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Strategies for Recruiting Women Living with Human Immunodeficiency Virus in Community-Based Research: Lessons from Canada

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Abstract

Objectives: This study sought to describe the recruitment of women living with HIV (WLWH) into the community-based Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), because women are under-represented in HIV research.

Methods: There were 1,424 WLWH were enrolled from British Columbia, Ontario, and Québec, who completed detailed questionnaires administered by peer research associates (PRAs; WLWH with research training). During screening, participants were asked: "How did you hear about the study?" We describe recruitment strategies by subpopulation and offer reflections on challenges and successes.

Results: Of 1,131 participants with complete data, 40% identified as White, 33% African/Caribbean/Black, and 19% Indigenous. The median age was 45 years (interquartile range, 37–51) and 4% identified as trans women. Overall, 35% were recruited through PRAs/peers, 34% clinics, and 19% AIDS service organizations (ASOs). PRAs/peers were the predominant recruitment method in Ontario (49%),

compared with clinics in British Columbia (40%), and Québec (43%). Nationally, PRAs/peers were more successful in recruiting WLWH commonly considered to be "harder to reach" (e.g., women identifying as trans, using drugs, not receiving HIV care). Clinics were more effective in recruiting younger women (16–29 years) and women not using ASOs. Recruitment challenges centered on engaging these harder to reach women. Successes included hiring PRAs who built participant trust, linking with clinics to reach women isolated from HIV communities, involving outreach workers to engage street-involved women, and disseminating study information to diverse stakeholders.

Conclusions: Having multiple approaches, engaging a diverse team of PRAs, ensuring flexibility, and cultivating reciprocal relationships with community stakeholders were key to recruiting a diverse and representative sample of WLWH.

Keywords

Recruitment, community-based participatory research, women, diversity, HIV/AIDS, CHIWOS

WLWH remain under-represented in research due to numerous sex- and gender-related structural challenges.¹ Even in women-exclusive HIV studies, samples have been historically made up of White, cis gender, heterosexual, educated, urban, and clinically engaged

women² or those with higher risk behaviours,^{3,4} potentially excluding WLWH who do not hold these experiences. Barriers to meaningful participation are diverse and may be related to 1) social status, with transportation, childcare, and competing family responsibilities often overlooked in funding structures

and study protocols; 2) cultural and linguistic diversity, with few studies catering to multilingual needs and providing culturally safe environments; 3) HIV-related stigma and discrimination; and 4) the distrust and power differentials that exist between researchers and participants, especially Indigenous and immigrant communities.^{5–8} Overcoming these intersecting barriers and ensuring greater inclusiveness and diversity in studies is essential in capturing the richness and complexity of women’s experiences, improving the generalizability of findings, and advancing more relevant and meaningful community action and change.⁹ Such feminist principles are increasingly accepted as reflective of “good science,” evident in the growing number of Canadian¹⁰ and global¹¹ funding bodies that now mandate consideration of sex and gender issues in health research. To support these goals and respond to women’s demands for more meaningful involvement,^{12–14} it is essential that research teams report on effective recruitment strategies. To date, however, the studies that do so are largely clinical,^{8,15,16} with few insights from community-based research (CBR) projects.^{17–19} In this article, we use quantitative data and reflections from the field to describe the experiences and lessons learned in recruiting diverse WLWH into the community-based CHIWOS.²⁰

PROCESS AND METHODS

Setting and Population: HIV among Women in Canada

There are approximately 16,600 WLWH in Canada, accounting for roughly one-quarter of all those living with HIV.^{21,22} The vast majority (81%) live in Ontario (38.5%), Québec (25.3%), and British Columbia (17.0%). National statistics data highlighting the diversity and complexity of women’s lives are sparse and limited to age and exposure categories.^{21,22} According to these data, women 30 to 39 years of age represent the greatest proportion of HIV-positive test results (37.6%), followed by women under 30 years of age (36.5%), and those aged 40 to 49 (17.5%) and those 50 or older (7.6%). HIV vulnerability and barriers to research and health care are compounded for women, particularly those from traditionally marginalized communities, through the intersecting effects of poverty,²³ unstable housing,²⁴ refugee and immigration status,^{25,26} violence and gendered power relations,²⁷ sexual and gender identity,^{28,29} addiction,²³ historical trauma including coloni-

zation of Indigenous women,³⁰ engagement in sex work,³¹ location (urban, rural, remote),³² and other sociostructural determinants of health.

The CHIWOS Study

Why the Study Was Formed. WLWH encounter inattention to their unique social vulnerabilities and health concerns, particularly those relating to sexual, reproductive, and mental health.³³ Holistic and integrated women-centered HIV care is one approach that may address women’s needs in a supportive, inclusive, and accessible manner, though research on this topic is extremely limited. CHIWOS was developed to address this evidence gap.

