

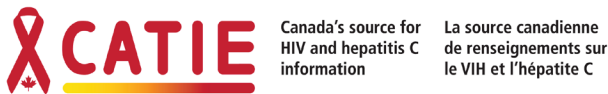
# The National Consensus Statement

On Women, Trans People and Girls  
and HIV Research in Canada

Jacqueline Gahagan & the Gathering of Spirits Collaborative



Suggested Citation: © Jacqueline Gahagan & the Gathering of Spirits Collaborative (2013). The National Consensus Statement on Women, Trans People and Girls and HIV Research. Halifax, NS: Dalhousie University, Gender and Health Promotion Studies Unit.



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We would also like to thank the various organizations and individuals who generously offered their time and expertise at in-person meetings and through electronic consultations in order to revise and finalize this document.



## Glossary of Terms

### GIWA

Greater Involvement of Women Living With or Affected by HIV/AIDS. GIWA is not a program or project, but a *principle* that aims to realize the rights and responsibilities of women living with HIV/AIDS, including their right to self-determination and participation in decision-making processes that affect their lives. GIWA empowers women living with HIV/AIDS to take a leading role in the work that most affects them, acknowledging the valuable contribution they make in advancing the HIV/AIDS movement.

### HIV, AIDS AND HIV/AIDS

In keeping with UNAIDS suggested usage, we use the term that is most specific and appropriate in the context to avoid confusion between HIV (a virus) and AIDS (a clinical syndrome). Where we once would have used HIV/AIDS (HIV and/or AIDS), we now use HIV, except when referring to people who are both affected by HIV and AIDS (not using the terms interchangeably).

### HEALTH

In this context, we use the term health in keeping with the definition put forth by the World Health Organization, which positions health as a comprehensive state of well-being and not just the absence of disease. Therefore, we use the term health to refer to physical health, as well as mental health, cognitive health, emotional health, and the various social factors that allow one to be and remain healthy.

### INCARCERATION POLICIES

By ‘incarceration policies’ we are referring to policies in penal institutions that compound women’s and trans people’s risk of HIV infection (e.g. banning harm reduction materials; housing trans women in men’s prisons).

### LIVED EXPERIENCE

By ‘lived experience’ we mean the direct personal experience of women, girls and trans people living with HIV or AIDS.

### MIWA

Meaningful Involvement of Women Living With or Affected by HIV/AIDS. Like GIWA, MIWA is a principle. It goes a step beyond GIWA, in that it calls for the involvement of women with HIV/AIDS to be meaningful and relevant.

### SOCIAL FACTORS

In this context, factors (social determinants of health) that affect people’s vulnerability to becoming infected or to access screening and treatment. These can include such factors as socio-economic status, race, education, gender, access to stable housing, access to health services, social support services and social networks, social environments, early childhood development, sexual and other forms of violence, culture and HIV-related stigma and discrimination.

### TRANS PEOPLE

We use the term “trans” as an umbrella term which includes transgender, transsexual, genderqueer and otherwise gender non-conforming people. Several people have suggested we narrow it to trans women only for the purposes of this document. However, we have decided to keep it wider in scope to be more inclusive, and to acknowledge that some trans men share some biological vulnerabilities to HIV with cisgender women. We also prefer ‘trans people’ because it includes all the people who identify outside of the gender binary.

## Foreword

Thank you for your interest in the *National Consensus Statement on Women, Trans People and Girls and HIV Research*. Emerging from a broader and ongoing national dialogue on issues related to HIV research with, by and for women, trans people and girls, this document was developed with specific goals and objectives in mind. We believe it is important to highlight these objectives as a way of framing the document as they directly inform how the document was formulated, as well as what was included (and excluded) from the final version.

The intended audience for this *National Consensus Statement* includes those who are involved in shaping or conducting research related to HIV in Canada, including researchers, policy-makers and research funders. It raises key research issues and needs as they relate to women's, trans people's and girls' experiences of HIV in Canada, in a concise and accessible manner. It is our hope that this resource will be of use to service providers, activists, researchers and others, as they advocate for a stronger focus on HIV research with, by and for women, trans people, girls in Canada.

