

COMMUNITY ENGAGEMENT IN RESEARCH: RECRUITING A LARGE, DIVERSE COHORT OF WOMEN LIVING WITH HIV IN CANADA

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BACKGROUND

Women have been excluded from HIV research for decades due to numerous structural challenges related to sex (e.g., pregnancy, hormonal fluctuations) and gender (e.g., childcare, transportation).

Even in women-exclusive studies, non-representative samples are common, with women who are the most marginalized by society often facing the greatest barriers to meaningful participation.

Objective: To describe our approach to recruiting diverse women with HIV in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

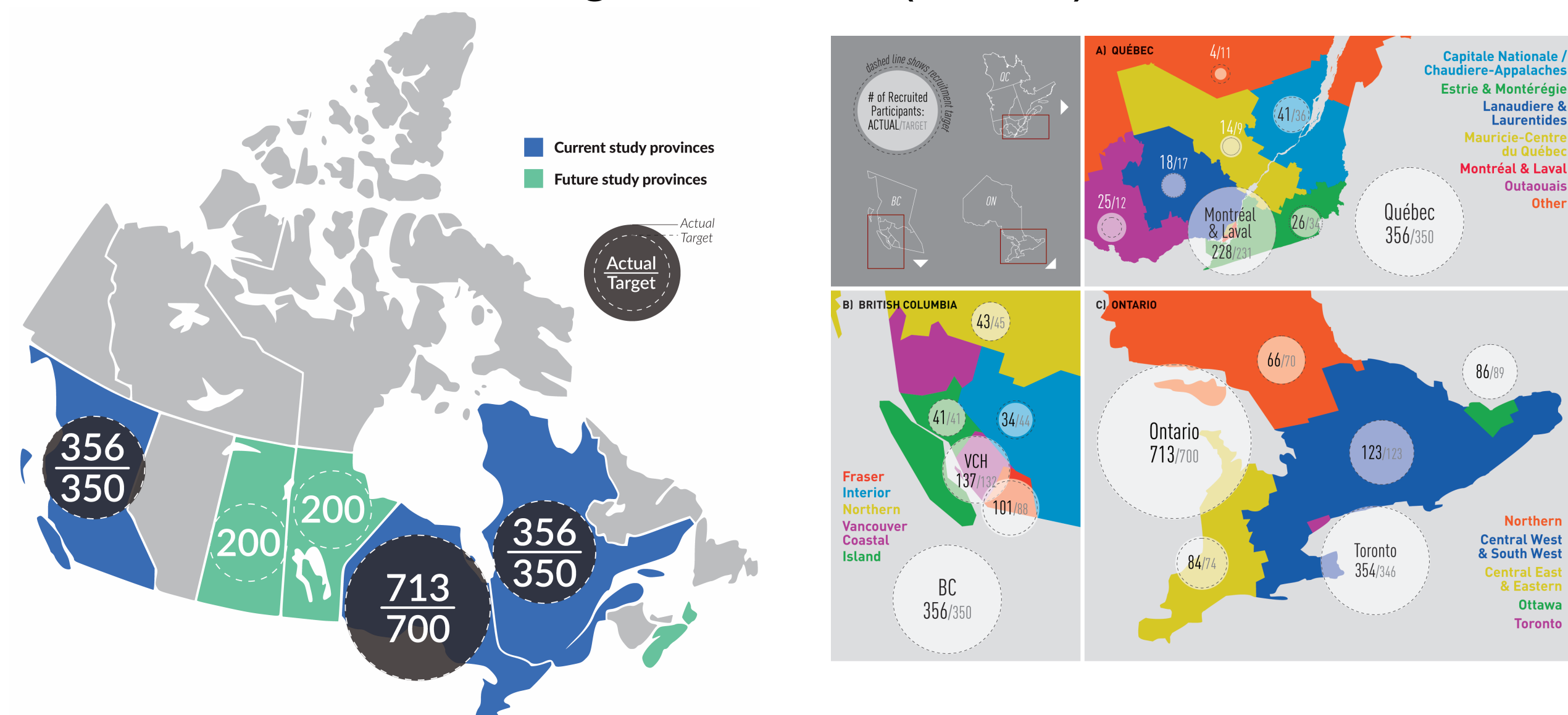
METHODS

CHIWOS is a longitudinal, community-based research study conducted by, with and for women with HIV in BC, ON, and QC (now expanding to MB and SK), in collaboration with researchers, providers, policy-makers and communities.

Peer Research Associates (who are themselves women with HIV) administer an online survey (median: 120 mins, IQR: 90-150) to participants at baseline and every 18-months, collecting socio-demographic, behavioral, clinical, and health information.

Between August 27, 2013 and May 1 2015, we enrolled 1,425 women with HIV in BC, ON, and QC. Our recruitment approach was diverse and included PRA-driven efforts, outreach to clinics and AIDS Service Organizations (ASOs), and online methods.

Figure 1.
Targeted and actual recruitment across Canada



At study enrolment, women were asked: *How did you hear about the study?* A coding framework was developed and two independent reviewers in each province coded the responses. Participants with missing data (n=294) were excluded from analyses.

