Integrating gender data in health information systems: challenges, opportunities and good practices
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Abstract

Health information systems are constantly generating data. Data on everyone who interacts with the health system, their health status, diagnoses, treatment, and outcomes, is kept on private record. While details remain confidential, data are aggregated to provide health statistics that guide decision-making.

Health statistics are crucial for public health policy, but not only that. These data are used for monitoring inequalities and tracking progress towards achieving goals like gender equality and sustainable development. This depends on quality data being collected, analysed, and produced so that it is sex-disaggregated wherever possible and brings to light how gender norms are shaping people's experiences and outcomes.

This paper explains the importance of gender data and statistics and how health information systems contribute. It explores the common challenges in producing and using gender and health data and suggests opportunities and examples of good practices. Recommendations to support national health systems improve data quality are provided.

This guidance document is part of the WHO Regional Office for Europe's work on supporting Member States in strengthening their health information systems. Helping countries to produce solid health intelligence and institutionalized mechanisms for evidence-informed policy-making has traditionally been an important focus of WHO's work and continues to be so under the European Programme of Work 2020–2025.

Keywords:
HEALTH INFORMATION SYSTEMS, GENDER, GENDER EQUALITY, DECISION MAKING, HEALTH POLICY
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Reliable health information and data embedded in a fully functioning and high-quality health information system (HIS) are the foundation of sound decision-making. WHO recognizes that the HIS is a cross-cutting issue and HIS improvement benefits many public health areas.

This paper was prepared by Jessica Gardner, International Consultant in Gender Data and Statistics. It is based on a literature review of guidance on gender data and statistics, both generally and in the health domain (see references).
1. Importance of gender data and statistics

Health is one of the widest statistical domains. The provision of health care is expensive, so it is important that governments have quality statistics available to inform and monitor health policy. Gender data, statistics and analysis are an essential part of evidence-based decision-making, with gender integration in health information systems being a prerequisite.

Gender data and statistics cut across all areas of public health and service delivery. Take life expectancy, for example, which is the ultimate measure of health used in calculating the Human Development Index. Women have a longer life expectancy than men, a phenomenon related to both biology and gender norms in society.

Fig. 1 Healthy life expectancy and life expectancy at birth (years), Uzbekistan, 2016

In the case of life expectancy, the reasons for gender gaps relate to both biology (for example, women are more protected from heart disease due to the production of estrogen) and gender (for example, men may not seek health care if it is perceived as unmasculine to do so). It is difficult to determine the extent to which biology and gender impact health outcomes, as the two do not act independently. Gender data and statistics provide the basis for identifying gaps and recognizing where policy interventions are needed.

In 2019, WHO’s annual statistics publication – World Health Statistics – focused on sex-disaggregated data and gender analysis. The report highlights the major improvements needed to improve data quality and integrate gender in national health data systems, with sex disaggregation currently available for less than half (11/28) of relevant SDG indicators at the global level.3

The COVID-19 pandemic has also shed light on the urgent need to equip health systems to respond with data that are disaggregated by sex, age and other characteristics. Few countries are able to report sex-disaggregated data along the clinical pathway. As at October 2020, out of 183 countries, eight had sex-disaggregated data on COVID-19 testing (4%), 126 on confirmed cases (69%), 21 on hospitalizations (11%), and 92 countries on deaths (48%).4 A lack of gender integration in health information systems will hold governments back from responding effectively, costing resources and lives. Integrating gender is not difficult but it requires political will, sustained investment and action to achieve.

“Understanding the role sex and gender are playing in the COVID-19 outbreak is essential to building an effective, equitable response to the pandemic.”5

Fig. 2 Screenshot from the COVID-19 Sex-Disaggregated Data Tracker on reporting of sex-disaggregated data, 2020


1.1 What are gender data and statistics?

Gender statistics help us to understand how the realities of life differ between the sexes, so that policy and services can be tailored to meet varying needs.

Integrating gender into health information systems starts with a clear understanding of what is meant by gender statistics. This also depends on understanding what gender is and how it differs from biological sex.

Sex refers to an individual’s biological sex. This is determined at birth – typically male or female – and is relatively fixed. Sex is a determinant of health, meaning boys and girls, and particularly women and men, have different health issues and health care needs based on being male or female.

Gender is a social construct which includes the norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other. The concept is often associated with what it means to be masculine or feminine. Gender refers to the social expectations of being a girl or boy, man or woman, for example, how they are expected to behave, dress, and function in the world. Gender varies within and between cultures and can change over time.

