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Pathways for Strong Gender Integration into Health Data in 21 Countries: Perspectives from Key Informant Interviews

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Abstract

Background

As gender equality efforts strengthen around the globe, an important focus on including gender in health data has emerged. Alongside successes, gender data gaps remain, making it difficult to measure change and address current needs. This study aimed to better understand the current context of how sex and gender are included in health data collection, analysis, and use within Data for Health focus countries from the perspective of key informants working in gender and health data.

Methods

Using a feminist, phenomenological approach, we conducted key informant interviews with local gender experts in participating Data for Health focus countries. Eligible participants were 18 years of age or older and involved in the decision-making process related to the collection, analysis, and/or use of health data (e.g., academic researchers in health, Ministry of Health staff, research leads working in health data collection). We incorporated narrative and thematic approaches in our qualitative analysis, integrating narrative summaries, coding, and memos to facilitate the development of themes. Reflexivity through memo notes and dialogue proved significant to fully grasp country successes and challenges to integrating gender in data.

Results

Thirty people from 21 countries participated in individual key informant interviews between July 2022 and September 2023. Of the 30 key informants, 21 identified as women and nine as men. Key informants worked in national governments, academia, consulting, non-governmental organizations, and human rights groups. Relevant themes included: current practices of sex/gender integration into data collection and analysis; and challenges to integration of sex/gender into health data, including lack of understanding of gender, competing priorities, and inadequate capacity-building resources.

Conclusions

To advance gender equality goals and to reduce the gender data gap, training and capacity-building activities can include understanding what gender means as an important step to fully integrate gender into health data. In addition, gender analysis can be improved with techniques and considerations beyond sex disaggregation. Lastly, as our understanding of gender grows, gender diversity and intersectionality must be systematically incorporated into health data with lasting funding and support to encourage sustainability.

Background

Gender data on health can provide insight into gendered health disparities as well as evidence of effective health policies and programs seeking to promote health equity. The past three decades have offered distinct opportunities for growth, and a clear and intentional focus on gender and health has improved globally. Since 1995, the United Nations (UN) and the World Health Organization (WHO) have set several long-term goals and declarations to address gender inequality, including in health. The Beijing Declaration and Platform for Action of 1995 provided a comprehensive framework and steps to action to move gender equality and the rights of women and girls forward [1]. Following this, in 2000, the Millennium Development Goals (MDGs) were signed, including a focus on reducing maternal mortality and increasing access to reproductive health care [2]. Finally, in 2015, the UN introduced the Sustainable Development Goals (SDGs), including 15 goals that serve as a guide to effective development and reducing poverty. SDG5 focuses on achieving gender equality and empowering young girls. The specific targets for this goal include ending discrimination against girls and women, providing universal reproductive health care access, eliminating forced marriage and female genital cutting, ending gender-based violence, valuing unpaid care and domestic labor, and improving economic empowerment and participation [3, 4].

Though we have seen a great deal of progress towards gender equality, significant gaps in gender data remain, making it difficult to measure change and address current needs [5, 6]. For example, the inclusion of sex and gender is uneven in health research [7]. It can be important to include both sex and gender when collecting health data because either on their own may not provide the full picture of factors that impact health outcomes and needs [8–11]. Both sex and gender are important in disease surveillance, for instance, because sex is more telling for vulnerability, how bodies respond to treatment, and how symptoms are experienced, while gender influences other aspects, such as exposure and access to care or treatment [12].

Inconsistent terminology in data collection efforts means sex and gender are often used interchangeably and incorrectly and that the way they intersect is not considered [8, 13]. While there is no one universally accepted definition of gender, the WHO defines it as “the characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviors and roles associated with being a woman, man, girl or boy, as well as relationships with each other” [14]. Notably, this definition includes a binary conceptualization of gender, which is not universal across all cultures. Furthermore, gender is separate from sex, which Merriam Webster defines as “the preferred term for biological forms” [15], including male, female, and intersex [8]. A person’s gender identity may be different from their biological sex as gender identity indicates an individual’s personal understanding about who they are and what they call themselves; indeed, gender exists on a spectrum [16] and goes beyond the binary of male and female [8, 9, 11].

Sex and gender cannot be considered in isolation, either, as other aspects of life intersect with an individual’s sex and gender to impact each person’s overall experiences. Intersectionality can be understood as the ways in which the different aspects of a person’s identity interact and impact each other to create an individual experience [17]. Marginalized groups, identified, for example, by race, socioeconomic status, sexual orientation, sex, and gender, are often at

increased risk of poor physical and mental health through higher exposure to risk factors and reduced access to care [18]. To fully understand exposure and risk to health complication and access to care, an intersectional approach is essential when completing health research.

With these definitions in mind, health data can become more inclusive, and therefore more impactful, by incorporating sex and gender as distinct considerations. Addressing the current gap in gender health data collection is important, as these data can help identify existing disparities in health [19–21]. This gender gap in health data may result in missing or incomplete data for diseases that disproportionately impact any given gender, or existing data may be interpreted with men's symptoms as the default [22]. Sex differences in vulnerability to disease, how symptoms are experienced, and how a person may respond to treatment highlight the importance of collecting sex variables in health data [6]. Historically, health research was conducted with largely male participants and these results were broadly applied to the entire population. This narrow representation created gaps in medical knowledge and in turn impacted quality of care [6], with women sometimes receiving ineffective or even harmful care [23]. In addition to considering both men and women, the exclusion of precise terms specifically related to gender minorities, has led to the invisibility of some populations in health data sets [24, 25].