RESULTS

The women: A diversity of lived experiences

Among participants with complete data (n=1,131), 40% identified as White, 33% African, Caribbean or Black, and 19% Indigenous. Median age was 45 (IQR: 37-51). 4% identified as trans-women and 12% as lesbian, gay, bisexual, two-spirited or queer. 10% were currently using injection drugs (25% previously). Most (82%) had high school education, though reported low incomes (65% <\$20K). 75% had children. Women were well connected to care: 95% accessed clinic care in past year, 88% were currently on treatment, 62% accessed HIV support services from a community agency.

Multiple approaches to increase recruitment of diverse women

PRAs and other peers recruited 35% of participants, clinics 34%, and ASOs 19%. PRAs/peers were the predominant method in ON (49%), vs. clinics in BC (40%) and QC (43%). PRAs/peers were more successful in recruiting women who were trans (47%), LGBTQ (41%), current injection drug users (37%), *not* currently on ART (39%) and *not* receiving HIV care (54%). Clinics were more effective in recruiting women aged 16-29 (49%) and not using HIV support services in the last year (50%). (Table 1)

RESULTS (CONTINUED)

Table 1. Recruitment methods, as self-reported by participants (n=1,131)

Variables	Recruitment Methods (self-reported)					p-value
	PRA/Peer (391 (35%)) N(%)	Clinic (385 (34%)) N(%)	ASO/CBO (211 (19%)) N(%)	Word of Mouth (71 (6%)) N(%)	Other (73 (6%)) N(%)	
Province						
BC	97(28)	139(40)	96(27)	4(1)	14(4)	<0.001
ON	209(49)	95(22)	36(8)	36(8)	54(13)	
QC	85(24)	151(43)	79(23)	33(9)	3(1)	
Gender						
Cis women	370(34)	375(35)	207(19)	63(6)	71(7)	<0.001
Trans/2spirited/Queer/Other	21(47)	10(22)	4(9)	10(22)	0(0)	
Sexual orientation						
Heterosexual	332(34)	351(36)	180(18)	61(6)	64(6)	0.049
LGBTQ	56(41)	32(23)	30(22)	12(9)	7(5)	
Age at interview (years)						
16-29	21(26)	40(49)	7(9)	9(11)	5(6)	0.017
30-39	105(35)	97(33)	53(18)	20(7)	23(8)	
40-49	144(37)	136(35)	65(17)	21(5)	21(5)	
50+	121(33)	112(31)	86(24)	23(6)	22(6)	
Ethnicity						
Caucasian	69(31)	62(28)	60(27)	15(7)	15(7)	0.018
Indigenous	123(33)	135(37)	56(15)	25(7)	29(8)	
African/Caribbean/Black Canadian	160(35)	163(36)	84(18)	26(6)	22(5)	
Other	39(45)	25(29)	11(13)	7(8)	5(6)	
Household annual income (CAD)						
<\$20,000	243(34)	223(31)	163(23)	44(6)	41(6)	<0.001
>=\$20,000	135(35)	147(38)	44(12)	28(7)	28(7)	
Highest level of education completed						
< High school	67(32)	66(32)	55(26)	9(4)	11(5)	0.022
>= High school	324(35)	317(34)	155(17)	64(7)	60(7)	
History of IDU						
Currently	42(37)	35(30)	31(27)	3(3)	4(3)	<0.001
Previously	102(36)	89(32)	76(27)	1(0)	12(4)	
Never	244(34)	257(36)	101(14)	66(9)	55(8)	
Accessed HIV clinical care in past year						
Yes	362(34)	380(35)	201(19)	67(6)	67(6)	0.001
No	28(54)	5(10)	10(19)	6(12)	3(6)	
Currently taking HIV medications						
Yes	338(34)	355(36)	184(19)	57(6)	57(6)	0.001
No	53(39)	28(20)	27(20)	15(11)	14(10)	
Accessed HIV support services in past year						
Yes	267(38)	174(25)	178(25)	43(6)	40(6)	<0.001
No	123(29)	210(50)	32(8)	29(7)	30(7)	
Have children						
Yes	96(34)	98(35)	42(15)	23(8)	21(8)	<0.001
No	259(33)	278(35)	163(21)	42(5)	50(6)	

Row percentages are shown. Some percentages are bolded to facilitate interpretation (see description provided at bottom of left column).

Challenges and successes: Reflections from the research team

Challenges

- Reaching women not accessing HIV services
- Engaging communities where isolation or stigma is high (e.g., trans, rural, ACB)
- Retaining women following pre-screening who had more transient lives
- Responding to challenges associated with childcare and transportation

Successes

- Hiring PRAs (from diverse communities, well-connected, built trust and rapport)
- Linking with clinics to reach large numbers & women less connected to community
- Involving outreach workers to increase engagement of street-involved women
- Presenting to stakeholders groups to target harder-to-reach populations
- Offering an honorarium of \$50 to honour women's time and cover costs
- Offering adjustments to protocol to accommodate life circumstances (e.g., children allowed to attend; option of doing survey at home or via skype)

CONCLUSIONS

Multiple approaches are key to recruiting a diverse sample. Peer-driven methods and clinics were especially effective, along with ASO supports to create opportunities for peers to connect. Additional targeted strategies are required to better engage hard-to-reach women. Study findings and reflections can offer insight to other teams aiming to increase the participation of women, in all their diversity, in HIV research.

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