

Mapping Gender Data Gaps in Health

INTRODUCTION

Gender data for tracking the health of women and girls throughout the life course are critical for generating evidence on best practices and for informing health policies and programs.

Unfortunately, gender data are not available for many aspects of women's and girl's health. Restricted sampling means that we know most about women of reproductive age (15-49), but less about children, younger adolescents, and older women, especially those with disabilities, LGBTQIA+ individuals, and women and girls in humanitarian settings.

Today, the most pressing gender data gaps for health are:

- violence against women;
- mental health;
- cause of death;
- adolescent health;
- utilization of health services by women;
- aging populations;
- sexual and reproductive health and rights; and
- disability

WHERE WERE THE GENDER DATA GAPS IN 2014?

Two of the eight MDGs were directly related to the health of women and girls — including MDG 4 to “reduce child mortality” and MDG 5 to “improve maternal health” — while other MDGs included gender-relevant health targets and indicators. Success in achieving health-related MDGs was ultimately mixed and for some goals (e.g. MDG 8.13 on access to affordable essential drugs), the level of progress made is unclear due to limited data.

In 2014, [Data2X identified](#) maternal mortality, women's excess disease burdens, violence against women, mental health, adolescent health, and utilization of health services by women as the most pressing gender data gaps in this area.


GENDER DATA AND HEALTH IN THE SDG ERA

Under the SDGs, the focus has become more nuanced and shifted to universal health coverage and the relationship between health and other dimensions of social and economic development. Health-related SDGs include Goal 2 on zero hunger, Goal 3 on good health and wellbeing, Goal 5 on gender equality, Goal 8 on decent work and economic growth, and Goal 16 on peace, justice and strong institutions. In total, there are 31 gender-relevant health indicators within the SDGs (full list available in appendix).

Since 2014, we have better data on women's excess disease burdens and on maternal mortality compared to 2014 (though multiple disaggregation is lacking for both). However, other gender data gaps remain, and through Data2X research, additional gaps have been identified since the initial mapping exercise, including data on sexual and reproductive health and rights, disability, cause of death, and aging populations.

Violence Against Women

Data on violence against women — be it physical, sexual, or psychological violence — is inherently difficult to collect due to its sensitive nature. Since 1995, only some 40 countries have conducted more than one survey on violence against women and many do not collect data on non-intimate partner violence (United Nations Statistics Division (UNSD) 2017). Most knowledge on violence against women comes from the United States Agency for International Development's (USAID) Demographic



and Health Surveys (DHS) or the United Nations Children’s Fund’s (UNICEF) Multiple Indicator Cluster Surveys (MICS), which is narrow in definition and sampling.

While international standards do exist for measuring the prevalence and attitudes toward physical and sexual violence through survey instruments, there is currently no international standard on the measurement of psychological violence. Relatedly, there is also almost no data on the immediate and long-term psychological effects of violence. Additional data gaps exist for violence committed against women with disabilities, LGBTQIA+ individuals, and women and girls in humanitarian settings, even though these groups are more likely to experience violence.

Mental Health

Mental health disorders remain widely underreported — particularly in developing countries — due to lack of attention, misdiagnoses, and stigma. When mental health data are reported at the country level, it is unlikely to be disaggregated by sex or age. The Global Burden of Disease is one of the only sources of global prevalence data on mental health disorders, drawing on a range of studies for national estimates that are often not internationally comparable and rely on modelling and imputation where data are not available. Mental health is also not present in the SDG framework, other than one indicator (SDG 3.4.2) on suicide, which the World Health Organization (WHO) monitors using civil registration and vital statistics (CRVS) data on cause of death. Suicide deaths are particularly difficult to track because they are sometimes registered under another cause of death (e.g. accidental injury) due to misdiagnoses or stigma (UNSD 2017).

Cause of Death

Less than one half of WHO member states have well-functioning death registration systems that record causes of death (UNSD 2017), and women’s deaths are systematically less likely to be registered than men’s (Data2X 2019). Accurate recording of cause of death is challenging because most deaths take place outside of medical facilities, especially

in rural areas, and health practitioners may lack the training and information needed to correctly identify the cause (WHO 2010). However, the medical community is constantly innovating and WHO has developed a protocol for “verbal autopsy,” which uses information gathered from people familiar with the deceased and trained recorders to produce a cause of death using standard WHO classifications (WHO 2017).

