

Compassion, courage, credibility, and commitment to women's choice

The British Pregnancy Advisory Service's response to the DHSC's Women's Health Strategy consultation

Background

The British Pregnancy Advisory Service (BPAS) is a healthcare charity that cares for 100,000 women a year via 60 clinics across Great Britain. For the past 50 years we have delivered pregnancy counselling, abortion care, miscarriage management, contraception, and testing for sexually transmitted infections (STIs) to those who need us. In 2021, we will be launching the first not-for-profit fertility service in England.

BPAS is also home to the Centre for Reproductive Research & Communication (CRRC), which develops and delivers a research agenda that furthers access to evidence-based reproductive healthcare and choices.

BPAS has a long history of advocating for women's reproductive health and rights, working to empower women and give them control over their own reproductive decisions and healthcare. BPAS's services, advocacy, and campaigning are inclusive of trans, non-binary and intersex people and we strive to deliver patient-centred care to every individual who needs us. We use the word women for simplicity, but also in recognition that the majority of those accessing our services identify as women.


Our approach to women's healthcare

BPAS exists to deliver reproductive choice. Reproductive choice means the ability to make one's own decisions in matters relating to one's own body - from the contraception needed to avoid conception to how to feed a new-born baby, the choice to start a pregnancy as well as to end one. It means the ability to access care and support for matters relating to reproductive health and wellbeing – from cervical smears to menopause care. It also means the right to access medical treatment free from restrictions based on reproductive status.

Through a combination of our service delivery, advocacy, campaigning, and research, BPAS aims to remove the barriers to exercising reproductive choice and autonomy. We want to put the technologies for reproductive control directly into women's hands where possible but are also committed to training and empowering healthcare staff who can provide support every step of the way for everyone who needs us, whenever they need us.

What women's healthcare needs

BPAS believes that for too long, conditions that are primarily or exclusively associated with women have been under-researched, under-funded, and overlooked. Women's healthcare has suffered from undue criminalisation, discrimination, and ignorance. Addressing this structural inequality must be the primary aim of a Women's Health Strategy and work at all levels of the NHS. Further priorities should include:

-  **Centring women's voices and experiences.** Too many targets, strategies, and goals are developed without women's voices or experiences being present. This is

particularly the case in public health messaging in relation to pregnancy, where women by which foetal and child outcomes can be improved, rather than as people with are often seen as means their own healthcare needs, concerns, and outcomes.

- Increasing responsiveness and accessibility of services. A lack of understanding of and training in woman-specific conditions such as endometriosis at a local level can require women to travel greater distances to access specialist care, without any recognition the impact on women who are unable to take time off work, afford travel or accommodation, or find childcare. Skilled, specialised care should be available as close to home as is safe and possible.
- Reducing fragmentation of services and removing barriers to access which have arisen as a result of commissioning practices and long-standing disparities of care between areas and across different providers and budget lines. These practices have led to cumbersome patient pathways and data gaps that would otherwise help drive the improvement of care, and the de-prioritisation of women's healthcare services including fertility services, which has led to inequitable provision of IVF.
- Removing legal impediments to providing high quality care. BPAS is the country's largest abortion provider – but our ability to innovate in women's healthcare is limited by outdated legislation and a sluggish response by government to improvement of the legal settlement. Healthcare should be governed by healthcare laws and abortion should be removed from the criminal law.
- Innovation of care to place power and technology in women's hands. Women's healthcare has long been subject to undue medicalisation – removing individuals' ability to manage their own care in a way that works for them. There should be more investment in and understanding of the role that technology and remote services can play in delivering healthcare to women as swiftly and privately as possible.
- Increasing research spend on women's conditions and women's experiences of conditions. There are shortcomings both in research and evidence-based care for conditions which exclusively affect women (e.g. endometriosis, menopause), and of the way in which women experience conditions that are common to everyone (e.g. differing symptoms of heart disease). There is also a lack of pregnancy-related research, with a related need to focus on maternal outcomes and experiences as well as those of the fetus. There should be additional investment in research which centres these experiences and recognises the value in diversifying recruitment and research topics.

