

MEANINGFUL INCLUSION AND TRAINING OF PEER RESEARCH ASSOCIATES BY, WITH, AND FOR WOMEN LIVING WITH HIV:

Teachings from the BC CARMA-CHIWOS Collaboration Study.



We gratefully acknowledge the Traditional, Ancestral, and unceded territories of the Coast Salish Peoples, including the Sk̓wx̓wú7mesh (Squamish), Səlíl̓wətaʔ/Selilwitulh (Tsleil-Waututh) and xʷməθkʷəy̓əm (Musqueam), on which this we work, learn, and live.

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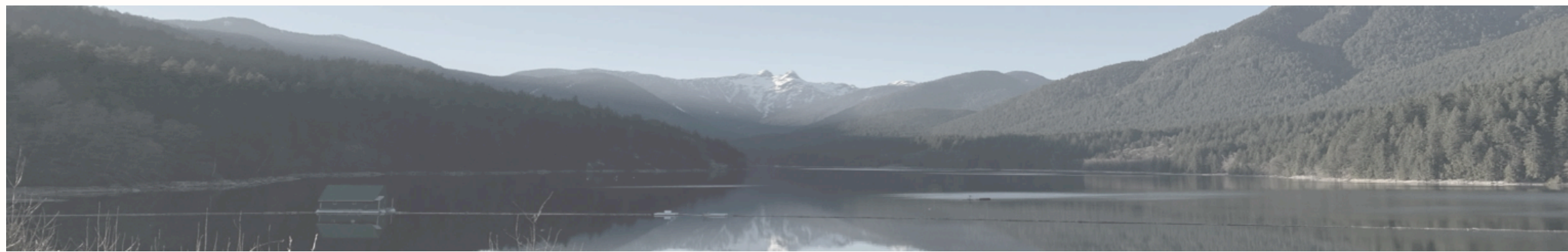
Thank you to our community partners!

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We have no conflicts of interest to declare.



Background



- Activism by people living with HIV has established calls for meaningful inclusion in research and programming that impacts their lives. This includes:

**Community Based
Research (CBR) Approach**

**Meaningful capacity
building and engagement**

**Women-Centered
Research Approach**

- Few studies describe the process of meaningful engagement, especially within clinical and basic science research.
- The British Columbia CARMA-CHIWOS Collaboration (BCC3) Study incorporates **clinical, cellular, and social sciences** in a **CBR** and **women-centered approach**¹⁻⁴ to better understand healthy aging by, with, and for women living with HIV (WLWH).
- We discuss how we hired, trained, and continue to support WLWH as **Peer Research Associates (PRAs)** in the BCC3 study, and how we are **meaningfully engaging WLWH** through a **peer-mentorship model**.



Our Training Process

- We **hired 5 women living with HIV** with diverse lived and living experiences and expertise as **Peer Research Associates (PRAs)**.
 - Some had previous research experience, while others did not.
- **Multi-modal experiential training** was held **virtually** between July–November 2020.
- An Indigenous Elder opened and guided sessions in a **Good Way**.
- **PRAs' strengths and expertise were emphasized** as they:
 - Led training sessions and activities.
 - Engaged in paid study opportunities beyond survey administration to knowledge translation events.
 - Were supported to set and achieve personal goals throughout and beyond training.

Training included:

Research ethics and study methods

Survey administration

Scientific teachings on hormones, cellular aging, and social determinants

Data Quality

Self-care and wellbeing



Lessons Learned

Uplift PRA voices
and priorities

Bidirectional
learning

Support goal
planning



Tailoring training to the goals, voices, and priorities of PRAs provided transformational learning opportunities for the entire research team. Tailoring included:

- Expanding the definition of the PRA roles and responsibilities.
- Mirroring the diversity of women's lives, needs, and experiences throughout and beyond the training.
- Adjusting to the physical (technology, space, etc.) and emotional (goals, self-care, etc.) learning needs of participants.

Challenges included:

- Engaging women virtually during a pandemic.
- Meaningful engagement with complex scientific concepts.
- Creating a curriculum built upon and responsive to the varying expertise of PRAs.

Our Recommendations

Research teams must:

- Be responsive to the **goals and priorities** of PRAs.
- Incorporate opportunities for **bidirectional** learning and knowledge sharing.
- Dedicate time for:
 - Team relationship building and **trust**.
 - Teaching of **scientific concepts**.
- Leverage **existing** community-based research training materials.
- Create a research environment that **supports WLWH** to share their expertise and experiences, ask questions, interrogate study practices, and mentor other team members.

Future Directions

- Our PRAs have begun conducting study visits with BCC3 participants and will provide feedback to the team on how to best improve the survey.
- Continue to educate PRAs in monthly meetings and support growth in their areas of interest.
- Engage with researchers to develop training with our PRAs to hire and train new PRAs.



Look for our training manual on our website: www.HIVHEARme.ca