

Hiring, training, and supporting peer researchers:

Operationalizing community-based research principles within epidemiologic studies *by, with,* and *for* women living with HIV

Angela Kaida¹; Allison Carter^{1,2}; Jo Lemay¹; Nadia O'Brien³; Saara Greene⁴; Valerie Nicholson¹; Jamie Thomas-Pavanel⁵; Karène Proulx-Boucher³; Johanna Lewis⁵; Anita Benoit⁵; Wangari Tharao⁶; Alexandra de Pokomandy³; Mona R. Loutfy⁵;


On behalf of the CHIWOS Research Team

¹Simon Fraser University, Burnaby, BC; ²British Columbia Centre for Excellence in HIV/AIDS, Vancouver, BC; ³McGill University Health Centre, Montreal, QC; ⁴McMaster University, Hamilton, ON; ⁵Women's College Research Institute, Toronto, ON; ⁶Women's Health in Women's Hands



Conflict of Interest Disclosure

I have no conflicts of interest to declare.



I would like to acknowledge that we have gathered together on the traditional territory of the Mi'kmaq people.

Acknowledgments

- All the women living with HIV involved in CHIWOS
- The CHIWOS PIs, Provincial Study Coordinators, Peer Research Associates, and all the co-investigators and collaborators
- Members of the national Steering Committee, three provincial Community Advisory Boards, and the CHIWOS Aboriginal Advisory Board – Positive Aboriginal Women (CAAB-PAW)
- Community partners, AIDS Service Organizations, Community-based Organizations
- Our funders: CIHR Institute of Gender and Health, the CTN, and OHTN
- Our affiliated studies: CANOC, REACH, & OCS.




Community-based research: *By, with,* *and for* women living with HIV

- In Canada, women comprise ~ 25% of people living with HIV
- Prevailing gendered gaps in HIV research
- Demands for **community-based research (CBR)** towards addressing gendered & social marginalization from research participation & benefit
- Articulate process of **operationalizing peer-involved research**
 - To increase understanding of challenges & opportunities
 - To support ongoing and future CBR capacity

Objectives

- (1) To describe the development and implementation of a national strategy of **hiring, training, and supporting** women living with HIV as Peer Research Associates (PRAs) with the CHIWOS cohort study;
- (1) To reflect on challenges and opportunities;
- (2) To offer recommendations for best practices.



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:

British Columbia: Alliance Center
604-205-5615, 1-855-506-5515 (toll-free)
allison_carter@ahc.ca

Ontario: Jamie Thesee-Pavoni
416-261-5800 Ext. 2223
jamie.thesee-pavoni@wchospital.ca

Quebec: Karelle Prud'homme Boucher
514-934-1504 Ext. 30148
krebouche@chivios.com

CHIWOOS
Étudier sur les besoins en soins de santé et de soins de santé des femmes vivant avec le VIH en Canada
Canadian HIV Women's Status and Reproductive Health Cohort Study

facebook.com/CHIWOS | twitter.com/CHIWOSresearch | www.chiwos.ca



- A multi-site, community-based, cohort study
- Enrolling >1,500 women living with HIV from BC, ON & QC
- **Study goals:** To assess barriers and facilitators to use of women-centred HIV care, and the impact on sexual, reproductive, mental and women's health outcomes
- **Methods:** PRA-administered web-based survey (90-120 minutes) at baseline with 18 month follow-up
- **Guiding Frameworks and Principles:** CBR, Meaningful Involvement of Women Living with HIV (MIWA), Social Determinants of Health, Critical Feminism, Anti-Oppression, Intersectionality, and Social Justice.

PRA Hiring: Goals and Policies

Goal:

- To build a **strong and diverse team** of PRAs who bring varied skills and experiences to the team and would reflect the diversity of WLWH across Canada

Policies:

- To actively recruit and **prioritize hiring** of women historically **under-represented** in research
- Value **lived experience**
- To engage women who may or may not have any previous research experience and **commit to providing training and capacity building**



Worked towards a supportive, inclusive, & accessible hiring process

Interview and hiring panel

- Included Principal Investigator, Study Coordinator, regional ASO/clinic partner, and woman living with HIV

Detailed and transparent job description

- Accessible job application process (E.g., “Tell us about yourself”)

Mix of recruitment strategies

- Clinics, AIDS Service Organizations, provincial CAB and the national Steering Committee, online, facebook & twitter, peer networks, and other informal channels

