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IMPLEMENTING COMMUNITY BASED HIV/AIDS RESEARCH IN RURAL, REMOTE, AND NORTHERN MANITOBA.

A PROJECT OF THE MANITOBA HARM REDUCTION NETWORK

MHRN

MANITOBA
HARM REDUCTION
NETWORK

The Manitoba Harm Reduction Network (MHRN) and all of our sites are located on Indigenous land. Specifically, we are located on Anishinaabe, Ininew, Anish-Ininew, Dene, and Dakota land and are also in the homeland of the Metis Nation. Our central office is in Treaty 1, and we have been invited to work in Treaty 1, 2, 3, 4 and 5 territories. As a non-Indigenous organization, we are committed to the principles of decolonization and reconciliation and are committed to integrating the TRC calls to action into our work.

LOVE · SAKIHIWEWIN · ZAAGI'IDIWIN · ZAAGI'IDIWIN · LOVE · SAKIHIWEWIN · ZAAGI'IDIWIN

LOVE IS A HUGE PART OF THE HEALING
PROCESS AFTER HIV/AIDS DIAGNOSIS

LOVE SAKIHIWEWIN ZAAGI'IDIWIN

'IT'S ABOUT MORE THAN JUST RESEARCH TO US' DEVELOPING A CAPACITY BRIDGING MODEL THAT ENABLES THE LEADERSHIP OF PEOPLE WHO USE DRUGS IN COMMUNITY BASED HIV/AIDS RESEARCH

This document was created collectively based on the research work undertaken by Peer[1] Researchers in Flin Flon, Selkirk, and Wuskwi Sipihk, three communities in Manitoba, from 2017-2020. Peer researchers participated in conversations, gatherings, ceremony, research processes, and recommendations that led to the creation of this document. We believe in research that is not used to forward the career or tenure tracks of university researchers, but rather used to forward the health and wellness of the communities that are engaging in the research process; research that contributes to the legacy of harm reduction- a model and approach that has been built by people who use drugs and that has been informed by Indigenous science and ways of being – by centering the knowledge and wisdom and expertise of people who use drugs; and research that serves to inform the future direction of harm reduction work overall. We hope our work will support other organizations to advocate for research that is led by people who use drugs and is undertaken primarily in order to improve life for people who use drugs.

A LITTLE ABOUT HIV/AIDS IN MB:

In Manitoba, incident HIV rates are consistently higher than national averages (Manitoba HIV Program 2018 Program Update, 2020). When compared to the national data, women and people who self-identify as Indigenous are significantly over-represented in new HIV cases in Manitoba, and in 2018, for the first time, injection drug use surpassed heterosexual contact as a possible exposure category. Late presentation to care is an issue in Manitoba with 34% of new patients presenting to care having CD4 counts < 350 cells/mm3 at the time of diagnosis (Manitoba HIV Program 2018 Program Update , 2020).

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 cities in the south of the province, Winnipeg and Brandon, yet approximately 20% of incident HIV cases are reported outside of these two cities (Manitoba HIV Program 2018 Program Update , 2020).

A LITTLE ABOUT US:

We know that the voices of people most impacted by HIV/AIDS are often ignored or not considered 'experts' in the field. This despite the fact that people living with HIV/AIDS (PLHA) and people who use drugs have been foundational in nearly every advancement and innovation in HIV/AIDS care and Harm Reduction practice since the virus came onto the scene in the late 70's and early 80's (France, 2016). Without the activism, advocacy, and innovation of scientists, clinicians, policy makers, activists and leaders who use drugs; and the scientists, clinicians, policy makers, activists, and leaders living with HIV/AIDS, the picture of HIV/AIDS prevention,treatment, and care would look very different. People impacted by HIV/AIDS hold

1 'Peer' is a term used and created by people who use drugs to describe their role and work in Harm Reduction, sexual health, reproductive justice. In the context of this research, APHA's who may or may not use drugs were also included.

the expertise and wisdom to move communities forward in how they care for one another and respond to issues related to HIV/AIDS (Peer Engagement and Evaluation Project Team, 2018).

A LITTLE ABOUT THIS WORK:

This Community Based Participatory HIV/AIDS Research project sought to explore the needs and issues faced by people impacted by HIV/AIDS who live in three different communities in MB, Flin Flon, Wuskwi Sipihk, and Selkirk. Specifically, this project explored how HIV/AIDS and substance use stigma impacts Peers' ability to access care, and what does contribute to their sense of community care and what keeps them in their communities. The goal was to learn about these issues in order to begin to address how best to respond to HIV/AIDS needs in communities that do not have access to traditional care but do have people impacted by HIV/AIDS living in them.

A LITTLE ABOUT HOW THIS DOCUMENT CAME TO BE:

In doing this work together, the team quickly realized that, in addition to the research being done by the Peer Research Teams to address these questions, they were also creating new ways to engage community in participatory, action based research that was meaningful, culturally grounded, and valued the expertise of people who use drugs and who are impacted by HIV/AIDS. As the teams worked, it was clear that what was being done supported a longstanding principle of peer engagement at the MHRN and in Harm Reduction overall – *Nothing About Us Without Us.* The MHRN believes that research that is in the hands of those most impacted is deeply valuable and provides solutions that traditional research is not able to discover simply because researchers typically do not understand the complexities and nuances of communities of people who use drugs (Peer Engagement and Evaluation Project Team, 2018). The MHRN's commitment to Peer-Led Innovation

in Harm Reduction prompted the development of this document with the goal of learning from the work that has been done by Peer Research Teams on this project so that it can inform future MHRN research, and potentially support other agencies, researchers, and organizations, and communities, that are engaged in community based research that is led by Peers.

This document will provide an overview of the initial development of this work – specifically how this project was grounded in community and collaboration from day one, describe the process the Manitoba Harm Reduction Network engaged in, and explain how People Who Use Drugs led the research process, directed the research, and maintained ownership and engagement in the research itself. It will describe the strengths of this approach, the shifts that needed to be made to ensure meaningful engagement and will provide recommendations for other agencies looking to ensure their research is participatory, community led, and action oriented.

