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

Kenya

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CONTENTS

ABBREVIATIONS

ART	antiretroviral therapy
DHS	Demographic and Health Survey
DREAMS	Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe initiative
EMR	electronic medical records
GBV	gender-based violence
HIS	health information system
HMIS	health management information system
HTC	HIV testing and counseling
IGWG	Interagency Gender Working Group
KI	key informant
M&E	monitoring and evaluation
MGCSD	Ministry of Gender, Children, and Social Development
NASCOP	National AIDS and STI Control Programme
NGO	nongovernmental organization
PEP	post-exposure prophylaxis
PEPFAR	President's Emergency Plan for AIDS Relief
RHIS	routine health information system
SGBV	sexual gender-based violence
STI	sexually transmitted infection
USAID	United States Agency for International Development

EXECUTIVE SUMMARY

The availability of sex- and age-disaggregated data allows program managers and decision makers to examine service delivery, treatment, and health outcome data in depth. This helps them detect differences between the sexes, age groups, and key populations, which can lead to better understanding of the health needs of each of these groups and populations. Access to these data can also ensure that health systems do not perpetuate inequities associated with negative health outcomes. Despite the importance of examining gender and age differences, sex and age disaggregation are not always included or maintained in routine data collection practices and national HIS databases, such as the DHIS 2. Collection and use of gender-related data are increasing globally, but information gaps still prevent full understanding of the factors that facilitate or discourage helpful data disaggregation and use.

To enhance the availability and use of gender data, MEASURE Evaluation—funded by the United States Agency for International Development (USAID) and the United States President's Emergency Plan for AIDS Relief (PEPFAR)—explored factors that contribute to collection and use of sex- and age-disaggregated data in Kenya. Our study used 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.

Many variables have an impact on when and how data are disaggregated, but we found common barriers and facilitators around the availability, production, and use of sex- and age-disaggregated data. The most common barriers to producing disaggregated data were low demand and the view that disaggregation was unnecessary. These barriers influenced data-collection tool design. We found that the availability of data by sex and age depended on the tool that was used and what type of data was collected. HIV data were generally disaggregated by sex and age, but there was variation in which age bands were used. Key informants (KIs) for this study said that registers at the facility were disaggregated by sex. This was confirmed by review of data collection tools. However, when aggregated into summary tools, the male and female fields were often aggregated into number of people, as programs did not require disaggregated summary reporting.

We also found that the production of disaggregated data was limited by the availability of resources and the added burden of reporting this type of data. Key informants strongly believed that data being collected should be used, or else it should not be collected. The KIs explored successes and challenges in analyzing and using disaggregated data. They were not sure who was responsible for ensuring disaggregation and providing technical support. Key informants working with PEPFAR data cited successes and supportive strategies more frequently than KIs in other health areas that also had implications for HIV (such as tuberculosis, malaria, and immunizations).

Our desk review revealed that a majority of Kenya's HIV reports include sex and age disaggregation in their data presentations and discussions. Kenya's progress in gender integration and sex and age disaggregation should be applauded. Kenya has shown substantial progress and has lessons to share with other countries, as it continues to strengthen data collection, analysis, and use of disaggregated data. Nevertheless, significant challenges remain that will require continued support to address.

At the end of this report, we offer recommendations for increased advocacy and awareness at all levels around the importance of data disaggregation by sex and age. We call for the development of guidelines, materials, and

examples of how such data should be analyzed to reveal important findings. We also recommend support from gender-mainstreaming officers throughout program cycles to ensure production and use of sex- and age-disaggregated data.

INTRODUCTION

The purpose of health systems is to improve health and health equity, according to the World Health Organization (WHO, n.d.). Gender and age are key components of health equity and must be explicitly examined and addressed. A health information system (HIS) must be able to produce, analyze, and disseminate reliable and timely information for decision making (WHO, n.d.) within the social context (Percival, Richards, MacLean, & Theobald, 2014). Having data to better track and understand sex and age differences will ensure that health systems do not perpetuate inequalities, but instead foster greater equality.

Research has demonstrated that gender inequality is associated with negative health outcomes, such as increased risk of HIV, maternal mortality, child stunting and wasting, and poor nutrition. Gender norms can have an impact on women's and men's health through improved access to and use of health services, financial resources, and decision making. Age can be a compounding factor in behavior, power and decision making, and health outcomes. For example, adolescent girls have been shown to be at compounded risk of HIV infection owing to gender inequities and age barriers. Recognition of this increased risk led to the creation of USAID's DREAMS Initiative (USAID, n.d.) focusing on preventing HIV among adolescent girls. The acronym DREAMS reflects the goal for this population to become "determined, resilient, empowered, AIDS-free, and safe." Health disparities between women and men and girls and boys must be acknowledged and addressed in order to strengthen health systems and improve health outcomes.

When gender and age are not acknowledged and addressed in health information systems, norms and inequalities that influence health and health-seeking behaviors remain invisible. For example, researchers stress that inadequate sex- and age-disaggregated data continue to obscure examinations in treatment access across the HIV cascade (Croce-Galis, Gay, & Hardee, 2015). In addition, few research studies have been conducted looking at gender differences in the efficacy of antiretroviral therapy (ART), with some showing no differences

Key Terms

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, 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. Transgender individuals, whether they identify as men or women, are subject to the same set of expectations and sanctions (IGWG, n.d.).

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 (IGWG, n.d.).

Disaggregation: Data that are stratified or separated by factors, such as age or sex, are considered disaggregated. This allows for comparison between groups or characteristics. Routine data are usually disaggregated by **sex** (not gender) because they are collected based on an individual's physical characteristics of being male or female. If data are collected based on an individual's gender identity, such as a woman, man, transgender woman, or transgender man, then it would be disaggregated by **gender**. Special studies are more likely to collect gender-disaggregated data, though it is becoming more common in routine health information systems in some countries.

and others indicating varying results between men and women (Croce-Galis, et al., 2015). In order to ensure that gender- and age-related health differences are revealed and recognized, data that are stratified by sex and age must be available for analysis and informed decision making. The availability of such data allows 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.

For these reasons, bilateral and multilateral organizations, country governments, and global initiatives have made gender equity and gender-related data top priorities. However, large gaps remain in the collection and use of gender-related data, obscuring inequities and barriers to reaching health goals. Efforts must be made to ensure that data are collected in a way that can show progress toward these goals, and the challenges that must be overcome to fully achieve them.

