NHS0013

Written evidence submitted by the Menstrual Health Coalition Consultation Response

Menstrual Health Coalition

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

The Coalition aims 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.

The MHC is submitting evidence to the consultation to raise awareness of the impact of NHS waiting times on care for menstrual health conditions, particularly in the context of the pandemic, and to call for increased focus on women-specific health conditions when addressing the care backlog.

Executive Summary

The MHC wishes to highlight the following key points:

- Women's health and specifically menstrual health needs to be prioritised within the recovery of NHS services. Women make up 51% of the population and on average women will menstruate 12 times a year over the course of a 40 year period. [i] Up to 1 in 3 women face heavy menstrual bleeding[ii] (HMB), and many others experience menstrual problems affecting their physical, psychological and social wellbeing. Therefore, it is vital that the issue of waiting times for care for menstrual health conditions is taken seriously and addressed within discussions about the NHS backlog.
- Concrete action needs to be taken to address the backlog of care for menstrual health conditions. This includes reviewing the classification of many menstrual health conditions as "benign" which risks de-prioritising these conditions for surgery, investing in community diagnostics to speed up access to diagnosis, and improving pathways for menstrual health conditions to support increased referrals to secondary care.

The importance of menstrual health and wellbeing

Women make up 51% of the population and on average women will menstruate 12 times a year over the course of a 40 year period, [iii] meaning menstrual health affects the majority of the population at some point in their lives. Menstrual health covers a wide range of issues, including endometriosis, polycystic ovary syndrome, perimenopausal symptoms and heavy menstrual bleeding (HMB). It also includes the overall wellbeing of women who menstruate.

Up to 1 in 3 women face HMB[iv] and 1 in 10 women suffer from endometriosis. [v] The impact on patients living with poor menstrual health can seriously affect both their physical and mental health and place an economic burden by reducing their ability to work and increasing sickness absence,[vi] with one survey showing that 42% of women living with endometriosis missed school or work due to symptoms "often, or very often" and 35% had seen their income reduced due to their condition.[vii]

The psychological impact of these conditions can also be great. A patient survey of over 1,000 women with heavy menstrual bleeding found that 74 percent had experienced anxiety and 67 percent suffered with depression.[viii] Out of women suffering from endometriosis, 81% reported that their condition had impacted their mental health "negatively, or very negatively" and 89% felt isolated due to their diagnosis.[ix]

The number of women suffering from menstrual health conditions and the significant impact on physical and mental health as well as opportunities such as participation in school and at work can drive inequalities in wellbeing and in life outcomes more broadly. This is particularly concerning as many women start to have symptoms at a very young age, and face these issues throughout their lifetime. The impact of these conditions on health inequalities and patient wellbeing is highly likely to worsen further due to longer delays to treatment brought on by the backlog. The MHC therefore believes urgent action must be taken to address delays to treatment and improve patient outcomes.

Prioritisation of menstrual health

Despite menstrual health and wellbeing being relevant to more than half of the population at some point in their lives, menstrual health is often de-prioritised and not given the attention required. The MHC's 2020 report on HMB found that women's health and menstrual health is not adequately prioritised, especially in primary care, and that many policy levers are focused on other priorities such as cardiovascular disease and long-term conditions.[x] This is echoed by a report from the British Medical Association which states that as poor reproductive health is not a significant contributor to mortality, "aspects of reproductive care such as heavy menstrual bleeding, infertility and menopause are often overlooked."[xi] Even within women's health, menstrual health often does not receive the same level of attention and concern as other conditions. Menstrual health conditions are sometimes perceived as being "just" heavy periods, which overlooks the significant impact menstrual health conditions can have and can lead to de-prioritisation vis-à-vis other women's health concerns.

The MHC wishes to see increased attention and focus placed on menstrual health conditions to address the historic de-prioritisation of menstrual health. This is particularly true following the pandemic, which has impacted on patients' ability to access care. There is a need to re-prioritise menstrual health to ensure services recover after the pandemic.

Waiting times and access to care for menstrual health conditions and the impact of COVID-19

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.