Key Partners and Roles. In 2010, more than 60 researchers, clinicians, community partners, and WLWH with a history of research collaboration^{2,6,34} united to initiate CHIWOS, drawing expertise and experience from various disciplines and areas of Canada. The process of establishing CHIWOS is described in detail elsewhere,³⁵ and our study team structure is shown in Figure 1. Briefly, a national management team consisting of one principal investigator, coordinator, PRA, and WLWH with research training from each of the three study provinces leads the day-to-day research activities provincially and meets monthly to discuss issues at a national level. This team is centrally run through four institutions (Women’s College Research Institute, McGill University Health Centre, Simon Fraser University, and the British Columbia Centre for Excellence in HIV/AIDS) and supported by more than 100 clinics and community organizations who help to recruit participants, provide interview space, and support PRAs (a full list of partners can be found on our study website: www.chiwos.ca).³⁶ Advised by a national steering committee, three provincial community advisory boards (each with membership from more than 100 individual and organizational stakeholders in the health of WLWH), and numerous group-specific advisory boards (e.g., CHIWOS Aboriginal Advisory Board for Positive Aboriginal Women), with study implementation led by PRAs with support from study staff, CHIWOS is informed by a rich diversity of perspectives and specialties. Consistent with CBR principles,^{19,37} community stakeholders, including WLWH, are engaged in all stages of the research process, from defining the research question, through data collection and analysis, to the publication and dissemination of findings. The current

analysis was co-led by one PRA (K.W.) and two academic researchers (A.C., A.K.), in collaboration with all co-authors who, collectively, make up every part of the team.

Study Goals and Guiding Frameworks. The overall goals of CHIWOS^{20,38} are to assess the patterns of use of women-centered HIV care and the impact of such patterns on women's, sexual, reproductive, and mental health outcomes. The study is grounded in CBR principles,¹⁷⁻¹⁹ and guided by the social determinants of women's health^{39,40} and critical feminism⁴¹ frameworks.

Study Design: Peer-led Formative Work and Longitudinal Questionnaires. As part of CHIWOS' formative phase (2011–2013), the team conducted relationship building with community partners, eleven focus groups with WLWH to determine community definitions of women-centered HIV care,^{42,43} and formal discussions with stakeholders to design the national survey instrument.⁴⁴ The quantitative phase of the study is currently on-going and involves 2-hour questionnaires administered to WLWH by PRAs at baseline and every 18 months (target $n = 1,400$). Wave 1 (baseline) was launched August 27, 2013, and completed May 1, 2015 (actual $n = 1,424$), and followed by 18-month (Wave 2: 2015–2017)

and 36-month visits (Wave 3: 2017–ongoing). Figures 2 and 3 show the regional target and actual numbers. Questionnaires were designed and reviewed by the entire national research team, with some stakeholders providing specific topical expertise (e.g., HIV criminalization) and others reviewing the survey for sensitivity, diversity, and relevance to key populations of women (e.g., trans women, Indigenous women).

Hiring, Training, and Supporting CHIWOS PRAs. To support the design and implementation of the study, we hired, trained, and supported 40 WLWH as PRAs (8 in British Columbia, 21 in Ontario, and 11 in Québec), who were diverse in sexual orientation, trans identity, ethnicity (including Indigenous and African, Caribbean, and Black Canadian ancestry), languages spoken (including French [$n = 8$]), and histories of drug use and/or sex work.⁴⁵ Most members of our PRA team, however, were older than 50 or were 30 to 49 years of age. Our overall approach is described in detail elsewhere⁴⁵ and included 1) a supportive, inclusive, and accessible equity-oriented hiring process; 2) a multiphase training curriculum that was viewed as directly related to our commitment to community capacity building; and 3) on-going learning and support opportunities, including monthly meetings, refresher

