Article:

Karavadra, B. orcid.org/0000-0002-1625-9469, Mawson, R. orcid.org/0000-0001-6377-6197, Dixon, S. orcid.org/0000-0002-7469-6093 et al. (2 more authors) (2025) Building bridges: enhancing diagnosis and care for endometriosis across the primary-secondary care continuum. Women's Reproductive Health. ISSN: 2329-3691

https://doi.org/10.1080/23293691.2025.2540344

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Women's Reproductive Health

ISSN: 2329-3691 (Print) 2329-3713 (Online) Journal homepage: www.tandfonline.com/journals/uwrh20

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To cite this article: Babu Karavadra, Rebecca Mawson, Sharon Dixon, Ulrik Bak Kirk & Andrew W. Horne (09 Sep 2025): Building Bridges: Enhancing Diagnosis and Care for Endometriosis Across the Primary-Secondary Care Continuum, Women's Reproductive Health, DOI: 10.1080/23293691.2025.2540344

To link to this article: https://doi.org/10.1080/23293691.2025.2540344

WOMEN'S REPRODUCTIVE HEALTH
https://doi.org/10.1080/23293691.2025.2540344

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Building Bridges: Enhancing Diagnosis and Care for Endometriosis Across the Primary-Secondary Care Continuum

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ABSTRACT
Endometriosis affects approximately 10% of women of reproductive age worldwide. Journeys to diagnosis can be complex, with an average of 9 years between development of symptoms and diagnosis, which has not improved despite guidance and policy focus. Learning how to reduce this time was identified as a James Lind Alliance Top Ten research priority. There are well-documented challenges throughout care journeys for people with known or possible endometriosis. Endometriosis can be associated with symptomatic impacts throughout the life course and across body systems, and support necessitates holistic attention to these. This opinion piece explores community-based support opportunities, advocating for a collaborative, cohesive approach among professionals. Endometriosis is a chronic condition, with treatment often extending across primary and secondary care for several years. Inequalities in care for endometriosis are evident, whether that be due to geographic variation in provision of specialist centers or racial disparities in diagnosis rates. Deprived communities also face lower referral rates and subsequent lower specialist diagnosis. The persistent focus of research on secondary care drives these inequalities as those unreferred and undiagnosed women are left unaccounted for within the endometriosis sphere. The role of primary care as advocates and enablers of these women is pivotal in reducing inequity of care. Smoother journeys for people living with endometriosis are urgently needed and we need to build bridges between our services to enable this to happen.

ARTICLE HISTORY
Received 30 April 2025
Revised 10 July 2025
Accepted 23 July 2025

KEYWORDS
Primary care; inequalities; endometriosis; general practice

Introduction

Endometriosis affects approximately 10% of women of reproductive age worldwide (Giudice, 2010). Journeys to diagnosis can be complex, with an average of 9 years between development of symptoms and diagnosis, which has not improved despite guidance and policy focus. Learning how to reduce this time was identified as a James Lind Alliance Top Ten research priority (Horne et al., 2017). There has rightly been a focus on the complexities associated with diagnostic processes and journeys in endometriosis. The focus on diagnosis is seen as pivotal to enabling evidence-based care but risks positioning diagnosis as an endpoint of a care journey, and not a point along it (Simoens et al., 2012; Staal et al., 2016). People with known, confirmed, possible or suspected endometriosis may experience symptoms and care needs which precede, follow or span the time of diagnosis. There are well-documented challenges to and through care journeys for people with known or possible endometriosis.

A holistic, life-course approach is vital, as endometriosis affects various aspects of life, from physical and mental health to social well-being and daily function (Maindal et al., 2025). Warzecha et al. (2020) found that endometriosis can cause significant psychological distress, including depression and

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anxiety (Warzecha et al., 2020). Similarly, Culley et al. highlighted its social and psychological impacts (Culley et al., 2013). This is a strength of primary care, from which specialists could benefit.

The 2024 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report re-frames endometriosis as a chronic condition, which can be associated with symptomatic impacts throughout the life course and across body systems (Aleboyeh et al., 2024). The NCEPOD report was produced using case report review combined with organization, clinician and patient surveys (in England). Holistic support necessitates personalized attention to all of these. This represents an opportunity for partnership; primary care has expertise and experience in holding support for people living with complex and long-term conditions, during and in between episodes of specialist care input. The NCEPOD report highlights the impact of the need for repeated re-referrals into specialist care for advice or treatment, once a diagnosis has been ascertained, each of which are associated with potential delays to care.

