

## Written evidence from All Parliamentary Group on Women’s Health [WRH0018]

The APPG on Women’s Health aims to empower women to make informed choices about their treatment and ensure they are treated with dignity and respect throughout their treatment pathway.

### Objectives:

- To raise the profile of issues affecting only, or predominately women, within Parliament and with decision-makers at NHS England.
- To break down cultural barriers that affect a women’s ability to access healthcare, and effective treatment. This includes speaking about menstrual health, menopause, reproductive health, and other women’s health-specific issues without stigma.
- To overcome system barriers and commissioning siloes that prevent women from easily accessing effective and timely treatment across the country.

### Inquiry Response

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#### 1. What constitutes healthy periods and reproductive health?

NHS England defines a period as “part of the menstrual cycle when a woman bleeds from her vagina for a few days. For most women this happens every 28 days or so, but it's common for periods to be more or less frequent than this, ranging from every 23 days to every 35 days.”<sup>1</sup> However, the APPG on Women’s Health knows that for women a period is often more complex and can come with a series of symptoms which impact on their day-to-day life. There are a number of gynaecological conditions which can impact on a women’s period and reproductive health including cervical and ovarian cancers, endometriosis, fibroids, heavy menstrual bleeding, menopause, pregnancies and vaginal conditions.<sup>2</sup>

Some women will experience physical symptoms associated to these conditions which are so severe they disrupt their quality of life, impacting on their social life and work. These physical symptoms can also have an impact on a woman’s mental health, which is often exacerbated by the long waits for diagnosis which many women experience. For example, 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.<sup>3</sup> The APPG on Women’s Health is concerned that women often do not know what constitutes a ‘normal’ period and therefore they are less likely to seek medical assistance for their symptoms. This can leave women suffering unnecessarily and has the potential to disproportionately impact on their outcomes.

#### 2. What are women’s experiences of being diagnosed with, undergoing procedures, and being treated for gynaecological or urogynaecological conditions?

Since the start of the pandemic, the APPG on Women’s Health has been concerned by the number of patients on waiting lists for treatment for gynaecological conditions. While the pandemic has caused a seismic shift to the health service, the impact on gynaecological conditions has been felt

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<sup>1</sup> NHS England, ‘Periods: Overview’, *NHS England* (2023). Available at: <https://www.nhs.uk/conditions/periods/>.

<sup>2</sup> NICE, ‘Gynaecological conditions’, *National Institute for Health and Care Excellence* (2023). Available at: <https://www.nice.org.uk/guidance/conditions-and-diseases/gynaecological-conditions>.

<sup>3</sup> Endometriosis UK, ‘Getting Diagnosis’, *Endometriosis UK* (2023). Available at: <https://www.endometriosis-uk.org/getting-diagnosed-0>.

disproportionately compared to other condition areas. During the pandemic the number of women waiting for gynaecological care in the UK rose dramatically. NHS England's Referral to Treatment waiting times for June 2023 found 595,556 people were on gynaecological waiting lists.<sup>4</sup> This figure has continued to rise since the start of the pandemic, impacting on patients' quality of life and their ability to return to work.

The Royal College of Obstetricians and Gynaecologists 'Left for too Long' report revealed that gynaecology waiting lists have faced the biggest increase of all medical specialities.<sup>5</sup> This rise has had a detrimental impact on the physical and mental health of women. The APPG supports the recommendations in the 'Left for too Long' report and would like to see the Government and NHS England take urgent action to reduce the backlog of gynaecological health. The APPG believes that a more holistic approach to women's health care is needed to improve outcomes and decrease the number of women waiting for treatment for gynaecological conditions on the NHS.

To support the experiences of women receiving a diagnosis, undergoing procedures, and being treated for gynaecological or urogynaecological treatment, the APPG believes it is vital that women are empowered to make an informed choice about their care. In the APPG's inquiry into informed choice in 2017, the group recommended that women should be offered written information on gynaecological issues with a full range of information about the condition and their options. During the inquiry the APPG found that 42% of women surveyed said they were not treated with dignity and respect and 39% of women sought a second opinion following a diagnosis. These figures show that women are often dismissed by healthcare professionals and do not feel satisfied with the information they are given to make the next step in their care.<sup>6</sup> The APPG remain concerned that women feel the need to seek further advice and are not satisfied with the information that professionals give them.

The APPG has heard that women regularly put up with symptoms and incredible pain because they are unaware of what is 'normal' and often feel stigmatised to talk about 'women's problems'. The APPG believes if women are empowered to make informed decisions about gynaecological or urogynaecological conditions their treatment outcomes and quality of life will improve.

For women seeking access to treatment for the menopause, systemic challenges related to capacity, referrals and pathway design often pose a barrier to care. One survey found that 44% of women who eventually received treatment for the menopause waited one year or more for treatment.<sup>7</sup> These delays are unacceptable, and it is important that the Government and the NHS take action to ensure that women are able to access care.

