

**HIV/AIDS PREVENTION FOR WOMEN AT RISK:  
AN EVALUATION OF THE ONTARIO POLICY TOWARDS AFRICAN AND CARIBBEAN MIGRANT  
WOMEN**

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## **ABSTRACT**

In Ontario, African, Caribbean and Black (ACB) migrants comprise 3.9% of the total population, yet account for 18% of the population who is HIV-positive. Women of this population are affected at an even higher rate, where they represent approximately 63% of the ACB population with HIV and over 50% of HIV-positive women in the province. In order to explore this phenomenon, I conduct a policy evaluation and review specific programs geared towards HIV-positive ACB women.

I use the Population Health Approach as the theoretical framework to support the policy evaluation and to explore the underlying barriers that ACB women face in terms of their sexual health. This approach reflects how social determinants, such as economic and environmental factors, can contribute to health outcomes. Using this approach, I first review the related policies and programs from the federal, provincial and municipal governments and non-governmental agencies. I then conduct a series of four elite interviews with participants working for various organizations that address HIV in the ACB community. Finally, I analyze the results of the interviews and these results reflect findings in the literature.

I explore the most frequently stated barriers for ACB women and they are as follows; there are issues with the immigration system in how HIV can be perceived to affect one's immigration status; there is often a power imbalance between men and women in this community that makes it difficult for women to negotiate safer sex practices - and this is exacerbated by the lack of financial freedom and increased economic dependence experienced by ACB women; as well as social factors such as stigma towards HIV in the community, and the lack of awareness about the general prevalence of HIV in Canada.

The results of this evaluation led me to offering three recommendations aimed at improving the sexual health of ACB migrant women. My first recommendation is to increase collaboration between government sectors, non-governmental organizations and social service providers to address the many competing needs of ACB migrant women. Second, programs and policies cannot solely be geared at women, as there many external factors that are beyond their control that influence their health and well-being. Programs addressing men and youth will address these external barriers, because without a supportive and healthy male population, the women will continue to encounter complicated social restrictions. Finally, HIV stigma needs to be addressed, not only within the ACB community, but in society at large. HIV messaging needs be more visible, as does culturally specific messaging surrounding HIV/AIDS. HIV programs need to be implemented to adequately reach the specific ACB population. Only then, with the valuable input of HIV-positive ACB women, will effective policies and prevention programs work together in a sufficient way to reverse the trend of ACB women being over-represented with HIV/AIDS.

## 1 INTRODUCTION

In Canada, there is a specific population experiencing disproportionately high rates of both new and existing cases of HIV/AIDS infection - namely African, Caribbean and Black (ACB) migrant communities. These communities are situated in a number of western industrialized countries and suffer from unusually high rates of HIV and AIDS within the Diaspora populations (Interagency Coalition on AIDS and Development, ICAD, 2012). Between 2001-2006, approximately 7.9% of the new migrants in Canada were from countries where HIV is endemic (PHAC, 2009). The ACB population are considered migrants from countries where HIV is endemic (See Appendix 1). Research has shown that this population is more vulnerable to contracting HIV than the local population in their new countries of settlement (ICAD, 2012). HIV-endemic countries are generally defined as countries that have an adult prevalence (ages 15-49) of HIV that is 1.0% or greater and has one of the following: 50% or more of HIV cases attributed to heterosexual transmission, a male-female ratio of 2:1 or less among prevalent infections, or HIV prevalence greater than or equal to 2% among women receiving prenatal care (PHAC, 2009). ACB women are increasingly over-represented with new and existing cases of HIV/AIDS in Ontario compared to ACB men as well as compared to other female populations.

The purpose of this paper is to conduct a policy evaluation of the current policy actions implemented in Ontario regarding the prevention of HIV/AIDS transmission to ACB women who are over-represented with HIV/AIDS in Ontario. I evaluate the policy actions implemented by both public and private organizations for women from ACB communities and the planned responses to address the issue. A policy evaluation is oft-needed where there are many players, an intense need for collaboration, and it is a 'newly' discovered issue with little updated information

collected about the whole picture on a year to year basis (Tieleman & Leroy, 2003). The issue of ACB women being disproportionately affected by HIV/AIDS in Ontario meets all the aforementioned criteria, and thus a scan of the environment to explore the current policy regarding ACB women and HIV/AIDS is warranted. I set out to examine the policy actions and programs adopted by public and private organizations in order address this demographic at higher risk of becoming infected with HIV.

In Chapter Two, I first examine the situation of HIV/AIDS in general terms, followed by a deeper review of more vulnerable populations, and then describe the ACB community with a particular focus on women. In this section, I set out the Population Health Framework under which I conduct this evaluation. The proceeding section sets up the body of the evaluation. Interviews were conducted with four members of organizations who work directly with the ACB population in Ontario. In chapter three, I analyze the qualitative data based on themes in conjunction with themes found in the literature.

Chapter Three begins with a description of the methodology. I then describe the policies, strategies and programs available to ACB women (if any) from the federal, provincial, and municipal governments as well as those available from non-governmental organizations and other agencies dedicated to HIV/AIDS in the ACB population in Ontario.

Chapter Four investigates the socio-economic and political factors that lend to increasing women's vulnerability to HIV. This was necessary as I believe that HIV programming needs to work in the much broader social context, one that addresses the determinants of health, and that systemic issues and policies must be rooted in the day to day reality of service and program delivery.

Chapter Five offers a series of policy recommendations aimed at improving the policy outputs to increase public knowledge and enhance inter-organizational collaboration in addressing the problem, reducing stigma surrounding HIV/AIDS specific to ACB women, and that will target issues that put these women specifically at risk by involving youth and men into the solution. The intentions of this review and analysis are to positively compliment existing literature and initiatives aimed at explaining and reducing the insurances of ACB women being affected with HIV/AIDS upon migration to Ontario. It is hoped that by having a clearer understanding of how such determinants affect ACB women, this will enable health policy to better target specific influences.

## **2 THE GENDERED CONSEQUENCES OF THE HIV/AIDS PANDEMIC**

As HIV/AIDS research has diversified, so too has the recognition of the wider range of health and social issues associated with the infection. There are five high risk populations in terms of HIV prevalence in Canada, including women and the ACB population. Women are not only physiologically more susceptible to HIV; they also face many additional barriers that lead to health inequalities. Migrant women represent an increasing proportion of people living with HIV/AIDS in Ontario, in part due to social and institutional barriers, along with added barriers to the healthcare system. Migrant ACB women are a highly marginalized group in society and are over-represented with HIV/AIDS in Ontario compared to ACB men and all other categories of women. The socioeconomic barriers will consequently be explored using the Population Health Approach, as explained in the following chapter.

### **2.1 THE EVOLUTION OF THE HIV/AIDS PANDEMIC AND ITS IMPACT ON WOMEN**

The mitigation of crises of communicable and endemic diseases remains an ever-present agenda item of the international community. Over the past 25 years, human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) have become one of the most prevalent endemics of this generation. HIV is transmitted from one person to another by transmission through the bloodstream and other bodily fluids (Public Health Agency of Canada, PHAC, 2008). When the body can no longer fight the HIV infection, the disease becomes known as AIDS. It can take on average 10 years to progress from HIV infection to AIDS. While the infection is largely preventable, there are an alarming number of new infections reported each year, both globally and locally. In Canada alone, thousands of new infections occur annually and the number of people living with HIV in Canada is rising (PHAC, 2008). The government of Canada has stated that it is committed to addressing HIV/AIDS, but further research is needed to assess who is most affected by the infection here in Canada, and why this is occurring.

#### **CORE ASPECTS OF THE HIV/AIDS PANDEMIC**

Historically, HIV/AIDS was commonly stereotyped as a disease unique to drug users and homosexuals. When the condition first appeared in Canada in the early 1980s, the infection was mostly seen among the gay male population and people affected through the blood supply (Federal Initiative, 2004). By 1990, the Canadian federal government recognized the need for a more formal and interconnected approach to HIV/AIDS that would eventually further broaden and deepen the Canadian response. The epidemic was an important health and social problem that had an impact on a much wider range of people than originally suspected. It then became apparent that many individuals were influenced by social, economic, political and biological factors that affected their health and susceptibility to acquiring HIV.

The federal and provincial governments have identified the current status of the face of HIV in Canada and Ontario. As a result, it has been categorized by groups with a higher prevalence and risk of HIV/AIDS as follows: Men who have sex with men, injection drug users, Aboriginal people, people coming from countries where HIV is endemic and women (Ministry of Health and Long-Term Care: AIDS Bureau, HIV/AIDS in Ontario, 2008). Women are represented in all of the aforementioned populations or may engage in high risk behaviour with members of each category. I will explore some of the factors that increase the consequences and their risks for women of becoming affected with HIV/AIDS.

### **WOMEN REPRESENTING AN INCREASING PROPORTION OF THE HIV POSITIVE POPULATION**

HIV transmission is linked to intimate contact involving shared bodily fluids. Heterosexual transmission of the virus now accounts for the majority of new HIV infections worldwide, and transmission is most efficient via anal sex and from male to female during vaginal intercourse (Marlink & Kotin, 2004). For the purposes of this paper, HIV/AIDS transmitted via heterosexual behaviour is the reproductive health issue that is considered. While prevalence continues to be higher among men than women, women have constituted an increasing proportion of the HIV-positive population over time (Bayoumi *et al.*, 2011). Physiologically speaking, women are at a higher risk of contracting HIV, in part because of the much larger surface area of the vagina and cervix, although every woman has a different level of biological risk. The vagina is particularly vulnerable to invasion of bacteria, viruses and other germs as it is a warm and moist place ideal for bacteria to grow, and because women are exposed to considerable amounts of seminal fluid during sex (Sheth & Thorndycraft, 2009). Other factors that make women more susceptible to the infection are: the general health of her genital tract, her age, hormones, the maturity of her cervix and pregnancy. In general, women are more likely than men to contract

HIV/AIDS during a single exposure. Younger women are at an even higher risk because they are physiologically less mature (ICAD, 2012). Whilst women are at a physiological disadvantage for contracting HIV, there are additional inequalities that women face that may increase their likelihood of becoming HIV positive.

