

Draft Minutes
CBR in BC Quarterly
May 1, 2012

Location: Tom Cox Room (2nd Floor) in the BC Centre for Disease Control, 655 12th Ave W. (at Ash), Vancouver, BC.

Dial-in: **1-888-626-7441**, pass code **34596265#**.

Confirmed Participants: **Terry Howard, Allison Carter, Darren Lauscher, Evin Jones, Andrea Langlois, Heather Peters, Cathy Worthington, Janice Duddy, Sara O'Shaughnessy, Marcie Summers, Patrick McDougall**

Regrets: Ross Harvey, Angela Kaida, Brian Chittock, Sarah Chown, Robert Hogg, Sean Rourke, Jean Bacon, Val Nicholson, Elisabeth Marks

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Agenda:

1. Approval of Previous Minutes – Sara O'Shaughnessy
2. Current Project Updates
 - a. PLPH – Evin Jones and Cathy Worthington
 - i. Face-to-face meeting in January, Blueprint Meeting at the same time. Very positive meeting to develop research question and capacity building. Two meetings since then to take feedback and move it forward to develop the proposal. Research team meeting in mid-May to present Operational Grant Proposal, get community members to help with the texture of grant. Andrea will be taking over the project when Sara goes on Maternity Leave. Goal to have solid draft by end of May. Also moving forward with some work around housing study which isn't specific to Operational Grant, but will move the project forward. Possibly getting someone to start working over the summer on policy pieces, come up with solid tangibles that we can use to move the issue forward regardless of whether we get the grant
 - b. Food Security – Evin Jones:
 - i. Food Security has 270 questionnaires completed. Target for BC cohort has changed over time. Originally 800, then down to 500, now we aren't likely to get 500. What gets done by the end of the month is what will get done. Recruitment continuing. Healing our Spirit conference this month, PRAs will be doing surveys there, likely to get more surveys done with Aboriginal people. Energy with this study has waxed and waned a bit, but for national picture, there is a solid body of data, especially Ontario which did over a 1000 surveys, we are meeting to talk about what each province

would like to see come out of the data and what are some of the bigger questions about food security that we would like to see looked at. We are continuing to hope that food security data will help inform PLPH proposal. Val Nicholson went to CAHR, a real force there. Also looking at coming to some consensus around authorship guidelines, looking at where data is housed, knowledge translation especially which requires some

c. CHIWOS – Allison Carter

- i. It now has been one full year since CHIWOS started. Last week a meeting with research coordinators and PIs, conversation around where we are at and what have to do. Great process to reflect on what we've done and will do. Huge grant, four PIs, many co-investigators, different engagement across three province, budget cut by 20%. We've been dealing with the challenge of really knowing what 'women's specific services' means. Hiring three coordinators, developing logo, launch, developing vision & mission and mandate, provincial site initiation. 3-4 focus groups in formative phase were completed in all provinces (12-13 in total). Powerful themes emerging around what women's centered services, differences and overlapping themes with lit review. Two abstracts – one to CAHR, one to IAS, submitting paper on lit review in next few days. Women living with HIV as authors, paper gone out to entire research team for feedback. Very substantive.
- ii. Authorship policy, translation policies, we'd be happy to share ours as well as our communications policies.
- iii. Survey development underway, 12 core sections (sod, demographics, etc.) plus topic specific sections (e.g., strength, resiliency, etc.). PRAs have been very involved, and helpful.
- iv. Sampling and recruitment. Survey is coming together we are moving into sampling and recruitment strategy, looking to enroll 300 or 350 women in BC. Majority from Vancouver, 40 in North, 40-50 on the island, representative of the distribution of the epidemic. Working with partners in each community to develop this strategy, make them site-specific. Plans worked out for North, Island, Interior. Trying to develop a provincial strategy, hoping to meet with Marcie and Oak Tree Clinic and BC based organizations.
- v. CAHR and CTN - quite a few CHIWOS meetings during these conferences, good turnout including PRAs, PIs, co-investigators, great bonding experiences. Conducted a 5 hour Aboriginal training session. Great for capacity building, especially for researchers to learn. Val had a few presentations that went really phenomenally. It is important to recognize the work being done by PRAs.
- vi. The CHIWOS update led to a lengthy discussion around supporting PRAs and tracking the number of hours that co-

development of survey tools with PRAs and community organizations take. Issues raised included:

- Not many research projects track the hours of PRAs and PHAs involved in projects – tension between volunteers and academic salaried professionals. CHIWOS trying to address this issue through applying for capacity building grants.
 - Need to have data on hours, in-kind contributions etc put into these studies, not just CHIWOS.
 - Need for a framework to emotionally support for PRAs and participants who tell their stories publicly.
 - Need for capacity building with ASOs who are asked to “support PRAs” but not told what this looks like.
 - Some of these issues also need to be addressed through realistic budgets.
 - Ontario PRA training incorporates a piece facilitated by the by Ontario AIDS Bereavement Society – great resources (Allie has offered to forward them to anyone who requests them).
 - Terry from Positive Living BC is looking to address this in a CBR manual project he is undertaking.
 - The strain on ASOs, the challenges of not offering child care in studies. These are the kinds of things we need to formalize as non-negotiable.
- vii. Is CHIWOS, capturing migration in urban/rural? Yes, in a few ways. Epidemic different in Quebec where PHAs largely immigrant populations, which is different than BC. We are looking to get into nuances of these, recognizes that these are trigger questions, too. Also looking at migration of Aboriginal peoples, on and off reserve. Also rural/urban migration.
- d. Hidden Drug Use – Heather Peters (UNBC)
- i. Overview of the Opening Doors to Harm Reduction project in Quesnel. We are about ½ way through a 3 year CBR grant. Purpose to gain a better understanding of illicit behaviours, patterns, who the illicit drug users are in our communities. The project came out of the community, who had been meeting about difficulty of providing services for illicit drug users, didn't know about population, and what they knew about risk behaviours and drug use, HIV, etc. Project has two pieces for data collection – surveys on as many illicit drug users that we could reach with respondent-driven sampling, completed survey data collection at this point with PRAs, 200 participants. We want to get a sense of whether there are different groups we still need to know about and get information on how to better reach them with services and prevention/harm reduction information. Data analysis on that. The next step for the project is to do more qualitative research,

interviews, more information on what works or doesn't work in our small community. Interviewing 10 services providers and 25 participants who are part of that hidden, illicit drug users.

- ii. Discussion around what drugs were being included: Illicit drug once in the last 12 months, excluded those whose only drug use was marijuana, though we are interested in that. Surveys focused on drugs in addition to or other than marijuana, especially to look at risk behaviours and connections to needle use. Cocaine & crack were most used, some heroine, prescription drugs. Surprising very little crystal meth, despite a lot of fear in the community.
- iii. Knowledge translation pieces will include reports and brochures, traditional route. Largely to service providers and illicit drug use. Community advisory board. Budget to pay honoraria to our peers to bring results back to the participants, who may not want to come to workshops, etc. Another process is to develop DVD presentations, e.g., one on experiences of our peers as a learning tool, and develop a DVD talking about some of our results and findings that we can give out.
- iv. Terry Howard initiated a photovoice project with our peers, very excited. RDS was most effective for training peers to get out into community, giving out coupons in waves of layers (4 layers in total). RDS helped access those who don't use survey providers. We set up an online survey & facebook page, and purchased facebook advertising targeted to facebook users in Quesnel, taking them to survey. We didn't get huge numbers in the online survey, but it did reach people, and I would encourage people to try that process.
- v. Discussion on use of technology and the concerns around tracking people who have completed surveys. Issues raised:
 - Are we getting into an area where we need to take a step back and ask if we are setting our participants up to being investigated? Maybe we need to go back to the scientific community and ask about this.
 - Fluid Survey, which is Canadian and gives the opportunity to 'turn off' tracking of how filled out the survey. That is what Ethics Board recommended.
 - Another option is for participants to complete the survey off-line and then upload it afterwards then taking any identifying information separate (e.g., hard copy which would get stored elsewhere.)
- vi. For more info: facebook page is 'Opening Doors to Harm Reduction', poster from CAHR and other resources.
- vii. Discussion about the ongoing challenges of unequal access to harm reduction services in BC and the need to work with pharmacies and other partners. Possible future research partnership between harm reduction in Victoria and Quesnel mentioned.

- e. CTN's Prevention and Vulnerable Populations Core – Cathy Worthington
 - i. PVP Core of the Canadian HIV Trials Network – an additional resources and support when thinking about CBR more than a project. CTN increasingly interested in non-drug interventions. Co-Chair of PVP Core is Mona Loufty (CHIWOS PI), we want to facilitate research that comes from community, engaged multidisciplinary and multisectoral research. CTN is fairly well resourced. We have the equivalent of about 1 and 1/3 research coordinator positions to offer people who want to move research forward. We are seeking out champions to take research projects forward. Room for different kinds of intervention research. CTN interested in engaging with social aspect of their work. Rebecca in CTN office in Vancouver, and Logan Kennedy in Toronto as resources to help develop projects.