Gender and sex are related to but differ from the concept of gender identity. Gender identity is a person’s “deeply felt, internal and individual experience of gender, which may or may not correspond to the person’s physiology or designated sex at birth”.

Gender statistics provide quantitative evidence of the realities of life for women, men, girls and boys. This includes, but goes well beyond, disaggregating data by sex. Gender statistics also involve measures that are only relevant to women (for example, the proportion of pregnant women who access antenatal care) and measures only relevant to men (for example, survival rates for prostate cancer).

Notably, gender statistics include the production of statistics on issues where inequalities exist due to gender. These gender inequalities are emphasized through the targets and indicators of Sustainable Development Goal 5, which aims to achieve gender equality and empower all women and girls. Priority statistics concern time spent on unpaid domestic work (SDG Indicator 5.4.1), women’s representation in parliament and local government (SDG Indicator 5.5.1), the prevalence of intimate partner violence against women (SDG Indicators 5.2.1 and 5.2.2), and harmful practices such as child marriage (SDG Indicator 5.3.1) and female genital mutilation (SDG Indicator 5.3.2).

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1. IMPORTANCE OF GENDER DATA AND STATISTICS

Box 1: How is gender integrated into national statistics?

The United Nations definition of gender statistics demonstrates what is involved in integrating gender into any statistical system. The four components relate to how data are collected, analysed, and disseminated:

a) Data are collected and presented by sex wherever applicable;

b) Data that reflect gender issues are produced;

c) Data are based on concepts and definitions that accurately reflect the diversity of women and men and capture all aspects of their lives;

d) Data collection methods consider and find ways to overcome stereotypes and social and cultural factors that may cause gender bias in the data.10

There is increasing recognition of the need for data systems to evolve further to represent individuals of all gender identities, whether they identify as men, women or other. The appropriate collection and analysis of data on gender identity or people who identify as non-binary (neither male nor female) is an area where statistical standards are still in the early stages of development. Some countries have introduced Other or Non-binary as response categories, in addition to Male and Female. Further work and testing are needed before international standards are available in this area.11

1.2 Why are gender data important for health information systems?

Health is one of the broadest statistical domains. The provision of health care is the cornerstone of socioeconomic development, but it is expensive. It is important for governments to have a comprehensive range of relevant health statistics available to inform and monitor health policy.12

Health care is not gender neutral. Health systems that are simply designed for everyone will be held back by being gender blind. Gender is a social stratifier, affecting freedom of movement, decision-making power, and health-seeking behaviour. Gender inequalities lead to different opportunities, different access to information and resources, and to different levels of power and influence. The social positioning brought about by gender norms translates to different health system needs, experiences and outcomes. Gender norms also shape the design of the health system itself, with women and men often segregated into different roles within the health workforce.

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“Gender affects how females, males and people of other genders live, work and relate to each other at all levels, including in relation to the health system.”

The health information system needs to respond by providing disaggregated data and analysis by sex, gender, age, location, and other variables. Within health information systems, the best sources of data come from administrative records, population-based sample surveys, and population censuses. Administrative records from hospitals and health care providers are perhaps the most valuable source of gender data, but they can be hampered by poor data collection, storage, transmission, and management processes. They are impacted by capacity of frontline health care workers to collect and report the information in the required format and in a timely manner, and by the information management systems and processes in place. Even when sex-disaggregated and gender data are collected and collated, they are often not analysed or made easily accessible within and outside the health ministry.

United Nations countries have made clear commitments to gender and health as signatories to the Beijing Platform for Action (1995) and commitments to human rights, such as the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). These are the detailed international frameworks for achieving gender equality and both include gender and health as priority areas. Reports on progress towards the Beijing Platform and to the CEDAW Committee need to include gender data to provide evidence of achievements. Concluding observations from the CEDAW Committee on State party reports often observe where gender gaps exist and call on countries to improve gender data production and use.

The adoption of the Global Goals has brought increased demand for disaggregated data. SDG 3 on health includes 28 indicators, six of which explicitly relate to gender equality. However, gender and health targets also feature in other goals, including SDG 2 (zero hunger), SDG 5 (gender equality), SDG 8 (decent work and economic growth), and SDG 16 (peace, justice and strong institutions). A recent study on gender data gaps across the SDGs identified 31 SDG indicators that are relevant to health (see Box 2).


