

Agenda
CBR in BC Quarterly
February 2, 2017
9:30 am - 12:15 pm

Location: McLaren Housing (1249 Howe Street) and via teleconference

In attendance: Mona Lee; Heather Holroyd; Jaydee Cossar; Sandy Lambert; Joanna Mendell; Josie Ross; Candice Norris; Patrick McDougall; Terry Howard; Sarah Kesselring; Sarah Moreheart; Allison Enjetti; Darren Lauscher; Patience Chamboko; Flo Ranville; Saira Mohammed; Heather Picotte; Janice Duddy; James Watson; Antonio Marante; Darcy McFadden; Becky Gormley; Ross Harvey

1. Welcome

2. Approval of Previous Minutes

3. Approval of Agenda

4. Presentations and clarifying questions

Candice Norris, PLDI Impact Evaluation (PAN)

- 11-year history in peer research: First experience was with the MAKa project, which was an early iteration of the SHAWNA project. The MAKa project focused on harm reduction and HCV co-infection with HIV and aimed to understand women's access (and barriers to accessing) ARVs.
- As a peer researcher, Candice gains insights related to academic research and brings lived experience to the work. Peer researchers can open up to participants and encourage them to do the same. We have the ability to think outside the box.
- As a peer researcher, she meets a lot of people who are on the same journey, who can "teach me, guide me, give me direction." It helps enhance her medicine wheel so in turn she can help the community become a healthier place. Being a PRA has increased her confidence and abilities and she brings that confidence to the table.
- Challenges of PRA work: If the research is really heavy – for example, the MAKa project was the first to use rapid HIV testing and women were getting their diagnosis there and we were asking tricky questions. There needs to be support and hope when working with people who are facing difficult experiences in the course of research.
- Personal challenges and growth related to PRA work: Early CBR work was with paper and pens, and now we are using technology, which can be unfamiliar and challenging. Hearing that the PLDI Impact Evaluation was a training program helped calm my nerves. Working in pairs to conduct the qualitative interviews has been really helpful – one peer evaluator is the note taker while the other peer evaluator is entirely focused on the interview.

- *Question about technology:* Are people hesitant about having their information collected using digital tools? No – the socio-economic level of the peers has shifted to a working class background so there is less hesitancy.

Sean Grieve and Jaydee Cossar, BC People Living with HIV Stigma Index Project (PAN):

- Sean sends his regrets.
- To use the word ‘peer’ is slippery, in that we can’t really put our finger on what that means. We can talk about peers as ‘fragile eggs’ which sets up people up for failure. We can also talk about peers as an emancipatory term. By looking at peers as individuals we avoid grouping them together in one basket, which doesn’t serve to build the research team.
- With the Stigma Index project, folks have blossomed into being ‘stigma warriors’ who bring tremendous engagement to the project. It has been very interesting to observe the different experiences in different regions – in the North, the peer-on-peer process has been a powerful experience where the interviews are emancipatory for the peer interviewer and the interviewee, who are sitting side by side and looking at the data interface together while collaboratively inputting information. There was even a case where the peer interviewee took over the notetaking process because they were faster at typing than the interviewer.
- As the Stigma Index reaches its halfway point, the question of what will happen afterward to this great team we have established is beginning to emerge for the peers involved in the project. They are working so closely together now, on the phone, over email, and feeling really connected and are unsure about what will happen for them as individuals after the project ends.
- *Question about challenges of projects ending:* Do you have ideas for the study end life? One possible way forward is to keep people on and involved for as long as possible – bring them onto the Steering Committee after the data collection ends and invite them to become involved in the analysis. And if that isn’t possible, encourage them to keep connections as a network.

Questions:

We ran into the same thing with a 10-year study - how do you close a study that long? We ended up having a closure celebration attached to an Ontario HIV Treatment Network (OHTN) conference and the peer researchers were tasked with taking photos to demonstrate their experiences. We had the large poster of photos framed and sent to the ASOs involved in the project.

Is wrapping up projects covered in university curriculum? No – you usually only get about an hour of training in a methods course about community based research. So it’s important to have groups like this one to discuss these issues. There is, however, a hunger and interest among students related to CBR training.

