COUNTING TRANS PEOPLE IN
Advancing Global Data Collection on Transgender Communities and HIV
Acknowledgments

This document is produced by the IRGT: A Global Network of Transgender Women and HIV (IRGT). The IRGT works with trans organizations, communities, and advocates around the world. Its members are transgender advocates with extensive experience in different world regions, including Africa, Latin America, North America, South and Southeast Asia, and Europe. Members have a wide range of skills, knowledge, and experience, including HIV, human rights, high-level advocacy, strategic planning, and programming and service delivery for transgender communities.

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Introduction

Trans (transgender) people exist in all societies and almost universally face stigma and discrimination that contribute to health inequities. Trans people are often highly visible and yet have been made invisible in most research and data collection. Trans advocates have long challenged this erasure, emphasizing the “right to be counted”—a critical right in an increasingly data-driven world.

An effective response to HIV epidemics among trans people requires high-quality data collection on the burden of disease across subpopulations, determinants of HIV risk, access to prevention and treatment, and structural factors that enable or hinder the HIV response. This brief aims to (1) review the current state of quantitative data collection on trans people and HIV globally, (2) assess data collection methods in use with trans populations, and (3) provide recommendations for improving data collection. It was developed by International Reference Group on Transgender People and HIV/AIDS, a global network of trans women that advocates for trans issues in the global HIV response. It is based on a review of existing publicly available data and interviews with stakeholders involved in collecting, analyzing, and using data on trans people and HIV. The brief focuses on descriptive population health data, but its recommendations are applicable across the full spectrum of data collection. It is intended to provide guidance to policy-makers, donors, researchers, health sector staff, and trans communities.
Executive Summary

Available data on the health of trans communities clearly demonstrate profound inequities, including an incredibly high burden of HIV among trans women who have sex with men and widespread human rights violations. While data collection on trans people is increasing, research has been concentrated in the global North. Data are largely absent across large swaths of the globe. A systematic review of peer-reviewed research on trans health published between 2008-2014 found 116 studies from 30 countries: over half were from the United States of America, and no other country had produced more than five studies. Published studies were unavailable for most of Africa, Central and Eastern Europe, Central Asia, and China. Trans men are particularly under-researched and under-counted: about three-quarters of published studies focused on trans women. Where data on trans people do exist their quality is often low, and inconsistent collection practices limit interpretability and utility.

High-quality disaggregated data on trans health and HIV are urgently needed at regional, national, and sub-national levels, including data on the social, legal, and political environments that may facilitate or impede an effective response to HIV. UNAIDS has set ambitious HIV treatment targets for the year 2020: for 90% of people living with HIV to be aware of their diagnosis, 90% of those diagnosed receiving sustained anti-retroviral therapy (ART), and 90% of those on ART achieving viral suppression. Without substantial scale-up of data collection—and intervention—on the continuum of HIV care in trans populations, it will be impossible for these targets to be met for trans people.

Researchers, monitoring and evaluation officers, community programmers, health care providers, donors, and policy-makers—all have critical roles to play in improving data collection on trans health and HIV globally. There remain challenges to data collection with trans populations, some of which are shared with other key populations and others that are unique. Foremost among these challenges are stigma and discrimination, which impact both the ability to collect data in trans communities and the political
will to do so. There are also methodological challenges, including measuring gender identity cross-culturally, sampling methods, and disaggregating data to the level of granularity required. However, strategies to address some of these challenges already exist. To begin improving data collection on trans communities and HIV, we make the following recommendations:

1. **Guided by trans communities, collect and report disaggregated data on the continuum of HIV prevention, care, and treatment among trans people.** This requires measurement of both gender identity and assigned sex at birth in all data collection efforts.

