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VIEWPOINT

An Invitation to a Feminist Approach to Global Health Data

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The notable gendered socioeconomic, health, and human rights implications of COVID-19 have sparked a renewed conversation on gender data gaps and the risks of gender-blind responses that ignore structural determinants of health and undermine social justice goals.[1] Higher mortality among men, disproportionate social, economic, and health effects on ethnic and racial minorities, high infection rates among the predominantly female health workforce, the rise in violence against women and people of diverse sexual orientation and gender identities, the heavy burden of unpaid care on women, and diminished access to essential services such as sexual and reproductive health services are some of the factors that bring to the fore the urgency of capturing disparities and delivering a gender transformative and equitable response to the pandemic.[2]

Delivering accessible, affordable, and equitable health care for all requires policies and strategies that are grounded in high-quality reliable data and are "conscious of the need to address the social determinants of health, including those related to gender, income, education, ability, conflict and ethnicity."[3] An intersectional feminist approach to global health data—for epidemiological surveillance, monitoring and evaluation, or research—has the potential to examine the intersectional nature of power and privilege, whether due to patriarchy, colonialism, capitalism, neoliberalism, or the many other endemic hierarchies, and reveal health disparities and gender-related barriers to health information and quality services. Drawing on feminist thinking, governments and global health actors can productively address the underlying causes of health inequities and deliver on the right to health, including the universal health coverage goal of leaving no one behind.[4]

COVID-19 on the heels of growing data activism

Despite the visibly gendered outcomes of COVID-19, the research and analysis of data on the pandemic continue to be remarkably gender blind.[5] Countries have been slow in reporting and analyzing COVID-19 infection and mortality data by sex and age, among other dimensions, and gender analyses on testing,

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hospitalization, access to services, and social and economic implications are missing.[6] The implications of intersecting axes of inequality—such as race and ethnicity, sexual orientation and gender identity, disability, migration status, and socioeconomic status—are even more rarely analyzed, concealing the compounded impact of the pandemic on different populations.[7]

The data activism of the last decade offers a useful critique of the gender biases in the way we produce and use data to respond to the COVID-19 pandemic. Authors including Sara L. M. Davis, Caroline Criado Perez, Angela Saini, Catherine D'Ignazio, Lauren F. Klein, and Alyson J. McGregor eloquently underline the power of data and the harms that biased or incomplete data can inflict on those whose experiences have been ignored.[8] The biases that have plagued systems are increasingly the focus of international global health and gender equality players—such as Data2X, an entity established by the United Nations Foundation with the sole purpose of improving "the availability, quality, and use of gender data." At the same time, we are also witnessing a long-overdue momentum to decolonize global health at a time when preexisting "racial, ethnic and financial inequities" are being exacerbated as a result of the COVID-19 pandemic, in a bid to finally reverse the remaining "colonial hangover," in the words of World Health Organization Director-General Tedros Adhanom Ghebreyesus.[9] As Clara Affun-Adegbulu and Opemiposi Adegbulu states, "the patterns or matrix of power, born of colonialism, … [continue to] define and control the economy, culture, knowledge production, body and psyche, and authority, beyond the limits or end of colonialism."[10] An intersectional feminist lens to data can uncover the multiplying effect of gender, race, ethnicity, poverty, and other dimensions of inequality on the physical, mental, and social health of different populations.

The growing recognition that biased and incomplete data render individuals' needs invisible and ignored is echoed in the human rights-based approach to data, which focuses on issues of data collection and disaggregation to improve "the quality, relevance and use of data and statistics consistently with international human rights norms and principles."[11] A report submitted to the 41st session of the United Nations Human Rights Council states that "disaggregation of data that allows a comparison of population groups … forms part of the human rights obligations of States and has become an element of the human rights-based approach to data."[12] Fragmented, partial, and gender-biased data that ignore the experiences of, health needs of, and barriers to access services faced by certain populations risks violating the rights of all to equal and nondiscriminatory access to health services, while infringing the right to enjoy the benefits of, and protection from the harmful effects of, scientific and technological development. These rights entail positive obligations on state parties. In the case of the Convention on the Elimination of Discrimination against Women, state parties must take proactive measures to modify or abolish existing laws, regulations, customs, and practices that result in discrimination against women. This includes the obligation to ensure that data collection and use reflect the real-world experiences of women and that any conclusions reached are supportive of equality.

