Barriers to and Facilitators of Sex- and Age-Disaggregated Data

Zambia

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USAID
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MEASURE Evaluation

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Zambia

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ABBREVIATIONS

ART	antiretroviral therapy
DHS	Demographic and Health Survey
DREAMS	Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe
EMR	electronic medical record
GBV	gender-based violence
HIS	health information system(s)
HMIS	health management information system(s)
HTC	HIV testing and counseling
KII	key informant interview
M&E	monitoring and evaluation
MOH	Ministry of Health
NGO	nongovernmental organization
PEPFAR	United States President's Emergency Plan for AIDS Relief
RHIS	routine health information system(s)
STI	sexually transmitted infection
TB	tuberculosis
USAID	United States Agency for International Development

EXECUTIVE SUMMARY

Decades of research demonstrate that gender inequality is associated with increased risk of HIV, maternal mortality, child stunting and wasting, poor nutrition, and other negative health outcomes. Data produced by health information systems (HIS) can be disaggregated by gender and age to advance understanding of factors associated with these health outcomes. Such data must be available for analysis and decision making to enhance health outcomes and address inequities across gender and age groups. This report summarizes our study exploring factors that contribute to the collection and use of sex- and age-disaggregated data in Zambia and presents our recommendations for improvements.

Between April and September 2016, MEASURE Evaluation—funded by the United States Agency for International Development (USAID) and the United States President's Emergency Plan for AIDS Relief (PEPFAR)—conducted a review of current practices and the barriers to and facilitators of sex and age disaggregation. This study had a two-pronged approach: (1) a desk review of key documents and literature, and (2) key informant interviews (KIIs) with national-level data producers and decision makers.

The Ministry of Health (MOH) and the Government of Zambia have made great strides in gender integration and sex and age disaggregation. Most key informants (KIs) in our study described what it meant to disaggregate data by sex and age. However, responses varied when KIs were asked if data for health indicators are disaggregated by sex and age, and if such disaggregation could be valuable. Key informants were aware of a greater push to disaggregate data but might not be internally motivated to do so, because they do not see the added value or use of these data, particularly given the added burden of collecting and analyzing sex- and age-disaggregated data. Electronic medical records (EMRs) are seen as a solution to this burden, but rollout may not be realistic in rural facilities.

We found that HIV indicators are more likely to be disaggregated than data from other health sectors that have HIV implications, such as tuberculosis (TB), malaria, nutrition, and immunization. The KIs agreed that external reporting requirements from donors facilitate data collection and use, but noted that, in the past, data requirements from the ministry and funders were not aligned. Recent moves to synchronize data needs of stakeholders with national data plans are laudable and can help other countries strengthen their collection, analysis, and use of disaggregated data.

Nevertheless, significant challenges remain, and addressing them requires continued support. Based on our findings, we recommend an increase in advocacy and sensitization around the importance of sex and age disaggregation in data at different levels within the health system and across different health sectors. We also

recommend improving capacity of facilities to use data for decision making, by improving feedback mechanisms and training on data analysis at the lower levels. Disaggregated targets should be developed to encourage reporting on health indicators by sex and age. To reduce the additional burden on health workers, we recommend continuing to expand the use of EMRs, such as Smartcare, where possible.

INTRODUCTION

Decades of research demonstrate the association of gender inequality with increased risk of HIV, maternal mortality, child stunting and wasting, poor nutrition, and other negative health outcomes. Gender norms can have an impact on women's and men's health-seeking behavior and use of health services. Such norms can also affect decision-making abilities and access to financial resources within health systems. Unequal power relationships increase women's vulnerability, by limiting women's ability to negotiate sexual relationships and condom use, restricting their access to health services, and exposing them to violence (Ghanotakis, Peacock, & Wilcher, 2012). Harmful gender norms and practices associated with a culture's understanding of masculinity can increase the likelihood that men and boys will engage in sexual risk taking and substance use that expose them to HIV (Sikweyiya, Jewkes, & Dunkle, 2014).

Similarly, research shows that age is an additional and compounding factor in behavior, power, decision making, and health outcomes. Adolescent girls are at compounded risk of acquiring HIV owing to inequities associated with gender and age (PEPFAR, n.d.). The very young and very old are more susceptible to infectious diseases. These considerations are imperative when targeting public health programs.

A strong health information system (HIS) is able to produce, analyze, and use information for decision making. Data produced by HIS can conceal or reveal inequalities. To promote health equity, HIS must have the capacity to produce data that can critically examine differences between men, women, boys, and girls within the social context (Percival, Richards, MacLean, & Theobold, 2014), especially the social and cultural norms around gender (Interagency Gender Working Group, n.d.)[1] and age.

In order to ensure that gender- and age-related health differences are addressed, data that are disaggregated by sex and age must be available for analysis and decision making. For example, the lack of sex- and age-disaggregated data can obscure differences in treatment access across the HIV cascade (Croce-Galis, Gay, & Hardee, 2015). Prevention, testing, and prevalence data are often disaggregated by sex, but in-depth examination of age groups is lacking. Antiretroviral therapy (ART) retention and viral suppression data are

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[1] Gender refers to a culturally defined set of economic, social, and political roles, responsibilities, rights, entitlements, and obligations, associated with being female and male. It also refers to the power relations between and among women and men and boys and girls. The definition and expectations of what it means to be a woman or girl, and a man or boy, and sanctions for not adhering to those expectations, vary across cultures and over time, and often intersect with other factors, such as race, class, age, and sexual orientation. Transgender people, whether they identify as men or women, are subject to the same set of expectations and sanctions. Source: Interagency Gender Working Group. (n.d.). Defining gender and related terms, adapted from UNFPA Gender Theme Group, 1988, for IGWG training module. Retrieved from: http://www.igwg.org/igwg_media/Training/DefinGenderRelatedTerms.pdf

often neglected when it comes to sex and age disaggregation. Few special studies have been conducted looking at gender differences in ART efficacy and national-level and routine data are limited (Croce-Galis, Gay, & Hardee, 2015).