2. **Do not pool data from trans women and men who have sex with men.**

3. **Collect data on trans men’s health needs, including but not limited to HIV.**

4. **Carry out trans-specific research.**

5. **Engage trans communities in developing and implementing data collection activities.**

6. **Synthesize and disseminate the evidence we already have.**

7. **Develop technical guidance for trans data collection.**

8. **Adequately fund trans data collection and hold funding recipients accountable for trans inclusion.**

**Key terms**

*Trans or transgender* is an adjective for individuals whose gender identity and/or expression vary from social expectations for their birth-assigned sex. It includes *trans women* and *trans men*, as well as *gender-nonconforming*, *genderqueer*, or *non-binary* individuals who identify as neither female nor male. *Trans women* are individuals who were assigned a male sex at birth and identify as female or feminine. *Trans men* were assigned a female sex at birth and identify as male or masculine. *Transfeminine persons* and *transmasculine persons* are alternative terms for trans women and men, respectively. We do not use or recommend terms that emphasize birth-assigned sex over gender identity, such as “male-to-female” or “female-to-male”. *Transgender* is distinct from *intersex*, which is a term for individuals born with biological sex characteristics that are not typically male or female. *Cisgender* is the opposite
of transgender, and is an adjective for individuals whose gender identity matches their assigned sex at birth.

Transgender and related terms are rooted in Euro-American conceptions of gender, although they are increasingly used globally. Many other culturally-specific terms for trans people exist including, but not limited to: hijra (India, Pakistan, and Bangladesh), kathoey (Thailand, Laos), waria (Indonesia), meti (Nepal), transpinay (Phillipines), fa’afine (Samoa), two spirit (Indigenous North America), muxe (Mexico), travesti (Latin America), shost (Tanzania), baboi (Zambia), stabane (South Africa). These terms are not necessarily interchangeable with trans, and may or may not be preferred by community members—they may even be offensive in some cases. Local community consultation is required to ensure terminology is respectful and accurate.

What data are currently available?

How many people are trans?

The estimated size of a population affected by HIV informs resource allocation and provides the denominator required for assessing the extent of service coverage and the impact of interventions. For populations that face stigma and are not easy identified through traditional demographic methods, size estimation is challenging. In high-income countries, a few population-based surveys have included items to identify trans and/or gender non-conforming individuals, finding that between 1 in 100 and 1 in 1000 people could be classified as trans. In Nepal and India, “third gender” options were added to the 2011 census. In theory, population-based surveys and censuses are the most sensitive way to collect population size data. However, they will only capture individuals willing and able to disclose their trans status to an interviewer and therefore surely underestimate the size of trans populations.

As part of the HIV response, program data, surveys, and mapping exercises are employed to generate estimates of the size of key populations at high risk of HIV. As all available methods have limitations, they are ideally used in combination to generate a range of size estimates. In Asia and the Pacific, some countries have publicly reported trans population
size estimates, but details on the methods used are scarce. While it is usually unclear which subpopulations were included, available information indicates that most estimates are based only on trans women, and often only those who are sex workers. As a proportion of the 15- to 64-year old population of each country, reported estimates vary widely, from approximately 8 per 100,000 (India) to 164 per 100,000 (Thailand). Stakeholders interviewed for this brief thought that the implementation of most existing population size estimates was of low quality. Invalid, unclear, or inconsistent population size estimates lead to faulty conclusions about the magnitude of HIV burden and success of the HIV response, and make it more difficult to obtain funding for trans health and HIV programs.

What is the burden of HIV among trans women?

Basic epidemiological data, while insufficient on their own, are a necessary starting point. A meta-analysis of peer-reviewed reports on laboratory-confirmed HIV seroprevalence among trans women from 2000-2011 estimated that globally, 19.1% of trans women were living with HIV. Data were only available for five high-income and ten middle-income countries with male-predominant epidemics. Within countries, data are concentrated in a small number of urban locales. HIV incidence estimates (the number of new infections over a given time period) for trans populations are incredibly rare despite their superiority for monitoring the evolution of HIV epidemics.

In addition to peer-reviewed research, many countries report national or sub-national estimates based on Integrated Behavioral and Biological Surveys (IBBS) and sentinel surveillance with key populations, explicitly including trans people in some cases. Beginning in 2014, the UNAIDS Global Progress Reporting program added optional disaggregation by transgender status (but not disaggregated by birth-assigned sex) to the indicators requested for sex workers. As of December 2015, reported data for trans sex workers could be located for 22 countries—all but one in Asia and the Pacific or Latin America. These data are sometimes challenged by small sample sizes and unclear operational definitions of trans sex workers.
The following section summarizes the availability of data on the HIV disease burden among trans women in each major region. Given the particular lack of data on HIV among trans men and gender non-conforming people, they are addressed separately on page 12.

