

# Factors Affecting Sex- and Age-Disaggregated Data in Health Information Systems

## Lessons from the Field

### Background

Gender is a central component of health equity and must be examined and addressed explicitly in health information systems (HIS) through sex and age-disaggregated data, at a minimum, and ideally, through gender-sensitive data, as well. The data that HIS produce can perpetuate inequalities or promote health equity. When sex and age are not acknowledged and addressed in HIS, gender norms and inequalities that influence health and health-seeking behaviors remain invisible. Disaggregated data allow program managers and decision makers to examine service-delivery, treatment, and health-outcome data in depth, so that they can detect differences between the sexes, age groups, and key populations.

Initiatives driven by the United States Agency for International Development (USAID), the Bill & Melinda Gates Foundation, Data2x, UN Women, and the Sustainable Development Goals have increased global attention on gender in data and improved the availability of data needed to assess potential gender-related patterns. Researchers agree that every country should strive to develop the capability for basic equity analysis.<sup>1</sup> Further, researchers stress that inadequate sex- and age-disaggregated data obscure examinations of access to treatment across the HIV cascade.<sup>2</sup> Nevertheless, large gaps remain in the collection and use of such data, obscuring inequities and barriers to reaching health goals.

MEASURE Evaluation—funded by USAID and the United States President’s Emergency Plan for AIDS Relief (PEPFAR)—has compiled evidence from desk reviews and key informant (KI) interviews in Kenya, Tanzania, and Zambia to illustrate trends and challenges in the

collection and use of sex- and age- disaggregated HIS data and provides recommendations to move the field of global health forward.<sup>3</sup>

### Summary of the Evidence

The availability and use of disaggregated data are tied to a cycle of value and demand for disaggregation. When stakeholders understand the value of disaggregation, they are more likely to demand it, leading to increased reporting requirements and use. Donor requirements often catalyze countries to move this cycle toward disaggregation. Valuing disaggregation influences program requirements and design, data collection tools, and data analysis. Using disaggregated data to inform policy and creating feedback loops to demonstrate this to health staff bolster support for disaggregation. Limited resources and the added burden of reporting placed on healthcare workers are significant challenges to expanding the collection and use of disaggregated data.



A man in Kenya enters malaria monitoring data in a ledger.

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## Key Terms

**Sex** is the classification of people as male or female. At birth, infants are assigned a sex based on a combination of bodily characteristics, such as chromosomes, hormones, internal reproductive organs, and genitalia.—Interagency Gender Working Group (IGWG): <https://www.igwg.org/wp-content/uploads/2017/05/HandoutGenderTerms.pdf>

**Gender** refers to a culturally defined set of economic, social, and political roles, responsibilities, rights, and obligations associated with being female and male. It also refers to the power relations between and among women, men, boys, and girls. What it means to be a woman or girl, and a man or boy, varies across cultures and over time. These distinctions often intersect with other factors such as race, class, age, and sexual orientation; for example, different age groups may experience different gender norms. Transgender people, whether they identify as men or women, are subject to the same set of expectations and sanctions.—IGWG: <https://www.igwg.org/wp-content/uploads/2017/05/HandoutGenderTerms.pdf>

**Disaggregated data** are stratified or separated by factors such as age or sex. This allows comparison between groups or characteristics. Routine data are usually disaggregated by **sex** (not gender), because they are collected based on a person's physical characteristics of being male or female. If data are collected based on someone's gender identity, such as a woman, man, transgender woman, or transgender man, then they would be disaggregated by **gender**. Special studies are more likely to collect gender-disaggregated data, but the practice is becoming more common in routine health information systems in some countries. For more information, see <http://usaidprojectstarter.org/content/data-disaggregation>

**Gender-sensitive indicators** are indicators that go beyond sex disaggregation (but are still to be collected by male/female, as applicable); that try to directly measure aspects of gender; and that try to more thoroughly examine how gender relations affect health and development outcomes. To learn more, see <https://www.globalhealthlearning.org/course/gender-m-e>

## State of Disaggregation

**HIV testing and counseling indicators are consistently disaggregated both by age and sex.** Although there were some inconsistencies in the age bands that ministries of health and external funders use, KIs and documents confirmed that the countries we studied regularly disaggregate HIV indicators by age and sex. This indicates significant progress in the past decade. But routine disaggregation did not extend to data on adherence to HIV treatment or on indicators of viral suppression captured in paper records. In areas with electronic health records, adherence and viral suppression data were increasingly being disaggregated by sex and age. Where some but not all facilities collect disaggregated data, we found that alternatives are occasionally used for reporting, such as using sex ratios from facilities that do collect by sex to project estimates for all sites. This could be problematic, because access to and use of services may vary by location, whether a location is urban or rural, and other factors.

