Discussion of a National Mandate on Women and HIV Research and Education in Canada: Presenting “Women for Positive Action” and the “Canadian HIV Women and Reproductive Health Cohort Study (CHIWOS)”

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Disclosure

• Mona Loutfy has received unrestricted research grants from and has acted as a speaker and advisor for Abbott Canada, Merck Frosst, Pfizer, Bristol-Myers Squibb, Tibotec, Boehringer Ingelheim, Glaxo-Smith-Kline Inc and ViiV Healthcare.
Objectives

• Review the importance of building a national mandate on women and HIV research and education

• Review successes of Women for Positive Action (Canada, Europe and Latin America)

• Present the recently-funded “Canadian HIV Women’s and Reproductive Health Cohort Study” (CHIWOS)

• Discuss possibilities and next steps
Recognizing previous and ongoing work – in Canada

• Grassroots organizations
  – VOICES, CASM and PWN … now VIVA

• Canadian Women's HIV Study
  – Led by Dr. Cate Hankins; enrolled from 1993 from 28 sites and 11 cities

• National Women and HIV Project
  – Led by the Canadian AIDS Society; from early 1990s

• First National Conference on Women & HIV/AIDS
  – In 2000; in Toronto; Recommendations published
Recognizing previous and ongoing work – in Canada

• National Women’s Working Group
  – Led by CTAC; “Recommendations for Action” made

• Blueprint for Action on Women and Girls and HIV

• National Aboriginal Women and HIV Strategy

• Second National Conference on Women & HIV/AIDS
  – This event; organized by CAS; > 30 people involved
  – CIHR MDG awardee; over 125 attendees

• Others
**Importance of Mandate**

- **Link all relevant Canadian stakeholders in a coordinated response to women and HIV**
  - Community
  - Care/Service providers
  - Researchers
  - Students
  - Policy makers
  - Knowledge brokers

- **Ensure inclusiveness**
  - All women
  - Transwomen
  - Girls

- **Include research & knowledge translation; but also action (care, treatment, support) in response**
Importance of Mandate

• Ensure relevance to HIV-positive women, transwomen and girls communities of vulnerable women

• Ensure Canada is contributing and leading in Women and HIV cause globally, with impact locally

• Ensure specific impacts:
  – Improve the health and well being of HIV-positive women, transwomen and girls
  – Improve access to care, treatment, diagnosis, support and education
  – Reduce the number of new infections among women
Building women and girls’ global meaningful participation in the High Level Meeting on AIDS

The ATHENA Network and the Global Coalition on Women and AIDS (GCWA) initiated a global virtual consultation with regional partners in order to ensure the broadest possible engagement and representation of women (and girls wherever possible) in the processes leading up to the High Level Meeting on AIDS in June 2011 – especially women living with and affected by HIV, and other key populations of women, who often lack platforms for priority issues to be raised and heard. The virtual consultation as a new platform has, for the first time in the 30 year history of the AIDS response, brought together women in (and from) many different areas and with multiple identities in a personal and political capacity to speak to the successes, challenges, and key lessons learned through the AIDS response since the 2001 Declaration of Commitment on HIV/AIDS and in the effort to achieve Universal Access. This virtual consultation was launched on 01 March 2011 and has gathered responses from more than 700 women from over 95 countries around the world.

The focal areas for the consultation were defined by 4 criteria: 1) Centrality of women’s rights to the success of the AIDS response; 2) Importance for women, girls, and gender equality; 3) Ability to speak to the future, specifically to move us toward realizing all the Millennium Development Goals; and, 4) Political opportunity to highlight an issue that has not received adequate attention to date in efforts to address women, girls, and gender equality in the context of HIV and AIDS.

