Ancillary Event:
The BC Community-Based Research Quarterly Meeting at CAHR 2018
April 26, 2018
8:30am – 12:00pm
Seymour Room, Westin Bayshore Vancouver

Attendees: Darren Lauscher, Janice Duddy, Mona Lee, Janet Madsen, Dan Wilson, Tabitha Steager, Sherri Pooyak, Antonio Marante, Flo Ranville, Charlotte Guerlotté, Cheryl Prescott, Ron Larsen, Desire Tibashuboka, Zoran Barazanci, Barb Borden, Kate Shannon, Caroline Ploem, Ben Klassen, Jackie Haywood, Carly Welham, Jaydee Cossar

1. **Welcome, Territory Acknowledgement, and Introductions**
- PAN (Pacific AIDS Network) introduced the event as a mock meeting of the "Community-Based Research (CBR) in BC Quarterly Meetings," a community of practice that meets 3 times a year. PAN acts as a convener and facilitator of the group.
- An elder Old Hands acknowledged that we gather on the territory of Coast Salish peoples, as well as sharing laughter, a song, and encouragement to keep up the fight and take care of each other.
- Participants introduced themselves to a partner and shared their answers to our opening questions: If you could become an expert in something instantly, what would it be? Why is a community approach to research important?

2. **Background on the BC CBR Quarterly Meetings**
- Janice Duddy and Darren Lauscher from PAN developed [a background document](#) that outlines the history, impacts and timeline of the BC CBR Quarterly Meetings since its inception in 2010.
- The Canadian Institutes of Health Research (CIHR) started a CBR stream of funding in 2003, and since then there has been more demand for community members to join research projects as collaborators and knowledge users. Recognizing a need for more thoughtful consideration of how community members were being engaged in meaningful ways in research, we convened a table in to support each other in CBR projects across the province.
- The first CBR Quarterly Meeting for groups to share their work and learn about new opportunities was held in 2010. A major feature of these meetings was seeing everyone at the table as an equal, as recognizing that everyone brings varied knowledge and experiences helps everyone collaborate effectively. Early on, the group recognized the importance of having people living with HIV (PLHIV) at the table, and including the Peer Research Associates (PRAs) on projects in the meeting.
- While meeting format evolved over the years and each meeting explored various topics (e.g. capacity building, discussion of emerging issues, report backs, etc.), program/project updates continue to be a central part of these meetings. As the group explored how to honour each project at the table and the people involved, they shifted from sharing entire program reports to focusing on key learnings and best practices.

This gave opportunities to learn from each other and spread best practices within and beyond the meeting table to help shape other projects.

- High level impacts of the meeting which were highlighted include:
    - Peer mentorship for PRAs helped new peer researchers gain opportunities and enhance skills, as well as helping to overcome silos in peer work.
    - A greater awareness of the breadth and depth of CBR in BC.
    - Recognizing emerging issues together as a community of practice.
    - The interdisciplinary nature of the meeting led to great networking opportunities for new researchers.
    - Sharing resources and ideas.
    - Providing/expanding access to and building relationships with academics provided opportunities to ask questions, network for new researchers, and identify gaps in research.
    - Capacity building and professional development meetings invited presenters to speak to a number of topics. For example, as a number of CBR projects around the table moved into the analysis phase, brought a presenter to talk about participatory analysis. The group is responsive to whatever issues meeting participants bring up.
    - The ability to openly discuss challenges of CBR, and receive support, tools, and solutions from others. This meeting has been a venue for brainstorming and collaborative problem-solving, allowing meeting participants to address difficult situations that can arise in CBR. For example, compensation for peer workers was raised as an issue, and a working group was formed from this meeting. The working group explored how different projects compensate peers, and created a "Compensating Peer Researchers Tip Sheet." This resource was distributed both within and outside of this network.
- Question from participant: How do you manage the work in between the quarterly meetings?
  PAN shared that they provide the backbone support to the group (e.g. meeting organization, communication, facilitation, agenda preparation, notetaking). Working groups that form out of CBR Quarterly Meetings based on special topics (e.g. peer compensation, CAHR ancillary event) determine their own work and schedules.