## **HEALTH INEQUALITIES**

Health inequalities are considered to be potentially avoidable differences in health (or in health risks that policy can influence) between groups of people who are more and less advantaged socially (Braveman, 2006). These differences systematically place socially disadvantaged groups at further disadvantage in health compared to other more advantaged groups. The most common groups referred to as disadvantaged, and who experience discrimination and health inequalities, are the poor, ethnic minorities, and females. For the purpose of this evaluation, I will be referring to the Population Health Approach to review the policy regarding health inequalities. This approach is also known as the Determinants of Health Approach (PHAC, Population Health Approach, 2012).

The Population Health Approach is a unifying force for the entire spectrum of health system interventions - from prevention and promotion to health protection, diagnosis, treatment and care - and integrates and balances action between them (PHAC, Population Health Approach, 2012). Population health refers to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services. As an evaluation approach, population health focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systematic variations in their patterns of occurrence, and applies the resulting knowledge to develop and imple-

ment policies and actions to improve the health and well-being of those populations (PHAC, 2012). Using this model, I will explore the many factors that attribute the increased prevalence of HIV/AIDS in the ACB migrant community.

## **2.2 THE WOMEN AT HIGHER RISK: MIGRANT WOMEN**

Migration can be defined as the movement of people from one geographical space to another (Sergent & Larchanche, 2011). For the purposes of this evaluation, I will use the term migrants to include all types of migration including refugees, immigrants, temporary workers, and foreign students. Studies of migrant health reveal the importance of social, economic and political production of distress and disease as well as the structures and dynamics that produce particular patterns of access to health services (Sergent & Larchanche, 2011). Increased research in this shifting phenomenon is necessary in order to influence health policy and effectively address health inequalities.

### **SOCIAL, CULTURAL, AND INSTITUTIONAL BARRIERS**

Migrants and refugees represent an increasing proportion of people living with HIV in Canada (Li, 2012). Migrant women face social and cultural barriers that increase susceptibility to HIV. These barriers are, but are not limited to, language barriers, lack of information, cultural beliefs related to sexuality and HIV/AIDS, and stigma. In society, important goods such as education, wealth, jobs and housing are unequally distributed across subgroups that differ by race, ethnicity, gender and class (ICAD, 2012). Migrant women often encompass all of these subgroups, in addition to their unfamiliarity with a new country and health norms. These social and economic inequalities can produce health inequalities. The complex mechanisms underpinning these communities need to be better understood in order to fully address these women and simul-

taneously prevent this cycle from continuing. Only then will there be sufficient advancement in this community. These barriers are part of the problem and have negative implications for women and for Canada's economic priorities pertaining to its immigration policies. It remains important to have a healthy migrant population for the Canadian economy. Reducing the prevalence of transmittable infections is in Canada's interest for the entire population.

Migrant women have more barriers to access and less familiarity of the Canadian health-care system than do Canadian women. Health policies for migrants are centered on determinations of who should be excluded from admission into Canada and not enough attention is paid to longer-term health issues (Health Canada, 2010). There is even less attention focused on smaller groups of migrants. Women's health issues are under-researched and especially lack focus on high-risk minority groups (Health Canada, 2010). A clearer understanding of immigration policy and migrant healthcare is necessary to develop policies that adequately address HIV transmission to migrant women from ACB communities.

### **2.3 THE SITUATION IN ONTARIO: THE SUB-SAHARAN AFRICA AND THE CARIBBEAN COMMUNITIES**

There is a wide variation of communities in Ontario of people from countries where HIV is endemic which are uniquely diverse with multiple identities reflecting diverse historical backgrounds, language and cultural traditions rooted in religion, culture, sexuality, class, ethnicity, gender, migratory status (ACCHO, The Strategy, 2012 & PHAC, 2009). Unfortunately, these communities are disproportionately affected by many social, economic, and behavioural factors that not only increase their vulnerability to HIV infection, but also act as barriers to accessing prevention, screening and treatment programs (PHAC, 2009). Migrant women from HIV-endemic regions are an increasingly marginalized category of women in our society, as well as in

their community, when compared to men from HIV-endemic regions<sup>1</sup>. They have characteristics of all the most marginalized groups: women, racial minority, and are affected by many of the key social determinants of health. This, in part, can be due to difficulties associated with the migration process such as lower income and access to services for housing, employment, and education.

## **THE VULNERABLE POSITION OF ACB WOMEN**

There is an imbalance in the frequency of HIV/AIDS infection, both in existing and new cases, for ACB women in Ontario. It is important to address these inequalities in order to keep people functioning normally by meeting their health needs. By keeping people functioning normally, we can protect their range of opportunities (Daniels, 2008). In order to address this, factors that influence the increased transmission of HIV/AIDS among ACB women must be explored.

The migrant population in Canada most affected by HIV/AIDS consists of people who originate primarily from Sub-Saharan Africa and the Caribbean where HIV/AIDS is endemic (Health Canada, 2010). Specifically, almost two thirds (60.4%) of Canada's ACB population in Canada lives in Ontario (ACCHO, 2012). These communities have seen significant increases in HIV/AIDS in recent years, with statistics indicating that the ACB population is disproportionately affected with HIV/AIDS in Ontario. From 1996 to 2008, the number of new HIV infections increased by 124% among Ontarians from African and Caribbean countries (PHAC, 2009). They compromise only 3.9% of the total population yet represent 18% of the population infected with

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<sup>1</sup> African and Caribbean women are a diverse group within diverse communities, and this evaluation is not assuming this is a homogenous community of women. Although I do not state such differences throughout this paper, ACB women are differentiated by their country of origin, religion and culture, HIV status, and immigration process (refugee, immigrant, resident, generational, etc.) and not all ACB women are at higher risk of HIV infection than the average population on women. Although not all ACB women are at higher risk of HIV transmission, there has been an increasing trend of HIV infection among women of these communities in Ontario.

HIV and 29% of new HIV diagnoses (PHAC, 2010). It is estimated that among people from the ACB community, 60% of new HIV infections are acquired post migration to Canada (Shimeles, Husband, Tharao, Adrien, & Pierre-Pierre, 2011).

In global terms, gender is also an issue and HIV/AIDS has been considered a women's epidemic; this is apparent in the ACB female population in Ontario (ICAD, 2012). Women in ACB communities are affected with HIV/AIDS at higher levels than those in the general population. In 2005, females from HIV-endemic countries accounted for a substantial proportion of newly diagnosed HIV infections among all Ontarian women (50.8%), and represented 63.9% of all new cases compared to men in similar ACB communities (PHAC, 2009). Given the relatively small size of the ACB population in Ontario, there are a disproportionately high percentage of women affected with HIV/AIDS. There is insufficient data collected in this area of research that may be causing barriers for HIV positive migrant women who need access to ethno-specific services (Jimenez, 2004, as cited in Karago-Odongo, 2008). There has been limited research on migrant health in terms of reproductive rights and culture (Sergent & Larchanche, 2011).

### **3 POLICY EVALUATION OF THE ONTARIO HIV/AIDS POLICY**

This chapter assesses the landscape of the policy actions adopted to prevent HIV/AIDS contamination within the ACB community. As much as possible I explore the policy and programming geared towards ACB women, but there is not always a gender distinction in the policy or programming. There is policy geared towards women, and policy for the ACB population, but only a few initiatives are targeted towards ACB women being affected with HIV. To better understand what certain HIV/AIDS organizations were doing in support of ACB women, I conducted interviews to gather qualitative data to obtain more information than was available from

supporting literature. In doing so, I was also thereby able to get the opinions of professionals surrounding the issue from the perspective of their associated organization and expert opinion.

In this chapter I first describe the methodology used to gather the qualitative data. Based on information provided by the participants, as well as public data provided by the organization, I describe the HIV/AIDS policies and initiatives put forth by federal, provincial and municipal government, as well as non-governmental organizations. Where applicable, I only describe policies for ACB women, but as not all organizations focus specifically on this population, I also analyze ACB policy and policy for women in general. This analysis outlines the collaboration that takes place between different governments and organizations, from shared initiatives to funding of support of community-based programming and research.

### **3.1 METHOD OF ANALYSIS**

The purpose of this study was to gather first hand information as to what the various organizations, and the people within those organizations, are doing in regards to ACB women affected with HIV/AIDS. In particular, I wanted to understand the collaboration of these organizations with different levels of government and other ACB support systems in order to evaluate the current state of policy surrounding this subject matter. This study is a qualitative body of research in which I used an interviewing approach to get a firsthand account of the activities of their organization and of their professional opinion on the potential social and political hindrances that lie beneath the disproportionate number of ACB women affected with HIV/AIDS in Ontario.

## **PARTICIPANTS**

After having received ethical approval from the University of Ottawa (see Appendix 2), I began recruiting participants. Four professionals working with the ACB community participated in this study. There were three females and one male. I contacted each participant via telephone or e-mail to request their participation. The only criterion necessary to participate in this study was that they were still working with the ACB community in Ontario. For confidentiality purposes, participants were numbered (P 1-4) consistently through the results of this study.

Participants who were involved in this study freely volunteered to give me additional information about their work within the ACB community, and specifically with the women in this community in Ontario. I chose the participants based on the nature of the HIV/AIDS organizations that they worked for, and only if there was support or programming for the ACB community being provided in that organization. Participants were chosen from representative urban areas in Ontario<sup>2</sup>. Two of the professionals were from Ottawa, and two were from Toronto.

