Research Update from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study: Envisioning a Women-Centred Model of HIV Care and Building a National Community-Based Research Study

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June 13th, 2018
CVIS Academic Rounds

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

Reconnaissances / Acknowledgements

CHIWOS reconnaît et remercie les propriétaires traditionnels des terres sur lesquelles nous nous rencontrons et les ancêtres qui nous précèdent.

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CHIWOS would like to acknowledge the traditional owners of the land on which we meet and the ancestors who have come before us.

Remerciements /Acknowledgments

We would like to thank everyone involved for their invaluable contributions to the study. Thank you to…

All the women living with HIV involved in this study;

The Coordinators, Peer Research Associates, and all the co-investigators and collaborators;

The enrolling partnering clinic and community-based organizational sites and partners*

The Steering Committee, CAB members, CAAB-PAW members and CACBAC members;

Our funders: CIHR Institute of Gender and Health, the CTN, and OHTN;

Our affiliated studies: CANOC, REACH & OSC; and

all of our partners for supporting the study.

Thank you to ViiV Healthcare for sponsoring today's academic rounds

*On next slide in detail

Remerciements / Acknowledgments

A tous nos partenaire cliniques et communautaires

All our community and clinical partners!

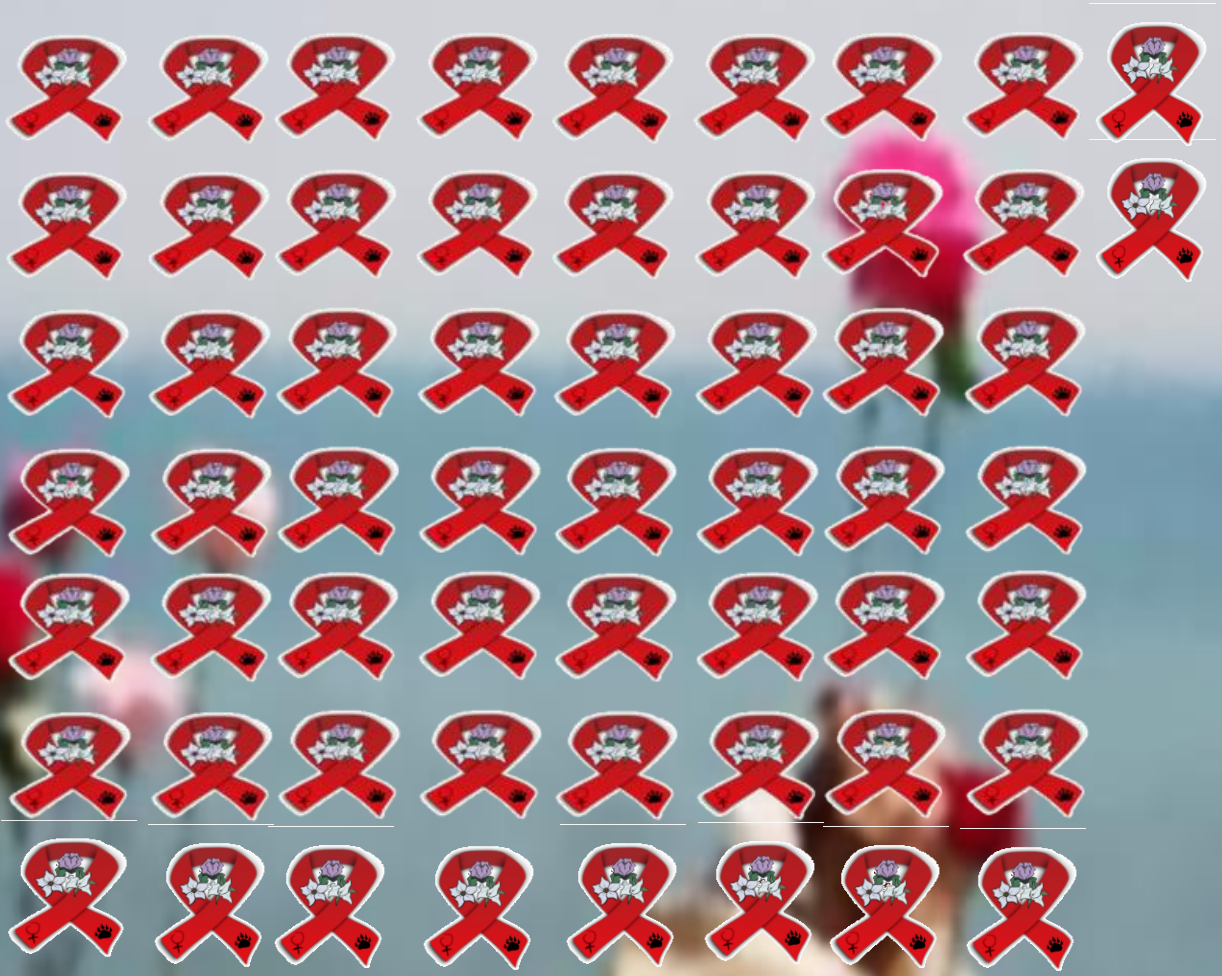
B.C.: Oak Tree Clinic at BC Women's Hospital, AIDS Vancouver Island, BC Centre for Excellence in HIV/AIDS, Cool Aid Community Health Centre, Downtown Community Health Clinic, Keys Housing and Health Solutions (Positive Haven), Living Positive Resource Centre,, Positive Living Fraser Valley, Positive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

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; Positive Pregnancy Program: P3; 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.

QC: ACCM; L'ARCHE de l'Estrie; ASTT(e)Q; BLITS; BRAS-Outaouais; CACTUS; CASM; Centre des R.O.S.E.E.S; Centre Sida Amitié; Corporation Félix Hubert d'Hérelle; COCQ-SIDA; GAP-VIES; 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; **MUHC Chronic Viral Illness Service**; UHRESS-Notre-Dame du CHUM.

Nous honorons et nous rappelons les 59 participantes CHIWOS de partout au Canada qui sont décédées et ne sont plus avec nous, mais demeureront dans nos cœurs à jamais.

We honor and remember the 59 CHIWOS participants from across Canada who have passed away and are no longer with us but will always remain in our hearts.



À la mémoire de Marisol Desbiens

PAR CHIWOS et une collègue appréciée

In memory of Marisol Desbiens

CHIWOS PRA and valued colleague

07 juin, 2018

Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

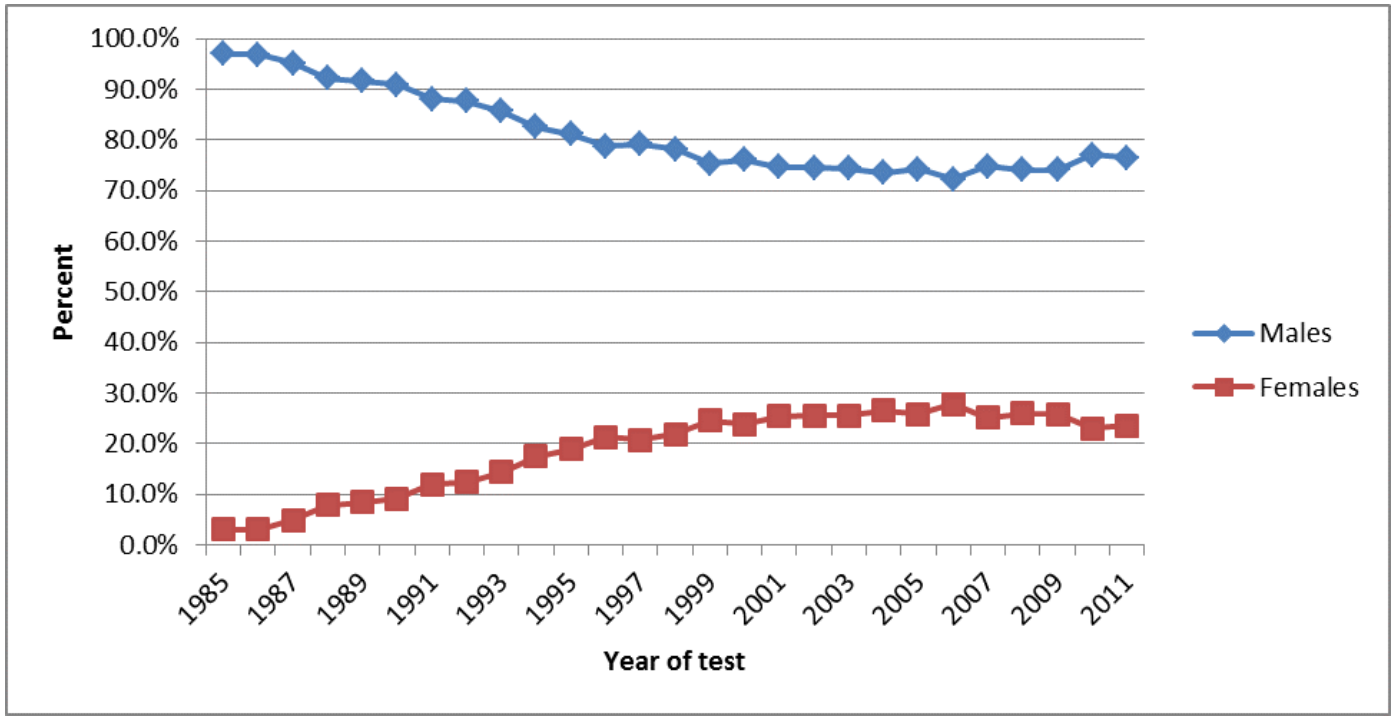
Canadian HIV WOmen's Sexual and reproductive health study

