MINUTES -- DRAFT CBR in BC Quarterly May 28, 2014

In attendance: Allison Carter, Andrea Langlois, Janice Duddy, Chuck Osborne, Surita Parashar, Kate Salters, Sandy Lambert, Bronwyn Barrett, Jasmine Gurm, Julia Dahlby, Sarah Kesselring, Patrick McDougall, Valerie Nicholson, Rob L., Darren Lauscher, Joanna Mendell

Video Conferencing: Sherri Pooyak

- 1. Welcome
- 2. Approval of Previous Minutes
- 3. Approval of Agenda add in items under #6 Emerging Issues and #7 Updates
- 4. Update from Honoraria and Compensation Working Group: Andrea Langlois
 - The Honoraria and Compensation Working Group has been working over the last 2.5-3 years to discuss how to best support peer workers within projects especially with regards to compensation and various complications with social assistance. Over the last year, through speaking with various people who engage peer researchers as well as PRAs, the working group has developed a "CBR Tips" sheet to support projects working with peer researchers. This is not meant to be prescriptive, but rather to provide individuals with tips and resources to help figure out what works best for themselves. The tips sheet has gone through several reviews and revisions and is now semi-finalized, Andrea will send out another version next week and feel free to circulate.
 - How should we share this document?
 - Send out to CBR Quarterly group, and people in similar roles across the country
 - Share on CBR list-serves
 - Post on PAN website
 - Present next year at CAHR
 - What are the next steps for the Honoraria and Compensation Working Group?
 - The group agreed to put the Working Group to sleep for the moment and to revive it if another core issue arises.
- 5. **Updated CBR Quarterly Web page and Project Summary Form**: Janice has set up a google forms on PAN CBR website and will move onto a list on website for project updates. ACTION ITEM please complete this form for your project.
- 6. Program and Project Updates:
 - a. CIHR Centre for REACH and the REACH CBR Collaborative Centre— Andrea Langlois
 Through the REACH CBR Collaborative, CBR priority setting activities have been taking place over
 the past year and presented a poster at CAHR. The Centre for REACH was successfully funded for 5
 more years. REACH 2.0 will concentrate on HIV program and implementation science with a
 community focus. Not a lot of work has been done previously as far as integrating program and
 implementation science with community-based research. Program and implementation science is a
 type of research that looks at evaluation of various elements of different programs and

interventions including cost-benefit analysis, what is working, if the program be scaled up or used elsewhere etc.

b. AHA Centre – Sherri Pooyak

- One success: the AHA Centre has had an abstract accepted at the International Network of Indigenous Health Knowledge and Development Conference to present about the Centre- overview of what we are and what we are doing.
- <u>One challenge</u>: applied for one of the REACH grants in hopes to develop a centre for research and development training in HIV research. Received good feedback but was not successful.
- One lesson learned: Have changed the language we use when referring to Peer Research
 Assistants or "PRAs" we now us Community Research Associates.

c. CHIWOS – Allison Carter

- Have applied for funding to expand study to Manitoba and Saskatchewan want to look more into geographic space and access to care and treatment and expand the cohort to 2000 participants.
- One success: our team meetings have been a big success. Hearing from peers regarding successes
 in the field and the connections they are making with study participants highlights that this is not
 just a study but we are also creating change and linking people with services and community.
- One challenge: up to this point we have enrolled over 190 participants in BC and 750 nationally. This is halfway to reaching our goal but some communities are still very underrepresented young women (under 30); trans women; African, Caribbean and Black women; and women who are not accessing care. At this point we are trying to prioritize connecting with women from these cohorts.
- One lesson learned: often PRAs responsibilities focus on data collection and KTE what we've found is involving them in review of data and data quality has been very enlightening and critical to the process. Meetings involve discussing recruitment strategies, and going over data quality reports; engaging PRAs in this process has been very helpful in understanding data and circumstances in peoples' lives.

d. ENGAGE – Sarah Kesselring and Chuck Osborne

- Recruiting people who have started HAART within the last 6 months. Since recruitment started in December 182 have started treatment and 33 people have done survey.
- One success: that 33 people have enrolled given the circumstances.
- <u>One challenge</u>: enrollment is difficult. We are adding the question to our survey "why did you decide to participate?" to help better understand and enhance recruitment.
- One lesson learned: we are talking to clinics and pharmacies to contact about the study to enhance recruitment. An effort is being made to have pharmacists and clinicians do more than just mention study but also talk about and advocate for the study on our behalf.

e. Peer Worker Industry Support Standards – Terry Howard Not present

f. Dr. Peter Centre Evaluation – Patrick McDougall

One success: Rob and Flo and the positive impact of having PRAs at the Dr. Peter Centre. We have set up an "Ask Me Desk" where clients can approach Rob and Flo to ask about the study. This has helped in relationship building. We have had great feedback about Rob and Flo's engagement with participants – people are having their voices heard, are engaging with more services, and are becoming more connected with the community. Relationships are being developed that weren't there before and people are developing a better understanding of research.