How to provide better women's healthcare

The problems associated with fragmentation of care are well known. Fragmentation leads to worse outcomes, poor patient experiences, and prevents people from being active participants in the healthcare process. Despite healthcare services needed by women being relatively simple to predict, many women struggle to access the services they need.

The patient experience

Take an example of a woman who has repeated bouts of unusual discharge, bleeding and cramping between periods. This woman is sexually active and knows these could be symptoms of an STI, so books herself in for a test at her local sexual health clinic, at the appointment she will be asked a number of questions about her personal and intimate health, her vagina will be swabbed, bloods and urine samples taken. If her tests come back negative, she will be advised to seek further advice from her GP. Still experiencing

symptoms, the woman then books an appointment with her GP where she will have to revisit her personal and intimate health history, be advised to come back for a cervical smear next week and also be referred for an investigative appointment at a hospital gynaecology department. The woman goes back for her smear the next week, where she is asked similar questions and uncomfortable, sometimes painful, vaginal swabs are taken. The appointment letter for the hospital takes 3 months to come through and at the hospital the woman is asked the same set of questions she has answered three times now, this time her vagina and cervix is numbed, a third set of swabs is taken as well as more urine samples and also a biopsy.

For women, fragmentation often looks like having to seek out and visit a multitude of different providers, wait months for appointments, continually repeat medical history and in this example undergo many uncomfortable intimate examinations. These experiences are tiring, dehumanising, frustrating and, particularly for younger women, often scary.

The provider's view

BPAS have worked with local bodies, providing women's healthcare, for over 50 years and understand the importance of creating and maintaining deep and meaningful relationships in local areas. We also recognise the difficulties in doing this, different demographics will present different problems and marginalised groups are not always visible. Any women's health strategy will have a bearing on these groups and it is important that any design for women's health clinics is broad enough to ensure care is not fragmented, whilst allowing enough flexibility for clinics to develop services in ways that suit their local demographics.

The new integrated care systems (ICSs), laid out in NHS white paper, provide an opportunity to address this fragmentation. **To address the shortcomings in women's healthcare in the short and medium term, the government should instruct commissioners to work with local GPs and health providers to develop, fund, and implement a system of local women's health hubs in ICSs across the country.** These hubs would help ensure a more joined-up approach to women's health, including preventative care.

Long term future of women's health

BPAS sees women's health clinics as an immediate solution to improve the pressing issue of women's poor access to services and bad healthcare experiences, but in our view, they should not be considered the end goal. Long-term, more should be invested into ensuring that women's health is a routine part of mainstream healthcare and that GPs are properly trained to recognise, diagnose, and treat women's health issues.

To ensure the long-term mainstreaming of women's healthcare in the primary care system, **the government should work with medical schools and nursing and pharmacy organisations to improve education and continuing professional development in the diagnosis and treatment of women's health conditions.**

Women's lives, women's health

A life course approach to women's health recognises the relatively predictable care needs a woman will have at different stages in her life and helps ensure that she is able to access this care with ease. It presents opportunities for prevention and will help to create more joined-up services that centre the experiences of women, give them better information about their healthcare choices, and improve outcomes and experiences.

Menstrual wellbeing

Menstruation is something that is experienced by most girls and women on a monthly basis for up to 40 years of their lives. Despite this, knowledge of menstrual health disorders is poor

and women struggle to access reliable information. On average it 7.5 years to get a diagnosis of endometriosis¹ - owing to a lack of awareness and training of GPs, a lack of specialised or dedicated care for women at a local level, and – quite simply – a lack of concern for women’s wellbeing. As such, successful diagnosis and treatment of conditions such as endometriosis often require high levels of self-advocacy and awareness from patients – often found from support groups or charities. Although this type of support can be very helpful, it should not be the only way in which women’s concerns are taken seriously.

To address the lack of expertise in women’s healthcare at a primary care level in the short to medium term, **local referral pathways into specialised hubs should be put in place in collaboration with local GPs and other services to enable accessible care for conditions specific to women including endometriosis, coil and implant fittings, cervical screening, and abortion care.**

Contraception

Women want to enjoy healthy sexual relationships and pre-menopausal women engaging in heterosexual sex want to control their fertility and decide if and when to become pregnant. This requires access to effective contraception and abortion services.

