

MIWA: Meaningful Involvement of Women living with HIV/AIDS – A critical component towards ‘Getting to Zero’

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**Simon Fraser University
AIDS Awareness Network
World AIDS Day 2013**



**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 acknowledge that we have gathered together on the traditional territory of the Cedar Coast Salish people

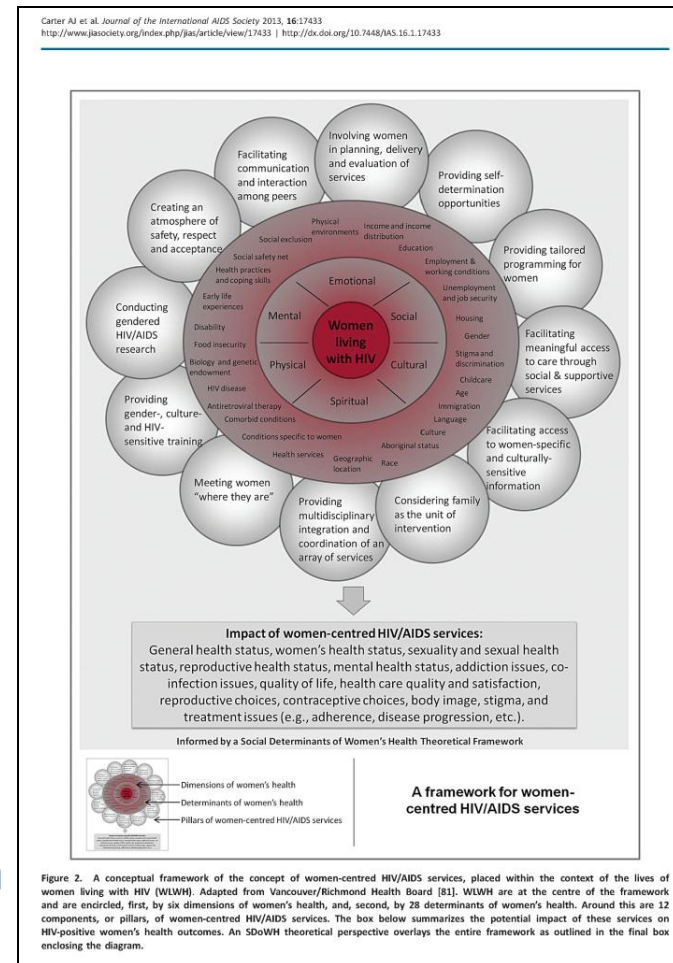
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- Thank you to our affiliated studies: CANOC, REACH, & OSC
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CHIWOS Study Goals

- Among HIV-positive women
 - To assess barriers to and facilitators of ‘women-centred HIV/AIDS services’ use
 - To assess the impact of such patterns of use on sexual, reproductive, mental, and women’s health outcomes
- Hypotheses:
 - Use of ‘women-centred HIV/AIDS services’ will a) be lower among more marginalized and stigmatized communities, and b) be shown to correlate with improved sexual, reproductive, mental and women’s health outcomes



CHIWOS Study Design

- Five year, multi-site, prospective cohort study rolling out in BC, ON and QC
- Target sample size = 1,250 women living with HIV
 - 350 women each in BC & QC; 550 women in ON
- Two phases:



- Formative phase (Done! In analysis stage)
- National survey phase (Launched Oct 1st, 2013!)
 - Recruitment at clinics, ASOs, community centres, online, word-of-mouth, peer-driven
 - Participants will complete a Peer Research Associate (PRA)-administered survey at baseline (Wave 1) and again 18 months later (Wave 2)
 - The survey is online, takes 2-2.5 hours and participants will receive a compensation of \$50