Pre-pandemic issues regarding access to treatment include both issues around referrals and pathways as well as capacity. An online survey on endometriosis or fibroids found that 40% of the women surveyed needed 10 GP appointments or more before being diagnosed[xii]. This suggests that current pathways for women suffering from menstrual health conditions mean women face delays in access to care and are left in pain. Waiting lists for women's health conditions were also already high before the start of the pandemic, with 286,000 women waiting for gynaecological care in February 2020. [xiii]

In addition to the pre-pandemic status quo, waiting times and backlogs have continued to grow throughout 2020 and 2021. Gynaecological services have been particularly hard hit by the COVID-19

pandemic and delays to care. Gynaecology experienced the largest percentage increase of all specialties in waiting list size since the start of the pandemic, increasing by 34% from 286,000 to 382,000.[xiv] Approximately 20% of all referrals to gynaecology services are for HMB, [xv] meaning around 76,000 women are likely waiting to receive care for HMB.

One issue affecting waiting lists for gynaecological procedures including menstrual health is the use by the Royal College of Obstetricians and Gynaecologists of the term ''benign gynaecology'' to refer to many life-altering gynaecological issues, despite potentially debilitating symptoms. This risks de-prioritising these conditions for treatment, and as services resume after covid could mean further, significant waits for surgery, with the risk of patients suffering worse outcomes due to delays to treatment. This means patients may need more intense and complex surgery further along the pathway, exacerbating capacity challenges in the future. The MHC has also heard anecdotal evidence that GPs are under increasing pressure from secondary care to hold back referrals to help clear the backlog, negatively impacting patient experience and outcomes.

The backlog and long waiting times for treatment for menstrual health conditions has had a severe impact on some patients' condition. During a recent Health and Social Care Select Committee oral evidence session as part of its inquiry into clearing the backlog caused by the pandemic, the MHC were appalled to hear about the experience of one endometriosis patient who suffered delays to treatment.

> When asked about her experience seeking treatment during the pandemic, Sarah Lambrechts explained that after being diagnosed with endometriosis in 2017, she was scheduled for surgery in March 2020 which was cancelled due to the pandemic and rescheduled for August 2020. After the surgery failed, she was unable to reschedule another surgery for six months due to the backlog. Instead, Lambrechts had to go on an injection treatment which significantly worsened her condition due to side effects.
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> When asked whether her experience of seeking care would have been different prior to the pandemic, Lambrechts stressed that she had "been used" to long waiting lists but noted that the issue had been exacerbated by the pandemic. In addition to the increased wait, Lambrechts was impacted psychologically as she felt invalidated by her GP and feared for her life as she could not seek medical treatment during the pandemic.

Opportunities to address the backlog

To address this backlog, there is a need to improve diagnosis to address delays to treatment and avoid wasting additional NHS capacity. This would make a big difference in addressing the issue of 40% of women suffering from endometriosis and fibroids needing 10 GP appointments or more before being diagnosed. [xvi] This should include investment in access to outpatient diagnostic clinics to ramp up capacity for the diagnosis of menstrual health conditions, and these should be fit-for-purpose in terms of the equipment needed to effectively diagnose women's health conditions such as endometriosis.

There is also an opportunity to break down silos in the provision of treatment. Currently, women needing support for gynaecological conditions are often sent to lots of different providers depending on their symptoms. To address this, Integrated Care Systems should develop women's health hubs to facilitate joined-up care for women's health conditions that will treat women as whole individuals with complex needs. Women's health hubs would optimise the expert skillset of a multi-disciplinary team to deliver targeted care for women for a number of conditions including menstrual health

conditions. These hubs would also enable patients to receive care closer to home in their local community, addressing challenges women may have to access services and reducing health inequalities.

There is also a need for a central, Government-led effort to join-up commissioning for women's health which is currently divided between local authorities, local commissioning and NHS England. The MHC supports the Royal College of Obstetricians and Gynaecologists (RCOG) in calling for mandated joined up commissioning of sexual and reproductive health,[xvii] to ensure parity of care for all women's health conditions and adequate funding for menstrual health. Joined-up commissioning can help ensure all women get access to the treatment they need, addressing backlogs.