BUILDING ON WHAT HAS COME BEFORE US:

This current research emerged out of previous community-based research capacity building work done by the MHRN. The MHRN has a long history of Peer Led Community Based Research which originated with Peers based in Winnipeg doing a Photovoice project about Harm Reduction and the way that they receive care from community health agencies. This was the catalyst for several Peer Led CBR projects including 'What Goes Around Comes Around: How Peers Use their Social Networks to Share STBBI Information and Education' (Manitoba Harm Reduction Network, 2013). Additionally, the MHRN has worked over the past 14 years to meaningfully engage and connect with work being done in Harm Reduction all over the province. This has included solidifying significant community connections, training, project development, collaboration, and Peer involvement (Manitoba Harm Reduction Network, 2020). The MHRN is,

at this point, an organization comprised of local community-based networks and Peer organizations and groups that inform these networks. This project was a natural progression of the long-term relationships built between rural and northern Peer organizations and the MHRN.

The provincial HIV/AIDS context and a shift in MHRN priorities to increasingly engage in harm reduction work outside of Winnipeg led the organization to consider how to best to support their network partners and Peers living in rural, remote, and Northern Communities in their efforts to tackle their priority issues. With the support and engagement of existing rural Peer groups and networks, the MHRN began to imagine how CBR could support the harm reduction work being done outside of Winnipeg. The following describes how this initial process evolved into this project.

'REMOTE CONTROL: BUILDING ON CAPACITY TO IMPLEMENT COMMUNITY-BASED HIV/AIDS RESEARCH IN RURAL, REMOTE, AND NORTHERN COMMUNITIES' CATALYST GRANT

In 2013 there were three cluster outbreaks of HIV in three remote northern communities, accounting for at least thirteen new cases in the Prairie Mountain and Northern Health Regions (Kasper, 2013). Because of these events it became clear that it was 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; ultimately with the goal of improving earlier diagnoses and HIV outcomes for everyone in Manitoba. It was 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 MHRN to build the foundations of a community-based research (CBR) initiative within three communities in Northern and Rural Manitoba.

As a first step, the MHRN applied for and received a CIHR HIV/AIDS Catalyst Grant in order to bring communities together. With this support the MHRN hosted 'Remote Control', a two-day capacity building training and discussion with key stakeholders, held in Winnipeg, Manitoba on June 18 and 19, 2015. 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. The event was meant to engage in dialogue with these communities, to introduce participants to the concept of community based research, 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. The MHRN and participants 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 with the goal of engaging in a long-term process to develop HIV/AIDS research strategies that were intersectoral, inter-disciplinary and community-driven. (Manitoba Harm Reduction Network, 2015)

COLLABORATIVE GRANT PROPOSAL DEVELOPMENT PROCESS

Over the two-day event, participants were asked to think about and discuss how they imagine a CBR project could look in their community as well as what they see as the most pressing needs around HIV/AIDS in their communities.

Two key themes emerged (Manitoba Harm Reduction Network, 2015):

1. CBR that is transformational for research participants as well as researchers is deeply valuable and the goal for any future Remote Control project: Participants saw CBR as a type of research that supports meaningful relationship building, where the community participant needs come first, and where the community sees the most benefit from the research. CBR held a lot of hope and possibility for participants. CBR was also described as being, in its best uses, more culturally appropriate, as having change at its heart, and as initiated or invited by community members, instead of simply being consented to by the community.

2. Engagement in CBR that addresses HIV/AIDS stigma in communities is a top priority for CBR in Rural, Remote, and Northern Communities: Stigma and discrimination was the most commonly identified challenge. 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 that contribute to fear and stigma related to drug use and HIV/AIDS.

A full grant was developed based on the work done over these two days, and the consensus of participants that building transformational CBR capacity with an emphasis on HIV Stigma was the direction this work needed to take moving forward. In January 2017, the MHRN was informed that they had received CIHR funding to take on this work over three years.

CREATING THE SPACE WHERE PEOPLE CAN TALK ABOUT THEIR HIV/AIDS STATUS SAFELY AND OPENLY IS A COMMUNITY EFFORT

HONESTY KWAYASKITAATISIWIN GWAYAKWAADIZIWIN

WHAT WE DID AND WHEN WE DID IT: REMOTE CONTROL TIMELINE

COMMUNITY BUILDING AND PROJECT DEVELOPMENT:

JAN 2017   MHRN learns they have been approved for a three-year HIV/AIDS CBR Project

MARCH 2017   Research Project Manager Hired

APRIL 2017   CBR Project Manager Started

MAY 2017   First Project Advisory Committee meeting with original Remote Control participants (including MHRN Coordinators from Thompson, Flin Flon, and Cree Nation Tribal Health, Researchers from the Canadian Aboriginal AIDS Network, and the U of M) invited.

Ethics Proposal developed

Site Coordinator Job postings developed and posted publicly in Flin Flon, Wuskwi Sipihk/Swan River, and Thompson, MB (the original three sites for the project)

JUNE 2017   Ethics Proposal Submitted

No local applications received for site coordinator positions.

Decision made to make in person connections with possible site coordinators and to reconnect with participants from original 2015 Remote Control Project –

MHRN CBR Project manager begins planning travel to the communities for face to face meetings with community members and previous Remote Control Participants to talk about the plans for the project and assess current interest in the Community Based Research project overall.

JULY 2017   Flin Flon visit included meeting with Margaret Steppen-Head, Knowledge Keeper and Elder to pass tobacco and ask for guidance in moving the project forward and to request her support in taking care of the project in a good way over the three-year period.

Margaret accepted the tobacco and agreed to serve as project Elder.

Met with two young people who had worked with the Play It Safer Network (a northern sex positive and harm reduction-oriented network) to describe the project and gauge their interest in acting as site coordinators for the project.