We believe that patients with endometriosis deserve a collaborative, cohesive approach among professionals, from primary care through to specialist care. Bridges between primary and specialist care silos will enable the smoother passage of patients and will also offer potential benefits for clinicians (Dixon et al., 2024). Recognizing and valuing the skills and expertise held across settings will foster collaborative multi-disciplinary care and enable bi-directional learning. This includes, for example, primary care research and expertise in supporting people with unexplained symptoms and pain, in exploring the impacts of access to care on diagnosis and researching and mitigating health inequities.

Inequalities in care for endometriosis are evident, whether that be due to geographic variation in provision of specialist centers or racial disparities in diagnosis rates. There is an inverse care law at play in endometriosis (Hart, 1971): deprived communities face lower referral rates and subsequent lower specialist diagnosis, within a context of greater multimorbidity and lesser access to primary care. The 2024 Office of National Statistics (ONS) report “Characteristics of women with an endometriosis diagnosis in England March 2011-December 2021” demonstrates vividly the impact of socio demographic characteristics on the likelihood of receiving a diagnosis, with lower diagnosis rates in the most deprived areas, and variance by documented ethnicity (Office for National Statistics, 2024). The persistent focus of research within secondary care, or only with those who have successfully navigated access to a diagnosis, exacerbates these inequalities because un-referred and undiagnosed women are left unaccounted for within the endometriosis evidence sphere. The role of primary care as advocates and enablers of these women is pivotal in reducing inequity of care.

In the UK, a two-tier system exists, where some areas only have access to generalist gynecology while specialist centers provide care for a minority (De Silva et al., 2024). This influences both access to diagnosis and access to specialist care. Furthermore, there is an additional two-tiered system, which is rapidly growing in a context of NHS waiting lists (longest for gynecology), creating a barrier between those who can pay for care (and a diagnosis) and those who cannot. This was evident in the NCEPOD report in which 28% of people identified with confirmed or known endometriosis had accessed private care (Aleboyeh et al., 2024). The ONS report also noted lower rates of NHS hospital diagnoses of endometriosis in the least deprived areas, thought to reflect this greater use of private healthcare.

In this article, we consider opportunities for enhanced collaboration within the United Kingdom (UK) National Health Service (NHS) along the care journey, to diagnosis and beyond. People living with endometriosis (both possible and recognised) need and deserve smoother care journeys. Delivery of endometriosis care requires communication and coordination between all those involved along the whole care pathway. Improving care journeys could be enabled by recognizing and breaking down the current silos in care and by building bridges between them.

We argue that achieving this is a collective responsibility, shared by all who deliver any aspect of endometriosis care or research, and which requires services and systems to work collaboratively and cohesively, underpinned by mutual respect and understanding.

Section 1: Opportunities for Bridge Building along Diagnostic Journeys

The complex journeys to receiving a diagnosis are well-documented. Improving time to diagnosis of endometriosis is a stated aim of the Women’s Health Strategy for England (Department of Health &

Social Care, 2022). However, knowing how to operationalize improvements effectively requires an understanding of how diagnostic journeys unfold, and the identification of opportunities for intervention throughout them. This includes recognizing the complex reality of care journeys and healthcare systems, and consideration of potential inequities that can arise along them. We need to be inter-disciplinary and inter-sectional. We have much to learn from the women who have endometriosis symptoms but are not diagnosed or do not successfully navigate healthcare systems, as they represent a critical unmet need. Doing this will require cross-sector cohesion and collaboration. General practitioners (GP) hold care for those who are and are not diagnosed with endometriosis (Burton et al., 2017; Dixon et al., 2021). Their insights and advocacy can contribute significantly in this space, although it is women's voices we most need to gather and hear. Counting the people who we do not see in our clinics (and who are therefore not included in research) is harder than counting those we see – but is crucial. Research that only includes those with a diagnosis is critically valuable but may not help us answer questions about inequity and underrepresentation. Primary care is often conceptualized as a bottleneck in diagnostic journeys, with lack of awareness, the suggested underlying mechanism, which can be fixed with education. However, evidence suggests that while this is welcome and essential, it needs to recognize the reality of GPs work and considerations (Dixon et al., 2024).

The lack of a noninvasive diagnostic test for endometriosis means that attaining a diagnosis necessitates a process of clinical assessment in primary care. This process is often followed by a guideline sanctioned trial of treatment and initial ultrasound scan followed by review of the outcome of these. If these are not effective, tolerated or acceptable, then referral to secondary care is advised for a repeated clinical assessment, and referral for further investigations followed by review as the minimum pathway steps, all of which have the potential to contribute an accumulation of time to what is conceptualized as the diagnostic journey. This also leaves open a critical uncertainty about ongoing care when the initial trial of treatment is (or is understood to be) effective in ameliorating symptoms. Recognizing the potential nuance here, it is worthy of reflection that the management sanctioned as symptomatic trials of treatment in guidance are the same options used as first-line choices when endometriosis is diagnosed, which risks a paradox (Dixon et al., 2021, 2024).