We had a celebration at the end of a project to mark its end that involved the PRAs, the partners who were involved in the community, and the residents of the centre who were involved in the project. But a focus on the next project is often the best thing, because projects aren’t programs so the focus can be on the next project. One former PRA asked me to come to this meeting today to find about different PRA opportunities.

- **From these questions, some Ideas:** Create a bank of employment opportunities for PRAs or opportunities for involvement on Community Advisory Committees. Project should include some training around identifying transferable skills – “on this project you learned accounts payable, that’s a transferable skill”. Another idea was to establish an alumni program through PLDI and that might encourage employment referrals and increase networking opportunities.

James Watson, What’s Hot with PRAs (OHTN)

- Flashing back to the beginning of his career in HIV research with the Positive Spaces, Healthy Places a housing study in Ontario: James was hired without much knowledge about research and completely unconnected to the HIV community. It was an extraordinary research team and knowing what he knows now, he recognizes it was something quite special – everyone was committed to GIPA/MIPA in every phase of the study, and there were 7 peer researchers. It was well-funded which helped. The value placed on lived experience and community connections altered his life and gave him purpose and he sees everything he’s done since through that first and profound experience. His goal is to pay that experience forward by creating a nurturing environment.
- When he was hired, he had a clash between idealism and the reality of budgets, research goals and competing priorities related to research agendas and so he learned that GIPA/MIPA principles are not always at the forefront of those priorities. So to find his voice as a person with lived experience and without academic background has taken time and it always goes back to GIPA/MIPA.
- In the current men’s health study James is involved with, they have hired 9 peer researchers. As the peer researcher role becomes more professionalized, it is getting harder and harder to bring on peer researchers who, like him when he started, have no experience. But through advocacy he has had the ability to bring people on with limited experience and to work with them to pay forward what he learned at the beginning of his career and it has been amazing.
- How can we encourage GIPA/MIPA in CBR hybrid studies? CBR hybrid studies have more constraints because of budget issues. Consulting with peers through questionnaires and focus groups at the beginning of studies can be ways of ensuring that their lived experience informs the study. When publishing papers or presenting at conferences, make sure that the names of all peer researchers are listed. And embrace any opportunity to provide training that’s not just for a task at hand but training for the future.
- What’s Hot with PRA Forum is a program that was designed not for academics but for the community and to benefit the community so the language is kept casual. The program’s goal is to bring people together to learn about what is going on across the country and to discuss the role of PRAs, even if people are not currently involved in PRA work. Currently looking at moving into a different direction by producing a ‘pozcast’ so the producers will be doing a relaunch with a new link – stay tuned!

Flo Ranville & Patience Chamboko, SHAWNA PRA team

- Lulu and Heidi send their regrets – Heidi is working on quantitative interviews for the project today.
- Patience: Involved with CHIWOS study and is quite involved with the SHAWNA study.

- Three upcoming photovoice projects with women, youth, and trans groups. The project has some new recruitment materials designed by peers.
- Flo has been with the SHAWNA project for two years and was hired after the training from the Dr Peter Centre and Terry Howard. The peer researchers are doing a number of interviews, attending conferences and authoring papers. Flo's position has changed to peer mentor and qualitative interviewer; a large part of her role is working with PRAs and academics to prepare them for working together.
- It is hard to build relationships as a team when you only work four hours/week so the SHAWNA group has been focusing on teambuilding because there are so many project members with so many diverse experiences involved in the work. A big part of this teambuilding has happened around structured check-ins and check-outs using a deck of four cards that correspond to the four elements of the medicine wheel. While these check-ins take time, team members find that these activities reduce misunderstandings and conflicts later, since every team member is aware of what is going on with their fellow team members each time they come together to do the work. This increased awareness reduces the chance that issues will be taken personally, as team members are aware of the different circumstances that people are bringing to a day's work.
- A key takeaway point is that being involved in projects as a PRA is a cyclical process: being in meetings informs how we do our research and it isn't a linear process. Including PRAs in the SHAWNA monthly team meetings has been important. For the first year, the PRAs felt a bit like an entity on the side as they were just there one day per week and weren't familiar with the team. But now, knowing the team, people are coming into the office feeling more connected.

