

## Written evidence from Professor Kay Marshall, University of Manchester [WRH0009]

### The University of Manchester: response to the Women and Equalities Committee inquiry on women's reproductive health

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- *Supported by Policy@Manchester*

#### In summary

This submission is based on expertise from The University of Manchester, with partners from across Greater Manchester, and the wider North West. This submission will primarily address endometriosis, both as a specific gynaecological condition, and the issues associated with its diagnosis and treatment among women and young girls. It will also cover wider issues that exist with how reproductive health – particularly periods – are treated in education and medicine. Lastly, it will discuss ethnic inequalities in reproductive health, and provide recommendations for policy and practice.

- Endometriosis affects around 190 million women and girls globally, and is the second most common gynaecological condition in the UK.
- It can result in severe pain throughout the monthly cycle, as well as during periods, sexual intercourse, and bowel movements, and some women and girls present with complex pelvic pain.
- In 2012, the cost of endometriosis to the UK economy was estimated at £8.2 billion – this figure is likely higher today.
- Women and girls living with endometriosis can experience significant delays in diagnosis – some women wait up to 11 years.
- This is partly as a result of few conclusive ways to diagnose the condition, with a surgical evaluation the preferred route.
- However, it is also partly a result of a lack of awareness of the condition from GPs and other medical professionals, with some girls being told they are too young to have endometriosis, or that the pain they are experiencing is a normal part of periods.
- There are wider issues with awareness of period health in medical and educational settings – the experiences of girls in schools are mixed with regard to how periods are treated.
- This is also reflected in the comparatively low level of research funding for medical conditions that primarily, or exclusively, affect women.
- For women from ethnic minority backgrounds, overlapping barriers to medical care, combined with socio-economic factors, create worse outcomes for reproductive health, including higher rates of death in childbirth, and stillbirths.
- Changes are needed in training and education of health practitioners, to highlight the complex symptoms of endometriosis and reduce the stigma associated with reproductive health conditions.

## In detail

Endometriosis is a gynaecological chronic condition characterised by the growth of uterine-like tissue outside of the uterus.<sup>1</sup> It affects approximately 190 million women and girls globally, and its prevalence in women with infertility can be as high as 30-50%. Endometriosis is the second most common gynaecological condition in the UK.<sup>2</sup> The cost to the UK economy was estimated to be around £8 billion in 2012, as a result of healthcare costs and loss of ability to work.<sup>3</sup>

Clinical symptoms of endometriosis are varied, with people experiencing no pain, some with painful periods (dysmenorrhoea), pain with intercourse (dyspareunia), pain with bowel movements (dyschezia), and some with a complex pelvic pain presentation with multiple pain complaints.<sup>4</sup>

## Experiences of being diagnosed and treated for endometriosis

Across the world, and in the UK, women face significant delays and obstacles in getting diagnosed for endometriosis. These delays can seriously affect treatment, chronic pain, and fertility outcomes. They also reduce quality of life for those suffering from endometriosis.<sup>5</sup> **In the UK, the average time from onset of symptoms to diagnosis of endometriosis is 8 years<sup>6</sup>**, due in part to the lack of an acceptable, objective, and non-invasive test to identify, and predict the severity of, endometriosis.

Scans, blood tests and internal examinations are not a conclusive way to diagnose endometriosis. A surgical evaluation – laparoscopic surgery – supplemented by a histological review remains the preferred way to diagnose endometriosis. In turn, this causes delays in diagnosis for many adults and adolescents across the world.<sup>7</sup> The surgery relies on the experience of the surgeon to adequately examine and accurately diagnose the disease.<sup>8</sup>

Other tools for diagnosis include ultrasound, and magnetic resonance imaging (MRI). Ultrasound has been found to be 93% specific in the diagnosis of endometriosis<sup>9</sup>, and represents a readily available, relatively inexpensive, option for initial investigation. However, its interpretation relies on the experience of the practitioner.<sup>10</sup>

MRI, on the other hand, can be reviewed by different radiologists, and expert opinion sought without the need for repeat examination.<sup>11</sup> It has shown similarly high specificity for the diagnosis of

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<sup>1</sup> Linda C Giudice and Lee C Kao, “Endometriosis”, *The Lancet* 364, no. 9447 (November 2004): 1789-99.

<sup>2</sup> *Endometriosis Awareness North*. [Accessed here](#).

<sup>3</sup> Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Human Reproduction*. 2012 May 1;27(5):1292–9.

<sup>4</sup> Paolo Vercellini, Paola Viganò, Edgardo Somigliana and Luigi Fedele, “Endometriosis: pathogenesis and treatment”, *Nature Reviews Endocrinology* 10 (December 2014): 261-275.

<sup>5</sup> Martha Grace Cromeens, Erin T. Carey, Whitney R. Robinson, Kathleen Knafl and Suzanne Thoyre, “Timings, delays and pathways to diagnosis of endometriosis: a scoping review protocol”, *BMJ Open* 11, no. 6 (2021).

<sup>6</sup> APPG on Endometriosis Inquiry Report 2020. Endometriosis in the UK: time for change (October 2020) [Internet]. Patient Safety Learning - the hub. [Accessed here](#).