- f. Terry's update:
 - i. Setting up infrastructure for CBR program at Positive Living. Now can be named on CIHR grants. Main role is writing grants to continue the program at BC Positive Living Society. Steering Community to guide this project. Some of the projects in addition to this are around Aboriginal projects. CAAN has lost their funding, including their two CBR Facilitators in Aboriginal Stream. Helping to get these projects funded. Helping them explore why there weren't accepted in Aboriginal funding stream. Very few Aboriginal projects funded, many deemed ineligible. We are going back to CIHR to ask for clarification on this.
 - ii. Co-chair of UBC CBR Task force, asking about what challenges are, hurdles around finances, credits for work, etc. Taking findings back to VP of Research at UBC to make CBR more supported and palatable to academics in University settings.
 - iii. At Langara College, interested in more CBR, asked me to start Ethics Review board as a community person. Very exciting opportunity to bring up voice of community.
 - iv. CAHR Council – I wasn't at CAHR, but I was elected to council as community rep for 2012-14. Monthly teleconference call & fall retreat. Duties mainly to provide a western voice around social sciences stream, making community voice heard.
 - v. Momentum – gay men's health promotion study. Not technically CBR, doing RDS. More gay men's health and risks than HIV-specific, but will be very interesting. Target of 800 participant, online but done in the office. Bob Hogg is PI, with BCCfE, Jamie Forrest (research coordinator).
 - vi. HIV + smokers study: Craig Phillips UBC Nursing, Bridge funding, still formative phase, trying to make it CBR, defining how we will involve that very specific community, possibly RDS or other networking forums. Just been transferred to U of Ottawa July

1st, but still interested in conducting study in BC, but will be based in Ottawa.

- vii. June Grant Call: Planning grant and dissemination grant (Terry PI for both). Planning: Partner matching, five workshops of guided discussions of relationship building. Other grant will be to fund CBR Manual, trying to write lay manual of CBR from CBR perspective. PAN & Dr. Peter Centre indicated that they would be open to sign onto these grants as partners.
- viii. ITRG workshop: Integration of Tobacco Reduction and Gender: Social marketing presenter on tobacco reduction and young people, touched on identifying identity of a person. How do you reach specific community? Multi-layered identities, and you need to pick the identity facet that would explain why they are part of the tobacco using community. Interesting presentation on social media and creative ways of approaching HIV community. I have been thinking about how to translate this into HIV prevention activity, there will be something up on the website on his presentation.
- ix. Discussion of other funding options for Terry's projects including ViiV and the Vancouver Foundation.

3. Honoraria & Disability Working Group – Darren Lauscher

- a. Our last meeting included some national partners to see if others were having the same dialogue around PRAs receiving disability payments. We talked with Shari Margolese, Sophie Wertheimer, and James Watson, same questions being raised across the country. Tackling the issues almost identically, even though dollar amounts vary from province to province, gift cards or not, SINs or not
- b. Discussion about engaging policy makers to make some changes on this issue, yet not a sense around the table that this is the direction that all want to go. Fear that if we come up with a policy that is rigid, it will have a chilling effect. One of the take home messages is that, a case-by-case issue. Some PRAs may not be an issue for, some who are more vulnerable. It might be about creating tools so that organizations, PRAs and researchers are all on the same page about the constraints.

4. Universities Without Walls Spring Learning Institute – Cathy Worthington

- a. SLI at UVic, may 18- June 1, public invitations should be going out this week. Three key sessions that are open to the public, and UWW Fellows working with SOLID and AVI on public events.
- b. Cathy: Planning some site visits to Vancouver the weekend after SLI.

5. Staffing Updates at PAN – Sara O'Shaughnessy

- a. Welcome Andrea – Sara is taking a maternity leave starting June 1 and Andrea (from AIDS Vancouver Island) will be covering her position.

6. Other Agenda Items – Everyone

- a. CIHR Advisory Committee & Steering Committee, two positions, nominations close May 18th, thought it would be interested
- b. Items for next meeting to be flagged: Emotional support for PRAs and tracking hours for voluntarism.