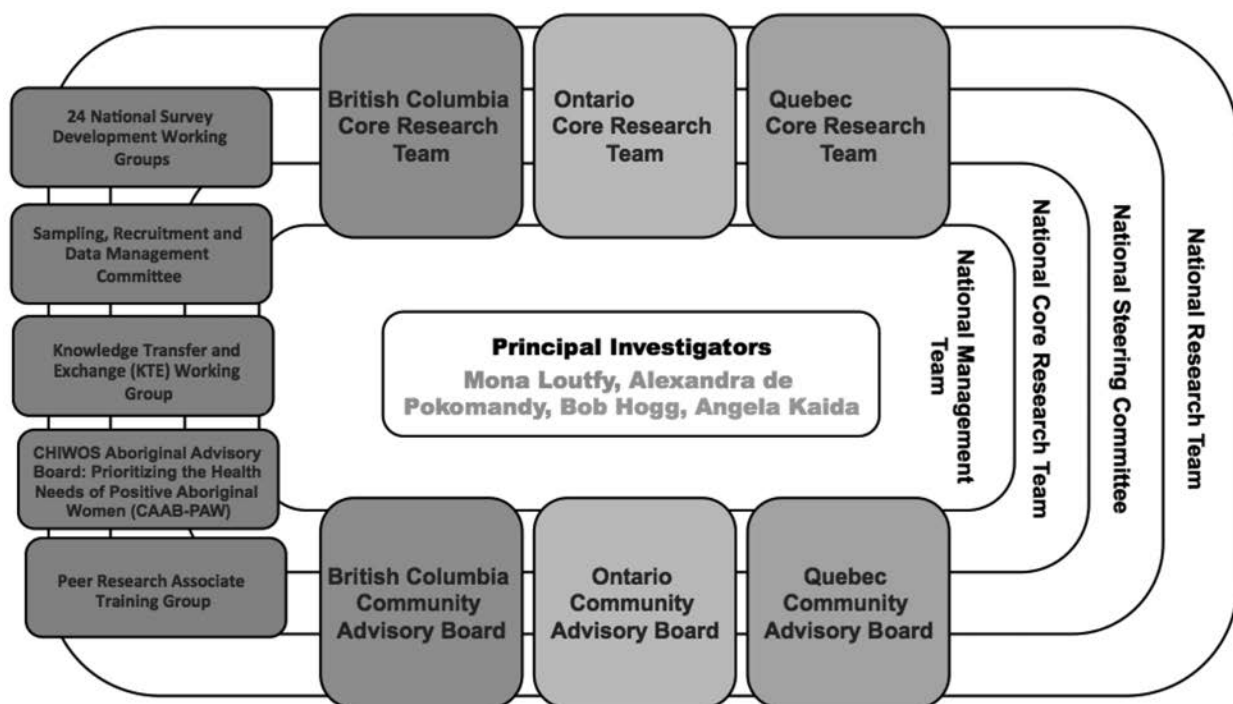


Figure 1. Canadian HIV Women's Sexual and Reproductive Health Cohort Study team structure

This figure has been previously published in an article in the journal *BMC Medical Research Methodology*.³⁵

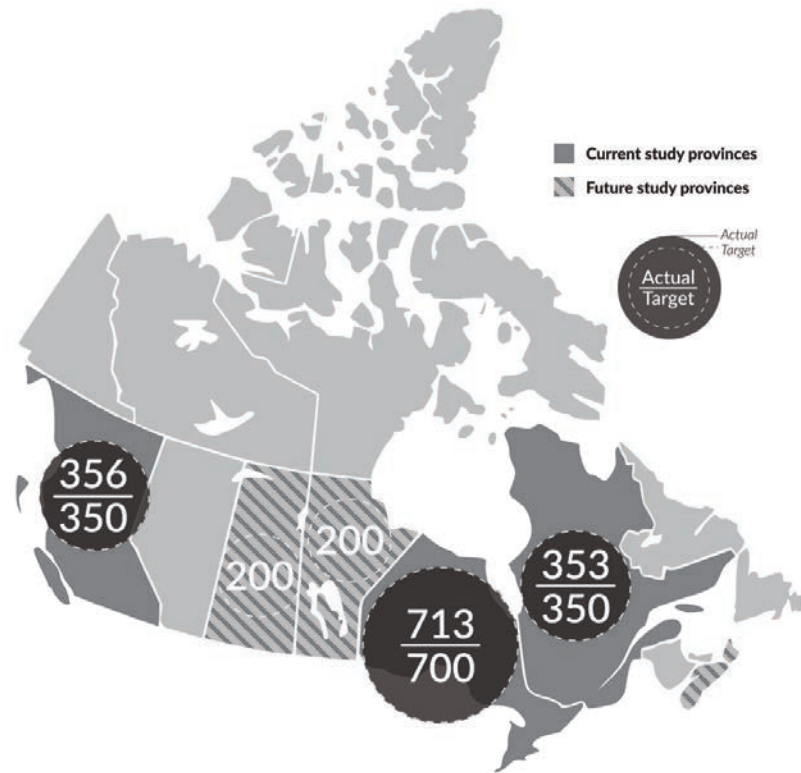


Figure 2. Targeted and actual recruitment of women living with human immunodeficiency virus (HIV) in the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study nationally.