5. Group discussion

- *Question: Any ideas for team building in the face of resource constraints?* The check-in tool has been really helpful – it can be hard to be vulnerable. We have changed up the interview questions to ensure that new team members will treat all members of the team equally regardless of the job title so that people know that peer researchers are just as important as interviewers and outreach workers. And recognizing that it will take time for people to come to staff meetings and feel comfortable, as these can feel like overly professional environments.
- *Question: How does the check-in process work?* The check-in process is a priority. The SHAWNA PRA team goes through all four cards in the morning, every person, to check in. At the end of the day, there's a check-out process to see how things have gone. It's helpful to get to know the team over time and over the day. With a team of five, it can take us 10 minutes or a bit longer but it is a time saver in the long run because it is a way to problem solve before issues become bigger. It helps avoid assumptions – you hear about whether a team member hasn't had coffee and addressing that can avoid misunderstandings around grumpiness, for example! Checking-in helps to ensure the quality of the data is strong too, because it facilitates that human connection. And it makes sense from a dollars and cents perspective. So we need to make sure we build these resources into our budget.
 - Flo agreed to share the cards for checking-in

- This conversation highlights how we all need to check in because we are all doing heavy work – peers AND academics. It is surprising that checking-in isn't a practice built into all of our work.
- The need to check-in is good and comes with its challenges too because we don't always have the training to do this effectively.
- AIDS Resiliency Resource Kits: <http://abrpo.org/> A really good tool that translates well with peer researchers.
- *Question about capacity and skills-building related to research: Do folks have experience or ideas about how to engage with people who don't have much experience with research in the face of tighter budgets – or suggestions for training related to building people's research-related capacities and skills?*
 - Could agencies build this into their budgets and forward money to PAN to do this training? This is how PLDI works, but it is a challenge in times of constricting budgets to find these additional small pockets of money.
 - Is it possible to work with RADIUS SFU or UBC Learning Exchange to find some resources and connections to do this work? At RADIUS, they are doing work with grassroots projects at the DTES.
 - Is there value in forming a connection with UBC Learning Exchange and possibly inviting someone from that staff to this table?
 - It was noted that there's a need for access to universities' library resources – Heather worked on an open access repository project and could connect with a Community Engagement Librarian.
 - Is there a need for needs assessment and bringing a graduate student here to do needs assessment? There is a lot of great expertise in this room so the danger with looking outside and getting people from outside to come in and tell us what the needs are is that we lose the expertise in this room – and to honouring the GIPA/MEPA principles, we should consult with those people in this room who have been doing this work since the beginning like Flo and Candice. Need to build more opportunities for PRAs into budgets so that money is allocated toward this expertise. We can continue to cobble together our 'needs assessment' as we go through these meetings. There are a lot of resources related to CBR practice and how to support with people with lived experience and engaging with allies, and we will keep this as an action point for PAN.
 - The professionalization of peer work is a problem – organizations want to pay them a living wage, support them, and so forth. But one of the tensions that might limit eager people from participating is a nervousness about the impact of this financial compensation on their benefits and fear about possible clawbacks.

