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This submission of evidence will address the topic of women's reproductive health via the specific condition of endometriosis. It will lay out the facts about the disparities and barriers in the treatment and diagnosis of endometriosis, and make the health, education, and scientific case for greater training, awareness, and investment in endometriosis and reproductive health more widely.

Together, the authors of this submission recently co-convened a high-profile multidisciplinary conference, [Reframing Endometriosis](#), from which many of the recommendations are derived. The conference, funded by the Wellcome Trust and British Academy, brought together national and international leading authorities on endometriosis, including the heads of national and international endometriosis patient organisations, clinicians, and bio(medical), clinical and social science researchers.

In summary

- Endometriosis affects 1 in 10 people assigned female at birth.
- Symptoms include severe pelvic pain, painful periods, pain during sex, and infertility.
- Serious issues exist around access to diagnosis and treatment, including women being told excessive pain is normal, or an unwillingness to seek treatment.
- The average time between onset of symptoms and diagnosis is around 8 years, though it can take up to 12.
- These barriers to diagnosis largely arise from, and are enforced by, social stigmas and taboos around discussion of menstruation, reproductive organs, and women's experiences of pain.
 - For instance, a lack of understanding about the age where symptoms may present means that, although up to 44% of patients first report symptoms before the age of 20, only 3.5% receive a diagnosis before this age.
- This lack of understanding and awareness is not limited to a single area: it pervades educational and healthcare settings, as well as society more widely.
 - In England, only 8% of teenage girls know what endometriosis is (compared to 24% in Australia), but 86% wanted to learn about it and 83% want boys to learn about it too.
 - Over a quarter (27%) of teenage girls in England do not know if their periods are 'typical' or 'normal' and pain was the most common reason 23% of girls missed school due to their periods.¹
- Women from marginalised racial and ethnic populations face additional barriers in the form of systemic racism, poor access to care, and a lack of peer support networks and charities compared to white women.
 - The same is true of patients who may not fit heteronormative identities.
- Characterisation of endometriosis solely as a 'women's disease' is harmful:
 - It ignores that the disease can also affect gender diverse people, and – in rare cases – cisgender men.
 - It reinforces a notion that endometriosis is an exclusively gynaecological condition, when in fact it is a whole-body chronic condition (something key to improving understanding and diagnosis).
 - And a reframing of endometriosis is needed to shift away from the historic focus on fertility/infertility that patients report doctors prioritise over their experiences of pain.

- Changes in policy and practice are needed to redress the imbalance in how reproductive health issues are discussed and treated.
- These include:
 - **Clear strategies for education, in both schools and healthcare settings.**
 - **Healthcare plans that specifically address inequalities in access to care and treatment.**
 - **Practical interventions, such as separate waiting rooms for endometriosis patients, and general gynaecology and obstetrics.**
 - **Addressing the funding imbalance for endometriosis, compared to other chronic conditions such as asthma.**
 - **Employment protections for those who require time off due to endometriosis.**

In detail

A note on terminology: we refer mostly to patients as ‘women’, but endometriosis also affects transgender and non-binary individuals, and in rare cases cisgender, biological men. Indeed, as we will discuss, characterisation of endometriosis as a “women’s disease” is harmful, and can create additional barriers to diagnosis and treatment on top of those already experienced by patients.

Endometriosis – a missed disease

Endometriosis is a chronic inflammatory condition that affects an estimated 10% of all people assigned female at birth. The condition causes tissue similar to the lining of the uterus to grow elsewhere – including on the ovaries, intestines, bladder, and bowels. Symptoms can include severe pelvic pain, painful periods, pain during sex, infertility, and fatigue.

Patients living with endometriosis face inconsistencies in its diagnosis and management. It is relatively ignored in government policy and research funding – both in the UK, and globally. This absence of knowledge is a result of, and contributes to, structural, cultural, and political processes which undervalue the experiences of women, menstruation, and pain.

This combination of a lack of awareness, research, and understanding around endometriosis has led some to describe it as a ‘missed disease’.²

Diagnostic delays

This section draws on evidence in a book by Dr Griffith; Healers and Patients Talk – Narratives of a Chronic Gynecological Disease.³

In the UK, the average time to diagnosis from onset of symptoms is around 8 years⁴, but can take up to 12⁵, or even 20³ years. This delay causes patients to struggle with continued pain, in isolation, and with feelings that they are ‘weak’ compared to other women, often doubting themselves in the process. The reasons for diagnostic delay in endometriosis are multiple,

and it has been linked to both doctors/healthcare professionals and patients, although much of the delay occurs after the patient has sought care.⁶

Patient-related delays are largely related to stigma around the discussion of menstruation, sexual intercourse, and childlessness, which prompt patients to avoid seeking help. These will be discussed in more detail in the next section of this submission, but one key finding from previous research is the delay in diagnosis of endometriosis because of normalisation of menstrual pain.^{7,8} With pain during periods seen as normal, women may also normalise or dismiss one another's menstrual pain.⁴ Patients have linked this menstrual communication taboo to being unable to speak about endometriosis and their symptoms as they relate to menstruation.