The APPG believes in the importance of improving collaboration to address current siloed working and fragmentation for women's health, particularly around the menopause. The APPG welcomed

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<sup>4</sup> NHS England, 'Referral to Treatment Waiting Times', *NHS England* (2023). Available at: <https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/rtt-data-2023-24/#Jun23>.

<sup>5</sup> Royal College of Obstetricians and Gynaecologists, 'Left for too Long', *Royal College of Obstetricians and Gynaecologists* (2022). Available at: <https://rcog.shorthandstories.com/lefttoolong/index.html>.

<sup>6</sup> 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: <https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/5d41adfc49a80d0001f41b82/1564585493903/Informed+Choice+Report+Final.pdf>.

<sup>7</sup> Dr Louise Newson and Dr Rebecca Lewis, 'Menopause at Work: a survey to look at the impact of menopausal and perimenopausal symptoms upon women in the workplace', *Balance by Newson Health* (2021). Available at: <https://balance-menopause.com/uploads/2021/10/Lewis-Newson-BMS-poster-SCREEN-1-1.pdf>.

the Government's announcement of £25 million in funding for Women's Health Hubs. This will ensure women receive tailored and expert care for gynaecological and urogynaecological conditions.

Nevertheless, there remains an issue around accountability for the implementation of Women's Health Hubs and an issue in the incentivisation in primary care of women's health which often causes GPs to deprioritise it. It is important to incentivise GPs to focus on women's health, and for ICSs to appoint someone responsible for overseeing women's health.

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

Previous research has revealed disparities, closely tied to socioeconomic status, in how patients access healthcare in the UK, both in terms of patient likelihood to seek care and ability to navigate the health system.<sup>8</sup> This disparity is likely to affect women's access to care for the menopause, which is exemplified by variation in access to hormone replacement therapy (HRT) across the country. One study found stark differences in HRT prescribing rates by socioeconomic deprivation, with prescribing 29% lower in the most deprived areas compared to the least deprived, and 18% lower even after adjusting for risk factors.<sup>9</sup>

In order to overcome these disparities in access to treatment for the menopause, there is a need for increased provision and signposting to information for women. Improved information about the menopause and the treatment available would support women to have an informed choice about their care and to advocate for themselves with healthcare professionals, thereby improving their likelihood of accessing the right treatment for them.

When it comes to prescribing treatments for gynaecological or urogynaecological conditions, many patients find that the treatment that may be best for them is not available to them for a variety of reasons. One example is the disparity of treatments available on the NHS versus in private practice. One survey found that 48% of women felt they had no option but to pay for private treatment – which can cost several hundreds of pounds - after not receiving the care they needed on the NHS.<sup>10</sup>

The APPG has also heard from patients from different socio-economic backgrounds who say they are less likely to seek help and get the help they need from their GP. This further exacerbates health inequalities for women. These barriers are unacceptable and the APPG believes that the Government and NHS England should implement measures such as providing written information for women in different languages to support women who are seeking medical support.

The APPG was delighted to see a focus on disparities in health outcomes between women in the Women's Health Strategy. The Strategy's Call for Evidence highlighted a number of barriers which continue to impact women. For example, 84% of respondents said there have been instances when they (or the woman they had in mind) felt they were not listened to by healthcare professionals. The Call for Evidence also found that 'not being listened to' appears to be prevalent across all stages of the healthcare pathway.<sup>11</sup> This data shows that following the launch of the APPG's report into

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<sup>8</sup> Martin Gulliford and Myfanwy Morgan (eds), 'Access to Health Care', Routledge (2003); Hillman et al, 'Socioeconomic status and HRT prescribing: a study of practice-level data in England', *British Journal of General Practice* (2020). Available at: <https://bjgp.org/content/70/700/e772>.

<sup>9</sup> Hillman et al, 'Socioeconomic status and HRT prescribing'.

<sup>10</sup> Menopause Support, 'National newspaper highlights our findings on a 'national disgrace'', *Independent*, (24 June 2021). Available at <https://menopausesupport.co.uk/?p=14775>.

Informed Choice published in 2017, there has been little change in the way women feel about their experiences with the health system. These issues will continue to impact on health outcomes for women.

There were also disparities between different demographics responding to the Women's Health Strategy's Call for Evidence, with 91% of respondents identifying as white which is disproportionate to the percentage of the population. The APPG believes NHS England and the Government need to do more to reach underserved communities and improve health outcomes for women across the country.

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

The APPG has heard from a number of patients with lived experience about the barriers they have faced when accessing treatment for gynaecological and urogynaecological conditions. These barriers include the stigma associated with periods, the lack of communication between doctors and women, and misinformation around women's health conditions.

##### *Awareness*

There is a general lack of awareness around gynaecological or urogynaecological conditions. In this inquiry response, the APPG has already highlighted the lack of understanding of conditions by GPs. This includes a lack of education around what conditions are, and what treatment options are available. There is also a lack of awareness around non-surgical treatment options, such as pharmaceutical options and non-surgical interventions.