Not only do current barriers to women accessing contraception and contraceptive advice and counselling need to be addressed, but we should listen to women who are telling us there are no suitable contraceptive methods out there for them. The common side effects of hormonal contraceptives include weight gain, headaches, sore breasts, irregular periods, mood changes, decreased sexual desire, acne, and nausea. Increasing numbers of women are deciding that these common side effects do not outweigh the risk of unplanned pregnancy and are instead making different contraceptive and reproductive choices – resulting in differing needs and considerations for women seeking to support to control their fertility.

Long-Acting Reversible Contraception

For similar reasons, LARC use – desirable as it may be from a public health perspective – is not suitable or acceptable for everyone. Many women may not wish to engage with a method of contraception over which they have no control – relying on healthcare professionals for fitting and removal, and often encountering difficulties when seeking replacement or removal.

Others may avoid an IUD due to what can be, particularly for those who have not had children, a painful insertion procedure. Women can report agony, fainting, or throwing up from the pain. Quotes on the experience of insertion range from: “this felt like being torn open from the inside, again and again and again”² to “I have never, ever experienced pain like that before or since” and “such blinding agony I could barely see. I’ve had major surgeries in the past and have a pretty decent pain tolerance, but this was something else.”³

Despite accounts such as these, limited research into the management of pain during and after an IUD insertion means healthcare providers have few evidence-based options to offer. No woman should have to encounter this level of pain in order to fulfil her reproductive choices and **the Women’s Health Strategy should address how female pain and the pain associated with procedures often required to address women’s health needs are approached and managed within the NHS**, not just in relation to contraception, but with

¹ Endometriosis UK

² <https://theoutline.com/post/6323/if-men-had-to-get-iuds-theyd-get-epidurals-and-a-hospital-stay>

³ <https://www.cosmopolitan.com/sex-love/news/a52561/what-getting-an-iud-really-feels-like-according-to-women/>

regard to all healthcare for women. The pain bias is a very real phenomenon that causes unnecessary suffering for millions of women accessing healthcare services across the UK.

Emergency Hormonal Contraception

Since its introduction, use of emergency hormonal contraception (EHC) in the UK has remained low, even though most women rely on user-dependent methods such as condoms and daily pills. Although it is difficult to determine the exact numbers of people accessing EHC from varying sources, official figures indicate that more and more women are buying it over the counter at a pharmacy rather than accessing it from sexual health clinics, GPs, or under Patient Group Directives (PGD) organised by Local Authorities. However, women who purchase EHC are still subject to a mandatory, clinically unnecessary, and stigmatising consultation with a pharmacist prior to access – which BPAS mystery shop studies have discovered can include incorrect information, requests for clinically unnecessary interventions such as pregnancy tests, and, especially during the pandemic, a lack of privacy for invasive questions.

EHC should be made general sales list (GSL) and be available off the shelf without the need for pharmacist consultation. EHC is known to be extremely safe and there are no contra-indications to its use, as such, it is approved for over-the-counter use in many countries including in Europe and North America. BPAS regularly sees women experiencing unplanned pregnancy who were deterred from seeking EHC because of the obstacles to access, such as cost and uncomfortable pharmacy consultations. Making EHC GSL gives women choice, privacy and power over their reproductive autonomy.

Abortion

Abortion is the most common gynaecological procedure in the world – one in three women will access abortion care in their lifetime and the care BPAS and others provide is a vital part of their healthcare journey. Despite this, abortion care can be marginalised, stigmatised, and separate from other forms of comparable healthcare. Specialist organisations like BPAS continue to provide high quality, dedicated care – but abortion's positioning outside the rest of the health sector acts as a message to women that abortion is not a part of 'normal' women's healthcare. This message has been further embedded amongst the sector by not including abortion either in the government's Women's Health Strategy or in the upcoming Sexual and Reproductive Health Strategy.

Abortion is a key component of reproductive healthcare and should be treated as such.