TOP PRIORITIES FOR POSITIVE CHANGE
as identified by women globally toward achieving Universal Access

1: Inclusive and holistic prevention, treatment, care, and support for women in all of their diversity
- Increase access to and uptake of HIV prevention and treatment services (including nutrition) for women and girls outside of the maternal and child health setting.
- Health services must be accessible, gender-sensitive, non-discriminatory, and uphold confidentiality. Services must be available for all women, regardless of age, HIV status, sexual orientation, or socio-economic status.
- Promote the inclusion of women and girls in all their diversity, such as those living in rural and hard-to-reach areas; young women; women living with HIV; women with disabilities; women in conflict areas; transgender women; women who have sex with women, women involved in sex work; refugees, women who use drugs, and indigenous women.
- Promote youth participation, and youth-friendly SRH/HIV services, in particular ensuring access to non-judgmental services for young people.
- HIV prevention and access to HIV testing must be available for all women, not only when they are pregnant, but also throughout their life cycle.
- Expand gender sensitive, non-discriminatory, and supportive harm reduction and need exchange services.

2: Solidarity
- Eliminate stigma and discrimination against women and girls – in particular women and girls living with HIV, and key affected women and girls.
- Repeal punitive laws that criminalize on the basis of drug use, sex work, sexuality, or HIV transmission and exposure.
- Address stigma and discrimination against people living with HIV, women on the basis of their sexuality, women who do sex work, and widows – both at a societal level and within health services.
- Ensure that HIV prevention and testing programs neither target nor stigmatize women or other key affected groups, and that HIV-related services are equally available to all who need them.
- Ensure women living with HIV have access to full and comprehensive sexual and reproductive health choices.
- Remove laws and policies that prevent women in sex work accessing safe places to live and work, health services, justice, and labor rights.
- Reform and strengthen drug policy away from punitive towards rights-based responses.
- Support peer-led programming for women living with HIV and other key affected women.
- Improve awareness around HIV through positive media coverage and discussion that aims to create a culture of solidarity and equality for women living with HIV.

3: Safety
- Promote gender equality through women’s empowerment, including through representation in parliament and in all other national decision-making fora, such as processes to develop National Strategic Plans on HIV and AIDS.
- Ensure National HIV Policies are gender sensitive, including recognition of the particular vulnerabilities and impact of HIV transmission on women and girls, and gender-sensitive budgeting and resource allocation.
- Engage men in various societal levels (family, community, institutional) in interventions to defend the rights of and protect women, including women living with HIV.

"Women who work in the same field as men should be given the same amount of pay as a man." (Caribbean)

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Global

TOP PRIORITIES FOR POSITIVE CHANGE towards Universal Access

1. Inclusive and holistic prevention, treatment, care and support for women in all of their diversity
2. Solidarity
3. Gender equality
4. Safety
5. Education, including sexuality education

Co-sponsored by the ATHENA Network and the Global Coalition on Women and AIDS Virtual Consultation 2011 www.athenanetwork.org
What role for Canada?

• **Review**
  – Women for Positive Action
  – Canadian HIV Women and Reproductive Health Cohort Study (CHIWOS)

• **Discuss**
  – Next steps for Canada for this Mandate
  – Brainstorm
  – Open exchange
What is “Women for Positive Action”?

- WFPA is a unique global initiative established in response to the need to address the specific concerns of women living and working with HIV.

- WFPA is led by a multidisciplinary international faculty of professionals from Europe, Canada and Latin America, including:
  - healthcare professionals
  - women living with HIV
  - community group representatives

- WFPA has two main regional groups
  - EU/Canada – 22 members (Canada representatives are Sharon Walmsley, Laurette Levy, Mona Loutfy – chosen by Abbott)
  - Latin America – 16 members
  - A total of 19 countries are directly represented
WFPA mission

To empower, educate and support women living with HIV and the healthcare professionals and community advocates/leaders involved in their treatment

To explore the issues facing women living with HIV and provide meaningful educational-based support to respond to these needs

To contribute towards an enhanced quality of life for women living with HIV
WFPA website

- Educational tools available for download
- News and polls
- Faculty members
- Links to other websites of interest
- English, French and Spanish versions with additional languages being developed
Educational slide kits

