

Minutes
CBR in BC Quarterly

Tuesday, September 20, 2016 from 9:30 am to 12:00 pm

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

In attendance: Janice Duddy, Heather Picotte, Jaydee Cossar, Mona Lee, Patrick McDougall, Chavisa Horemans, David Boyack, Sarah Kesselring, Darren Lauscher, Terry Howard, Chuck Osborne, Sean Grieve, Jennifer Matthews, Joanna Mendell, Allison Laing, Sarah Moreheart

1. Welcome
2. Approval of Previous Minutes
3. Approval of Agenda
4. Panel and Group Discussion: **Development and maintenance of connections between research and community-based organizations (CBOs)**
 - FYI, this topic is relevant at a larger level, as it was reflected in and shared by national scope of researchers during CAHR strategic planning. More training on how to build communications and relationships with community ranked high in priority.
 - **Heather Picotte**, *CBR Positive Living Positive Homes Project Manager, PAN*
 - **Introduction:** PLPH is a CBR study, co-led by PAN and University of Victoria, investigating the relationship between housing and health at 3 sites in BC: Prince George, Kamloops, and Greater Vancouver. HIV and Housing was discussed as a priority advocacy issue at PAN Conference about 7-8 years ago, which led to the birth of this study.
 - **Relationship with CBOs:** Given that PAN members are organizations and there were pre-established relationships, the study had an advantage of being connected to many CBOs from the beginning.
 - **Challenges and Tips:** Despite the pre-existing relationships, there were challenges. CBOs do find the research pertinent but they are faced with limitations in terms of time for assisting with recruitment and getting involved in addition to their primary work. In order to mitigate this in some ways and to ensure both parties were aware of what to expect, PAN outlined compensation for and roles expected from the CBOs we primarily work with using Memorandums of Understanding (MOUs). PAN also provided the site coordinators with technologies and tools (e.g. laptop and phone) so that the study does not infringe on the CBOs' capacity or resources beyond the private physical space site coordinators used at CBOs for confidentiality.

- **Kamloops as a special site example:** The site coordinator works out of ASK Wellness. PAN and ASK Wellness have a good relationship, and they do a lot of work in housing (e.g. HIV-dedicated housing). However, PLPH faced some challenges with recruitment in Kamloops. ASK Wellness used to be HIV-dedicated, but their mandate expanded to a broader at-risk population. This meant that ASK Wellness staff couldn't breach confidentiality to identify who is HIV positive, an eligibility criterion to participate in PLPH (in comparison, recruitment has been easier in Prince George, where the site coordinator works out of HIV-specific CBO – Positive Living North). Thus site coordinator did a lot of relationship building (more in relation to other two sites) and raising the profile of PLPH (including media interviews). PLPH also submitted an ethics application to Northern Health and Interior Health to expand recruitment sites (e.g. specialist's offices). What we learned is that the nature of the organization plays a role in recruitment. Additionally, despite the benefit of having guidance of experienced staff at CBOs, research fatigue contributes to recruitment challenges (which is the case in Kamloops). Another challenge was stigma – disclosing status in a community suffering from high levels of stigma is difficult.
 - **Tips continued:** To allow potential participants to get in touch with the site coordinators, PAN created business cards for site coordinators for distribution; site coordinators left phone number at CBOs, asked CBO staff to hang study posters around the office, and hung out at CBOs to get faces known to the community.
- **Chavisa Horemans, Research Coordinator of the Prevention and Vulnerable Populations (PVP) Core, CIHR CTN (Canadian HIV Trials Network)**
- **Introduction:** The process of developing a community engagement resource (a document) has been a hard journey, more than anticipated. The resource provides guidance on how to effectively engage communities and the targeted users are clinical scientists. In revising the resource to include more community input, a community advisory committee was formed and consulted. The pertinent pieces of a very broad, Canadian-bodied conversation with the advisory committee is now embedded in the document/resource, and the goal is to present this at the November CTN meeting and release the resource to a broader audience in the new year.
 - **Contents of the community engagement resource:** Topics of this resource include: What is community engagement; why engage community members in clinical studies; when, how, and where to engage community members; and practical tips (e.g. meaningful engagement rather than tokenism, supporting engaged community members, etc.). There is also a whole section on engaging Indigenous communities. The resource not only questions who is community, but also discusses practical aspects such as compensation (a whole section on this). As a result of this engaged process, the resource is becoming a set of rich and dense documents.
 - **Lesson learned:** Don't make the assumption that people are up-to-date on policies (e.g. working with Indigenous populations). Change the language from being prescriptive to being more embodied guidelines. Earlier the community

engagement, the better. There is plenty of room for challenges to arise, and good intentions can be insufficient.

