Summary

1. There is still stigma surrounding women’s reproductive health issues that prevent women from receiving care and impede the development and implementation of innovative treatments in reproductive health. Investment, education, and research into women’s reproductive health is essential for progress in this area and to prevent detrimental impacts on the quality of life and productivity of women.

2. Improving the education and awareness of healthcare professionals (HCPs) and the wider public, including boys and men, is important for improving women’s reproductive health by reducing stigma, taboo and bias. The Women’s Health Strategy for England (WHSE) has made commitments to women’s health education, including more information on women’s health through the dedicated area on the NHS website for women and girls’ health issues. Other important intervention points suggested by our experts are:
   - Primary and secondary education (preferably prior to or around when a girl first experiences menstruation) for girls and boys.
   - School nurses for education and early identification of those with reproductive and menstrual health problems.
   - Pregnancy and the post-partum period are highly important intervention points for education, with targeted parenting support and education likely to benefit the health of both child and mother.

3. The intersection of gender with ethnicity, language, level of education and other characteristics also impacts a woman’s ability to access reproductive healthcare. Therefore, we believe it is necessary to consider the effects of intersectionality across all themes outlined in the consultation to ensure equity of access to high quality care for all women.

4. There is currently a lack of women’s health-specific research, insufficient inclusion of women in clinical research, and a lack of sex-disaggregated data.\(^1\) This could be addressed by funding streams specific to women’s health and by funders acknowledging the importance of women’s health issues during prioritisation exercises, as well as supporting women’s involvement in pre-clinical and clinical studies, including pregnant women.

5. Every time a woman accesses healthcare should be seen as an opportunity to pick up hidden health concerns and risk factors, put a plan in place to mitigate the risk of developing further reproductive health conditions, and enable precision prevention.\(^2\) Common intervention points, such as accessing sexual health services and ante- or post-natal care, were identified by our experts as particularly useful opportunities to apply these practices.

\(^1\) National Institutes of Health. How Sex/Gender Influence Health & Disease (A-Z).
\(^2\) Academy of Medical Sciences (2021). Precision prevention for modifiable health risks: Steps to achieving personalised preventive healthcare workshop. [https://acmedsci.ac.uk/file-download/48790754](https://acmedsci.ac.uk/file-download/48790754)
6. **Ongoing evaluation of the impact of interventions on women’s reproductive health is vital.** There should be a comprehensive post-market surveillance (PMS) in place to monitor sex-specific health issues and treatment impacts. Infrastructure for PMS should be improved by addressing current data gaps, optimising data linkage, and improving data quality.

**Introduction**

7. The Academy of Medical Sciences is the independent, expert voice of biomedical and health research in the UK. Our Fellowship comprises the most influential scientists in the UK and worldwide, drawn from the NHS, academia, industry, and the public service. Our mission is to improve the health of people everywhere by creating an open and progressive research sector. We do this by working with patients and the public to influence policy and biomedical practice, strengthening UK biomedical and health research, supporting the next generation of researchers through funding and career development opportunities, and working with partners globally.

8. Our response to this call for evidence[3] is based on our previous policy work across a broad range of topics with relevance to women’s health, as well as evidence from members of our elected Fellowship. Our response echoes the Academy’s response[4] to the Department of Health and Social Care (DHSC) call for evidence[5], April 2021, to inform the priorities content and actions of England’s first Women’s Health Strategy (WHSE).

9. In this response we primarily focus on the disparities and barriers women and girls* face in reproductive health when seeking and receiving diagnoses and treatments. This includes the bias and stigma surrounding reproductive health topics, the level of education and awareness of these issues in the population and the gaps and disparities in reproductive research.

**Women’s experiences of being diagnosed with and/or undergoing treatment for reproductive health issues**

10. The burden of women’s reproductive health issues such as heavy menstrual bleeding, fibroids[6,7], endometriosis[8] and chronic pelvic pain, as well as symptoms of menopausal transition, cause women to lose productivity[9,10], reduce their working hours, resulting in disciplinary action, resigning from leadership roles, and leaving the workforce altogether[11,12] due to reduced quality of life and

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stigma around these conditions. This has significant impact on the individual, society and the economy.

11. Stigma surrounding gynaecological health influences women’s care seeking behaviours and ability to communicate symptoms, which has consequences for their future reproductive and sexual health. A survey of 7,367 women revealed that over 30% experienced severe reproductive health problems in the last 12 months, yet less than half sought help. Menstruation, sexual health, the transition to menopause, incontinence and perinatal mental illness all have significant impacts on women’s physical, sexual, mental and social wellbeing and yet are still seen as taboo subjects, discouraging women from seeking advice and treatment. We therefore welcome the ambition to improve access to reproductive healthcare and reduce stigma in the recently published WHSE. Education is an important means to reduce stigma and empower women to make informed evidence-based decisions about their health.