3. **Demonstrating the Value and Success of Peer Work in Research, Evaluation, and Knowledge Translation with a focus on impacts**

   A. SHAWNA: Flo, Barb, and Desire
- Peer research associates (PRAs) from the SHAWNA study shared their data findings and the process through which they have engaged PRAs over the last three years.
- This five year, longitudinal CBR project launched in April 2015. The goal of project is to interview 500 women living in or accessing care in Metro Vancouver to examine how women navigate HIV care and housing. So far, they have 326 participants.

- Three PRAs were involved in recruitment for the project, as well as participating in team building and training on facilitation skills. They did outreach to over 300 organizations, and developed elevator speeches about the project.
- They also have a Positive Women's Advisory Board where twelve women meet quarterly. All research findings are brought to Positive Women's Advisory Board, who are very involved. The research team also brings any questions related to analysis and ideas for the future to them. It's been a venue for learning as well, such as giving a PowerPoint presentation about going to CAHR and what CAHR is. It was important to give the group time to develop into a space of friendships and meaningful experiences for people.
- PRAs shared their experiences of feeling cared for and supported by other staff on the project. If they needed time off for health reasons, they felt they were welcomed back with open arms. A PRA who was on the Positive Women's Advisory Board and became a quantitative researcher shared her experience and the value that working with a courageous group of resilient women had brought to her life.
- A peer mentor on the project shares knowledge and experiences with PRAs and plays an important role in knowledge translation.
- They have found that it's important to provide training on all aspects of the research process. For example, having conversation about what an abstract is or what it means to have your name on a paper as a co-author to ensure that everyone understands exactly what is going on.
- For SHAWNA team members, the CBR Quarterly Meetings have been an important place to connect with others doing similar work, and feeling that "You mean we're not the only one?"
- SHAWNA team uses the medicine wheel to share values and successes, and overall encourages teamwork, empowerment, and personal goal-setting. The team checks in regularly about how everyone is doing spiritually, socially, emotionally, physically, and mentally.
- Question: How do you assist in "Indigenizing" research articles as an author, and what kinds of things do you look for when doing that? A PRA shared that they have assisted in studies by being aware of language that is more relevant for Indigenous communities and suggesting adding visuals, such as of Indigenous women, an eagle feather, and a medicine wheel. As a visual learner, they shared that they help to code posters through Indigenous lens by using images so other Indigenous folks will want to come read it.

B. Oral History Project: Ben and Jackie
- The Oral History Project involves collecting the stories and experiences of long-term survivors of the HIV/AIDS epidemic in Vancouver and their caregivers, mainly focusing on the first decade of the epidemic before medication advances. As this group ages, it's essential to collect and preserve these stories for the community.
- The team has emphasized CBR principles since the beginning of the project. They began by reaching out to a peer mentor who assisted in building a research team, which balanced academic and peer voices.

- Experiences from all areas of life are brought to the table, whether experiences in the bar, protesting on the street, or working.
- They found that the war against HIV has bonded the queer community, and they have been uniting some shared experiences.
- PRAs on the team have found it meaningful to continue engaging in the battle against HIV after having been involved in the community for many decades. They recognize that the work is both emotionally difficult and rewarding at the same time, and shared that sitting in the room with people's stories, passion, and truth was such a touching experience. Those with personal connections were not always prepared for the emotional impact of interviewing, as they may have known a person or event someone was discussing. They shared that it was a privilege to be a peer interviewer, hear the pain and creativity in the words of community members, and honour those stories for others.
- Question: Is this history available online for the public?
  The Oral History Project team wants to create an archive, which could potentially be shared online.