Initiatives driven by USAID, the Bill & Melinda Gates Foundation, Data2x, and the Sustainable Development Goals have increased global attention and progress on improved gender data through such means as data disaggregation by sex. Researchers agree that every country should strive to develop the capability for basic equity analysis (Nolen, et. al., 2005). Sex- and age-disaggregated data are essential to examine health equity and to reach PEPFAR's 90-90-90 targets.[1] In response to increasing evidence of variations in risk of HIV infection and access to treatment across age groups, PEPFAR is collecting detailed data to recognize and track these nuanced differences. With clear information, programs can make informed decisions to better target disparities and at-risk populations.

This report focuses on health data that are routinely collected through a national health information system, (HIS) or a health management information system (HMIS). Facility-based data are an example of routine data. The census and household surveys are examples of nonroutine data. While nonroutine sources, such as the Demographic and Health Survey (DHS), collect data that are disaggregated by sex and age about every five years, it is important for routine health information systems to integrate gender through sex disaggregation and gender-sensitive indicators.[2] This would allow for continuous monitoring and timely course corrections. Despite the importance of examining gender and age differences, sex and age disaggregation are not always maintained in routine data collection practices or the national HIS.[3] While use of gender-related data is increasing globally, gaps remain in fully understanding the factors that can facilitate or discourage data disaggregation and use.

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[1] 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. Source: United States President's Emergency Plan for AIDS Relief (PEPFAR). (2014). PEPFAR 3.0. Controlling the epidemic: Delivering on the promise of an AIDS-free generation. Washington, DC: PEPFAR. Retrieved from https://www.pepfar.gov/documents/organization/234744.pdf

[2] Throughout the report, the terms national HIS and DHIS 2 are used to refer to Kenya's health information system. Key informants often used DHIS 2 to refer to the national HIS. DHIS 2 is the software platform upon which Kenya's HIS reporting system and PEPFAR's Data for Accountability, Transparency and Impact (DATIM) portal are built. We continue to use the term DHIS 2 to reflect key informant interview wording accurately.

[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.

In order to recognize gaps in availability of gender and age data, MEASURE Evaluation explored factors that contribute to the collection and use of sex- and age-disaggregated data in Kenya and Zambia. This report documents the process and findings of our exploration in Kenya. We had the following objectives:

1. Determine the availability of sex- and age-disaggregated data for HIV and HIV-related health indicators in Kenya.
2. Explore if and how sex- and age- disaggregated data were used for decision making.
3. Investigate the facilitators of and barriers to collecting and using sex- and age-disaggregated data across various indicators.

We will share the results of this study with stakeholders to guide next steps towards improving sex- and age-disaggregated data collection and use. This will enhance decision making to ensure equitable access to health services, particularly HIV treatment and adherence services, to support an AIDS-free generation and 90-90-90 goals.

METHODS

We conducted our research from April–September 2016. We used a two-pronged approach: (1) a desk review of key documents and literature, and (2) KIIs with 20 national-level data producers and decision makers. The University of North Carolina Ethics Review Board deemed that this study was not research with human subjects and did not require full ethical review.

Desk Review

Our study team conducted a desk review of key documents in Kenya. This helped us understand the current levels of sex and age disaggregation and discussion of gender issues in national HIV documents. We reviewed a range of government and Ministry of Health documents related to HIV, HIS, and monitoring and evaluation (M&E), such as national strategic plans for HIV and other sexually transmitted infections (STIs), M&E plans, and data collection forms. Our study team collected relevant documents from the Government of Kenya website, other documentation available online, and materials shared by stakeholders and partners in-country, such as M&E officers, data producers, and program directors. Appendix A lists the documents we reviewed.

Key Informant Interviews

Primary data collection was conducted in Nairobi, Kenya from June 27–July 8, 2016. Fifteen KIIs were conducted with data producers, data users, and decision makers working at the national level with experience in routine health data, collection, analysis, and use. Some interviews included more than one person. To gather the perspectives and experiences of people working on HIV at different levels, we purposefully selected key informants in tandem with in-country partners (such as the National AIDS Control Council and the National AIDS/STI Control Programme), related health programs, and routine data collection (such as the HIS unit at the Ministry of Health). Appendix B lists the 20 key informants.

Interviews explored barriers to and facilitators of collecting, reporting, and using sex- and age-disaggregated data. Questions also explored stakeholders' understanding of the importance of disaggregation in health indicators and ways to improve sex and age disaggregation. A lead researcher and a local research counterpart conducted the KIIs in English. Interviews lasted 30–60 minutes, were audio recorded with permission, and transcribed by a local consultant. Questioning was based on a semi-structured interview guide, which allowed the interviewers to follow themes and raise additional questions that emerged during the interviews. Appendix C presents the interview guide.

Analyses

We analyzed desk review findings in tandem with results from KIIs. Documents were reviewed for availability of sex and age disaggregation on data collection forms, DHIS 2 database fields, and attention to gender and age in national policies and documents, such as sex and age disaggregation in indicator definitions or targets. Results from the desk review were compiled and analyzed using a Microsoft Excel-based matrix. Documents were analyzed to identify the extent to which sex and age disaggregation were included in graphs, charts, indicator descriptions, or general discussion. We also considered other mentions of gender-related factors and gender-sensitive indicators. Documents from the desk review were used to corroborate or inform questions during KIIs.

Key informant interviews were compiled and analyzed using ATLAS.ti software. Interviews were coded using an *a priori* codebook, with the addition of *in vivo* codes and collapse of redundant codes. Interviews were then analyzed to reveal domains and themes around common challenges and successes.

In-country research partners at MEASURE Evaluation PIMA reviewed and validated our analysis, results, and recommendations. Additionally, review and feedback were solicited from stakeholders who participated in interviews.

RESULTS

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

—Key informant

Results revealed complex interwoven barriers to and facilitators of the availability and use of sex- and age-disaggregated data. In this report, we discuss our results in this order:

- Barriers to and facilitators of availability and production
- Barriers to and facilitators of analysis and use
- HIV retention and viral load data
- Gender-sensitive indicators

Barriers to and Facilitators of Data Availability and Production

We found that the availability and use of disaggregated data are tied to a cycle of value and demand for disaggregation. This influences program requirements and design, the type of data being collected, and the type of tool being used. In this section, we examine results around value and demand for disaggregation, followed by types of data and data collection tools. We also discuss the challenges of limited resources and the added burden of reporting placed on healthcare workers.

Value of and Demand for Disaggregation

Key informant interviews revealed a range of opinions on the value of disaggregation. One KI reported that data should always be collected by sex if the disease affects both men and women. Several other KIs expressed strong support for disaggregation. More KIs expressed uncertainty about the need for sex and age disaggregation. Many KIs said if they could see examples and convincing arguments of why disaggregated data are necessary, then they might be more supportive of such data's added value.

