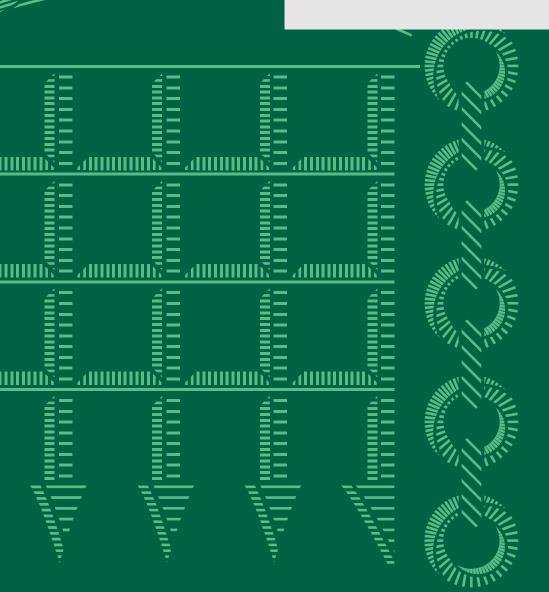




Women's reproductive health conditions

First Report of Session 2024-25

HC 337



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Publication

This Report, together with formal minutes relating to the Report, was Ordered by the House of Commons, on 4 December 2024, to be printed. It was published on 11 December 2024 by authority of the House of Commons. © Parliamentary Copyright House of Commons 2024.

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Summary

Women's reproductive health conditions, such as endometriosis, adenomyosis and heavy menstrual bleeding are highly prevalent in the UK. Yet many who experience them find their symptoms dismissed and normalised by those they turn to for help. For some conditions, accessing diagnosis and treatment can take years, leaving women and girls to "suck it up" and endure pain that interferes with every aspect of their daily lives, while their conditions worsen.

Women and girls are missing out on their education, career opportunities, relationships, social lives and are having their fertility impacted because of neglected reproductive health conditions. Many are resorting to expensive private healthcare.

Pervasive stigma associated with gynaecological and urogynaecological health, a lack of education and "medical misogyny" has contributed to poor awareness of these conditions. This is mirrored in a lack of medical research, treatment options, specialists, and the de-prioritisation of gynaecological care as evident by waiting lists, which have grown faster than any other specialty in recent years. Although there are patches of progress since the Women's Health Strategy for England published in 2022, it has been too slow. The strategy lacks an implementation plan and resource, yet studies show that increases in funding for gynaecology services for early diagnosis and treatment provide a significant return on investment, reduces the burden on primary and secondary care settings and helps reduce sick leave and unemployment. The Government should provide the funding necessary to truly transform the support available to the millions of women affected by reproductive ill health in this country.

Education and awareness

Girls are leaving school not knowing what constitutes a 'normal' period, unequipped to spot the symptoms of reproductive health conditions. The Government should ensure teachers receive the training necessary to deliver menstrual and gynaecological health education effectively. Statutory guidance should require women's reproductive health conditions to be taught to girls and boys early on in secondary education and include intersectional differences. Trustworthy public information is vital and the NHS's website, app and social media presence on these conditions must be comprehensive, accessible, inclusive and highly visible.

Diagnosis, treatment and support

Diagnosis is slow not only because reproductive health conditions often have non-specific symptoms, but because of a lack of expertise and resource. Women are being told symptoms such as heavy, painful bleeding and incontinence are "normal", that they are either too young to have a condition, or too old to expect treatment. As a result, women and girls are making repeat GP visits and ending up in A&E as their conditions worsen and become more complicated to treat.

The NHS must urgently implement a training programme to improve the experience of treatment and diagnosis of reproductive health conditions. Improving early diagnosis, including follow-up appointments, should be a key performance indicator for the Women's Health Strategy for England. Individuals with a suspected or diagnosed reproductive health condition should be offered specialist mental health support.

Painful investigations

Women continue to undergo harrowing experiences of painful procedures such as hysteroscopy and having a contraceptive coil fitted. This includes not being informed of the potential pain, feeling they cannot stop procedures and not having access to sufficient pain relief. This is against medical best practice and guidelines. The NHS must do more to monitor and enforce protocols. A risk assessment that allows a patient to make an informed choice on the recommended procedure should be undertaken as standard, accounting for any relevant medical and personal history. This should include consideration of the full range of options on pain relief, including anaesthesia. The NHS should collect data on whether guidelines for potentially painful gynaecological procedures are being adhered to, including patients' experiences.

Training and standards

Primary care is under pressure. GPs lack time for professional development and funding for training is prioritised for other long-term conditions. However, professional bodies acknowledged the need to improve interactions with female patients and that medical training and education on women's health should not be "left to choice". The Department of Health and Social Care should set out plans to improve the accessibility and take up of professional development in women's reproductive health conditions, with increased funding for training and protected time for GPs to undertake it.

The Government should also consider how to better incentivise healthcare professionals to specialise in women's reproductive health, including making obstetrics and gynaecology a mandatory rotation in training. The annual GP appraisal process should include a performance indicator on the diagnosis and treatment of women's reproductive health conditions. While there have been recent updates and additions to medical guidelines, the Department of Health and Social Care and NHS England should commission NICE to develop comprehensive guidelines for all reproductive health conditions. Adherence to these guidelines and any barriers must be monitored.

Women's health hubs

Women's health hubs are being established across integrated care boards as part of the previous Government's Women's Health Strategy for England. The model has the potential to be a positive step towards providing the joined-up care and commissioning needed to support women with reproductive health conditions but it requires funding to do so effectively. There are challenges in accessing hub services and despite often being described as "one-stop shops", multiple services are rarely offered at the same time. The Government must allocate long-term, ring-fenced funding and resource to embed the hub model and further support its development.

Medical research

Research into women's reproductive health conditions lags behind other, similarly prevalent conditions. It is not adequately prioritised by funders or commissioners and is not incentivised enough in clinical academia. While these issues are recognised by the Women's Health Strategy for England and some positive work is underway, the Government needs to be more ambitious and more targeted approaches are needed. The Women's Health Strategy for England should be updated to include priorities for specific, common conditions. We recommend the Government commits to reducing waiting times for an endometriosis diagnosis to less than two years by the end of this Parliament and to improved understanding and treatment of heavy menstrual bleeding over the same period.

1 Introduction

- 1. Female reproductive health covers a woman's life from puberty through to the menopause, although some related conditions can appear before and after these stages. For many, a healthy reproductive life course is the norm but a significant proportion of women experience a range of painful conditions which interfere with their daily life and, in some cases, result in repeated, significant trauma. Stigma and the normalisation of symptoms of reproductive ill-health make it difficult to know the true extent of these conditions. However, among the population it is estimated that up to one in three women live with heavy menstrual bleeding,¹ around two in three women will develop at least one uterine fibroid in their lifetime, and urinary incontinence affects as many as 40% of women.² One in ten women in the UK will suffer from endometriosis when they are of reproductive age.³ Adenomyosis affects around one in ten women in the UK.⁴
- 2. Women told us they have had painful gynaecological issues ignored, misdiagnosed and mistreated, resulting in them losing their jobs, affecting their relationships, mental health and wellbeing. In 2021, nearly two million girls in the UK missed a part or full day of school or college because of their period, 13% missed an entire school day at least once a month.⁵

 Research published in January 2024 found that one in eight women in the UK had taken time off work in the previous 12 months due to symptoms linked to periods—more than a third of whom gave a different reason to their employers.⁶ Despite the impacts these conditions have on the lives of women and girls, studies have shown that less than half of women with severe reproductive health conditions seek help and those that do experience delays and disbelief.

The NHS defines heavy menstrual bleeding as needing to change a tampon or pad every one to two hours and lasting longer than seven days. It is also called also called menorrhagia, see NHS website, heavy periods

² Royal College of Obstetricians and Gynaecologists (WRH0056)

³ Endometriosis UK, Endometriosis facts and figures, accessed 29 April 2024

⁴ Circle Group, Women's Health Matters 2021 (PDF)

⁵ Plan International, Nearly two million girls in the UK miss school because of their period, 20 October 2021

Bupa, Why more than a million women are keeping period sick days a secret, 31 January 2024

Women's Health Strategy for England

3. Recognising the challenges women face in their engagement with the healthcare system, in 2022 the previous Government published the Women's Health Strategy for England, a 10-year programme committed to improving women's health. The strategy seeks to address disparities in women's healthcare, including across factors such as region, age, ethnicity, gender identity and disability status, and the underrepresentation of women in medical research. One of the strategy's eight priority areas is menstrual health and gynaecological conditions. Dame Lesley Regan was appointed as Women's Health Ambassador to help support the implementation of the strategy. The new Government has said it is committed to prioritising women's health as it reforms the NHS and will be considering how to take the strategy forward. But the strategy forward.

Our Report

- 4. In this Report we explore the adequacy of support for and recognition of reproductive ill health conditions, including any relevant measures set out in the Women's Health Strategy for England. We consider the diagnosis and treatment of gynaecological and urogynaecological conditions such as endometriosis, adenomyosis, fibroids, polycystic ovary syndrome (PCOS), urinary incontinence and vaginal prolapse. We chose not to consider in detail the menopause or maternity as these issues had been covered by separate inquiries undertaken by our predecessor Committee.⁹
- 5. The issues we discuss in this report are specific to people born biologically female. We mostly use the term women and girls throughout the report but these conditions also affect other people, including trans men, non-binary people, and anyone registered female at birth, who may face additional challenges. We want to see everyone's quality of life who may experience reproductive ill health improved.
- 6. The Report draws upon evidence collected by our predecessor Committee, who launched their inquiry into women's reproductive health in autumn 2023. They received written evidence from academics, charities, organisations and medical bodies, which they published, and intensely personal and valuable testimonies from individuals sharing their own experiences, which they chose not to publish to protect people's privacy.

⁷ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, 30 August 2022

^{8 &}quot;How ICBs are setting up women's health hubs", Healthcare leader, 29 October 2024

⁹ Women and Equalities Committee, Third Report of Session 2022–23, <u>Black maternal health</u>, HC 94; Women and Equalities Committee, First Report of Session 2022–23, <u>Menopause and the workplace</u>, HC 91

Due to the calling of the General Election they were unable to report their findings. We felt it was important to conclude their work. We would like to thank everyone who contributed to this inquiry, but particularly broadcasters Naga Munchetty and Vicky Pattison for giving evidence in public on their lived experience of having a reproductive health condition, and to Dame Lesley Regan, who gave oral evidence on this issue to both ourselves and our predecessors.

2 Public understanding of reproductive health conditions

- 7. The World Health Organisation (WHO) defines reproductive health as a "state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes." It adds: "Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so."¹⁰
- 8. NHS England defines a normal 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."¹¹
- 9. Good reproductive health is enabled by women being able to make informed decisions about their health and care throughout their life. However, many women and girls and, as we discuss later, members of the medical community, do not understand what a healthy period and good reproductive health look like. This lack of understanding can lead to individuals normalising painful symptoms, such as long, heavy and painful periods, while others may find them normalised for them, by friends and family—who may have experienced similar symptoms in their lifetime—and by healthcare professionals who are often ill-equipped to provide adequate support. A contributor to the inquiry told us:

As a young girl, I never learnt anything about endometriosis or other gynaecological conditions in school. At home, I was told by my own mother that periods are not a disease and therefore I should not be in bed and I should not be complaining. I now know that endometriosis runs in families and therefore the symptoms, such as period pain,

¹⁰ World Health Organisation, Reproductive health

¹¹ NHS England, Periods: Overview, 5 January 2023

¹² Royal College of Obstetricians and Gynaecologists (WRH0056)

abdominal discomfort, digestive issues and heavy bleeding are commonly dismissed and normalized by others around us. "You have painful periods? So what? I have painful periods too." ¹³

10. A lack of understanding and knowledge of what constitutes a 'normal' period or menstrual cycle delays people from seeking help and can leave family and friends uncertain on how to provide support. It also makes it difficult for women to advocate for themselves to medical practitioners without fear of being dismissed.

Stigma and shaming

11. Stigma around menstruation, sex, fertility and childlessness is a barrier to discussion of reproductive ill health. It contributes to delays in diagnosis and treatment, and can lead women and girls to turn to online forums to self-diagnose or to avoid seeking treatment altogether. A poll commissioned by the Royal College of Obstetricians and Gynaecologists (RCOG) found that over half (53%) of women in the UK who had experienced symptoms of pelvic floor dysfunction did not seek help from a healthcare professional, with 21% feeling too embarrassed to seek support. In 2018, a YouGov poll found that 'period shaming' happened at home, in the workplace and at school in the UK. The RCOG noted:

There is an immense societal pressure on women and girls to conceal their periods due to beliefs that menstruation is unhygienic or unclean, and talking openly about periods is often not considered as a social norm. Women are expected to anticipate and tolerate period pain, heavy bleeding and negative mood changes. ¹⁸

12. If women do not feel they are able to seek help it can lead to the progression of disease and worsening of symptoms that may result in the increased need for clinical interventions and further impact on women's lives. 29% of respondents to the Women's Health Strategy for England's call for evidence

¹³ Evidence submitted in confidence (WRH0030)

¹⁴ Nottingham Women's Centre (WRH0032)

The Academy of Medical Sciences (<u>WRH0033</u>); The Royal College of General Practitioners (<u>WRH0034</u>); Dr J P White MRCPsych et al, National High Secure Healthcare Service for Women, Rampton Hospital, Nottinghamshire Healthcare NHS Foundation Trust (<u>WRH0040</u>); Bayer PLC (<u>WRH0041</u>); Bloody Goody Period, FRSH (<u>WRH0048</u>)

¹⁶ Royal College of Obstetricians and Gynaecologists (WRH0056)

ActionAid, More than one in three UK women face period stigma, 25 May 2018, accessed 27 October 2024

¹⁸ Royal College of Obstetricians and Gynaecologists (WRH0056)

- said they did not feel comfortable talking to healthcare professionals about gynaecological conditions, this rose to 40% among respondents aged 16 to 17.¹⁹
- 13. While stigma and shaming around menstruation is widespread, it can be particularly acute in certain communities. For example, academics sharing concerns about the experiences of some South Asian girls and women in the UK described how cultural and religious issues profoundly impacted their sexual and reproductive knowledge, needs, and access to services. They explained: "In South Asian cultures, it is generally believed that unmarried women do not need to be educated about their sexual and reproductive health", and that there is a belief that discussions regarding sexual and reproductive health could encourage premarital sexual relations.²⁰

Education and awareness

- 14. Knowledge is one of the major barriers that people face when accessing treatment and diagnosis. ²¹ We heard that understanding the symptoms, available treatment options, including suggested surgical procedures, their benefits, risks, and potential outcomes is crucial for women to be able to make informed decisions. ²² However, just 8% of respondents to the call for evidence on the Women's Health Strategy for England felt that they had access to enough information on gynaecological conditions and only 17% on menstrual wellbeing. ²³ Broadcaster Vicky Pattison told our predecessor Committee that reproductive health conditions are "woefully misunderstood":
 - [...]there is such an ignorance surrounding it and loads of stigma as well. I think because of all that, women are then ashamed to talk about it. We are just perpetuating this cycle, this horrible culture.²⁴
- 15. Poor menstrual health knowledge is particularly high among young women and girls, with one in seven reporting that they didn't know what was happening when they started their period.²⁵ We heard how up to 50% of women may have had an anatomical prolapse, but that many women in

¹⁹ Department for Health and Social Care, <u>Call for evidence outcome</u>: <u>Results of the</u> 'Women's Health – Let's talk about it' survey, 13 April 2022

²⁰ Dr Amit Anand, Dr Preethi Lolaksha Nagaveni and Ms Riya A. Singh (WRH0008)

²¹ Bloody Goody Period, FRSH (WRH0048)

²² Muslim Women's Network UK (WRH0031)

Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Menstrual health and gynaecological conditions, updated 30 August 2022

²⁴ Oral evidence taken on 18 October 2023, Q24 [Vicky Pattison]

Plan International UK, <u>Break the Barriers: Girls' experiences of menstruation in the UK</u> (PDF), p15, January 2018

- the UK, particularly in the 18 to 34 age range, do not know what the pelvic floor is.²⁶ A 2017 survey found that almost half of those who responded were unaware of what the cervix is.²⁷ Young women participating in research on women's health undertaken by the University of York and the King's Fund described not knowing what was 'normal' or 'what to expect' making it difficult to know when to seek help with regards to menstrual health.²⁸
- 16. By lacking knowledge on important aspects of their anatomy, women are more likely to suffer from poor health. The Scottish Women's Convention observed that it is "vital that sex education is modified to adequately teach young women about red flags and unhealthy reproductive health", a view echoed by many contributors to our inquiry.²⁹

Relationships, sex and health education

- 17. Education on reproductive health is delivered in schools as part of the health element of relationships, sex and health education (RSHE).³⁰
 Government guidance states that the curriculum should include "puberty, including menstruation, and this should as far as possible be addressed before onset."³¹
- 18. Comprehensive education for all young people on menstrual health is essential to break down stigma and embarrassment and to improve understanding of reproductive health in general. Yet, during our inquiry we heard that gynaecological care does not feature sufficiently and consistently

The Pelvic Obstetric and Gynaecological Physiotherapy organisation (<u>WRH0025</u>); Royal College of Obstetricians and Gynaecologists (<u>WRH0056</u>)

Jo's Cervical Cancer Trust, Half of women don't know what the cervix is (charity and website have since closed); "11 things you didn't know about your cervix", Cosmopolitan, 25 September 2020

Holly Essex, Julia Cream, Barbara Hanratty, Laura Jefferson, Laura Lamming, Asri Maharani, Jane McDermott, Thirimon Moe Byrne, Gemma Spiers, Karen Bloor, Women's priorities for women's health: a focus group study (PDF), The King's Fund and the University of York, December 2021

²⁹ Scottish Women's Convention (<u>WRH0003</u>), Bayer PLC (<u>WRH0041</u>), Academy of Medical Sciences (<u>WRH0033</u>); Birmingham City University (<u>WRH0005</u>); Menstrual Health Coalition (<u>WRH0020</u>)

The Relationships Education, Relationships and Sex Education and Health Education (England) Regulations 2019, made under sections 34 and 35 of the Children and Social Work Act 2017, made relationships education compulsory for all pupils receiving primary education and relationships and sex education (RSE) compulsory for all pupils receiving secondary education. They also made health education compulsory in all schools, except independent schools. Personal, social, health and economic education (PSHE) continued to be compulsory in independent schools. Parents have the right to request that their child be withdrawn from some or all of sex education delivered as part of statutory RSE.

³¹ Department for Education, The Education Hub, 10 March 2023

during RSHE, and a lack of understanding among teachers affects the ability of girls and young women to spot and report problems.³² One contributor to our inquiry explained:

In sexual education at primary and secondary schools, periods are not taught in depth. No child goes away knowing what is normal, the different types and sizes of products out there, when to visit a GP, what PCOS, endometriosis, adenomyosis, fibroids, PMDD is. To empower women, you need to educate women.³³

Women's Health Ambassador for England, Dame Lesley Regan, noted that while sex education is mandatory, "what has not been mandated is the training for the staff to deliver it." She drew attention to "a massive need to put sex education in schools right front and centre":

The average age of menarche—of periods starting—has gone down to 10 years of age. Therefore, if you are not teaching the eight and nine-year-olds—and you need to teach the boys and the girls about it—you're going to miss it."³⁵

Concern was raised that menstrual education that focuses primarily on accessing and using menstrual products, and managing and concealing bleeding, may also serve to reinforce stigma rather than tackling it.³⁶

Relationships, sex and health education review

- 19. In March 2023, the then Government committed to reviewing relationships, sex and health education.³⁷ A consultation was published in May 2024 alongside draft, updated statutory guidance on RSHE.³⁸
- 20. The Women's Health Strategy for England contains an ambition for "comprehensive menstrual and gynaecological health education for both girls and boys from young age".³⁹ We note that the draft guidance includes more topics on reproductive health than covered in the current (2019) guidance. Specifically, it states that by the end of secondary school students should know about "menstrual and gynaecological health, including what is

Professor Kay Marshall, University of Manchester (<u>WRH0009</u>); Menstrual Health Coalition (<u>WRH0020</u>); Q42 [Dame Lesley Regan]

³³ Evidence submitted in confidence (WRH0024)

³⁴ Q42 [Dame Lesley Regan]

³⁵ Q42 [Dame Lesley Regan]

³⁶ Brook (WRH0051)

³⁷ Gov.uk, Review of relationships, sex and health education to protect children to conclude by end of year, 31 March 2023

³⁸ Gov.uk, Review of the RSHE statutory guidance, 16 May 2024

³⁹ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, updated 30 August 2022

an average period, period problems such as premenstrual syndrome, heavy menstrual bleeding, endometriosis, and polycystic ovary syndrome (PCOS), and when to seek help from healthcare professionals." This is alongside: "The facts about reproductive health, including fertility and menopause, and the potential impact of lifestyle on fertility for men and women." These are important and welcome additions to the curriculum.

