Supporting Safe HIV Disclosure:

Canadian Webinar Series on Implementing the WHO Guidelines on Sexual and Reproductive Health and Rights for Women Living with HIV

Date: Thursday, November 16, 2017
Time: Time: 9-10:30am PST / 10-11:30am MST /12-1:30pm EST / 6-7:30pm Geneva
Link: https://attendee.gotowebinar.com/register/18421540 3037620737

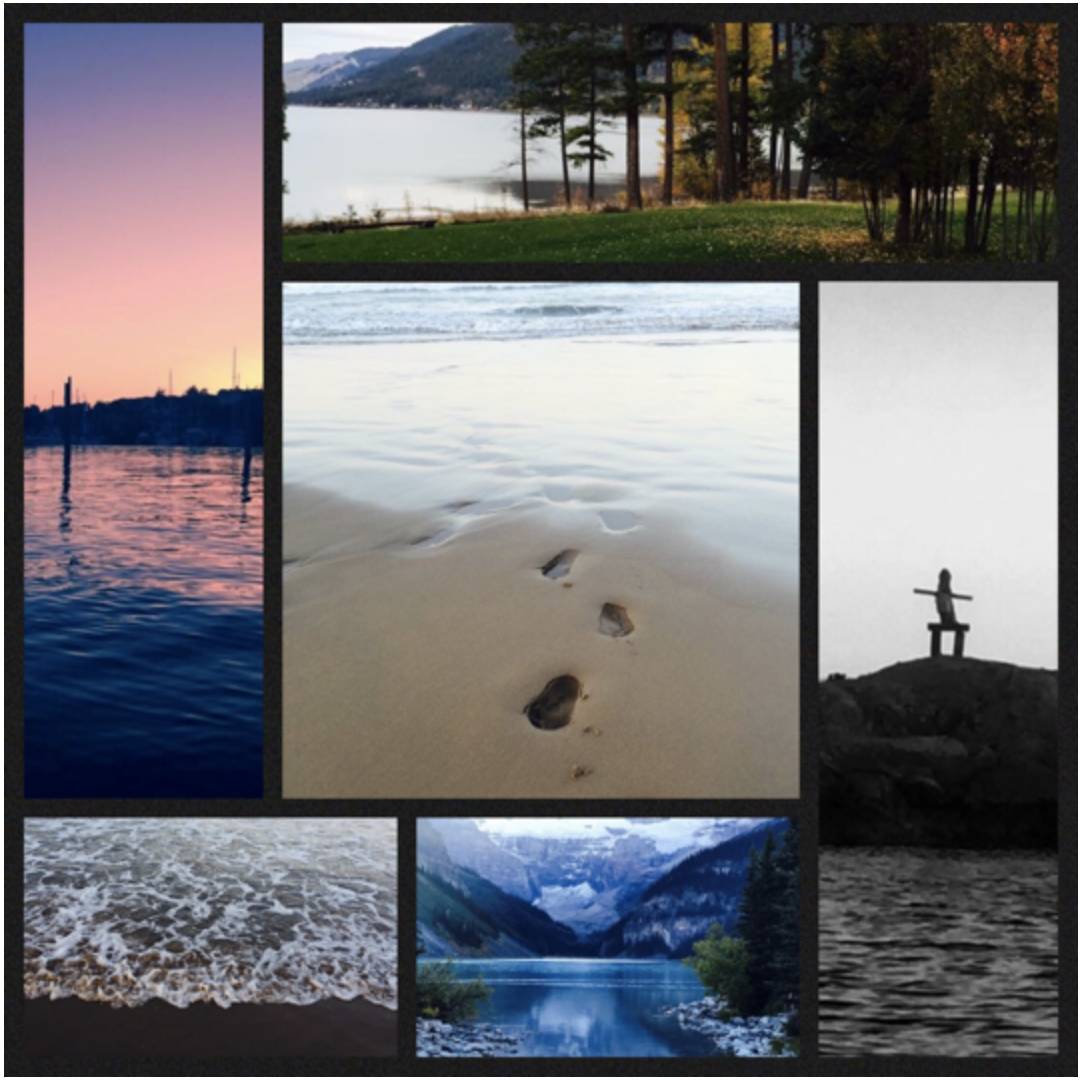
Webinar series hosted in collaboration with:

WHO HRP, CHIWOS, Canadian Positive People's Network, Oak Tree Clinic, Women's Health in Women's Hands, Canadian Aboriginal AIDS Network and the IBP Initiative

Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada

This research was supported by the Social Sciences and Humanities Research Council of Canada.

Welcome



Remembrance

In our Canadian Study involving 1422 Women with HIV

48 Women have died to date

We hold an Annual Remembrance Ceremony on December 1st in Toronto, please join us

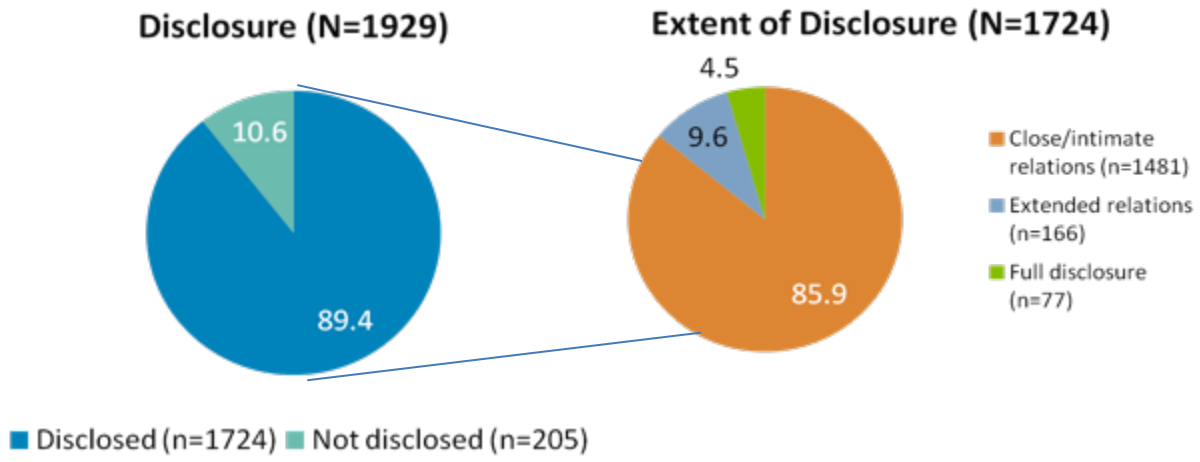
Topic at hand

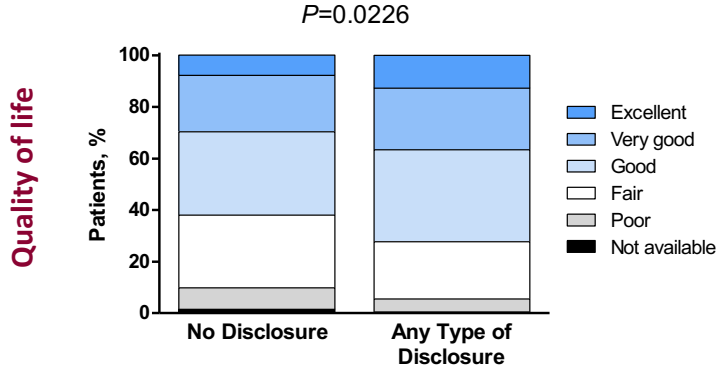
- **HIV disclosure** - the process of telling someone that you are living with HIV
  - Family, friends, colleagues, healthcare workers, strangers, etc.
  - Voluntary vs. involuntary
  - Complex phenomenon (much consideration & potential impact)

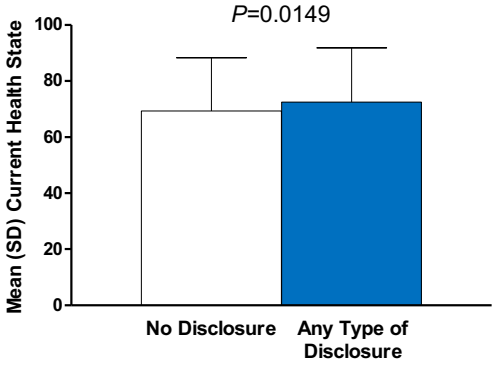
- **Many related issues** – self-worth, worry, fear, stress, stigma, discrimination, criminalization, depression, isolation, relationships, sexual life, trauma, violence, retention in care, adherence, quality of life, etc.

