Meeting Minutes
Community Based Research in BC
LISA and CBO Collaboration Meeting—Tuesday Oct 19th, 12-4pm, BC-CDC

Present:

Alexis Palmer, CANOC/LISA
Jennifer Evin Jones PAN
Darren Lausher PAN
Deb Schmitz Hep C council
Brian Chittock AIDS Vancouver
Terry Howard CBR PCPWA
Ross Harvey BCPWA
Stacy Leblanc PAN
Marcie Summers PWN
Siobhan Gallagher, MacLaren Housing Society
Andrea Langlois, AIDS Vancouver Island (teleconferencing)
Nadia O'Brien, LISA
Janice Duddy PHSA
Rosa Jamal, Dr Peter's Centre
Bob Hogg, LISA

1) Introductions

Goal for the Meeting- Evin

- To get the BC-CfE LISA team and community organizations at the table.
- Move forward with community research collaborations in BC
- Set up communication systems
- Review projects happening in BC
- Identify mechanism to support community-based research

2. Overview of the Harmonized Questionnaire- National Picture-Ali

Background

- Graph to explain links between CANOC-LISA- Food Security
- CANOC: National, clinical data, data request process. Pubmed CANOC Cohort profile and CANOC.ca website for more info
- Bob Hogg is the PI (principal investigator) and the director of DTP
- DTP is BC-CFE Drug Treatment Program gathers clinical information
- LISA (substudy of DTP) started in 2007-2010, 1000 people interviewed in the province, provides social determinants, socio demographic information. (not originally conducted as community based research project)

3. CBR Approach- Current Projects-Ali

Food Security

- Aranka Anema at the BC-CfE in 2008 received a grant for a Food Security study.
- Community-Based Research (CBR) grant structure
- Links to OHTN in Ontario (Ruth Ann Tucker co-investigator)
- General Acknowledgement that CBR is needed for change.

LISA

- Grant was for three yrs. 2007-2010
- New funding in needed
- Acknowledge that the CBR model should used for future research
- "LISA" is the old name, new grant would mean a new project and new name.
- New LISA would be modeled under the Food Security CBR project.

CHIWOS

- National women's health questionnaire.
- Grant submitted in September
- Would be a module added to the "harmonized core"

Harmonized Questionnaire

- Hope is for a large comprehensive survey
- Same questions asked nationally in the "core" for comparison and reduced research fatigue.
    - Modules could be added/removed based on themes. Women's health, housing, mental health, food security.
    - There is also a push from PHAC to Nationalize
- STATUS: the questionnaire was 200page, now 70page. Will circulate for review once it is a manageable size.

4. Collective vision for Community-Based Research in BC-Terry

- Current funding climate-support research that is housed in agencies like BC-CfE and partner with community agencies.

Food Security Example:

-Train 8 peer research assistants (PRA)
-800 surveys will be conducted in BC
-Contract paid work for PLWA
-Data entered and kept at BC-CfE
-CfE has data, security, time resources and capacity
-Community key knowledge disseminators
-CfE- publish in academic venues
-PRA Coordinator Ben Stevenson has been hired
-Participant 25$ food gift card

- Creates potential for ongoing work for PLWA
- Potential for creative methods ie- photovoice.
- Potential for supporting a pool of trained PRA
- Site in Prince George in being set up for future studies-upcoming-stay tune

- Opportunity to collect provincial outcomes (link to outcomes working group?)

Various Questions about research:

- I-pad/tablet technology?
- New participant recruitment?
- Electronic release?
- Privacy agreements?
- Goal/impact of research-how to impact change?
- ASOs- needs common indicators of work.
  ex. Outcomes Measures and Evaluation Plan (PHAC)- AIDS Vancouver.

Short Break

4) Where does CBR go from here?

Aim is a full partnership between ASOs and BC-CfE

Overview of CBR -Terry:

- In 2003 CIHR developed CBR branch. Intended for community organizations to do their own research and use data to inform change
- Response to academics "swooping into communities" leaving with the knowledge
- Now 7 CBR reps in the country- to build research capacity
- CBO-very difficult to navigate funding procedure. Now partner with academics.
- Goal is to have CBO's meaningfully involved in all the stages of research.
- Terry listed 20 grants that he is currently working on. See his website www.bchivcbr.org
- "Gold standard of CBR" should still be sought but in this climate equal collaborations make perfect sense-it capitalizes on both strengths"
- So how can academic and community process become fruitful?
- Terry is the broker between academics and CBO

Issues with CBR attempts in the past:

- Timing: perception of last minute rushing
- Unclear definitions of "collaboration"
- What are the demands/commitments of the community
- Not feeling as an "add on"
- How can an organization move forward in research
  - What services can an organization offer
  - How to build capacity

AIDS Vancouver provides an example:
- Organization set up systems to deal with the personnel time constraints
-Identified cost in terms of human resources

Research timelines (Bob):

- At time have 4-5 weeks of time B-4 submission

- We are funded out of research grants-not BC-CfE operations
    - 20% of grants get funded. Grants need to be submitted sometimes 2, 3times to different funding calls.
    - Example NIH Nov 15th (applying)
- SFU Endowment in December (not sure if applying)
- Note: BC-CfE its mandate is treatment.
    - Research is funded by grants.
- BC-CfE has received some small funding for Evaluation of the program but no money is being given to LISA project for any research.
- Note: Seek and Treat is happening in the province-any research would directly or indirectly be studying its impacts. And it's good grantsmanship to link current policy changes and interventions to research.

Evin-suggestion for process:
-Given tight turnaround time we could come together previously and agree on certain points so we can move more quickly.

Terry:
-It could be his role to create a database of community and academic interest and match.
-The work could be done upfront based on declared interest.
-Note: this position may not be funded by CIHR for long.

Question: How can community priorities be translated to research?

Bob: possible process could be for community to request data by 1) requesting information, 2) Analysis in report, 3) if more research is needed apply for grant .

Proposal: Quarterly meetings like this one to identify priorities and future projects.

Terry: CBRF Website could have five questions on CBO, interests capacity etc for matching with academics

Broader question: how do we get a collective push to make change?
-How do we move research into policy and practice?
-(politics….money…timing….)
-Suggested involvement of REACH.

5. What is happening in the province?

[long list of projects in the province-not included in notes-sorry folks too long to note]

6. "What's coming down the pipeline?" Upcoming opportunities

- NIH- National Institute fore Health (US)
  - Grant call due Nov 15th
  - Call for Seek and Treat, and Vulnerable Populations
  - Feedback received for LISA grant, we will tweak and go forward.

- Must better define “vulnerable populations”
- Same basic grant as CIHR- we are just trying for a new pot of money.
- looking at social determinants in the context of seek and treat for people living with HIV on and off treatment in BC using the PRA-and CBR model

NEXT STEPS

Ali- email for next meeting times (goal is quarterly)
Nadia will organize collaboration around NIH grant.
Definition of roles and responsibilities for ASO will be provided.
Request for letters of support will be sent ASAP.