4. **Exploring how CBR Findings are Put into Action and Influence Programming: Tabitha, Mona, Dan, Antonio,**
- PAN is not a front-line organization. It provides a network for almost 50 member organizations that they support through leadership training, capacity building, advocacy, evaluation, and community based research.
- Whatever data is gathered in evaluation or research, PAN strives to use those findings and put them into action. Today they'll share two studies they're doing and how the findings are being utilized.
- First is the Positive Living Positive Homes (PLPH) study, which spoke to 99 PLHIV and 42 service providers and policymakers through in-depth qualitative interviews across 3 sites in BC (Kamloops, Prince George and Greater Vancouver). Currently in final stages of analysis and sharing findings as much as possible on an ongoing basis. PLPH team started to share preliminary findings even before data collection was over. They did this through data parties, which allows stakeholders to come together and make sense of the data in a participatory way. Data parties included PLHIV, service providers, policy makers and other key partners/stakeholders, who provided guidance on which findings are important to them and what data to dive deeper into. This also allowed them to start thinking about resources and tools to share from the study. Visiting the study sites/communities in person during data parties reinvigorated the community's interest in the study and issue. More recently, the study team also has been sharing findings through community meetings/presentations by going back to partner agencies from which study recruited participants.
  - What came out of the PLPH sharing?
  - Increasing awareness and understanding of housing issues for people with HIV. 85% of community meeting participants said that the data sharing events were useful in increasing their awareness of housing and health experiences of PLHIV.

- o PLPH study findings provide evidence to advocacy efforts. Partners used PLPH data in letters to city councils and policymakers to advocate for more funding on HIV-specific housing, and to advocate against passing a bylaw that could result in a wave of evictions, particularly putting those who use drugs at risk of homelessness. The PLPH findings demonstrate that pets are crucial to people's health, and supported greater advocacy to abolish the no-pet policy common in many buildings.
  - o PLPH findings will mobilize action (e.g. creating a working group on HIV and housing with community-based organization partners).
  - o PLPH findings are being translated into creating useful resources. For example, an online HIV housing toolkit is being developed (which includes a tenant guide and a self-assessment tool for PLHIV to determine housing that's most appropriate for them).
- Second project is BC People Living with HIV Stigma Index. It is based on an international tool, the BC team is the first in Canada to implement this tool. The BC model has been revised to reflect the local context and populations, and is being used as a model for other Canadian adaptations (Manitoba, Ontario). The project is not only sharing the data gathered from the survey tool, but also the process of the work (e.g. learnings from PRA perspectives, and the limits/strengths of using a tool like this). Findings: stigma is still a big deal, and in fact, it's coming back in big way because many people feel HIV isn't an issue anymore, so they are less informed about it. Stigma is being experienced in health care, as well as socially (still struggling with what people faced 30 years ago, even with great strides in medical management). The project team started to share preliminary findings through a webinar, at Positive Living BC, with a CAHR poster, PAN Conference, and board of directors at AIDS Vancouver Island. The narratives include what types of stigma, and how people overcome it. The project team will also present to health care workers, online. One project PRA shared their involvement in the project has been useful for health education and they used these learnings in personal life (e.g. how they interact with doctors, friends, community organizations). This is a quantitative tool and the data so far have created a number of qualitative questions for the team and communities (e.g. WHY did 55% of people say they are not sexually active – was it internalized stigma? medical reasons?) A lesson learned was to keep detailed records of WHY project decided to ask certain questions, and phrased them in particular ways; WHAT is the intent behind asking this? Because 3 years and 3 research coordinators later, it'll be hard to remember.

5. **Group Discussion on Presentations (agenda 3 &4):**
- Does the BC Stigma Index project address criminalization of HIV? In a different CBR project, they have noticed a lot of people were hesitant to discuss sexual activity due to risk of criminalization associated with non-disclosure of their HIV status.
- It emerged that when studies move into various phases of the research (e.g. analysis), it's useful to talk to others at the CBR Quarterly Meeting for tips/guidance.
- Question for BC Stigma Index: Comparisons across different regions of BC? Yes, there are some differences between regions, e.g. there are many more people in urban areas.

