

HIV/AIDS Statistics and the Census

*Select Topics in International Censuses*¹

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INTRODUCTION

Global HIV/AIDS programming, in particular, the effort to attain epidemic control within this decade, has been successful in large part because it has been data-driven. Resources have been directed to countries based on the need to focus investments in geographic areas and populations with the greatest HIV/AIDS burden. The information being used for decision-making in these efforts relies heavily on data coming from population and housing censuses (PHCs). This makes a high-quality census imperative to data-driven HIV/AIDS programming and reaching UNAIDS Fast-Track targets (UNAIDS, 2018).² Further, census data are critical as the basis for other large-scale household surveys that provide fine-grained information on various determinants of HIV and other health outcomes.

Long-term programmatic success depends on having an accurate assessment of the state of the epidemic and the identification of people in need of prevention, testing, and treatment services. Recent population counts are critical for obtaining accurate estimates of population size and its composition by age and sex (Figure 1).

¹ This technical note is part of a series on *Select Topics in International Censuses* that explore matters of interest to the international statistical community. The U.S. Census Bureau helps countries improve their national statistical systems by engaging in capacity building to enhance statistical competencies in sustainable ways.

² The UNAIDS Fast-Track targets for 2030 are fourfold: (1) 95 percent of people living with HIV knowing their HIV status, 95 percent of people who know their status receiving treatment, and 95 percent of people on HIV treatment having a suppressed viral load; (2) 200,000 new HIV infections or fewer each year; (3) zero HIV-related discrimination; and (4) eliminate new HIV infections among children.

Population-based counts form the appropriate denominators for measuring both program coverage and the impact that the national program had on the HIV epidemic.

Population-based denominators are more representative of the population of interest than program-based indicators such as the number of women on treatment; using program-based denominators to measure coverage risks excluding individuals who do not know their HIV status and are not receiving HIV services. This technical note helps to highlight the importance and use of census data in generating HIV/AIDS statistics, key to attaining epidemic control.

Key Indicators to Measure the HIV Response

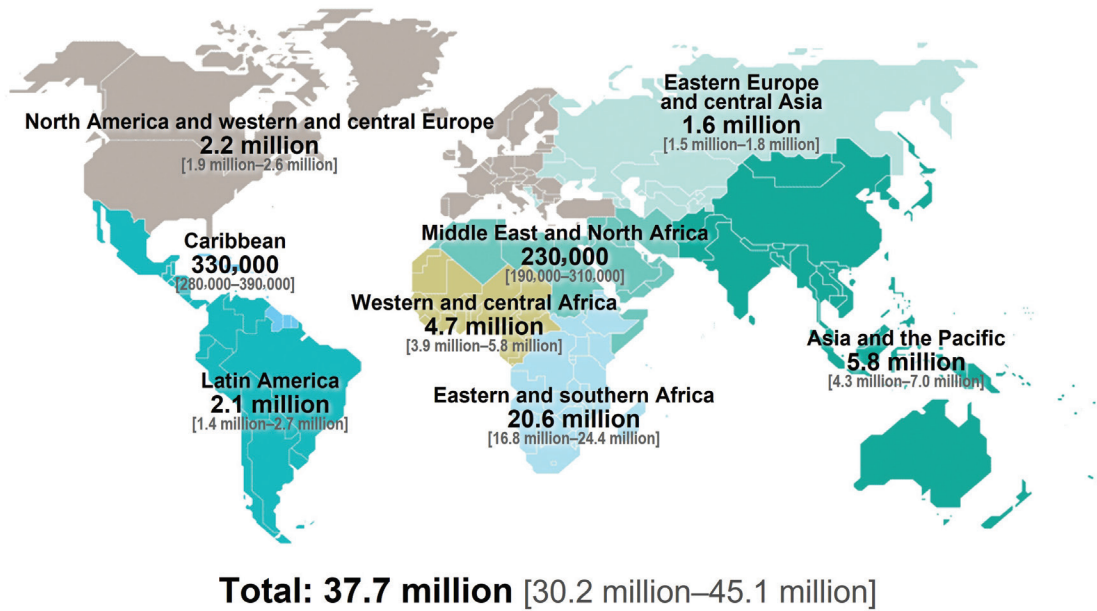
Indicators to measure progress towards the UNAIDS Fast-Track targets include:

- The number of people living with HIV (PLHIV).
- The number of new HIV infections.
- Known status and linkage to treatment.
- Viral load suppression.

