

Ensuring the voices, recognition, and well-being of peer researchers in the application of GIPA/MIWA principles: ethical tensions in conducting research with women living with HIV in Canada.

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Conflicts of Interest Disclosure

We have no conflicts of interest to declare.



Acknowledgments of Study Partners

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Objective of the Presentation

- To examine the question:

What tensions emerge when applying GIPA/MIWA principles in Community Based Research (CBR) projects with women living with HIV in Canada?

- Our presentation draws upon our experiences as peers, academics and community researchers working with the CHIWOS project.



CHIWOS CBR Cohort Study

- Canadian HIV Women's Sexual and Reproductive Health Cohort Study
 - Longitudinal cohort study
 - Investigating Women-Centred Care
 - Five year funding (2011-2016)
 - Multi-centred, in QC, ON, BC
 - Community-Based Research (**CBR**)



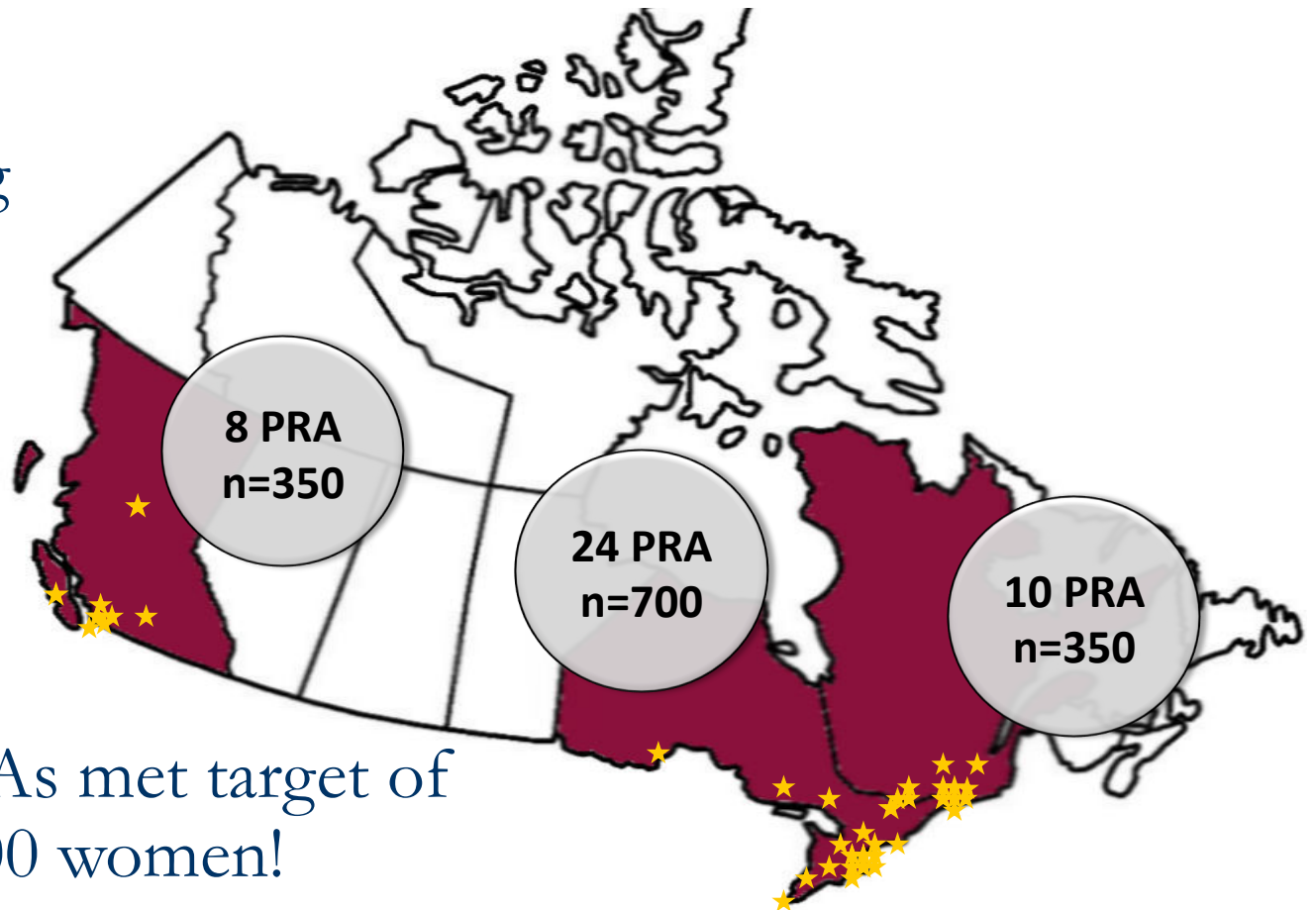
CBR Approach and Benefits

- **CBR principles** (Minkler, 2004)
 - Equitable involvement of those affected *by* the research *in* the research (GIPA/MIWA)
 - Shared decisions making over life of study
 - Focus on action and change
- **Benefits of CBR approach:** (Cargo 2008; Jagosh, 2012)
 - Strengthen stakeholder collaboration
 - Improve research effectiveness
 - Ensure relevance and cultural safety
 - Enable empowerment
 - Facilitate knowledge to action



CHIWOS CBR Principles in Practice

- National Steering Committee
- Three Provincial Community Advisory Boards
- Over 40 PRAs
- May 1st 2015 PRAs met target of interviewing 1,400 women!



Navigating Challenges and Lessons Learned

Nadia- Researcher Perspective

1. PRA recognition and HIV confidentiality

Tracey- PRA Perspective

2. Meaningful involvement and capacity building
3. Meaningful involvement and wellbeing



1. Recognition vs. Confidentiality

- Working groups:
 - Representatives vs. “meeting women where they are at”
- Interviews:
 - PRA wellbeing vs. PRA model
- CHIWOS as a CBR study:
 - Confidentiality vs. legitimacy as CBR study



2. Meaningful Involvement vs. Capacity Building

- Diverse teams with various experiences
 - PRA expectations and goals
 - Capacity building vs. using existing skills
- PRA representation
 - New PRA opportunities on working groups (KTE/NMT)
 - New PRA- led assessment process
- Capacity building is reciprocal
 - PRA ↔ Researcher



3. Meaningful Involvement vs. Wellbeing

- Meaningful Involvement must include:
 - Self care & maintaining boundaries
 - Support systems & resources
 - Appropriate & transparent compensation
- Richness of the PRA/Participant experience
 - what is gained in CBR!

Conclusions

- Challenges and tensions will arise
- Context of HIV-stigma, disclosure, inequities persists
- Conflict can be productive (Jagosh, review, 2012)
- Take away messages:
 - PRAs can provide rich insights to mitigating challenges
 - Research teams must be flexible, communicative and creative

References

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Thank you! Questions?



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