

Endometriosis and adenomyosis research priorities in India and Sri Lanka: a call for regional collaboration

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Summary

Endometriosis and adenomyosis are major gynaecological conditions affecting women of reproductive age-group, particularly in low- and middle-income countries. This Health Policy outlined research priorities for India and Sri Lanka, derived from a structured debate during the 'Future Directions in Endometriosis and Adenomyosis Research' workshop. Researchers from both countries emphasise the need for nationally representative data, improved diagnostic tools, and comprehensive care models. Shared priorities include developing patient registries and improving healthcare access. India focuses on multidisciplinary care centres, advanced diagnostic research, and public education, while Sri Lanka highlights integrating traditional medicine and assessing economic impacts. Both countries prioritise non-invasive diagnostics to address diagnostic delays and healthcare limitations. Establishing patient registries and consortiums for large-scale studies could inform healthcare strategies. Collaborative research among Asian countries could generate tailored regional solutions. Coupled with a strong political will, and adequate funding, the initiative can potentially improve diagnosis, treatment, and quality of life for affected women.

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Introduction

Endometriosis is a multi-factorial disease characterised by the presence of endometrium like tissue outside the uterine cavity.¹ Adenomyosis on the other hand is a gynaecological condition where the uterine endometrium invades the myometrium.² Globally, endometriosis has emerged as a major public health concern, affecting approximately one in every ten women of reproductive age.³ Isolated adenomyosis is estimated to be prevalent in about 10% women with subfertility and about 1% overall.^{4,5} Dysmenorrhoea, dyspareunia, chronic pelvic pain and subfertility are shared symptoms between the two diseases that significantly affect the quality of life of women.⁶ Another concerning aspect of endometriosis is the delay in diagnosis of the disease that ranges from 5 to 11 years across various countries and has been documented as a function of healthcare availability, accessibility, and affordability.^{7–9} Specialised requirements for endometriosis and adenomyosis diagnosis and management also entails that majority of

the existing data on these two diseases stems from high-income countries (HICs) and becomes sparse in low-income countries (LICs) and low- and middle-income countries (LMICs). With the LICs and LMICs facing a multitude of public health issues to deal with, resource allocation substantially affects the prioritisation of needs for endometriosis and adenomyosis. With the given constraints, it becomes imperative to chalk out priorities requiring urgent attention.

The World Bank currently classifies both India and Sri Lanka as LMICs. India contributes to about 18% of the global population and Sri Lanka makes up about 0.3%.¹⁰ While the growing numbers and geographical distribution stretch India's public health system,¹¹ the economic crisis in Sri Lanka affects the healthcare seeking behaviour.¹² Coupled with the diversity of sociodemographic and cultural factors, these result in a lack of nationally representative credible data on the burden, determining factors and management modalities for endometriosis and adenomyosis. With minimal exceptions, all Asian countries present a similar situation, warranting an urgent requirement to prioritise endometriosis and adenomyosis research activities specific to each country's needs.

With this end in mind, researchers in the field of endometriosis and adenomyosis gathered in Colombo, Sri Lanka in July 2024 to participate in the workshop on

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'Future Directions in Endometriosis and Adenomyosis Research'. The Endometriosis and Adenomyosis Association of Sri Lanka jointly organised this two-day event in collaboration with Center for Research Development and Innovation (CRDI), Faculty of Medicine, University of Colombo and the Asian Society for Endometriosis and Adenomyosis (ASEA). Authors of the present manuscript were invited to share their research experience to a wider audience. The conference agenda was to discuss facilitators and barriers in implementing endometriosis and adenomyosis research, present findings from studies and network for future collaborative projects. The discussants utilised a structured debate and consensus approach to develop country-specific priorities. This Health Policy compiles the outcome of these discussions for India and Sri Lanka.

Research priorities

As per World Bank's population estimates for 2023,¹³ it can be roughly calculated that about 50 million women in India and about 0.35 million women in Sri Lanka are affected by endometriosis, while about 5 million Indian women and about 35,000 Sri Lankan women have adenomyosis. However, these estimates are based on global aggregate data and do not account for local factors that may significantly affect the burden of these diseases. The foremost priority for both India and Sri Lanka that emerged during the discussions was therefore to generate nationally representative data that can drive the resource allocation for early detection and management

of endometriosis and adenomyosis. Similarly, providing diagnostic services, maintaining patient registries as well as implementing measures to improve quality of life emerged as shared priorities for both countries (Fig. 1).