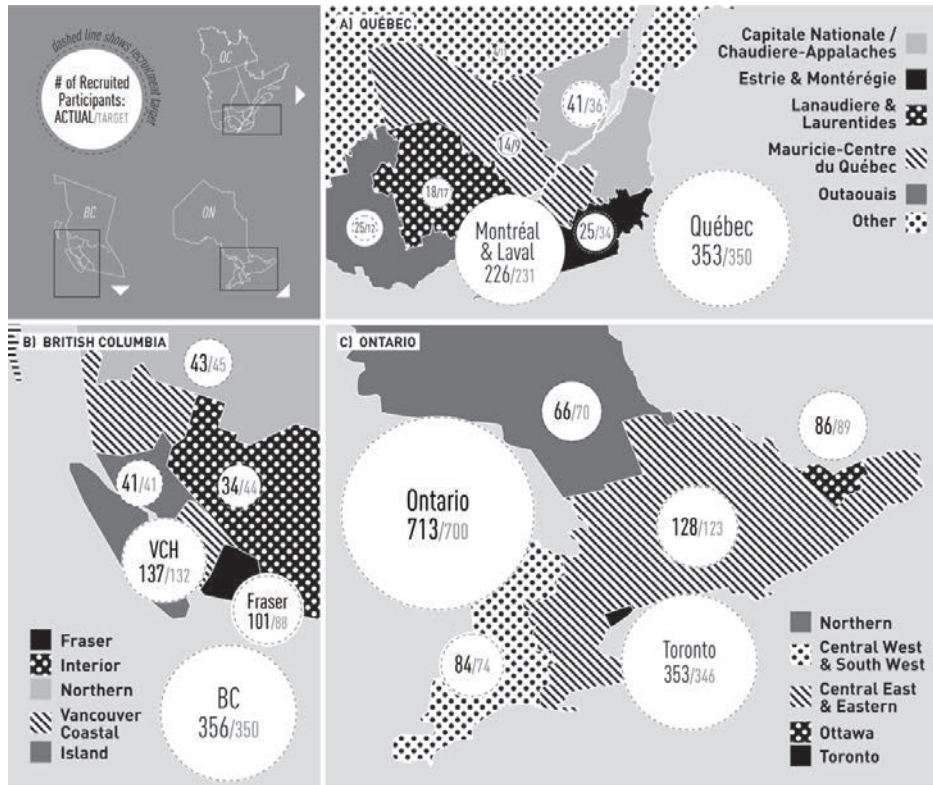


Figure 3. Targeted and actual recruitment of women living with human immunodeficiency virus (HIV) in the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study provincially.

trainings, and on-call counselling. PRAs are paid \$75 per completed survey (which includes roughly 3 hours of time for survey and other activities such as record keeping and meetings), and \$25 per hour for other tasks. Nonmandatory activities (e.g., community advisory board meetings) are volunteer. We involved other staff not living with HIV as interviewers as necessary, including upon participant request.

Participant Recruitment, Screening, and Enrolment at Baseline. We developed detailed recruitment plans for each health region within each province (e.g., in British Columbia, we had six health regions and six recruitment plans), which included the following information: target numbers for different sociodemographic groups (based on available surveillance data), a comprehensive list of clinic, ASO, and other community contacts (including PRA networks), and strategies for recruitment. The main recruitment strategies included PRA- and peer-driven efforts (some of whom worked in ASOs), recruitment through clinics and community agencies, and various online methods. Recruitment protocols and implementation varied across health regions owing to diversity in sociodemographic groups and community contacts. For example, in Northern British Columbia, young Indigenous women with intergenerational trauma and drug use histories are disproportionately affected by HIV; hiring a PRA with a similar lived experience and engaging with local harm reduction services was critical to recruitment in that region.

Nationally, recruitment began by PRAs contacting their close networks of friends. After gaining confidence with the interview process, PRAs then recruited other women by advertising at support groups, posting flyers at places they visited for their own care, providing study information to HIV doctors, and word-of-mouth. Study coordinators provided direct recruitment support to PRAs as well as various other components of the interview (e.g., booking appointments, finding interview space, conducting reminder calls). Coordinators also advertised the study to a broader audience, notifying members of our national steering committee and provincial community advisory boards, mailing print materials to contacts identified in our recruitment plans, and sharing electronic posters via Facebook (www.facebook.com/CHIWOS), Twitter (www.twitter.com/CHIWOSresearch), and our website (www.chiwos.ca).

Many clinics assisted with recruitment by placing colorful

flyers and postcards in waiting rooms, whereas others created discrete business-like study cards that staff added to patient charts and providers shared with women during appointments. ASOs and other non-HIV community-based agencies (e.g., shelters, food banks, sex worker support centers) also posted flyers and postcards onsite, and used listservs, newsletters, and social media to advertise the study to their membership. Outreach workers at both clinics and community settings helped in disseminating study information to hard-to-reach populations (e.g., street-involved women), as did actual study participants (e.g., trans women) who were asked to share recruitment flyers with their peers.

Overall, recruitment was a highly iterative process. Target numbers were monitored monthly and recruitment strategies were adapted when gaps were identified. For instance, upon noting an underrepresentation of women from Interior and Northern communities in British Columbia, as well as transgender women, we conducted a mass mail-out to physicians who prescribe antiretroviral therapy in the Interior and delivered study presentations to key stakeholder groups such as the Interior STOP HIV nursing team, the First Nations Health Authority, and the British Columbia Trans Clinical Care Group. Central to our overall approach was a commitment to relationship building. Sustaining personal communication was more time consuming than mail-outs or online methods but necessary to demonstrate the merits and potential of the study to stakeholders. Importantly, our aim was not only to provide study information to support recruitment, but also to establish connections with end-users of the research.