Visited The Pas, MB to meet with Nursing administrator from the University of the North Nursing program. Staff and students who had previously participated in the original Remote Control catalyst event were no longer connected to the university or had graduated and moved on. The level of engagement on the project for the department was low due to other departmental demands and staffing issues.

AUGUST 2017

Thompson visit included meeting with Safer Choices Coalition (sister network to the Play It Safer Network) coordinator and members from local agencies, Public Health Nurses from the Northern Health Region, and academics working out of the northern social work program for the University of Manitoba. The landscape in Thompson had shifted in the two years since the original Remote Control event took place and connections to Peers were more tenuous, and supportive academics had changed roles or moved out of the community. Interest was still high despite uncertainty around how to move the project forward in the community.

Ethics proposal came back requiring follow up that the MHRN felt required the input of the communities who would be doing the research themselves.

Decision made by the MHRN to re-engage community interest, re-commit to the research, and review the Ethics Proposal feedback in order to prepare a community based response to the Joint Faculty Research Ethics Board (JFREB) at the U of Manitoba. The MHRN began planning an event called 'Remote Control Reboot' and invited Peer organizations and network members for a 2 day gathering in Bakers Narrows, MB.

OCTOBER 2017

Remote Control Reboot takes place.

Peers from Flin Flon and Wuskwi Sipihk First Nation attend along with MHRN staff from Flin Flon, Thompson, The Pas, and Swan River, and members of the Play it Safer Network, The Safer Choices Coalition, and advisory committee members.

Pipe Ceremony for project takes place.

Guest Speaker, Jaqueline Anaquod, presented on her work using Indigenous Science and Wisdom to lead community based research that is culturally grounded and community oriented.

Researchers from the University of Manitoba, Javier Mignone, Paula Migliardi and Marleny Bonnycastle reviewed the principles of Community Based Research and provide an overview of the research process.

Participants reviewed ethics proposal and provide feedback to be integrated into the resubmission for the JFREB.

Sharing Circle closed the event.

NOVEMBER 2017   Ethics proposal re-submitted with community responses to the feedback.

Following 'Remote Control Reboot' event, there is some interest in the site coordinator roles for folks from Flin Flon and Wuskwi Sipihk.

PROJECT ENGAGEMENT WITH PEER RESEARCH TEAMS:

DECEMBER 2017   Ethics Approved.

JANUARY 2018   Site Coordinators for Flin Flon and Wuskwi Sipihk hired.

Wuskwi Sipihk Site Coordinator met with the local Peer-led Harm Reduction Committee there to   begin the work of creating a Peer Research Team.

Flin Flon site visit at the Flin Flon Friendship Centre for Project Manager. This included meeting with the PISN Peer Group, Site Coordinators and Elder to begin to build Peer Research Team from existing Peer groups.

Shift from Thompson MB as the third Site to the MHRN Peer Group in Selkirk, MB.

FEBRUARY 2018   MHRN Harm Reduction Conference attended by all three site coordinators.

Meeting to discuss project.

Site Coordinator Hired for Selkirk.

MARCH 2018   Staff Orientation for Selkirk and Flin Flon site coordinators (Wuskwi Sipihk site coordinator had been previously oriented).

APRIL 2018

Site Visits to Wuskwi Sipihk, Selkirk, and Flin Flon to discuss methodology, PHIA, site specific amendments to the ethics proposal, and to provide some HIV/AIDS training.

Approval granted from Elders Council and Chief and Council in Wuskwi Sipihk First Nation to engage in CBR in their Territory and with their community.

MAY 2018

Peer Research Teams engage in Ceremony, CBR Training, and group planning.

JUNE 2018

Site Specific Ethics Amendments for Wuskwi and Flin Flon submitted to JFREB.

DATA COLLECTION:

JULY 2018

Amendments Approved – Teams are able to start recording their sessions. Data Collection begins.

Selkirk Site Coordinator goes on sick leave.

SEPTEMBER 2018

Remote Control Reboot Tri-Site Gathering. Emphasis on Data Collection and Analysis. Sherri Pooyak and Marni Amirault from the AHA Centre at the Canadian Aboriginal AIDS Network provide training on CBR Data Analysis. Doris Pelletier provided expertise on HIV/AIDS CBR projects from the perspective of APHA Researchers. HIV/AIDS 101 Q&A session with the MHRN.

OCTOBER 2018

STIMULUS National Drug Policy Conference Site Coordinators and Peer Researchers attend and deliver Oral Presentation on project.

DATA ANALYSIS:

NOVEMBER 2018

Data Analysis Training and Indigenous Health Symposium 2-day event with Site Coordinators to learn how to analyze data.

JANUARY 2019   Second Site Coordinator Hired for Selkirk.

Selkirk Amendment submitted and approved.

MARCH 2019   Data Analysis Wuskwi/Flin Flon

Data Collection/Photovoice project in Selkirk takes place.

KNOWLEDGE TRANSLATION:

MAY/JUNE 2019   Knowledge Translation (KT) Projects Developed/completed for Flin Flon (7 sacred Teachings and Research posters) and Wuskwi Sipihk (community BBQ and report back to community).

Data Analysis – Selkirk.

SEPTEMBER 2019   Tri Site Knowledge Translation Gathering and project Closing Ceremony in Swan River MB. KT presentations from all three sites on the work they have done over the three years of the project and the results and teachings that emerged from their work. Giveaway and closing ceremony.

