healthwatch Oxfordshire

Your voice on health and care services

"Just listen to me" Using women's health services in Oxfordshire

July 2025

"Just because I am young, and a woman doesn't mean I don't know what I am talking about. I know my cycle, I know my pain, just listen to me."
(online survey)

Contents

Content note

This report includes experiences of pain, trauma and discrimination. It contains references to baby loss, pregnancy loss, domestic abuse, sexual abuse and gender dysphoria. Please read with care. See Useful Links for information about support.

A note on terminology and language

In this report we have focused on people's experiences of getting help for concerns that usually come under the umbrella of 'women's health services' – including hormonal contraception, pregnancy, menstrual pain and associated conditions, perimenopause, and breast and cervical screening. We know that these concerns do not arise in isolation from other health issues, and that gender can have an impact on people's experiences of any health and care services.

We have used the language of "women's health" as this is more accessible than medical terms like "gynaecology". We acknowledge that not everyone who uses women's health services is a woman – for example, trans men and non-binary people may also use these services – and in our survey and this report we used the terms "women and people who use women's health services" to include these people.

Acknowledgements

Many thanks to everyone who shared their experiences and supported us with this project.

Executive Summary

> *"Just because I am young, and a woman doesn't mean I don't know what I am talking about. I know my cycle, I know my pain, just listen to me."* (online survey)

There is a growing awareness of the health inequalities faced by women and people who use women's health services. These includes gaps in medical research and understanding, unconscious bias and barriers to healthcare. In recent years, national research and policy, including the Women's Health Strategy for England, has started to address these challenges. In this changing context, Healthwatch Oxfordshire wanted to hear from local women and people who use women's health services about their experiences of getting help and their ideas for improving support for women's health issues.

From August to October 2024-5, we heard from **684 women and people who use women's health services** from across Oxfordshire, through a combination of an online survey, face-to-face conversations during outreach across the county, in-depth interviews and focus groups with community groups. These included people from a range of ages and ethnic groups and from across the five districts. We asked women and people who use women's health services to tell us about using and accessing, and experience of:

- women's health services
- health services more generically
- cervical and breast screening, and what supports or hinders uptake of these.

Key findings

We heard about a **range of experiences**, and many people had had both good and bad experiences of women's health services. We heard many examples of good practice, but also that these experiences are not consistent, and many people have struggled, sometimes over many years, to get the help they need.

We heard that most people seek and receive treatment and support for women's health issues from their GP or are referred to specialist clinics by their GP. The most common **barriers** people told us about, in common with what we hear from the wider population, were around **appointments for health services,** particularly GPs: not being able to get an appointment at a time that suits them or finding it difficult to get to the appointment. Other common barriers included not knowing what services are available, feeling embarrassed, having caring responsibilities (for example for older relatives or for young children) or not having time. We heard that people '*didn't want to make a fuss'*, or that they felt their concern was '*too personal'* to talk about. We also heard about challenges people experienced getting referrals for the specialist care they needed. We heard that some people who struggled with getting the care they need looked to alternative routes to care, including using emergency health services, using private healthcare providers and self-medicating.

People told us about **good experiences of care** where they were listened to, their symptoms taken seriously, and they were provided with clear, accessible, useful information that enabled them to make decisions about treatment. They valued being able to get help quickly, or if waiting for appointments, being given support and information while waiting. People also appreciated when care was centred around their needs and they were treated holistically rather than for individual symptoms.

Unfortunately, we also heard that people experienced **challenges** around:

- Feeling they were not listened to or taken seriously
- Seeing health and care professionals who did not have enough understanding of women's health to support them or make appropriate referrals
- A lack of person-centred care, services not working well together, and symptoms being considered in silo
- Waiting for appointments, referrals and test results
- Sexism and being treated differently because of gender, as well as other forms of discrimination around factors like race, age and disability

We also heard how these challenges could compound each other, meaning that some people were unable to get the help they needed for many years, with serious impacts on their wellbeing and life choices.

People told us about specific challenges around **menopause**, particularly a **lack of information and culturally appropriate support**, and delays to diagnosis and treatment, as well as good experiences of getting the right support.

We also heard about experiences of **screening and procedures** such as cervical screening and hysteroscopy. While some people had good experiences, people told us about gaps around accessibility and inclusion, being treated compassionately, difficulty making screening appointments, pain and a lack of pain relief, and a need for trauma-informed care. People told us about barriers to screening including misconceptions about eligibility, shame and embarrassment, and how this could be improved.

Finally, we heard from women and people who use women's health services about their **ideas for how things could be improved**. Their suggestions focused on:

- Improving public information to support understanding and awareness of women's health issues
- Improving health and care professionals' understanding of women's health issues, and support for people living with women's health issues
- Joining up care and making sure it is person-centred and holistic
- Tackling barriers to health and care services
- Listening and involving patients in their care.

Recommendations

We would like to make the following recommendations based on what we have heard and people's suggestions.

- Recommendations are for response and comment for all system partners – including Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) with Oxfordshire Place-Based Partnership, Oxford University Hospitals (OUH), Oxford Health (OH), Oxfordshire County Council Public Health (OCC), Community Gynaecology Service (PML) and Oxfordshire GP network – as to how they will address them.

Listening and involving patients

- Involve women and people who use women's health services at every stage of local service design and delivery, including in the development of BOB ICB women's health strategy
- Use insights from this report to inform the future development of 'Neighbourhood Health' initiatives, including shift to community-based support, joined up care, information and advice and working with local groups to co-develop services such as menopause support, and community champions to promote screening
- Prioritise listening to people from seldom heard communities and 'inclusion groups' to co-develop services that reach those at most at risk of health inequalities, and that are inclusive and culturally appropriate.

Information and communication

- System partners to work together to ensure consistent communication and information is available across all formats, about pathways for care including self-referral options, drop-in clinics and eligibility for screening
- Improve patient information and communication about screening and procedures, including offering pain relief and other modifications
- Ensure that accessible and culturally appropriate information about women's health issues and services is available to all, including for those who need translated information, and through linking to community and voluntary groups, priority groups and areas in the county
- Build on opportunities such as Making Every Contact Count (MECC), and wider prevention and wellbeing initiatives to support women on waiting lists, and spread information and advice

Tackling barriers and improving quality of care

- Join up care around patients and review patient pathways across the system to ensure that people are not waiting years for the care they need, especially around critical time-frames such as potential impact on fertility
- Address waiting times for specialist clinics, and improve support for people waiting for referrals (e.g. information on self-management and links to Livewell and other support).
- Explore more accessible options for appointments, including non-urgent appointments – such as flexible appointments, drop-in clinics, one-stop-shop clinics, menopause clinics
- Ensure health and care professionals receive relevant and up to date guidance and training – for example in holistic view of women's health issues, trauma-informed care, cultural competence and unconscious bias, and current treatment options
- Identify women's health champions within health services – for example, designated women's health GPs

1. Why did we do this research?

There are significant health inequalities experienced by women and people who use women's health services. These have been highlighted by research including the Women and Equalities Committee's inquiry into women's health. New policy including the UK Government's 2024 Women's Health Strategy for England aims to address these inequalities and provide more integrated and community-based services. Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board are developing a local Women's Health strategy[1], and this report will feed people's voices into it (See Appendix 2: Background and Appendix 3: Women's health services in Oxfordshire for context and more information.)

To inform the development of services and policy development in this shifting context, Healthwatch Oxfordshire decided to hear from women and people who use women's health services about their experiences.

2. What did we do?

We designed an online survey, with input from women, health services and commissioners. This was shared widely through channels including social media, the Healthwatch Oxfordshire news briefing, local newsletters, health services, and sent directly to women's community groups across the county. The survey was live from August to October 2024. It asked questions about people's experiences of getting treatment and support for women's health issues, as well as using health services more generally. We asked what worked well, what could be improved, and what ideas people had for making things better. The survey included questions about experiences of cervical and breast screening, what might prevent people from attending these and what would support them to attend.

To make sure we heard from people who would not usually respond to online surveys, we also designed a shortened version of the survey to complete to people during our face-to-face outreach across the county. We heard from people at events including Play Days at Eynsham, Berinsfield, Witney, Banbury and Bicester, Kidlington Gala Day, Abingdon Health Fest, Oxford Older People's Day. We heard from community groups including an Asian women's group and a support group in Banbury for people seeking asylum. We also held focus groups with Oxford Community Champions and a women's group supported by Refugee Resource.

We carried out a thematic analysis of the data, which is presented in this report.

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[1] BOB Local Maternity and Neonatal System - webpage on women's health strategy

3. Who did we hear from?

We heard from a total of **684 women and people who use women's health services**:

- **425 people** who responded to our online survey
- **214 people** who we had face-to-face conversations with during outreach
- **16 women** who took part in focus groups with Oxford Community Champions or the Refugee Resource women's group
- **27 people** who shared their experiences through our Feedback Centre, outreach conversations and signposting calls
- **2 women** who shared their experiences in in-depth interviews

We heard from all ages, though the biggest groups we heard from were aged 25-49 (314 people, 56%) and 50-64 (169 people, 30%) – perhaps reflecting that these are ages when women are most likely to come into contact with women's health services.

