

DRAFT Minutes
CBR in BC Quarterly
June 11, 2015
9:00 am – 11:30 am

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

Attendees: Janice Duddy, Andrea Langlois, Mona Lee, Sarah Kesslering, Dan Wilson, Saira Mohammed, Christiana Miewald, Grace Dalgarno, Michael Varma, Sean Grieve, Megan Woodward, Norman Rossetti, Jaydee Cossar, Heather Picotte, Saranee Fernando, Terry Howard, Chuck Osborne, Heidi Safford, Surita Parashar, Darren Lauscher, Patrick McDougall, Allison Carter, Sandy Lambert, Joanna Mendell, Chrissy Taylor, Micaela Bajard, Cheryl Dowden, Jody Jollimore, Gina McGowan, Chavisa Horemans

Agenda:

1. **Welcome**
2. **Approval of Previous Minutes:** Approved
3. **Approval of Agenda** – add in items under #5 Emerging Issues and #6 Updates
4. **Conference Season Run Down** – CAHR, Canadian Evaluation Society (CES), etc... there have been a number of big conferences this spring, if so inclined share one key learning from a conference you attended
 - A small envelope containing a visual guide on how to take part in CBR if you are a person who uses drugs (includes key definitions, list of rights, how to participate in research, etc.)
 - o **See email attachment**
 - CAHR supports CBR – Fill out the evaluation form for the conference if you have attended and haven't completed it yet
 - Post cards can be a vehicle to advertise studies to be launched
 - Canada's strict legal position on disclosure and how it leads to criminalization
 - Program Science vs. Implementation Science
 - o Evaluators as scientists –Is there a responsibility to be an advocate? (being an advocate vs. neutral and objective scientist)
 - Self-assessment tool developed to check your own stigmatizing thoughts as a service provider
5. **Emerging issues discussion:** What are common/cross-cutting Issues that would benefit from a discussion at the CBR Quarterly table?
 - Criminalization and HIV disclosure – and how it relates to research

- Maintain participant anonymity to researcher's best ability
- Ask ourselves "Why are we asking this question?" – Not collecting more personal information than what's needed for the purpose of the research
- SHAWNA – questions related to HIV are on a separate questionnaire from questions related to sexual behaviours and drug use (adding a protective layer)
- Editing the content to the right reading level (e.g. grade 9) for best utility and accessibility
 - Suggested contacting CATIE or Francisco Ibanez-Carrasco at the OHTN for suggestions of editors
 - For one of the STOP initiative projects (provincial) – what demographics characteristics are associated with moving down the cascade of care
- Evaluating participant experience in a study
 - What are the long-term and short-term **benefits** for research participants of participating in a survey or research? What's the process like after the participant leaves the room (e.g. effects on mental health)? Is this something that we can evaluate?
 - Ask the participants before leaving the room – how it was for them and how they're feeling
 - Might be something worth exploring with the CBR Process Evaluation Working Group

6. Program and Project Updates:

a. CIHR REACH CBR Collaborative Centre and REACH 2.0 – Janice Duddy & Andrea Langlois

Summary: National research centre funded by CIHR, meant to bring together decision makers, policy makers, people with lived experience, community, academics, etc. REACH is focused on program science and participatory evaluation and the CBR Collaborative is focused on increasing CBR capacity.

Success: Janice is now available to support evaluation – contact her if you have any questions regarding how to do an evaluation

Challenge: Need more capacity building. Definitions around program science can be tricky – need to put the language and methods around it. Can learn more at:

<http://www.reachprogramscience.ca/>

Lesson Learned: keep people in the loop and inform people on a continuous basis

b. Aboriginal HIV & AIDS Community-Based Research Collaborative Centre (AHA Centre), Wise Practices and other events – Sandy Lambert

Summary: Aboriginal HIV & AIDS Community-Based Research Collaborative Centre (AHA Centre) is holding Wise Practices (July 17 – 18) conference on

Aboriginal HIV/AIDS CBR. For more information, visit <http://pacificaidsnetwork.org/cbr-musings/aha-centres-wise-practices-gathering-july-17-18-vancouver/> There will be an additional joint session (AHA Centre and REACH) on the morning on Sunday, July 19th exploring Aboriginal and non-Aboriginal partnerships in research. Register here: <http://pacificaidsnetwork.org/cbr-musings/july-19-working-together-a-dialogue-for-aboriginal-and-non-aboriginal-research-partners/>

c. **CHIWOS** – Allison Carter

Summary: National longitudinal CBR study, driven by and for HIV-positive women

Success: Data collection is pretty much done – have engaged 1,430 women nationally

Challenge: Engaging woman from particular demographic groups, i.e. transgendered women and women from the ACB community. Also women who were first interviewed 18 months ago are due for their follow-up interview so we are prepping our PRAs for this.