Hired a national team of PRAs

- Received nearly 70 applications
- Hired a **national team of 37 (amazing!) PRAs**
 - 8 in BC; 20 in ON; 9 in QC
- Included women who reflected the diversity of women living with HIV across Canada + with a range of skills and research experience (none → CBR expertise)



BC PRAs at Harbour side Park, Vancouver



Overview of PRA training process

- Viewed training as directly related to our study goal of *capacity building*
- Acknowledged the development of a training curriculum as an *expertise*
- Hired experienced *PRA Training Consultant* (Jo Lemay) and created a *PRA Training Committee* (researchers, CBR experts, WLWH)
- Engaged in a *collaborative process over several months* to develop a multi-phase training curriculum
- Training adhered to *experiential learning and adult learning principles*

Team brainstormed and prioritized the critical topics for inclusion in training

CHIWOS PRA Training Outcomes Guide				
Entry Requirements	Concepts and Issues	Skills	Assessment Activities and Tasks	Training Outcomes
When hired, PRAs will come with the following skills and attributes:	PRAs will understand and integrate knowledge about:	PRAs will practice and perform how to:	PRAs will demonstrate what they know and can do through:	The roles and responsibilities of the PRAs when they are out in the community are:
<ul style="list-style-type: none"> Diverse lived experience Women living with HIV Interest in: research; working with women living with HIV; learning; and making a difference in community Open, compassionate and sensitive to broad range experiences/identities Willing to build knowledge and compassion around experiences of women who are LGBTQ, sex workers, racialized, Aboriginal, people using substances, and others who often experience oppression and stigma Ability to work as part of community/academic team Effective communication and good judgment skills (e.g., ability to remain non-judgmental, listen carefully, ask for help when needed) Reading and comprehension skills (can comfortably use a computer, use email) 	<ul style="list-style-type: none"> Research/types of research (REB) Ethics/Research Ethics Boards (REB) Community-based research (CBR) Cultural competency Issues around stigmatization 	<ul style="list-style-type: none"> Identify, share and build on personal strengths, experiences and knowledge Understand what to expect in terms of working for CHIWOS (e.g., times, delays, payment, roles, support) Describe and respond to questions about CHIWOS accurately Build connections in community Navigate Fluidsurveys: login, online/offline, security/safety Inform participant of next steps regarding CHIWOS End interview Administer and manage participants' honoraria and other administrative aspects Problem solve and respond to difficult situations (e.g., debriefing, supporting participant, providing resources, confidentiality, safety) Navigate shifting roles Support participants and refer to further resources Care for self (with the support of the team and ASOs staff) Respond to grief and loss healthfully Demonstrate inter-cultural competency and empathy for others Unlearn stigma about sex/drugs/sex work, etc., transphobia, homophobia, colonization, and racism 	<ul style="list-style-type: none"> Role play scenarios and practice administering surveys Problem-solve case studies Self-assess their work through checklists Assess peers and give constructive feedback through checklists and small group discussion Check for understanding and retention through game quizzes Muddiest Point questions Map conceptual map to review learning at the end of sessions 	<ul style="list-style-type: none"> Steward and represent CHIWOS proficiently in the community Demonstrate familiarity with the project, background, context, and team Interview and assist research in confident, independent, professional manner Apply ethics, principles and teamwork in practice Communicate constructively with survey participants and with the CHIWOS team Practice self-care, communication, debriefing, and safety precautions Make informed decisions about the impact on themselves of doing the research with CHIWOS Empower themselves and the community leadership role Build capacity and transfer knowledge through CHIWOS to other researchers

Concepts and Issues

PRA Skills

Assessment Activities & Tasks

Intended Training Outcomes

PRA entry requirements

Developed a tailored training agenda that went beyond the basics of survey research

Incorporated training on positioning, traversing roles, unlearning prejudices, self-care, ethics, informed consent procedures, challenging interview scenarios, and technology and computer skills

Day One Training Agenda (March 20th 2013)

Time	Topic	Facilitated by:
9:00-10:00	Welcome <ul style="list-style-type: none"> o Acknowledg territories o Introduction Scavenger H o Learning Out 	In & Valeria
10:00-12:15	Orientation to Study <ul style="list-style-type: none"> o Project Back o Provincial HI Update o Study Justifi o 15 minute b o Guiding Fran o Study Desig Orientation to Job <ul style="list-style-type: none"> o What to Exp o CHIWOS 	
12:15-1:15	Group lunch provide	
1:15-3:30	Roadmaps for Conn <ul style="list-style-type: none"> o Poem: Turni o Storytelling o 15 minute b 	
3:30-4:30	Closing <ul style="list-style-type: none"> o Review: Con o What We'll l o Evaluation: f o Closing Rour o Leaving Wit 	