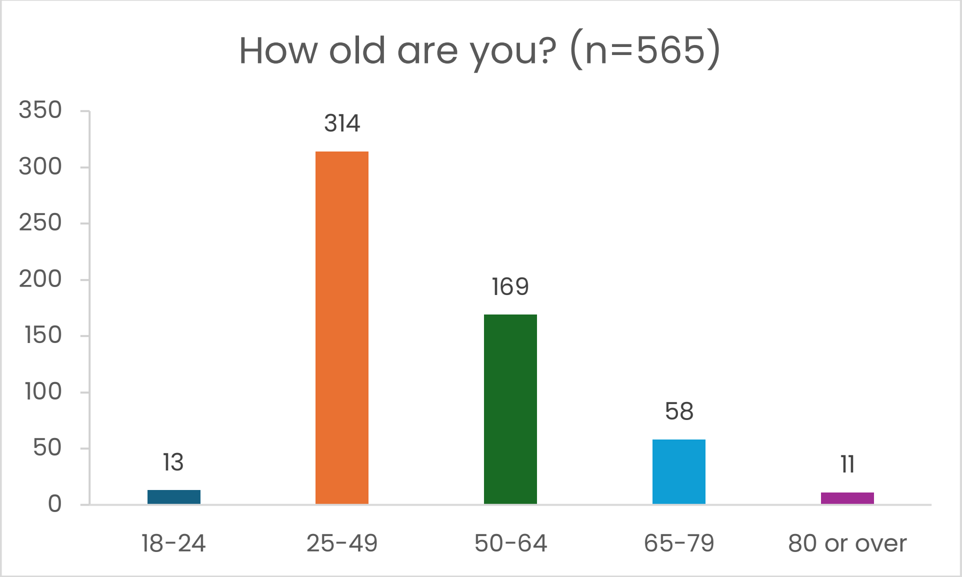

Figure 1: Bar graph showing the ages of people who shared their experiences for this report (n=565).

Of those who told us their gender, two people were non-binary and one was a trans man; the rest were women.

Most respondents (470 people, 84%) were White British. We heard from small numbers of people from a wide range of ethnicities, including White: Any other White Background (31 people, 6%), Asian / Asian British: any other Asian / Asian

British background (17 people, 3%), Asian / Asian British: Chinese (4 people, 0.7%), Black / Black British: African (5 people, 0.9%) and Mixed / Multiple ethnic groups: Any other Mixed/ Multiple ethnic background (5 people, 0.9%). These included those from minoritised ethnic backgrounds that do not map well onto standard UK ethnicity categories including Syrian, Kurdish and Iranian women and women with Latin American heritage.

We heard from people across the five districts of Oxfordshire, as well as several people who live out of county but use health services in Oxfordshire, or do not have a fixed address.

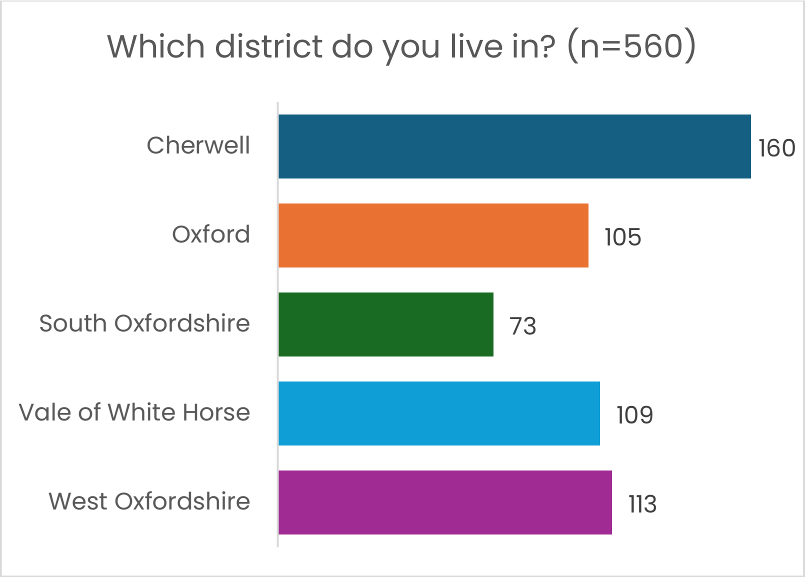

Figure 2: Bar graph showing which Oxfordshire district those who shared their experiences for this report live (n=560).

4. What did we hear?

People told us about a wide range of experiences: often there were things that had worked well and things that could be improved. Similar themes came up in both positive and negative experiences – for example, people told us about how well they had been listened to, while others told us that they felt they had not been listened to at all.

This suggests that there is good practice already happening within Oxfordshire's women's health services and health services more broadly, but that this is not happening consistently. We heard that some women – for example migrant women, disabled women and those without access to transport – faced more barriers to good care than others.

In the following sections we look at what people told us about what they needed help for, where they looked for and got treatment and support, and what barriers they faced in getting care. We then look at what people's experiences of care were – what worked well and what could be improved. We focus on two areas we heard a lot about – menopause and experiences of screening, tests and procedures. Finally, we look at people's ideas for improving health services for women and people who use women's health services.

4.1 What women's health issues did you seek help for?

We asked people what women's health issues they had needed treatment or support for in the last year. The most common answer (163 online survey respondents, 46%) was menopause or perimenopause. Other popular answers included help with mental health and wellbeing (105 people, 30%); periods or menstrual problems (89 people, 25%), contraception (62 people, 17%) and breast health (including breast screening; 59 people, 17%). Smaller numbers of people told us they had needed treatment and support for other women's health issues including fertility, pregnancy, prolapse or a pessary, incontinence or sexual health.

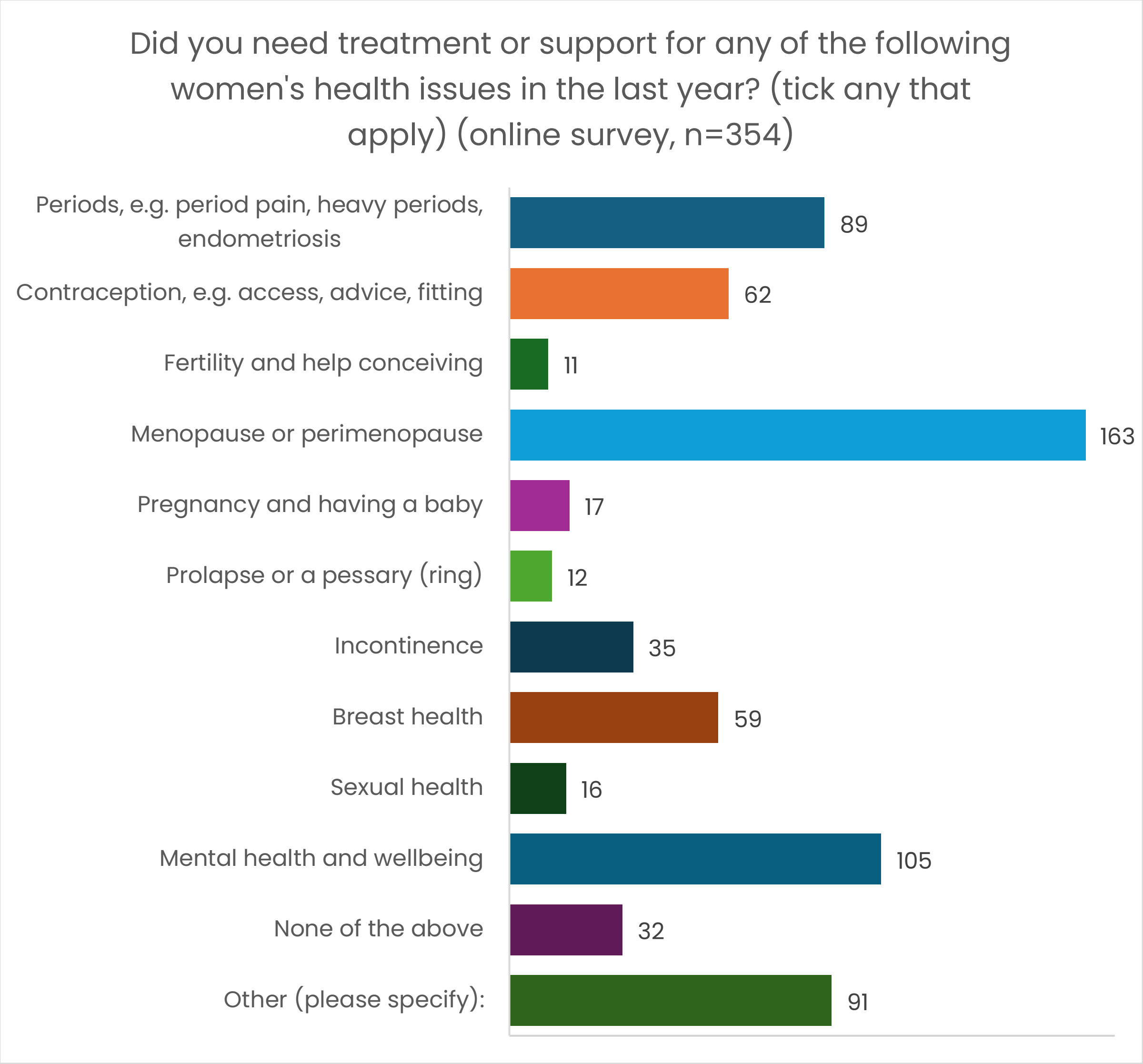

Figure 3: Bar graph showing responses to online survey question about what women's health issues people sought treatment or support for during the last year (n=354).

Other women's health issues that people had sought treatment or support for included urinary tract infections (UTIs), thrush, premenstrual dysphoric disorder (PMDD), post-menopausal issues, gynaecological cancers, ovarian cysts, musculo-skeletal disorders, migraines, pelvic pain and iron deficiency.

4.2 Where did you seek help for women's health issues?

The majority of people had sought help from their GP surgery (281 online survey respondents, 80%). This was also where the majority of people got treatment and support (221 people, 64%). Although only a small number of people sought help from a specialist clinic (31 people, 9%), a higher proportion of people got treatment or support from one (82 people, 24%), reflecting the fact that the main pathway to most specialist clinics is via a GP referral. Similarly, no one had sought help from the Community Gynaecology Service, which is referral-only, but 23 people (7%) had got treatment or support there.

