

ACCEPTABILITY OF A COMMUNITY-CONTROLLED COMPLAINTS PORTAL FOR HIV STIGMA: CONSULTATIONS WITH PEOPLE LIVING WITH HIV AND COMMUNITY-BASED ADVOCATES

Authors:

Treloar C¹, Melanie LR^{1,2}, Newham B^{1,2}, Cogle A², Cama E¹

¹ Centre for Social Research in Health, UNSW Australia ² National Association of People Living with HIV Australia, Sydney Australia

Background:

Stigma continues to undermine the health and quality of life of people living with HIV. Reducing stigma experienced within health care is a core priority to address to achieve HIV elimination goals. However, making complaints about stigma in health care through formal mechanisms can be very challenging for individuals. This project examined the acceptability of a proposed complaints process for HIV stigma that would place control of the process within the HIV community sector.

Methods:

Focus group discussions were conducted with people living with HIV (24 participants) and community-based advocates working in the HIV sector (12 participants) in Australia. Participants were asked to comment on plans for the proposed community-controlled complaints portal. Data were examined in relation to the theoretical framework of acceptability.

Results:

Participant were broadly supportive of the proposed portal and their perceptions of ethicality (*whether the intervention is “morally good or correct”*) permeated their assessment of all aspects of the proposed portal design and operations. For example, getting input from outside of the “HIV bubble” to understand the perceptions of communities who may not be “flourishing” with HIV was considered an inherent ethical responsibility in portal design. Promoting the portal was seen to rest on careful consideration of who will “own” the portal and resultant data. Participants from HIV organisations indicated the potential usefulness of the portal in “lightening our load” in advocating for people experiencing stigma. People living with HIV saw the benefits in a public facing aspect of the portal and in the sharing of positive experiences (not only complaints) to build community connection.

Conclusion:

Ongoing support is needed to manage the impacts of HIV stigma. Support for a community-controlled stigma portal from the HIV sector and people living with HIV was contingent on a careful and multifaceted understanding of its myriad ethical implications.

Disclosure of Interest Statement:

The Australasian Society for HIV, Viral Hepatitis & Sexual Health Medicine recognises the considerable contribution that industry partners make to professional and research activities. We also recognise the need for transparency of disclosure of potential conflicts of interest by acknowledging these relationships in publications and presentations.

CT has received speaker fees from Gilead Sciences

No pharmaceutical grants were received in the development of this study.