Epidemiology and prevalence

Currently, India and Sri Lanka prioritise research aimed at understanding the prevalence and clinical phenotypes of endometriosis. India emphasises on determining the socioeconomic burden and health-related quality of life of women with the condition along with role of geographic and ethnic diversity of its population in disease presentations and risk factors. Sri Lanka shares this priority but expands its focus to include the study of adenomyosis and the exploration of environmental risk factors.

Patient demographics and clinical manifestations

The demographic influences on endometriosis are of particular interest in Sri Lanka, with research priorities focussing on how factors such as body mass index (BMI) and age affect disease outcomes. India, on the other hand, stresses upon understanding the natural history of the disease, including non-human primates as models for studying the aetiology and pathogenesis. Both countries seek to better document the disease's clinical presentations, with focus on the prevalence of pain and subfertility and their impact on patients' quality of life.

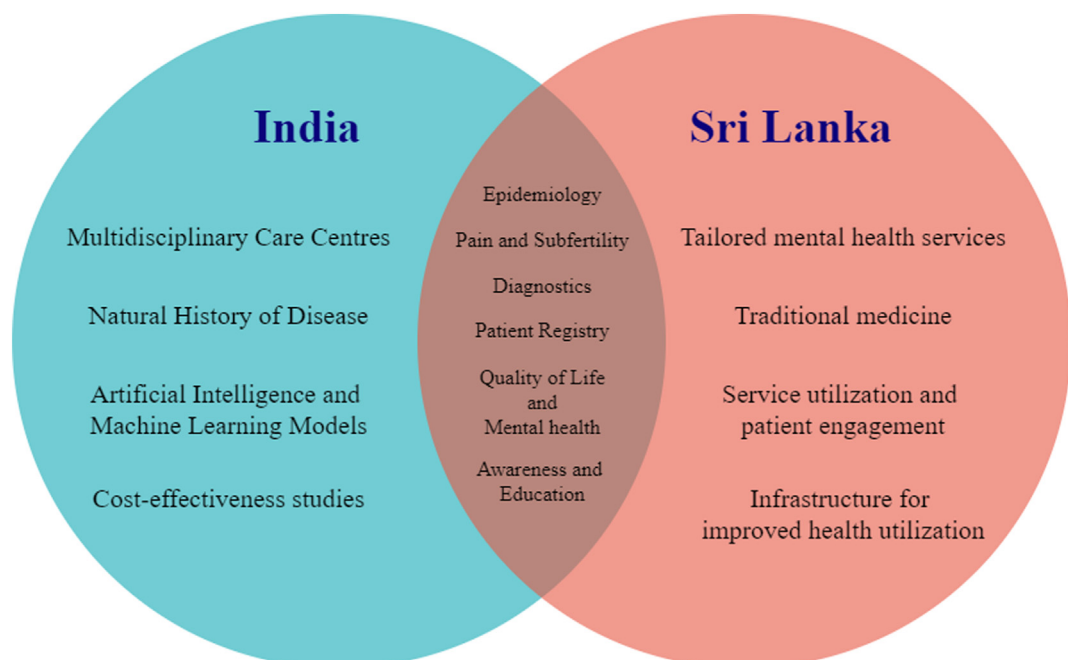


Fig. 1: Country-specific and shared endometriosis and adenomyosis research priorities of India and Sri Lanka.

Gaps in healthcare system and comprehensive care

Both countries prioritise addressing the gaps in healthcare systems, although their approaches vary. India's focus is on identifying and mitigating systemic gaps within public and private healthcare sectors, seeking to establish multidisciplinary care centres that provide comprehensive care. These centres would integrate medical and surgical treatments with psychosocial support and counselling, aiming to improve patient outcomes. Both countries focused on improving capacity of peripheral public health facilities, like the Community Health Centres or Sub District Hospitals or the District Hospitals for providing affordable and accessible diagnostic and treatment facilities especially for women dwelling in rural areas. Sri Lanka further emphasises on investigating barriers to gynaecological services and exploring ways to enhance patient utilisation and satisfaction with healthcare services.

Patient registry and data collection

A notable shared priority between India and Sri Lanka is the establishment of national patient registries. India seeks to create a national registry for women with endometriosis, facilitating research efforts and supporting a data-driven approach to disease management. Sri Lanka mirrors this interest by proposing a patient registry for both endometriosis and adenomyosis, with a strong emphasis on validating and standardising global data collection tools for use in the local context.

