

# Establishing a Profile of Disability and Rehabilitation Services Use Among People Living with HIV in Canada: Lessons Learned from Piloting the HIV, Health and Rehabilitation Survey (HHRS)

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# Purpose



To describe the lessons learned from piloting the

**HIV Health and Rehabilitation Survey (HHRS)**

with adults living with HIV in Canada.

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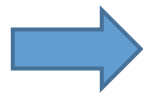
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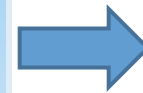
**HIV Health and Rehabilitation Survey  
(HHR)**

with adults living with HIV in Canada.

What is the  
HHR?



Who is the  
HHR?



What did we  
learn in the  
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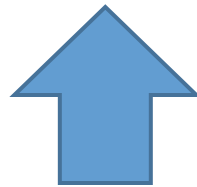
As adults age with HIV,  
many are living with  
**physical, social and psychological health-related  
challenges**  
resulting from HIV,  
consequences of treatment,  
and comorbidities associated with aging.

## **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.

## **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:**

Any service or provider that addresses or prevents impairments, activity limitations or participation restrictions experienced by an individual.

However,  
the nature and extent of  
**disability,**  
**rehabilitation services use,**  
**and living strategies**  
among adults with HIV  
**is unknown**



# Purpose of the HHRS



To establish a comprehensive profile of **disability** experienced by PHAs in Canada and determine how intrinsic and extrinsic **contextual factors** such as **comorbidities**, **rehabilitation services use** and **living strategies** influence the disability experience.

# About the HHRS



## Study Design

- Cross-sectional self-administered **online survey** using modified Dillman approach

## Inclusion Criteria

- Adults (18 years of age or older), living in Canada, able to read and understand English who have access to internet and email.

## Community-Engaged Approach

- 8 collaborator organizations and knowledge user organizations in BC, Manitoba, Ontario, Nova Scotia, Nfld and Labrador

# About the Survey



## 1) Disability

- HIV Disability Questionnaire

## 2) Rehabilitation Services Use

- Occupational therapy , physical therapy , speech-language pathology, physiatry
- Complementary and Alternative Therapies
- AIDS Service Organizations and Community-Based Service Organizations

## 3) Comorbidities

- Any condition that coexists with HIV infection

## 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.

# About Recruitment



- 8 Collaborator and Knowledge User Organizations email / e-blast to organization client list (modified Dillman)
  - Initial email invitation
  - Thank you / reminder
  - Second thank you / reminder
  - Final (last chance) thank you / reminder
- Supplemented by posters, recruitment cards, word of mouth
- \$25 Token of Appreciation gift card

# About Recruitment



## Questionnaire administered via Lime Survey

- Estimated ~30-40 minutes to complete the HHRS

## Sample Size Estimation

- Based on the power needed for the structural equation modeling analysis
- Targeted sample size
  - 3575 invitations
  - to result in 1400 complete responses

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To describe the lessons learned from piloting the HIV Health and Rehabilitation Survey (HHRIS) with adults living with HIV in Canada.

What is the HHRIS?

Who is the HHRIS?

What did we learn in the pilot?

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To describe the lessons learned from piloting the HIV Health and Rehabilitation Survey (HHRS) with adults living with HIV in Canada.



# HHSR Team

## Researchers

Kelly O'Brien

University of Toronto

Catherine Worthington

University of Victoria

Patty Solomon

McMaster University

Francisco Ibanez-Carrasco

Ontario HIV Treatment Network

Jacqueline Gahagan

Dalhousie University

Stephanie Nixon

University of Toronto

Steven Hanna

McMaster University

Brenda Merritt

Dalhousie University



## Knowledge Users

Elisse Zack / Le-Ann Dolan (Principal Knowledge User)

Canadian Working Group on HIV and Rehabilitation (CWGHR)

Will Chegwidan

Barts and the London NHS Trust

Patriic Gayle

Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) / Three Flying Piglets

Larry Baxter

CWGHR



Greg Robinson

CWGHR



Tara Carnochan / Katie Kitchen

Nine Circles Community Health Centre

Rosalind Baltzer-Turje / Patrick McDougall

Dr. Peter AIDS Foundation

## Research Coordinator

Nkem Iku (University of Toronto)



University of Victoria





# HHRS Team - Collaborators

Positive Living Society of British Columbia  
Neil Self / Glyn Townson



Casey House  
Soo Chan Carusone



CASEY HOUSE

Toronto People with AIDS Foundation  
Murray Jose



AIDS Coalition of Nova Scotia  
Laura Toole



Direction 180  
Cindy MacIsaac



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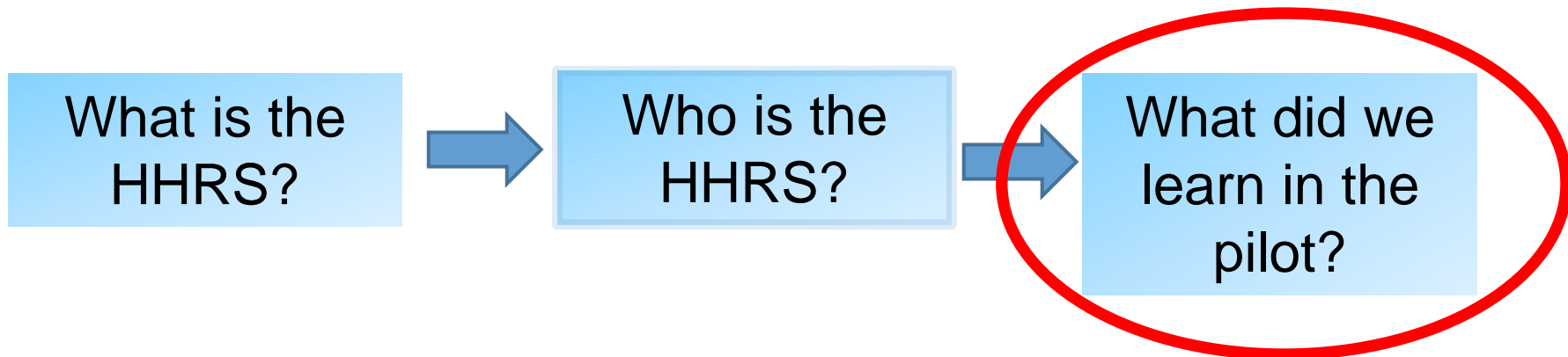
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# How did we do the pilot?



