

# What is **CHIWOS**?

## Aboriginal Review Committee (ARC) meeting

Angela Kaida (BC PI),  
Allison Carter (BC Coordinator),  
Valerie Nicholson (Community  
Representative and PRA), on behalf of  
the CHIWOS BC team

Monday, January 28<sup>th</sup>, 2013



# Acknowledgement



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

# Overview



- 1. What is CHIWOS?**
- 2. Brief Progress Update**
- 3. Next steps**
- 4. Questions and Discussion**

# What is CHIWOS?



# The Epidemiology and Feminization of HIV in Canada and Globally

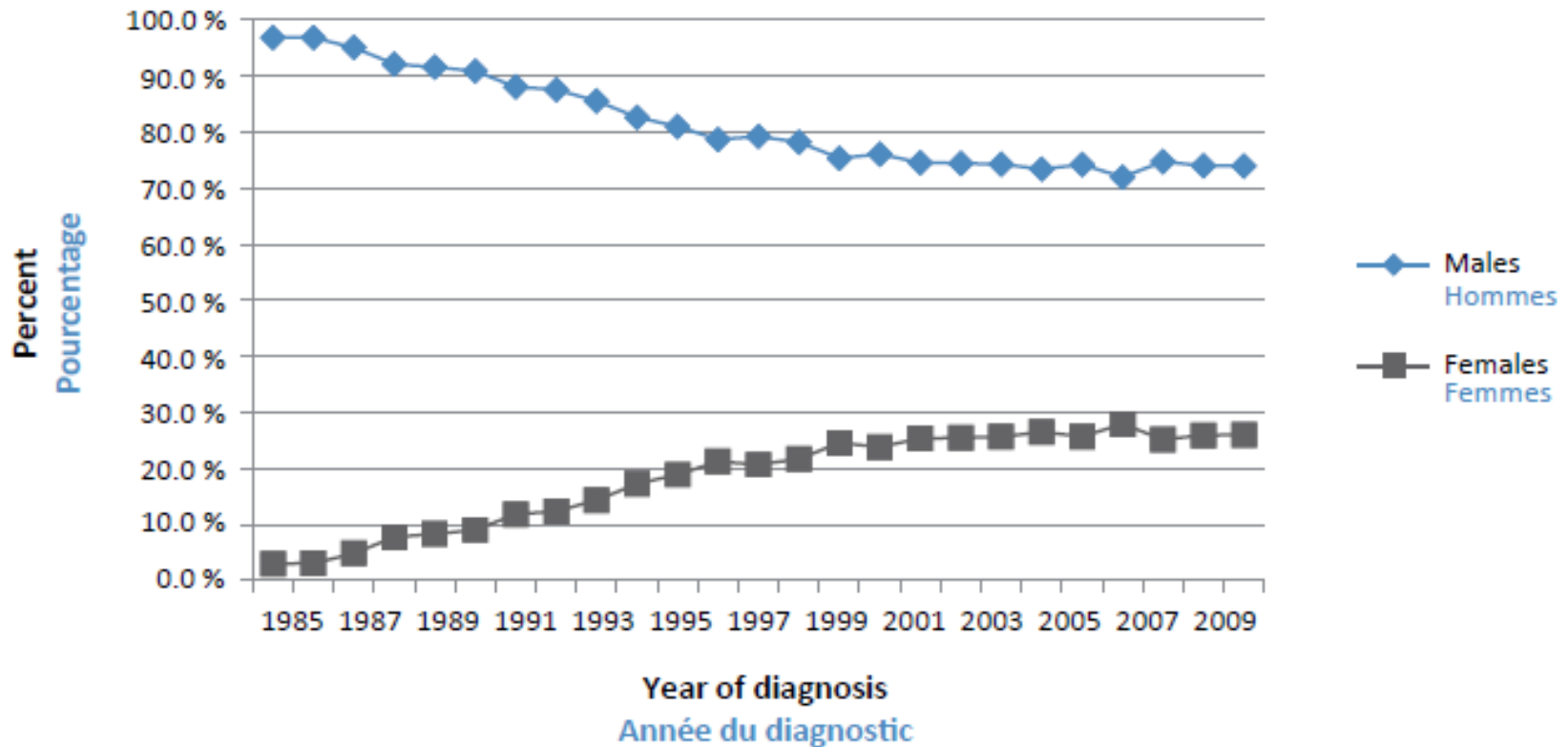
- Women now make up more than half of the world's HIV-positive population<sup>1</sup>
  - In Canada, 22% of the PLWHIV are women<sup>2</sup>
- Women are a group whose risk of HIV infection is rapidly increasing
  - 26% of new infections in Canada in 2008 were women (double what it was in 1999)<sup>2</sup>
- The gendered dynamics of HIV must be incorporated into research and care practices