This represents a barrier to medical care as patients and serves to increase diagnostic and treatment delays ultimately increasing stress and worsening endometriosis symptoms.

Another stigma which creates a barrier to diagnosis and treatment is childlessness. While some patients with endometriosis cannot have children, they still want to. Other patients do not want children but feel that their biomedical treatment has been in large part linked to the assumption that they will want children at some point. Even if they have decided not to have children, it is often assumed by medical professionals that they may change their minds in the future.

Stigma relating to voluntary childlessness appears to originate from the medical professionals themselves and directly impacts clinical care. **Patients report that medical professionals took their symptoms more seriously when patients were looking to get pregnant.**

Patients also felt medical professionals did not believe or trust women's decisions about having children or not. For them, medical decisions that could have improved their quality of life were not taken, in order to preserve fertility – regardless of their desires.

These women had no intention of getting pregnant and expressed frustrations that some surgical treatment options that might have relieved endometriosis symptoms but resulted in sterilisation were denied to them.

Women stated that medical professionals expected them to change their minds, as if it were not possible for a woman to prefer or choose childlessness. The stress linked to the social stigma of childlessness through infertility, or to reactions to voluntary childlessness, likely increases these women's inability to have children if they do wish to, since it has been shown that stress hormones interact with hormones responsible for normal ovulatory cycles.⁹ Women with endometriosis who encounter less than understanding and supportive responses to their decisions and experiences with fertility from health professionals and friends or family members may in fact experience more endometriosis symptoms, as the resulting stigma-driven stress has an impact on their reproductive hormones.

At the medical level, eight factors may contribute to delays in diagnosis:

1. The normalisation of pain by GPs and other health professionals such as nurses in school, primary care, and secondary care settings, and gynaecologists.
2. The suppression of symptoms through medical treatment.

3. The use of investigations such as scans or measurement of non-specific biomarkers to rule out endometriosis, despite their inability to do so.
4. The primary method of diagnosis of endometriosis remains laparoscopy (keyhole surgery). Surgical procedures (particularly in endometriosis) have long waiting times and clinically may be avoided due to the elevated risks a surgery may pose to patients. In addition, the identification of endometriosis cells requires a high level of training due to the variety of ways endometriosis cells can look. This means patients may have been seen and evaluated for endometriosis through surgery, but the endometriosis not identified. Biopsy and visualisation through microscopy (seeing it under a microscope) requires doctors to be able to identify potential endometriosis spots.
5. Surgical identification of endometriosis – may require multi-disciplinary involvement as endometriosis has been shown to impact most organ systems. Involvement of the bladder and the intestines is particularly common. But, as currently the training of the various surgical subspecialties is largely separate, this often means increased waiting times for those patients with the most complicated cases as patients would need to be seen/evaluated by multiple doctors/clinics.
6. Long waiting times including for any referrals to specialist care (gynaecology) and additional long waiting times for surgical diagnosis and treatment of endometriosis. Waiting times can be further increased if
7. Symptoms of endometriosis can be non-specific and may relate to other organ symptoms outside of traditional gynaecology. Commonly, patients may suffer from involvement of endometriosis in the bladder and have urology symptoms that would need to be evaluated by urologists. Similarly, involvement of endometriosis in the intestines may cause IBS-like symptoms. Teasing out whether these types of symptoms are due to endometriosis or are linked to co-morbid conditions that are commonly seen with endometriosis such as IBS or interstitial cystitis can be complicated and may require patients to see multiple specialists.
8. There are also some key considerations around common co-morbidities relating to endometriosis such as interstitial cystitis, IBS, certain gynaecological cancers, and heart disease (which has been shown to be increased in endometriosis patients).