## Pilot 1

Dec/11 – Feb/12

- Survey implementation
- Follow-up telephone interviews

## Pilot 2

Jan – Mar/13

- Survey implementation

# How did we do the pilot?



## **Pilot 1**

**Dec/11 – Feb/12**

- Survey implementation
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## **Pilot 2**

**Jan – Mar/13**

- Survey implementation

## Pilot #1 - Survey Implementation

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

## Pilot #1 – Follow-Up Telephone Interview

- Structured 30-min interview
- 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
- Analyzed using directed content analysis

# Pilot #1 - Who took part



- At least 56 people with HIV were invited to participate
- *View rate*: 30 accessed the survey link (53%)
- *Participation rate*: Of those who viewed, 24 (80%) initiated the survey
- *Survey completion rate*: **Of those who viewed, 16 (53%) completed the survey**
- *Interviews*: 17 provided feedback on the pilot survey, 14 had completed the survey and 3 had not



# Pilot #1 - Who took part



## Demographic Characteristics

- Median age: 51.5 years (Range: 34-63)
- Majority were men (71%)
- Metropolitan geographic area (500,000 or more) (88%)
- Diagnosed prior to 1996 (67%)
- All taking antiretroviral therapy
- From BC, Alberta, Manitoba, Ontario, Nova Scotia
- Majority rated health status as 'very good' (33%) or 'good' (38%)
- **Comorbidities:** Mental health conditions (58%), joint pain (46%), muscle pain (42%), addiction (29%)

# Pilot #1 - What did we learn?

**HIV, Health and  
Rehabilitation  
Survey**

**Time to Complete the Survey:** 67% completed in 30-45 minutes, range: 10-60 mins

**Overall Strengths:** 'comprehensive', 'to the point', 'detailed', 'straight forward' indicating content validity in each section

**Drawbacks:** Survey instrument length 'very long' and language was 'too wordy', but unable to suggest how to pare down

## **Lesson:**

- Tension between comprehensiveness and feasibility of survey.
- While some felt survey questionnaire was burdensome, others wanted more items (and open-ended items) to explain further.

# How did we do the pilot?

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## **Pilot 1**

Dec/11 – Feb/12

- Survey implementation
- Follow-up telephone interviews

## **Pilot 2**

Jan – Mar/13

- Survey implementation

# Pilot #2 - Survey Implementation



- Our Collaborator and Knowledge User Organizations emailed 4-5 clients inviting them to participate in the pilot survey
- Administered electronically using Lime Survey software and modified Dillman Tailored Design Method (January – March 2013)
  - Initial invitation email with link to survey
  - Thank you / reminder email (1 week later)
  - Final thank you / reminder (2-4weeks later)
- \$25 e-gift card (Amazon, Best Buy, Starbucks, Bath and Body Works)
- 1-855 number if any questions or feedback

# Pilot #2 - Who took part?



## ■ Response Rate

- 30 PHAs were invited to participate
- 3 stage emails, in-person, snowball sampling
- *View rate*: 23 accessed the survey link (77%)
- *Participation rate*: Of those who viewed, 20 (87%) were eligible & agreed to participate
- *Completion rate*: **Of the 20 eligible who viewed, 17 (85%) completed the survey.**

Of the 30 invited to participate, 17 (57%) completed the survey

## ■ Demographic Characteristics – **Similar to Pilot #1**

# Pilot #1&2: Strengths

- Pilot refined **survey instrument** and **recruitment process**
- Collaborator and knowledge user organizations became familiar with methods and provided key FB on how to improve
- Lime Survey Software was easy to use
- Allows participants to complete questionnaire on own time at own pace anonymously
- Ability to obtain geographic variation among participants at low cost

# Pilot #1&2: Improvements

- Making language even more **straightforward**, add pop-ups, and add definitions
- Add a **4<sup>th</sup>** Dillman Stage
- Important to mitigate burden of Modified Dillman Tailored Design Method on Collaborator and Knowledge User Organizations
- Anticipating varying computer skills across participants
- Respondent burden and fatigue
- Potential neurocognitive challenges
  - Challenges assessing capacity to consent
  - Challenges understanding survey instrument items
- Importance of providing emotional support for participants if response triggered
- How to ensure data security

# Next steps



## For the (big) HHRS Team:

- Academic paper under review
- Revisions to survey underway
- Full launch of the HHRS in Fall 2013!

## For you:

- **Individuals:** spread the word
- **Organizations:** consider joining the recruitment network



# Acknowledgements

We thank the participants who were involved in the pilot phases, and Nicole Gervais for conducting the interviews.

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## For more information:

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