Trans-specific quantitative studies have not yet been conducted in East, West, Central, or Southern Africa, and trans people have most often been overlooked in HIV data collection across the continent. However, data are available from recent studies focused on men who have sex with men (MSM) that include questions about both sex assigned at birth and gender identity. Wherever these questions have been asked, researchers have found that anywhere from 8-25% of study participants report being assigned male at birth, but in fact identify as women. In the Middle East and North Africa, trans-specific quantitative data are unavailable, and studies that have included trans women have failed to disaggregate data. Therefore, no data on HIV among trans people are publicly available from the MENA region. It is likely that some of the data reported for “male” sex workers and MSM are in fact from trans women.

**BOX 1: Data Collection in West and Southern Africa**

Data that allow for separate analysis of trans respondents have been collected in at least seven countries in West and Southern Africa: Burkina Faso, Côte d’Ivoire, Gambia, Lesotho, Malawi, Swaziland, and Togo. In recent respondent-driven sampling studies of individuals who were assigned a male sex at birth and who have sex with men in three West African countries, participants were asked to describe their gender identity (S. Stahlman & S. Baral, personal communication, 4 Dec 2015). Consistent with previous findings in the region, trans women comprised 17% of participants, and had higher HIV prevalence. Contrary to some assumptions, female identification was independent of sexual position (i.e., trans women were not necessarily receptive partners in anal intercourse). Very few identified with the term “transgender”, but rather identified as women, highlighting the importance of “two-step” assessment of sex assigned at birth and current gender identity. Inclusion of two-step measures across countries enabled separate analyses focused on trans women, using data pooled across sites. Stakeholders noted that as trans communities in the region increasingly form autonomous organizations and social networks, trans-specific research becomes more feasible. In 2016, a bio-behavioral survey on HIV prevalence among trans women will be conducted in three South African cities, in partnership with local trans organizations.
In Asia and the Pacific, available data are concentrated in South and Southeast Asian low- and middle-income countries, and such data are often collected as part of MSM-focused studies. While only a few trans-specific studies have been fielded in countries including Thailand and India, the amount of trans-specific research in the region is growing. However, only a handful of studies related to HIV among trans women are available in China in most of the region’s high-income countries, and in the Pacific. A number of countries (Bangladesh, Cambodia, Fiji, India, Indonesia, Laos, Malaysia, Pakistan, Papua New Guinea, Philippines) have reported HIV prevalence estimates for trans (women) sex workers. Interpretation of data from this region is challenged by a multitude of trans identities, and the overlap between some of those identities and non-transgender, sexual minority identities.

**BOX 2: Collecting Data on Gender Identity in Nepal**

Despite inclusion of a “third gender” option, Nepal’s 2011 census failed to produce usable data on trans people due to limited training and stigma among enumerators. In response, the Williams Institute at the University of California, Los Angeles and Nepal’s Blue Diamond Society (BDS) partnered to implement a survey of Nepalese sexual and gender minorities. Manisha Dhakal of BDS explains that although the term third gender refers to trans people, it is often applied to all LGBTI (lesbian, gay, bisexual, transgender, intersex) people in Nepal. The survey assessed self-identification, behaviour, and attraction related to gender and sexuality, using both Nepali and English terms. Among 1,178 respondents, 21 identity terms were used. The majority of respondents identified with a term that references gender non-conformity, and about half identified with the term third gender. Given that some sexual minority (e.g., lesbian or gay) individuals may have described themselves with this term, it is difficult to disaggregate the data by trans status. It appeared uncommon for people to express binary cross-sex identities; all but one of the participants who identified their gender as “male” or “female” were assigned that sex at birth. The Nepali experience underscores the need for methodological research on measuring sex and gender and identifying trans respondents across diverse cultures.
Almost no data are publicly available on HIV among trans people in Eastern Europe and Central Asia, with the exception of a single HIV prevalence data point reported in Serbia for 2013. In the absence of appropriate measurement of gender identity, data on trans people are likely conflated with data from MSM. A recent study of MSM and trans women in Mongolia inquired about assigned sex at birth and gender identity, and found that 11% of participants were trans.