Ultimately, the primary barriers to integration are the limits placed on clinical provision and innovation by the Abortion Act 1967 and the underlying Offences Against the Person Act 1861. The legal framework has been an impediment to the implementation of evidence-based advances in abortion care that have been researched and recommended in national and international guidelines. Most recently, they have made it the responsibility of the Department of Health and Social Care to approve clinical innovation even in the face of an oncoming pandemic.

It is ludicrous that abortion across England and Wales is governed by a law passed half a century before women even had the vote. As a result of the current legal settlement, a woman who ends her own pregnancy can be sent to prison for life. We are aware of multiple women in recent years who have been arrested, investigated, and in some instances even prosecuted as a result of these laws.

If we are serious about recognising the distinct health needs of women at a clinical level, **abortion must be decriminalised.**

Fertility

In 2021 BPAS will establish the UK's first not-for-profit fertility service, providing affordable care to those who do not qualify for NHS funding. We are starting this service in response to the many problems people face when trying to access NHS-funded fertility care. A postcode lottery of commissioning policies across the UK means that many people are refused the three funded cycles of IVF, which have been recommended by NICE on the basis of both clinical effectiveness and cost effectiveness. Unlike in Scotland and Wales, IVF availability in England is in the hands of local CCGs or ICSs – exacerbating the issues around patchwork access, and minimising the ability of MPs, Government, or central campaigns to make wholesale change to funding and provision arrangements.

This can leave those who need assistance conceiving with no other option but to privately fund their own care, putting the choice of when to start a family in the hands of only those who can afford to choose. The fact that fertility care in England is now mostly self-funded⁴ is antithetical to the core principles of the NHS, and this systemic inequity must be addressed.

Women are at an age disadvantage when it comes to declines in fertility and likelihood of live birth. Data collected by the HFEA on IVF trends in 2018 found that birth rates decline with age – from 31.3% live births for every transferred embryo for those under the age of 35, to 18.7% for those aged 38-39, to just 3.5% for women over 44⁵. By 45, women's egg reserves have declined to a point that getting pregnant naturally is unlikely for most women.

Current NHS-funded fertility care provision is inadequate for most women living in the UK. It also fails to reflect the changing society in which we live. More women than ever before are choosing to have children outside their most fertile bracket – often as a result of wider economic circumstances including career progression, job stability, and house prices. The fact many women choose not to simultaneously pursue the goal of starting a family alongside other goals arguably points to pervasive hostile work environments that disadvantage mothers. Moreover, an increasing number of single women and people in same-sex relationships are choosing to have a child through IVF.

It is vital the health service adapts and catches up to women's changing fertility choices, recognising that current fertility care provision is not fit for purpose. **The government must take responsibility and address the postcode lottery of care faced by people trying to access NHS-funded fertility treatment.**

Pregnancy and parenting

As detailed below, there is a prevailing cultural climate where pregnant women's own needs are often seen as secondary to her foetus. This has impacted the research agenda, and has also impacted how advice, care and treatment is offered and accepted. It also influences targets used to measure progress and improvement within the healthcare system, particularly within maternity services. For example, the Health and Social Care Select Committee recently announced that they will be holding the government to account over maternity improvement targets. The government targets selected - halving the rate of stillbirths, neonatal deaths, maternal deaths, and brain injuries that occur during or soon after birth by 2025, are incredibly important and valuable and it is right that work is done to ensure these targets are being met for women and babies.

However, ensuring the delivery of a healthy baby and avoiding maternal death is the

⁴ HFEA, *Fertility treatment 2019: trends and figures* (2021) <https://www.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2019-trends-and-figures/#Section8>

⁵ HFEA, *Fertility treatment 2018: trends and figures* (2020) <https://www.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2018-trends-and-figures/#birthrates>

minimum requirement of a maternity service. By using data points such as a patient reported outcomes, examining morbidities that are more often overlooked - such as obstetric injuries and faecal incontinence - and capturing the 'near misses' that often leave a woman walking away from maternity services with lasting physical and emotional trauma, the government can begin to build targets for improvement that will reflect the range of experiences women face when accessing maternity care. To develop and provide a truly woman-centred service, **additional, ambitious maternity targets should be developed that include women's experiences and health outcomes as a measure of whether services are improving.**