Increase in women with HIV

Globally, women now over 50% of PLHIV

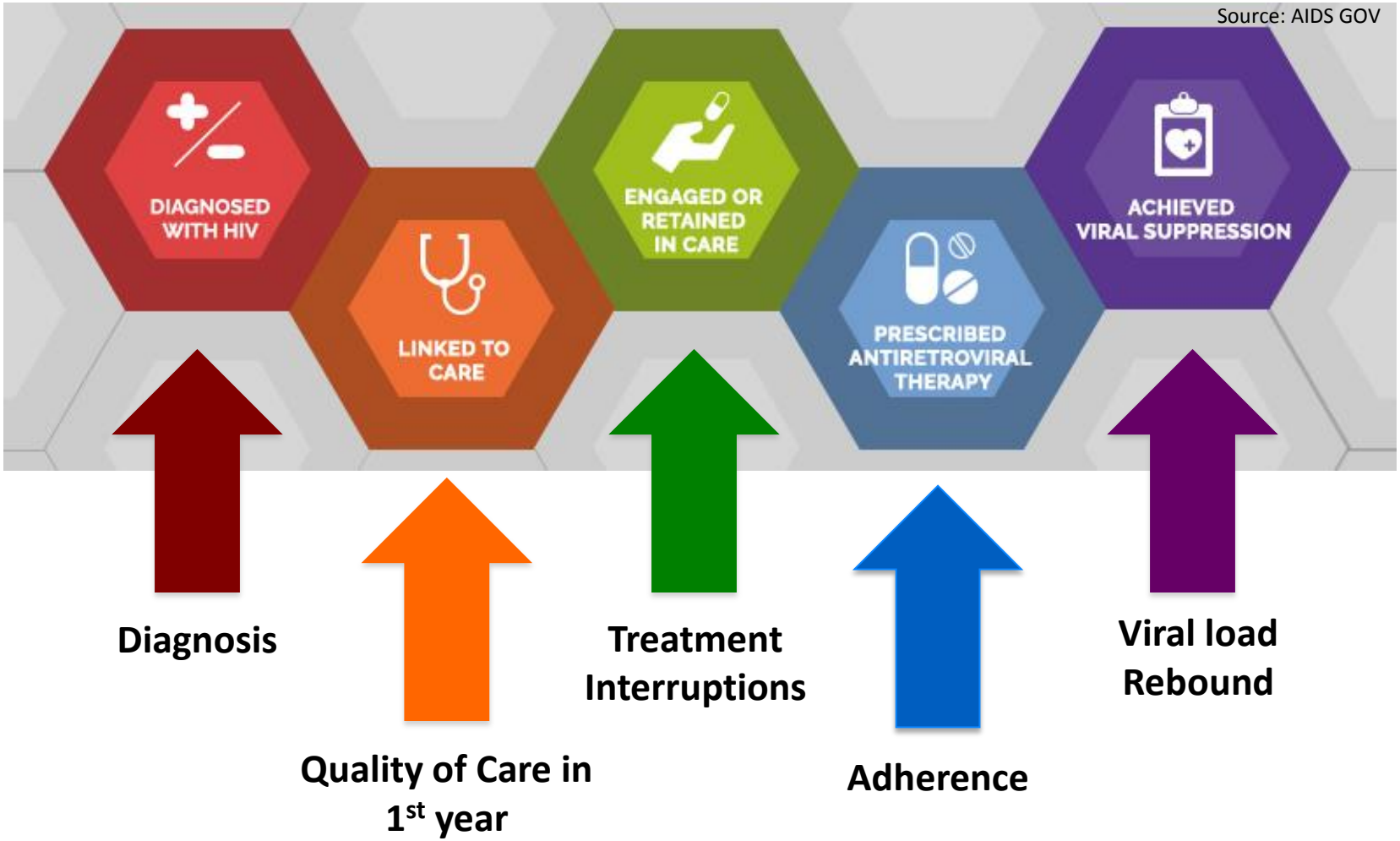
Canada, women now 23% of ~75,000 PLVIH

Proportion of positive HIV test reports, by sex (all ages), 1985-2011 (n=71,361)



Source: Public Health Agency of Canada, Internal data 2012

Challenges – HIV Cascade of Care



Inequity in life expectancy

Patterson *et al. BMC Infectious Diseases* (2015) 15:274

32 women
39 men

at 20 years

7 years difference!

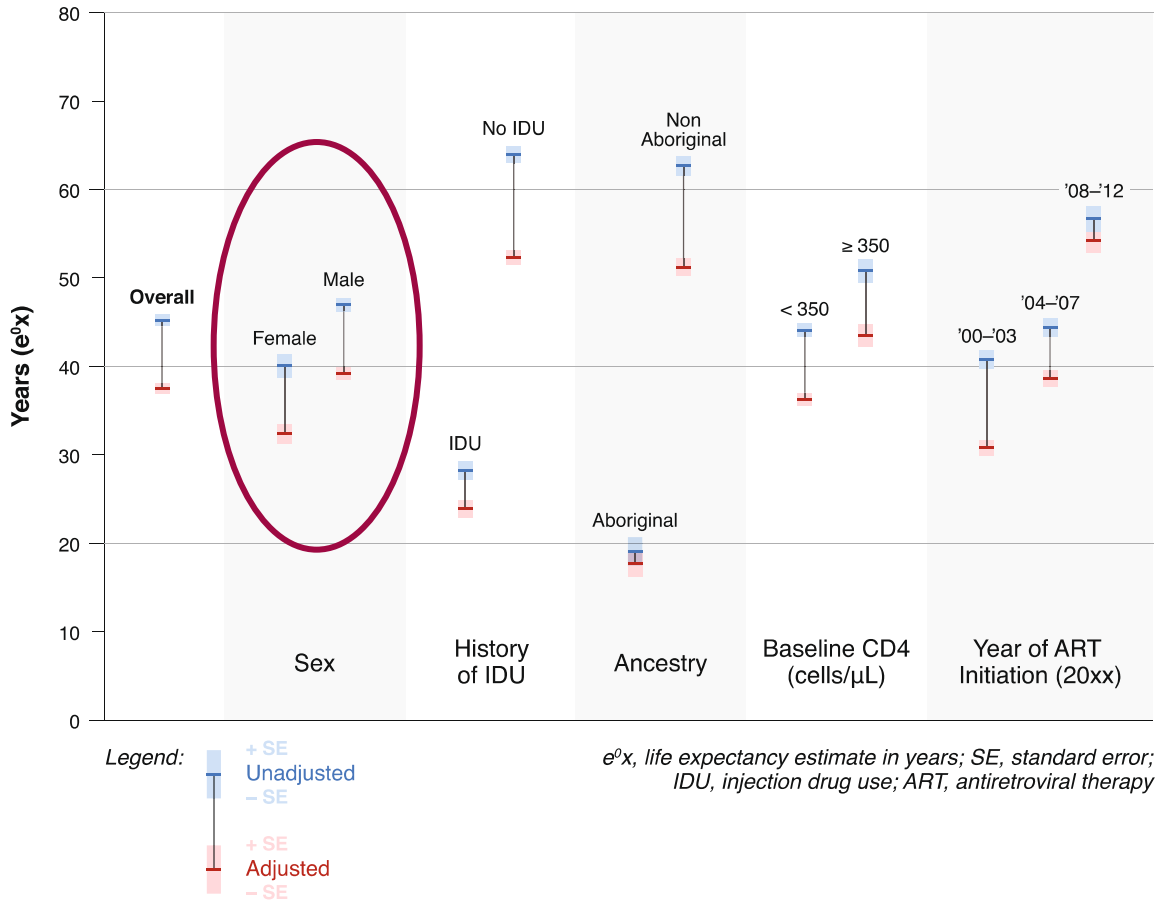
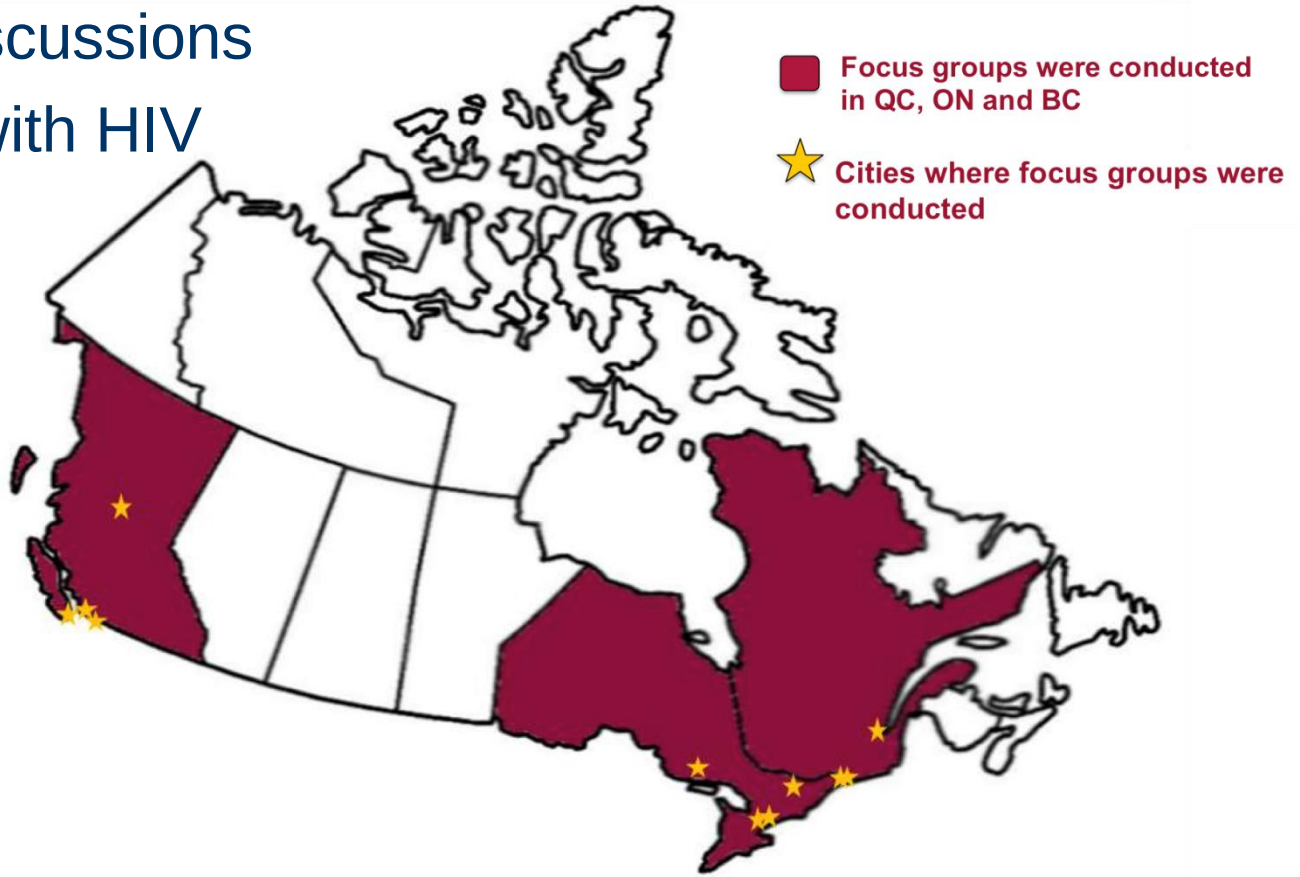


Fig. 1 Life expectancy estimates at age 20 years, showing unadjusted and adjusted values, by clinical and sociodemographic characteristics at baseline

Focus Groups:
What is women centred HIV care

- Co-led by women living with HIV with research training
- In collaboration with ASOs & clinics
- 11 focus group discussions
- 77 women living with HIV



Envisioning women-centered HIV care

Question: What does women-centered HIV care mean to women seeking HIV care in Canada?