## **MATERIALS**

The materials used for this study was a voice recorder and an outline of five questions with added probing questions (see Appendix 3). I asked questions about how the participant viewed the issue. The emphasis in the interview was on what they or their organization understood to be the best possible policy recommendations to continuously improve the sexual health and safety of ACB women. I placed an emphasis on the process they are going through when supporting and engaging these women. The participant did not have to complete any forms, other than an informed consent (see Appendix 4), and this was done orally and in writing. We sat to-

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<sup>2</sup> It should be noted that there are still many unexplored stakeholders working with the ACB community that I was not able to define in this paper, specifically at the municipal level and community level.

gether or communicated via Skype and had an open-ended conversation about their work with women in Ontario from HIV-endemic regions of the world. Following the interview, the participants were thanked and offered a copy of this Major Research Paper upon its completion.

## **PROCEDURE**

I wanted to understand more about why ACB women are disproportionately represented with HIV/AIDS in Ontario. I had already researched the issue and read available literature as to what government and ACB specific organizations had written about ACB women affected with HIV/AIDS, so I was especially interested in understanding how the individual organizations viewed the issue and how various organizations were collaborating to strengthen resources for ACB women.

I conducted a series of elite interviews. In an elite interview, as defined by Leech (2002), the investigator is willing and often eager to let the interviewee teach him what the problem is, the question, and what the situation is. They can explain how they see the situation and what the problem is as they view the matter instead of just accepting the assumptions. As my purpose for these interviews was to gather information about this topic from professionals who work with the ACB community, open-ended elite interviews was an appropriate choice for this study.

Each participant was asked to respond to five open-ended questions. They were then asked to elaborate on certain points, as required, throughout the interview. After each question I probed to get them to explain as much as possible about their experiences, and if they mentioned something interesting that was not on the questions list, I also asked them to elaborate. The purpose of these questions was to have the participants describe, in their own words, the process and experience that ACB women faced that render them at higher risk of HIV infection. I recorded

the interviews to remain accurate, and then transcribed the interviews into text format for analysis.

I analyzed the interview transcripts by taking a grounded-theory approach to the data (Glaser & Strauss, 1967). My focus was on clearly understanding the “lived” experience of working with ACB women affected with HIV/AIDS in Ontario and what their view was as to the factors were that helped determine their health. To draw observations from the interview notes, I then extracted common themes from the data based on the participants’ responses to the interview questions. The results of my analysis of the interviews were then organized by theme. The results are presented below.

### **3.2 THE FEDERAL CONTEXT AND IMMIGRATION POLICY**

Canadian health policy has shifted to a population health framework that is increasingly focused on the social determinants of health. This has encouraged relationships between the sectors, communities and groups and has facilitated collaboration in the fight of HIV/AIDS, particularly in high risk populations such as the ACB community in Ontario. The following sections will examine the policy and efforts put in by the various actors targeting HIV/AIDS in the ACB community, focusing on women where they are specifically the target of certain policies and initiatives. The sectors must work together as federal, provincial and regional and local public health authorities have a substantial role in addressing the epidemic.

#### **PUBLIC HEALTH AGENCY OF CANADA**

The Public Health Agency of Canada (PHAC) is responsible for the *Federal Initiative to Address HIV/AIDS in Canada*, in partnership with Health Canada, the Canadian Institute of

Health Research, and the Correctional Service of Canada (PHAC, 2012, Federal Initiative). Through this initiative, the Government of Canada monitors the epidemic through its national surveillance system; develops policies, guidelines and programs; and supports voluntary sectors in response to HIV/AIDS in communities across the country. Voluntary sectors are comprised of national HIV/AIDS organizations, AIDS service organizations (ASOs) and community-based organizations. Among many things, PHAC is also responsible for national and regional programs, policy development, surveillance, and policy advice.

PHAC is developing programs along the prevention-care continuum, with and for people living with HIV/AIDS, men who have sex with men, injection drug users, Aboriginal people, federal inmates, youth and women at risk for HIV and people coming from countries where HIV is endemic (PHAC, 2012, Federal Initiative). Their programs are evidence-based and aligned with the regional characteristics of the epidemic and the specific needs of the vulnerable populations. The government policies are being re-aligned to support innovative approaches to addressing the epidemic, and this is where the collaboration with federal departments and the provinces will increase to funnel funding programs for community-based organizations. There are three directions that guide federal action under the Federal Initiative:

- **Partnership and Engagement:** Locally, nationally and globally it will focus on the determinants of health and increased engagement at all levels and sectors, including people living with HIV/AIDS.
- **Integration:** Many people living with HIV/AIDS are more vulnerable to other communicable infections and this program will be linked to other programs to ensure an integrated approach to program implementation.

- **Accountability:** The federal government will continue to foster mutual accountability among its delivery partners.

In 2009, for the first time, PHAC conducted a population specific HIV/AIDS report on people from countries where HIV is endemic - the ACB population living in Canada. Although this policy evaluation is specific to the ACB population in Canada and not exclusively in Ontario, it must be discussed at the federal level when evaluating federal policy.

The ACB population has been identified in the Federal Initiative as a key population at risk, but there is growing importance of community involvement in the response, as well as more culturally appropriate services from people of different backgrounds (PHAC, 2009). The report included data about age, immigration, socio-economic conditions and gender, among other facets. It was clearly recognized that women are becoming increasingly affected by HIV in Canada. PHAC concluded that cross-sectoral and cross-jurisdictional activities to share best practices, to increase partnerships among a wider range of stakeholders and to better use evidence in the development of strategies and interventions should be fostered and encouraged. Through community programming, PHAC provides support services to all people living with HIV/AIDS and those vulnerable to HIV infection, including people from countries where HIV is endemic. Among other areas of funding, PHAC funds National Specific Populations HIV/AIDS Initiatives to prevent HIV infection; increase access to appropriate diagnosis, care, treatment, and support; and increase healthy behaviours amongst Canada's populations most affected by HIV/AIDS and most vulnerable to infection.

## **HEALTH CANADA**

Health Canada is in partnership in the *Federal Initiative to Address HIV/AIDS in Canada*. Health Canada is responsible for community-based HIV/AIDS education, prevention, and related

services for certain populations, specifically Aboriginal communities (Health Canada, 2011). The department, in partnership with the Public Health Agency of Canada, is also responsible for coordinating global engagement activities under the Federal Initiative, as well as program evaluation activities. Beyond working in partnership with PHAC, Health Canada has recognized the ACB population as one of the most vulnerable groups in society and has produced reports and bulletins outlining the issue and the need for more research (Health Canada, 2010). In 2010, Health Canada stated that the priority of the government, concerning ACB migrant women and HIV, is to conduct more research.

#### **CANADIAN INSTITUTE OF HEALTH RESEARCH**

The Canadian Institute of Health Research (CIHR) is the Government of Canada's health research agency and is responsible for setting priorities and administering the Federal Initiative's extramural research program, in partnership with PHAC (CIHR, 2011). Combined with the Canadian HIV Vaccine Initiative, CIHR provides \$22.5 million annually to support researchers through various funding streams - specifically community-based, population-specific (ACB) research. CIHR has many initiatives that target specific HIV/AIDS vulnerable populations but it is worth noting their research pertaining to the resilience, vulnerability and determinants of health. CIHR recognizes that HIV infection varies greatly in different populations in Canada and they find it critical to effectively address the epidemic to have a better understanding as to why there is so much variation (CIHR, 2007). They recognize that determinants of health can have a major impact on the health and well-being of individuals and communities, including their vulnerability to HIV. Stigma and discrimination towards people living with HIV, as well as vulnerable populations, also drive the epidemic and CIHR recognizes that increased research could create a better understanding of these issues and effective mechanisms of reducing such conditions (CIHR,

2007). CIHR has identified four key areas of research targeting these conditions, where policy addressing women from the ACB population could benefit from these areas of research:

- The impact of structural, social, cultural and individual determinants of health on transmission and acquisition of HIV and common co-infections, and on quality of life for those infected;
- Effective strategies to decrease vulnerabilities and increase resilience in specific populations;
- How different individuals and communities are affected by and deal with HIV/AIDS; and
- Other factors (e.g., psychological) that result in increased susceptibility to HIV infection in specific populations.

#### **CITIZENSHIP AND IMMIGRATION CANADA**

In 2002, Canada replaced the *Immigration Act, 1976* with the *Immigration and Refugee Protection Act* (IRPA) as the primary federal legislation to regulate immigration to Canada, respecting immigration to Canada and the granting of refugee protection to persons who are displaced, persecuted or in danger (IRPA, 2001). IRPA is the legislation for migrants and refugees, most of which was put in place to support and protect migrants on their journey into Canada. Included in the legislative mandate under IRPA is the need to protect the health and safety of Canadians from risk inherent in the migration of people to Canada. The legislation and regulations have exclusion criteria that render migrants inadmissible. In terms of health status, Section 38.1 (a-c) render foreign nationals inadmissible on health grounds if their health condition is; likely to danger public health, is likely to danger public safety, or might reasonably be expected to cause

excessive demand on health or social services (IRPA, 2001). Data is not made public about cases that are refused on health grounds.

Citizenship and Immigration Canada (CIC) has required a medical exam for all migrants and refugees since 2002. HIV testing has been a mandatory part of the immigration examination for everyone over the age of 15 (Bisaillon, 2011). While HIV does not render you inadmissible to Canada, some HIV/AIDS positive migrants will not be considered for residency if they are expected to place excessive demand on the healthcare system (Karago-Odongo, 2008). Additionally, a second Immigration Medical Examination may be requested once the status of the migrant changes

Immigrants and refugees must have their status confirmed through Citizenship and Immigration in order to apply for permanent residency in Canada and must also pass an Immigration Medical Examination to be able to qualify to apply for health insurance (Ministry of Health and Long-Term Care, 2011). Once residency is granted, migrants must wait a minimum of three months to qualify for health insurance.