ELLA Study – Cross-sectional study

1929 women with HIV surveyed in 4 regions of the world







Loutfy et al. AIDS Pt Care & STDs. 2015

Webinar Objectives

- **Provide an overview** of current research about **HIV disclosure** in the Canadian context using data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).
- **Respond** to recommendations provided by the WHO Consolidated Guidelines of the Sexual and Reproductive Health and Rights of Women living with HIV (attached).
- **Introduce a toolkit** developed by women living with HIV and stakeholders for health and social service providers to support safer HIV disclosure.
- **Gain insights** from women living with HIV to highlight gaps in research and priority areas for further attention.
- **Develop an action plan** on to support the sexual and reproductive health and rights of women living with HIV in the Canadian context, including actions to support safe HIV disclosure

Today's Speakers

Kerrigan Johnson

Dr. Mona Loutfy

Dr. Manjulaa Narasimhan

Dr. Angela Kaida

Valerie Nicholson

Jasmine Cotnam

Sandra Godoy

Marvelous Muchenje

Overview of the Agenda

Time	Title of Presentation	Presenter	Affiliation
9:10-9:20 PST 10:10-10:20MST 12:10-2:10EST	Consolidated guidelines on sexual and reproductive health and rights of Women Living with HIV	Dr. Manjulaa Narasimhan	World Health Organization – Department of Reproductive Health
9:20-9:30 PST 10:20-10:30MST 12:20-2:30EST	Research overview: Disclosure in the context of the criminalization of HIV non-disclosure among women living with HIV in Canada	Dr. Angela Kaida, Valerie Nicholson	Simon Fraser University, Canada Research Chair Woman Warrior, CHIWOS PRA
<u>Implementation</u> 9:30-10:05 PST 10:30-11:05MST 12:30-1:05EST	Indigenous communities HIV Disclosure to sexual Partners	Jasmine Cotnam	Canadian Aboriginal AIDS Network (CAAN)
	"To Tell or Not to Tell:" Barriers and Facilitators for HIV Disclosure	Marvelous Muchenje	Canadian Coalition to Reform HIV Criminalization, Women's Health in Women's Hands Community Health Centre
	The HIV-Positive Sero-Status Disclosure Support Model	Sandra Godoy	Women's Health in Women's Hands Community Health Centre
10:05-10:30 PST 11:05-11:30MST 1:05-2:30EST	Discussion & Next Steps		

Housekeeping

1. Asking questions

- During presentations, please submit any questions using the text feature of the application
- We have allotted 20 minutes at the end of the webinar for discuss and Q&A
- If you are joining us on the phone, please send any comments or questions to Ontario CHIWOS coordinator Mina (mina.kazemi@wchospital.ca)
- If we do not get to answer or discuss all questions posed during the webinar, the organizing team will collate the questions and send responses to all webinar attendees after the webinar. Questions & answers will also be posted online with the recorded version of the webinar.
- Please type any technical difficulties into the text feature.

2. Webinar recording

- This webinar will be recorded and posted on the IBP Channel and the WHO RHR Youtube Channel. Links will be posted at the end of the webinar.

3. Handouts

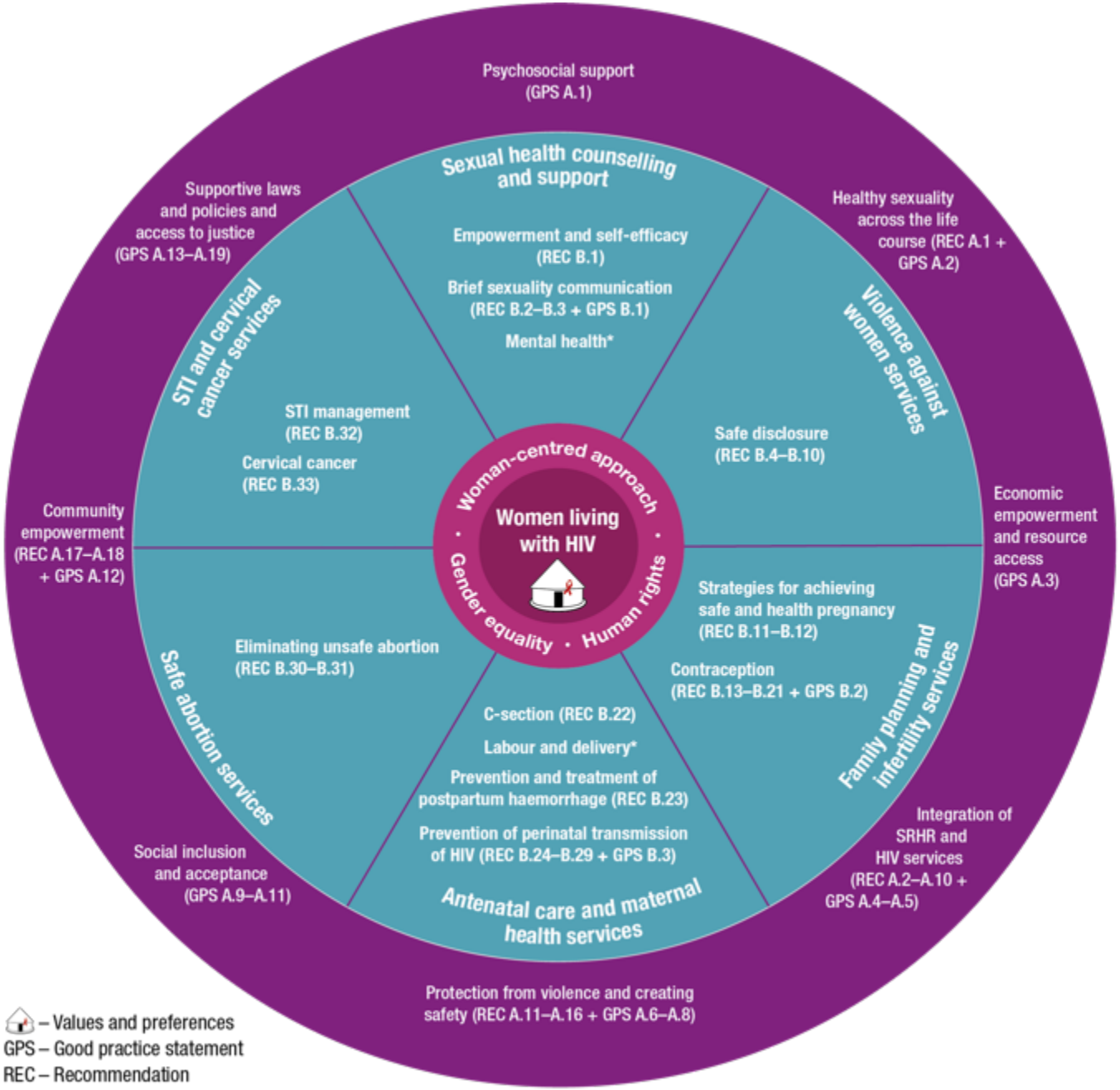
- There are handouts that you can download for your own viewing and reference

Conflict of Interest

Today's webinar presenters have no conflicts of interest to declare.

Consolidated guideline on **sexual and reproductive health and rights of women living with HIV**

March 18



– Values and preferences
GPS – Good practice statement
REC – Recommendation
– Enabling environment
– Health interventions

C-section: caesarean section; SRHR: sexual and reproductive health and rights; STI: sexually transmitted infection.

* For sections on "Mental health" and "Labour and delivery", this guideline does not include any RECs or GPSs but refers to existing WHO guidance.

NEW recommendations on safe disclosure

REC B.4 (NEW): WHO recommends that policy-makers and service providers who support women living with HIV who are considering voluntary HIV disclosure should recognize that many fear, or are experiencing, or are at risk of intimate partner violence.	Strong recommendation, low-quality evidence
REC B.5 (NEW): WHO recommends that interventions and services supporting women living with HIV who are considering voluntary HIV disclosure should include discussions about the challenges of their current situation, the potential associated risk of violence, and actions to disclose more safely, and facilitate links to available violence prevention and care services.	Strong recommendation, low-quality evidence

REC B.6: Adolescents should be counselled about the potential benefits and risks of disclosure of their HIV status to others and empowered and supported to determine if, when, how and to whom to disclose.

REC B.7: HIV testing services for couples and partners, with support for mutual disclosure, should be offered to individuals with known HIV status and their partners.

REC B.8: Initiatives should be put in place to enforce privacy protection and institute policy, laws and norms that prevent discrimination and promote tolerance and acceptance of people living with HIV. This can help create environments where disclosure of HIV status is easier.

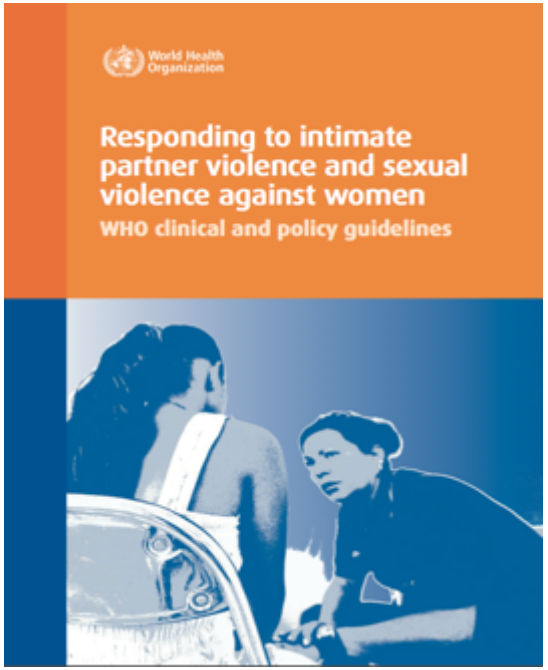
REC B.9: Children of school age should be told their HIV positive status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure.