Adolescent Health

The SDG focus on adolescents (ages 10-19) created a surge in interest, research, and investments on adolescents. Yet health data for adolescents is not always sex-disaggregated and data on socially excluded girls is particularly scarce, e.g. girls with disabilities and adolescent refugees. There is also limited self-reported data on young adolescents (aged 10-14 years), as major population-based surveys including the DHS and MICS only sample adolescents as young as 15. However, MICS do include a questionnaire on children aged 5-17 administered to the primary caregiver (usually the mother). Specific topics for improved gender data collection among adolescents include mental health, violence and conflict, disability, sexual and reproductive health, and education.

Utilization of Health Services by Women

Just as in 2014, there remain serious gaps in knowledge on the predictors of women’s utilization of health services, including for sexual, reproductive, and maternal health. Utilization of health services is not captured by SDG 3.8, which looks at coverage of health services but not uptake. Women’s demand and use of health services can be impacted by accessibility, affordability, quality, appropriateness, and social norms. Reliable data — especially at the individual level — on the factors that lead women to use or not use health services would go a long way towards the design of health interventions that better meet women’s needs, especially for women with disabilities, LGBTQIA+ individuals, and women and girls in humanitarian settings.

Aging Populations

Major population-based surveys like the DHS and MICS focus data collection on women of reproductive age (15–49 years old), leading to gaps in data on women in their post-reproductive period. Women above 49 years old are also not adequately covered in the SDG monitoring framework. Yet this is an important demographic considering that women live longer than men, and the additional years are not always healthy. Quality of life can reduce significantly once a spouse dies (e.g. loneliness and economic vulnerability), and women’s longer life expectancy increases their vulnerability to diseases that materialize in old age (e.g. Alzheimer’s and certain cancers).

Sexual and Reproductive Health and Rights

Obtaining reliable data on sexual and reproductive health and rights can be difficult due to its deeply personal nature and the persistence of social and cultural taboos. While data on family planning needs (SDG indicator 3.7.1) and on adolescent birth rate (indicator 3.7.2) are regularly produced by countries, data on women’s informed decision-making (indicator 5.6.1) and on laws guaranteeing full and equal access to sexual and reproductive health care, information, and education (indicator 5.6.2) are not. Additional data gaps outside the SDG framework include women’s and girls’ unmet needs for menstrual hygiene management, the prevalence of illegal and unsafe abortions, and health outcomes associated with them.

Disability

Disability and gender inequality are closely interlinked, and while a significant portion of women and girls are born with disabilities, others can become disabled as a result of lack of access to sexual and reproductive health services and exposure to violence and harmful practices like FGM and child marriage (UN Women 2017). Women with disabilities also experience multiple and intersecting forms of discrimination based on factors such as income or race, in addition to

gender and disability.

Between 2005 and 2014, 125 countries and territories collected data on persons with disabilities in their censuses, while 88 countries collected disability data in labor force surveys and 46 in living standard measurement surveys (UNDESA 2015). However, there is significant underreporting and not all disability data that is reported is sex-disaggregated. Countries also use different definitions and questions to monitor disability, impeding international comparability.

WHERE DOES GENDER DATA ON HEALTH COME FROM?

Population-based surveys are key sources of information for women’s health include the DHS, MICS, Reproductive Health Surveys (RHS), and World Bank Living Standards and Measurement Study (LSMS). Population-based surveys are limited by the fact that they occur at wide intervals (usually between three and five years apart) and do not sample at the sub-national level. However, these are crucial instruments for capturing prevalence levels among populations and for uncovering underreported issues.

Administrative data from health service providers are a better source for sub-national data but are unsuitable for determining the overall prevalence of health issues within a population and do not capture underreported and often hidden problems like violence against women or mental health disorders. CRVS data are a type of administrative data that provides crucial sex-disaggregated demographic information and is a key data source for health. However, reliable CRVS data are unavailable for more than 100 low- and middle-income countries. Women and girls face gender-specific barriers to CRVS registration in the form of poverty, geography, lack of knowledge and discriminatory laws that, for example, require children to be registered by their father or with their father’s name (Centre of Excellence for CRVS Systems 2019).

WHAT EFFORTS ARE UNDERWAY TO IMPROVE GENDER DATA ON HEALTH?