1. What's missing from your healthcare?
2. What is working well?
3. In an ideal world, what would your care look like?

Analysis process

Researchers and women living with HIV conducted a thematic content analysis:

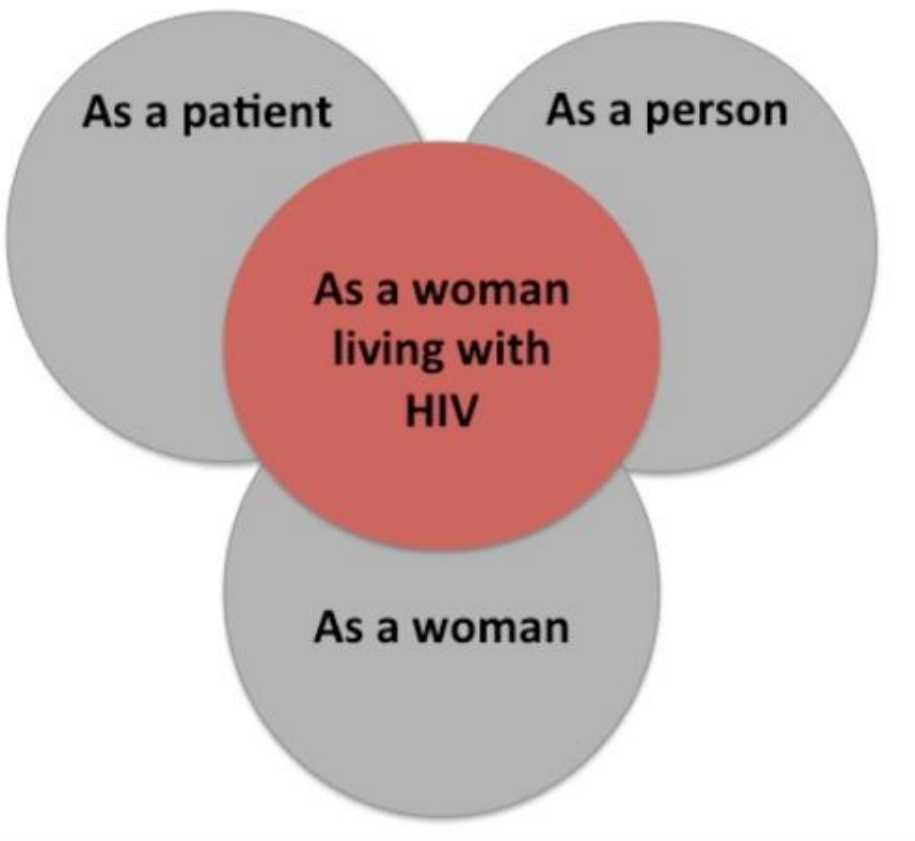
- close readings of the transcripts
- highlighting important passages
- coding key themes
- reflexive provincial & national discussions

- Preliminary findings were presented for feedback:
  - provincial Community Advisory Board (CAB)
  - national Steering Committee
  - and conferences (CAHR, IAS, IWHW)

CHIWOS

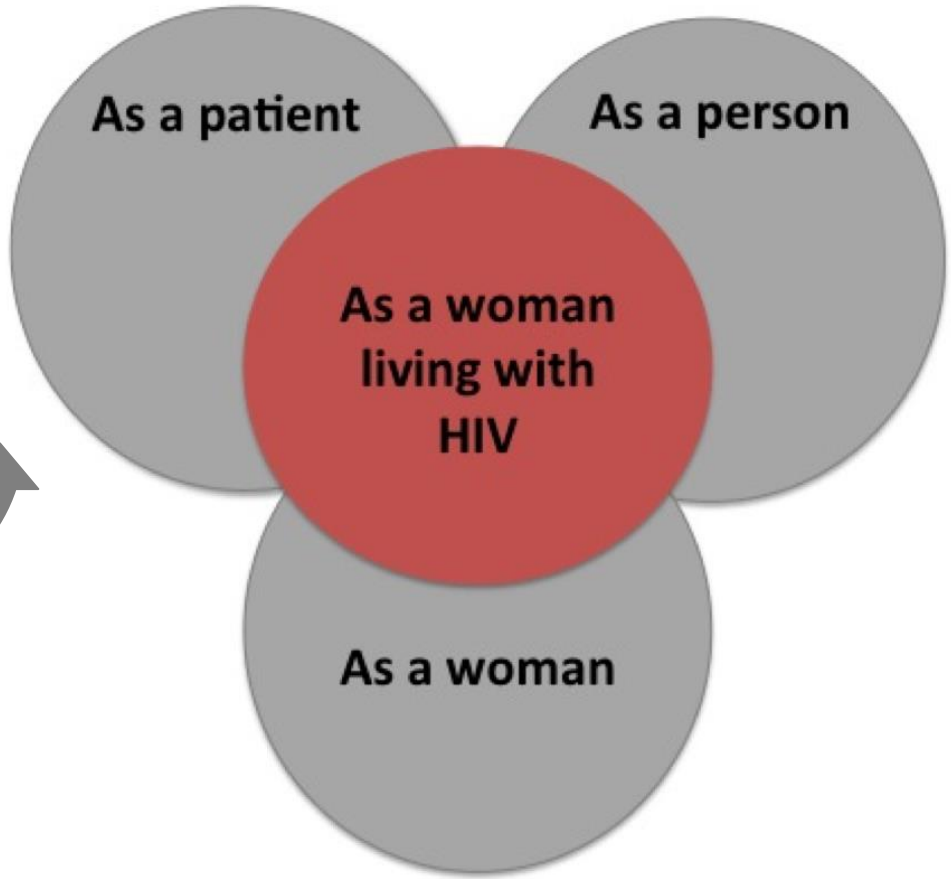
Vision of Women Centred HIV Care (WCHC)

Women's recommendations for how to devise health care services were structured around care that respond to their complex needs as a patient, a person, a woman, and as a woman living with HIV.

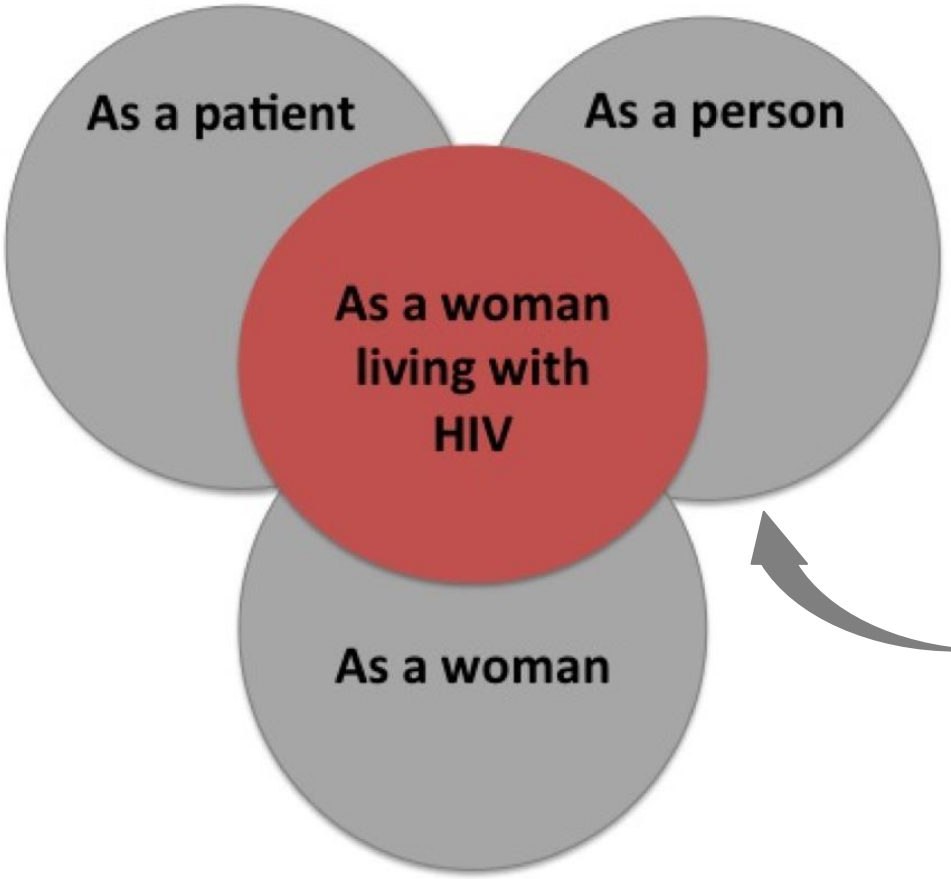


Vision of WCHC – as a patient

As a patient: *I went to see a gynecologist and he didn't know about HIV and I was trying to explain to him where I was, you know my CD4 count, and I was informing - educating my doctor.*