21. There are calls for information on conditions such as heavy bleeding and endometriosis to be taught "as early as possible" so that girls and young women are aware of their symptoms and treatment options at the earliest opportunity.⁴¹ We heard that specific information on how women and girls from minority ethnic groups might be affected by reproductive health conditions is missing from reproductive health education.⁴²

Educating boys

22. The draft statutory guidance removes reference to boys learning about menstruation, which is set out in the 2019 edition. This is a surprising omission; educating girls alone about periods can promote the idea that periods are something shameful to be talked about in secret or to be hidden. Overnment guidance on the period product scheme for schools, for example, notes, "You should consider what you can do to create an open, whole-school approach to menstruation, for example by [...] including pupils and students who do not have periods in your discussions. We note that young women participating in a Department of Health and Social Care-funded period project run by Brook reported a desire to ensure their male peers were educated about menstruation alongside them.

Department for Education, <u>Draft Relationships Education</u>, <u>Relationships and Sex Education</u> (RSE), and Health education, 16 May 2024, p29

HC Deb, 21 May 2024, <u>col 340WH</u> [Westminster Hall]; Circle Health Group, <u>Living with</u> endometriosis: Keisha's story, 23 October 2023

⁴² Birmingham City University (WRH0005)

Department for Education, <u>Relationships and sex education (RSE) and health education</u>, updated 13 September 2021, p31

⁴⁴ Brook (WRH0051); Royal College of Obstetricians and Gynaecologists (WRH0056)

Department for Education, <u>Period product scheme for schools and colleges</u>, updated 30 May 2024

⁴⁶ Brook (WRH0051)

23. CONCLUSION

High quality education about reproductive health is vital. Educating girls about their periods and the possibility of related conditions at a young age safeguards them against the distress of not understanding what is happening to their bodies and empowers them to identify problems and to seek help. We welcome the inclusion of teaching about reproductive health conditions in the draft RSHE statutory guidance.

24. CONCLUSION

However, we are concerned that the teaching of the menstrual health element of relationships, sex and health education is insufficient and inconsistent. It is often delivered too late in a child's development to be of use and by teachers who lack the necessary training. The requirement in the draft guidance that schools need to cover reproductive health conditions only by the end of year 11 contrasts with Government advice that puberty and menstruation should be addressed before onset. It needs revising.

25. RECOMMENDATION

The Government should ensure teachers tasked with delivering the menstrual and gynaecological health element of RSHE receive the training necessary to deliver it effectively. Information on women's reproductive health conditions should be taught early on in secondary education, preferably around the time most girls first experience menstruation. That information should include guidance on what is and is not considered to be healthy reproductive health and cover intersectional differences, preparing pupils to advocate for their needs and seek help when necessary.

26. RECOMMENDATION

The guidance fails to recognise the importance of boys and men understanding reproductive health conditions that their peers might experience and their role in changing the culture and stigma that girls face. The statutory guidance should specify that boys should be taught about female reproductive health conditions.

Publicly available information

NHS website

27. The Women's Health Strategy for England includes action to improve the information available to women via the NHS. It states that the NHS will transform its website into a "world-class, first port of call for women's health information" by updating content, adding new content and including third-party content to create a "trusted and comprehensive guide to women's health." The former Minister for Women and Women's Health Strategy told our predecessor Committee:

One of the big pieces of feedback we had from women is that, when they have maybe gone to the [NHS] website because they are concerned about some signs and symptoms they are having, when they ask for help, they are very often not listened to or have a negative experience.⁴⁸

- 28. The NHS has a dedicated 'women's health area' on its website. It includes information on reproductive health, including periods, womb and ovary health, premenstrual dysphoric disorder (PMDD), and adenomyosis, as well as symptoms, when to see a doctor, and possible treatments. This is a positive step, as women with lesser-known conditions such as PMDD are struggling to get their doctors to recognise it. Although general information on mental health features in the women's health area of the website, there is a lack of signposting to support in sections relating to specific conditions, such as heavy periods. Naga Munchetty and Vicky Pattison called for the introduction to the website of an interactive tool such as a series of questions or flowchart to help guide women towards potential diagnosis.
- 29. Giving evidence to us in November 2024, Dame Lesley Regan stressed the importance of how information on reproductive health conditions is communicated and said that social media should be utilised better:
 - [...]we have to recognise that if we want the next couple of generations of young girls and boys to understand what these things are, then we have to communicate with them in the way they receive and absorb their information, and it is not on pieces of paper.⁴⁹

Department of Health and Social Care, <u>Women's Health Strategy for England</u>, our top commitments, updated 30 August 2022

⁴⁸ Oral evidence taken on 29 November 2023, Q137 [Maria Caulfield]

⁴⁹ Q48 [Dame Lesley Regan]

Dr Sue Mann, National Clinical Director for Women's Health at NHS England said that the NHS needed to "get better" at producing its own digital information and to "start keeping pace" with existing women's health apps: "We could use the NHS app better and YouTube, but we need to get out into the space to understand that a little bit better." 50

30. This is urgent with the rise of femtech, such as period-tracking or fertility-monitoring apps, some of which may present a risk to women, especially in areas of data protection. Respondents to the Women's Health Strategy for England's call for evidence suggested further research into digital technologies that help women understand their bodies better and to consider how the femtech sector could collaborate with the NHS.⁵¹ We heard that those within the NHS found it "really difficult" to keep pace with the "explosion of femtech apps" and that a funding call had been issued for femtech proposals.⁵²

Access to intersectional information

31. Some cohorts of girls and women are more prone to particular reproductive health conditions. For example, Black women are more likely to have uterine fibroids and they tend to be greater in size, number and severity than experienced by women in other ethnic groups;⁵³ while research suggests that autistic people have a higher-than-average rate of challenging periods and hormonal conditions which affect the regularity of periods.⁵⁴ Women from South Asian ethnic groups are thought to be at a higher risk of polycystic ovary syndrome.⁵⁵ During the inquiry we heard that there is a need for information to be tailored to the needs of specific groups, with relevant factors including ethnicity, disability, socio-economic status, geographic region, disability and age. The Royal College of Obstetricians

⁵⁰ Q28 [Dr Sue Mann]

⁵¹ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Data and digital, updated 30 August 2022

⁵² Q28 [Dr Sue Mann]

⁵³ Black Women's Reproductive Health project report, July 2022

⁵⁴ Dr Rachel Moseley, Bournemouth University (WRH0022)

Ouma Pillay, Kimmee Khan, Kamal Ojha, "Polycystic ovary syndrome in South Asians", Science Direct, 6 April 2023, pp185-190; D A Rodin, G Bano, J M Bland, K Taylor, S S Nussey, "Polycystic ovaries and associated metabolic abnormalities in Indian subcontinent

Asian women", Clinical Endocrinology, Vol 49, No 1, July 1998; "Woman shares yearslong experience with PCOS to spotlight the impact on South Asian women", ABC News, 23

May 2023; Written evidence received for the Women and Equalities Committee's inquiry into Changing the perfect picture: an inquiry into body image, Professor Wiebke Arlt and Professor Shakila Thangaratinam (MISSO032), July 2020

and Gynaecologists suggested that the roll out of women's health hubs (see later in this report) presented "a great opportunity for locally-tailored information that reflects the needs of the local population".⁵⁶

32. Different groups also have different accessibility needs. Contributors to the inquiry raised concerns with us that women without English as a first language or those without access to the internet face higher levels of exclusion from healthcare. A research study published in the British Journal of General Practice in May 2023 found that women from Black African ethnic groups and South Asian communities seeking help for perimenopause and/or menopause symptoms experienced communication gaps in consultations. These women requested changes such as more representation in health messaging, access to non-digital information—something the Women's Health Strategy has committed to delivering—and a checklist of symptoms to take to the doctor. Medical practitioners have also expressed the need for more educational resources in different languages, such as Urdu and Punjabi.

33. CONCLUSION

We welcome the ongoing improvements to the NHS website to include information about a wider range of women's reproductive health conditions, information to specific communities and signposts to support and the ambition to include that information in alternative formats.

34. CONCLUSION

We know that many women and girls are using online spaces to get information and seek help while there are gaps in support in medical fields. It is therefore imperative that the NHS and trusted sources become a first-port-of-call to prevent misinformation. The NHS website and app must therefore be comprehensive, accessible, inclusive, and highly-visible.

⁵⁶ Royal College of Obstetricians and Gynaecologists (WRH0056)

⁵⁷ This Independent Life (WRH0026)

Jennifer MacLellan, Sharon Dixon, Sultana Bi, Francine Toye and Abigail McNiven,

"Perimenopause and/or menopause help-seeking among women from ethnic minorities:

a qualitative study of primary care practitioners' experiences" (PDF), British Journal of General Practice, 3 May 2023, p514

Jennifer MacLellan, Sharon Dixon, Sultana Bi, Francine Toye and Abigail McNiven, "Perimenopause and/or menopause help-seeking among women from ethnic minorities: a qualitative study of primary care practitioners' experiences" (PDF), British Journal of General Practice, 3 May 2023, pp513–515

35. RECOMMENDATION

To supplement improvements in the provision of information on the NHS website, we recommend the inclusion of an interactive tool which can help women to determine whether they might have a reproductive health condition. We further recommend that information on specific conditions contains links to the relevant medical guidelines so that patients can make themselves aware of the care they should expect. Information on the website should be made accessible by default, including in different languages. The link between reproductive health conditions and mental ill health should also be clearer, with information on how to access support signposted. Women's health hubs should be commissioned to provide tailored information at a local level, in a range of formats suited to their local population.

36. RECOMMENDATION

With women and girls relying on online spaces and a proliferation of femtech apps to fill gaps in their knowledge of reproductive health conditions, the NHS should increase its own digital and social media presence in relation to reproductive health conditions. This should be consistent rather than a one-off campaign and monitored to ensure it reaches those in need of support with their reproductive health.

3 Accessing diagnosis

- 37. While personal and societal barriers, such as the stigma in discussing reproductive health and the normalisation of symptoms, contribute to women avoiding seeking medical support, 60 many women and girls who do turn to healthcare practitioners often find a service that is ill-equipped to help them with a diagnosis or is dismissive of their concerns. 61
- 38. Delays in diagnosis of a reproductive health condition can leave women with prolonged experience of chronic pain.⁶² It can have long-term irreversible consequences for women's physical and mental health and lead to a worsening of symptoms and the onset of other conditions such as diabetes and heart disease, and infertility.⁶³

Dismissal of symptoms

- **39.** Our predecessor Committee heard from women who had lost trust in the medical care they were being provided with, many of whom had undergone repeat appointments with their GP only for their symptoms of menstrual pain to be routinely dismissed. ⁶⁴ Such experiences occur across women's lifespans.
- **40.** In a 2024 report based on a survey of 4,371 people in the UK who had received an endometriosis diagnosis, the charity Endometriosis UK found that almost half had visited their GP 10 or more times with symptoms before receiving their diagnosis. 70% had visited five times or more, 52% had visited A&E at least once and 20% reported seeing a gynaecologist 10 or more times before being diagnosed. The charity found an increase in the number of people reporting that one or more doctors had told them they were making a "fuss about nothing" or similar comments from

⁶⁰ Professor Kay Marshall, University of Manchester (WRH0009)

All-Party Parliamentary Group on Women's Health, <u>Informed Choice? Giving women control of their healthcare</u>, 27 March 2017; Evidence submitted in confidence (WRH0019); Muslim Women's Network UK (<u>WRH0031</u>); Academy of Medical Sciences (<u>WRH0033</u>); Ms Sara Peat, Clinical Psychologist in training at NHS (<u>WRH0038</u>); Birmingham City University (<u>WRH0005</u>) and others

Nottingham Women's Centre (<u>WRH0032</u>); Royal College of Obstetricians and Gynaecologists (WRH0056)

⁶³ Muslim Women's Network UK (WRH0031)

⁶⁴ Evidence submitted in confidence

69% of respondents in 2020 to 78% in 2023.⁶⁵ Research commissioned by the previous Government to inform the Women's Health Strategy for England found that some primary care clinicians did not think a diagnosis was necessary if the symptoms of a gynaecological condition could be adequately controlled in primary care.⁶⁶

- 41. We heard that GPs were not always aware of conditions such as PMDD and adenomyosis, requiring women to self-diagnose and then push for official diagnosis, or to seek private medical care, often taking years.⁶⁷ Research conducted by the Circle Health Group on women's health found that 80% of women it spoke to with suspected or diagnosed adenomyosis in the UK felt dismissed throughout their healthcare journey.⁶⁸
- 42. For most, the journey to a diagnosis for adenomyosis is a long one, with 26% of women surveyed in the UK waiting 10 years for diagnosis and 43% waiting more than five years. ⁶⁹ Endometriosis affects one in 10 women, yet in the UK it takes an average of around eight years and 10 months to be diagnosed, having increased since the pandemic. ⁷⁰ Global research shows that women from Black ethnic backgrounds are 50% less likely to be diagnosed with endometriosis than White women. ⁷¹ Research by Holland & Barrett found that 75.2% of endometriosis patients reported being misdiagnosed with another physical or mental health condition. ⁷² Vicky Pattison described her experience of PMDD:

PMDD gets zero sunlight. Not a lot of people know about it or understand it. It is commonly misdiagnosed in women as ADHD or depression. The first thing I was offered was antidepressants. I am not depressed; I am happy, I am strong, I am mentally well, I have a good life. It is not that I am depressed; I have PMDD. The fact that was offered as a first port of call was incredibly frustrating.⁷³

⁶⁵ Endometriosis UK, Years of being "dismissed, ignored and belittled": Endometriosis UK urges improvement to deteriorating diagnosis times, March 2024

⁶⁶ Simon Briscoe, Jo Thompson Coon, GJ Melendez-Torres, Rebecca Abbott, Liz Shaw, Michael Nunns, and Rush Garside, "Primary care clinicians' perspectives on interacting with patients with gynaecological conditions: a systematic review", interpretive analysis, BJGP Open, 2024, 8 (1).

⁶⁷ Oral evidence taken on 18 October 2023, Q26 [Naga Munchetty]; Q27 [Vicky Pattison]

⁶⁸ Menstrual Health Coalition (WRH0020)

⁶⁹ Menstrual Health Coalition (WRH0020)

⁷⁰ Endometriosis UK, Years of being "dismissed, ignored and belittled": Endometriosis UK urges improvement to deteriorating diagnosis times, March 2024

⁷¹ Dr Véronique Griffith, The University of Manchester, Dr Andrea Ford, University of Edinburgh, and Dr Annalise Weckesser, Birmingham City University (WRH0047)

⁷² Holland & Barrett (WRH0027)

⁷³ Oral evidence taken on 18 October 2023, Q12 [Vicky Pattison]

43. Ms Pattison's symptoms, including fatigue, insomnia, anxiety, self-doubt and suicidal thoughts were dismissed as a normal part of ageing for women with doctors across the country telling her: "This is PMS. This is what women go through. Every other woman in the world is dealing with this." Like many other women who submitted evidence to this inquiry, Ms Pattison said that it was not until she also accessed private medical care that a diagnosis was forthcoming. Without a quick diagnosis and support from doctors, Ms Pattison described being left feeling "weak, stupid and ashamed":75

I cannot tell you how many times I got told, "Oh, they will get worse as you get older, this is just natural," and you believe it. "You absolutely believe it, and you believe that you are weak, that you cannot cope with what every other woman is coping with."⁷⁶

The Pelvic Obstetric and Gynaecological Physiotherapy organisation described women presenting with conditions such as bladder and bowel incontinence and vaginal prolapse being told "well what do you expect, you've had children".⁷⁷

Effect of age on diagnosis

- 44. Medical practitioners appear to have a poor understanding of the age that symptoms of some reproductive health conditions can appear, which contributes to women being dismissed and delays in diagnosis. Symptoms of endometriosis can start with a girls' first period, yet, as Kay Marshall, Professor of Reproductive Endocrine Pharmacology, University of Manchester, explained, women are being told by GPs that they are too young to have endometriosis "despite age not being a diagnostic criterion".⁷⁸
- **45.** Broadcaster Naga Munchetty described to us how she had experienced severe reproductive ill health since puberty aged 15, including heavy, prolonged bleeding and nausea:

I would bleed for 11 or 12 days; I would say about eight or nine of them were very heavy. I would throw up on the first day, at least once or twice—I would be wrapped around a toilet—and I would pass out at least once or twice but I would still go to school. [...] That lasted

⁷⁴ Oral evidence taken on 18 October 2023, Q6 [Vicky Pattison]

⁷⁵ Oral evidence taken on 18 October 2023, Q6 [Vicky Pattison]

⁷⁶ Oral evidence taken on 18 October 2023, Q6 [Vicky Pattison]

⁷⁷ The Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

⁷⁸ Dr Véronique Griffith, The University of Manchester, Dr Andrea Ford, University of Edinburgh, and Dr Annalise Weckesser, Birmingham City University (WRH0047); Endometriosis UK, Is this normal? Educating young women about endo, accessed 27 November 2024; Professor Kay Marshall, University of Manchester (WRH0009)

throughout the whole of my life. Whenever I went to the doctor, I was told it was normal.[...]It made relationships difficult: I had to have very understanding partners. I would worry about what I wore, particularly when I was in front of the camera because of leaking, but my adenomyosis was not diagnosed until I was 47.

Chair: Thirty two years?

Naga Munchetty: Yes.

Chair: How much of that time were you told that this was just a period,

this was normal?

Naga Munchetty: Thirty two years.⁷⁹

46. A study looking at experiences of urogynaecological conditions and related health services found that some women felt they were an anomaly for being a younger person with urinary incontinence, and others felt trivialised as an older person with the same condition. The advocacy and support group This Independent Life warned that harmful myths that reproductive conditions disappear with menopause leave older women's concerns dismissed. We heard how some GPs incorrectly believe that pelvic floor muscle training is not effective for older women and containment is the only option. The Pelvic Obstetric and Gynaecological Physiotherapy organisation told us that longer GP appointment times are needed to properly assess pelvic floor symptoms, ensure optimum results and reduce symptoms.

