

**Draft Minutes**  
**CBR in BC Quarterly**  
**June 8, 2017**  
**9:30 am - 12:00 pm**

**Attendees:** Mona Lee, Heather Holroyd, Heather Picotte, Jaydee Cossar, Darcie Bennett, Darren Lauscher, Sandy Lambert, Heather Picotte, Allison Enjetti, Katrina Koehn, Rebecca Gormley, Sarah Kesselring, Ama Kyeremeh, Patrick McDougall, Chuck Osborne, Nathan Lachowsky, David Boyack, Ross Harvey, Saira Mohammed

**Location:** McLaren Housing (1249 Howe Street)

**Teleconference call-in details:**

Toll Free Dial-in Number: (+1) 888 884 4539

Guest Code: 1061180 #

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**1. Welcome**

**2. Previous minutes approved**

**3. Agenda approved**

**4. Aging and HIV**

- a. *Report back from the PLHIV (PHA) Forum at the PAN Fall Conference:*** Pacific AIDS Network (PAN) organizes an annual Forum for persons living with HIV/AIDS at its fall conference. The Forum is an opportunity for the HIV positive community to identify and reach a group consensus on priority advocacy issues for PAN to champion over the next year. For example, the PLHIV Forum identified stigma related to HIV as a priority: since then, the BC People Living with HIV Stigma Index was brought to BC. Similarly, Positive Living Positive Homes came from the Forum's identification of housing as a critical and priority issue. The 2016 Forum identified the following priorities: HIV and aging; long-term survivors and aging; peer based advocacy; and promotion of harm reduction.
- b. *Group discussion around HIV and aging:*** Learning and planning around this priority item – has your study explored or gathered data around HIV and aging (if so, please share)? Have you found any research or knowledge gaps around HIV and aging?
- Patrick McDougall and Darren Lauscher: A small grant (funded through ViiV) received at the beginning of the year to do a feasibility study for people living with HIV, who are over the age of 50, gay or other men who have sex with men, and coping with social isolation. The study was motivated by service providers recognizing the social isolation experienced by folks who have been living with HIV for a long time on a fixed income.
    - o Challenging to recruit folks who are socially isolated. Major strategy used to recruit was word of mouth. Learned the importance of showcasing the benefits of being involved in the study. Another challenge is that this project is temporary – even though participants understand this, the temporary nature of engagement can be difficult. Need to acknowledge the historical piece as a challenge too – folks who have been living with HIV for a long time engaged extensively at the beginning of the epidemic but may no longer be engaged and it is difficult to bring them back in.
    - o There is a 'perfect storm' brewing, where people 50+ are doing well right now re: the cascade of care, but with funding changes to ASOs and issues related to aging

(entering long-term care, mobility, increased costs of living on fixed incomes...), there needs to be planning now.

- Gaps in research include data about long-term care and personal care, and explorations around hiring bonded caregivers to help with financial assistance.
- Allison Enjetti: Environmental Scan on Aging and Home Care. Developing a community-based organization (CBO) survey and holding a stakeholder meeting to assess the gaps in home and community care for people living with HIV. Included in this environmental scan are: mapping the resources in the community for aging folks living with HIV; mobility issues; and older adult-specific resources (e.g. senior centres, peer-facilitated training programs like those at the UBC Learning Exchange). A challenge or gap is the lack of support/involvement from policy makers. The team hopes to have a draft by the summer for the environmental scan and CBO online survey. The findings will be shared with the larger community.
- CHIWOS (Canadian HIV Women's Sexual and Reproductive Health Cohort Study) has many participants who are aging and will be able to present women-specific data related to aging, including menopause. Currently, the study is conducting the third wave of 36 month follow-ups and cleaning up the data from wave 2. The hope is to do some longitudinal analyses. A challenge is the attrition rate between the waves – first interviews, 18 month follow-ups, and 36 month follow-ups... people change their phone numbers, move, and many have unfortunately passed away from the opioid crisis.
- PLPH (Positive Living Positive Homes) is a CBR on HIV and housing. Housing is a big issue in general but the study also found that it is particularly an issue for positive folks who are older (50-55+). Their income may decrease, they may be leaving provincial disability assistance (Persons with Disabilities; PWD), or they may be losing their partner's income. Without making a generalization, the Greater Vancouver participants of PLPH tend to live in more stable housing and have a better access to social services compared to participants in Prince George or Kamloops. These folks are able to think about long-term planning including housing; but many folks in Prince George or Kamloops did not have the capacity to plan long-term. We need to do public education around this – people don't know what to plan for – hugely concerning and is a big gap.
- Other research gaps related to HIV and aging
  - o Suicide and mental health (related to social isolation)
  - o Role of Technology – this can be challenge for the aging population (e.g. navigating the complex applications and systems for various supports relating to finance, health, housing, etc.). Need more consistent support in the community, including case management.
  - o Substance use – this is a spectrum and includes many things (not just “illicit” substance), including alcohol. Also related to social isolation.
    - Harm reduction support was touched on PLHIV Forum at PAN
  - o Common terminology: What does “long term” mean? What is it that people are suffering from? How far does the isolation go (isolation in community vs. in building vs. in neighbourhood)?
  - o How many seniors' centres have Gay Straight Alliances or are otherwise open and safe spaces?
  - o Dr Alexandra King's study is also looking at some elements related to aging
- PAN will stay connected to bring this piece back to the PAN Fall Conference and specifically the PLHIV Forum.