CIC offers the Interim Federal Health Program (IFHP) to provide limited, temporary health coverage for specific groups of people in Canada and is a last resort, very limited, health coverage when the beneficiary has no access to provincial or territorial healthcare coverage or private coverage (CIC, 2013).<sup>3</sup> Refugees and protected persons have access to the IFHP that allows them immediate access to healthcare, but immigrants, students and workers are ineligible for this program. They have to pay for their own private insurance if they wish coverage (Ministry of Health and Long-Term Care, 2012). There are some organizations that provide healthcare

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<sup>3</sup> Coverage is limited, it covers visits to hospitals and doctors, as well as very limited coverage for medications, vaccines and services only when required to prevent and treat a disease posing a risk to public health or to treat a condition of public safety concern such as HIV and Tuberculosis.

services to uninsured people via welcome centers and orientation centers, but the resources are scarce.

There is no policy or specifications for the ACB population, nor is there a gender specific policy. CIC does, however, have a policy for gender-based analysis to be an integral part of their mandated work.

### **3.3 HIV/AIDS POLICY AT THE PROVINCIAL LEVEL: THE PROVINCE OF ONTARIO**

In Canada, each province and territory assumes responsibility for the administration and delivery of healthcare services within their jurisdiction. Ontario has a coordinated response to HIV/AIDS that includes both policy development and program delivery. This section will examine the financial and policy contributions provided by the province of Ontario towards HIV/AIDS, and specifically in the ACB community.

#### **MINISTRY OF HEALTH AND LONG-TERM CARE: AIDS BUREAU**

The Ministry of Health and Long-Term Care, AIDS Bureau (AIDS Bureau) plays an active role in the fight against HIV/AIDS in Ontario. The province spends approximately \$60 million a year on HIV/AIDS-related initiatives, not including physician billings to OHIP or HIV/AIDS medications. The Ontario government provides funding for more than 90 programs and services across the province to deliver HIV/AIDS prevention, education and support programs for those infected and affected by HIV/AIDS, and those most at risk of acquiring HIV/AIDS in Ontario (Ministry of Health and Long-Term Care, 2012). Ontario has developed HIV/AIDS prevention strategies for people in the five categories at highest risk of infection, including African and Caribbean Ontarians and women. While many provincial strategies or advisory committees on HIV/AIDS identify people from countries where HIV is endemic or

ethno cultural communities as key populations, Ontario is the only jurisdiction to have developed a population specific strategy for its African and Caribbean Black population. It is notable that within the AIDS Bureau strategies, although not specific to ACB women, it defines the women's strategy as "women who form a part of the above groups or engage in HIV risk activity with them" (Ministry of Health and Long-Term Care, 2012). Following are some initiatives that the AIDS Bureau is currently engaged in:

- Anonymous HIV testing in communities throughout Ontario, including pre and post test counselling that provides information on risk reduction, partner notification and referral;
- A prenatal testing program, geared towards healthcare practitioners, to offer HIV testing to all pregnant women in Ontario; in addition to funding research, and promoting awareness among pregnant women, physicians and HIV test providers;
- Funding for multiple stakeholder agencies to support research in a number of HIV/AIDS related areas;
- Seventeen clinics across Ontario to provide multi-disciplinary care for people living with HIV/AIDS;
- The AIDS and sexual health line to provide anonymous counselling and referrals to community service agents; and
- Hospice programs for people with HIV/AIDS at the end stages of their lives.

Along with several other organizations, the AIDS Bureau also supports the work of the African and Caribbean Council of Ontario by funding a coordinator position to assist in implementing recommendations contained in the *Strategy to Address Issues Related to HIV Faced by People in Ontario from Countries Where HIV/AIDS is Endemic* (see section III.9.ii for details). Additionally, the AIDS Bureau supports a provincial working

group that is addressing increased rates of HIV among women in Ontario. As part of this work, AIDS Bureau supports research into best practices in HIV prevention in women, as well as the development of a strategy to address HIV/AIDS amongst women in Ontario.

### **3.4 HIV/AIDS POLICY AT THE MUNICIPAL LEVEL: OTTAWA AND TORONTO**

Many municipal governments in Ontario are involved in addressing HIV/AIDS in the ACB community in various ways. It is not clear however, whether these the initiatives are solely targeted towards the women of ACB communities.

#### **TORONTO PUBLIC HEALTH**

Toronto Public Health (TPH) is involved in HIV/AIDS initiatives. One way TPH provides support is through funding community organizations that specialize in HIV within specific communities. One such initiative is an ongoing project called "AIDS Prevention Community Investment Program" that was established in 1987. The purpose of this initiative is to support strategic, targeted education programs to influence behaviours and situations that put people at risk of acquiring HIV thereby reducing HIV transmission (TPH, 2012). The objectives of the program are to:

- Decrease behaviours that put people at risk for HIV infection;
- Enhance access to HIV prevention and sexual health promotion messages; and
- Address social and economic factors related to discrimination, poverty, race, sexual orientation, culture, gender, language skills, age, physical or mental ability, and an HIV positive status.

Of the many organizations that TPH provides funding, there are at least six that are geared towards, or in cooperation with, ACB HIV organizations; one of which is targeted spe-

cifically to ACB women. One of TPH's top funding priorities is women and men coming from countries where HIV is endemic (TPH, 2012). TPH reviews epidemiological trends for HIV/AIDS in the city of Toronto annually, and they have found that HIV and AIDS disproportionately affect migrants compared to non-migrants with an increasing proportion having been identified as being from regions where HIV is endemic. In 2011, HIV-endemic was the second highest proportion (22%) of all HIV positive cases, with a highly increasing trend. ACB women represented 76% of all women living with HIV in Ontario (Communicable Diseases in Toronto, 2011.)

TPH also runs free sexual health clinics, facilities that do not require referrals or OHIP coverage. These are busy centers and they do not guarantee they will get to see everyone. A province wide AIDS and Sexual Health Infoline is also available to get current and detailed information and support surrounding HIV, including anonymous counselling in multiple languages.

### **OTTAWA PUBLIC HEALTH**

Ottawa Public Health (OPH) has taken an active role in the ACB community in terms of HIV initiatives. Founded in 2005, OPH created an innovative approach to providing HIV/AIDS prevention education the ACB communities within the city of Ottawa, called "Operation Hairspray" (OPH, 2013). It is a peer-led health promotion initiative which enlists hairdressers and barbers from the ACB population to: increase the community's capacity and awareness to respond to HIV, as well as to increase access to and reduce barriers to health information. Building on the success of "Operation hairspray", OPH partnered with Somerset West Community Health Centre to expand the reach of the project and provided funding for them to hire a prevention worker for the second (implementation) phase.

Ottawa collects epidemiological statistics and has reported that women coming from an HIV-endemic country were the most frequently reported exposure category, at 57% for those reporting being HIV positive in 2010, whereas only 20% of overall reported cases of HIV were from the ACB population (Health Status Report, 2011). OPH runs a Sexual Health Center as well as the AIDS Sexual Health Information Line which is serviced by OPH nurses in both official languages. It also provides a HIV/AIDS referral services to callers from across the province.

### **3.5 NON-GOVERNMENTAL ORGANIZATIONS AND NOT-FOR-PROFIT ORGANIZATION NETWORKS OF ACTION**

It is important to recognize the role of community based expertise to inform immediate action where there is a lack of long-term research studies tracking measurable indicators. There is a significant list of organizations that support ACB women affected by HIV/AIDS throughout the province of Ontario, however the scope of this paper will not include every organization and agency. Included only are the organizations with whom I interviewed someone, or that is a major player in addressing ACB women with HIV/AIDS in Ontario. All the professionals that I interviewed said that they and their organizations had very high levels of coordination between agencies, including at the governmental levels. Additionally, they collaborate as much as possible with other social service providers such as migrant housing support, employment services and other similar agencies.

### **FUNDING AND ORGANIZATIONAL STRUCTURES OF THE ORGANIZATIONS**

Information pertaining to the individual organizations where an interviewed participant is employed was also collected. This data can be seen in Table 1. Three of the participants encouraged my mentioning of the name of their organization as they saw it as promoting visibility of

their agency that would further promote awareness of their work with HIV/AIDS in the ACB community. The other participant requested complete anonymity, including that of her associated organization. In her case, she wished to preserve her confidentiality as well as her clients. The ACB community is considered a communal community and there was a fear of identification of an HIV positive status being revealed. It should be noted that this data is not exhaustive and is an account given by the individual participant.

Table 1. Funding and organizational structure of the agencies that participated in the interview process.

	<b>Community Health Centre</b>	<b>ACO</b>	<b>Black CAP</b>	<b>ACCHO</b>
<b>Funding</b>	Ontario Ministry of Health and Long-Term Care, AIDS Bureau, PHAC, CIC	Ottawa Public Health. Ontario Ministry of Health and Long-Term Care, AIDS Bureau.	Ontario Ministry of Health and Long-Term Care, AIDS Bureau, PHAC, CIC City of Toronto Corporate and community sponsors.	Ontario Ministry of Health and Long-Term Care, AIDS Bureau
<b>Staff/Volunteer Base</b>	Participant is the only staff. 57 volunteers at her organization.	P2 is the only ACB support worker at ACO. Many volunteers at ACO but not that can help with ACB support work due to confidentiality of files.	18-19 Staff. A couple hundred volunteers.	5 staff. Dependent on volunteers.

\*Sources: Data provided by interview participants.

## **AFRICAN AND CARIBBEAN COUNCIL FOR HIV IN ONTARIO (ACCHO)**

ACCHO is a council that works in partnership with many organizations and provides leadership in the response to HIV/AIDS in the ACB communities. P4 stated that ACCHO works with two major frameworks. The first is the anti-racist/anti oppression framework (ARAO), where the organization is to understand that there are systems of oppression that privilege one group but can also oppress another. This works in regards to race, ethnicity, nationality, gender and so forth. The second is a framework of the social determinants of health. Health is greatly affected by factors outside the individual, systemic issues and structural factors, political, economical, social or cultural factors.