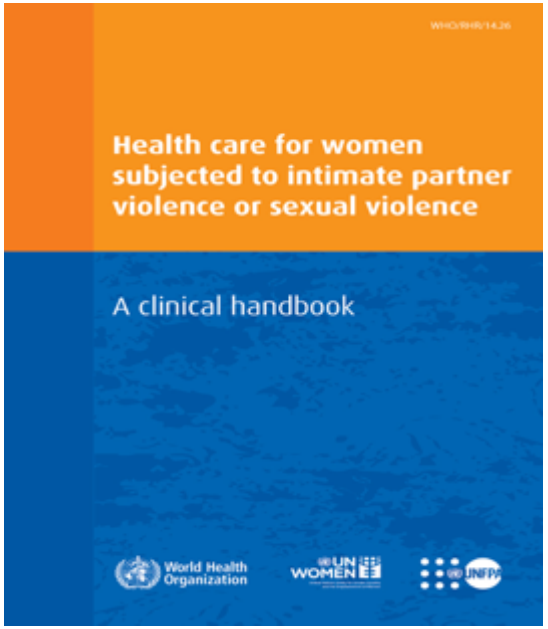
- Policy-makers & service providers should recognize that many considering HIV disclosure either fear, or are experiencing or are at risk of intimate partner violence (Strong, low-quality)

- Interventions & services should:
  - ✓ include discussions about the challenges of their situation, potential risk of violence, and actions to disclose more safely; &
  - ✓ facilitate links to available violence prevention & care services

  (Strong, low-quality)

Avni Amin – amina@who.int
http://www.who.int/reproductivehealth/topics/violence/hiv/en/





Research overview: Disclosure in the context of the criminalization of HIV non-disclosure among women living with HIV in Canada

By: **Valerie Nicholson** and
Dr. Angela Kaida,
on behalf of the
CHIWOS Research Team

Canadian Webinar Series on SRHR of women living with HIV

November 16, 2017

CHIWOS
Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada
Canadian HIV Women's Sexual and Reproductive Health Cohort Study

Acknowledgements

We would like to thank…

- All the women living with HIV who participate in CHIWOS;
- The national team of Peer Research Associates, Co-investigators and Collaborators;
- The Steering Committee, Community Advisory Boards, and Aboriginal Advisory Board;
- The BC Centre for Excellence in HIV/AIDS for data support and analysis;
- Our affiliated studies: CANOC, REACH, OSC;
- And all our partnering organizations who support study recruitment and operations.
- **Our funders: CIHR Institute of Gender and Health, the CIHR Canadian HIV Trials Network (CTN 262), the OHTN, and the Academic Health Science Centres Alternative Funding Plans Innovation Fund**;

•Thank you to the following organizations who have partnered with CHIWOS to provide interview space:

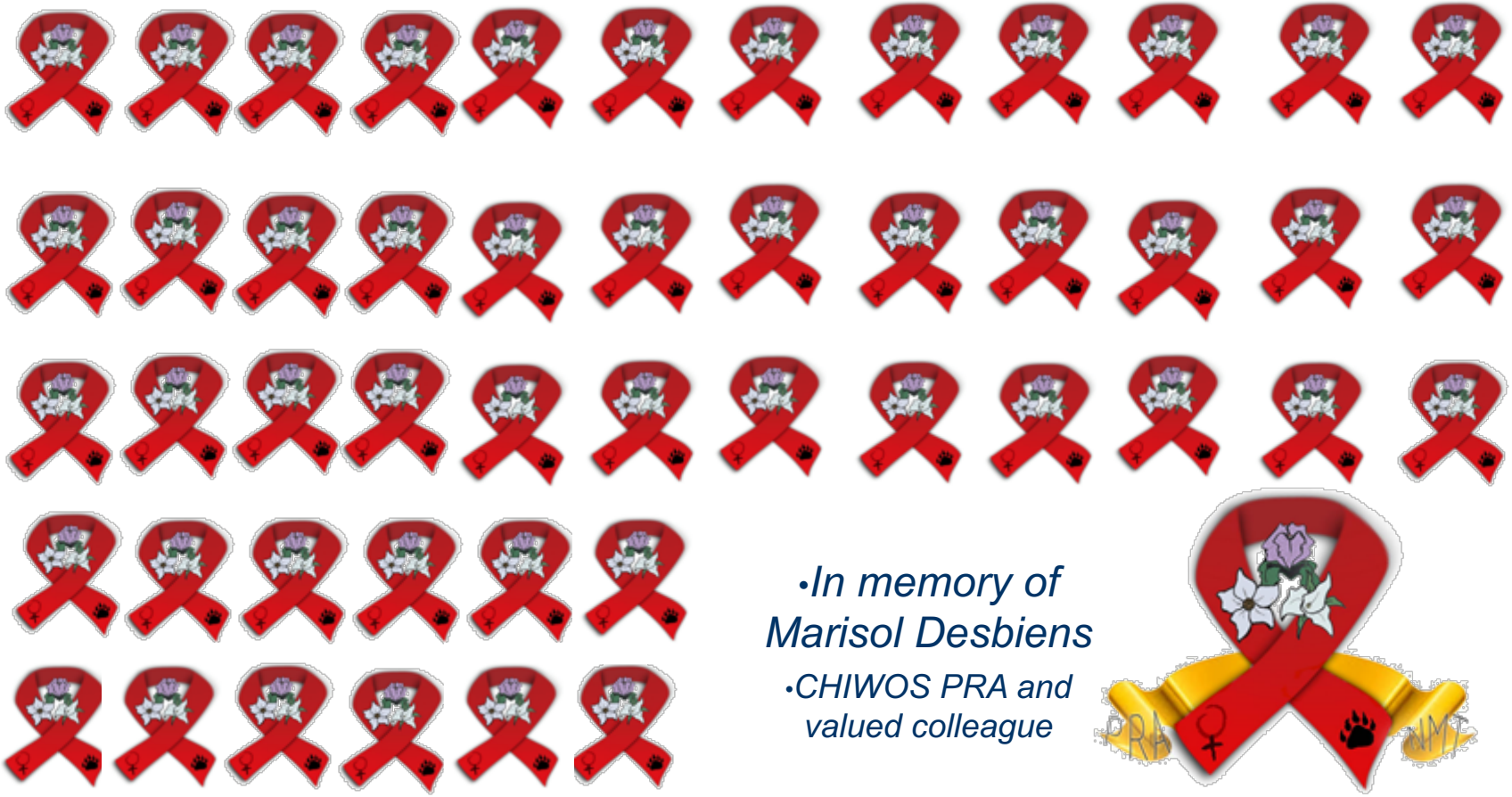
•In **BC**: Oak Tree Clinic at BC Women's Hospital, AIDS Vancouver Island, BC Centre for Excellence in HIV/AIDS, Cool Aid Community Health Centre, Downtown Community Health Clinic, Keys Housing and Health Solutions (Positive Haven), Living Positive Resource Centre, Positive Living Fraser Valley, Positive Women's Network (closed), Positive Living North, and Vancouver Island Persons with AIDS Society.

•In **ON**: 2-Spirited People of the 1st Nations; 519 Community Centre; ACCKWA; Africans in Partnership Against AIDS (APAA); AIDS Committee of Durham Region; AIDS Committee of Guelph and Wellington County; AIDS Committee of Simcoe County; AIDS Network Hamilton; Alliance for South Asian AIDS Prevention; Black Coalition for AIDS Prevention; Bruce House; Casey House; Centre Francophone; Elevate NOW; Fife House; Hemophilia Ontario; HIV/AIDS Regional Services (HARS); Maggie's: Toronto Sex Worker's Action Project; Peel HIV Network; Positive Living Niagara; Prisoners with AIDS Support Action Network; Réseau Access Network; Toronto PWA Foundation; Women's Health in Women's Hands; Children's Hospital of Eastern Ontario; Kingston Hotel Dieu Hospital; Health Sciences North, Sudbury Regional Hospital, HAVEN Program; Lakeridge Health; Maple Leaf Medical Clinic; McMaster Family Practice; Ottawa General Hospital; Riverside Family Health Team; SIS Clinic, Hamilton Health Sciences; St. Joseph's Healthcare London; St. Michael's Hospital; Sunnybrook Health Sciences Centre; Toronto East General Hospital; Toronto General Hospital; William Osler Health System; Windsor Regional Hospital, HIV Care Program.

•In **QC**: ACCM; L'ARCHE de l'Estrie; ASTT(e)Q; BLITS; BRAS-Outaouais; CACTUS; CASM; Centre Sida Amitié; Corporation Félix Hubert d'Hérelle; COCQ_SIDA; Fondation d'Aide Directe-SIDA Montréal; GAP-VIES; GEIPSI; M.A.I.N.S-Bas St-Laurent; Maison Plein Coeur; Maison Dominic; Maison du Parc; Maison Re-Né; MIELS-Québec; Le MIENS Chicoutimi; Portail VIH/sida du Québec; Sidaction Mauricie; Sida-Vie Laval; Stella, l'amie de Maimie.

Acknowledgments

We honour and remember the 48 women living with HIV who participated in CHIWOS from across Canada who have passed away.



- *In memory of Marisol Desbiens*
- *CHIWOS PRA and valued colleague*

HIV disclosure: Consequences and context

- When women can safely disclose their HIV status, disclosure is associated with:
  - Fewer barriers to accessing HIV care (Loutfy AIDS Patient Care STDS. 2016)
  - Improved ART adherence (Stirratt AIBE 2006)
  - Better quality of life (Loutfy AIDS Patient Care STDS. 2016)
  - Reduced HIV transmission risks (Pinkerton, AIBE 2007)
- Disclosure must, however, be contextualized within the woman's life.
- Disclosure can lead to (more) violence, fear, dissolution of relationships, abandonment, stigma, and discrimination (Gielen J Urban Health 2000)
  - 80% of women with HIV in Canada have experienced violence in adulthood (Logie 2017)
  - Violence both compromises ability to disclose and can be manifested through the experience of disclosure
- In Canada where HIV non-disclosure is criminalized there are additional expectations, barriers, and consequences to disclosure.

