

Draft Minutes
CBR in BC Quarterly
December 7, 2011

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

Confirmed Participants: Andrea Langlois (AIDS Vancouver Island) [dial in], Surita Parashar (BCCfE), Angela Kaida (SFU), Allison Carter (CHIWOS Study), Val Nicholson (Food Security Study), Michael Kwag (BCCDC), Janice Duddy (BCCDC), Darlene Taylor (BCCDC), Sarah Chown (Universities without Walls), Cathy Worthington (UVic, UWW) [dial in], Darren Lauscher (PAN), Heidi Standeven (PAN), Evin Jones (PAN), Sara O'Shaughnessy (PAN), Patrick McDougall (Dr. Peter Centre)

Regrets: Sean Rourke (Centre for REACH), Meaghan Thumath (VCH), Ross Harvey (Positive Living BC), Aranka Anema (BCCfE), Marcie Summers (PWN), Shanti Besso (SFU), Terry Howard (CBRF), Tasha Riley (AIDS Vancouver), Elisabeth Marks (Centre for REACH), Brian Chittock (AIDS Vancouver)

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Agenda:

1. Welcome and introductions
2. Approval of previous minutes
 - Cathy – SHRAC to SSHRC or CHARAC?
 - Evin – Terry updating re: competition for CUBER
 - Clarification on CHARAC – CIHR HIV/AIDS Research Advisory Committee – CIHR holds research funds for National Act on HIV, Committee to distribute the funds, helping guide where CIHR HIV research money goes. CHARAC wanted to do something new with money – funding CBR Center
3. Current Project Updates
 - Mike Kwag – Acute HIV Study
 - First CBR Quarterly meeting, thank you Janice for introducing Mike to Sara ☺
 - CIHR funded project, 2008, 5 year multidisciplinary study that covers all the different streams of health research, main objective to pilot use of nucleic acid amplification testing to increase testing of acute HIV among gay men and MSM. Partnering with clinics around Vancouver. Enrolling subjects into cohorts until end of next year

- Laboratory objectives around cost-effective way of diagnosing acute infections. Hopefully will improve public health capacity among these populations
- Learning about lived experience of those given acute diagnosis. Qualitative component for those enrolled in the project
- Employing professional counselor for research subjects, linking subjects to peer counseling resources, e.g., Positive Living, both at the beginning and on an ongoing basis
- Questions: Angela – recently infected or recently diagnosed?
- Mike – both recently infected and diagnosed. Also a separate cohort of those diagnosed negative, and cohorts of recently diagnosed (negative diagnosis in past year) and acutely diagnosed (based on lab tests – six weeks after infection). Aiming to enroll participants just after diagnosis, though there are challenges to that
- Sara – what are some of the successful strategies for recruiting?
- Mike – diversity in terms of people’s readiness and willingness to participate. Some sign up same-day. In-house professional counselor meeting with patients right away, which provides a critical link to enrolling people. Other strategy to be as operationally flexible as possible. Ideal to enroll within a week of diagnosis, but that was not feasible. Not the easiest project to become a part of. No additional blood work required. Detailed questions about sero-status, sexual history, coping with disclosure at such a sensitive and vulnerable period. We try to be very transparent. Participants do get a lot of value of it, even though counseling services are not contingent on enrollment. Approximately half of those receiving an acute diagnosis access counseling services (from Bill Coleman), and half of those enroll in the study
- Darlene – number of acute infections diagnosed in a year are really small – needle in a haystack.
- Mike – new testing technologies are helping with recruitment, as previously these individuals would have received negative result. Diagnosed 155% more acutes from this year to last. Social marketing campaigns with Health Initiative for Men (HIM). Raising awareness
- Heidi – just in Vancouver? Are there plans to expand that outside of Vancouver or to other populations?
- Mike – Something we are considering. Analyses around cost-effectiveness of protocol are needed; most studies show that acute testing is not cost-effective except where prevalence is very high. Gay men have high testing rate, which increases marginal benefit of a more sensitive test than for populations that do not get tested as frequently