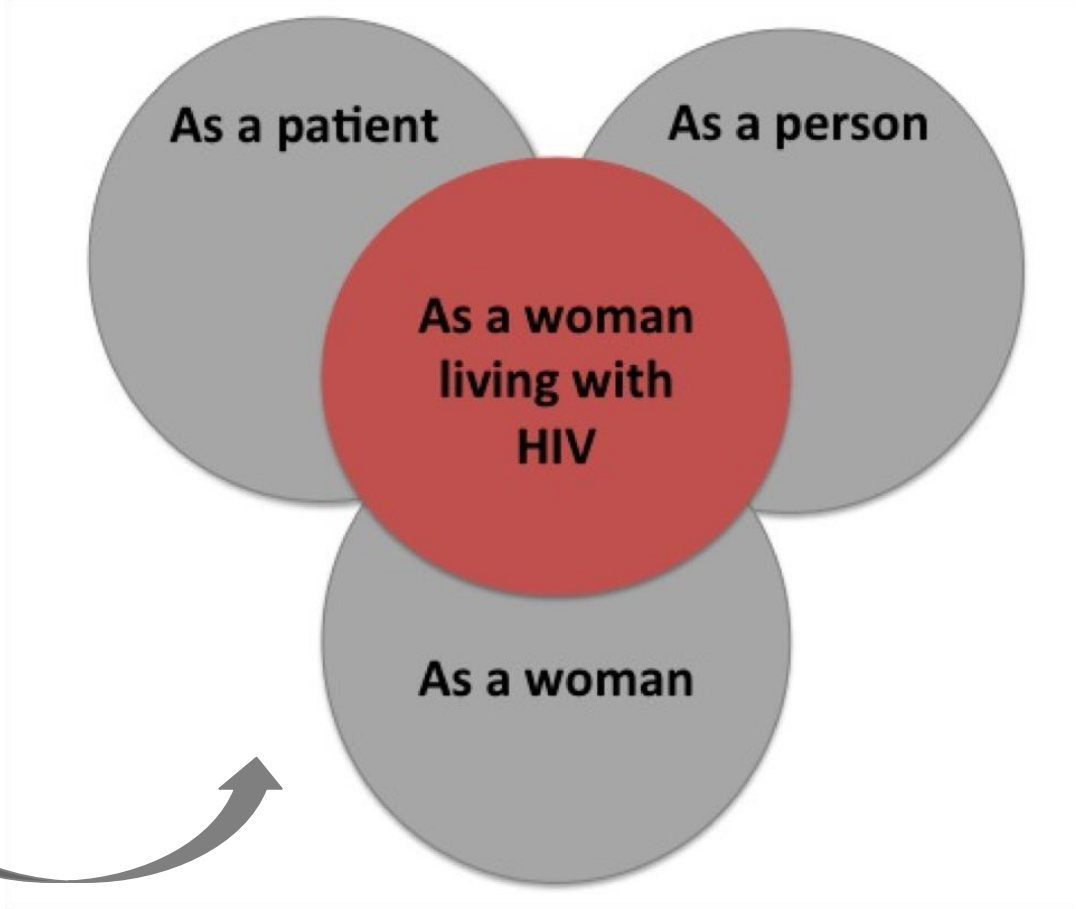
Vision of WCHC - as a person



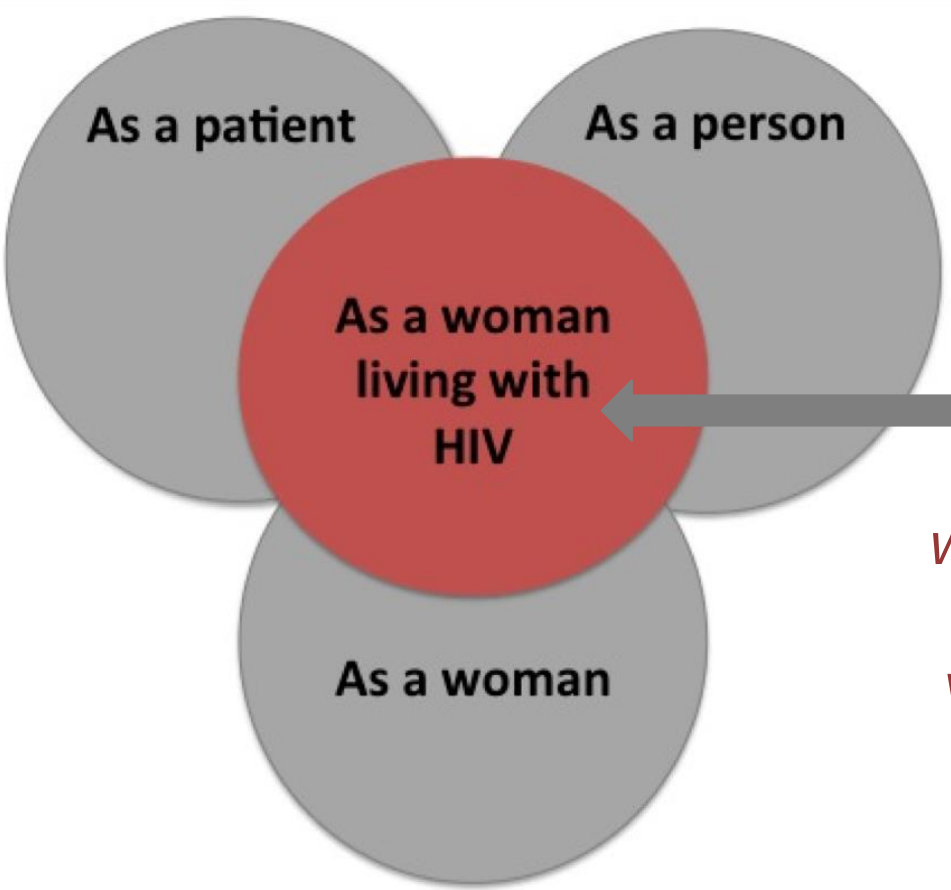
As a person: *He doesn't just check with your health . . .He was interested in all those aspects that make you a whole person . . . He'd always ask if I was working on my garden. You weren't just a chart with a bunch of numbers.*

Vision of WCHC - as a woman

As a woman: *It's been 3½ years that I haven't managed to get an appointment . . . I'm no longer pregnant, but I'm still living with HIV and I need follow-up [for a Pap Test].*

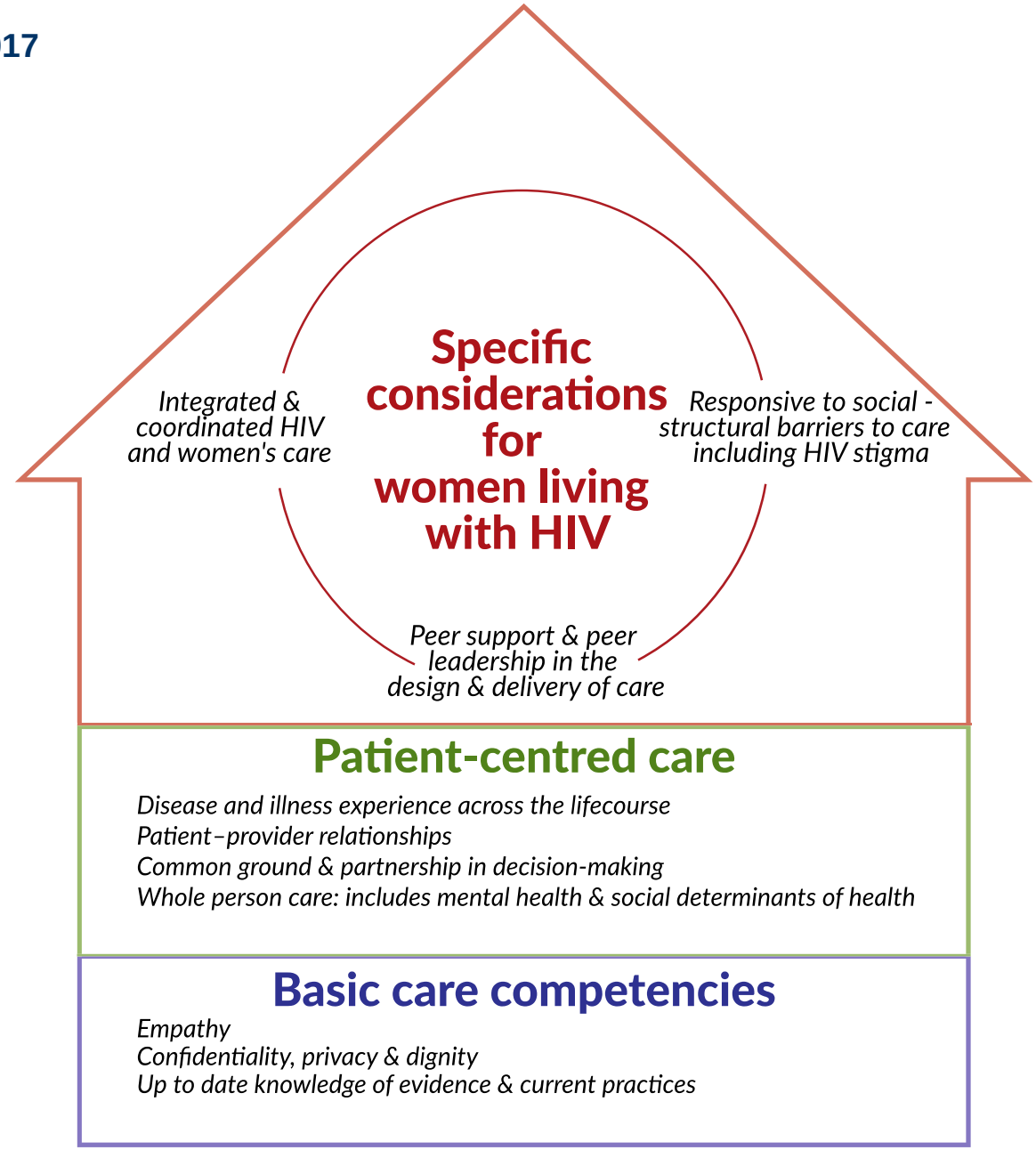


Vision of WCHC - as a women with HIV



As a WLHIV: *I think that everything is working well when we go to [HIV] specialized clinics . . . They know us, and they're very friendly. However, when we go to other clinics, when we're asked for our [HIV] status, then they discriminate against us.*