Diagnostic methods

India prioritises translational research to develop symptom-based clinical screening tools and biomarkers, which would be especially useful in low-resource settings. Sri Lanka shares this focus but also highlights the need for improved detection methods for adenomyosis, specifically mentioning the use of pelvic ultrasound scans. The development and validation of non-invasive diagnostics remain a critical priority for both countries, aimed at improving early and accurate detection.

Treatment and management modalities

As mentioned before, India proposes the establishment of multidisciplinary care centres that incorporate a range of therapeutic options, including surgical intervention, pain management, and psychosocial support. Sri Lanka takes a similar approach by prioritising research on the effectiveness of various management modalities, with a focus on both medical and surgical treatments. Sri Lanka also proposes conducting research on the use of traditional medications in the management of endometriosis and adenomyosis, assessing their efficacy and safety.

Pathogenesis and translational research

India prioritises research into advanced technologies such as artificial intelligence, machine learning, and

organ-on-chip models, aiming to explore personalised medicine and preventive measures. Sri Lanka, while not explicitly mentioning these technologies, calls for multidisciplinary research teams to address the underlying biological mechanisms of both conditions.

Public awareness and educational programmes

Raising public awareness and educating healthcare providers about endometriosis and adenomyosis is a key priority for both countries. India emphasises the need for educational programs aimed at increasing awareness among community members and healthcare providers. This includes school programs that teach students about menstrual health and hygiene and importance of accessing early healthcare for menstrual irregularities. Sri Lanka similarly highlights the need to evaluate and improve patient awareness but places greater emphasis on addressing the barriers to acceptance of gynaecological services.

Quality of life and mental health

Both countries acknowledge the significant impact of endometriosis on quality of life and mental health. India seeks to develop guidelines for improving the quality of care and patient outcomes through early recognition, timely referral, and optimal management. Sri Lanka places a particular focus on mental health support, calling for the development of comprehensive services tailored to the needs of patients with endometriosis and adenomyosis.

Health economics and policy development

Both India and Sri Lanka explicitly prioritise research into the economic burden of endometriosis and adenomyosis. Both advocate for cost-effectiveness studies to inform healthcare policies and improve resource allocation for the management of these conditions. Additionally, policy development to support research funding and healthcare infrastructure is also a critical focus area. [Table 1](#) provides a summary of the research priorities.

Discussion

This Health Policy outlined and compared the research priorities for endometriosis and adenomyosis in India and Sri Lanka, two LMICs facing unique healthcare challenges. Both countries emphasise the need for national patient registries, epidemiological studies, and the development of non-invasive diagnostic tools. India places a strong focus on comprehensive multidisciplinary care and educational programs, while Sri Lanka highlights the importance of economic studies and the evaluation of traditional medicine. These priorities reflect a pressing need to address gaps in healthcare infrastructure, diagnostics and resource allocation, while also focussing on improving patient outcomes and awareness.

Category	India	Shared priorities	Sri Lanka
Epidemiology	Determining role of geographic and ethnic diversity in disease presentation	Documenting burden and clinical phenotypes	Exploration of environmental risk factors
Clinical manifestations	Research on natural history, including primates for studying pathogenesis	Prevalence of pain, severity, and subfertility	Role of patient demographics on disease outcomes
Healthcare gaps	Identifying and mitigating systemic gaps in public and private healthcare sectors	Improving comprehensive care	Focus on accessibility, barriers to services, and enhancing patient utilisation
Patient registry	Establish national registries for data-driven disease management	–	Registry for standardising global data collection tools
Diagnostics	Translational research for developing non-invasive diagnostic methods and biomarkers for low-resource settings	Development of non-invasive diagnostic methods for early detection	Improving detection methods for adenomyosis, including pelvic ultrasound scans
Management modalities	Establish multidisciplinary care centres offering medical, surgical, and psychosocial support	Evaluating the effectiveness of existing and newer treatment modalities	Use of traditional medications in management
Translational research	Use of artificial intelligence, machine learning, and organ-on-chip models, with a focus on personalised medicine	Research into the aetiology of endometriosis and adenomyosis	Multidisciplinary research to address underlying aetiology
Awareness and education	Raise awareness among community members, healthcare providers, and schools	–	Improving patient awareness and addressing barriers to acceptance of gynaecological services.
Quality of life	Guidelines for improving quality of care through early recognition, timely referral, and optimal management	Acknowledging the impact of endometriosis and adenomyosis on quality of life and mental health	Tailored mental health support services
Economics and policy	Cost-effectiveness studies to inform healthcare policies and improve resource allocation	Conducting economic studies to evaluate the burden of disease, and develop policies to support healthcare	Policy development, resource allocation, and healthcare infrastructure improvements for disease management

Table 1: Summary of the country-specific and shared research priorities of India and Sri Lanka related to endometriosis and adenomyosis.