# The Epidemiology and Feminization of HIV in Canada

FIGURE 3

Proportion of positive HIV test reports by sex, 1985-2009  
Proportion de rapports de tests positifs pour le VIH, selon le sexe, 1985-2009

[8]



# Demographics and Intersections of Identity

- Further marginalized women are even more vulnerable to infection and less able to access care
- In Canada, Aboriginal women, trans women, young women, women from countries with a high prevalence of HIV, and women who are or have been incarcerated, involved in sex work, or involved in drug use are at higher risk<sup>2,3</sup>

# The Missing Gender Analysis in HIV Research and Services

- The vast majority of research studies in HIV have focused on a mostly male population, preventing women from thoroughly benefiting from HIV research and from advances in care
- A review of HIV literature showed that < 8% of articles and abstracts were women-specific; over a quarter were not even disaggregated by sex<sup>4,5</sup>
- Result: many of women's needs are unmet



# Women's Unique Medical Needs

- Medical conditions that are unique to women may be prioritized less
- Medical conditions and treatments that manifest themselves differently in women may be treated as though identical to men
- Obstetric, gynaecological, and fertility care may not be addressed at all
- Women struggling with trauma, depression, and other mental health issues may not be supported

# Women's Unique Social Needs

- Women's social positioning also often results in distinct needs that should be considered when providing care or conducting research
- The roles that women often hold within families and communities may impact their usage of and access to care and services
- Social and economic marginalization, and a lack of access to or control over resources and supports, may contribute to competing needs (healthcare may not be top priority)
- Women's positioning may require alternative modes of care delivery (such as in-home care)
- Unfortunately common histories of trauma may dictate appropriate care delivery and needs (having female HCPs, establishing safe spaces, etc)
- Programs must address women's mental, medical and emotional needs in a supportive, non-judgemental, and non-stigmatizing way



# The Potential of Women-Centred HIV/AIDS care

- Previous studies have indicated that women-centred HIV/AIDS services may offer improved care for women, and are desired by, though often not available to women living with HIV<sup>6</sup>
- Could assist in addressing the health (broadly defined) needs of women

# CHIWOS:



**The Canadian HIV Women's Sexual and  
Reproductive Health Cohort Study**

**Pronounced:**

**'chee – wose'**



# CHIWOS: Study Goals

- Among HIV-positive women
  - To assess barriers to and facilitators of women-centred HIV/AIDS service use
  - To assess the impact of such patterns of use on sexual, reproductive, mental and women's health outcomes
- Hypothesis: Usage of women-centred care will a) be lower among more marginalized and stigmatized communities, and b) be shown to correlate with improved sexual, reproductive, mental and women's health outcomes

# CHIWOS Funding

- **Submitted to CIHR Gender, Sex Health Committee for funding in Sept 2010 Operating Grant call**
  - 4 co-PIs: Mona Loutfy (ON), Angela Kaida (BC), Alexandra Depokomandy (QC), Bob Hogg (CANOC)
  - Over 29 co-investigators and 25 collaborators from BC, Alberta, Ontario, Quebec, Nova Scotia
  - Strong community partnership
- **Announced February 2011; Started April 2011**
  - Successful: 1.19 million dollars over 5 years