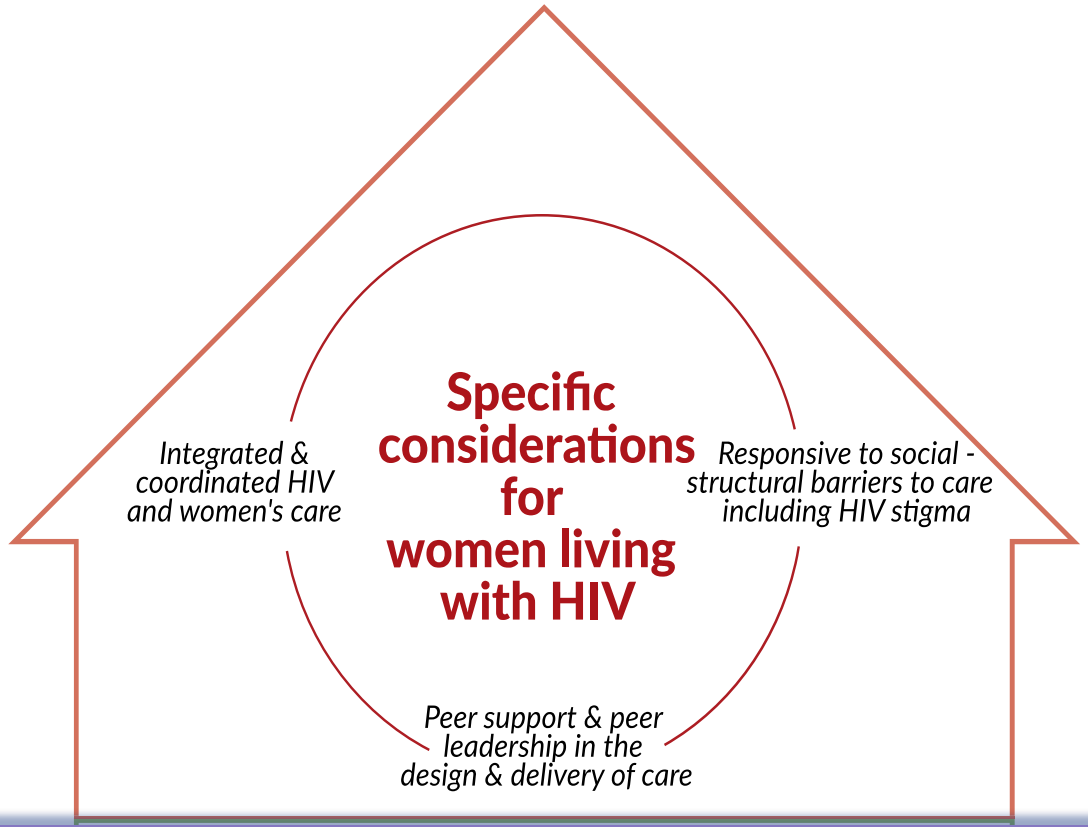
O'Brien et al, 2017



Women-Centred HIV Care

CHIWOS

O'Brien et al, 2017



Basic care competencies

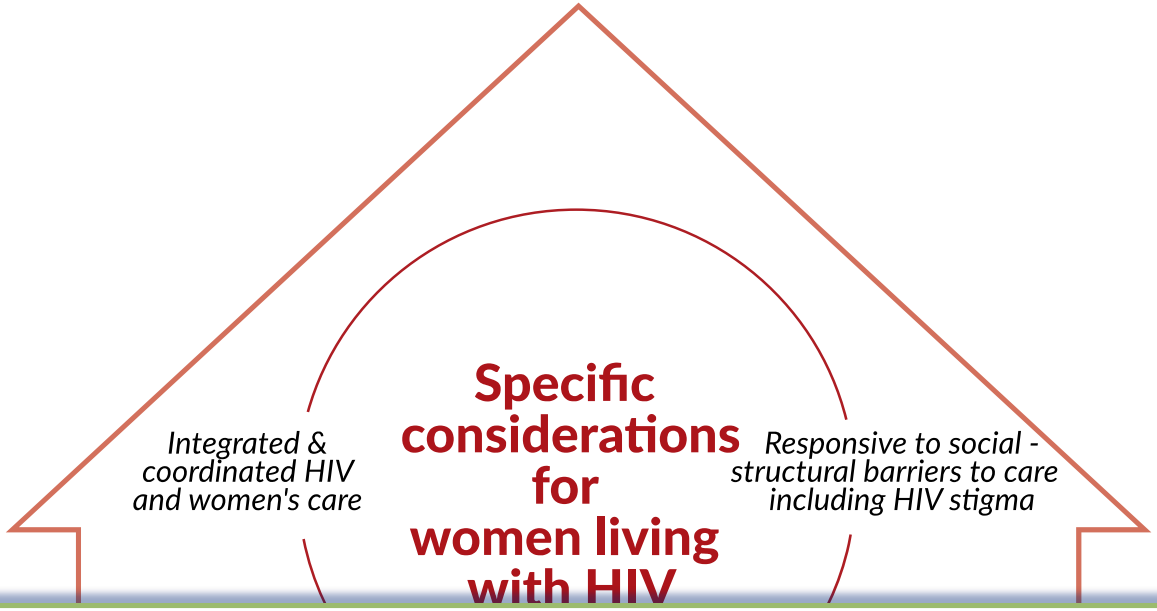
Empathy
Confidentiality, privacy & dignity
Up to date knowledge of evidence & current practices

Confidentiality, privacy & dignity
Up to date knowledge of evidence & current practices

Women-Centred HIV Care

CHIWOS

O'Brien et al, 2017



Patient-centred care

Disease and illness experience across the lifecourse
Patient–provider relationships
Common ground & partnership in decision-making
Whole person care: includes mental health & social determinants of health

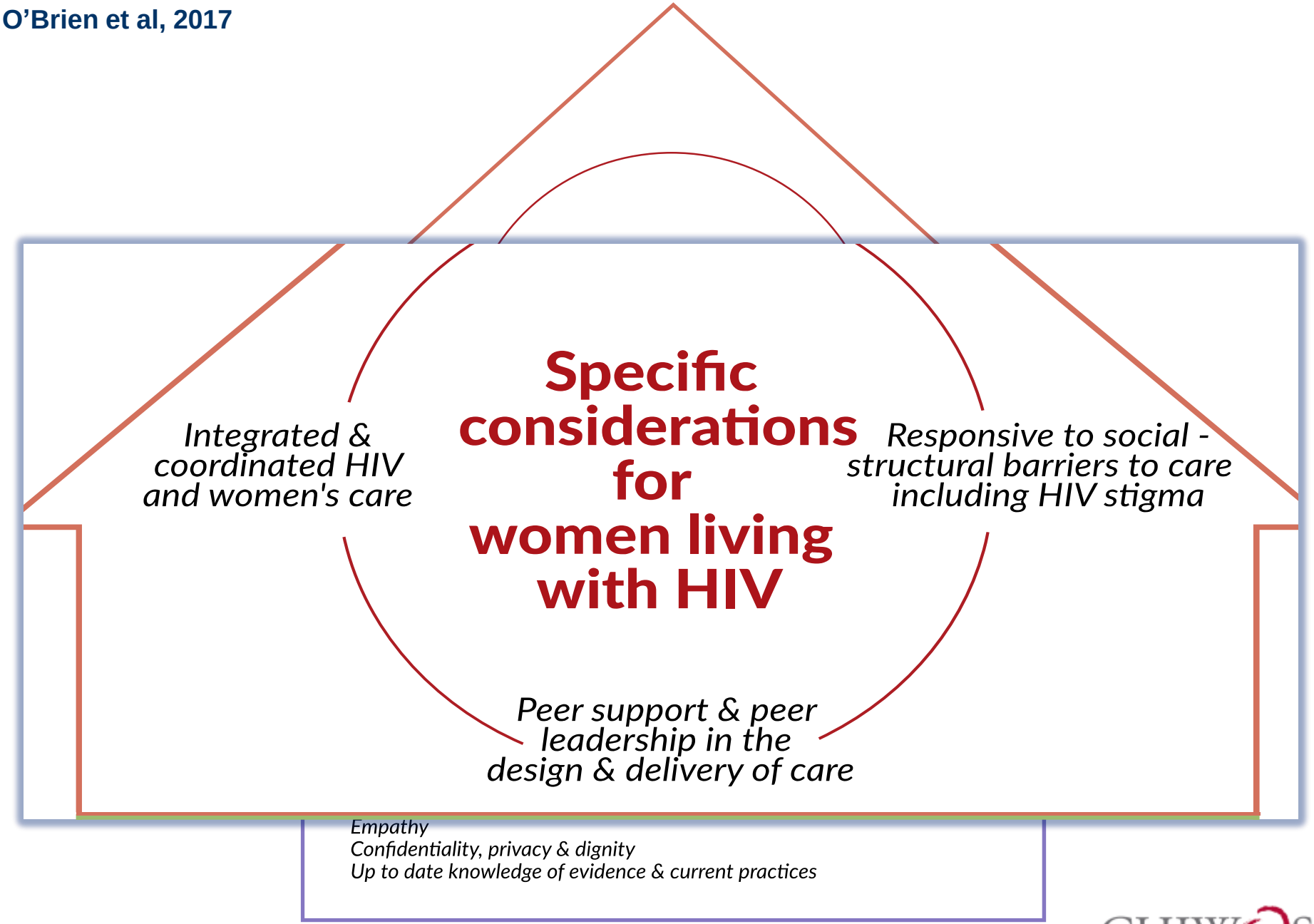
Basic care competencies

Empathy
Confidentiality, privacy & dignity
Up to date knowledge of evidence & current practices

Women-Centred HIV Care

CHIWOS

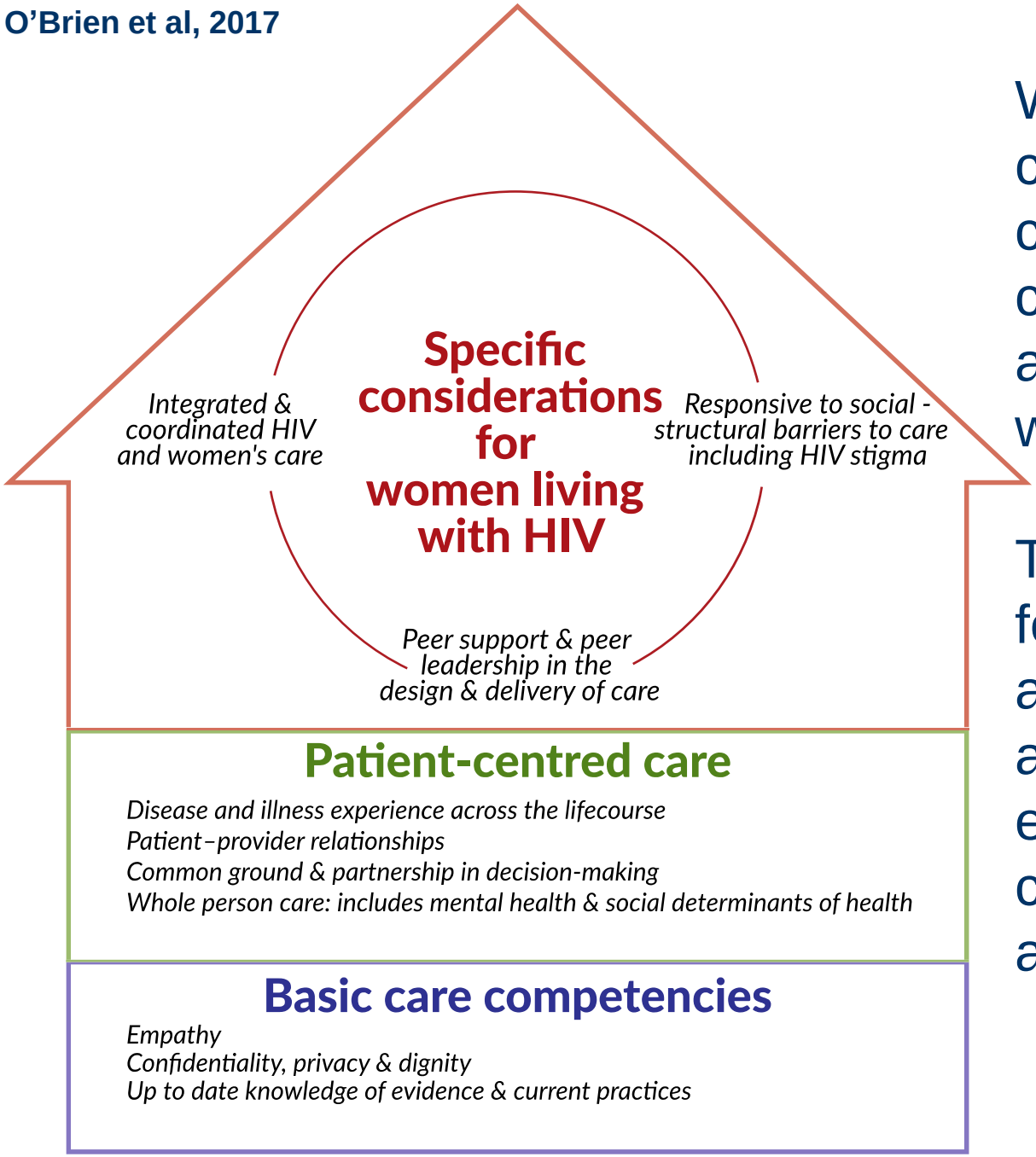
O'Brien et al, 2017



Women-Centred HIV Care

CHIWOS

O'Brien et al, 2017



Women centred HIV care includes basic care competencies, patient-centred care principles, and features specific to women living with HIV.

