Draft Minutes CBR in BC Quarterly October 9, 2019

Time: 1 – 4 PM

Location: McLaren Housing (1249 Howe Street)

Attendees: Sharyle Lyndon (Thrive, BC-CfE), Antonio Marante (Thrive, BC-CfE), Tim Wesseling (SHAPE, BC-CfE), Sean Grieve, Mona Lee (PAN), Paul Kerber (PAN), Madeline Gallard (PAN), Joanna Mendell (Making It Work, PAN), Flo Ranville (CGSHE), Darren Lauscher (many hats), Doug Locke (Thrive, BC-CfE), Janice Duddy (PAN), Sarah Moreheart (CGSHE), Ben Klassen (CBRC), Clara Tam (SHAPE, BC-CfE), Sindi Addorisio (CGSHE), Surita Parashar (BC-CfE), Scott Neufeld (Research 101, BCCSU), Samona Marsh (Research 101, VANDU), Jinny Choi (Snack Chat), Kyla Turner (Positive Living North)

- 1. Welcome & Check-in
- 2. Previous minutes approved
- 3. Agenda approved
- Changes to agenda: Snack Chat presentation postponed
- 4. Knowledge Translation and Exchange (KTE) Showcase

The Knowledge Translation and Exchange (KTE) Showcase is an opportunity for teams to share about their own innovative KTE work, well as hear from other teams about how they have approached KTE.

- Community Impact Statement, Cheque Day Study, BCCSU

Presented by: Joanna Mendell

- Cheque Day Study: Changes to income assistance payment date currently, everyone's paid on the same day. Acknowledgement in the community that this can create harm (e.g. increases in drug use, overdose, hospitalization, violence, emergency calls, etc.).
 Study looked at what happens when people go on different payment schedules.
- Community Impact Statement: To share the experiential knowledge gained from communities in addition to randomized control trial data. Community Impact Statement survey gathered knowledge/wisdom from 500+ respondents affected by income assistance across the province (8 communities) included people who receive income assistance, people who use drugs, people who use drugs but do not receive income assistance, service providers, emergency responders, etc.
 - Served as a direct channel to sharing valuable knowledge and experiences alongside data/results of the study. Community Impact Statement includes key messages from consultation!

- One of key learnings: keep thinking about/re-evaluating your end goal, for your project and KTE.
- Question: Was there a consensus on what works best in terms of income assistance payment schedule(s)? Study's recommendation is to consider each individual's preferred choice and circumstances – there is no silver bullet. Changes to payment schedule can also create unintended harms.
- Question: What would you have done differently? Having a dedicated knowledge broker/knowledge translation person had huge benefits often times, KTE is done off the side of people's desk at the end of the study. Intentional and ongoing KTE and dedicated resources is important. Community Impact Statement was also not part of the original KTE plan but realized along the way that this was very much necessary to provide more context (e.g. to explain potential unintended harms associated with changed payment schedule at the community level). KTE needs to be reflexive (adaptive to changes and shifts in needs) and thoughtful about who need to know about the information gathered.
- Question: Did this impact statement collect responses from people who sell drugs? Not part of targeted recruitment, but responses from both the Community Impact Statement and the Cheque Day Study both included the voices of people who sold drugs.
- Research 101: A Manifesto for Ethical Research in the Downtown Eastside

Presented by: Samona Marsh and Scott Neufeld

To connect or get in touch with Scott, email sdn2@sfu.ca

- Research 101 series of workshop came together at the end of Spring 2018 to address
 a common larger issue in DTES. Researchers, documentary film- makers, artists,
 journalists, etc. who come to DTES as outsiders often go somewhere else to tell the
 community's stories; and often this relationship does not go well. The benefits for the
 outsiders are much greater than those for the community members.
- Project aim: What does more ethical and respectful research look like? How to build research-community partnerships.
- Authorship for the Manifesto: work acknowledged as long as you have attended at least one workshop.
- Different sections of the Manifesto:
 - How to do more ethical and respectful research in DTES
 - Getting to know each other (researchers and community members), questions researchers need to answer – what should the community members know about you and your project, what's your plans for KTE, etc.
 - Call for community-based ethics review—whose ethics?
 - Experiences of peer researchers and power e.g. stigma, tokenization, how to reach participants, etc.
 - Community expectations on KTE and reciprocity

- What are the researchers getting out of this vs. what are the community members getting out of this if there is an imbalance, what needs to happen?
- Other than research, what else can researchers do to get involved and contribute (e.g. accompanying community members when going to policy makers/politicians; volunteering in the community; etc.)
- Acknowledge that workshops did not represent all of DTES, but have done due diligence to share this work by visiting members and organizations across DTES to make sure what is reflected in the Manifesto is accurate and also for endorsement.
- "Don't read us the book that we wrote"
- What's happening with the Community Research Ethics Board? What are the directions
 e.g. for advocating to CIHR to ensure community ethics review is part of their process.
 - The group has continued to work on this for the last 6 months. Piloting "Community Research Ethics Workshop (CREW)". Looking at other models and navigating what CREW will look/work like. Working with Research Ethics Boards (REBs) from SFU, UBC and Providence Health great partners who are supporting this work. Another question that is being explored is how to we make sure that this body and work has "teeth".
 - Greenlight to share this Research 101 Manifesto with our networks! Online version available.
 - Recognizing that ethics are constructed in particular communities and may not translate to other communities with different contexts and histories.
 - Research Ethics BC to harmonize ethics across BC been in touch and they have been supportive of the work. Trigger process for ethics review – how to get this in front of people to think about these important questions at the right time that they should be...