# CHIWOS: Funding and Affiliations

**Canadian Observational Cohort Study (CANOC):** CIHR Emerging Team Grant of 9 HIV cohorts across Canada; aims to develop policy, contribute to research, improve training opportunities, and translate knowledge into action



CANOC

CIHR TEAM IN HIV TREATMENT OUTCOMES:  
THE CANADIAN OBSERVATIONAL  
COHORT (CANOC) COLLABORATION  
ÉQUIPE IRSC DE RECHERCHE SUR LES  
EFFETS DES TRAITEMENTS CONTRE LE VIH:  
COLLABORATION PANCANADIENNE DES  
COHORTES OBSERVATIONNELLES (CANOC)

**Research Evidence in Action for Community Health (REACH):** CIHR-funded centre fostering Canada-wide collaboration among researchers, service providers, PLWHIV, policy makers, etc to establish an innovative infrastructure to improve the health and wellbeing of PLWHIV and affected communities



**Canadian HIV Trials Network (CTN):** CIHR-funded innovative partnership of clinical investigators, physicians, nurses, people living with HIV/AIDS, pharmaceutical manufacturers and others that facilitate HIV/AIDS clinical trials



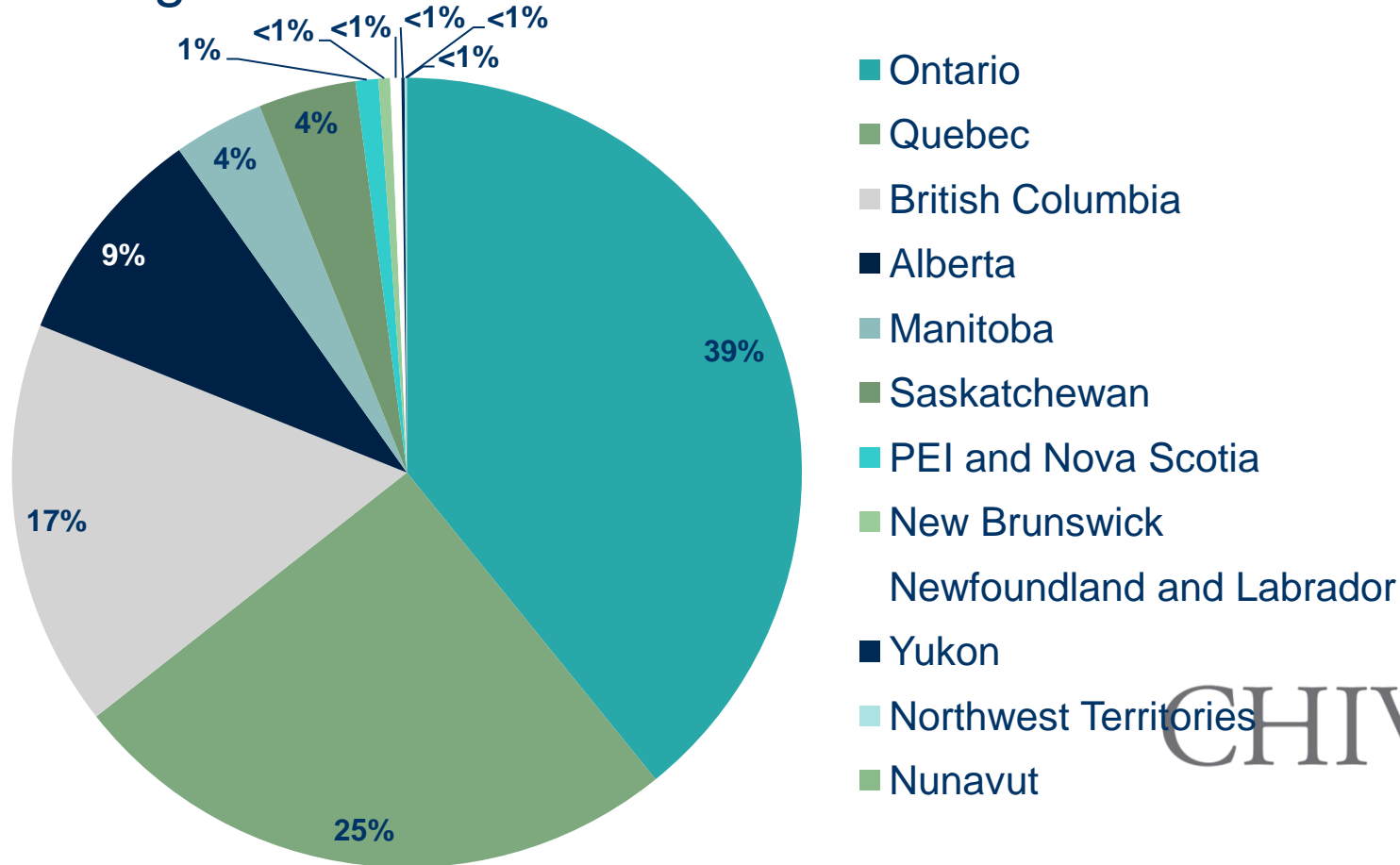
the CTN  
CIHR Canadian  
HIV Trials Network