Current pathways for the management of menstrual health conditions also need to be reviewed to address barriers to referrals which leave patients waiting for effective treatment. The MHC wishes to see user-friendly information on relevant guidance such as the recent NICE Quality Standard on HMB to support GPs to diagnose and recommend treatment for menstrual health conditions, streamlining referrals and treatment decisions.

Recommendations

- Menstrual health must be prioritised within efforts to address the backlog to address historic de-prioritisation and the massive increase in waiting lists since the pandemic
- The classification of many menstrual health conditions as "benign" should be reviewed to ensure patients are not de-prioritised for surgical treatment
- There needs to be investment in diagnostics, particularly in the community through community diagnostics hub or through the development of women's health hubs to address backlogs in access to diagnosis
- There is a need to deliver joined-up, multi-disciplinary care for women's health conditions including menstrual health to ensure that women are better able to receive expert care
- There needs to be a review of current pathways for the management of menstrual health conditions to address barriers to referral from GPs to secondary care which impede patient access to appropriate care

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[i] "Better for Women", Royal College of Obstetricians and Gynaecologists (2019), https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf

[ii] "Heavy Menstrual Bleeding – breaking silence and stigma", Menstrual Health Coalition (2020), https://www.menstrualhealthcoalition.com/s/HMB_Report-020320.pdf

[iii] "Better for Women", Royal College of Obstetricians and Gynaecologists (2019), https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf

[iv] "Heavy Menstrual Bleeding – breaking silence and stigma", Menstrual Health Coalition (2020), https://www.menstrualhealthcoalition.com/s/HMB_Report-020320.pdf

[v] "About us", Endometriosis UK, https://www.endometriosis-uk.org/about-us [Accessed 22nd November 2021]

[vi] "Heavy Periods", Wear White Again, https://www.wearwhiteagain.co.uk/heavy-periods/ [Accessed 22nd November 2021]

[vii] "Endometriosis in the UK: time for change", APPG on Endometriosis (2020), https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf

[viii] [viii] "Heavy Periods", Wear White Again, https://www.wearwhiteagain.co.uk/heavy-periods/ [Accessed 22nd November 2021]

[ix] "Endometriosis in the UK: time for change", APPG on Endometriosis (2020), https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf

[x] "Heavy Menstrual Bleeding – breaking silence and stigma", Menstrual Health Coalition (2020), https://www.menstrualhealthcoalition.com/s/HMB_Report-020320.pdf

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

[xii] "Informed Choice? Giving Women Control of Their Healthcare" APPG on Women's Health (2017), http://www.appgwomenshealth.org/s/Informed-Choice-Report-Final-s88t.pdf
[xiii] NHS Waiting List Tracker, *Lane Clark & Peacock LLP* (2021), https://nhswaitlist.lcp.uk.com/ [Accessed 22nd November 2021]
[xiv] "Women bearing brunt of indirect impacts of Covid-19 pandemic as new analysis shows gynaecology waiting lists have shot up by 60% in three years", *Lane Clark & Peacock LLP* (2021), https://www.lcp.uk.com/media-centre/2021/07/women-bearing-brunt-of-indirect-impacts-of-covid-19-pandemic-as-new-analysis-shows-gynaecology-waiting-lists-have-shot-up-by-60-in-three-years/
[xv] Rebecca Sally Geary, Ipek Gurol-Urganci, Amit Kiran, et al., "Factors associated with receiving surgical treatment for menorrhagia in England and Wales: findings from a cohort study of the National Heavy Menstrual Bleeding Audit" (2019), *BMJ Open* 2019;9:e024260
[xvi] "Informed Choice? Giving Women Control of Their Healthcare" APPG on Women's Health (2017), http://www.appgwomenshealth.org/s/Informed-Choice-Report-Final-s88t.pdf
[xvii] Royal College of Obstetricians and Gynaecologists, "Better for Women: Improving the Health and Wellbeing of Girls and Women" (2019), https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf

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