Day Two Training Agenda (M

Time	Topic
9:00-10:00	Opening: <ul style="list-style-type: none"> o Welcome o Acknowledgement of First territories o Agenda o Question and Answer Peri o Clarifying 'Muddiest Point
10:00-12:00	Successful Surveying: <ul style="list-style-type: none"> o Brainstorm skillful/unskill practices o Demonstration o Discussion o Rationale of Survey Desig o 15 minute break
12:00-1:00	Group lunch provided
1:00-3:45	Practice and Give Feedback on Su <ul style="list-style-type: none"> o 15 minute break
3:45-4:30	Closing: <ul style="list-style-type: none"> o Concept Mapping: Debric Process and Experiences o Next Training o Closing Round: Head, Hea Hands

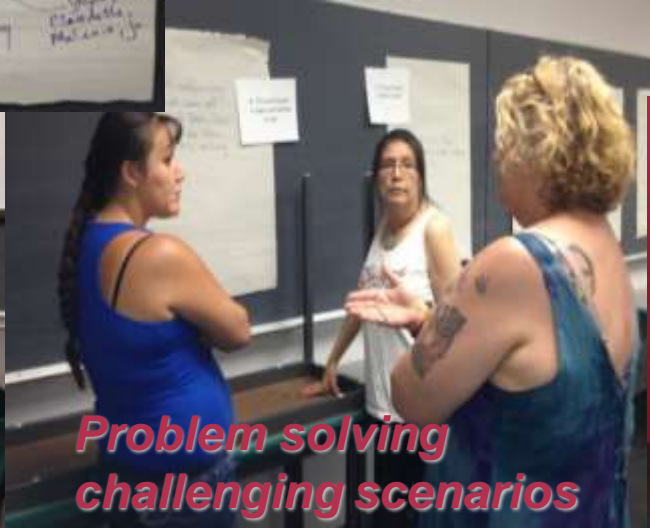
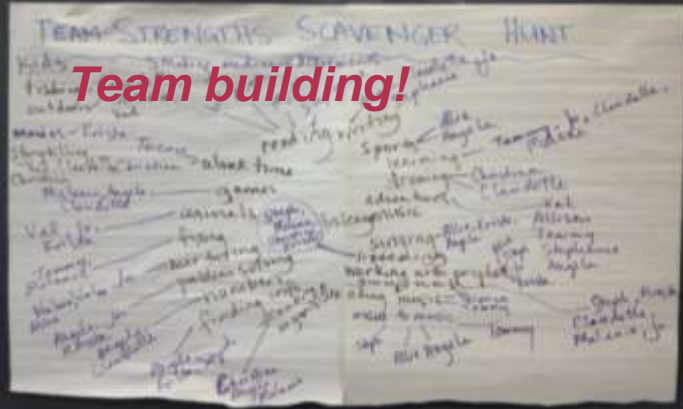
Day Three Training A

Time	Topic
9:00-10:00	Welcome/Opening <ul style="list-style-type: none"> o Welcome o Acknowledgement territories o Agenda o Review of last train o Project Details Scav
10:00-12:00	How To's <ul style="list-style-type: none"> o Overview of binder agreements to be s o The job o Recruitment o Appointment logist o What to bring (prac materials) o 15 minute break
12:00-1:00	Walk and enjoy a picnic lun catered by Potluck Cafe, at Park in Coal Harbour.
1:00-2:30	Safety and Wellbeing <ul style="list-style-type: none"> o Supports for Partici o Emotional/Psychok o Boundaries and trig o Self-care plans o 15 minute break
2:30-4:00	Problem-Solving Scenarios
4:00-4:30	Closing <ul style="list-style-type: none"> o Reviewing through o Evaluation: Muddiest Point

Day Four Traini (July 3rd 2013)