All recruited WLWH underwent a 10- to 15-minute screening interview during which we assessed participant eligibility, outlined study procedures, and prepared participants for the sensitive nature of the questionnaire. Screening was conducted by PRAs or coordinators depending on the region, with the latter sometimes introducing a lag time that yielded some loss to follow-up (amount unknown). After screening, PRAs consented eligible participants and administered baseline questionnaires in English ($n = 1081$) or French ($n = 344$) using online FluidSurveys software on study laptops. Several strategies were used to ensure the safety of PRAs and participants, including creating an emergency “call tree” that included access to an on-call counsellor and providing resource brochures of services in the community.

Table 1. Baseline characteristics of women living with HIV enrolled in CHIWOS (N = 1,131)

Variables	Baseline characteristics of women living with HIV enrolled in CHIWOS (N = 1,131)				p Value
	Total n (%)	British Columbia, 350 (31%) n (%)	Ontario, 430 (38%) n (%)	Québec, 351 (31%) n (%)	
Gender					
Cis women	1,086 (96)	336 (96)	415 (97)	335 (95)	.748
Trans women	45 (4)	14 (4)	15 (3)	16 (5)	
Sexual orientation					
Heterosexual	988 (88)	291 (83)	373 (87)	324 (93)	< .001
LGBTQ	137 (12)	58 (17)	54 (13)	25 (7)	
Age at interview (y)					
16–29	82 (7)	25 (7)	31 (7)	26 (7)	.004
30–39	298 (26)	91 (26)	135 (31)	72 (21)	
40–49	387 (34)	121 (35)	151 (35)	115 (33)	
≥50	364 (32)	113 (32)	113 (26)	138 (39)	
Ethnicity					
Indigenous	221 (20)	155 (44)	59 (14)	7 (2)	< .001
African, Caribbean, or Black	368 (33)	27 (8)	179 (42)	162 (46)	
White	455 (40)	141 (40)	151 (35)	163 (46)	
Other ethnicities	87 (8)	27 (8)	41 (10)	19 (5)	
Household annual income (CAD)					
< \$20,000	714 (65)	254 (75)	245 (59)	215 (63)	< .001
≥\$20,000	382 (35)	86 (25)	167 (41)	129 (38)	
Highest level of education completed					
< High school	208 (18)	93 (27)	63 (15)	52 (15)	< .001
≥High school	920 (82)	256 (73)	366 (85)	298 (85)	
History of IDU					
Currently	115 (10)	73 (21)	26 (6)	16 (5)	< .001
Previously	280 (25)	148 (42)	68 (16)	64 (18)	
Never	723 (65)	128 (37)	328 (78)	267 (77)	
Accessed HIV clinical care in past year					
Yes	1,077 (95)	344 (98)	396 (93)	337 (96)	< .001
No	52 (5)	6 (2)	32 (7)	14 (4)	
Currently taking HIV medications					
Yes	991 (88)	312 (89)	357 (83)	322 (92)	.001
No	137 (12)	37 (11)	71 (17)	29 (8)	
Accessed HIV support services in past year					
Yes	702 (62)	249 (71)	251 (59)	202 (58)	< .001
No	424 (38)	101 (29)	174 (41)	149 (42)	
Have children (among females)					
No	280 (26)	71 (21)	123 (31)	86 (26)	.012
Yes	792 (74)	267 (79)	278 (69)	247 (74)	

LGBTQ, lesbian, gay bisexual, two-spirited, and queer; HIV, human immunodeficiency virus; IDU, injection drug use; CHIWOS, Canadian HIV Women's Sexual and Reproductive Health Cohort Study; LGBTQ, lesbian, gay, bisexual, two-spirited or queer.

All participants provided voluntary informed consent at study enrolment and were provided with \$50 to honor their time and contributions.

The 18-month follow-up survey (wave 2) was conducted between July 2, 2015, and January 31, 2017, and preliminary data indicate a national retention rate of 87%. Wave 3 (i.e., the 36-month visit) is currently ongoing. Similar procedures as those described were used to find and re-interview participants, and future work will explore retention by subpopulation and recruitment strategy.

Data Collection, Measures, and Statistical Methods for the Current Analysis. During the screening process, women were asked: “How did you hear about the study?” Of the 1,424 WLWH enrolled at baseline, 294 did not respond to this question and were excluded from analyses (final $n = 1,131$; Table 1). Participants with missing responses were more likely to be from Ontario, under age 40, Indigenous, and not engaged in HIV medical or social care in the past year ($p < .05$; data not shown).

A coding framework was developed to guide the categorization of open-ended responses, and two independent reviewers (including a PRA) in each province coded the answers. Agreement between reviewers was high: 87% in British Columbia, 94% in Ontario, and 98% in Québec. Disagreements were resolved with the help of a third reviewer. The coding framework included 19 recruitment strategies, but categories were collapsed through team consensus to 5 major categories: PRAs/peers, clinics, ASOs/CBOs, word-of-mouth, and other strategies.

We calculated descriptive statistics for baseline recruitment strategies, overall as well as by province and key health and sociodemographic groups, using frequencies (n) and percentages (%) for categorical variables and medians (M) and interquartile ranges for continuous variables, and tested for statistically significant differences via the chi square and Fisher’s exact tests, and the Wilcoxon rank-sum and Kruskal-Wallis tests.