DECEMBER 2019   Public Poster Launch Flin Flon, MB

JANUARY 2020   Indigenous Health Symposium in Winnipeg, MB. Oral presentation on Remote Control work with an emphasis on Flin Flon's work on culturally grounded and Land Based research.
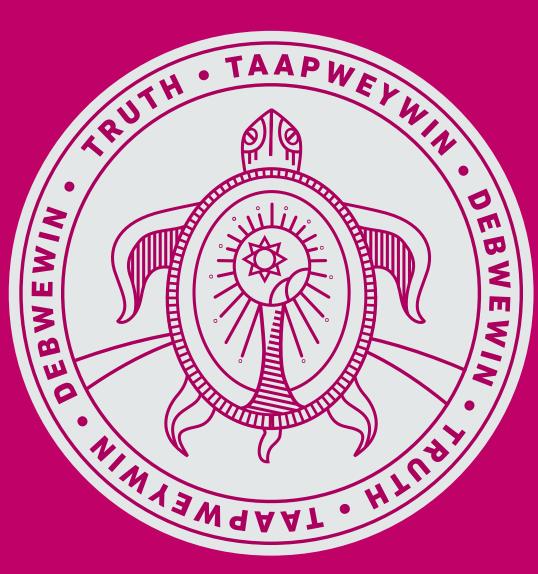
MARCH 2020   2 project reports completed and made available publicly.

APRIL 2020   Canadian HIV/AIDS Health Research Conference in Quebec City. Oral Presentation on Remote Control Work. (postponed due to COVID-19)

SERVICE PROVIDERS NEED TO TRUST THAT PEOPLE WHO USE DRUGS KNOW WHAT THEY NEED

TRUTH TAAPWEYWIN DEBWEWIN

WHAT EXACTLY WAS THIS RESEARCH ABOUT: THE RESEARCH QUESTION

The initial proposal identified as its goal: to better understand and document the lived experience of PLHIV and affected individuals, families and communities in relations to HIV/AIDS care, treatment and support in Northern, rural and remote communities in Manitoba.

It laid out the objectives as follows:

1. Identify and document the care, treatment and support needs of PLHIV and affected communities in rural, remote and Northern communities in Manitoba, including barriers and facilitators to accessing care.

2. Strengthen partnerships among community members, community organizations, and academic institutions.

3. Increase the relationship people have to CBR projects and approaches. In particular working towards using CBR to highlight the work and innovation taking place in Northern Manitoba among community members, community organizations and academic institutions.

The Peer-Led Research Teams further developed how they would approach these research questions by re-stating the questions in their own words. They sought to answer the following two questions based on the above goal and objectives:

1. How does our community respond to people who are impacted by and living with HIV/AIDS and how do we as Peers support one another to tackle the stigma that exists (everywhere) around HIV/AIDS?

2. What are some key ways to build and capitalize on Peer Interest and Capacity Bridging for Community Based Research?

From there each site decided on how they would be tailoring their projects to answer these questions in ways that made sense for their communities.

Each site contemplated these questions in different ways that were uniquely linked to the local context and community landscape:

1. Flin Flon: How does connection to culture, ceremony, and each other heal and support those of us impacted by HIV/AIDS in our community?

2. Wuskwi Sipihk: How does our work as a Harm Reduction Committee and our HIV/AIDS awareness work impact our community as well as us?

3. Selkirk: Why do people who use drugs and who are impacted by HIV/AIDS and HCV not access the resources that exist in our community?

HOW WE BROUGHT OUR HEARTS TO WORK AND HOW WE GOT IT DONE:

Peer Led Remote Control Community Based Research Themes:

The following six themes emerged as key factors in the Peer Led Research Teams' engagement and execution of their CBR work. These themes align with work done by other community based participatory action research teams that work to decentralize the power relationships in research and move forward more research approaches that are imagined and practiced collectively. (Survived and Punished, 2019) :

1. Ceremony should lead the research process and Indigenous Science and Knowledge should be centered in CBR that is connected to Indigenous People and Communities:

   'Everyone has a place in the circle and stigma is what pushes people out of the circle'
   – Peer Researcher

   This project was led by people who use drugs, most of whom were Indigenous, and supported by Indigenous Site Coordinators. Ensuring that identity and culture was centered allowed

teams to engage fully in the research process. Connecting community-based research to ceremony and Indigenous science was crucial in bringing spirit into the conversation and ensuring that Indigenous Ways of Knowing were honoured and brought into the work that was done collectively by the research team. This project started by engaging more western research approaches to setting up the research project: developing an advisory committee, posting for site coordinators, developing an ethics proposal. This did not result in the engagement that was needed for Peers to take ownership of the project and figure out what they wanted to do and share with their communities. Early in the project, a shift was made to emphasize more relational connections in order to build Peer Research Teams from the ground up. Traveling to communities to talk to folks in person and leaning on previous relationships with local folks who could introduce the project manager to Peers and Knowledge Keepers made the difference in how this project was able to move forward in a good way. Building a connection with an Elder and Knowledge Keeper who helped lead this project shifted how this research felt and whose expertise was prioritized. This project began and ended with a pipe ceremony, our gatherings always began in ceremony and ended in circle with one another. Ceremony was a significant part of the research process and how teams engaged with the research question. This included conversation about how we know what we know, how connection to land informs our understanding of how we think about HIV/AIDS, collective care, and anti-stigma work. It also included sweats, naming ceremonies, cleansing ceremonies, crafting, and art making, giveaways, and letting go ceremony. This project welcomed Indigenous researchers working in other territories into the circle to share their teachings, and our methodologies were informed by how knowledge is shared

in each of the communities. Welcoming spirit, culture, and Indigenous science into the research process made the space teams needed to be vulnerable, open, creative, and committed. This ceremony centered research process made the circle open to Peers who did not always feel welcome.

'I feel that I have a sense of purpose and belonging'
-*Peer Researcher*

2. Researchers should be a part of the community the research is engaging with:

    'The research should be hands on, building relationships instead of helicopter research where the researcher flies in and flies out'.
    – *Community Member*

    Community Based HIV/AIDS Research must be done by the communities themselves. In its most meaningful form CBR is a process that is facilitated by community, for community. This CBR project centered the power in the hands of the Peer Research Teams. These teams were responsible for deciding how they would work together as a group, what direction they wanted their projects to go, and how they would share their expertise and knowledge. This project did not have outside researchers – the Peers engaged in community action and engagement and their reflections on their work and role in destigmatizing HIV was the 'data' that they collected. They answered their research questions by engaging in grassroots, anti-stigma work.