Normalisation and dismissal of pain

47. A common theme in the evidence received was that of women's pain being dismissed, not just due to a lack of understanding as to what might be causing it but because of a lack of empathy and "medical misogyny". 84 Women reported not feeling listened to and being "gaslit", especially when accessing NHS services about a gynaecological issue that included pain. 85 A 2024 survey of more than 5,000 UK adults by Reckitt, the manufacturer of Nurofen, found that the proportion of women who reported their pain being ignored or dismissed by healthcare professionals had increased from 49% in 2023 to 62% in 2024. Over a quarter of women said they had started to

⁷⁹ Oral evidence taken on 18 October 2023, Qq2-4 [Naga Munchetty]

⁸⁰ Dr Abigail Niven and Dr Francine Toyle, University of Oxford (WRH0013)

⁸¹ This Independent Life (WRH0026)

⁸² Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

⁸³ Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

This Independent Life (WRH0026); Q49 [Rebekah Lloyd]

This Independent Life (WRH0026)

question themselves; believing their pain was not serious or real after being dismissed. 86 One in ten respondents to Reckitt's 2023 survey reported their GP describing them as overly emotional and 17% were told they were being overly dramatic. One in two women reported that they had had their pain dismissed because of their gender. Naga Munchetty told our predecessor Committee:

No woman says she is in pain unless she is in real pain. No woman says she is anxious unless she is really anxious. No woman wants to appear weak or appear incapable until she really is, until she cannot cope any more, and it should not be that way.⁸⁷

- 48. How women's pain is considered and managed can depend on their ethnic group and cultural belief, described by Charlotte McArdle, the Deputy Chief Nursing Officer at NHS England, as a "huge awareness issue" and a priority area of the Women's Health Strategy for England. While there is a general lack of research on how menstruation and reproductive health conditions affect people from different ethnic groups, people of African descent are more likely to report having their pain dismissed or minimised by medical practitioners, despite research suggesting that chronic pelvic pain is highly prevalent in Black British women. Research has also shown that racial biases in healthcare lead to practitioners believing that Black people have a different pain threshold than other ethnic groups. This is wholly unacceptable and dangerous.
- 49. Since the Women's Health Strategy for England was published we heard there has been some progress in building up trust with women from disadvantaged and marginalised groups to provide feedback on their care. However, we were also told that clinicians still need to "get smarter" at not making assumptions, there is "a lot of unconscious bias going on" and training is needed. P2
- **50.** Several contributors to the inquiry also highlighted problems with access to care for trans, non-binary and intersex people, as well as the distress that reproductive health conditions and procedures can cause for these

⁸⁶ Nurofen, Gender Pain Gap: Index Report Year 3, October 2024

⁸⁷ Oral evidence taken on 18 October 2023, Q31 [Naga Munchetty]

Oral evidence taken on 18 October 2023, Q151 [Charlotte McArdle]

Mayo Clinic, Uterine fibroids are more common and severe in Black women -- but there are treatment options, 4 January 2024; Brook (WRH0051); Black Women's Reproductive Health project report, July 2022, p24

Oral evidence taken before the Women and Equalities Committee on 30 March 2022, HC 1232, Q10 [Professor Knight]; Oral evidence taken before the Health and Social Care Committee on 15 December 2020, HC (2019–2021) 677, Q133 [Professor Knight]

⁹¹ Q2 [Dame Lesley Regan]

⁹² Q2 [Dr Sue Mann]

groups.⁹³ The Academy of Medical Sciences said the limited evidence available "suggests that these groups face discrimination within the health system and worse health outcomes."⁹⁴ The RCOG is developing clinical guidelines on inclusive and accessible obstetrics and gynaecological care for trans and gender diverse individuals.⁹⁵

51. The experiences that many women have described to us are devastating. One patient who was diagnosed with mild endometriosis seven years ago and advised that it was nothing to be concerned about told how she had to "plead" with her GP to be referred for ultrasounds due to the pain they were experiencing. A new diagnosis showed ovarian cysts and endometriosis. 96 Another contributor told us:

I was dismissed and not listened to by the first two gynaecologists who kept telling me my pain wasn't as bad as I was telling them. It was hell. The third gynaecologist changed my life but I'll never get my fertility back or those 11 years of pain, fatigue and misery.⁹⁷

Even when treatment is recommended, a waiting list of over six months left one patient, "in constant pain, with heavy bleeding and [considering] taking their own life as a result."98

- **52.** The Women's Health Strategy for England includes ambitions to:
 - end taboos and stigmas that "reinforce beliefs among women, health and care professionals, and wider society that health problems or painful symptoms—in particular 'hidden pain', which could be a symptom of gynaecological conditions—are normal and something to be endured".
 - ensure that "healthcare professionals in primary care are well informed and trained in menstrual and gynaecological health, and can offer women and girls evidence-based advice and treatment." 99

⁹³ Dr Rachel Moseley, Bournemouth University (WRH0022)

⁹⁴ Academy of Medical Sciences (WRH0033); Brook (WRH0051)

⁹⁵ Royal College of Obstetricians and Gynaecologists (WRH0056)

⁹⁶ Healthwatch Liverpool (WRH0002)

⁹⁷ Evidence submitted in confidence (WRH0012)

⁹⁸ Healthwatch Liverpool (WRH0002)

⁹⁹ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Women's voices, updated 30 August 2022

53. CONCLUSION

There is a clear lack of awareness and understanding of women's reproductive health conditions among primary healthcare practitioners, particularly when those conditions occur in young women and girls. Women are finding their symptoms normalised and their pain dismissed, with an ingrained belief among some healthcare professionals that women, particularly those from a minority ethnic background, are exaggerating their symptoms. Such medical misogyny and racism is unacceptable.

54. RECOMMENDATION

The NHS needs to urgently implement a training programme to improve the experience of treatment and diagnosis in primary care for women, girls, trans and non-binary people with reproductive ill health. Improving early diagnosis, including through the provision of follow up appointments, must be a priority to prevent a worsening of symptoms. The programme should seek to challenge racial biases and ensure that all those experiencing pain are believed and able to access treatment and support quickly. It should include training to support women and girls whose socio-cultural situation or beliefs make it harder to discuss reproductive health conditions and involve women and girls with lived experience.

55. RECOMMENDATION

Improvements in diagnosis times should be made a key performance indicator for the Women's Health Strategy for England.

56. RECOMMENDATION

We support the Royal College for Obstetricians and Gynaecologists' initiative for a guideline on inclusive care. When finalised it should be implemented throughout the healthcare system and medical practitioners must receive adequate training, with implementation monitored by the RCOG.

57. We discuss some of the challenges to improving healthcare and the steps needed to address them later in this report.

4 Accessing treatment and support

58. Women who have accessed treatment for reproductive ill health report common negative experiences and concerns including limited treatment options, adverse side effects, an unwanted emphasis on fertility, painful investigative procedures and unequal access to treatment.

Limited options

59. Individuals giving evidence to this inquiry described a lack of treatment options for their conditions. We heard that contraceptive pills were often "seemingly the answer to any and every female issue" which is "perpetuated by current guidelines and medical training"; with doctors preferring to prescribe oral contraceptives to treat the symptoms of heavy menstrual bleeding and endometriosis, "instead of developing a plan that met the needs of the individual". We were told that "lose weight" was common advice from doctors, including to women with polycystic ovary syndrome (PCOS)—a condition which notably makes weight loss challenging. One contributor to the inquiry observed:

At 26, I was finally diagnosed with PCOS via some seemingly very simple tests, after a significant increase in symptoms; the only treatment recommended was a birth control pill. Ten years on, my lack of understanding of PCOS and poor guidance and treatment from the NHS regarding the condition have left me with worsening hormonal health, more distressing symptoms of the illness, and increasing difficulty with food and weight. I face possible infertility, impacting my husband and our future plans, but am now too old for help from the NHS. It is only this year that I have been prescribed metformin and given clear advice and guidance on next steps; unsurprisingly, this was by a private consultant who expressed real surprise that I had not been given this option much earlier by NHS professionals.¹⁰²

¹⁰⁰ Academy of Medical Sciences (<u>WRH0033</u>); This Independent Life (<u>WRH0026</u>); Holland & Barrett (<u>WRH0027</u>); Evidence submitted in confidence (<u>WRH0030</u>)

¹⁰¹ Muslim Women's Network UK (<u>WRH0031</u>); Evidence submitted in confidence (WRH0030); This Independent Life (<u>WRH0026</u>)

¹⁰² Evidence submitted in confidence (WRH0017)

- 60. Treatment on offer can be variable across the country, or among the population. For example, we heard how potential non-surgical treatments such as the use of a vaginal pessary device used to help women with pelvic organ prolapse to stay active are dismissed by GPs as "something only older women get". Women diagnosed with fibroids are often directed towards a hysterectomy, without being offered any alternative interventions, or other surgical options. It was also made clear to us that some treatment options, such as pelvic floor therapy and psychological therapies, are not uniformly offered or available.
- 61. Naga Munchetty described how a lack of treatment options for adenomyosis, other than hysterectomy or contraception, leave women who do not want or are not able to have these to "suck it up". While treatment with the Depo-Provera contraceptive injection was initially successful, doctors withdrew it in Ms Munchetty's early forties due to concerns about osteoporosis, despite her wishing to stay on it and take precautionary measures. The contraceptive coil did not work as a replacement and she was "told there was nothing else":

I was in floods of tears. I was panicked. I thought, "I can't go back to the life I used to have," when I used to have periods every three weeks and bleed for 11 days. It was, "Tough, you'll find something that works". 106

Dr Sue Mann, who was appointed as the first National Clinical Director for Women's Health at NHS England in April 2024, told us that GPs needed to get better at listening:

Rather than say, "Well, that is the best thing for you," we need to get good at listening and saying, "Okay. That would be the best treatment at this stage for you, but it is your choice." It is about having those initial conversations in a sympathetic way and saying, "Here is a range of treatments. These are the kind of things that may happen, and this is what won't. What would you like to do?" 107

We note that recently updated National Institute for Health and Care Excellence guidelines on the diagnosis and management of endometriosis recommends that investigations such as ultrasound and referral take place in conjunction with initial pharmacological treatment.¹⁰⁸

¹⁰³ Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

¹⁰⁴ All Parliamentary Group on Women's Health (WRH0018)

¹⁰⁵ This Independent Life (WRH0026)

¹⁰⁶ Oral evidence taken on 18 October 2023, Q14 [Naga Munchetty]

¹⁰⁷ Q13 [Dr Sue Mann]

National Institute for Health and Care Excellence, <u>Endometriosis: diagnosis and</u> management, last updated 11 November 2024

Fertility

- 62. Some women told us that it was only in relation to their fertility that they felt their symptoms and concerns were taken seriously by medical practitioners, while others recounted being denied treatment if medical professionals believed that it could affect their fertility, despite them not wanting to have children.¹⁰⁹
- 63. A focus on fertility in these circumstances can undermine the impact of these conditions on women's daily lives and their full body experience of pain and discomfort. Catherine McKinnell MP described the impact of such an approach during a parliamentary debate on endometriosis:

Thinking of the disease primarily as a barrier to pregnancy or as simply making a girl's or woman's periods more painful is a gross oversimplification and, in many cases, incredibly inaccurate[...] The disease can vary widely in severity in the way it manifests. For example, 12% of endometriosis cases target women's lungs and can cause symptoms beyond chronic pain—symptoms that can shatter a woman's confidence and have a debilitating effect on her mental health. Endometriosis can also cause chronic bowel and bladder-related symptoms.¹¹⁰

64. Notwithstanding these concerns, discussion on fertility remains a necessary part of the conversation with patients. We heard from women who described being desperate to ensure that any treatment did not jeopardise their chances of having children, as well as those whose treatment had done exactly that.¹¹¹ Contributors to our inquiry suggested that more information should be made available to patients ahead of surgery about risks to fertility, including options regarding egg freezing.¹¹² Delays in diagnosis contribute to increased infertility risks.

¹⁰⁹ Evidence submitted in confidence (WRH0023); Dr Véronique Griffith, The University of Manchester, Dr Andrea Ford, University of Edinburgh, and Dr Annalise Weckesser, Birmingham City University (WRH0047)

¹¹⁰ HC Deb, 21 May 2024, col 344WH [Westminster Hall]

¹¹¹ Evidence submitted in confidence (WRH0030)

¹¹² Evidence submitted in confidence (WRH0030)

65. CONCLUSION

Healthcare practitioners lack sufficient understanding of the range and suitability of treatment options available to treat reproductive health conditions. Too often conditions are viewed through the prism of fertility which, while a necessary consideration, should not be the only factor influencing a clinician's judgement. There is also an evident lack of empathy in primary care around the adverse effects some treatment options may have on a patient. For example, approaches which focus on managing symptoms rather than diagnosis risk diseases progressing with potentially life altering consequences.

66. RECOMMENDATION

The NHS must take steps to ensure healthcare practitioners keep up to date with the full range of diagnostic and treatment options available for reproductive health conditions. Those options, as well as waiting times and potential outcomes of surgical procedures and non-invasive alternatives, should be communicated to patients as a matter of course to allow informed, shared decision making. The NHS should identify and address any regional disparities in the availability of particular treatments and support.

Pain of investigation

While investigations and procedures for gynaecological and urogynaecological conditions can be lifesaving and result in reduced overall pain, one of the most troubling aspects of our inquiry is the evidence we received of women undergoing painful procedures such as hysteroscopy (a test to look inside a woman's womb) and having a contraceptive coil fitted. Women told us they had not been properly prepared for what was involved or given adequate pain relief. Informed consent is vital yet we heard many examples of women not being given sufficient information, particularly in relation to anaesthesia, to be able to make an informed choice on pain relief. In some cases, women were told to attend for "a small procedure", without being advised what it was and they did not feel they could ask for it to stop. One contributor described her experience of a hysteroscopic myomectomy:

I was concerned about being awake but they assured me it would be fine if I took two paracetamol before my appointment which I did. It was the most horrendous experience of my life. It was painful and undignified.[...]I was having metal instruments being forced through my cervix. After the procedure I could not stop crying[...]I do not wish

¹¹³ Evidence submitted in confidence (WRH0004) and (WRH0039)

the hysteroscopy myomectomy on anyone awake and I hope no woman has to go through the trauma of it. Even thinking and typing about it now makes me sick to my stomach.¹¹⁴

The Campaign Against Painful Hysteroscopy shared with us many similar stories—from over 4,000 that they had collected—from women in the UK who had endured "brutal procedures".¹¹⁵ Naga Munchetty described to our predecessors how having an IUD (intrauterine device, or coil) fitted caused her to "scream the place down" due to the trauma involved.¹¹⁶ She told BBC Radio's 5 Live that she had felt "violated" by the procedure.¹¹⁷

68. The long-lasting effects and trauma resulting from painful medical procedures cannot be underestimated. Women should not be living with PTSD because of a routine procedure. One woman who underwent a hysteroscopy described how she felt like she had been "subject to an assault" when the pain of the procedure caused her to shake, leading to concerns she would have a seizure. Yet she was encouraged to keep going:

In the weeks and months following my outpatient experience I began to suffer frequent trauma symptoms. I found sexual intimacy impossible, any suggestion of it triggered terrifying flashbacks of the procedure and panic attacks where I'd feel like I was hyperventilating and desperate; there were incidences of self-harm in these moments. [...]

I was made to feel, by the staff involved, like an absolute anomaly as I was consistently told most women find this procedure totally acceptable and if they did find it painful they 'got through it'; I felt as though what I experienced must have been my fault and I'd failed to be brave enough.¹¹⁹

69. Law firm Bolt Burdon Kemp LLP told us it had seen cases where significant pain following gynaecological surgery had been dismissed, with women sent home only to be re-admitted to A&E in critical conditions with extensive sepsis. It said:

¹¹⁴ Evidence submitted in confidence (WRH0029)

¹¹⁵ The Campaign Against Painful Hysteroscopy (WRH0037)

¹¹⁶ Oral evidence taken on 18 October 2023, Q1 [Naga Munchetty]

[&]quot;Having coil fitted should not hurt, experts say", BBC News, 22 June 2021

¹¹⁸ The Campaign Against Painful Hysteroscopy (WRH0037)

¹¹⁹ Evidence submitted in confidence (WRH0043)

We have acted for women where their doctors have missed bowel perforations because concerns were dismissed as 'normal'. The common theme throughout our clients' experiences is severe pain being disregarded and women's concerns regarding their bodies being dismissed.¹²⁰

70. Dr Sue Mann said that while there was "really good information on the NHS website about procedures" it was important that people access it and at an early stage. Dr Mann added:

Of course, that information may not be accessible; for example, we have heard a lot about the issues, in particular, for women who do not speak English. How are we going to cater for them? Again, that will be down to really understanding local populations and making sure that local areas know their local population, so that they can ensure that they have the resources in the right languages. That is at an ICB [integrated care board] level, but making sure that we support them to do that kind of work is essential.¹²¹

Access to pain relief

71. The Campaign Against Painful Hysteroscopy raised concerns that women undergoing hysteroscopy and related biopsies are "routinely" denied sedation, in favour of outpatient treatment using over-the-counter pain relief and 'distraction techniques'. Where pain relief is taken, delays in appointments mean it can wear off by the time of being seen. Many women reported not having their concerns about pain taken seriously. One contributor observed following her experience of an outpatient hysteroscopy:

Women are told it will be no worse than a period cramp. Women are experiencing procedures where the Dr refuses to stop when it is clear the woman is in distress, saying "just a couple more minutes". Can you imagine having your teeth drilled for just a couple more minutes without any pain control.¹²⁴

72. Patients who recall a negative experience of treatment may hesitate to report new or different pain symptoms that may require evaluation in the future. The Department of Health and Social Care is unable to provide

¹²⁰ Bolt Burdon Kemp LLP, evidence submitted in confidence (WRH0019)

¹²¹ Q3 [Dr Sue Mann]

¹²² The Campaign Against Painful Hysteroscopy (WRH0037)

¹²³ Evidence submitted in confidence

¹²⁴ Evidence submitted in confidence (WRH0039)

- data on how many invasive surgical procedures to diagnose and treat a reproductive health condition were not completed because of the level of pain experienced by the patient.¹²⁵
- 73. The Campaign Against Painful Hysteroscopy told us it was concerned that NHS England's maternity and gynaecology 'Getting it right first time' report states that £6.6 million could be saved per year if 75% of endometrial ablations (thinning and destroying the lining of the uterus) could be done within outpatient care, meaning the patient is awake and it is not possible to fully anaesthetise the uterus with local anaesthetic. ¹²⁶ It warned: "we fear that NHS financial pressures are blinding gynaecologists to the severity of pain that 1 in 3 hysteroscopy outpatients suffers." ¹²⁷

Medical guidelines on pain relief for procedures

- 74. In 2023, the Royal College of Obstetricians and Gynaecologists (RCOG) published its good practice guide on pain relief and hysteroscopy. It states that "Most women describe a positive experience of hysteroscopy, with levels of discomfort acceptable to them, rapid recovery and avoidance of the need for a general anaesthetic." But it concedes: "However, it is important to recognise that hysteroscopy can cause severe pain and be traumatic for women. This is difficult to predict". It says women need to receive accurate written and verbal information: "It is of vital importance that women feel they can make informed and authentic decisions and choices" and that units need to match a woman's preferences, "which may necessitate referral to another colleague or an alternative hysteroscopy unit with additional facilities or pain control measures." The NHS webpage on hysteroscopy, updated in January 2024, states that "for many people a hysteroscopy can be very painful". 129
- 75. On general anaesthetic or sedation, the RCOG notes there are few units that currently offer sedation in an outpatient setting and that post-operative pain may not be any less. It compares the pain that women are likely to experience during and after the procedure to "period-like cramping and lower abdominal pain" but that if it's too painful or distressing the procedure should stop.¹³⁰ The Campaign Against Painful Hysteroscopy

¹²⁵ Genito-urinary Medicine: Surgery, PQ10152, 28 October 2024

¹²⁶ The Campaign Against Painful Hysteroscopy (<u>WRH0037</u>); NHS England and NHS Improvement, <u>Maternity and gynaecology GIRFT programme national speciality report</u> (PDF), September 2021, p105, table 9

¹²⁷ The Campaign Against Painful Hysteroscopy (WRH0037)

Royal College of Obstetricians and Gynaecologists, <u>Pain Relief and Informed Decision</u>

Making for Outpatient Hysteroscopy (PDF), Good Practice Paper No.16, p2, February 2023

¹²⁹ NHS, Hysteroscopy

Royal College of Obstetricians and Gynaecologists, <u>Pain Relief and Informed Decision</u>

Making for Outpatient Hysteroscopy (PDF), Good Practice Paper No.16, p2, February 2023

contends that the suggested tolerance level of this procedure is indicative of the view that women should be accustomed to and accept having painful periods and that risking severe pain is preferable to the inconvenience of missing time away from work or childcare.¹³¹

76. In response to media attention on distressing IUD fittings, in 2021 the Faculty of Sexual and Reproductive Healthcare (FSRH)—a membership body which issues clinical guidance and standards—recommended that:

Healthcare professionals should create a reassuring, supportive environment, offer appropriate analgesia (and referral on to another provider if they cannot offer this) and ensure that the patient is aware that they can request that the procedure stops at any time.¹³²

The Royal College of GPs told us that any healthcare professional who performs IUD fittings should be aware of the updated standard on consent from the FSRH as well as their updated statement on pain with IUD insertion:

It is unacceptable for any woman to walk away from an IUD fitting feeling traumatised by the level of pain she has experienced and GPs have a duty to ensure that all pain management options are discussed and that shared decision making takes place regarding analgesic options for IUD insertion.¹³³

77. The General Medical Council's (GMC) Good Medical Practice guidance, and the general duties of a doctor, include "good care, good communication and alleviating pain" as a general duty."¹³⁴ The GMC's Deputy Medical Director told us: "We should not have patients in pain. We should alleviate distress as a fundamental duty of a doctor."¹³⁵ It is clear from the evidence we received that this basic guidance has often been ignored when it comes to pain experienced by women, including due to a lack of shared decision making and informed consent. Medical practitioners should always be aware of the possibility that a woman may have prior history of experiencing pain during procedures such as a smear test or have experienced trauma during childbirth or sexual assault, which should be accounted for when procedures and options for pain relief are discussed.¹³⁶

¹³¹ The Campaign Against Painful Hysteroscopy (WRH0037)

¹³² FSRH, FSRH statement: Pain associated with insertion of intrauterine contraception, 30 June 2021

¹³³ Royal College of General Practitioners (WRH0034)

¹³⁴ Q88 [Professor Sue Carr]. The General Medical Practice is the independent regulator of doctors in the UK. It sets professional standards and oversees education and training.