Most data are disaggregated by age to some extent. The KIs discussed variation in age brackets; some disaggregated by finer age groups; others disaggregated by less than 15 years or greater than 15. One KI said that age disaggregation is more of a challenge than sex disaggregation, and this variation creates uncertainty around the need for certain brackets.

> *We need to make sure that we see value in what we are collecting, and making use of the small disaggregations for decision making. Otherwise, there will not be value.*

While HIV data are generally sex-disaggregated, this is less common in other health areas, depending on the indicator objectives and data use. One KI, who focused on HIS, said that disaggregation is based on the strategic objective of the indicator: If the strategic objective focuses on disaggregation, then the data will be disaggregated. Other KIs reported similarly that they capture data only for a specific purpose. They said that if the indicator objectives do not include targets by sex and age or if the objectives include universal coverage, there is resistance to disaggregation. A majority of KIs mentioned the desire to see examples of how data would be used in order to help justify the collection of sex-disaggregated data.

> *If you then show the stakeholders—all the relevant entities and players in the sector—that disaggregating will lead to this, then we are able to make possible decisions or improvements; then that will help, so I see the value.*

Key informants also noted evidence is lacking to show the magnitude of the problem. They said that demonstrating need and generating demand would more likely convince program staff to disaggregate data. However, other KIs said that the need or demand comes from the program: If the program is not asking for it, the M&E team is unlikely to push disaggregation. One decision maker explained that some managers and government stakeholders do not understand the importance of disaggregation; if higher-level stakeholders do not see the importance, it is unlikely that those below will understand the need.

This showed us that the value and demand for disaggregation influences program design, data collection tools, and use of data. If disaggregated data are not valued, data collection tools will not be designed to collect disaggregated data, which in turn will impede data analysis and use. The importance of buy-in and value from multiple levels was also discussed. One high-level stakeholder mentioned stakeholder buy-in specifically, noting:

> *Get stakeholder buy-in, then move slowly to explore how we begin doing it. I think they are willing to participate in some of these initiatives. Start with cabinet secretary all the way down.*

Our desk review indicated that the Ministry of Gender, Children, and Social Development is responsible for advocating "the generation of sex-disaggregated data to guide interventions" (MSGCSD, 2011; see Appendix A).

One approach to increasing value and demand for data was the development of the *Plan of Action (2008-2012) to Implement the National Policy on Gender and Developmen*t (Ministry of Gender, Sports, Culture, and Social Sciences, 2008; see Appendix A). The plan—designed to promote gender equality through gender mainstreaming—involved the creation of gender officers to encourage production and use of gender-sensitive and sex-disaggregated data within sectors. A national M&E framework was developed that included an indicator to track this progress: "Proportion of ministries collecting and disseminating sex disaggregated data" (MGCSD, 2009; see Appendix A). Our desk review did not reveal documents with baseline or ongoing data to monitor these indicators.

Type of Data

PEPFAR data. PEPFAR data are increasingly available by sex, with some remaining challenges around retention and viral load indicators. Key informants from Kenya's National AIDS & STI Control Programme and National AIDS Control Council overwhelmingly said that sex disaggregation is common practice. This indicates significant progress in the past decade. Our desk review identified a gender audit conducted in 2009 that found that few HIV indicators were disaggregated by sex until 2008 (National AIDS Control Council & UNFPA, 2009; see Appendix A).

Key informants discussed sex disaggregation as part of PEPFAR's requirements, but also as a key principle of Kenya's Ministry of Health. They said that PEPFAR indicators are collected by sex for reporting and use, with KIs stressing that disaggregation for HIV treatment and counseling (HTC) data have been collected for some time, and that retention and viral load data in disaggregated format became available more recently. Key informant interviews revealed that the retention and viral load indicators are available by sex within electronic systems (such as a viral load database); however, disaggregation is not available in paper-based facilities (discussed separately below).

Key informants overwhelmingly agreed that data are collected by age and that the Government of Kenya supports PEPFAR disaggregation requirements. There was variation around what degree of disaggregation occurs and what age bands are being collected across data sources and health areas. Informants noted that the Ministry of Health is interested in age disaggregation, but there have been differences between PEPFAR and MOH bands: PEPFAR requires data by the age band 1–4 years, and the MOH uses the age bracket 1–9 years. Several KIs reported that the smaller age bands required by PEPFAR are feasible; however, other KIs discussed different age categories, particularly in non-HIV data sources, that do not allow such fine disaggregation. KIs reported that these differences were discussed at length in stakeholder meetings to gain consensus on age categories to be collected and reported.

Other health areas. The interviews and desk review revealed that disaggregation in health areas not defined by HIV is not necessarily the standard of practice and not perceived as necessary. One KI noted that there are no significant differences in immunization coverage between males and females according to the DHS, and so there is no basis to disaggregate in DHIS 2. Immunization data are disaggregated by geographic location, with KIs stressing that there are no sex-specific targets for immunization coverage, owing to goals for universal coverage. When all children are immunized regardless of sex, program staff do not feel the need to disaggregate if the goal is to reach all children. One KI discussed the possibility of exploring the feasibility of disaggregation, but noted it will require training to change data capture forms, electronic data transmission, analysis templates, and more. Prior analysis revealed that disaggregation in the malaria program was also not previously prioritized (Malaria Control Unit, 2015). With regard to age and non-HIV data, most indicators are disaggregated by age, but in larger brackets. For example, immunization data are disaggregated as under or over one year of age; full immunization is measured at one year of age. Other data are collected above and below age 15.

Population-specific data. The KIs said that data on key populations (men who have sex with men, female sex workers, people who inject drugs, and people with disabilities) are disaggregated. Because data on men who have sex with men and female sex workers are generally sex-specific, disaggregation has not been an issue. Key informants reported recent efforts to begin further disaggregation by gender in order to include transgender people among sex workers. The KIS who focused on these key populations stressed the importance of talking about sex and gender from the beginning and throughout the program cycle to normalize the practice and ensure that no one is left behind. They also indicated that age-disaggregated data are being collected at the implementing partner level for PEPFAR programs, but are not routinely examined at the national level.

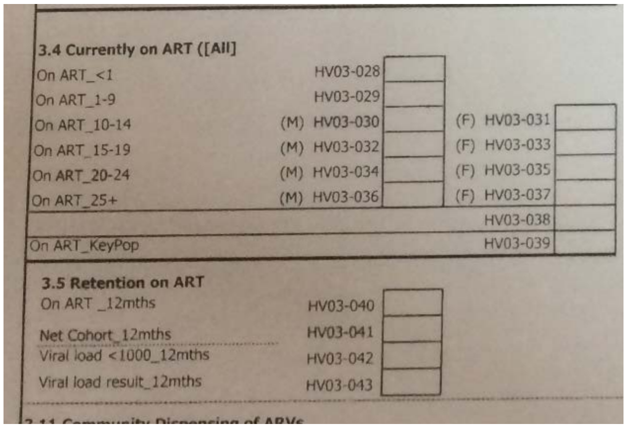
Another common theme was age disaggregation to track HIV among adolescents. The KIs discussed the DREAMS initiative and support from Kenya's president to fast-track the elimination of AIDS among adolescents. They said this is changing disaggregation practices, creating clear data on 15–19 year olds. The KIs said this is necessary, because adolescents fall between children and adults. Having separate data on adolescents will improve targeting and decision making.