We know that relationships between women and their healthcare team are central to maternity care trajectories and that communication around pregnancy impacts women's experiences hugely. BPAS are worried about trends towards unprecedented and unjustifiable monitoring of mothers during pregnancy. In early March 2020, NICE published draft Quality Standards on Fetal Alcohol Spectrum Disorder (FASD) and the source guidance they draw upon argues that all alcohol consumption during pregnancy should be recorded and transferred to a child's health record. There is insufficient evidence on the harm caused by low levels of alcohol in pregnancy to warrant this significant intrusion into a woman's life. The routine sharing of private information on a child's health records fundamentally comprises a woman's own right to medical confidentiality and thwarts the opportunity to develop trusting, personal relationships between a woman and her care provider. This does not benefit the woman or child and indeed may place them at considerable risk if the end result is women declining to disclose clinically-relevant information for fear of disclosure. **The government should address the unjustified intrusion into women's rights to privacy and recognise the impact of foetal-centred interventions on the pregnant woman.**

Every week in the UK, two babies are born with neural tube defects (NTD), these babies will need a lifetime of specialist medical care. Currently, 85% of NTD cases end in abortion⁶ and BPAS know first-hand just how challenging and upsetting women can find a decision to end a much-wanted pregnancy because of NTD. **The government should introduce mandatory fortification of all flour and gluten-free products with folic acid**, this will prevent around half of all neural tube defects and ensure babies the best start in life.

BPAS recognise the important health benefits of breast feeding for both babies and mothers, however, we are troubled by reports of babies going hungry due to new mothers, who cannot or choose not to breastfeed being unable to access formula milk. BPAS has heard stories of midwives seeking out charities that provide formula milk to ask for "contraband" to be "delivered secretly" for mothers who are struggling to breastfeed. **There must be a measured approach to increasing rates of breastfeeding in the UK and women must be trusted to make the decision that is right for them and their baby.** Presenting women with the facts includes giving them impartial advice regarding infant feeding and providing them with the support they require to access formula milk if that is what they choose.

Menopause

The menopause will affect all women, despite this, few women feel prepared for the symptoms they experience or able to seek help. Stigma attached to ageing and the menopause negatively impact a woman's quality of life and 45% of women report

⁶ RCOG: Better for Women (2018) <https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf>

menopause symptoms having a negative impact on their work.⁷

Commissioners must ensure that women are able to access menopause care locally as part of their routine healthcare and mandatory menopause workplace policies should be introduced to reduce stigma attached to menopause and enable women to stay in work.

Women's healthcare and the wider system

More and better research

To create better care outcomes and experience for women, we need more and better research. For too long women's health has been considered a niche area and gender bias in medicine and medical research has created disparities that must be corrected. Conditions that are more prevalent in women, such as autoimmune diseases or chronic pain conditions like fibromyalgia, are under-researched and therefore often go undiagnosed and untreated. Persistent failures to include sex difference as part of study design means that diagnosis and treatment favours male biology resulting in women experiencing a delayed diagnosis or a misdiagnosis, as is often the case with heart disease. And research that involves improving the experiences and health outcomes of pregnant women – for instance to address hyperemesis gravidarum, or use of essential vaccinations during pregnancy – are stymied because of concerns about fetal effects.

Despite one in three women in the UK suffering from reproductive or gynaecological health problems, less than 2.5% of publicly funded research is dedicated solely to reproductive health. Moreover, women live in a cultural climate in which their own needs are often not prioritised in the same way of that of her foetus, this approach has impacted reproductive research agendas. BPAS is committed to reducing the disparities in research and in 2019 we established the Centre for Reproductive Research & Communication (CRRC) to develop and deliver a research agenda that furthers access to evidence-based reproductive healthcare and choices. Through rigorous multidisciplinary research and impactful communication, the CRRC aims to inform policy, practice, and public discourse. We draw directly on BPAS' own work as a reproductive health provider to inform our agenda and work in collaboration and through strategic partnerships to achieve our mission.