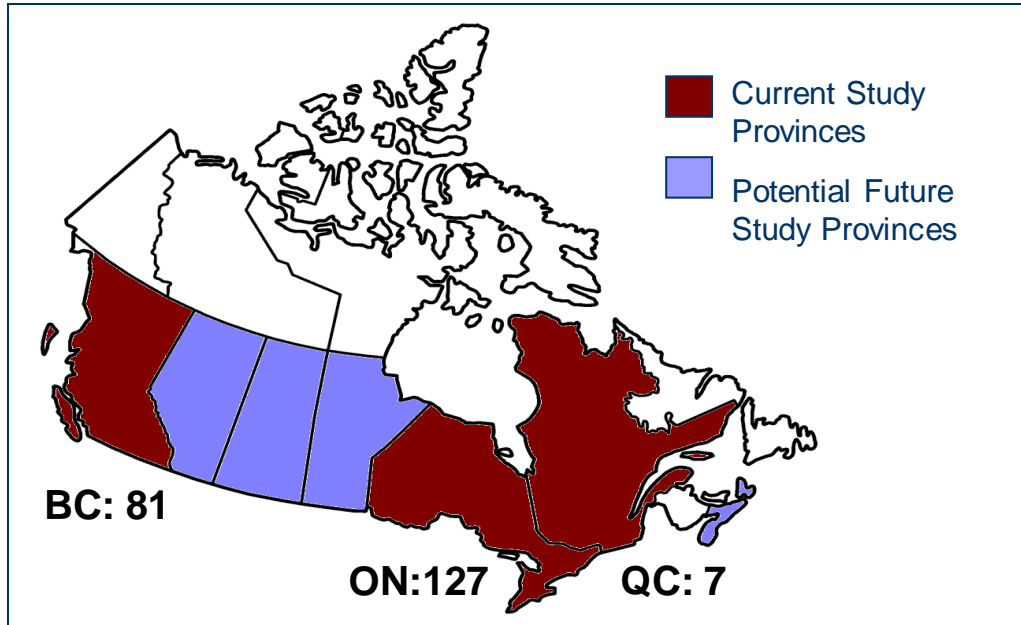
CHIWOS Study Design (continued)

- Draws on **Critical Feminist** and **Social Determinants of Health (SDoH)** frameworks, and is grounded in a **community-based research (CBR)** approach



Participants enrolled nationally

October 1st 2013: *CHIWOS* officially Launched!



(Numbers enrolled as of Nov 26 2013)

ARE YOU A WOMAN LIVING WITH HIV?

Participate in a study about the health care needs of women living with HIV in Canada.

What is the goal of the study?

To create new knowledge about women-centred care that will be used to support women living with HIV in Canada to achieve optimal health and well-being.

You are eligible to participate if you:

- Identify as a woman
- Are HIV-positive
- Are 16 years of age or older
- Live in British Columbia, Quebec or Ontario

What is involved in the study?

The study involves answering a 2-2½ hour questionnaire with a trained peer interviewer, plus a follow-up interview 18 months later.

You will receive an honorarium to cover your participation expenses. Confidentiality is assured.

For more information and to participate, please contact:

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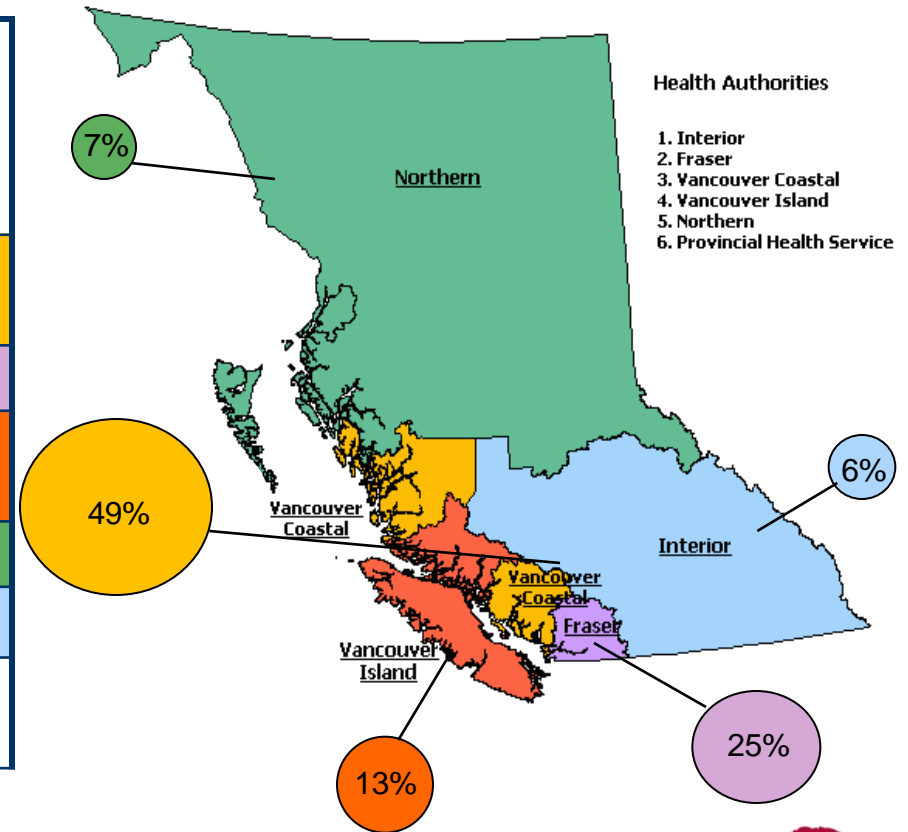
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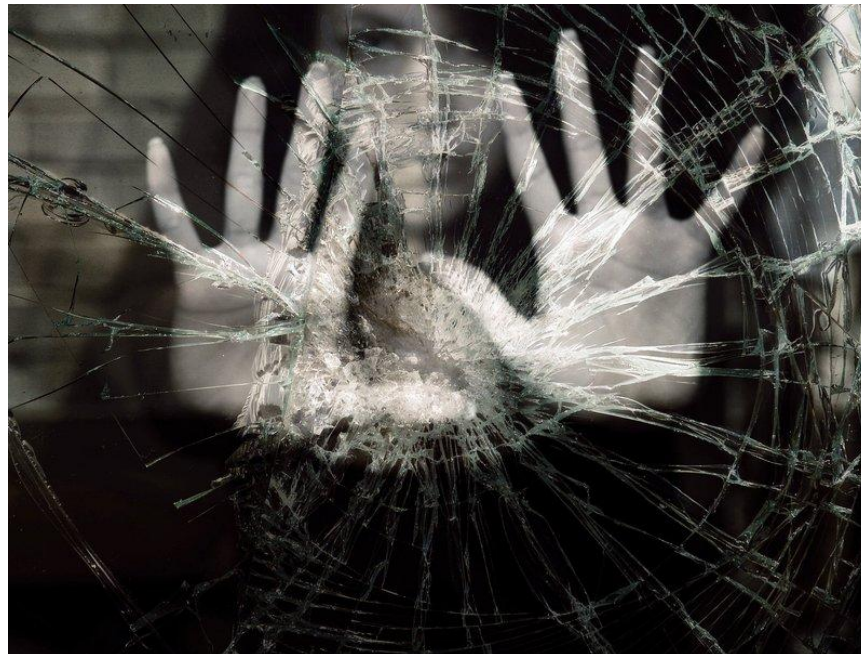


Participants enrolled in BC

Region	# women testing newly HIV+ in BC (1994 to 2009)	# women enrolled in CHIWOS (as of Nov 26 2013)
Vancouver Coastal	765 (49%)	41
Fraser	389 (25%)	13
Vancouver Island	197 (13%)	6
Northern	103 (7%)	10
Interior	99 (6%)	<5
Oak Tree Clinic	--	10



Breaking the glass ceiling: Increasing the Meaningful Involvement of Women Living with HIV/AIDS (MIWA) in the design and delivery of HIV/AIDS services



Background

- The right of people living with HIV to participate as active and equal agents of change in their own health has long been recognized (GIPA/MIPA)
- Previous research has examined the contributions of people living with HIV in CBR, ASOs and clinics and critiqued the benefits, challenges, and ethical tensions emerging from this involvement
- However, very little is known about the involvement of **women** living with HIV
- The **objective** of this study was to explore the lived experiences of HIV-positive women's meaningful involvement in the design and delivery of HIV/AIDS services in British Columbia (BC), Canada

Methods

- 4 focus groups with 28 diverse women living with HIV in Vancouver, Victoria, and Prince George, BC
- Conducted between August and October 2011
- Co-facilitated by 3 Peer Research Associates (women living with HIV) and 1 Research Coordinator
- Analyzed using thematic analysis, peer debriefing, and investigator triangulation
- All names and places changed and pseudonyms used to protect confidentiality



Results – The benefits of receiving peer-driven services

“Facebook, I have a community of women, Positive Aboriginal Women, PAW, that I support; I network; I share information.” (Emma)

“The retreat that I went to at X... It was absolutely life-affirming, single most important service I’ve accessed, because I got to surround myself with positive people...” (Shelia)