**Other health outcomes, such as immunizations, malaria, and tuberculosis, were less likely than HIV outcomes to be disaggregated by sex** and fewer KIs thought this was important enough to justify the additional burden. For these non-HIV outcomes, age disaggregation was more common than sex disaggregation, but the age bands that were used varied.

*“Under nutrition, disaggregating wouldn't necessarily be that helpful. Children are children.”*

*—Zambian key informant*

**Sex and age disaggregation of data on key populations are uneven.** In some cases, data on key populations (men who have sex with men, female sex workers, and people who inject drugs) are disaggregated when possible. We received reports that Kenya has begun to extend disaggregation by gender among sex workers to include transgender people. We also found that implementing partners of PEPFAR programs are collecting age-disaggregated data, but these data are not routinely examined at the national level.

**Few gender-sensitive indicators are routinely collected.** These indicators often interact with health outcome indicators, such as HIV prevalence. Knowledge of gender-sensitive indicators, such as perpetration or experience of gender-based violence and norms for the acceptability of wife-beating or household decision making by couples, was often low. Few if any gender-sensitive indicators are being collected routinely. Data on gender-based violence are more

“[We] lose some data when the registers are collated— some indicators are left out due to space. These decisions about what rolls up is decided by the planners and not necessarily the program people. Program people need to have input in what is actually collated.”

—Zambian key informant

likely to be collected, but may not be disaggregated by sex or specify the type of violence.

## Factors that Influence Disaggregation

**The type of tool used to collect data directly affects whether and to what degree data are disaggregated.** We found that data in facility health registers are disaggregated by sex. However, when aggregated into summary tools, the male and female fields are often aggregated into total number of people, and fine age disaggregation tends to be lost.

**Creating new systems for data collection and analysis that allow disaggregation by sex and age requires significant resources.** Changing tools is expensive and time- consuming, because the new tools must be distributed and staff at all the service delivery points must be trained to use them. Ensuring data quality is challenging, and introducing data elements increases the risk for error in data entry and the potential for bad data. KIs mentioned the enormous amount of reporting expected of health workers. Data producers and decision makers alike noted that adding sex and age disaggregation fields would add significant time and effort to the workloads of these overburdened health workers. Electronic medical records (EMRs) were discussed as a potential solution to this burden, but rollout is not realistic everywhere.

“Once I enter into the register, I now have to get another paper and start recording. And I don’t have time. And these then go to another worker. It’s time for an electronic system, so we don’t burden the health worker.”

—Zambian key informant

“Epidemiologically, why would you not want to look at male/female unless the disease is only for females or only for males?”

—Kenyan key informant

“Partners come with good systems, but at the end of the project, sustainability issues are not addressed. Hence, at the end of the project, the system crumbles. Many EMRs [electronic medical records] are driven by donors and once they pull out—that’s it. These are some of the issues facing us.”

—Kenyan key informant

**Creating strong feedback loops, or consistently demonstrating how disaggregated data inform policy, are critical steps in building buy-in for data disaggregation.** There is significant tension between balancing the utility of age- and sex-disaggregated data and the added burden of collecting and analyzing them, especially in areas with paper-based data collection systems. Busy health workers may not see the value of disaggregation. Although some KIs expressed strong support for disaggregation, more KIs expressed uncertainty about the need for it.

**Ensuring that stakeholders at many levels feel responsible for advocating data disaggregation is an important facilitator.** Without a clear point person advocating change, the demand and buy-in needed to make changes are lacking. One decision maker explained that some managers and government stakeholders do not understand the importance of disaggregation, and said that if such higher-level stakeholders do not see the importance, those below probably won’t see the importance, either, or advocate it.