People told us they looked for help from friends and family (34 people, 10%) or on the internet (49 people, 14%). Smaller numbers of people had sought or got help in other places, including via NHS 111, a sexual health clinic, an urgent care centre like Accident and Emergency, or a health visitor.

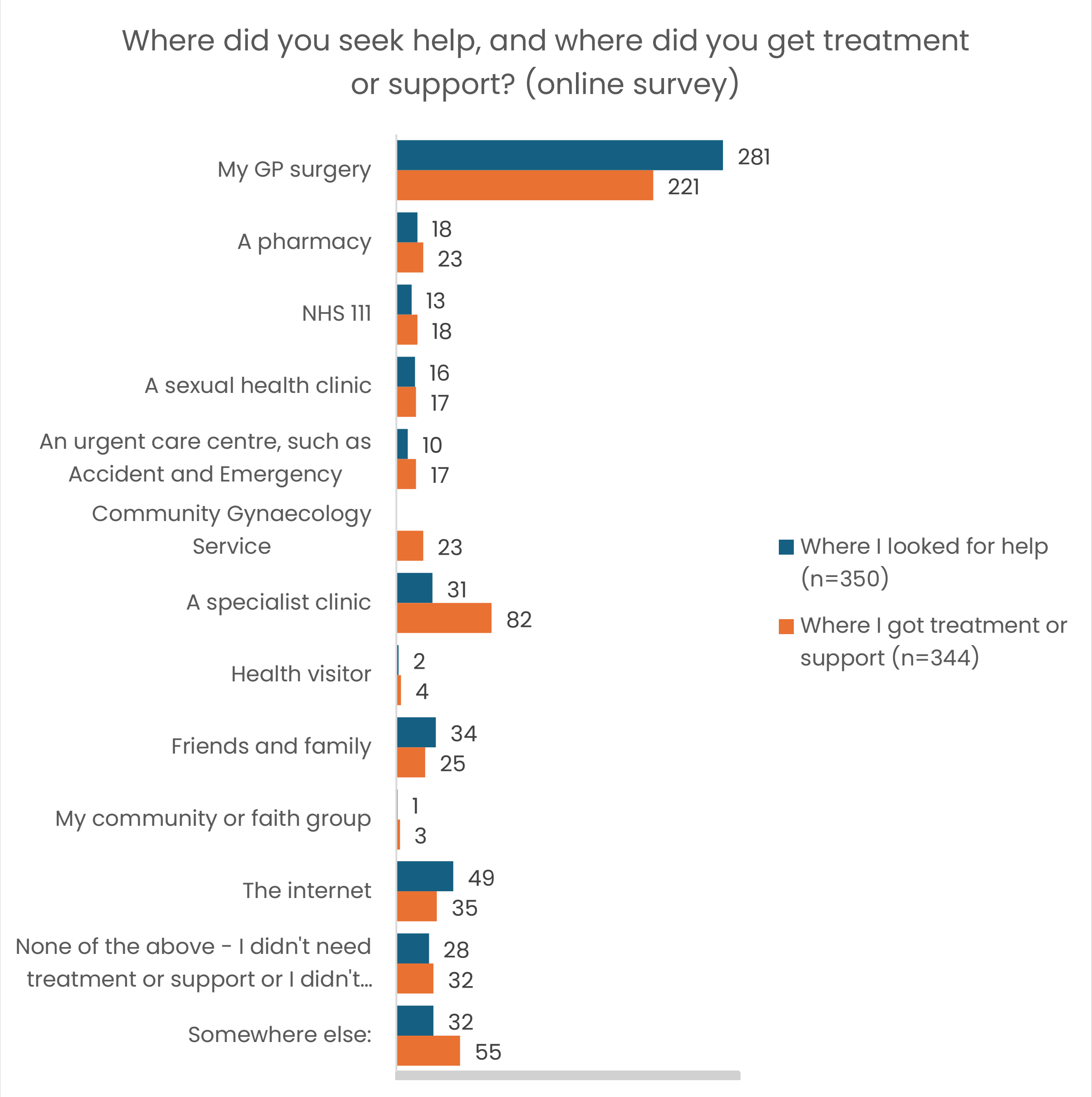

Figure 4: Bar graph showing responses to online survey questions about where people looked for help for a women's health issue (n=350) and where they got treatment or support (n=344).

Other places that people looked for help, or got treatment or support included through workplace support programmes, charities such as Oxfordshire Mind or

Maggie's, private care, healthcare abroad, or alternative medicines (e.g. homeopathy).

These responses highlight the importance of GPs as the first place of contact and referral on to specialist services, emphasising the importance of this initial interaction for women.

5. Accessing services

5.1 How easy is it to get the help you need?

In our **outreach survey**, we asked people how easy it is to get the help they need from health services generally. Just over a third of people (70, 34%) said it was "very easy", while only a few (14, 7%) said it was "very difficult". Similar numbers of people said it was "easy", "neither easy nor difficult", or "difficult" – suggesting that pathways to getting treatment and support can work very well but are inconsistent.

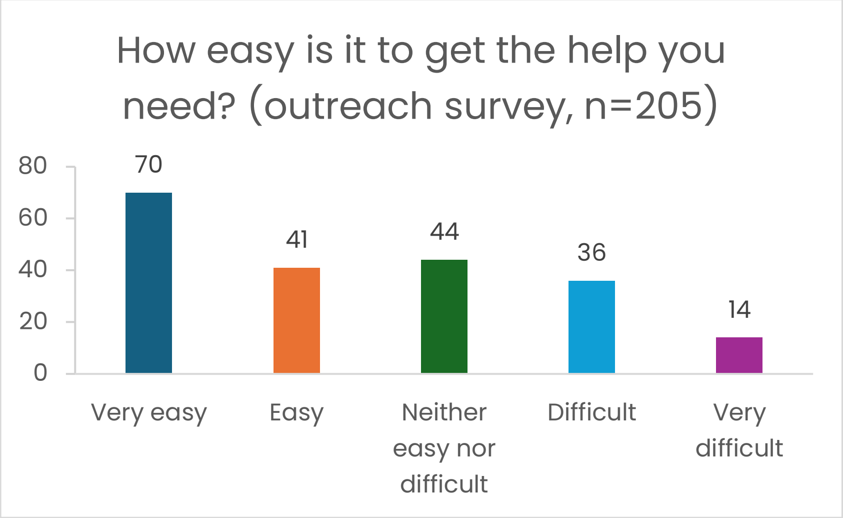

Figure 5: Bar graph showing responses to outreach survey question about how easy people find it to get the help they need from health and care services (n=205).

5.2 What stops you from getting the help you need?

We asked people who about what reasons might stop them from getting help with a women's health issue. The most common barriers people told us about were around:

- **Practical issues** – such as being able to make an appointment at a convenient time and place
- **Emotional, social and cultural barriers** – such as not wanting to make a fuss, or feeling embarrassed
- **Lack of information** – such as not knowing what services are available.

5.2.1 Practical barriers

Given that GPs are the first place many people seek help for women's health issues, being able to get GP appointments was crucial to people getting help, and a common theme in what people told us. We also heard a small number of comments about non-GP services including pharmacy and sexual health services. The key issues that women and people who use women's health services told us about were:

- Being able to make **appointments at convenient times and places**
- Being able to get appointments for **non-urgent concerns** like perimenopausal symptoms or contraception
- The importance of **face-to-face appointments** for treating some women's health issues
- **Access needs** being met – such as being offered an interpreter.

Some people told us they had experienced a combination of barriers.

> *"For me the GP is good but it's hard to get an appointment. I need to show them my problem (rather than talking on the phone). Sometimes they send me to another doctor who is not a woman. Or they said they only have urgent appointments so I wait for two weeks until it's an emergency. It's hard to know if something is urgent or not. I can't wait two weeks – I need help now! They tell me to wait until the doctor calls me, then the doctor forgets to call me. But you can go to the JR any time."* (feedback from outreach with Refugee Resource women's group)

Convenient appointments

The most common barriers to getting help that people told us about were not being able to get an appointment at a time that suits them (89 people, 29% of online survey respondents) or finding it difficult to get to the appointment (72 people, 23%). We heard that people appreciated flexibility around appointment times and locations, and work. Some people liked being able to have appointments over the phone because of the convenience. Others appreciated local appointments with limited travel.

> *"The appointment time, location and venue were great and I was able to book around working and family commitments."* (online survey, Heart Health check-up)

> *"I was able to raise an online form about my non urgent health problem and a GP was able to determine whether I needed to make an appointment or not. I was also able to speak to a GP on the phone. This saved me time and the process was very straight forward."* (online survey)

> *"Prompt service when referred and easy contact. Info sent through text and allowed timely contact. Very impressed with service only had to travel 6 miles to attend a clinic."* (online survey – Community gynaecology Service)

We heard that in some areas, it is not possible to make appointments for contraceptive services or cervical screening outside of Monday to Friday, 9-5. This could be particularly difficult for people who work during these hours – some felt unable to make an appointment during working hours for something not related to an illness, such as contraception, or did not want to have to disclose details to their employer.

> *"Coil changes happen 1 afternoon a week for short hours. I work 2 jobs. And 1 is in a school and don't finish till 6, after surgery has finished. Was told to then go to Oxford and wait then on a weekend. No flexibility at all."* (online survey)

> *"The online triage form is only open from early morning to 4pm each day so that requests can be triaged during the working day. However, this makes it inaccessible to women who are working, particularly if they are seeking treatment such as contraception where they are not ill so can't take time off work to do it."* (online survey)

We heard that people valued being able to get care and support near to where they live, such as attending breast screening in a mobile unit at Millets Farm. This could be a bonus for people who face barriers to travel, including not having access to transport or having anxiety about hospital appointments. We also heard about the positive difference made by health visitors making home visits. However, we also heard from people who had not been able to get care locally, and the impact of this on their experience.