All UNAIDS targets rely on accurate and up-to-date estimates of PLHIV. Age-sex disaggregated PLHIV estimates require population data obtained from PHCs. These population counts can then be combined with HIV prevalence data from nationally and subnationally representative surveys to obtain estimates of PLHIV (Figure 2).

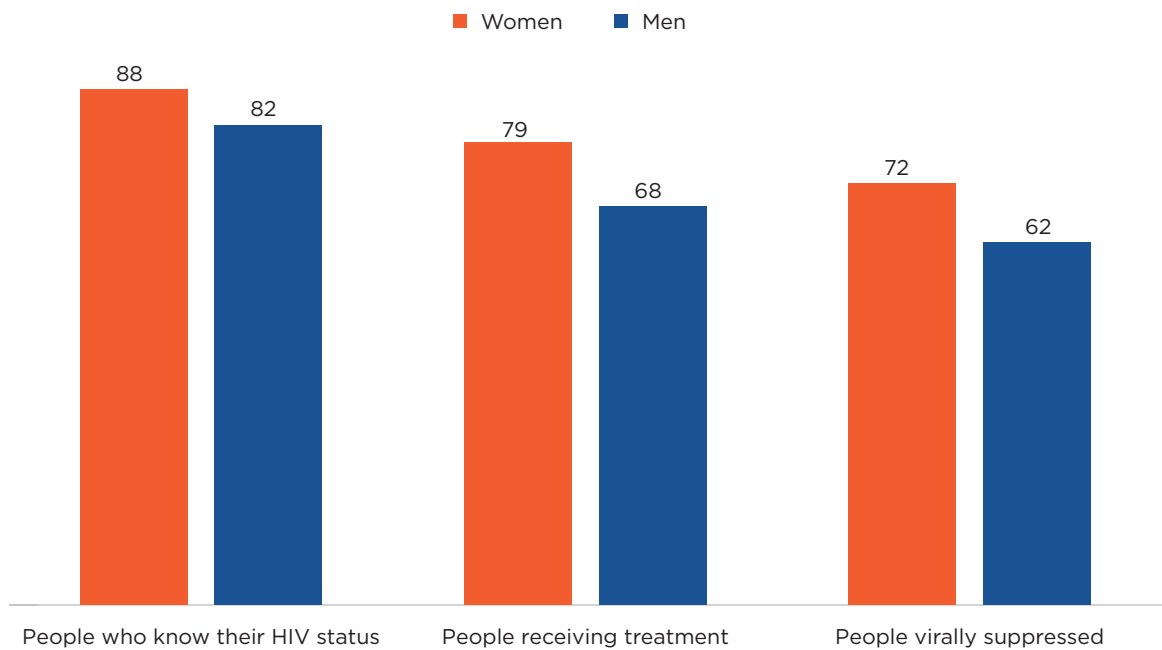
In spite of a global expansion of HIV testing, including increases in self-testing and index testing of the partners

Figure 1.
Adults and Children Estimated To Be Living With HIV: 2020



Note: Map reprinted from United Nations (UN) source. UN and U.S. representations of international boundaries do not align in all cases. Map is shown for informational purposes only and does not reflect U.S. government policy. Lower and upper bounds of estimates are shown in brackets. Source: United Nations Programme on HIV and AIDS, 2021.

Figure 2.
Percentage of Female and Male People Living With HIV Aged 15 and Older Who Know Their HIV Positive Status, Who Are on Treatment, and Who Are Virally Suppressed: 2020
 (In percent)



Source: United Nations Programme on HIV and AIDS, 2021.

and children of PLHIV, many individuals still do not know that they are HIV positive. This makes it impossible to count the total number of people who are HIV positive, who are newly infected with HIV, or who have died from AIDS-related causes. These complications make it impossible to directly measure many HIV indicators. For this reason, modeling in the HIV/AIDS research space is vitally important for truly understanding the epidemic. Model-based indicators include:

- PLHIV who know their HIV status.
- PLHIV on treatment.
- Infant treatment prophylaxis coverage.
- Treatment coverage among pregnant women.
- Outcomes of interventions to prevent mother-to-child transmission of HIV.