Box 2: Gender-relevant SDG Health Indicators (31 total)

2.2.1 Prevalence of stunting among children under 5 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)
3.1.1 Maternal mortality ratio (Tier I)
3.1.2 Proportion of births attended by skilled health personnel (Tier I)
3.1.3 Under-5 mortality rate (Tier I)
3.1.4 Neonatal mortality rate (Tier I)
3.1.5 Number of new HIV infections per 1 000 uninfected population, by sex, age and key populations (Tier I)
3.1.6 Tuberculosis incidence per 100 000 population (Tier I)
3.1.7 Malaria incidence per 1 000 population (Tier I)
3.1.8 Hepatitis B incidence per 100,000 population (Tier I)
3.1.9 Number of people requiring interventions against neglected tropical diseases (Tier I)
3.1.10 Mortality rate attributed to cardiovascular disease, cancer, diabetes or chronic respiratory disease (Tier I)
3.1.11 Suicide mortality rate (Tier I)
3.1.12 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)
3.1.13 Death rate due to road traffic injuries (Tier I)
3.1.14 Proportion of women of reproductive age (aged 15–49 years) who have their need for family planning satisfied with modern methods (Tier I)
3.1.15 Adolescent birth rate (aged 10–14 years; aged 15–19 years) per 1 000 women in that age group (Tier I)
3.1.16 Coverage of essential health services (Tier I)
3.1.17 Mortality rate attributed to household and ambient air pollution (Tier I)
3.1.18 Mortality rate attributed to unsafe water, unsafe sanitation and lack of hygiene (Tier I)
3.1.19 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)
Box 2: Gender-relevant SDG Health Indicators (31 total)

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)

Note: Tier I indicators have internationally accepted standards for measurement and data are collected regularly. Tier II indicators have internationally accepted standards for measurement but data collection by most countries is irregular. Tier III indicators do not have internationally accepted standards and countries do not collect the data needed.

Gender data priorities go beyond any one set of indicators. International commitments and measurement frameworks such as the SDGs are a starting point for improving gender data across all fields. The indicators above can be expanded to include the remaining SDG 5 indicators to capture a broader range of related inequalities that impact health. For example, the COVID-19 pandemic has drawn attention to the gender divide in unpaid care work and the implications this has on women’s well-being and capacity to engage in paid work. The importance of women in leadership and the need for more inclusive institutions and decision-making has been emphasized as essential for building back better.

Further to the SDG indicators identified above, it is important to raise awareness of all the indicators under SDG 5 concerning gender equality and empowerment of women and girls. There are 14 indicators under SDG 5 that shed light on the priority areas and enabling factors for achieving equality:

- 5.1.1 Whether or not legal frameworks are in place to promote, enforce and monitor equality and non-discrimination on the basis of sex
- 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
- 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
- 5.3.1 Proportion of women aged 20–24 years who were married or in a union before age 15 and before age 18
- 5.3.2 Proportion of girls and women aged 15–49 years who have undergone female genital mutilation/cutting, by age
- 5.4.1 Proportion of time spent on unpaid domestic and care work, by sex, age and location
• 5.5.1 Proportion of seats held by women in (a) national parliaments and (b) local governments
• 5.5.2 Proportion of women in managerial positions
• 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
• 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
• 5.a.1 (a) Proportion of total agricultural population with ownership or secure rights over agricultural land, by sex; and (b) share of women among owners or rights-bearers of agricultural land, by type of tenure
• 5.a.2 Proportion of countries where the legal framework (including customary law) guarantees women’s equal rights to land ownership and/or control
• 5.b.1 Proportion of individuals who own a mobile telephone, by sex
• 5.c.1 Proportion of countries with systems to track and make public allocations for gender equality and women’s empowerment.

Minimum set of gender indicators

Adopted by the United Nations Statistical Commission in 2013, a set of 54 statistical indicators represents the minimum information for gender statistics production and use in countries.

Indicators fall under five domains:

1. Economic structures and participation in productive activities and access to resources
   Labour force participation rate, youth unemployment rate, gender gap in wages, population using mobile phones, etc.

2. Education
   Primary education completion rate, school enrolment ratios, youth literacy rate, etc.

3. Health and related services
   Under-five mortality rate, antenatal care coverage, smoking prevalence, obesity, etc.

4. Public life and decision-making
   Seats held by women in national parliament, women’s share of managerial jobs, etc.

5. Human rights of women and girl children
   Proportion of women subjected to physical or sexual violence, adolescent fertility rate, etc.
Earlier advances in gender statistics support the response to an increasing demand for gender data and statistics. The minimum set of gender indicators adopted in 2013 by the United Nations Statistical Commission (see adjacent box) provides another framework for identifying gender-sensitive measures.