- HIV Housing Toolkit, PAN

Presented by: Madeline Gallard

- o Multi-module toolkit for people living with HIV, service providers, etc.
- A KTE tool that came out of Positive Living Positive Homes (PLPH) study, meant to be a broadly useful tool. Modules were reviewed and developed in partnership with community members
- E.g. Applying for BC Housing, checklists/self-assessment questions for considering different models of housing, considerations for moving, etc.
- There are printable and downloadable graphics
- Question: are there tips in the toolkit for folks who do not have regular access to a phone – e.g. to update status to BC housing every 6 months. Some information on this but also acknowledge that there are limitations on what we can offer in terms of recommendations/resources
- The plan is to keep this online module up to date, especially around links and information provided in the resources section. For the study team to consider: add "updated on" date at the bottom of modules

- Comments: maybe people need to apply to different housing in advance as a plan for the future in case something happens (e.g. illness); the government needs to change their policy that requires people to update their info every 6 months
- Share this module/resource through avenues beyond ASOs/CBOs e.g. public libraries,
 MLAs, hospitals, health clinics and teams, etc.
- The focuses and topics of Online Housing Toolkit came out of PLPH study data (what people told us were important; what people told us in terms of knowledge gaps or what they wished they knew)... But it is important to think about audiences and venues beyond where we typically work. This toolkit can also be an opportunity to start conversations and provide resources around other important issues like stigma.

- Snack Chat

Presented by: Jinny Choi

- Aim: to create a platform for reciprocal conversations between researchers and community members
- E.g. Researchers come to Dr. Peter Centre or any other low-barrier community gathering places
- Can service as an education opportunity for researchers on how to have these conversations with communities – to see knowledge to be shared in a reciprocal manner not researchers informing/dumping knowledge and findings to community in one way
- Project waiting to hear about funding result if successful, will start back up in January and in other venues too like Positive Living BC
- SHAWNA is very interested in coming to present/share
- People who come and share the information can also be PRAs not just academic researchers. The funding successful, the PRAs will do some education with the academic researchers.
- Looking for low-barrier environments
 - Dr. Peter Centre's presentations tended to be attended by ~10. PLBC said maybe 5-10 people. Audience size varies.
 - Nicholson Tower (a mixed residential building) has a common space as well as the "library" on 17th floor – that can host presentations.
 - 312 Main St. (a purpose built for community meetings and groups)
 - UBC Learning Exchange
 - Friends for Life
 - Heart of Richmond

5. Program & Project Updates

- SHAWNA

 Sindi is a new hire – background working in community working in AIDS Vancouver, Boys R Us, etc. Centre for Gender and Sexual Health Equity (CGSHE) is now separated from BC-CfE and formed its own centre on 647 East Hastings. If in the neighbourhood come say hi! Reached recruitment target. Digital storytelling focusing on women from SHAWNA cohort sharing post-incarceration experiences – to take photographs of what has been impactful, etc. Qualitative interviews will be facilitated by PRAs and participants can narrate their own stories or have someone else tell their story.

- SHAPE

- Success to have Clara come onboard as the new study coordinator. Closed baseline, getting up to follow-up. Have been placing postcards for study follow-ups at ASOs and places that Tim and Sean have identified as good places for postcard drop offs. Question for the group what's a good way to follow up with folks without contact info. Thinking about mapping those folks' connections in the community, etc. Also will be updating postcards to revamp colours.
 - Suggestion: through the mapping, if there is a place that is identified as a popular gathering place for folks lost to follow-up, can host a pizza night to do all follow-ups in one go.

- BC People Living with HIV Stigma Index

Moving into phase two – to develop stigma reduction interventions. Part of this work is to organize a Deliberative Dialogue that brings stakeholders across BC to speak to what's needed and appropriate in terms of stigma interventions and around intersections of stigma. Going to be presenting at the Summit and have been engaging and sharing the data with health authorities too. Question for the group: as we move into qualitative interviews, we need to think beyond ASOs for recruitment. We are only doing 25 interviews and want to make sure we are able to capture the voices of diverse priority populations. Please be in touch if you have suggestions and thoughts about this.

- Positive Living Positive Homes (PLPH)

Online Housing Toolkit is launched! Will also be doing a presentation at the BC Non-Profit Housing Association Conference. Lesson learned: keep knocking on people's doors and people are willing to help. Another lesson learned – to think about meaningful KTE and knowledge mobilization all the way through the study so we don't leave it until the end of the study. And especially so that we are able to support people with lived experience to do KTE.

- Combating Stigma Group

 Not successful for provincial funding but will be hosting facilitated workshop to identify different types of stigma – and then coming up with ways to combat stigmas. More to come.

Sex Now Survey (CBRC)

Biggest national survey for gay and queer men – finally close to the launch! The Summit
is coming up in November too.

6. Meeting Adjourned