The council is made up of researchers, policy makers, service providers and community members from all across Ontario. There are 19 members on the council varying from community organizations, municipal, provincial and federal governments, and community members. Their primary role is to coordinate and support the "Strategy to Address Issues Related to HIV Faced by People in Ontario from Countries where HIV is Endemic" (the Strategy) implementation, revisions and renewal, monitoring, and evaluation (ACCHO, 2013). The strategy was developed in 2002, and was launched in 2005 by ACCHO and the AIDS Bureau. It was the first of its kind in both Ontario and Canada. The Strategy was developed to address issues related to HIV faced by people in Ontario from countries where HIV is endemic and is a framework to coordinate and guide action. The overarching goal is to reduce the incidence of HIV among ACB people in Ontario as well as to improve the quality of life of those infected and affected by HIV/AIDS (ACCHO, 2013). The objectives are to:

- Coordinate the work of the agencies, institutions and policy makers working in ACB communities regarding education, health promotion, treatment, care and support;
- Facilitate community development in response to HIV/AIDS challenges faced by ACB communities; and
- Identify research needs, priorities and opportunities.

The role of ACCHO is to advise and advocate on HIV/AIDS related issues affecting ACB communities, promote greater and meaningful involvement of ACB people living with HIV into the response, and to engage the ACB communities in the response (ACCHO, 2012). The programs ACHO runs are social marketing campaigns, capacity building programs for agencies that work with ACB populations throughout the province, and research shaped by the priorities of the Strategy and the priorities identified by the stakeholders (ACCHO, 2013). ACCHO recognizes that research alone is not a sustainable response, and can only attain its potential if it takes place in an enabling environment of institutional development, community engagement and advocacy, and is linked to policy and programming. P4 informed me that ACCHO works with policy-makers at all three levels of government. ACCHO has been described as the umbrella organization for ACB HIV related initiatives throughout Ontario.

### **BLACK COALITION FOR AIDS PREVENTION (BLACK CAP)**

Black CAP is an organization that works to reduce HIV/AIDS in Toronto's Black, African and Caribbean communities and enhance the quality of life of Black people living with or affected by HIV/AIDS (Black CAP, 2013). As described by P3, Black CAPs initiatives for women include:

- **Outreach Programs:** That are not only designed for women but that get into spaces where they have access to women to give out female condoms, provide resources and

education on the spot to help women better recognize their risk and better negotiate condom use.

- **Prevention:** Black Cap has a series of specific programs and workshops in relation to women and their sexual health. They explore the broader sexual health needs of women that are unique from men and support discussions in relation to HIV, other sexually transmitted infections, family planning etc. They use evidence based interventions focused on the basics of HIV and helping women identify resources, tools and tactics to understand what a healthy relationship is and how to put these tools into practice.
- **Support Department:** The women's support coordinator works only with women in the delivery of support services. This is where the majority of work with women takes place. It is often about helping women get access to housing, employment, settlement processes; dealing with a new HIV diagnosis; getting them to the doctor or legal support; getting them on treatment; and addressing needs in relation to childcare and family support and other needs specific to women. They deliver a number of groups that focus on the broad diversity of women in their community.

Additionally, they have a settlement program focused on people living with HIV/AIDS, women living with AIDS and LGBT women. The program is focused on supporting women in their early days in Canada, making sure women get through the refugee claims process, get through the legal issues of new comers, filling out forms, getting a work permit and other general settlement issues. There is also an employment program where over half of all participants are women, and they can access tools they need surrounding employment services, whether it is educational equivalency, resume and interview skills, getting a job, or determining what their goals are. They are currently about to launch a women's peer support program focused on identifying

HIV positive women in the community who will be recruited and trained, and then be placed in the community as resources available for one-on-one peer support for other ACB women living with HIV or otherwise dealing with related issues associated with having HIV/AIDS.

Black CAP is Toronto based, and does a lot of work in the city and has close ties to other organizations as they collaborate on a large number of services. This kind of collaboration amongst five organizations created a group called the Circle of Care, which formed when the Voices of Positive Women closed in 2009, says P3. The AIDS Bureau preserved the money saved from the closure to create a consortium of interconnected agencies to serve the needs of ACB women living with HIV/AIDS in Toronto.

### **AIDS COMMITTEE OF OTTAWA (ACO)**

The AIDS Committee of Ottawa is a community-based, non-profit organization providing free, confidential services for people living with, affected by and at risk of HIV in the Ottawa area (ACO, 2013). Their mission is to provide support, education and outreach services from an anti-racism/anti-oppression (ARAO) framework and to promote the well-being of those affected with HIV/AIDS in Ottawa. The policies that guide ACO are:

- Gender Identity Policy;
- Anti-Racism/Anti-Oppression Policy; and
- The greater and more meaningful involvement of people with HIV/AIDS in their work.

ACO does education and prevention work, and has a Women and HIV Prevention Initiative to reduce transmission among women and to help build the capacity of local organizations to respond to women and HIV/AIDS; and includes a Woman's Outreach Coordinator to support women living with and at risk of HIV/AIDS (ACO, 2013). An ACB Support Worker (funded since 2009) was also added to support HIV affected people in this community in a variety of

ways; from general support to support in the settlement process if they are migrants, and accessing health services particularly related to HIV/AIDS. P2 stated that there is too little funding for there to be a position specific for ACB women as there is much competition for the funding that is available for the ACB community across Ontario.

### **VARIOUS COMMUNITY HEALTH CENTRES**

There are a variety of community health centres (CHC) across Ontario that provide services or have an employee on staff who works with ACB communities in the area. In Ottawa, there is a HIV Education and Prevention Program for ACB communities with services including outreach, support and capacity building. The CHCs, however, do not all have workers specifically funded to work within the ACB community. As a result, many work in collaboration with each other on various HIV services (testing, GLBT support, etc.), as well as in supporting newcomers and cultural groups. Across Ontario, there are twelve workers funded to work through CHCs and in various organizations to support and represent the ACB community affected with HIV/AIDS. The responsibilities of the individuals in these positions include HIV prevention work, education, awareness and support for people living with HIV, including addressing stigma and discrimination, using the Strategy as a guide. They put together brochures with information that is culturally appropriate as well as do community outreach in ways that are appropriate for the ACB population.

### **WOMEN'S HEALTH IN WOMEN'S HANDS (WHIWH)**

Women's Health in Women's Hands is a community health centre for women of diverse backgrounds in Toronto and surrounding municipalities that specialize in the health and wellness needs of racialized women (WHIWH, 2013). One of their commitments is to address the issue of access to healthcare encompassing all determinants of health caused by poverty, gender, race, violence, sexual orientation, religion, culture, disability, class, and socio-economic circumstances. WHIWH develops strategies to remove the barriers embedded within the healthcare system to enhance a woman's sense of well-being and supporting their right to make informed decisions about their health (WHIWH, 2013). Of the services and programs offered through WHIWH, they offer community health promotion of HIV/AIDS that links solutions to the infection with education, prevention, treatment, support care and advocacy to policy and research framed with the determinants of health. They provide HIV prevention, awareness education, anonymous testing, clinical care and health promotion and skills development for HIV Positive women (WHIWH, 2013). WHIWH supports a variety of diverse backgrounds, but there is a wide focus within the health centre on ACB women in their research and support services.

#### **4 BARRIERS AND INEQUALITIES FOR ACB WOMEN IN ONTARIO**

Many health issues are a function of gender-based social status or roles. The literature on HIV/AIDS and health determinants notes that women's gender-based biological susceptibility to HIV/AIDS is exacerbated by their social and economic circumstances (PHAC, 2012). This has many implications for policy. P3 states that:

"It is really no surprise that our institutional and systemic policy framework haven't really caught up with the realities that ACB women represent the predominant portion of all women living with HIV, and we haven't really seen a response by

policy makers, but considering the unique and significant risk factors at play here, there are some challenges that have not yet been addressed."

Recent surveys conducted among ACB communities in Toronto found that factors such as racism, poverty, underemployment, settlement and status concerns, fear and stigma, lack of social support, fear of deportation, and power relations presented barriers to HIV/AIDS program access (Doyle & Bales, 2011). The surveys also found that the lack of culturally competent and accessible services in part due to language barriers and the concern that healthcare may not be free depending on immigration status were additional barriers. These findings are consistent with previous literature as were all the themes presented by the participants of my interviews.

To identify these barriers, I outlined the recurring themes discussed by all participants during the interview phases. These were concurrent with barriers addressed in the literature. This chapter highlights the most common barriers for ACB women that may heighten their risk of being affected with HIV. The most common barriers are:

- Determinants stemming from the migration process, including access to healthcare;
- Power imbalance in female and male relationships, often stemming from the immigration process and economic dependence;
- The misconception that HIV/AIDS does not exist in Canada;
- Social and cultural differences; and
- Stigma surrounding HIV in society in general, and in the ACB communities in particular.

#### **4.1 BARRIERS FOR HEALTH REGARDING THE IMMIGRATION SYSTEM**

The Canadian immigration system is not only complex, it is confusing and can be very intimidating for newcomers. Migrants already face complex demands during their journey that

are exacerbated when they are immigrating with HIV, or if their fear of additional consequences should they become HIV positive post-migration. There are numerous potential implications particularly if persons testing positive are unaware of their rights, fear that the positive diagnosis will jeopardize their chances of staying in Canada, or are unable to access care and services (PHAC, 2009).