Despite a long tradition of medical and psychological research on trans people in Western Europe, surprisingly limited data exist on the burden of HIV among trans people in Western and Central Europe. In a meta-analysis of HIV sero-prevalence research published from 2000-2011, the only countries in the region with data available were Italy, the Netherlands, and Spain. All were samples of trans women sex workers, primarily immigrants from Latin America. Trans people are most often invisible in HIV surveillance data. Stakeholders described having to rely on data from the United States, which are unlikely to generalize to Europe. However, data collection on current gender identity was recently added to HIV surveillance in the United Kingdom, and will be introduced to public sexual health services in 2016.

The majority of research on transgender health and HIV has been conducted in North America, primarily in the United States of America. Nevertheless, most data come from a few large urban centers, particularly Los Angeles and San Francisco, California, where many studies have been conducted and public health surveillance data for trans women are the most extensive. The U.S. Centers for Disease Control collect disaggregated data on trans people at CDC-funded testing sites, and have added an optional current gender identity field to their case reporting tool for state governments. California, Michigan, and New York State collect and report gender identity data, but efforts are required to improve ascertainment of sex and gender in testing encounters. In Canada, only self-reported prevalence data are available. Finally, substantial amounts of data are collected in administrative and programmatic databases held by government agencies, but only a fraction are publicly available.

Data collection on trans people and HIV occurs in many countries in Latin America, while quantitative data are almost entirely absent for the Caribbean. Most data are collected as part of MSM-focused studies, but trans-specific studies have been conducted in Brazil, El Salvador, Mexico, and Peru. Country reports to UNAIDS include HIV prevalence estimates for trans sex workers in Argentina, Bolivia, Colombia, Ecuador, Guyana, Honduras, Mexico, Panama, Paraguay, Peru, and Uruguay. Data are primarily available from urban areas in these countries, and sample sizes are sometimes inadequate (e.g., 62 in Managua, Nicaragua). Interpretation of existing data is challenged by conflation of trans women and trans sex workers.
What is the burden of HIV among trans men?

Trans men have been excluded from HIV-related data collection in most of the world, with the exception of small studies focused on trans men in North America. Promisingly, small samples of trans men who have sex with men have been included in some recent MSM studies beyond North America. Where data do exist on HIV prevalence among trans men who have sex with men, self-reported HIV prevalence is often higher than among other reproductive-age adults. Moreover, trans men may belong to other key populations, such as sex workers and people who use injection drugs. In countries with generalized epidemics where sexual violence affecting trans men is prevalent, HIV risk may be elevated for trans men of all sexual orientations. In 2014 guidance, UNAIDS recommended data collection for both trans women and men. Nevertheless, stakeholders reported that HIV-focused donors discouraged or disallowed them from extending their outreach or data collection efforts to trans men. In the many countries where trans programs are entirely funded by HIV donors, trans men are in effect excluded from all trans health research.

What is the burden of HIV among gender non-conforming people?

Disaggregated data are scarce for trans people who identify as neither men nor women. Many forms or questionnaires that do identify trans people only have options to identify trans men or women. Community-based data collectors will sometimes allow individuals to “write in” a gender identity of their choosing. These data can be difficult to categorize, and the need for quantitative data summaries often results in collapsing trans participants into two groups based on assigned sex at birth. When sample sizes have been sufficient to separate out those with non-binary identities, important differences have been found. For example, in a large U.S. trans survey, gender non-conforming people experienced higher levels of anti-transgender violence and were somewhat more likely to report being HIV-positive.
Disaggregation of data from sex workers

Many trans women living with HIV have never been sex workers, and many trans sex workers are HIV-negative. In addition, HIV risk is high among trans women who have sex with men regardless of sex work history, though higher among trans sex workers. However, it can be challenging to draw conclusions about the relative HIV burdens because data from sex workers and non-sex workers are infrequently disaggregated. Related to widespread discrimination and exclusion from the formal labor market, sex work is indeed common among trans women, particularly in Asia and Latin America, but is not universal. For example, estimates of the prevalence of sex work in Asia range from 36% in Cambodia to 90% in India. However, sampling methods that are most efficient for accruing samples of trans women are likely to over-represent sex workers, complicating interpretation. Sex work among trans men should also be considered; 7-15% reported sex work experience in some North American surveys.

What do we know about other key indicators for HIV prevention, treatment, and care?