12. One problem identified across a range of women’s reproductive health issues was the frequent focus on, and treatment of, symptoms rather than causes. For example, the practice of using oral contraceptives to treat the symptoms of heavy menstrual bleeding and endometriosis, instead of developing a plan that meets the needs of the individual.

13. The Independent Medical Devices and Medicines Safety Review exposed systematic problems with respect to how the healthcare system in England listens and responds to women’s concerns about their health and care, including:

- Evidence of pain or symptoms being normalised or being dismissed entirely by healthcare professionals (HCPs). Our experts highlighted examples relating to menstrual disorders (including abnormal uterine bleeding and menstrual pain), pregnancy, miscarriage, and chronic pain.
- Dismissal at the institutional level can also be seen in miscarriage care, with a lack of progress in care and medical research being attributed to a ‘pervasive acceptance’ of miscarriage.

14. One concern repeatedly emphasised to us was the observed decline in the quality of antenatal and post-natal care services over recent years, pre-dating but exacerbated by the COVID-19 pandemic. Of note, insufficient numbers of midwives, reduced in-person visits and reduced support with infant feeding have been associated with the increasing prevalence of perinatal mental health issues.

References:

22 The Independent Medicines and Medical Devices Safety Review (2020). First Do No Harm.
23 Clark M (2012). Experiences of women with endometriosis: an interpretative phenomenological analysis [thesis]: Queen Margaret University.
and infant re-admissions.\textsuperscript{30} There is a need for reinvestment, and the implementation of already well-evidenced innovations, in post-natal service delivery, such as midwifery-led post-natal care.\textsuperscript{31} The Academy is exploring these issues more widely in a policy project looking at improving child health in the early years.

**Disparities in diagnosis and treatment of women’s health conditions**

15. HCPs exhibit the same levels of implicit bias as the general population with regards to characteristics such as gender and race, likely influencing diagnosis and treatment decisions and levels of care.\textsuperscript{32} This extends to reproductive care, with women from ethnic minority groups more likely to report not always being involved in decisions about their care or not having confidence and trust in HCPs before, during and after pregnancy.\textsuperscript{33}

16. Language and low health literacy have been identified as the most significant barriers to communication of information and care provision, particularly affecting those not fluent in English, those with learning, speech or hearing impediments, those with heavily stigmatised health issues, and older people. It was also noted that reduced ability to eloquently describe symptoms can affect timeliness of care.

17. Disparities also exist within reproductive health issues, with some areas more widely acknowledged, accepted, and discussed than others. Notably, there is a lack of awareness around the prevalence and prevention of urinary incontinence despite being experienced by over a third of women post-natally.\textsuperscript{34} The WHSE has informed investment in exploring urinary incontinence and we look forward to the results of this research. The WHSE also made commitments to improve integrated care specifically through women’s health hubs and women’s health champions, and we understand this incorporates new perinatal pelvic health clinics, which may help to address the lack of attention to this common problem. It is important that women’s health issues with less attention are not forgotten and should also be addressed.

18. Apps that improve menstrual health literacy were noted by our experts as important shared decision-making tools for healthy women, patients and HCPs.\textsuperscript{35} However, most digital health start-ups focus on applications associated with fertility, meaning significant unmet need remains in conditions more stigmatised by society such as menopause, pelvic pain and menstrual disorders. Of the top 39 women’s health start-up companies (of which 15% were UK-based), 54% focus on reproductive health whereas only 5% focus on menopausal symptoms.\textsuperscript{36} While using more technology may be convenient for some patients, it should be noted that some may be disadvantaged if they are less able to engage with the

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\textsuperscript{33} National Perinatal Epidemiology Unit (2014). \textit{Safely delivered: a national survey of women’s experience of maternity care}.


\textsuperscript{36} \url{https://www.medicalstartups.org/top/women-health/} (accessed 11/05/21)
technology or articulate symptoms, reducing the likelihood of seeking professional medical advice.

19. There is a need to ensure women’s reproductive health provisions are interdisciplinary, encompassing a range of biomedical, technological, public health and policy interventions, which considers how to connect with women from ‘underserved’ groups. For example, a service innovation is the implementation of high-risk human papillomavirus (hrHPV) testing as the primary approach in cervical screening. Women from more deprived areas are at greater risk of hrHPV, yet less likely to attend screening. An interdisciplinary approach could help to target women less likely to access screening programmes.