The APPG has found a lack of signposting to reliable information. Women need spaces where they are able to learn and discuss the variety of symptoms they may be experiencing. It is important that suitable after-care following a diagnosis is available in accessible formats. The APPG believes to help raise awareness of women's health conditions, information and resources need to be accessible in a variety of languages and care needs to take a holistic approach. This is only possible when patients and medical professionals have an understanding of women's health symptoms and conditions.

##### *Stigma*

There are a number of myths associated with gynaecological or urogynaecological conditions. This includes assumptions that pregnancy will cure endometriosis, that a hysterectomy is the only option for those suffering with endometriosis, and that it will completely cure the condition. The stigma associated with women's health conditions can further delay women presenting at primary care, therefore delaying treatment, and creating a greater impact on the quality of life for women.

Among the public, there is a lack of awareness of what is a 'normal' period or menstrual cycle, which can put patients off seeking the help or advice they need. Women often fail to get a diagnosis when they seek initial help from their GP and are frequently told 'it's just a period' or 'it's all in your head'. More needs to be done to ensure patients are treated with dignity and respect when addressing painful periods. Women should also be empowered to make a choice regarding their treatment, having been given all the information they need to do this.

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<sup>11</sup> Department of Health and Social Care, 'Women's Health Strategy: Call for Evidence', *Department of Health and Social Care* (2022). Available at: <https://www.gov.uk/government/consultations/womens-health-strategy-call-for-evidence/outcome/results-of-the-womens-health-lets-talk-about-it-survey#research-and-data-gaps-1>.

An example of this regards local or general anaesthetic options for a hysteroscopy. There can often be a lack of communication between GPs and patients, with medical professionals sometimes failing to recognise the pain women experience during procedures. The stigma associated with pain tolerance is also more prevalent amongst certain groups of women across all areas of healthcare. Women are left with surgical trauma if their pain is overlooked by medical professionals.

#### *Communication between doctors and patients*

When women are better informed on their treatment options, they are more likely to be satisfied with the results and the outcomes of treatments. When there is a lack of communication between doctors and patients, women can feel dismissed and ignored. It is important that medical professionals and women discuss together all the available options before proceeding. This ensures women are able to make an informed choice about their care and improve patient satisfaction and treatment outcomes.

For example, currently, the majority of care provided in the UK for menopause takes place in primary care. However, many GPs do not feel comfortable managing the menopause. In one survey, only 66% of GPs reported feeling confident managing the menopause.<sup>12</sup> This means that the expertise available to patients about the menopause varies depending on their GP. To ensure patients can access the best care possible, there is a need to provide additional education and support to GPs on the menopause.

In addition to providing information to healthcare professionals across the NHS through a centralised, easy to access platform, such as NHS England's communication channels, additional training should be provided to healthcare professionals, and GPs in particular. This training should be available at a variety of different levels depending on the interest and expertise of the healthcare professional. Some healthcare professionals may have a special interest and would benefit from more in-depth training on the menopause, whilst some GPs providing care for a wide range of conditions in a primary care setting might need training tailored to their needs and capacity. The APPG has heard evidence that noted the importance of providing information for GPs in a concise and accessible format.

For example, when women are diagnosed with fibroids, they are rarely given a full range of options, and are therefore denied the opportunity to make informed choices about their care. Women are often directed towards a hysterectomy, without being offered any non-surgical interventions, or other surgical options. It is vital that women are able to access appropriate information and that conditions which only impact women are treated on par with other conditions, meaning that all treatment options should be accessible and offered across the country.

#### *Pathway and referral barriers*

There are a range of pathway barriers that mean that even once a woman has sought help there can be countless problems before their symptoms are alleviated.

In primary care, the APPG has heard concerns around GP failures to refer patients, in particular those with endometriosis. The findings from the APPG's 'Informed Choice' report showed that prior to diagnosis, women commonly experience repeated visits to doctors where symptoms are normalised, dismissed or even trivialised. This results in women feeling ignored and often

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<sup>12</sup> Louise Newman and Rob Mair, 'Menopause survey: The results', *British Journal of Family Medicine* (2017). Available at: <https://d2931px9t312xa.cloudfront.net/menopausedoctor/files/information/179/menopause-survey-FINAL.pdf>.

disbelieved. This lack of awareness among clinicians and attitudes towards conditions can deter women from seeking the help they need and delays treatment.

The APPG believes timely referral and more holistic support is needed to support women. Specialist support should also be offered to women who have experienced the psychosocial impact of endometriosis, as this is not always readily available.

The APPG believes healthcare professionals should be better supported to deliver this care. This requires training and education to be promoted by NHS England and the Government. The rollout of Women's Health Hubs has the opportunity to deliver the tailored and specialist support that women need to improve the delivery of care and reduce the long waits for treatment.

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