A critical barrier in addressing endometriosis and adenomyosis in both India and Sri Lanka is the lack of comprehensive, nationally representative data on the prevalence, clinical manifestations, and socioeconomic impact of these conditions. The Global Burden of Endometriosis study suggests that the burden of the disease may be an underestimate in the LMICs.¹⁴ Women with a better socioeconomic status in HICs have a better access to healthcare and are more likely to be diagnosed compared to women in LICs and LMICs.¹⁵ Similarly, geographic diversity, ethnic variations and environmental factors play a significant role in presentation and outcomes of endometriosis and adenomyosis.^{16–19} A wide data gap hinders the development of effective healthcare policies and limits our understanding of unique risk factors that may influence disease presentation. The World Endometriosis Research Foundation's (WERF's) Endometriosis Phenome and Biobanking Harmonization Project (EPHect) provides standardised tools including the Endometriosis Patient Questionnaire²⁰ and Standard Surgical Form.²¹ The Physical Examination tool is the recent addition.²² Utilisation of these tools can generate credible, uniform and credible data.

Establishing patient registries as a potential solution can become a rewarding priority for both the countries. The Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry assesses the overall quality of life of women with endometriosis and

adenomyosis using patient-reported outcome measures.²³ The registry has played a pivotal role in developing the National Action Plan for Endometriosis in Australia.²⁴ Resources for health providers could be modelled like the British Society for Gynaecological Endoscopy (BSGE) registry that has significantly contributed to understanding disease phenotypes and outcomes in different populations.^{25,26} Another critical aspect that can be addressed by the registry is generating evidence on women diagnosed with endometriosis and adenomyosis both and its implications. To the best of our knowledge, no study has documented that in India or Sri Lanka.

A major challenge in both India and Sri Lanka is the reliance on invasive and often expensive diagnostic methods for endometriosis and adenomyosis, leading to delayed diagnosis and suboptimal patient care.^{27,28} Both countries have prioritised the development of non-invasive diagnostic tools, which could revolutionise early detection and treatment, especially in low-resource settings. Translational research aimed at developing symptom-based screening tools, non-invasive biomarkers, and advanced imaging techniques has the potential to mitigate the financial and infrastructural barriers that currently delay timely diagnosis.^{29,30} Non-invasive diagnostics would also be critical in improving patient access to care, reducing diagnostic delays and addressing the significant underreporting of these conditions in LMICs.^{31,32}

Multidisciplinary care is essential for the effective management of endometriosis, integrating medical, surgical, psychological, and rehabilitative interventions to address the complex needs of patients.^{33–36} Specialist intervention and coordinated holistic care has been associated with improved outcomes in endometriosis.^{34,36} However, the shortfall of trained specialists including anaesthetists, laparoscopic surgeons, and gynaecologists, especially in the rural landscape of both countries poses a major challenge, requiring not only an increase in their numbers but also their distribution across the length and breadth of the country. Educational programs are another critical component of this approach, aimed at raising awareness among healthcare providers, patients, and the public. Initiatives like ‘Menstrual Health and Endometriosis’ (ME) in New Zealand, or the Endometriosis Awareness Promotion Project have demonstrated that educational programs can improve awareness and knowledge of endometriosis and dysmenorrhoea among young women.^{37,38} The Ministry of Health & Family Welfare, Government of India under the National Health Mission launched the Menstrual Hygiene Scheme (MHS) to increase awareness, access and utilisation of sanitary napkins in the age group 10–19 years.³⁹ Broadening the scheme’s mandate to include education about early signs of endometriosis and adenomyosis can be a crucial value addition to the program.

Sri Lanka’s focus on integration of traditional medicine in the management of endometriosis and adenomyosis represents a distinctive research priority not commonly seen in HICs. Many patients in LMICs, including India and Sri Lanka, continue to rely on traditional remedies due to cultural preferences and limited access to conventional healthcare services.⁴⁰ Products like Epigallocatechin Gallate (EGCG), Curcumin, Ginsenoside Rg3, Resveratrol, β -Caryophyllene, and herbal decoctions like *Pancamuli lagudraksha Kashaya*, *Sukumara Kashaya*, *Kanchanara Guggulu*, *Yogaraja guggulu*, among others have shown promise in pre-clinical trials and/or small scale studies in reducing inflammation and lesion size. However, large-scale trials are required to ascertain their actual utility.^{41–43} Research into the efficacy of these treatments is crucial, as integrating traditional practices with modern medical approaches could provide a culturally acceptable and cost-effective solution for managing these conditions.^{44,45} However, this integration must be informed by validated credible evidence with a special focus on potential adverse effects of these modalities, individually and in combination.