In addition, the belief by many clinicians that endometriosis does not present in teenagers may also increase time to diagnosis¹⁰, with as many as 44% of women reporting symptoms of endometriosis to their doctors before age 20 and only 3.5% diagnosed before reaching 20 years of age.¹¹

Patients report negative experiences in primary care with GPs adopting two main negative attitudes. The first was that patients' symptoms were either dismissed as period pain or as being psychological in origin. The second attitude reported by patients was the normalisation of symptoms which included being told that menstrual pain was normal and that "*you are unlucky to suffer from bad periods*".³ Such forms of dismissal of symptoms as psychiatric in origin or as 'normal' are commonly reported in endometriosis care.

Catalysts allowing women to receive the endometriosis label successfully, termed 'circuit-breakers'⁶, include:

1. When other people such as partners or mothers encouraged help-seeking.
2. When their social roles were significantly disrupted.
3. When they experienced biographical disruption through, for example, inability to be a mother.

4. When “women’s confidence in their interpretation of their embodied experience [held] greater power than the medical construction of their illness”.

These ‘circuit-breakers’ allowed women’s recognition that what they were experiencing was problematic and prompted their persistent search for care.

Stress, stigma, and endometriosis

Research led by Dr Griffith – involving interviews and questionnaire responses from both women with endometriosis, and gynaecologists – found that stress and stigma around endometriosis combine to have a greater negative health impact than would otherwise occur (a ‘syndemic’ model).^{12,13} Through a series of biological pathways, stress contributes to worsening endometriosis symptoms, which in turn increase stress. For instance, rat models of endometriosis have demonstrated that higher levels of stress resulted in an increase in the size and number of endometriotic cysts and vesicles.¹⁴

Combined with gendered stigma around endometriosis, which also increases stress, these pathways form the endometriosis-stress-stigma syndemic.

In the interviews and questionnaire responses, women reported experiencing communication taboos related to stigma associated with three aspects of endometriosis: menstruation, dyspareunia (genital pain before, during, or after sexual intercourse), and involuntary childlessness. **These taboos increased levels of perceived stress in women with endometriosis.**

Participants also reported that the stigmatisation of endometriosis leads women to hide their illness, leading to a perception that they are “*suffering in silence*”. This ultimately exacerbates their disease progression, and the severity of symptoms. They reported clear lines between who could, and could not, be told certain information, as well as different levels of information, drawing a distinction between general understanding of endometriosis, and details about their specific experiences of the disease.

A majority of women in the study reported feeling unable to discuss the condition, stating; “*It’s not something you talk about, is it?*” This was linked to a perception of endometriosis as a “*women’s disease*”, or about “*women’s bits*”, with one participating saying:

“I struggled socially in my teens because I didn’t go out as much as my friends. It also made things tricky with gatherings if I’d had to cry off certain activities and been unable to explain why because I don’t necessarily know people that well, or because middle-aged men were involved who would be uncomfortable with being told about “women’s things”! Boyfriends sometimes found it tough too, if I didn’t feel much like being intimate at times – I’m lucky that my husband is very patient and understanding.”

Women’s suffering is seen as acceptable, thus normalising the stress-producing stigmatisation of their lived experiences. **This is a form of structural violence – because endometriosis is linked exclusively to women, broader society does not want to discuss it, ultimately worsening the experience of the disease.**

This extended to women’s sexual lives as well. Women who participated in the study discussed their experiences of pain during sex, with 10 women saying they felt pressure to pretend to enjoy the sex. This pressure was not necessarily from their male partners, but

rather, a result of an unspoken society norm to conform to their expected role as sexual partners. One woman said:

“I’m not sure if I should tell my boyfriend that it hurts again to have intercourse. I’ve just been putting up with it, I lock myself in the bathroom afterwards and have a bath which helps a bit but... I don’t think he knows. I want the lights off so he won’t see the tears.”

Other women had similar experiences, or feared that their partners would leave them because of decreased sexual activity. It was not uncommon for women to feel that their inability to have or enjoy sex “challenges my femininity”. This stigma extended to seeking medical help, with many reporting going to the doctor with the intention of asking about pain during sex – but leaving without approaching the topic. One participant said “*It was like trying to talk about sex with my father*”.

However, there are some signs that this is changing, with women who participated in the study – as well as those who take part in online forums for endometriosis patients – showing an increasing confidence in recognising and challenging the taboo around reproductive health issues. One participant in the study said:

“I have no “fear” anymore. If people are uncomfortable I don’t care anymore. I don’t want anyone lese to have to go through what I went through. So I talk about it. If I tell just one person about endometriosis then maybe that knowledge will trickle down. If just one person had talked about endometriosis at work for example during lunch I might have thought “Oh, I have that” I have that even had I not wanted to join in the conversation. Or if someone talked about their periods and those were normal I would thought oh is my period not normal then. Maybe I would have gone to the GP sooner?”