Needless to say, the increasing focus on data surveillance to control and contain community transmission of COVID-19 raises concerns about infringement of the right to privacy and confidentiality, potentially exposing individuals to serious human rights violations. Hence, the need to collect granular data for an effective response must go hand in hand with data protection and respect for human rights. As a result, it is not sufficient to consider the intersection of gender with other dimensions of oppression regarding what data are collected. We also need a critical reflection on the ways in which data are collected and evidence is produced, further emphasizing our call for the adoption of feminist principles to global health data.

A call for a feminist approach to global health data

Feminist approaches to knowledge production are concerned primarily with the issue of power differentials—understanding how people's lived realities are captured by data processes and how this affects the power structures that help or hinder people from realizing their human rights. Feminist thinking is particularly useful in contemporary global health discourse, as it reaches beyond gender and applies an analytical approach to power hierarchies rooted in colonial and other forms of oppression. By employing a feminist approach to global health data (from developing data collection strategies to analysis, interpretation, and reporting), one can "make visible aspects of … the world that are unavailable from dominant [white male] perspectives, and in so doing, generate the kinds of questions that will lead to a more complete and true account" of events and our societies.[13]

Most importantly, what distinguishes the feminist stance toward data from traditional practices is its critical reflection on the influence of our biases and subjectivities on the process of data collection and knowledge production. Data are not objective. Decisions about what needs to be measured and how, and the evidence that is constructed based on the analyses and interpretations of large scale data, are inevitably subjective and political.[14] Individuals who already face discrimination or are marginalized are most at risk from policy decisions resulting from gender-biased and partial data, most often collected through bureaucratic and exclusionary processes.

Therefore, feminist principles, similar to the human rights-based approach to data, emphasize the participation of women and other marginalized communities to inform methodological and analytic decisions on which data are to be collected and how, striving for this engagement to be emancipatory and the benefits reciprocal.[15] Participatory processes offer space to these groups to understand the data, interpret the meanings that these findings have for their lives, and guide how this knowledge could inform investments, strategies, and programmatic decisions in a way that is relevant to their needs. Participatory processes can also engage communities in addressing the gender, decolonial, and ethical issues pertaining to data protection, privacy, and confidentiality.

While applying feminist methodologies systematically to big data will undoubtedly generate greater insights into health disparities, we need to caution about an over-reliance on numbers. Unraveling the nuanced and complex causes of health disparities identified through quantitative measures requires complementary qualitative inquiries that can unmask the complexities of lived experiences.[16] As observed in every health crisis—from HIV to COVID-19—an in-depth examination of the intersections of oppression, vulnerabilities, and marginalization can reveal essential insights about the realities of our diverse lives and offer innovative solutions on how to equitably meet the diversity of needs and realities. As an illustration, country-level HIV responses are based on the principle "know your epidemic," which relies on subnational data disaggregated by sex, age, and other factors (such as wealth quintile and education status) to identify disparities. In many countries in sub-Saharan Africa, quantitative information has revealed disproportionate HIV rates among young women and identified areas with the biggest increases in HIV incidence. The quantitative data were supplemented with consultations with adolescent girls and young women to understand the lives behind the numbers. The consultations were run by organizations led by young women using methodologies to gather and analyze the data to collectively agree on program recommendations on the most effective response. The process brought to the fore ideas on why and how to include economic empowerment programs, and preferences regarding contraceptive and HIV prevention commodity.

Embracing intersectional feminist perspectives—and their inherently decolonizing features—in national and global health data collection methodologies necessitates a transformation of institutions within which data and knowledge are produced and used to guide responses to heath crises, such as the COVID-19 pandemic. A reconstruction of the health data and knowledge production system will undoubtedly require international institutions, including donors and global health bodies, that control and shape the global health agenda to reckon with the persistence of patriarchal and colonial ideologies and legacies, and their influences on data systems.