A gap in gender data can also impact the quality of vital statistics, including birth and death statistics. These statistics are essential in building population level indicators and are used to set targets and develop national health plans [22]. By collecting inclusive gender data, disparities can be reduced by improving access to care, improving patient-provider communication, and impacting health policy for all people [22, 24].

Data for Health, a program funded by Bloomberg Philanthropies, the Australian government, and the Bill & Melinda Gates Foundation, provides low-and middle-income countries (LMICs) with training, assistance, and support for improved health data collection and use, working with governments to strengthen and standardize birth and death records and to inform policymaking [26]. The Data for Health Gender Equity Unit at the Johns Hopkins Bloomberg School of Public Health supports all Data for Health partners in promoting gender equity within health data collection and use across the globe [27]. Some organizations, like the UN [28], UN Women [29, 30], Open Data Watch [31, 32], and Data2X [7, 33, 34], are striving to measure and understand the integration of sex and gender into data globally. Through this study, the Data for Health Gender Equity Unit intends to add to this body of work through a focus on the expertise and insight of key informants. Key informants can provide important qualitative data to encourage a deeper understanding of the realities of gender and health data collection and use. This study aimed to better understand the current context of how sex and gender are included in health data collection, analysis, and use within the Data for Health focus countries from the perspective of key informants working in gender and health data.

Methods

Study procedures

Setting and participants

Using a feminist, phenomenological approach, this study aimed to better understand the current context of gender integration in health data. To achieve this aim, we conducted key informant interviews (KIIs) with local gender experts in participating Data for Health focus countries. Eligible participants were 18 years of age or older and involved in the decision-making process related to the collection, analysis, and/or use of health data (e.g., academic researchers in health, Ministry of Health staff, research leads working in health data collection). Participants were not considered if they did not work directly with one of the 25 Data for Health-supported countries.

Recruitment

Countries were selected based on participation as a country supported by the Data for Health Initiative. Data for Health partners (Vital Strategies, the CDC Foundation, and the Global Health Advocacy Incubator) introduced the research team at the Gender Equity Unit to in-country representatives who participated as key informants (KIs) or recommended other potential KIs who worked in gender and health data. After confirming the eligibility of recommended KIs, the research team contacted the potential participant with details about the study. All participants provided verbal informed consent prior to beginning the interview.

Data collection

Trained members of the Gender Equity Unit's research team conducted interviews via Zoom in the participant's preferred language, including live interpretation as needed. The interview guide was developed by the Gender Equity Unit specifically for this study (Interview Guide S1). Interviews lasted between one to two hours. Interviews included questions about barriers and potential facilitators to enacting gender-focused data collection at the population level and/or data use in the form of policies and programs that ensure gender equity in health. Interviewers used a semi-structured interview guide that asked questions regarding each country's definitions of gender, common gender roles and norms, laws and policies impacting different gender groups, data collection and analysis of health data related to sex and/or gender, including civil registration and vital statistics (CRVS) data, and how findings from these data are disseminated.

Interviews began in July 2022 and concluded in September 2023. Midway through the interview process, some questions in the interview guide were altered to directly inquire about the transgender and nonbinary population of each country instead of the overall lesbian, gay, bisexual, transgender, intersex, plus (LGBTI+) population. Interviewers and research assistants working on data analysis had noted a conflation among some participants between gender and sexual diversity, and we wanted to clarify our focus on gender within this study.

Data analysis

Interviews were transcribed and translated where necessary; transcripts were quality checked by two Gender Equity Unit research assistants (IE, AB). Members of the research team who collaborated on data analysis met regularly, with initial meetings focused on the development of a codebook. We developed codes from the interview guide, focusing on understanding definitions of gender, gender-related data collection and analysis, dissemination of information, and law and policy impacting different gender groups. We incorporated narrative and thematic approaches in our analysis, integrating narrative summaries, coding, and memos to facilitate the development of themes. Two research assistants (IE, AB) wrote a narrative summary for each interview to better engage with the contextual realities described by each participant in their respective country settings, and then, used Atlas.ti (v.23) to code the data. Our first interview was coded by all research assistants participating in coding. We met as a team to review agreements and discrepancies and to discuss any points of confusion or disagreement with code definitions. After the first interview, each research assistant coded separate interviews, and we continued to meet weekly as a team for in-depth discussions about codes and meaning throughout coding and analysis. Following each coding session, research assistants wrote memos to notate important findings, salient quotes, and any relevant data analysis insights. The codebook was updated utilizing an iterative process to change existing codes or create new codes for findings that appeared as analysis progressed. Codes with interconnected meaning were reviewed side by side to establish distinctions or similarities.

We read through the data multiple times and continued our weekly discussions to provide clarity on prominent themes and to understand relationships among themes. By providing space for movement within codes and themes, we developed a more thorough understanding of meaning, including relevance and connectedness within the results. The results of this analysis identified important themes within individual interviews and reflected shared themes across interviews. Our analysis explored themes across individual countries and across geographic regions.