- Darlene – fourth generation tests are just around the corner, despite problems with them. Difference of a week with nuclear to fourth generation tests. Will be rolled out provincially
- Mike – NAT testing extremely expensive, not new, Canadian Blood Services has been using it for a number of years. Novel way of applying it more cost effective ways in this study
- Sara – Is CIHR funding counselor?
- Mike – yes, all from CIHR funding budget. Half-time position, solely dedicated to providing services and training peer counselors, and other capacity building in the community
- Angela – how many men enrolled?
- Mike – 23 participants. Our original goal was too ambitious. We'll try to get as many as we can. Acute infections diagnosis is a small pool to draw from. Hope for up to 40 – 50. First year only 5 participants
- Darren – I'm surprised you have that number. That's good, especially knowing how long it took me to reach out
- Patrick – were you recruiting at HIM four weeks ago?
- Mike – comparative sample of negative men. HIM is one of the pilot sites for pooled NAT testing. Similar design as positive participants study, but separate study
- Patrick – can't say enough positive things about HIM. Well-designed space and organization. Fantastic set up. Great spot for doing that
- Mike – thank you for that feedback. We feel privileged to be able to work with HIM
- Darlene – is there thoughts that there may be people in the negative cohort that become positive, would they cross over?
- Mike – voluntary participation. Efforts would be made to enroll someone that crosses over into positive cohort, especially since they'll have heightened awareness. We do probe whether they continue to get tested
- Sarah – as one of the research assistants on the negative study, even a month later some participants are demonstrating more awareness around testing. That's something that wouldn't necessarily come from a regular testing site
- Mike – contact info on the sheets handed out. Enrolling until end of next year, including those who may have tested outside the sites
- Angela Kaida – CHIWOS update
 - Angela – wanted to provide a quick update on where we are. Three team members here today – Val and Allie. Five year CIHR project. Start up phase. Nominated PI is Mona Loufty at the University of Toronto. Site in Quebec and BC. 'National', aim to include prairies and other regions as we expand

- Objectives to look at use, barriers and facilitators to women's specific services, patterns of use, and whether use of those services correlate to better health outcomes, esp. mental and sexual health
- 350 sample aim. CBR model, hoping to get the voice of community at every level of operation
- Last time we were here, we talked about the beginning phase. Since then, we've completed the formative phase. Needed to get a handle on what we meant by women's specific services, the work necessary to inform our survey and recruitment process, lit review, environmental scan to understand existing services that may be considered women's specific and some solid work around the epi profile – who the community and population of women living with HIV are, using BCCDC data, treatment data from BCCfE, great existing resources. Planning to make that data into PowerPoint slide presentation. First community advisory board (CAB) meeting, really amazing meeting, over 20 in person and 18 on the phone and another 15-20 committed to the board but unable to attend. Great geographic diversity and population representation of the CAB
- Transitioning from formative phase to preparing the survey and recruitment tools, created teams around different parts of the survey, will share early draft of survey with CAB and National Steering Committee. Next CAB meeting probably March. CAB members will sit on survey development teams to make sure relevance of survey development is there
- Goal is to actually start data collection in May. Flexible goal ☺
- Hiring additional PRAs in the next four to five months to conduct interviews
- Sara – should we keep our eyes and ears open for possible PRAs looking for opportunities?
- Angela – creating a PRA hiring team, will circulate to the document
- Questions: Sara – I would love to hear more about PRA training
- Angela – will let Allie and Val speak to it
- Allie – small group, intimate, focused on the core team of PRAs, quite a learning experience for everyone team building for everyone. Training on facilitating focus groups. Could have been a few days longer, lighter content
- Val – very intense, created a great bond, amazing to be apart of it, knowing who everyone was a key part of the training. Easier to get our head around who's who. Made it a richer experience
- Angela – because we're a national study, we have resources to bring in people like Shari Margolese to learn things like women-specific CBR, and Dr. Saara Greene from McMaster University, a social worker with qualitative expertise. Two days of intensive training on focus groups, pilot focus group with women living with

HIV at the training, great for PRA training and hands-on. Each of three PRAs went to their communities and conducted focus groups around what women's specific services mean to them

- Allie – Each went home with tool kit of what to do
- Val – debriefing is very necessary for knowing who to contact and dealing with triggering issues
- Darlene – your team involves PRAs, and stakeholders, services providers?
- Angela – on CAB we have service providers, nurses from DTES, clinicians from Oak Tree, public health officials
- Darlene – you mentioned asking service providers what they want to see on survey?
- Angela – we have those voices as part of our survey working groups
- Darlene – are they part of the team or ad hoc?
- Angela – committee/working group, volunteer, bringing people in where there is interest
- Darlene – quantitative survey?
- Angela – longitudinal quantitative study. Year one survey, year two follow up phone call to touch base, year three repeating the survey
- Darlene – retention strategies?
- Angela – not there yet, but are developing a recruitment and retention working group. Touching base part of the strategy. Keeping our CAB involved in the process (two CAB meetings a year), also key. We welcome ideas. PRAs also key. Hoping for 10
- Darren – are the 3 PRAs there now, have they given feedback on the questions?
- Angela – surveys not developed yet, but will come together to do that. PRAs are part of the core team and will be providing feedback on how things are phrased, outcomes, obviously differences at different sites
- Janice – same study in three sites?
- Angela – not sure, I'm a data person so I hope it is, but local nuances will have to be taken into consideration
- Mike – related question around governance model. Three CABs?
- Angela – yes, local CABs in each province. Mona Loufty has clinical background, but does CBR work. She is very organized, helping with the structure of the project. Each CAB has 50+ people. National steering committee (40 people). 60 collaborators and co-investigators. Group specific advisory boards coming around the corner. Very bureaucratic. Going to document the structure to share the learning. Model based on equity, capacity-building
- Allie – tricky, aiming for model of partnership, not bureaucracy