While these priorities offer the potential to reshape the disease landscape in India and Sri Lanka, their implementation is likely to involve certain obstacles. Research on endometriosis and adenomyosis in these countries will depend heavily on the availability of resources and the political will to prioritise women’s

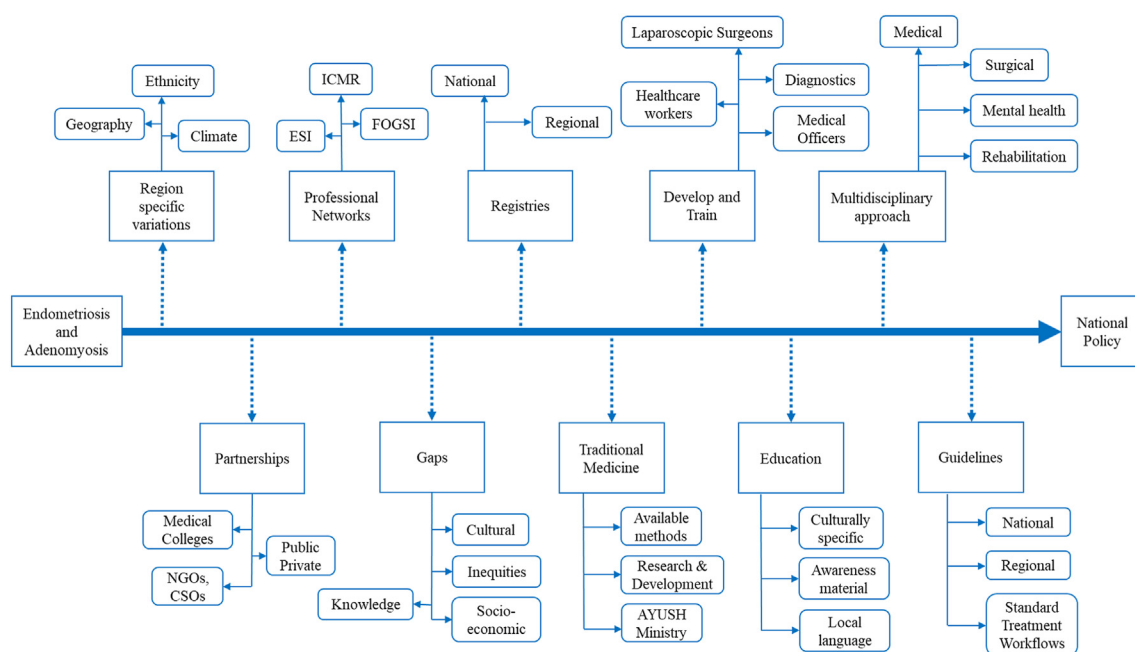


Fig. 2: Proposed roadmap for addressing the research needs of endometriosis and adenomyosis in India and Sri Lanka. ESI: Endometriosis Society India; ICMR: Indian Council of Medical Research; FOGSI: The Federation of Obstetric and Gynaecological Societies of India; NGO: Non-Government Organisation; CSO: Civil Society Organisation; AYUSH: Ayurveda, Yoga & Naturopathy, Unani, Siddha, Sowa Rigpa, and Homoeopathy.