These combined features promote care in a manner that is safe and accessible, while ensuring medical competency in both HIV and women's health.

CHIWOS

Women's Health Issues 27-6 (2017) 721–730

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Healthcare Services

Envisioning Women-Centered HIV Care: Perspectives from Women Living with HIV in Canada

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A B S T R A C T

Background: Women comprise nearly one-quarter of people living with human immunodeficiency virus (HIV) in Canada. Compared with men, women living with HIV experience inequities in HIV care and health outcomes, prompting a need for gendered and tailored approaches to HIV care.
Method: Peer and academic researchers from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study conducted focus groups to understand women's experience of seeking care, with the purpose of identifying key characteristics that define a women-centered approach to HIV care. Eleven focus groups were conducted with 77 women living with HIV across Quebec, Ontario, and British Columbia, Canada.
Results: Women envisioned three central characteristics of women-centered HIV care, including i) coordinated and integrated services that address both HIV and women's health care priorities, and protect against exclusion from care due to HIV-related stigma, ii) care that recognizes and responds to structural barriers that limit women's access to care, such as violence, poverty, motherhood, HIV-related stigma, and challenges to safe disclosure, and iii) care that fosters peer support and peer leadership in its design and delivery to honor the diversity of women's experiences, overcome women's isolation, and prioritize women's ownership over the decisions that affect their lives.
Conclusion: Despite advances in HIV treatment and care, the current care landscape is inadequate to meet women's comprehensive care needs. A women-centered approach to HIV care, as envisioned by women living with HIV, is central to guiding policy and practice to improve care and outcomes for women living with HIV in Canada.

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

CHIWOS: Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

- Cohorte canadienne longitudinale
- Enquête sur les soins VIH centrés sur les femmes
- Deux suivis à 18 mois (vague 2 et vague 3)
- 2011-2019
- Multicentrique: QC, ON, C-B.
- Basée sur les principes de la recherche communautaire (RC), GIPA et MIWA.

Principes de la recherche communautaire (Minkler, 2004)

- Un engagement équitable des personnes affectées *par* la recherche *dans* les projets de recherche
- Prise de décision partagée tout au cour de l'étude
- Axé sur l'action et les changements positifs

Survol du processus de formation des PARs

- Objectifs de renforcement des capacités.
- Processus collaboratif sur plusieurs mois afin de développer une formation à multi-phases et à plusieurs niveaux.
- Groupe de travail national (chercheurs, expert en RC, FVVIH) et embauche d'une consultante en éducation des adultes pour la conception de la formation des PARs

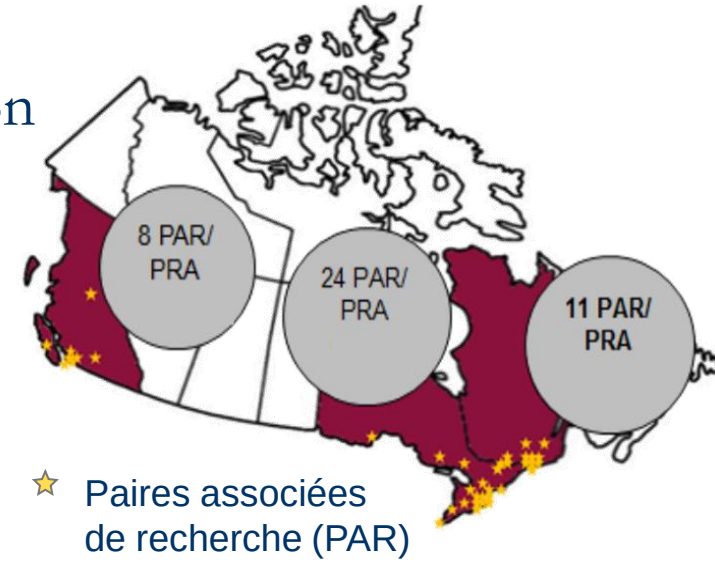
CHIWOS

Survol du processus de formation des PARs

- Formations
  - Vague 1 (Baseline): 2 sessions de formations en personnes de 2 jours, basées sur un curriculum national.
  - Formation continue et interactive tout au long de l'étude et formation spécifique et de révision en personne pour les vagues 2 et 3.
- Thèmes abordés:
  - La mission et les objectifs de l'étude, le rôle des PARs, l'éthique de la recherche, l'entretien de recherche, introduction au questionnaire et à la banque des participantes (informatique), le recrutement et la rétention des participantes, le bien-être et le soutien aux PARs.

Rôle des Paires Associées de Recherche (PARs) dans CHIWOS

- 35 PARs au Canada dont 11 au QC
- Rep. provinciales NMT
- Rep. provinciales au transfert des connaissances
- Participent au recrutement et au suivi des participantes
- Consentement libre et éclairé lu et discuté avec les PARs
- Passation des questionnaires
- Participation active à la rédaction et révision des publications
- Activités de transfert des connaissances, de recrutement et de rétention des participantes initiées et menées par les PARs



Développement du questionnaire

Questionnaire développé à partir de 11 focus group Menés entre 2011 et 2012 au QC, ON, C.-B. (O'Brien et al., 2017) :

Plusieurs groupes de travail (PARs, chercheurs, cliniciens, intervenants, etc) guidés par différentes approches telles que:

- Déterminants sociaux de la santé;
- Intersectionnalité;
- Critique féministe
- Anti-oppression et justice sociale

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

Section 1: Données démographiques et statut socioéconomique
Section 2: Information médicale et sur l'infection par le VIH
Section 3: Soins de santé et utilisation des services sociaux
Section 4: Santé reproductive des femmes
Section 5: Stigmatisation et discrimination
Section 6: Consommation de drogues et d'alcool
Section 7: Violence et maltraitance
Section 8: Santé sexuelle des femmes
Section 9: Bien-être émotionnel, résilience et qualité de vie liée à la santé

Dans quelle province se déroule l'entrevue?

- Colombie Britannique
- Ontario
- Québec

Critères d'éligibilité

-S'identifier comme femme

-Vivre avec le VIH

-Être âgée de 16 ans et plus

-Vivre au QC, en ON ou en C.-B.

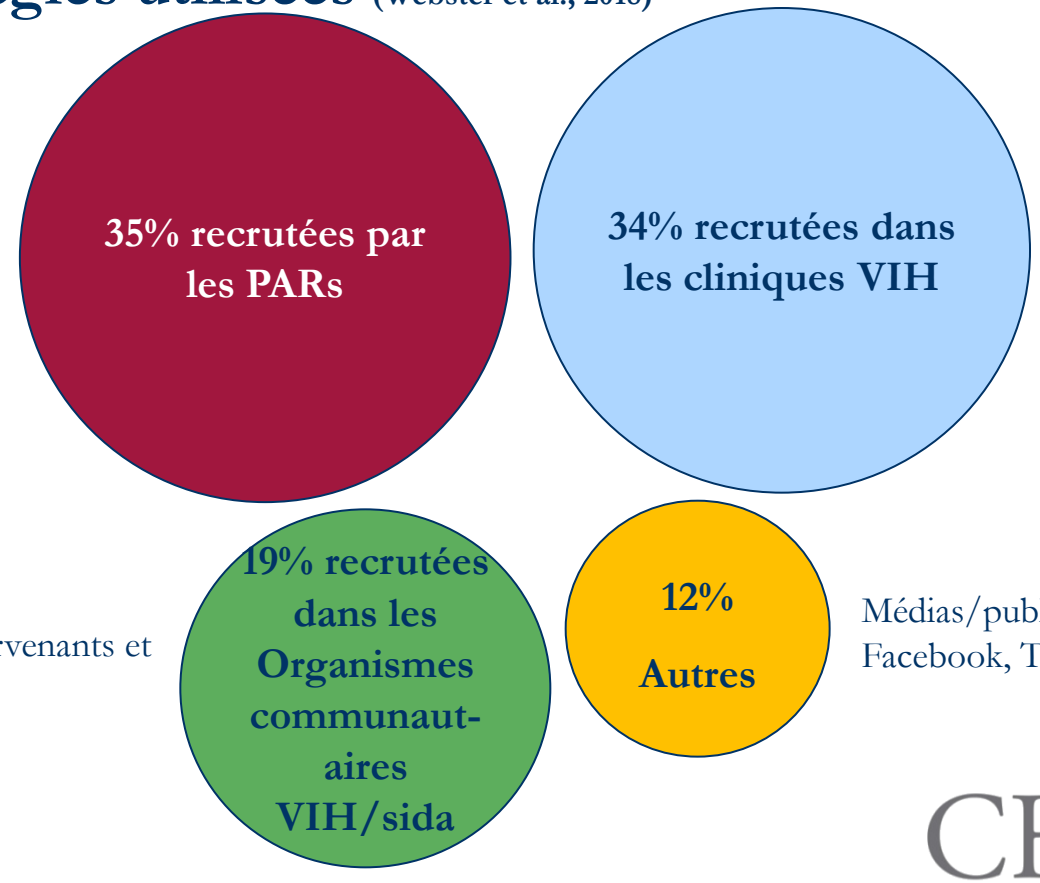
-Parler français ou anglais (possibilité de faire appel à un traducteur)

CHIWOS

Recrutement

Plusieurs stratégies utilisées (Webster et al., 2018)

-Réseau des PARs et bouche-à-oreilles
-Forme de recrutement le plus efficace en ON (49%)
-PARs plus efficace pour recruter: LGBTQ, UDI, sans traitements ARV, sans soins VIH.