**Barriers to diagnosis and treatment of women’s reproductive health conditions**

20. A lack of understanding and awareness among HCPs was identified as a barrier to correct diagnosis and good care in menstrual health (including fibroids), endometriosis, the menopause and perimenopause, and during pregnancy. This has a direct impact on women’s reproductive health outcomes and productivity and increases healthcare costs. It is important that HCPs at all career levels (including in decision-making roles) are kept up to date with the relevant NICE guidelines and latest diagnostic and treatment strategies by continued training and embedding research into the NHS.

21. Education of the population is an important means to reduce stigma and empower women to make informed evidence-based decisions about their reproductive health. In a YouGov survey, one in four women reported not understanding their menstrual cycle. A lack of awareness about ‘normal’ menstruation translates to a normalisation of abnormal symptoms of disorders such as heavy bleeding, endometriosis and fibroids, delaying diagnosis. The WHSE has recently included educational resources specific to women and girls’ health issues on the NHS website. However, there are other important intervention points for education, particularly for involving boys and men in the discussion:

- The Menstrual Health Coalition, the Royal College of Obstetricians and Gynaecologists (RCOG) and others have identified primary and secondary education (preferably prior to or around when a girl first experiences menstruation) as an important intervention point for educating girls and boys about women’s health and sexual wellbeing and reducing stigma. The inclusion of men and boys in women’s sexual, menstrual and gynaecological health education was highlighted as essential to help reduce stigma.

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37 AbbVie (2021). *Empowering conversations: Making shared decision making a reality for patients in an evolving NHS.*
42 APPG on Endometriosis (2020). *Endometriosis in the UK: time for change.*
43 ActionAid (2017). *1 in 4 UK women don’t understand their menstrual cycle.*
48 Plan International UK (2018). *Break the Barriers: Girls’ Experiences of Menstruation in the UK.*
• The lack of investment in school nurses was identified by some of our Fellows as a lost opportunity for education and early identification of those with reproductive and menstrual health problems.

• Pregnancy and the post-partum period were identified as other significantly underutilised but highly important intervention points for education, with targeted parenting support and education likely to benefit the health of both child and mother.

**Barriers to research into women’s reproductive health issues**

22. Women’s reproductive health issues are frequently understudied, and their research underfunded. For example, for every £1 spent by the NHS on reproductive care, just 1p is spent on reproductive research in the UK, substantially less investment than for other conditions such as heart disease (7p for every £1) and cancer (12p for every £1).⁴⁹ The WHSE has commitment to invest in reproductive health through the NIHR.

23. Clinical research has historically excluded women, partly due to a false assumption that drugs work similarly in both sexes and partly to avoid variability introduced by women’s hormonal fluctuations.⁵⁰ Although international guidelines have been introduced to increase the enrolment of women, their recruitment is still often insufficient. Women are frequently only included later in the drug development process, and those from ethnic minority and low socioeconomic groups, as well as pregnant women, are typically under-represented. Furthermore, many clinical studies still fail to power and stratify their results to identify sex-specific side effects or outcomes.⁵¹ Consequently, women can be prescribed medicines where there is no evidence of the potential harms (e.g. sodium valproate is used as a treatment for epilepsy but has been found to increase the risk of birth defects if prescribed during pregnancy),⁵² or else denied access to potential life-saving medicines or vaccines entirely:

• Despite menstruation and menstrual disorders affecting so many so regularly⁵³, no new non-hormonal medical interventions for heavy menstrual bleeding have been developed in the last 30 years.⁵⁴

• Furthermore, changes in drug responses and efficacy throughout the life course are poorly studied. Despite preclinical and clinical evidence showing that oestrogen and progesterone levels affect the response of individuals to addictive drugs including nicotine, alcohol, cocaine and stimulants,⁵⁵,⁵⁶ there is a paucity of research examining the effect of menopause and menstruation on the efficacy of medical drugs.

• Menopause and menopause-related symptoms (MRS) are poorly characterised. For 20–40% of women the symptoms are debilitating, affect their daily lives, and can last for up to 10 years. The WHSE is introducing hormone replacement therapy (HRT) hubs to improve access to HRTs to treat MRS in many women. However, more research in women’s health could help

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⁵² The Independent Medicines and Medical Devices Safety Review (2020). *First Do No Harm.*


to improve understanding and prevention of adverse effects of menopause, for example regulators of neurokinin pathways are also being explored as promising non-hormonal alternatives.