It is not unusual for health programs to rely on varied data sources, such as program household surveys, periodic Demographic and Health Surveys (DHS), and routine health management information systems (HMIS). The DHS data are disaggregated by sex and age, but the surveys are conducted only every five years. Routine health information systems (RHIS) should integrate gender through sex-disaggregation and gender-sensitive indicators[2] (Global Learning Center, n.d.). Routine sex- and age-disaggregated data allow program managers and decision makers to be more responsive in targeting health services, programs, and resources to ensure all age groups, genders, and key populations are reached.

USAID and other leading bilateral and multilateral organizations, country governments, and global initiatives (such as the Sustainable Development Goals) have committed to increased gender integration for health equity. However, large gaps remain in the collection and use of gender-related data, obscuring inequities and barriers to reaching health goals. Initiatives driven by USAID, the Bill & Melinda Gates Foundation, and Data2x have led to global progress in collecting sex-disaggregated data (Temin & Roca, 2016). Sex- and age-disaggregated data are essential in reaching the 90-90-90 targets endorsed by PEPFAR (PEPFAR, 2014).[3] In response to increasing evidence of variations in risk of infection and access to treatment across age groups, PEPFAR is collecting detailed data to elucidate and track nuanced differences. Data disaggregated by sex and age must be more widely collected, analyzed, and used to show progress and reveal shortfalls in meeting these goals.

To assess how extensively sex- and age-disaggregated data are collected and used in RHIS and decision making, MEASURE Evaluation researchers explored factors that contribute to these practices in two sub-Saharan African countries: Kenya and Zambia. This report documents the process and findings of our exploration in Zambia. We had the following objectives:

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[2] 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. For examples, see https://www.globalhealthlearning.org/course/gender-m-e.

[3] By 2020, 90 percent of people with HIV will have been diagnosed, 90 percent of those diagnosed will be on ART, and 90 percent of those on ART will be virally suppressed.

1) Determine the availability of sex and age disaggregation of HIV and HIV-related health indicators in Zambia

2) Explore if and how sex- and age-disaggregated data are used for decision making in-country

3) Investigate the facilitators and barriers to collecting and using sex- and age-disaggregated data across a set of indicators

We will share the results of this study with stakeholders to guide next steps toward improving sex- and age-disaggregated data collection and use for decision making; to ensure equitable access to health services, particularly HIV treatment and adherence services; and to support USAID's goal of an AIDS-free generation and PEPFAR's 90-90-90 targets.

METHODS

We conducted this study from April–September 2016 using a two-pronged approach: (1) a desk review of key documents and literature for each country, and (2) KIIs with national-level data producers and decision makers. The University of North Carolina Ethics Review Board deemed that this study was not considered research with human subjects and did not require full ethical review.

Desk Review

The goal of the desk review was to help us understand the current levels of sex and age disaggregation and discussion of gender issues in national HIV and HIS documents The study team reviewed 12 key documents in Zambia, spanning government and MOH documents related to HIV, HIS, and M&E, such as national HIV/STI strategic plans, M&E plans, and data collection forms. We collected relevant documents from the Government of Zambia website, other documentation available online, and documents shared by stakeholders and partners in-country. A list of documents reviewed appears in Appendix A.

Key Informant Interviews

We conducted interviews with 15 participants in all. Primary data collection in Zambia from May 17–June 1, 2016, consisted of nine interviews with ten key informants (KIs). In the United States in September 2016, we conducted two interview sessions with five representatives of Zambia's MOH and Ministry of Community Development and Social Affairs. Because of scheduling constraints, some interview sessions had more than one KI. Participants were purposively selected based on their experience as decision makers or data producers working with the Zambian HIS, HIV/AIDS programs, and other relevant health areas. Interviews were designed to explore barriers and facilitators to collecting, reporting, and using sex- and age-disaggregated data. Interview discussions also covered stakeholder understanding of the importance of disaggregation in health indicators and ways to improve sex- and age- disaggregation. Each KII was conducted in English by a lead researcher and, when possible, a second researcher. Detailed notes were taken. Interviews lasted 30–60 minutes. The researchers used a semi-structured interview guide, which allowed them to follow themes and ask additional questions as needed during the interviews. A list of key informants appears in Appendix B and the interview guide is in Appendix C.

Analyses

Desk review findings were reviewed in tandem with results from KIIs. We reviewed national policies, strategic frameworks, M&E plans, HMIS manuals, and data collection forms. We analyzed these documents to identify how extensively sex and age disaggregations were included in narratives, graphs, charts, and indicator descriptions. We also reviewed these documents for the existence of other gender-related factors and gender-sensitive indicators.

Notes from KIIs were analyzed using ATLAS.ti software. Codes were developed *a priori*, with adjustments made to the codebook to add or collapse codes after initial interviews were coded. Interviews were coded by one researcher for common themes around challenges and successes in the understanding, availability, production, and use of disaggregated data. A second researcher reviewed codes. Both researchers analyzed the data, discussing and agreeing on most salient themes, successes, and barriers.

Review and comments were solicited from in-country stakeholders who participated as KIs and validated analysis, results, and recommendations.