For those who attain a diagnosis of endometriosis, there are well-documented benefits, which must not be underestimated. These include access to evidence-based treatments, both medical and surgical. Several studies have found that hormonal treatment in particular is associated with a greater improvement in health-related quality of life outcomes, although we note that this is often effective for those with symptoms aligned to endometriosis or without a diagnosis (Souza et al., 2011; Tripoli et al., 2011). However, the shared decision making process is informed by knowledge of the diagnosis and attendant focussed evidence.

Women who are identified as having deep disease, might be offered treatment in a specialized center that offers advanced endometriosis surgery and access to specialist pain services, although it has been argued that consideration should be given to expanding holistic support to all with impactful symptoms, whether their endometriosis is categorized as deep or superficial, noting the heterogeneity of the association between categorization and symptomatic impact (De Silva et al., 2024).

A diagnosis of endometriosis can be experienced as something which legitimizes women's symptoms and allows them to seek the respective support for their condition, whether this be professionally via medical practitioners or through their employer for work-based adjustments (Ballard et al., 2006). In addition, a diagnosis allows women to have a common language in which they can express the impact of their symptoms to other people and therefore find ways of coping with them (Ballard et al., 2006). Primary research has consistently shown that work-related productivity and employment is also negatively impacted for those women with endometriosis (Hansen et al., 2013; Moradi et al., 2014; Nnoaham et al., 2011); again, a diagnosis enables women to negotiate any workplace adaptations with their employer as necessary. However, while diagnosis is constructed as necessary or helpful in negotiating adjustments and support in the workplace, there is scope to reflect on this societal norm, including the potential for unintended impacts, such as the hierarchy of support predicated upon diagnosis, but perhaps not on symptoms. This acts as a relentless driver toward the perceived necessity of diagnosis, which has impacts for those with symptoms without a confirmed or unifying diagnosis, including after investigations.

We note that these studies recruited women from specialist centers, and as GPs we see women whose care remains with us, whether they receive a diagnosis of endometriosis or not. Consideration and care need to be given to the support and legitimacy of all of these women. We can be mindful in our rhetoric to ensure that we do not inadvertently delegitimise chronic pelvic pain syndrome.

The barriers to a timely diagnosis are complex. In a healthcare system, which can be experienced as complex to navigate and appear fragmented, collaborative working between primary and secondary care specialists can be challenging but is essential. Patient, healthcare professional related and healthcare structure-related factors all contribute to a delay in diagnosis, akin to those seen in cancer diagnosis (Dixon et al., 2021; Olesen et al., 2009). These are structural or systemic barriers, and they require a structural response, which considers inequities within the inequity of care, and recognizes and responds to intersectionality. Interventions are often predicated upon single interactions, but thinking of care journeys as a process may offer value (Black et al., 2023).

Section 2: Inequities in Diagnosis, with Impacts on Access to Care

There are stark inequalities in diagnosis and management of endometriosis with evidence of intersectional accumulation, which creates overlapping discrimination and disadvantage. The lack of easily accessible noninvasive diagnosis compounds this by the need for access to secondary care services. The inverse care law seemingly applies, both for access to primary care and to secondary care (Hart, 1971).

Clear racial disparities are present, with Black, Asian, and Minority Ethnic (BAME) women facing longer delays and misdiagnoses. Evidence suggests Black women are 50% less likely to be diagnosed with endometriosis than White women (Bougie et al., 2019). In the United States, Black women account for around 5% of diagnosis, with 72% being White women (Christ et al., 2021). Yet, there is no evidence that White women are more likely to have endometriosis (Bougie et al., 2022). There are likely to be multiple mechanisms for this inequality, but the long shadow of racist myths about biological pain thresholds for Black women is a likely contributory factor. Normalization of pain and how pain is perceived cause unacceptable healthcare delays in surgery and diagnosis. Research participation also has potential to worsen disparities, with the lack of diversity in studies leading to guidelines developed for predominantly White heterosexual women through the lens of secondary care (Khan et al., 2024).