- **Goal for future:** To document the process of engaging the community, which has been much more extensive than expected (publication idea is on hold, but it will live as an internal CTN document). It will serve as a cross-core resource for Prevention and Vulnerable Populations team at CTN (there are 4 cores, 3 of which are hard science and 1 is social science) and address lack of information and awareness. Uptake of this resource by science cores is expected to be high, and its projected implementation as a broader umbrella framework will bring more cohesion and promote learning.
- **Other notes:** CIHR is doing similar work, offering help on how to more effectively work with and engage communities (not HIV-specific). This integrative work also resonates at the national level, with increasing uptake by various institutions. However, we need to think about how to address the structural barriers at institutions that hinder engagement of and relationship building with communities.

- **Jaydee Cossar**, *PLDI & Stigma Index Project Manager, PAN*

- **Introduction:** The BC People Living with HIV Stigma Index (or commonly known as the Stigma Index) was born out of a community-identified need like PLPH, and it is a first-ever CBR study in BC to document experiences of stigma and discrimination from the perspective of people living with HIV. Right from the core, it is community-based and community-engaging – designed and led by, and for people living with HIV. The project is about to launch its second phase, data collection.
- **Relationships with communities:** Being in a dual role of also managing PLDI (a professional development training for poz folks), we have the advantage of having pre-established relationships with various CBOs and ASOs (AIDS Service Organizations). In vetting the instrument and ensuring that the contents are specific to Canada and the tool is applicable to various populations, engaged youth-focused CBO (YouthCO) and Indigenous CBO (Canadian Aboriginal AIDS Network). Also, developing a broadest and most representational research team involving all regions of BC is important for this project. However, it is important to understand that sites outside of Lower Mainland need support and the team needs to think about how to maintain relationships with various communities.
- **Tips:** Communicate as much as possible. Ask (before we even start the research/project) the community, whether they feel supported and what they need to feel supported.
- **Discussion from the table: Tips and skills on relationship maintenance?**
 - Account for relationship building and maintaining in the budget, right from the planning stage. Simultaneously, communicate to funders and raise awareness around why this is important to funders.
 - A key learning from food security study: how to give the data back to the community and assisting the community in thinking about how to utilize the findings is an important community-engagement piece during the knowledge translation phase.

- Challenge: keeping stakeholders/community engaged and giving back in a timely manner (community may find the CBR process painfully slow).
 - Despite the long process, more effective in creating change when research teams take time to analyze the data, collate the community-relevant pieces, and put the findings into community-accessible language so it can be presented and shared for policy change and other proposals.
 - Academics have lots of skills and talents complementary to research in creating intermediary resources that community may find valuable (e.g. literature review) – think about give backs in planning and implementation phases, and not just at the end.
 - Transformation has to be bidirectional: Academics challenge themselves and the larger research community around structural components (e.g. funding, team structure), and as well, question what data is meaningful, and to whom. At the same time, communities challenge themselves in questioning what it is they want and need from the academic and/or research community (what is valuable to them).
 - Communication discord may happen when there is change in the person the community communicates with (e.g. bringing in the same research coordinator, who you've built relationship with during data collection phase, to communicate the findings might be a good idea, instead of the community having the research findings communicated through principal investigators)
- **Patrick McDougall**, *Knowledge Translation and Evaluation Coordinator, Dr. Peter AIDS Foundation*
 - **Theme:** How do we become ambassadors to those who are not yet aware or involved in the research processes and approaches that we believe in and work with?
 - **Tip 1:** Ongoing dialogue and communication are important, and we need to recognize that every situation is unique in the face of limited time, money and energy (think about how we can best facilitate some of those limited resources)
 - **Tip 2:** "Q&A Day"
 - Have someone from the research team come to the CBO to talk about what's involved in the research and to answer any questions potential participants may have is very helpful (CBO staff often is flooded with inquiries when research posters go up). Some folks may need some help translating the contents of the recruitment material, and best yet, showing in person also helps building relationship, which is beneficial to recruitment.
 - **Tip 3:** Build compensation for CBO staff into the budget even in small amounts, if funding allows. If funding is limited, taking steps to show appreciation (e.g. thank you cards) is important.

