

ENDOMETRIOSIS: CHARTING THE WAY FORWARD IN POLICY AND PRACTICE



Endometriosis is a painful gynaecological condition that affects approximately 10 percent of women worldwide. Its impact on women and their families in India is not well studied, impeding effective policy interventions. Better understanding of endometriosis is essential to alleviate the suffering of women living with the condition and improving diagnosis and support.

WHAT'S AT STAKE?

The effects of endometriosis are pervasive and impact almost every aspect of a woman's life. It is estimated to affect 10 percent of women of reproductive age in any given population, with over 4.2 crore Indian women being affected.¹ Despite these figures, it receives little policy attention, and research funding remains woefully inadequate. With focus largely on Maternal and Child Health (MCH), gynaecological morbidities have been relegated to the sidelines of women's health.

While the impact of endometriosis on women is significantly more than its impact on men, the psychological, financial and emotional toll it takes on their male partners cannot be understated. Men caring for their partners face financial distress due to out-of-pocket expenditure (OOPE), helplessness for being unable to alleviate their partners' pain and increased uncertainty about the future, in addition to added responsibilities and other stresses.

In order to examine further the current situation of women living with endometriosis and find ways to reduce its impact, the George Institute for Global Health India (TGI) organised a stakeholder consultation "Tackling Endometriosis Together to Improve Women's Lives" on 15 February 2024 with researchers, women with lived experience, representatives from government and quasi-government organisations, and, among others, health practitioners. This brief is an outcome of the discussions held and insights shared in the consultation.

1 Gajbhiye RK, Montgomery G, Pai MV, Phukan P, Shekhar S, Padte K, et al. Protocol for a case-control study investigating the clinical phenotypes and genetic regulation of endometriosis in Indian women: the ECGRI study. *BMJ Open*. 2021;11:e050844 [PMC free article] [[PubMed](#)] [[Google Scholar](#)] (Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8354274>)

INSIGHTS

There is a need to further understand the long-term impact of endometriosis on women's lives, which is essential for informed policymaking. The primary impediments to women living with the condition from leading normal and fulfilling lives are multi-fold:

Gaps in Epidemiological Research and Treatment Guidelines

The large body of research on endometriosis is from High Income Countries (HIC), predominantly from the west. The conditions faced by Asian women are different compared to the west,² and therefore, existing epidemiological research is insufficient for effective diagnosis and management of endometriosis in India.³ Better knowledge sharing, research collaborations, and engagement with the community are necessary to address the lacunae in diagnosis, treatment, and social perception. The detailed set of guidelines for the diagnosis and management of Endometriosis, developed by the Federation of Obstetrics and Gynaecological Society of India (FOGSI), "Good Clinical Practice Recommendations on Endometriosis," clinicians in India has been an important step in this direction, however, there may be a greater need to take up wider training and implementation of these guidelines.

2 Bougie O, Yap MI, Sikora L, Flaxman T, Singh S. Influence of race/ethnicity on prevalence and presentation of endometriosis: a systematic review and meta-analysis. *BJOG*. 2019 Aug;126(9):1104-1115. doi: 10.1111/1471-0528.15692. Epub 2019 Apr 29. PMID: 30908874. (Available at: <https://pubmed.ncbi.nlm.nih.gov/30908874/>)

3 Gajbhiye RK. Endometriosis and inflammatory immune responses: Indian experience. *Am J Reprod Immunol*. 2023 Feb;89(2):e13590. doi: 10.1111/aji.13590. Epub 2022 Jul 1. PMID: 35751585; PMCID: PMC7615030. (Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7615030/>)



Access to Care and Burden on Women

Access to care continues to be a challenge and there is an acute lack of affordable health infrastructure for early diagnosis and treatment of endometriosis. From policy to practice, government programmes that are aimed at women's health typically focus on MCH, causing endometriosis and other gynaecological morbidities to largely be ignored. Dignified treatment and involvement of women in decisions related to their own gynaecological health is often overlooked. Individual aspirations in the career and life of such women, and the role of social determinants of health call for women's needs and priorities to be at the centre of endometriosis care. Shifting the power imbalance and enabling women with endometriosis to make an informed decision with respect to diagnosis, treatment and care can ensure that policies and programmes are inclusive and responsive to their needs. Their unique lived experience ought to be included in conversations around endometriosis at the policy level.

Financing mechanisms to reduce out-of-pocket expenditure (OOPE)

Women with endometriosis face difficulties in accessing financial aid for specific procedures such as laparoscopic surgery under private health insurance schemes, which is essential for diagnosing endometriosis. Due to the high cost of such procedures, OOPE is high, which compels people to live with the condition to refrain from pursuing treatment. To reduce OOPE, it is recommended that funding support schemes through centrally sponsored insurance such as PM Jan Arogya Yojana can aid women living with endometriosis and their families, especially in terms of medication. Additionally, other suitable mechanisms to subsidise the cost of treatment can be explored.

