



# 2017 PAN Fall Conference – Day 2

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*Thursday October 26, 2017*

## **DRAFT NOTES**

**Minutes:** Madie Eirikson (Contractor)

### **Welcome**

*Opening: J. Evin Jones*

Announcements:

- Please complete evaluation form in registration package and be entered in a draw.
- Free and confidential peer-to-peer Hep C Helpline (further info from Deb and Daryl from PHCN). Please take a poster and promote this excellent service back at your organization/in your communities.
- (Lara Barker – Regional Health Educator for BC at CATIE) Our blended learning program includes free trainings for front-line service providers across the country. There are 2 courses: Hep C basics; and Preventing transmission of HIV.
- (Jaydee) As part of the conference closing, there will be an opportunity to be smudged by members of the Greater Vancouver Native Cultural Society. .

The rest of the fall meeting is devoted to examining the findings from two large provincial community-based research projects that PAN has been privileged to help lead: Positive Living Positive Homes (PLPH), and the BC People Living with HIV Stigma Index Project. We are so excited to share with the preliminary research findings, and to hear from you how we can use the data and take the “knowledge to action” – how to focus our policy change and advocacy work in the coming year(s) on these two critical areas: housing for PLHIV and HIV-related stigma.

Thank you to PAN member organizations, peer researchers and consultants, and others who have been involved in the PLPH and Stigma Index work – it is because of their efforts that we are able to present these findings to you today.

We so value the voices of everyone in the room and look forward to your input as we discuss these important issues.

## Spotlight on CBR at PAN: Data from Positive Living Positive Homes (PLPH)

*Facilitator: Heather Picotte (Research Manager at PAN)*

*Attachment: Powerpoint Presentation*

- Territorial acknowledgement.
- Beginning in reflection: what does home mean to you? Reflect on a time when you felt happy or safe.
- A key finding in the study is that each person needs something different; we cannot generalize, and we are here to listen to diverse stories.

### PLPH Background

*Cathy Worthington (Principle Investigator for PLPH)*

- Qualitative, longitudinal case study that adheres to Community-Based Research (CBR) principles and GIPA/MIPA.
- There already existed a lot of research on this already, so this was meant to help understand the BC context. Study took place in Greater Vancouver, Prince George and Kamloops. Each city representing a different kind of service community.
- Finding out about a range of diverse housing-health experiences.
- In-depth interviews (about 100 people) over a year followed by another interview a year later.

### Results

*Darren Lauscher (Community Advisory Member)*

- This is not a generalisation about people living with HIV in BC, rather it's a reflection of the participants.
- Breakdown of sample population (see slides for stats).

### Primary Findings

*Mona Lee (Vancouver Site Coordinator and KTE Coordinator for PLPH)*

Stats and slides interspersed with personal, composite stories from participants.

Key themes from the data:

- Mental health & co-morbidities. Many participants living with a mental health issue or a mobility issue (see slides for stats).
- Substance use. Many participants had actively used substances in the year leading up to the interview (see slides for stats).
- Social life, connections and stigma. Personal relationships and community connections can have major impacts (good and bad) on housing and health.
- Access and using services. Overall, there were more positive than negative experiences using services.

## Spotlight on CBR at PAN: The BC People Living with HIV Stigma Index

*Facilitator: Heather Picotte (Research Manager at PAN)*

*Attachment: Powerpoint Presentation*

- This is a study across BC, interviewing people living with HIV across all health sectors. Collected 181 surveys in 5 months.
- Thank you Jaydee for coordinating PHASE I of the project and to all the Peer Research Associates (PRAs) for their exemplary work.
- Ongoing, peer-led, peer-driven. This international tool is being used worldwide and for the first time in Canada, here in BC.
- Led by team of stakeholders (people living with HIV, service providers, other CBR practitioners, policy members etc.)

### What is the HIV Stigma Index?

*Heather Holroyd (CBR and Evaluation Coordinator PAN)*

- HIV Stigma Index is a survey tool designed by people living with HIV for people living with HIV.
- Process is just as important as the product.
- Implemented in over 80 countries worldwide.

### Implementation of BC Stigma Index

*Janet Madsen (Capacity Building & Knowledge Translation Coordinator, PAN)*

- Community-based research approach, establishing best practice.
- 2015/16: gathering/hiring team.
- May 2016: ethics approval.
- Oct 2016: six peer research associates hired & trained.
- Nov 2016-Mar 2017: data collection of 181 complete surveys across BC.
- March 2017- present: team transitions and start of analysis/knowledge translation (KT).
- Team role breakdown: PAN is the bus, The Steering Committee and KT members are the drivers (see slide).

