DATA.FI WHITE PAPER

Standardizing the Collection of Gender-Identity Data for HIV Programming

SEPTEMBER 2022

PEPFAR

USAID FROM THE AMERICAN PEOPLE

Data.FI Data for Implementation

Author:

Caitlin Showalter, MSGH, Senior Associate, Monitoring, Evaluation, and Learning, Data.FI, Palladium

September 2022

This publication was prepared by Caitlin Showalter.

Cover photo illustration by Denise Todloski

Suggested citation: Showalter, C. (2022). Standardizing the Collection of Gender-Identity Data for HIV Programming. Washington, DC, USA: Data.FI, Palladium

This report was produced for review by the U.S. Agency for International Development. It was prepared by Data.FI. The information provided in this report is not official U.S. Government information and does not necessarily reflect the views or positions of the U.S. Agency for International Development or the U.S. Government.

Introduction

USAID Ambassador Samantha Power recently shared her strategic vision for USAID, which emphasizes equity, the needs of those in the most marginalized groups, and making sure their/those voices are heard and acted upon. She called this inclusive development.

Like Power, we see an evolution in thinking around the world recognizing that gender identities are diverse, that gender minorities are often vulnerable in their communities, and that naming—and thereby giving visibility to—gender identities can support more inclusive development. Collecting specific, gender-inclusive data on a routine basis, in parallel with sex-disaggregated data, would be a big change for USAID-funded projects working on HIV and health.

I've been working in monitoring, evaluation, and learning (MEL) on the Data.FI project since its inception in 2019. Our primary focus is ensuring that program managers and decision makers have access to needed health data, that it is of high-quality, and that they use it to improve clinical outcomes for COVID-19 and HIV. During a recent conversation with a project team, my colleagues in Tanzania posed a thought-provoking question: "How do we capture gender-inclusive data on our registration forms used for workshops and trainings?" This got me thinking about gender identity and an individual's right to be represented in the way in which they identify.

With the release of the United States' first national gender strategy—the 2021 U.S. National Strategy on Gender Equity and Equality—and a revamping of our own gender strategy on Data.FI, I am curious how HIV projects can be more gender-inclusive in the work that we do and the data we collect.

What kind of data are we collecting related to gender identity for USAID-funded programs? Are we excluding people by only looking at sex and considering that to be adequately gender inclusive? Why is gender-identity data important? What data ***could*** we be collecting related to gender, and how would we ***use*** it?

Gender-Specific Terms

While sex is defined as the anatomical body in which we are assigned at birth—male, female, or intersex—gender is often constructed by society to describe the characteristics, roles, and norms of men and women (2). Gender identity is "a person's deeply felt internal and individual experience of gender, which may or may not align with the sex assigned at birth" (3). Some other gender-specific terms include:

- **Gender and sexual minorities:** everyone who doesn't fall into the heterosexual, male, or female categories (3)
- **Transgender:** an umbrella term used to describe an individual whose gender identity is different from their sex assigned at birth (3)
- **Cisgender:** a person whose gender aligns with the sex they were born at birth (4)
- **Nonbinary/genderqueer/gender nonconforming:** people who do not identify themselves or their genders into the categories of man or woman (4)

What is gender-inclusive data?

Gender data include “data disaggregated by sex (female/male) AND data that affect people based on their gender (e.g., woman, man, boy, girl, transgender, gender nonbinary and gender nonconforming people, and other gender identities)—exclusively or primarily” [1]. Gender-inclusive data collection goes beyond simply collecting data on men and women, to including specific gender identify data.

Where is gender identity data currently being collected?