RECOMMENDATIONS & LESSONS FOR POLICY & PRACTICE

Given the prevalence of endometriosis and gaps in evidence, the following recommendations could be valuable in alleviating the social, financial and psychological pressures caused by the lived experiences of this condition.

Awareness to bridge the knowledge gap

Women's gynaecological health is still a neglected area in the Indian context. While there are various initiatives such as the School Health Program⁴, which includes health promotion on menstrual hygiene, awareness about conditions like endometriosis is still deficient in the community at large. These initiatives are opportunities to increase awareness among girls and their parents about endometriosis and other gynaecological morbidities and educate them to seek medical help when required. Such support systems during formative years of young girls can go a long way in destigmatizing conversations around health conditions related to gynaecology and provide access to verifiable knowledge. Similarly, attitudes at the workplace regarding women's gynaecological health that put an additional burden of guilt on women suffering from endometriosis are avoidable with increased sensitisation.

Facilitating early diagnosis and management

There are numerous diagnosis challenges, however building awareness is a key factor that encourages health-seeking behaviour among women living with endometriosis.⁵ Analysis of the data generated by research collaborations can be used to improve presumptive diagnosis in different settings. This must be supplemented by creation of patient registries for easier access to diagnostic and treatment data and the outcomes. Simultaneously, future research on non-invasive diagnostic tools must be encouraged.

4 Operational Guidelines on School Health Programme under Ayushman Bharat, April 2018 (https://nhm.gov.in/New_Updates_2018/NHM_Components/RMNCHA/AH/guidelines/Operational_guidelines_on_School_Health_Programme_under_Ayushman_Bharat.pdf)

5 Oberoi S, Chaudhary N, Patnaik S, Singh A. Understanding health seeking behavior. J Family Med Prim Care. 2016 Apr-Jun;5(2):463-464. doi: 10.4103/2249-4863.192376. PMID: 27843863; PMCID: PMC5084583. (Available at : <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5084583/>)



Policy interventions

The Government of India has been keen to address various aspects of women's health, including recent initiatives in reducing the burden of cervical cancer.⁶ However, existing policies and guidelines must rely on evidence-based research for improved outcomes. Standard Treatment Guidelines for Obstetrics and Gynaecology⁷ by the Ministry of Health and Family Welfare (MoHFW), for instance, do not have any reference to endometriosis. Further considering that women's health programmes by governments at the centre and states focus on MCH, it is curious that RMNCAH+N⁸ (Reproductive, Maternal, Newborn, Child, Adolescent Health and Nutrition) programme under National Health Mission (NHM) does not address conditions such as endometriosis.

The need for a holistic approach towards addressing women's health needs to be cognisant of the urban-rural divide as well. While endometriosis is increasingly being reported from urban areas, not much is known about how women from rural areas are being supported in diagnosis and referral. This increases the risks that women face especially with pain management, stigma and misdiagnosis. Establishment of nodal departments or focal points in the health departments, especially at the district or cluster level will be beneficial to understanding the extent to which this condition persists in India.

Additionally, it is essential for valuing lived experience of endometriosis as evidence to inform practice and policy. As urgent steps, it is necessary for:

- Engagement with sub-national stakeholders at the local and district levels, particularly PHCs, increasing interaction with the community to understand challenges, needs and priorities.
- Care plans responsive to the needs of individual women, which can help build trust between institutions, healthcare providers and people with lived experience.
- Guidelines advising/mandating supportive workplaces and infrastructure there for.

6 'Nari Shakti' Takes Center Stage; Union Finance Minister Announces Vaccination To Prevent Cervical cancer (Available at: www.pib.gov.in/PressRelease/NirmalaSitharamanproposedvaccinationforpreventionofcervical%20cancer).

7 Standard Treatment Guidelines on Obstetrics and Gynaecology (Available at: <http://clinicaestablishments.gov.in/WriteReadData/4571.pdf>)

8 *A Strategic Approach to Reproductive, Maternal, Newborn, Child and Adolescent Health (RMNCH+A) in India*

- Increasing meaningful involvement of women living with endometriosis in research, policy and programme arenas.

ACKNOWLEDGMENT

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2. Office of the Registrar General & Census Commissioner India. SPECIAL BULLETIN ON MATERNAL MORTALITY IN INDIA 2018-20. Sample Registration System; 2022.
3. International Institute for Population Sciences (IIPS) and ICF. National Family Health
4. International Institute for Population Sciences. National Family Health Survey-5 2019-21 [Internet]. Mumbai: International Institute of Population Sciences; 2021 [cited 2021 Dec 18]. Available from: http://rchiips.org/nfhs/NFHS-5_FCTS/India.pdf