Written Evidence from the Menstrual Health Coalition [WRH0020]

Menstrual Health Coalition

The Menstrual Health Coalition (MHC) is a coalition of patient and advocate groups, leading clinicians and individuals who have come together to discuss and make recommendations around menstrual health. The coalition is supported by the life sciences industry.

The purpose of the MHC is to raise the profile of menstrual health on the political and policy agenda, to reduce the stigma around talking about periods, and campaign for change to help women adversely affected by their menstrual health.

Inquiry Response

1. What constitutes healthy periods and reproductive health?

The definition of healthy periods and reproductive health is a complex and individual matter, meaning diagnosis is often subjective. The NHS defines heavy menstrual bleeding (HMB) as needing to change your pad or tampon every one to two hours, and that last longer than 7 days.[1] HMB may be caused by processes that interfere with normal endocrine, paracrine or haemostatic functions of the endometrium – the innermost lining layer of the uterus.[2] As such, conditions associated with HMB include uterine pathologies (polyps, fibroids, adenomyosis, and uterine cancer) and endometrial pathologies (endometriosis, endometrial cancer).

HMB is one of the most common reasons for gynaecological consultations in both primary and secondary care and affects a women's physical, psychological and social health and wellbeing. One in five women experience heavy periods and one in twenty women aged 30-49 present to primary care each year.[3]

Focussing on endometriosis and polycystic ovary syndrome (PCOS), there is a lack of research into the occurrence of these conditions and the impact no a patients quality of life, however through the Department of Health and Social Care's Major Conditions Strategy we have seen a big focus on other long-term condition areas such as diabetes and asthma. The MHC believes more research and data is needed into endometriosis, PCOS and other menstrual health conditions to better understand the impact these conditions have on inequalities.

Despite impacting more than one in ten women in the UK, Adenomyosis has been overlooked. Adenomyosis is a condition where cells of the lining of the women (endometrium) are found in the muscle wall of the womb (myometrium). Symptoms include heavy, painful and/or irregular periods, changes to bowel movements and pain during or after sex.

The MHC believes that the wider impact on women with gynaecological conditions needs to be considered, such as the wider mental health and physical impacts beyond the primary symptoms.

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[1] NHS England, 'Heavy periods', *NHS England,* (2023). Available at: https://www.nhs.uk/conditions/heavy-periods/.
[2] Dharani K Hapangama and Judith N Bulmer, 'Pathophysiology of Heavy Menstrual Bleeding', January 2016; 12(1): 3-13.
[3] Royal College of General Practitioners, 'Menstrual Wellbeing Toolkit', *Royal College of General Practitioners*. Available at: https://www.rcgp.org.uk/menstrualwellbeingtoolkit.

Linked to this is the lack of clear data that would demonstrate the financial costs across the system of women with gynaecological conditions. For example, improving care could help reduce unemployment as a result of menstrual problems and related issues, reduce sick leave, hospital appointments, surgery, and the general inequality that menstrual health concerns resulting from HMB produce.

2. **What are women's experiences of being diagnosed with, undergoing procedures and being treated for gynaecological or urological conditions?**

The MHC is concerned about the impact of the care backlog on menstrual health conditions, and the lack of attention paid to menstrual health conditions and other gynaecological conditions in public discussions about elective recovery. Menstrual health has historically been overlooked in the UK as it is not a significant contributor to mortality, discounting the significant detriment menstrual health conditions can have on patient's lives.[4]

Throughout the COVID-19 pandemic, all aspects of healthcare were disrupted, preventing patients across the country from accessing care for chronic and acute conditions alike, and exacerbating already long waiting lists, with long-term implications for service capacity and patient outcomes. Analysis from the Royal College of Obstetrics and Gynaecologists (RCOG) has shown that gynaecology has seen the largest percentage increase of patients waiting more than 18 weeks from a referral to treatment.[5]

Even prior to COVID-19, women living with menstrual health conditions faced long waiting times and struggled to access care due to longstanding NHS capacity challenges and the de-prioritisation of services for menstrual health conditions. In February 2020, 286,000 women were waiting for gynaecological care and to date waiting lists stand at 570,000 up by 60% since February 2020.[6] This means women face delays in accessing care and are left in pain.

