



The BC People Living with HIV Stigma Index

REPORT ON RESEARCH PROCESS
AND PRELIMINARY DATA FROM THE STUDY



Introduction

- An ongoing, peer-led, peer-driven, community-based research study housed at PAN and supported by PAN staff
- Led by a team of stakeholders – primarily people living with HIV, but complemented by service providers, policy makers, and academics
- At the analysis and knowledge translation phase



In this session...

- Provide background on the project
- Update on accomplishments
- Share preliminary findings
- Discuss next steps

Please join our knowledge-to-action session later this morning to take part in action planning for using the data in our communities!

What is the HIV Stigma Index?

- A survey tool designed *by* people living with HIV *for* people living with HIV
- Intended to gather information about HIV-related stigma and discrimination experiences of PLHIV, while at the same time, creating connections among members of the HIV community
- To date, has been implemented in more than 80 countries worldwide
- The *BC People Living with HIV Stigma Index* is the first implementation of the Index in Canada
- Funded by the Vancouver Foundation, Canadian Institutes of Health Research, the Canadian Centre for REACH in HIV/AIDS (REACH 2.0)

Implementation of the BC Stigma Index



- 2015-16: gathering/hiring management, research team and steering committee
- May 2016: ethics approval
- Oct 2016: six peer research associates hired & trained
- Nov 2016 – March 2017: data collection of 181 complete surveys across BC
- March 2017 – present: team transitions and start of analysis/KT

Team roles

- Steering committee – provides input, approves, and otherwise guides all study activities
- AKT group – reviews study findings, provides direction for further analysis, and makes decisions on how to transform data into useful information for communities
- PAN staff – provides logistical and administrative support for study activities



PAN is the bus. The SC and AKT members are the drivers!

Side by Side: the peer-to-peer survey experience

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.



A privilege to be trusted: the peer researchers' experience

“I was living with HIV, doing the study, and she understood that I was closer to her because we were experiencing the same life situation – she felt less stressed about the interview and sharing her experiences.”

“I was amazed at how they opened up to me so freely, as if they needed to just voice things that they held inside for so long. Many had low self-esteem and struggled with disclosure due to the stigma attached to HIV.”



Some early findings

➤ **Interviews completed: 181**

➤ **Regional breakdown:**

Northern: 13%

Interior: 8%

Coastal: 40%

Island: 14%

Fraser: 22%

unknown: 2%

➤ **Gender:**

Male: 58%

Female: 39%

Trans: 1%

other: <1%

missing: 1%

➤ **Age:**

15 – 19: 1%

20 – 24: 3%

25 – 29: 10%

30 – 39: 35%

40 – 49: 36%

50 – 59: 12%

60 – 69: 3%

missing: 2%

➤ **Time living with HIV:**

0 – 1 year: 6%

1 – 4 years: 24%

5 – 9 years: 22%

10 – 14 years: 33%

15 – 19 years: 15%

Some early findings

➤ Physical disability:

No: 60%
Yes: 38%
missing: 2%

➤ Mental health issues:

No: 45%
Yes: 49%
missing: 6%

➤ Co-infected with hep C:

No: 58%
Yes: 27%
Treated: 16%

➤ Education:

No formal education: 1%
Primary school (K-8): 8%
Secondary school (9-12): 46%
Technical college/university: 40%
Missing: 4%

➤ Employment and Income:

Full-time employee: 7%
Part-time employee: 12%
Full-time self-employed: 2%
Casual/part-time self-employed: 12%
Unemployed, not working at all: 9%
Disability/unemployment insurance: 65%
Retired: 6%

PRA perspectives on the research process



- There were few study participants from rural and remote areas, so these areas need further investigation
- PRAs identified a need to include more survey questions focused on gbMSM experiences; this is a limitation of using an international tool
- Having researchers who are able to openly disclose their HIV status to participants can be an important factor in building trust and confidence in the Stigma Index survey situation
- Working collaboratively with multiple teams takes time, patience, and flexibility. We have learned much about communicating effectively, building consensus, and letting everyone be leaders in their own way

Pathways forward

(Nov 2017- March 2018)

- Analysis and knowledge translation (AKT) working group is delving deeper into the data, and making decisions about building a shared agenda to improve programs, services and policies
- Planning in-depth, qualitative interviews to fill gaps in the survey data and gain a deeper understanding of the complexities of HIV-related stigma.
- Actively working with the wider Canadian People Living with HIV Stigma Index project to help guide implementation of the Index in other provinces, beginning with Manitoba and Ontario

So what???

In keeping with the community-based nature of the project, please attend our Knowledge-to-Action session to help inform decisions and see how these data can **benefit you and your organization!!**