    'We don't need educated people talking high up/bossy, we need our own ways. We know what is best for our communities.'
    – *Peer Researcher*

    'Amplify Community Voices. Research must be about giving not taking'
    – *Peer Researcher*

WISDOM • NIPWAAHKAAWIN • NIBWAAKAAWIN • NIBWAAKAAWIN • WISDOM • NIPWAAHKAAWIN

WE SHOULD BE CONSULTED WHEN PEOPLE ARE DESIGNING PROGRAMS FOR PEOPLE WHO USE DRUGS. NOTHING ABOUT US, WITHOUT US

WISDOM NIPWAAHKAAWIN NIBWAAKAAWIN

3. Prioritize 'Boots on the ground' research.

'Give us the opportunity to prove ourselves and we will step up and we'll give it all we got until we have reduced all the harms for each other.' – Peer Researcher

Action oriented research, where the methodology can also be the intervention, is important when the urgency felt by People Who Use Drugs around system change and reducing stigma is so great. Peer Led Research Teams all felt that any work they did should immediately benefit their community and have a lasting impact that contributed to improved care and services for people who use drugs. Whether it was HIV/AIDS Bingos, Naloxone training, STBBI testing days, ceremony, or art-making, each team took action in their community to address the research question even as they were talking about the research question together and collecting data from their sessions. This CBR project worked because Peers saw what they were doing as an opportunity to take concrete and meaningful action that would support their communities.

4. People who use drugs carry the wisdom they need to care for each other.

'We are strong, and we care and want to make a difference.' – Peer Researcher

Peer Research Teams applied the ways that they care for their communities to the ways that they did their research. For instance, teams placed heavy importance and value on times they could come together to meet and connect with each other. Sharing information across sites enabled them to build off of each other's work. Ensuring that teams came together once a year to sit in circle together and to learn from the work happening in other communities was one of the most meaningful components of this project. These gatherings had a strong emphasis on sharing knowledge

and expertise and asking questions of one another. Learning how folks were organizing and what issues came up and how they were handled allowed teams to integrate these lessons into their own organizing. For instance, knowing that having Elders get tested for STI's at a testing day in Flin Flon made it more comfortable for others to get tested was helpful for other sites organizing their own testing days. Peer Led Community Based Research needs to honour the wisdom people who use drugs carry to take care of each other.

'We know about testing and are knowledgeable about it and wise.' – Peer Researcher

5. Capacity Bridging not Capacity Building

'eyes are opening to the [research] that we produce' – Peer Researcher

'Capacity Building' assumes that in order to do research peer researchers need to gain skills and be taught about how to do their work. The Peer Research Teams reject this idea as hierarchical and paternalistic. Instead they see their role(s) as bridging roles that allow them to support agencies, universities, health authorities, and other places they work and access in their efforts to create meaningful service for people who use drugs and people living with HIV/AIDS. This is a concept originally developed by Visioning Health and described by the Canadian Aboriginal AIDS Network as 'a more inclusive, less hierarchal concept that recognizes the richness and diversity that exists within and across Indigenous and Non-Indigenous communities and looks for ways that we can extend our reach to produce more wholistic and meaningful research that serves our communities in a good way.' (AHA Centre, 2017). Capacity Bridging is the idea that everyone comes to the table with skills and capacity to make meaningful change related to HIV/AIDS and substance use stigma. That many

of us hold multiple roles – as peers, and service providers, as researchers, as people living with HIV/AIDS, as Knowledge Keepers etc. and that bridging our multiple knowledges and identities decenters the power dynamics in research.

6. Democratizing research

    'Peers have Power.'
    – Peer Researcher

    Peer Research Teams provide a roadmap for the democratization of research. In other words, teams took back ownership of how research happens in their communities, provided leadership on how to engage safely with one another and in their communities, and demystified the research process in order to understand how to execute their work. What Peers initially understood as 'research' sometimes minimized the value

of what they were doing, it became the site coordinators and project manager's role is to reframe the work so that what folks are doing and sharing is seen as research by the researchers themselves. It also meant that the research process was collectively driven by the Peer researchers. They decided on their methodologies, they reviewed the consent forms, and contributed to the site-specific amendments to the University of Manitoba Joint Faculty Research Ethics Board. Engagement in the entire process contributed to strong ownership in the research and meant that the Peer Research Teams were the leaders and sentinels – making the decisions about how this work would impact them and their communities and being accountable for their engagement.

PRACTICAL LESSONS LEARNED AND RECOMMENDATIONS

PROJECT MUST BE RELATIONAL

Engaging people who use drugs and people living with HIV/AIDS in research requires a pre-existing relationship and on-going, in person connections. This project worked because the MHRN has been working with Peers in each of these communities for a minimum of 5 years, most for over 10 years. Peers came into this work already trusting the MHRN and willing to connect with staff that they may not know as well because of the pre-existing relationship. Built into the project was capacity for the program manager to accept invitations into communities to attend meetings and to connect with Peers. Additionally, this project supported

three tri-site gatherings that brought Peers from all three sites together for knowledge translation and capacity bridging activities.

Recommendations:

•   Peer-Led CBR must be a component of a larger Peer engagement strategy within the organization hosting the research project.

•   Projects must support on the ground relationship building activities such as visits, feasts, and gatherings in order to create the context required for meaningful, trusting, and non-coercive Peer engagement.