6. Break

7. Project updates

- **Joanna Mendell, Cheque Day Study:** Are there groups who would benefit from hearing about the Cheque Day study, and are their service providers who might have information to share about the impacts of changing the cheque day that we should talk to?
 - What is the Cheque Day study? Assistance cheques are delivered to everyone on the same day and there is evidence about the harms associated with this one-day distribution model. Looking at three different options regarding the timing of cheque distribution: on the same day, one day that's a different day per month, or twice per month on days that are different than the typical cheque distribution day.
 - Are you able to access the line-ups at the ministerial office? Huge number of dealers standing next to the line-up ready to take people to the bank.
 - Is there an update on recruitment? 116 people enrolled in the study and the goal is to enrol several hundred more people.
- **Joanna Mendell:** There is a community of practice related to knowledge translation and exchange. Along the lines of that work, there is an upcoming Pecha Kucha event to highlight interesting ways people have engaged community and shared findings with community – for example, a poem people shared about research findings. The event will be on May 9 and the call for proposals will be due March 1. Joanna will forward details about the knowledge translation exchange group and Pecha Kucha event to distribute with the meeting minutes.
- **Sarah Kesselring, SHAPE study:** This is study of 800 people linked with STOP HIV/AIDS program about testing. We have 430 participants enrolled and have been getting a lot of great feedback in the comment boxes. This feedback will inform our follow-up survey.
 - A lesson learned in this study: The study used quotas to get people who are demographically similar to people living with HIV/AIDS in the province. We should have left ourselves a bit of room in each quota because now we are struggling to fill certain boxes where we could have prevented that if we had done some more careful selection earlier. We are having to turn people away because some of our quotas are overfull and it will be difficult for us to maintain these quotas. Interesting to know if the population size estimates are off because there are far more people with HCV interested in participating and that quota has been full for months.
- **Jaydee Cossar, BC Stigma Index update:** We are at the mid-way point of data collection and looking at who is participating in the project and how we can bring in those folks that are a little harder to reach. A lot of our PRAs are at ASOs so we have tapped that population but finding it difficult to connect with men between 20-30, women, and people who aren't accessing ASOs. So we need to start focusing more on migrant workers, refugees, experiences of women aged 20-30. We have two months left of data collection and we built this time to rethinking our recruitment into our planning.
- **Jaydee Cossar, PLDI Program:** Applications for the June 2017 Core Training are up on the PAN website.
- **Janice Duddy, PLDI Impact Evaluation project:** Working with a team of 4 Peer Evaluators to do an impact evaluation. PLDI has been running for 8 years and has had 170 participants. The peer

Evaluators were brought on to do some training around evaluation and they have been leading an online survey, conducting interviews with PLDI grads and community stakeholders, examining historical evaluation data collected after each of the trainings, and co-facilitating a focus group with the PLDI trainers. The peer evaluators have been doing this work at a breakneck speed – hired in July, developing evaluations questions, drawing up a logic model, launching an online survey, developing interview questions, and so on! Survey response rate has been really positive: the survey link made it to about 300 people and there were 80 survey responses as of February 2.

- **Saira Mohammed, Incentive study:** 139 participants enrolled in the second phase and focused on data collection. Assessing a novel strategy for getting people on ARVs and suppressing viral loads. The study has been going on for 5 years and we are hoping to start analysis this year.

Brief Summary: The “Incentives – Phase 2” study, also titled “A randomized clinical trial evaluating the role of contingent reinforcement in the engagement and retention of drug users in HAART programs”, is being led by Drs. Mark Hull and Julio Montaner from the BC Centre of Excellence in HIV/AIDS. The study is funded by a 5-year US National Institute of Drug Abuse (NIDA) grant. Phase 2 will assess a novel strategy, a monetary-based contingency management approach, to engage people living with HIV and using drugs on HIV treatment and achieve long-term sustained virologic suppression. Currently, data collection for follow up visits is underway for all sub-sites across the province. Data entry is ongoing.

Success: Proactive recruitment strategies were effective with ongoing effort to liaise and communicate with collaborators, especially by direct contact.

Challenge: Recruitment was a challenge at sites where site study coordinators were balancing a 1.0 FTE position in addition to their study role.

Lesson Learned: Study staff, if trained effectively and with the available resources, can successfully fulfill their study role, including successful recruitment and retention of participants. It is also important to build capacity as a part of a community-based research model to hire and train Peer Research Assistants/Associates to support research in all stages. In turn, this has the potential to allow community members contribute to the success of the research study in a meaningful way but also to empower and support them for career development and advancement.

- **Heather Picotte, Positive Living, Positive Homes study:** A participatory data analysis session for PLPH will be hosted at the Learning Exchange later this month. So far, the guest list for the data party is by invitation-only due to space constraints and trying to get as many people who have participated in the study as possible into the room, so please RSVP if you have been invited. A second, more broad invitation will be going out in the next few weeks. We also still have a survey open related to the PLPH study.

8. Meeting adjourned