RESULTS

Most KIs described what it means to disaggregate data by sex and age. However, responses varied when KIs were asked whether data for health indicators are being disaggregated by sex and age, and whether it is valuable to do so.

Availability and Production of Data

> *Without the data, we are comfortable saying everything's okay, but truthfully, we don't know what we don't know.* (KI)

We found that sex- and age-disaggregated data production and availability depend on many factors. Whether such data are available depends on a perceived need for information at multiple levels (facility, program, and national), and for appropriate tools to be created and used within different health sectors. The KIs said they prioritize disaggregating data based on whether tools contain fields for sex and age and if data points transfer to the next form or database. In the following subsections, we examine the consequences of these added data elements with particular consideration to the limited resources available.

Perceived Importance of Disaggregated Data

The perceived need for sex- and age-disaggregated data strongly influences the availability of such data, according to the KIs. When considering indicators, stakeholders at a variety of levels are consulted (such as facility health workers, program managers, district statisticians, and funders). However, the HMIS Unit in the health ministry's Department of Policy and Planning, responding to requests from program offices, ultimately determines how data are collected, reported, and filtered through the system. Therefore, whether program data are disaggregated by sex is dependent on national-level M&E officers who may be more focused on technical system concerns. One KI said:

> *[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.*

There was consensus among KIs that certain health outcomes (such as HIV and STIs) are important to disaggregate by sex. However, some KIs described situations in which they do not see the same need for disaggregation in other health areas, such as nutrition and malaria. Here are two KI comments related to this:

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

> *A mosquito does not choose (who it bites), so we refused to disaggregate.*

Some KIs discussed the need for capacity building at the program level for healthcare workers to understand better how data disaggregation could be helpful and could influence health programming. The KIs frequently mentioned the importance of disaggregated data. They gave examples of specific situations where one sex is disadvantaged in services or outcomes over the other. One KI said that if a program finds more males are infected with HIV, then interventions could be developed that address that population. But if the data are not sex-disaggregated, no one will know to target the male population.

Types of Data

The types of data collected, which vary widely among health sectors, strongly influence the perceived importance of sex- and age-disaggregated data. KIs said that in the past there had been challenges in collecting data that aligned both with PEPFAR and MOH disaggregation requirements. However, KIs overwhelmingly reported that most international indicators for HIV are now disaggregated by sex in the HMIS (built on DHIS 2 software)[4] and PEPFAR's DATIM (Data for Accountability, Transparency, and Impact) portal. This was confirmed by a review of HMIS indicators, although many mistakenly report gender disaggregation rather than sex. (The exception is ART retention and viral suppression indicators, which we discuss in the section "HIV Treatment Retention and Viral Load Data.") KIs also agreed that data are collected by age; however, there is variation around what degree of disaggregation and what age bands are being reported across data sources and health areas. One KI mentioned that age categories for some indicators include only those younger than 18, 18–65, and older than 65 years of age.

Recent initiatives (such as DREAMS) emphasize more age disaggregation with respect to HIV, and KIs have seen a greater push both for sex and age disaggregation. The National AIDS Strategic Framework (2014–2016) calls for age disaggregation where appropriate, but it does not state the age groups to be used. The KIs revealed that age bands have not remained consistent. One KI said the MOH prefers to disaggregate data at age bands other than those that PEPFAR requires. For example, PEPFAR recently changed the required age bands for male circumcision data, which do not match the age bands in recently revised MOH tools. New data collection plans were designed to align MOH and PEPFAR requirements so that they address all stakeholder needs, but this will not occur until the next time the ministry revises the tools.

Data on other health outcomes (such as malaria, TB, nutrition, and immunization) are not commonly disaggregated. Immunization data are disaggregated by age, but only above or below one year of age, according to one KI; this was confirmed by review of the HMIS manual. Furthermore, these data are sex-disaggregated, so it is not possible to assess how many boys, girls, men, and women are reached through immunization campaigns. Depending on the question or indicator, decision makers may want more detailed age-disaggregation for such HIV co-infectors as TB. Unfortunately, it is not possible to produce this information with the existing data. Similar data disaggregation trends and resistance were reported for nutrition and malaria data. KIs explained why these health program variations may exist, based on perceived usefulness, program area priorities, and system restrictions.

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[4] KIs used the terms HMIS and DHIS 2 interchangeably to discuss the national RHIS. For this report's purposes, we have used HMIS to refer to this system.

Type of Tools

> *The system itself, looking at the history, does not accommodate a lot of data—that's why the details remain at the facility. System limitations.*

The tools by which data are collected, stored, and reported have strong influence on whether data disaggregation occurs. Registers at the facility level identify sex and age of the patient, according to our KIs and desk review. However, for many health indicators these data are aggregated, summarized, and reported in the HMIS as total number of people. This often means that data are available only in aggregate at the national and subnational levels, lacking separate numbers for men, women, girls, and boys. One KI discussed how this can be problematic with epidemic data, which may not be disaggregated even though sex and age disaggregations are needed for decision making:

> *You can go back to the source to ask to disaggregate by sex—sometimes there is a back and forth to get more information about the data—we send data back to district reporting system to ask for sex disaggregation.*

This back-and-forth process is costly and resource-intensive. Some programs have developed their own systems, triangulated with larger surveys (such as DHS), and/or supplemented information with nonroutine survey data. For example, the HMIS does not disaggregate nutrition data at the national level. A separate nutrition database begun in 2010 disaggregates by sex, but it contains only facility-level data. Malaria data are not disaggregated by sex in HMIS; however, KIs reported that survey data have been used to periodically supplement and determine if sex-disaggregation in routine systems data is necessary.