The minimum set includes 54 quantitative indicators, 11 of which are health-related and most of which are also SDG indicators. They emphasize where gender gaps and concerns are most evident, such as tobacco use, obesity, HIV, and mortality rates attributed to cardiovascular disease, cancer, diabetes, or chronic respiratory disease.¹⁶

2. Challenges

2.1 Overarching challenges in producing and using gender data

The challenges associated with integrating gender in statistical systems are well known. They stem from a weak policy space for gender data, including a lack of dedicated legal instruments and financial resources to produce and use gender statistics at the national level. There are significant technical challenges in measuring gender issues that limit the production of gender data. These include developing culturally appropriate and cost-effective methods for measuring time use, for example. Another major task involves removing gender bias from the data collection process by overcoming challenges that might preclude women from being interviewed or feeling comfortable to disclose accurate information safely and ethically. The final challenges for gender data relate to limited dissemination of and access to data, as well as a lack of skills to use gender data, when they are available, to inform policies.17

Gender data are often lacking or of poor quality because gender is not seen as a priority. In some cases resources may be limited and competing priorities may make it challenging for the statistical system to produce gender data. There may also be a low capacity for how to integrate gender in statistics effectively – a matter of not knowing what to do or where to start.18

2.2 Specific challenges for gender and health data

Gender norms may be an obstacle to gathering accurate information, for example, in cultures where women are prohibited from speaking with health care professionals or authorities on their own.

A key challenge for gender and health data is that health information systems rely on health workers to collect the data. Health care workers can be overburdened by excessive data and reporting demands from multiple poorly coordinated subsystems, which will result in poor-quality data.19 The need to collect disaggregated data, such as data disaggregated by sex and age, must be carefully weighed against the burden on health care workers to capture such data and the impacts this has on data quality.

While the need for disaggregated data is undisputed, the specific purposes for and frequency at which specific disaggregations are required, warrants careful consideration. This is particularly important in relation to disaggregation into multiple age/sex groups, as the reporting burden may be substantially increased (and data quality consequently decreased), particularly in paper-based systems.\textsuperscript{20}

The WHO framework and standards for country health information systems noted that health data are often acquired and presented in crude formats, without the synthesis or analysis required for day-to-day management or planning for future needs.\textsuperscript{21} Valuable time and resources used in the process of data collection are largely wasted if there is no commitment to analysing the data, disseminating the resulting information, and using it to improve health system functioning.

Mainstreaming gender in statistics calls for collaborative and sustained action across several fronts.\textsuperscript{22} It requires strong leadership and political will for collecting and using gender data, not only in the national statistical office, but across government in all line ministries and agencies. There should be a legal framework for gender statistics that provides a clear mandate for sex-disaggregated and gender-related data. Cooperation between users and producers of statistics is essential, so that the gender issues and policy priorities are clear enough to enable data producers to respond with the information needed. Policy-makers in health and other sectors need to be sensitized to both gender and statistics. They should understand why gender data are important, how national statistics are produced, and where they can obtain gender data. Users and producers also need to work together to improve gender and health statistics by improving concepts and methodologies in emerging areas, such as disability statistics, data on the ageing population, and mental health.


3. Opportunities

There are myriad opportunities for statisticians to access health systems data so as to provide further insight on gender needs and create situations to promote improvements in gender-related policies and systems.

In many countries, the enabling environment for gender statistics is improving. The effectiveness of a law guaranteeing equal rights and opportunities for women and men will depend on all ministries and agencies contributing to its implementation, including the health sector. This is an opportunity for the health system to respond with analysis and communication of gender data. There should be policies and processes within the health system to guide the collection and production of gender data and data on health inequalities.

3.2 Tools to support improvements in data quality

Addressing gaps in gender and health data requires a strong data ecosystem of both survey and administrative data, including civil registration and vital statistics data. There are strong international standards and guidance to support countries in improving these systems. The WHO SCORE for Health Data Technical Package has been developed to assist countries in increasing the quality of health information systems data. It brings together best practice tools to address critical data gaps and improve country health data for planning and monitoring health priorities. The SCORE acronym relates to technical guidance and tools on five components of a well-functioning system of health data:

- Survey population and health risks
- Count births, deaths and causes of death
- Optimize health service data
- Review progress and performance
- Enable data use for policy and action.

Tools relating to optimizing health service data include classifications and guidance on coding morbidity and mortality, training packages, and rapid assessment tools for identifying data quality concerns so they can be addressed.