The needs of women, trans people and girls in Canada as they relate to HIV and related issues are extremely complex and diverse, and span across legal, cultural, social, political, economic and other spheres. The following *National Consensus Statement* does not presume to provide a definitive and comprehensive picture of these issues, but rather it aims to raise key points and needs related to HIV research as determined through an extensive consultation process with varied stakeholders across Canada. For the sake of coherence, these points and needs have been classified under various types of research, as outlined in Section 3: Canadian research priorities. However, it is important to stress that because the needs of women, trans people and girls are so diverse and reach across various inter-connecting spheres, future research is required that can capture and mitigate these complexities. Beyond addressing the needs of women, trans people and girls as they relate to clinical, social, epidemiological and public health-based research, this *National Consensus Statement* is also premised on a fundamental belief in the value and importance of multi-disciplinary HIV and AIDS research that cuts across and recognizes these various spheres and how they impact the lived experiences of women, trans people and girls in Canada.

by Jacqueline Gahagan and the Gathering of Spirits Collective

## Section 1: Introduction

The idea for a *National Consensus Statement on Women, Trans People and Girls and HIV Research* emerged over a number of years, beginning at the 2009 Canadian Association for HIV Research (CAHR) annual conference. It continued through several other conferences and regional meetings focused on the HIV-related research issues faced by women, trans people and girls in Canada. *The Gathering of Spirits: Canadian Women, Trans People and Girls' Collaborative* (Gathering of Spirits Collaborative) was formed in April 2011 at the CAHR conference. Open to anyone with an interest in HIV research, the Gathering of Spirits Collaborative seeks to create opportunities for dialogue, to facilitate the exchange of knowledge and skills, and to connect diverse stakeholders in working together to ensure that our HIV research efforts are meeting the needs of women, trans people and girls, as well as their families and their communities.

The *National Consensus Statement on Women, Trans People and Girls and HIV Research* has undergone a series of public consultations in an effort to solicit feedback from a broad range of stakeholders during 2012 and 2013. This process provided numerous opportunities for input from community, government, and research sectors across Canada. This resultant document is meant to be used as an advocacy tool to ensure the specific HIV research priorities of women, trans people and girls are included in the next generation of HIV and AIDS research responses undertaken in Canada. We are grateful to the International AIDS Society (IAS) for offering an overview of the prioritization process used in the development and finalization of their 2010 consensus statement, which was instrumental

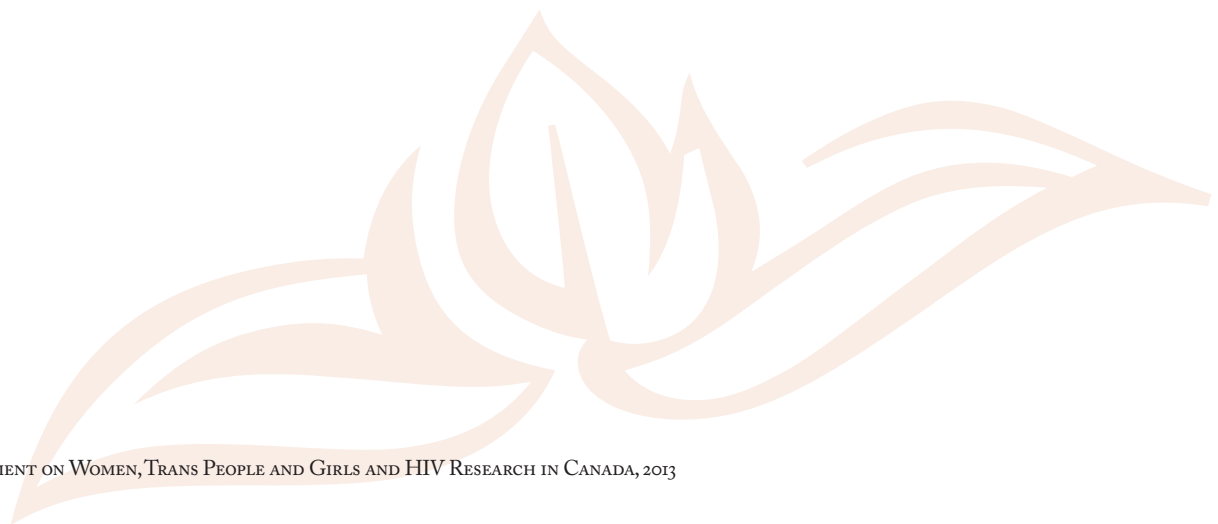
in the development of this *National Consensus Statement* (For more information see the IAS website for the document 'Asking the Right Questions: Advancing an HIV Research Agenda for Women and Children').