Lesson Learned: it always takes longer than you think.

d. **ENGAGE** – Sarah Kesselring and Chuck Osborne

Summary: Explore people's decisions and attitudes toward starting HAART by looking at persons who started HIV medication within last 1 year

Success: Both were able to attend CAHR conference

Challenge: Recruitment due to a particular eligibility criteria

Lesson Learned: A successful study requires a collaboration and cooperation between large numbers of people

e. **Dr. Peter Centre Evaluation** – Patrick McDougall, Norman Rossetti, Dan Wilson, Michael Varma, and Saranee Fernando

Summary: Mixed method evaluation on Dr. Peter Centre model consisting of virtual, qualitative, and quantitative methodologies. Currently base-line and qualitative portions of the study are closed.

Success: Working collaboratively with good communication

Challenge: Getting things organized (e.g. a hold on ethics has delayed sending out follow-up letters)

Lesson Learned: Predict potential problems and challenges and proactively prepare and come up with strategies

f. **Food as harm reduction strategy** – Christiana Miewald, Sean Grieve, Megan Woodward, and Grace Dalgarno

Summary: Mixed-method study exploring the health effects of food provision for people who use drugs. The study aims to map people's daily pathways to explore spaces of care vs. spaces of exclusion.

Success: Great hiring process, and enormous learning from Terry Howard

Challenge: Survey revision was long, but the final product is worth the process. This challenge is also a success.

Lesson Learned: Took longer than what was anticipated in the proposal, but going slow is not necessarily bad. Just need to put it into the planning process.

g. **Positive Living, Positive Homes** – Heather Picotte and Mona Lee

Summary: A CBR study exploring the relationship between housing and HIV through in-depth qualitative interviews with people living with HIV, service providers, and policy makers.

Success: Data collection is starting next week

Challenge: Kamloops (last to come on board) is facing some challenges in getting people on the advisory board. But this challenge has a potential to be a success as the team recognizes that relationship-building is important.

Lesson Learned: Having many pairs of eyes looking at various materials and being patient (even if it means a slower process) lead to great and better end results.

h. **“At Home at Howe” McLaren housing study** - Heidi Safford

Summary: Exploring how supportive housing affects the health of people living with HIV/AIDS. Interviews are nearly finished. Currently moving onto the next phase – tweaking the survey for people who have moved out of the building

Success: High participation rate – 93 out of 150 residents enrolled, and 86 completed the interview. Great support by the community, great experience and relationship-building.

Challenge: Interviews took place in the building of participants' residence – safety and comfort level were problematic at times (e.g. voices traveling). Brought in a waterfall to buffer the sound.

Lesson Learned: Don't book interviews during cheque week (high rate of no shows).

i. **BC Stigma Index Project** – Jaydee Cossar

Summary: Research survey study previously conducted in more than 50 different countries. BC is the launching point in Canada to explore and reduce stigmatization around HIV and AIDS.

Success: Research team built with people living with HIV/AIDS around the province who can provide rich wealth of knowledge. Decision-making process is also reflective of CBR principles.

Challenge: Difficult for team composition to reflect the diversity of larger HIV community which covers a large geography (currently looking for people in the interior). Also challenging to remain adaptable to youth or people who do not work 9-5.

Lesson Learned: Timing – need to keep patient.

j. Food Security – Nourishing Communities Dissemination – Joanna Mendell

Summary: Dissemination of results and knowledge translation for CBR in British Columbia, Ontario, and Quebec that examined food security and other determinants of health in people living with HIV.

Success: Received grants to do knowledge translation and dissemination work and processes are happening. Presented two posters at CAHR conference based – one on scientific findings and one on the experience of people living with HIV/AIDS. Fact sheets and post cards to be distributed soon.

Challenge: Takes longer than expected.

Lesson Learned: Need to be patient.

k. Updates on multiple studies and projects – Terry Howard

PRA+ Project: Peer mentor program is for peer research associates (PRAs) to further job skills and for PRAs to take steps above and beyond regular duties/tasks. A pilot training program was recently funded (April to April) to train PRAs to become mentors

PRA Dialogue: Will be taking place in Halifax on June 23 and 24. Partnership with CBR Collaborative and REACH to have an open dialogue around confidentiality of PRA in Atlantic regions (will report back at next CBR Quarterly)

PRA Support Workshop: Will be held at Positive Women's Network on Tuesday, June 30 from 1pm to 4pm on boundary issues and self-care in PRA work

CAHR: Terry is on board of directors as a secretary to provide mentorship to the community representative group

Positive Living Relevancy Study: Province-wide survey of membership and relevancy of programs/services for Positive Living BC (do they need to adapt or tweak services to better meet the needs of the population?)

