Priority Action Points for Gender in Health Information System Improvement[1]

- Established national systems and guidelines support standardized routine reporting of sex-disaggregated data.

- Training for HIS staff stresses the importance of gender- and sex-disaggregated and gender-sensitive data collection, analysis, and reporting.

- Training, academic curricula, and processes for developing training and education programs to build HIS skills and competencies nationally are standardized and include a gender component.

- All data sets include sex disaggregation and gender-sensitive indicators, where applicable, and are developed in line with national guidelines.

- Processes for collecting and storing indicator metadata maintain sex disaggregation.

- Defined aggregate data exchange standards and guides exist and are used nationally to support aggregate data reporting. Processes are in place to maintain disaggregated data (e.g., for sex and age) where applicable.

- Procedures for data collection, processing, analysis, and use are defined and implemented nationally and include sex-disaggregated and gender-sensitive data.

- A national coordinating body to oversee data quality is established and meets regularly. Data reviews and audits that include sex-disaggregated data are integrated in the HIS plan/health plans and conducted on a regular schedule.

- The HIS data use strategy includes use of sex-disaggregated and gender-sensitive data.

- Automated data reporting from the point of service occurs nationally and includes sex-disaggregated and gender-sensitive data. Features to support data discovery, integration, analysis, and visualization exist at all levels.

- Parameters on the measurement of the impact of data use are defined and documented and include use of sex-disaggregated and gender-sensitive data.

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The Importance of Gender in HIV Health Information Systems

Addressing gender while strengthening HIV health information systems (HIS) ensures equity in access and benefits for women, men, girls, boys, and transgender people. This brief establishes the importance of addressing gender in HIS activities and suggests a series of action points that will promote the integration of gender in HIV HIS and ultimately improve HIV outcomes.

Background

The data that HIS produce can perpetuate inequalities or promote health equity, and developing an HIS that has the capability for basic equity analysis should be a priority for every country (Nolan, 2005).

The purpose of an HIS is to collect, report, and disseminate health data from all sources, including health facility and community data, electronic health records for patient care, population-based data, human resources information, financial information, supply chain information, and surveillance information (WHO, 2012).

Gender[2] is a central component of health equity, and it is essential to examine and address gender explicitly in HIS. When sex and age are not acknowledged and addressed in HIS, gender norms and inequalities that influence health and health-seeking behaviors remain invisible. Having data to track and understand these differences will ensure that health systems do not perpetuate inequalities, but instead foster greater equality. Ultimately, addressing gender in HIS strengthens these systems and improves health outcomes for all (Payne, 2009).

Gender inequality is a key driver of the HIV epidemic, and it negatively affects people of all genders. HIV is the leading cause of death for women of reproductive age, worldwide (UNAIDS, 2019a), and transgender women are 49 times more likely to have HIV than others of reproductive age (Baral, et al., 2013). Globally, men who have sex with men are 22 times more likely to acquire HIV than the general population (UNAIDS, 2019b). (See the related brief: The Importance of Gender in HIV and AIDS Data.)

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[1] Drawn from the Scale for Measuring the HIS Stages of Continuous Improvement: https://www.measureevaluation.org/resources/publications/tl-19-27. Access the full toolkit for more detail: https://www.measureevaluation.org/his-strengthening-resource-center/his-stages-of-continuous-improvement-toolkit/his-stages-of-continuous-improvement-toolkit.

[2] Gender refers to a culturally defined set of economic, social, and political roles, responsibilities, rights, entitlements, and obligations associated with being female and male and the power relations between and among women, men, 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. http://www.igwg.org/igwg_media/Training/DefinGenderRelatedTerms.pdf

Recently, global attention has increasingly focused on the availability of and need for gender data and data to assess potential gender-related patterns, particularly for HIV. Inadequate sex- and age-disaggregated data obscures examinations of access to treatment across the HIV cascade (Croce-Galis, Gay, & Hardee, 2015). Given the strong relationship between gender inequality and HIV, it is particularly important that HIV HIS are gender sensitive.