Key informants said that HIV indicators are more likely to be disaggregated than indicators for other health areas, because disaggregation is built into the tools and the system. Most HIV data elements are disaggregated, but retention data elements are not disaggregated at the next level up from the facility. Retention is reported only in cohorts combining sex (Ministry of Health, 2012). As previously discussed, age disaggregation is often available but not always consistent or aligned with donor-required age bands. For example, data are collected and aggregated for 15–24 year olds (National HIV/AIDS/STI/TB M&E Plan 2011–2015) rather than for ages 15–18/19 and 18/19–24 for most indicators. The PEPFAR-funded HIV programs are required to report through DATIM. The DATIM indicators must be entered by sex and by the specific age-bands that PEPFAR mandates. However, KIs noted, estimates are used to satisfy these reporting requirements, because DATIM has more detailed age disaggregation than the national HMIS and data collection tools.

Key informants said the use of electronic patient records can make it easier to disaggregate data. Smartcare, an electronic patient record program, is currently being rolled out to improve service delivery and support continuity of care. The goal is eventually to have all services under Smartcare, starting with HIV, then adding other services over time. This system is more likely to have disaggregated data across health areas, because collecting and maintaining this level of detail is much easier in an electronic system. However, the electronic system is not currently interoperable with the HMIS, and facilities must print out a Smartcare summary form, then enter that in HMIS. In addition, rollout of these programs to rural areas is challenging because of the distance between facilities, inadequate power supply, and lack of Internet service.

Limited Resources and Added Burden

The KIs frequently mentioned the additional effort and burden in disaggregating data at all levels (facility, health worker, and health ministry). Ministry of Health officials discussed the burden of changing forms and the time and resources needed to do so. Indicators and data elements are reviewed and revised every two years for the HMIS. Program managers assess whether data elements and disaggregation categories (such as age and sex) already exist within the program or are necessary for decision making. Additionally, program managers look at the costs and benefits of disaggregating the data, particularly if it means that all the facility reporting tools have to be changed.

Data producers and decision makers are also aware that adding sex and age disaggregation fields would increase the time and effort expended by already over-burdened health workers. The KIs mentioned the enormous reporting expectations on health workers. One said:

> *In most facilities, you only have a single staffer; there are often more than 15 registers at one clinic. You can't do away with [certain indicators or registers], because they're tied to funders and partners.*

The same KI noted that disaggregation could impact data quality: Ensuring data quality is already challenging, and introducing more data elements introduces room for more errors, increasing the potential for bad data. Informants said that EMR systems could be helpful. One said:

> *Once I enter into the register, I now have to get another paper and start recording. And I don't have time. And this then goes to another worker. It's time for an electronic system, so we don't burden the health worker.*

However, electronic systems are not yet realistic in rural areas.

Many KIs discussed what happens when new data forms are required without a clear understanding of use. One KI said:

> *Changes to the data set makes more work for the health workers who have a lot of other responsibilities. Don't want to burden them with more work if we won't use it. Question, is this information that we need, or is it something that you're going to be using?*

Informants discussed the need to balance the burden of work on health staff with the usefulness of the disaggregated data. If data are not perceived as useful, the extra burden on the health worker to collect that data is seen as unnecessary.

Data Analysis and Use

Data availability and production are inextricably linked to analysis and use. The perceived importance of asking data producers to collect data by sex and age is tied to understanding how, when, and why these data will be used. Key informants discussed successes and challenges in analyzing, reporting, and using disaggregated data, citing the need for supportive environments and human capacity. One KI said:

> *If sex-disaggregated data were available, it would be used.*

Structural Factors and Enabling Environment

The KIs frequently cited the interest and support of development partners as facilitating the use of sex-disaggregated data. They mentioned the roles of USAID, PEPFAR, and Global Fund (GF) in supporting the increased collection and use of gender-related data. One KI said that the USAID gender policy and ADS 205-- Integrating Gender Equality and Female Empowerment in USAID's Program Cycle (USAID, 2013) provide important guidance on gender integration. However, these documents are primarily for programming and do not focus on data disaggregation and use. Another KI discussed how GF's support for disaggregation has evolved. Sex and age disaggregation was not a priority for GF until the 2015 and 2016 New Funding Models included revised reporting templates that require disaggregation. A similar evolution has occurred in PEPFAR's requirements.

The KIs also discussed the evolution of internal national support for disaggregation. Zambian national policies and strategies are aligned with international commitments to gender and gender equity. The Zambian National AIDS Strategic Framework is "designed to contribute to the achievement of Zambia's obligations in the context of the African Union Abuja and Maseru (SADC) declarations, and the SADC Protocol on Gender and HIV and AIDS." (National HIV/AIDS/STI/TB Council, 2014) Clear support from donors and the MOH have resulted in special attention paid to gender-related HIV and AIDS outcomes and the development of data plans to examine differences among men, women, boys, and girls. The KIs said that sex and age have been increasingly included in consultations to discuss revisions to data forms and systems. However, changes in the data systems have been slower than changes in funder reporting requirements, and these are not always aligned. While there have been limitations and challenges in addressing PEPFAR-required sex and age disaggregation, the support for aligning data needs has changed common practice in Zambia with respect to HIV data.

