

# CHIWOS: Views on operationalizing women-centred community-based research

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Igniting Knowledge : Updates and findings from  
BC CBR Projects

PAN Knowledge to Action conference  
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# Acknowledgement



I would like to acknowledge that we have gathered together on the traditional territory of the Coast Salish people.

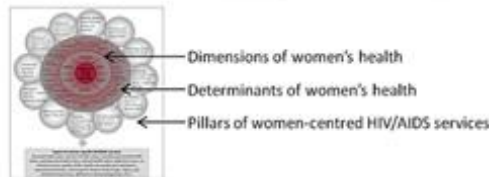
# What is CHIWOS?

- The Canadian HIV Women's Sexual and Reproductive Health Cohort Study
- Aim to recruit 1,250 women living with HIV from BC, ON and QC (n=350 in BC) and follow prospectively
- 4 co-Principal Investigators, 3 provincial coordinators, 29+ co-investigators, 25+ collaborators
- Strong and active community partnership
- Funded by CIHR in 2011
- Starting cohort recruitment in May 2013



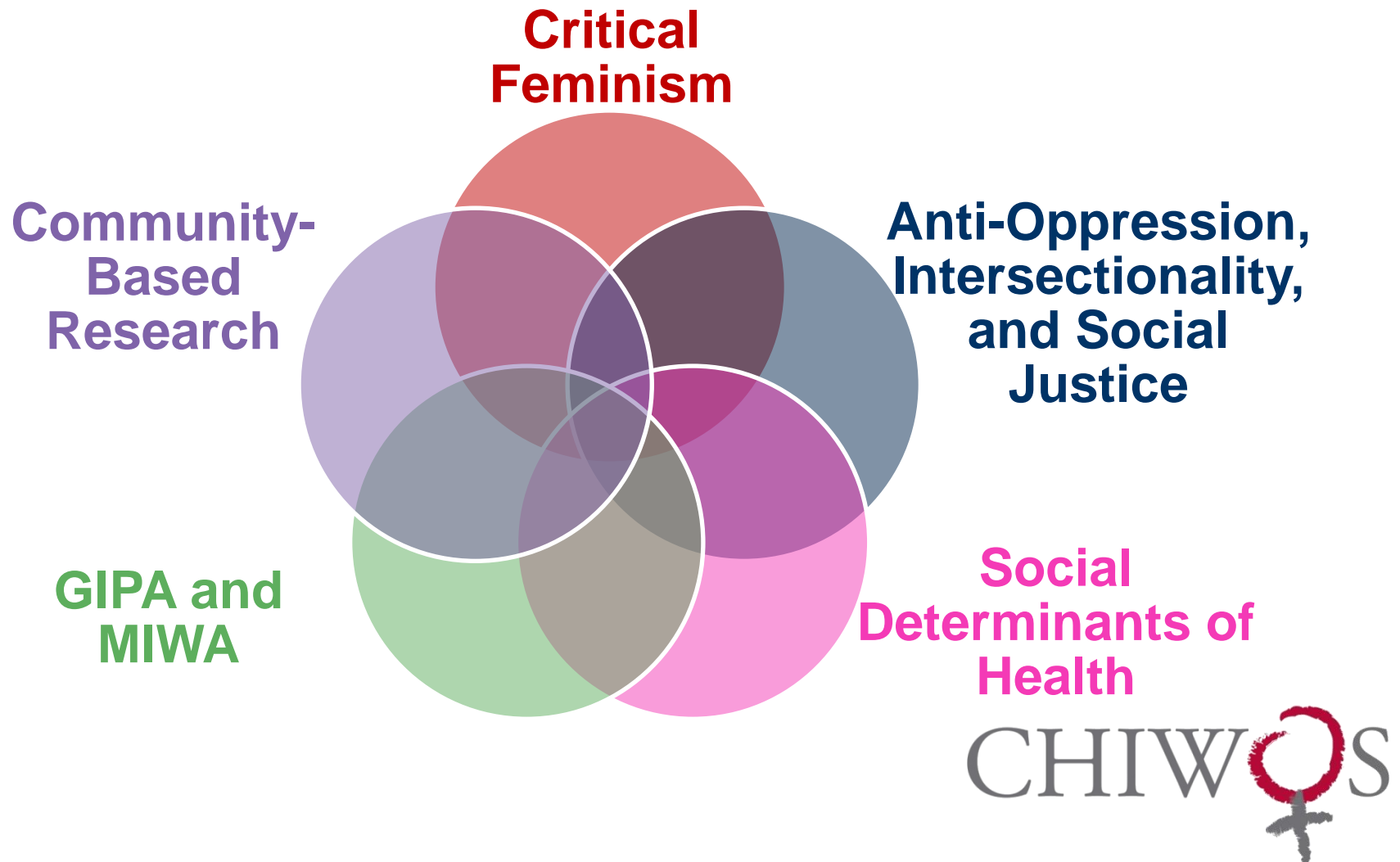
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## –Barriers to and facilitators of women-centred HIV/AIDS services use