Conceptual framework

We approached this study from the perspectives of two different but related gender equity frameworks. The first, the Spectrum of Gender Integration (Fig. 1 [35]), incorporates a continuum of research, programmatic and policy approaches from gender inequity to gender equity. This framework allows us to visualize the path to gender equity in health data as well as how data approaches can be improved to promote gender equity.

The second framework, the Expansive Gender Equity Continuum Model (Fig. 2), follows a similar pattern but specifically includes gender diverse individuals in the approach. This framework was adapted from the above Spectrum of Gender Integration and the Gender Responsive Assessment Scale from the WHO [35–37]. This gender inclusivity became particularly relevant as we conducted our interviews and considered initial findings, noting that gender diverse people were rarely included in national data [11, 38].

We did not categorize countries according to these frameworks but rather used the frameworks to situate and guide our thinking as we familiarized ourselves with and analyzed the data.

Reflexivity

As researchers at a university in the United States, we felt it was important to consider reflexivity throughout the interviews and the coding and analysis process, both as individuals and as a group. Team members wrote reflexive memo notes after interviews and during coding and analysis, and we discussed our personal views during our research team meetings to inspire curiosity and to consider the impact on our results. Because our team comes from a largely Western, feminist perspective, it was crucial for us to consider our position and our opinions in relation to the interview data [39–41]. As our intention with this study was to better understand the context of gender integration in health data to identify and address existing gaps, we were able to consider our opinions while also setting them aside to fully grasp successes and challenges to integrating gender in data.

Results

A total of 30 people from 21 countries participated in individual KIIs between July 2022 and September 2023. Eight countries had two KIs. Of the 30 KIs, 21 identified as women and nine as men. No participant identified as gender diverse. KIs worked in national governments, academia, consulting, non-governmental organizations (NGOs), and human rights groups, with the majority of participants in national governments (Table 1).

Table 1
Participant gender and occupation

Country[1]	Gender n(%)		Occupation n(%)				
	Female	Male	Government	NGO	Academia	Consultant	Human Rights Group
Bangladesh	1		1				
Bolivia		1		1			
Cameroon	1	1	2				
China	1		1				
Ethiopia	1	1	2				
India	1					1	
Indonesia	2		2				
Kenya	1	1	2				
Morocco		1			1		
Philippines	1		1				
Rwanda		1	1				
Senegal	1	1	2				
Solomon Islands	1					1	
South Africa	1				1		
Sri Lanka	2		2				
Tanzania	1			1			
Thailand	2		1		1		
Uganda	1		1				
Viet Nam	2				1		1
Zambia	1	1			2		
Zimbabwe		1			1		
Total	**21(70%)**	**9(30%)**	**18(60%)**	**2(7%)**	**7(23%)**	**2(7%)**	**1(3%)**

[1]At the time of this study, other Data for Health focus countries included: Cambodia, Colombia, Mozambique, and Papua New Guinea.

Two distinct themes emerged through our analysis of interviews:

(1) Current practices of sex/gender integration into data collection and analysis. Results included specific insight into government documents.

(2) Challenges to integration of sex/gender into health data. These challenges fell within three separate subthemes:

1. lack of understanding of gender;
2. competing priorities with integrating gender into health data; and
3. inadequate capacity-building resources.

Current practices of sex/gender integration into data collection

When asked about the integration of sex and/or gender in health data collection, participants in every country noted that male/female health data are routinely collected and recorded. One KI explained that *"...for any condition from pediatrics to gerontology or whatever, from birth to death, any health data in between, whether it's heart condition, whether it's cancer ... [the male or female] distinction is always there"* (Zambia, male [M]). KIs reported male/female indicators as routine, but most countries do not ask about sex or gender identity beyond the male/female binary: *"...the most that is done is to find out, "Are you male or are you female?" But going beyond male/female I think it's not something...that has been adopted"* (Kenya, female [F]).

A total of seven KIs from Cameroon, Kenya, Indonesia, South Africa, Sri Lanka, Thailand, and Uganda detailed efforts to collect data beyond male/female options when working with specific populations. One participant explained that national documents only include a sex category, but projects working with key populations in more local settings (e.g., people who use pre-exposure prophylaxis for HIV; people experiencing gender-based violence) intentionally include a gender category, so data collection encompasses broader identities. *"Even [the] registers [for key populations] are special and they usually put the word gender so that they are able to identify them correctly ... there could be, like, the other nonbinary gender"* (Uganda, F). One KI from Thailand noted that hospital data and most doctor's offices "*have only two options"* regarding gender identity, and *"the only clinic that has the third one is the transgender clinic"* where transgender people specifically seek gender-affirming care (Thailand, F). In addition, a KI from Cameroon discussed how birth registration and other

official documentation only collect male/female data, but they have "*specific projects or surveys or things that can have an interest in the specific question of gender...*," where they add "other" as a gender identity option (Cameroon, F). Kenya and Indonesia were the only countries to indicate the option of intersex on the census.

Integration of sex/gender in government documents

Almost all KIs denoted male/female as the only options on most legal identity documents, including birth and death certificates. One KI explained they only *"consider the physical elements, biological elements that are materialized. So, the boy, if he has the sexual parts of the boy, he's recognized as a boy. The same goes for the girl"* (Senegal, M).