- Due to a lack of experimental models of pregnancy and underrepresentation of pregnant women in clinical trials, only two drugs have been approved for treatment of pregnancy-specific conditions since the 1990s. As pregnant people are rarely included in clinical trials, drugs taken during pregnancy are often not tested for impacts to mother or foetus which can also vary person-to-person based on differences in physiology and drug mechanism or dosage. For example, although antenatal corticosteroids are used widely to improve preterm birth outcomes, no robust evaluation of dose responses was ever performed. The Academy’s FORUM is hosting an event on ‘understanding pregnancy: baby steps to developing drugs for pregnancy-specific conditions’ and a report will be published shortly after the event with next steps in this area, which we are happy to share with the Women and Equalities Committee when it becomes available.

- Another consequence is that women miss out on the benefits both of participating in trials and from the outputs of research. For example, despite women making up over half of HIV patients globally, a Phase III trial of the drug Descovy for HIV-1 pre-exposure prophylaxis did not include a sufficient number of women, resulting in the FDA imposing a restricted label, preventing its use by those ‘at risk from vaginal sex’.

Opportunities to address barriers in women’s reproductive healthcare

24. Every time a woman accesses healthcare should be seen as an opportunity to pick up hidden health concerns and risk factors, put a plan in place to mitigate the risk of developing further reproductive health conditions, and enable precision prevention. Common intervention points, such as accessing sexual health services and ante- or post-natal care, were identified as particularly useful opportunities to apply these practices. For example, pelvic floor dysfunction (PFD) can be prevented by identifying risk factors such as BMI and birth method, then prevented by recommending pelvic floor muscle training during post-natal care.

25. There is an urgent need to research and address the impact of debilitating reproductive health problems on younger women and of the menopausal transition on the ability of women to remain productive in the work place, particularly in the over half of women in low-paid or manual jobs. To facilitate this, menstrual disorders and menopausal symptoms should be listed as reasons for absenteeism in the ONS annual ‘Sickness absence in the UK labour market’ datasets. The WHSE also includes plans to work with bereaved families to develop a voluntary pregnancy loss certificate application process.

26. There is currently a lack 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 (e.g. maternal health topics like placental biology into endocrine/physiology fields). The experts that we consulted suggested that this could be addressed by women’s health-specific funding

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59 https://acmedsci.ac.uk/more/events/understanding-pregnancy
60 FDA (2019). FDA approves second drug to prevent HIV infection as part of ongoing efforts to end the HIV epidemic.
61 Academy of Medical Sciences (2021). Precision prevention for modifiable health risks: Steps to achieving personalised preventive healthcare workshop.
streams and by funders acknowledging the importance of women’s health issues during prioritisation exercises.

27. The Academy supports the clinical trial and regulatory community in working towards safe inclusion of pregnant women in clinical trials as a default position. Some key recommendations to address this are laid out in the RCOG paper ‘Developing New Pharmaceutical Treatments for Obstetric Conditions’.63 A report by Modi et al. (2021) outlined the evidence that should be collected and considered to enable such safe inclusion, including the balance of risks of exclusion from or inclusion in initial studies, patient and public perspectives, preclinical and clinical developmental and reproductive toxicity data, and approaches to collect data systematically from participants who are unknowingly pregnant at the time of exposure.64

28. It is important that health data is inclusive of diverse populations. Exclusion of sex- and gender-disaggregated evidence endangers women’s health.65,66 This knowledge can be improved by standardisation of data collection (e.g. standardisation of data capture using systems such as SNOMED CT),67 incorporation of patient-reported outcome measures, and supporting the implementation of existing NICE guidelines including education on sex-specific adverse drug reactions (ADRs) and sex-specific prescribing and dosing guidelines for HCPs (e.g. Janusmed Sex and Gender knowledge bank).68 Considerations on the most effective use of existing treatments based on sex must become commonplace.69

29. Evaluation of plans to improve reproductive health services should be a priority to provide evidence for their effectiveness. There should be a comprehensive post-market surveillance (PMS) in place to monitor sex-specific health issues and treatment impacts. Infrastructure for PMS should be improved by addressing current data gaps, optimising data linkage, and improving data quality.

This response was prepared by Danielle Groves and Olivia Conway, Policy Interns, and Angel Yiangou, Senior Policy Manager, and informed by members of the Academy’s Fellowship and previous policy work in this area. For further information, please contact Angel Yiangou, Senior Policy Manager (Angel.Yiangou@acmedsci.ac.uk)

65 United States General Accounting Office (2001). Drug Safety: Most Drugs withdrawn in Recent Years had Greater Health Risks for Women.
68 https://janusinfo.se/beslutststod/janusmedkonochgenus/janusmedsexandgender/inenglish/workingprocess.5.728c0e316219da8135e7339.html
69 Academy of Medical Sciences (2017). Personalised psychiatry. https://acmedsci.ac.uk/file-download/16107617