Carter AJ et al. *JIAS* 2012

### A framework for women-centred HIV/AIDS services

# CHIWOS Guiding Frameworks





# What we envisioned women-centred Community-based research might look like....



# What women-centred CBR sometimes feels like for all of us involved....



# Some differences between Community Based Research and Traditional Academic Research\*

Guiding Principles	Community-Based Research	Traditional Academic Research
<i>What is the purpose of the research?</i>	To provide the community with the tools and information necessary to enact change	To contribute to the body of knowledge on a given topic
<i>Who is the research intended to serve?</i>	The local community <i>and</i> the academic community	The academic community
<i>Whose knowledge counts?</i>	Both community members and academic experts	Academic experts
<i>Who controls the research process?</i>	Community members <i>and</i> the researcher	Researcher

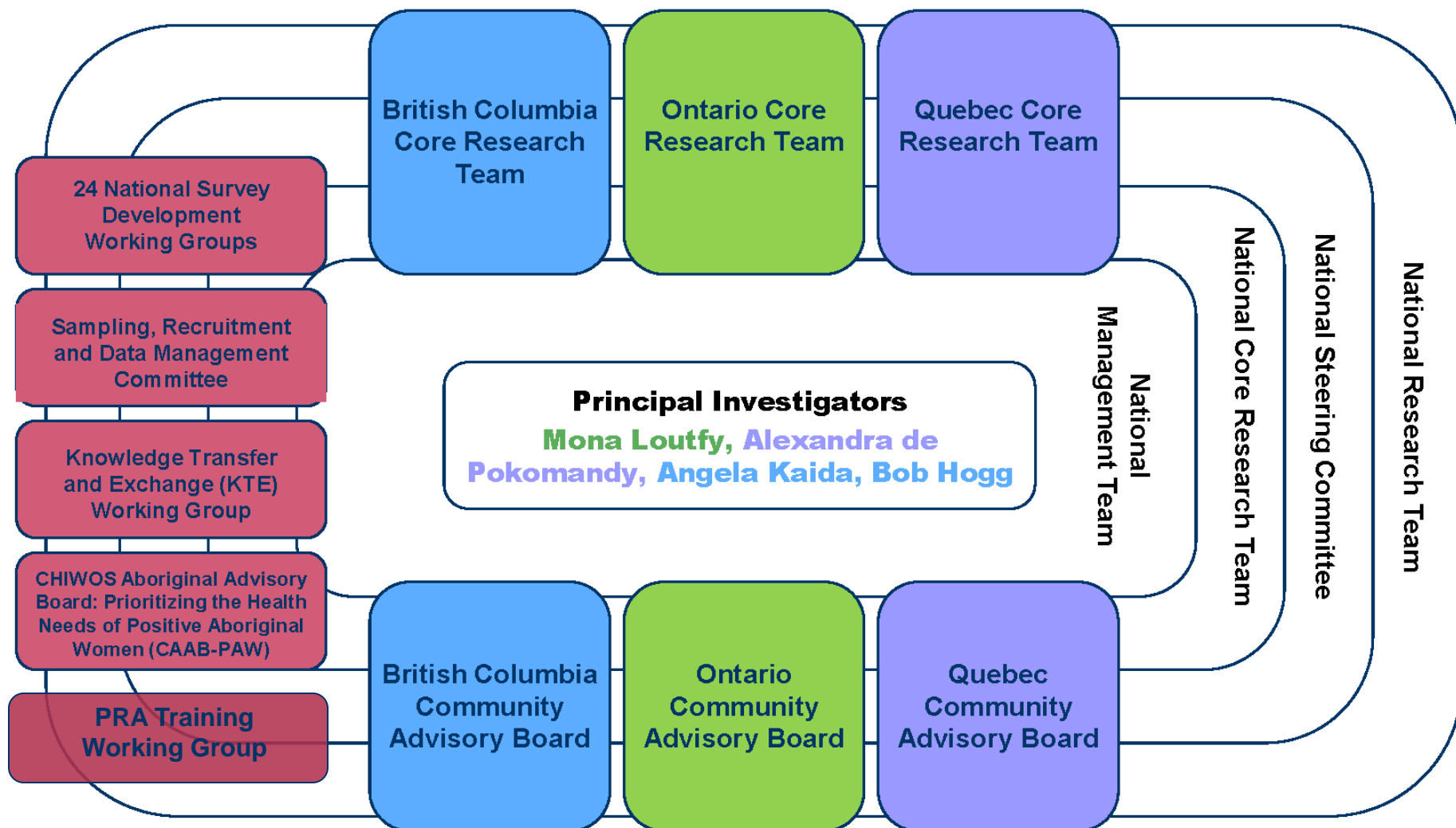
•(University of Michigan Edward Ginsberg Center for Community Service and Learning,  
<http://quod.lib.umich.edu/m/mjcs1>)