### **FEAR OF INADMISSIBILITY BASED ON HIV STATUS**

People with HIV have tremendous fear and concerns about the possibility of their request for immigration status being rejected because HIV testing is a mandatory part of all newcomer applications (Li, 2012). Many of the ACB population only learn they are HIV-positive during this testing. The medical officers offer counselling under such circumstances, but there is the added stress and insecurity on the part of the migrant if they are unsure about how their HIV status may affect their chances of becoming a Canadian citizen. Consequently, the stigma instilled by the possibility of being denied status can render a migrant woman extremely reluctant to disclose their personal situation should they contract the infection while already in Canada. P2 states that "everything is a big deal to migrants because every detail will determine your future", thus discouraging women from seeking adequate healthcare. Advocators insist that any decision made based on the presence or absence of illness is discriminatory and emphasizes the stigmatizing nature of political debate (Karago-Odongo, 2008). Although the law no longer applies once the migrant has been granted permanent status, the fact that it has been declared as a threat to their status in the first place is often enough to deter women from seeking treatment, or even being tested in the first place. P1 says "that the fear of deportation is so high and there is no certainty in the migration process that many ACB women just live in fear and we need a policy that can help".

HIV in itself is not considered to be a danger to public health, therefore does not exclude the admissibility to Canada. However the cost of treatment for HIV could render the migrant inadmissible since it is reasonably expected that it would place excessive demand on health and social services compared to the average Canadian. Although information is not released when one's HIV status was a determinant of their immigration status, it has the ability to deter newcomers from receiving regular HIV testing once they have entered Canada out of fear that it could affect their citizenship status. Both P1 and P3 believe the lack of statistics about why migrants are rendered inadmissible is a barrier hindering change. P3's organization attempts to keep track of the clients they work with who get deported, but it becomes difficult to track.

#### **“HIV/AIDS DOES NOT EXIST IN CANADA”: A COMMON MISCONCEPTION**

A common misconception among migrants HIV endemic areas of the world is that the risk of HIV does not exist in Canada. All four participants agreed that this is a major issue facing ACB women, and the ACB population in general. According to P1, there is a false notion that it is something they escaped once they left their country because everyone gets tested before entry to Canada and thus HIV cannot be a reality in Canada. This misconception gives a false sense of security if one is not informed of the risks and/or options to protect themselves upon arrival to Canada. Canada's decision to screen potential migrants for HIV/AIDS may also have had unexpected effects on the attitudes of ACB youth, as they feel less vulnerability and generally agreed that the Canadian immigration service only awards visas to migrants who have a clean bill of health (PHAC, 2009). Not understanding that HIV exists in Canada can lead to high risk sexual behaviour without fear of relevant consequences. Additionally, "HIV messages are not as predominant in Canada as they might be in the home countries of some women, and therefore HIV is not visible "says P2. P3 agrees that the lack of messaging with respect to HIV/AIDS in Canada

can lead to higher risk of HIV since many ACB women are being infected with HIV within five years of arriving in Canada. Adequate information upon arrival and proper medical accessibility could prevent such misconceptions.

### **BARRIERS TO ADEQUATE ACCESS TO HEALTHCARE**

Having no status and /or no health coverage for new migrants is a major barrier to access to Canadian healthcare. There is a clear need to provide a supportive environment for migrants living with HIV/AIDS. They face challenges associated with access to healthcare and treatment such as lack of health insurance, including ineligibility for provincial assistance and high drug costs. Research has identified the importance of access to appropriate healthcare services for migrants to address the multilayered level of stress and burdens of this population (PHAC, 2009). Recent changes to the IFHP have further limited healthcare resources for refugees and their families (Fitzpatrick, 2013). Migrants are not getting treated for their treatable conditions and are not having access to adequate preventative care and this is viewed by advocates as bad policy. This is commonly considered equally as bad for the health of refugees as it is for the health of all Canadians. These reductions are also bad for the taxpayer as it will cost taxpayers dramatically more money (Fitzpatrick, 2013).

Upon arrival, there are also challenges of service provision. Systemic exclusion can be seen in the healthcare environment in which ACB women seek assistance (Tshisekedi, 2008), and P3 believes this is a major barrier, stating that "the immigration system is failing women". There is little guidance in the immigration process about how the Canadian healthcare system works or and how to get language or culture specific assistance, says P4. Experts on access to healthcare for underserved populations believe that language is the most important barrier preventing some migrants from staying healthy and being able to communicate their needs (Taylor,

2012). The needs of these migrant women do not conform to North American systems of health-care delivery (Hyman, 2003). Consequentially, they tend to receive diagnosis and treatment later than other populations due to barriers embedded within the system. Institutional discrimination and the poor representation of ACB women among healthcare personnel, especially at the decision-making levels must be improved to begin to address these systematic challenges (PHAC, 2009). The lack of healthcare services from migrant women can be exacerbated by cultural and social variations.

#### **4.2 ECONOMIC AND SOCIAL BARRIERS**

Differences in culture present a distinct barrier for migrant women from HIV/AIDS endemic regions. Many ACB are not familiar with the culture of seeking help from agencies says P1, as ACB women often fear authority because authority is a source of distrust in their county; or talking about problems with people who they are unfamiliar with. Migrant women respond better to treatment by women and respond better when unaccompanied by their spouses. Migrant women often maintain strong beliefs in their traditions and religions, and approaches to reproductive health for this group are not always culturally sensitive (PHAC, 2009). Practitioners often say that cultural taboos, such as fear of discrimination or deportation, and the shame associated with HIV, makes people from regions where the disease is endemic reluctant to be tested or to seek medical attention (Jimenez, 2004, as cited in Karago-Odongo, 2008). Lack of culturally sensitive approaches to healthcare support, prevention and education is a determinant preventing migrant women from seeking medical services.

#### **GENDERED NORMS AND POWER IMBALANCE FACED BY ACB WOMEN**

The migration process is only one part of the problem. There are other determinants that are exacerbated from the immigration process that put ACB women at a higher risk of HIV/AIDS once living in Canada. Women from HIV/AIDS endemic regions generally do not immigrate alone, but they come as a sponsored spouse. Women can apply to come independently, but it is much more common for men to immigrate and bring the women as dependents (Karago-Odongo, 2008). All four participants agreed that migrating dependent on a spouse is a barrier to many ACB women as many ACB cultures have a patriarchal hierarchy in the family and in the community (PHAC, 2009).

Gendered norms in ACB communities make both men and women vulnerable to HIV. For financial, social, emotional and immigration reasons, female partners may accept to maintain a relationship where she is unable to negotiate safe sex or demand fidelity (PHAC, 2009). Many ACB women are sponsored to migrate, and many women in turn become highly dependent on their husband and lack financial freedom to become independent. Consequently, the migrant woman is economically disadvantaged and discriminated against through her limited access to services due to her sponsored spouse (Karago-Odongo, 2008). A sponsored woman who is unemployed lacks economic autonomy and thus opportunity. She is often deprived of rights and suffers from a lack of sexual control over her body (Tharao, Massaquoi, & Teclom, 2006). P2 believe the immigration system needs to empower women to take ownership over their financial freedom, yet P4 says many women are financially and economically dependent on their partner and that compounds the issues of being a newcomer in Canada. Barriers in the immigration process in Canada create additional social inequalities to healthcare for migrant women. This exacerbates other negative health outcomes, increasing their risk of HIV prevention or treatment. There are still other barriers for ACB women that limit their financial freedom.

## **ECONOMIC AND EMPLOYMENT BARRIERS**

There are unique and deeply rooted health inequalities in socio-cultural and structural factors that intersect with gender, race, class, and political and economic status (Karago-Odongo, 2008). Generally speaking, people with low incomes or living in poverty are more likely than those with higher incomes to be at risk for HIV infection (PHAC, 2009). Economic marginalization is the most powerful social barrier to HIV prevention upon migration and has additional consequences for women. P3 states that ACB women are racialized, stigmatized and marginalized and hence are more likely to endure greater difficulty in the process embedded in the labour market and in socio-economic sectors. Race continues to interact and weave together with gender and class.

The employment rate for migrant women is low compared to Canadian-born women or their male migrant counterparts, with recent migrants being the least likely to be employed (Chui, 2010). Often their education or skills are devalued, and according to P2 this hinders ACB women from achieving their financial freedom and forces them to rely on their partners and on social services from the state. When income is threatened, other determinants of health are destabilized. Women are less likely to insist on fidelity, demand condom use, or refuse sex with their partner (Tharao, Massaquoi, & Teclom, 2006). Having an income is a key element in the foundation of good health.

Social inequities contribute to women's risk of HIV (Robertson, 2007). Violence, coercion, and economic dependence in relationships make it difficult to negotiate condom use or leave a partnership that puts them at risk (ICAD, 2012; Tharao, Massaquoi, & Teclom, 2006). According to P4, "condoms are not negotiable in many of these relationships so women cannot choose to participate in sexual practices that will reduce their risk". Many societies discourage

women and girls from learning about their bodies or sex, and sexual decision-making is left to men. Gender based social norms can lead men to seek multiple partners. P1 says that in African and Caribbean countries polygamy can often be normal practice, while women bear the burden of shame and stigma associated with the infection (Robertson, 2007). Other identified gender differences include a tendency for ACB heterosexual men to be more likely to deny being HIV positive, having a negative impact on intimate relationships after diagnosis for many women, and the threat and experience of physical and sexual violence against women (PHAC, 2009).

### **SEXUAL VIOLENCE**

While sexual violence is linked to other determinants of health, it warrants special attention both for its gendered nature and for its particular manifestation in ACB communities. Sexual and physical violence against women and children has a direct impact on the ability of women and children to practice HIV prevention (PHAC, 2009). Underlying issues of sexual and physical violence are not openly discussed within ACB families and/or communities. Both P1 and P2 feel a strong need to address the culture of silence in many ACB communities, as women who come forward often face stigma and risk reprisal from family for speaking out or seeking support (Tharao, Massaquoi, & Teclom, 2006). This is particularly true if the perpetrator is a member of the immediate or extended family or part of the larger African and African-Caribbean community. Additionally, forced sexual activity may lead to HIV infection. Survivors of abuse may limit their ability to negotiate safer sex or make them feel as if they do not have the right to protect their body (PHAC, 2009). This will continue to remain an issue while the stigma associated with speaking out and surrounding HIV is still predominant in many ACB cultures.