le Réseau  
Réseau canadien  
pour les essais VIH des IRSC



# Distribution of positive HIV test reports among females by province/territory between 1985-2009 (n=11,805)<sup>[8]</sup>

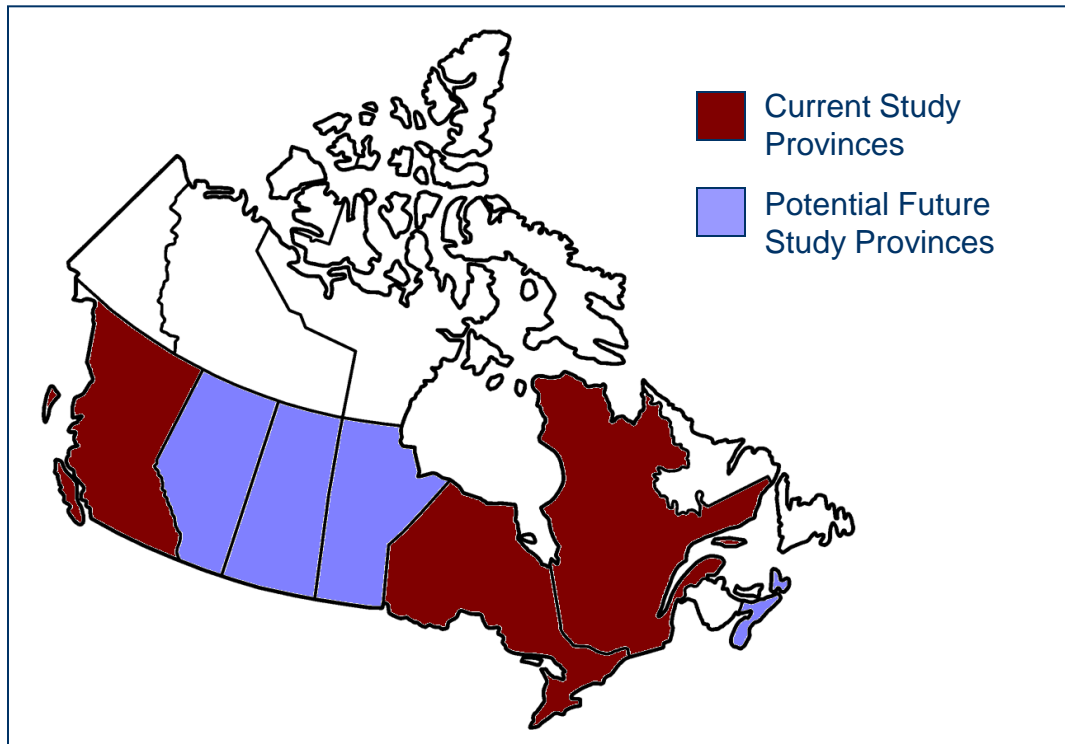
• Study is rolling out in BC, ON, QC - The three provinces with highest HIV rates