SIGNIFICANT TIMELINE FOR ENGAGEMENT AND CAPACITY BRIDGING REQUIRED

This research project required significant time for Peer engagement. For communities exhausted by traditional research being done on their communities by outsiders, supporting a slow, progressive pace for community based research allowed Peers to gradually trust that this process was in their control and was not coercive or forcing a particular idea or approach on communities. The MHRN did not anticipate how important this would be as it believed previous relationships would be enough to ensure participation. The MHRN did not factor in Peers' previous relationships and understanding of what research is. In particular, Indigenous Peers were wary of participating in research given how often their communities are the subject of research that is embedded in settler colonialism with no benefit for the subjects (Castleden, Garvin, & Huu-ay-aht First Nation, 2008). Early in the project, the MHRN, after realizing that more time would be needed to ensure process transparency, began visiting Peer organizations in their communities and hosted an initial gathering to start the project with a pipe ceremony, review the original proposal, ensure peer engagement in the ethics process, and to describe the ways that this CBR project could be different from what folks were expecting. Taking this time to slowly ensure meaningful capacity bridging, trust, and understanding of how this research may be different allowed teams to settle into their role as researchers and commit to the process.

Recommendations:

• Plan for a long project set up period in order to give Peer Research Teams the time they require to trust the research process. This project took a year and a half from the time the project manager began till the time teams were able to begin data collection to work through the research requirements (training, ethics proposal, methodology development,

consent process, research process overall), and the team building required to build trust within teams and with the broader research team.

• Anticipate the reluctance and uncertainty of Peers around participating in research and the benefits of research, and make choices that enhance transparency, clear process, and acknowledge the inherent harms and risks for Indigenous people, people who use drugs, and people living with HIV/AIDS in traditional research models, including some forms of CBR.

HIRING MUST BE THOUGHTFUL, INTENTIONAL, AND MOVE BEYOND SIMPLY SHARING JOB POSTINGS ON WEBSITES.

This project involved the hiring of a Research Project Manager and three Site Coordinators to engage and support Peer Research Teams. The reality is that formal research is often positioned as requiring high level training and education in order to roll out a research project (Banks, et al., 2013). This means potential applicants do not always see themselves as possessing the skills required to execute a research project. The hiring process must, therefore, be strategic around the democratization of research in order to be welcoming to the communities the project is seeking to support. The MHRN hired a CBR Manager that had years of connections to the Peers of the network, who practices from a deeply ethical place, and who has worked on Peer Led CBR projects before. Hiring Peer site coordinators that were from or engaged with the local community required the project manager to rely on her existing community relationships and their connections, and to go into the communities to meet and connect with potential site coordinators. The project manager participated in Flin Flon's first Pride and met with possible site coordinators and Elder on the Pride Float for the Play It Safer Network. From there they agreed to come to the initial gathering. In Selkirk, the program manager met multiple times with the Peer Network and

I DESERVE RESPECT REGARDLESS OF MY HIV / AIDS STATUS

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relied on the coordinator of that group to talk to Peers who might be interested in working as site coordinators for the research project. Relying on existing relationships and meeting with people in spaces and places that were distinctly theirs helped shift the power in relationship in order to work with a team that was intrinsically connected to the Peer Researchers.

Recommendations:

- Job postings must specify that Peer expertise is required.

- Job postings alone should not be relied on to ensure that Peers apply.

- Meeting Peers in person to describe the research, how it differs from much of the research that people have interacted with previously, and what the project position for hire actually entails is a beginning step in building trust and relationship.

- Creating opportunities to demystify the research process and to connect research to everyday undertakings (like the first gathering for this project that took place in Northern Manitoba) gives Peers a better sense of what the work will be, prior to applying, and creates the comfort required for folks to see themselves in a research role.

- Hire a research manager that is connected to the community, has a deeply ethical understanding of how community based research should look, and who trusts and respects Indigenous ways of knowing and science, and who works from a heart based perspective on harm reduction. It is integral to have someone with these qualities to support the goals and work of the Peer Research Teams and Site Coordinators.

- Ensure that the project underpinnings emphasize community focus and democratizing research in every aspect. This facilitates the hiring of a research team that reflects the demographic of people centered in the research itself.

SUPPORT STAFF TO ENSURE PROJECT SUCCESS

Staffing for Peer-led Community Based Research involves a strong mix of mentoring, freedom, and flexibility. The expertise of the site coordinators was invaluable, in particular, in working with their teams, connecting the project to people who had never considered engaging in research, and walking teams through the process in a clear and predictable way. In order for them to be able to do this work they required ongoing training and support throughout the project. Initially this involved learning about confidentiality, submitting ethics proposals, and supporting Peers to begin to see themselves as researchers with expertise. Later, training included data collection training, data analysis training, and developing knowledge translation plans. In addition, having clear supports in place for site coordinators ensured that they had local support available as needed.

Recommendations

- Put Site Coordination supports in place early. This means connecting site coordinators with local people who have experience with research, organizing, or community engagement so that they can support one another. So, for example, in Flin Flon site coordinators were supported by a manager at the Flin Flon Friendship Center as well as the MHRN project coordinator for the region. The CBR project manager was supported by a team of researchers who made themselves available as needed when navigating formal research systems and refining tools developed by the Peer Research Teams. The Selkirk site coordinator was supported by the local MHRN network coordinator and the public health manager for the regional health authority – both people known and trusted by the group.

The Wuskwi Sipihk site coordinator was supported by a local nurse who works directly in the community and the harm reduction manager for Cree Nation Tribal Health Centre. The overall team should bring a wide variety of expertise, teachings, and wisdom to the table in order to facilitate a process where knowledge is shared, and teams are supported.

- Pay support people for a small number of hours per week (2-4) so that site coordinators can depend on the responsiveness of their supports in the moment.

- Create flexible but clear timelines for site coordinators. Site Coordinators worked a maximum of 15 hours per week, or two days a week. Tailoring work schedules to each person ensured that their work style could be accommodated. For example, one Site Coordinator required a clear and scheduled plan for each day worked, another spread their hours out over the week, another preferred to work nights rather than days. Flexibility allowed site coordinators to work in a way that worked for them.

- Set regular meeting times. Site Coordinators connected once every two weeks via teleconference with the CBR research manager in addition to regular contact as needed. Regular meeting times ensure a minimum level of contact.

- When hiring people who actively use drugs, in particular if they use drugs in a way that impacts work, work together at the outset to create a plan that maximizes their ability to work meaningfully and minimizes the risk (to the staff person, other Peers, and the organization).