¹³⁵ Q88 [Professor Sue Carr]

Healthwatch Birmingham (<u>WRH0049</u>); NHS, <u>Hysteroscopy</u>; Royal College of Obstetricians and Gynaecologists, <u>Outpatient hysteroscopy</u>.

78. In January 2023, former Women's Health Minister Maria Caulfield said that following the updated guidance on pain relief by the Royal College of Obstetricians and Gynaecologists, the Women's Health Strategy for England would consider hysteroscopy a "high priority", with work starting in 2023. The strategy includes an ambition that:

women and girls report improved experiences of care and gynaecological procedures, in particular experiences of pain during procedures such as hysteroscopy and IUD fittings. Disparities in access to care and experiences of care are tackled.¹³⁷

However, giving evidence in November 2024, Dr Sue Mann noted that "It is one thing having a guideline, but—really important—the next thing is making sure that people adhere to it." Dr Mann explained that medical professionals sometimes had difficulty adhering to guidelines because of what the health system could provide, but also that professional education was needed, guided by trauma-informed principles.¹³⁸

79. CONCLUSION

The NHS is failing many patients who undergo routine reproductive healthcare procedures such as hysteroscopy, IUD fitting and cervical screening. In too many cases, we find that a duty of care from gynaecologists and other medical practitioners is absent. Women are being pressured into enduring severe pain and find that they are ignored or belittled by those charged with their care when they cannot. The Women's Health Strategy for England does not sufficiently prioritise challenging this behaviour.

Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Menstrual health and gynaecological conditions, updated 30 August 2022

¹³⁸ Q5 and Q7 [Dr Sue Mann]

80. RECOMMENDATION

The NHS must do more to monitor and enforce protocols governing procedures such hysteroscopy, IUD fitting and cervical screening and ensure that they are underpinned by informed consent and are trauma-informed. A risk assessment that allows a patient to make an informed choice on the recommended procedure should be undertaken as standard, taking account of any previous history of undergoing related procedures. This should also include consideration of the patient's mental and physical preparedness for a penetrative procedure, particularly in cases where the individual has not had or recently had penetrative sex. The full range of options on pain relief, including anaesthesia, should be considered and a clear commitment made that if the level of pain during the procedure is unbearable, that procedure will be halted and a separate appointment will be made. As membership bodies, the Royal College of Obstetricians and Gynaecologists and the Royal College of General Practitioners should be doing far more to ensure their members adhere to guidelines and best practice.

81. RECOMMENDATION

Concerns about painful procedures have been raised for years with little sign of progress. We recommend the NHS collects data on whether guidelines for hysteroscopy, IUD fittings and other potentially painful gynaecological procedures are being adhered to. That data must include surveys of patient experience. Without the pressure of having this information captured we are sceptical there will be the necessary drive to improve the level of care.

82. RECOMMENDATION

Reducing the pain women experience during invasive procedures should be made a key performance indicator for the Women's Health Strategy for England.

Effect on mental health

83. The effect of reproductive ill-health on a person's mental health can be significant. Contributors to our inquiry described lost careers, relationships, hopes for a family, and spending huge amounts of money on period products and private healthcare because they were not able to manage the pain they experienced. Some had become addicted to painkillers because of

- their reproductive health conditions. Some had considered taking their own lives. A recent survey of women with heavy menstrual bleeding found that of 1,000 people surveyed, 67% suffered with depression. 40
- 84. We heard how women have changed careers or no longer work at all to better manage pain, symptoms and mental health by avoiding commuting and unsupportive workplaces. In 2024, the RCOG found that more than three quarters (76%) of women waiting for gynaecological care in the UK that it had surveyed reported worsening mental health. A respondent to a survey by the organisation This Independent Life described her experience of having such a condition:

It has taken a major toll on my body and mental health. It has had an impact on my relationship because all my energy goes to managing pain and trying to push through life and then I have nothing left for anything else. It has had a huge impact on both professional and personal life. I had to quit my job due to severe mental health issues as a result of having to live in chronic pain as my team didn't understand and weren't able/willing to offer the flexibility and support I needed.¹⁴³

- 85. A 2023 systematic review of research found a strong association between higher rates of depression and anxiety symptoms and pain associated with endometriosis. Hand Many contributors to our inquiry called for improved provision of mental health support, including its integration into treatment for reproductive ill health. Concern was raised that such support was only available in a handful of areas and that the support which was available was often too generic and did not take into account the specific needs of women with reproductive ill health. Health.
- **86.** Hospital waiting areas and wards that bring together patients with reproductive health conditions and women who are pregnant or have recently given birth can also have a negative effect on mental health and may prevent patients from seeking further medical support. We heard that

Evidence submitted in confidence; This Independent Life (<u>WRH0026</u>); Nottingham Women's Centre (<u>WRH0032</u>); Oral evidence taken on 18 October 2023, <u>Q17</u> [Naga Munchetty]

¹⁴⁰ Royal College of General Practitioners (WRH0034)

¹⁴¹ The Scottish Women's Convention (WRH003); This Independent Life (WRH0026)

¹⁴² Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward</u>, Impact on mental health, 18 November 2024

¹⁴³ This Independent Life (WRH0026)

¹⁴⁴ Małgorzata Szypłowska, Rafał Tarkowski and Krzysztof Kułak, <u>The impact of</u>
endometriosis on depressive and anxiety symptoms and quality of life: a systematic
review, Front Public Health, vol 11 (2023)

Nottingham Women's Centre (<u>WRH0032</u>); Ms Sara Peat, Clinical Psychologist in training at NHS (<u>WRH0038</u>); Evidence submitted in confidence (WRH0030); Muslim Women's Network UK (<u>WRH0031</u>)

¹⁴⁶ This Independent Life (WRH0026)

waiting areas and wards for patients requiring diagnosis and treatment for endometriosis are often shared between general gynaecology and obstetrics which can be "distressing, potentially triggering, and stressful, given that endometriosis is linked to infertility." ¹⁴⁷

- 87. Improving women's mental health and wellbeing is one of the priority areas of the Women's Health Strategy for England. The strategy includes the ambition to ensure "equitable and timely access to specialist support for those who are struggling with their mental health." The Department of Health and Social Care told us that "all ICBs are expected to commission NHS Talking Therapies services which are integrated into physical healthcare pathways." However, the specification for women's health hubs, which we discuss later in this report, includes mental health services as an optional care pathway rather than a core service. This is despite the Women's Health Strategy for England pledging to prevent "the onset of mental health conditions wherever possible," and to ensure "equitable and timely access to specialist support for those who are struggling with their mental health."
- 88. Dr Sue Mann told us that NHS England needed to "connect the dots better" in relation to mental health and reproductive health conditions and that access to multidisciplinary teams is important to address related issues such as pain and weight management:

Learning how to incentivise that connection is really difficult, and at the moment the system does not do that. Those commissioning levers are important, as is helping ICBs to determine how that pays and how it is more efficient. That is complex, obviously, and it is locally determined.¹⁵¹

In July 2024, a National Confidential Enquiry into Patient Outcome and Death report on endometriosis found that 44.6% of survey respondents were not asked at any point about the impact of symptoms on their quality of life.¹⁵²

Dr Véronique Griffith, The University of Manchester, Dr Andrea Ford, University of Edinburgh, and Dr Annalise Weckesser, Birmingham City University (WRH0047)

Department for Health and Social Care, <u>Women's Health Strategy for England</u>, 30 August 2022

¹⁴⁹ Department of Health and Social Care and NHS England (WRH0057)

Department for Health and Social Care, <u>Women's Health Strategy for England</u>, 30 August 2022

¹⁵¹ Q24 [Dr Sue Mann]

National Confidential Enquiry into Patient Outcome and Death, Endometriosis: A Long and Painful Road (PDF), 11 July 2024. Based on data collected between 2018 and 2020 including hospitals in England, Wales and Northern Ireland.

89. RECOMMENDATION

Individuals with a suspected or diagnosed reproductive health condition should be offered specialist mental health support from when they start to report distressing and/or painful symptoms and throughout diagnosis and treatment. Delays at each step of the process and a lack of treatment options make mental health support all the more essential.

90. RECOMMENDATION

All women's health hubs should be commissioned to include mental health support as part of their core specification.

91. RECOMMENDATION

NHS England should implement policies to ensure there are separate spaces for patients undergoing investigations or treatment for reproductive health conditions and obstetrics patients.

Waiting lists

- 92. Delays in access to treatment exacerbate mental ill health as well as worsen physical health.¹⁵³ The RCOG has been tracking waiting times for gynaecological elective care, which have grown faster than any other specialty.¹⁵⁴ Across the UK, more than three-quarters of a million women (763,694) were waiting for gynaecology care in June 2024. In England, there were 592,662 people on the waiting list for gynaecology in August 2024; an increase of almost a third compared to January 2022 and 107% compared to February 2020. The number waiting over the 18-week target increased by 482% as of October 2024, compared to before the pandemic. The number of emergency admissions are increasing, and the number of new referrals has consistently stayed higher than the number of patients seen.¹⁵⁵ The RCOG emphasised that gynaecology waiting lists were growing faster than any other specialty "long before the pandemic".¹⁵⁶
- 93. However, this only "tells part of the story". The data does not include women waiting in primary care or those waiting for cancer-related gynaecological care and so thousands more women are likely to be waiting for diagnostic

¹⁵³ Royal College of Obstetricians and Gynaecologists (WRH0056)

Royal College of Obstetricians and Gynaecologists (WRH0056); Gynaecology has had the highest percentage increase of any specialty since the start of the pandemic and is also one of the highest specialties in terms of absolute volume increase.

Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward</u>, 18
November 2024; <u>RCOG Elective Recovery Tracker (lcp.com)</u>

¹⁵⁶ Royal College of Obstetricians and Gynaecologists (WRH0056)

tests or care following treatment.¹⁵⁷ Nor does it show where in the system the delays are taking place, how many women are waiting for more than one type of treatment, where women are being referred from, or enough about health inequalities. It also does not explain why waits are so long in some areas, such as in the North West, South East and East of England.¹⁵⁸

- 94. The RCOG argued that a key reason for the unequal growth of waiting lists is that "a continued focus solely on clinical need has neglected the impact of ongoing symptom management on women's physical and mental health, and their quality of life". It suggested that a lack of awareness of the true impact of reproductive health conditions among those responsible for allocating clinic and theatre capacity meant that elective services related to gynaecology were often the first to be cancelled. The RCOG called for clinical prioritisation of care to be reformed "to take into consideration the wider impacts of an individual waiting for care." It said women need more support and better communication while waiting for care.
- 95. Several organisations called for the NHS to move away from the use of the term 'benign' to describe life-altering reproductive health conditions. ¹⁶²
 Benign is traditionally used to indicate non-cancerous conditions. The RCOG told us that the use of this term in gynaecology "has contributed to the deprioritisation of gynaecological conditions, misrepresenting them as not progressive and not adequately reflecting the significant impact on quality of life symptoms can have." ¹⁶³ The Department told us that it recognised concerns around the use of the term and would "support a move away from using the term 'benign' to describe gynaecological conditions and symptoms if evidence suggests this would be beneficial." ¹⁶⁴
- **96.** Other factors driving long waiting times include problems with commissioning and reduced resourcing. The Women's Health Ambassador for England, Dame Lesley Regan, explained that more effort needed to go into the pre-referral pathway, so that more women and girls are treated in the community and those on waiting lists are "the people who

¹⁵⁷ Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward</u>, Executive summary, 14 November 2024

¹⁵⁸ Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward</u>, Issues identified across the UK, 18 November 2024

¹⁵⁹ Royal College of Obstetricians and Gynaecologists (WRH0056)

¹⁶⁰ Royal College of Obstetricians and Gynaecologists (WRH0056)

¹⁶¹ Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward</u>, 18 November 2024

Brook (<u>WRH0051</u>); Royal College of Obstetricians and Gynaecologists (<u>WRH0056</u>); Menstrual Health Coalition (<u>WRH0020</u>)

¹⁶³ Royal College of Obstetricians and Gynaecologists (WRH0056)

¹⁶⁴ Correspondence from the then Minister for Women's Health to the then Chair of the Committee, 24 January 2024

need admission, invasive procedures or surgery."¹⁶⁵ Dr Sue Mann also drew attention to increased HRT prescriptions, which can cause irregular bleeding, as another reason for increased waiting lists, alongside GPs needing more support to better triage and treat patients. ¹⁶⁶ We heard that follow up appointments were important for women and girls to ensure recommended treatments were working, particularly for those seeking support for the first time, such as trying a contraceptive pill for relief from pain or heavy bleeding, however the onus was mostly on women to advocate for such appointments.

97. RECOMMENDATION

The use of terminology such as 'benign gynaecology' downplays the impact of reproductive health conditions and risks de-prioritising them for treatment that could significantly improve patients' health and lives. NHS England should cease to use the term benign in relation to reproductive ill health. The NHS should work with stakeholders to develop a way to describe these conditions that more accurately reflects the serious impact they can have on people's lives. This should include a wider discussion about what treatments take precedence for surgery and the steps necessary to ensure that chronic conditions primarily affecting women, such as endometriosis, are appropriately prioritised. This re-prioritisation is required to address the fact that gynaecology waiting lists have grown at a faster pace than any other specialty since the pandemic.

98. RECOMMENDATION

Measures to reduce waiting lists for elective surgery should prioritise areas where waiting lists are longest and disparities greatest. The NHS should provide financial support to women to allow them to travel further to access care earlier.

99. RECOMMENDATION

Data and analysis must improve. The NHS should collect data on where there are delays in the system, where women are being referred from (which could highlight areas where community provision is lacking), which groups of women are most affected by delays (to allow better understanding of health inequalities), how many women are waiting for more than one type of treatment, and the satisfaction and outcomes of follow-ups, including which women and girls access this pathway.

¹⁶⁵ Q30 [Dame Lesley Regan]

¹⁶⁶ Q30 [Dr Sue Mann]

Period poverty

100. Women with reproductive health conditions can struggle to access sufficient and appropriate period products, particularly for heavy bleeding, with products available through public schemes often unsuitable, as one contributor to the inquiry explained:¹⁶⁷

At University, with no money at all, I remember having to travel outside of Birmingham to find sanitary towels thick enough to manage at least 15 minutes of my menstrual flow[...]I experienced my first episode of suicidal thoughts as each month feelings of dread and hopelessness arose knowing I had no products available nor did I have the money or energy to travel outside central Birmingham to go and search for any.¹⁶⁸

101. The coronavirus pandemic and increased cost of living in the UK in recent years has shown how prevalent period poverty remains, with new groups of people now affected, including NHS staff and students. ¹⁶⁹ In May 2023, a poll by the charity ActionAid found that the proportion of women in the UK unable to afford period products had increased from 12% to 21% in one year. ¹⁷⁰ As the RCOG has highlighted, women living in areas of deprivation often wait the longest for treatment, which increases the financial burden. ¹⁷¹ One woman with PCOS described how she regularly bled for 14 days straight, describing the cost of menstrual products and replacing and cleaning her clothes as "ridiculous" alongside the fear of leaking at school, on public transport, at work, or while out with friends while others act as if it's the "most disgusting, unnatural thing to happen". ¹⁷²

¹⁶⁷ Period poverty refers to the difficulty people may experience accessing period products often because of financial constraints. It may also refer to a poverty of education, resources, rights and freedom from stigma for women, girls and those who menstruate, Birmingham City School of Health Sciences, Periods in a Pandemic: how UK period poverty initiatives are mitigating Covid-19 related challenges, January 2022. In 2020 the Government introduced a scheme to fund free period products in schools and colleges across England, which is currently set to last until 2025. The NHS also provides free period products on request for those under its care and free incontinence products, although this depends on a person's local integrated care board. Further free provision depends on charitable organisations, workplaces and local schemes.

¹⁶⁸ Evidence submitted in confidence (WRH0024)

¹⁶⁹ Birmingham City University (WRH0005)

¹⁷⁰ ActionAid, Cost of living: UK period poverty has risen from 12% to 21% in a year, 26 May 2023

¹⁷¹ Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward, work and</u> social life, 18 November 2024

¹⁷² Evidence submitted in confidence (WRH0014)

102. CONCLUSION

More than half of the population will experience menstruation yet women and girls are financially disadvantaged by having to pay for essential products without which they cannot leave their homes, work or attend education. This is an unfair burden, not least given the existing context of a gender pay gap and a cost of living crisis which disproportionately affected women. For those with conditions such as heavy bleeding, the cost is higher and products are not always effective, further affecting their mental health. Existing period and incontinence product schemes are inadequate.

103. RECOMMENDATION

The Government should review existing period and incontinence product schemes alongside the burden of need. We recommend the Government considers the merits of legislating for free provision for particular groups such as children, students, people seeking asylum and those in receipt of benefits. Products that are appropriate for heavy bleeding and other urogynaecological conditions should be available on free prescription. As part of their corporate social responsibility we call on the major manufacturers of period and incontinence products to help fund the provision of those products. The introduction of such policies should be supported by a public awareness campaign.