# National Scope

- Plans to eventually expand to Nova Scotia, Manitoba, Saskatchewan, and Alberta
  - Co-investigators from these provinces already on board



# CHIWOS Guiding Frameworks

- Critical Feminism
- Anti-Oppression, Intersectionality, and Social Justice
- Social Determinants of Health
- GIPA - Greater Involvement of People living with HIV/AIDS
- MIWA - Meaningful Involvement of Women living with HIV/AIDS
- Community-Based Research

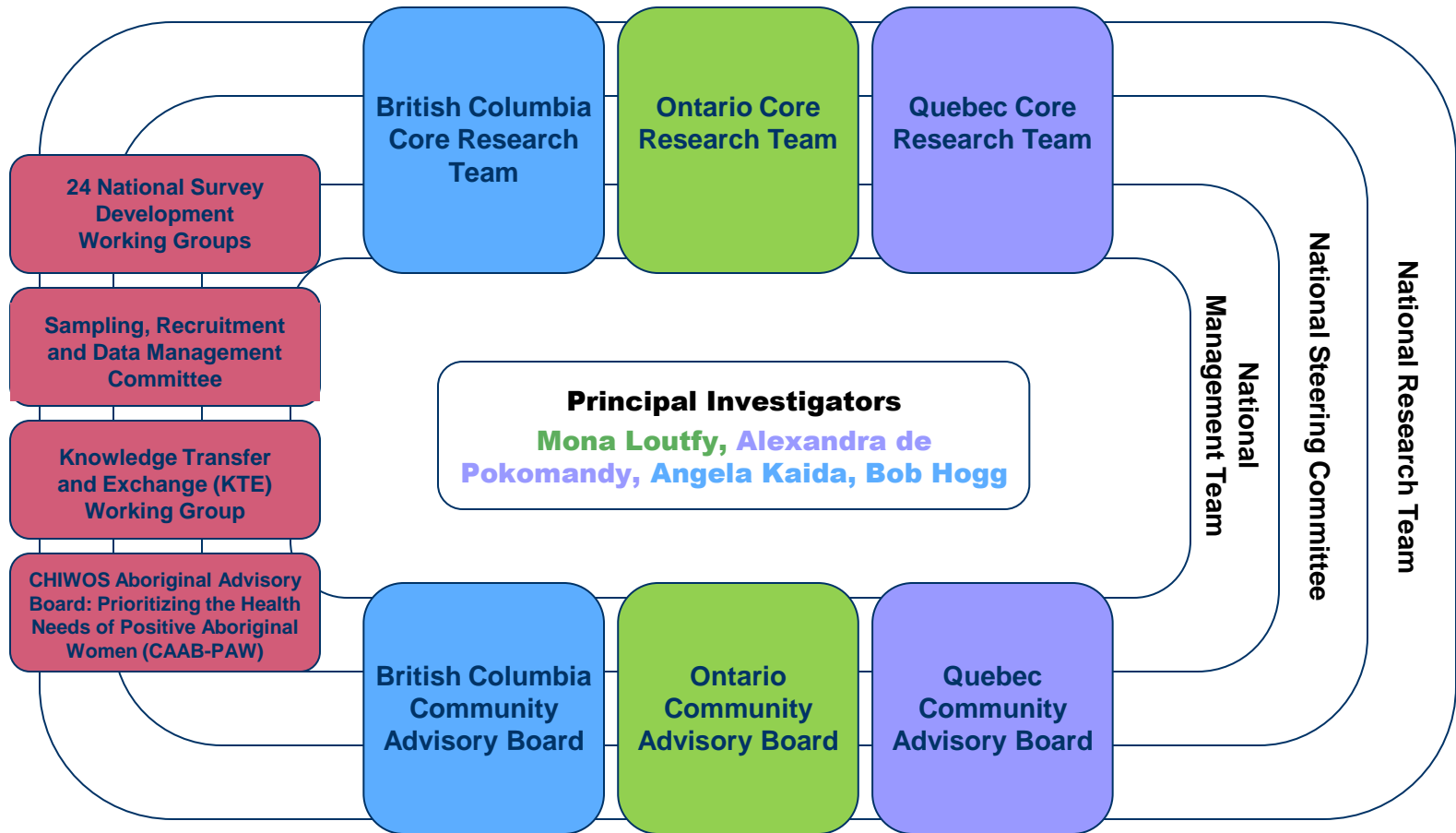


# CHIWOS Study Design

- Five year, multi-site, prospective cohort study rolling out in BC, ON and QC
- Target sample size = 1,250 women living with HIV
  - 350 women each in BC and QC; 550 women in ON
- Two phases:
  - Formative phase (wrapping up)
  - National survey phase (launch in May 2013)
    - Participants will complete a Peer Research Associate (PRA)-administered web-based survey at baseline (Wave 1) and again 18 months later (Wave 2)



# CHIWOS Study Team Structure



# Brief Progress Update

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CHIWO S

Canadian HIV  
Women's Sexual  
and Reproductive  
Health Cohort Study



# Major activities of the last year

1. Formative work to understand ‘women-centred care’
2. CAAB-PAW – *“CHIWOS Aboriginal Advisory Board (CAAB): Prioritizing the Health Needs of Positive Aboriginal Women (PAW)”*
3. Communications strategy
4. Survey development

# 1. Formative work to understand women-centred care (WCC)

- Completed a **literature review** to identify and define what key elements underlie this approach to care