The following official surveys and tools collect gender identity data:

- The people living with HIV (PLHIV) stigma index is a standardized tool used at the global level to “gather evidence on how stigma and discrimination affects the lives of people living with HIV.” The tool was developed to be used by PLHIV for PLHIV—recruiting data collectors who are HIV positive and other key populations (KPs) like transgender people and gender-nonconforming people who undergo data collection training grounded in gender sensitivity. Because the PLHIV tool collects gender-disaggregated data, studies have used this data to show that transgender people experience higher levels of stigma—a vital piece of knowledge for those developing and implementing HIV programs, as well as for program decision makers (7).
- The South Asia Census system now includes options for respondents to say they belong to an “other” gender category, separate from M/F, in census and voter rolls (7). Evidence showed that “continued focus and advocacy efforts by and for marginalized gender populations has resulted in changes in discriminatory practices and the inclusion of non-cisgender populations in national censuses” (7).
- The U.S. Department of State is the first federal government agency offering the “X Gender marker” on U.S. passports. The third gender marker is now available for non-binary, intersex, and gender non-conforming individuals on State Department public forms as “unspecified or another gender identity” with the intent to respect individuals’ privacy and advance inclusion (8).

Today’s gender environment

GENDER REPRESENTATION IN PEPFAR MER INDICATORS

Ensuring we reach groups disproportionately affected by HIV or that have been marginalized is paramount in global efforts to control the HIV epidemic. USAID uses performance monitoring indicator data to identify gender gaps [5] but collecting gender-identity data isn’t yet standardized for USAID-funded projects. Current monitoring, evaluation, and reporting (MER) indicators for programs supported by the President’s Emergency Plan for AIDS Relief (PEPFAR) are disaggregated by sex, but not by gender identity.

Some MER indicators are disaggregated by key populations – defined as persons disproportionately affected by HIV (e.g., men who have sex with men, transgender individuals, sex workers, people who

inject drugs, and people in prisons and other closed settings), but indicator data for these groups are not further disaggregated by sex or gender identity [6].

Why is gender identity data important?

Considering the cultural and legal sensitivities surrounding gender minorities, and their high risk of discrimination and stigma, the data we collect on them, and their specific health needs, are important to understand. This is particularly true as we consider how gender expression or identity can vary across countries, cultures, communities, and at the individual level—particularly when thinking about "the appropriate terminology to accurately capture meaningful HIV M&E data for transgender clients" [9].

From a human rights perspective, we should all be entitled to the same rights and freedoms—including the representation of our individual gender identity. The United Nations Declaration of Universal Human Rights states that we are entitled to these rights and freedoms despite "race, color, sex, language, religion, political, or other opinion, national or social origin, property, birth, or other status" [10]. The UN Sustainable Development Goals also include two goals—gender equality and reduced inequalities—dedicated to ensuring fair representation and treatment of peoples [11]. Data.FI champions these rights in our gender strategy, and they inspire us to explore the capture of data on gender identity.

Recent efforts have recognized the importance of moving beyond capturing the sex of individuals. For example, in 2019, the USAID-funded MEASURE Evaluation project released a set of best practices for collecting gender data for HIV programs. The guidance notes the importance of capturing sex and gender identity in HIV service provision and highlights the need to continue to collect data on the sex people are assigned at birth (male/female) and gender identity [9]. We can also find a Key Population Classification Form for capturing gender identity data in the PEPFAR MER Guidance [6].

The prioritization of gender identity in national policy is illustrated through the recent development of the U.S. National Strategy on Gender Equity and Equality, the USAID Equity Action Plan, and the U.S. Department of State's new gender marker on U.S. passports. A 2021 policy brief by a PEPFAR implementing partner highlights the need for gender-disaggregated data in international development to ensure we capture quality data that is representative of cisgender, transgender, nonbinary, genderqueer, and gender-nonconforming peoples [7]. The 2021 U.S. National Strategy on Gender Equity and Equality contributes an entire section to measurement and data, noting the importance of U.S. and global tracking and measurement of systematic barriers faced by underserved populations, stating "adequate collection of gender data is critical to establishing a baseline against which agencies can rigorously measure progress on identified priorities," and promising to lead a government-wide effort to strengthen data collection and analysis of gender data, including gender identity data. It recognizes that "improvements in gender data collection are integral to advancing gender equity and equality worldwide" [12].