Time	Topic	Facilitated by:
9:00-9:45	Welcome/Opening <ul style="list-style-type: none"> o Welcome o Acknowledgement of First Nations territories o Agenda o Respond to Muddiest Points o Elevator Speeches 	Angela Christina Angela Tammy and Krista
9:45-10:45	Survey Rationale <ul style="list-style-type: none"> o Go through the survey section-by-section, explaining the rationale behind the survey questions o *15 minute break* 	Angela
11:00-12:00	Review Informed Consent Process <ul style="list-style-type: none"> o Demo o Practice How to Close the Survey <ul style="list-style-type: none"> o Resources for Participants o Demo o Practice 	Kath and Claudette Allie and Stephanie
12:00-1:00	Walk and enjoy a lunch offsite at Steamworks. The reservation is under Allison Carter.	
1:00-2:00	FluidSurvey/Database Training	Jay
2:00-4:00	Practice Surveying	ALL!
4:00-4:30	Closing <ul style="list-style-type: none"> o Next steps for work and training (survey piloting, team meeting) o Round: Heart, head, hands and health 	Angela Valerie

Tailored Provincial PRA Training



Ongoing PRA learning and support

- *Regular PRA team meetings* to foster learning, support, & team-building
- *PRA counselling resources and supports*
- Partnership agreements with clinics/ASOs to provide ongoing *regional support for PRAs*
- Developed a *private, online PRA learning hub* (chiwospra.org)



The screenshot shows the CHIWOS PRA Learning Hub website. At the top, the logo features the text "CHIWOS" in grey, with a red female symbol (a circle with a vertical line and a horizontal crossbar) to its right. Below the logo, the text "Équipe sur le santé sexuelle et reproductive des femmes inscrite avec le PRCS du Canada" and "Canadian HIV Women's Sexual and Reproductive Health Cohort Study" is visible. A dark red banner contains the welcome message: "Welcome to your learning hub! Bienvenue dans votre espace pour l'éducation!" followed by the subtitle "A place for learning, sharing, and discussing. Un lieu pour apprendre, partager et discuter." Below this is a search bar with the placeholder text "Search the knowledge base... Recherchez la base de connaissances...". The bottom section is divided into three columns, each with an icon and a title: 1. A document icon for "Online Workshops/ Cours en ligne", with the subtitle "Access training activities and materials. / Accès des activités de formation et du matériel sci." 2. A speech bubble icon for "Discussion Forum/ Forum de discussion", with the subtitle "A place to connect with your colleagues/Un lieu pour se connecter avec vos collègues." 3. A smiley face icon for "Your Team/ Vos collègues", with the subtitle "See who is working alongside you on this project/Voir qui travaille avec vous sur ce projet."



Challenges

- 1) Remaining responsive to the range of PRA skills and experiences
- 2) Ensuring PRA safety, health and well-being
- 3) Ensuring PRA confidentiality relating to HIV status and other personal factors
- 4) Managing tensions around PRAs' shifting roles from community member to PRA and study steward
- 5) Dedicating sufficient time and resources to translation

Opportunities

- 1) Overall team capacity building
- 2) Co-production of innovative solutions to study challenges
- 3) PRAs becoming study stewards in their communities and supporting engagement of harder-to-reach women
- 4) Stronger community connections facilitating knowledge translation, advocacy, and action on study findings

Recommendations

- Commit seriously and rigorously to the training process and associated resource implications
- Create employment and training processes that are flexible and responsive to women's needs and experiences;
- Allot sufficient resources for translation and cultural adaptation of training tools;
- Integrate PRAs as training facilitators based on their skills and experiences
- Foster team building, trust, self-care, and communication;
- Support tailored implementation to match regional contexts.
- Opportunity to build both researcher and PRA capacity

Final words

- **Time and resource intensive** work; we need to learn from and build on each others' contributions
- Full CHIWOS PRA training **curriculum available online:**
<http://www.chiwos.ca/chiwos-study/chiwos-documents/?lang=en>
- Opportunity & responsibility for transformational research towards enacting change



Thank you

For more information, please contact:

Angela Kaida, PhD

Faculty of Health Sciences, Simon Fraser University

Email: kangela@sfu.ca ; Skype: akkaida; Tel: 778-782-9068

For more information about CHIWOS or to participate, please contact:

Allison Carter (BC): 604-806-8615, Toll-free: 1-855-506-8615, allison_carter@sfu.ca

Jamie Thomas-Pavanel (ON): 416-351-3800 x 2323, jamie.thomas-pavanel@wchospital.ca

Karène Proulx-Boucher (QC): 514-934-1934 x 32146, chiwos.quebec@gmail.com

CONNECT!

www.chiwos.ca

 facebook.com/CHIWOS

 twitter.com/CHIWOSresearch

CHIWOS
