

# The BC People Living with HIV Stigma Index Project: Planning Phase Evaluation

Jonathan Postnikoff,<sup>1,2</sup> Andrea Langlois,<sup>3,4</sup> Janice Duddy,<sup>3,5</sup> Catherine Worthington,<sup>4</sup> Jaydee Cossar<sup>3</sup>  
<sup>1</sup>Positive Living BC, <sup>2</sup>Universities Without Walls, <sup>3</sup>Pacific AIDS Network, <sup>4</sup>CIHR CBR Collaborative Centre (A Program of REACH), <sup>5</sup>CIHR Centre for REACH in HIV/AIDS, <sup>6</sup>University of Victoria



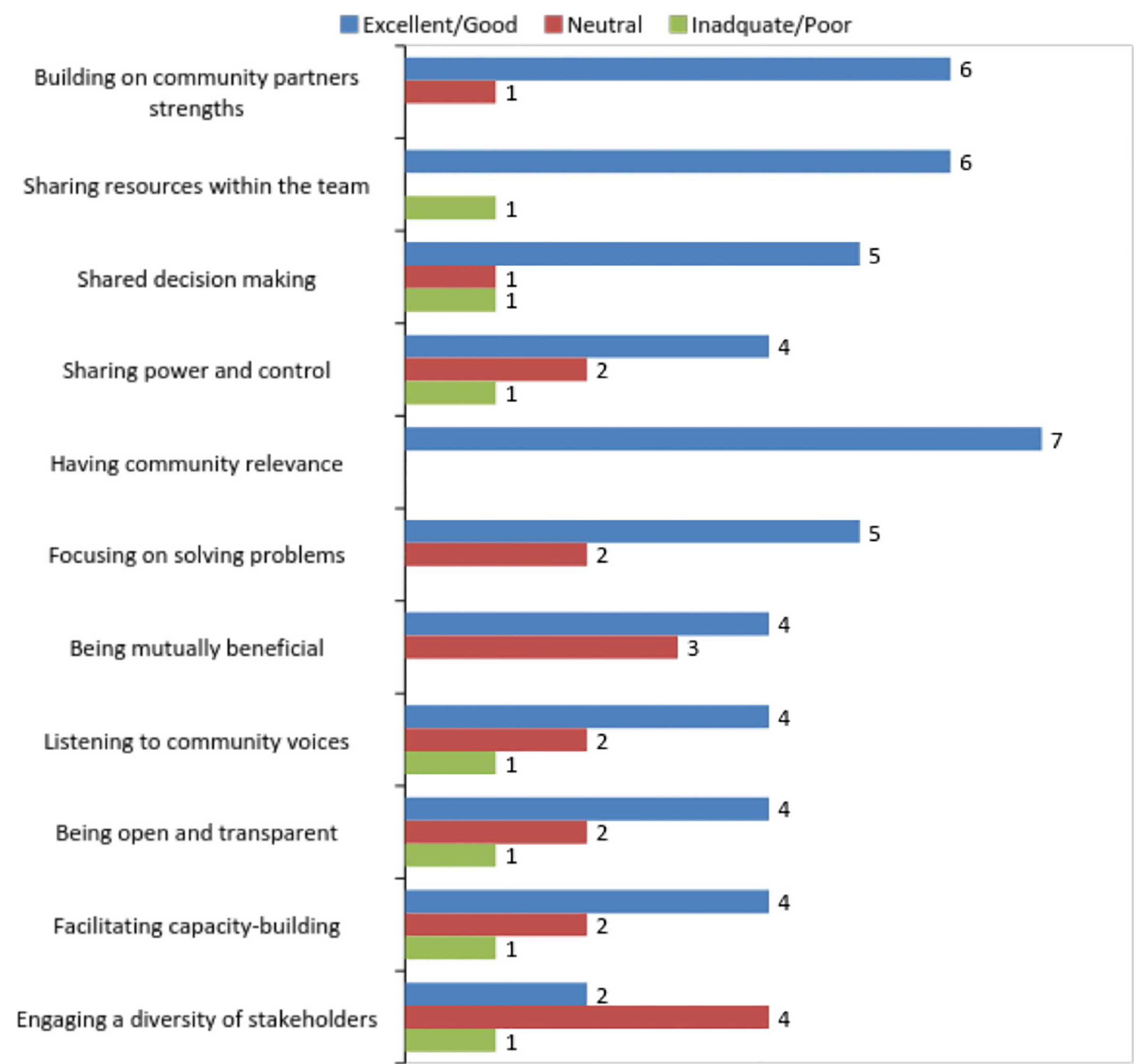
## Background

The People Living with HIV Stigma Index Project is an international tool aimed at identifying the intersections of society where HIV stigma persists, and has been implemented in over 65 countries to date. British Columbia will be the first region to implement this study in Canada. While most work to-date internationally has focused on the end results of this project, the team in British Columbia believed it would be valuable to identify opinions of the planning phase of team members and to evaluate adherence to community-based research principles: community, capacity-building and collaboration.

## Methods

All team members (community, agency, and academic) were invited to participate in the evaluation. We used a mixed methods approach, employing a quantitative survey for those team members who chose to participate (n=8 of 10 team members), complemented by in-depth interviews with 2 front-line/community team members. The survey and interview asked respondents about the project's respect for CBR principles, reflections on their involvement, and recommendations for implementation in other regions. Participant observation was also employed by the principal investigator to reflect on the study processes, and these observations were incorporated into the analysis.

Figure 1: How would you rate BC Stigma Index Project's success thus far?



## Recommendations:

Based on the evaluation findings the evaluation team made the following recommendations for the British Columbia team, as well as others considering conducting People Living with HIV Stigma Index within the Canadian context:

- ➔ Continue to make efforts to increase representation from areas outside of major urban centres and from the diverse group of key populations affected by HIV.
- ➔ Identify individuals from outside institutions (such as policy makers and health authority representatives) to support the study.
- ➔ Purposively identify time for the team to meet to be able to discuss stigma more generally, particularly how it is experienced by individuals both acquainted with and new to the project.
- ➔ Offer a one- or two-day research methods training to ensure to new team members to ensure everyone has the same basic understanding of community-based research.
- ➔ Provide capacity-building workshops on translating research findings into policy and programs.