Delays in diagnosis and treatment mean that women suffering from poor menstrual health are left suffering for longer, with implications for both their physical and mental health. Poor menstrual health does not only negatively impact individual girls and women, but also has ramifications on the wider economy. One survey found that 43% of women have taken time off work due to their heavy periods, and 82% of women said that their condition has a negative financial impact.[7] Sickness absence related to HMB is estimated to result in five million sick days in the UK annually, costing the economy over £500 million.[8] The ROCG's report on the backlog found that women felt their conditions had severely deteriorated due to longer waiting lists.[9] Women then require more invasive treatments, placing a higher burden on NHS resources.

In addition, women often find themselves 'bounced around' the system and are not able to easily access the care they need in primary or community care. In the case of HMB, women may be

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[4] Dr Sue Mann and Professor Judith Stephenson, 'Reproductive Health and Wellbeing – Addressing Unmet Needs', *British Medical Association* (2018). Available at: https://www.bma.org.uk/media/2114/bma-womens-reproductive-health-report-aug-2018.pdf.

[5] Royal College of Obstetricians and Gynaecologists, 'Left for too long: understanding the scale and impact of gynaecology waiting lists', *Royal College of Obstetricians and Gynaecologists* (2022). Available at: https://rcog.shorthandstories.com/lefttoolong/index.html.

[6] RCOG, 'Left for too long'.

[7] Wear White Again, 'Am I Number 5? Market Research Summary Report', *Wear White Again funded by Hologic Inc.* (2017).

[8] Ibid.

[9] RCOG, 'Left for too long'.

referred to secondary care gynaecology services – where, according to the latest NHS data, only 54% of patients referred are seen within the 18-week target.[10]

With lesser-known conditions such as adenomyosis, more needs to be done to educate healthcare professionals and to ensure respectful and compassionate care. The Women's Health Matters report[11] on adenomyosis revealed that 80% of women with suspected or diagnosed adenomyosis felt dismissed throughout their healthcare journey, which was often a long one with 26% of women waiting 10 years for diagnosis and 43% waiting more than five years.

3. **What disparities exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?**

The COVID-19 pandemic exacerbated disparities in the diagnosis and treatment of menstrual health across the country. A study from Imperial College Business School found that people living in the country's poorest areas and those from Black, Asian and Minority Ethnic backgrounds have experienced the most disruption to their care.[12] A British Medical Association report noted "stark inequalities in health between women in different socio-economic groups, ethnicities and geographic regions".[13] This extends to menstrual health.

It is our opinion that there needs to be greater focus on the promotion of early intervention and prevention for menstrual health conditions. This will ensure women, girls, trans and non-binary people are empowered to make informed decisions about their care, which starts with school-age education on menstrual health. The MHC believes there needs to be more recognition that endometriosis and PCOS are long-term conditions and there needs to be parity of esteem compared to other long term conditions in areas such as research, treatments and the importance of early intervention and prevention.

The MHC also believes more needs to be done to support women working in lower paid manual jobs or in work where they cannot take appropriate toilet breaks and are often more compromised. Women with menstrual health conditions such as endometriosis and PCOS do not get a fit note as the problem often lasts for less than 7 days. This leaves women needing to make their own adjustments to accommodate their condition.

The Government and NHS England should work together to put measures in place to support women who may be reluctant to present in primary care. Information should be given to women through language which is easy to digest and support materials should be written in a language which is easy to understand. The Government should work with stakeholders to ensure there is support which adequately meets the needs of women, in particular women who face a disproportionate number of challenges to access care. Women should feel supported by their health system and made to feel that they can access care when it is appropriate for them.

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[10] Bayer UK, 'Informed, hear, empowered: Placing women at the heart of reproductive health policy', *Bayer UK* (July 2023). Available at: https://politicshome.com/ugc-1/1/21/0/Informed, heard, empowered- Placing.pdf; NHS England, Consultant-led Referral to Treatment Waiting Times Data 2023-24, April 2023.

[11] Women's Health Matters. 2021 'Women's Health Matters 2021' Circle Health Group Available at: https://www.circlehealthgroup.co.uk/womens-health-matters/download-report

[12] Carol Propper, 'The pandemic divide: how COVID-19 has increased health inequalities', *Imperial College Business School* (2022). Available at: https://www.imperial.ac.uk/business-school/ib-knowledge/health/the-pandemic-divide-how-covid-19-has-increased-health-inequalities.

[13] Dr Jessica Allen and Dr Flavia Sesti, 'Health Inequalities and Women – Addressing Unmet Needs', *British Medical Association* (2018). Available at: https://www.bma.org.uk/media/2116/bma-womens-health-inequalities-report-aug-2018.pdf.