> *"I had to travel all over Oxfordshire for the care I needed."* (outreach survey)

Non-urgent appointments

People told us that it could be difficult to make GP appointments for non-urgent issues, such as contraception, or perimenopausal or menstrual symptoms.

> *"GP didn't contact me to review my HRT following the letter from the gynae clinic [recommending a review]. I came off it by myself. It is hard to get an appointment for that kind of non-urgent question."* (online survey)

> *"Do not feel that my surgery wants appointments to be made for things that aren't illnesses."* (online survey)

> *"It isn't likely that a women's health issue is an "emergency", so it means getting a "routine" appointment, which means waiting weeks and weeks…"* (online survey)

We heard that when people had regular contact with a health or care professional, such as seeing a practice nurse for contraception reviews, this could be helpful in supporting them with other aspects of women's health.

> *"My contact is mainly through appointments with my GP practice nurse. The appointments are routine (contraception), but it is a space to raise questions about menopause etc. If I did not have this regular contact with the practice nurse, I am not sure where I would raise questions concerns about women's health prior to feeling very worried and seeing a GP appointment."* (online survey)

5.2.2 Emotional, social and cultural barriers

People also told us about emotional, social and cultural reasons that might stop them getting help with a women's health issue. These included:

- **Not wanting to make a fuss** or bother health services
- **Embarrassment** or **fear** of not being taken seriously
- Not being able to see a **female health professional**
- Not having **time**, often due to caregiving responsibilities

"Maybe it wasn't that bad"

Of the 312 people who responded to our online survey question about this, 20% (62 people) said that they might not get help because '*I don't want to make a fuss*'. People also told us they did not want to put pressure on the NHS.

> *"I felt like it wasn't worth mentioning, maybe it wasn't that bad, maybe it'd pass and so on, finding that my surgery has a clinician specialising in*

> *women's health was a real help to me seeking an appointment."* (online survey)

Embarrassment and fear

We also heard how previous distressing experiences, such as feeling they hadn't been taken seriously, could make people less likely to seek help. (Experiences like this are discussed in more detail below, Experiences of care).

> *"Years of having my symptoms dismissed and being made to feel like they're in my head [have] caused so much trauma. I now don't trust GPs very much."* (online survey)

Being able to see a female health or care professional

Some people told us that not being able to see a female health or care professional, or not being offered this, might affect whether they sought help for a women's health issue. This may be linked to cultural competency – ensuring that health and care professionals understand different communities' preferences around care for women's health issues.

> *"A lot of women would not feel comfortable asking for a female GP, it's like asking for an interpreter, it should be offered."* (feedback from Oxford Community Champion)
>
> *"Wouldn't go to the pharmacy (Pharmacy First) because the pharmacist is a man."* (feedback from outreach with Refugee Resource women's group)

Some comments indicated that some people felt less likely to be listened to or believed by male health or care professionals.

> *"I should say my experience has varied depending on who I see but I have found female GPs generally (though not universally) more understanding, and feel they actually listen to me and take me seriously compared to male GPs."* (online survey)

We heard that it was important for patients to understand what to expect from a procedure and be informed of the gender of the staff carrying it out so that they were able to decide what they felt comfortable with or could request a chaperone.

> *"My ultrasound was a pelvic ultrasound and I was informed correctly that I might need an internal scan as well however it didn't mention that the sonographer may possibly be a man which I think you should have*

> *forewarning of to prepare yourself mentally but also to decline early so that the appointment can be rearranged."* (Feedback Centre review)

People told us that they might have to wait longer to be seen by a female health or care professional.

> *"My GP practice are good about making sure I can see a female GP but I might have to wait longer."* (feedback from Oxford Community Champion)

Not having time

We heard that for some people, their own health was a low priority compared to other needs, such as work and caring responsibilities.

> *"My health is low on list of many work & family priorities I'm juggling."* (online survey)

> *"Quicker access to GP appointments and more follow up post partum to avoid issues getting so bad (hard for women to make time to access help early when looking after a baby and having to go back to work to earn money)."* (online survey)

5.2.3 Information about services

Some people told us that not knowing what services are available might stop them getting help for a women's health issue (56 people, 18% of 312 online survey respondents). We also heard that people were not always sure when it was appropriate to seek help.

> *"Life is busy and I put issues on the back burner rather than deal with them. Sometimes it's embarrassing to talk to someone and it's hard to sit down with these thoughts and confront an issue. Also, I don't know what is normal, perhaps every mum experiences these feelings and this is not unusual therefore should I just live with it? Mild mental health problems aren't openly discussed too much."* (online survey)

5.3 Getting referrals to specialist services

We heard that once people saw a health or care professional, it could be difficult to get a referral to a specialist service. This was often linked to people feeling they were not listened to or taken seriously, or feeling that health and care professionals did not have sufficient understanding of women's health to make an informed decision about whether or not to refer them. (These themes are discussed in more detail below, under Experiences of care.)

> *"I feel my conditions are understood and listened to but not referred to gynaecologists which I've been requesting. Menopause and adenomyosis issues."* (online survey)

> *"When I finally got a referral to gynae they are fab and asked why I had not come in sooner. GP refused 3 times to refer me."* (online survey)

> *"Having to cry before community gynaecology would refer me to the menopause clinic for severe and continual bleeding (apparently it's normal)."* (online survey)

We heard from some people that they were encouraged to use urgent and emergency care services, or ended up using them, because they could not get the help they needed from primary care.

> *"After going to my GP for months due to no period and severe pain in my abdomen I had to go to A&E to be listened to! I knew I had a cyst outside of my ovaries, but no one would listen until I went to A&E."* (online survey)

We heard several experiences of people feeling like they were being bounced between different services without getting the help they needed.

> *"GP will tell you to take paracetamol for pelvic pain and there is no follow up, so it turns into a vicious cycle of turning up at the A&E when the pain is too much, only to be told there is a 12-hour wait to see a doctor. Sent home with no help only to go back to the GP and told to take codeine, even after telling the GP you can't take it."* (online survey)

> *"I was referred in April for endometriosis, it took months for them to decide it needed to be referred back to my GP so she could physically examine me and now I'm September this has just happened for exactly the same referral to be sent again."* (online survey)

6. Experiences of care

We heard about a wide range of experiences, and from many people who had had positive and negative experiences of quality of care from different services. Half of people who responded to our outreach survey (106 people, 50%) said they had a 'good' experience of health and care services, but many described their experiences as 'poor' (20 people, 10%) or 'neither good nor poor' (59 people, 28%).

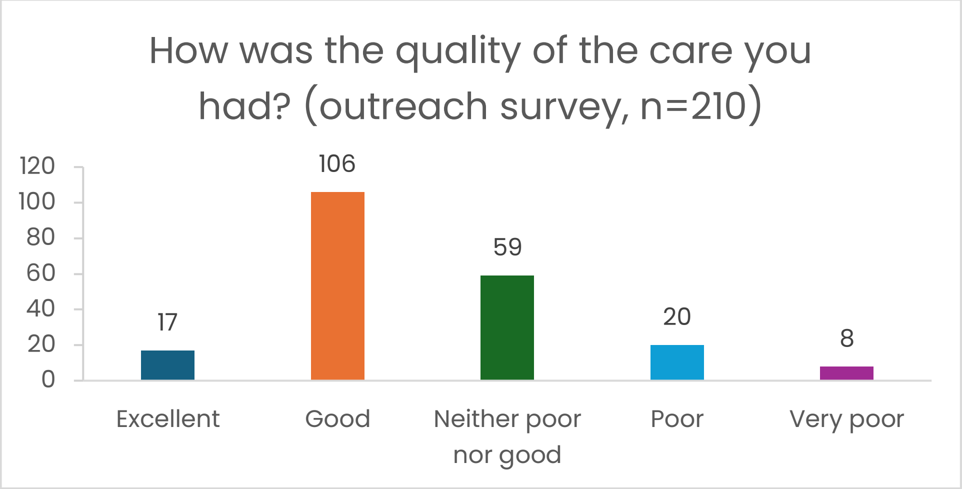

Figure 6: Bar graph showing responses to outreach survey question about the quality of care they received from health and care services (n=210).

In their qualitative responses, people shared with us what worked well and what could be improved. The **main themes** weaving through these responses were around:

- Whether people **got help and support** that met their needs
- **How well people were listened to**, or whether their symptoms and experiences were taken seriously
- Whether **health and care professionals had sufficient knowledge** and understanding of women's health to provide support
- Whether people were provided with **good quality information and tools** to make an informed choice
- How long people had to **wait for care**, and what support was provided while they waited
- The quality of care people received – particularly whether it was **joined-up, holistic and person-centred**
- Whether people were treated fairly, or experienced **discrimination**

We heard these themes from across the range of women's health services in Oxfordshire – including primary care, community services and specialist secondary care. We also heard about how in some cases, different challenges compounded each other, with significant impacts on people's wellbeing.

We also heard how each of these different **problems with people's care could be compounded by others**. For example, if a woman does not have good information about women's health issues, and sees a health or care professional who also lacks knowledge and understanding of women's health, and may also have unconscious bias, her symptoms may not be taken seriously and she may have to go through several appointments or be told to wait and come back, before getting a referral to a specialist clinic that can support her. There may be a long wait for an appointment with that clinic, or for tests that she needs to have. If her symptoms are not taken seriously by health professionals in the clinic, she lacks the information to ask the right questions, or has to go through trial-and-error tests of different treatments, then she may end up going for years or even decades without getting the help she needs. We heard from one woman (see Stories below) whose journey to get help for endometriosis took so long that by the time she was referred for fertility support, she had passed the age limit for NHS fertility treatment in Oxfordshire, and felt forced to move to a different county.