Reflection Process. We engaged in critical reflection on the key challenges and opportunities of the recruitment process to offer lessons learned to other teams conducting CBR with WLWH. PRAs involved in recruitment, coordinators, and principal investigators were all involved in this reflective process through on-going discussion during the recruitment period through to writing this manuscript.

Ethics. Ethical approval was granted from the all principal investigators’ institutional research ethics boards.

RESULTS AND LESSONS LEARNED

Baseline Characteristics

Among women with complete data ($n = 1,131$ of total 1,424 enrolled), the median age was 45 (interquartile range, 37–51). Forty percent identified as White, 33% African, Caribbean or Black Canadian, and 19% Indigenous. Participants were also diverse with respect to gender (4% trans), sexual identity (12% lesbian, gay, bisexual, two-spirited, or queer [LGBTQ]), injection drug use history (25%), and other social positions. In the past year, 95% had accessed HIV clinical services, and 62% accessed HIV support services from at least one community agency (Table 1).

Recruitment Strategies

Overall, 35% of participants were recruited through PRAs and other WLWH (“peers”), 34% clinics, 19% ASOs and other CBOs, and 6% through word-of-mouth. An additional 6% heard about the study through other strategies such as online, other studies, or a poster in an unspecified location (Table 2). By province, PRAs/peers were the predominant recruitment method in Ontario (49%), compared with clinics in Québec (43%) and British Columbia (40%). ASOs and CBOs were also a major source of recruitment in British Columbia (27%) and Québec (23%), but less so in Ontario (8%).

Recruitment Methods	Total (%)
PRAs/Peers	35
Clinics	34
ASOs/CBOs	19
Word of mouth	6
Other	6

CHIWOS, the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study.

Table 3. Bivariable Associations of Baseline Characteristics With Recruitment Methods, as Self-Reported by Women Living With HIV Enrolled in CHIWOS (N = 1,131)

Variables	PRA/Peer (391)	Clinic(385)	ASO/CBO(211)	Word of Mouth (71)	Other (73)	p Value
	n (%)	n (%)	n (%)	n (%)	n (%)	
Province						
British Columbia	97 (28)	139 (40)	96 (27)	4 (1)	14 (4)	<.001
Ontario	209 (49)	95 (22)	36 (8)	36 (8)	54 (13)	
Québec	85 (24)	151 (43)	79 (23)	33 (9)	<5 (1)	
Gender						
Cis women	370 (34)	375 (35)	207 (19)	63 (6)	71 (7)	<.001
Trans women	21 (47)	10 (22)	4 (9)	10 (22)	0 (0)	
Sexual orientation						
Heterosexual	332 (34)	351 (36)	180 (18)	61 (6)	64 (6)	.049
LGBTQ	56 (41)	32 (23)	30 (22)	12 (9)	7 (5)	
Age at interview (y)						
16–29	21 (26)	40 (49)	7 (9)	9 (11)	5 (6)	.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						
Indigenous	69 (31)	62 (28)	60 (27)	15 (7)	15 (7)	.018
African, Caribbean, Black	123 (33)	135 (37)	56 (15)	25 (7)	29 (8)	
White	160 (35)	163 (36)	84 (18)	26 (6)	22 (5)	
Other ethnicities	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)	<.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)	.022
≥High school	324 (35)	317 (34)	155 (17)	64 (7)	60 (7)	
History of IDU						
Current	42 (37)	35 (30)	31 (27)	3 (3)	<5 (3)	<.001
Previous	102 (36)	89 (32)	76 (27)	<5 (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)	.001
No	28 (54)	5 (10)	10 (19)	6 (12)	<5 (6)	
Currently taking HIV medications						
Yes	338 (34)	355 (36)	184 (19)	57 (6)	57 (6)	.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)	<.001
No	123 (29)	210 (50)	32 (8)	29 (7)	30 (7)	
Have children (among females)						
Yes	96 (34)	98 (35)	42 (15)	23 (8)	21 (8)	<.001
No	259 (33)	278 (35)	163 (21)	42 (5)	50 (6)	