CHIWOS

Criminalization of HIV non-disclosure in Canada

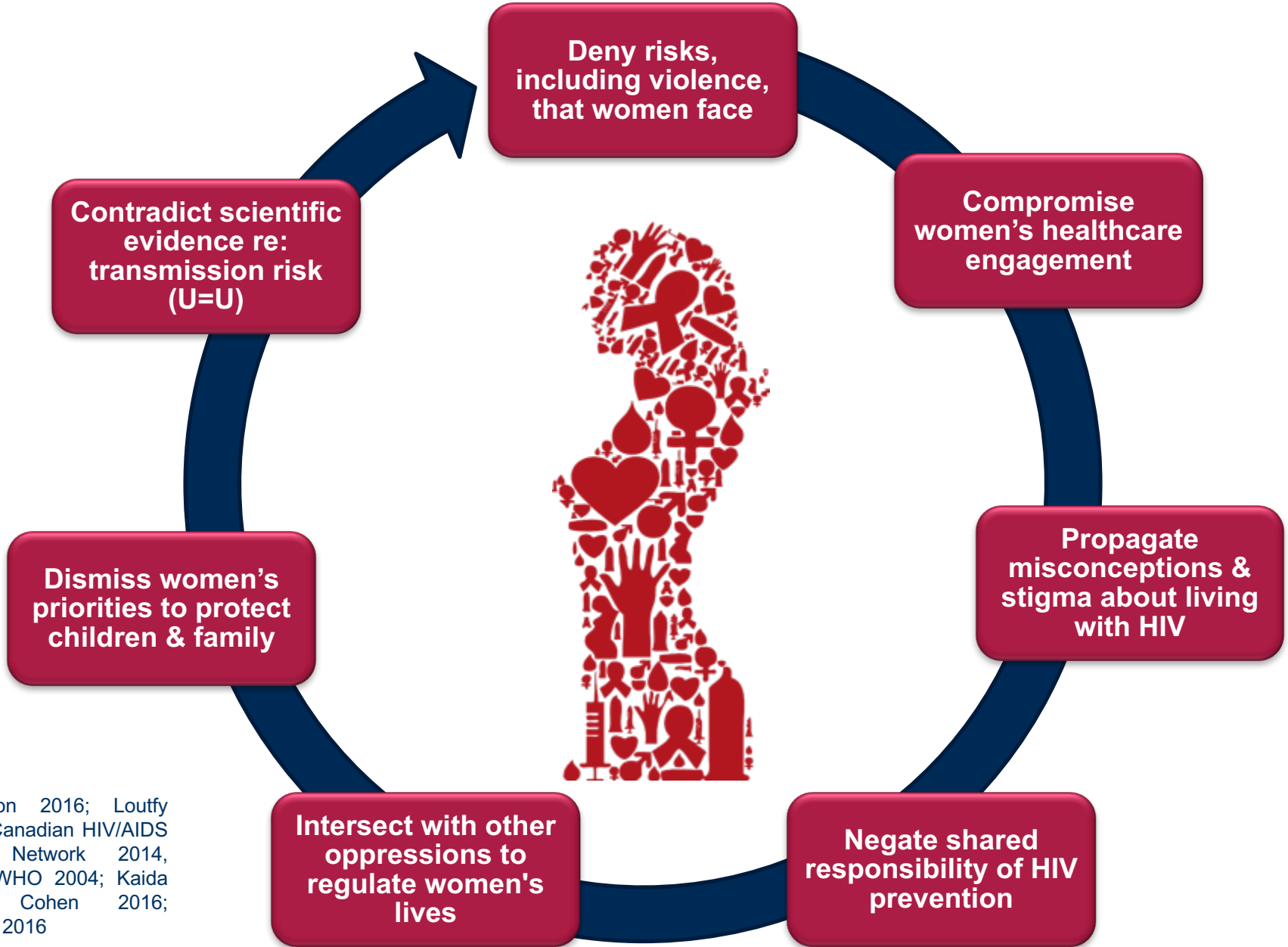
- People living with HIV can face charges for failing to disclose their HIV status to sexual partners prior to sex that that poses a "realistic possibility of HIV transmission" (R v. Mabior, R v. DC (2012); Canadian HIV/AIDS Legal Network, 2017)
  - Based on a legal interpretation of HIV transmission risk
  - Regardless of transmission or intent to transmit
  - Duty to disclose averted in the case of condom-protected vaginal sex with a low HIV plasma viral load (defined as <1500 copies/mL)

- No HIV-specific laws
  - Sexual assault laws most commonly applied
  - Conviction can result in imprisonment and registration as a sex offender

- Legal and social expectations of disclosure are not gendered and do not function to increase disclosure nor safer sex practices (O'Byrne 2011)

CHIWOS

Expectations of disclosure are not gendered



Patterson 2016; Loutfy 2014; Canadian HIV/AIDS Legal Network 2014, 2017; WHO 2004; Kaida 2015; Cohen 2016; Rodger 2016

Under current legal requirements for non-disclosure, women are two-fold more likely to face a legal obligation to disclose their HIV status to sexual partners compared to men.

Table 2: Patterns of condom use stratified by plasma HIV-1 RNA viral load (< 1500 v. ≥ 1500 c/mL) among 176 male and female people living with HIV who inject drugs

Participants' condom use, %	Viral load < 1500 c/mL, *n* (%)	Viral load ≥ 1500 c/mL, *n* (%)
All (*n* = 176)		
100	99 (56)	7 (4)
< 100	67 (38)	3 (2)
Male (*n* = 99)		
100	64 (65)	2 (2)
< 100	33 (33)	0 (0)
Female (*n* = 77)		
100	35 (45)	5 (7)
< 100	34 (44)	3 (4)

CMAJ OPEN
Research

Prevalence and predictors of facing a legal obligation to disclose HIV serostatus to sexual partners among people living with HIV who inject drugs in a Canadian setting: a cross-sectional analysis

Sophie Patterson MBChB, Angela Kaida PhD, Paul Nguyen PhD, Sabina Dobrer MA, Gina Ogilvie MD, Robert Hogg PhD, Thomas Kerr PhD, Julio Montaner MD, Evan Wood MD, M.-J. Milloy PhD

CHIWOS

Research questions

How prevalent are worries about disclosure among women living with HIV in Canada?

Are women living with HIV aware of the current legal expectations of disclosure?

Do women have the information that they need and deserve about the law in Canada?