6.1 *"Nothing can be done"*: getting help and support

Half of online survey respondents said they had got the help they needed (211 people, 50%) but over a quarter (114 people, 27%) said they had not, and over a fifth were not sure (94 people, 22%).

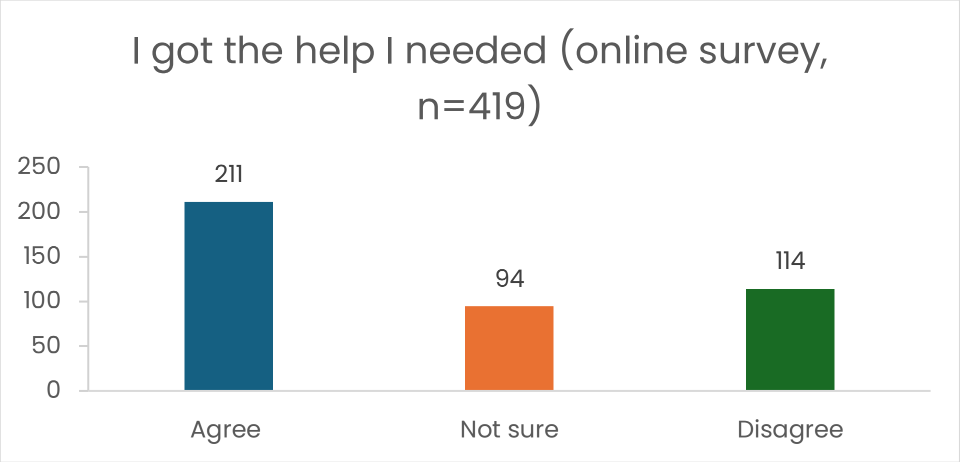

Figure 7: Bar graph showing responses to online survey question about whether people felt they got the help they needed from health and care services (n=419).

We heard about the life-changing positive difference it could make to people's lives when they got the help they needed, especially after years of trying to find a solution to a problem.

> *"I came to my GP experiencing peri-menopausal symptoms. She reassured me and assisted me with this, and noticed I was also experiencing a flare-up of rosacea, a skin condition I have been trying to control for the past ten years. She acknowledged my red skin, and kindly enquired if I would like something to help get it under control. I nodded and burst into tears, explaining that I had tried "everything" and nothing had helped. She asked exactly what I had tried; found out what I had not tried, and within five minutes I had a prescription for a medication which has cleared my skin. I could not be happier…"* (online survey)

> *"I have needed physical and mental health support regarding pregnancy and post-natal depression. They have always been incredibly helpful, non-judgmental, and very supportive."* (Feedback received by Healthwatch Oxfordshire during Health Promotion Event at Rose Hill Community Centre)

However, we also heard about experiences where people did not get the help they needed – in some cases, because tests, pathways and systems were not geared to treating the person's issue. Some people were told that "*nothing can be done*" for their women's health issue, or were disappointed to have been recommended herbal remedies such as evening primrose oil.

> *"I have heavy periods and the GP said, 'nothing can be done'. I was advised to have a coil fitted but I tried this and I could not manage the pain. I just feel left to manage this."* (outreach survey)

> *"Main issue was the limitations in what the GP could do for me. Lack of tests available for endometriosis - she seemed to only be able to request an ultrasound, which even she confirmed are rubbish for diagnosis."* (online survey)

Some people who struggled to get the help they needed from health and care services told us that they found alternative forms of support. We heard that some people turned to herbal remedies, while others self-managed their prescribed medication (e.g. titration of HRT). Several people told us they have turned to private health services to get the diagnoses and/or treatment they needed.

> *"I was told repeatedly I had nothing wrong with me despite there being a serious problem the whole time. I had to go privately and pay large costs for my problem to finally be treated seriously and taken care of."* (online survey)

6.2 Being listened to and taken seriously by health and care professionals

Women and people who use women's health services told us that it made a real, positive difference when they were listened to by health and care professionals and their pain or other symptoms taken seriously.

Of those who responded to our online survey, 258 people (62% of 417 respondents) agreed that they felt health professionals had listened to them, and 239 (57% of 419 respondents) agreed that they felt their needs were taken seriously. However, a substantial 80 people (19%) did not agree that they felt professionals listened to them, and nearly a quarter of people (100 people, 24%) said they did not feel their needs were taken seriously.

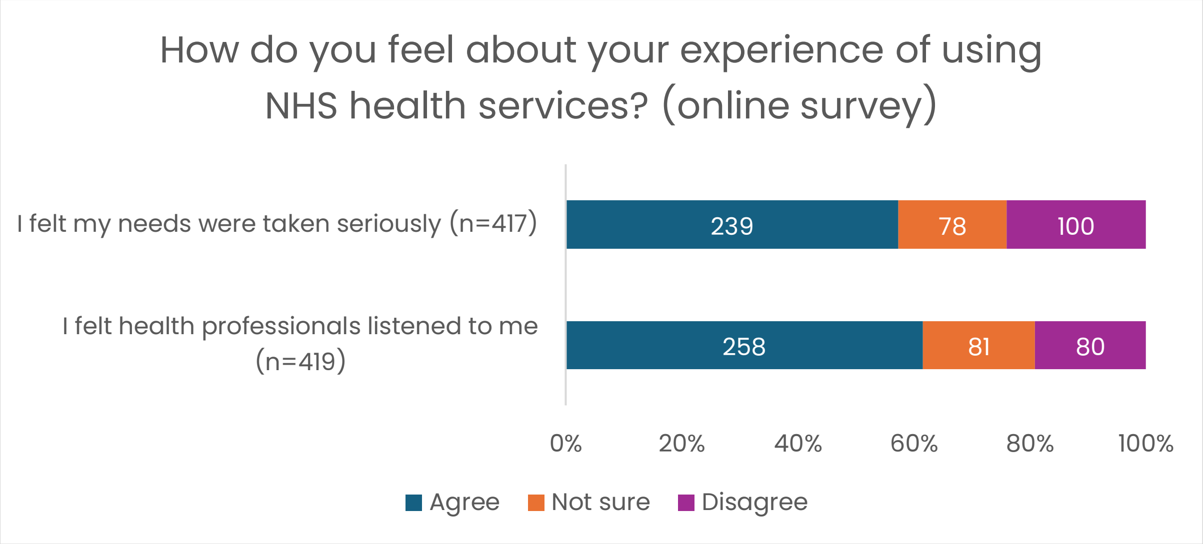

Figure 8: Bar graph showing responses to online survey questions about whether people felt their needs were taken seriously (n=417) and whether they felt health professionals listened to them (n=419).

Similarly, most respondents to our outreach survey said they felt they were listened to by health professionals (162 people, 79%) but 29 people (14%) said they did not feel listened to.

The main themes we heard around listening and being taken seriously were:

- Examples of health and care professionals **listening well** – for example by giving patients time to explain their symptoms and needs, and responding empathetically
- Experiences of people feeling they were **not listened to properly**
- Experiences of **pain or other symptoms not being taken seriously** by health and care professionals, or **being told that pain or other symptoms were 'normal'**
- People **feeling dismissed because of their age, weight or other factors**
- People feeling that they had to **advocate for themselves** or **do their own research** to be taken seriously.

Listening well

We heard that there were lots of good examples of health and care professionals listening to patients, taking the time, and being taken seriously. This made a real difference to their experience.

> *"Kind, friendly, primarily female practitioners who made me feel listened to and taken seriously."* (online survey)

> *"Despite my appointments being on the phone I felt unrushed to share what was happening for me, I felt listened to and I was given options with an offer of a follow up appointment to share my options."* (online survey)

We heard about cases where health and care professionals made the most of appointments, following good practice of 'making every contact count' (MECC) by having meaningful conversations with patients about their health and wellbeing, even if they had come in for something else.

Not feeling listened to

However, we also heard from many women about experiences where they felt they had not been listened to or had been dismissed. This was sometimes linked to perceived sexism (this is discussed in more detail below, under Sexism).

> *"They roll out the hysterical woman routine rather than listen to you."* (signposting call)

> *"I feel my aches and pains are just me whinging. My brother-in-law always has things treated straight away."* (online survey)

Pain or other symptoms not being taken seriously

The most common theme in not being listened to was people feeling their pain or other symptoms were not being taken seriously by health and care professionals.

We heard about people being told by health and care professionals that they did not have conditions which they were later diagnosed with – particularly menstrual disorders like endometriosis, adenomyosis and fibroids.

> *"I eventually had 2 adenoma removed that I was told I couldn't possibly have!* [Q: What could have been better?] *Someone who knew the illness believing my symptoms earlier."* (online survey)

> *"I have recently been diagnosed with Endometriosis. Prior to this I had a very harrowing journey with my GP and A&E. I finally felt listened to when I paid for a private consultation with a specialist. I was repeatedly ignored by my GP, out of hours and A&E when my pain and bleeding was so severe I was passing out and couldn't move out of my bed. I was repeatedly told that I couldn't be in that much pain and all they seemed interested in was doing repeated pregnancy test and give me pain relief. I sat in A&E for 12 hours bleeding heavily only to have a pregnancy test and told to ask my GP for STI tests. I had to leave my place of work as I couldn't cope with the pain."* (online survey)

People told us about situations where tests had negative results but their symptoms continued, and health and care professionals told them they were 'fine'.

> "Then tests come back clear and they tell you are fine but you're still struggling, there are other tests and also sometimes the tests don't show the diagnosis first time. Doctors are very quick to believe a handful of tests over the patient and they refuse to work with the patient. It feels like they are trying to prove you wrong and work against you." *(online survey)*

We also heard from several people about experiences of health professionals suggesting that their women's health symptoms were due to mental health problems, in a way that felt unsatisfactory or dismissive.