Despite their limitations, data on HIV prevalence among trans women are relatively robust in comparison to data on other key issues. Recommended indicators for data collection in trans populations include: biological determinants of HIV transmission risk; sexual and injection risk behaviors; access to HIV and general health services; the HIV care continuum; and critical enablers for HIV prevention such as community engagement, access to justice, stigma, and violence. In most regions, data on these fundamental indicators are absent, limited, or of dubious quality. Across the following themes, stakeholders consistently identified need for systematic reviews and syntheses of existing data.
The HIV care and treatment continuum, from diagnosis to viral suppression.

Data on uptake of HIV and other sexually transmitted infection (STI) testing within trans communities have not been consistently collected or summarized. That the burden of HIV among trans women is much higher when laboratory-confirmed versus self-reported data are employed indicates substantial levels of undiagnosed HIV, and underscores the need to investigate barriers to testing. Coverage of testing for other STIs, particularly where more invasive screening is required (e.g., rectal or cervical swabs) may be even more inadequate among trans people, but few data are available. With respect to engagement and retention in HIV care among trans people living with HIV, in a 2014 review, no studies were found from outside the United States. In the U.S., some evidence suggests that trans women living with HIV may have poorer outcomes across the continuum of care, being less likely to be engaged and retained in care, to receive antiretroviral therapy (ART), be adherent to ART, and achieve sustained viral suppression.

Access to other health services. Outside of a small number of countries (e.g., Canada, Thailand, Laos, and the United States), data appear to be scarce on access to gender-affirming care including hormones and surgery. These are often the health care services of highest priority to trans communities, and have the potential to facilitate use of HIV services. Quantitative data are lacking in the very settings where access to gender affirming care is most restricted, such as countries where gender-affirming surgery is unavailable. Stakeholders highlighted the efforts of community organizations to fill these knowledge gaps, but noted the potential to collect these data as part of ongoing HIV surveillance and research. Data on access to, and experiences of stigma within, primary health care services have primarily been collected in North America.

Sexual and injection risk behaviors. Behavioral questionnaires used with trans populations often inquire about condom use for anal intercourse only. While most trans women do not have access to genital surgery, for those who do, HIV risk related to receptive vaginal intercourse is seldom captured. For trans men, this is especially problematic as much of their HIV risk appears related to vaginal intercourse. Few studies inquire about injection of drugs, hormones, silicone, or other soft tissue fillers. When hormone use or injection data are collected, binary assessment of hormone use
or injection is common. Data are needed on access to sterile injection equipment, risks associated with injection, sources of hormones (e.g., prescribed, purchased from the illicit market), and access to medical monitoring. These issues have been examined in a number of Southeast Asian countries, where the inaccessibility of medically supervised hormone therapy puts the health of trans people at risk, and in Latin America, where unsafe silicone injection is widespread.

**Critical enablers for the HIV response.**
Mapping of the legal, social, and political context for trans people varies greatly by region. Most publicly accessible data are from high-income countries, with some from Southeast Asia and Latin America. Data on violence, stigma, and discrimination—key indicators required to assess the potential for an effective HIV response—are often collected through community surveys. Greater resources for such community-led research and better integration with data collection on HIV-related outcomes are required. Lack of access to documentation matching one’s lived gender is the norm for most trans people globally, and may increase vulnerability to HIV and limit access to care. Yet, with few exceptions, access to identification is not currently considered in HIV-related data collection. Similarly, community-level protective factors for HIV risk such as collective efficacy are rarely assessed, within only one data point available in a low or middle-income country.
Methodological issues in trans data collection

Collecting high-quality data on trans health and HIV requires a culturally relevant operational definition of the trans population of interest, questions that allow for the identification and description of trans individuals, and a sampling strategy that can reach members of the defined trans population. The following section explores current practices and challenges in each of these areas.

Operational definitions of trans in diverse cultural contexts. There are a number of ways in which a trans population can be defined for data collection: self-identification as transgender or a similar term, reporting a gender identity that differs from birth-assigned sex, using feminizing or masculinizing hormones, undergoing gender affirmation surgery, or changing one’s name and sex marker on identification. Each of these definitions will correspond to different, but overlapping, groups of trans people.