Although the focus of this document is specific to women, trans people and girls and HIV, we recognize the gendered dimension of both HIV prevention and treatment and believe that everyone has a significant role to play in the Canadian context. We also understand the important interplay between gender as a social construct and the broader social factors that create contexts of HIV risk. It is for these reasons that we believe it is important to include the HIV research priorities of trans people in this statement due, in part, to the gendered aspects of HIV risk. The recommendations in this document are also seen as crucial elements in a strategic and coordinated approach to HIV and AIDS research in Canada as it impacts the lives of diverse populations of women, trans people and girls. Of particular note is the need to ensure that future HIV research addresses the factors that impact on how the research is undertaken, the types of HIV research funded, as well as the ways in which research findings are utilized.

## Section 2: Background

The number of women living with HIV in Canada has been increasing since the mid eighties (Blueprint for Action on Women and Girls and HIV/AIDS, 2012; Public Health Agency of Canada, 2012a). In 2012, the Public Health Agency of Canada (PHAC) reported that the number of women living with HIV had increased by 12.6% between 2008 and 2011, and that women accounted for 23.3% of all cases of HIV in the country. HIV infections among particular segments of the Canadian population have varied over time but are consistently overrepresented among Aboriginal women, African, Caribbean and Black women, women who inject drugs, women between the ages of 15 and 29 and trans people (Blueprint, 2012, Public Health Agency of Canada, 2012a). Many of these individuals experience overlapping inequities such as social stigma, low socioeconomic status, housing and food insecurity, and domestic and sexual violence. These inequities and related determinants of health have been shown to increase HIV risk contexts and limit the ability to access prevention, testing, treatment, care and support services (Martin Spigelman Research Associates, 2002; Public Health Agency of Canada, 2012b).

Despite the significant advances made in HIV treatment in Canada, it remains that many who are at the greatest risk of HIV infection are least able to protect themselves from infection or access prevention, testing, treatment, care and support services. Addressing these structural inequities has been prioritized by international and national HIV and AIDS advocacy organizations. These organizations have suggested that HIV responses targeted at women, trans people and girls would be most effective if based on evidence and tailored to the specific contexts in which they live (UNAIDS, 2010). Despite this, the existing knowledge base is insufficient to fully understand the lived experiences of women, trans people and girls with HIV, the factors that contribute to HIV risk contexts or prevent access to prevention, testing, treatment, care and support services, and the ways in which biological and gender-based differences between men and women influence the progression of HIV, including the effectiveness of antiretroviral treatment (Canadian AIDS Society, ND; UNAIDS, 2010). Future research must therefore address these and related knowledge gaps in order to accelerate our response to the issues faced by women, trans people and girls in relation to HIV and AIDS in Canada.



## Section 3: Canadian research priorities

This document outlines a number of recommendations intended to forward a national HIV research agenda focused on the unique needs and realities of women, trans people and girls. These recommendations are offered to help guide the planning and implementation of HIV and AIDS research, policy and programming in Canada. In order to promote the compatibility between Canadian and international HIV and AIDS research, these recommendations are based on a research agenda outlined by the International AIDS Society (IAS) in 2010. Although informed by the recommendations put forth by the IAS, the following were altered in order to address the specific needs of women, trans people and girls living in Canada, and to reflect the nature of the social, political and economic climate of this country. In an effort to blend the IAS recommendations with current HIV and AIDS research in Canada, this document synthesizes the categories used by the IAS with those used by the Canadian Institutes of Health Research (CIHR, 2012) and the Canadian Association for HIV Research (CAHR, ND). The overlap between these research categories is summarized below in Table 1.

Broadly speaking, the IAS's 'clinical research' category encompasses research related to the biomedical aspects of HIV, its progression, treatment and biological consequences of treatment (IAS, 2010). 'Operations research' encompasses research related to the provision of treatment and support services to women, trans people and girls living with HIV (IAS, 2010). The following recommendations are organized according to the IAS categories, and sub-divided to reflect the research themes of CAHR.

**TABLE 1**

Overlap between CIHR, CAHR and IAS research categories

CIHR research themes (2012)	CAHR research themes (ND)	IAS recommendation category (2010)
<ul style="list-style-type: none"> <li>• Biomedical</li> <li>• Clinical</li> </ul>	<ul style="list-style-type: none"> <li>• Basic science</li> <li>• Clinical science</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical research</li> </ul>
<ul style="list-style-type: none"> <li>• Health services</li> <li>• Social, cultural, environmental and population health research</li> </ul>	<ul style="list-style-type: none"> <li>• Epidemiology &amp; public health</li> <li>• Social science</li> </ul>	<ul style="list-style-type: none"> <li>• Operations research</li> </ul>



## Section 4: Recommendations for HIV research with, by and for women, trans people and girls in Canada

### **4A: OVERARCHING RECOMMENDATIONS TO PROMOTE HIV RESEARCH WITH, BY AND FOR WOMEN, TRANS PEOPLE AND GIRLS**

These recommendations apply to all categories of HIV and AIDS research, and are intended to foster research that addresses existing knowledge gaps and to further advance the unique needs of diverse populations of women, trans people and girls living with HIV, and to improve the effectiveness of HIV prevention initiatives.