5. Theme ideas for future CBR in BC Quarterly Meetings

- PRAs would be happy to come and speak in this space (e.g. PRA team at AESHA and SHAWNA)
- Living up to MIPA/GIPA principles in CBR
 - o Thinking beyond data collection – e.g. PAN is training the first cadre of peer evaluators – and engaging peers from planning stage to KT stage.
- Expanding career opportunities beyond research for peers
 - o Current gap: need more career choices beyond PRA or mentor. In order to facilitate confidence- and resume-building and translating of the PRA skills to other employment opportunities (formal or informal), need to brainstorm what kind of skills training the sector can provide (e.g. computer-related, budgeting, and soft skills).
 - o How can we be most efficient with our resources? E.g. resource pooling, like sharing the training cost (one option “Digital Badging” an organization in DTES)
 - o Need to be cognizant of systems and structures in place and constraints and barriers they can pose (e.g. disability)
 - City of Vancouver is currently working to change the policy to remove penalization of someone moving from informal to formal economy

6. Program Updates

- **TASA “Cheque Day” Study** (in-meeting notes, supplemented with what was shared via email by Joanna Mendell)
 - o **Summary:** In BC, and similarly in most places in North America, social assistance is paid once a month to all recipients on the same day, here it is usually the last Wednesday of the month. While income assistance is crucial to help lessen the health and social harms of poverty, synchronized payments can have unintended negative impacts, particularly among people who use drugs. This is widely acknowledged in the community in the Downtown Eastside and research evidence continues to build from not only Vancouver, but BC wide, and in places across North America. The TASA study was born out of this community-identified issue, to examine whether changing when and how often recipients receive their social assistance can reduce drug-related harm around cheque day.
 - o **Eligibility criteria:** used illicit drug in past 6 months (occasional users not included), living in Lower Mainland and receiving some assistance from the provincial government. Study has been ongoing for 6 months, with the participant number goal of 400 (at 82 currently). **Methodology:** Randomized Controlled Trial – controlled group continues with current schedule; test group receives staggered payments. Bimonthly follow-up on: service use (including emergency room visits); substance use; treatment adherence (methadone, HAART), etc. Recruitment ongoing, with simultaneous KT. **Participant Honoraria:** baseline \$30 and follow-up at least \$10, with bonus available (accumulating follow-ups which can be done over the phone; but baseline needs to be done in person).

- **Success:** Operations have been going very well through a busy start to recruitment and data collection, a success with thanks to study partners including community members, service providers, and policy makers for all their hard work in developing the study. In particular, our partner Pigeon Park Savings, a community branch of VanCity Savings and Credit Union that is operated by the PHS Community Services Society and is managing the alternative social assistance payment schedules.
- **Challenge:** One of the most important things we have learned so far is that the intervention works well for some, but not well for others. We have been interviewing participants about their experiences with the intervention and it has been very helpful to hear about how alternate schedules are working for some people across a range of personal and financial management strategies.
- **Lesson learned:** In response to what participants are sharing about their experiences with the alternative schedules, we have implemented additional strategies to support people's ongoing participation in the intervention. We are also building in a 90-day adjustment period into the study design. For more information about the TASA study please don't hesitate to contact Joanna Mendell, jmendell@cfenet.ubc.ca
- **National Stigma Project**
 - REACH is launching \$500,000 in Spring – calls for proposals on anti-stigma initiatives, with maximum of \$100,000 available per community group.
- **Food as Harm reduction**
 - Finished data collection (both quantitative and qualitative – interviews and mapping)
 - Challenge: database creation (excel)
- **Shared Measures for CBOs Addressing HIV & Hep C**
 - PAN worked with PHSA on developing a common set of indicators for CBOs addressing HIV and Hep C around the provinces, partially in hopes of demonstrating to government bodies, a collective impact of CBOs on taking the provincial strategy *From Hope to Health* to address HIV and Hep C. Update from Health Authorities has been great. Check it out here!
<http://pacificaidnetwork.org/resources/evaluation/shared-measures-for-community-organizations-addressing-hiv-hepatitis-c/>
- **Incentives Study – Phase 2** (shared via email by Saira Mohammed)
 - **Summary:** Total study enrolment= 131. Recruitment/enrolment is ongoing across all provincial sites (Vancouver, Surrey, Victoria, Prince George, and Interior Health region). Study recruitment cards were recently ethics approved for distribution to health care professionals and community staff to provide information on the study for recruitment.
 - **Success:** Creased outreach efforts within the community of each study location have helped to improve study awareness and enrolment.
 - **Challenge:** Calculation of study visit dates were difficult at times to calculate for study coordinators (clinical research associates) and errors were often made to determine visit dates.

- **Lesson Learned:** A new standard operating procedure (SOP) was developed to calculate study visit dates including the window period for scheduling allowance will prevent any possibility of such an error to occur.

7. Next Meeting

- In the New Year, perhaps January. Look for an email from PAN!