Where you live also factors into inequalities with geographic disparities in access to primary and secondary care. A population-based Spanish study showed those in rural areas have lower rates of diagnosis of endometriosis, even when removing deprivation as a cofounding factor (Medina-Perucha et al., 2022). Similarly, a Danish study revealed significant regional differences in the incidence of hospital-diagnosed endometriosis (Illum et al., 2022), even though another study found no major regional differences in endometriosis symptoms and indicators (Josiasen et al., 2025). The availability of specialist endometriosis centers may impact on management, particularly in those with severe endometriosis who are often managed by general gynecologists when there is no tertiary referral center (NHS England, n.d.).

Historically, endometriosis was seen as a condition of White professional women (Bougie et al., 2022). This exemplifies how diagnosis can be affected by affluence, with those least deprived being more likely to get referred and diagnosed (Medina-Perucha et al., 2022). Those who can afford to see specialists will be the ones who get the diagnosis. Even within the UK NHS setting where healthcare is universally accessible, disparities occur due to long waiting lists and poor access to specialist centers leading to increase in private healthcare access (Aleboyeh et al., 2024; Office of National Statistics, 2024). In the United States, those in the public health system were 3.5 times less likely to have a laparoscopy and 2.7 times more likely to be prescribed opioids than those in the private sector (Fourquet et al., 2019).

These disparities layer upon each other when we consider the impact of intersectionality, and how some will be impacted by multiple disadvantages. When we consider women from Black, Asian and ethnic minorities who live in deprived communities, the barriers can be insurmountable. This leads to a vicious cycle of detriment with the socioeconomic impact of endometriosis and the impact of symptoms on education, relationships, and social mobility. These communities get managed predominantly in the primary care setting, therefore, capturing the respective individuals for diagnosis early is key to preventing the growing gap in outcomes.

Section 3: The Role of Primary Care in Addressing Inequities in Diagnosis of Endometriosis

Primary care functions as a gatekeeper to healthcare within many single-payer national health systems including UK, Netherlands, Spain, Italy, Australia, and New Zealand (Innocenti et al., 2025). By managing referrals and triaging the health needs of the population, primary care provides a highly cost-effective model. Unfortunately, endometriosis presents a challenge as there is no universally accessible way to differentiate endometriosis from other conditions which may cause similar presentations (de Kok et al., 2024).

Primary care has a central role in providing early identification and advocacy for women with suspected endometriosis, but we lack the tools to be able to do this. In the UK setting, the gynecology waiting lists have doubled with around 600,000 women waiting to be seen (NHS England, 2025). Raising awareness of endometriosis in primary care is only part of what will reduce delays; easy to use diagnostic techniques that do not require invasive testing via secondary care, and timely access and liaison with secondary care specialists, both for initial referrals and the ongoing care journey is important.

For those living in areas of high deprivation, primary care can act as a bridge to reduce inequalities and improve access to secondary care services. General practice has a legacy of research into health inequities and of considering how to act cohesively and structurally to consider, identify, and mitigate against these. Initiatives such as the Deep End movement (Watt, 2011), and the focus on health inequalities in general practice conferences are exemplars of areas where there is scope for bidirectional learning.

This is also of potential importance to endometriosis researchers. Tackling the well-documented inequities in endometriosis requires better representation in inclusion in trials and research. This risks a paradox; recruiting participants with known endometriosis effectively acts in opposition to studying those who have not been enabled to navigate care systems. Utilizing data routinely collected in primary care is a possible strategy to enhance representation, but this is subject to the same difficulty if we include those who have attained a diagnosis. Primary care data is not collected for research purposes, and research using these datasets are a good example of an area whereby collaborating on sensemaking about GP records and the dataset being used could enhance research.

The lack of funding for primary care, specifically for reproductive health conditions, risks deprioritising women's health, however within this context, there is scope for active consideration of justice and equity (Kirk et al., 2024). We need to create and use opportunities to recognize practices in high deprivation areas and increase funding. The impact could be significant for those women who have the greatest barriers to access, which could benefit both clinical care and research.

At times, the disconnect between primary care and secondary care professionals can fragment the diagnostic journey. Although secondary care colleagues have their own service delivery challenges, it is key that specialists in secondary care further recognize the importance of primary care within the scope of endometriosis and endometriosis care. This includes our knowledge of our patients and our communities, and our role as enduring advocates throughout whole journeys, between sporadic and intermittent contacts with specialist care. Building bridges between primary and secondary care is crucial to improve communication and relationships to ease the journey to diagnosis.