USAID's Equity Action Plan recognizes that "Missions often lack the specific expertise and resources required to program on inclusive development" and promotes strengthened accountability and protection of human rights and non-discrimination for services provided under USAID programs by "utilizing data collected on key issues on gender and LGBTQI [lesbian, gay, bisexual, transgender, queer, questioning, intersex] to establish baselines for diversity, equity, inclusion, and accessibility (DEIA) programming and protecting those at higher risk of experiencing discrimination based on sex, gender identity, sexual orientation, and other identity traits" [13]. Yet, there is little evidence that many USAID-funded projects have adopted or operationalized these processes.

Risks of collecting gender identity data

While there are many benefits to capturing and using data on gender identity, programs are sure to confront a variety of challenges if they choose to incorporate gender identity and gender-inclusive data collection into routine programming. Consider the following:

- **Context variability and resistance:** Cultural, religious, and political resistance surrounding gender identity and the collection of this data persist in many countries, and laws criminalize and persecute non-cisgender people [7]. Collecting data on gender identity could have legal or social backlash for individual clients of HIV services, depending on where they live and the values and beliefs in which their communities follow. Stigma, maltreatment, and ostracism towards gender and sexual minorities is prevalent in many parts of the world. It would be critical to avoid undue pressure on these groups to share information they are not comfortable sharing, and prudent to discuss with project country teams what is showing up on these issues in their country context to understand if gender non-conforming individuals want to be represented more broadly by gender identity within data.

- **Data collection and capacity:** Would the inclusion of a gender identity category on data collection forms be useful and inclusive, or inappropriate and unnecessary depending on the context? From a rights point of view, the inclusion of other gender categories on data collection forms seems important to ensure all people are properly represented. From a practical perspective, there are implications to consider on the nuances of language, standardization of how we define and measure gender identity, training, and capacity building for data collection on gender identity data, and on ensuring truthful responses. Understanding gender biases would be more important for service delivery and community-based work, where data collectors and programmers are interfacing with clients directly. There is evidence that clients trust data collectors whom they identify with and are comfortable around, and that this leads to higher quality data and more reliable interpretation of that data [7]. At the higher levels, stakeholders may be more concerned with consistency of terminology, reporting processes, and use of gender data.
- **Data security:** Safeguarding clients and maintaining data confidentiality throughout collection and storage is always a priority when collecting and using sensitive information in global health. How can we ensure inclusivity with confidentiality and proper safeguards and risk mitigation strategies Do programs have the human resource capacity, processes, and information systems in place to ensure data security, avoid data breaches, and ensure that safeguards are sustainable?

Data.FI promotes responsible and inclusive data

On Data.FI, we support PEPFAR and country decisionmakers to prioritize policy and program questions, identify the data needed to answer them, run the analyses, and build information systems to optimize the use of data for decision making and program improvement. How can we improve the meaningfulness and use of data in HIV programming?

On Data.FI we are already doing the basics—collecting, analyzing, and using age- and sex-disaggregated data aligned with USAID's ADS Chapter 201 and 205 [5]. In all our work, we advocate for responsible data collection, management, and use—including gender data.

- We supported the development of a safe, unique identifier in Uganda—a mobile and web-based application—to identify KPs and help them safely access HIV services.
- In Namibia, we estimated the size of KPs using available data sources like census and programmatic data to direct resources to the most needed locations and to support PEPFAR Country Operational Plan (COP) planning and national and subnational HIV programming.
- In Nigeria, we work on information systems that use gender-based violence (GBV) data and dashboards for analytics and are always looking for ways to further interoperate GBV and gender data with HIV data within the health information systems in which we work. But we want to do more.

Our gender strategy supports the collection, analysis, use, and dissemination of high-quality gender data of people-level MEL indicators [1]. It also supports the 2021 U.S. National Strategy on Gender Equity and Equality, which aims to address barriers faced by those in underserved and historically marginalized communities, including LGBTQI people, recognizing how gender data gaps can compound problems and diminish the effectiveness of programming and policy, and ultimately fail the populations we are seeking to serve [12]. How can our work help advance the capture and use of data for people identifying as nonbinary, genderqueer, gender expansive, or transgender?