Search strategy and selection criteria

Scientific articles were identified through searches of PubMed (<https://pubmed.ncbi.nlm.nih.gov/>), Google Scholar (<https://scholar.google.com/>), and Scopus (<https://www.scopus.com/>) using the following keywords: ("Endometriosis" OR "Adenomyosis" OR "Pelvic Pain" OR "Dysmenorrhea" OR "Dyspareunia" OR "Subfertility"); ("Prevalence" OR "Epidemiology" OR "Burden" OR "Quality of Life" OR "Healthcare Access"); ("Diagnostic Tools" OR "Biomarkers" OR "Ultrasound" OR "Non-invasive Diagnosis" OR "Surgical Treatment" OR "Medical Treatment" OR "Multidisciplinary Care"); ("Health Policy" OR "Healthcare Infrastructure" OR "Resource Allocation" OR "Patient Registry" OR "Healthcare Accessibility" OR "Public Health"); ("India" OR "Sri Lanka" OR "South Asia" OR "Low- and Middle-Income Countries" OR "LMICs"); ("Alternative Medicine" OR "Herbal Treatment" OR "Ayurveda" OR "Traditional Therapies" OR "Complementary Medicine"); ("Health Economics" OR "Cost-effectiveness" OR "Socioeconomic Factors" OR "Mental Health Impact" OR "Work Productivity"). Searches were conducted for peer-reviewed journal articles, institutional reports, and conference proceedings, with no restrictions on publication date until July 2024. Two authors (HM, IP) independently performed literature searches and crosschecked extracted data. Articles were excluded if they did not directly address endometriosis, adenomyosis, epidemiology, diagnostics, treatment, health policy, or economic impact. References from selected papers were reviewed for additional relevant studies. Only English-language publications were included in the final review.

reproductive health. Both countries face significant challenges in healthcare infrastructure and resource allocation, with India's vast population and Sri Lanka's ongoing economic crisis further complicating the situation.^{11,12,46,47} Securing adequate funding, improving healthcare infrastructure, and fostering political commitment are essential to ensure that research efforts translate into meaningful healthcare improvements. Recently, the Indian Council of Medical Research (ICMR) formed a National Task Force (NTF) for research on snakebite in India. The NTF then funded nationally representative studies on data generation⁴⁸ as well as implementation research projects.⁴⁹ A similar model, funded by the central funding agency can be adopted for promoting endometriosis and adenomyosis research. Political will is particularly important in advocating for policy changes that support national action plans, research, funding for patient registries and the development of cost-effective diagnostic and treatment options, all of which are crucial for improving care in resource-limited settings. Establishment of a research consortium between India and Sri Lanka and later expanding it to other Asian countries can generate credible national data that can then be compared across countries for addressing common risk factors. This exercise has the potential to be resource-friendly and impactful for the region. The findings of the consortium would also be useful for draughting the evidence-based guidelines for the clinical diagnosis and management of endometriosis and adenomyosis as both countries currently lack such specific protocols (Fig. 2).

The comparative analysis of research priorities for endometriosis and adenomyosis in two LMICs is the core strength of the study. By considering the socio-economic and healthcare challenges specific to India and Sri Lanka, this analysis provides a nuanced understanding of how each country is trying to address critical gaps in research and clinical practice. Additionally, the use of a structured discussion method during the Colombo conference ensured that the resulting research priorities are both comprehensive and tailored to the needs of each country. The involvement of experienced researchers from both countries promotes cross-border collaboration, which may lead to more coordinated regional research efforts in the future. However, the focus on just two countries, while providing detailed insights, may not fully capture the diversity of challenges faced by other Asian LMICs in addressing endometriosis and adenomyosis. Furthermore, existing healthcare and research infrastructure limits the outlined priorities affecting their immediate implementation. Additionally, the absence of real-time economic and political data, especially in the context of Sri Lanka's current economic crisis, may influence the feasibility of some research initiatives. Lastly, while traditional medicine plays an important role in Sri Lanka's healthcare system, implementing more rigorous clinical trials to validate its efficacy in treating endometriosis and adenomyosis might prove challenging.

Conclusion

Research priorities for endometriosis and adenomyosis in India and Sri Lanka highlight both shared goals and unique challenges within each country. Models from HICs, such as patient registries, menstrual education programmes and potential non-invasive diagnostics, provide valuable frameworks; however, the distinct socio-economic conditions, stretched healthcare infrastructure and lack of trained human resource in LICs and LMICs require customised approaches. Shared research priorities among LMICs in Asia and globally should promote a culture of collaborative and coordinated research, optimising resource allocation for cost-effectiveness. To advance research and enhance women's healthcare in Asia, regional capacity building, strong political will and adequate resource allocation is essential. Establishing research and clinical consortia for endometriosis and adenomyosis could transform both diagnosis and management, leading to significant improvements in disease outcomes.

Contributors

RG and HS were part of the workshop to discuss the research priorities for India and Sri Lanka. RG and HS compiled the country-specific priorities. HM carried out the literature review. HM and IP wrote the first draft of the manuscript. RG and HS provided critical feedback and intellectual inputs. All authors agreed to the final version of the manuscript.

Declaration of interests

We declare no competing interests.

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