

## Minutes

### CBR in BC Quarterly

September 30, 2020

Time: 1 – 4 PM

Paul Kerber, Darren Lauscher, Daniel Sands, Martin Morberg, Joanna Mendell, Clara Tam, Anna Vorobyova, Jonathan Easey, Megan Deyman, Anita David, Niloufar Aran, Anita David, Claudette Cardinal, Surita Parashar, Rachel Landy, Andrea Mellor, Madeline Gallard, Sylvain Beaudry, Becky Gormley, James Watson, Carrielynn Lund, Brittney Udall

#### 1. Welcome & Check-in

#### 2. Approval of Previous Minutes

*Minutes approved with no changes*

#### 3. Approval of Agenda

*Guest presentations changed order. Sylvain will be presenting instead of Patrice.*

#### 4. Guest Presentations –

- [Me, you and HIV : First Results from The Québec PLHIV Stigma Index](#)

*Presented by Sylvain Beaudry*

- [Walk the Talk: A Support Framework for Working with Peer Researchers](#)

*Presented by James Watson*

#### 5. Break

2:16 – 2:25

#### 6. Guest Presentations

- Presentation from DRUM & SASH team

*Presented by Carrielynn Lund and Rachel Landy*

Please feel free to reach out to Carrielynn: [carriel@caan.ca](mailto:carriel@caan.ca) and Rachel: [rlandy@uvic.ca](mailto:rlandy@uvic.ca)

Check out DRUM & SASH's website: [drumandsash.ca](http://drumandsash.ca) and CAAN's website: [caan.ca](http://caan.ca) (under construction)

## **7. Open floor discussion – Participation and Non-Participation in Community-Based Research – building off of this presentation from CAHR**

- Questions about supports for both PRAs and participants. Is it hard to justify to funders cost for counsellors? Has there been a project that has had a counsellor embedded on the team?
- A lot of the work of supporting participants and doing this emotional labour falls on PRAs.
- It presents a challenging grey area when PRAs fall outside of health insurance for non-profits and aren't covered by research ethics. It is important to make sure that PRAs are taking advantage of what is available to them under extended health coverage.
- Current REB guidelines don't cover a lot of consideration around PRAs for supports – right now it is okay to just say we will refer to counselling but the truth of the matter is that there are lots of barriers in this.
- Is it time to bring people in internationally for these topics? Is there traction around this elsewhere? Discussion around the work of the *Research 101 Manifesto* which engages much of this discussion.

## **8. 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.

- CHIWOS-PAW: Sub-study of CHIWOS – focused on the experiences of Indigenous women living in BC and Indigenous women living with HIV. Invited 6 Indigenous women living with HIV to attend 3 different gatherings – 1<sup>st</sup> just to connect, 2<sup>nd</sup> gathering 4-day retreat style workshop. Activities centred around how Indigenous women living with HIV understand their health through Indigenous Ways of Knowing.

In March, they had planned to come back together to have a closing ceremony and to share back teachings and histories that were shared – this was not able to happen during COVID. Challenge: how can they stay connected with the women from the retreat and moving forward on sharing their teachings and stories?

Heart-to-heart chats – different members of the team meet with women one-on-one to talk about their experience and share some of the findings and finding that the findings resonated with the women and accurately reflected the teachings. These have been going really well –

beautiful and helpful to maintain that connection. They have earmarked their original funding to do a retreat in-person once it is safe together.

New study: BCC3 study – BC CHIWOS and CARMA, merged – CARMA is a cohort of both women living with HIV and women not living with HIV – this merging study will be focused on healthy ageing.

Snack Chat:

Idea borne out of work by Jinny Choi – doing presentations for community – accessible and topics they are interested in. Knowledge translation led by community. Tim is developing a presentation on how to become a peer research associate – and would like a panel of peers to share how they became involved. If you are interested in joining the panel or know someone who would be, please reach out to Tim Wesseling: [twesseling@bccfe.ca](mailto:twesseling@bccfe.ca)

SHAPE:

Finally getting going! Ethics has taken a while. Getting it off the ground with a long pause. One challenge has been getting access to the office for phone interviews. Communication was really important to explain why this is necessary.

SHAWNA:

Still adapting to new limitations with COVID. Challenges with tech e.g. getting people phoning into Zoom. Starting small groups – Peer Advisory Working Groups – talking about things they are seeing in the research e.g. HIV and sex work. All facilitated by peers. Having to work to make sure they are small enough to meet in person. Due to COVID guidelines, they can't have drop-ins which has had really big impacts on research. No longer able to knock on doors to follow up with people or to find them out in community – so unfortunately people with the most barriers to participation are the people they aren't able to connect with.

Thrive:

Thrive is going well! Challenging to carry a lot of the administrative tasks – peers take on a lot for this.

Proceeding interviews by phone – have interviewed 16 folks and more coming. Challenges: one component – second interview going to involve mapping as a methodology – but realized they can't do this on the phone. Maybe a different method – provider interviews? Diaries? If you have worked with travel diaries at all, please reach out to Anna!

Building More Bridges:

Nilou recently became the Coordinator! Led by Val Nicholson and Dr. Denise Jaworsky. Had a retreat in Saskatoon last October. Wonderful and empowering. Challenge: staying connected. Building More Bridges started meeting with community to identify the research question. In the step of taking pieces back to data analysis team to identify questions.

**Making it Work:**

Really excited to be growing our team! Have a strong PRA team now. Success: even with COVID, work has gone on and the team has become even more engaged. We're being careful asking people about what we're asking them to use their time to do.

*The Positive Effect:*

**A Message from the Positive Effect (TPE):**

The Positive Effect is a facts-based, lived experience movement powered by people living with HIV and the people and communities that support them.

It provides a collaborative and creative platform for people's voices, stories and experiences to be heard, to spark dialogue and to meaningfully connect.

As the platform continues to grow and push out important stories about community and resilience, they are looking for your help. If you are able to follow 1 or all 3 of their three social media accounts listed below – they will be sure to follow you back!

Following TPE on social media is a great way to keep up-to-date with new content published to the website, new stories available to read, and keep informed about what conversations and initiatives are taking place across the country.

Visit The Positive Effect online at [www.positiveeffect.org](http://www.positiveeffect.org) or on their [Facebook](#), [Twitter](#) and [Instagram](#) pages. If you have any further questions about how to submit a story or if you are interested in contributing to the blog, email [hello@positiveeffect.org](mailto:hello@positiveeffect.org).

**9. Meeting Adjourned at 4:00 PM**