

Draft Minutes

CBR in BC Quarterly

February 27, 2019

1:10 – 3:30 PM

Attendees: Angela Paul (PLN), Alexa Norton (FNHA), Tim Wesseling (SHAPE), Mona Lee (PAN), Madeline Gallard (PAN), Darren Lauscher, Paul Kerber (PAN), Janice Duddy (PAN), Daniela Michel (DPC, UVic), Carly Welham (DPC), Flo Ranville (CGSHE, AESHA), Janet Madsen (PAN), Joanna Tulloch (PAN, UVic)

Location: McLaren Housing (1249 Howe Street) and teleconference

1. Welcome & Check-in

2. Approval of Previous Minutes

3. Approval of Agenda

4. Group Discussion – upcoming Peer Research Associate meeting proposed at the last CBR Quarterly Meeting

- This PRA meeting could piggyback off of AHA Centre – they're going to be planning a PRA only space, looking to plan a 2-day meeting in April or May. First day would be CBR 101, second day a 201/next phase of work. Focus on Indigenous PRAs.
- CAHR would be a good place to do an ancillary event with a peer focus (there are other groups doing similar things across the country). Concerns about silo-ing if separate Indigenous and non-Indigenous PRAs.
- This meeting can be an opportunity to share successes, challenges, needs, and networking for peers.
- Discussion around whether this should be a one-off meeting or regularly happen. A few years ago, there was a peer meeting held ahead of CBR Quarterly.
- A peer-only group is going to be different than what is currently happening at CBR Quarterly. It is important for peers to be able to talk about the process and it helps to sort out processes that might not make sense; it's also a good opportunity for students to learn from peers.
- Peers opted not to come to this CBR Quarterly meeting because they felt intimidated - so we need to be intentional about making the next CBR Quarterly more inviting and open.
- Suggestion to invite PLDI grads to the meeting.
- Discussion around whether the space should be peers-only, or have peers-only space first then invite others to learn from the peers. If latter, peers should be allowed to leave before the community joins if they wish.
- Discussion around how these meetings will be held, since there are currently no resources to do a regular face-to-face meeting. Meetings could be held by video call, but we would have to find another place to meet as a group to ensure good WiFi.
- In terms of planning, all peers who attended the last CBR Quarterly wanted to be involved. Tim would also like to be involved. PAN can facilitate email approach to peers if there are folks who may wish to attend who are not currently connected to CBR Quarterly.

- Discussion around how we define “peer.” Suggestion to open this up more to invite folks like the Investigaytors; and ask Zack Marshall for guidance on this? This conversation has happened many times and never really been concluded. There is lots of CBR happening around harm reduction and the opioid crisis and peer researchers can share a lot with each other – we may not want to limit the definition of peer to “people living with HIV.” General consensus to start with peers working on CBR projects on HIV and affected communities and to widen the invitation as desired.
- REACH can be involved in some ways in this work.
- We need funding to do this long term – maybe we need to look at funding streams outside of our normal niche, ex. universities, banks? To keep this as an agenda item for future CBR Quarterly (about the human resources involved and work of doing grant proposals).
- General agreement that PAN will provide backbone support to help organize the initial meeting.
- Date: If PRA meeting is to be held in tandem with CBR Quarterly, it would be in June. Janice will connect with the AHA Centre folks and report back. CAHR is in May so maybe people will be too busy – can we bring something to CAHR? CAHR is a good time to have meetings to connect about this with other folks, ex. James Watson, Francisco Ibáñez-Carrasco.
- Next steps: Janice will go talk to the AHA Centre, and then PAN will send out an invitation for folks to volunteer as core planning team. PAN will send out the date once it is nailed down.

6. Discussion – Conducting Research with Indigenous PWUD (agenda item brought forward by FNHA)

- Project update on the Indigenizing Harm Reduction project – it is funded, and will roll out in 3 phases. First, scoping interviews, then work in each of the health authorities. The final piece will be creating a model of Indigenous harm reduction.
- Currently, the PI is on sabbatical and two of the Co-PIs are on parental leave, so Alexa is managing this project.
- Alexa is working to get the scoping review up and going – the initial grant was done from a very standard research lens, but they are trying to work to a more Indigenous lens and frame things in a culturally safe way. The interviews can include Indigenous PWUD, elders, youth – it’s an opportunity to build the consent process out. FNHA is grappling with ongoing consent – current system for research consent is protective of institutions, so how do we shift this away from protecting SFU and UVic to protecting the communities involved (and convince the Ethics Board)? Several layers of complexity – want to do an ongoing consent piece, but also integrate doing an oral consent. Especially with PWUD, how can they ensure that participants are clear about feeling okay to engage? FNHA has no consent protocols at this point and so this is starting from scratch. Two of the Co-PIS have done work with PWUD, but none of it was done from Indigenous perspective.
- Question: Are you creating a dictionary of language that you are using? Alexa says that in their application, they have Western words in brackets next to the language they are using. Tip for Alexa to the Canadian Trial Network – they have a community advisory committee.
- Flo explains that in her teachings, when you ask people for information, there is an exchange of tobacco. So in the process, even with a traditional consent form, if someone wanted information, you would offer tobacco. Flo suggests including names of elders on the form – and also creating an explicit separation of what is protecting the institution and what is protecting

the community. Flo also mentions that SHAWNA project adapted the Medicine Wheel for this process – Flo will forward this to Alexa!