For intersex babies, countries have different approaches to birth registration. Most KIs explained the medical provider chose male or female based on their perception, but a few KIs described distinct ways of registering babies born as intersex. For example, if a baby is born in the Philippines with ambiguous genitalia, the doctor will leave the sex blank on the birth certificate until the baby matures or genetic testing is completed: *"So they leave it [the sex] if they really cannot determine, but otherwise another [doctor] was saying that you can check the chromosome level...so they have two options, check the lab for chromosome and the one as I said, that they wait until the child [matures]"* (Philippines, F). For babies born with ambiguous genitalia in China, the doctor will register the baby in their "*registration system for birth defects. If it [is] unclear whether it is male or female, or if there is definitely malformation of the genitalia, it will be registered"* (China, F).

Twenty-one KIs specifically noted their country's birth certificates only have male and female options with no third option. However, three KIs (Rwanda, India, Sri Lanka) stated the possibility of changing a person's sex on their birth certificate if their gender does not match their sex assigned at birth. In both Rwanda and Sri Lanka, only male/female options are available, but India includes a third transgender option as well. Sixteen participants noted that death certificates in their country only offer male/female options. No KIs indicated a third gender option on death certificates.

Current practices of sex/gender integration into data analysis

Although all KIs reported their countries collect sex in their routine health data, their approach to data analysis differs. Most KIs noted their countries disaggregate by sex during data analysis. Only one individual explained they do not disaggregate by sex when analyzing data because "*[they] have yet to see any policy or any data that shows disaggregating impact or gives a different dimension, other than data collected for HIV, which is code disaggregated by age, cohort, and gender*" (Kenya, M). However, at least some data in Kenya are disaggregated by sex or gender, as a second KI from Kenya noted that "*during COVID, we undertook a study on implications of COVID-19 on gender. So…actually we did the analysis at the level of gender. You know, it was [disaggregated] at the level of gender, you know, just beyond male-female.*" (Kenya, F).

One KI described that Uganda sometimes disaggregates by sex because "*we know [sex] is a predictor of some diseases*" (Uganda, F). Another acknowledged that Rwanda *"make[s] sure that [data] are sex disaggregated"* (Rwanda, M), which helps them identify sex differences in health behaviors. For example, Rwanda *"disaggregate[s] the beneficiaries of health insurance by males and the female [and] find[s] that there's no significant difference between the males and the females"* (Rwanda, M) regarding health insurance coverage. The majority of KIs did not discuss any analysis including gender outside of the male/female binary though one KI from South Africa described an analytical barrier she faced associated with gender diverse data:

Should we include an item that said 'nonbinary' or 'trans' or 'queer,' whatever you want to ask? We tested this in a small thing, and we wanted to see: 'Is it worthwhile to add it in detail, because can we use that data for analysis?' And we actually found that–first of all, I don't really know how much of the population are going to be nonbinary, but currently amongst the small group that we looked at we had one case. You can't do an analysis on that case. (South Africa, F)

Overall, KIs agreed that despite progress, there is continued room for improvement in both collecting and analyzing comprehensive gender health data.

Challenges to integrating gender in health data collection and analysis

Though KIs described successes in integrating sex (and sometimes gender) into health data, participants also readily acknowledged the various challenges associated with integrating gender, specifically. These challenges fell within three subthemes: (i) lack of understanding of gender; (ii) competing priorities with integrating gender into health data; and (iii) inadequate capacity-building resources.

Lack of understanding of gender

Some KIs demonstrated confusion about how gender is defined. This lack of gender definition resulted in the interchangeable use of sex and gender when discussing data collection and analysis, and it was frequently noted as one of the biggest barriers to successfully integrating gender into health data.

The first barrier for [gender and sex] remains that they have to be well defined. Unless there is a well-defined...there's always going to be a position or a situation where it's easy to confuse sex with gender. (India, F)

In fact, there is no clear conceptualization, even by the authorities, when you talk to them about sex and gender, you know? In the training given to personnel, even health care and judicial personnel and so on, … they don't know the difference between sex and gender, so in the documents, or online forms, in the various, say… platforms where this information is shown… requested, they do not req… They do not ask for gender (Bolivia, M).

Basically, I can say that still, we have issues to do with gender because initially as a culture, we understood gender to be just male and female and then of course, how someone really identified themselves, it was still– we just categorized it as male and female and that is what is still happening in our data sets and there are so many things surrounding that issue, especially when we have the fact that there are key populations–I mean, the other genders (Uganda, F).

Additionally, some KIs discussed the varied understanding of gender across agencies as a major barrier to integrating gender into health data.

The challenge would be understanding gender. How important gender is in health work. The other thing would be even if they see the importance of gender within the health work, at the end of the day resources are determined by the Ministry of Finance who well may not be on the same page as those within health (Solomon Islands, F).

Our job is to ensure [clear understanding] in every way, even in data collection, but because it's not– for example, for health data it's not run by us. It's run by our health college, and somehow it very much depend on their understanding of gender as well…just men and women, just girl and boys, and for some reason it's neglected, and it's not taken into consideration carefully, and that's why we have to talk, talk, talk all the time. Somehow they say that "You talk too much. You raise your voice, strong voice," but that is our job, because if we do not raise our voice it will be immediately ignored by everyone... (Vietnam, F).