### 3.3 Making data meaningful through effective dissemination and communication

Improving the analysis, dissemination and informed use of gender data is an important opportunity for health information systems. Health inequality monitoring should be a central component of national health information systems, but it is often neglected. Opportunities to analyse and communicate analyses and underlying disaggregated data to the appropriate target audiences should be identified and maximized. This will demonstrate the importance and utility of such information and its value for informed decision-making. Conducting more analysis and increasing the discussion and use of data will lead to better quality data. This provides the impetus for health system managers to advocate for more resources to improve the quality, scope and reach of data collection efforts.²⁵

The opportunities for disseminating data are increasing as technologies make it easier and cheaper to collect, store and make data available. The national statistical office is typically the lead agency for the production of official statistics in any country. It coordinates with other data-producing ministries and agencies, such as the ministry of health, to collect, collate and disseminate data and statistics.

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Legislation on gender equality and gender statistics represents a good practice that provides clear mandates for producing and using gender data.

4.1 Training and guidance for capacity development

Integrating gender into health statistics requires education, training and guidance, and much has already been developed and made available for use. UN Women has been working on strengthening gender data across the globe through its flagship initiative, Women Count. Its website contains links to resources and examples of the importance of gender data.26 The Pan American Health Organization (PAHO) offers a virtual course in Gender and Health: Awareness, Analysis and Action, providing foundational skills to increase knowledge in health related to sex, gender norms, roles, relations and other determinants of health.27 The United Nations Economic Commission for Africa (UNECA) offers a free, self-paced online course in gender statistics. The course covers four modules of general training on gender data, including how to identify gender issues, integrate a gender perspective in data production, and how to communicate and use gender statistics as a tool for change.28

Collecting new data is not always the answer to filling data gaps. Some gender concerns are highly sensitive to measure, such as violence against women (see box below). The increasing demand for data on domestic violence during COVID-19 has highlighted that women’s safety and the “do no harm” principle must always take priority over data needs. WHO, UN Women and the United Nations Population Fund (UNFPA) worked together to quickly release guidance on safe measurement of domestic violence during COVID-19 lockdowns. The advice is clear: do not include questions about experiences of violence as part of population-based rapid assessments.29

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Guidance on safe gender data collection in times of emergency

An early priority during times of emergency is to collect robust data on how people are being impacted. These data need to be sensitive to gender, age and other characteristics to be relevant for policy-making.

The COVID-19 pandemic has had huge impacts and is raising many concerns. One is that lockdowns could increase the prevalence of domestic violence against women. Stakeholders have wanted data on this but collecting such data is complex and the options need to be carefully considered.

Data on the prevalence of violence can only be collected from a random sample of women when safety and ethical protocols can be ensured. This includes interviewing only one woman from a household in private, without anyone else knowing the interview included questions on violence. Telephone interviews are not a solution as the privacy and safety of the person on the other end of the line cannot be assured.

Data from service providers can be useful for tracking reported cases during an emergency but they reveal nothing about what is happening behind closed doors and in communities. In some situations, reported cases might increase but during COVID-19 lockdowns fewer women are likely to be seeking services if they are at home with their abusers and if those services are interrupted due to the lockdown.

Qualitative data collected through focus groups and key informant interviews can be good for understanding women’s experiences during emergency situations, such as their experiences in seeking and receiving help.

Pre-existing data, such as national prevalence surveys conducted before an emergency, are also valuable sources of information during the emergency. Although they cannot reflect changes due to the emergency, they provide data on the types and patterns of violence and can support informed decisions. These data assets are often underutilized.

Data on violence against women reported to authorities and services represent only the tip of the iceberg. Research shows most women do not report their experiences to authorities and, in some cases, an increase in reporting could reflect less tolerance of violence and better support.

4.2 Online databases and data visualization

The Organisation for Economic Co-operation and Development (OECD) has a Gender Data Portal providing gender data on employment, education, entrepreneurship, health, development, and governance for OECD members and the partner countries of Brazil, China, India, Indonesia, and South Africa. Interactive charts enable users to examine data by different time frequencies and variables (Fig. 3). The portal also provides gender articles – short analytical pieces explaining the data and drawing out the main messages.