Workplace support

104. Reproductive health conditions can have a significant effect on women's experience at work. Contributors to this inquiry described the difficulties in remaining in work while experiencing chronic pain and severe changes in mood because of reproductive ill health. One contributor observed:

I am now back working in the job I love. To do this I take nerve blockers, bladder medication, bowel medication, HRT and pain killers.¹⁷³

105. The charity Bloody Good Period said that employment was a "large barrier to people accessing treatment and diagnosis of gynaecological and/or urogynaecological conditions, due to the inability to take leave and/or speak openly about conditions." Nottingham Women's Centre told us that

¹⁷³ Evidence submitted in confidence (WRH0001)

¹⁷⁴ Bloody Good Period, FRSH (WRH0048)

- "Pre diagnosis—which could take up to eight years—women face apathy, distrust and risk of redundancy from their employers as they struggle to prove their need for entitlements such as sick leave at work". 175
- 106. Bloody Good Period said a third of employees say their workplace does not have policies relating to menstruation and/or menopause. Even when workplaces have policies in place they are "unseen or overlooked". In its 2019 'Have Your Bloody Say' survey, half of respondents didn't know if their workplace had any relevant policies. Another survey, by the organisation This Independent Life, found that 100% of respondents felt that women's health was still a stigma in the workplace. The Menstrual Health Coalition called for more support for women working in lower paid manual jobs or in work where they cannot take appropriate toilet breaks and are often more compromised. The Menstrual Health Coalition are compromised. The Menstrual Health Coalition called for more support for women working in lower paid manual jobs or in work where they cannot take appropriate toilet breaks and are often more compromised. The Menstrual Health Coalition work where they cannot take appropriate toilet breaks and are often more compromised. The Menstrual Health Coalition work where they cannot take appropriate toilet breaks and are often more compromised.

Existing menstrual health guidance for employers

- 107. It is estimated that neglecting women's health in the workplace costs the UK economy £20 billion a year.¹⁷⁹ Research published in 2022 by the femtech company Parla found that 23% of women take time off work because of period health issues, while 80% lie about the reasons for absence if they are related to their periods.¹⁸⁰
- 108. Guidance for employers is available; in 2023 the British Standards Institute published standards on menstruation, menstrual health and menopause in the workplace. The British Standards Institute said: "A lot of misinformation is being used to shape new policies, training materials and practice in this area, which can leave organizations with negative or even legal consequences." Charities, trade unions and professional bodies have also conducted extensive research to provide guidance and best practice for employers, including paid menstrual leave schemes such as those implemented in Spain in 2023. 183

¹⁷⁵ Nottingham Women's Centre (WRH0032)

¹⁷⁶ Bloody Good Period, FRSH (WRH0048)

¹⁷⁷ This Independent Life (WRH0060)

¹⁷⁸ Menstrual Health Coalition (WRH0020)

¹⁷⁹ Corporate advisor, <u>Neglecting female health in the workplace costs the UK economy</u> £20bn, 25 October 2023

Parla, Reproductive Health in the Workplace... and Why It Matters (PDF), p6. Data based on academic studies, government reports and global research initiatives, along with the results of surveys of its own community.

British Standards Institute, Menopause standard launched to help organizations support experienced workers. The standard is BS 30416.

¹⁸² British Standards Institute (WRH0007)

¹⁸³ See for example CIPD, Menstruation and menstrual health in the workplace: Guide for people professionals, 20 November 2023; BBC, UK charities call for menstrual leave for severe pain, 22 May 2022; Endometriosis UK, Menstrual Health at Work

109. In 2023, the former Government announced a pilot evaluation of the impact of endometriosis on women's participation and progression in the workforce. The Government said the pilot would "improve understanding and help inform government plans to support women with the condition in their careers." The Women's Health Strategy for England recognises the debilitating effect that menstrual health and reproductive health conditions can have on women in the workplace. Over the next ten years the strategy envisages that:

Women feel able to speak openly about their health and to be confident that they will be supported by their employer and workplace colleagues, with an end to taboos.

[...] women experiencing women's health issues such as period problems, endometriosis, fertility treatment, miscarriage and menopause feel well supported in their workplaces. 185

This includes workplace policies for "issues such as menopause". The strategy spotlights support available to women in the civil service and NHS England, particularly for its menopause policies. The Employment Rights Bill, introduced in October 2024, proposes an addition to the Equality Act 2010 which would require large employers to publish 'equality action plans' detailing how they are taking steps towards gender equality. Those steps include supporting employees going through the menopause, however there is no reference to the reproduction conditions discussed in this report.¹⁸⁶

110. CONCLUSION

Workplaces must be incentivised by the Government to have strategies in place to support women experiencing reproductive ill health. The availability of flexible working patterns, a workplace that provides easy access to period products, and time off to attend appointments are just some of the measures that can better support women at work. While some employers have recognised the benefits of policies such as paid leave for fertility treatment, pregnancy loss, menopause symptoms, and menstruation-related issues, there is not consistency across employers and sectors. The Employment Rights Bill is a good opportunity to address these concerns.

¹⁸⁴ HM Treasury, £12.4 million to help choices about work, 12 September 2023

Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Health in the workplace, updated 30 August 2022

¹⁸⁶ Employment Rights Bill, Explanatory notes (PDF), p38

111. RECOMMENDATION

Clause 26 of the Employment Rights Bill should be amended to make clear that supporting women with reproductive health conditions falls under the definition of advancing gender equality.

Violence against women and girls

112. Although the Women's Health Strategy for England has the health impacts of violence against women and girls as one of its priority areas, alongside fertility, pregnancy, pregnancy loss and postnatal support, we are concerned that it does not reference the impact of pregnancy as a result of rape or recognise the support needed for expectant mothers in this situation. Research by the Centre for Women's Justice suggests that in England and Wales, more than 3,000 children could have been conceived as a result of rape between January and December 2021. This can have profound effects on mothers and children who may need support. Dame Lesley Regan told us that while obstetrics and gynaecologists have traumainformed training, and are often the first to see survivors, "an awful lot more training and education" was needed across sectors.

113. RECOMMENDATION

The Government's plans for the Women's Health Strategy for England should include support and guidance for women who have conceived as a result of rape, and for children born as a result of rape. This should include tailored information on the NHS website, including on rape-induced gynaecological issues.

¹⁸⁷ Centre for Women's Justice, <u>Daisy's Law: New Research Commissioned by Centre for Women's Justice Demonstrates Why Children Born From Rape Should Be Recognised As 'Victims' In Law, 15 August 2022</u>

¹⁸⁸ Q39 [Dame Lesley Regan]

5 Training and standards

Impact of pressure on primary care

- 114. Early intervention and diagnosis are crucial for some conditions. Without it, diseases progress, more invasive treatments may be needed, women and girls experience more time in pain with physical and psychological effects, and fertility may be affected. However, reproductive health conditions are not always straightforward to diagnose. Many conditions have non-specific symptoms, such as pelvic pain; such symptoms can overlap with other conditions or be associated with other underlying causes. The Royal College of General Practitioners explained that this "can make it harder to rule out other causes for symptoms caused by gynaecological ill-health, and reach the correct diagnosis in order to provide the right treatment and support."
- 115. In early 2024, a blood test which is already used by the NHS to investigate fertility was approved to help diagnose polycystic ovary syndrome (PCOS), as an alternative to a transvaginal ultrasound. We received mixed evidence on the effectiveness of the test to help diagnosis PCOS. Dr Anne Connolly, Co-Chair of the Menstrual Health Coalition, told our predecessor Committee that the test would "make life so much easier" but was concerned it would only be available in private clinics. It has also been welcomed by those who have the condition. However, while the National Clinical Director for Women's Health, Dr Sue Mann, said the NHS needs to get better at diagnosing PCOS, she told us that the blood test needed to be evaluated: "We need to really understand in what circumstances it is best used and how it can be helpful in terms of shaping treatment."
- 116. For endometriosis, the average time of eight years for a diagnosis is due, in part, to the lack of an acceptable, objective and non-invasive test to identify it and predict its severity. The need for surgery to diagnose the condition increases the likelihood of GPs wanting to rule out other diagnoses

¹⁸⁹ Royal College of Obstetricians and Gynaecologists (WRH0056)

¹⁹⁰ Royal College of Obstetricians and Gynaecologists (WRH0056)

¹⁹¹ Femtech world, New diagnostic test approved for PCOS, 31 January 2024

¹⁹² Oral evidence taken on 8 November 2023, Q65 [Dr Anne Connolly]

¹⁹³ Femtech world, New diagnostic test approved for PCOS, 31 January 2024

¹⁹⁴ Q37 [Dr Sue Mann]

¹⁹⁵ Professor Kay Marshall, University of Manchester (WRH0009)

first.¹⁹⁶ While not conclusive, tools such as ultrasound and MRI are over 90% specific in the diagnosis of endometriosis.¹⁹⁷ However, the UK has significant regional variation in access to MRI machines, both because of a shortage of the machines and a workforce sufficiently experienced to use them.¹⁹⁸

117. Witnesses explained that GPs are fundamental to the "effective diagnosis, treatment and support of women with gynaecological and urogynaecological conditions" but that "general practice is so pressured at the moment" that "people are not getting the time". 199 Since the start of the pandemic there has been a 10% increase in consultations, with a 7% increase in patients registered with GPs. At the same time as there has been a decrease in the full-time equivalent GP numbers. 200 We were told that GPs could be doing more if the resources were there. Dr Michael Mulholland, Honorary Secretary at Royal College of General Practitioners, explained:

We feel that, if primary care or general practice is well funded, GPs have the skills to do an awful lot of those steps and to organise the investigations before secondary care referral is needed.²⁰¹

- 118. We note that primary care funding for training for nurses and doctors is currently prioritised for other long-term conditions such as diabetes and cardiovascular diseases rather than reproductive health.²⁰² Witnesses called for an equal focus on early intervention and prevention for reproductive ill health.
- 119. The pressures on a GP's time make it challenging to deliver in depth consultations while also making it difficult for GPs to protect time to ensure they can remain knowledgeable and skilled in supporting women with gynaecological health.²⁰³ Dr Mulholland observed that 60% of GPs do not have the time to adequately maintain professional development.²⁰⁴ This is worrying given the evidence submitted to our inquiry of low awareness of reproductive health conditions among some GPs.

¹⁹⁶ Royal College of Obstetricians and Gynaecologists (WRH0056)

¹⁹⁷ Professor Kay Marshall, University of Manchester (WRH0009)

¹⁹⁸ Professor Kay Marshall, University of Manchester (WRH0009)

¹⁹⁹ Royal College of Obstetricians and Gynaecologists (<u>WRH0056</u>); Oral evidence taken on 8 November 2023, Q70 [Dr Michael Mulholland]

²⁰⁰ Oral evidence taken on 8 November 2023, Q70 [Dr Michael Mulholland]

²⁰¹ Oral evidence taken on 8 November 2023, Q87 [Dr Michael Mulholland]

²⁰² Oral evidence taken on 8 November, <u>Q60</u> [Dr Connolly]; Professor Kay Marshall, University of Manchester (WRH0009)

²⁰³ Simon Briscoe, Jo Thompson Coon, GJ Melendez-Torres, Rebecca Abbott, Liz Shaw, Michael Nunns, and Rush Garside, "Primary care clinicians' perspectives on interacting with patients with gynaecological conditions: a systematic review", summary, BJGP Open, 2024, 8 (1); Oral evidence taken on 8 November 2023,

²⁰⁴ Oral evidence taken on 8 November 2023, Q90 [Dr Michael Mulholland]

120. RECOMMENDATION

The Department of Health and Social Care should set out plans to improve the accessibility and take up of professional development in women's reproductive health conditions among practitioners in primary care. Those plans should include allocating increased funding for training on reproductive health conditions and protected time for GPs to undertake that training.

121. RECOMMENDATION

The approval of the anti-mullarian hormone blood test as another tool to assist in the diagnosis of polycycstic ovary syndrome is a welcome development. NHS England should evaluate the merits of rolling it out nationally as a matter of priority.

Listening to patients

- 122. We acknowledge the challenges primary care practitioners face. However, the overwhelming concern remains that women who do present with symptoms are not being listened to and are dismissed far too readily. As Dr Connolly observed, "there is no justification for being told you just have to tolerate it". 205 The previous Government recognised this as a problem area and commissioned research through the National Institute for Health and Care Research to better understand healthcare professionals' perspectives of listening to women with menstrual and gynaecological symptoms in primary care.
- 123. One study looking at primary care clinicians' perspectives found there were concerns that stigma and embarrassment, particularly among women from some minority ethnic groups, led to delays in seeking care. However, clinicians may also stereotype how minority ethnic groups view medical conditions rather than engage with individuals.²⁰⁶
- 124. Clinicians also found decisions on when to refer patients challenging for various reasons and referrals were not always made, even if women had symptoms that could justifiably lead to a referral. This is because of concerns over the potential adverse effects of invasive diagnostic tests, and pressures on secondary care. The research found that women who did not have English as a first language; those not wanting to be examined by

²⁰⁵ Oral evidence taken on 8 November 2023, Q58 [Dr Anne Connolly]

Simon Briscoe, Jo Thompson Coon, GJ Melendez-Torres, Rebecca Aboott, Liz Shaw, Michael Nunns, and Rush Garside, "Primary care clinicians' perspectives on interacting with patients with gynaecological conditions: a systematic review", Summary, BJGP Open, 2024, 8 (1). The studies included Australia, The Netherlands, Norway, Sweden, the UK, and the US.

- a male clinician; where infertility was a concern; and "more engaged and proactive women" might be more likely to be referred. Younger women were seen as less likely to have serious pathology and were less likely to be referred. ²⁰⁷
- 125. Worryingly, the research found differences in how male and female primary care doctors interact with women. With respect to heavy menstrual bleeding, some male doctors reported relying solely on patients' experience, feeling ill-equipped to do anything else. Female doctors were more confident in combining patients' experiences with clinical judgement about the abnormality of the symptoms.²⁰⁸
- 126. In its latest research, the Royal College of Obstetricians and Gynaecologists (RCOG) notes that both primary and secondary care practitioners have "serious concern" for their patients stuck on waiting lists for gynaecological care and see a worsening of their wider health outcomes. The long waiting times also contribute to more complex care and treatment needs, making it difficult to support them. The RCOG said: "professionals in secondary and primary care [are] reporting that the impact of gynaecology lists on their workload is significant." Their own health has also been affected, with many reporting burn out and feeling "helpless".²⁰⁹
- 127. Professional bodies told our predecessor Committee that they acknowledged the need for improvement in practitioner interactions with female patients. The General Medical Council (GMC) noted that it has "work to do" to better implement standards. Professor Sue Carr, the GMC's Deputy Medical Director, explained that: "we have to work harder to get those standards met in respect of the communication skills, listening skills, and working in partnership with women."²¹⁰ She noted that these skills were now a particular focus of the Good Medical Practice guidance that doctors must demonstrate they meet as part of their annual appraisal. In January 2024 this guidance was updated. It states that medical professionals must not allow personal views to affect the treatment they provide and patients should be listened to and their concerns acknowledged.²¹¹

²⁰⁷ Simon Briscoe, Jo Thompson Coon, GJ Melendez-Torres, Rebecca Aboott, Liz Shaw,
Michael Nunns, and Rush Garside, "Primary care clinicians' perspectives on interacting
with patients with gynaecological conditions: a systematic review", Interpretive analysis,
BJGP Open, 2024, 8 (1)

²⁰⁸ Simon Briscoe, Jo Thompson Coon, GJ Melendez-Torres, Rebecca Aboott, Liz Shaw,
Michael Nunns, and Rush Garside, "Primary care clinicians' perspectives on interacting
with patients with gynaecological conditions: a systematic review", Interpretive analysis,
BJGP Open, 2024, 8 (1)

²⁰⁹ Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward</u>, How professionals view gynaecology waiting lists and their impact, 18 November 2024

²¹⁰ Oral evidence taken on 8 November 2023, Q76 [Professor Sue Carr]

²¹¹ General Medical Council, Good medical practice domain 2: Patients, partnership and communication

128. The Royal College of General Practitioners' curriculum stresses the need for GPs to "understand that some women may find it difficult to discuss intimate health issues, for many reasons" and that GPs should "endeavour to adopt a 'woman-centred life course' approach, using contact opportunities occurring over a woman's life.²¹²

129. CONCLUSION

GPs face difficulties diagnosing complicated reproductive healthcare conditions which may present with a variety of symptoms. They face workplace pressures, have short consultation times, and can struggle to access training and guidance. While it is positive to see that medical guidelines and assessments are being updated, further work on professional standards is required if the invalidation that women have reported during this inquiry is to be adequately addressed.

130. RECOMMENDATION

The annual GP appraisal process should be strengthened to include a specific performance indicator on the diagnosis and treatment of women's reproductive health conditions, including intersectional considerations. That indicator should include patient experience.

131. RECOMMENDATION

NHS Digital should collect data on how many hours of training primary care practitioners undergo annually in the field of women's reproductive health.

Medical education

132. Healthcare professionals who gave evidence to our predecessor Committee agreed that training for medical professionals at undergraduate and postgraduate level needed to improve. Dr Geeta Kumar, Vice President for Clinical Quality at the RCOG said that training on women's health needed to be "a lot more integral to the medical curriculum and should not be left to choice." Professor Sue Carr agreed that training should be "more explicit in preparing doctors to deal with women's health issues." She observed:

²¹² The Royal College of General Practitioners (WRH0034)

²¹³ Oral evidence taken on 8 November 2023, Q92 [Dr Geeta Kumar]; Q92 [Professor Sue Carr]

²¹⁴ Oral evidence taken on 8 November 2023, Q92 [Professor Sue Carr]

There needs to be a greater awareness of women's health issues, as you describe. As we have talked about, in undergraduate medical education the medical schools themselves set the syllabus for the course. The GMC sets the standards, and we expect within that syllabus that women's health issues will be covered.²¹⁵

For 2024–25, the GMC introduced a new medical licencing assessment for medical students and international doctors joining the UK register. Within this assessment are a number of topics relating to women's health including fibroids, endometriosis and urinary incontinence.²¹⁶ Professor Carr noted:

Let us not forget that a significant proportion of our medical healthcare professionals are international medical graduates from overseas, and there is a lot more that can or should be done to improve their awareness, knowledge and cultural beliefs about women's health issues.²¹⁷

133. Practitioners told our predecessor Committee that it can be difficult finding gynaecological expertise and that a lack of education on women's reproductive health in early years may affect medics' choices later in their career when deciding to specialise.²¹⁸ The dearth of specialists in women's reproductive health conditions was highlighted by many contributors to the inquiry.²¹⁹ Witnesses described problems caused by having to see multiple specialists because of the comorbidity of many reproductive health conditions, which delays treatment.²²⁰ The Menstrual Health Coalition suggested that clinicians needed to be more aware of reliable, publicly available information and tools such as the Royal College of General Practitioners' Menstrual Health Toolkit and the Royal College of Nursing's women's health education booklets.²²¹ The Royal College of Obstetricians and Gynaecologists has called on the Government to consider whether gynaecology could be added as a mandatory training rotation for medical professionals, a minimum training time spent on women's health, and how senior professionals can train others while refreshing their own training. 222

²¹⁵ Oral evidence taken on 8 November 2023, Q76 [Professor Sue Carr]

Oral evidence taken on 8 November 2023, Q92 [Professor Sue Carr]; Department of Health and Social Care and NHS England (WRH0057), para 46

²¹⁷ Oral evidence taken on 8 November 2023, Q94 [Dr Geeta Kumar]

²¹⁸ Oral evidence taken on 8 November 2023, Q58 [Rebekah Lloyd]

²¹⁹ Besins Healthcare UK (WRH0052), Dr Véronique Griffith, The University of Manchester, Dr Andrea Ford, University of Edinburgh, and Dr Annalise Weckesser, Birmingham City University (WRH0047), This Independent Life (WRH0026)

²²⁰ Dr Véronique Griffith, The University of Manchester, Dr Andrea Ford, University of Edinburgh, and Dr Annalise Weckesser, Birmingham City University (WRH0047)

²²¹ Menstrual Health Coalition (WRH0020)

²²² Royal College of Obstetricians and Gynaecologists, <u>Waiting for a way forward, Our asks</u> of the UK Government, 14 November 2024

134. Dr Connolly observed that training on women's health needs also to be improved for nurses and the "extended multidisciplinary team, such as pharmacists and physician associates":

I do a lot of nurse education. The nurses will say, "I don't know the answer, so I don't ask the questions". When they are doing smears, they do not feel able to talk about, "What are your periods like?"[...] We will fund our nurses to go on diabetes, respiratory disease and cardiovascular clinic courses, because that will then get the QOF [quality and outcomes framework] moneys that help fund the practice, whereas we are not funded for women's health these days. Nurses will fight hard to go on nurse training courses and the training priorities will not be on women's health. ²²³

- 135. A general lack of sufficient knowledge in reproductive health conditions means that medical staff are not routinely using other opportunities to talk to women and girls about their menstrual cycles despite guidance to do so. Common intervention points could include cervical screening, anteand post-natal care and visits to sexual health clinics.²²⁴ This is a missed opportunity to support women experiencing reproductive health problems, particularly for those who may have normalised their symptoms or be more reluctant to seek help.
- 136. In the Women's Health Strategy for England, the former Government's ambitions to improve medical education, training and standards include for all healthcare professionals to be well informed about the importance of women's health; for undergraduate curricula to include teaching and assessment on women's health; and to improve lifelong learning for all healthcare professionals.²²⁵ The Menstrual Health Coalition cautioned that improved teaching on women's health and the introduction of the new medical licensing assessment will not by themselves incentivise more healthcare professionals to specialise or take up training in women's health or particular conditions. The MHC called on the Government to use quality and outcomes framework (QOF) or commissioning for quality and innovation (CQUIN) indicators to incentivise healthcare professionals and providers to prioritise gynaecological healthcare.²²⁶

²²³ Oral evidence taken on 8 November 2023, Q49 [Dr Anne Connolly]

²²⁴ The Academy of Medical Sciences (WRH0033)

Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Education and training for health and care professionals, updated 30 August 2022

Quality outcomes framework refers to a voluntary annual reward and incentive programme for all GP practices in England, detailing practice achievement results. It is not about performance management but resourcing and rewarding good practice, NHS England, Quality and Outcomes Framework, 2023–2024. Commissioning for quality and innovation indicators is a system introduced in 2009 to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of care, Hertfordshire Partnership University, CQUIN

137. CONCLUSION

Training on women's reproductive health in medical schools needs to be improved. Healthcare practitioners are graduating without sufficient knowledge of the conditions that may affect women over their lifetime. Without that education, healthcare professionals are less likely to choose women's health as a specialty and less able to support women during their interactions with the health service.