  - Manuscript published in *JIAS*; posters at AIDS 2012 + CAHR '12
- Conducted an **environmental scan** of services for women living with HIV in BC
  - Highlighted the diversity of services that may be considered 'women-centred' (e.g., OTC, PWN, Around the Kitchen table, etc.)
- Conducted 11 **focus groups** (4 in BC) to explore what 'women-centred care' meant to women living with HIV
  - Submitted abstracts to CAHR 2013 and IAS 2013
- Collectively, this work informed our survey instrument
  - We developed and are testing a **scale** for measuring WCC

## 2. CAAB-PAW: CHIWOS Aboriginal Advisory Board – Positive Aboriginal Women

- **Aboriginal Research Training Workshop for CHIWOS**
  - April 2012 in Montreal
  - Led by Aboriginal women
  - Provided training on Aboriginal health research models.
- **CIHR meeting grant**
  - PI: Anita Benoit
  - Awarded in June 2012
  - Funded a 2-day meeting in September 2012 where colleagues discussed opportunities to involve more Positive Aboriginal Women (PAW) in CHIWOS and to better address issues important to the PAW community



# 3. Communications

- Follow us on **twitter!** (@CHIWOSresearch)
- Released the **1<sup>st</sup> CHIWOS BC newsletter**
- Initiated a **CHIWOS KTE working group**
- Developed several study **policies**: e.g., Authorship policy, Student policy, Social media policy, Translation policy.
- **Website and facebook page** are under development

## Sample tweets:



**CHIWOSresearch** @CHIWOSresearch

Dr. Loutfy of [@WCRInstitute](#) [@WCHospital](#) shares CHIWOS as an example of GIPA/MIWA at work! [#HIVwomen](#) [#HIVCan](#) [#AIDS2012](#)