- Evin – kudos to you for that, very inspiring to hear what you are doing
- Angela – having experienced people like Val, Kecia and Stephanie really helpful
- Patrick – are you working with COCQ-SIDA? Do they have quarterly meetings there? Central data network?
- Allie – not sure on service providers and quarterly meetings, but in Quebec, CABs are operating similarly
- Angela – Funding from CTN for translation, bilingual coordinator in Quebec filling the gaps
- Darlene – are you gathering questions the CBOs want answered as well or those that are specific to the grant? I’m just learning about CBR and how it works
- Angela – first bit is that it is research driven, I can only give small examples right now, in our epi profile, CAB members in PG want data stratified by HA. So we have divided up our epi profiles that way
- Darlene – are those requests coming to you or are they part of that process?
- Angela – it’s not an explicit part of our process, but with our CAB invitation (which was organic in recruitment), we did then put that out there that we wanted the information to be useful. So we are looking to community to provide that input. But not necessarily doing it systematically. It’s part of the discussion
- Heidi Standeven – PLPH update
 - Heidi – we aren’t at the formative stage yet. Since June, conducted literature review, on PAN website. Bibliography, snapshot of existing housing research. Biggest piece is two-day BC team meeting in January. One of the objectives of phase one is capacity building for community collaborators and for co-investigators to learn from community and to get together. First day will be capacity-building around research methods, ethics, how to develop a research question, finding out what we can do to ensure that everyone at the table can do to feel their voice is important. This meeting is coinciding with OHTN’s National Blueprint for Housing conference, will give national picture. Second day is actually developing the research question. Open-space facilitation format. What do we know, what do we need to know?
 - Sarah – can I ask what your funding looks like?
 - Heidi – CIHR catalyst grant. Operational grant to be submitted next September

4. OHTN Conference – Val Nicholson

- Val – Amazing conference. Got to talk to a gentlemen for two hours named Tim, who turned out to be Timothy Brown (the Berlin patient).

Highlight for me. Four more attempts at the Berlin patient's procedure since, two lived, two passed, not successful.

- Day before panel, invited by PRA team there to participate in training course. Had Dr. David Hoe who gave life-coaching skills, Francisco did wonderful workshop, and the best one was on bereavement and loss, how to deal with it. As PRAs, we're finding that we're losing participants. We need support system for this. Met with CHIWOS participants from Ontario, Food Security PRAs from Ontario and Quebec
- Discussions around what we perceived as support and lack of support. Message got to who needed to hear it. PRA network across Canada being implemented. Truly honoured to be able to have taken this training. Self-care and bereavement
- Sara – term Peer Research Associate/Peer Researchers was put forth at the OHTN Conference, recognizing the importance of the work they do and the respect they deserve. Hope this term becomes the standard
- Val – almost 200 people in attendance

5. Honoraria for Community Advisory Boards – Heidi Standeven

- Heidi – one question coming up at other tables, mentioned at last quarterly meeting, is piece around honoraria for CABs and what is acceptable. Trying to get everyone on the same page. E.g., \$15/hour, \$17/hour. Hopefully make sure everything is on the same page
- Darlene – just boards, or all participation?
- Heidi – all
- Janice – is there standardization across the board for survey amounts?
- Heidi – no
- Sara – boards are different because usually not remunerated, overlap, not everyone is paid for their time (e.g., employees versus community members, etc.)
- Darren – this came up at STOP table, too
- Heidi – Renewing our Response pays honoraria to positive members
- Evin – distinction to be drawn with Societies Act in BC, you can't pay someone to sit on board of directors and any work related to being a board member can't be remunerated. But you can compensate board members to do work that is not related to their being on a board. I.e., you can contract them separately from board work as long as it's not some sweetheart work. What is the context of board members participation in boards?
- Darlene – I don't know much about this, but I think there's something different about this. The board I've had exposure to is VANDU, is one of their board members sit on my not-non-profit board, I think I can pay them
- Heidi – yeah, I think that's what Evin is discussing
- Darlene – at VANDU, wanted to pay peer researchers \$20 an hour, but they pay \$10 an hour. Control is an issue
- Surita – project I mentioned in my intro has had meetings with community providers. Anyone not being paid through work is being paid \$25 an hour.