#### ***Recommendation 1:***

Augment and conduct multidisciplinary HIV research that adopts the MIWA and GIPA principles (see glossary of terms) (NGO Code of Good Practice & International Community of Women Living with HIV/AIDS, 2009; UNAIDS, 2012) by ensuring the meaningful involvement of women, trans people and girls' as leaders and partners in research rather than only as subjects, and ensure active inclusion in all stages of the research process. This must be done in a flexible manner that accounts for competing needs, including time, childcare and proper compensation (e.g., monetary, authorship, data access).

#### ***Recommendation 2:***

Encourage culturally and socially sensitive and inclusive research by establishing ethics review committees that include HIV positive women, trans people and girls from a diverse range of cultural, racial, gender expression, sexuality and economic backgrounds.

#### ***Recommendation 3:***

Provide targeted funding at the federal and provincial levels in order to support novel HIV research that focuses on women, trans people and girls, including the most affected populations (See Public Health Agency of Canada Surveillance Report, 2012a for more details).

#### ***Recommendation 4:***

When HIV research is conducted with both male and female participants, ensure that researchers, where possible, report sex-disaggregated data and highlight significant gender differences between men, women and trans people.

#### ***Recommendation 5:***

Researchers, funding agencies and policy makers should place increased emphasis on mobilizing the results of population specific HIV research from all research categories to support the development of policies and programs that meet the needs of women, trans people and girls and recognize them as active agents in this regard.

#### 4B: CLINICAL RESEARCH: TREATMENT FOR WOMEN, TRANS PEOPLE AND GIRLS

##### Basic

###### **Recommendation 6:**

Conduct clinical research that examines the ways in which biological differences influence the progression of HIV, including the effectiveness and side effects of antiretroviral treatments for women, trans people and girls.

##### Clinical

###### **Recommendation 7:**

Review existing clinical data and conduct novel studies to determine the ways in which clinical HIV treatment programs can be adapted to better meet the needs of women, trans people and girls, particularly those from the most affected populations.

###### **Recommendation 8:**

Initiate novel studies to identify interactions between hormone replacement therapies, hormonal contraceptives, and HIV and antiretroviral drugs in order to provide women, trans people and girls with safe and effective care.

###### **Recommendation 9:**

Ensure that Canadian physicians, including physicians working in family practice clinics or rural and remote areas, are kept informed of developments in HIV research related to sex and gender differences in infection and treatment, and use this knowledge to minimize negative side effects and increase adherence to treatment regimens.

#### 4C: CLINICAL RESEARCH: VERTICAL TRANSMISSION AND ADDRESSING PEDIATRIC TREATMENT

##### Basic

###### **Recommendation 10:**

Re-examine existing research and conduct additional research to examine the ways in which HIV treatments affect pregnant women and the developing fetus.

##### Clinical

###### **Recommendation 11:**

Conduct additional research to determine the long-term effects of antiretroviral drugs on fetal development, and to determine optimal dosages for pregnant women and infants.

###### **Recommendation 12:**

Encourage pharmaceutical companies to develop and distribute antiretroviral drugs in formats and dosages appropriate for use by pregnant women, infants and young children.

###### **Recommendation 13:**

Conduct longitudinal studies to determine the effects of lifelong antiretroviral treatment for children born with HIV.

#### 4D: OPERATIONS RESEARCH: TREATMENT FOR WOMEN, TRANS PEOPLE AND GIRLS

##### Social Science

###### **Recommendation 14:**

Conduct research that examines the lived experiences of positive women and trans people as they age and enter short- or long-term care facilities.

###### **Recommendation 15:**

Review existing data and conduct novel research that examines the lived experiences of women, trans people and girls living with HIV. Emphasis should be placed on examining the social factors that increase women's, trans people's and girls' risk of contracting HIV and limit their ability to access screening and treatment, and in a manner that accounts for women's, trans women's and girls' complex environments, roles and relationships.

###### **Recommendation 16:**

Conduct novel research that examines the lived experiences of women, trans people and girls from communities most affected by HIV. Emphasis should be placed on examining the social factors that increase women's, trans people's and girls' risk of contracting HIV or limit their ability to access screening and treatment.