The increased attention to disaggregation appears to be limited to certain health outcomes, as discussed earlier. A KI from the MOH reported that in all ministries there is now a "gender mainstreaming focal point" person; the gender ministry works with all ministries and departments. However, this was only brought up in one interview. To understand what drives data analysis and use in non-HIV sectors, KIs indicated that what is analyzed and reported is directly linked to the reporting expectations of programs. One said:

> *The main limitation is not having separate targets for men or women. If they aren't required, they won't collect it. Programs don't plan on looking at sex-disaggregated data; there aren't sex-disaggregated targets because they aren't planning based on that.*

Even if data are available and analyzed, reporting and use of those data by sex and age are not guaranteed. One KI mentioned that the HMIS bulletin only reports in aggregate, despite the availability of disaggregated data. Another informant discussed the limitations of programs analyzing and reporting disaggregated data:

> *The data is there, but have the programs looked at it? Having national requirement for sex disaggregation is just one piece; we will be sure to report, but we want people to start making decisions based on them.*

In asking KIs why such limitations occur, we found some programs rely on one-off measures or periodic monitoring of sex differentials in health outcomes. One example involved malaria data. Programs at one point used survey data to see if there were sex differences in incidence; however they found no significant differences and therefore have not disaggregated routine data since that time.

The Human Element

Data producers and decision makers discussed the need for motivation to offset the increased burden involved in collecting and analyzing disaggregated data. External sources of motivation were discussed, including donor-driven requests and job requirements. Many KIs also noted the importance of internal motivation, such as the wish to improve health programming and reduce inequalities. This motivation is closely tied to training on the greater importance of sex disaggregation. One KI said:

> *They have the data and they do it for the sake of checking the box. They don't understand the importance of it on their programs. USAID pushes them to disaggregate, but they wouldn't need pushing if they understand the importance. They would see the implications.*

The KIs noted the importance of understanding the value of disaggregated data and how the data would be used. Several KIs talked, mostly through examples and indirect narrative, about feedback and how that may motivate health workers to collect, analyze, and use data. One KI used a hypothetical adolescent program to illustrate this point:

> *If you want to do a program that will target the reduction of HIV among adolescents (adolescents are at very high risk), of these adolescents, which ones and in which specific age group? Once you study the data, you're left with wondering why it's that particular group or particular area. Once you show the policy makers all of those statistics, the program managers get to see the importance. The disaggregation brings in the human aspects of what you're looking it. You stop seeing statistics, and start thinking of them as people.*

Key informants also mentioned the importance of creating awareness about the need for critical analysis of sex and age inequalities. They mentioned that medical practitioners rarely learn about data in their training. This creates a problem with data use at the facility level. Another KI said that program staff should be better trained on data systems. The KIs recommended more orientation on running reports in HMIS. They want people to feel comfortable using the data themselves rather than relying on upper levels to do it. Our interviews revealed that program staff may not run their own reports in HMIS because of a lack of interest, time, or capacity.

HIV Treatment Retention and Viral Load Data

Because KIs indicated that HIV data are more likely to be disaggregated than data for other health areas, we dove deeper into the different types of data within HIV programs. Although most HIV indicators are disaggregated by sex and age in the HMIS and DATIM, historically, more complex indicators such as TB co-infection data (TB_OUTCOME), treatment retention (TX_RET), and viral suppression (TX_VIRAL) have not been disaggregated.

However, PEPFAR's interest in sex- and age-disaggregated data across the HIV care continuum has resulted in revised requirements for partners reporting on PEPFAR indicators. The GF has made similar changes in its reporting requirements and data needs. Key informants said these new requirements are challenging, because the MOH, partner organizations, and donor agencies ask for different information at different times. Data are fragmented within systems and difficult to compare or triangulate across parallel systems. One KI said they are required to present certain disaggregations to GF, but they do not have the required data within the HMIS. The program is starting to "do a workaround" with Smartcare to calculate retention; the KI added that HMIS revisions would be more useful.

After stakeholder consultations, the MOH revised its data collection tools to better coordinate and respond to data needs. It was said these would go into effect in January 2017, but that could not be confirmed at this writing. Tools should be helpful, but challenges may remain, such as difficulty in collecting data and understanding their usefulness. A few KIs noted concerns about maintaining quality with some indicators. They worry about disaggregating while maintaining usefulness of the data. One KI commented that a new tool, Quality Improvement through Data Use (QIDU), has been introduced for data quality improvement.

Gender-Sensitive Indicators

> *Gender-sensitive indicators, we need to have awareness of these and practice use. We now only have sex, we're not going beyond to look at roles and perceptions of people. If we could start to track such indicators, that could be really helpful.*

The KIs discussed several instances where they see differences in data between men and women, and realize there are gender norms driving those differences. We examined knowledge and use of gender-sensitive indicators, such as perpetration or experience of gender-based violence, norms around acceptability of wife beating, household or financial decision making within couples, and women's abilities to decide when to seek healthcare. These indicators often interact with health outcome indicators, such as HIV prevalence.

For the most part, KIs indicated they are unaware of these types of indicators in a formal sense. A few are aware of data on gender-based violence (GBV), but they are unsure if the data are currently being collected or included in HMIS. Additionally, there is confusion around classification of GBV and where those indicators may be found/recorded. Through our document review, we found that the Revised National HIV and AIDS Strategic Framework (R-NASF) 2014–2016 identifies GBV as an important driver of the HIV epidemic in Zambia. We also found at least one key indicator for GBV: proportion of ever-married or partnered women ages 15–49 who experienced physical or sexual violence from a male intimate partner in the past 12 months (indicator 7.1).

Other gender-sensitive indicators were rarely discussed in the informant interviews. One KI mentioned that an indicator on gender norms was removed during this country operational plan (COP) year as programs do not need to report it to PEPFAR/DATIM and money is not available to make these changes.