## Results

Planning team members brought a diversity of knowledge and perspective from lived realities of HIV, local community organizations, and research/academic experience. Overall, respondents indicated satisfaction with the project, particularly with respect to the need for the study; this echoes other findings and reports that point to how stigma remains a pressing issue in the lives of PLHIV. With regards to team engagement in study activities and decision-making, respondents indicated that they felt they were actively engaged in most areas and indicated areas for greater involvement and further capacity-building. One challenge identified for the planning phase was gaining more diversity from affected-populations including the ability to engage team members who live in more rural and remote areas of the province. While many attempts were made to accurately reflect the demographics of the HIV epidemic in BC on the research team, this continues to be a challenge due to geographic, capacity and technological limitations. Overall, team members found the study planning process as valuable and necessary for addressing HIV stigma in British Columbia. This evaluative process has allowed the team in British Columbia to identify successes of the project thus far and to determine those areas in need of further attention (see Figure 1). Community engagement and capacity-building activities were identified as being integral part to the process and to adhere to the CBR principles.

## Conclusions

Overall, the planning process for the BC Stigma Index has shown genuine respect for CBR principles. Considerations for implementation nationally and for the next phase in BC include enhancing efforts to diversify the team, continuing to prioritize capacity-building, and continuing to engage in evaluation. In community-based research it is imperative that all individuals on the team are provided with the same opportunities to participate and should include additional support for individuals outside urban centers or those with multiple barriers to participation. Clear and concise communications can help increase team member engagement and space needs to be created for everyone to actively participate in the multiple stages of the project. Study process evaluations, such as this, are important tools in conducting community based research.

For more information, please visit:

[www.pacificaidsnetwork.org/stigma](http://www.pacificaidsnetwork.org/stigma)

### BC People Living with HIV Stigma Partners



### Thank You to Our Funders & Supporters



**Acknowledgements:** Phase one of this study was funded by the Canadian Institutes for Health Research the CIHR Centre for REACH in HIV/AIDS, and the Vancouver Foundation. The authors would like to acknowledge all BC People Living with HIV Stigma Index team members for their contributions to the project.

*Conflict of interest disclosure: We have no conflicts of interest.*