Type of Tool

The type of tool used to collect data affects the extent of data disaggregation. Multiple KIs said that registers at the facility are disaggregated by sex. This was confirmed by review of data collection tools. However, when aggregated into summary tools, the male and female fields are often aggregated into number of people owing to program specifications.

Paper-based registries. The KIIs confirmed that facility register tools and individual data collection forms include a field for sex. Monthly summary tools do not. When information is transferred from paper-based registries for services and diagnoses to monthly summary tools, it is not required to be disaggregated on summary forms; hence, data are lost. Summary tools include HTC indicators that are disaggregated by sex, but viral load and retention indicators are not recorded by sex or age. For example, the revised 731 form (Figure 1) collects many indicators by sex, but does not include a field for sex for retention and viral load data; however, the viral load database does have fields for sex.

Figure 1. Extract of the HIV reporting form (MOH 731) used by Kenya's National AIDS and STI Control Programme



3.4 Currently on ART ([All]		
On ART_<1	HV03-028	
On ART_1-9	HV03-029	
On ART_10-14	(M) HV03-030	(F) HV03-031
On ART_15-19	(M) HV03-032	(F) HV03-033
On ART_20-24	(M) HV03-034	(F) HV03-035
On ART_25+	(M) HV03-036	(F) HV03-037
		HV03-038
On ART_KeyPop		HV03-039
3.5 Retention on ART		
On ART _12mths	HV03-040	
Net Cohort_12mths	HV03-041	
Viral load <1000_12mths	HV03-042	
Viral load result_12mths	HV03-043	

Key informants said it is difficult to track individual patients over time with paper records to assess 12-month retention rates; adding additional steps to include sex and age disaggregation is not practical and would be burdensome. The KIs reported that the paper tools have sufficient disaggregation to meet data needs for stakeholders, but there are also national algorithms to assist with reporting sex and age groups across all indicators. They also said this information is more easily captured in the electronic viral load database, which includes sex and age.

Electronic medical records. Discussion of electronic medical records (EMRs) or other automated systems surfaced in eight interviews. The KIs frequently said electronic records are more likely to have disaggregated data, provided the program requires this, because an electronic system makes collecting and maintaining this level of detail much easier. Informants often considered EMRs to be facilitators for collecting detailed data. Two different KIs estimated that EMR coverage ranges from 30–70 percent of facilities. Furthermore, KIs explained that some implementing partners and nongovernmental organizations create their own EMRs, raising issues related to consistency and comparability if systems record data differently or track different indicators. Although EMRs were designed for HIV data, one stakeholder suggested that they should be expanded to cover other areas such as malaria and the HIS in general. The KIs often saw electronic records as the solution to challenges around sex-disaggregated and finer age bands in retention data. Electronic medical records were cited for collecting data in all age bands and reducing burden. Key informants pushed for expanded and fully functional EMRs.

However, one KI expressed concern about sustainability with regard to donor-funded EMR systems:

> *Partners come with good systems but at the end of the project, systems sustainability issues are not addressed. Hence, at the end of the project, the system crumbles. Many EMRs are driven by donors and once they pull out, that's it. These are some of the issues facing us.*

This informant said that government commitment needs to be strong for projects to be sustained when donor support ends.

Limited Resources

Using sex-disaggregated data is also constrained by limited resources for materials, tools, personnel, and training. Key informants said that changing paper forms to capture disaggregation would be costly and time consuming, requiring trained staff with adequate tools at various service delivery points. Tool revision occurs every two years, and the process involves multiple stakeholders at all levels. Informants said that justification for additional data points should be demonstrated with concrete need for the data. Kenya has 47 counties and one national government that must be included in decision-making, distribution, and capacity building.

Informants discussed similar concerns about the resource costs for age disaggregation. They also noted that data collection practices are not harmonized among all donors. Several KIs mentioned the burden placed on implementing partners to report different age groups in different systems, such as PEPFAR's reporting system and the national DHIS 2.

Added Burden for Healthcare Workers

The additional burden that further disaggregation of data would place on healthcare workers arose throughout the KIIs. Data producers and decision makers were aware that adding a field for sex on monthly summary tools would add significant time and effort on already over-burdened health workers. One KI working outside the HIV sector noted that disaggregating all data by sex would have "huge program implications" owing to additional burdens on workers. Those collecting PEPFAR data agreed, noting that HIV testing and counseling alone involves 17 disaggregations. Nevertheless, one KI expressed appreciation of the benefits of sex-disaggregated data:

> *If you want to end the epidemic and understand the epidemiology of the landscape of HIV, data has to be further disaggregated, because some of the interventions are gender-specific.*

Several KIs said they had not received training on why it was important to disaggregate, leaving them with increased reporting requirements without a rationale. Key informants also expressed having difficulty with too many age-disaggregation requirements and changing guidelines. Several KIs described challenges surrounding recent revisions and updates from donors, requiring new disaggregations:

> *The issue we have about PEPFAR indicators is the age disaggregation; they want so fine disaggregations, and some of those are not realistic if you are using paper-based.*

Another KI described recent efforts to integrate multiple tools and data collection forms, including the goal of reducing data elements collected; these are barriers to disaggregate data by sex. Although other PEPFAR data are typically disaggregated, KIs said it is difficult to disaggregate retention data by sex. Retention requires linking individual patient data to previous points in time, which is especially difficult and burdensome to complete without EMRs. The lack of electronic records in some areas is a barrier to collecting all necessary data points. Several KIs reported that this is not feasible with paper tools.

Further, one KI commented that DHIS 2 has the capacity to include sex disaggregation, but data quality could be compromised by too many complicated disaggregations.

Barriers to and Facilitators of Data Analysis and Use

Key informants also discussed successes and challenges in analyzing and using disaggregated data. Successes and supportive strategies were cited more frequently by KIs working with PEPFAR data than by those in other health areas, such as tuberculosis, malaria, and immunization.

Structural Factors and Enabling Environment

Policy. Key informants highlighted the trend that sex and age are increasingly included in policy development and strategies. They said significant data are collected and used as part of planning from a gender perspective. One KI mentioned that the Kenya National Strategic Plan (KNSP) includes sex-disaggregated graphs. The same KI also said it is a challenge to systematically translate evidence into program implementation and design to ensure gender sensitivity. Nevertheless, KIs reported significant efforts are being made to develop gender-sensitive programs.