While encouraging, the onus should not be on women to challenge these barriers. **Change must be led from the top, with policymakers and public health officials addressing the stigma and taboo around endometriosis, and reproductive health in general, through targeted training and awareness campaigns.**

Ethnic, socioeconomic, and LGBTQ+ inequalities in care access and quality

Endometriosis has long been considered a disease of white, career women and in the past was known as the ‘career-women’s disease’. The characterisation of endometriosis as a disease of white, educated, and heterosexual women is problematic and misleading.

As highlighted above, the average waiting time for a diagnosis of endometriosis is between 8 and 12 years. However, for Black women, this picture is even worse, with research showing women from Black ethnic backgrounds are 50% less likely to be diagnosed with endometriosis than white women.^{15,16} A study from the US in 2021 found that, when they are diagnosed, Black women receive their diagnosis on average two and a half years later than white women.¹⁷

Analysis by Drs Weckesser and Griffith has highlighted barriers to care for Black women which may be a factor in lower diagnosis rates of endometriosis, including¹⁸:

- A lack of menstrual health education in schools.
 - This affects women’s ability to recognise symptoms of medical conditions, and limits their capacity to advocate for their own care.

- Poor access to menstrual and reproductive healthcare, including long waiting times – made worse by the COVID-19 pandemic.
- A lack of funding and research evidence relating to menstrual health and care in marginalised racial and ethnic communities.
 - This limits the development of health policy, and the implementation of best practice in clinical care.
- Limited charity/peer network support for Black women around reproductive health.

This research adds to a [wider body of evidence](#) on barriers to gynaecological care, systemic racism in the medical field, and other factors which combine to limit diagnoses for Black women. For example, a survey in the UK in 2022 found that almost two-thirds of Black respondents had experience prejudice from doctors and other staff in healthcare settings, rising to three-quarters among respondents aged 18 to 34.¹⁹ The survey also found that Black women experience dismissive attitudes towards their pain, which is a result of a misguided stereotype of Black women as being somehow more resilient to pain – an unfounded idea which has its roots in 19th Century medical experiments on slaves in the United States.²⁰

The outcome is that Black women may suffer with endometriosis for longer before getting a diagnosis and treatment – if at all.

There are specific considerations in endometriosis care for subpopulations of patients that need to be addressed. Patients whose identities do not fit heteronormative notions struggle to feel welcomed or comfortable in settings set up for ‘women’s health’, making a clinic visit something difficult and often triggering. Similarly, patients who are not having heterosexual penetrative sexual intercourse, are likely to struggle to discuss pain linked to sex (a main symptom of endometriosis), meaning that this symptom may not be addressed in their clinical care.²¹

Recommendations for policy and practice

Practical changes in clinical settings

Often, waiting areas for patients requiring an ultrasound or other scan to diagnose endometriosis are shared with general gynaecology and obstetrics, meaning that endometriosis patients may wait in the same space as patients who are currently pregnant. Consider, for example, a patient who has recently been diagnosed with endometriosis and has recently been told they may not be able to have children.

Patients report this as distressing, potentially triggering, and stressful, given that endometriosis is linked to infertility.

Patients may recall these negative experiences of care going forward, which may cause patients to hesitate to report new or different pain symptoms that may require evaluation. Such experiences may contribute to delayed treatment of endometriosis, but may also limit evaluation of other causes of new pain (for example a ruptured ovarian cyst, ovarian torsion, or appendicitis – all of which may present similarly to an endometriosis exacerbation).

We suggest that this is something that can be quite easily addressed by providing 2 different waiting areas for ultrasound/scans in gynaecology/obstetrics.

- Scans can take place in the same clinic rooms, but patients should be called in from two separate sections.
- This would require a quick check as to why the patient is requiring an ultrasound, but this is something that would normally be done in clinical care anyway.

Similarly, for endometriosis patients requiring a longer stay in hospital, they are often placed on the same ward as obstetrics patients. As stated above, this is particularly difficult given the link of endometriosis to infertility. But, unlike the example above of an ultrasound scan waiting area, patients may be admitted to hospital for several days, particularly if they are recovering from surgery for endometriosis including a hysterectomy (while hysterectomy is known not to cure endometriosis, it is still sometimes used as a treatment).

Additionally, being in the same room as a patient who have recently given birth will likely overhear many congratulating phone calls or visits and may additionally see the baby wheeled in several times a day. This can be extremely upsetting for patients and can impact an already stressful experience particularly post-surgery.

