisfaction with the design and delivery of the event, the impact of the event on participants and how it resonated with their work, life and studies. The evaluation form had mostly close-ended questions but also invited the participants to provide us with their comments on whatever they wished to tell us. We elected to do a short form that could be filled out immediately in order to increase the response rate. Approximately 25 people attended the Remote Control event, and we received 15 filled-out evaluations (60% response rate).

Participants were asked a series of eight questions about how the objectives of the event and their stated expectations were met. The evaluation form was designed keeping in mind the objectives of the events, as well as the expectations and questions that the participants noted in the questionnaire participants filled out before the event.

As detailed in Figure 1, when asked about how the event highlighted the ways in which research is relevant to the work of community-based organizations, all the respondents (100%) indicated that it was "excellent". The same result was also obtained with their experience with information sharing on existing HIV/AIDS research projects in Manitoba and with existing CBR project in Manitoba. We are also happy to report that 100% of the respondents answered that their experience with how the event inspired local researchers to get involved in CBR was excellent. When it comes to the way in which the event identified HIV/AIDS research priorities for rural, northern and remote areas of Manitoba, 13 respondents (86,7%) indicated that it was "Excellent" while 2 (13,3%) indicated that it was good. All of the respondents except one (93,3%) indicated that the event was "Excellent" in its building on current community-based momentum in rural, northern and remote areas in Manitoba. The same results were obtained when they were asked about their experience with how the event provided op-

portunities to network and to create collaborations. Finally, when asked about the event's contribution to building capacity for CBR in rural, northern and remote areas of Manitoba, 13 respondents (86,7%) indicated that they thought the event was "Excellent" in that regard, while one respondent thought it was "Good" and another did not answer.

The comments that the participants provided us with were consistent with the overall results of the evaluation and provided some insights into ways to improve an event like this, and ways to move forward. The vast majority of the comments were positive and enthusiastic as seen in these examples:

"Variety of expertise in the room which was all valued. Increased knowledge, built capacity within my position. Motivated/removed myths/ thoughts or previous opinions of how hard CBR is to do- it seems POSSIBLE! Thanks so much for this opportunity. "

"This has been one of the best, most relevant conferences I have been to in a long, long time. I was so impressed with the speakers' knowledge and expertise. I love research and community health is my background so this committee is a great fit. I look forward to more involvement in the future."

"Excellent day. Valuable information shared and great tips. A wealth of valuable individuals around the table sharing their knowledge and expertise. The topics presented were very relevant."