Recruitment (particularly in smaller communities) is a common challenge at the CBR Quarterly table. Often, CBR projects recruit at community-based organizations (CBOs) /partner agencies, which gives a specific subset of PLHIV. It is an ongoing homework for all to strategize around how to recruit folks who do not access CBOs – they may have different experiences than those who do. Also, negative experiences of stigma, particularly in health care, were higher in the Interior of BC than in Metro Vancouver.

- Question: What is the best way to move findings into action? Ability to dialogue with health care providers and share findings with students before they start working in the field (changing attitudes before they get into the field). Doing community sharing events. Sharing back through diverse mechanisms within your organization (advisory board) and with all research participants (or as many as possible). Data parties are fantastic for this – as preliminary findings are shared (i.e. the study is not done), higher chance of still being in contact with a lot of participants. PLPH and BC Stigma Index teams noticed that only a few actual research participants came to the knowledge translation events at partner CBOs; however, many other clients/members as well as service providers and other people in the sector also came. So the event was still perceived useful by the attendees as they got to hear the peers' stories. You're preaching to the choir, but it affirms that people are not alone in their challenges.
- Health Mentors is a program out of Patient and Community Partners in Education – embedding patient voices into education curricula. You get students for 4 months across 9 streams of health sciences who you educate. Using current data as case studies for students really helps people understand the full context.
- Events like this contribute to the feedback loop that brings research back to people (communities with lived experience in partnership with academic). CBR is not a linear model of A - B - C - D of traditional research; it provides many opportunities to share knowledge in different and fluid ways.
- One PRA shared an experience of educating nurses during a time of hospitalization as an Indigenous woman in health care setting.
- Moving advocacy to policy level – engaging decision makers and potential partners in other sectors like lawyers in assisting our education efforts.

6. **Break and Networking**

7. **Project Updates:**

   A. AHA Centre
- Collaborative Centre founded in 2012 to unite Indigenous Health and HIV Research Communities, partner to REACH.
- Success: Had applied for a CBR Collaborative Centre grant in 2012, and were refunded last year for another 5 years. National organization. In the past, they focused a lot on building networks, and now shifting focus to Indigenous ways of knowing and doing. Not just the knowledge, but the whole process of getting there. Helping Indigenous and non-Indigenous people understand that perspective or connect them to people who can lend

a different lens to their work. One new thing they're looking at is land-based work – connecting PLHIV to land and culture for healing.

- Lessons learned: They heard from first evaluation that they weren't branded well enough. People knew the researchers and individuals, but not really the work they did as a centre. Their new grant included funding for a communications person, which made a big difference in outreach and public awareness.
- AHA Centre does not do research themselves, but they support, connect academics and communities, and help to facilitate research relationships. The Canadian Aboriginal AIDS Network (CAAN) does research – they're national, but don't have as many connections in some areas, so use events like CAHR as a tool for relationship building.
- Support and mentorship are other big areas of focus – mentoring students on different PhD projects, and helping to create roles for people to move up. Play a big role as connector, getting people the relationships and resources needed.
- They also received a grant for the Weaving Our Wisdom Together study. Planned a grant to develop land-based methodologies to explore health and long-term HIV experiences, particularly for people who are not engaged with other HIV research, people in rural or northern areas.
- Question: Does the AHA Centre help non-Indigenous researchers navigate doing research in a good way? Yes, through capacity bridging (assumes each party brings different capacities to the table). What are the barriers for non-Indigenous people wanting to do land-based research? It's cultural appropriation if you're not partnering with Indigenous people. Have to be allied with people doing the work.