138. RECOMMENDATION

The Government should work with the RCOG, RCGP and the GMC to improve the teaching of women's health at undergraduate level and ensure it is an integral part of medical education for all those seeking a career in healthcare. As part of that work the Government should consider how to better incentivise healthcare professionals to specialise in women's reproductive health, including making obstetrics and gynaecology a mandatory rotation. This is necessary to address current shortages in this area and to tackle the long waiting lists for gynaecological care. The merits of using the quality and outcomes framework (QOF) or commissioning for quality and innovation (CQUIN) indicators should be part of its consideration of potential incentives.

139. RECOMMENDATION

Primary care practitioners should be trained to use women's common interactions with the healthcare system, such as cervical screening appointments, ante- and post-natal care checks and visits to STI clinics, as an opportunity to pick up hidden health concerns relating to reproductive health.

Medical guidelines and standards

- **140.** Clinicians use medical guidelines to make decisions about diagnosis, management and treatment. In the field of reproductive healthcare, we heard that evidence-based, clear guidelines and pathways were needed, integrated from primary care to secondary and tertiary care. ²²⁷ These are integral not only to deliver effective healthcare, but to aid patients' understanding of their treatment choices and any implications, such as adverse effects from hormonal contraceptives.
- **141.** The Women's Health Strategy for England includes ambitions for Health Education England, professional bodies and providers to review their resources to add content on women's health; for National Institute for

²²⁷ Oral evidence taken on 8 November 2023, Q85 [Dr Geeta Kumar]

Health and Care Excellence (NICE) guidelines to be added, updated and implemented; and for the guidelines to be accessible, to reflect diversity and evidence gaps to be filled.²²⁸ All GP practices are expected to take into account the recommendations in NICE clinical guidelines when deciding what treatments to offer people.²²⁹ In 2024, NICE updated its guideline on diagnosing and managing endometriosis, including where fertility is a priority.²³⁰

- 142. NICE guidelines are "supported by patient decision aids that have been produced to help women understand the options that are available to them."²³¹ It is also planning the development of a guideline on the assessment and management of polycystic ovary syndrome.²³² NHS England has committed to updating the service specification for severe endometriosis to improve standards of care for women who have it.²³³
- 143. NICE's 'Women's and reproductive health guidelines' webpage includes guidelines on issues such as endometriosis, menopause, pregnancy, fertility, abortion and heavy menstrual bleeding. It does not have standalone guidance on conditions such as adenomyosis, fibroids or premenstrual dysphoric disorder, although there are references to adenomyosis and fibroids in other guidelines. ²³⁴ The Royal College of General Practitioners, Royal College of Obstetricians and Gynaecologists, and the Faculty of Sexual and Reproductive Health all also provide educational resources and guidelines on women's health that are relevant to GPs and other primary healthcare professionals.
- 144. The Pelvic Obstetric and Gynaecological Physiotherapy organisation cautioned that as many organisations develop their own guidelines there is "considerable overlap of time and resource", recommending a centrally driven evidence-based pathway for all major conditions from which patients could identify what the 'gold standard' of care looks like. ²³⁵ It argued that where guidelines exist, healthcare implementation needs to improve, both making patients aware that they exist and enabling healthcare providers to adjust their provision. ²³⁶ Concern was also raised with us that NICE and other organisations developing guidelines are reliant on an evidence base

²²⁸ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Education and training for health and care professionals, updated 30 August 2022

²²⁹ Royal College of General Practitioners (WRH0034)

²³⁰ NICE, Endometriosis: diagnosis and management, last updated 11 November 2024

²³¹ Department of Health and Social Care and NHS England (WRH0057)

²³² Polycystic Ovary Syndrome, PQ 10150, 28 October 2024

^{233 &}lt;u>Endometriosis: Health Services</u> PQ 19740, 26 March 2024. Service specifications define the standards of care expected from organisations funded by NHS England to provide specialised care, NHS England, Service specifications

²³⁴ NICE, Women's and reproductive health guidelines, accessed 27 November 2024

²³⁵ Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

²³⁶ Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

that has gaps relating to conditions such as menopause, endometriosis and PCOS as well as how some of those gaps relate to women from different ethnic groups.²³⁷

145. RECOMMENDATION

The Department of Health and Social Care and NHS England should commission NICE to develop comprehensive guidelines for all reproductive health conditions. Those guidelines should be communicated to GPs and made accessible to patients through the NHS website to allow informed patient-GP discussions. Adherence to these guidelines by medical practitioners and any barriers to following them must be monitored, including their usefulness to patients.

A fragmented commissioning system

146. Responsibility for commissioning women's reproductive health services is split between local authorities, integrated care systems and NHS England.²³⁸ The fragmentation of services was raised by several witnesses as a barrier to diagnosis and treatment in gynaecology and urogynaecology, preventing women from getting timely multidisciplinary care.²³⁹ Dr Anne Connolly, Co-Chair of the Menstrual Health Coalition, explained:

Fragmentation in commissioning is the biggest barrier and particularly affected women's health more than any other aspect. You can get a coil, a Mirena or an intrauterine system fitted here but you cannot have your smear. You can have your smear done there but you cannot have it done, or you could have it done for contraception there, but you cannot have it done for heavy menstrual bleeding. ²⁴⁰

147. The Royal College of General Practitioners (RCGP) observed that providers are delivering separate services "without clearly defined accountabilities, and the linkages between different parts of the care pathway have been lost ..."²⁴¹ Contributors to our inquiry described the challenges of moving from one part of the healthcare system to another including delays, loss of their data and the weariness of having to advocate for themselves at every stage.²⁴² The RCGP called for a coordinated approach to the commissioning of sexual and reproductive healthcare with "shared aims" to improve a

²³⁷ Oral evidence taken on 29 November 2023, Q124 [Dr Judith Richardson]

²³⁸ House of Commons Library, <u>Sexual and reproductive health statistics for England</u>, 18 July 2024

²³⁹ Oral evidence taken on 8 November 2023, Q60 [Dr Anne Connolly]

²⁴⁰ Oral evidence taken on 8 November 2023, Q51 [Dr Anne Connolly]

²⁴¹ Royal College of General Practitioners (WRH0034)

²⁴² Healthwatch Liverpool (WRH0002)

patient's experience and make a more robust healthcare system.²⁴³ The pharmaceutical company Bayer PLC argued that not enough is being done to address "inadequate commissioning practices and barriers to access", with a cross-system approach needed.²⁴⁴

Long-acting reversible contraception

- 148. The commissioning of treatments such as long-acting reversible contraception (LARC), which can be used to treat some reproductive health conditions such as heavy menstrual bleeding, are particularly complex and fragmented. While local authorities are responsible for commissioning LARC as a contraceptive, the NHS is responsible for commissioning it for gynaecological purposes. There is "significant variation in scope and funding between different geographies," as a result, and GP practices "decide whether to sign up—based on availability of the trained workforce, or decisions on financial viability." The Department of Health and Social Care was unable to provide data on the proportion of GPs commissioned to fit LARC, the costs involved or the fees that are charged. 46
- 149. In 2023, the Primary Care Women's Health Forum found that funding for LARC was inconsistent, medical professionals had limited access or options for training, yet demand between 2020 and 2023 either remained the same or increased. It noted that around a third of GP practices were only commissioned to fit LARC for contraception, and not for heavy menstrual bleeding or menopause—despite this requiring the same skills. Of the GP practices that were commissioned to fit gynaecological LARC, just 16% reported that the fitting fee was adequate to cover the cost of providing the service. 248
- 150. The Women's Health Strategy for England notes these concerns. It says that greater collaboration between local authorities and the NHS, and co-commissioning of women's reproductive health and sexual health services "will be important to delivering integrated provision at a local level, particularly regarding contraception where responsibility is shared by local authorities and the NHS." The strategy suggests that one solution to the issues caused by fragmentation is the development of women's health hubs, a "key aim" of which "is to improve women's access to the full range

²⁴³ Royal College of General Practitioners (WRH0034)

²⁴⁴ Bayer PLC (WRH0041)

²⁴⁵ Bayer PLC (WRH0041)

²⁴⁶ Contraceptives, PQ 10151, 28 October 2024

²⁴⁷ Primary Care Women's Health Forum, On the brink: The reality of Long-Acting Reversible Contraception (LARC) provision in primary care, June 2023

²⁴⁸ Advisory Group on Contraception (WRH0045); Brook (WRH0051)

Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Access to services, updated 30 August 2022

of contraceptive methods and, in particular, LARC".²⁵⁰ It gives the example of women's health hubs in Liverpool as a model which has resulted in an increase in LARC prescribing rates.

Women's health hubs as a solution?

- 151. Women's health hubs are defined as bringing together: "healthcare professionals and existing services to provide integrated women's health services in the community, centred on meeting women's needs across the life course." They aim to "improve access to and experiences of care, improve health outcomes for women, and reduce health inequalities" and fill the gap between primary and secondary care. ²⁵¹
- 152. The hubs refer to joined-up services, for example so that when having LARC fitted or removed, a woman should be able to also have her cervical screening if due or STI testing if appropriate within the same appointment, minimising the need for multiple appointments and invasive procedures. Rather than necessarily requiring a single space, they may involve clinics and care in a range of locations and online and can take a variety of forms, including as 'one stop shops', primarily virtual, hub and spoke models, or mixed models. Core services include menstrual and menopause assessment and treatment, contraception provision including LARC, and cervical screening.²⁵²
- 153. The hubs are set up and managed by commissioners and providers, in particular integrated care boards, which are statutory bodies responsible for planning and funding most NHS services in an area.²⁵³ The previous Government said that "when setting up hubs, commissioners and providers should consider how the location and services can "best meet population needs and reduce inequalities, and help meet the priorities identified through local needs analysis and integrated care strategies."²⁵⁴

²⁵⁰ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Access to services, updated 30 August 2022

²⁵¹ Department of Health and Social Care, <u>Women's health hubs: core specification</u>, updated 21 March 2024

²⁵² Department of Health and Social Care, <u>Women's health hubs: core specification</u>, updated 21 March 2024

²⁵³ Integrated care boards are part of integrated care systems. Each integrated care system has an integrated care board (planning and funding) and an integrated care partnership (statutory committees bringing together local government, the voluntary, community and social enterprise sector, NHS organisations and others to develop a health and care strategy for the area), The King's Fund, Integrated care systems explained, updated 19 August 2022

Department of Health and Social Care, <u>Women's health hubs: core specification</u>, updated 21 March 2024

- 154. NHS planning guidance asks for at least one hub to exist in each of the 42 ICBs by the end of December 2024.²⁵⁵ The previous Government committed £25 million between 2023 and 2025 for the hubs, with each ICB receiving £595,000 between 2023 to 2025. NHS England explained that the funding was to support a "proof of concept" rather than to fund the model as a whole.²⁵⁶ As of September 2024, 36 ICBs had reported to NHS England that a hub was open in their area.²⁵⁷
- 155. There is a great deal of optimism about the creation of women's health hubs, particularly as they present the opportunity to embed a joined-up approach to reproductive healthcare over a woman's life course and improve triage and signposting. Witnesses welcomed the focus of hubs on the needs of their local communities and the commitment of those involved in their establishment. The Pelvic Obstetric and Gynaecological Physiotherapy organisation highlighted the opportunities to integrate specialist physiotherapy services within the hub model. Dame Lesley Regan, Women's Health Ambassador for England told us the hubs also offered an opportunity to up-skill trainee GPs and those who have not done an obstetrics and gynaecology rotation. The hubs also pose an opportunity for research into diverse experiences of reproductive healthcare conditions and treatment.
- 156. To its credit, the Department of Health and Social Care commissioned an early evaluation of the hub model. The evaluation was generally positive about the concept. It found the creation of hubs "was helped by passionate leaders" and that "women who have used hubs report a good experience, with caring and convenient services". The review also highlighted a number of concerns, many of which had also been expressed by witnesses to this inquiry, such as the impact of existing healthcare pressures, including a lack of funding, clinic space, equipment and staff. Women also described some challenges in accessing hub services, including difficulties making a GP appointment in order to be referred to the hub. Worryingly, and in contrast to a core purpose, the review found:

NHS England, Women's health hubs, 22 April 2024. By the end of December 2024, each ICB must have at least one hub that is operational and providing clinical support and consultations and/or triaging against all core services, one of which is menstrual problems.

²⁵⁶ Health Services Women, PQ 18793, 25 March 2024

²⁵⁷ Health Services: Women, PQ 10149, 28 October 2024

²⁵⁸ All Parliamentary Group on Women's Health (WRH0018); Menstrual Health Coalition (<u>WRH0020</u>); Oral evidence taken on 29 November 2023, <u>Q153</u> [Dame Lesley Regan]

²⁵⁹ Pelvic Obstetric and Gynaecological Physiotherapy organisation (WRH0025)

²⁶⁰ Q15 [Dame Lesley Regan]

²⁶¹ Professor Hilary Critchley (WRH0065)

²⁶² National Institute for Health and Care Research, <u>Women's Health Hubs: a rapid mixed</u> methods evaluation, September 2024

While many hubs were reported as being one-stop shops, it was rare for them to offer multiple services at the same time and those that did were often opportunistic rather than a planned service offer (e.g. offering a smear test at the same time as fitting a coil).²⁶³

157. The Advisory Group on Contraception said it was concerned about oversight of the hubs:²⁶⁴

While the Government has rightly acknowledged that ICSs [integrated care systems] should have the freedom to design women's health hubs around the specific needs of their local populations, it is imperative that national policymakers retain sufficient oversight to ensure ICSs are appropriately supported and that transformation is harnessed equitably.²⁶⁵

The review team noted that a lack of agreed definition of a hub and that a "heterogeneity in hub models can also hinder evaluation, monitoring and comparison of hub impact". The previous Government responded to the first report on the evaluation by setting set out a core specification of hubs and has developed regular data collection to "provide assurance against delivery targets" and "inform impact evaluation". The Government appointed a network of women's health champions across ICSs, who are leaders in women's health "to support collaboration across system partners to improve provision for women's health across the life course and reduce health inequalities." The health champions were involved in developing the data collection on women's health hubs. ²⁶⁷

158. Dame Lesley Regan told us that more resource was needed to improve the hub model. She reported that ICB representatives did not think the funding for the hubs was being used "in the right way" because it had not been ringfenced, other than for maternity. ²⁶⁸ Dr Sue Mann, National Clinical Director for Women's Health, explained that primary care and secondary care needed to work better together to get the system to work effectively. This, she said, would require a "change in culture". ²⁶⁹

²⁶³ NIHR, Women's Health Hubs: a rapid mixed methods evaluation, September 2024

²⁶⁴ Advisory Group on Contraception (WRH0045)

²⁶⁵ Advisory Group on Contraception (WRH0045)

²⁶⁶ Department of Health and Social Care, Letter to the chief executives of integrated care boards from health ministers, the Women's Health Ambassador and the Chief Nursing Officer, 25 September 2023

²⁶⁷ NHS England, Women's health hubs

²⁶⁸ Q20 [Dame Lesley Regan]

²⁶⁹ Q23 [Dr Sue Mann]

159. CONCLUSION

The expansion of the women's health hub model has the potential to be a positive step towards providing the joined-up care and commissioning needed to effectively support women experiencing reproductive health conditions. However, the women's health hub model exists within a healthcare system which has significant commissioning, funding, workforce and expertise problems, particularly in the area of reproductive health. There are also risks that those not yet served by hubs, or with limited access such as in rural areas, will be disadvantaged.

160. CONCLUSION

It is positive to hear that many of the leaders in the ICBs are focusing their hubs on disadvantaged groups. While local ownership, management and decentralisation of the hubs is important to meet local needs, regular national-level evaluations are also required to ensure that the hubs are providing the intended additional benefits and are not just a rebadging of existing services. It disappointing, for example, that it is rare for hubs to offer multiple services at the same time—something we view as a key benefit of the hub model.

161. RECOMMENDATION

We find that women's health hubs have proven the concept that they can deliver improvements to women's healthcare. The Government must now allocate long-term, ring-fenced funding and resource to embed the hub model and further support its development. That development should include increased provision of ultrasound facilities within hubs. Funding should be accompanied by a break-down of how it will be used and which services will be available in each area.

162. RECOMMENDATION

Integrated care boards must ensure that their hubs meet the specific demographic needs of their populations, particularly accounting for religious and cultural considerations.

163. CONCLUSION

There remains a postcode lottery of access in primary care to long-acting reversible contraception. As a result, some women are having to seek care from secondary or community services, leading to delays in treatment and an unnecessary burden on secondary care. This is a preventable cost to the system and to the wellbeing of the individual. While the establishment of women's health hubs may go some way to addressing this concern, in areas where hubs are not established other solutions will be required.

164. RECOMMENDATION

The Government should develop a funding and training strategy to address the lack of LARC provision in general practice, particularly in those areas not covered by a women's health hub. This should include an assessment of whether the current fee structure is fit for purpose.