We found that in materials discussing Kenya's national strategies, gender is often included in a general overarching manner. However, there are few action steps or benchmarks. For example, in the *Kenya HIV Estimates*, the preface states: "We also need to tackle the fundamental drivers of the epidemic, particularly gender inequality, poverty, stigma, and discrimination in family and health service settings. In doing so, we will achieve our goals" (National AIDS STI Control Programme, Kenya, 2014; see Appendix A). However, this is the only mention of gender in the report. Similarly, in the *Kenya AIDS Indicator Survey 2012* (Ministry of Health, 2014c; see Appendix A), gender is mentioned in the final strategy to achieve national goals: "All stakeholders coordinated and operating within a nationally owned strategy and aligned results framework, grounded in mutual accountability, gender equality, and human rights." How to operationalize gender equality as part of meeting this goal is not mentioned anywhere else in this document. In both of these documents, many graphs are disaggregated by sex, and the narrative mentions that women carry a higher burden, but there are no details about gender inequality and how it contributes to HIV. Moreover, addressing gender inequity is not mentioned in the sections on next steps or sustained action.

Development partners. Key informants frequently acknowledged that the interest and support of development partners facilitate the use of sex-disaggregated data. They mentioned USAID, PEPFAR, the United Nations, gender-focused nongovernmental organizations, and the Global Fund to Fight AIDS, Tuberculosis and Malaria. The KIs noted that while donors have initiated the efforts, once the Ministry of Health has understood, donors and the ministry work together to achieve results. The KIs also said that age disaggregation is mentioned in policies and strategies, but there has been less focus on ensuring that age disaggregation is included, particularly in the updated age bands that PEPFAR requires. Nevertheless, PEPFAR's support and encouragement to collect the smaller age bands have changed common practice in Kenya with respect to HIV data.

Responsibility. About half of the KIs discussed who is responsible for ensuring sex disaggregation and gender sensitivity. Some informants said they were not responsible. Instead, they said it is the program staff's responsibility to request analysis by age, or that disaggregation is determined by the objective of the indicator only. Other KIs said the gender-mainstreaming department is responsible. Several KIs could not identify a gender-mainstreaming officer working in their department; one KI said the officer had left and not been replaced, and another KI could not recall support from the gender-mainstreaming ministry in the past.

Gender officers have been appointed in sector ministries, institutions of learning, and other units to mainstream gender and coordinate the collection, analysis, and updating of relevant sex-disaggregated data, according to Kenya's *Plan of Action, 2008-2012, to Implement the National Policy on Gender and Development* (Ministry of Gender, Sports, Culture, and Social Services, 2008; see Appendix A.) The plan calls for lobbying the National Bureau of Statistics to provide sex-disaggregated statistics. Though the plan expired in 2012, it was designed to work toward Vision 2030 (Government of the Republic of Kenya, 2007). We have not found a more current plan. It is unclear how often gender officers have been engaged to ensure the production, availability, and use of sex-disaggregated data within different sectors. A representative of the Gender Mainstreaming Office acknowledged that mandates of gender inclusivity and mainstreaming do not have enough financial support or staff to ensure the inclusion of gender in all procedures and documents.

Standard practice. Key informants working in the National AIDS Control Council (NACC) reported routinely analyzing all HIV indicators by sex, including PEPFAR indicators. One KI said that they routinely note in the discussion section of their reports that results were analyzed by sex, even if no differences were found. For example, the Kenya AIDS Indicator Survey highlighted analysis by sex even though there were no significant differences between men and women for HIV incidence in 2012 (Ministry of Health, 2014c). This demonstrates that analyses by sex and age are becoming common practice, but the ensuing discussions or attempts to address disparities remain weak.

It was also reported that the NACC routinely requests data from the national HIS to be disaggregated by sex (and age if appropriate) for reports and baselines. One KI discussed the importance of creating and maintaining the habit of looking at sex and gender differences so that this becomes a routine practice for program managers and M&E.

This is also connected to data use. The habit of analyzing data by sex leads to data use, which in turn encourages use in the future.. For example, one KI explained how data is being used and has been helpful:

> *Male-female data is being collected through and through. Does it help us? Yes, like in HTC, I can tell you if you look at the age group between 15 and 24 most of the positives are the females—twice as much as males! And it now helps (to know this) even going about DREAMS, because the DREAMS theme [working with young women and girls on HIV prevention] came out of that.*

Key informants said they often analyze and report data by age. They gave examples of presenting data by graphing differences between people older than 15 years and younger than 15, and going deeper into smaller age groups, such as 0–5 years and adolescents. Informants indicated a strong habit of disaggregating by age; however, there is variation in the age categories used. Outside of HIV data, standard practice procedures are also a barrier to data analysis and use, if disaggregation is not common practice. Other barriers to using data overlapped with the previously presented themes around producing data.

Individual Factors

Value and demand for disaggregation. Limited understanding of the value and demand for disaggregated data arose as a factor in analysis and use of data. Several KIs demonstrated value and demand for disaggregation. One said:

> *As I started by saying, male-female is the starting point you look at if there's a difference [in sex], before you go to age groups, and then place. Epidemiologically, why would you not want to look at male-female, unless the disease is only for females or only for males?*

This sentiment was not as common among the other KIs, who expressed lukewarm opinions or doubts about the value of disaggregation. Several KIs said they do not feel the need to analyze data by sex for all indicators, because they already know that data generally are split 50/50 between males and females, for example among children with HIV and retention. One KI explained that for those younger than age 15, the sex ratio was the same for males and females in terms of access and prevalence, precluding the need to disaggregate. This informant confirmed that analyses were conducted showing clear differences above age 15, where it becomes more necessary to look at sex. When asked how they knew the data are split equally, one KI said the data were analyzed by sex to obtain that information initially; they were still checked periodically. KIs also mentioned that the issue of disaggregation did not often arise in discussions.

Multiple KIs said that such data are more likely to be used if people understand the need for nuanced gender analyses, or if programs demand them. Lack of anticipated future use of data arose as a barrier to collection of sex-disaggregated data. KIs noted that there are a lot of data, and some data are disaggregated, but they struggled with the question, "Will it be used?" This question surfaced periodically during KIIs. Informants wanted to ensure data are collected only if they would be used. While many KIs recognized that age disaggregation is more difficult, they also acknowledged that it is important for DREAMS, because the program's goal of preventing HIV among girls requires nuanced data. One KI said that, among those at risk, 39 percent are adolescent girls. To get this data, it was necessary to go back to the registers. Such information is not available in DHIS 2, because it is not collected by narrow age bands. Another KI described recent revisions that aligned tools so they can follow age groups, such as 15–19 and 20–24, as required by PEPFAR. This will make it possible to track sex and age groups across PEPFAR's 90-90-90 goals.