## 5. CAHR: Thinking Back to Montreal, and Looking Ahead to CAHR 2018 in Vancouver

- a. **Key learnings from CAHR 2017 in Montreal:** For those who attended, please share. Were there issues and topics that came up and may have relevance for the Vancouver meeting?

- Many presentations are moving away from traditional research methods and towards CBR methods (e.g. Indigenous, arts-based, community-engagement methods).
- Academics presented in a manner that was community-friendly and in a language that was easier to understand.
- Important to make space at the table for emerging groups who need to be heard, so that they can be heard in a way that is respectful and inclusive.
- Would have appreciated more organized opportunities for community folks and peer-based groups to get together and discuss issues specifically relevant to their interests.

b. **Group discussion about CAHR 2018 in Vancouver:** What do projects and organizations want to see at CAHR in Vancouver? Does the CBR or CBO community want to form a working group to organize an ancillary event?

- In 2013, a tour of CBOs took place on a Friday evening when CAHR AGM was happening (many folks were free).
- Thinking about who are we missing at our table – connect with organizers/community liaison of CAHR (Terry Howard?).
- Need to make a stronger connection back to the community (i.e. relaying the work, research findings and discussions back to the community). How is this research benefiting you, your organization and your community? Need to better communicate and showcase the benefits.
  - o BC is a champion in the community- and peer-based work. How can we share this with the national group?
  - o Is there a way to show successful examples of how research has benefited programs, communities, individuals, etc?
  - o Need to make sure this is a bidirectional sharing – both the researchers and communities need to be at the table.
  - o Include funders in this conversation.
  - o “Testimonial” idea – folks from various groups come forward and speak about how the research or program has impacted them/their organization.
- Pair up peers and form mentorships (new peers with “old” peers).
- **Working group:** Heather Holroyd, Heather Picotte, Mona Lee, Ama Kyeremeh, David Boyack and Darren Lauscher will put something together and share it back with the group. The working group will also loop in Patrick McDougall and Nathan Lachowsky for various pieces.

## 6. Break

## 7. Project Updates

### Positive Living Positive Homes (Heather Picotte & Mona Lee)

- **Summary:** CBR taking place in Greater Vancouver, Kamloops and Prince George using a qualitative, longitudinal, case study methodology. Aim to investigate the relationship between HIV and housing, as well as successes and challenges in services and policies related to HIV and housing. Currently at the end of data collection for Greater Vancouver and Prince George (Kamloops will be finished later in the summer). Data analyses are ongoing and entering Knowledge Translation and Exchange (KTE) phase.
- **Success:** Data parties in Greater Vancouver in February 2017 and in Prince George in May 2017. Great turn out and community engagement, including from participants who are living with HIV. Data parties are great ways to continue community engagement and this marked a solid start to the KTE.
- **Challenge:** Kamloops is going at a different pace (due to recruitment challenges, medical leave of the coordinator, etc.). Also, keeping communities engaged as we move through the knowledge to action

is challenging due to budgetary restraints (i.e. having more dollars for travel, etc. would allow more frequent visits to communities). Social media is great but it is tricky to balance the sharing of findings with communities and providing enough support with it (i.e. don't want to just dump the information).

- **Lesson learned:** To strategize early on around how to better engage policy makers.
- **Idea pitched by Allison Enjetti:** Create a body that liaises between communities, researchers, and policy makers. This body can look at what has been done in research in the past 5 years and collate important findings and action items for programs and policies (evidence-based practice and policy). A way to better collaborate our efforts for a bigger collective impact and this will also ensure CBOs are innovative in their programming. This body can act as a central place for KTE materials to go to for implementation and policy change. [Community Campus Partnership for Health](#) in the States can be a model to explore.