6 Research into women's reproductive health conditions

- 165. Government policy has not historically prioritised women's reproductive health and we were told that there is insufficient funding for its research today.²⁷⁰ However, better diagnostic tools are desperately needed to reduce the use of invasive procedures, pain relief requires improvement, treatment options for conditions such as heavy menstrual bleeding, endometriosis and adenomyosis are limited and there is an over-reliance on hormonal contraception to manage symptoms.²⁷¹
- 166. The Royal College of Obstetricians and Gynaecologists explained that the lack of research into reproductive health conditions has contributed to long diagnosis times and poorer treatment options, leaving women struggling with challenging symptoms that impact their health and quality of life. 272 A lack of large-scale clinical trial data is holding back potential treatment options that may be viable 273 and more data on endometriosis, polycystic ovary syndrome and other menstrual health conditions is required to better understand the impact these conditions have on inequalities. 274
- 167. An overwhelming theme in the evidence we received was that research is required into the root causes of conditions, not just how to diagnose and treat them. Rebekah Lloyd, founder of the organisation This Independent Life, explained, "if we do not understand a problem, how are we going

²⁷⁰ Dr Véronique Griffith (Lecturer (Assistant Professor) in Healthcare Sciences at The University of Manchester), Dr Andrea Ford (Research Fellow in Biomedicine, Self and Society at University of Edinburgh), and Dr Annalise Weckesser (Reader in Medical Anthropology at Birmingham City University) (WRH0047); Professor Kay Marshall (Professor of Reproductive Endocrine Pharmacology at The University of Manchester) (WRH0009)

²⁷¹ The Academy of Medical Sciences (<u>WRH0033</u>); This Independent Life (<u>WRH0026</u>); Evidence submitted in confidence (WRH0030)

²⁷² Royal College of Obstetricians and Gynaecologists (WRH0056)

²⁷³ Oral evidence taken on 8 November 2023, <u>Q68</u> [Rebekah Lloyd]; Caroline Criado Perez, Invisible Women, 2019, Chatto and Windus, London, pp229-231

²⁷⁴ Menstrual Health Coalition (WRH0020)

to create a sustainable solution that is not just putting a plaster on it". ²⁷⁵ Professor Hilary Critchley, Fellow at the Academy of Medical Sciences, told our predecessors:

The big questions for the basic scientists are: if you have a uterus, why is it heavier if you have adenomyosis? Another cause we have hardly heard anything about is uterine fibroids: 70% of white women and 80% of black women will have fibroids by the age of 50. They are the single biggest cause of bleeding. Bleeding causes iron deficiency, it causes anaemia. These are major cross-health issues, they can affect pregnancy outcomes, they are completely under-recognised.²⁷⁶

The potential to identify causes and uncover solutions is being held back by a lack of funding, a lack of women participating in clinical trials (as well as a male bias in animal-based research) and a lack of prioritisation at commissioning level. We consider each of these below.

Funding

168. Comparatively, there is a lower level of research funding for medical conditions that primarily or exclusively affect women than for those affecting men.²⁷⁷Approximately 2% of overall public research funding in the UK is dedicated to reproductive health and childbirth,²⁷⁸ while past research has shown that five times more research is conducted into erectile dysfunction than premenstrual syndrome.²⁷⁹ This is staggering considering that 19% of men are affected by erectile dysfunction, while 90% of women have premenstrual syndrome.²⁸⁰ Diseases that are unique to women are underfunded compared to the burden they place on the population,²⁸¹ while levels of funding also compare poorly against other similarly prevalent conditions such as diabetes and asthma, as Janet Lindsay, Chief Executive of the charity Wellbeing of Women, explained:

In 2018, searching for endometriosis in the UK Research and Innovation awards database, there were 35 hits, meaning that it had funded 35 endometriosis-related projects since 2003. On the other hand, if you search diabetes, a condition with the same incidence rate but one that affects both sexes, it has funded a total of 1,758 projects in the

²⁷⁵ Oral evidence taken on 8 November 2023, Q68 [Rebekah Lloyd]

²⁷⁶ Oral evidence taken on 29 November 2023, Q123 [Professor Hilary Critchley]

²⁷⁷ Professor Kay Marshall, University of Manchester (WRH0009)

²⁷⁸ NHS Confederation, <u>Women's health economics: investing in the 51 per cent (PDF)</u>, p13, footnote 4

²⁷⁹ Oral evidence taken on 8 November 2023, Q68 [Janet Lindsay]

²⁸⁰ Oral evidence taken on 8 November 2023, Q68 [Janet Lindsay]

²⁸¹ Professor Kay Marshall, University of Manchester (WRH0009)

same period, and the amount of money is much bigger. This gives you a flavour of how little money is invested in research [into women's reproductive health conditions].²⁸²

- 169. Women's health continues to be considered a "niche area" for research despite affecting more than half the population.²⁸³ The Academy of Medical Sciences highlighted a scarcity of women's health-specific research streams of funding in the UK, "meaning women's health is often grouped into broader fields that are dominated by non-sex-specific diseases". The Academy said that experts it had consulted suggested this could be addressed by women's health-specific funding streams and by funders acknowledging the importance of women's health issues during prioritisation exercises.²⁸⁴
- 170. The Department of Health and Social Care commissions research through the National Institute for Health and Care Research (NIHR). In contrast to evidence from other witnesses, the Government told us the "NIHR have funded a significant amount of research into reproductive, gynaecological and urogynaecological health including recurrent urinary tract infections and pelvic pain."²⁸⁵ This included £53 million for research on women's health between April 2022 and July 2023 and a further 18 women's health projects expected to have started by April 2024, totalling £8.5 million.²⁸⁶
- 171. Janet Lindsay observed that the funding allocation was welcome but "simply is not enough". 287 Ms Lindsay described Wellbeing of Women as "the only voluntary body that is funding research across women's health across the life course" but that the organisation's contribution "is relatively small [...] this year we will be making available just short of £1.5 million. It is a drop in the ocean." To improve the quantity and quality of relevant research, she called for women's health experts on NIHR panels, more women's health research fellowships and for women to play a greater role in clinical trials. 289
- 172. We note that over the last 10 years an average of 1.3% of the NIHR's annual research budget was spent on gynaecological and urogynaecological conditions, less than that spent on equally prevalent conditions such as asthma (1.42%) and diabetes (3.7%). In 2023–24, this amounted to £6.34m, compared to £8.73m and £25.27m respectively.²⁹⁰

²⁸² Professor Kay Marshall, University of Manchester (WRH0009)

²⁸³ Nature, Funding research on women's health, 11 October 2024

²⁸⁴ Academy of Medical Sciences (WRH0033)

²⁸⁵ Department of Health and Social Care and NHS England, par 87 (WRH0057)

²⁸⁶ Department of Health and Social Care and NHS England, par 68 (WRH0057)

²⁸⁷ Oral evidence taken on 8 November 2023, Q68 [Janet Lindsay]

²⁸⁸ Oral evidence taken on 8 November 2023, Q68 [Janet Lindsay]

²⁸⁹ Oral evidence taken on 8 November 2023, Q68 [Janet Lindsay]

²⁹⁰ Medicine: Research, PQ10148, 31 October 2024

173. The Medical Research Council, part of UK Research and Innovation (UKRI) and funded by the Government, said it spends around £325 million a year on health research, about £25 million of which goes on women's reproductive health research.²⁹¹ Dr Robin Buckle, Chief Science Officer at the Medical Research Council (MRC), told our predecessor Committee that the MRC's women's health portfolio was "smaller than ideal" though the award rate was higher.²⁹²

Commissioning

- 174. The NIHR commissions research based on several factors, including policy needs, patient needs and recommendations from the National Institute for Health and Care Excellence. The NIHR also runs a clinical research network, with reproductive health and childbirth usually being "one of the top three recruiting specialties. Professor Lucy Chappell, Chief Executive at the NIHR, told our predecessor Committee that there was an "active and thriving portfolio across all women's health areas. The NIHR reported that research prioritising women's perspectives had been "highly successful" and informs commissioning calls. However, Professor Chappell acknowledged that gaps exist around menstrual health, endometriosis and menopause.
- 175. The MRC told our predecessors that it commissions research in response to "the best ideas" put to it unless it feels that certain research areas need building. Research into women's reproductive health is not considered one of these areas. Dr Buckle noted that applications for research in this area were "less than what we would like". Both the MRC and NIHR called for a stronger "applicant community", saw a need to increase the number of women undertaking research and for such strategies to start at undergraduate level. 1998
- 176. The General Medical Council (GMC), which regulates GPs, said there are several barriers preventing doctors from undertaking research, affecting opportunities for their patients to be involved. This includes a lack of time in their work schedules and being based in a rural area. Barriers are more prevalent for female doctors, those from minority ethnic groups, and

²⁹¹ Oral evidence taken on 29 November 2023, Q116 [Dr Robin Buckle].

²⁹² Oral evidence taken on 29 November 2023, Q116 [Dr Robin Buckle]

²⁹³ Oral evidence taken on 29 November 2023, Q128 [Professor Lucy Chappell]

²⁹⁴ Oral evidence taken on 29 November 2023, Q128 [Professor Lucy Chappell]

²⁹⁵ Oral evidence taken on 29 November 2023, Q110 [Professor Lucy Chappell]

²⁹⁶ Oral evidence taken on 29 November 2023, Q125 [Dr Robin Buckle]

²⁹⁷ Oral evidence taken on 29 November 2023, Q116 [Dr Robin Buckle]

²⁹⁸ Oral evidence taken on 29 November 2023, <u>Q127</u> [Dr Robin Buckle] and <u>Q114</u> [Professor Lucy Chappell]

international medical graduates.²⁹⁹ Far fewer women than men become clinical academic doctors and they have a high attrition rate, all affecting research into women's health issues.³⁰⁰ The GMC said it was engaged with stakeholders and is "making good progress" to address these barriers.³⁰¹

Participation in research

- 177. Evidence to this inquiry called for greater inclusion of women in clinical trials, more sex-disaggregated data and for women to be represented in proportions that match the prevalence or burden of disease. This extends to ensuring there is sufficient and relevant diversity of women taking part—though a lack of data can make this challenging. For example, research has tended to look at Black and minority ethnic groups together, which fails to reveal differences between multiple groups of people. One US-based study found that Black women only comprise 15% of participants in published clinical trials for uterine fibroids, despite being disproportionately impacted by the condition. Witnesses also noted that the potential for drug responses and efficacy to change during a patient's life course had been poorly studied.
- 178. The NIHR recognises the concerns over representative participation and a lack of data. Professor Chappell explained that the NIHR had launched a race equality framework and a research inclusion strategy which requires researchers to ensure they are recruiting participants that are representative. She told our predecessors:

It is not good enough to say, "That was too difficult" or, "We didn't have the funds." NIHR is very clear that that is what we expect and that you may need to adapt your methods to ensure you have a representative population.³⁰⁶

²⁹⁹ Oral evidence taken on 8 November 2023, Q102 [Professor Sue Carr]

³⁰⁰ Oral evidence taken on 8 November 2023, Q104 [Professor Sue Carr]

³⁰¹ Oral evidence taken on 8 November 2023, Q103 [Professor Sue Carr]

³⁰² Professor Kay Marshall, University of Manchester (<u>WRH0009</u>); Academy of Medical Sciences (<u>WRH0033</u>)

³⁰³ Black Women's Reproductive Health project report, July 2022, p11

³⁰⁴ Royal College of Obstetricians and Gynaecologists (WRH0056)

³⁰⁵ Academy of Medical Sciences (WRH0033)

³⁰⁶ Oral evidence taken on 29 November 2023, Q110 [Professor Chappell]

Pledges in the Women's Health Strategy for England

179. The Women's Health Strategy for England includes an ambition for publicly funded health research to include data on the sex breakdown of participants and for this to be kept under review. It called for an increase in participation of women and under-represented groups in research, more research into women's health issues and support for female researchers, routine data collection on participants, and for research to reach more people, including clinicians.³⁰⁷ The Department of Health and Social Care said it would work with the NIHR to make improvements, including in commissioning calls and would establish a new policy research unit dedicated to reproductive health.³⁰⁸ Endometriosis UK called for action to reduce average diagnosis times for endometriosis from eight to four years by 2025 and to less than one year by 2030.³⁰⁹ Professor Critchley noted that there was a gap in research on fibroids despite them affecting 70-80% of women by the age of 50 and having heavy bleeding as a major symptom.³¹⁰ We note that the Women's Health Strategy does not have any specific targets for individual conditions.

180. CONCLUSION

Finding the causes of women's reproductive health conditions and new and better diagnostic tools and treatments for them cannot happen without sufficient research, which includes all groups of women and others affected, at different life stages. Yet research remains lacking because it is not adequately prioritised by funders or commissioners and is not incentivised enough in clinical academia. While these issues are recognised by the Women's Health Strategy for England and some positive work is underway, the Government needs to be more ambitious and more targeted approaches are needed.

³⁰⁷ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Research and evidence, 30 August 2022

³⁰⁸ Department of Health and Social Care, <u>Women's Health Strategy for England</u>, Research and evidence, updated 30 August 2022. The policy research unit in reproductive health is a £3 million investment over three years. See also UCL, <u>Policy Research Unit in Reproductive Health</u>

³⁰⁹ Endometriosis UK, Endometriosis in the UK: Time for Change, 19 October 2020

³¹⁰ Professor Critchley (WRH0065)

181. RECOMMENDATION

The Women's Health Strategy for England should be updated to include priorities for specific, common conditions. We recommend the Government commits to reducing waiting times for an endometriosis diagnosis to less than two years by the end of this Parliament and to improved understanding, diagnosis and treatment of heavy menstrual bleeding over the same period.

182. RECOMMENDATION

The Government should allocate increased, ringfenced funding to support research into the causes, diagnosis and treatment of women's reproductive health conditions. While increased funding will in itself attract more researchers to this area, NHS England and research bodies should also consider what steps they can take to increase interest among clinical academia.

7 Conclusion

Implementing the Women's Health Strategy for England

183. It has been more than two years since the publication of the Women's Health Strategy for England and although there are patches of progress, it has been too slow and the strategy lacks an implementation plan. Giving evidence in November 2024, Dame Lesley Regan, Women's Health Ambassador for England, said that women are now much more aware about their own health.³¹¹ While this is a vital aspect, it is not enough and the onus should not fall on women and girls to advocate for their own health needs. The strategy and those charged with implementing it must be properly resourced and there should be timelines and regular evaluations.

184. RECOMMENDATION

The Government should publish an implementation plan for the Women's Health Strategy for England detailing timelines, costs and resource.

Funding

185. In this report we have called for additional funding to support much needed improvements in healthcare and increased research into reproductive health conditions. We are aware of the significant financial pressures the Government is faced with. Yet studies show that increases in funding for gynaecology services for early diagnosis and treatment provide a significant return on investment. We know that improving primary care could help reduce the burden on both primary and secondary care settings and help reduce sick leave and unemployment as a result of reproductive ill health and related issues.³¹²

³¹¹ Q35 [Dame Lesley Regan]

³¹² Menstrual Health Coalition (WRH0020)

186. The previous Government's central assumption in its cost benefit analysis for women's health hubs is that there will be £5 of benefits for every £1 spent on a primary care network-sized hub.³¹³ A recent report by the NHS Confederation identified that the economic cost of absenteeism due to severe period pain and heavy periods alongside endometriosis, fibroids and ovarian cysts is estimated to be nearly £11 billion per annum. It found that for every £1 of investment in obstetrics and gynaecology services per woman in England, there is an estimated return on investment of £11.³¹⁴

187. RECOMMENDATION

We call on the Government to recognise the financial benefits of increased investment in early diagnosis and treatment of women's reproductive health conditions and provide the additional funding necessary to truly transform the support available to the millions of women affected by reproductive ill health in this country.

Department of Health and Social Care, Letter to the chief executives of integrated care boards from health ministers, the Women's Health Ambassador and the Chief Nursing Officer, 25 September 2023

³¹⁴ NHS Confederation, Women's health economics: investing in the 51 per cent | NHS Confederation

Annex - definitions

The NHS provides the following definitions of common gynaecological conditions:³¹⁵

- Heavy menstrual bleeding is when a woman loses 80ml of blood or more in each period, has periods that last longer than 7 days, or both. Premenstrual syndrome (PMS) is the name for the symptoms women can experience in the weeks before their period. Most women have a degree of PMS at some point, but a small number of women may experience more severe symptoms of PMS known as premenstrual dysphoric disorder (PMDD). Symptoms of PMDD are similar to PMS but are much more intense and can have a much greater negative impact on a woman's daily activities and quality of life. Treatments for these conditions can include taking hormonal medicine, such as the combined contraceptive pill.
- Endometriosis is a condition where tissue similar to the lining of the uterus (womb) starts to grow in other places, such as the ovaries, fallopian tubes and outside the reproductive tract in the pelvic or abdominal cavity or even farther afield. The only way to confirm the diagnosis of endometriosis is by performing a laparoscopy—an operation in which a camera is inserted into the pelvis via a small cut through the navel. Due to the invasive nature of this diagnostic procedure and the need for general anaesthetic, it may be better to offer medical treatment for mild symptoms and reserve a laparoscopy for women with more debilitating symptoms who usually require surgical removal of endometriosis tissues by laser of diathermy.
- Adenomyosis is a condition where the lining of the uterus starts growing into the muscle in the wall of the uterus which may lead to intense pain. Medical treatments that can help with any symptoms include oral hormonal medication and long-acting reversible contraception (LARC) devices inserted into the uterine cavity.
- Fibroids are non-cancerous growths that develop in or around the uterus. They are a frequent cause of heavy bleeding, pain, fertility problems and pressure symptoms on other organs such as the bladder or bowel.

³¹⁵ Department of Health and Social Care and NHS England (WRH0057)

 Polycystic ovary syndrome (PCOS) is a common condition that affects how a woman's ovaries work. The 3 main features of PCOS are irregular periods, excess androgen production which may contribute to acne and increased hair growth, and the appearance of multiple cysts of the ovary at ultrasound examination.