The COVID-19 pandemic presents an opportunity not only to reinvigorate our demands for a gender-transformative, nondiscriminatory, and equitable response but also to transform global health institutions, dispose of our harmful historical legacies, and implement equitable measures to guard against the already insipid regression in the realization and protection of rights. This is not a utopian dream. This is a chance to reshape our thinking and redraw our future. The time to act is now.

Visit www.gendro.org/statements to endorse our call for urgent action: a renewed commitment to gender-responsive research for health equity and human rights in the context of the COVID-19 pandemic.

Disclaimer

The views and opinions expressed in this commentary are those of the authors and do not necessarily reflect the views, decisions, or policies of their respective organizations.

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References

1. C. Wenham, J. Smith, and R. Morgan, "COVID-19: The gendered impacts of the outbreak," *Lancet* 395/10227 (2020), pp. 846–848.
2. World Health Organization, *Gender and COVID-19: Advocacy brief* (Geneva: World Health Organization, 2020).
3. "The Mexico statement: Strengthening health systems," *Lancet* 364/9449 (2004), pp. P1911–P1912.
4. Office of the United Nations High Commissioner for Human Rights, *A human rights-based approach to data: Leaving no one behind in the 2030 Agenda for Sustainable Development* (Geneva: United Nations, 2018).
5. World Health Organization (see note 2).
6. S. Heidari, C. Ahumada, and Z. Kurbanova, "Towards the real-time inclusion of sex- and age-disaggregated data in pandemic responses," *BMJ Global Health* 5/10 (2020).
7. "Does Covid-19 hit women and men differently? U.S. isn't keeping track," *New York Times* (April 3, 2020); "Government criticised for not collecting sex disaggregated Covid-19 data," *Digital Health* (April 7, 2020).
8. S. L. M. Davis, *The uncounted: Politics of data in global health* (Cambridge: Cambridge University Press, 2020); C. Criado-Perez, *Invisible women: Data bias in a world designed for men* (New York: Abrams Press, 2020); A. Saini, *Inferior: How science got women wrong and the new research that's rewriting the story* (Boston: Beacon Press, 2017), p. 213; C. D'Ignazio and L. F. Klein, *Data feminism* (Cambridge, MA: MIT Press, 2020); A. J. McGregor, *Sex matters: How male-centric medicine endangers women's health and what we can do about it*, First (New York: Hachette Books, 2020).
9. A. M. Büyüm, C. Kenney, A. Koris, et al., "Decolonising global health: If not now, when?," *BMJ Global Health* 5/8 (2020), p. e003394.
10. C. Affun-Adegbulu and O. Adegbulu, "Decolonising global (public) health: From Western universalism to global pluriversalities," *BMJ Global Health* 5/8 (2020), p. e002947.
11. Office of the United Nations High Commissioner for Human Rights (see note 4).
12. Human Rights Council, Data Collection and Management as a Means to Create Heightened Awareness of Violence and Discrimination based on Sexual Orientation and Gender Identity: Report of the Independent Expert on Protection against Violence and Discrimination based on Sexual Orientation and Gender Identity, UN Doc. A/HRC/41/45 (2019).
13. T. Bowell, "Feminist standpoint theory," in *The Internet encyclopedia of philosophy.* Available at https://www.iep.utm.edu; E. Prügl, "Feminist methodology between theory and praxis," *Review of International Studies* 46/3 (2020), pp. 304–314.
14. G. Beetham and J. Demetriades, "Feminist research methodologies and development: Overview and practical application," *Gender and Development* 15/2 (2007), pp. 199–216.
15. M. Lokot, "The space between us: Feminist values and humanitarian power dynamics in research with refugees," *Gender and Development* 27/3 (2019), pp. 467–484.
16. V. Rutledge Shields and B. Dervin, "Sense-making in feminist social science research," *Women's Studies International Forum* 16/1 (1993), pp. 65–81.