Key actors providing guidance on gender data on health are:

- [WHO](#) is the key custodian agency for monitoring SDG 3 on health and wellbeing, with [UNICEF](#) and other agencies acting as custodians or partner agencies on specific indicators.
- [UNICEF](#) is the custodian agency for SDG 5.3 on ending harmful practices like FGM and child marriage, while the United Nations Population Fund ([UNFPA](#)) is the custodian agency for SDG 5.6.1 on decision-making around sexual relations, contraceptive use and reproductive health.
- SDG 5.2 on violence against women and girls is monitored by several co-custodian agencies including [WHO](#), [UN Women](#), [UNICEF](#), [UNFPA](#) and others.
- [UNSD](#) and [UNFPA](#) provide national statistics offices with guidance on collecting, processing, disseminating, and analyzing data on violence against women.

Some significant large-scale efforts are under way to collect, analyze, and disseminate sex-disaggregated health data, among them:

- The [Global Burden of Disease \(GBD\)](#) Study, which uses the **Disability-Adjusted Life Year (DALY)** measure to estimate morbidity and mortality globally since 1990 — including mental health disorders — and can assess prevalence trends disaggregated by sex, age, country, and region.
- University of Oxford's [Young Lives](#) qualitative longitudinal study looks into 12,000 children's experiences in four countries (Ethiopia, India, Peru, and Vietnam), including the impact of gender and other equity issues in relation to health, for instance, cognitive development, nutrition, and violence.

- On disability, the [Washington Group on Disability Statistics](#)' short set of census questions for adults and children has been adopted by national statistical offices in at least 78 countries and is widely considered the most robust way to collect internationally comparable sex-disaggregated data on disability.
- [UNFPA](#) has scaled up its technical and financial support to ensure all countries collect high-quality georeferenced sex-disaggregated census data. UNFPA is also advocating to integrate questions on CRVS into the 2020 census round to better assess the quality and coverage of national CRVS systems.

Organizations calling for, supporting, or using gender data on topics related to women's and girls' health include:

- [Countdown to 2030](#) is a global movement providing the independent monitoring, analysis, and reporting on progress to meet SDG commitments around women's, children's and adolescents' health.
- The [Evidence-based Measures of Empowerment for Research on Gender Equality \(EMERGE\)](#) initiative at University of California, San Diego is developing, testing, and promoting robust measures of gender equality and empowerment including measures of reproductive health, maternal and child health, mental health, and gender-based violence.
- On adolescent girls, the Population Council's [Girl Innovation, Research, and Learning \(GIRL\)](#) Center is harnessing the power of open data, through its **Adolescent Data Hub**, to connect decision-makers with the evidence needed to maximize investment and transform the health and lives of adolescents, especially girls.
- The UNFPA's [kNOwVAWdata](#) project, launched in 2016, supports countries in Asia and the Pacific to systematically measure prevalence of violence against women and girls, including a specific focus on women with disabilities.



- The [Centre of Excellence for Civil Registration and Vital Statistics](#) at the International Development Research Centre advocates for stronger CRVS systems to monitor and support progress towards gender equality, including on health outcomes.

International efforts to compile existing sex-disaggregated health data include:

- The [Integrated Public Use Microdata Series \(IPUMS\)](#) is a database of international census and survey data, harmonized for international comparison. More than 105 national statistical offices provide their data to IPUMS on topics including maternal, child and reproductive health, and violence against women.
- The [World Health Statistics](#) report, one of WHO's annual flagship publications, compiles data from the organization's 194 Member States on all health-related SDG targets. The 2019 edition contains the first ever analysis of all SDG health-related indicators disaggregated by sex, including a list of SDG indicators for which sex-disaggregation would be informative but is not currently reported. The 2020 edition will aim to reduce the number of relevant health indicators that are not sex-disaggregated and report by sex where possible.
- UNFPA and WHO maintain two of the largest repositories of global population data and health statistics: [World Population Dashboard](#) and the [Global Health Observatory](#), respectively.

RECOMMENDATIONS

To address gender data gaps in health, greater investment should be geared toward supporting a strong system with a mix of survey and administrative data (including CRVS data) to provide sub-national and individual level estimates on different health issues facing women and girls throughout the life-course. Existing instruments should be expanded in terms of sampling to capture the experiences of underrepresented groups, including children, younger adolescents, and older women — especially those with disabilities, LGBTQIA+ individuals, and women and

girls in humanitarian settings.

