

CBR Quarterly

June 24, 2020

1 – 4 PM

Zoom

Attendees:

Joanna Mendell, Paul Kerber, Michelle Stewart, Madeline Gallard, Andrea Mellor, Anita David, Darren Lauscher, Leanne Zubowski, Brittney Udall, Anna Vorobyova, Becky Gormley, Tim Wesseling, Clara Tam, Riley Bizzotto, Debbie Cardinal, Cheryl Dowden, Ashley Stoppler, Tatiana Pakhomova, Surita Parashar

1. Welcome, territorial acknowledgement & check-in

2. Approval of Previous Minutes - approved

3. Approval of Agenda – no changes/additions

4. Virtual CAHR Follow-Up - Presentations

1. [Weaving Our Wisdoms: Optimizing Whole-istic Health among Indigenous People Living with HIV through Teachings from and on the Land](#) (scroll down to view poster from CAHR 2020 Virtual) – presented by Andrea Mellor
 - Recently moving away from the term land-based wellness, thinking about creative ways to talk about this
 - Have 4 HIV elders, elders is a term that has been developed by Valerie Nicholson that means someone who has been living with HIV for a long period of time and are knowledge holders with a lot of wisdom about living with HIV.
 - The project is about understanding how connecting with the land can support Indigenous people living with HIV – gathering on the land, taking medicine from the land, urban agriculture – how do these things help with coping
 - Looking at different research methods to help us understand these.
 - There are lots of biomedical advances, but the wholistic piece can be further developed
 - In September, 10 team members and 15 IPHAs, all came together in Saskatoon. Began retreat at home of one of team members, led by an elder with a pipe ceremony and led us in a sweat (or the choice of doing land based activities). To help us start the work in a good way and get to know each other.

- Had four different teepee talks that each addressed one of the research questions – like focus groups. Also held one-on-one interviews. It was a wonderful and emotional gathering, but then we all had to leave and we are looking at ways to keep working together.
- Working on a unique data analysis method. We want to be mindful that we are not compartmentalizing their words and things people are sharing. Looking at ways to do a narrative analysis without breaking things up that people are saying.
- Being a national team, we are working to develop virtual methods instead of coming together. Collective Consensual Data Analytical Procedure – looking into. Will be an interesting learning experience.
- Have a national gathering that we will do at the end, and work to develop the next phase of the project.
- An attendee shared how special it was to be there and learn together at the gathering.
- On working virtually – we are well set up as we work nationally. But to work at a distance means being open that it's not the same, maybe changing what you think should be done. And there are also benefits. Now that travel and cost aren't limiting factors we might be able to bring people in who might not have been able to.
 - A CBR Quarterly meeting attendee shares – we had to move to phone interviews, but realizing that we may reach more people (i.e. people in assisted living or long term care facilities). Also one PRA could not participate as much in the office work, but has been able to participate meetings virtually fully.
 - A CBR Quarterly meeting attendee shares– recently we've hired PRAs virtually and done all the training virtually. We have been able to do all the training online with a focus on keeping the training interesting. In a way it has been more equitable for people to access.
 - A CBR Quarterly meeting attendee shares – COVID has created a silver lining that we are sharing so much online. Thinking about all the work that has not been shared/saved but has been lost

2. [“My Heart’s Full. My Spirit’s Flying”: Creating a CHIWOS PAW Gathering with Indigenous Women living with HIV on the Coast Salish Territories](#) - presented by Becky Gormley and Debbie Cardinal

- CHIWOS-PAW (Positive Aboriginal Women) was born out of CHIWOS with a focus on women living with HIV
- Developed a series of gatherings with participants and people working on the research team to help everyone get to know each other
- Used Indigenous methodologies, imagery (see poster)
- Each woman created their own canvas to represent their own health and healing
- Were supposed to meet in March, which has been postponed due to COVID

- A CBR Quarterly meeting attendee suggests that perhaps there are ways to prepare for the gathering
 - We are staying connected with the women, sending them study material and medicine bundles
 - We're also being respectful because a lot of the women have a lot of other priorities to take care of right now – we're going to discuss more as a smaller CHIWOS PAW team
 - A presenter notes that she thinks if she was on the other side she would have a hard time doing everything on the computer. During this time, we're all in isolation, we have felt that this not a good time to meet, people have a lot of stress and are tired at this point.
- A CBR Quarterly meeting attendee asks – how were women recruited for the project?
 - Flyers that were circulated through community advisory boards, and networks
 - Did one-on-one conversations to see if they were interested and able to participate in a 4 day retreat, and what they would need
- A presenter shares that it would be nice if more peers were hired on teams. Being a peer associate opened my eyes to research. A lot of women want to know why we are doing so much research. Maybe focus a little more about giving that information out in a good way and focus on hiring peers.