table continues

Table 3. continued

Variables	PRA/Peer (391)	Clinic(385)	ASO/CBO(211)	Word of Mouth (71)	Other (73)	p Value
	n (%)	n (%)	n (%)	n (%)	n (%)	
Region						
British Columbia						NA
Fraser Health Authority	20 (20)	42 (42)	32 (32)	<5 (1)	<5 (4)	
Interior Health Authority	7 (21)	18 (53)	9 (26)	0 (0)	0 (0)	
Northern Health Authority	23 (55)	4 (10)	12 (29)	0 (0)	<5 (7)	
Vancouver Coastal Health Authority	31 (23)	68 (51)	27 (20)	<5 (1)	6 (4)	
Vancouver Island Health Authority	16 (39)	7 (17)	16 (39)	<5 (2)	<5 (2)	
Ontario						NA
Central East and Eastern	21 (40)	9 (17)	11 (21)	<5 (4)	10 (19)	
Central West and South West	26 (35)	30 (41)	10 (14)	4 (5)	4 (5)	
Northern	18 (44)	18 (44)	<5 (2)	<5 (2)	<5 (7)	
Ottawa	50 (74)	9 (13)	<5 (3)	<5 (4)	<5 (6)	
Toronto Central	94 (48)	29 (15)	12 (6)	26 (13)	33 (17)	
Québec						NA
Capitale Nationale	39 (98)	<5 (3)	0 (0)	0 (0)	0 (0)	
Estrie	<5 (80)	0 (0)	<5 (20)	0 (0)	0 (0)	
Lanaudiere and Laurentides	<5 (13)	8 (50)	6 (38)	0 (0)	0 (0)	
Mauricie-Centre du Québec	<5 (43)	<5 (14)	6 (43)	0 (0)	0 (0)	
Montréal	26 (11)	126 (54)	46 (20)	31 (13)	3 (1)	
Outaouais	7 (30)	<5 (9)	13 (57)	<5 (4)	0 (0)	
Other	<5 (5)	12 (57)	7 (33)	<5 (5)	0 (0)	

ASO, AIDS Service Organization; CBO, community-based organization; CHIWOS, the Canadian HIV Women's Sexual and Reproductive Health Cohort Study; HIV, human immunodeficiency virus; IDU, injection drug use; LGBTQ, lesbian, gay, bisexual, two-spirited, or queer; PRA, peer research associate.

Recruitment Strategies by Sociodemographic Characteristics of Participants

Nationally, PRAs/peers were more successful in recruiting women who were LGBTQ, transgender, using injection drugs, not currently on antiretroviral therapy, and not currently receiving HIV clinical care (Table 3). For example, PRAs/peers accounted for 41% of LGBTQ women enrolled, versus clinics ASOs/CBOs who each recruited 22% to 23% of this population. Similarly, 47% of trans women heard about the study through peers/PRAs, 22% clinics, and 9% ASOs/CBOs, whereas 54% of women not engaged in HIV clinical care were recruited through PRAs/peers, only 10% through clinics and 19% through ASOs/CBOs. Clinics were effective in recruiting young women (16–29 years [49%] vs PRAs/peers [26%] and ASOs/CBOs [9%]), and women who reported

not currently using community-based HIV support services (50% vs. PRAs/peers 29% and ASOs/CBOs 8%). ASOs/CBOs accounted for a substantial proportion of enrolment across all sociodemographic groups, although PRAs/peers and clinics were the predominant methods. Last, clear patterns were also observed by region. In northern British Columbia, most women heard about the study through a PRA/peer (55%) or ASO (29%), with clinics accounting for only 10% of those recruited, whereas the opposite was seen in the interior of British Columbia, where most women were recruited through clinics (53%). Likewise, in Ontario and Québec, most women were recruited through PRAs/peers in Ottawa (74%) and the Capitale Nationale region (98%), whereas clinics were most effective in the Central West and South West region (41%) and Montréal (54%).

REFLECTIONS: CHALLENGES, OPPORTUNITIES, AND LESSONS LEARNED

During recruitment, we encountered several issues common to CBR projects¹⁷⁻¹⁹ such as engaging smaller or marginalized communities (e.g., trans women, African women in British Columbia, women not accessing care), retaining women between initial contact and screening, particularly for women with more transient lives (e.g., homeless women), and overcoming structural barriers to participation such as childcare demands, distance from study centers, and language diversity. We implemented various strategies to reach and involve women with different needs. These strategies included, for example, building relationships with diverse stakeholder groups to support recruitment of harder-to-reach women; conducting interviews in women's homes and local organizations to help meet participants "where they are" (physically and emotionally), supporting young children to attend study interviews and providing child-minding support, conducting the interview over multiple visits of shorter length, and ensuring flexible times for completing interviews (e.g., weekends, evenings). In reflecting on these challenges and opportunities, as well as the distribution of effective recruitment strategies by participant characteristics, we identified three primary lessons learned from implementing CHIWOS that may be helpful to future CBR studies.

Lesson 1: Different Recruitment Strategies Are Needed to Attend to Women's Diversity

Intersectionality theory draws attention to women's social identities (e.g., gender, sexual orientation, race, and class) and structural inequities (e.g., sexism/genderism, heterosexism, racism, classism, and HIV stigma) that intersect in complex ways to produce distinct and multiple advantages or disadvantages.^{46,47} Different recruitment strategies are needed to operationalize a commitment to intersectionality and inclusiveness in quantitative research by, with, and for WLWH. Obstacles and opportunities for participation vary by age, identities, and other characteristics, and recruitment strategies must adapt accordingly. For instance, in our study, trans women were primarily reached through peer networks, whereas young women were recruited through clinics, highlighting a risk of under-representing particular groups of women if we relied exclusively on PRA-driven or clinic-driven recruitment.