- <u>One challenge</u>: trying to keep Rob and Flo engaged and come up with different ways to have them involved in the community.
- <u>One lesson learned</u>: Peer mentor, Terry Howard, has been very helpful for this project for everyone involved.

g. Positive Living, Positive Homes – Andrea

- One success: Last Friday we submitted our ethics application.
- <u>One challenge</u>: Christina Bielek is moving to Mexico and we will be hiring a new research coordinator over the next few months.
- One lesson learned: we will be up in Prince George in June. The response from the community callout to attend a lunch has been motivating. It reinforces how important it is to do CBR with integrity and humility but not rush things and follow the community's pace.

h. "The Way I See It" – Surita Parashar and Val Nicholson

- One success: pretty much come to a close photos are mounted.
- <u>One challenge</u>: we still see people who were engaged some of whom are not doing well, and it is difficult.
- One lesson learned: from the get-go it is smart to set up parameters around time when we were ready to celebrate it was hard to reengage people who had were no longer closely engaged.
 Learning about how to keep people engaged through the end of the project.

McLaren housing study

- <u>One success</u>: we were able to link to *the Access Study* (people living with HIV who have had some experience with drug use) as a comparison group for the McLaren study. We will be using some of their data.
- One challenge: The Howe street building hasn't been ready for the survey because of heat and hot water issues. Study will begin in September.
- <u>One lesson learned:</u> There have been a lot of issues with the building, and tenancy contracts etc. so we will be starting interviews in September.
 - i. Momentum Health Study Have hired a new coordinator, Ashley Rich. Gay men's health project recruiting positive and negative guys looking at treatment as prevention and treatment optimism in the Greater Vancouver Area.
 - j. Moving Mountains Jamie Reschny and Andrea Langlois a partnership with PAN and UNBC. A CBR conference will be hosted in Prince George June 17-19. Will be doing capacity building and priority setting.
- One success: the Prince George program is setting up well key note from Carrielynn Lund, workshops on developing partnerships, and an arts-based research methods presentation are all part of the program.
- One challenge: mining conference is happening at the same time.
- One lesson learned: hoping to help support CBR outside of Vancouver.

k. Mothering Study: - Valerie Nicholson

- The study in Ontario looked at struggles and what mothers go through while having children, issues with disclosure, and the stigma experienced. Focus groups were done in BC and now we are trying to tie together the data from both provinces.
- September 8th grand rounds at St. Paul's and Oak Tree Clinic will be presenting information from Ontario and some from BC and will be answering questions.

- Still working on getting it out here – tying together with Ontario data, and figuring out lessons learned.

I. CANOC Centre (The Canadian Observational Cohort Collaboration):

- New centre funded to support the CANOC cohort study. Pan-provincial (BC, Ontario and Quebec): group of investigators and community advisory to look at experiences and outcomes of treatment and co-morbidities. Hoping to bring in Saskatchewan.

m. Building Bridges - Valerie Nicholson

- Have done sharing circles. Decided Mark (PI) would be present in healing circles so that he could answer questions directly. We will meet again and end with a feast.

7. Share about CAHR

- Allison Carter won the new investigator award!
- Interesting presentation from Fife House on research and evaluation of transitional housing for immigrants living in HIV care ACTION ITEM: Patrick will connect with presenter and find more details regarding not having a safe space for refugees free from re-traumatization and exposure to triggers. A gap exists between shelters and transition housing. Also something created around PRA legislation ACTION ITEM Jasmine will send info and share tip sheet as well.
- Many discussions around criminalization and disclosure.
- Launch of the national consensus statement around HIV research with women, transwomen, and girls, good document for having a gendered lens when doing research.
- Dr. Richard parker the necessary fictions we use: e.g. "Moving towards zero" and "AIDS free generation" catch phrases that people throw around that he sees these as necessary fictions to keep us going forward and staying engaged.
- New investigators workshop very valuable Surita and Terry presented 85% of people attended were interested in CBR!