The MHC has produced a series of recommendations which the group would like to see the Government and the Department of Health and Social Care implement to address inequalities across menstrual health:

1) Women, girls, trans and non-binary people should be empowered to make informed decisions about their care, and this starts with school-age education on menstrual health.
2) The MHC is calling for the NHS website to be updated to include more up to date information in easy-to-understand language, including videos in different languages to help those who have low literacy or do not speak English. The website should also incorporate wider sources of information and all registered community organisations that offer support for menstrual health conditions.
3) The Government should focus on the recruitment, retention and training of healthcare professionals with an interest in women's health.
4) The MHC would like to see NHS England offering incentives to prioritise women's healthcare to place more emphasis on these long term conditions and fund training courses in the area.
5) The MHC is calling on the Government to collect data on ethnicity and age. It is known that data collection can help drive forward outcomes for women, girls, trans and non-binary people it can also help to better understand how women, girls, trans and non-binary people access their care.
6) The Government and Department of Health and Social Care should outline the steps they are taking to promote early intervention and prevention for menstrual health conditions.
7) There is a lack of research into women's health research projects in England. The Government should review its plans to announce funding for research projects into menstrual health.
8) The MHC would like to see the Government join up budgets and commissioning for sexual and reproductive health and women's health to reduce the number of women slipping through the system and improving care outcomes.

4. What barriers exist in the treatment and diagnosis of gynaecological and urogynaecological conditions?

Stigma and education

Across menstrual health conditions, this stigma is preventing women of all ages from learning about symptoms and understanding what is normal for them during their menstruation, and therefore when to seek help. Stigma also results in women being reluctant to talk about menstrual health conditions with friends, colleagues or healthcare professionals. Compounded with a lack of awareness, the MHC believes that stigma leads women to be less cognisant of symptoms, which in turn delays access to appropriate diagnostic services and treatment. This is supported by evidence which shows that 44% of women with adenomyosis feel embarrassed or ashamed to talk about their condition[14], data also shows that one in three women who have heavy periods have never spoken to their doctor about it.[15]

The Truth Undressed Campaign shines a light on this stigma and the unintended consequences.[16] The campaign aims to address the stigma and barriers to teaching schools by working with the PHSE Association to provide free supplementary KS3-5 school lesson plans to teachers. The MHC believes

[14] Women's Health Matters. 2021 'Women's Health Matters 2021' Circle Health Group Available at: https://www.circlehealthgroup.co.uk/womens-health-matters/download-report
[15] Wear White Again, 'Heavy Menstrual Bleeding Information for Healthcare Professionals' (2017). Available at: https://www.wearwhiteagain.co.uk/info-for-healthcare-professionals/.
[16] The Truth Undressed Campaign. Available at: https://www.truthundressed.co.uk/homepage.

the Government, the Department of Health and Social Care, and the Department for Education should aim to break down the stigma and embarrassment associated with menstrual health conditions through comprehensive and effective RSE in schools and should look to update upcoming RSE guidance for schools.

A combination of a lack of awareness and education, as well as limited access to information about treatment options and services have contributed to a delay in diagnosis and treatment for those affected by menstrual health conditions. This has an impact on the quality of life of patients. Women's health issues must be destigmatised through education awareness and better access to information so that symptoms can be identified early, and women are able to take an active and informed role in their treatment pathway.

Information and training

The MHC believes the Government and the Department of Health and Social Care should provide reliable, publicly available information for clinicians and patients through adequate training tools for clinicians and signposting to relevant resources e.g. Royal College of General Practitioners Menstrual Health Toolkit and Royal College of Nursing's women's health education booklets.

The MHC believes there is a lack of clinical awareness of menstrual health conditions and the associated diagnostics and treatments. Women suffering from menstrual health conditions currently face significant barriers in getting an appropriate diagnosis. An online survey on endometriosis and fibroids found that 40% of the women surveyed needed ten GP appointments or more before they were diagnosed.[17] Further, it is well documented that women with endometriosis often wait seven and a half years between first seeing a doctor about their symptoms and receiving a firm diagnosis.[18] To address the backlog, women need to receive an appropriate diagnosis to progress along the pathway, and consequently free up capacity in primary care by negating repeated visits to the GP.

