Minutes CBR in BC Quarterly June 26, 2019

Time: 1 - 4 PM

Location: McLaren Housing (1249 Howe Street)

Teleconference call-in details:

Toll Free Dial-in Number: (+1) 888 884 4539

Guest Code: 1061180 #

Attendees: Sharyle Lyndon (BC-CfE), Antonio Marante (community member), Sarah Spencer (CHIWOS), Heather Burgess (Thrive), Tim Wesseling (SHAPE, BC-CfE), Andrea Bever (SHAPE, BC-CfE), Madeline Gallard (PAN), Janice Duddy (PAN), Becky Gormley (CHIWOS, WATCH), Brittany Barker (FNHA, Indigenizing harm reduction), Kate Salters (BC-CfE), Karen Slakov (BC-CfE), Mona Lee (PAN), Paul Kerber (PAN), Andreea Bratu (COAST study, BC-CfE), Joanna Mendell (PAN), Sean Grieve (SHAPE, BC-CfE)

1. Welcome & Check-in

2. Approval of Previous Minutes

3. Approval of Agenda

4. Quick overview of CBR Quarterly – brief orientation

- CBR Quarterly has been meeting for about 10 years. Came about from partnership with J. Evin Jones at PAN, Janice Duddy at PHSA and Bob Hogg at BC-CfE – to share about CBR and to seek opportunities for joint partnership/learning.
- Has been a great space for people who are doing community-based and community-engaged research. Nobody owns this meeting/space, so it is a very inclusive space for anyone and everyone to come and put forward agenda items.
- o In the past, we have done collaborative problem solving (e.g. recruitment) at the table and many folks used this meeting as networking opportunity.
- Last year at the CAHR conference, we hosted an ancillary event, for which a CBR Quarterly timeline (that tells history about the group and its work) was developed. Janice will share this along with CBR Tip Sheet.
- Community of practice like-minded people coming together to support learning and each other. PAN supports by taking on the facilitation role but does not own the meeting and is open to agenda items from everyone (and feedback/suggestions for format, content like presentation topics and guest presenters). PAN is able to support this work with contribution from two national research centres (REACH and CBR Collaborative Centre).
- o It is a useful space for peer research associates (PRAs) learned things about CBR and also to connect with one another.

5. Share back and next steps from the PRA meeting

- O Discussions around who should be invited/at the table how to define "peer." What's the purpose of this gathering? We need to do some work to define peer.
- Decision to hold the next PRA meeting before next CBR Quarterly (September/October)

- o If anyone has knowledge of who wants to join the meeting, please connect with Paul Kerber at PAN (paul@pacificaidsnetwork.org).
- COAST study looking at people who are HIV-positive vs. general population. Two comparison groups. Should we include people from the general population?
- **6. 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

A. WATCH

- Body mapping impacts of criminalization of non-disclosure
- o Data collection ended early 2018

B. CHIWOS

- Longitudinal Cohort of women living with HIV in BC, ON, QC
- Quantitative surveys in 3 time points ended in Dec 2018
- Moved to qualitative phase
- Success: PRAs won CIHR CANFAR award
- Challenge: taking on smaller projects transitioning from core team post data collection. Had a one-day sharing circle with team talking about journeys, lessons learned and what to share outward. Good closure. Taken on doing focus groups getting feedback on toolkit on operationalizing women-centred care. Done focus groups, partnered with ON group to make updates by Jan 2020. Valerie Nicholson taking on retreat-based project with Indigenous women.
- CHIWOS and WATCH: both focused on KTE. Big event in early June 2019 as part of Women Deliver – criminalization of HIV non-disclosure on women – responding to Sex 2 guidelines around gaps. Developed postcards for David Eby and David Lametti, federal Attorney General of Canada.

C. Making It Work (MIW)

- Indigenous focused CBR across BC likely 4 different case study sites (to be determined). Pilot interviews from test case study sites have been completed – analyzing the data and determining where case study sties will be.
- Success: Having Joanna on board as coordinator for the project.
- Challenge: Human resources last coordinator left in December so keeping up the momentum has been challenging.
- D. Viral hepatitis program at BC Centre for Excellence
 - Success: adapting and evolving a research program.
 - Challenge: inheriting new research programs administrative health cohort with a lot of data at raw level + ongoing clinical work with viral hepatitis.
 - Learning: taking foundational program and building/morphing it into a new program. In the past – investigator driven. Now, trying to ensure community engagement/consultation.
- E. BC People Living with HIV Stigma Index (Stigma Index)
 - o PAN has been leading this, using international Stigma Index tool. BC is the first site in Canada to implement this tool. We worked with 6 PRAs to gather data and now in the process of data analysis and sharing this. Now we are moving into phase 2 of the project as this is meant to be an action tool. Using the data from phase 1, we are planning the development of stigma reduction intervention. First part of this work will be to do a literature review and looking at intersectionalities of stigma beyond HIV (e.g. around

gbMSM, people who use drugs, Indigenous peoples, etc.). We put in a couple of proposals to get funding for this phase 2 of project – currently waiting to hear back. Would also like to hold a deliberative dialogue to develop an effective intervention and also develop a harmonized/standardized evaluation tool to evaluate this intervention (and other stigma reduction interventions). This is in partnership with Community Action Initiative as part of their contracted organizations funded through OPEN working on reducing stigma around drug use. In addition to stigma reduction intervention work, project plans to do 25 qualitative interviews to supplement/provide context to phase 1 quantitative data and also working with the national stigma index team to inform each other's work.

