

# Conducting Online Survey Research with People Living with HIV: Lessons Learned from Piloting the HIV, Health and Rehabilitation Survey

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# Background

- As adults age with HIV, many are living with physical, social and psychological health-related challenges of HIV, consequences of treatment, and comorbidities associated with aging.
- **Disability:** Any symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion and uncertainty or worrying about the future experienced by an individual.
- Rehabilitation can assist in managing the health challenges (or disability) associated with HIV, and complex comorbidities.
- **Rehabilitation:** Any service or provider that addresses or prevents impairments, activity limitations or participation restrictions experienced by an individual.
- We established the *HIV, Health and Rehabilitation Survey* to establish a profile of disability, comorbidities, rehabilitation services use, and living strategies among adults with HIV in Canada.

# Purpose



To describe the lessons learned from piloting a cross-sectional online self-administered instrument  
*(HIV, Health and Rehabilitation Survey)*  
with adults living with HIV

# Methods



- We piloted the *HIV, Health and Rehabilitation Survey* with adults living with HIV in Canada.
- Survey Purpose
  - To describe disability, comorbidities, rehabilitation services use and living strategies among adults living with HIV in Canada
- Inclusion Criteria
  - Adults (18 years of age or older), living with HIV in Canada, able to read and understand English who have access to internet and email.
- Community-Integrated Approach
  - Five collaborator organizations and knowledge user organizations
  - British Columbia, Manitoba, Ontario, Nova Scotia and nationally

# Methods: Survey Instrument



## 1) Disability

- HIV Disability Questionnaire – presence, severity and episodic nature of disability

## 2) Rehabilitation Services Use

- Traditional Rehabilitation Services - Occupational therapy (OT), physical therapy (PT), speech-language pathology (SLP), physiatry
- Complementary and Alternative Medicine (CAM)
- AIDS Service Organizations (ASOs) and Community-Based Service Organizations (CBOs)

## 3) Comorbidities

- Any condition that coexists with HIV infection
- Currently living with and whether comorbidities existed prior to HIV diagnosis

## 4) Living Strategies

- Behaviors, attitudes and beliefs adopted to deal with HIV and resulting disability

## 5) Social Support and Stigma

## 6) Demographic and Disease Characteristics

- Age, gender, length of time since diagnosis, ARV use, geographical status, etc.

# Methods: Recruitment



## ■ Part A – Pilot Survey Implementation

- Collaborator and Knowledge User Organizations
- Each emailed 7-15 clients inviting to participate in the pilot survey
- Administered electronically using Lime Survey software and modified Dillman Tailored Design Method (December 2011-February 2012)
  - Initial invitation email with link to survey
  - Thank you / reminder email (1 week later)

## ■ Part B - Telephone Interview

- Structured, 30 minute interview
- To obtain feedback on the survey process and instrument (how well it captured disability, types of health and rehabilitation services used, and living strategies used to address health challenges)
- \$40 gift card token of appreciation
- Responses documented verbatim
- Analysis - directed content analytical techniques

# Results: Part A Pilot Survey



**HIV, Health and  
Rehabilitation  
Survey**

## ■ Response Rate

- At least 56 people with HIV were invited to participate (4 reminders to organizations)
- *View rate*: 30 accessed the survey link (53%)
- *Participation rate*: Of those who viewed, 24 (80%) initiated the survey
- *Completion rate*: Of those who viewed, 16 (53%) completed the survey

## ■ Demographic Characteristics

- Median age: 51.5 years (Range: 34-63)
- Majority were men (71%)
- Metropolitan geographic area (500,000 or more) (88%)
- All taking antiretroviral therapy
- Represented British Columbia, Alberta, Manitoba, Ontario, Nova Scotia
- **Comorbidities**: Mental health conditions (58%), joint pain (46%), muscle pain (42%), addiction (29%)

# Results: Part B Interviews



**HIV, Health and  
Rehabilitation  
Survey**

- **Participants**
  - 17 provided feedback on the pilot survey (16 interviews; 1 email)
  - Of the 17 who provided feedback, 3 did not complete the survey
- **Time to Complete the Survey**
  - Majority (67%) completed in 30-45 minutes (Range: 10-15 to over 60 min)
- **Overall Strengths**
  - ‘comprehensive’, ‘to the point’, ‘detailed’, ‘straight forward’ indicating content validity in each section
- **Drawbacks**
  - Survey instrument length: ‘very long’, language was ‘too wordy’.
  - Unable to suggest areas to pare down items

**Lessons Learned:** Double-edged sword - comprehensiveness of survey content balanced with length of time to complete. While some felt it was burdensome others wanted more (and open ended) items to explain further

# Results: Part B Interviews



**HIV, Health and  
Rehabilitation  
Survey**

- **Ease of Usage and Format**

- Majority (76%) felt instructions and item wording were clear, easy to understand

- **Software**

- Lime Survey – easy to navigate
- Pop-up reminder directing them to accidentally missed items would be useful
- Ability to skip items
- Ability to navigate forwards and backwards
- Completion proportion rate (%) at top of survey
- No timeout factor – ability to complete at own pace on own time

**Lessons Learned:** Consider barriers with an online survey including access to computer and internet, varying computer and language skills will result in variation in time to complete the survey

# Results: Part B Interviews



- **Token of Appreciation**
  - Should not be less than \$20
  - Liked having a choice of electronic gift card
  
- **Additional Observations**
  - Instrument: comprised of different measures, each refer to a different timeframe (challenges experienced today versus past week, month)
  - Way in which respondents interpret an item can vary
  - Telephone Interviews: identified some challenges with understanding the survey items

**Lessons Learned:** Challenges associated with measurement (accuracy of responses) - variability in item interpretation;  
Inability to have discussion of informed consent

# Strengths of Online Survey

## Lessons Learned

- Pilot – provided key information to the refinement of the survey instrument and implementation process
- Enabled collaborator and knowledge user organizations to become familiar with the implementation process and provide feedback throughout
- Software easy to use
- Allows participants to complete questionnaire on own time at own pace
- Anonymity
- Ability to obtain geographic variation in participants at low cost



# Considerations for Future

## Lessons Learned

- Consider burden of Modified Dillman Method on Collaborator and Knowledge User Organizations to administer electronically
- Consider access to computer and internet; varying computer skills across participants
- Respondent fatigue
- Potential neurocognitive challenges
  - Challenges assessing capacity to consent
  - Interpretation of survey instrument items
- Consider risks of triggering emotional response
  - importance of providing contact information for participants

# Conclusions



- Online self-administered questionnaires are becoming increasingly popular in survey research
- Results will inform revisions to the *HIV, Health and Rehabilitation Survey* Instrument and Implementation
- May provide broader considerations for others interested in conducting online survey research with adults living with HIV.
- Next Steps
  - HIV, Health and Rehabilitation Survey – Full Implementation
  - Funded by CIHR

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