### Peer-to-Peer Survey Experience

*Hesham Ali (PRA/Stigma Index)*

- The HIV Stigma Index is a lengthy survey, completed in a side-by-side fashion between peer researcher and participant. The process of answering the survey questions while incorporating meaningful discussion about stigma and discrimination is empowering for both parties. Described the trust aspect of the PRA-participant relationship.

### Early Findings

*Cathy Worthington (Principle Investigator for PLPH)*

Breakdown of participant data (on slide).

Thematic data to be discussed during the Knowledge to Action session.

## Research Process & Next steps

*Antonio Marante (PRA/Stigma Index Knowledge Translator)*

- Rural and remote areas need further investigation.
- PRAs identified a need to include more survey questions focused on gbMSM experiences.
- Having researches who are able to openly disclose their HIV status to participants can be an important factor in building trust and confidence.
- We have learned much about communicating effectively and working with a diverse team.
- Next Steps: Nov 2017- March 2018: the research team will be delving deeper into the data, making decisions about building a shared agenda to improve program, service and policies, filling in gaps in the survey project, actively working with wider index project to help guide implementation in other provinces.

Questions from the floor:

- (Chad) Any findings in feedback about long-term, residential care for LGBTQ+? (Answer): There is some around aging, life planning post 65 etc. but not specific to health care.
- (Jenny) How can we better resource the smaller communities that are in desperate need of resources, housing etc.? (Answer): We hope to find out what specific communities are lacking and why.

## Positive Living Positive Homes Knowledge to Action - Roundtable

*Facilitator: Heather Picotte*

*Attachment: Notes from facilitators*

4 stations were set up with facilitators, and all participants will rotate through:

*Station 1: Sharing Data with Target Groups (Facilitated by: Simon & Jaydee)*

*Station 2: Alignment with other projects and research (Facilitated by: Cathy Worthington & Heather H.)*

*Station 3: Topics for Education (Facilitated by: Janet & Darren)*

*Station 4: Topics for Advocacy (Facilitated by: Janice & Paul)*

## Stigma to Knowledge - Roundtable

*Facilitator: Heather Picotte*

*Attachment: Notes from facilitators*

The main purpose of this session is to find out what types of information the PAN membership think will be useful to your clients and your organizations, so our research team is able to dig through our data, find those things, and give them to you when and in the format you need them. We also hope that this session will give

us an even better, more current sense of the landscape around stigma in BC, since we will be finding out the issues you see as priorities. The study will wrap up by March 2018, and hopefully KT efforts will continue after that.

#### Table Discussion (facilitators guide participants)

1. Brainstorm around clients you serve at your organization and the needs they face around HIV-related stigma.
2. Do any of the situations you just brainstormed contain elements of the topics covered in the Stigma Index survey? (Refer to the handout on the table with the list of topics covered) Which ones? Please note these down in the space provided.
3. Are there currently any initiatives in your organization that are addressing (directly or indirectly) HIV-related stigma?
  - a. If no, is there any data from the Stigma Index that might help you develop those programs?
4. Are the programs you currently have addressing the major stigma issues faced by your clients, or is there a gap in your services that you have the capacity to fill (or will have the capacity for in future)?
5. Do you see any ways in which data from the Stigma Index might help you fill those gaps?
6. One important aspect of the study raised by our PRA team was that individual ability to safely and comfortably disclose one's HIV status was a very important factor in empowerment to disclose and create stronger connections to community. With that in mind, can you think of how the study can support this type of empowerment on a small scale?

We will be bringing results of these conversations to you and moving some of these things to action. We ask for your continued support over the coming months as we move forward. Thank you all!

## Closing

### *Closing remarks: Jennifer Evin Jones*

- Thank you to everyone who completed evaluation forms! The draw mystery prize is joined by a beautiful handmade gift from Chad Davies – a darling pair of moccasins made by a family member.
- Thank you again to event funders and sponsors! (PHSA, Merck Frosst, Vancouver Foundation, Canadian Institute of Health Research, CIHR Collaborative Center for Research for HIV/AIDS.)
- Thank you Antonio, Darren, Hesham - who presented today and deeply appreciate their integral role in supporting PLPH and/or the Stigma Index studies.
- Thank you Heather Picotte (PANs research manager) and CBR evaluation team - great job on the studies and today's sessions.

- Thank you to Cathy Worthington (Principle Investigator for PLPH and for the BC Stigma Index Study ) - an invaluable ally to PAN & a true champion of Community-based research.
- Thank you Cam Routledge – registration table volunteer.
- Thank you Belle Ancelle – photographer.
- Thank you Madie Eirikson – minute taker.
- Thank you Marriott staff for hosting us.
- Thank you mother earth for the amazing food.

Thank you all for coming, your participation and contributions, and for being so present and engaged. With the PAN staff and board, we've learned a lot, been challenged and inspired by all of you.

Conference closing and smudging by Greater Vancouver Native Cultural Society.