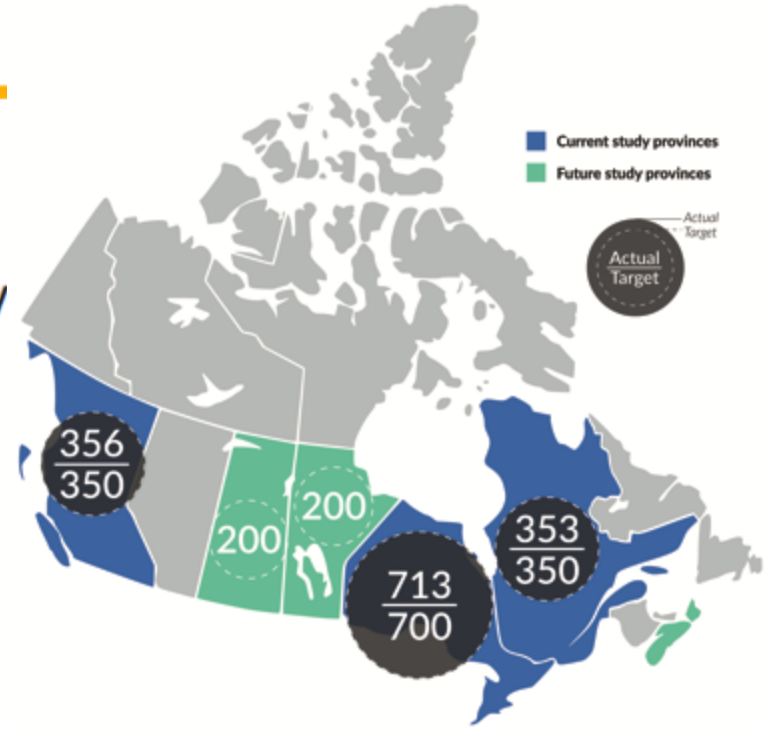
CHIWOS

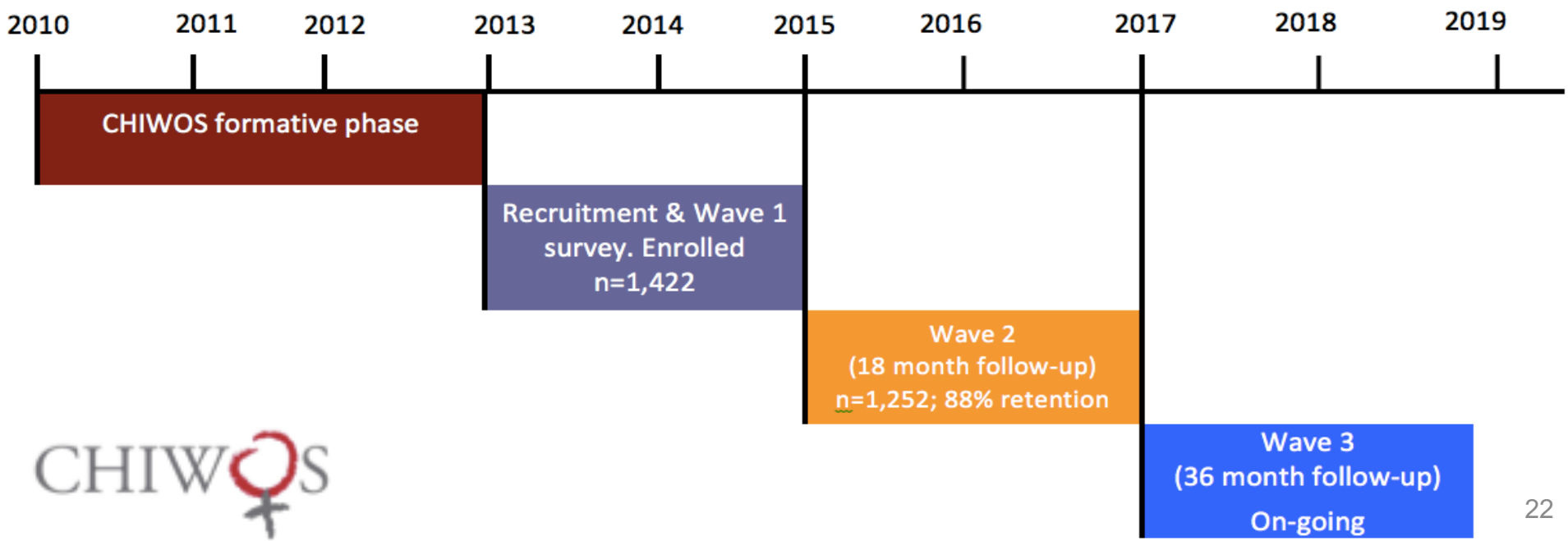
PLOS | ONE

RESEARCH ARTICLE

Cohort profile: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)

Mona Loutfy[1,2,3]*, Alexandra de Pokomandy[4,5], V. Logan Kennedy[1], Allison Carter[6,7], Nadia O'Brien[4], Karène Proulx-Boucher[5], Erin Ding[7], Johanna Lewis[1,8], Valerie Nicholson[6], Kerrigan Beaver[1], Saara Greene[9], Wangari Tharao[10], Anita Benoit[1,3], Danièle Dubuc[5], Jamie Thomas-Pavanel[1,2], Paul Sereda[7], Shahab Jabbari[7], Jayson H. Shurgold[6,11], Guillaume Colley[7], Robert S. Hogg[6,7], Angela Kaida[6], on behalf of the CHIWOS Research Team[¶]

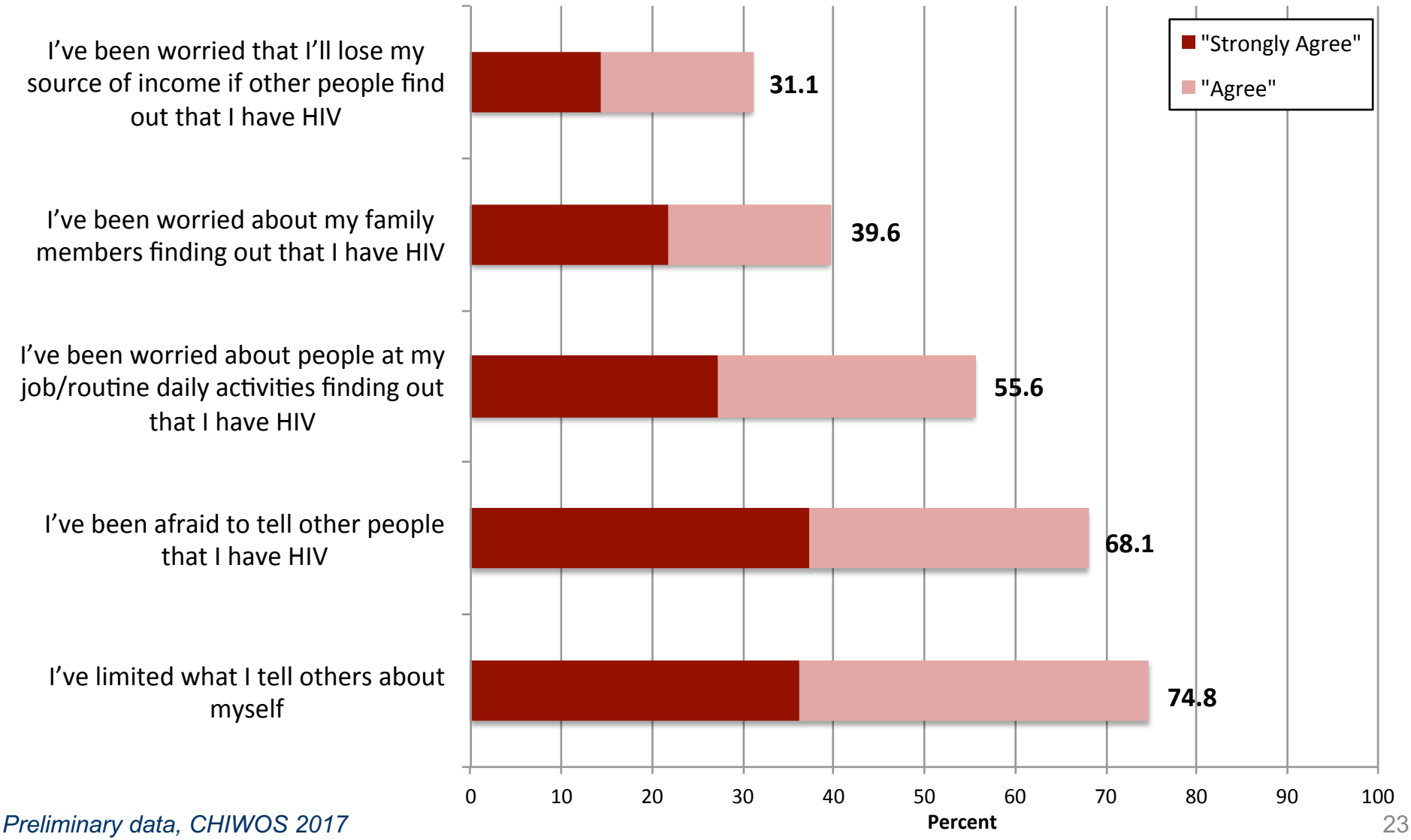




CHIWOS

HIV disclosure worries in the past month among women living with HIV (CHIWOS n=1,419)

Median HAT-QoL scale = 60 [IQR: 40-75] (Holmes & Shea, Medical Care 1998)



Preliminary data, CHIWOS 2017

High Disclosure Worry (HAT-QoL ≥ 75) varies by social and clinical factors (Row %)

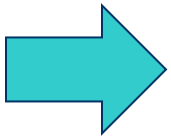
Characteristics	High Disclosure Worries (HAT-QoL ≥ 75)	Low Disclosure Worries (HAT-QoL < 75)	P-value
Province of residence			<0.001
British Columbia	22%	78%	
Ontario	37%	63%	
Quebec	41%	59%	
Ethnicity			<0.001
Indigenous	31%	69%	
African/Caribbean/Black	54%	46%	
White	22%	78%	
Other	33%	67%	
Median Age [IQR]	40 (34-48)	44 (36-51)	<0.001
Median years living with HIV [IQR]	8.4 (4-14)	12.4 (7-18)	<0.001
Received HIV medical care in last year			0.005
Yes	33%	67%	
No	48%	52%	

* No association with HIV clinical outcomes including undetectable viral load or CD4 count

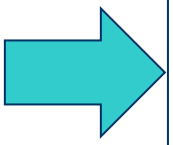
Are women living with HIV aware of the current legal expectations of disclosure?

Awareness

"In 2012, the Supreme Court of Canada made a new ruling regarding the conditions under which a person living with HIV has to disclose his or her HIV status to a sexual partner. **Are you aware of this new ruling?**"



PRA interviewer provided a concise definition of the most recent case law



Understanding

"How similar is this definition to what you thought you understood about HIV disclosure and the law in Canada?"