Integrating Gender into HIV Health Information Systems

When thinking about integrating gender into HIV HIS, it is useful to consider integrating gender into each area of the Health Information System Strengthening Model (HISSM): the enabling environment (HIS leadership and governance and HIS management), information generation (data sources, data management, and information products and dissemination), and HIS performance (data quality and use).[3] The model also includes contextual factors, such as gender, that affect everything else in the model, and the human element, which forms the backdrop of data users, producers, and beneficiaries of the health system.

The Enabling Environment

The enabling environment lays the foundation for planning, implementing, and maintaining an HIS. Two key subareas to consider when thinking about gender and the enabling environment of HIV HIS are HIS governance and leadership and HIS management. It is important that HIS leaders be aware of and champions for, the importance of gender in HIV and HIS. Including gender in HIS policies, standards, financing, human resources, and capacity strengthening efforts will create a gender-sensitive enabling environment, which will fully support HIV data and decision making that benefit all citizens.

Information Generation

Disaggregated data and gender-sensitive indicators[4] allow program managers and decision makers to examine service-delivery, treatment, and health-outcome data in-depth so that they can detect differences between genders, age groups, and key populations.

Data collection for HIS draws on a variety of sources: census, vital registration, household survey and facility-based data. Owing to international recognition of the importance of gender in the HIV epidemic, HIS HIV data are frequently collected by sex. However, in some instances the sex variable is dropped when data are aggregated from facility registers to regional and national levels (MEASURE Evaluation, 2017a; MEASURE Evaluation, 2017b; MEASURE Evaluation–Tanzania, 2016), preventing analysis of gender differences. This loss of sex disaggregation is more common in non-HIV HIS data; however, some challenges remain, including disaggregation of retention and viral load data (MEASURE Evaluation, 2017a). Building disaggregation into HIS from the beginning, through a collaborative process, will ensure the collection of data that identify and address inequities does not overburden healthcare workers.

In addition to sex disaggregation, gender-sensitive indicators can further illuminate gender inequities. Gender-sensitive indicators are often collected in surveys or special studies, but select indicators should also be included in routine HIS, such as experience of gender-based violence (GBV). Studies have demonstrated a strong association between GBV and HIV, with GBV both a risk factor for infection and a consequence of infection (Program on International Health and Human Rights and Harvard School of Public Health, 2009; WHO & UNAIDS, 2010). Thus, it is important that GBV be included in routine data reporting, analysis, and decision-making.

HIS Performance

Data use is a key output of a strong HIS, making gender integration at this stage critically important. Maintaining an awareness of gender inequity while analyzing, synthesizing, and interpreting data will highlight gaps and lay the foundation for gender-sensitive decision making for HIV programming. Researchers have also noted the importance of building a culture of equity-oriented decision making in HIS (Nolan, et al., 2005). HIS should include components that raise awareness among and build capacity of system users, preparing and encouraging them to use health data to examine and address gender inequities, demand rich gender data, and influence policy change to support gender equality.

Health Information System Improvement and Gender

The HISSM offers a conceptual framework to guide HIS strengthening, which, as we have detailed, should include gender. The HIS Stages of Continuous Improvement Toolkit guides users through how to measure current and desired HIS status across the five core domains of an HIS. This toolkit includes key gender attributes that can be measured and monitored both during assessment and roadmap development, for HIS improvement overall or within a programmatic area, such as HIV. See the sidebar for priority action points for gender in HIS improvement.

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[3] This brief uses the HISSM as a frame for integrating gender into HIS. See https://www.measureevaluation.org/his-strengthening-resource-center/his-strengthening-model for more information on the model.

[4] Gender-sensitive indicators are indicators that go beyond sex disaggregation (but are still collected by male/female, as applicable). Their purpose is to measure aspects of gender directly and to examine more thoroughly how gender relations affect health and development outcomes. For examples, see https://www.global-healthlearning.org/course/gender-m-e.

