

Draft Minutes
CBR in BC Quarterly
September 27, 2018
1:30 PM – 4:30 PM

Attendees: Mona Lee (PAN), Flo Ranville (GSHE, AYESHA), Janet Madsen (PAN), Darren Lauscher, Jill Aalhus (FNHA), Alexa Norton (FNHA), Carly Welham (DPC), Meghan Mullaly (DPC), Meika Uy (DPC), Sean Grieve (SHAPE), Antonio Marante (DPC), Andrea Bever (SHAPE), Sarah Watt (Canadian Webinar Series, CHIWOS), Becky Gormley (CHIWOS, WATCH), Joanna Mendell (Cheque Day Study), Janice Duddy (PAN), Jennifer McDermid (SHAWNA), Madeline Gallard (PAN), Tabitha Steager (PAN)

Location: McLaren Housing (1249 Howe Street) & Teleconference

1. Welcome & Check-in

2. Approval of Previous Minutes

3. Approval of Agenda

4. Panel Presentation on Knowledge Translation, Exchange and Mobilization:

Each presenter/team will share learning and innovative/effective knowledge translation or knowledge mobilization practice or tool. Q&A followed each presentation.

• Cheque Day Study, BC Centre on Substance Use (<http://www.bccsu.ca/cheque-day-study/>)

Presented by Joanna Mendell

- This study is looking at when and how often people receive their income assistance cheques (any provincial assistance), and related impacts. Looking at whether there might be less harm to community and individuals if cheques were distributed on alternative schedules different from the current government cheque issue day (i.e. control group continues to receive it monthly on government cheque issue day; staggered intervention group receives it monthly on a day outside of government cheque issue week; split and staggered intervention group receives it bi-monthly on days outside of government cheque issue week).
- Consideration of context for knowledge translation/exchange/mobilization is key. For this study, need to remember that the focus is on an ongoing, existing government policy.
- What has worked?
 - o Listening – this has led to more information being gathered beyond what was collected by the research. One example is learning from participants that giving people cheques on different days might lead to those people becoming targets.
 - o Be flexible – the development of the Community Impact Statement was not something that was originally planned but grew out of engagement with participants. Presenting this statement alongside scientific research results allows the study to be more relevant and useful.
- What is not effective is “yapping.” Studies need to cater to their knowledge translation (KT) audience (e.g. do not “yap” to people who are living it every day). Rather than giving people a long introduction to the project or sharing what people already know, create something concise and simple to share for people to take and read on their own.
- Resources mentioned:

- KT Planning Guide from PHAC <http://publications.gc.ca/site/eng/434858/publication.html>
fasttrackimpact.com <https://www.fasttrackimpact.com/>

- **CHIWOS, BC Centre for Excellence in HIV/AIDS**

(http://www.chiwos.ca/home/?doing_wp_cron=1537461941.2153959274291992187500 &lang=en)

Presented by Becky Gormley and Sarah Watt

- The Canadian Webinar Series is a partnership of CHIWOS and many other stakeholders to provide a Canadian perspective on WHO's Consolidated Guideline on Sexual and Reproductive Health and Rights of Women Living With HIV. CHIWOS has hosted four webinars so far on topics related to sexual reproduction and rights, including trauma and violence aware care and safer HIV disclosure.
- One strength of the Canadian Webinar Series is its broad reach – it has had 1,100 views with quite diverse stakeholders. An in-person event was also held at the 2017 CAHR conference. The focus was bringing people together interested in developing a National Action Plan, and it led to diverse discussion about research consideration and policy gaps within Canadian context.
- Key learnings from the Canadian Webinar Series: working collaboratively with different organizations across Canada allowed expansion of the scope. Also the interdisciplinary audience allows for richer discussions and for the process to be iterative (able to solicit feedback and refine as we go).
- Obstacles in the Canadian Webinar Series: timing has been a challenge. In the first webinar, there were too many presenters, which led to not being able to go into depth on topics. One way of resolving this was to ensure that community perspectives are given first, so that they are not lost if there is not enough time. Discussion periods have been really valuable.
- The webinars follow a similar structure – priorities are determined by collaborating group, and team members present, as well as different experts. One priority is the need to protect community members, give lived experience space, and value the importance of these voices. CHIWOS has created resource sheets that could go along with presentations – they allowed people to follow-up further.
- Having recordings of the webinars was really valuable – it leads to people being able to email in and ask questions after the presentation. The presented questions and answers are collated after the presentation.