CHIWOS

Women's awareness and understanding of the law (n=1,230)

Awareness

73%

of participants were aware of the HIV non-disclosure law in Canada

Only **51%** of those aware reported a complete **understanding** of the legal obligation to disclose

PRA interviewer provided a concise definition of the most recent case law

Understanding

37%

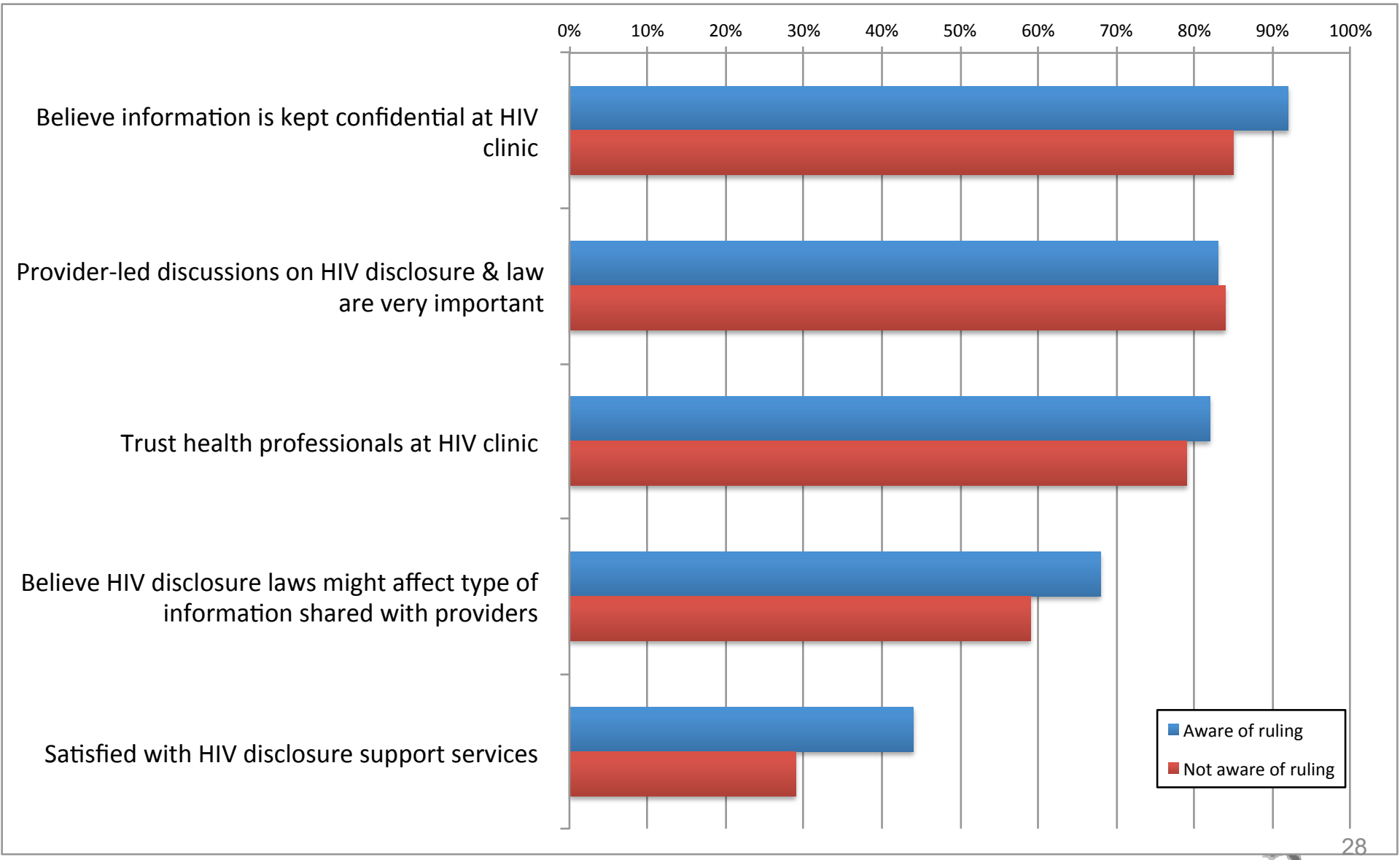
were both aware and had a complete understanding of the legal obligation to disclose.

CHIWOS

Correlates of awareness of 2012 Supreme Court ruling on HIV non-disclosure (n=1,155)

Characteristics	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age at interview (per year increase)	1.01 (1.00-1.03)	Not selected
Province of interview: Ontario	1.00	Not selected
British Columbia	1.25 (0.90-1.73)	
Quebec	1.01 (0.74-1.37)	
Ethnicity: White	1.00	1.00
Indigenous	0.61 (0.44-0.85)	0.81 (0.57-1.15)
African/Caribbean/Black	0.75 (0.55-1.03)	**0.66 (0.47-0.92)**
Other	0.87 (0.51-1.47)	0.77 (0.44-1.33)
Education <= High school	0.58 (0.45-0.76)	**0.71 (0.53-0.94)**
Unstable housing	0.67 (0.45-1.00)	Not selected
HIV work in community since last interview	2.27 (1.65-3.13)	**1.98 (1.43-2.74)**
Injection drug use in the last 6 months	0.64 (0.41-0.98)	0.70 (0.44-1.12)
Viral load at interview: Undetectable	1.00	1.00
Detectable/don't know	0.46 (0.33-0.64)	**0.59 (0.41-0.85)**
HIV medical care since last interview	0.47 (0.29-0.77)	Not selected
Unaware of ART prevention benefits	0.54 (0.41-0.71)	**0.66 (0.49-0.88)**
Tested for STI in past year	0.97 (0.74-1.28)	Not selected
Violence as adult ever	0.92 (0.65-1.29)	Not selected
High HIV-related stigma	0.63 (0.49-0.82)	**0.76 (0.58, 1.00)**

Perceived disclosure support in the climate of HIV non-disclosure criminalization (CHIWOS)



Discussion

- Women living with HIV express substantial worry about disclosure to family, friends, colleagues. Such worries vary by markers of social and clinical vulnerability.
- Although women are less likely than men to meet the legal criteria for non-disclosure, only one-third are aware of and understand the law.
- Women with lower awareness of the legal requirements to disclose include women who are less engaged in HIV care and who experience violence and other forms oppression.
- Women are willing to receive information on disclosure and the law from providers and want to engage in a safe way
- Current disclosure support services are insufficient.

CHIWOS

- Interventions and services supporting safer HIV disclosure must contextualize support to the woman's current situation, including risk of violence.
- Need to create enabling environments that support safer HIV disclosure.
- Ensure that women are leading disclosure decisions with support, not risking forced disclosure

CHIWOS

Meaningful involvement of women living with HIV

Meaningful involvement of women living with HIV is a critical part of this research to empower community leadership in this field

CHIWOS

Criminalization changes our

LIES	L	LISTEN
INSECURE	I	INVOLVE
VIOLENCE	V	VOICES
EMOTIONAL	E	EDUCATION
SEX OFFENDER	S	SAFE CHOICES

CHIWOS

"It is a terrible irony that we have come to a place where the medications we fought for will allow us to live a relatively normal quality of life, and now we are going to go to jail for doing so."

Louise Binder, July 2012

Canadian woman living with HIV and human rights activist

CHIWOS

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Thank you!

- **For more information about CHIWOS, please contact:**
- **Rebecca Gormley (BC)**
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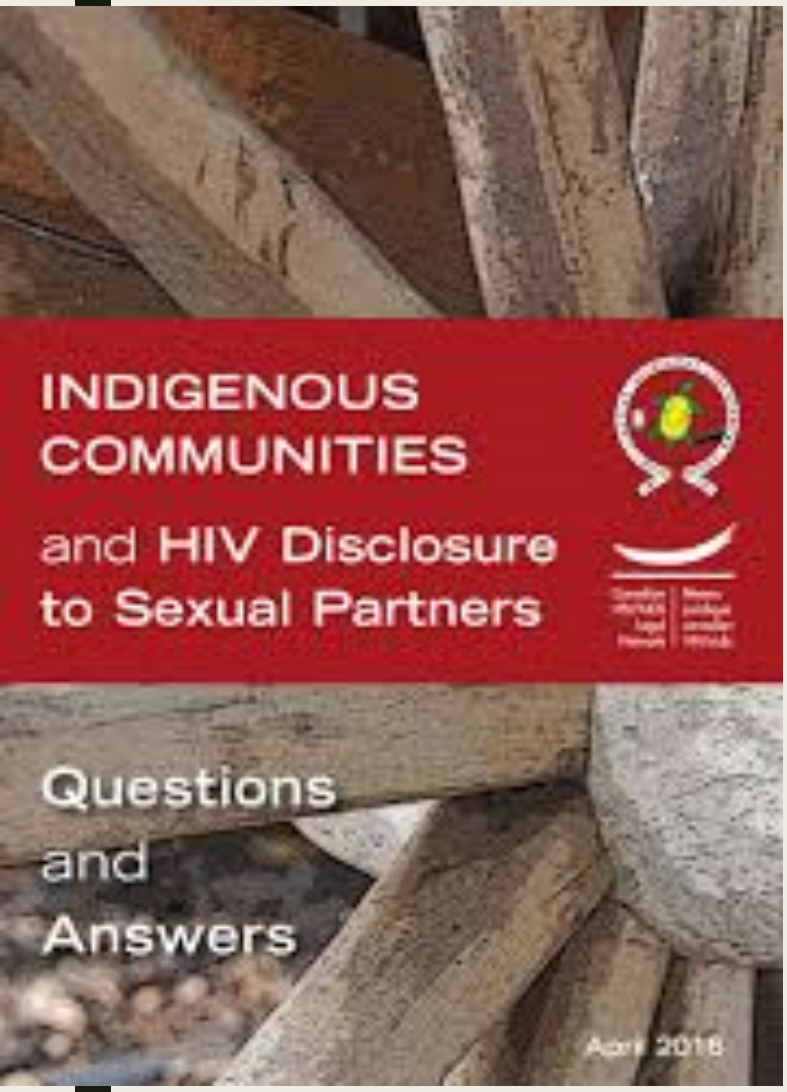
CHIWOS

INDIGENOUS COMMUNITIES HIV DISCLOSURE TO SEXUAL PARTNERS

Jasmine Cotnam
APHA Liaison
Canadian Aboriginal AIDS Network

Acknowledgements



This brochure has been prepared by the Canadian HIV/AIDS Legal Network with the Canadian Aboriginal AIDS Network. It will provide you with important information about the law in Canada as it relates to HIV disclosure
http://www.aidslaw.ca/site/indigenous-communities-and-hiv-disclosure-to-sexual-partners-questions-and-answers/

Disclosure to Sexual Partners

- Because HIV can be transmitted during sex, the criminal law in Canada imposes an obligation on people living with HIV to share, or “disclose,” their HIV-positive status to their sexual partners in certain circumstances.
- More than 180 people have been charged in Canada for not disclosing their HIV status to a sexual partner.