Conclusions and recommendations

Education and awareness

- 1. High quality education about reproductive health is vital. Educating girls about their periods and the possibility of related conditions at a young age safeguards them against the distress of not understanding what is happening to their bodies and empowers them to identify problems and to seek help. We welcome the inclusion of teaching about reproductive health conditions in the draft RSHE statutory guidance. (Paragraph 23)
- 2. However, we are concerned that the teaching of the menstrual health element of relationships, sex and health education is insufficient and inconsistent. It is often delivered too late in a child's development to be of use and by teachers who lack the necessary training. The requirement in the draft guidance that schools need to cover reproductive health conditions only by the end of year 11 contrasts with Government advice that puberty and menstruation should be addressed before onset. It needs revising. (Paragraph 24)
- 3. The Government should ensure teachers tasked with delivering the menstrual and gynaecological health element of RSHE receive the training necessary to deliver it effectively. Information on women's reproductive health conditions should be taught early on in secondary education, preferably around the time most girls first experience menstruation. That information should include guidance on what is and is not considered to be healthy reproductive health and cover intersectional differences, preparing pupils to advocate for their needs and seek help when necessary. (Paragraph 25)
- 4. The guidance fails to recognise the importance of boys and men understanding reproductive health conditions that their peers might experience and their role in changing the culture and stigma that girls face. (Paragraph 26)

Publicly available information

- 5. The statutory guidance should specify that boys should be taught about female reproductive health conditions. (Paragraph 26)
- 6. We welcome the ongoing improvements to the NHS website to include information about a wider range of women's reproductive health conditions, information to specific communities and signposts to support and the ambition to include that information in alternative formats. (Paragraph 33)
- 7. We know that many women and girls are using online spaces to get information and seek help while there are gaps in support in medical fields. It is therefore imperative that the NHS and trusted sources become a first-port-of-call to prevent misinformation. The NHS website and app must therefore be comprehensive, accessible, inclusive, and highly-visible. (Paragraph 34)
- 8. To supplement improvements in the provision of information on the NHS website, we recommend the inclusion of an interactive tool which can help women to determine whether they might have a reproductive health condition. We further recommend that information on specific conditions, contains links to the relevant medical guidelines so that patients can make themselves aware of the care they should expect. Information on the website should be made accessible by default, including in different languages. The link between reproductive health conditions and mental ill health should also be clearer, with information on how to access support signposted. Women's health hubs should be commissioned to provide tailored information at a local level, in a range of formats suited to their local population. (Paragraph 35)
- 9. With women and girls relying on online spaces and a proliferation of femtech apps to fill gaps in their knowledge of reproductive health conditions, the NHS should increase its own digital and social media presence in relation to reproductive health conditions. This should be consistent rather than a one-off campaign and monitored to ensure it reaches those in need of support with their reproductive health. (Paragraph 36)

Accessing support and treatment

10. There is a clear lack of awareness and understanding of women's reproductive health conditions among primary healthcare practitioners, particularly when those conditions occur in young women and girls. Women are finding their symptoms normalised and their pain dismissed, with an ingrained belief among some healthcare professionals that women,

- particularly those from a minority ethnic background, are exaggerating their symptoms. Such medical misogyny and racism is unacceptable. (Paragraph 53)
- 11. The NHS needs to urgently implement a training programme to improve the experience of treatment and diagnosis in primary care for women, girls, trans and non-binary people with reproductive ill health. Improving early diagnosis, including through the provision of follow up appointments, must be a priority to prevent a worsening of symptoms. The programme should seek to challenge racial biases and ensure that all those experiencing pain are believed and able to access treatment and support quickly. It should include training to support women and girls whose socio-cultural situation or beliefs make it harder to discuss reproductive health conditions and involve women and girls with lived experience. (Paragraph 54)
- 12. Improvements in diagnosis times should be made a key performance indicator for the Women's Health Strategy for England. (Paragraph 55)
- 13. We support the Royal College for Obstetricians and Gynaecologists' initiative for a guideline on inclusive care. When finalised it should be implemented throughout the healthcare system and medical practitioners must receive adequate training, with implementation monitored by the RCOG. (Paragraph 56)
- 14. Healthcare practitioners lack sufficient understanding of the range and suitability of treatment options available to treat reproductive health conditions. Too often conditions are viewed through the prism of fertility which, while a necessary consideration, should not be the only factor influencing a clinician's judgement. There is also an evident lack of empathy in primary care around the adverse effects some treatment options may have on a patient. For example, approaches which focus on managing symptoms rather than diagnosis risk diseases progressing with potentially life altering consequences. (Paragraph 65)
- 15. The NHS must take steps to ensure healthcare practitioners keep up to date with the full range of diagnostic and treatment options available for reproductive health conditions. Those options, as well as waiting times and potential outcomes of surgical procedures and non-invasive alternatives, should be communicated to patients as a matter of course to allow informed, shared decision making. The NHS should identify and address any regional disparities in the availability of particular treatments and support. (Paragraph 66)

Pain of investigation

- 16. The NHS is failing many patients who undergo routine reproductive healthcare procedures such as hysteroscopy, IUD fitting and cervical screening. In too many cases, we find that a duty of care from gynaecologists and other medical practitioners is absent. Women are being pressured into enduring severe pain and find that they are ignored or belittled by those charged with their care when they cannot. The Women's Health Strategy for England does not sufficiently prioritise challenging this behaviour. (Paragraph 79)
- The NHS must do more to monitor and enforce protocols governing **17.** procedures such hysteroscopy, IUD fitting and cervical screening and ensure that they are underpinned by informed consent and are trauma-informed. A risk assessment that allows a patient to make an informed choice on the recommended procedure should be undertaken as standard, taking account of any previous history of undergoing related procedures. This should also include consideration of the patient's mental and physical preparedness for a penetrative procedure, particularly in cases where the individual has not had or recently had penetrative sex. The full range of options on pain relief, including anaesthesia, should be considered and a clear commitment made that if the level of pain during the procedure is unbearable, that procedure will be halted and a separate appointment will be made. As membership bodies, the Royal College of Obstetricians and Gynaecologists and the Royal College of General Practitioners should be doing far more to ensure their members adhere to guidelines and best practice. (Paragraph 80)
- 18. Concerns about painful procedures have been raised for years with little sign of progress. We recommend the NHS collects data on whether guidelines for hysteroscopy, IUD fittings and other potentially painful gynaecological procedures are being adhered to. That data must include surveys of patient experience. Without the pressure of having this information captured we are sceptical there will be the necessary drive to improve the level of care. (Paragraph 81)
- 19. Reducing the pain women experience during invasive procedures should be made a key performance indicator for the Women's Health Strategy for England. (Paragraph 82)

Effect on mental health

- 20. Individuals with a suspected or diagnosed reproductive health condition should be offered specialist mental health support from when they start to report distressing and/or painful symptoms and throughout diagnosis and treatment. Delays at each step of the process and a lack of treatment options make mental health support all the more essential. (Paragraph 89)
- 21. Women's health hubs situated in areas where access to appropriate mental health services is lacking should be commissioned to include mental health support as part of their core specification. (Paragraph 90)
- 22. NHS England should implement policies to ensure there are separate spaces for patients undergoing investigations or treatment for reproductive health conditions and obstetrics patients. (Paragraph 91)

Waiting lists

- 23. The use of terminology such as 'benign gynaecology' downplays the impact of reproductive health conditions and risks de-prioritising them for treatment that could significantly improve patients' health and lives. (Paragraph 97)
- 24. NHS England should cease to use the term benign in relation to reproductive ill health. The NHS should work with stakeholders to develop a way to describe these conditions that more accurately reflects the serious impact they can have on people's lives. This should include a wider discussion about what treatments take precedence for surgery and the steps necessary to ensure that chronic conditions primarily affecting women, such as endometriosis, are appropriately prioritised. This re-prioritisation is required to address the fact that gynaecology waiting lists have grown at a faster pace than any other specialty since the pandemic. (Paragraph 97)
- 25. Measures to reduce waiting lists for elective surgery should prioritise areas where waiting lists are longest and disparities greatest. The NHS should provide financial support to women to allow them to travel further to access care earlier. (Paragraph 98)
- 26. Data and analysis must improve. The NHS should collect data on where there are delays in the system, where women are being referred from, which could highlight areas where community provision is lacking, which groups of women are most affected by delays, to allow better understanding of health inequalities, how many women are waiting for more than one type of treatment, and the satisfaction and outcomes of follow-ups, including which women and girls access this pathway. (Paragraph 99)

Period poverty

- 27. More than half of the population will experience menstruation yet women and girls are financially disadvantaged by having to pay for essential products without which they cannot leave their homes, work or attend education. This is an unfair burden, not least given the existing context of a gender pay gap and a cost of living crisis which disproportionately affected women. For those with conditions such as heavy bleeding, the cost is higher and products are not always effective, further affecting their mental health. Existing period and incontinence product schemes are inadequate. (Paragraph 102)
- 28. The Government should review existing period and incontinence product schemes alongside the burden of need. We recommend the Government considers the merits of legislating for free provision for particular groups such as children, students, people seeking asylum and those in receipt of benefits. Products that are appropriate for heavy bleeding and other urogynaecological conditions should be available on free prescription. As part of their corporate social responsibility we call on the major manufacturers of period and incontinence products to help fund the provision of those products. The introduction of such policies should be supported by a public awareness campaign. (Paragraph 103)

Workplace support

- 29. Workplaces must be incentivised by the Government to have strategies in place to support women experiencing reproductive ill health. The availability of flexible working patterns, a workplace that provides easy access to period products, and time off to attend appointments are just some of the measures that can better support women at work. While some employers have recognised the benefits of policies such as paid leave for fertility treatment, pregnancy loss, menopause symptoms, and menstruation-related issues, there is not consistency across employers and sectors. The Employment Rights Bill is a good opportunity to address these concerns. (Paragraph 110)
- **30.** Clause 26 of the Employment Rights Bill should be amended to make clear that supporting women with reproductive health conditions falls under the definition of advancing gender equality. (Paragraph 111)

Violence against women and girls

31. The Government's plans for the Women's Health Strategy for England should include support and guidance for women who have conceived as a result of rape, and for children born as a result of rape. This should include tailored information on the NHS website, including on rape-induced gynaecological issues. (Paragraph 113)

Training and standards

- 32. The Department of Health and Social Care should set out plans to improve the accessibility and take up of professional development in women's reproductive health conditions among practitioners in primary care.

 Those plans should include allocating increased funding for training on reproductive health conditions and protected time for GPs to undertake that training. (Paragraph 120)
- 33. The approval of the anti-mullarian hormone blood test as another tool to assist in the diagnosis of polycycstic ovary syndrome is a welcome development. NHS England should evaluate the merits of rolling it out nationally as a matter of priority. (Paragraph 121)
- 34. GPs face difficulties diagnosing complicated reproductive healthcare conditions which may present with a variety of symptoms. They face workplace pressures, have short consultation times, and can struggle to access training and guidance. While it is positive to see that medical guidelines and assessments are being updated, further work on professional standards is required if the invalidation that women have reported during this inquiry is to be adequately addressed. (Paragraph 129)
- 35. The annual GP appraisal process should be strengthened to include a specific performance indicator on the diagnosis and treatment of women's reproductive health conditions, including intersectional considerations. That indicator should include patient experience. (Paragraph 130)
- **36.** NHS Digital should collect data on how many hours of training primary care practitioners undergo annually in the field of women's reproductive health. (Paragraph 131)

Medical education

37. Training on women's reproductive health in medical schools needs to be improved. Healthcare practitioners are graduating without sufficient knowledge of the conditions that may affect women over their lifetime.

- Without that education, healthcare professionals are less likely to choose women's health as a specialty and less able to support women during their interactions with the health service. (Paragraph 137)
- 38. The Government should work with the RCOG, RCGP and the GMC to improve the teaching of women's health at undergraduate level and ensure it is an integral part of medical education for all those seeking a career in healthcare. As part of that work the Government should consider how to better incentivise healthcare professionals to specialise in women's reproductive health, including making obstetrics and gynaecology a mandatory rotation. This is necessary to address current shortages in this area and to tackle the long waiting lists for gynaecological care. The merits of using of the quality and outcomes framework (QOF) or commissioning for quality and innovation (CQUIN) indicators should be part of its consideration of potential incentives. (Paragraph 138)
- 39. Primary care practitioners should be trained to use women's common interactions with the healthcare system, such as cervical screening appointments, ante- and post-natal care checks and visits to STI clinics, as an opportunity to pick up hidden health concerns relating to reproductive health. (Paragraph 139)

Medical guidelines and standards

40. The Department of Health and Social Care and NHS England should commission NICE to develop comprehensive guidelines for all reproductive health conditions. Those guidelines should be communicated to GPs and made accessible to patients through the NHS website to allow informed patient-GP discussions. Adherence to these guidelines by medical practitioners and any barriers to following them must be monitored, including their usefulness to patients. (Paragraph 145)

A fragmented commissioning system

41. The expansion of the women's health hub model has the potential to be a positive step towards providing the joined-up care and commissioning needed to effectively support women experiencing reproductive health conditions. However, the women's health hub model exists within a healthcare system which has significant commissioning, funding, workforce and expertise problems, particularly in the area of reproductive health. There are also risks that those not yet served by hubs, or with limited access such as in rural areas, will be disadvantaged. (Paragraph 159)

- 42. It is positive to hear that many of the leaders in the ICBs are focusing their hubs on disadvantaged groups. While local ownership, management and decentralisation of the hubs is important to meet local needs, regular national-level evaluations are also required to ensure that the hubs are providing the intended additional benefits and are not just a rebadging of existing services. It disappointing, for example, that it is rare for hubs to offer multiple services at the same time—something we view as a key benefit of the hub model. (Paragraph 160)
- 43. We find that women's health hubs have proven the concept that they can deliver improvements to women's healthcare. The Government must now allocate long-term, ring-fenced funding and resource to embed the hub model and further support its development. That development should include increased provision of ultrasound facilities within hubs. Funding should be accompanied by a break-down of how it will be used and which services will be available in each area. (Paragraph 161)
- **44.** Integrated care boards must ensure that their hubs meet the specific demographic needs of their populations, particularly accounting for religious and cultural considerations. (Paragraph 162)
- 45. There remains a postcode lottery of access in primary care to long-acting reversible contraception. As a result, some women are having to seek care from secondary or community services, leading to delays in treatment and an unnecessary burden on secondary care. This is a preventable cost to the system and to the wellbeing of the individual. While the establishment of women's health hubs may go some way to addressing this concern, in areas where hubs are not established other solutions will be required. (Paragraph 163)
- **46.** The Government should develop a funding and training strategy to address the lack of LARC provision in general practice, particularly in those areas not covered by a women's health hub. This should include an assessment of whether the current fee structure is fit for purpose. (Paragraph 164)

Research

47. Finding the causes of women's reproductive health conditions and new and better diagnostic tools and treatments for them cannot happen without sufficient research, which includes all groups of women and others affected, at different life stages. Yet research remains lacking because it is not adequately prioritised by funders or commissioners and is not incentivised enough in clinical academia. While these issues are recognised by the Women's Health Strategy for England and some positive work is underway, the Government needs to be more ambitious and more targeted approaches are needed. (Paragraph 180)

- 48. The Women's Health Strategy for England should be updated to include priorities for specific, common conditions. We recommend the Government commits to reducing waiting times for an endometriosis diagnosis to less than two years by the end of this Parliament and to improved understanding, diagnosis and treatment of heavy menstrual bleeding over the same period. (Paragraph 181)
- 49. The Government should allocate increased, ringfenced funding to support research into the causes, diagnosis and treatment of women's reproductive health conditions. While increased funding will in itself attract more researchers to this area, NHS England and research bodies should also consider what steps they can take to increase interest among clinical academia. (Paragraph 182)

Implementing the Women's Health Strategy for England

50. The Government should publish an implementation plan for the Women's Health Strategy for England detailing timelines, costs and resource. (Paragraph 184)

Funding

51. We call on the Government to recognise the financial benefits of increased investment in early diagnosis and treatment of women's reproductive health conditions and provide the additional funding necessary to truly transform the support available to the millions of women affected by reproductive ill health in this country. (Paragraph 187)

Formal minutes

Wednesday 4 December

Members present

Sarah Owen, in the Chair

Alex Brewer

David Burton-Sampson

Kirith Entwistle

Natalie Fleet

Christine Jardine

Samantha Niblett

Rachel Taylor

Women's reproductive health conditions

Draft Report (Women's reproductive health conditions), proposed by the Chair, brought up and read.

Ordered, That the Report be read a second time, paragraph by paragraph. Paragraphs 1 to 187 read and agreed to.

Annex agreed to.

Summary agreed to.

Resolved, That the Report be the First Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Adjournment

Adjourned till Wednesday 11 December at 2.00pm.

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the inquiry publications page of the Committee's website.

Wednesday 18 October 2023

Naga Munchetty, Broadcaster and Journalist; **Vicky Pattison**, Broadcaster and Personality

Q1-46

Wednesday 8 November 2023

Janet Lindsay, Chief Executive, Wellbeing of Women;
Rebekah Lloyd, Founder, This Independent Life;
Dr Anne Connolly MBE, Co-Chair, Menstrual Health Coalition

Q47-69

Dr Michael Mulholland, Honorary Secretary, Royal College of General Practitioners; **Professor Sue Carr**, Deputy Medical Director, General Medical Council; **Dr Geeta Kumar**, Vice President for Clinical Quality, Royal College of Obstetricians and Gynaecologists

Q70-108

Wednesday 29 November 2023

Professor Hilary Critchley FMedSci, Fellow, Academy of Medical Sciences;
Dr Robin Buckle, Chief Science Officer, Medical Research Council;
Dr Judith Richardson, Programme Director, National Institute for Health and Care Excellence (NICE); Professor Lucy Chappell FMedSci, Chief Executive Officer, National Institute of Health and Care Research

Q109-136

Maria Caulfield MP, Parliamentary Under-Secretary of State (Minister for Mental Health and Women's Health Strategy), Department of Health and Social Care; Charlotte McArdle, Deputy Chief Nursing Officer, NHS England; Professor Dame Lesley Regan, Women's Health Ambassador, for England

Q137-171

Wednesday 13 November 2024

Professor Dame Lesley Regan, Women's Health Ambassador for England; **Dr Sue Mann**, National Clinical Director for Women's Health, NHS England

Q1-48

Published written evidence

The following written evidence was received and can be viewed on the inquiry publications page of the Committee's website.

WRH numbers are generated by the evidence processing system and so may not be complete.

1	Abel, Professor Kathryn (Professor of Psychological Medicine and Reproductive Psychiatry, The University of Manchester); Hope, Dr Holly (Research Associate, The University of Manchester); and Kearney, Dr Rohna (Consultant Urogynaecologist and Deputy Medical Director, Saint Mary's Hospital, Manchester University NHST Trust)	WRH0050
2	Academy of Medical Sciences	WRH0033
3	Advisory Group on Contraception	WRH0045
4	Afghan, Dr Saifullah (Consultant Forensic Psychiatrist); Beryl, Dr Rachel (Consultant Forensic Psychologist); Galway, Dr Roisin (Clinical Psychologist); Siddall, Ms Yasmin (Consultant Forensic Psychologist); White, Dr James (Consultant Forensic Psychiatrist); and Wilkinson, Ms Dawn (Clinical Nurse Practitioner) - National High Secure Healthcare Service for Women, Rampton Hospital, Nottinghamshire Healthcare NHS Foundation Trust	WRH0040
5	All Party Parliamentary Group on Women's Health	WRH0018
6	Anand, Dr. Amit (Assistant Professor of Law and Coordinator, Centre for Human Rights Law and Policy, REVA University, Bengaluru); Nagaveni, Dr. Preethi Lolaksha (PhD (Law) Graduate, Lancaster University, UK); and Singh, Ms. Riya A. (Undergraduate Student, Presidency University, Bengaluru)	WRH0008
7	Bayer Plc	WRH0041
8	Besins Healthcare UK	WRH0052
9	Birmingham City University	WRH0005
10	British Association for Sexual Health and HIV	WRH0021

WRH0036

British Pregnancy Advisory Service

11

12	British Standards Institution	WRH0007
13	Brook	WRH0051
14	Carr, Professor Sue (Deputy Medical Director,	
	General Medical Council)	WRH0061
15	Changing Lives	WRH0046
16	Critchley, Professor Hilary (Fellow, Academy of Medical Sciences)	WRH0065
17	Department of Health and Social Care; and NHS England	WRH0057
18	FSRH; and Bloody Good Period	WRH0048
19	Fair Play for Women	WRH0016
20	Ford, Dr Andrea (Research Fellow in Biomedicine, Self and Society, University of Edinburgh); Griffith, Dr Véronique (Lecturer (Assistant Professor) in Healthcare Sciences, The University of Manchester); and Weckesser, Dr Annalise (Reader in Medical Anthropology, Birmingham City University)	WRH0047
21	Healthwatch Birmingham	WRH0049
22	Healthwatch Liverpool	WRH0002
23	Holland & Barrett	WRH0027
24	King, Dr Sally (Founder/ ESRC Postdoctoral Fellow, Menstrual Matters/ King's College London)	WRH0044
25	Lloyd, Rebekah (Founder, This Independent Life)	WRH0060
26	MSI Reproductive Choices UK	WRH0054
27	Marshall, Professor Kay (Professor of Reproductive Endocrine Pharmacology, The University of Manchester)	WRH0009
28	McNiven, Dr Abigail (Senior Qualitative Researcher, University of Oxford); and Toye, Dr Francine (Senior Qualitative Researcher, University of Oxford)	WRH0013
29	Menstrual Health Coalition	WRH0020
30	Moseley, Dr Rachel (Principal Academic in Psychology, Bournemouth University)	WRH0022
31	Muslim Women's Network UK	WRH0031
32	Nottingham Women's Centre	WRH0032
33	Peat, Ms Sara (Clinical Psychologist in training, NHS)	WRH0038
34	Pelvic Obstetric and Gynaecological Physiotherapy	WRH0025
35	Privacy International	WRH0035

36	Royal College of General Practitioners	WRH0034
37	Royal College of Obstetricians and Gynaecologists	WRH0063
38	Royal College of Obstetricians and Gynaecologists	WRH0056
39	Terrence Higgins Trust	WRH0042
40	The Campaign Against Painful Hysteroscopy	WRH0037
41	The Scottish Women's Convention	WRH0003
42	This Independent Life	WRH0026