Momentum (gay health study): Exploring harm-reduction and drug use in organized group sex events amongst men who have sex with men

Sero-discordance Study: National study capturing the experiences of sero-discordant couples (what it's like, harm-reduction practices, stigma, etc.). Currently, data collection tool is being developed

Senior Voices: A digital story telling project focusing on the lived experiences of seniors living with HIV (seniors will visit Loon Lake for a training) being led by Suzann at Positive Living BC

Peer Navigator Program at Vancouver Island People with AIDS Society: Will contact Janice for process and program evaluation

l. **Moving Mountains** –Andrea Langlois

Summary: Conference was held a year ago on CBR and HIV research priorities in Northern BC. Based on this, trying to initiate a study on HIV, substance use, and sex work (in relation to access to health care services). Currently developing a research question and looking for funding. Potential collaboration with industry on the table for partnership and funding, and may take a Program Science approach

Success: A good group of people with passion and experiences

Challenge: Grant writing

Lesson Learned: Other parts of Canada are interested in study and have similar issues and there are different geographical challenges.

m. **SHAWNA Project** – Chrissy Taylor

Summary: Sexual Health & HIV/AIDS: Women's Longitudinal Needs Assessment (SHAWNA) aims to examine unique barriers to women living with HIV within metro Vancouver (inclusive of transwomen and sex workers). Positive women's advisory group is involved and recruitment has begun. Eligibility criteria was adjusted from women who live in metro Vancouver to women who access services in metro Vancouver.

Success: Peer Research Associates (PRAs) are instrumental in getting new people engaged in the study (PRAs also hold info sessions and reach out to communities)

Challenge: Some challenging questions are asked when out in the community. Also currently going through a large staff transition – trying to retain the knowledge of staff who are leaving. Looking for clinical research associates (need to be nurses)

Lesson Learned: To create a Frequently Asked Questions guide for the research team

n. **Incentive Project** – Saira Mohammed

Summary: 5-year, multi-site randomized control trial to assess the effectiveness of the use of financial incentives to recruit and retain people living with HIV, who have used injection drugs in the past 3 months and are either not adherent to HAART or not on HAART (with unsuppressed viral load).

Success: Oak tree became an additional site, which increased enrolment. Planning on engaging a new site through Interior Health

Challenge: No study coordinator in Surrey (a call out) – deadline next week

Lesson Learned: Recruitment areas that were successful in other studies were helpful in making connections and networking

○ **See email attachment**

o. **CANOC** – Micaela Bajard

Summary: Speaker series and networking session on Saturday, July 18 from 3pm to 6pm “Challenges and Opportunities in Rural HIV Health.” For more information, visit <http://www.eventbrite.ca/e/challenges-and-opportunities-in-rural-hiv-health-tickets-16227748633>

- **See email attachment**

p. **Shambala** – Cheryl Dowden

- Study to look at harm-reduction services at the Shambala music festivals
- 182 people used ANKOR’s harm-reduction services
- Can be access through www.ankorsvolunteer.com
- Success: many people were willing to participate (not many turned down). Water and flashlights as “thank you.” Assumptions were challenged which led to improvements in the future
- Problem:
- Lesson Learned: doing data collection out in the field can be challenging. Had 4 researchers, who needed breaks. Could have used more researchers

q. **Heads Up** - Patrick McDougall

Summary: Received a Catalyst Grant to explore the lived experiences in HIV-related neurocognitive disorders based on 3 sites (2 hospitals in Toronto and Dr. Peter Centre in Vancouver)

Success: Reduction of potential identifiers in data through swapping data between Toronto and Vancouver for analysis (Peer Research Associates – PRAs – in Toronto will analyze Vancouver data and vice versa). PRAs capacity building through Skype data coding session

Challenge: Thinking larger than what the grant allows

Lesson Learned: Great learning on how to do CBR

7. **Other Agenda Items** – Everyone

Resources:

- 1) “Choose your own adventure” for Peer Researchers at The Learning Place <http://www.hivlearningplace.ca/modules/peer-researchers/>
- 2) “What’s Hot with PRAs!” Online talk show hosted by The Learning Place (the next show “Climbing the PRA ladder: how to begin, survive and advance” is on July 8th at 11am Vancouver time) <http://www.hivlearningplace.ca/talk-show/>

- 3) Resources for Peer Researchers
<http://pacificaidnetwork.org/resources/cbr/cbr-toolkitresources/peer-researchers/>
- 4) Participatory data analysis – DEPICT model (article attached to the email)

8. Next Meeting