- For physicians, service providers, community leaders and women living with HIV
  - HIV, conception, pregnancy and contraception
  - Emotional wellbeing of women living with HIV
  - Women and clinical trials in HIV
  - Women and HIV testing
  - Supporting the patient-healthcare professional relationship
  - Beliefs, spirituality and HIV: harnessing benefits and overcoming barriers
  - HIV and ageing

- Available in English, French and Spanish
WFPA publications

• Position paper
  ~ ‘Better mind the gap: addressing the shortage of HIV-positive women in clinical trials’
  ~ Published in May 2010 in AIDS Journal

• Position paper opinion editorial
  ~ ‘HIV-positive women in clinical trials: a gap in the facts’
  ~ Published in June 2010 in HIV Treatment Update

• Faith and beliefs feature article
  ~ ‘Faith and spirituality in the lives of women living with HIV’
  ~ Published in Autumn issue of Positively Women
Better mind the gap: addressing the shortage of HIV-positive women in clinical trials

Antonella d’Arminio Monforte, Lorena González, Annette Haberl
Lorraine Sherr, Winnie Sanyu-Sseruma, Sharon L. Walmsley,
on behalf of Women for Positive Action

AIDS 2010, 24:1091–1094

Introduction

Worldwide, over 50% of the people with HIV are women, and women represent a growing proportion of new diagnoses [1]. Other than for studies to evaluate mother-to-child transmission, women are poorly represented in HIV clinical trials [2]. This opinion piece aims to raise awareness of the need for women to be considered at all stages of the design, conduct, interpretation, reporting, knowledge translation, and application of clinical HIV research. Studies are usually underpowered for sex comparisons due to low rates of enrolment of women [3], and failure to report sex subanalyses has also contributed to a knowledge gap. A recent meta-analysis reported that since 2000, only 20% of participants in clinical trials of antiretroviral therapy (ART) were women and the proportion has declined in the past 8 years [4] (Fig. 1). Women are biologically different than men and in order to gain a better understanding of the potential sex influences on HIV therapies, trials need to better reflect the population living with the disease by routinely including an appropriate proportion of women [3] or by conducting concurrent similarly powered trials in each sex.

Why data in women are essential

Women are entitled to equal access to successful treatment and the ability to make empowering informed choices.
WFPA at EACS

• WFPA faculty members to participate in a mini-lecture as part of the women’s plenary session at EACS ‘When Girls Living with HIV Grow Up To Become Adults or Want Children’

• Aims to help understand the challenges facing women, living with HIV in Western and Eastern Europe, who would like to have a family and discuss the options available to these women
Local implementation case study: WFPA Italy

Objective

• Facilitate uptake, adaptation and creation of Women for Positive Action materials in Italy

Approach

• Professor d'Arminio and Dr Ammassari coordinated an Italian WFPA Board of 10 Italian stakeholders
• 1 WFPA Advisory Board meeting implemented
• 2 CME courses implemented across Italy with the WFPA Board as speakers and Prof d'Arminio and Dr Ammassari as Discussants
• Slide kits updated
• Women focused section during 2010 International Guidelines meeting (Prof D'Arminio as speaker)
• Women-dedicated clinical cases/lectures during 3 national events “HIV therapy: tailoring to protect patients”
• **Clinical study focused on body and mind topics in women with HIV**
• WFPA Board involved in editorial activities on women and HIV
Local implementation case study: German AIDS meeting

Objective

• Raise awareness of the Women for Positive Action initiative in Germany, Austria and Switzerland

Approach

• Presentations from Annette Haberl, Annette Piecha and Ulrike Sonnenberg-Schwan on women and HIV, WFPA mission and initiatives, with insights on the use of WFPA educational tools
• Held at the "Münchner AIDS-Tage", a bi-annual interdisciplinary AIDS conference (1,500 participants from Germany, Austria and Switzerland
• Slides translated into German and adapted
• Video launched on International Women's Day on www.hiv-und-aids.de
New national endeavour: develop nation-wide community-based research (CBR) prospective cohort study to:
- assess barriers to and facilitators of women-specific HIV/AIDS services use and patterns
- assess the impact of such patterns of use on sexual, reproductive, mental and women's health outcomes among HIV-positive women across Canada.