The European Institute for Gender Equality (EIGE) publishes a comprehensive Gender Statistics Database with data for the countries of the European Union (Fig. 4). Indicators are grouped by thematic areas (for example, work and labour market; health and mortality; living conditions), by the 12 areas of the Beijing Platform for Action, and for the main measures with which the EIGE works, including the European Gender Equality Index. The database also includes gender-related European Union policies and strategies and Data Talks – short articles that discuss and present gender data.
The Institute for Health Metrics and Evaluation (IHME) Global Burden of Disease Viz Hub illustrates the power of gender data in effective health monitoring.\textsuperscript{31} Causes of death for the total, male and female populations are visualized using state-of-the-art technology. The database is easy to navigate and has a range of measures over time that provide a powerful basis for gender and health analysis. The data for causes of death among men aged 15–49 show that noncommunicable diseases are slowly replacing injuries and self-harm as top causes of death among young people (Fig. 3). For women, there has been a rise in NCD-related deaths and a decline in maternal deaths (Fig. 4). This database is an example of the powerful messages gender data can provide when it is accessible and easy to understand. As with any presentation of data, users need to be well-informed by metadata – information that describes the data, such as the primary sources, definitions and methods used for its collection.

The United Nations Economic Commission for Europe (UNECE) collates gender data annually from all 56 of its member States and publishes them in the UNECE Gender Statistics Database. The site

includes population and gender overviews for each country as well as selected indicators under 10 domains. The UNECE Gender Database is part of the broader UNECE Statistical Database, which includes SDG indicators and data on the economy, transport, and forestry.

Fig. 5 Homepage of the UNECE Statistics Database


4.3 Supporting data users to access, understand and use statistics

Improving access to gender data and developing the skills to use them is a strategic priority for better gender statistics. Data literacy depends on several components. Health and gender policy- and decision-makers need to know what data exist, where to find them and how to assess whether they are fit for their purpose. Documentation (metadata) is needed so users can find out how the data have been collected, how key concepts have been defined and what classifications have been used. Data users must also be equipped with the skills to analyse and interpret statistical information. These can be developed through training and written guides to statistical indicators that explain how they are produced and how to interpret the results. The skills to present and communicate statistics effectively are also needed. This includes being able to create effective graphs, tables and possibly maps, but also to communicate key messages and explain the data verbally and in writing so that they can be correctly understood.
Beyond the online dissemination of data, there are many good practices in presenting and writing about gender and health data. Such examples include regional publications on the health and well-being of men in Europe\(^{32}\) and on women’s health and well-being in Europe.\(^{33}\) This analytical product brings together available data and statistics, which are analysed and presented as a snapshot of key health issues for men and women, the causes of ill health and the ways in which the health system responds to their needs. The publications are written to support policy- and decision-makers; to make gender data more accessible and relevant for their needs. They show the value of applying a gender lens to health statistics and the powerful information that can be developed when combined with qualitative data and other forms of research.


5. Recommendations

1. **Facilitate dialogue and collaboration.** Everyone has a role to play in promoting the production and use of gender statistics. Managers of the health information system, the national statistical office, and policy- and decision-makers who use the data all play a role in seeing gender statistics produced and used effectively. There should be opportunities for dialogue between these different groups to agree upon priorities and pool resources for collective advantage.

2. **Establish priorities.** Given the breadth of both gender and statistics, it is essential to identify priorities for making improvements. Efforts should be made to address issues that have already been identified, such as the lack of cause-of-death data on women and girls. Countries looking to produce gender-sensitive health statistics should consider producing the combined United Nations minimum set and the SDG gender-related indicators for Goals 3 (health), 4 (education), 5 (gender equality), and 8 (decent work).

3. **Provide regulations, guidance and training.** Instructions about the management of national health information systems should include gender sensitization and the importance of gender data and statistics. Everyone involved in the collection, management, processing, analysis, and use of health information system data needs to know why gender data and statistics are an important aspect of this and understand their own role in their production and use.

4. **Increase data literacy.** Policy- and decision-makers, their advisors and staff may be hampered by a lack of data literacy. Users of health statistics need to be supported in finding, accessing, understanding, interpreting and applying statistics in policies, plans and programmes. Documentation, training, coaching and other methods should be made available to improve data literacy.

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References


REFERENCES


Annex I: Summary of key literature on gender and health data

Developing Gender Statistics: A Practical Tool


Developed by the UNECE Task Force on Gender Statistics Training for Statisticians, this is a key, overarching, 180+-page publication on how gender in populations should be measured and viewed in order to provide the most valuable insights. It is a template that countries and statisticians can use to gain clear direction on gender as it is viewed by the United Nations and develop/update/implement changes to their respective health systems.

This wide-ranging publication on the importance of gender in statistics presents numerous opportunities. Each of the six main chapters highlights important aspects of advancing towards gender equality.