- UBC Learning Exchange is trying to build a community ethics board (idea is to have any research projects conducted in DTES to be approved by this board) – reps from SFU, UBC, Providence Health are having community conversations with people living in the DTES. The next meeting to discuss this is in March. Mona will connect Alexa with UBC Learning Exchange to talk about this.
- Jane Buxton at VGH has been doing peer harm reduction project that involved folks from VANDU, Warm Zone.
- PAN's Making It Work (MIW) project is looking at Indigenous service models and would love to learn from this project.

7. Program & Project Updates

SHAWNA (Centre for Gender and Sexual Health Equity)

Summary: (Sexual Health and HIV/AIDS: Women's Longitudinal Needs Assessment)

The **SHAWNA Project** is a research project that focuses on the social, policy, legal, gender, and geographic gaps in women's sexual health and HIV care across Metro Vancouver.

Success: We have done several well received presentations in community. This has been a great opportunity for the team to bring findings back to partner organizations, and engage with participants outside of a research setting. Sharing a personal story during these presentations (i.e. trauma's impact on viral load – showed doctors/audience why someone is or isn't taking medication is complex) was powerful and engages the audience in a different way.

Challenge: It often feels like there are 'too many cooks in the kitchen'. Because each team member has a clear vision for the direction they would like to see each project go in, it can sometimes be hard to ensure that we are on the same page, and are moving forward in the same way. Still building structure with PRA team – it is challenging to fit in the roles of others (PRAs don't know who to turn to and talk to). Have put out guidelines for team to help set boundaries. PRAs are now on payroll and have signed contracts! Challenges around getting PRAs paid.

Lesson learned: We've learned a lot through our community presentations. For example, we have realized how important it is for us to coordinate every detail beforehand, including: ensuring each presentation is tailored to the organization/audience. Be really transparent and don't leave PRAs out of the changes that have happened. **Learning about the transparency and PRA inclusion to be highlighted for PRA meeting** (agenda item #4 in this meeting minutes).

PLPH (PAN)

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.

Success: Lots of KTE! Very close to finishing a whiteboard explainer video! Online Housing Toolkit also being developed – a 7-module online resource for PLHIV and people supporting them (talks about things like finding housing that is appropriate, etc.). We are attending the National Congress on Housing and Homelessness in Victoria in April, and we will be able to share some of our findings.

Challenge: Getting through the data! Analyzing – but sometimes folks have questions, and then we analyze that specific part of the data. Continuing KTE work without funding is a challenge.

Lesson learned: If you have 3 years of funding, 1 year should be for KTE. Be more intentional about the tools we are producing for KTE. KTE also takes time because we are checking in with everybody.

BC People Living with HIV Stigma Index (PAN)

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. This project is moving into KTE, which is going well – digging into data and message planning. Also doing a script for a whiteboard explainer video! Looking towards qualitative data collection and interventions.

Success: Presentation at PAN's 2019 Educator's Forum (in partnership with FNHA, for Indigenous front-line educators). BC's learning about the process is informing the National Committee for Stigma Index – e.g. national team took our learning and incorporated qualitative data collection to supplement the quantitative tool. Also sharing the experiences of PRAs who led the BC Stigma Index as a checklist to help other CBR projects with some guiding questions to consider when working with and supporting PRAs.

Challenge: Looking forward to interventions, figuring out what interventions are effective. Can we build a tool to measure the impact of interventions?

Making It Work (PAN)

Summary: CBR project of Pacific AIDS Network in partnership with the AHA Centre at CAAN. The focus: people living with HIV and hepatitis C 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. This project is using Realist Evaluation Framework – a framework that considers context very acutely (you don't ask, 'did it work?')

Success: We are working with folks on the Island, Ktunaxa Nation in Cranbrook, and up North. Lots of talk around bringing on a 4th study site. Big success in closing the Catalyst Grant. We did pilot interviews to build a theory of change. Another success is that we completed these interviews and can move into

the next stage. Angela mentions that the PRA in Prince George really enjoyed doing interviews and did a great job.

Challenges: Tabitha Steager, the Making It Work Coordinator, resigned, and we are having challenges finding a new person, especially since there is a very specific skill set involved.

SHAPE (BCCfE)

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. Finished the baseline last August, continuing with the follow up, and in the finishing stages of follow up #2.

Success: After finishing the baseline study, the research coordinator asked what resonated – Tim: connection is the key to positive health outcomes; Sean: stigma was a common theme when doing interviews. Both were asked to develop abstracts and Tim's went through – hoping to present at CAHR. Developing a community presentation on Sean's piece and doing a presentation at Dr. Peter Centre on March 12 at 11 AM.

Challenges: Contacting people for follow ups. This is an ongoing thing. Also connects to successes – they are in contact with a peer navigator at IDC to have letters handed out to people they are having trouble doing follow up with. Another challenge – peers need to be informed of all the things their jobs entail, because they may not be aware or prepared, and need the support of having things explained.

Lesson learned: So many opportunities for peer researchers! Peer meeting in Halifax, PLDI trainings. Take advantage of all the things coming your way – grow and learn.

8. Meeting Adjourned