More UK public funding needs to be made available and ring-fenced for research on women's health.

Information, education, and public health messaging

Women's health is still not talked about openly and honestly, it means that myths persist and that many girls and women are still unaware of symptoms, treatments and where to seek support. Access to reliable, accurate, unbiased education and information about women's health is essential to reducing health inequalities.

Paternalism is built into women's access to and experiences of healthcare and BPAS believe we must move away from an approach that limits women's autonomy.

Through the WRISK Project, the CRRC is currently working with stakeholders from a wide range of disciplines, drawing on women's experiences to understand and improve the development and communication of risk messages in pregnancy. Women who are planning a pregnancy or who are pregnant receive many public health messages that are intended to

⁷ British Menopause Society: More than half of women feel negative about their experience of the menopause: https://thebms.org.uk/wp-content/uploads/2017/10/EMBARGOED-UNTIL-18-OCT-2017-00.01_BMS-Survey-Results-2017_Press-Release.pdf

guide their decision making. For example, they receive advice about what to eat, drink, how much they should weigh, and what medications they should or should not take. These messages are intended to improve outcomes for babies and mothers. However, there is growing concern that messages do not always fully reflect or explain the evidence base underpinning them, and that negotiating the risk landscape can sometimes feel confusing, overwhelming, and disempowering. This may negatively affect women's experiences of pregnancy and motherhood and be exacerbated by a wider culture of parenting that tends to blame mothers for all less-than-ideal outcomes in their children.

Realigning public health messaging with an understanding of women's needs and lived experiences will result in more effective information that supports both principles of maternal autonomy and public health objectives. Women must be trusted to make informed healthcare decisions and can only do this when they are presented with information that fully reflects the evidence. **Healthcare providers and health promotion bodies must re-establish a system of providing women with impartial information that empowers them to advocate for themselves and become an active participant in their own healthcare.**

Conclusion

Society has taught women to minimise their pain and discomfort, their symptoms are often dismissed and ignored by healthcare professionals, and women have very limited control over their own healthcare. We can and must do better for women.

Systems must adapt and change to ensure they are delivering better healthcare outcomes and experiences for women. Women should be given information, choice and trusted to make decisions about their own healthcare - particularly their reproductive healthcare.

We hope the government will continue to seek out women's voices and place their needs and concerns at the heart of healthcare.

Recommendations

1. To address the shortcomings in women's healthcare in the short and medium term, the government should instruct commissioners to work with local GPs and health providers to develop, fund, and implement a system of local women's health hubs in ICSs across the country.
2. The government should work with medical schools and nursing and pharmacy organisations to improve education and continuing professional development in the diagnosis and treatment of women's health conditions.
3. Local referral pathways into specialised hubs should be put in place in collaboration with local GPs and other services to enable accessible care for conditions specific to women including endometriosis, coil and implant fittings, cervical screening, and abortion care.
4. The Women's Health Strategy should address how female pain and the pain associated with procedures often required to address women's health needs are approached and managed within the NHS.
5. EHC should be made general sales list (GSL) and be available off the shelf without the need for pharmacist consultation.
6. Abortion must be decriminalised.
7. The government must take responsibility and address the postcode lottery of care faced by people trying to access NHS-funded fertility treatment.
8. Additional, ambitious maternity targets should be developed that include women's experiences and health outcomes as a measure of whether services are improving.
9. The government should address the unjustified intrusion into women's rights to privacy and recognise the impact of foetal-centred interventions on the pregnant woman.
10. The government should introduce mandatory fortification of all flour and gluten-free products with folic acid.
11. There must be a measured approach to increasing rates of breast feeding in the UK and women must be trusted to make the decision that is right for them and their baby.
12. Commissioners must ensure that women are able to access menopause care locally as part of their routine healthcare and mandatory menopause workplace policies should be introduced to reduce stigma attached to menopause and enable women to stay in work.
13. More UK public funding needs to be made available and ring fenced for research on women's health.
14. Healthcare providers and health promotion bodies must re-establish a system of providing women with impartial information that empowers them to advocate for themselves and become an active participant in their own healthcare.