Lesson 2: Diversity Within the PRA Team Is a Recruitment Strength

The collective identity of our PRA team influenced the makeup of participants recruited to our study. For instance, in Northern British Columbia, we engaged a young Indigenous PRA and, in turn, were able to recruit a representative sample of young WLWH with similar lived experiences. If we engaged a different PRA in that region, we may not have achieved the same recruitment success and representation from that community. However, although our overall PRA team was diverse with respect to many social positions (e.g., ethnicity, sexual orientation, class, language, geography), a disproportionate number were 50 years of age and older, long-term survivors (e.g., more than 10 years living with HIV), and publicly disclosed. Such lived experiences may have limited our ability to recruit younger, recently diagnosed, or more isolated, non-publicly disclosed women who may fear research participation. Thus, we encourage studies to consider and invest in supporting diversity within their PRA teams in relation to the diversity of populations they aim to recruit.

Lesson 3: Investing in Relationship Building with Community Partners

Strong community relationships are key to a successful recruitment process. Clinics and ASOs/CBOs accounted for a large proportion of women recruited to CHIWOS. In addition to more traditional recruitment methods (e.g., study posters), outreach workers were crucial in reaching more vulnerable women, often going out of their way to find and engage street-involved women. ASOs also offered a safe, familiar, and nonthreatening space for women to complete the interview. Nurturing these relationships, ensuring open lines of communication, disseminating study information and findings back to community partners, and building in formal processes that acknowledge partner contributions was essential to recruitment success.

DISCUSSION AND CONCLUSIONS

In this paper, we provide insight into recruitment strategies that can increase women's engagement in HIV research. Peer-driven methods and clinics were particularly effective in recruiting women into our study, along with ASO supports that created opportunities for peers to connect on familiar

ground. Additional targeted strategies (e.g., active outreach, presentations to key stakeholder groups) helped to engage women traditionally considered “harder-to-reach.” Further, offering considerable flexibility with respect to the time, place, and setup of the interview was essential to encouraging research participation by women with limited prior research participation experience.

The sociodemographic characteristics of participants included in this study suggest a diverse sample. In contrast with an early study conducted among Canadian WLWH,² we recruited a sizable proportion of gender, culturally, sexually, and socioeconomically diverse women likely owing to differing recruitment methods: the former study relied exclusively on hospital- and community-based clinics whereas our study built on a network of clinics, peers, outreach workers, ASOs, other non-HIV community-based agencies, and additional informal networks.

Our findings reflect past research showing that health care providers and clinics, ASOs and CBOs, and peers/friends are the most common ways to recruit women.^{2,7,48} Our study adds unique contributions to this literature by highlighting which methods work better for reaching which populations. Likewise, although the challenges (e.g., reaching hidden populations, retaining women after screening, establishing community trust) and successes (e.g., offering honoraria, employing PRAs with similar lived experiences to build participant trust and rapport) we encountered were consistent with other projects,⁵⁻⁸ our study also underscores three important lessons learned related to operationalizing intersectionality in recruitment, engaging a diverse team of PRAs, and investing in community relationships.

In conclusion, the findings and lessons learned from Canada’s largest bilingual community-based cohort study by, with, and for WLWH point to the need for flexible, diverse, and intentional recruitment strategies to successfully recruit diverse and representative samples of WLWH in CBR studies. We call on research teams to embrace participatory approaches and on WLWH to participate in such studies, to ensure that the voices and experiences of WLWH, in all their diversity, are heard and prioritized.

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APPENDIX

Listed here are all research team members and affiliated institutions.

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British Columbia: Aranka Anema (*University of British Columbia*), Denise Becker (*Positive Living Society of British Columbia*), Lori Brotto (*University of British Columbia*), Allison Carter (*British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University*), Claudette Cardinal (*Simon Fraser University*), Guillaume Colley (*British Columbia Centre for Excellence in HIV/AIDS*), Erin Ding (*British Columbia Centre for Excellence*), Janice Duddy (*Pacific AIDS Network*), Nada Gataric (*British Columbia Centre for Excellence in HIV/AIDS*), Robert S. Hogg (*British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University*), Terry Howard (*Positive Living Society of British Columbia*), Shahab Jabbari (*British Columbia Centre for Excellence*), Evin Jones (*Pacific AIDS Network*), Mary Kestler (*Oak Tree Clinic, British Columbia Women’s Hospital and Health Centre*), Andrea Langlois (*Pacific AIDS Network*), Viviane Lima (*British Columbia Centre for Excellence in HIV/AIDS*), Elisa Lloyd-Smith (*Providence Health Care*), Melissa Medjuck (*Positive Women’s Network*), Cari Miller (*Simon Fraser University*), Deborah Money (*Women’s Health Research Institute*), Valerie Nicholson (*Simon Fraser University*), Gina Ogilvie (*British Columbia Centre for Disease Control*), Sophie Patterson (*Simon Fraser University*), Neora Pick (*Oak Tree Clinic, British Columbia Women’s Hospital and Health Centre*), Eric Roth (*University of Victoria*), Kate

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