> *It has been difficult. Advocacy around that has been [difficult]; [we] don't know how to tackle the Zambian gender norms and beliefs. To date, we still have women who need permission to get ART, etc. It comes down to power relations, but those are hard to change.*

DISCUSSION

Key informants showed varied perspectives on collecting, analyzing, and using sex- and age-disaggregated data. While KIs were knowledgeable about what it means to disaggregate by sex and age, they disagreed on its value, and reported differences in how often disaggregation is applied.

There does not seem to be one primary reason for this variation, but rather a cycle of facilitators and barriers that can positively or negatively influence data disaggregation depending on the type of data, the enabling environment, and structural factors. Health programs determine if there is value to producing disaggregated data. This is weighed against the burdens of modifying or adding new data or procedures to existing health information systems and health worker capacity. The value of producing these data depends on the perceived usefulness of such data to make decisions about the health program in question. Usefulness is linked to the reporting requirements of the program, the MOH, and funders. This, in turn, loops back to the value placed on producing disaggregated data.

For some time, HIV indicators have benefited from this loop. Sex and gender have long been recognized as important factors in HIV outcomes. Therefore, funders have prioritized sex disaggregation as part of their reporting mechanisms. Governments have responded by incorporating these considerations in the development of their HIS and trainings. The increased availability and awareness of disaggregated data improve analyzing and using such data for decision making. Understanding how data are used improves health workers' inclination to collect data and the likelihood that programmers will advocate making data available.

Alternatively, other crucial health data (such as data on immunization, malaria, TB, and nutrition) that have implications for HIV are more likely to be challenged by this loop. Funders and governments rarely require sex and age disaggregation within these health areas. Therefore, such disaggregation is not built into RHIS or trainings. Consequently, routine data on sex differences are not available for decision making. Health workers and decision makers are less likely to see the data's usefulness, and the data's perceived value diminishes. Without demand, there seems to be no reason (or motivation) to build disaggregation into reporting.

Each of these points in the cycle is critical. Gender is increasingly included in policies and national strategies, but those goals and principles are not easily brought down to the programmatic level. While funders may have reporting requirements, use of this data for decision making is often more internally motivated. Decision makers in our interviews said they do see the need for data disaggregation in certain areas, such as immunization, despite external pressure. It is not enough to create policies or expand forms for data disaggregation. Efforts to educate and build capacity for this must reach those who are affected at all levels of the health system. Creating interest and value for such data disaggregation will engender more sustainable production and use.

Multiple KIs expressed a belief that if the data are not going to be used, they should not be collected. While this attitude is valid, it could prevent data collection and use before they begin. Some KIs suggested using nonroutine data sources (such as surveys) to identify potential gender imbalances, and investigate further with routine data if necessary. However, some health areas have seen that a survey does not show imbalance at one point in time, and this has bolstered resistance to sex disaggregation moving forward. Similarly, a periodic or isolated study could miss a significant trend. For example, a single study may find no difference between the rates of men and women testing positive for malaria. Follow-up is needed every few years to discover whether equity in health outcomes remains or is changing; then programs can respond more effectively.

Many KIs agreed that changing data collection forms and practices is cumbersome, costly, and time-consuming; hence they expressed resistance to such changes. Moreover, adding data fields requires training and increases the burden on already over-worked health facility staff. Some KIs suggested that EMR systems, such as Smartcare, could help address these challenges. However, there are limitations to EMRs. While Smartcare may improve efficiency in sharing and analyzing disaggregated data, evidence suggests that there are barriers to its widespread use (such as lack of perceived benefit for users who collect the data, lack of training to ensure data quality and completeness, complex systems, and poor system security). Data producers and users may experience barriers similar to those encountered during current collecting and reporting of disaggregated data. Additionally, these systems are unlikely to be rolled out on a national level in the near future.

While HIV programs are leaders in sex disaggregation, challenges remain around reporting the narrow age bands and retention data. Smartcare has been used recently as a “work around” for retention data in some areas, but it is not available nationwide. Challenges remain in areas that still rely on unwieldy paper tools.

Despite these challenges, Zambian government officials have made efforts to include gender in programming and data collection, analysis, and use. Such efforts are vital as data production, availability, and use rely heavily on internal and external supportive structures. “Gender mainstreaming focal point” staff and similar supportive structures should be leveraged to increase advocacy and sensitization on the importance of sex- and age- disaggregation.

CONCLUSIONS AND RECOMMENDATIONS

Officials in the MOH and the Government of Zambia as a whole have made great strides in gender integration and sex and age disaggregation of health data. Recent moves to synchronize data needs among stakeholders and to adopt new policies in national data plans are worth sharing globally, to strengthen other countries’ collection, analysis, and use of disaggregated data. Nevertheless, significant challenges in Zambia remain. Additional resources and interventions are needed to overcome barriers to and increase facilitators of effective sex and age disaggregation of health data.

Based on the findings of our KIIs and desk review, we recommend the following steps and initiatives:

- Increase advocacy and sensitization regarding the importance of sex and age disaggregation in data at different levels within the health system and across health areas.
    - Provide training to promote understanding of why it is important to look at sex and age differences routinely and across the board.
    - Build the capacity of programs, by using case studies to highlight the utility if data disaggregation.
    - Leverage gender mainstreaming focal point staff to advocate within their health sectors.
- Improve capacity and use of data for decision making.
    - Provide training for program officers in using the HMIS.
    - Create more routine-feedback systems for when gender gaps exist, and to show how disaggregated data can be used for decision making.
- Use alternative sources of information when HMIS data are not available, to examine gaps or equity issues and to inform programs and changes in routine data collection.
    - Use DHS and survey data to elucidate gender gaps for health areas such as malaria on a semi-periodic basis.
    - Use Smartcare data to report retention data.
    - Advocate increased disaggregation within HMIS during future revisions of tools.
- Require sex-disaggregated targets for which data would need to be reported.
- Continue to expand Smartcare in all facilities for ease, accuracy, and increased data use, especially with regard to retention data.
    - Expand disaggregation beyond HIV to other health areas.