- When hiring people who are a part of an existing Peer group, give consideration to how the hire may impact group dynamics, relationships, and talk to the staff person about how they want to address any interpersonal issues that arise.

PUT RESEARCH FUNDS IN THE HANDS OF PEER RESEARCH TEAMS

This Peer Led Community based research included ensuring that budgetary decision making was diffused across the project, in other words sites had a say in how project funds were spent. This allowed teams to create research opportunities that made sense for their communities. Site coordinators made decisions with their teams around how they wanted to spend funds, and the Project Manager worked to facilitate what sites wanted to do as much as possible. For Wuskwi Sipihk, being able to engage in supporting recreation that also combined HIV/AIDS Health Promotion was important for the group. These activities drove their group conversations which served as their data collection for the project. Balancing the participatory action work that they were engaged in in their community and their research exploring how they saw their roles in reducing community stigma about HIV/AIDS was possible because they had the flexibility to work in ways that were meaningful to them and their community. In Flin Flon, the team's work centered ceremony, art-making, and land-based learning that supported group healing as well as community healing led by this group of people who used drugs. This project supported the team to integrate their research work into their collective healing and care work. Flexibility in how funding is used in community allowed teams to feel like there was immediate benefit for their communities as well as a long-term benefit from the research results. Additionally, Peer Researchers were paid for their time via honoraria which is in keeping with MHRN practice and best practice in peer engagement. (Peer Engagement and Evaluation Project Team, 2018)

Recommendations

- Pay research teams for their work. No other researcher would expect to work for free and neither should Peers.

- Add honoraria information and justification into grant proposals. Describe the ethics and importance of avoiding paternalism when working with Peer researchers. And ensure that honoraria are included in any Ethics proposal and consent forms.

- Engage in budget conversations and updates with Peer Research Teams and Site Coordinators regularly. Budgets reflect the research being done and they need to be participatory in order to ensure the participatory nature of the research.

- Discuss and respect Site Coordinator's comfort level in managing petty cash for honorarium and food for Peer Research Teams. This project had site coordinators who could not get bank accounts, and who were very tenuously housed, or who lived places where significant substance use took place. For them adding financial management to their role was unfeasible and not something they wanted to take on. For others, managing a small petty cash was an opportunity to gain some financial skill, for others it was a regular component of the work that they have done in the past. The MHRN took the site coordinators' lead and either provided very small petty cash amounts initially and built them up over time, provided standard petty cash, or simply paid for a project support person connected to a local agency to manage honoraria and food for their site.

ACKNOWLEDGE THE ETHICS PROPOSAL AS BOTH A BARRIER AND AN OPPORTUNITY

University research boards are not always in tune to the nature of how Peer-led community based research works, nor the collective nature of research development. This means that methodologies are requested before Peers have decided what tools they will use, it means that traditional ways of getting consent do not always perfectly reflect the

values and wise ways in which the teams operate to get permission and consent, and it means that proposals are often submitted prior to Peer engagement due to the fact that the researchers and the subjects are often the same people and consent is required to even begin the conversation with folks who may end up as Peer Researchers. This project submitted an ethics proposal to the University of Manitoba Joint Faculty Research Ethics Board (JFREB) prior to hiring site coordinators. This proposal was based on the initial Remote Control Catalyst Grant proposal and had been developed by people involved in the original remote control catalyst grant. As is common with ethics committees, the project was asked about methodology, consent, subject recruitment etc. In this first ethics proposal, a variety of examples of tools that might be used were included, data collection tools, sample consents, and posters. The proposal could not be specific because nothing had been confirmed with sites and peer research teams had not even been established. The MHRN has traditionally developed these research tools with the Peer Researchers themselves. Unsurprisingly, the ethics proposal came back with feedback and questions asking the team to be more specific about what the project would look like. This project benefitted from the decision to begin to re-energize interest in communities with a gathering called 'remote control reboot'. This Northern gathering allowed participants to provide input into the JFREB's ethics proposal feedback and to answer some of the JFREB's questions. The core takeaway was that sites would develop their own processes and make their own decisions about tools. A decision was made to remove all tools from the ethics proposal and, instead, commit to Ethics amendments for each site as they decided how they would move forward. Instead the re-submission included a consent to participate as a Peer researcher and a description on how the project would roll out the site specific research tools. From there, the proposal was approved. Three amendments were submitted following the initial approval. The ethics process was cumbersome and required intense engagement on the part of the

program manager. That said, the process this project undertook around ethics approval ensured the most Peer Researcher engagement possible and allowed teams to decide how they would move their projects forward. It also ensured significant reflection around project ethics and how to do this work in the best way possible and minimize potential harms for the teams. This slow and reflective process gave teams the confidence they needed to proceed safely in their communities and with each other. Additionally, this project received approval from both the Elder's Council, Chief and Council in Wuskwi Siphik, passed tobacco to the Elder at the friendship Center in Flin Flon, and completed an ethics review under the Interlake-Eastern Regional Health Authority for the Selkirk Site. These other informal ethics committees helped center the ethics of each site in the work that was done.

Recommendations

- Work with someone who is experienced and has expertise in working with and submitting to research ethics boards. Having relationships and support from researchers who work in a university setting and have expertise working through ethics proposals meant this project had folks walking teams through the process and breaking it down into manageable components.

- The Program Manager must be responsible for ensuring that the project reflects the ethics proposal, and for submitting and resubmitting documentation as needed.

- The Program Manager must be able to 'translate' academic interpretations around ethics into the community setting and take the feedback from Peers and ensure that it is integrated into anything going to the ethics committee.

- Establish community based ethics committees to support ethical research engagement. This means consulting with local leadership and Knowledge Keepers in the communities in order to move forward in a good way.

- Use existing structures (such as proposal amendments) to create opportunities for Peer engagement.

SUBSTANCE USE

Peers often believe that they have to be sober to participate in meetings, conferences etc. and often their attempts at sobriety prevent them from participating fully. They end up experiencing withdrawals or other symptoms related to not using. At the MHRN there is no requirement to be sober at meetings. People are asked to come 'sober enough' to participate. Early on, this project made an assumption that people knew this was the common practice and ended up hosting a meeting where some folks were quite dope sick and unable to be present in the way that they wanted to. This mistake meant some researchers experienced harms related to lack of access to drugs that could have been avoided with more clarity at the outset. This experience moved the team to be regularly and repeatedly explicit about expectations regarding substance use. Bringing harm reduction supplies was not enough, the team required regular repeated assurances that people should do what they need to do to participate fully, and if that meant minimizing the risk of withdrawal by using at gatherings, that was ok.

Recommendations

- Ensure that Peer Researchers that are travelling know that the MHRN does not take issue with people being high/using at meetings and that a practice of participating while 'sober enough' is the approach used to ensure maximum participation of Peers who use drugs.

- Be prepared to roll with the ways substance use might impact meetings (start times, breaks, people's ability to engage in full days of activity). These accommodations are necessary and crucial to ethical and democratic CBR.

SERVICE PROVIDERS NEED TO UNDERSTAND THAT THEY DO NOT KNOW WHAT IS BEST FOR US. THEY NEED TO HONOUR OUR CHOICES AND WALK BESIDE US

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MAKE A LOT OF SPACE FOR FUN AND LAUGHTER, GRIEF AND LOSS, LAND AND SPIRIT

Research should be alive with spirit. CBR should be about story-telling, collective discovery and include opportunity to enter into relationship with one another. Peer led research is so much heart work for folks and deeply personal and meaningful and honoring that requires connections that cannot be developed through the research process alone. This means that teams must be intentional about making space for these things within the research process. It cannot be an afterthought . We make meaning collectively and understanding that research is about making meaning reminds teams to center collective care and being present makes for a CBR process that remembers all of our humanity.

Recommendations

- Create moments with the teams that are fun and playful. Gatherings began in the evenings with games such as harm reduction 'Guesstures' and HIV 'Pictionary', surprise swag bags for participants in cabins/hotel rooms, campfires, swimming, sit down meals, community tours, and bingos. We intentionally created opportunities for laughter and joy. When one of our gatherings missed the evening games, Peers felt disconnected and talked about how much they missed those light moments together.

- Make space for grief and loss. Two of our Peer Researchers from two different teams passed away suddenly, and it was important to honour their role in the project and to name our grief at their loss. We asked our Elder to help us honour them during a pipe ceremony. It was an opportunity to make sure that the teams could share in each other's grief, offer comfort and connection as we came together, and honour the Peers that journeyed to become ancestors.

- Gather around the fire. Our first gathering started with teams meeting and sitting in circle

and ceremony together outside around a fire in Northern Manitoba. Connecting the land with spirit and the work that we wanted to do together created meaning and purpose that shaped the tone and approach of the project.

- Be present with the Land. The land that the teams worked on was an important part of the research team. Community, place, and the natural landscape informed how teams did their work and shaped each team's unique approach to their research. In Flin Flon, the team met with the Knowledge Keeper on her land, in Wuskwi Sipihk, the team did door to door outreach because their community is small enough for that to work. In Selkirk, the proximity to Winnipeg and the inaccessibility to resources like transportation informed how people thought services should be offered in their community. The story that each team told was uniquely connected to the place where they lived. The project as a whole gathered once in each team's territory and this was intentional so that teams could introduce the land to one another.

- Sit in Circle together. Most of the training happened in a circle. This equalized the power dynamic and avoided a teacher/student dynamic. The circle reinforced that what we each brought wisdom and expertise to the project. Each gathering ended with a circle where each person had an opportunity to contribute. These circles were powerful and full of spirit and healing. Storytelling was such a huge part of this project and the stories and collaboration that was shared and gifted in these spaces demonstrated the value and potential of culturally grounded community-based research. Stories about how HIV/AIDS disclosures could take place in healing ways, about how lack of HIV/AIDS information and care led to fear and losing time with loved ones, still others about how important supporting loved ones when others rejected them was, and how sharing resources across jurisdictions could happen despite harmful policy. These

circles connected communities and shaped the ways that teams engaged in their research.

- Feed people very well. Ensure that Peers have access to hot breakfast, ample lunch, and full dinners. Access to food, water, snacks, and candy help keep people focused and engaged. When food scarcity is an issue for people as it was for some Peer Researchers, it is necessary to make sure that food is delicious, protein rich, plentiful and available. Additionally, sharing food and meals is such an important part of connecting and building relationship that ensuring that it is not stressful for people who are hungry is a priority.

THE END IS JUST AN OPPORTUNITY TO BEGIN AGAIN

Peer Led Community Based Research is urgently needed to inform and lead harm reduction work at all levels. Peer expertise ensures that money is spent in wise ways that provide meaningful care to people who use drugs. It must be integrated into a larger strategy to avoid piecemeal projects and ensure ongoing work and opportunity for Peer Researchers. All three research teams folded back into the Peer Networks as their projects wrapped up. This meant that their research can seamlessly inform their ongoing work. Project ends must be seen as continuations and beginnings rather than something that is put away and forgotten. Organizations and institutions applying for CBR funding need to have a plan in place that centers the 'Action' component of Participatory Action Research. CBR is not a program, despite the fact that it can offer a service or support the work of people who use drugs. This is why it should be a part of a whole rather than a one-off project. The MHRN works to integrate research into the work that is ongoing, and this is how Peers stay engaged and have trust for the work that they do.

'Some people are healers and you can spot the ones who are healers. Because everyone is worth healing.'
-Peer Researcher

WHEN SOMEONE DISCLOSES THEIR HIV/AIDS STATUS TO YOU – RECOGNIZE THAT IT TAKES A LOT OF COURAGE

COURAGE SOOHKITEHEWIN ZOONGIDE'EWIN

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