### 4.3 STIGMATIZATION OF HIV/AIDS: IN SOCIETY AND WITHIN ACB COMMUNITIES

Stigma towards HIV/AIDS is promoted within the ACB community, as well as by mainstream society, which marginalizes ACB communities and their families, and risk endangering their physical and mental health (Karago-Odongo, 2008). Stigma is a term applied to a condition, trait or behaviour that marks an individual or community as culturally unacceptable or inferior and is often linked to feelings of shame and disgrace (Karago-Odongo, 2008). There is a whole host of issues surrounding stigma, says P4, and this proves to be one of the biggest challenges and barriers within all aspects of HIV response in ACB communities. Stigma that surrounds HIV/AIDS is present enough in society and is even more of a determinant for women from regions where HIV is endemic. P1 is convinced that ACB women "will die of stigma, not from AIDS", which P3 supports as it was mentioned that "it is too difficult to get to the root of the issue because stigma drives new infections and risk in the community".

HIV stigma has negative impacts on health that affect social networks, personal health practice like seeking medical guidance and coping skills (Tharao, Massaquoi, & Teclom, 2006). Migrant women rely heavily on their social community networks, so fear of stigmatization can be justified. There is a need to address the systemic forces that sustain stigma and discrimination (Shimeles *et al*, 2011). Addressing deep seated issues such as race, culture, social exclusion, racism, stigma and discrimination will produce more comprehensive health behaviour theories, which in turn will lead to more informed interventions in racialized communities – some of which have often been ignored.

## 5 POLICY RECOMMENDATIONS

The following recommendations are based on the evaluation that was done in this research and the current work of many governmental and non-governmental organizations who are addressing HIV/AIDS for ACB women. These recommendations are also guided by suggestions offered by the interview participants based on their professional experience and suggested best practices. I would like to emphasize that all participants, as well as recommendations contained in reviewed literature, suggest that the meaningful involvement of ACB women affected with HIV/AIDS must be an integral component of any decision making and policy making process. This includes leading the development and implementation of projects, support services and counselling other women with HIV. Affected women know their needs and their engagement in the policy development and prevention programming will allow them control and freedom to be the primary actors in their own life and assume control over their right to self-determination. This ensures that the programs and services are relevant, and accessible to ACB women living with HIV/AIDS. The meaningful involvement of ACB women is the most important aspect in considering the following recommendations.

### 5.1 ENHANCED, MEANINGFUL COLLABORATION: ENABLING MIGRANT WOMEN

**Recommendation 1:** Eliminate silos and increase collaboration between the different levels of government, non-governmental organizations, and social service providers to increase accessibility to culturally specific health information and accountability.

Continued and enhanced collaboration between all levels of government and community-based organizations is necessary to adequately addressing ACB women affected with HIV/AIDS

in Ontario. Increased collaboration with additional social service providers such as housing and employment services is also recommended. This has the ability to increase the accountability in helping new migrants address their basic needs (housing/jobs) in order to reduce burdens stemming from migration, especially if there is an open source of information for organizations to track the progress on migrants. This will in turn increase available time and resources to the people in the ACB community to take time to care for their health, and to have a vested interest in addressing health issues such as HIV/AIDS. Such collaboration could open up the lines of communication to educate service providers in culturally specific and gender specific needs of varying ACB populations.

It is recommended that general and specific information should be provided to newcomers in a clear and culturally specific manner. Easier access to other services that in turn are determinants to health will allow migrants greater stability in their transition and adequate time and resources to focus on their health and healthcare. Currently, outside organizations are unable to leave such culturally appropriate information at immigration sites. P2 attempted to leave HIV brochures at one immigration site to inform newcomers about the risks in Ottawa of HIV/AIDS, the risks to them in the ACB community, as well as with information about how to access healthcare and HIV services, and the participant was refused by immigration officials. The information provided by immigration is generally confusing to navigate through and very generalized. Allowing professionals who are expert in HIV/AIDS in the ACB community (and the determinants that affect them) to participate in the development of education materials would enable a mutually beneficial compromise where the burden of the work is shared, and migrants would be rewarded with access to valuable information that could aide in preventing HIV infection or facilitate access to adequate services if the migrant is entering Canada HIV-positive.

P3 recommends that there is no longer any room to work in silos among different government departments, levels, and community based organizations. At the end of the day, the funds are coming from taxpayers and we need to make use of that funding in a responsible and effective way. HIV/AIDS should be a public health issue that is not separate from other determinants of health. Public officials need to be open and address these issues in order to address HIV/AIDS. Everyone needs to get involved, not just in a funding sense, but in recognizing that HIV is a real problem and all sectors need to get involved. The lack of culturally appropriate services can be addressed if all sectors continue to collaborate, at the research level, in implementing programs and in dissemination of information, thus also addressing other determinants of health.

## **5.2 HIV INITIATIVES FOR MEN AND YOUTH**

**Recommendation 2:** An increase in ACB women specific policies and initiatives is imperative, however earlier sexual health education and initiatives for ACB men will help address social barriers to health outside the control of ACB women.

Initiatives targeting men and youth should be a major part of the prevention and education programs. Men, especially heterosexual men, need to be targeted more aggressively in HIV prevention campaigns, due to their strong influence on women's risk. The rate of service usage is three times higher in women than in men (Doyle & Bales, 2011), indicating the need for increased programming and participation for men. Educating women must continue, but as P2 stated, "simply educating the women won't help because women have a partner somewhere who affects their health and well-being." Campaigns geared towards men may encourage higher incidence of male HIV-testing, as P1 notes a major issue is that we don't know if the man in that

relationship has been tested. Women often convince other women to get tested, or they have more opportunity to get tested when they go to the doctor with the children. ACB men rarely are faced with the circumstances to get an HIV test, thus there should be increased promotion in the communities for men.

Youth initiatives are recommended as an investment in our future. P2 states that young women are not properly equipped with tools to advocate for themselves and make good decisions. Introducing youth initiatives to both males and females will help alleviate the stigma attached to HIV, as well as increase awareness of proper tools to protect oneself and the community. P1 suggests that there is not enough sexual health taught in school and that HIV is only briefly touched upon. Sexually transmitted infections (STIs) are an issue among youth and the presence of an STI renders a person more susceptible to HIV (OPH, 2013). By addressing HIV and STIs earlier in life we will have people talking about it (even in the broader community) , and then new migrants will be more aware, helping discount the misconception that HIV/AIDS is not a problem in Canada.

### **5.3 REDUCING STIGMA SURROUNDING HIV/AIDS**

<p><b>Recommendation 3:</b> Increase HIV/AIDS messaging in society in an attempt to normalize the infection, as well as creating anti-stigma campaigns and population targeted programming.</p>
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All interview participants argued that challenging stigma and raising awareness of HIV in ACB communities and among the public is a key factor to address HIV/AIDS in the ACB community. In the 2011, a needs assessment of HIV positive women in Ontario congruently identified that the barrier to service that most all groups of informants identified was the stigma associated with HIV/AIDS and the resultant fear of disclosure (Doyle & Bales, 2011). The main fears

were being ostracized from their communities, and in the case of new migrants, the fear of losing their sponsors and immigration repercussions.

Stigma cannot be separated from race, racialization, and gender issues (ACCHO, 2013). A barrier for many ACB women is getting into the community-based organization for fear of disclosure and stigma within their community. P3 noticed that once a person has accessed these centres for the first time, it can help them overcome the initial fears, and they become better equipped to deal with that stigma in their lives. Once the woman has peers and allies to support them, they find a stable social network and the fear of losing the other networks in their life diminishes. Therefore, getting women and men from the ACB community into the agency and connected to others is an important task in addressing the HIV stigma in the community.

In addressing HIV stigma, we must first begin by tackling HIV and HIV messaging. P2 knows that HIV/AIDS is a difficult topic to address openly, especially given how HIV has become so political, but if we want a solution, we must first talk about the problem. P1 believes that knowledge will stop the stigma. Currently it is difficult to normalize HIV in the ACB communities because it is not normalized in the general Canadian population. Not only do we need to raise public awareness, we need to change people's minds to reverse the understanding of what is happening and reduce the negative connotations surrounding HIV and HIV positive people (Doyle & Bales, 2011). Normalizing HIV/AIDS will help reduce stigma, which in turn can lead to a reduction of infections. All interview participants agreed that many people do not get tested for HIV because of the stigma surrounding it.

Targeted outreach within the ACB communities will enhance awareness and can help the stigma attached to HIV. These are unique communities, and as many outreach programs are currently demonstrating, more efforts must be put towards getting people talking about HIV, by lo-

cating them and by creating programs specific to the ACB culture. As Ottawa Public Health has done with "Operation Hairdresser", many outreach coordinators are following suit and accessing these populations in faith-based places, cultural events and holding more artistic events. They are not addressing HIV/AIDS by way of workshops and other more formal events. They know that ACB women and men are not likely to attend because of stigmatization.

## **6 CONCLUDING THOUGHTS**

Historically, social and cultural determinants of health, especially among ACB migrant women from endemic countries, have not been considered in policy development. It is only recently that more research has been done in Ontario to examine the over-representation of women with HIV/AIDS from endemic countries. However, research alone is not enough. Institutional development, community engagement and advocacy - linked to policy and programming - is needed if this research is to achieve its full potential (Shimeles *et al*, 2011). Policy needs to emphasize the need for gender based analysis and programming given the reality that gender inequality and gender-based hatred and violence affect all women's lives. This is especially true given the fact that ACB women must deal with all the barriers and issues that ACB people face, plus the additional marginalization that comes with being a woman within these communities, and, the physiological differences between men and women that render women more biologically vulnerable to HIV infection through heterosexual sex than men (ACCHO, The Strategy, 2012). There are specific considerations that would advance policy development in this area.