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APPENDIX B. KEY INFORMANTS INTERVIEWED

Interviewee	Organization	Professional Title
Agness Aongola	Ministry of Health (MOH)	Chief Nutrition Liaison Officer
Boniface Mwanza	MOH/Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM)	M&E Specialist, GFATM
Boyd Kaliki	MOH, Lusaka	Provincial Monitoring and Evaluation (M&E) Officer
Brivine Sikapande	MOH	Acting Principal M&E Officer
Calvin Kalombo	MOH	Senior M&E Officer
Caroline Phiri	MOH	Lecturer, Unza
Charles Banda	MOH	Chief M&E Officer
Chipalo Kaliki	MOH	Deputy Director, M&E
Dr. Kaonga	MOH	Pediatrics HIV Specialist
Edmond Mwakalombe	Ministry of Community Development and Social Welfare	Chief M&E Officer
Emmanuel Ngulube	United States Agency for International Development (USAID)	
Erick Musenga	Ministry of Community Development, Mother Child Health	Senior Information and Communication Technology (ICT) Officer
Joseph Simuchimba	MOH, Lusaka Province	Senior Health Information Officer
Katongo Mumbi Silwizya	National HIV/AIDS/STI/TB Council	Research, M&E Coordinator
Trust Mufune	MOH	Principal M&E Officer

APENDIX C. KEY INFORMANT INTERVIEW GUIDE

Assessment of Barriers and Facilitators to Availability and Use of Sex- and Age-Disaggregated Data in Zambia (4HIV-206)

Key Informant Interview Guide

Complete this section before starting the interview

Date and time of interview:

Name of interviewer:

Name of key informant interviewee:

List participant's sex:

Key informant's place of employment:

Key informant's professional title:

Documents/photos from this interview:

Introduction to Interview

Thank you for taking the time to speak with me today. My name is (FILL IN THE BLANK) and I work for MEASURE Evaluation, a USAID-funded project that strengthens capacity in developing countries to gather, interpret, and use data to improve health. I am working with a team to explore the availability and use of gender-related data. I would like to learn about the practices of your ministry/agency/organization related to sex-disaggregated and gender-sensitive health data. I'm also interested in whether gender data are used when making decisions about health programs and policies; and the facilitators and barriers of using sex disaggregated and gender sensitive data for decision making.

Your responses will be kept confidential. Any information gathered in this interview will be de-identified and combined with other findings, so that your responses are unidentifiable. Your participation in this interview is completely voluntary and you may stop at any time, with no penalty. We expect this interview to take 45 minutes. Is it okay for me to start?

Decision-maker questions are in blue. After Q3 they can be skipped if the KI does not make decisions.

1. How many years have you worked with this ministry/agency?

2. How many years have you worked in your current position at this ministry/agency?

3. Describe the type of work you do.

    a. PROBE: How much do you work with data?

    b. PROBE: How much of your work involves using data for writing reports?

    c. PROBE: How much of your work involves using data and reports to make recommendations for program and policy decisions?

4. (IF RESPONSE TO QUESTION 3 INDICATES THAT KEY INFORMANT ANALYZES DATA) How do you decide what data to include in your analysis? Who, if anyone else, is involved in that decision-making?

5. (IF RESPONSE TO QUESTION 3 INDICATES THAT KEY INFORMANT WRITES REPORTS USING DATA) How do you decide what data to present in the reports you write? Who, if anyone else, is involved in that decision-making?

6. (IF RESPONSE TO Q3 INDICATES THAT KI MAKES RECOMMENDATIONS/DECISIONS) How do you decide what data or reports to use to make decisions?

    a. How often do you use data to make decisions? (Every time? More than half? About half? Less than half? Never?)

b. How do you decide which types of data to use in making decisions?

c. PROBE: Can you share an example of a time when you used data to make recommendations or decisions for health programs and policies?

d. PROBE: Where do you get this data from?

7. Please describe your understanding of sex-disaggregated data?

IF KEY INFORMANT DOES NOT ADEQUATELY DESCRIBE OR DEFINE SEX-DISAGGREGATED DATA, PROVIDE THE FOLLOWING DEFINTION:

Sex-disaggregated data is data that is separated for males and females.

a. PROBE: Please give me an example of sex-disaggregated data?

IF KEY INFORMANT DOES NOT GIVE A CORRECT EXAMPLE OF SEX-DISAGGREGATED DATA, PROVIDE THE FOLLOWING EXAMPLE:

b. *An example of sex-disaggregated data is from the 2012 Zambia AIDS Indicator Survey. The results of the survey showed that among 20–24 years olds, 91.6% of women and 67.3% of men reported being tested for HIV.*

8. Please describe how, if at all, you think sex-disaggregated data could be useful in your current professional responsibilities?

IF KEY INFORMANT DOES NOT ADEQUATELY DESCRIBE HOW IT COULD BE USEFUL, PROVIDE THE FOLLOWING DEFINTION:

a. One example of how it could be useful is using data that showed 91% of women and 67% of men received HIV testing to make decisions. With these statistics, national, district, and community HIV programs can examine why young men are less likely to go for HIV testing and counseling, and develop strategies to overcome such gender barriers.