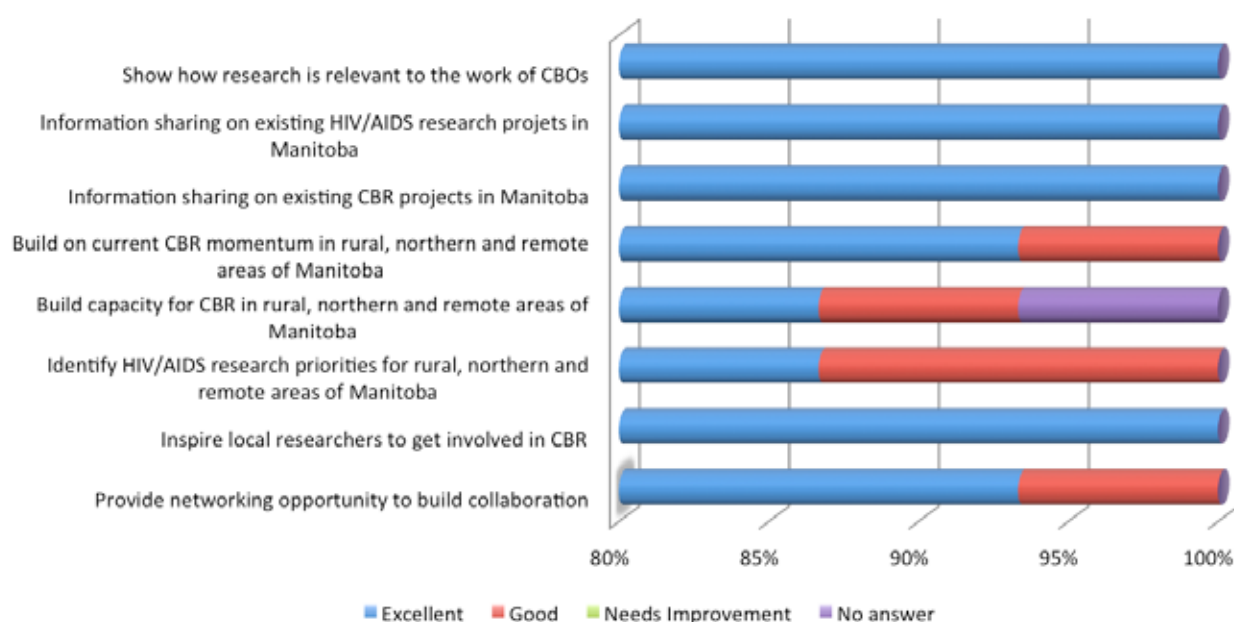


TABLE 1

<i>Structural issues</i>	<ul style="list-style-type: none"> • Racism • Systemic and structural barriers 	<ul style="list-style-type: none"> • Disproportionate burden of HIV among marginalized/vulnerable folks and Indigenous peoples
<i>Community perspectives</i>	<ul style="list-style-type: none"> • Lack of engagement of grassroots and local communities • Confidentiality of diagnosis • Disparities among Indigenous women 	<ul style="list-style-type: none"> • “helicopter” research • Competing priorities for women living with HIV/AIDS (family, childcare, etc.) • Jurisdiction issues
<i>Health system</i>	<ul style="list-style-type: none"> • Late presentation to care • Difficulty engaging with HIV care • Disconnect between prevention and care • Access to services • Inadequate access to testing/ no routine testing 	<ul style="list-style-type: none"> • Lack of research • Missed opportunities to test • Lack of understanding of PrEP • Treatment as Prevention • Inconsistent access to services across province

FIGURE 1

Figure 1. Evaluation results



THE DISCUSSIONS AND SESSIONS AT THE REMOTE CONTROL EVENT CLEARLY INDICATED THAT CBR IS AS MUCH ABOUT PROCESS AND ABOUT RELATIONSHIP BUILDING AS IT IS ABOUT RESEARCH.

“Networking and all the people who are able to explain and support my questions. Excited to see research in the North with all the right people. “Community-based”. Thank you for inviting me, I learned so much. Re-motivated me to re-visit research!”

Three respondents pointed out that it would have been crucial to have more people living with HIV around the table for the discussions we had, and that more people from the rural, northern and remote communities that the event focused on. For example, one person commented:

“Re: setting priorities, I think that it would be best done with communities because each will have their own nuances and needs that will need to be attended to. Also, would have been good to have more Aboriginal people living with HIV at the meeting, but I also know how challenging this can be. (...) Maybe next meeting could be in northern Manitoba? You did bring an excellent group of people around the table.”

These comments are very useful and will orient the ways in which we move forward with the lessons and the questions that were identified during the event.

Overall the evaluation showed that Remote Control was a success and that the event’s design and delivery led to positive outcomes for the participants.

Conclusion and Next Steps

The discussions and sessions at the Remote Control event clearly indicated that CBR is as much about process and about relationship building as it is about research. The different accounts of participants’ experiences with CBR praised the processes where there was accountability and mutual respect and a commitment to social justice. In this sense, the event was purposely organized in a way that emphasized collaborative activities and a dynamic and engaging atmosphere. Remote Control hopes to have helped create a network of people committed to advancing CBR in rural, northern and remote communities in Manitoba.

During the summer and early fall of 2015, the event participants and other interested individuals will continue to be in touch via email and telephone to further the plan for CBR in rural, northern and remote communities in Manitoba. A strategy to develop an application for a collaborative CIHR Operating Grant is currently being developed based on the priorities and the plan developed during the Remote Control event.



REMOTE CONTROL WAS A SUCCESS AND...
THE EVENT'S DESIGN AND DELIVERY LED TO POSITIVE
OUTCOMES FOR THE PARTICIPANTS

THANK YOU TO OUR FUNDERS AND SUPPORTERS



UNIVERSITY
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Northern Social Work Program
Thompson



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