B. Dr. Peter Centre (DPC)

- In an integrated, multidisciplinary model, the DPC provides three programs: a day health program, a 24-Hour licensed nursing care residence, and an enhanced supportive housing program. Last year, we expanded to offer an Evening Program as well, after both peer researchers and staff revealed that there was an emerging at-risk group of people over 50 living with HIV. We held a 13-week pilot program of an Evening Program for people over 50 who identify as gay or MSM, and are also experiencing social isolation and food insecurity.
- The Dr. Peter Centre Evening Program runs each Wednesday for two hours. This pilot evening program sought to explore the impacts of aging with HIV and social isolation among the target population through an integrated program with four main components: individual and group counselling; art, music, and recreation therapy; a nutritious communal dinner; and opportunities for peer support and socializing. We found that the integration of these services made the DPC Evening Program a unique program, which was engaging for this hard-to-reach population and allowed DPC to address the various physical, mental and social aspects of aging with HIV in one program.
- Success: PRAs led the program throughout the process, including defining the issue, designing the program, recruiting participants, and evaluating the feasibility of a DPC Evening Program. Peers recognized that there was a group of men over 50 living with

HIV in Vancouver's West End whose needs were not being met by other programs in the area. They recognized that this group has been somewhat neglected in this Treatment as Prevention era because they have demonstrated more stable adherence rates in the past, but now are an emerging at-risk group as they are coping with the additional challenges of aging, co-occurring mental and physical health problems, and rising costs while on a fixed income. They also really understood the social context of this group being hesitant to re-engage with community organizations. They recognized that a barrier to engagement is how many in this group have felt cast aside by HIV/AIDS organizations that they had at one time been foundational to building, or that they had turned their backs on them once they were no longer the face of the epidemic – a deep understanding of how to build that trust. Peers also lead the evaluation process. They quickly realized that our intended approach of doing questionnaires was not appropriate for this group. They helped to foster feelings of trust and safety which were instrumental in talking about topics such as stigma and social isolation and evaluating how to program address them. We gained richer data due to their understanding of context.

- Challenge: Recruitment was very slow and took significantly longer than anticipated/accounted for – it's hard to reach out to socially isolated folks. Difficult for folks who lost their partners to re-engage with the community and leave their doors. There is a lot of stigma related to isolation. We had to look beyond traditional marketing techniques and focused on word-of-mouth recruitment. Also recognizing that the issues we were trying to address carry a lot of stigma – as a PRA said, "nobody wants to admit they're isolated and don't have enough to eat." This could also be a barrier to referring people to the program who you think might benefit from it. We found it was easier to promote the program and activities offered, rather than the issue we were trying to address.

- Lesson Learned: Regaining trust and taking time to make people feel comfortable is key. Peer leadership was critical. There is a value in offering different pieces of services and supports in one place, for example, counselling, food, social support, art and music therapy. The program created feelings of community and family for participants.

8. **Group Discussion**
- What came up for you during presentations today?
- Would you find this type of meeting useful for your work?
- How could you implement a similar community of practice in your region?

  Comments and questions included:
- Folks on the West Coast know how to make CBR fun! Data parties is a great tip. Very interesting to hear about the work going on.
- Question: Participation in CBR Meetings – do you have people representing national groups at the table? A couple (e.g. CAAN representative).

- Question: Preparing for and attending these quarterly meetings – is this asking too much from people? It's up to each project to decide who is best to come, who won't get burnt out. A lot of people also come based on their project needs. Attendance is not mandatory but we find that people keep coming for the benefits they get (e.g. collaborative problem solving, help with recruitment, networking, professional development).

9. **Closing**
- Each participant closed by sharing a word to summarize how they're feeling, which included: connected, inspired, rejuvenated, blessed, empowered, invigorated, eager, excited and impressed, impressed, well-informed, privileged and blessed to be among group, enthusiastic and motivated, pumped, privileged envious and thankful, inspired, "the most fun I'm going to have at CAHR", motivated-full-of-hope, enriched and excited, inspired to go do research, and continuity.