#### 4E: EPIDEMIOLOGY & PUBLIC HEALTH

###### **Recommendation 17:**

Conduct research to determine the ways in which the criminalization of non-disclosure and incarceration policies may compound the risks faced by women, trans people and girls in terms of testing uptake rates, exposure to infection, ability to disclose, exposure to violence, stigma and discrimination, and ability to access treatment and other services and supports.

###### **Recommendation 18:**

Examine the viability and implementation of different methods of HIV counseling and testing for women, trans people and girls (Opt in/opt out; Nominal/non-nominal/anonymously; point of care, etc.) and compare their potential risks and benefits while recognizing the importance of both pre- and post-test counseling and informed consent to testing.

###### **Recommendation 19:**

Establish short- and long-term studies of provincial and community-level health care systems in order to identify shortcomings in the provision of sexual health care services, and devise strategies to extend these services to women, trans people and girls living with HIV. Targeted studies should focus on ensuring that these services meet the diverse needs of HIV-positive women, trans people and girls from the most affected populations.

###### **Recommendation 20:**

Ensure that HIV research reflects changes in Canadian demographic trends. For example, conduct research that examines the different experiences of women and trans people and girls who have been living with HIV for many years, and those who have received a recent diagnosis.

**Recommendation 21:**

Encourage surveillance studies to understand the prevalence of HIV infection among trans people, insofar as it is possible to do so in a manner that is respectful of autonomy and privacy.

#### **4F: OPERATIONS RESEARCH: TREATMENT AND SUPPORT FOR WOMEN AND TRANS PEOPLE WITH DEPENDENT CHILDREN**

##### **Social Science**

**Recommendation 22:**

Conduct novel research to examine the unique treatment barriers and stigma experienced by women and trans people who are living with HIV and raising children.

##### **Epidemiology & Public Health**

**Recommendation 23:**

Establish short and long-term studies to determine optimal means of providing women and trans people raising children with additional support, such as childcare and access to pediatric services.

**Recommendation 24:**

Ensure that studies aimed at improving the provision of treatment and support services to women, trans people and children living with HIV account for the diverse needs of those from the most affected communities.

#### **4G: PREVENTION RESEARCH: NEW AND EMERGING PREVENTION STRATEGIES WITH, FOR AND BY WOMEN, TRANS PEOPLE AND GIRLS**

##### **Basic Science**

**Recommendation 25:**

Conduct research to examine the compartmental pharmacokinetics and pharmacodynamics of ARVs in vaginal and cervical tissues, and develop appropriate in vitro assays and animal models of the vaginal ecology.

**Recommendation 26:**

Conduct research to understand the physiological vulnerability of the mucosal tissues in the female reproductive tract throughout the reproductive life cycle (including cervical ectopy during adolescence, hormonal changes during pregnancy, vaginal tissue thinning during menstruation, and vaginal atrophy during menopause).

##### **Clinical Science**

**Recommendation 27:**

Conduct research to understand the interactions between hormonal contraceptives, hormone replacement therapy and ARV-based methods of prevention (e.g., PrEP and microbicides).

**Recommendation 28:**

Support and conduct research to test the safety and efficacy of biomedical approaches to HIV prevention, such as microbicides, PrEP, cervical barriers and vaccines.

***Recommendation 29:***

Support and conduct research on women's vaginal and anal practices (e.g., douching, lubrication) and their effects on HIV transmission and infection.

**Operations Research**

***Recommendation 30:***

Support and conduct research to understand the barriers to adherence faced by women, trans people and girls with respect to regimens for PrEP and microbicides.

**Social Science**

***Recommendation 31:***

Support and conduct research to examine the impact of emerging biomedical prevention strategies (e.g. treatment as prevention, pre-exposure prophylaxis) on diverse populations of women, trans people and girls to understand which populations are accessing and/or benefiting from new prevention technologies, including PrEP and microbicides, and in what ways.

## Section 5: Conclusion

Underlying these recommendations is a concern for the general well-being of Canadian women, trans people and girls living with and/or at risk for HIV, and a desire to preserve and promote their inherent right to health. Advancing these goals will not be possible without the collaboration of researchers across multiple disciplines, public officials, and members of formal and informal community groups, including women, trans people and girls living with HIV and AIDS. This document therefore provides a starting point for future research, and offers some key recommendations of the work that must be done to ensure that all Canadians have the highest attainable health. To achieve the recommendations identified in this document, it is imperative that, at the very least, we recognize and address the structural drivers of HIV infection while at the same time valuing the contributions of women, trans people and girls in all aspects of HIV and AIDS research in Canada.



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