Other KIs struggled to see the value of such small age bands. Even those who recognized the data's potential usefulness were reluctant to disaggregate to small age bands, because of the additional burden. They felt that this burden will discourage the motivation to collect and use high-quality data. One KI understood the value of collecting and analyzing data, and found it personally worthwhile to do so, but also acknowledged that if the process is not easy, then it is less likely to happen at the lower levels. She noted:

> *The bottom line is, if you make reporting easy, then they begin to enjoy looking at their data.*

Capacity. More than three-fourths of interviewees discussed capacity as a factor in the analysis and use of sex-disaggregated data. Only a handful of KIs were able to give concrete examples of how they or others use disaggregated data for decision making. One KI said data showed that 92 percent of people who inject drugs and access services are men, with women making up the remaining 8 percent. This prompted program managers to adjust programs to be more inclusive of women, while also prompting program managers to be on the lookout for potential gender-related barriers to accessing services. The key populations team described how data use and demand for data are integral in their program and have led to strong partnerships with communities and stakeholders around data use. Other KIs had difficulty offering examples of data analysis and use, sometimes citing low capacity or demand.

One KI expressed dismay that the facilities do not use the sex-disaggregated data they collect. Informants also expressed concerns that disaggregation requires additional personnel resources and technical skills training. In addition to the staff time and capacity required to accurately collect and maintain disaggregated data, the technical skills needed for analysis are complex when dealing with narrow age bands and, at times, small numbers. One statistical challenge noted with regard to the small age bands was wide confidence intervals, because there are few data points in each age group. According to KIs, a group of statisticians and researchers are tackling these issues. The KIs said that gender-mainstreaming officers do not necessarily have backgrounds in health data, epidemiology, or M&E.

HIV Retention and Viral Load Data

HIV data are often disaggregated, especially for use in counseling, testing, care, and treatment. However, USAID requested a specific focus on HIV retention and viral load data: namely, the pieces of information that are necessary to complete the HIV cascade by sex and age. Key informant interviews showed that the barriers to and facilitators of disaggregating these data often match those discussed in our previous sections.

Challenges around disaggregation of retention data arose in nearly every interview. Responses varied around whether disaggregation is considered vital, with some KIs noting that existing data do not show sex differences in retention. KIs reported that retention data are currently disaggregated within the viral load database, and coverage of EMRs ranges from 30–70 percent of facilities. Retention data collected and managed by EMRs are analyzed and used by sex, but data in the paper-based system are not disaggregated. Summary tools do not have a field for sex on the form, precluding the possibility of additional analyses by sex.

The additional time and resources needed to maintain this information were considered prohibitive. Informants expressed concerns about sustainability and increasing the burdens on healthcare workers. When asked why all retention data are not collected by sex, one KI offered this explanation:

> *It's because it's paper-based, and you are expecting health workers to do it. Do you know how hard it is to count? Can you imagine the cohort register, to count the number of people who started ART in January with your eyes and you did not write with a different pen? Nobody is going to count, already they struggle to report cohort data. Cohorting is poorly done now, and you want to tell me to go looking for male and female? It's hard!*

Key informants mentioned that one would need to return directly to the facility registers in order to examine that facility's retention or viral load rates by sex. Alternatively, several KIs mentioned that it is common, and even recommended by some, to take the existing sex proportion from the EMR system and apply that proportion to the remaining total numbers being collected at paper-based facilities, using this new total for reporting. One KI noted:

> *For you to do retention and viral suppression, what you need is more of EMR, not paper- based records, so…we have a viral database so we are able to collect that data and see male-female data. And for the retention for the last two years, we have been using the EMR data warehouse so that we are able to get male-female….*

One KI reported that the retention data show that differences between men and women are insignificant; however, men are dying more frequently than women, seemingly because they are coming in later, with lower CD4 counts. This KI discussed the value of this information and said it will be used for programming and targeting.

Gender-Sensitive Indicators

Gender-sensitive indicators measure elements of gender directly. They are designed to capture changes in status of gender norms, by measuring behaviors, expectations, and attitudes associated with gender. Examples of gender-sensitive indicators are perpetration or experience of sexual or gender-based violence (GBV), norms around acceptability of wife beating, household or financial decision making within couples, and women's ability to decide when to seek healthcare. These indicators often interact with health outcome indicators, such as HIV prevalence. Fewer than half of the KIs were able to describe what gender-sensitive indicators are, with even fewer KIs able to offer examples.

Key informants who were aware of gender-sensitive indicators reported that GBV is the only gender-sensitive indicator being collected in the HIS. Even among KIs who reported that GBV data are collected, there was discrepancy in how widely these are collected and the level of detail that is captured. One KI reported that GBV data are collected as part of violence and injury indicators, with GBV as an option of the type of violence experienced (review of the national HIS verified this). In addition, we reviewed the Sexual Gender Based Violence (SGBV) Register, MOH 365, and the SGBV Monthly Summary MOH 364. The SGBV register records incidents of sexual violence, specified as "rape, attempted rape, or sexual assault." Other forms of GBV, including physical or psychological violence, are not included in this form or the summary tool. While the register collects data on attempted rape and sexual assault, the summary tool was designed to capture numbers of rape survivors, excluding attempted rape and other sexual assault captured in the register. Similarly, the current MOH 731 captures the provision of post-exposure prophylaxis (PEP) because of occupation, sexual assault, or other exposure; however, the forthcoming MOH 731 drops the sexual assault option, thus obscuring important PEP data related to GBV. It is possible that this information will be captured elsewhere; however, the tools reviewed here reveal gaps in documentation and reporting for nonrape GBV and PEP administered following sexual assault. In addition, the data on administration of PEP are not disaggregated by sex or age.

The National Monitoring and Evaluation Framework towards the Prevention and Response to Sexual and Gender Based Violence (2014; see Appendix A) acknowledges a lack of routine data and describes ongoing efforts to improve data collection around sexual gender-based violence (SGBV). The document highlights all forms of GBV, but describes the framework's focus on sexual forms of GBV. It is necessary to start somewhere with the daunting task of monitoring GBV, but the exclusion of physical and other forms of GBV in national strategies is a concern, particularly when such frameworks often take years to be updated.