Data.FI delivers gender-integrated solutions.

We are delivering solutions that address many of the risks mentioned above surrounding the capacity for responsible data collection, management, and use. Data.FI strengthens host country capacity to lead and sustain the national HIV and COVID-19 response through the development and use of robust and resilient HIV and COVID-19 information systems and digital solutions. We work with ministries of health and their partners to develop and build open-source technology solutions to provide impartial, evidence-based advice on policies and protocols—such as systems interoperability and data security—and work side-by-side with government counterparts to transfer leadership skills in data review, interpretation, and action planning.

TRANSFERRING LEADERSHIP SKILLS

Data.FI supports the transfer of leadership skills in data review, interpretation, and action planning, and support local digital health partners for systems development and curriculum development and training. These partnerships often involve assessing and strengthening local partners' organizational as well as technical capacity, with the aim of expanding the availability of local resources to promote sustainable, country-led solutions for achieving and maintaining epidemic control.

PRIORITIZING DATA SECURITY

We train in-country M&E partners on data protection—including data breaches, the risks and benefits of decision making related to data collection, and appropriate storage, digitizing, and safekeeping of paper records. We also support Missions to strengthen analysis and use of data for decision making, improve the quality of high-frequency HIV reporting, and orient teams on global guidance related to deduplication of data and data security for key populations (KPs). These solutions support USAID's goals for improving gender capacity at the Mission level, providing expertise in governance, capacity building, and development of gender-specific indicators, data collection tools, and local government training to use indicators, analyze them, and incorporate them into existing information systems to promote the regular collection of gender identity data.

"We decide, on issues large and small, whether we will be bystanders or upstanders."
— Samantha Power, The Education of an Idealist: A Memoir

Advocate for gender-inclusive data

There is clearly momentum for gender-responsive data collection and programming right now. Between the U.S. National Gender Equity and Equality Strategy and USAID's Agency Equity Action Plan, it is clear that USAID Administrator Power's call for inclusion and local voices is prioritizing gender-inclusive programming.

Data.FI is invested in the conversation on gender identity data. Our next steps as a project are to conduct an analysis of the illustrative activities in our gender strategy to see where we can strengthen gender data, have a collaborative discussion with project staff to solidify our gender strategy, and hold a gender training to discuss gender terminology and issues around the collection of gender identity data with our country teams in hopes of understanding how we can work to promote the collection and use of gender identity data on our project, giving special attention to the risks mentioned above. We even have a country team advocating for additional gender category options on registration forms, thinking through what works best for their country context and language, while ensuring privacy for individuals.

Recommendations

More inclusive programming might include these steps at the project level:

- Formal inclusion and integration of gender identity data collection processes in gender strategies and other guidelines
- Addition of gender identity-specific questions to baseline surveys, needs assessments, and other formal surveys when doing data collection.
- Integration of gender identity data collection in gender-sensitive trainings
- Conversation with country-level teams to understand country-specific contexts, needs, and potential barriers

And at the donor level:

- Consider expanding the mandatory sex disaggregations to add more gender-inclusive categories for routine reporting for MER indicators

If your aim is inclusion and the granularity of data matters to your analysis, there is an argument to be made for integrating gender identity data in HIV programming. To start small, consider changing the language used on data collection forms. Institutionalizing and socializing gender minorities and their needs means asking better questions and might make a difference in how we use and analyze data for decision making in HIV programming.