> *"Symptoms experienced ignored, I have suffered for several years with various women's health symptoms and have never got to the bottom of it. Each time I am turned away and asked, 'Are you perhaps just anxious?'"* (online survey)

> *"I was told by gynaecology consultant that I was mentally unstable when I was trying to express my concern and got teary due to previous traumatic birthing experience."* (online survey)

People told us about the negative impact that not being taken seriously had on their physical and mental wellbeing.

> *"Replacement of vaginal pessary without examination of vaginal tissue despite me complaining of discomfort. This resulted in a vaginal ulcer."* (online survey)

> *"For the most part I felt that [GPs] did not believe my symptoms were real or, even if they did believe they were real, they were unwilling to take them seriously because they were usual. Just because what was happening to me was rare doesn't mean it wasn't real. The lowest point was being told I was 'hypersensitive' and being referred to talking therapy."* (online survey)

"It's part of being a woman"

We heard several cases where people were told their pain or other symptoms were 'normal' by health and care professionals, or felt they were expected to live with debilitating symptoms.

> *"When I discussed premenstrual dysphoric disorder (PMDD) & perimenopause symptoms with a gynaecologist she told me to block out a week of my diary every month and that what I was experiencing (feeling suicidal and bleeding) was normal after having children and as I get older."* (online survey)

> *"B12 given for over a year but not feeling any better, have tried telling them but they just shrug and say it's part of being a woman."* (online survey)

Feeling dismissed because of age, weight or other factors

Some people felt their concerns had been dismissed because of factors such as their age or weight. Others felt that assumptions had been made about them – such as their level of sexual activity – which they found upsetting.

> *"Ageism and sweeping generalisations need to be addressed - if you're young 'it must be your hormones', if you're older 'it must be your age'."* (online survey)

> *"My GP sometimes makes me feel like a hypochondriac - especially as a mother - I'd like to be listened to and respected."* (online survey)

> *"Often dismissed as issues being in relation to weight/ anxiety. Never taken seriously. Not respected. GP refused to offer me a chaperone for an*

> *intimate examination because "she's never had a woman want one with a female GP before."* (online survey)

Several people told us that health professionals had dismissed their perimenopausal symptoms because they were "too young for menopause", when in fact they were experiencing early menopause.

> *"I was diagnosed with an early menopause 4 years ago. I am now with the Menopause Clinic who have given me exceptional care. However, despite going to my GP over a 4-year period with textbook menopause symptoms, I was refused any treatment and told I was "too young" to be going through menopause. Those years were the worst I have experienced in my life."* (online survey)

Having to advocate for yourself or do your own research
A recurring theme was that, in order to be taken seriously and get the care they needed, women and people who use women's health services felt they had to advocate for themselves, do their own research, or both. People found information online, from friends or community members, and in books such as Davina McCall's *Menopausing.*

> *"I have been fighting for over 2 years to get a PMDD diagnosis. It has been the fight of my life. I have been ignored, chuckled at, told "it's not that bad," "every women has some sort of problems relating to their period," "No, I don't think it's PMDD because I haven't heard of it before and so it must be quite rare," "Let's give you an internal ultrasound to make sure it's not PCOS or endometriosis," even after saying I don't have pain until I ovulate and even then it's in my joints and muscles, not ovaries (clear sign of PMDD)."* (online survey)

> *"I needed to be very insistent and persistent to get them to listen."* (online survey)

> *"I have to fight tooth and nail for every little thing and I just don't have that in me anymore. I've accepted a lower quality of life in living in the UK unless I suddenly get rich."* (online survey)

6.3 Health professionals' understanding of women's health

We heard that just over half of people (217 people, 52%) felt that health professionals had a good understanding of their health problem or situation, and most (243, 59%) said they had confidence and trust in the health professionals they spoke to, but again, this was not consistent across the board.

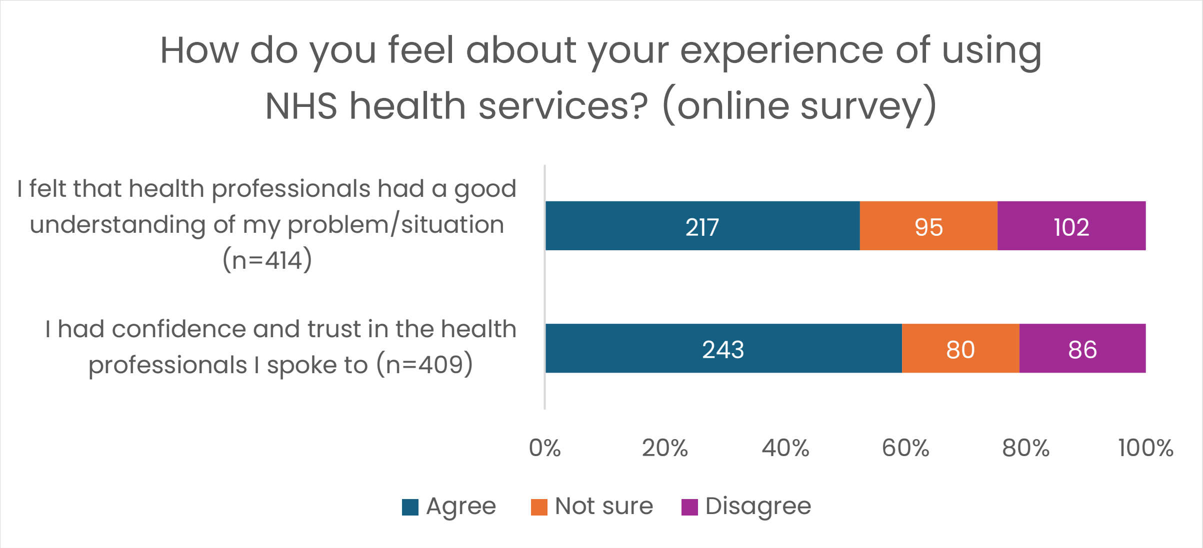

Figure 9: Bar graph showing responses to online survey questions about whether people felt that health professionals had a good understanding of their problem/situation (n=414), and whether they had confidence and trust in the health professionals they spoke to (n=409).

People told us the positive difference they felt when they saw health and care professionals who they felt had a **good, in-depth understanding** of their condition or situation, and how this helped them find treatment and support that worked for them.

> *"What worked well was my GP's understanding of perimenopause, the symptoms, and available treatments, and her being both kind and very good at explaining things and coming up with solutions. My psychiatrist also knew about the link between the oestrogen and dopamine systems and was able to help me to titrate my medication to manage this. My life is much better because of their interventions and I have been able to remain at work because of them."* (online survey)

People told us about specific examples where **limited understanding** of women's health from primary care professionals, or **limited access to more specialist care**, had affected their care or their own understanding of their particular condition or situation.

> *"The lack of understanding of women's health conditions, I have endometriosis, and I have had doctors refuse me referrals because there are no cures so there is no point. I had to go private to get a diagnosis, but I still have no support for it and this impacts my life every month, I get symptoms for most of the month."* (online survey)

> *"Nobody really understands either menopause or fibromyalgia. They're sympathetic but don't have the skills to help. I feel abandoned and let down."* (online survey)

6.4 Information and tools to make an informed choice

People told us about how much they valued being given **good quality, clear information** about their condition and options for treatment. People valued when this was provided by health and care professionals in an accessible way, and also noted the impact of online advice, books, community groups and public health information campaigns.

> *"I have had the best care and support from my GP surgery in the last year around a number of new health issues. They have been communicative and taken time to sit and listen and talk through reports with me in accessible language so that I have understood exactly what is taking place. For one of these health issues, I also needed to use the hospital services and again, the staff were well trained, thoughtful, calm and courteous. They made sure that I understood what was going to happen at every stage of the investigation."* (online survey)

> *"I delayed getting my breast symptoms checked because I had recently had a reassuring mammogram. It was cancer, and it never did show up on an ordinary mammogram, but you could see it with ultrasound and other scans. It was lucky that I saw that poster in the Marks and Spencer changing room that finally made me decide to get it checked out anyway, as I could see my symptom clearly on the poster."* (online survey)

> *"A menopause talk arranged by the local surgery with Docs and other speakers was incredibly well attended. But regular support groups would be useful as when menopause kicks in you don't realise what's happening to you!"* (online survey)

Good information also contributed to being able to make an **informed choice** about treatment options – though health professionals were able to support this in other ways too, for example by providing advice practical assistance to try out different pessary rings.

> *"I was given all my options and was able to make an informed decision."* (online survey, perimenopause)

However, we heard from some people who had been given **conflicting information** or advice from different health and care professionals, which could make it harder to know what to do.

> *"Speaking to different GPs in my practice all giving different advice about my HRT."* (online survey)

> *"The overall medical care and visits has been fine. The doctors, midwives, MSWs etc have been kind and caring: they are by far the best thing going for the experience in this maternity ward. Advice though has been inconsistent [like] the following of crucial things like how much the newborn baby should be feeding and what medication the mother's been taking."* (Feedback Centre review)

We also heard how a **lack of information** about treatment options or procedures could limit people's ability to take up care or make an informed choice.

> *"I'm intimidated to schedule any gynaecological appointments because it's not clear who would be doing them or what exams I should be getting including breast exams and smear."* (online survey)

> *"I called the GP […] about my HRT and wasn't informed that I could change my oral progesterone to patches. I have struggled with anxiety and forgetting to take the oral progesterone."* (online survey)

6.5 Waiting for referrals, appointments and results

We heard that people appreciated it when they **did not have to wait long**, particularly to access treatment or hear about something potentially serious such as tests for cancer. People also valued **getting support while they waited**.

> *"I was given my results straight away so no worrying wait."* (online survey)

> *"I was treated for endometriosis within 6 weeks, my consultant listened to me and offered several options for treatment for me to consider."* (online survey)

However, we heard that many people had experienced **long waits** for appointments, specialist referrals and to hear back about tests and diagnostic procedures. Reasons for waiting included long waiting lists for some clinics, needing tests before treatment could be started, and being told to wait and come back if symptoms continued.