BOX 2: Disaggregating trans data in the iPrEx study

Representation of trans women in pre-exposure prophylaxis (PrEP) research has been relatively poor, but a new analysis of the iPrEx randomized controlled trial and open-label observational study (iPrEx OLE) shows that data were collected from more trans women than previously thought. The studies were conducted with individuals assigned male at birth in Brazil, Ecuador, Peru, South Africa, Thailand, and the United States. Gender identity was assessed with two questions by computer-assisted self-interview: (1) gender as male or female
identification as a man, woman, or transgender (travesti was later added in Ecuador to reflect local terminology). Feminizing hormone use was assessed at study visits. The authors conducted an analysis of PrEP efficacy, effectiveness, and adherence among trans women, defined as participants who met one or more of these criteria: identification as a woman; identification as trans; reported use of feminizing hormones. Dr. Madeline Deutsch of the Center of Excellence in Transgender Health at the University of San Francisco, California and lead author of the paper, explained:

“If you identify as a gay male but have presented as female every day for the last 15 years, you are experiencing social determinants of health and disparities related to [trans]gender identity and presentation, regardless of how you internally identify. We don’t want to force identities on people, but if someone is presenting as female we should group them based on their lived experience.”

175 trans women were identified in the first analysis of iPrEx OLE, and 192 in this analysis. Across both phases there were 339 trans participants (14% of all participants). Most of those individuals (86%) identified as transgender, with the remainder split between those who identified only as women, and those who were male-identified but used hormones. The study found that while PrEP was effective for trans women who used it, their adherence was lower than that of other iPrEx participants.

Comparing trans health and HIV data across settings is made difficult by the numerous definitions of “trans” or “transgender” employed. Ninety-five definitions were found in 116 studies from 2008-2014. Often, samples of “transgender women” could be more accurately described samples of trans women who are sexually active with cisgender men and/or sex workers. In light of the epidemiology of HIV, research focused on these subgroups should be prioritized. More precise descriptions of the populations under study, however, are important for ensuring that resources are allocated to groups that require them, and to acknowledge diversity among trans women.
In Asia and the Pacific, fluidity and overlap of culturally-specific gender and sexual identities is common, and thus it can be challenging to enforce rigid operational definitions of transgender. It is relatively straightforward to categorize people as trans if they identify as trans, transgender, or as women assigned male at birth. It is less clear how to categorize people who identify, for example, as “long hair MSM” in Cambodia, particularly in the absence of an a priori definition of the trans population of interest. Stakeholders from the region observed that in some settings (e.g., in some Pacific nations) communities do not differentiate between sexual and gender minorities, and find the distinction requested by researchers to be an imposition. On the other hand, in South Asia, “hijra” and “transgender” are often used interchangeably in data collection and reporting, but these do not describe equivalent concepts or populations. In the South Asian context, it is important to decide whether and how to include those who are part of gender non-conforming spiritual or cultural traditions, and may not be connected to trans networks.

**Questions to identify trans people in data.** Many reports on data collection activities with trans people provide no details on how trans people were identified and categorized. Stakeholders reported that many ongoing research and surveillance activities continue to use suboptimal methods for identifying trans individuals. For example, they may ask if participants in an IBBS survey of people assigned male at birth identify as “gay, bisexual, or transgender”, despite the fact that a person may identify as both transgender and gay or bisexual. In many countries, identification with the term “transgender” is relatively rare, so this type of question will result in substantial misclassification of trans people. In addition, trans people may be hesitant to disclose their trans identity or history of gender transition due to stigma, and/or because they live as men or women and consider gender transition an irrelevant detail of their past. While these obstacles to ascertaining trans status cannot be entirely overcome in a stigmatizing social environment, they can be mitigated through careful and respectful data collection practices.
The current best practice for ascertaining gender identity and trans status is known as the “two-step method”, in which both sex assigned at birth and current gender identity are assessed. This method has high sensitivity (correctly identifies trans respondents) and specificity (does not incorrectly identify cisgender people as trans) with adults in the United States. It identifies individuals who describe themselves with trans-specific terms, as well as those who have a cross-sex identity (e.g., identifies as male but assigned female at birth). Inquiring about gender identity before assigned sex may enhance comfort for trans respondents, and thus improve data quality.