The Government has acknowledged the importance of diagnostics to address the COVID-19 backlog, investing hundreds of millions into community diagnostic centres to give patients access to diagnostic checks, scans, and tests outside of primary care and hospital settings.[19] It is also important to improve the information provided on menstrual health conditions to healthcare professionals, particularly in primary care, to ensure that they have the resource and support needed to diagnose menstrual health conditions and refer patients for specialist treatment where appropriate.

The Women's Health Strategy recommends that undergraduate curricula for all healthcare include teaching and assessments on women's health.[20] The Strategy also makes reference to the General Medical Council Medical Licensing Assessment for incoming doctors in the academic year 2024 to 25 and onwards. The assessment will include a number of topics relating to women's health and will encourage a better understanding of women's health among doctors.[21] However, these recommendations do not incentivise more healthcare professionals to specialise or take up training on women's health and particular condition areas.

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[17] All-Party Parliamentary Group on Women's Health, 'Informed Choice? Giving Women Control of Their Healthcare', *All-Party Parliamentary Group on Women's Health* (2017). Available at: http://www.appgwomenshealth.org/s/Informed-Choice-Report-Final-s88t.pdf.

[18] Endometriosis UK, 'Getting Diagnosis', *Endometriosis UK* (2023). Available at: https://www.endometriosis-uk.org/getting-diagnosed-0.

[19] Department of Health and Social Care, '40 community diagnostic centres launching across England', *Department of Health and Social Care* (2021). Available at: https://www.gov.uk/government/news/40-community-diagnostic-centres-launching-across-england.

[20] Department of Health and Social Care. 'Women's Health Strategy for England', *Department of Health and Social Care* (2022). Available at: https://www.gov.uk/government/publications/womens-health-strategy-for-england/womens-health-strategy-for-england.

[21] Ibid.

The MHC would like to see the use of Quality and Outcomes Framework (QOF) or Commissioning for Quality and Innovation (CQUIN) indicators to incentivise healthcare professionals and providers to prioritise gynaecological and other women's health conditions and encourage GPs, nurses and other healthcare professionals to take up training on women's health. The Government should better incentivise NHS Trusts to encourage doctors to specialise and take up training on women's health there will be more doctors who are able to treat the large number of patients currently waiting for gynaecological care in England.

Another issue affecting waiting lists for gynaecological procedures, including menstrual health, is terminology such as ''benign gynaecology'' used by NHS providers to refer to many life-altering gynaecological issues. Downplaying the importance of these conditions risks de-prioritising them for treatment and ignores the patient's quality of life. This means patients may need more intense and complex surgery further along the pathway, exacerbating capacity challenges in the future.

NHS England should work with stakeholders at the Federation of Surgical Specialty Associations, the Royal College of Surgeons and the Royal College of Obstetricians and Gynaecologists to review the classification of menstrual health conditions and ensure that the impact of menstrual health conditions is taken seriously. This should include a wider conversation about what treatments take precedence for surgery and ensuring that chronic conditions primarily affecting women, such as endometriosis are appropriately prioritised. This can be done by taking into consideration wider healthcare knock on impacts from gynaecological symptoms, and the impact of symptoms on quality of life. This re-prioritisation is required to address the disparity present in the fact that gynaecology waiting lists have grown at a faster pace than any other speciality since the pandemic.

Coordinated services and accountability

The MHC believes the Government and the Department of Health and Social Care should join up commissioning of services with additional accountability of local organisations to provide relevant services. The MHC believes that commissioning barriers, service fragmentation and lack of access to services means women may not receive the timely access to treatment they need, impacting their quality of life.

Responsibility for commissioning of women's health services is currently split between local authorities, local commissioning, and NHS England, causing issues around silo budgeting, service provision and access to care. For instance, the intrauterine system (IUS) for contraception is funded by national public health budgets, but is funded by local commissioning for conditions like heavy menstrual bleeding, meaning GPs are often not funded to provide IUSs as a treatment for non-contraceptive purposes.[22] With the roll-out of Integrated Care Systems (ICSs) and the encouraging moves to implement women's health hubs, ICSs should take a holistic approach to women's health including menstrual health to improve patient experience and care. ICSs should be encouraged to develop women's health hubs to centralise and optimise expertise and improve diagnosis and access to care for menstrual health conditions. Furthermore, GP practices should work together to pool resources to provide specialist nurses and clinicians, offering a range of services.

August 2023

[22] MHC, 'Heavy Menstrual Bleeding'.