-Forme de recrutement le plus efficace en C.-B. (40%) au QC (43%)
-Cliniques plus efficace pour: femmes de 16 à 29 ans, n'utilisant pas les services communautaires VIH

Recrutées par des intervenants et référées au PARs

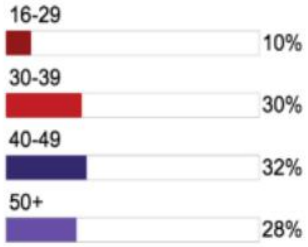
Médias/publicité (site internet, Facebook, Twitter, affiches, dépliants)

CHIWOS

Cohorte CHIWOS

- **1,422** femmes vivant avec le VIH
- De Août 2013 à Mai 2015

Âge: 43µ
(16-74)



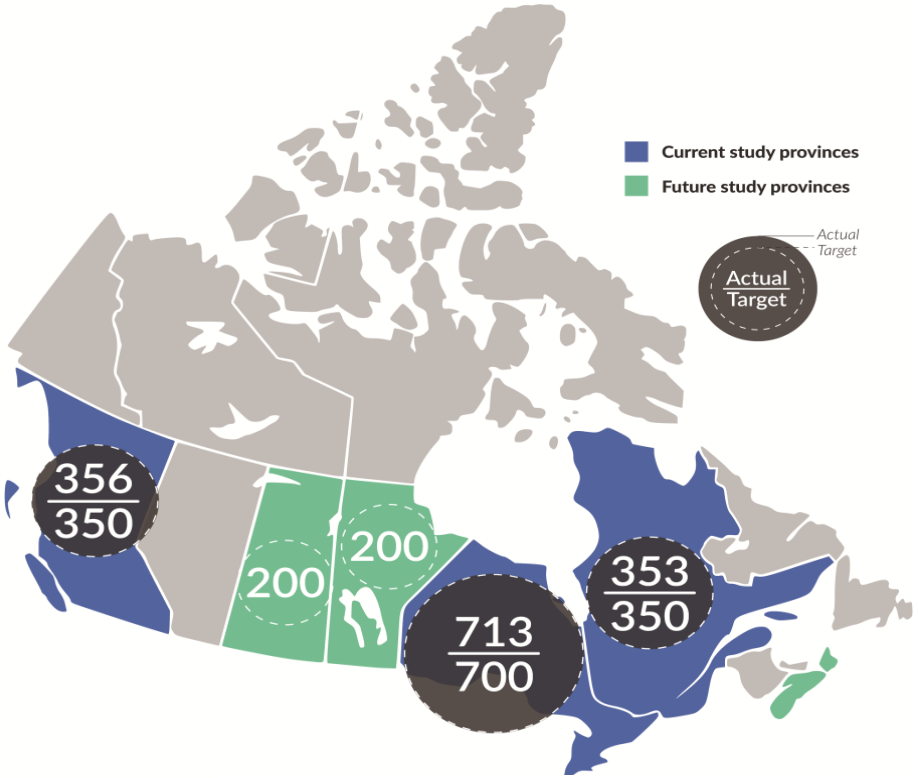
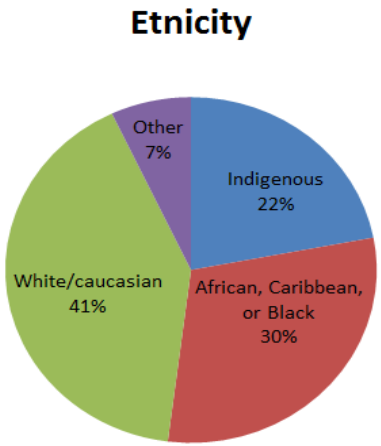


Fig 1 : Current and upcoming CHIWOS sites with target and actual recruitment numbers.

CHIWOS

Cohorte CHIWOS

CHIWOS a recruté des participantes représentant la diversité des femmes vivant avec le VIH au Canada



Historique d'injection de drogues
n=438

Femmes trans
n=54

LBQ2S
n=180

Femmes actuellement impliquées dans le travail du
n=82

Jeunes femmes
n=137

Femmes n'ayant pas de soins VIH
n=77

Vague 2

- De juin 2015 à janvier 2017
- Questionnaire de suivi à 18 mois
- **1,252/**1,422 entrevues vague 2
- **88 % taux de rétention au plan national**

CHIWOS

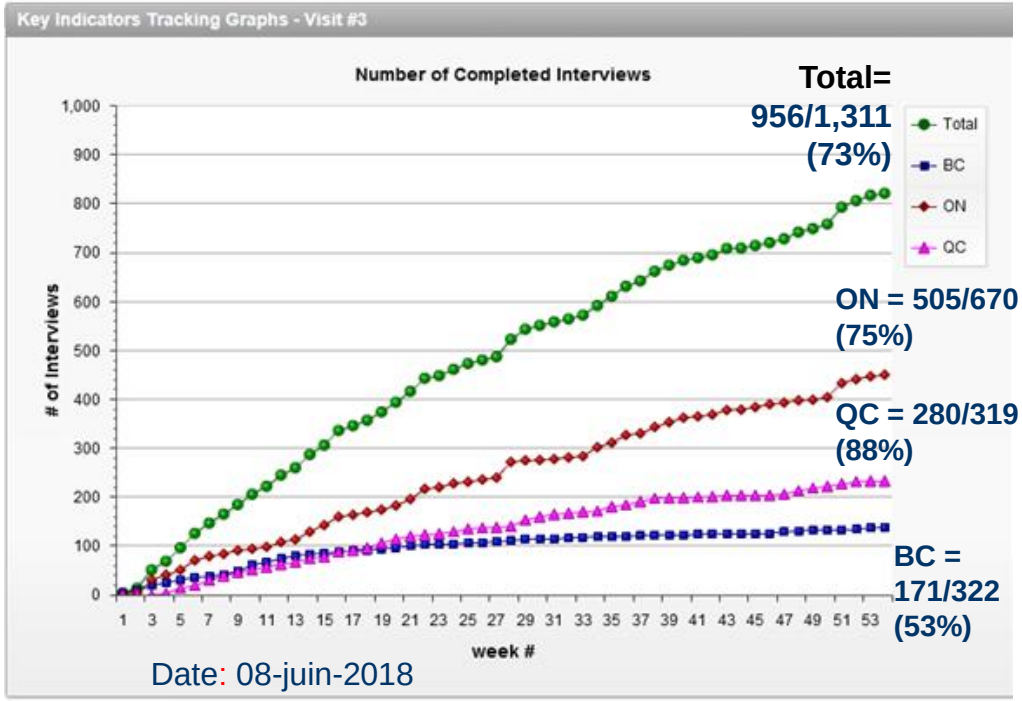
Vague 3- en cours

Lancée le 1er Fév 2017 (17 mars 2017 au QC)

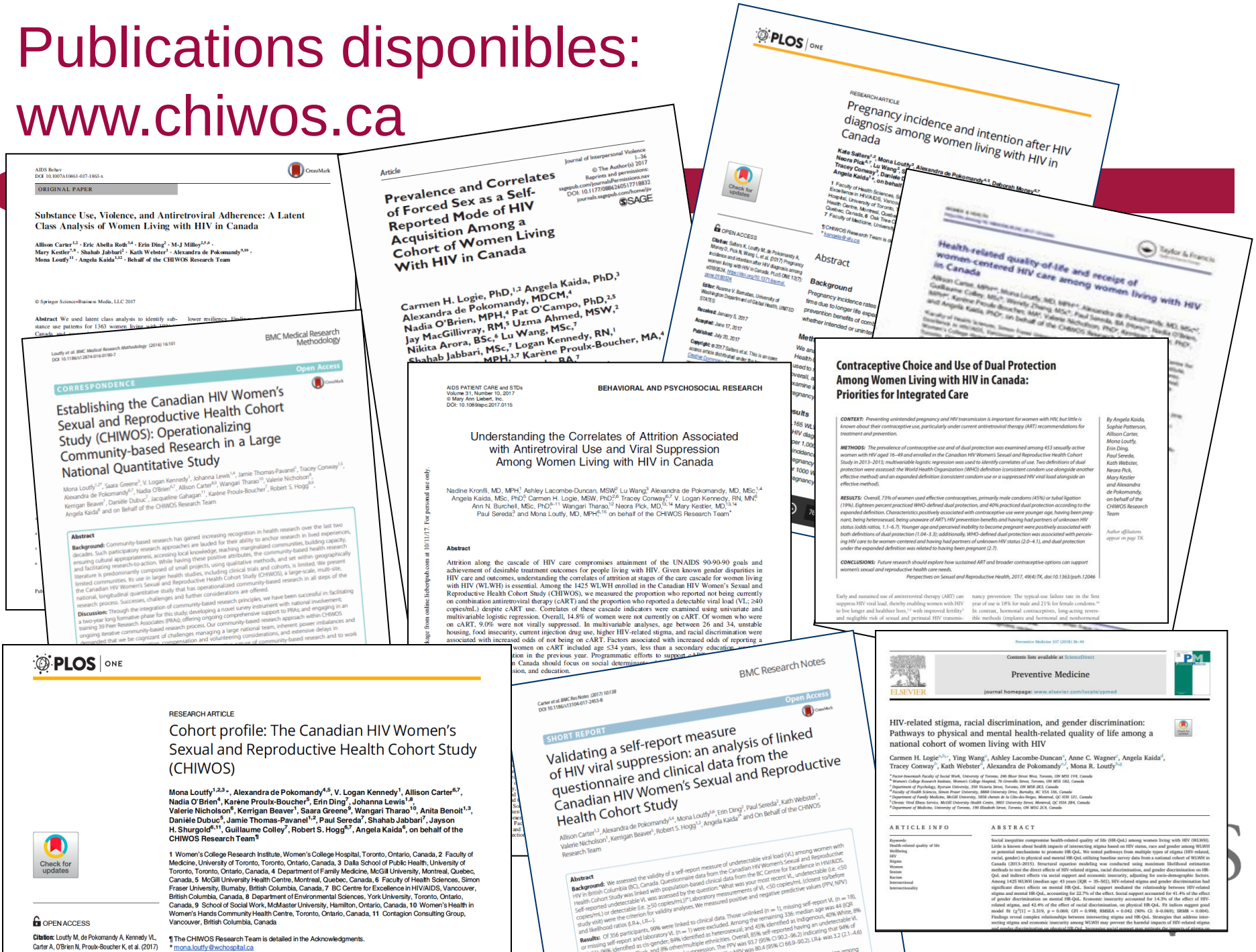
- Suivi à 36 mois
- Mise à jour du questionnaire avec de nouvelles priorités

Au plan national:

- **956** entrevues de suivi à ce jour
- **73 %** de rétention à ce jour



Publications disponibles: www.chiwos.ca



Analyses menées au QC

Quebec-led DRFs

1. Pap screening
2. Pap and HPV vaccine
3. Pregnancy and Motherhood experiences
4. Co-morbidities: Prevalence and risk factors
5. Comprehensive health care
6. Reproductive discussion between women and MD
7. Reproductive intentions and maternal support
8. Overall satisfaction with HIV care

À venir……

Accéder aux données CHIWOS?