Competing priorities with integrating gender into health data

Thirteen KIs across 12 countries discussed competing priorities to integrating gender into their health data efforts, ranging from the individual level to the government level and often stemming from cultural and political barriers. Some KIs described cultural and political components of gender roles that make it difficult to successfully include gender in health data collection and analysis. For example, in several countries, KIs explained that women require permission from their husband, who is the head of the household and in control of the family's finances, to provide data on the health of family members.

"So the challenge sometimes come especially in those cultures where it's only men who are allowed to discuss or to be interviewed about this familiar affair… The female cannot talk to like, let's say, people come to collect data… So in that case, we have limited data because some of the issues that might be asked on Demographic Health Surveys… So that's the challenge where sometimes in some instance we may have limited correct information if the female in the household for religious or other issues may not be allowed to speak" (Zimbabwe, M).

These factors make it challenging to know where and how to start integrating gender into health data, even if on a smaller, more acceptable scale.

In addition, because gender norms influence cultural and political expectations, KIs noted the authorities must also view integration of gender as a priority, but they often do not. One KI explained that the first barrier is "*how receptive the state authorities are"* (India, F). A second KI described, more specifically, that there are a constant variety of other priorities within the government: *"So [the] Ministry of Health is very busy in dealing with so many things at the same time. So sometimes [a] gender perspective is not becoming the priority right now. And so, the priority mostly on addressing, like, when we have COVID, for example… So the–probably the gender perspective or addressing the issues through a gender lens are not the priority right now"* (Indonesia, F).

Lastly, a KI emphasized the importance of gender as a guiding principle across government sectors: *"Gender is not the responsibility of one unit. It has to be integrated into different department in the ministry as well as some national levels"* (Ethiopia, M).

Inadequate capacity-building resources

Sixteen KIs across 14 countries detailed the need for capacity building and other resources to successfully and effectively integrate gender into health data collection and analysis. KIs described needing additional growth and support with digitization of health records, gender sensitization training for health care providers, collaboration across industries, and sustainable funding.

When asked about challenges specifically regarding gender integration into health data work, one KI explained that digitization of data is necessary to improve the quality of data and ultimately understand the health trends across populations, which includes different genders:

Most of our work is done in paper and aggregated, so digitalization remains to be the key thing. Because once you get the digitalization, we'll be able to follow people longitudinally... If you do it on paper, it's just increasing the workload for whoever is working, which now brings an issue of data quality, work, and everything, and it makes people stop doing their core activity (Kenya, M).

A different KI indicated that help from other institutions or agencies would be useful in building capacity for integrating sex and gender into health data because they do not have adequate resources to train employees:

Because, as I said earlier, if we want to train (we're at the national level, so we have an obligation to train all agents in all health districts), but sometimes the human, material and financial resources aren't available (Senegal, F).

Another KI described a more specific scenario where *"we identify a female body and that that person was killed as a homicide ... then we need to link that body to an investigation with police. Those two systems are not linked, so we need to do the linkages as researchers"* (South Africa, F), but the researchers do not consistently have the capacity to find those connections across systems that are not already linked.

One KI explained the current landscape of data collection and analysis in Indonesia and the lack of knowledge creating barriers to making an impact: *"We are going through a big transformation and basically, Ministry of Health alone cannot have the capacity both in terms of the resources, in terms of the capacity, of human resource capacity to direct this big plan into action, into something that can...really result in change in the community ... So, you know, capacity building in terms of how best to use–how best to collect the data and what can be simplified. Because I think right now we have so many variables to be collected, but we really, do we really need this [many] variables? Well, at the end and it is not even analyzed, it's a huge–You know, it's a waste of time of the health providers also to fill in all this information and then at the end, it is just lying there without any further analysis or feedback to them* (Indonesia, F).

Finally, some KIs described the impact of external funders on the capacity of an agency to sustainably integrate gender into health data. Specifically, one KI explained that many funders only support one stage of a project, such as the formative or design stages, and the internal personnel do not have the capacity to continue: *"We may make action plans, and outcomes achieved from these workshops but sometimes it just ends there. It doesn't get integrated into the day-to-*

day… Once it's externally funded, there's no ownership to it. So, ownership of action plans or whatever is coming from externally supported activities or programs [is necessary]" (Solomon Islands, F).

These myriad challenges to integrating gender into health data expose the reality of the experiences of these KIs, but sustainable, effective solutions can encourage progress.

Discussion

This study explored gender integration in health data in 21 countries. Findings support the overall progress regarding the systematic integration of sex in health data collection although KIs described fewer examples of gender analysis of these data. In addition, gender, as differentiated from sex, and gender diversity were rarely considered within health data collection or analysis. The comprehensive integration of sex and gender into health data holds its own set of challenges; our results provide insight on how to improve the inclusive integration of sex and gender within health data overall.

