

# FROM DARKNESS TO LIGHT

## Bringing HIV related stigma to the fore in British Columbia with the BC People Living with HIV Stigma Index Project

The BC People Living with HIV Stigma Index Research Team, including: Andrew Beckerman, Colt Burrows, Darren Lauscher, Janet Madsen, Antonio Marante, Alan Samuelson, Tabitha Steager, and Catherine Worthington.

### ROOTED IN THE PRINCIPLES OF COMMUNITY-BASED RESEARCH (CBR) AND THE GREATER/ MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV/AIDS (GIPA/MIPA)

#### BACKGROUND

Designed by and for people living with HIV (PLHIV), the People Living with HIV Stigma Index has been used to document experiences of HIV-related stigma in more than 80 countries worldwide. BC is the first province to implement this study in Canada and included 176 survey participants.

It serves to explore the stigma landscape in different regions of BC and as a learning model for a broader application across Canada. BC experiences are helping to shape its implementation nationwide.

#### KEY LEARNINGS TO DATE

##### The Centrality of PLHIV in the Survey Process

Administered by peer research associates (PRAs) who were trained in advance on interview dynamics, communication, the survey tool, data collection & entry. PRAs felt that this strengthened the survey process and asking difficult questions (sexual behaviour, drug use, internal stigma, traumatic experiences).

*"Stigma is core to being HIV+ so disclosing that you yourself are managing HIV really changes the dynamic of the interaction."*

*"I was living with HIV, doing the study, and [the study participant] 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."*

##### Reflections on the Survey Tool

How is the stigma experience expressed through the tool itself? While there was some freedom to alter the international tool to local contexts (edits were determined by the Steering Committee in advance of the survey process), seeing how the survey worked in a real-time setting was instructive to the peer research associates (PRAs). Questions about some groups were plentiful (heteronormative expectations of the survey); others were missing (transgender folks), which could prompt feelings of stigma.

**Quantitative vs Qualitative:** The tool begins with extensive quantitative sections that took up to 90 minutes for many participants. The short qualitative section followed. However, PRAs reported that there was a lot of qualitative discussion/narrative during the quantitative sections, and while PRAs did their best to capture it, it wasn't possible to capture it all. Once they reached the qualitative section at the end, participants could be spent and responses were not as extensive as they might have been.

**How Research Impacts PLHIV:** Consider exploration into how PLHIV feel about taking part in research and how it impacts them. For those working as PRAs, there can be a differential in money paid for work vs money paid for participants.

**Chronological Timing:** The survey asks questions about the past 12 months in a participant's life, then goes back to experiences at the time of diagnosis. PRAs observed that asking questions about a person's current situation first and then going back to their diagnosis is very challenging.

##### Analysis Process

- Survey tool structure can be challenging given the intimate questions of stigma.
- Identifying necessary supports for peer researchers; and connecting the research team with harder-to-engage rural and remote populations is best suited to planning process.
- Building relationships with community organizations is necessary to support the research.

##### Conclusions

Levels of stigma people experience accessing healthcare are still disturbingly high.

*"There are a lot of lonely people out there; isolation and mental health issues; this was a tough, sad question for a lot of people; self isolation and internalized stigma happened frequently."*

*"We have made huge advances in science and meds but the social issues, stigma, isolation, drug use, mental health etc., has not changed for 30 years. The science and social don't match."*



## THE BC PEOPLE LIVING WITH HIV STIGMA INDEX