Co-PIs: Drs Mona Loutfy, Angela Kaida, Bob Hogg, Alexandra dePokomandy

Over 50 national, multi-stakeholder co-investigators and collaborators
CHIWOS

• Affiliated with CANOC (Canadian Observational Cohort Study)
  – CIHR Emerging Team Grant of 8 HIV cohorts across Canada

• Submitted to CIHR Gender, Sex Health Committee for funding in September 2010 Operating Grant call

• Announced February 2011
  – SUCCESSFUL!!!
  – 1.2 million dollars over 5 years
• Some unique features of CHIWOS:
  
  – **Nation-wide**
    
    • initial enrolment from ON, BC, QC
    
    • NS, MB, SK, AB already on board as co-investigators for second phase to expand to those provinces
  
  – **Multi-stakeholder**
    
    • Community partnership is KEY right from the beginning (developing research questions, methods, on RT, SC, KT)
    
    • Researchers, policy-makers, KT brokers, care providers, students, etc
  
  – **Community-Based Research (CBR) Study**
    
    • Probably CIHR’s largest CBR project funded through general Operating Stream
Unique aims of CHIWOS are to estimate the:

1) Proportion, distribution, and patterns of uptake of **women-specific HIV/AIDS services (WSS)** and factors associated with uptake among women living with HIV (WLWH).

2) Effect of WSS uptake on
   - **reproductive and sexual health outcomes** of WLWH
   - **women’s health outcomes and screening** of WLWH
   - **mental health outcomes** of WLWH
CHIWOS

• **More unique features of CHIWOS:**
  – guided by the Critical Feminist and Social Determinants of Health frameworks
  – as well as GIPA/MIPA and OCAP principles

• **Study details:**
  – Enrol 1,050 WLWH from BC, ON, QC (350 each province)
  – Attempt to enrol hard-to-reach women (e.g. travel costs covered, interpreters)
  – Participants will complete a PRA-administered survey at baseline and two years, with a phone call and brief survey at one year to ensure continuity of contact.
  – Survey data will be linked to existing national and provincial cohorts
Please join us

CHIWOS
Canadian HIV Women and Reproductive Health Cohort Study, Canadian Observational Cohort (CANOC) Affiliated Study

National Launch Celebration!
Please join us as we launch the Canadian HIV Women and Reproductive Health Cohort Study

When:
Thursday April 14th 1pm – 2pm Steering Committee Meeting
2pm-3pm CHIWOS National Launch Introduction & Celebration

Where:
Westin Harbour Castle – Regatta Room

Who:
Research Team Members and other interested individuals

Tentative speakers will include:
Dr. Cate Hankins (confirmed)
Dr. Mona Loutfy (confirmed)
Dr. Robert Hogg (confirmed)
Dr. Angela Kaida (confirmed)
Ms. Shari Margolese (confirmed)
Ms. Doris Peltier (confirmed)
Dr. Alexandra de Pokomandy
CHIWOS

• **Take opportunity and step back**
  – Let’s look at what role CHIWOS can play
    • Nationally and internationally
  – **Mandate for right-based approach to research in Women and HIV**
    • Women and Girls’ Rights; including Transwomen rights
    • Women and HIV Rights
    • Sexual and Reproductive Rights for WLWH (PW)
  – **Research that has a local and global impact**
Next steps

• **Next session: 11:15 – 12:15:** Large Group Discussion: Next Steps and Moving Forward

• **Think about WFPA and CHIWOS in our discussion:**
  – Should we or could we have a WFPA Canada?
    • Should we mirror other countries – regional and national research & education projects?
  – What role can CHIWOS play?
    • Can we leverage the great news of CHIWOS?
    • Can we link more provinces? Who else should be involved?
    • Greater vision and mandate? What else?
CHIWOS Acknowledgments

- Funders: CIHR
- Investigators’ salary support from CIHR and the Ontario HIV Trials Network
- Community partners
- Co-investigators, collaborators
- Research coordinators, students for their dedication to the project
- CHIWOS Steering Committee
- CTN for working with us