PRAs being paid \$30 an hour plus bus fare, etc. Not necessarily sustainable. We're discussing it as a team. Uncomfortable discussions but necessary

- Val – I don't think we were that uncomfortable. No more funding that people are willing to donate time until more funding comes up. The rest of us are doing it in donation. Group decision because we are so passionate about.
- Angela – tricky issue. Important equity and ethical issue. CBR is premised on equity. In CHIWOS, we had this discussion, many people are employees whereas others are on their own time. We're putting forward a REACH grant to specifically fund participation of women living with HIV in our CAB and advisory groups. Work in progress. We realized this late in the process, but should have budgeted for that. Shari Margolese spearheading that process
- Sara – it's great to hear that REACH is a source for that funding
- Angela – We'll see if it plays out
- Darren – Community-based peer administrative costs – should be a new budget line
- Darlene – an important distinction. CIHR rule that researchers don't get paid from budget. Collaborators can get paid, but not researchers. Terminology tricky
- Janice – CIHR needs to change, though how do we do that?
- Darlene – there should be something already in there
- Cathy – there's never been an issue with compensating people for work outside of their employment boundaries. Academics can't get paid from grant. Putting aside complexities of Evin's point about board members, it's not difficult to build this in. It's about pragmatism. Question around what number there should be varies from community to community, jurisdiction to jurisdiction. Range from \$15 - \$50
- Sara – if a PRA is listed as co-investigator, can they get paid?
- Darlene – can't get paid salary
- Cathy – can't get paid, but you can list it as meetings budgets, etc.
- Patrick – knowledge user listing could get paid
- Cathy – yes, knowledge users can get paid. Allowed a proportion of salaries paid up to a certain amount depending amount of time put in. Terminology makes a difference
- Darlene – that labeling is important, the system is broken in some ways.
- Cathy – whole departments of bean counters and authority structures around financial responsibilities. People who get paid need to be staff. But you can still maintain equity of CBR. Bundle payment into meeting expense
- Patrick – trying to change classifications is important. Like Darren at STOP table providing expertise and strategic direction. That should be a different category from knowledge user

- Surita – I've had issues with vocabulary. Funders are receptive to when we point out the challenges of that, i.e., students as co-investigators can be paid. Good to suggest this to CIHR. If they will make that exception for students, they might stretch it to community members
- Cathy – community trainee versus student trainee
- Darren – the way laws have changed in Victoria (Ministry of Social Services), honorariums may be out the window. Bean counters might be looking into honorariums and pulling that funding for folks on disability. Claw-back versus tax reasons. Amount one can earn while on disability is changing, more information sharing between government agencies, more rules on self-reporting. \$500 a month income allowed for those on DB2. Theoretically declared monies, and has to be approved by government. Community needs to be aware of. Not sure how to be proactive, but definitely need to keep in mind.
- Heidi – maybe we need to pay cash
- Janice – if you were audited, that could be a problem, you need a name attached
- Heidi – argument around confidentiality issue? E.g., revealing a person's sero-status
- Janice – with public funds, those things have been tightening up. With my Health Authority hat on, I wouldn't recommend it. But I understand why CBOs do it. Darren, do they look at your personal accounts?
- Darren – on DB2, you sign your life away, they have full access to account
- Darlene – at VANDU, I gave them a lump sum, and they issue cash to individuals
- Darren – we just need a red flag up about how privacy laws are changing, especially about those of us doing CBR, maybe need high level meeting with politician, policy shift
- Patrick – they may be receptive to this with STOP going on
- Angela – maybe we need to have a presentation on this at a place like CAHR. Being aware of the back end, and potentially deleterious impacts. This is a big deal
- Darren – yes, theoretically, you could be cut off
- Darlene – breeds a mentality of exploitation
- Angela – do no harm is key, and with that law there is a great possibility to do harm with research. Important research discussion
- Darren – and probably Canada isn't the only country with this problem
- Sara – I'd be happy to help with that presentation, logistically
- Surita – I'm interested
- Patrick – very good topic for CAHR
- Cathy – UWW Sarah – the three UWW writing groups are engaged in topics related to this. A couple groups related to ethics. That your group?
- Sarah – other group