The collection of data on violence against women, mental health, and sexual and reproductive health rights ideally require dedicated surveys. For such sensitive and underreported health problems, cell phone (SMS, social media, or app-based) surveys are a useful tool for anonymous reporting. Big data from cell phones and geographic information systems can also be used to create accurate visual mapping and insights into the factors influencing women's utilization of health services in different locations.

Health information and indicators for adolescent girls should be available through expanded coverage of existing survey instruments (the DHS and MICS) and through expanded sampling to capture the self-reported experiences of girls aged 10-14 years. Dedicated panel surveys covering adolescents — with prospective panel cohorts that are followed over time (e.g. Young Lives) — are highly desirable to fill policy gaps on adolescent girls' health, especially socially excluded girls.

Improved and expanded efforts are needed to collect sex-disaggregated disability data globally. The inclusion of the Washington Group questions within national censuses and surveys could yield significant improvements in data availability on women with disabilities, but only if the data are simultaneously disaggregated by sex and disability.

This brief is part of "Mapping Gender Data Gaps: An SDG Era Update." The full report can be accessed here: data2x.org/MappingGenderDataGaps.

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Appendix: Gender-Relevant SDG Health Indicators (31 total)



- 2.2.1 Prevalence of stunting among children under five years of age (Tier I)
- 2.2.2 Prevalence of malnutrition among children under 5 years of age, by type (wasting and overweight) (Tier I)
- 3.a.1 Age-standardized prevalence of current tobacco use among persons aged 15 years and older (Tier I)
- 3.b.1 Proportion of the target population covered by all vaccines included in their national programme (Tier I)
- 3.c.1 Health worker density and distribution (Tier I)
- 3.1.1 Maternal mortality ratio (Tier I)
- 3.1.2 Proportion of births attended by skilled health personnel (Tier I)
- 3.2.1 Under 5 mortality rate (Tier I)
- 3.2.2 Neonatal mortality rate (Tier I)
- 3.3.1 Number of new HIV infections per 1,000 uninfected population, by sex, age and key populations (Tier I)
- 3.3.2 Tuberculosis incidence per 100,000 population (Tier I)
- 3.3.3 Malaria incidence per 1,000 population (Tier I)
- 3.3.4 Hepatitis B incidence per 100,000 population (Tier I)
- 3.3.5 Number of people requiring interventions against neglected tropical diseases (Tier I)
- 3.4.1 Mortality rate attributed to cardiovascular disease, cancer, diabetes or chronic respiratory disease (Tier I)
- 3.4.2 Suicide mortality rate (Tier I)
- 3.5.2 Harmful use of alcohol, defined according to the national context as alcohol per capita consumption (aged 15 years and older) within a calendar year in litres of pure alcohol (Tier I)
- 3.6.1 Death rate due to road traffic injuries (Tier I)
- 3.7.1 Proportion of women of reproductive age (aged 15–49 years) who have their need for family planning satisfied with modern methods (Tier I)
- 3.7.2 Adolescent birth rate (aged 10–14 years; aged 15–19 years) per 1,000 women in that age group (Tier I)
- 3.8.1 Coverage of essential health services (Tier I)
- 3.9.1 Mortality rate attributed to household and ambient air pollution (Tier I)
- 3.9.2 Mortality rate attributed to unsafe water, unsafe sanitation and lack of hygiene (Tier I)
- 3.9.3 Mortality rate attributed to unintentional poisoning (Tier I)
- 5.2.1 Proportion of ever-partnered women and girls aged 15 years and older subjected to physical, sexual or psychological violence by a current or former intimate partner in the previous 12 months, by form of violence and by age (Tier II)
- 5.2.2 Proportion of women and girls aged 15 years and older subjected to sexual violence by persons other than an intimate partner in the previous 12 months, by age and place of occurrence (Tier II)
- 5.3.2 Proportion of girls and women aged 15–49 years who have undergone female genital mutilation/cutting, by age (Tier I)



- 5.6.1 Proportion of women aged 15–49 years who make their own informed decisions regarding sexual relations, contraceptive use and reproductive health care (Tier II)
- 5.6.2 Number of countries with laws and regulations that guarantee full and equal access to women and men aged 15 years and older to sexual and reproductive health care, information and education (Tier II)
- 8.8.1 Frequency rates of fatal and non-fatal occupational injuries, by sex and migrant status (Tier II)
- 16.1.1 Number of victims of intentional homicide per 100,000 population, by sex and age (Tier I)