- **Evening Program, Dr. Peter Centre**

Presented by Carly Welham

- This program started as a 13 week pilot, after realizing that there is an emerging at-risk group of gay or men who have sex with men, over 50 years old, living with HIV, and experiencing isolation and food insecurity. The program sought to explore the impacts of aging with HIV and social isolation among the target population through an integrated program with four main components: individual and group counselling; art, music, and recreation therapy; a nutritious communal dinner; and opportunities for peer support and socializing. Communal dinner together on a long table was a hit of the program.
- Knowledge translation for this program has been ad hoc because it is not a research study. Part of the purpose of sharing about this program through various KT efforts is to gain funding (so the program can run permanently beyond pilot) and to attract more participants. The program is pleased to announce it has secured funding to run the program for 2 years!
- The KT activities and products shifted as time went along.
 - o A written report was not read by many (as is the case for other projects and programs).
 - o Poster did better, especially with a non-traditional colour theme which attracted more audience.

- Media coverage (e.g. funding announcement in the news) was a great KT success in generating conversation in the public about the topic (i.e. aging with HIV and social isolation) and in increasing recruitment for the program).
- Creative and interactive KT:
 - Role play (at the International AIDS Conference) using a script/description based on true experiences of program participants
 - “On the table conversations” by engaging people with lived experience at the table to have discussions about the program and its impacts
- Challenge: making innovative/creative strategy work in traditional environment can be tricky.
- Learning: creative KT work better in your own space or space you have control over.

4. Break

5. Program & Project Updates

Please provide a short summary of each project and consider these three points: one success, one problem encountered, and one lesson learned

SHAPE

Summary: STOP HIV/AIDS evaluation on what retains people in care. This included a closed baseline survey and continuing to do follow-up. 644 participants in study. One analysis – data request looking at how stigma impacts treatment outcomes and accessing proper care. Another analysis – data request on social connectedness and how it impacts people’s ability to stay linked to care.

Success: representation across the province of BC. Recruitment trips to Fraser Health and Vancouver Island.

Challenge: Youth, recruiting youth into the study. Also thinking about doing a qualitative component and engaging youth more in this part of the study.

Making It Work

Summary: CBR project of Pacific AIDS Network in partnership with the AHA Centre at CAAN. The focus: people living with HIV and HCV have other complex social and health issues. The hypothesis is that we have better health and social outcomes when using Indigenous Service Delivery Models, and if we link case management and community development. They will develop an evaluation tool that organizations can use evaluate how well they are meeting their clients’ needs.

Success: Building a strong team, especially while working with PRAs and community meetings remotely.

Challenges: Time! Things always take longer than we expect. Our study team is all in different locations across the province.

FNHA

Summary: The FNHA has been funded to do a 5 year project on “Indigenizing Harm Reduction” with 5 CBR sites. Indigenous Wellness Team – Not Just Naloxone Training, decolonizing addiction. FNHA released harm reduction grants that went to communities – the question is how do we turn this into evidence? Currently in ethics review. Projected: Year 1 will be a scoping review with an Indigenous lens (could take 1-2 years), using storytelling interviews and interviews with stakeholders across the studies. Years 2-4: Capacity-building exercise at the same time around harm reduction. Run an intervention where there is capacity in the community. Develop a Harm Reduction Model with Indigenous framework. They are currently developing an application process for sites participating in the CBR project.

SHAWNA

Summary: Arts-based research in their PhotoVoice project, which looked at disclosure and the law and stigma for women living with HIV, in the form of a photo voice book. This included collages and narration. The pilot focused on African, Caribbean and Black (ACB) and Indigenous women, as well as youth and trans women.

Success: Gathering diverse voices around stigma. Working with a very engaged elder on the project. Having different groups of women represented in our project. Women came multiple times to show people their photos during the openings.

Challenges: Inclusion of trans-women, as there is no existing trans group to work with in Vancouver.

Lesson Learned: Everyone felt the need for a weekly group to share their voices. Starting things early in terms of invites. Making the book – getting all the pieces organized more in advance.