- Chapters 1 and 2 of the manual explain the importance of producing and analysing statistics on gender differences
- Chapter 3 provides guidance on data production
- Chapter 4 looks in detail at selected topics relevant to gender statistics and the implications for data collection
- Chapter 5 examines methods for improving the use of gender statistics through communication strategies and dissemination platforms such as interactive databases and websites. An important component of any initiative to develop statistics on gender is advocacy and partnership-building
- Chapter 6 provides guidance on making it happen through campaigning for top management support, creating legislation and defining a gender statistics programme.

Notably, there is a section explaining the significance of health statistics and what health statistics can tell us in a gender sense. Health is one of the broadest statistical domains, and the provision of health care is expensive, so it is important for governments to have a comprehensive range of relevant health statistics available to inform and monitor health policy.


This publication by WHO is, as the title suggests, a step-by-step guide for countries to identify, and then determine how to remedy, inequities in national health systems.

This comprehensive guide allows for wide-ranging monitoring of inequities, or perhaps more specific monitoring in one or more areas. The five-step procedure remains the same, offering best-practice guidance across the full spectrum of health system inequality monitoring:
1. Determine the scope of monitoring
2. Obtain data
3. Analyse data
4. Report results
5. Implement changes (note: the fifth step is not covered in the manual as implementing policy changes requires multiple stakeholders and/or budgetary allowances. However, WHO publications are listed to provide specific guidance on implementing changes).

Each step provides checklists on how to execute each step effectively and allows for adjustments in the scope of monitoring. The manual assists with investigating multiple factors of inequity in health systems, or just one, such as gender inequities. Examples and resources are provided for each step (for step five, only resources and no examples are listed).

SCORE for Health Data Technical Package – Essential Interventions and Tools and Standards for SCORE Essential Interventions


The SCORE for Health Data Technical Package has been developed by WHO for countries to assist in increasing the quality of health information systems data. The SCORE acronym represents the following steps in addressing improvements in health data disaggregation:

- Survey population and health risks
- Count births, deaths and causes of death
- Optimize health service data
- Review progress and performance
- Enable data use for policy and action
The two publications featured here are the first of a number of publications to come at the time of writing, and all will form part of the overall SCORE for Health Data Technical Package. The full SCORE package can be viewed at https://www.who.int/data/data-collection-tools/score.

Each of the five interventions would be considered good/leading practices, and each of the interventions features links to other resources with additional information. Some of the interventions feature links to specific examples of leading practices, such as the United Nations Principles and Recommendations for Population and Housing Censuses in the Survey Populations and Health Risks section.

**World Health Statistics 2019: monitoring health for the SDGs, sustainable development goals**


The World Health Statistics 2019 report reviews, for the first time, the availability of country data for global Sustainable Development Goal (SDG) reporting. This review suggests the need for major improvements to country data systems:

- one in seven indicator country values included in this report has had no underlying data since 2000; low-income and lower middle-income countries in particular lack underlying data
- for about one third of countries, over half of the indicators have no recent primary or underlying data
- 11 health-related SDG indicators require cause-of-death data, yet only around half of countries are able to register more than 80% of adult deaths, and less than one third of countries have good-quality cause-of-death data
- sex disaggregation is currently available for less than half (11/28) of relevant SDG indicators at global level where it would be of interest (WHO, 2019).

Some key actions suggested on the basis of the findings of this report are outlined below.
1. Improve access to health services
2. Address risks to health
3. Make health systems responsive to sex and gender
4. Invest in data systems for health, including disaggregated data.

The scope of this publication is huge, and the countries have considerable ability to a) contribute with statistics across multiple fronts, and b) compare with different countries, regions and even different points in history.

The push of this publication to display sex- and gender-disaggregated data is clearly seen in the introductory pages, and is remains a constant theme throughout. Clearly, many countries are still not producing data of this nature at this time, but, as noted above in the Challenges, it is key to
WHO’s agenda to encourage and support countries to produce comprehensive disaggregated sex and gender statistical information. This allows for greater shared learning across the globe and continues the forward march towards gender equity.

How to (or not to do)... gender analysis in health systems research


This document lists a number of key papers in the area of health/health systems gender frameworks and development gender frameworks. Based on the combined findings from these papers, the authors have developed their own framework, Gender as a power relation and driver of inequality, which is based on developing answers/further insights into the following questions: who has what (access to resources); who does what (the division of labour and everyday practices); how values are defined (social norms, ideologies, beliefs and perceptions), and who decides (rules and decision-making).