**The interest and support of development partners catalyzes sex and age disaggregation.** Informants mentioned USAID, PEPFAR, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United Nations, and gender-focused nongovernmental organizations as supporting the increased collection and use of gender-related data. KIs also noted that while donors may initiate these efforts, ministries of health work with donors to achieve results. They said that challenges have arisen when data requirements from national ministries and funders were not aligned, as with PEPFAR’s updated age bands. Nevertheless, PEPFAR’s support and encouragement to collect these new age bands have no doubt changed these countries’ common practice with respect to HIV data. Recent moves to synchronize stakeholders’ data requirements and incorporate them in national data plans are laudable and worth sharing to strengthen the collection, analysis, and use of disaggregated data in other countries. The sustainability of electronic systems when donors pull out also surfaced as a concern.

Just as the collection of sex- and age-disaggregated data has increased, the consideration of these data in policy development and strategies is increasing, too, although to a limited extent. KIs reported that it was a challenge to translate evidence systematically into program implementation and design to ensure gender sensitivity.

## Recommendations

Significant progress in gender integration and sex and age disaggregation has occurred in Kenya, Tanzania, and Zambia, but work remains to be done. We recommend the following steps:

- Increase advocacy and awareness at all levels of the importance of sex and age disaggregation in national HIS.
- Improve facilities' capacity to use gender-related data for decision making, by improving feedback mechanisms and training on data analysis.
- Develop guidelines or materials showing how data can and should be analyzed to reveal important gender-related findings.
- Increase awareness of how disaggregation will help meet program and epidemic goals, such as PEPFAR's 90-90-90 target for HIV.<sup>4</sup>
- Disaggregate summary tools and maintain disaggregation throughout the national HIS.
- Continue to expand EMRs when possible for ease and accuracy of maintaining disaggregated data, especially regarding retention data.
- When collecting sex- and age-specific retention data among all paper-based facilities is impossible, conduct spot checks or data verification at selected facilities in locations without EMRs.
- Include gender officers/focal persons in national HIS working groups, decision-making meetings, and regular communication to allow opportunities for gender advocacy and technical assistance.
- Incorporate gender-based violence and sexual violence indicators in routine data collection and analysis to inform policy and programming.

The integration of sex- and age-disaggregated data should be approached as a collaborative endeavor to avoid overburdening healthcare workers while balancing essential data needed to identify and address inequities. Countries should build the capacity of HIS to examine and address gender inequities, increase demand for richer gender data, and influence policy change to support gender equality.

<sup>1</sup> Nolen, L.B., Braveman, P., Dachs, J.N.W., Delgado, I., Gakidou, E., Moser, K., . . . Zarowsky, C. (2005). Strengthening health information systems to address health equity challenges. *Bulletin of the World Health Organization*, 83(8), 579–603. Retrieved from <https://iths.pure.elsevier.com/en/publications/strengthening-health-information-systems-to-address-health-equity>

<sup>2</sup> Croce-Galis, M., Gay, J., & Hardee, K. (2015). Gender considerations along the HIV treatment cascade: An evidence review with priority actions. Treatment brief for the USAID Evidence Project and What Works for Women and Girls. Washington, DC: PEPFAR. Retrieved from: [http://www.whatworksforwomen.org/system/attachments/76/original/Gender\\_Considerations\\_Alone\\_the\\_HIV\\_Treatment\\_Cascade.pdf?144262311](http://www.whatworksforwomen.org/system/attachments/76/original/Gender_Considerations_Alone_the_HIV_Treatment_Cascade.pdf?144262311)

<sup>3</sup> For detailed methods and country-specific results and recommendations, please see full reports at:

MEASURE Evaluation. (2017). Barriers to and facilitators of sex- and age-disaggregated data: Kenya. Retrieved from <https://www.measureevaluation.org/resources/publications/tr-17-163>

MEASURE Evaluation. (2017). Barriers to and facilitators of sex- and age-disaggregated data: Zambia. Retrieved from <https://www.measureevaluation.org/resources/publications/tr-17-160/>

MEASURE Evaluation–Tanzania. (2016). Availability and use of sex-disaggregated data in Tanzania: An assessment. Retrieved from <https://www.measureevaluation.org/resources/publications/tr-16-132/>

<sup>4</sup> By 2020, 90 percent of those with HIV will have been diagnosed, 90 percent of those diagnosed will be in antiretroviral treatment, and 90 percent of those in treatment will be virally suppressed. Source: PEPFAR. (2014). PEPFAR 3.0. Controlling the epidemic: Delivering on the promise of an AIDS-free generation. Retrieved from <https://www.pepfar.gov/documents/organization/234744.pdf>