- Cathy – these fellows are CBR keeners, and an issue that crops up a lot. PAN Sara, if you want to be put in touch with those fellows, might be something we can put together
- Sarah – UWW working on language of PRA on resumes, etc.
- Sara – I'll put an action item and send out a follow up.
- Darlene – perfect topic for CIHR Café Scientifique, which fund controversial topics
- Sarah – seminar series, meetings around a topic
- Darlene – key to generate discussion
- Surita – tend to be institute specific, not much around about CBR. We might have to put in a special request
- Heidi – keep this on the agenda
- Darren – even a base guideline would be good. Maybe this is one for Evin, when we calculate volunteer hours, can base it off that model
- Evin – I can look around for standards. Some might be established by provincial government, community gaming grant proposals. Formula for cost-replacement for value of volunteer contribution. I can bring that back to the next meeting. Making recommendations can build momentum, without undercutting across studies, the 'you pay more than we do' problem
- Heidi – it would provide a good starting point
- Evin – I'll work on that with Sara, get a read on what other people are paying in BC, Ontario, Quebec

6. Knowledge Mobilization – Sara O'Shaughnessy

- Opportunities for PRA authorship
 - Sara – Interested in discussing this, figuring out how we can think about ways to include PRAs in authorship opportunities, and considerations around that. E.g., seeking ethics approval to use field notes and informal focus groups as data, what kind of training needed?
 - Cathy – current practice in most CBR studies, depending on institution, statement of principle or working group documents. Writing teams and authorship. Some documents are more specific than others. Writing teams lead or co-lead by academic members, usually open to community members. Community members mentor on sensitizing to language and community issues, academics mentor on authorship conventions, etc. Even if not authored, important to be acknowledged
 - Sara – I'm just wondering what kind of training and resources exist that other projects can access
 - Cathy – learning by doing is really the best way to do. Not sure if there is active capacity building around that? Huge learning for me taking part in a project that did this.

- Sara – data is often different, ethics issues. Do we need to be thinking about this at the beginning stages of projects? Can it be organic?
- Angela – CHIWOS has an authorship policy. Lead author has sway, PI team members are co-authors and CHIWOS investigative team is hyperlinked as co-authors (e.g., names will come up on PubMed databases, though not on the papers).
- Darlene – is that because your team is so big?
- Angela – if a PRA is active on the paper, they will be listed as author. If not active, the team is hyperlinked
- Heidi – that’s how Positive Spaces, Healthy Places study did it
- Angela – the negotiation process is always tricky, can’t set policy around that
- Patrick – this has come up in the last six or seven months at Dr. Peter Centre where work has been done where counselors are collaborators but not listed, and our board is asking what the return on research is without that acknowledgement. If there are policies on authors that are good examples, that would help to take back to our board and committees to show the recognition of our efforts. We’d love that
- Angela – OHTN has a great policy on their website, and I’m happy to share ours once it’s public. We learned a lot
- Janice – Sara, it sounds like there is a question around peer research associates, and the learning from that. Maybe Val, at the network of PRAs that there could be some discussion around that
- Darren – maybe Glen Branford’s peer navigators
- Val – we had some training on writing a paper, but it’s too intensive. We had challenges with a food security paper
- Janice – needs to be a system in place to facilitate those steps
- Sara – I’m wondering if the key point is that PRAs want their voices to be heard more than wanting the actual skill-building of learning to write academic papers, which is not a practical skill outside of academia
- Val – we want our voices to be heard, I have a paper from someone writing a book with Joan Sieber, there is concern around being just a hired hand
- Darren – as board member, if we aren’t on the paper, we lose the opportunity on the fundraising side by not being able to say we are authors, we took a peer on this journey with us. They are now an asset in the community. People who may not have bought in really get it when you can show that, and it increases fundraising opportunities. Shifts image of people from victim to asset
- Darlene – real spectrum of opportunity around knowledge translation, and thinking about other ways to produce knowledge, not just academic journals

- Patrick – Viiv Grant (Pharmaceutical company) call would be an ideal mechanism to design KTE program around skills building in this area, up to around \$20,000. Could be a very dynamic day.
- Sara – I've been interested in doing this with Food Security, maybe expand out to other projects, project wide?
- Darren – partnership with Impact BC, program Patient Voices, might be useful

Other items:

- Evin: Chatting with Brian re stigma project ideas. Hopefully building relationships around it
- Janice – stigma comes up a lot with Aboriginal partners, Chee-Mamouk, renewing our response. Lots of interest
- Cathy – Judy Mills (UofA) and Vera Caine working on project on reducing stigma among nurses. Mentorship program with PHAs and nurses with HIV experience, currently recruiting BC, Barney Hickey at Langara, Paul Kerston, and Cathy in BC, running across the country. National study. Results of mentoring program, intervention work will be useful. Great allied work
- Janice – similar study with Charlotte Reading, doing other studies