•\*Thank you to Saara Greene and Mona Loutfy





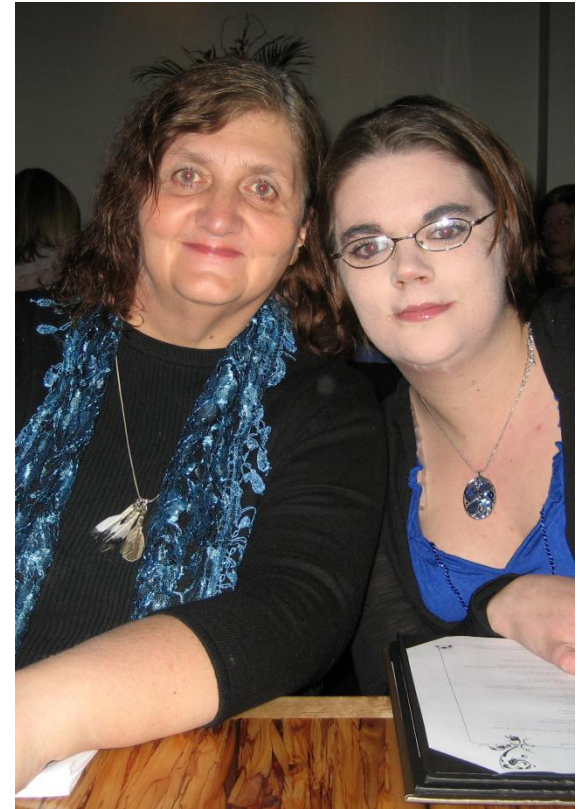
# Operationalizing CBR & MIWA through study team structures



# Operationalizing CBR & MIWA through study team leadership

## Peer Research Associates (PRAs)

- Hired as study partners to:
  - Guide the study
  - Inform the survey design
  - Facilitate focus groups
  - Administer surveys
- Advocates for the study among peers and in the community



# (Some) Challenges of CBR

- **Inequities in CBR stakeholder relationships**
  - E.g., community partner contributions as ‘volunteers’ vs. salaried research staff
- **Negotiating and valuing diversity in stakeholder needs, incentives, and priorities**
- **Funding**
  - E.g., \$1.19M across 5 years across 3 provinces across multiple provincial stakeholders/sites = not enough funding.
- **System barriers: Finance, Accounting, HR, Income Assistance**
  - How to hire PRAs without jeopardizing current disability benefits?
- **Time!**
  - CBR requires TIME. Lots of meetings. Lots of emails. Lots of talking.

# Facilitators of CBR...



CHIWOS Aboriginal Advisory Board – Positive Aboriginal Women (CAAB-PAW)

# Questions for Discussion

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From your own perspective, what are the key challenges to engaging in effective, respectful, and valuable community-based research?

And what actions can we take towards addressing these challenges in a sustainable way?



# Thank you!



CHIWO<sup>+</sup>S

# Acknowledgements

- Thank you to the CHIWOS co-PIs, provincial co-ordinators, PRAs, and the entire national core research team
- Thank you to the Steering Committee members, CAB members, CAAB-PAW members, and all the co-investigators, collaborators, working group members, and community partners committed to this study!
- Thank you to our affiliated studies: REACH and CANOC
- Thank you to our funders: CIHR (Institute of Gender and Health) and the CTN



the CTN  
CIHR Canadian  
HIV Trials Network

le Réseau  
Réseau canadien  
pour les essais VIH des IRSC