> *"Gynaecology could do with more care and more staff to deal with the massive waiting lists (9 months minimum to be seen is what they quote when I have rung)."* (online survey)
>
> *"The two week wait for a GP appointment is challenging, particularly as this is often only a gateway to the service you actually need which might mean it takes much, much longer to get help."* (online survey)
>
> *"I asked my GP for an appointment to discuss menopause support (I'm perimenopausal). I'm experiencing urinary incontinence. I was told to come back once I hadn't had any cycles for more than 12 months."* (online survey)

Waiting for appointments and tests can also make it difficult for people to get help with **chronic or recurring conditions**, or to synchronise investigative test with flare-ups.

> *"Issues can come and go, so it's not always easy to pinpoint what is wrong."* (online survey)

We heard that waiting could delay people getting treatment and have a **significant impact on their quality of life**. For some people, waiting also limited their ability to make choices about their life, such as fertility and contraception.

> *"Waiting times feel excessive and cause a good deal of sustained stress and anxiety."* (online survey)
>
> *"I am at a loss to know what to do when I have a question in between appointments. The service is in such demand and appointments take such a long time to come round I don't know what to do - I feel I am in a crisis*." (online survey)

6.6 Quality of care

The UK government women's health strategy recognises a need for care to be joined-up and holistic, and for "personalised care [to be] embedded in all areas of women's health".[2] The key themes we heard around the quality of care people received were:

- Appreciation for **compassionate, person-centred care** – and examples where people had not received this kind of care

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[2] UK Government - Women's Health Strategy for England

- The importance of **services and professionals working together**
- People feeling that their **symptoms were treated in a silo**
- Gaps in **continuity of care**, and a **lack of follow-up**

Compassionate, person-centred care

We asked online survey respondents whether they agreed with the statement **'I was treated with care and concern'**. We heard that the majority of people agreed (267 people, 65%) but some disagreed (69 people, 17%) or were not sure (76 people, 18%).

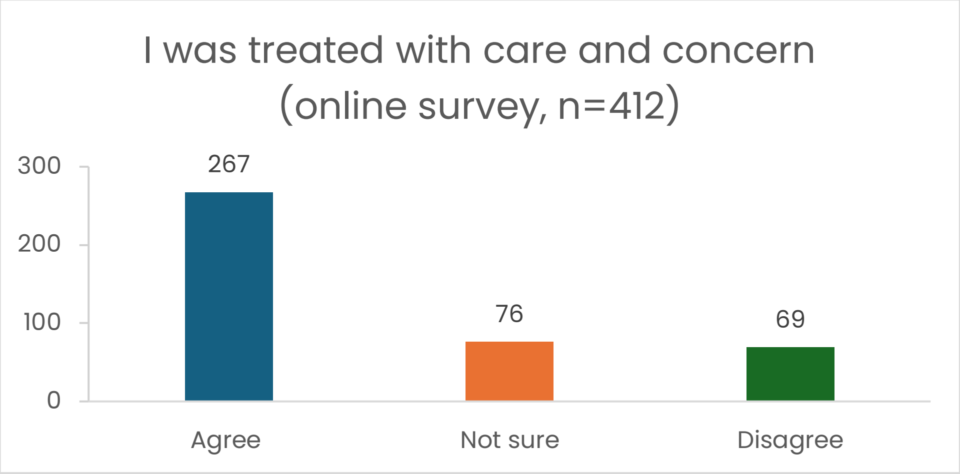

Figure 10: Bar graph showing responses to online survey question about whether people felt they were treated with care and concern when using NHS health services (n=412).

We heard a lot of praise for kind, compassionate health and care professionals and services that met people's individual needs.

> *"Lovely caring GP who was knowledgeable."* (online survey)
>
> *"The early maternity unit in Rose Hill were really kind and talked and listened."* (outreach survey)
>
> *"Gynae at the JR automatically having a chaperone for all examinations, being caring and compassionate down to the little things like tissues."* (online survey)

We heard that people valued good communication and being able to contact health and care professionals if they had concerns about their symptoms or treatment.

> *"The ability to contact a named person after the mastectomy was essential for me. They responded quickly and offered advice, and appointments were made quickly if necessary."* (online survey)

However, we also heard from people who felt they had not been treated in a person-centred way, or whose needs and preferences had not been listened to. Examples included being asked about or tested for pregnancy despite having had reproductive organs removed, or assumptions being made about people's preferences or home life.

"Passed from pillar to post"

People shared examples of good communication and cooperation between services involved in their care.

> *"I have been very pleased with most services, particularly liaison between my GP and the breast clinic as the speed at which I was seen - and the timeframe between the two - was excellent."* (online survey)

However, we also heard examples of health services including primary, specialist and secondary **services not working together in a joined-up way**, which could result in delays to care.

> *"I was told my GP surgery would fit the coil but when I called them, they no longer offer that service. They told me to contact Sexual health at the Churchill but they only fit them if required for contraception. I needed it to keep my uterus lining thin while being on HRT. I felt like I was passed from pillar to post at a difficult time. In the end I waited until my follow up at Women's Gynaecology and it was fitted then."* (online survey)

> *"The GP services and Midwifery services seem completely disconnected and there seemed to be very little information shared about any of my medical history - my miscarriages weren't properly recorded and I continued to receive pregnancy communications even when I was no longer pregnant and there seemed not to be any knowledge of these passed on to help inform my care in my current pregnancy."* (online survey)

"No joining up of the dots"

People told us they valued **being treated holistically** – their whole-body system rather than individual symptoms being treated in silo.

> *"What worked well was talking to a GP that had an interest in Women's health care and took the time to listen and didn't make assumptions or diagnose on a symptom in silo."* (online survey)

> *"Sexual health services have always taken a holistic approach, and considered the way that my symptoms make me feel. They have also been very good at signposting to other services."* (online survey)

We also heard about experiences where people felt their symptoms were not being considered as part of a larger whole-body system, which prevented them from getting the understanding and care they needed.

> *"I get that we can only go in with one problem but when the problem is painful sex and pain in the ovaries I imagine there is a connection."* (online survey)

> *"PCOS has deeply affected me, with infertility being only one element of the condition. Fertility seems to have been the only matter of interest re PCOS and treatment which is mind blowing considering all the other symptoms and health risks it means I have with this common diagnoses. I can see the same thing happening with my perimenopause symptoms. No joining up of the dots regarding the wider effects hormones have on metabolic, joints, mental health, insulin resistance, and general wider system."* (online survey)

Continuity of care and follow-up

People told us about gaps in the continuity of their care, and the impact of this on getting the care they needed.

> *"With GP services I rarely ever saw the same person twice, meaning I had to start from scratch each time explaining issues that had been going on for years which meant I made little progress with diagnosing my problem."* (online survey)

> "*To find appointments with the same GP was super difficult and every GP had different views… In the meantime, I struggled for two years with symptoms that as soon as they listened and did tests, and gave me something to treat my migraines and hormonal fluctuations I have been better."* (online survey)

We heard about limited follow-up from health and care professionals, such as following tests or to carry out medication reviews for people taking HRT medications, antidepressants or oral contraception.

> *"I got put on HRT 3 years ago, but it has never been reviewed. I was only in my early 40s."* (online survey)

6.7 Sexism and other inequalities

The national government inquiry into women's health found evidence of unconscious bias and the far-reaching effect this has on women and people who use women's health services. Unconscious bias on the basis of sex and gender plays out in medical research, the design and delivery of health services, and how individuals are treated by health and care professionals.

Unfortunately, we heard that some people felt they had been treated differently because of their gender or sex. Although most online survey respondents (252 people, 61%) disagreed with the statement 'I felt that I was treated differently because of my gender/sex', 74 people (18%) said they were not sure, and 87 (21%) said they agreed – they felt they had been treated differently.

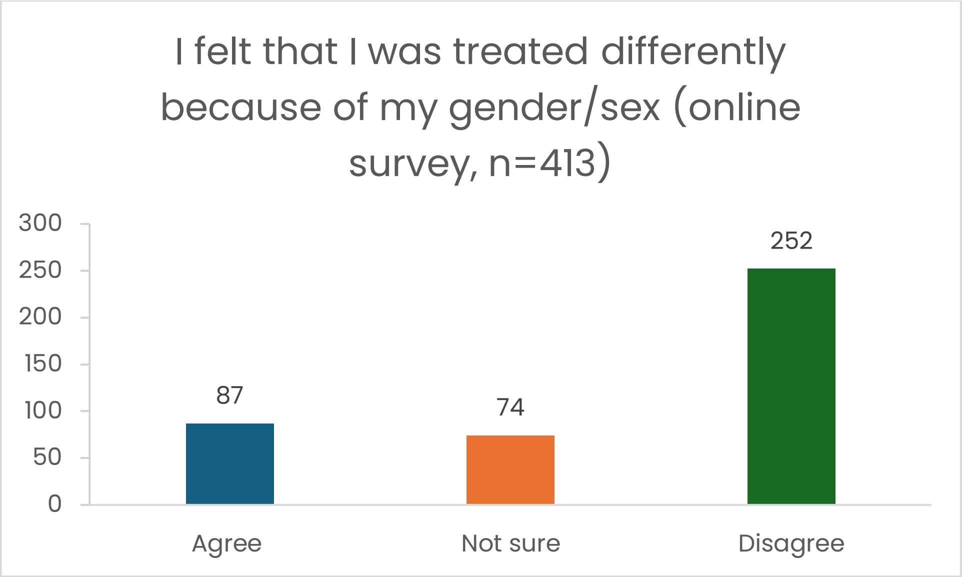

Figure 11: Bar graph showing responses to online survey question about whether people felt that they were treated differently because of their gender or sex while using NHS health services (n=413).