Data collection

All 21 countries included in this study routinely collect male/female indicators within their health data systems. This success aligns with other reports of progress on including women specifically within data collection systems. For example, though often used sporadically and reliant on donor funding, the Demographic and Health Surveys [42] and the Multiple Indicator Cluster Surveys [43] used in many countries now incorporate indicators related to women and girls' health, including sexual and reproductive health, decision-making, gender-based violence, and harmful traditional practices, such as child marriage or female genital cutting [5, 44]. In addition, the UN developed international protocols for collecting certain types of data impacting women and girls, such as violence [44], economic assets and opportunities [45], and unpaid care and domestic work [46]. Despite these successes, data collection needs continued improvement to meet global gender equality goals. UN Women—a UN organization dedicated to promoting the rights of women and girls [29]—noted in its "Progress on the Sustainable Development Goals: The Gender Snapshot 2023" that nearly half of the data needed to track SDG5 is missing or insufficient [30]. In addition, Open Data Watch—an international organization focused on improving data and its accessibility [32]—reported in its "2023 Report: Gender Data Compass" that over half of countries rank low to medium in terms of capacity to effectively collect, analyze, and use gender data [31].

The progress related to integrating the binary male/female indicators into health data collection is to be celebrated and promoted, and now is the time to move beyond sex to fully integrate gender into health data [8]. Some key informants mentioned specific organizations or projects collecting health data on genders outside of the male/female binary, but these data were specific to the project rather than at the population level. Most participants denoted that health data collection broadly speaking did not systematically include any gender outside of male/female. This gap creates a dynamic where people are either not captured or are captured incorrectly [20, 25]. It is imperative that we reach beyond the binary and include all people in health data in ways that promote equity and safety for individuals and communities. Documenting health experiences for all genders can bring forth evidence on health disparities, mental health, access to care, gender-based violence, and more [21]. For example, when death registration includes comprehensive gender options, alongside cause of death, the deaths of men, women, and gender diverse individuals will be better understood (e.g., if gender diverse individuals are dying due to violence at higher rates than cisgender binary populations) and can be addressed appropriately and intentionally through policies and programs [47–50]. The choice of who to include in data collection and analysis efforts will impact who can receive appropriate interventions and resulting improvements to health.

Gender must be properly considered in the conversations surrounding health data as well as within the implementation of improvements within these systems and approaches.

Data analysis

We must also consider what happens beyond data collection. Many KIs relayed that their countries routinely disaggregate data by sex but do not conduct further gender analysis. The UN calls for disaggregation of data by sex and age, at a minimum; therefore, sex disaggregation meets the current global standards and should be acknowledged as progress [51]. That said, a deeper dive into gender analysis can provide more depth and insight into the data and can lead to a better understanding of where interventions are needed and impact of current programs and policies by gender. For example, sex disaggregation can expose a disparity, and further analysis can reveal why that disparity may exist [52], which can lead to appropriate program development or impactful policy change. Gender analysis may involve incorporating a relevant gender framework within the data analysis plan to guide thinking and approach [52].

Data2X—an organization that uses research, advocacy, and communications to strengthen the production and use of gender data [34]—also denoted the ubiquitous lack of in-depth gender analysis beyond sex disaggregation in their "Mapping Gender Data Gaps" report from 2020 [33]. Though the approach used by Data2X focuses on global gender data gaps as opposed to the current context of gender integration in data overall and includes only women and girls as opposed to all genders, the findings in our current study are very much consistent with what they found. Indeed, multiple players in the gender data field have reported a lack of disaggregation beyond sex and call for improved collection and analysis of gender data, specifically indicating the need for other types of disaggregation to intentionally account for intersectionality [30, 31, 33]. Our results did not portray many intersectionality considerations within data analysis, which may indicate a real need for growth in this relevant and significant approach to health data.

Including people with diverse gender identities is also important to consider during data analysis. One participant from South Africa described the challenges associated with a lack of usable data for analysis when gender diversity was included in data collection. As a response to this challenge, one group of researchers suggests storing the gender data for use in the future and adding to it over the years to create a larger dataset that may have more meaning [25]. Collecting the data is the first step, and finding ways to analyze the data in meaningful ways must follow.

In general, consistent and appropriate gender analysis beyond sex disaggregation can have a positive impact on health policies and programs [20, 53, 54] and should be promoted within countries and across the globe.

Data Challenges

Integrating sex and gender into health data presents myriad challenges. KIs in our study clearly denoted the need for training, capacity-building, and improved resources to elevate knowledge, cultural capacity, and skills within this work. In addition, KIs discussed the varied cultural and political challenges faced in some of the focus countries, including a lack of prioritization by the government. Data2X and Open Data Watch acknowledged similar challenges contributing to the persistent gender data gap [31, 33].

Many KIs described the difficulty of capturing gender without a clear and consistent definition of gender. This difficulty may be exacerbated because gender is understood differently within individual cultures and communities, and language around gender evolves over time [20, 25]. Gender exists beyond male and female, incorporates social expectations and norms, and intersects with other parts of identity [8, 20]; therefore, effectively collecting and analyzing gender health data requires clarity and thoughtfulness about gender overall. The terminology used to describe and define different genders must be carefully and intentionally considered in each cultural context to be both relatable and inclusive [20]. This lack of distinction and homogeneity in terms of language, definition, and understanding can create serious challenges to systematically integrating gender into data [25]. The need for training, capacity-building, and resources becomes even more evident when considering the nuances of culture and language; indeed, training and capacity-building must carefully cater to each individual context to be effective and impactful [55].

KIs also described a lack of government buy-in as a barrier to successfully integrating gender into their data work. In both government and societies, existing gender power relations will impact who participates in data activities, what data are collected, how that data are analyzed, and how that data will be used [52]. In the "2023 Report: Gender Data Compass," Open Data Watch showed nearly two-thirds of countries have low financing for gender statistics [31]; UN Women called for investment in gender data, analysis, and research [30, 38]; and Data2X denoted the need for increased investment to provide capacity-building and training opportunities and to educate government bodies, especially national statistics offices, on the value held within gender data [33]. If political will is lacking, sustainable and lasting progress in gender data will be difficult, if not impossible.

Looking ahead

The past three decades have shown great strides in integrating sex into health data, but there is still work to be done. First and foremost, tangible and relatable ways of understanding gender need to be included in training and capacity-building activities to fully integrate gender into health data. In addition, gender diversity and intersectionality must be systematically incorporated into health data with lasting funding and support to encourage sustainability. Data collection and analysis plans can include gender frameworks with an intentional focus on intersectionality to ensure gender is being considered appropriately. Every stage of health data work must incorporate a gender lens to ensure all people are counted, considered, and cared for.

Limitations

There are a few limitations to this study. Because this is a qualitative study with no more than two participants per country, our results cannot be generalized beyond the opinions of the informants. Instead, we have recorded the perspectives and experiences of individual KIs and can learn from their knowledge within each of their varied contexts.

In addition, this study included high level perspectives and did not incorporate KIs who were, for instance, collecting data or interacting directly with communities to better understand those firsthand experiences. The results of this study could be more robust with the addition of further research focusing on the local perspectives from within the field.

Additionally, our data collection tools did not include specific questions related to intersectionality, which is an important consideration when thinking about gender. Future studies should explore the current context of intersectionality within health data collection, analysis, and use to gain a fuller understanding of gender data.

Lastly, team members who participated in analysis are rooted in a United States Western perspective, which may result in a skewed understanding of the data. We intentionally focused on reflexivity of our positions throughout data analysis to reduce any potential bias within our team.

Conclusions

The increase in interest and activity related to gender across the globe has created positive movement promoting gender equality and health equity. Within health data, both males and females are being counted on a more consistent basis, which will lead to improved health policies and programs. We can celebrate these successes while also continuing to advance gender equality goals. People outside of the male/female binary must be counted within all health data systems; and gender analysis should be bolstered with techniques and considerations beyond sex disaggregation. It is time to continue moving health data forward with inclusivity and consideration for the health and wellness of all people.

Abbreviations

CRVS civil registration and vital statistics

F female

KI key informant

KII key informant interview

LGBTI+ lesbian, gay, bisexual, transgender, intersex, plus

LMIC low- and middle-income country

M male

MDG Millennium Development Goal

NGO non-governmental organization

SDG Sustainable Development Goal

UN United Nations

WHO World Health Organization

Declarations

Ethics approval and consent to participate

This research was conducted in accordance with the Declaration of Helsinki and the National Institutes of Health Guiding Principles for Ethical Research. This study was reviewed by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board, which determined the study was exempt and therefore did not require IRB oversight. All participants provided verbal informed consent before participating in the interview.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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Author Contribution

KW contributed to study design, data collection and analysis, and write-up of results. IE contributed to data analysis and write-up of results. AB contributed to data analysis and write-up of results. TSK contributed to study design and data collection and analysis. VM contributed to data collection. AVM contributed to study design, data collection, and write-up of results. MRK contributed to study design, data collection, and write-up of results. All authors read and approved the final manuscript.

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Data Availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Figures

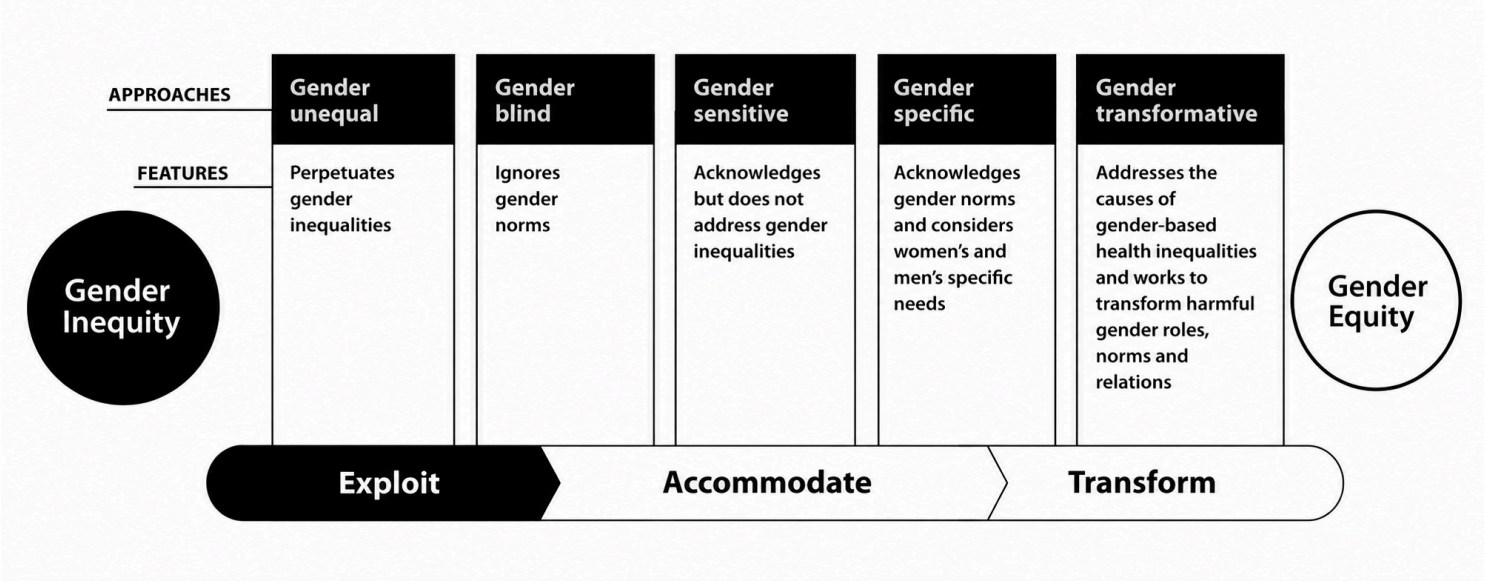


Figure 1

The Spectrum of Gender Integration into Health Promotion [35]

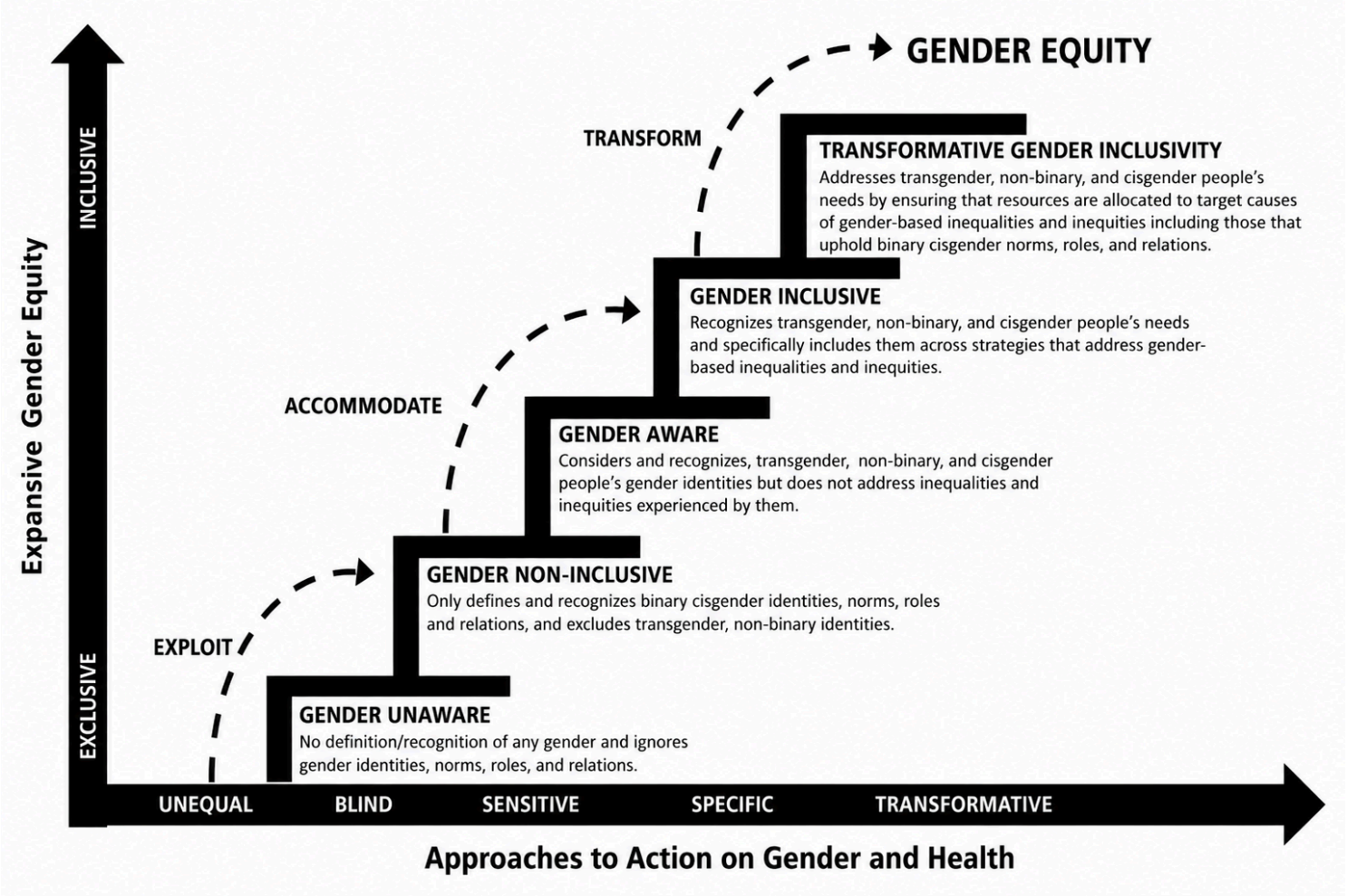


Figure 2

The Expansive Gender Equity Continuum Model [36]

Supplementary Files

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- KIIoneIJEHKIIGuideSupplementary15Oct2026.pdf