9. Please describe your understanding of gender-sensitive indicators.

a. PROBE: Can you given an example of gender-sensitive indicators?

IF KEY INFORMANT DOES NOT ADEQUATELY DESCRIBE OR DEFINE GENDER SENSITIVE INDICATORS, PROVIDE THE FOLLOWING DEFINTION:

Gender-sensitive indicators are those that directly address gender. They go beyond sex-disaggregated data (though they should be presented separately for men and women).

IF KEY INFORMANT DOES NOT GIVE AN EXAMPLE OF GENDER SENSITIVE INDICATOR, PROVIDE THE FOLLOWING EXAMPLE:

An example is the % of women and men who think wife-beating is justifiable; or % of men and women who share in decision-making with their spouse. While these indicators are disaggregated by sex, the reason they are gender-sensitive is because they focus on a gender norm, such as the power dynamics between women and men in decision-making, or the belief that men are justified in beating their wives.

10. Are the data your ministry/agency collect disaggregated by sex and age in your databases? Please describe the age categories that are used in your databases, if any.

    a. What proportion of indicators are disaggregated?

    b. Have there been changes in how many and which indicators are disaggregated in the past 12 months? What/who initiated these changes? Why were they initiated?

    c. Who makes decisions about what data are included on data collection forms at the facility level? At the regional or national level?

    d. Who decides what data are included in the national databases?

        i. Probe: Sometimes data is collected by sex at the facility level, but the disaggregation is lost by the time it gets into the national database. Have you seen this in your position? If so, please describe.

        ii. Who makes decisions about how and when data are aggregated to report up to the national level?

            1. Probe: Often data is collected in the daily registers by sex. Sometimes when it is entered into the summary tools, male and female numbers are combined to be “total number of people”. This may happen at higher levels as well. Who

makes the decisions whether to keep number of males and number of females separate in reporting, versus total number of people?

Let's take a moment to talk more specifically about PEPFAR data.

11. As you may know PEPFAR is very interested in sex and age-disaggregated data and has recently changed the requirements for partners reporting on PEPFAR indicators. The data for many indicators must now be disaggregated by age and sex when reporting it.
    a. What was the reaction of the Zambian MOH to these new requirements?
    b. How has the push from PEPFAR changed, if at all, the way your department/agency collects data?
    c. Are there PEPFAR indicators that are more difficult to collect by sex than others? Which ones are more challenging? Why are these more challenging?
    d. Does your ministry/department collect ART/treatment retention data by sex and age? Analyze it? Report it?
        i. Can you give an example of time you used it for recommendations or to make decisions?
    e. How many other HIV indicators are being collected outside the required PEPFAR indicators?
        i. Are they disaggregated by age and sex?
    f. For example, in the *Zambia AIDS Indicator Survey*, Chapter 12: Care and treatment of adults and adolescents with HIV, does not present retention and viral load data by sex. What steps would need to be taken or processes put into place for the MOH to report disaggregated data in the next report?

12. How much do you consider using or analyzing gender-related data or indicators when writing reports?
    a. PROBE: How often do you use sex- and age-disaggregated data when writing reports? (Every time you write a report? More than half? About half? Less than half? Never?)

    b. PROBE: For what types of health topics or reports do you use sex- and age-disaggregated data?

    c. PROBE: Can you give 1-2 examples of reports that you have analyzed data for or reports you have helped write that highlight sex differences or gender sensitive information? Age differences?

13. (IF RESPONSE TO QUESTION 12A. IS "EVERY TIME" OR "MORE THAN HALF"): What has helped or encouraged you to use sex-disaggregated and gender-sensitive data when writing such reports?

14. (IF RESPONSE TO QUESTION 12A. IS "ABOUT HALF", "LESS THAN HALF", OR "NEVER"): What would help you to use sex-disaggregated and gender-sensitive data more often?

15. Are there any instances when you wanted to include sex- or age-disaggregation in your analyses or reports, but were unable to because disaggregated data were not available? Please describe.

16. What, if any, barriers prevent you from using sex- and age-disaggregated data when writing such reports?

    a. PROBE: What challenges, including policy or logistical challenges, if any, prevent you from using sex- and age-disaggregated data?

IF RESPONSES INDICATE KI MAKES DECISIONS ABOUT DATA (IF NOT, SKIP TO Q22)

17. How much do you consider gender-related data and information when making programmatic or policy decisions?

    a. PROBE: How often do you use sex- and age-disaggregated data when making decisions? (In all your decisions? More than half? Half? Less than half? Never?)

    b. PROBE: FOR THOSE WHO HAVE RESPONDED THEY HAVE EVER USED GENDER DATA: Please describe an example of when you used sex-disaggregated data?

       Ex: probe/example: Do you use it for target setting? Resource allocation?

18. Are there any instances in which you would have preferred to have information that was disaggregated by sex, but found it was not available? Please describe.

19. What has helped or encouraged you in using sex- and age-disaggregated data when making decisions?

20. What are the barriers, if any, that may prevent you from using sex- and age-disaggregated data when making decisions?

    a. PROBE: What are some barriers including those related to policy, logistics, lack of availability?

21. What would encourage you to use sex-disaggregated data more frequently for decision-making?

22. What could be done to encourage or better support you to use sex- and age-disaggregated data for decision making?

23. What could be done to encourage program managers and policy makers (apart from yourself) to more frequently use sex- and age-disaggregated data for decision-making?

Closing of Interview

Thank you again for taking the time to talk with me. My team and I will use the responses you provided to help draft recommendations for increased collection and use of sex- and age-disaggregated data within PEPFAR-funded projects and the Zambian government.

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