

EDITORIAL

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Toward an Equity-Based Response to Endometriosis

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Introduction

Endometriosis affects 190 million, or 1 in 10, women worldwide.¹ It is a complex chronic condition with an impact extending from menarche through menopause, causing chronic pain during menstruation and negatively impacting sexual and reproductive health and rights, including fertility, sexual well-being, overall health, and quality of life of those affected.¹ Endometriosis has been neglected as both a public health concern and a women's health priority, with effective treatments still limited. Its economic burden is comparable to that of chronic diseases such as diabetes and Crohn's disease, yet it receives far less attention and funding.²

"More research is needed" is a familiar refrain, yet data, innovation, and expertise on endometriosis remain fragmented and inequitably concentrated in a few regions. Investments in understanding its origins, progression, pain mechanisms, and broader health impacts continue to lag behind.³

Building on existing evidence, this Editorial calls for equity-driven innovation and global collaboration to close these gaps—moving beyond the traditional "Global North first, Global South later" model toward a truly inclusive approach to scientific discovery and knowledge sharing.

The Health, Social, and Economic Implications of Endometriosis

Endometriosis is a chronic, estrogen-dependent inflammatory condition that mainly affects women during

their reproductive years¹ and also impacts transgender and gender-diverse individuals. It is characterized by heavy bleeding, debilitating pelvic pain, fatigue, and infertility.^{1,4} If pregnancy occurs, endometriosis increases the risk of complications during pregnancy and childbirth.⁵

Women with endometriosis often experience poorer sexual health, including reduced satisfaction and desire, bleeding, and pain during intercourse.⁶ They also face higher risks of anxiety, depression, and reduced quality of life, impacts beyond physical health. Stigma surrounding menstruation and endometriosis exacerbates these challenges, leading to low self-esteem and isolation.⁷ In many cultures, menstruation remains taboo, with pain and heavy bleeding dismissed as something to endure in silence.⁷ Because symptoms vary widely and diagnosis often involves ruling out other conditions,¹ persistent stigma and limited awareness can delay care seeking and diagnosis for years—an average of seven in some countries—worsening women's well-being and increasing health system costs.⁸ Delays are often longer in low- and middle-income countries (LMICs), where barriers to care, limited data, and weak diagnostic systems persist.

Endometriosis severely affects women's quality of life, energy, and participation in work, education, and daily activities.⁸ Its symptoms often begin in adolescence and persist through peak productive years, compounding social and economic impacts.⁸ Diagnosis

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typically depends on costly or hard-to-access imaging or surgery, especially in LMICs,¹ while limited provider awareness and insufficient research and investment in data, diagnostics, and treatment continue to hinder care.

Equity-Driven Approach for Research and Innovation on Endometriosis

Global efforts to address endometriosis are expanding through collaboration among stakeholders and civil society,⁹ yet progress remains driven by the Global North. At the same time, the needs of women in LMICs continue to be overlooked, underscoring a need for inclusive, equity-driven research and action that reflects diverse regional realities. With rising global attention, we now have a critical opportunity to act collectively and equitably. This requires breaking from the prevailing model—seen again during COVID-19—where innovations developed in the Global North take years to reach or become affordable in the Global South.¹⁰

As a global convener, the World Health Organization (WHO) has effectively used roadmap development to accelerate research and coordinate action during public health crises and persistent global health challenges. An Endometriosis Roadmap could similarly channel attention and investment toward critical data generation, research priorities, equitable Target Product Profiles, and affordable access to new therapies. It could also foster collaborations in diagnostics, drug development, and service delivery. As the leading United Nations agency for global health guidance, WHO could further translate this process into evidence-based recommendations that drive equitable, sustainable progress.

A global roadmap is needed to equip health and care workers to better recognize and manage endometriosis, strengthen disease classification, accelerate noninvasive diagnostics, expand safe and affordable treatment options, and ultimately find a cure. These are not just research gaps—they are equity gaps that demand coordinated global action, investment, and solidarity to ensure that no woman continues to suffer in silence.^{1,3} This moment offers an opportunity to advance an equity-driven, globally inclusive approach to endometriosis research and innovation. Achieving this requires investing in researchers, health, and care workers across high-, middle-, and low-income countries as equal and collaborative partners—co-creating knowledge, shaping priorities, and driving solutions

that reflect the lived realities of all women affected by endometriosis.¹¹

In practice, this means equitably shared research funding, multicountry collaborations that enable innovation to be developed and tested across diverse settings, and investment in local infrastructure, leadership, and capacity. Shared responsibility and training across regions are essential to ensure that progress is both inclusive and sustainable. As scientific discovery evolves and our understanding of endometriosis improves, health and care workers in *all* countries will need access to clinical training on the diagnosis and management of the disease, emphasizing a respectful and unbiased care approach.

Additionally, it is vital to center the voices of those with lived experience—especially from underserved communities and LMICs—from the very start. By 2030, Africa will have the world's largest youth population, implying more Africans could potentially be affected by endometriosis in future. Developing an inclusive global roadmap for endometriosis while leaving no one behind is critical to achieve universal access to sexual and reproductive health-care services for all.

Conclusions

To achieve meaningful progress by 2030, we must build an inclusive and equitable global framework that recognizes and responds to the needs of *all* women living with endometriosis—especially those in regions where the burden is greatest. As global priorities evolve, women's health cannot be sidelined. Investing in and strengthening research and health systems in the Global South is essential to close the equity gap. With balanced investment and genuine collaboration, we can ensure that innovations in endometriosis care are accessible, affordable, and responsive, advancing the shared goal of universal access to sexual and reproductive health for all women.

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Authors Contributions

A.C.-G. drafted the initial version of this article with substantial contributions from G.M. and L.G. E.O.M., Y.C., and P.A. provided critical review and substantive revisions. All authors reviewed and approved the final article.

Author Disclosure Statement

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Abbreviations Used

COVID-19 = Corona Virus Disease 2019
LMIC = Low and Middle-income countries
WHO = World Health Organization

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