Stakeholders described successful use of this approach for identifying trans respondents in broader population surveys, categorizing gender identity and birth-assigned sex in trans-only samples, and collecting data in clinical settings for surveillance or administrative use. This method has been formally evaluated in the United States, and among trans people and MSM using Spanish and Portuguese sexual networking websites. Stakeholder consultation and qualitative research are required to identify which gender identity options should be offered, based on local terminology. Instructions to respondents should also be developed and evaluated for clarity (for example, to explain what is meant by “gender”). Depending on research aims, questions on other gender and sex characteristics (e.g., hormone use, gender presentation in daily life) may be essential for interpreting findings. Questions to be used in studies that include cisgender individuals require validation in cisgender populations as well; to avoid misclassification, measures need to be simple and clear.

**Sampling and data collection methods.** Probability-based samples such as random household surveys are the gold standard for sampling, but are not feasible for trans health research in most settings. In research with key populations, adaptive probability-based sampling methods have been introduced, in the forms of time-location sampling (TLS) and respondent-driven sampling (RDS). The details of these methods are described...
elsewhere. RDS has been used more frequently with trans populations, and while not perfect, likely introduces less bias than TLS. The latter relies on recruitment in venues with high traffic from the target population, which for trans women, are often sex work venues. RDS has been successfully used in studies of trans people in Canada, and trans women in the United States, Peru, and Brazil. Trans women have also been recruited through RDS studies focused on MSM, providing valuable information in settings where trans-specific data are unavailable. However, in addition to other limitations, sampling trans women through MSM networks will exclude those who are not connected to MSM, such as those who have transitioned and do not disclose their trans history publicly. Partially addressing this concern, in some cases, trans women have been intentionally selected as “seed” participants.

Most trans health and HIV research continues to rely on convenience sampling from community organizations, social networks, and health services. Sample sizes for these studies are often unacceptably small. For instance, in two meta-analyses conducted in the past decade, sample sizes were smaller than 100 in 40% and 48% of included studies. Large, online surveys are increasingly feasible and have been carried out with trans communities across North America, Oceania, and Western Europe. However, analysis of mixed-mode (online and in-person) data collection suggests that online-only surveys will under-represent trans people most at risk of HIV. Self-administered or complex questionnaires may also lead to under-sampling of trans people who have low literacy in the language of administration.
Recommendations


Local trans communities must be meaningfully engaged to ensure that data collection approaches are respectful, acceptable, and do not threaten the safety of trans people. Access to health services and freedom from violence and criminalization must be prioritized over data needs.

Considerations for collection

a. Include fields for both current gender identity and assigned sex at birth in all data sources that contribute to estimates. Trans people can be identified as those who indicate a gender identity that differs from birth sex, whether or not they identify with a term such as transgender. For example, a trans woman might report her gender identity as “female” and her birth-assigned sex as “male”.

- Consult with communities to determine appropriate response options for gender identity. Recommendations for the United States are available, and potentially suitable for similar cultural contexts.

- Add definitions of gender-related terms to manuals and implementation instructions, and provide training to data collectors on asking these questions.
b. Inquire directly about sex work status whenever possible; do not automatically categorize all trans women as sex workers.

c. Population size estimation should be undertaken following best practice, ideally employing multiple methods for triangulation. The safety of community members is paramount, and specific issues for sex workers must be considered and addressed before undertaking enumeration research. Size estimates should be reported alongside details regarding excluded subpopulations and methodological limitations.

Considerations for analysis and reporting

a. Whenever possible, report data disaggregated by gender spectrum (assigned male versus female at birth, or trans women and men), age group, and sex work status. Where HIV burden and outcomes are known to vary by race/ethnicity, report data disaggregated by relevant racial and ethnic categories. Do not collapse data for trans women and men.

b. In all publications, describe the questions or data elements used to identify trans individuals.

c. To maximize sample size, consider combining data across time points and jurisdictions. Consistent wording of questions to identify trans respondents will facilitate data pooling.

2. Do not pool data from trans women and men who have sex with men (MSM).

Trans women are women, and not a subgroup of MSM. Their networks may overlap with those of MSM, particularly in settings where autonomous trans networks are newly emerging. However, trans women accessible via MSM networks represent an unknown fraction of the total trans population. Therefore, we recommend trans-specific data collection whenever possible (see Recommendation 4). Irrespective of how data are collected, they should be disaggregated in analyses using gender identity and birth-assigned sex variables. In addition to making trans women and their health needs invisible, aggregated analyses of data from MSM and trans women reduce the quality and validity of data on MSM, and may inflate estimates of HIV prevalence among MSM.