HIV THRIVES WHERE SOCIAL INJUSTICES LIVE

- In Canada, Indigenous people, especially women and youth ,are disproportionately affected by HIV. It is estimated that in 2011,Indigenous populations represented 12.2% of new HIV infections and 8.9% of people living with HIV in Canada.
- Indigenous populations are extremely diverse, with communities that reflect variations in historical backgrounds, language and cultural traditions .In their diversity, these communities are more affected by HIV because of a variety of factors and social determinants of health that influence vulnerability to HIV infection, including poverty, housing and homelessness, early childhood development, physical environments, access to health services, support networks and social environments, gender, violence and incarceration, as well as racism and the multigenerational effects of colonialism and the residential school system.

What is Disclosing to a sexual partner?

Informing a possible sexual partner that you are HIV-positive.

This person could be anyone with whom you have or want to have a sexual relationship with

*spouse

*regular sexual partner

* someone you might have sex with only once.

What the law means

1

There is duty to disclose before any sexual relations that pose a “realistic possibility” of transmission.

2

Individuals are not required to disclose their HIV status before having sex if a condom is used and the HIV-positive person has a “low” HIV viral load. In one of the decisions, the court considers an HIV viral load of 1,500 copies of the virus or fewer per millilitre of blood to be “low.”

Telling others that you are HIV positive can be difficult and stressful

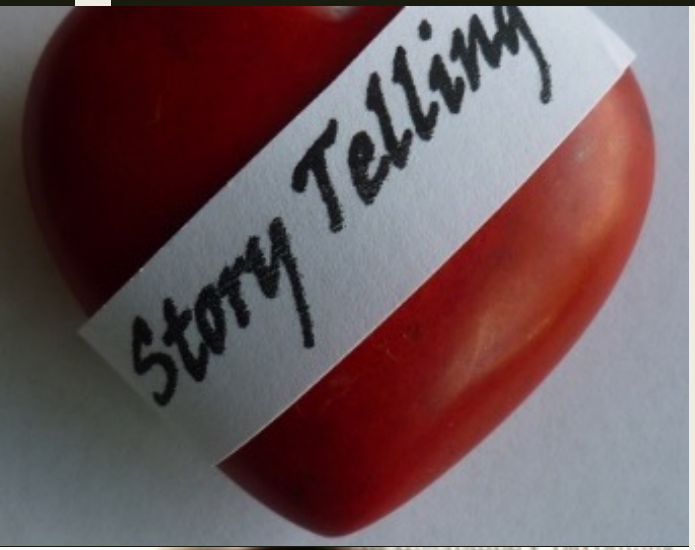
You may be afraid of

- Rejection
- Violence
- Discrimination
- Having your confidentiality breached.

Such concerns are particularly real for those living in tight-knit communities and in communities where sexuality and HIV are taboo. Racism, gender norms, economic conditions, and cultural and language barriers are all factors that can also affect a person's ability to disclose their status, take precautions to reduce risks of HIV transmission, and access support.

Contacting your local AIDS organization can be a good first step to finding help and support. There are also a number of health organizations that provide services specifically for Indigenous communities (contact CAAN for referral). You may also want to seek legal advice before deciding whether to disclose your HIV status.

Support around HIV disclosure



This Photo by Unknown Author is licensed under CC BY-SA

Disclosure is a legal term

Unpacking what it means to share a part of your life that may make others uncomfortable

There is a lot great support and literature out there about HIV disclosure

Please remember as long as stigma exists it is harder and more complicated in real life to share with somebody that you are living with HIV

“To Tell or Not To Tell”

Barriers and Facilitators for HIV Disclosure

Presented By

Marvelous Muchenje

Women’s Health in Women’s Hands, CHC

Introduction

- Discussing HIV Serostatus disclosure is a critical, yet challenging issue for both service providers and WLHIV
- Most people living with HIV are usually willing to disclose HIV status to significant others in their lives
- **So why don't they?**

Barriers to Disclosure

The risks of disclosure can be great and involve loss of:

- Family and friends
- Job and job opportunities
- Security: emotional, physical, financial
- Reality when your world seems to fall apart after disclosure
- For migrants threat to getting legal status

Facilitators to Disclosure

Words from PHAs

"When I disclose, I feel like a flower: vulnerable and exposed, but powerful."

http://www.employmentaction.org/job-seekers/what-about-working-with-hiv/what-about-disclosure-and-my-legal-rights/oan-disclosure-pdf

"You get peace of mind when you disclose. "

"Own your story. Don't live under a veil of secrecy."

"I sacrificed myself by disclosing to save my community. It was worth the personal risk."

"One minute you have control, and then you don't."

"Story telling encourages the hearts of others to receive your disclosure. "

http://www.employmentaction.org/job-seekers/what-about-working-with-hiv/what-about-disclosure-and-my-legal-rights/oan-disclosure-pdf

Disclosure Strategies

Strategies

- Point-blank disclosure
- Subtle hints
- Partial disclosure
- Incremental disclosure

Involuntary Disclosure

- Rumours within the community
- Service provider indiscretion
- Accidental disclosure
- Unplanned self disclosure

Laws Surrounding HIV Disclosure

- The laws surrounding HIV Disclosure have negative social impacts
  - creates inconsistency in a segment of the legal system and are so outdated to modern medical advancements
- The laws that are supposedly meant to protect women
  - now threaten the health and well being of both HIV negative and positive communities

Canadian Coalition to Reform HIV Criminalization

- Formed following the HIV Is Not A Crime 2 Training Academy convention held in Huntsville, Alabama
- Made up of people living with HIV, community workers, lawyers and academics from across the country
- Joined forces at a national level to progressively:
  - ***reform discriminatory and unjust criminal and public health laws and practices that criminalize and regulate people living with HIV in relation to HIV exposure, transmission and non-disclosure in Canada***

Advocacy

Consensus Statement

- calling for various actions by federal, provincial and territorial governments to address the overly broad use of the criminal law in cases of alleged HIV non-disclosure

Women, ART and the Criminalization of HIV (WATCH)

- Body Mapping project with WLHIV

Premier's Roundtable in Violence Against Women

- Wrote a letter to Minister Naidoo-Harris - Ministry of Status of Women
- Call for limiting the use of criminal law, including sexual assault law in the context of HIV non-disclosure

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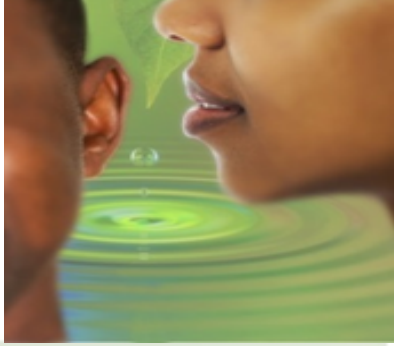
“To tell or not to tell”



THE HIV-POSITIVE SERO-STATUS DISCLOSURE SUPPORT MODEL

Sandra Godoy MSW
HIV Disclosure Intervention Coordinator
Women’s Health in Women’s Hands Community Health Centre

OBJECTIVES

- The aim of the model is to provide a systematic way of supporting people living with HIV through the process of disclosure
  - Everyone experiences disclosure differently however, most will undergo similar stages of disclosure each time the disclosure process is initiated
- The model is a template for service providers that outlines the stages involved in the HIV disclosure process, how to explore the challenges, barriers, and possible strategies associated with HIV status disclosure in a collaborative and person-centred approach
- Measure of success: Engagement in HIV-Disclosure conversations

GUIDELINES, PRINCIPLES & FRAMEWORKS

The intervention known as **"The HIV Positive Sero-Status Disclosure Support Model "** is a 6-step process designed to guide users through the initial steps of determining the need for disclosure and the subsequent steps required for a successful disclosure to occur based on the research conducted by our team. These are the frameworks and guiding principles that guided the development of the model.

- FEMINIST & CRITICAL RACE +
- TRANSNATIONAL PERSPECTIVES +
- GIPA/MIPA +
- PERSON-CENTERED +
- HOLISTIC PROCESS +

RESEARCH PROCESS

1. DEVELOPMENT

- Literature review of disclosure studies, models, theories
- 2 focus groups (women who had and had not disclosed their status) and 4 in-depth interviews with ACB HIV-positive women
- 2 focus groups with service providers working with ACB women
- Total n=30

2. PILOT TESTING

- May-September 2010: 22 Women, 5 service providers, 4 peers, 1 counsellor
- Women participated in 8-10 sessions with their service provider and peer support worker
- Data recorded in tracking forms filled by the participants, peer support worker, and service provider
- Total recruited=28

3. EXPANSION

- 3 Focus groups in Toronto with: Heterosexual Men (n=13), MSM/Gay Men= 9 , Youth (n=6)
- 8 in-depth Interviews in Cambridge, Kitchener, and Waterloo area and 5 in-depth interviews in Niagara
- Heterosexual Men, Gay Men/MSM, Youth, and Rural communities found the model effective

HIVDISCLOSURE.CA

hivdisclosure.ca

HOME TOOLKIT DIGITAL STORIES CONTACT

NEGOTIATING DISCLOSURE

THE HIV SERO-STATUS DISCLOSURE TOOLKIT

HIV disclosure is complex. It's so much more than sharing a status. This resource aims to humanize this complex, emotional, and personal process; give context to the experience of persons living with HIV/AIDS; and engage professionals looking to be resources in the area.