### **Project Inclusion** (Darcie Bennett)

- **Summary:** Pivot Legal Society is a human rights org. in DTES born out of public health emergency but services and mandate are not tied to geographical region (i.e. DTES). Pivot's theory of change has been that the law, once change, should apply to everyone and thus there should a trickle-down effect leading to greater justice even for cases outside of Vancouver; however, an investigation of municipal bylaws has revealed that this trick-down effect isn't happening as anticipated. Thus, Pivot is leading a project funded by PHSA on the intersections and impacts of bylaws of 60 municipalities on folks who are demographically similar (i.e. experiencing deep poverty, criminalization, housing insecurity, homelessness, drug use, etc.). The project wants to make the connection on deep poverty, drug use and criminalization across BC.
- **Success:** Enthusiasm from so many people to share their experiences and stories. Recognized the regional differences – e.g. folks in Vancouver are more aware of their rights around street checks – and so the interviews are taking longer than anticipated because they are including significant educational components around participants' rights. The project team is also strategizing around how and where to make immediate impacts in addition to the long-term goals and changes (i.e. bylaw changes).
- **Challenge:** Pivot has been working in DTES for quite some time and has built relationships in the community and has familiarized itself with services and resources in the area. Going into new communities and organizations to build relationships and navigating an unfamiliar space (e.g. finding a private space for interviews; figuring out organizational flow around when are people accessing services; not knowing the street names, and where the community services and resources are located; etc.) were much more time- and money-consuming to overcome or address than expected. The overdose crisis is an immediate threat and is an important area of focus, but this also means it can be difficult to look beyond and consider "less threatening" areas.
- **Lesson Learned:** Invest the time to build relationships and find ways to work with someone (doesn't have to be a huge thing; can be as simple as finding a resource/fact sheet for someone), especially in new communities. The project team has been bringing maps of the new communities they visit to their interviews as they are less familiar with resources and services in the area; having the maps handy makes it possible for participants to show red zones and provide a sense of the spatial dimension of their experiences.
- **Strategies:** Trying to divide what's legally actionable vs. others; making connections with other service providers (e.g. doctors) so that they can improve their services to better support folks; challenging the current system and leveraging with collective cases; identifying champions (business owners, families, etc.)

### **Oral History of HIV Project (Nathan Lachowski)**

- **Summary:** A project funded by CIHR HIV/AIDS CBR Catalyst Grant to document the history of HIV with an intergenerational sharing piece. The team is comprised of half academic and half community researchers. Community consultation (invited broadly) took place in May and had a great turnout (50 people). Important to create an archive of stories given the stories are time sensitive (we are losing folks for various reasons – passing away due to health issues, suicide, etc.). Some money allocated for arts-based community report-backs to create a space for people to hear the stories. Hope to have this fuel the momentum of the ongoing HIV movement for the community.
- **Success:** Active engagement in talking about various periods of HIV epidemic in Vancouver.
- **Challenge:** Navigating bureaucratic (cash honoraria (need for a SIN) vs. gift cards; university and CIHR policies). Understanding how institutions committed to community-based actually embody the CBR principles in their policies and practices.
- **Lesson Learned:** The project team put off submitting the ethics application to the research ethics board in order to gather feedback from the community consultation first, but now realize that is going to hold up the process; in hindsight, it would have been better to submit the application followed by an amendment.

### **BC People Living with HIV Stigma Index (Jaydee Cossar & Heather Picotte)**

- **Summary:** A CBR study documenting experiences of stigma and discrimination from the perspective of people living with HIV in BC. The 6 peer research associates successfully finished data collection in 5 communities. Heather Picotte has come on board to take over the data analysis and KTE for the BC Stigma Index, as Jaydee Cossar has transitioned full-time into the PLDI manager role. Data analysis will start in July. Project hopes to keep a strong and unique BC voice while aligning the BC study with the national study.
- **Success:** 6 PRAs – superstars who worked through data collection very quickly and successfully. Interview goal was met and the stories were documented from diverse communities across BC. The steering committee who took the time to develop the index tool (or data collection instrument), as well as thinking through the hiring of PRAs, greatly contributed to the success in grounding the study early on. Jaydee Cossar's dual role as both the Stigma Index manager and PLDI manager also opened up doors to PLDI grads across various communities in BC through pre-established connections.
- **Challenge:** Uncertainties in certain partner agencies at the launch of data collection (some turbulence related to funding, etc.). Data collection happened very fast (a positive) but also a challenge as now there needs to be a catch up (so much data came in).
- **Lesson Learned:** A slower process that allows more one-on-one working with each PRA would have been helpful to strengthen the capacity and leadership skills. Also, test the study instrument live (i.e. with real people) as much as possible before data collection.

### **Positive Leadership Development Institute (PLDI) Impact Evaluation (Heather Holroyd)**

- **Summary:** PLDI is a leadership program by and for people living with HIV. Came to BC in 2009 in partnership with Ontario AIDS Network (OAN). Currently, there are 3 core modules with an additional one being piloted. Every training has been evaluated but no comprehensive evaluation of the whole program and its impact. To answer, how is the program contributing to peer leadership in BC? – an impact evaluation project was initiated. Following the philosophy of PLDI program, a steering committee came together to guide this evaluation with the peers at the forefront. Four Peer Evaluators were hired and 81 online survey responses were collected, as well as 28 qualitative interviews, a focus group, and the analysis of 14 sets of historical evaluation data from surveys conducted after each training. Data collection and analysis has wrapped. Peers devised a communications plan – first report back to PLDI grads and participants of the evaluation. Then Knowledge-to-Action briefs will be available for the larger community (by September/October).