Kenya does not collect any other gender-sensitive indicators in its HIS. However, the government is undertaking a review of all of its national HIS indicators. Stakeholders have initiated a gender working group to discuss the addition of gender-related indicators to the national indicator list and recommendations to disaggregate all indicators by sex. Suggested indicators would measure aspects of gender such as training of healthcare workers on gender mainstreaming, attention to gender in work planning, and GBV. Indicators remain under revision, with gender to be discussed as part of the ongoing National Strategic HIV/AIDS Plan midterm review process, according to stakeholder reports. The plan of action calls for the Ministry of Gender, Children, and Social Development to advocate and ensure the use of gender-sensitive indicators (Ministry of Gender, Children, and Social Development, 2008; see Appendix A). Gender officers proposed the suggested gender indicators; however, a stakeholder meeting for additional discussion and indicator refinement lacked a representative from the Ministry of Gender, leaving others without gender expertise to interpret and define the indicators.

DISCUSSION

This study is the first in Kenya to examine national stakeholders' perspectives on the importance of gender and the availability and use of sex and age disaggregation in HIS. We found varied results in the value of disaggregation and the current state of disaggregation and use, but many stakeholders also reported that gender mainstreaming is increasing and acknowledged the importance of using disaggregated data for decision making. Findings are consistent with those in other countries in eastern and southern Africa, indicating that although attention to gender is increasing in HIS, sex- and age disaggregated data are not always available or used (Mandal, et al. 2016; Iskarpatyoti, in press).

Overall, KIIs provided a varied and in-depth picture of experiences and understanding of the importance of sex- and age-disaggregated data. Although key informants were knowledgeable about what it means to disaggregate data by sex and age, there was significant variation in the value they placed on these practices. The majority of KIs agreed that PEPFAR data are important to disaggregate by sex and age, despite challenges in collecting the narrow age bands. Some KIs agreed that sex and age disaggregation are necessary for epidemic control, and said that they enjoy using disaggregated data when it is easy and when they understand the value. Alternatively, a smaller number of KIs said disaggregated data are important because donors request them, which indicates that work remains to be done to help stakeholders understand the importance of gender regardless of reporting mandates. This is an important distinction, because if people do not see the need to disaggregate other than for reporting purposes, the data are less likely to be used for program planning or decision making. Multiple KIs said that if data are not going to be used, they should not be collected. Although this concern is understandable, it could also prevent data collection and use before they begin.

In addition, if health workers do not see value in recording the disaggregation, the data may be less likely to be of high quality. This issue is particularly acute in non-HIV data; other health areas that intersect with HIV are less often disaggregated and KIs were less likely to express value in disaggregation. Despite the crosscutting nature of age and gender and the intersectionality of HIV with other diseases and health behaviors, there appears to be a lack of understanding and drive to disaggregate non-HIV data. Given the added burden to collect disaggregated data, stakeholders may be justified in questioning disaggregation if data will not be used. One KI's suggestion to address this was to use nonroutine data sources, such as the DHS, to identify potential gender imbalances; if identified, then investigate further with routine data. Another approach would be to increase training and capacity building to promote understanding of why it is important to look at sex and age differences routinely and across the board.

We found that gender is increasingly included in policies and national strategies, but bringing those goals and principles down to the programmatic level remains challenging. Gender is often discussed in strategic approaches or principles, but is frequently left out of additional discussions or analyses thereafter. Gender may be a priority, but clear guidelines, operational practices, and assignment of responsibilities are lacking at lower levels. Concrete steps are needed to integrate gender in monitoring, evaluation, and other program aspects. The high number of KIs requesting examples of how sex-disaggregated data could be useful indicates a lack of understanding of the importance of gender and what gender integration would look like in practice.

Opinions varied about whose responsibility it is to ensure that gender is addressed throughout the data collection, analysis, and reporting process. Some KIs indicated they initiated analysis and reporting by sex, or advocacy for disaggregation, but others did not. Some were prone to shift responsibility to the program staff, while the program staff felt it was the responsibility of decision makers or M&E directors to guide what data are collected. Because gender is a crosscutting area and often not included in job descriptions or responsibilities, it was common for informants to regard it as beyond their responsibilities. Often, no one believed it was their responsibility, leading to missed opportunities for gender discussions and advocacy. Several KIs reported that the gender-mainstreaming ministry should be supporting gender initiatives. However, they noted that gender-mainstreaming officers have limited oversight, budget, and authority to change practices for data collection and use and are not always involved in pertinent discussions. Gender-mainstreaming officers discussed these challenges and expressed the need for further support and collaboration among health programs and decision makers. While there are mandates for the Ministry of Gender, Children, and Social Development to generate sex-disaggregated data, limiting this responsibility to gender officers could disassociate the responsibility from the sector itself.

Many stakeholders acknowledged that they resisted changing data collection forms and practices, because doing so is cumbersome, costly, and time consuming. While tool revision takes place every two years, it seems advocacy of sex disaggregation outside of PEPFAR and HIV data has been minimal. Because revising tools is such a lengthy process, advocacy and sensitization about the importance of disaggregation is crucial to get buy-in and support at all levels.

Two-thirds of our key informants discussed EMRs, mostly focusing on how EMRs could facilitate sex- and age-disaggregated data, with a few mentions of potential challenges. Although the majority of KIs referred to EMRs as a solution to data disaggregation challenges and healthcare worker burden, EMR systems are not a panacea. Stakeholders acknowledged challenges of coverage, the exclusion of non-HIV data, lack of a unified EMR system among implementing partners, and questionable sustainability, but most were able to overlook these challenges and viewed EMRs as the most efficient way to encourage disaggregated collection and use, through ease of collecting, maintaining, and analyzing data in detail. However, evidence suggests that complex systems, inadequate training and security, and a lack of perceived benefit for data collectors could be barriers to implementation and uptake of EMRs (Fraser, et. al., 2005). Thus EMRs cannot be seen as the only solution to collecting and reporting disaggregated data.

Interestingly, KIs did not discuss the fact that DHIS 2 is designed to be adapted to data needs, so adding disaggregation or capturing individual data within the existing Kenyan system would be relatively simple. The challenge would be the added detailed data collection for disaggregation at the facility level, which is also the case with EMRs, though this was overlooked in KIIs. Electronic records will not eliminate the need for someone to enter detailed data, though entering data in a computer may be easier than entering data on paper, as many stakeholders pointed out.

Within existing electronic systems for HIV data, retention data are disaggregated by sex and age; however, data collected using paper summary tools are not disaggregated. It is reassuring that our results show that available retention data are being used to look at sex differences and reveal useful information, such as that men enter HIV care later. The current practice of using electronically collected retention data to estimate sex and age disaggregation at facilities without electronic systems, however, is concerning. This could obscure sex and age data that may be systematically different at nonelectronic facilities, leading to missed opportunities to target certain populations. The challenge remains to balance which data are available and required by PEPFAR against the immense burden of collecting retention data by sex and age with unwieldy paper tools.