<sup>7</sup> Sanjay K Agarwal, Charles Chapron, Linda C. Giudice, et al, “Clinical diagnosis of endometriosis: a call to action”, *American Journal of Obstetrics and Gynecology* 220, no. 4 (April 2019): 354.

<sup>8</sup> Kiesel L, Sourouni M. Diagnosis of endometriosis in the 21st century. *Climacteric*. 2019 Jun;22(3):296–302.

<sup>9</sup> Guerriero S, Ajossa S, Orozco R, Perniciano M, Jurado M, Melis GB, et al. Accuracy of transvaginal ultrasound for diagnosis of deep endometriosis in the rectosigmoid: systematic review and meta-analysis. *Ultrasound Obstet Gynecol*. 2016 Mar;47(3):281–9

<sup>10</sup> Piessens S, Edwards A. Sonographic Evaluation for Endometriosis in Routine Pelvic Ultrasound. *J Minim Invasive Gynecol*. 2020 Feb;27(2):265–6.

<sup>11</sup> Saba L, Sulcis R, Melis GB, de Cecco CN, Laghi A, Piga M, et al. Endometriosis: the role of magnetic resonance

endometriosis, and is particularly useful pre-operatively to identify the extent of the disease, and help surgeons to plan for surgical intervention. However, the UK suffers from significant regional variation in access to MRI machines, both as result of a shortage of machines themselves, and a shortfall in workforce.<sup>12</sup>

### *Medical practitioners' understanding of endometriosis – or lack thereof*

While 8 years is the average delay, diagnosis of endometriosis can take up to 11 years. This can be due to personal and societal barriers, and the actions and training of healthcare professionals. For example, stigma surrounding discussing menstrual problems, and society viewing menstrual pain as normal, may have contributed to delayed diagnosis.<sup>13</sup> **There are also reports of GPs brushing off concerns surrounding painful periods as well as a general lack of knowledge and inadequate training on endometriosis within health services.**<sup>14</sup>

From our experience talking to women and girls affected by endometriosis at an Endometriosis Awareness North event in March of this year, we have found that young women in particular have struggled to get a diagnosis from their GPs, and are told that they are too young to have endometriosis – despite age not being a diagnostic criterion. **Indeed, a lack of understanding from GPs and other healthcare providers is a common theme that we encounter when speaking with endometriosis patients.**

A 2016 Danish study found that the working culture of nurses affected their perception of endometriosis patients, and where they prioritised them in terms of administering care. To some nurses, endometriosis patients were perceived as making “excessive demands for care” that nurses neither could nor would meet.<sup>15</sup>

Delays in diagnosis and treatment can lead to chronic pain. If it goes untreated, it may contribute to dysregulation of the peripheral and central nervous system. Over time, untreated chronic pain can increase the risk of developing abnormal pain referral patterns.<sup>16</sup>

**The assumption that painful periods are normal, and the lack of knowledge and training of healthcare professionals surrounding endometriosis, are all factors influencing delays in diagnosis and should be addressed individually.**

## **The impact on education, and wider issues with awareness of reproductive health**

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imaging. *Acta Radiol.* 2015 Mar 1;56(3):355–67.

<sup>12</sup> Merriel S W D, Francetic I, Buttle P. Direct access to imaging for cancer from primary care *BMJ* 2023; 380 :e074766 doi:10.1136/bmj-2023-074766

<sup>13</sup> Jessica Freeborn, “Why does receiving a diagnosis for endometriosis take so long?”, *Medical News Today* (July 2023). [Accessed here](#).

<sup>14</sup> Pettersson A, Berterö CM. How Women with Endometriosis Experience Health Care Encounters. *Womens Health Rep* (New Rochelle). 2020;1(1):529–42.

<sup>15</sup> Back, AM *et al*, “Practices and Attitudes Concerning Endometriosis Among Nurses Specializing in Gynecology”, *Glob Qual Nurs Res* 2016

<sup>16</sup> Pamela Stratton and Karen J. Berkley, “Chronic pelvic pain and endometriosis: translational evidence of the relationship and implications”, *Human Reproduction Update* 17, no. 3 (May-June 2011): 327-346.

The high levels of pain associated with endometriosis inevitably affects young women's ability to focus on their education. Endometriosis UK has published testimony from patients who have lived with endometriosis since their teens<sup>17</sup>:

*“Having endometriosis throughout my education was difficult. In school and college I suffered from heavy, irregular, painful periods. Often I would pass out and be sick when I came to but I was very shy about periods and assumed this was a normal reaction. I remember being in a Science lab and telling the teacher I needed to go to see the nurse as I was going to pass out. Her response was “wait until class has finished”! So unsurprisingly I passed out in class and hit my head on the table! I think school would have been easier to manage if I could have spoken to someone about my symptoms, maybe the school nurse. At the time my GP was dismissing what I was going through as normal.”*