Ensuring gender bias is eliminated as much as possible throughout health information systems is a very important and complex undertaking. It is clear that, during interviews with respondents, the answers given by men when women are present, for instance (and vice versa), might be different than if the interviewer was of the same sex, or if the interviews were conducted in a private, one-on-one situation with no others present. Moreover, that in-built gender bias may affect how the interviewer interprets the information received, and bias is unintentionally or unknowingly allowed to affect the data and subsequent findings.

The gendered dimensions of COVID-19


Written in April 2020, this short journal article emphasizes the need for sex-disaggregated data in the fight against the COVID-19 pandemic. It also highlights the fears concerning discrimination in the data being collected.

The Global Health 50/50 website (https://globalhealth5050.org/the-sex-gender-and-covid-19-project/) tracks sex-disaggregated infection and mortality COVID-19 data from many of the most affected countries, and the data show more men are dying from COVID-19 than women. Adverse outcomes of COVID-19 appear to be associated with conditions such as hypertension, cardiovascular disease, and lung disease, which occur more frequently in men.

This clearly demonstrates that in fighting the COVID-19 global pandemic, sex- and gender-disaggregated data are essential.
COVID-19: Emerging gender data and why it matters


This UN Women website resource provides information regarding COVID-19-disaggregated gender data and insights, especially as they relate to women and girls. It is the product of a collaboration between the United Nations and WHO.

The “Learn more” link on the website leads to further resources on aspects of gender-related data, such as exploring the UN Women Thematic Dashboard and multiple other data dashboards. There is also a section that explains why some data are missing in the various charts, tables and other statistical information featured on the UN Women website (and many others), listing the following reasons:

- Countries often do not invest enough in collecting gender statistics
- Data on issues facing women and girls are not collected frequently
- There is a knowledge gap on collecting data on new and emerging issues.

Framework and standards for country health information systems, 2nd ed.


The Health Metrics Network (HMN) was launched in 2005 to help countries and other partners improve global health by strengthening the systems that generate health-related information for evidence-based decision-making (WHO, 2008).

HMN is a health partnership that focuses on two core requirements of health systems strengthening, specifically for low- and low middle-income countries.

- The need to enhance entire health information and statistical systems, rather than focus only upon specific diseases.
- To concentrate efforts on strengthening country leadership for health information production/use.

Reliable and timely health information is an essential foundation of health systems strengthening, both nationally and internationally.
The HMN framework for improving health information systems by means of introducing best practices has three core aspects:

1. **Rationale, Approaches and Vision** – focuses on the rationale, approaches and vision required for strengthening health information systems. A new approach to health information systems strengthening is described and specific solutions proposed to the problems identified. The key role of global health partnerships and HMN is discussed.

2. **Components and Standards of a Health Information System** – describes the components and standards of a health information system. These are health information system resources, indicators, data sources, data management, information products, and dissemination and use. Desirable standards to be attained when strengthening or establishing each health information system component are reviewed. Data management methods are proposed and subsequent practical use of the information generated is discussed.

3. **Strengthening Health Information Systems – Principles, Processes and Tools** – guiding principles for health information system development are outlined, and practical steps for implementation proposed (WHO, 2008).

### The Sex, Gender and COVID-19 Project


The Sex, Gender and COVID-19 Project website (https://globalhealth5050.org/the-sex-gender-and-covid-19-project/) is a collaboration of Global Health 50/50, the African Population and Health Research Center and the International Center for Research on Women. By means of the COVID-19 Sex-Disaggregated Data Tracker, the website produces updated data and information every two weeks, specifically regarding sex-/gender-disaggregated data on the COVID-19 pandemic, with a focus on how it relates to women and girls.

The COVID-19 Sex-Disaggregated Data Tracker collaboration is looking into what roles sex and gender are playing in the COVID-19 pandemic by means of seeking out and interpreting sex-disaggregated data, building the evidence base of what works to tackle gender disparities in health outcomes, and advocating for effective gender-responsive approaches.

Aside from the above-mentioned benefits of sex-disaggregated data regarding COVID-19, the website itself is easy to navigate, with plenty of regularly updated information across many fronts, clearly illustrated in accessible tables, charts and graphs.

Visitors to the website can investigate further using the links provided to explore data in a global sense, by country or by variable, and data can also be readily downloaded.

The sex-disaggregated information being displayed is dynamic and regularly updated. It is responsive to new information being delivered from various sources around the globe, and can therefore readily demonstrate patterns and changes of note.
The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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