- Success: Launched a whiteboard video to summarize study and high level findings.
 Learned about how to be concise in our KTE. Up on PAN website
 [https://pacificaidsnetwork.org/training-leadership/stigma/]. Also developed summary sheets.
- Challenge: Prioritizing work (juggling finalizing phase 1 while bringing phase 2 up to speed).
- Lessons Learned: Being clear about messaging before developing the KTE projects. Who
 is it for, for what purpose, how will it be used ask these questions first.

F. Thrive

- New project looking at older adults living with HIV (over 50 years old) in relation to home support services, supportive housing/residential care homes, etc. People are getting pushed to care homes due to lack of care supports. Katrina Koehn looked at our admin data to see how people have used home and community care. Between 2004 and 2014, 15% of adults over 50 living with HIV accessed home or support care (mostly residential and long term care).
- Next stage is a qualitative piece CAC to work on the interview guide. Growing our team with two new PRA positions. Human resources is a challenge.

G. SHAPE

- Evaluation of provincial HIV STOP program.
- Success poster at care "Connection is the Key" increase social supports = decreased treatment interruptions. Was great as a PRA to be involved in the creation of the question. Presented at the DPC.
- Challenges: trying hard to reach out to participants who are due for follow-up but we haven't been able to connect with them. Trying to find people at organizations where they go.
- Lessons Learned: need to think forward to how we are going to reach people moving forward. Never give up.

H. Positive Living Positive Homes (PLPH)

- CBR study led by PAN on relationship between housing and health for people living with HIV (PLHIV) at 3 case study sites in BC (Greater Vancouver, Kamloops and Prince George). Qualitative interviews done with 99 PLHIV and 43 service providers and policy makers. Currently analyzing and sharing findings – presented at CAHR this year and developed whiteboard video [https://pacificaidsnetwork.org/research-andevaluation/plph/]. Also in the process of developing online housing toolkit.
- Success: great KTE.

- Challenge: finding a person to translate the online housing toolkit contents into digestible online format.
- Lessons learned: things always take more time than expected.

7. Break

8. Open discussion – what are methods of qualitative research that you have been involved with/what are some innovative methods of qualitative research?

- CHIWOS and WATCH both have been doing quite a bit of qualitative research using approaches like focus groups and sharing circles but also innovative methods like body mapping. Chose body mapping because criminalization is a difficult topic of conversation requires trust body mapping allows information to be processed in a different way than verbal discussions. Used self-identified women living with HIV each person traces their own body on a piece of blank paper (with support shadow person) and through guiding questions, work on these bodies to create their own personal maps. At the end, verbally share about what each person has put on their maps. These can also serve as knowledge translation tools.
 - O What does analysis look like for body mapping?
 - Two different types: narrative and thematic analysis of transcripts of end-of-day sharing circles (virtual small groups) & visual analysis (in-person, week-long retreat). Some themes as a team want to focus on that answer primary research question → create images based on themes (e.g. one body map might have 10 images on injustice). Some images are more descriptive while others are more abstract. Had to ensure the visual analysis happened alongside narrative analysis (to make sure analysis was accurate to what the women meant by their image).
 - Saara Greene from McMaster literature on arts-based work/analysis.
- Supportive housing for people living with HIV expressions of depressive symptoms (data collected through one-on-one interviews). Interpretive description way of analyzing information so it's applicable to practice. Instead of using qualitative analysis software, write down themes on post-its used this as a way to do a participatory analysis. Did qualitative training prior to the interpretive description participatory analysis.
 - 1st step: go through the transcript whatever jumped out/concepts and quotations that stood out – wrote them down on post-its. Paraphrase, concepts, feelings.
 - o 2nd step: post-its were put into mind maps.
 - o 3rd step: create a framework based on the mind maps deconstruct and reconstruct into categories, themes.
 - What happens next? Once all post-ins are re-organized into themes, develop codes and apply these codes to transcripts.
 - Been taking pictures of the process (as well as before and after for mind maps time sequence) – to preserve this.

9. Meeting Adjourned

Next meeting – other meetings to consider (do we want to piggyback/avoid?):

- Qualitative research conference (some time in October)
- o CBRC Summit: end of October/beginning of November