25 WOMEN'S HEALTH IN WOMEN'S HANDS COMMUNITY HEALTH CENTRE INCREASE • INNOVATE • IGNITE

OVERVIEW & BACKGROUND

SUPPORT MODEL

GUIDELINES FOR ORGANIZATIONS

RESOURCES FOR DISCLOSURE

DOWNLOAD WORKBOOK

hivdisclosure.ca/support-model/

THE HIV-POSITIVE SERO-STATUS SUPPORT MODEL

IN THIS SECTION

GUIDING PRINCIPLES & FRAMEWORK

STRUCTURE & ELEMENTS

THE HIV-POSITIVE SERO-STATUS DISCLOSURE SUPPORT MODEL

HIV DIAGNOSIS → DISTRESS | SHOCK | DISBELIEF | DENIAL | WITHDRAWAL I LOSS ANGER | FEAR| REGRET | VICTIMIZATION | SADNESS DEVISTATION | HOPELESS | NEED FOR SUPPORT COMBINATION WITH OTHER TRAUMAS → **IS DISCLOSURE NECESSARY?**

1 Acceptance & Empowerment

- Comining to terms with an HIV-postive diagnosis
- Adjusting to being a person living with HIV (PHA)
- A continuous process of personal growth, self-assessment, recognition & struggle to accept the new self-identity of being a PHA

2 Education & Preparation to Disclose

- Knowledge of HIV 101
- Comfort level discussing HIV/AIDS
- Availability, awareness & accessibility of services
- Understanding the potential repercussions of disclosure & non disclosure

3 Establishing Motivation for Disclosure

- Identify reason(s) why the person wants to disclose and to whom
- Is it driven by a need to access resources services, or additional support?
- Is it due to a sense of personal responsibility?
- Is it driven by legal obligations?

Is it necessary?
Is it voluntary?

4 Evaluating the Disclosure Environment

- Determine the social support available to the person; will culture, community and/or faith impact the disclosure environment?
- Determine safety and wellbeing will disclosure:
  - Threaten the person's/family's safety?
  - Lead to a possibility of violence stigma and /or family problems
- Develop a safety plan if necessary

5 Assessing Potential Outcomes of Disclosure

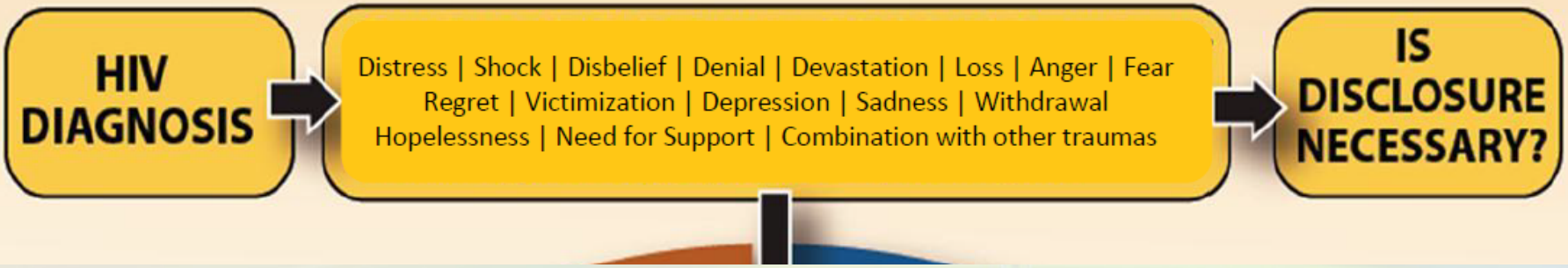
- What are the potential reactions?
- Is safety and wellbeing accounted for? Is a safety plan ready?
- Do the benefits outweigh the risks associated with disclosure?
- How will disclosure affect a person's: Future? Health? Wellbeing? Family?

6 Disclosure a. Plan b. Event

- If ready to implement action plans ensuring all support systems are in place
- If not ready continue preparations, support & revisit previous steps
- Where? Who will be present?
- Who will support the person being disclosed to immediately & long term?
- Finalize safety plan

March 18

THE START OF THE JOURNEY



STEP ONE

ACCEPTANCE & EMPOWERMENT

- Coming to terms with an HIV-positive diagnosis
- Adjusting to being a person living with HIV
- Encompasses a continuous process of personal growth, self-assessment, recognition and struggle to accept the new self identity:
  - A PHA

STEP TWO

EDUCATION & PREPARATION TO DISCLOSURE

- Knowledge of HIV 101
- Comfort level discussing HIV/AIDS
- Availability, awareness and accessibility of services
- Understanding the potential repercussions of disclosure and non disclosure

STEP THREE

ESTABLISHING MOTIVATION

- Identify reason(s) why the person wants to disclose and to whom.
  - Is disclosure driven by a need to access resources services or additional social support?
  - Is it due to a sense of personal responsibility?
  - Is it driven by legal obligations?
- Is it necessary?
- Is it voluntary?

STEP FOUR

ESTABLISHING THE DISCLOSURE ENVIRONMENT

- Evaluation of the physical environment where disclosure will take place
  - Is the disclosure environment favorable?
- Determine social support available to the person
- Determine safety and wellbeing of the person
  - Will disclosure threaten the safety or welfare of the person and their family members?
  - Is there possibility of violence, stigmatization, rejection, or family problems?
  - Develop a safety plan if necessary
- Determining if culture, community, faith and social supports will impact the disclosure environment.

STEP FIVE

ASSESSING POTENTIAL OUTCOMES

- What are the potential reactions to disclosure?
- Is safety and wellbeing accounted for?
  - Is a safety plan ready?
- Do the benefits outweigh the risks associated with disclosure?
- How will disclosure affect a person's future?
- How will it affect health and wellbeing?
- How might it impact on the person's family?

STEP SIX-A

A DISCLOSURE PLAN

- Where will the event take place?
- Who will be present?
- Who will support the person being disclosed to immediately and long-term?
- What mechanisms will be followed in case of negative impacts?

STEP SIX-B

A DISCLOSURE EVENT

- If ready implement action plans ensuring all support systems are in place
- If not ready continue preparations, support and revisit previous steps

POST-DISCLOSURE PLANNING

POST DISCLOSURE CONSIDERATIONS

- **Debrief:** will be important to address important things like partner testing, legal counsel if necessary, etc.
- **Assess:** whether additional support is required, the types of support and duration
- **Provide:** referrals as needed
- **Follow-up:** until the client indicates they no longer require follow-up support
- **Determine:** if further disclosures need to take place (the client may feel encouraged by the experience and may identify others they want to disclose to)
- **Develop:** strategies for breaches of confidentiality after disclosure

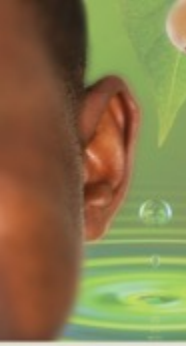
PARTICIPANT'S EXPERIENCES

"All issues have been encompassed and listed. It is like you knew what I was feeling and what I was going through."

-African Woman

"Thanks to all the organizers and all those who have helped me walk this journey. It was life changing and once again thank you for helping me go into the unknown."

-Caribbean Woman



THE AIDS NETWORK
Hamilton, Halton, Haldimand, Norfolk and Brant

PORT DOVER HAMILTON GEORGETOWN BURLINGTON HAGERSVILLE

Commitee for Accessible AIDS Treatment
Toronto, Canada

Regional HIV/AIDS Connection
Community Inspired. Courage Driven.

BLACK C•A•P

CASEY HOUSE
inspired HIV AIDS care

act
AIDS Committee of Toronto

WOMEN'S HEALTH IN WOMEN'S HANDS
COMMUNITY HEALTH CENTRE
INCREASE • INNOVATE • IGNITE

PWA

ACCKWA
The AIDS Committee of Cambridge, Kitchener, Waterloo & Area

Positive Living NIAGARA

CACVO
Le conseil des africains et caraïbéens sur le VIH/SIDA en Ontario
ACCHO
African and Caribbean Council on HIV/AIDS in Ontario

AIDS Committee of Ottawa
Since 1985, ACO has worked to offer support, education and prevention services to the Ottawa Community.

The Teresa Group

Public Health Agency of Canada
Agence de la santé publique du Canada

AFRICANS IN PARTNERSHIP AGAINST AIDS
A.P.A.A.

Thank you!

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Discussion

Reminder:
Please type your questions into the text box at the bottom of your screen.

If your question does not get answered, please check back on the uploaded link (provided below). We will review and answer any remaining questions, and post alongside the recorded webinar.

The Webinar will be posted in the HRP Video Library:
https://www.youtube.com/user/MediaHRP

IBP video library:
https://webinar.com/channel/965084607443925509

Next Steps

- Developing a **Canadian Action Plan** to address the Sexual and Reproductive Health and Rights for Women Living with HIV, including priorities highlighted from this webinar on HIV disclosure and related issues for women.

Webinar 3: Save the Date!

Reproductive Health, Rights, and Justice: Canadian Webinar Series on Implementing the WHO Guidelines on Sexual and Reproductive Health and Rights for Women Living with HIV

January 2018, 9-10:30am PST / 10-11:30am MST /12-1:30pm EST / 6-7:30pm Geneva

Thank you!

For more information about the Canadian Webinar Series, please contact:

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