Section 4: After Diagnosis: Collaborative Approaches for Holistic Ongoing Care

Once diagnosed, the management of endometriosis necessitates a multidisciplinary approach that integrates primary and secondary care to provide comprehensive support to patients. Endometriosis is a complex condition that affects not only reproductive health but also physical and mental well-being, necessitating the involvement of various healthcare professionals, including gynecologists, primary care physicians, colorectal surgeons, urologists, pain specialists, radiologists, specialist nurses, psychologists, and physiotherapists (Omtvedt et al., 2022). Without coordination, patients face fragmented care, delayed diagnoses, and suboptimal treatment outcomes.

A systematic review by Dancet et al. emphasized that integrated care models, which include pain management, psychological support, and physiotherapy, are critical for improving patient-centered outcomes in endometriosis care (Dancet et al., 2014). O'Farrell et al. emphasized the importance of measuring integrated care at the interface between primary and secondary care, indicating that effective collaboration may lead to better health outcomes for patients (O'Farrell et al., 2022).

Breaking down silos between primary and secondary care is essential for enhancing the management of endometriosis. Poor coordination often results in delayed diagnosis and treatment, worsening symptoms and reducing quality of life (Dunlea et al., 2023). Shared care pathways and interdisciplinary meetings can align healthcare providers, enabling seamless, patient care (Warzecha et al., 2020). Furthermore, people are bounced between services, with frequent discharges from specialist care back to primary care; further exacerbating the inequalities in access to healthcare for patients. The NCEPOD report highlighted the impact of delays in referral and re-referrals, on experiences of care (Aleboyeh et al., 2024). This fragmentation adds to the burden for people with endometriosis and for the GPs supporting them. Access to specialist input is difficult and this extends beyond diagnosis.

A holistic, life-course approach is vital, as endometriosis affects various aspects of life, from physical and mental health to social well-being and daily function (Maindal et al., 2025). Warzecha et al. (2020) found that endometriosis can cause significant psychological distress, including depression and anxiety (Warzecha et al., 2020). Similarly, Culley et al. highlight its social and psychological impacts (Culley et al., 2013). This is a strength of primary care, from which specialists could benefit.

By adopting a coordinated approach that addresses the full spectrum of symptoms, healthcare providers can ensure women receive personalized, comprehensive care. This fosters early intervention, improves symptom management, and enhances overall well-being of those affected by endometriosis.

Conclusion

Improving experiences for people with known or suspected endometriosis requires consideration of the whole care journey. It requires systems that help our patients navigate smooth and untroubled passage as they journey to and from between primary and secondary care. This holds equally true for initial assessment and diagnosis and for onward care throughout the life course.

We argue that it is our collective responsibility to develop and nurture bridges between our care settings, because if we do not, it is our patients who risk falling into the void. If we continue to function as disconnected sites, perhaps akin to gated cities—at either end of the bridge—with complex tolls or entry requirements to our zones, then it is our patients who will flounder. If we keep our work apart in discreet silos, in our clinical work, our research, or our systems, then we miss out on opportunities to learn from each other and smooth the road. If we allow oppositional or divisive discourse, then we risk transitioning the bridge between care settings to one which effectively functions as a drawbridge, which can be pulled up and between sites of care. It is our patients who will fall into the moat, and together we must not allow that to happen.

Acknowledgements

Sharon Dixon is supported by an NIHR Doctoral Research Fellowship.

Rebecca Mawson is an NIHR Academic Clinical Lecturer.

Babu Karavadra is an NIHR Academic Clinical Fellow.

The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Author Contributions

CRediT: **Babu Karavadra**: Conceptualization, Writing – original draft, Writing – review & editing; **Rebecca Mawson**: Conceptualization, Writing – original draft, Writing – review & editing; **Sharon Dixon**: Conceptualization, Writing – original draft, Writing – review & editing; **Ulrik Bak Kirk**: Conceptualization, Writing – original draft, Writing – review & editing; **Andrew W. Horne**: Conceptualization, Writing – original draft, Writing – review & editing.

Disclosure Statement

Andrew Horne's institution (University of Edinburgh) has received payment for consultancy and grant funding from Roche Diagnostics to assist in the early development of a blood diagnostic biomarker for endometriosis, and further received payment for consultancy fees from Gesynta and Joii. Andrew Horne has received payment for presentations from Theramex and Gedeon Richeter.

Ulrik Bak Kirk's institution (Aarhus University) has received grant funding from the European Union's Horizon 2020 research and innovation program to coordinate the project Finding Endometriosis using Machine Learning (reference: FEMaLe/101017562).

Rebecca Mawson has received payment for consultancy from Roche Diagnostics to assist in the early development of a blood diagnostic biomarker for endometriosis.

Sharon Dixon is an unpaid voluntary member of Endometriosis UK medical advisory panel.

The remaining authors have declared no competing interests.

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Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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