3. Collect data on trans men’s health needs, including but not limited to HIV.

Trans men are excluded from trans health research in many countries because they are believed to be at low risk of HIV. There is little evidence to support this claim, precisely because trans men have been excluded from research. Regardless of their level of HIV risk, data collection is needed on the myriad health issues facing trans men (e.g., mental health). When broader health
and social data are being collected from trans people, exclusion of trans men runs counter to the principle of holistically addressing health and development challenges.

Trans men who have sex with men may identify with and participate in MSM communities and sexual networks, and should be considered for inclusion in MSM data collection using the “two-step” method. Trans men should be consulted in decisions regarding their inclusion.

4. Carry out trans-specific research, employing explicit operational definitions of “transgender” (or alternative culturally-specific terms) that are concordant with local community definitions.28

Consider network-based sampling methods such as respondent-driven sampling, instead of venue-based recruitment. The need for larger samples of trans people has been widely noted, and trans-specific studies are the best way to accomplish this.

To increase acceptability and relevance, this research should consider HIV alongside other health conditions. Specific topics for such research should be based on globally recommended indicators as well as community data needs and priorities, but could include:

- Discrimination, violence, and access to justice: these are community priorities and must be addressed to enable successful HIV prevention and treatment
- Access to gender-affirming care, including in relation to HIV risk and the care continuum
- Encounters with anti-transgender stigma in health services
- Socioeconomic conditions that may potentiate or reduce HIV vulnerability, including housing situation, family support or rejection, employment, and income

5. Engage trans communities in developing and implementing data collection activities.

Trans people should be meaningfully involved at all stages of data collection, from conceptualization to presentation of findings. As part of the ethical review process for proposed research, community involvement should be assessed and mandated. Meaningful involvement requires soliciting and incorporating feedback on research aims and outcomes to be measured. Even if some outcomes are pre-determined, questions can be added to address community priorities. Community engagement is the best way to develop buy-in, which is critical for recruitment and promotion. Ideally, meaningful involvement will include creation of capacity-building and employment opportunities for trans people. This serves the dual purposes of economic empowerment and improving data quality.
6. Synthesize and disseminate the evidence that we already have.

With the exception of HIV prevalence among trans women, data on trans health have rarely been systematically synthesized and made available in accessible formats. Advocates, program implementers, and policy-makers would benefit from a searchable online database on trans health and HIV, including data on structural factors and critical enablers. Such a database should include summaries of limitations of these data to avoid over-interpretation by end users.

7. Provide technical guidance and assistance for trans data collection.

This will require investment in methodological research to understand how gender identities are described, and can best be measured, in diverse cultural contexts and languages. Recent investment towards enhancing the HIV response for trans people has resulted in a series of important and helpful programmatic and policy guidance documents. Each of these documents recommends greater quantity and quality of data collection, but detailed technical guidance and assistance will be required to realize these goals, particularly for monitoring and evaluation personnel who may be quite unfamiliar with trans communities. Such technical assistance might begin with training on trans issues for national health sector staff and others who will be responsible for carrying out trans-inclusive data collection.

8. Donors and funders: adequately fund trans data collection and hold recipients accountable for trans inclusion.

Stakeholders described being stuck in a cycle of invisibility and inaction: because of a lack of local data, some funders are reluctant to support trans-specific programs. Yet, such programs are required to create an enabling environment for data collection, and are best situated to support effective data collection (see Recommendation 5). Thus, funders should support data collection on HIV, alongside assessment of the social, legal, and political environment— prioritizing settings where data do not yet exist. Beyond supporting trans-focused research, funders can implement policies to require demonstration of trans inclusion (or a legitimate rationale for exclusion) to obtain research funding. Donors can invest strategically to enhance trans inclusion by requiring that recipients—be they organizations or governments—report on key indicators related to trans health.
References


The IRGT, a Global Network of Trans Women and HIV composed of members from diverse parts of the world, is responsible for initiating and promoting advocacy on trans health and rights as they relate to HIV/AIDS. The group is comprised of advocates, service implementers, researchers, and other health and rights experts from different regions of the world, including Africa, India, South America, North America, Asia, and Europe. The IRGT is hosted and supported by the MSMGF.

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