While gender-sensitive indicators are more commonly collected in special studies, indicators for GBV should be collected routinely. The current focus on collecting data on sexual violence highlights Kenya's commitment to track and prevent SGBV, with significant progress made in the past decade. However, KIs differed on knowledge regarding whether and how GBV data are being collected. No KIs mentioned the national M&E framework for prevention of and response to SGBV; this points to a gap between program and policy. Additionally, the focus on sexual violence leaves a worrisome gap in attention to other forms of GBV, such as physical, psychological, and economic violence, which are also associated with risk of HIV and other health issues.

Despite these challenges, our desk review revealed that a majority of Kenya's HIV reports present and discuss sex- and age-disaggregated data. Kenya sets a good example in the ongoing effort to document that analyses are conducted by sex, even in the absence of significant differences. This is important, because these Kenyan government documents show decision makers and program managers that gender-based analysis is routine practice, and the data are being used even when no disparities are found. This provides a positive example for other countries.

CONCLUSIONS AND RECOMMENDATIONS

Kenya's progress in gender integration and sex and age disaggregation should be applauded. Kenya has made substantial progress, and its experience as it strengthens its collection, analysis, and use of disaggregated data offers lessons for other countries. Nevertheless, significant challenges remain and will require continued support to address successfully.

Based on the results from KIIs and our desk review, we offer the following recommendations for Kenya:

- Increase advocacy and awareness at all levels around the importance of sex and age disaggregation in the national HIS.
    - Offer tailored training sessions for decision makers and data analysts, to clarify why gender is important at various levels and to discuss roles and responsibilities for gender integration at each level.
    - Stress the cross-cutting nature of gender, placing shared responsibility on all stakeholders for gender integration and advocacy
- Develop guidelines or materials showing how data can and should be analyzed to reveal important age- and gender-related findings.
- Increase awareness of how disaggregation will help meet program and epidemic goals, such as 90-90-90.
- Disaggregate summary tools and maintain disaggregation throughout the national HIS.
- Until routine data are available, use DHS or other surveys to examine gaps or equity issues to inform programs and changes in routine data collection. Develop pilot programs to examine sex and age differences in routine data for health areas that do not currently disaggregate.
- Continue to expand EMRs when possible for ease and accuracy of maintaining disaggregated data, especially with regard to retention data.
- When it is not possible to collect sex- and age-specific data among all paper-based facilities, use spot record checks or data verification from selected facilities to examine sex and age breakdowns in locations without EMRs.
- Include gender-mainstreaming officers in national HIS working groups and leadership groups where decisions are made about scope, development, implementation, and use of HIS. Gender-mainstreaming officers should also be included in other relevant discussions, meetings, and regular communication to allow opportunities for gender advocacy and technical assistance. Within this, acknowledge that gender-mainstreaming officers can be helpful in starting and guiding conversations, but emphasize that attention to gender falls within all staff responsibilities.
- Integrate gender in HIS curriculum and training content, particularly around importance of disaggregated data availability and use.

- Increase capacity of gender-mainstreaming officers to understand and advocate measurable and realistic M&E indicators to track gender progress.
- Include discussion of gender on agendas for decision making, program planning, and M&E meetings.
- Expand the National Monitoring and Evaluation Framework towards the Prevention of and Response to Sexual and Gender-Based Violence in Kenya to include forms of GBV other than sexual violence.
- Maintain "sexual assault" as an option for the reason for PEP in MOH 731 in addition to disaggregating this indicator by sex and age.

Gender integration should be approached as a collaborative endeavor to avoid overburdening healthcare workers, while balancing essential data needed to identify and address inequities. In addition to enabling data collection and analysis structures to collect and stratify data by sex, age, and other gender-sensitive indicators, it is equally important to build a culture of equity-oriented decision making in HIS (Nolen, et al., 2005). Health information systems should raise awareness and build capacity to examine and address gender inequities, increase demand for richer gender data, and influence policy change to support gender equality.

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APPENDIX B. Key Informant Interview Participants

Interview participants are listed here in the order in which they were interviewed.

Interviewee	Organization	Professional Title
Mr. Peter Nasokho	ICF International	County monitoring and evaluation capacity building advisor
Mr. Nicolas Kweyu	U.S. Centers for Disease Control and Prevention	Monitoring and evaluation technical team lead
Dr. David Soti	Ministry of Health	Head, Health Informatics and Monitoring and Evaluation
Dr. Isabella Maina	Ministry of Health	Head, Health Sector Monitoring and Evaluation Unit
Ms. Helgar Musyoki	National AIDS and STI Control Programme (NASCOP)	Key populations program manager
Ms. Janet Musimbi-Mbole	National AIDS and STI Control Programme (NASCOP)	Technical manager, key populations outreach and mobilization
Ms. Mary Mugambi	National AIDS and STI Control Programme (NASCOP)	Key populations program officer
Mr. Japheth Nyambane	National AIDS and STI Control Programme (NASCOP)	Technical advisor, technical support unit
Dr. Wesley Aoga	Health Information Systems Unit, Ministry of Health	Medical statistics
Ms. Nancy Amayo	Health Information Systems Unit, Ministry of Health	Health information manager
Mr. Francis Gikunda	Health Information Systems Unit, Ministry of Health	Chief health record and information officer
Dr. Collins Tabu	National Vaccines and Immunization Programs, Ministry of Health	Head, Immunization Policy and Performance Monitoring
Dr. Jacob Odhiambo	National AIDS and STI Control Programme (NASCOP)	Field epidemiologist
Dr. Joyce Wamicwe	National AIDS and STI Control Programme (NASCOP)	Head, Strategic Information Management
Mr. Kennedy Mutai	National AIDs Control Council (NACC)	Statistician
Mr. John Kanyigwe	National AIDs Control Council (NACC)	Deputy director, Policy Research and M&E
Dr. Sam Munga	Global Fund Secretariat	Kenya Country Coordinating Mechanism Secretariat

Dr. Joyce Muthuuri	Ministry of Health, Gender Unit	Gender-mainstreaming officer
Dr. Benjamin Elly Odongo	U.S. Centers for Disease Control and Prevention	Technical advisor, prevention of mother-to-child transmission of HIV/maternal health
Ms. S. Katherine Farnsworth	Health, Population, and Nutrition Office, USAID	Deputy HIV/AIDS team leader

APPENDIX C: Key Informant Interview Guide

Assessment of Barriers and Facilitators to Availability and Use of

Sex- and Age-Disaggregated Data in Kenya (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 Kenya 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 Kenyan 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 *Kenya 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 Kenya government.

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