References

1. Data for Implementation (Data.FI). (2022) Data.FI Gender Equality Strategy and Workplan. Washington, DC, USA: Data.FI Project, Palladium
2. Ontario Human Rights Commission. (n.d.) Gender Identity and Gender Expression. Ontario, Canada. Accessed at: https://www.ohrc.on.ca/en/policy-preventing-discrimination-because-gender-identity-and-gender-expression/3-gender-identity-and-gender-expression#:~:text=A%20person's%20gender%20identity%20may,up%2C%20body%20language%20and%20voice
3. Health Policy Project. (n.d.) Gender and Sexual Diversity Training Slide Deck. Washington, DC, USA: Health Policy Project, Palladium
4. National Public Radio (NPR). (2021). A Guide to Gender Identity Terms. Washington, DC, USA: NPR. Accessed at: https://www.npr.org/2021/06/02/996319297/gender-identity-pronouns-expression-guide-lgbtq#cisgender
5. USAID. (n.d.) USAID ADS Chapters 201 and 205. Washington, DC, USA: USAID
6. U.S. President's Emergency Plan for AIDS Relief (PEPFAR). (2021). Monitoring, Evaluation, and Reporting Indicator Reference Guide. MER 2.0 (Version 2.6). Washington, DC, USA. Accessed at: https://www.state.gov/wp-content/uploads/2021/09/FY22-MER-2.6-Indicator-Reference-Guide.pdf
7. Research Triangle International. (2021). A Global Call to Action for Gender-Inclusive Data Collection and Use: Policy Brief. Research Triangle Park, NC, USA: RTI Press. Accessed at: https://www.rti.org/rti-press-publication/gender-inclusive-data-collection/fulltext.pdf
8. U.S. Department of State. (2022). X Gender Marker Available on U.S. Passports Starting April 11: Press Statement. Washington, DC, USA: U.S. Department of State. Accessed at: https://www.state.gov/x-gender-marker-available-on-u-s-passports-starting-april-11/
9. MEASURE Evaluation Project. (2019). Best Practices for Gender in the Monitoring and Evaluation of HIV Programs. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina at Chapel Hill. Accessed at: https://www.measureevaluation.org/resources/publications/fs-19-400/at_download/document
10. United Nations. (n.d.) Universal Declaration of Human Rights. New York, NY, USA: United Nations. Accessed at: https://www.un.org/en/about-us/universal-declaration-of-human-rights
11. United Nations Development Programme. (2022). Sustainable Development Goals. New York, NY, USA: United Nations Development Programme. Accessed at: https://www.undp.org/sustainable-development-goals?utm_source=EN&utm_medium=GSR&utm_content=US_UNDP_PaidSearch_Brand_English&utm_campaign=CENTRAL&c_src=CENTRAL&c_src2=GSR&gclid=CjwKCAjwp7eUBhBeEiwAZbHwkQX6jQh7UqgAQrSf6GXL9YG3P37WtyPeZl2VllbnUrJrv-CSIgBTqxoCIV0QAvD_BwE
12. United States Government. (2021). National Strategy on Gender Equity and Equality. Washington, DC, USA: The White House. Accessed at: https://www.whitehouse.gov/wp-content/uploads/2021/10/National-Strategy-on-Gender-Equity-and-Equality.pdf
13. United States Government. (2022). Executive Order 13985 USAID Agency Equity Action Plan. Accessed at: https://www.usaid.gov/equity/documents/eo-13985-agency-equity-action-plan

TR-22-108

Data for Implementation (Data.FI) is a five-year cooperative agreement funded by the U.S. President's Emergency Plan for AIDS Relief through the U.S. Agency for International Development under Agreement No. 7200AA19CA0004, beginning April 15, 2019. It is implemented by Palladium, in partnership with JSI Research & Training Institute (JSI), Johns Hopkins University (JHU) Department of Epidemiology, Right to Care (RTC), Cooper/Smith, DT Global, Jembi Health Systems, and Macro-Eyes, and supported by expert local resource partners.

This publication was produced for review by the U.S. President's Emergency Plan for AIDS Relief through the United States Agency for International Development. It was prepared by Data.FI. The information provided is not official U.S. Government information and does not necessarily reflect the views or positions of the U.S. President's Emergency Plan for AIDS Relief, U.S. Agency for International Development, or the United States Government.

September 2022

FOR MORE INFORMATION

Brian Bingham, Data.FI AOR
bbingham@usaid.gov

Jenifer Chapman, Project Director
datafiproject@thepalladiumgroup.com

https://datafi.thepalladiumgroup.com/

PEPFAR

USAID
FROM THE AMERICAN PEOPLE

Data.FI
Data for Implementation