Resources

- The Importance of Gender in HIV and AIDS Data: https://www.measureevaluation.org/resources/publications/fs-17-205c

- HIS Stages of Continuous Improvement Toolkit: https://www.measureevaluation.org/his-strengthening-resource-center/his-stages-of-continuous-improvement-toolkit/his-stages-of-continuous-improvement-toolkit

- Gender considerations along the HIV treatment cascade: An evidence review with priority actions: https://cquin.icap.columbia.edu/wp-content/uploads/2017/05/Gender_Considerations_Along_the_HIV_Treatment_Cascade.pdf

- Guidelines for integrating gender into an M&E framework and system assessment: https://www.measureevaluation.org/resources/publications/tr-16-128-en

- Improving gender equity and health outcomes: By addressing gender in health information systems: https://www.measureevaluation.org/resources/publications/tr-18-290

- How can gender equity be addressed through health systems? http://www.euro.who.int/en/health-topics/health-determinants/gender/publications/2009/how-can-gender-equity-be-addressed-through-health-systems

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Gender is the culturally defined set of expectations about the roles, rights, and responsibilities associated with being female and male, as well as the power relations between and among people based on those expectations. Gender varies over time and within and between cultures. Transgender persons, whether they identify as women or men, are also subject to these gender expectations. (Interagency Gender Working Group [IGWG])

Sex refers to the classification of people as male or female. At birth, infants are assigned a sex based on a combination of bodily characteristics including chromosomes, hormones, internal reproductive organs, and genitalia. (USAID, March 2012 Gender Equality and Female Empowerment Policy)

Gender identity refers to a person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth. It includes both the personal sense of the body, which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical, or other means, and other expressions of gender, including dress, speech, and mannerisms. (American Psychological Association [APA], 2015)

Sexual orientation refers to whom a person is physically, spiritually, and emotionally attracted. Categories of sexual orientation typically have included attraction to members of one's own sex (homosexual), attraction to members of the other sex (heterosexual), and attraction to members of both sexes (bisexual). While these categories continue to be widely used, sexual orientation does not always appear in such definable categories and instead occurs on a continuum and is fluid for some people. (APA, 2012) Public health professionals often use the abbreviations MSM (men who have sex with men) and WSW (women who have sex with women) as neutral terms to describe sexual activity of individuals, which may not necessarily correlate with a person's sexual orientation.

Gender equality is the concept that all human beings, both men and women, are free to develop their personal abilities and make choices without the limitations set by stereotypes, rigid gender roles, or prejudices. Gender equality means that the different behaviors, aspirations, and needs of women and men are considered, valued, and favored equally. It does not mean that women and men have to become the same, but that their rights, responsibilities, and opportunities will not depend on whether they are born male or female. (Global Fund Gender Equality Strategy, 2009)

Gender integration entails identifying gender differences and resulting inequalities pertaining to specific programs and projects. Gender integration is the process of addressing these differences and inequalities in the design, implementation, monitoring, and evaluation of programs. (USAID, March 2012 Gender Equality and Female Empowerment Policy)

Gender analysis is a systematic way of looking at the different impacts of development, policies, programs, and legislation on women and men that entails, first and foremost, collecting sex-disaggregated data and gender-sensitive information about the population concerned. Gender analysis can also include the examination of the multiple ways in which women and men, as social actors, engage in strategies to transform existing roles, relationships, and processes in their own interest and in the interest of others. (Global Fund Gender Equality Strategy, 2009)

Sex- and age-disaggregated indicators are regular health indicators that are presented both for men and women or boys and girls. We emphasize disaggregating by sex, because most data are collected according to male and female sex. However, some surveys are beginning to include other identities, such as transgender, in which case the data would be disaggregated by gender identity. Striving to include all gender identities in future M&E efforts will enhance health- and gender-focused programs, by allowing them to understand and respond to all gender differences. (Population Reference Bureau's Framework to Identify Gender Indicators for Reproductive Health and Nutrition Programming, 2002)

Gender-sensitive indicators are those that address gender directly and go beyond sex disaggregation alone—for example, gender-based violence, as well as other more complex indicators such as gender attitudes and norms, power differences, female autonomy, and access to educational and economic opportunities. Gender-sensitive indicators should be disaggregated by sex, when possible. Gender-sensitive indicators make it easier to assess how effectively gender dynamics that negatively influence health service access and outcomes have been addressed. (USAID, ADS Chapter 205)