We therefore suggest that a policy be put in place to prioritise the separation of obstetrics and gynaecology patients on inpatient wards to avoid these added stresses to patients.

Referral systems

Diagnosis and treatment delays in endometriosis are largely impacted by long waiting times within the NHS. There are several key moments when patients may face long waiting times:

1. GP referral – to specialist care (may be more than one – but this is often done one after the other as opposed to concurrently)
2. Referral between specialists (if this is only done at the point of the first visit to a specialist, this may push back patient care to nearly a year before any surgical diagnosis or treatment has been done)
3. Surgical waiting list (for both diagnosis and treatment)

We therefore suggest that in the short term referrals to specialists for endometriosis care be done concurrently to the various specialists (particularly gynaecology, urology, and gastroenterology) by GPs.

In the long term, we suggest referrals from GPs be sent directly to a centralised endometriosis clinic with direct/internal access to related subspecialty care.

A specialised endometriosis clinic would then serve as a central pool of all endometriosis-related sub-specialties where patients would be attended to by all the necessary specialists in a single extended appointment. Breast cancer care is a good example of such a model of clinical care.

Education and awareness

As discussed, many of the additional burdens placed on endometriosis patients arise from a lack of awareness – on both their part, and that of healthcare staff. In turn, this is a result of social taboos on discussion of reproductive health. We suggest the following interventions across health and education policy, and research practices.

Fuller menstrual health education should be provided in schools, to set the stage for later life.

- This education should provide an overview of the signs and symptoms of menstrual abnormalities, such as severe period pain or heavy bleeding.
- It should also recognise intersectionality and consider the lived experiences of marginalised populations, and equip women with knowledge of when to advocate for their own care – particularly when symptoms are disregarded by clinicians.

Mandatory training for healthcare professionals and those who teach about menstrual health in schools, including the historical development of current menstrual health knowledge and attitudes, and the impact of these on people who menstruate.

- This education should provide an overview of the signs and symptoms of menstrual abnormalities, such as severe period pain or heavy bleeding.
- This should include a particular focus on racially marginalised populations and other populations historically left out endometriosis care such as adolescents and post-menopausal women.
- This should focus on the multi-organ system involvement of endometriosis and should highlight the various symptoms of endometriosis.
- Specialist clinics need to be funded to enable access to diagnosis and care.
 - The number of specialist clinics across the country should be increased to allow patients to access care locally or regionally.
 - The number of specialist health professionals (including nurses and specialists from various relevant clinical backgrounds such as gynaecology, gastroenterology, urology, pain specialists etc.) needs to be increased, alongside associated funding.

An increase in funding and support for research on non-invasive diagnostic methods, the prevalence and impact of menstrual health related conditions, with a particular focus on women historically left out of the endometriosis diagnosis such as women from racially marginalised populations, adolescents, post-menopausal women, and non-binary/transgender patients.

- Without a solid research base, the development of health policy and clinical best practice will be limited at best.
- Research and treatment should be approached comprehensively – that is with integrated specialisms and a consideration of the role of GPs and primary care:
 - Primary care, gynaecology, rheumatology, urology, gastroenterology, fertility specialist, pain specialist, cardiology must all be accounted for.
 - And of particular importance is mental health care, with great consideration taken to ensure poor mental health is not framed as a contributing factor, but because of the life-altering consequences of chronic disease and frequent resultant co-morbidity of depression and anxiety.

A recognition by policymakers and public health officials of the systemic barriers to racially marginalised women in accessing care.

- Scotland's [Women's Health Plan](#) seeks to address system inequalities that create barriers to care, and should serve as a model for a UK-wide strategy.

Endometriosis should not be treated/classified as solely a gynaecological disorder – and the damage done from it having been classified as such should be addressed and rectified.

- Rather, it is a chronic pain disorder that is systemic and inflammatory.
- Identifying endometriosis as the multi-system/systemic disease that it is should help decrease diagnosis and treatment waiting times.
- The damage done includes dearth of research funding, stigma shame and taboo, marginalization of women's health issues as "niche", and erasure of trans and non-binary people.

Many people experiencing endometriosis, or endo-like symptoms, self-manage. This is inevitable given the chronic nature of the condition and the lack of institutional support.

- Self-management should be adequately supported with policies like:
 - Employment protections for those needing extra time off, potentially including financial support through established long-term sick leave mechanisms.
 - Menstrual leave/disability leave (though these terms are contested).

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