“They have a lot of workers there that are young and they are positive, and they’re on the board, so they run the place... It’s just a really warm, comforting environment... and when I did go there I was able to open up... I felt like my word was valued, that it was trusted... I felt like I was being heard there.” (Lauren)

Results – The benefits of providing peer-driven services

“X [a clinic]... they have this pilot project with Peer Navigators... So, if you want to go and sit and talk to someone that’s positive, while you’re waiting for your appointment there’s someone there from 9:00 a.m. to 7:00 p.m. that’s positive, every day... To have Peers in a clinical environment I think is taking what GIPA Principles were about in the late mid-nineties to what they should be today.” (Sheila)

“How about peers there that understand what you’re going through, kind of like myself? Who have done the drug addiction, who have been homeless, who have worked the streets, who are HIV-positive who will help you to understand exactly what your needs are...” (Elina)

“I do it for others as much as it is for myself” (Sheila)



Results – The tensions that arise as their role shifts from service user to provider

(1) Being required to choose between remaining clients or becoming paid employees:

“I started volunteering there... We had X group. I started that group. But I felt very uncomfortable, that because I access their Food Bank I can never work there. And because of that, I stopped doing it... You can never really get into the system... just because you have HIV.” (Hope)

(2) Being positioned unequally as providers who are good enough to volunteer yet not good enough for paid work:

“I’m expected to put in volunteer hours. I see a couple of my neighbours, they drive them like slaves. They work like dogs and don’t get a penny for it. They don’t get recognition. They don’t even get a cake or something on volunteer day. It’s like there’s this glass ceiling...” (Veronica)

(3) serving as a resource but without equal ownership / control:

“Every time I walk in that door... I’m paying somebody’s salary and they’re able to write another grant because I fit into many different demographics. So, if they’re applying for Aboriginal money, we have Aboriginal women... But I have no control over how they use my membership. I have no control over whether they hire positive people, Aboriginal people, and I’m not about to get on the Board and try and change things. Not my thing. What I would rather do is revoke my membership... and say, see you later.” (Emma)

Results – The tensions that arise as their role shifts from service user to provider

(4) Confronting organizational attitudes that espouse empowerment yet fail to fully acknowledge women's capacity to contribute in practice

“Where I live, it's X [a community-based organization]. And for whatever reason, the further you get away from Vancouver, the more closed-minded and weird they get. They just seem to have this mentality of, oh those poor people. We're going to help them. We're going to give them all these services but we're not going to recognize their ability to help themselves. There's no empowerment.” (Reba)

(5) Needing transparency around having women with HIV working in organizations while balancing the need to protect HIV status confidentiality

“At X [an ASO]...I don't know if any of them are HIV-positive or not. I don't get a feeling that they really know what they're talking about. If they would just come out and say, look, I'm not HIV-positive, but I am a support worker, I just feel like there needs to be more openness about the situation there...Then, I did ask somebody and they said, yes, but it's very secretive who on the Board at X [an ASO] is HIV-positive, very, very secretive. I just thought if that's the case, I'm just not up for that kind of a place where there's this big, secretive thing happening.”(Darlene)

Results – Visions of women-centred care include a commitment to MIWA

“I’ve dreamt about this...I’d want a house...a big house...someplace rural, with a garden to grow fruits and vegetables...I see a community kitchen...I see a home that also functions as...a safe place...a place where children are welcome...” (Karen)

“Yeah.” (Monika)

“Community, a real community...” (Vera)

“I think of the Ronald McDonald House, where kids go and they can just be themselves. We can just hang out with other women...” (Veronica)

“A summer camp for adults...” (Karen)

“This is our house guys.” (Linda)

“Yeah.” (Multiple voices)

“Our house.” (Multiple voices)

“There needs to be more peer education, peer mentoring, empowerment, opportunities.” (Sheila)

“Yeah, a big word, opportunity. There needs to be more opportunity out there for people, for those who are positive. We have a lot of skills to bring to the table.”(Veronica)

Conclusions / Implications

- Urgent need to ensure that the pathway to women's meaningful engagement and leadership in the design and delivery of HIV/AIDS services is unobstructed
- By supporting meaningful user engagement, organizations have the potential to contribute to more effective health services and improved health outcomes for women living with HIV
- This will be evaluated in the next phase of CHIWOS and will have important implications for models of system design and delivery in Canada

Final questions / thoughts?

For more information, please contact:

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