

Research Stream: Social/behavioural science;

Population Focus: People living with HIV;

CONDUCTING ONLINE SURVEY RESEARCH WITH PEOPLE LIVING WITH HIV: LESSONS LEARNED FROM PILOTING THE HIV, HEALTH AND REHABILITATION SURVEY

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Plain Language Summary: We piloted an online self-administered instrument (The HIV, Health and Rehabilitation Survey) developed to describe disability, health conditions, rehabilitation services use and living strategies among people living with HIV (PHAs) in Canada. We describe our lessons learned for conducting an online self-administered survey with PHAs.

Background: Our aim was to describe lessons learned piloting a cross-sectional online electronic self-administered survey with PHAs.

Methods: We piloted the HIV, Health and Rehabilitation Survey, with a sample of adults living with HIV in Canada. Collaborator organizations emailed potential participants to invite them to complete the online questionnaire. The questionnaire was comprised of six components: disability, rehabilitation services use, comorbidities, living strategies use, stigma and social support, demographic and disease characteristics. We solicited feedback on the survey process and instrument in a structured phone interview with respondents. Participant responses were documented verbatim and analyzed using directed content analysis.

Results: At least 56 PHAs were invited to participate. Of the 30 who accessed the survey link, 24 (80%) initiated and 16 (53%) completed the survey. Median age of participants was 51.5 years (range: 34-63), the majority were men (71%), and all were taking antiretroviral therapy. Seventeen respondents participated in post-survey interviews. The majority (67%) completed the questionnaire in 30-45 minutes (range: 10-15 to over 60 minutes). Participants described the survey instrument as comprehensive and well-detailed, indicating content validity in each section. The majority (76%) felt instruction and item wording was clear and easy to understand, and found the use of Lime Survey software easy to navigate. While participants did not intentionally skip items, they felt having a pop-up reminder directing them to accidentally missed items would be useful. Some commented on the length of the instrument as burdensome; others desired more open ended questions to explain their circumstances or leave a comment. Participants were divided on preferences for completing the survey in one anonymous sitting versus a 'save and return' option. Overall, strengths of implementing an online self-administered survey included ease of software use, ability to complete the questionnaire on one's own time at one's own pace, opportunity to obtain geographic variation, and the ability for anonymity. Considerations for future survey implementation include the burden on collaborator organizations to administer the survey electronically, varying computer skills across participants, respondent fatigue, potential neurocognitive challenges among respondents, challenges assessing capacity to consent, and the importance of providing contact information for participants to follow-up if needed.

Conclusion: Results will inform revisions to the instrument and implementation, and provide broader considerations for researchers conducting online survey research with PHAs.

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