## **INCREASED PARTICIPATION IN HIV POLICY BY ACB WOMEN**

There is currently a lack of migrant women in HIV/AIDS policy work and that has created a systemic barrier and can lead to these women being underrepresented or misunderstood. They lack power over their bodies and sexual and reproductive health (Tharao, Massaquoi, & Teclom, 2006) and often have difficulty reaching out to the healthcare system for disease prevention. Therefore, the feeling of being adequately represented on issues specific to them may allow for a clearer line of communication and result in input to the debate that would not be acquired otherwise. Individual values and a community-based response would also be needed in order to properly understand all of the issues.

Culture must be adequately addressed when formulating policy and intervention. Lack of culturally sensitive and appropriate approach to healthcare, prevention and education is an incomplete approach, one that prevents migrant women from seeking and accessing services (Hyman 2003). The implications of immigration policy should be reviewed for future changes to be made. Investing additional resources to more effectively inform migrant women as to the functions and features of the Canadian healthcare system will reduce fear and confusion, especially upon their arrival in Canada. Furthermore, increased interim funding in the health programs for high-risk migrant women from HIV/AIDS endemic regions would enable appropriate care for all migrants - especially those women who are financially dependent or unable to pay for the additional care in their first three months following entry to the country.

## **INCREASED AWARENESS OF THE REALITIES OF HIV/AIDS IN CANADA**

It would also be useful to address common misconceptions concerning what to expect upon migration into Canada. These include, but are not limited to, the fact that many women

never expected HIV/AIDS to continue to be part of their reality in Canada, the false belief that AIDS is not curable, and that HIV/AIDS is no longer a death sentence because of life-prolonging antiretroviral treatment (Karago-Odongo, 2008). Clarifying such inaccurate or misleading details may be the simplest way to promote awareness in this group of women. Future research addressing men's health and lifestyles, as well as youth access to information, would also be beneficial in developing policy that affects women and future generations.

The investments made by organizations such as the ACCHO are helping to advance understanding of these issues and help promote the creation of strategies that will result in more effective care and awareness for this community. Although they do not always focus specifically on the needs of women, there is significant work being done for women in these organizations. The scope of this paper is provincial, but there are many other organizations in Canada that are addressing similar problems. National research on HIV among migrants is consistent with findings for Toronto and Ontario. Canadian research has shown that migrants from HIV-endemic regions, and particularly women from these regions, make up an increasing proportion of HIV cases in Canada. National research has also found higher HIV/AIDS mortality rates among ACB migrants, and among migrant women, than in the general Canadian population (Khandor & Koch, 2011).

The goal of many organizations is to challenge stigma by raising awareness of HIV/AIDS in ACB communities. They promote the continuous link of health to the broader issues facing ACB communities, and women in particular.

Ultimately, HIV/AIDS cannot be separated from race, culture and gender issues in order to promote the range of opportunity facing ACB people (ACCHO, 2012). There are many initiatives that have begun to address the health inequalities for these women, but these efforts by

themselves are not enough. If people migrate to Canada to start a new and better life, they deserve the freedom of equal opportunity upon arrival to achieve such a life. There are many social issues related to ethnicity and gender. Providing equality of opportunity in healthcare at the outset reduces the incidence of the over-representation of these specific Diaspora of women with HIV/AIDS post-migration.

It should not, however, be overlooked that the majority of the interview participants mentioned that ACB women are an extremely resilient group of women, and they have overcome much to arrive at this point. The story should not always be seen as a story of victimization (although it often is), but should also be recognized by their strength and perseverance in the face of adversity. Involving migrant ACB women in HIV prevention and policy processes will give women more control over their health-based decision making and allow them to re-write their story to a reality of resilience and perseverance.

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## APPENDIX 1 LIST OF HIV-ENDEMIC COUNTRIES (PHAC)

### **Caribbean**

Anguilla  
Antigua and Barbuda  
Bahamas  
Barbados  
Bermuda  
British Virgin Islands  
Cayman Islands  
Dominica  
Dominican Republic  
  
French Guiana  
Grenada  
Guadeloupe  
Haiti  
Jamaica  
Martinique  
Montserrat  
  
Netherlands Antilles  
St. Lucia  
St. Kitts and Nevis  
St. Vincent and the Grenadines  
Trinidad and Tobago  
Turks and Caicos Islands  
U.S. Virgin Islands

### **Africa**

Angola  
Benin  
Botswana  
Burkina Faso  
Burundi  
Cameroon  
Cape Verde  
Central African Republic

Chad  
Congo  
Djibouti  
Equatorial Guinea  
Eritrea  
Ethiopia  
  
Gabon  
Gambia  
Ghana  
Guinea  
Guinea-Bissau  
Ivory Coast  
Kenya  
Lesotho  
Liberia  
Malawi  
Mali  
Mozambique  
Namibia  
Niger  
  
Nigeria  
Rwanda  
Senegal  
Sierra Leone  
Somalia  
South Africa  
Sudan  
Swaziland  
Tanzania  
Togo  
Uganda  
Zaire  
Zambia  
Zimbabwe

## **APPENDIX 2 ETHICS APPROVAL**



**Université d'Ottawa**  
Bureau d'éthique et d'intégrité de la recherche

**University of Ottawa**  
Office of Research Ethics and Integrity

## Ethics Approval Notice

### Health Sciences and Science REB

#### Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
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#### Special Conditions / Comments:

N/A

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**University of Ottawa**

Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at: <http://www.research.uottawa.ca/ethics/consent.html>.

Please submit an annual status report to the Protocol Officer four weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: <http://www.research.uottawa.ca/ethics/consent.html>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: [ethics@uOttawa.ca](mailto:ethics@uOttawa.ca).

**Signature:**

Kim Thompson

Protocol Officer for Ethics in Research  
For Barbara Graves, Chair of the Social Sciences and Humanities REB

### **APPENDIX 3: INTERVIEW QUESTIONS**

1. Can you take a moment to describe the situation of African, Caribbean and Black (ACB) women being disproportionately affected with HIV/AIDS in Ontario?
2. What involvement does your organization have on this subject? Do you have any programs or policy in place?
3. Who, if at all, do you collaborate with on the subject? Government? Other organizations?
4. Are you free to discuss where you get your funding sources? If yes, how is your organization funded? What is your staffing and volunteer structure?
5. Do you have any recommendations for best practices to continue to address the issue? Are there other initiatives that could be created or expanded upon that are not currently being addressed or addressed to a higher extent?



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## APPENDIX 4: INFORMED CONSENT

Ottawa, Month, Date, 2013

### Consent Form

#### **Title of the study: A Policy Evaluation of Migrant Women Over-Represented with HIV/AIDS in Ontario**

Research by Jena Roy, M.A Public and International Affairs. Phone number: 613-600-6123, e-mail: jroy011@uottawa.ca

Supervised by Isabelle Engeli, Ph.D Political Science, Professor in the Faculty of Social Sciences, Graduate School of Public and International Affairs. Phone number: (613) 562-5800 ext. 8804, e-mail: isabelle.engeli@uottawa.ca

**Invitation to Participate:** I am invited to participate in the abovementioned research study conducted by Jena Roy and Isabelle Engeli.

**Purpose of the Study:** The purpose of the study is to evaluate policy about migrant women and HIV/AIDS. Specifically, I will be researching migrant women from HIV/AIDS endemic areas of the world, mainly from Sub-Saharan Africa and the Caribbean. This subgroup of the population is over-represented with HIV/AIDS in Ontario. I will examine the social determinants of health at the root of this endemic. I will also evaluate the Canadian immigration system to determine what tools are available to migrant women, especially migrant women from HIV/AIDS endemic regions. I will be making recommendations for future directions of this specific policy with the collection and analysis of the interviews conducted here

**Participation:** My participation will consist essentially of one (1) session of approximately forty-five (45) minutes during which I will answer questions and expand on those questions related to this research topic. The session has been scheduled for Month, date, 2013. I will also be asked to offer the possibility to be contacted in the future in the event that a clarification or follow-up is necessary.

**Risks:** My participation in this study will entail that discuss observations and experiences I have had working with women from HIV/AIDS endemic region in terms of their health or experiences/barriers with the Canadian health system. There are no foreseen risks to my participation.

**Benefits:** My participation in this study will add valuable insight to this newly recognized phenomenon as it has been minimally explored by the Canadian government. Further research will contribute to the prevention of the spread of HIV/AIDS in this sub-group of women. This will improve overall health of people living in Ontario. There are other provinces with a similar migrant health problem, and perhaps this research can be lent and applied elsewhere in Canada. This contribution will be for academics and health practitioners alike.

**Confidentiality and anonymity:** I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for descriptive purposes to make inferences about what would be needed in creating policy. I understand I may be quoted. My confidentiality/anonymity will be protected by using codes in the paper that make references to my contribution in the interview without revealing directly my identity or any personal information. There will be no reference to my identity anywhere in future publications. I am aware that the organization where I am employed and that my position within the organization will be mentioned in the final research paper, and I understand the possibility that my identity may be indirectly identified.

**Conservation of data:** The data collected will be hand written and then transcribed and stored on a data stick. It will be kept in a secure manner as it will always be locked up at my house when I am not working with the information. During the retention period once I am finished with the research, paper files will be destroyed and the data stick will be locked up securely in the office of my supervisor, Isabelle Engeli on the University of Ottawa Campus.

**Voluntary Participation:** I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be destroyed and not used in anyway in moving forward with this research.

Acceptance: I, \_\_\_\_\_ agree to participate in the above research study conducted by Jena Roy of the Graduate School of Public and International Affairs, in the Faculty of Social Sciences at the University of Ottawa, under the supervision of Isabelle Engeli. If I have any questions about the study, I may contact the researcher or his supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: [ethics@uottawa.ca](mailto:ethics@uottawa.ca)

There are two copies of the consent form, one of which is mine to keep.

Participant's signature:

Date:

Researcher's signature:

Date: