Technical Brief 2: A guide for more gender-responsive health research

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What is gender-responsive health research, and why does it matter?

The health of individuals and communities is shaped by a range of factors, including biological characteristics, socio-cultural and political-economic dynamics, and one's physical environment—each of which is also shaped by gender. The impacts of gender on health determinants are vast and diverse. For example, global evidence indicates that men who subscribe more strongly to traditional masculinity beliefs are less likely than women to seek preventative care, including testing and treatments for HIV, TB, and COVID-19.[1] In Cameroon, children and men work outside more than women due to local gender norms, resulting in men and children's greater risks of black fly bites, and consequently, of onchocerciasis infection.[2] Meanwhile, in Ethiopia, research illustrates that "when girls are seen as a lesser financial asset than boys, parents might invest less in girls' health and education," resulting in gender disparities in access to treatments for common childhood illnesses—and consequently, disparities in health and wellbeing. However, such insights are often overlooked in health research due to (a) gender data gaps, as well as (b) capacity gaps related to conducting gender analysis.

By gender data gaps, we mean the **lack of evidence on the relationship between social determinants** (including gender, as well as other social factors such as age, race, income, etc) **and differential risks, exposures, vulnerabilities, and outcomes in health**.[3] Much of health research has been limited to a focus on the "neutral male", which has hidden the impact of other social determinants on health outcomes. For example, research on coronary heart disease has historically drawn upon data on men's experiences. The exclusion of data on women's experiences has resulted in women's symptoms being categorized as 'atypical', with the consequence of delayed diagnosis and higher mortality rates.[4]

Even when such gender data exists, health studies have traditionally lacked **a feminist lens to understand *how* and *why* differences in power relations result in differential risks, exposures, vulnerabilities, and outcomes in health among individuals and different sub-populations.**[5] Gender analysis contextualizes data, enabling health researchers and other relevant stakeholders to connect findings to action. Indeed, while sex-disaggregated data on COVID-19 cases provides an important

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[1] Springer & Mouzon 2011; Chikovore et al. 2014; UNAIDS 2017.
[2] Wanji S, et al. 2015.
[3] Fuentes & Cookson 2020.
[4] Criado-Perez 2019; Pot et al. 2019.
[5] John Hopkins University. Gender Analysis Toolkit for Health Systems.

foundation for understanding the pandemic's gender differentiated impact, gender analysis is needed to *explain* these differences and craft appropriate responses.

Responding to these data and capacity gaps, **gender-responsive health research seeks to capture the ways in which gender differences and power dynamics interact with health determinants**. Gender-responsive health research is intersectional: it seeks to understand how and which factors intersect to accentuate vulnerability and exclusion among individuals and different sub-populations. Furthermore, gender-responsive research recognizes that gender is a relational structure, thus requiring an analysis of gender differences and power dynamics across different levels, including interpersonal, community and institutional health systems. **By generating evidence about differentiated experiences and related inequities, we are better able to develop targeted health interventions, services, and policies to address them.**[6]

Key Concepts for Gender Analysis: Gender norms and health-seeking behaviors

A growing literature on the relationship between gender norms and health-seeking behaviors (HSB) illustrates the need for more gender-responsive research. HSB, defined as "any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy,"[7] has a significant impact on individual and community health. A well-planned health intervention first requires a deep understanding of the target population's ability or propensity to access the proposed intervention. Across vastly different regional contexts, including low-, middle-, and high-income countries, **gender norms (which are the informal rules and shared beliefs that distinguish expected roles and behaviors on the basis of gender in a given society) shape HSB.**[8]

Yet, to capture any of these insights—health researchers must first (a) collect the appropriate gender data to evidentiate these HSB differences and social and structural inequities (in the cases above, time use data can help indicate when women are more likely to access essential health services), and then (b) leverage a feminist lens to understand, explain, and respond to them (that is, then use time use data, among other data sources, to develop programs that support a more equitable access to essential health services). **Such gender analyses require an examination of how gender norms influence health at multiple, interacting levels: the individual, interpersonal, community, and institutional (i.e. health and political systems).** Lastly, it is important to note the importance of engagement with local gender experts, including feminist and women-led civil society organizations (CSOs), in order to connect gender data to contextualized gender analysis.

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[6] WHO 2020.
[7] Oberoi 2016.
[8] Marcus & Harper 2015.

Efforts to advance gender-responsive research: 'Big Data' and precision medicine

Precision medicine seeks to "optimize the pathway for diagnosis, therapeutic intervention, and prognosis by using large multidimensional biological datasets that capture individual variability in genes, function and environment."[9] To do so, precision medicine often leverages artificial intelligence (AI) technologies and new 'big data' sources (for example, personal health data collected via digital watches or other digital applications). For some, the use of AI and big data for precision medicine presents an exciting opportunity to move beyond historic gender biases in health research in order to create deeper understandings of inter-individual differences in health, and thus provide more relevant and impactful research insights, diagnosis and treatments.

However, feminist advocates warn that there is need for caution: big data should not be viewed as a silver bullet for 'objective' knowledge and decision-making. Rather, the degree to which precision medicine can advance more inclusive research, programs, services and treatments depends on a number of factors, such as the degree to which women and other marginalized groups are included in the development and testing of new health research methods, in order to ensure these new methods do not exacerbate or create additional risks. Furthermore, while new data sources may contribute to more representative and inclusive understandings of differential risks, exposures, vulnerabilities and outcomes in health—big data is not the only 'new' data source available. Rather, gender-responsive health research draws upon a diversity of qualitative and quantitative data to provide a more complex and representative understanding of differences and inequities.

Lastly, while precision medicine presents a potential pathway for more inclusive research, all forms of data collection and generation necessarily include biases. For example, electronic phenotyping (a methodology that seeks to discover patient characteristics that patients didn't disclose or weren't aware of) draws upon **electronic health record (EHR) data**, which is often viewed as less biased. However, EHR data is "inherently biased by the patient population structure, frequency of healthcare visits, diagnostic criteria, and care pathways."[10] EHR data also reflects the quality of treatment received by doctors—which is a concern, given that women and other marginalized groups tend to be taken less seriously, with health issues often dismissed as psychological. These types of discriminatory practices may result in women and other marginalized groups being misrepresented in these data sets.[11]

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[9] Uddin et al. 2019, page 1.
[10] Prosperi et al. 2018, page 10.
[11] Pot et al. 2019.

> The goal of gender-responsive research is to not only reduce biases when and as possible, but also to be reflective of and responsive to where data is coming from, who has been excluded from this data, and how potential biases will influence insights and any accompanying actions. For those interested in using big data and AI for precision medicine, or other data-driven health interventions, **it is critical to reflect upon gender biases and make "their potential effects on the distribution of power and agency visible, and thus provide a starting point to counteract them."**[12]
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> *For guidance on how to reflect upon biases in biomedical data, see **The Gender of Biomedical Data: Challenges for Personalised and Precision Medicine** in the resources section below.*

Challenges for gender-responsive research

Despite a growing body of guidelines, recommendations, and policies calling upon health researchers to examine sex and gender in health outcomes—progress on this front continues to lag, especially in clinical research and biomedical studies. Day et al's (2016) research highlights four key challenges for conducting gender-responsive health research, from the perspective of health researchers:[13]

1. **Inconsistent terminology**. As a consequence of limited training on gender-responsive health research (and gender analysis more broadly), sex and gender are often used interchangeably (and incorrectly) in health studies, thus limiting comparability and obscuring important insights.

2. **Applying the concepts.** Capturing men and women's differential risks, exposures, vulnerabilities and outcomes in health requires asking different research questions and observing different phenomena than has traditionally been asked and observed in health studies. Thus, gender-responsive health research requires considering gender from the inception of research projects.

3. **Acknowledging the impact**. Sex and gender are still not acknowledged as 'serious' issues to consider in biomedical research, being viewed instead as 'extra' or optional considerations—"or only incorporated in a tokenistic way in order to satisfy funding application requirements."[14] Advocacy is needed to illustrate why meaningful consideration of sex and gender, from the onset of health research, matters.

4. **Data collection and datasets.** Lastly, health researchers may lack access to the data needed to pursue gender analysis. This is especially the case with administrative data, which may include data on sex, but is less likely to include other relevant gender indiactors (such as income, caregiving status, etc). Moving forward, gender-responsive health research requires

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[12] Ibid, page 183.
[13] Day et al. 2016.
[14] Ibid, page 3.

datasets that go beyond clinical indicators (which are often limited in their explanatory power) to consider new data collection methods and mixed-methods analyses that provide researchers with the data needed for more impactful gender analysis.

Gender data gaps: Sexual orientation and gender identity

Sexual orientation and gender identity (SOGI) are key determinants of health outcomes. Yet, across diverse contexts, such gender data is rarely collected—despite being mandated by a number of countries.[15] Without this data, discrepancies based on SOGI are invisibilized, and important services may be ignored. For example, recent inclusions of SOGI are beginning to highlight that women who identify as lesbian have lower rates of cervical cancer screening than those who identify as heterosexual, while bisexual people report more unmet health needs than heterosexual people.[16] Such insights can help practitioners, advocates and policymakers to design appropriate interventions to ensure equitable access to essential health services.

There are several reasons why SOGI data has been historically difficult to collect. First, in contexts that stigmatize or discriminate against LGBQT+ communities, disclosing this information may present a risk to an individual's safety and wellbeing. **Indeed, while data collection helps to visibilize disparities based on SOGI, visibilization is a double edge sword, and may also present new risks or create additional stigmas against LGBQT+ communities.** Even in contexts with less stigma, disclosing SOGI may depend on the trust, quality and effectiveness of the service-provider.

Given the potential risks of SOGI data collection, **feminist researchers look to participatory action research** to determine impacted communities *interest* in data collection (Is it desired? What will this data be used for?) and to identify *how* to effectively and safely collect sensitive data (for more on feminist research methods, see **Technical Brief #1**). For example, follow-up interviews with patients in the United States who had disclosed their SOGI data illustrated several useful insights for future SOGI data collection efforts:[17]

- Providing a variety of options for SOGI is not only practical (helping to capture the diversity of identities that exist) but also indicates a health organization's commitment to inclusivity, which was found to give patients a "positive impression", and make them more likely to share their data;
- With that said, some patients reported not being sure of their own identities, and that an open option could have been more welcoming;

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[15] Streed et al. 2020.
[16] Pinto et al. 2019.
[17] Ibid.

- Patients also reported they felt uncomfortable answering questions concerning their SOGI because it brought up previous experiences of discrimination.

Equipped with such insights, researchers can consider new ways to design data collection methods that better meet local needs, and respond or mitigate identified risks. **With that said, while some of these findings may be relevant for different contexts, universality cannot be assumed:** risks to data collection will depend upon local contexts and thus require contextualized, local research.

Recommendations for conducting more gender-responsive health research

Consider change from the outset. Feminist research is about change. Considering a potential change process, or a problem that your research seeks to help address, from the onset of the research guides not only which data to collect—but also who to collect it from, and with whom you collect and analyze it.

Engage with relevant CSOs throughout the research process to connect data to action. Partnerships and engagement with relevant CSOs, including feminist and women-led CSOs, are key to develop problem- and change-driven reserach questions; reflect upon potential biases or risks from data collection; verify data findings with lived experiences; and finally, to connect data findings to policy, program and service change. For example, Ladysmith's gender data project at the Colombian-Venezuelan border, Cosas de Mujeres[18] was designed collaboratively alongside local feminist CSOs, which allowed the project to identify local data needs and the potential risks of data collection, and thus design a locally responsive data collection intervention. Furthermore, through ongoing partnerships with local CSOs, Cosas de Mujeres regularly co-analyzes and co-presents data findings in order to leverage data findings for local policy impact.

Employ an intersectional feminist lens to your research: analyze how gender intersects with other sociodemographic and structural factors to shape health outcomes. Gender intersects with a number of other factors (including biological characteristics, socio-cultural and political-economic dynamics, and one's physical environment) to create differential risks, exposures, vulnerabilities, and outcomes in health. While capturing the impact of gender on health is an important first step in addressing historic gaps and advancing gender-responsive research—employing an intersectional lens is critical for developing more relevant and impactful research. To do so, ask: What other sociodemographic and structural factors might be influencing the study's outcomes? Which factors are most relevant to the study's local context and desired impact? What local CSOs can I engage with to understand how to capture this data in a safe and ethical way?

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[18] Zulver et al. 2021

Compliment quantitative data with qualitative data. Different data sources are likely to tell different stories. For example, while quantitative data on global COVID-19 mortality rates suggests that men have been disproportionately impacted by the COVID-19 pandemic,[19] qualitative data indicates that women have faced increased risks of violence, increased burdens of time poverty, and disproportionately detrimental economic impacts.[20] Furthermore, while quantitative data is often descriptive (e.g., sex-disagreggated COVID-19 mortality statistics), qualitative data is generally more explanatory (e.g., focus group discussions with COVID-19 survivors and frontline responders can provide potential hypotheses on the pandemic's gendered impacts).[21] Therefore, it is important for health research to consider diverse datasets in order to develop more in-depth analyses that not only *describe* differential health outcomes, but also begin to *explain* them in order to then inform policy, program and service responses.[22]

Reflect on data and data biases in all dimensions of the research. Gender-responsive research seeks to reduce biases when and where possible by engaging with CSOs representing marginalized communities; expanding the range of social determinants captured in the dataset; and by leveraging multiple, complementary datasets. However, feminist frameworks recognize that data is, inherently, biased. Therefore, in analyzing data collected for health research, it is important that researchers reflect upon potential biases at all stages of the research process, and integrate these reflections into their data analysis and reporting of research findings (see *The Gender of Biomedical Data: Challenges for Personalised and Precision Medicine* below).

Additional tools and resources

- Incorporating Intersectional Gender Analysis into Research on Infectious Diseases of Poverty: A toolkit for health researchers (World Health Organization)
- Resource Compilation: Data, Gender, and COVID-19 (Data 2X)
- The Health Researcher's Toolkit: Why Sex & Gender Matter (Women's Xchange)
- Guidelines for Gender based Analysis of Health data for Decision Making (Pan American Health Organization)
- What are the key ethics issues in health systems research? (Ethics Resource)
- Sex and Gender Equity in Research: rationale for the SAGER guidelines and recommended use (Heidari et al. 2016)
- How to do (or not to do)… gender analysis in health systems research (Morgan et al. 2016)

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[19] Dehingia and Raj 2020
[20] Cookson & Fuentes 2020; Seck et al. 2021
[21] Fuentes & Cookson 2020
[22] Hankivsky and Kapilashrami 2021

● [The Gender of Biomedical Data: Challenges for Personalised and Precision Medicine](#) (Pot et al. 2019). The table below, published in Pot et al. 2019, provides six sets of questions to increase the visibility of gender bias in biomedical data.

Topic	Questions
Coordination	● Who has what kind of influence in the development and coordination of health data projects and can decide on the purposes, procedural aspects, and questions pertaining to intellectual property? ● What are the role and interests of the state, of public and private bodies, and particularly technological and pharmaceutical companies involved in health data projects? ● What are the gender structures in these organisations and groups, and how do they work towards gender equality, if at all?
Participation	● What are the explicit and implicit mechanisms – including the availability or unavailability of institutional, technological, financial, and educational resources – that influence participation in health data projects? ● What are the enabling and constraining factors that affect the quantitative representation of women and gender minorities in health data projects? What are their motivations to participate, and what forms does their participation take? ● How are core issues of health data projects perceived by different groups of participants? For example, do women and gender minorities have other motivations for participation than central coordinating actors, and are their interests accounted for?
Community	● Are women and gender minorities invited to participate *qua* their genders, or is gender not a visible and explicit category in this health data project?
Evaluation	● Who has the power to decide what good outcomes of health data projects are? ● How are the criteria of evaluation decided upon, and what happens to the results of an evaluation? ● Who defines how gender biases are defined and how datasets and technologies are dealt with, once gender biases have been detected? ● What is done to reduce biases?
Openness	● How are access to data and openness of data regulated? ● Who has access to the data and who has what kind of rights and competences relating to the curation of data? ● Can participants – in our case, in particular women and gender

	minorities – access their data in uncomplicated ways, if they so desire, and decide themselves what they want to happen with their data? ● By whom, and how are attempts to 'de-bias' datasets undertaken? ● What other mechanism of data quality control are in place?
Entrepreneurship	● How are the financial needs of data projects met, and how are for-profit and other interests aligned or where do they conflict? ● What commercial stakes are involved in data projects? ● Has health data originally been generated for other purposes? And was there awareness and reflection about possible gender biases in the first instance? ● Have commercial stakes outside of the healthcare system been inscribed in the data sets or infrastructures (e.g. in how and what data were collected, how people were compensated or not compensated etc.)?