**CHIWOSresearch** @CHIWOSresearch

Interested in health promotion for HIV+ ppl? Check out [#PWNSpringBoard](#) conference on May 3! [@PWN\\_BC](http://tinyurl.com/72qou5s) [#HIVwomen](#) [#HIVCan](#)

# 4. Overview of Survey Development and Review Process

- 24 national working groups developed various survey sections
- Mixed groups of researchers, clinicians, service providers, policy-makers, & women living with HIV, bringing professional and lived experience, expertise, and passion to the process
- Survey drafts were tested with PRAs in each province
- Numerous rounds of cuts, revisions, debates, and negotiations (first draft was >250 pages! Latest draft is 84 pages)
- Sharing the survey with 3 provincial CABs and several community-specific review groups for feedback
- Conducted 1<sup>st</sup> phase piloting with women living with HIV
- Will be administered using FluidSurveys online software

# Looking Forward



Étude sur la santé sexuelle et reproductive  
des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and  
Reproductive Health Cohort Study

# Timeline

## Winter 2012 – Spring 2013:

- Program survey into web-based format (FluidSurveys), pilot, IRB approval, confirm and initiate recruitment sites

## Spring 2013:

- Hire additional PRAs across the province

## March to April 2013:

- Provincial PRA Training
- National PRA Training at CAHR

**May 1st: Begin recruitment!**



# Recruitment plan

- Developing and finalizing sampling and recruitment plan
  - Recruiting 350 women across BC
  - 6 sampling and recruitment strategies (5 RHAs + Oak Tree Clinic)
  - 1 Peer Research Associate (PRA) per region
  - Recruitment from clinics, ASOs and other non-HIV organizations (e.g. immigration, food banks)
  - Work with CAB members in each region to develop tailored S&R plan
  - Aiming for a proportional representation by region
  - Proposed over-sampling of particular populations of women (e.g., Aboriginal women, women from smaller regions)
  - The survey will be ~ 2 hours (TBC) and participants will receive a compensation of \$50
  - PRAs compensated \$75 for each completed survey

# Number of women testing newly positive for HIV, 1994-1999\*

RHA	# OF WLWH	PROPORTION	TARGET # FOR CHIWOS
Vancouver Coastal	765	49%	172
Fraser	389	25%	88
Vancouver Island	197	13%	45
Interior	99	6%	21
Northern	103	7%	24
<b>Total</b>	<b>1561</b>	<b>100%</b>	<b>350</b>

## The distribution of women testing newly positive for HIV in BC by race/ethnicity, 2002-2009:

Ethnicity	# of WLWH	Proportion	Target # for CHIWOS
Caucasian	251	44%	154
Aboriginal	190	34%	119
ACB	47	8%	28
Other	77	14%	49
<b>Total</b>	<b>565</b>	<b>100%</b>	<b>350</b>

# Hiring and Training Peer Research Associates (PRAs)

- Plan to hire an additional 3-5 PRAs
- Circulating PRA job ad this week
- Collaborating with community organizations and ASOs in each RHA throughout hiring process
- Hired a PRA Training Consultant, Jo Lemay, who is developing a multi-phase CHIWOS PRA Training Curriculum
- Training in research methods, privacy and confidentiality, self care, and availability of community resources to support women living with HIV.



# Acknowledgements



- Thank you for your presence and contributions today
  - CHIWOS PIs: Mona Loutfy, Angela Kaida, Alexandra de Pokomandy, and Bob Hogg
  - Provincial coordinators: Allie Carter (BC), Nadia O'Brien (QC), and Johanna Lewis (ON)
  - CHIWOS Peer Research Associates (PRAs), Steering Committee members, CAAB-PAW members, CAB members, and all the community partners involved in this study
  - CHIWOS is supported by the Canadian Institutes of Health Research (CIHR) Institute of Gender, Sex, and Health and the Canadian HIV Trials Network (CTN 262)
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# Questions and Discussion

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**Thank you!**

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