# Disaggregating HIV Data to Improve Knowledge of HIV Rates and Understanding of Risk Factors Among African Immigrants and Refugees

#### Introduction

Analysis of national HIV surveillance data has revealed that the percentage of annual HIV diagnoses among foreign-born people in the U.S., including African immigrants, is growing. However, in most data sources, African immigrants are subsumed under other categories such as "black," "African American" or "other."

## Purpose and Scope

The purpose of this policy paper is to highlight and provide recommendations regarding the importance of collecting and disaggregating HIV surveillance data on African immigrants residing in the U.S.

Studies that analyze and report HIV surveillance data by country of birth:

- Examine HIV prevalence in African immigrant communities
- Explore socio-cultural factors influencing HIV prevalence in African immigrant communities, highlighting a few U.S. states that are collecting and reporting HIV data by country of birth
- Make recommendations for disaggregating HIV surveillance data

## Socio-Demographic Profile of African Immigrants and Refugees

The term "African immigrant" refers to an individual born on the African continent who now resides in the U.S. The country's African immigrant population has been increasing steadily since the 1960s.

Table 1. Total and African Foreign-Born Populations, 1960 to 2009

Year	Total Foreign Born	African Born	
		Number	Share of Total Foreign Born
1960	9,738,091	35, 355	0.4%
1970	9, 619,302	80, 143	0.8%
1980	14, 079,906	199, 723	1.4%
1990	19,797,316	363, 819	1.8%
2000	31,107,889	881,300	2.8%
2009	38,517,104	1, 492, 785	3.9%

Source: Data for 2000 from the 2000 census10; 2009 data from the American Community Survey 2009 9. Data for earlier decades from Gibson and Lennon 11.

- Africans comprise a small (3.9 percent) but growing share of the country's 38.5 million immigrants.
- Africans are scattered throughout the country, with the largest concentrations near big cities and in the Northeast (see Figure 1).
- Thirty-seven percent of African immigrants reside in major cities in 5 states (California, New York, Texas, Maryland and Virginia) and Washington, DC, each of which have between 60,000 to 100,000 Africans8.

#### **Data Limitation**

Currently, HIV surveillance data are reported by "race/ethnicity," thereby grouping African immigrants and U.S.-born blacks in the same category. This is an inherent limitation because there are significant epidemiological and cultural differences between African immigrants and U.S.-born blacks.

- Analysis of 2003-2004 HIV diagnosis data in five states (California, Georgia, Massachusetts, Minnesota and New Jersey) and three localities (King County, WA; New York City; and Virginia) revealed that African immigrants accounted for 0.6% of the population and 3.8% of HIV diagnoses. However, close to 41% of diagnoses in women and up to 50% of diagnoses in blacks occurred among African-born individuals.
- From 2001 to 2007, an estimated 100,000 black adults and adolescents were diagnosed with HIV infection in 33 U.S. states, for which country-of-birth information was available. Of these, 11.7% were foreign-born, with most from the Caribbean (54.1%) and Africa (41.5%)

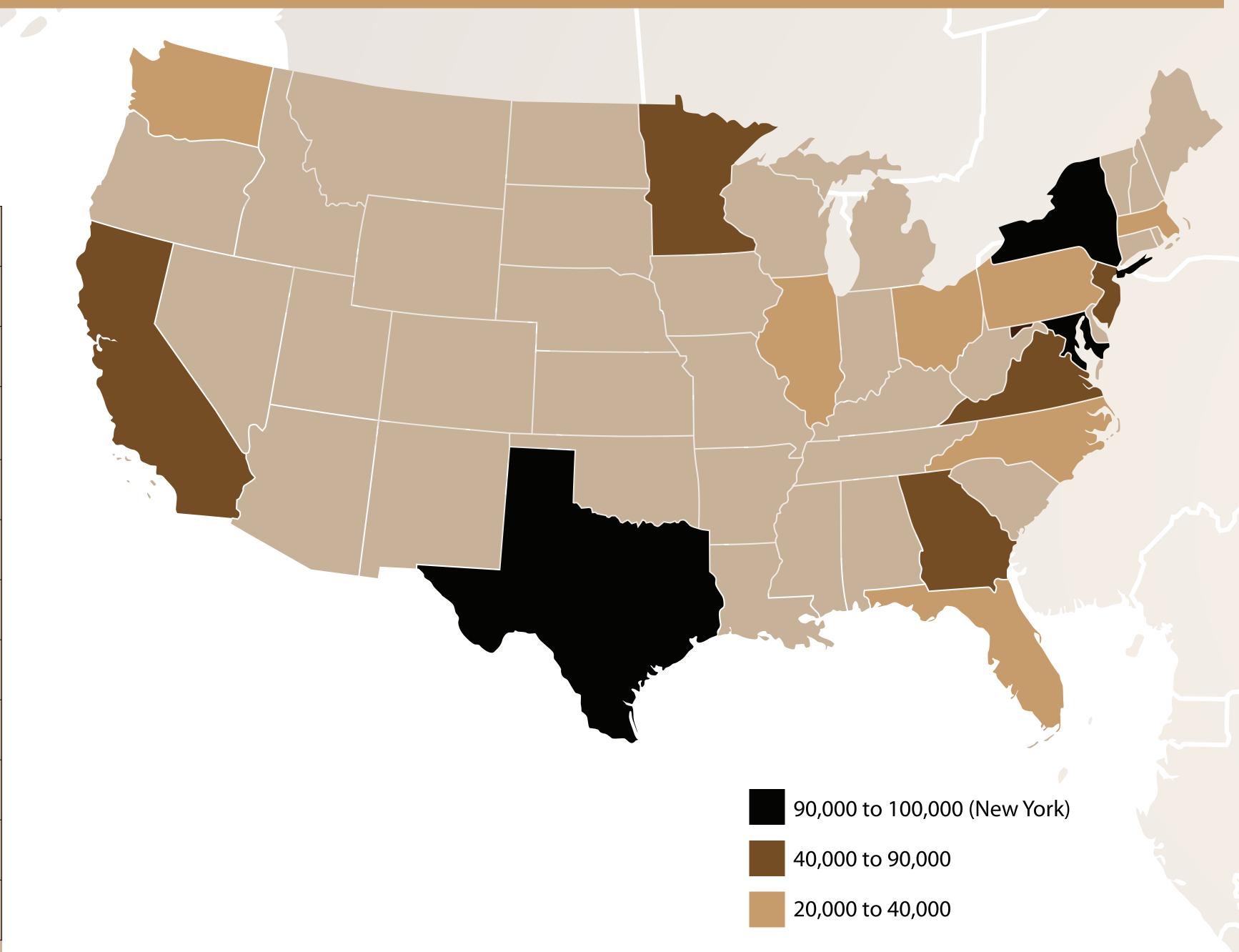
Other analysis of surveillance data from Minnesota3; Massachusetts; Washington, DC; and Los Angeles, CA; showed that African immigrants

account for a substantial portion of HIV diagnoses. Despite these findings, ongoing data limitation appears to be a result of:

- Inadequate funding of state surveillance programs that can lead to low prioritization of country of birth in data collection and analysis by HIV surveillance programs and health care providers
- Failure to consistently collect and report data by country of birth
- Limited requests from community leaders for disaggregated HIV data by country of birth

This failure to record country of birth information has resulted in under-estimation of HIV prevalence in the African immigrant population, and has several critical implications:

- Inability of planners to appropriately allocate resources for HIV prevention and treatment in African immigrant populations
- Inability of providers to tease out pertinent epidemiological information that can help highlight and address barriers to HIV prevention and care services
- Inability of researchers to evaluate gaps in knowledge and justify the need for research grants and funding



## African Immigrants and Culture

Certain beliefs in African culture provide a stark contrast to current beliefs in African American culture, greatly impacting testing, treatment and prevention of HIV. These cultural values and practices, among many others, differentiate African immigrants from other minority groups in the U.S.

- Sexual health topics are not considered appropriate for public discourse.
- Sexual intercourse is seen as an act that happens between a man and a woman—generally at the behest of the man. Single women are believed to be virgins, while married couples—especially married women—are believed to be faithful.
- Gender roles in African culture impact health.
- Culturally, HIV is seen as a virus carried by sexually promiscuous women.
- The lack of awareness about reproductive health issues, how HIV is transmitted, who is at risk and ongoing stigmatization of individuals who are HIV positive all contribute to transmission rates.
- Heterosexuality is considered the norm; homosexuality is largely not accepted.

# Policy Recommendations

Access to reliable and disaggregated HIV surveillance data by country of birth will improve understanding of HIV rates and risk factors among African immigrants.

#### Department of Health and Human Services (HHS)

- Invest in and provide more guidance on the collection of comprehensive surveillance reports complete with country of birth, risk behavior and HIV incidence and prevalence
- Recommend states disaggregate and report HIV surveillance data, using country of birth as an indicator, as part of routine analysis
- Require collection of country of birth information on the Office of Management and Budget's "HIV Confidential Case Report Form" (OMB No: 0920-0573)
- Update Affordable Care Act Section 4302 data collection standards to require country of birth
- Provide funding, statistical, logistical and other pertinent support for researchers working with disaggregated data

#### State HIV Surveillance Programs:

- Train health care providers on the importance of capturing country of birth data
- Urge health care providers to document and use country of birth as an indicator in HIV surveillance and reporting

### Community Organizations and Researchers:

- Encourage members to participate in their organizations' HIV planning groups and the Ryan White Planning Council to help prioritize the need for disaggregated data
- Request disaggregated data from their local HIV surveillance programs for planning efforts
- Urge African researchers to avail themselves of opportunities to serve as principal investigators on federal research projects as well as on grant review boards