These indicators are modeled using software, such as the Spectrum AIDS Impact Model (AIM) (Avenir Health, 2022), the Estimation and Projection Package (Eaton et al., 2019), Shiny90 (Maheu-Giroux, 2019), and Naomi (Eaton et al., 2021). These models require accurate and timely population and demographic data as inputs and are typically obtained from censuses. For example, all calculations in the AIM model are based on demographic data outputs from DemProj, the demographic and population projection model within Spectrum. Data inputs into the Spectrum DemProj model that are derived from censuses include population size by age and sex, urban/rural population, number of women aged 15–49 who are in union, percentage of childless women aged 45–49, estimates of life expectancy, and migration.

Direct Uses of Census Data for HIV Programming

Successful HIV programming focuses on the individuals most at risk of acquiring and spreading HIV, including priority and key populations.

Priority populations for HIV prevention are those most vulnerable to HIV infection and present the greatest risk of infecting others, which include:

- Adolescent girls and young women (AGYW).
- Children and adolescents.
- Pregnant and breastfeeding women.
- Orphans and vulnerable children.
- Uncircumcised men.

The size of various priority populations can be calculated using routine census data at either the national or subnational level and is used for measuring coverage, assessing need, and setting targets for programming. Population size estimates derived from current censuses can also be projected forward to account for population

Box 1.

Estimating Count of Transgender Individuals and the Census

Size estimations of transgender individuals are often difficult to obtain. However, transgender and nonbinary individuals are increasingly included in census data. The 2011 census in India included three codes for recording gender: male, female, and other.¹ The 2019 census in Kenya included a category for intersex.² The 2021 census in Canada included questions on sex at birth as well as gender identification, allowing for the enumeration of transgender and nonbinary individuals.³

¹ Mandal, C., P. Debnath, and A. Sil, “‘Other’ Gender in India: An Analysis of 2011 Census Data,” 2018.

² Kenya National Bureau of Statistics, “2019 Kenya Population and Housing Census Volume I: Population by County and Sub-County,” Nairobi, Kenya, 2019.

³ Statistics Canada, “Filling the Gaps: Information on Gender in the 2021 Census,” available at <<https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0001/982000012021001-eng.cfm>>, accessed April 29, 2022

growth over time. Accounting for these demographic shifts over time is vital to ensure the proper forecasting of programmatic need. For example, to project future needs in pre-exposure prophylaxis implementation among AGYW, the current number of adolescent girls and young women can be projected to the desired year of implementation (UNAIDS, 2021).

Key populations are individuals who, due to specific higher-risk behaviors, are at increased risk of HIV infection. The size of key population groups, such as men who have sex with men, commercial sex workers, people who inject drugs, and transgender individuals, are more difficult to directly measure using census data (Box 1). These populations require behavioral information that is not routinely asked in censuses. However, many key population-size estimation methods use census population counts as a starting point, especially when nationally representative behavioral data are available. If the behavioral data exist as a population percentage, then this percentage can be multiplied by the census projections to obtain a total size estimate. For example, to obtain the number of clients of sex workers, the proportion of male respondents who reported buying sex can be multiplied by the census denominators for men aged 15–49 (UNAIDS, 2010).

Direct measurements of AIDS-related mortality are also difficult to obtain. Routine vital registration data are still of poor quality in many low- and middle-income countries, so modeling remains the gold standard. One method for measuring AIDS-related mortality is a system using verbal autopsy to assess cause of death. Many censuses include a question about household deaths occurring in

the past 12 months before the census reference date. A special follow-up, post-census survey of households with reports of those recent deaths can be conducted to assess cause of death (World Health Organization and UNAIDS, 2014). Following the 2007 census in Mozambique, verbal autopsies were conducted in a sample of households with recent deaths to measure AIDS-related mortality (Mozambique National Institute of Statistics et al., 2012).

Finally, PHCs provide the sampling frame used for nationally representative surveys, including the Population-Based HIV Impact Assessments and Demographic and Health Surveys. These two surveys can provide nationally and subnationally representative data on the status of the HIV epidemic, including the programmatic impact of HIV prevention and treatment programs. The surveys combine sociodemographic and behavioral information, HIV testing

and measurement of HIV viral load, and information on the uptake of HIV treatment and prevention services. The survey data estimates the prevalence of people living with HIV and the incidence of new HIV infections, and when combined with census data, the number of people living with HIV, and the number of new annual HIV infections.

CONCLUSION

Access to data has been key to measuring, monitoring, and reducing the global AIDS burden. Data from PHCs provide crucial denominators for measuring both program coverage and the impact that the national program has had on the HIV epidemic. Furthermore, representative surveys on the AIDS epidemic rely on drawing their sampling frame from census data.

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