- Contacter la coordonnatrice CHIWOS QC
- Karène Proulx-Boucher

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

For internal use only
Project number:

CHIWOS PROJECT AND DATA REQUEST FORM

Date of request:
Name:
Contact phone:
E-mail address:
Province the request comes from:
☐ British Columbia ☐ Ontario ☐ Québec ☐ Saskatchewan ☐ Manitoba
☐ Other:_____

Instructions:
Please complete an electronic copy of this form and submit to your Provincial Coordinator.
Please review the 'CHIWOS PROJECT AND DATA REQUEST POLICY' of this document before beginning.
For most sections below you only have to write one or two sentences. If you have any questions, please contact your Provincial Coordinator.

DRF =Data Project and Request Form

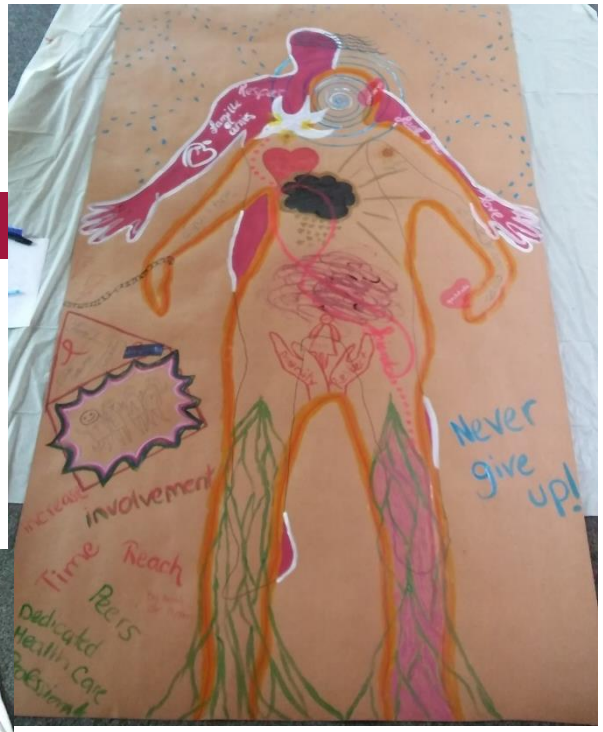
SFU · BC Centre for Excellence in HIV/AIDS · Providence Health Care · Women's College Research Institute · Centre universitaire de santé McGill · McGill University Health Centre · Ontario HIV Treatment Network · CIHR IRSC Canadian Institutes of Health Research · Instituts de recherche en santé du Canada · the CTN CIHR Canadian HIV Trials Network · le Réseau Réseau canadien pour les essais VIH des IRSC

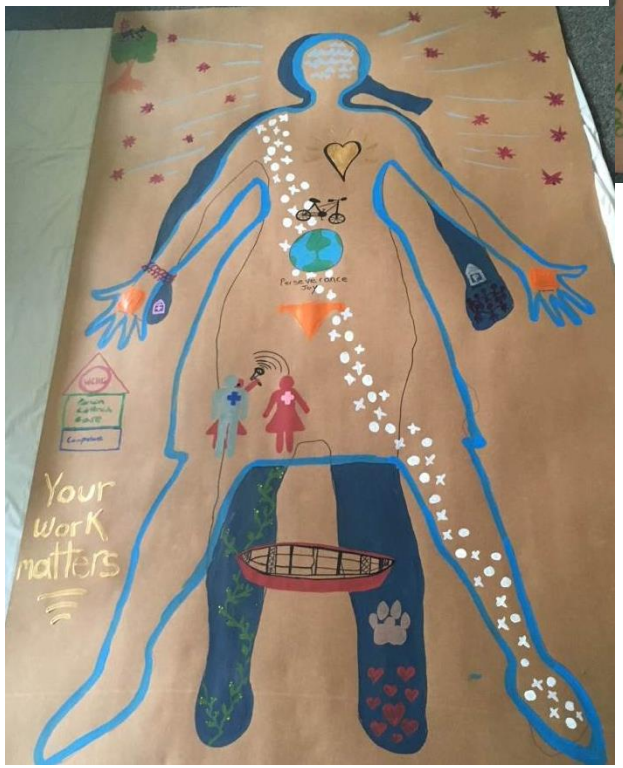
CHIWOS

Prochaines étapes !

Body Mapping

- Mené par Saara Greene
- Possibilité d'adapter l'art-thérapie à la recherche et à un outil de revendication pour CHIWOS, en mettant l'accent sur de nouvelles perspectives sur les soins centrés sur les femmes.
- Ateliers sous forme de retraite tenues dans chaque province





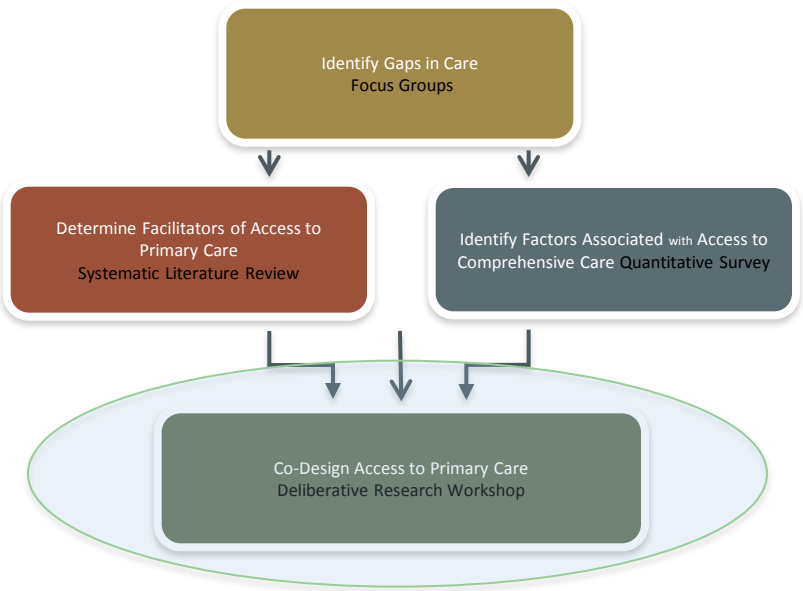
CHIWOS

Upcoming Deliberation Project

Purpose: engage patients & providers in deliberations

1) discuss, support, and refute findings from my PhD
2) identify key intervention opportunities
3) produce recommendations for policy and practice.

Grant Funding Secured : FRQS -Réseau SIDA - $30,000



What is Deliberative Dialogue?

- Stakeholder **engagement** method
- Particular type of discussion
- **Diverse** participants are provided with **evidence**
- Encouraged to discuss and challenge information and **consider each other's views**
- Identify recommendations or directions **for action**

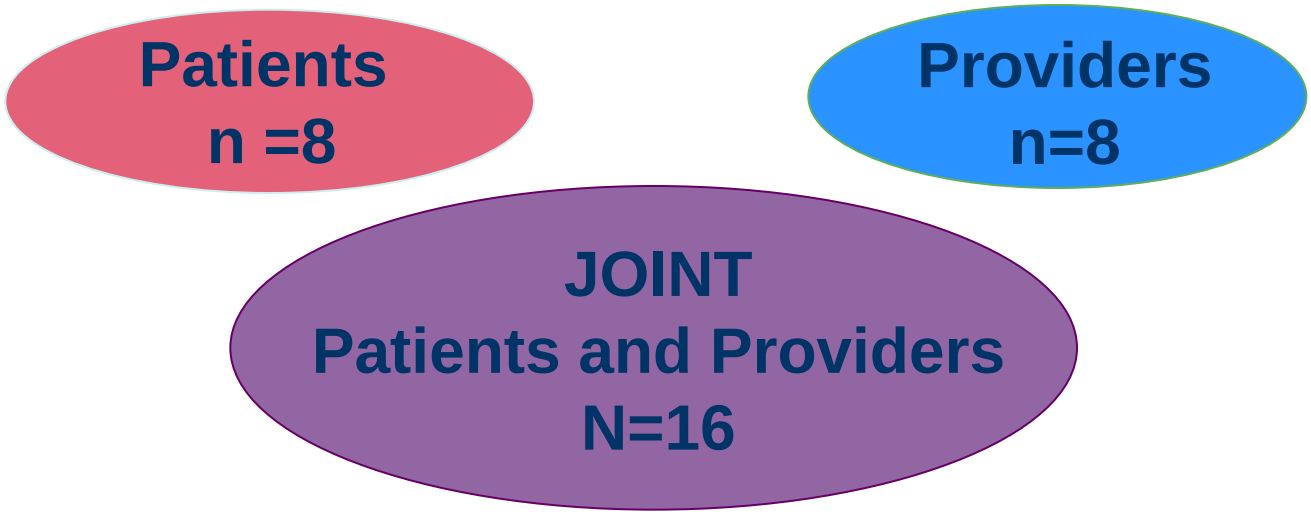
– Abelson, 2003

Deliberation "*is used not so much to give participants a 'voice'… but to create a process in which the* ***participants themselves produce conclusions*** *that can then be relayed to others, for example policy makers*" - Evans & Kotchetkova, 2009

Upcoming Deliberation

Method : To be conducted in 2018

- 1 patients & 1 provider deliberations "similar power"
- Time for critical reflection
- 1 joint deliberation – expert facilitation
- Not consensus driven, multiple recommendations



Interested in participating?

- We are looking for 8 care providers
  - Nurses
  - Physicians
  - Social Workers
  - Etc..
- Participation will be compensated
- Come see me after the rounds
- Or email me: obrien.nadia@gmail.com

Questions

Merci !
Thank you!

Pour plus d'informations:

For more information :

Karène Proulx-Boucher (QC)

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Autres provinces:

Rebecca Gormley (BC)

BC Coordinator info will be available shortly

604-806-8615 or 1-855-506-8615 (toll-free), kangela@sfu.ca (Dre. Kaida's email)

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