There are also issues with awareness of how periods affect education in general. In a meeting earlier this year, we learned that in some schools, girls had difficulties accessing toilets between lessons. And in one school, girls were made to carry a 'red card' to go to the toilet if their period started before the lesson ended. **The Committee does not need to be told how mortifying this would be for a girl experiencing menstruation, potentially for the first time, and underscores the need for greater emphasis on period health in schools.**

Moreover, women's health research lacks funding. Conditions that create the highest burden, such as depression and headaches, tend to affect women more (at least 60% of people with the disease are women). **Diseases that are unique to women, or affect women more – such as migraines, endometriosis, and anxiety disorders – are underfunded compared with the burden they create on the population.** The degree of underfunding or overfunding is also different for the groups of conditions. This means that female-dominant diseases that are underfunded are more severely so.<sup>18</sup>

The UK Medical Research Council (MRC) spent £96 million on women's health (which includes preterm birth and perinatal health, and long-term studies such as the Million Women Study) between 2014 and 2019. This figure is roughly equivalent to its spending on cardiovascular disease alone in the same period (the MRC spends about £325 million a year on health research overall). **Women's health funding should cover more than just female-specific conditions.**

Furthermore, there is evidence of a serious historical bias within medical research. Indeed, women have been under-represented in parts of the medical research pipeline, such as clinical trials. Efforts to rectify this omission have been ongoing with increasingly more women being included in clinical trials. However, we need to ensure that women are represented in proportions that match the prevalence or burden of disease.<sup>19</sup>

**Finally, the impact of the media on women's health has not always been positive, especially with respect to hormonal contraceptive pills.** For example, the 1995 'pill scare' is said to have had a negative impact on public health. Data suggests a strong association between the pill scare and a substantial increase in the number of unintended pregnancies. Nearly 50% of combined pill users claimed their pregnancy resulted from panic-stopping because of media-promoted fear of health risks, especially "clots".<sup>20</sup> This resulted in an increased cost in births and abortions to the NHS, estimated at about £21 million for maternity care and £46 million for abortion provision.<sup>21</sup>

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<sup>17</sup> Endometriosis UK, "THE IMPACT OF ENDOMETRIOSIS ON A WOMAN'S EDUCATION". [Accessed here.](#)

<sup>18</sup> Kerri Smith, "Women's health research lacks funding – these charts show how", *Nature* (May 2023). [Accessed here.](#)

<sup>19</sup> Jecca R. Steinberg, *et al*, "Analysis of Female Enrollment and Participant Sex by Burden of Diseases in US Clinical Trials Between 2000 and 2020", *JAMA Network Open* 4, no. 6 (June 2021).

## Inequalities in reproductive health

It is a tragically well-recognised fact that Black women are four times more likely to die in pregnancy or childbirth in the UK compared with white women, while South Asian women are twice as likely to die as white women.<sup>22</sup> Stillbirth is also twice as likely to occur in Black women compared to white women.<sup>13,23</sup>

**While access to primary care across ethnic groups is fairly equitable, it is not the case when looking at access to other health services.** Indeed, ethnic minority patients report a poorer experience of using some healthcare services. Thus, healthcare services need to be aware of the specific health care needs, risk factors, and treatment requirements in different communities – and ensure services are culturally sensitive and adapted.

**These inequalities and disparities in healthcare access reflect themselves in access to gynaecological services too.** Some ethnic minority patients may be less inclined to consult specialists for reproductive health issues, which leads to delays or even prevents diagnoses and treatments.

## Recommendations for policy and practice

There is a pressing need to address the significant delays in diagnosis and treatment of endometriosis, which arise through a number of – often overlapping – factors.

Stigma surrounding menstrual pain and women's reproductive health should be addressed through education and training, so women are comfortable enough to address any issues or queries they may have with their GPs. Further training opportunities for GPs and healthcare professionals should be provided as to equip them with the most up-to-date information about the illness and enable them to give informed and relevant advice.

The need for training goes beyond the medical profession; teachers must also be educated on the impact of reproductive health, including endometriosis, on children's education. In Australia, EndoZone have produced resources for use by teachers<sup>24</sup> – the Department for Education should work with Ofsted and other bodies to develop similar resources for use in the UK.

Research into endometriosis and other gynaecological conditions should be representative of the number of women affected by them. It might also be useful to assign funding based on burden so that medical conditions affecting women are effectively researched.

There are wider ethnic inequalities in healthcare that are reflected in gynaecological conditions, and these should also be addressed to ensure that no woman is left behind.

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<sup>20</sup> Felicity Goodyear-Smith and Bruce Arroll, "Termination of pregnancy following panic-stopping of oral contraceptives", *Contraception* 66, no. 3 (September 2002): 163-167.

<sup>21</sup> Ann Furedi, "The public health implications of the 1995 'pill scare'", *Human Reproduction* 5, no. 6 (November-December 1999): 621-626.

<sup>22</sup> Veena Raleigh, "The health of people from ethnic minority groups in England", *The King's Fund* (May 2023), [Accessed here](#).

<sup>23</sup> Anita Sharma "What is England's women's health strategy hoping to achieve?", *GP Online* (February 2022), [Accessed here](#).

<sup>24</sup> EndoZone, "How you can support students with endometriosis". [Accessed here](#).

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