CHIWOS

Summary: Canadian HIV Women’s Sexual and Reproductive Health Cohort Study is a longitudinal national study focusing on sexual and reproductive health and mental health of women living with HIV. Completed data collection – doing data cleaning and thinking through next steps.

Challenge: keeping people engaged in coming back to do follow-up recruitment. How do we stay together as a team of PRAs who were really involved in doing surveys to doing activities that aren’t as frequent and more spread out. Looking at doing more KTE and capacity-building. Looking to do a qualitative phase as well – looking at women-centred care in BC.

WATCH

Summary: Women, ART, and the Criminalization of HIV (WATCH) is a community and arts-based study that aims to explore the impacts of the criminalization of HIV non-disclosure on the lives of women living with HIV in Canada using **Body Mapping**. WATCH conducted retreat style Body Mapping workshops across British Columbia, Saskatchewan, and Ontario. You can learn more about the WATCH study at: watchHIV.ca

WATCH – body mapping, analysis and KTE at AIDS Conference. Were able to share body maps and narratives.

Challenge: national team, how do we really stay engaged when we are all spread out. Having an Analysis Retreat

Positive Living, Positive Homes (PLPH)

Summary: [PLPH](#) examines the relationship between HIV and housing within a BC context. Three study sites: Greater Vancouver, Prince George, and Kamloops. People with lived experience, policy-makers, and service providers were interviewed. The team is continuing to analyse data and share findings, even though funding has come to an end.

Success: Got to present at the North American HIV and Housing Research Summit in Washington DC. Interesting to see the differences and overlaps in policies and programs between US and Canada.

Challenge: Difficult to maintain our KTE momentum and engagement of study teams.

Lessons Learned: Policies shift and change over the period of the study team. Need to stay on top of things over the course of the project and need to keep track of these when reporting out.

BC People Living with HIV Stigma Index

Summary: Designed by and for people living with HIV, and led by people living with HIV (PLHIV), the [BC People Living with HIV Stigma Index](#) (referred to as the BC Stigma Index; first in Canada) is a dynamic CBR project that was born out of a community-identified need to turn the tide against persistent HIV stigma and discrimination. The BC Stigma Index worked across the BC province, using an international action-based research tool [HIV Stigma Index](#) that has been implemented in over 50 countries. Data collection is completed and the team has been data cleaning. The team also been sharing the findings alongside data analysis through various community presentations, and will be moving into deeper level analysis with a data party in June. The team dove into further questions that communities wanted to know, and will be bringing some community calls for action to the PAN Fall Conference at the end of October. The team also has been engaging the health authorities through

sharing how stigma impacts access to healthcare – many people living with HIV are avoiding care. The project also conducted debrief interviews with the PRAs, which informed and helped support the development of the National Stigma Index work. The team plans to do further qualitative interviewing to add to the quantitative data.

Challenge: Time, time time! Quantity of information and prioritizing knowledge translation/exchange (KTE) work. How can we create one report from Canada for this international tool?

Lessons Learned: Ongoing. Stigma is still so prominent in impacting how one sees oneself.

6. New Business:

- Other innovative KTE resources include: www.becauseshecares.com (a poetry and CBR project with ACB women in Ontario), [Strong Medicine](#) (an educational video developed by the Canadian Aboriginal AIDS Network and CATIE, with and for Indigenous people living with HIV), *A Mile in Our Moccasins* (a short film that was co-created by five Indigenous youth), and whiteboard videos (something PLPH is planning on developing).
- Darren Lauscher discussed [SFU's Engagement Night on HIV Research](#). Scientists in Health Sciences are inviting community folks to come and chat. It is on November 1st and capped at 10 people. Please contact Shayda Swann (shayda_swann@sfu.ca) if you are interested in attending.
- **PRA Meeting** – our PRA circle is growing and it might be a good time to have a PRA meeting to support new people in meeting those who have been doing this work for a long time. There is a lot of support and interest to move this forward. How can we mentor the next generation? PAN will work to help facilitate. There is a page of resources on engaging and supporting peer workers on PAN's website: [Peer Worker Support and Compensation](#).
- Learnings from CAAN – have a box of Kleenex on every table and have a pile of pillows so that people can sit comfortably.

7. Meeting Adjourned