3. [The Role of Peer Research Associates in Collecting Data in Longitudinal Health Surveys](#) – presented by Tim Wesseling and Clara Tam

- PRA involvement has identified benefits for research, but few studies have quantitatively assessed PRA involvement in data collection
- Looked at which populations chose to complete surveys with PRAs, and survey completeness
- Participants completing the survey without PRAs had significantly higher 'prefer not to answer'
- Utilizing PRAs showed higher participation in the study
- By sharing their responses with someone who can empathize with them such as peers, participants may feel safe and supported and more willing to answer.
- Future reference could focus on differences between key populations
- Discussion:
 - As PRAs people often share a lot of information with us, sometime things they have not shared with anyone else. Part of the reason why we have PRAs is to get these "real" answers
 - Coming from the mental health space as a peer researcher and connecting with the participants over and over again and form relationships over time. As a Peer

Researcher I was fortunate to do all sorts of different things, teaching presenting etc. So much value in having PRAs on research team. As a PRA you are hired for your lived experience, so you are identified as such, where everyone else around the table doesn't have these personal things identified about them. Doing this work, the good outweighs the uncomfortable spaces.

- Sitting on the other side of things, before becoming a PRA, I know how it feels and now I know that I'm helping people feel more comfortable.
- Importance of connecting with each other and developing relationships.
- PRAs can give a voice to the researchers at higher tables where they are being dismissed by funders – especially around knowledge exchange.

4. [Using a Two-Eyed Seeing Approach to Realist Evaluation in a Community-Based Research Project](#) – presented by Joanna Mendell, Darren Lauscher, and Madeline Gallard

- *Making it Work* study – community-based research study exploring services for people living with HIV, hepatitis C, and/or challenges with mental health and substance use. Looking particularly at Indigenous worldview in services
- Approaches to research include Two-Eyed Seeing, Community-Based Research, and Realist Evaluation
- Approaching Two-Eyed Seeing in our project – working to take an Indigenous perspective in work, for example using medicine wheel, using a strengths-based approach, reviewing findings first with Indigenous team members. Western way of seeing – Realist Evaluation – very linear.
- Building realist evaluation program theory – creating spirals to show Context-Mechanism-Outcome configurations, using medicine wheel framework
- Key learnings:
 - Stick to our principles; ensure CBR and Indigenous ways of knowing and doing are central to work.
 - Realist evaluation works well for bringing in different sources of data.
 - Realist evaluation has pushed us to be innovative and adaptive – “outside the box”.
 - Importance of dialogue –bringing people together with different perspectives
 - Being clear with our language – define our concepts (e.g. “key definitions” document)

5. **Break**

6. **Virtual CAHR discussion – open floor**

Watched the video: “Youth give and take a lot to participate:” making a case for non-participation in HIV CPBR and youth programming (presented at CAHR 2020)

https://www.youtube.com/watch?v=IRk_mZGgdHI&feature=youtu.be

- Tension between youth in terms of the law and the way we consider them in an organization and in society
- Interest in discussing research participation and non-participation further at subsequent CBR Quarterly meetings

7. 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. We would also like to invite teams to use this time to share about their projects in light of COVID-19 – how you are doing, how you have adapted your work, etc.

- SHAPE/RETAIN: Treatment interruptions. Interviewing people with lived experience, health care providers, examining the barriers and facilitators for Indigenous clients in partnership with someone from VCH Aboriginal Health. Looking for a coordinator, preferably Indigenous person – please feel free to pass it on.

- SHAWNA: have been doing COVID related research, asking people about their experience with social isolation, checking in with people. Back to seeing participants week of July 13th.

- SHAPE: Currently working on ethics amendments to restart the study after a pause due to coronavirus. We recently published our first paper that describes the SHAPE cohort (it can be found on the SHAPE website or on BMJ Open) and we also had two posters that were accepted to CAHR 2020: The role of PRAs in health surveys; and Characteristics of individuals with depressive symptoms in the SHAPE cohort.

- Indigenizing Harm Reduction: The ethics application for the virtual interviews with Harm Reduction Community Champions (Phase 1) has been submitted for review, we hope to hear back from the REB shortly. We are in the beginning stages of developing site selection criteria for Phase 2 of the study. We have recently hired a research coordinator and are drafting a job description for a community based research coordinator.

- Thrive: ethics approval to conduct phone interviews was granted and the first interview on the phone was conducted last week. Everything went better than we had anticipated. We are starting a new partnership (a planning award) with a Positive Health Services Clinic in Surrey looking at the home and community care needs of older adults living with HIV in the Fraser Health authority region.

8. Meeting Adjourned