- **Success:** In addition to gathering much-needed data about PLDI's impacts, this evaluation project provided practical and on-the-job training for a group of peers. A [Peer Evaluator Training Manual](#) (that will help guide any organization to develop their own team of peer evaluators and initiate an evaluation project) is available on PAN and REACH websites.
- **Challenge:** Tricky timelines – as PRA contracts were ending, PHAC report deadline was coming up.
- **Lesson learned:** No budget for transcriber – but got around this by having one peer conducting interviews and one peer taking notes. Also, got around the trickiness of training peer evaluators on data analysis on a short time period by facilitating data synthesis events (asking peers to highlight key messages from data).

#### REACH (David Boyack)

- **Update:** The CBR Collaborative Centre just received another 5 years grant from CIHR (HIV research grants).

#### CHIWOS (Becky Gormley)

- **Summary:** Canadian HIV Women's Sexual and Reproductive Health Cohort Study is a longitudinal national study focusing on sexual and reproductive health and mental health of women living with HIV.
- **Success:** Began recruitment in 2014, and at 36<sup>th</sup> month follow-up visits now. In BC, 6 PRAs throughout the province to administer the survey.
- **Challenge:** Anticipated challenge of retaining the participants and supporting PRAs – dealing with funding cuts. Particularly the closing of PWN has impacted the study (PWN provided a safe and comfortable space for women and facilitated the process of staying connected with the study). Other challenges include passing of participants, especially in relation to the overdose crisis.
- **Lesson learned:** Take a step back from research roles and connect with and support each other on this process of grief (passing away, closing of ASOs).

#### SHAWNA (Sarah Moreheart – shared via email)

- **Summary:** Sexual Health and HIV/AIDS: Women's Longitudinal Needs Assessment is a five-year, CIHR-funded research project focusing on the social, policy, legal, gender, and geographic gaps in women's sexual health and HIV care across Metro Vancouver. Since our last meeting our PRA team have assisted us in our on-going recruitment to our SHAWNA study. We have almost reached our goal of 350 enrolled! Our PRAs and other SHAWNA student and staff presented at CAHR. We were pleased to bring our entire PRA team to CAHR where they presented on a variety of topics including using arts-based methods to explore gender, stigma, disclosure and the impact of Criminalization of HIV on WLWH. impact of the non-disclosure laws on women. Our PRA Lulu Gurney was awarded one of 5 peer scholarships to go to CAHR! We were really happy to be there and support our fellow researchers and investigators from BC (great work, Jaydee!). We are currently employing our PRA-team to do qualitative work on the impact of incarceration on WLWH.
- **Success:** Doing our start-of-shift check-ins have been working well. This has helped us manage the stresses that can impact our ability to be fully present for work. It also brought to our team's attention that we should consider employing a code word when in community to address safety concerns.
- **Challenge:** Currently we are reflecting on our next steps with our PRA team as we are beginning to transition from recruitment for the SHAWNA study into retainment of our participants.
- **Lesson Learned:** I would have introduced the idea of transitioning of our activities as the needs of the project change earlier to anticipate any stress this may have on the PRA team.

## 8. Other

- Our sector has a great pool of peer volunteers/workers. We should make sure to not lose the capacity to utilize this resource and maximize the utilization of this capacity we're building. Darren attended the [C2U Expo in Vancouver](#) and recognizes there is a desire to do this but we need to brainstorm on how to do this well. We have great academics we work with and we need to loop them in better with this pool of resources.
  - o How can ASOs best support the PLDI grads when they go back to their communities?
  - o UBC is hosting a series of dinner dialogues with community partner organizations as they prepare their next strategic planning – providing input at these tables might be a way of facilitating this connection with universities.
- In their new building (move happening July 2017), Positive Living BC will have women-only lounge. PLBC is aware of the closing of PWN and is trying to fill in some of the gaps for women-specific services.
- Been hearing that some PLHIV have not been treated equitably at the decision-making tables.
  - o We need to continue struggle together and support each other in this journey to promote equity in this area.
  - o What can this group do to survey/address the sense that agencies aren't treating people people with HIV equitably? – possibly a discussion topic for future meetings
- CHIWOS practicum student plans to do a mapping of the distribution of funding and how that translates to services on the ground. This can be a good vehicle to provide information to policy makers/funders around the impacts of changes in funding and services. Connect with Ama Kyeremeh ([akyereme@sfu.ca](mailto:akyereme@sfu.ca)) if you have more info/questions.

## 9. Meeting Adjourned