People told us about experiences of feeling belittled because of their gender, receiving sexist remarks from health and care professionals, or feeling they had very different experiences from male relatives. Although some people felt they were more likely to have a good experience with a female health or care professional, we heard about examples of sexism from health and care professionals of all genders.

We heard about the impact it had on people’s experience of care and their experience, particularly on people’s sense of whether they were listened to and their symptoms taken seriously. People also told us about coping strategies used to combat these problems, such as attending appointments with a male partner.

> *“I always discuss my GP appointments with my husband and he has never received the sorts of dismissive comments about his health problems that I regularly do, or made to feel like he’s imagining symptoms.”* (online survey)

> *“After I had my daughter sex was and still is extremely painful, I was told by a male GP that my husband's penis must have got bigger!!”* (online survey)

> *“I have to take my fiancé with me to all my appointments, if I don't I am told I'm fine and then the appointment is over. When I have my fiancé with me, most doctors talk to him and believe him over what I say.”* (online survey)

We heard that the experiences of women and people who use women’s health services were affected by other factors – such as being a migrant, having caregiving responsibilities, cultural and religious difference, digital access, disability, and racism and other forms of discrimination.

Experiences of women who are migrants, asylum seekers and refugees

We heard that asylum seekers face additional barriers to accessing health and care services, and that migrants may face additional challenges due to being far from their communities of origin and associated support networks. We also heard a need for support for people who do not have English as their first language.

> *“It is very difficult for asylum seekers to get help with their health. Sometimes I feel I have no voice.”* (feedback from outreach with asylum seeker support group in Banbury)

> *“We have no family here, it means we feel everything more because we are alone here, we feel more stress.”* (feedback from Oxford Community Champion)

> *"Please listen and care for women who cannot speak English language very well."* (outreach survey)

Caregiving responsibilities

We heard that caregiving responsibilities can affect people's access to and experience of health services in multiple ways, including advocating for the health of those they care for, having additional demands on their time and energy even while recovering from childbirth or surgery, and needing to make appointments around childcare arrangements.

> *"People are also being discharged more quickly from maternity now. I was begging the nurse not to make me go home because getting home meant I would have to do the cooking, the cleaning and everything."* (feedback from Oxford Community Champion)

> *"One challenge I have had is managing my own health with my children being at appointments with me. I found it very challenging to discuss mental health, for example, with my children in the background."* (online survey)

Cultural and religious differences

We heard that different cultural and religious expectations and beliefs could affect people's relationship to seeking help, and that some standard health policy feels inappropriate for some people.

> *"There are people who don't go to the doctor at all, they don't want to be told to get rid of the baby if there are problems, they say "God gave me this present", they don't want contraception."* (feedback from Oxford Community Champion)

> *"Health visitor appointments should be optional - and health visitors must be aware that visits to a newborn's home are unacceptable in some cultures for 6 weeks post-birth. Personally, I found those visits intrusive and unhelpful. Although I understand that some families need the support, the timing and location of these appointments must be less prescriptive."* (online survey)

Digital access

We heard concerns from people who are not confident with digital access or do not have the relevant equipment or connections, about how they would access appointments or information.

> *"It's not clear how to get repeat prescriptions done, there is no one to explain things that can be confusing such as how to access my records because they require using the NHS app, which I don't know how to access or use."* (online survey)

Disability

Several people told us about experiences of reasonable adjustments not being made for them, or a need for more training for health and care professionals on how best to support them.

> *"Training required on disability, staff coming into NHS from other countries. Powered wheelchair user. Not to grab hold of wheelchair control yank it up down pull it, the user can be hurt the imaging equipment and the person the chair could be hurt."* (online survey)
>
> *"Specialist found I have likely large dermoid cyst on ovary. Letters advise the GP for rescanning every 3 months, this does not get booked unless I call and remind the GP. Reminding them is difficult for me, I have memory issues due to disabilities and then they make it so you can only contact them Mon-Fri working hours, I work too during these hours! When I do remember in the evening they have closed the option to contact them."* (online survey)
>
> *"Need deaf awareness training."* (online survey)

Racism and other forms of discrimination

People told us about experiences of racism and other forms of discrimination such as anti-fat bias or stigma around mental health. We also heard about a lack of support for people with health conditions that adversely or exclusively affect diverse and multi-ethnic communities, such as sickle cell anaemia and Female Genital Mutilation/Cutting (FGM).

> *"We are from the Windrush generation and somehow we are still having this conversation decades later, people patronize us and then we are told it is unconscious bias."* (feedback from Oxford Community Champion)
>
> *"Nothing. I've been trying to conceive for 5 years. I've been trying to lose weight for longer. Nothing works. I'm too fat to access NHS fertility treatment but not unhealthy enough to access NHS weight loss treatment. This is related to my diagnosed PCOS. I can't afford private care and I don't drive. I can't be covered by private insurance because I'm an immigrant so*

> *every condition is considered "pre-existing" and anything new can be related to said pre-existing conditions so only new injuries would ever be covered."* (online survey)
>
> *"Female GP told me I didn't look like the sort of person who would suffer from anxiety and depression."* (online survey)

7. Menopause

Menopause was the most common women's health issue that respondents had sought help for. As something that is experienced by all people who menstruate, the last few years have seen a growing awareness of symptoms and treatment. The main themes we heard were around:

- A **lack of widely available, accurate and culturally appropriate information** about menopause
- **Positive experiences** of getting help for perimenopausal symptoms – including speaking to a health or care professional with a **good understanding** of menopause
- **Negative experiences** due to a **lack of understanding** of menopause in primary care, and limited access to specialist clinics
- **Challenges accessing hormone replacement therapy** (HRT).

"It's 2024, they should tell you about menopause"

We heard that some women and people who use women's health services felt they lacked information about what would happen to them and what they could do to improve their experience. We heard this from a range of people, including migrant and refugee women, people who had been through 'surgical menopause' following a hysterectomy, and people who experienced early menopause (before the age of 45). Several people pointed out that as women and people who menstruate reach their 40s, health and care services have an opportunity to educate them about perimenopause before symptoms start.

> *"I didn't know there was something called menopause. I had a coil fitted; it lasts for five years but I asked them to take it out after 3 years. No nurse told me that I would get hot flushes, mood swings, that I needed to drink water. My friend told me, "You've got menopause". My doctor should have told me, with my age. I did not know that I had stopped my periods because of the coil. I looked online and found out how to look after myself – so I take magnesium and collagen now. This is shameful! It's 2024, they*

> *should tell you. They should tell you in your 40s, run classes – like in school when they teach you about periods and sex, or during pregnancy. No-one told me what changes in my body would happen."* (feedback from Oxford Community Champion)

> *"When you are running around with your kids and everything, you don't have time to feel what is happening, and then you are shouting at your husband and your children! They could send you leaflets when you reach 40, and make it accessible in different languages, saying "if you feel like X, talk to your doctor". It would help to communicate with our husband and children. We don't understand the mood swings ourselves, so how can we explain to our husband?"* (feedback from Oxford Community Champion)

> *"It's not very black and white and there's not very much information about it. The GP would never mention it unless you asked them. If you don't have the information, you can't get help."* (feedback from Oxford Community Champion)

Positive experiences of menopause support

Some people told us about good experiences of getting help for perimenopausal symptoms – for example, feeling comfortable enough to discuss it with health and care professionals, and the difference made by hormone replacement therapy (HRT). People told us they appreciated being able to speak to a health professional with a good understanding of menopause.

> *"GP callback for perimenopause advice also great following e-consult request. GP listened to me, gave plenty of options and advice, leaving it to me to decide what best course of action for me would be."* (online survey)

> *"Spoke to a doctor regarding menopausal symptoms and was prescribed HRT. Appointment was the day I registered a query which was very good, and the doctor seemed knowledgeable and helpful."* (online survey)

> *"I was referred by my GP to the clinic with severe perimenopause symptoms which I have struggle to keep under control, such as hot flushes, mood swings and other common symptoms. The call was for over 45 mins and the person I spoke to was so very understanding and actually listened and gave advice. My medication was changed and my symptoms improved."* (online survey)

“Nobody seemed to know anything about it”

However, we also heard about challenges that people had experienced. These included delays to treatment, which people felt were caused by a lack of knowledge in primary care and long waits for specialist appointments.

> *“Faster diagnosis. Not taking over 4 years to get a diagnoses and treatment. GPs [should be] trained in spotting the symptoms of menopause in all ages of women.”* (online survey, early menopause)

> *“I have had to wait for 11 months for treatment because, in spite of agreeing that I need HRT given my blood test results, my GP is unable to prescribe it for me. I have to wait until the end of November when I have a telephone call with the specialist. I have felt suicidal at times while waiting. GPs will prescribe antidepressants in a heartbeat but the understanding about perimenopause is not there and so neither is the treatment.”* (online survey)

One woman told us that she felt dismissed when she raised the idea of treatment for perimenopausal symptoms, and that the health and care professionals she spoke to did not seem to know about the Community Gynaecology Service.

Challenges accessing HRT

We heard stories about people who wanted to start hormone replacement therapy (HRT) but were told they could not, as well as others who were prescribed HRT even though it was not suitable for their needs.

> *“I was referred to a "specialist menopause" clinic - I spoke to them on the phone every 6 months - when I complained about my increasingly awful menopause symptoms, they just upped the dose of HRT - after 3 years I was constantly bleeding and in pain - had experienced a blood clot in one eye reducing my vision - and had dreadful mood swings and depression. A vaginal ultrasound revealed that I had adenomyosis and should never have been prescribed HRT in the first place - turns out they had never once looked at my records - not once in 3 years - which would have shown suspected adenomyosis. I came off HRT straight away the bleeding and pain stopped immediately - and am much, much better.”* (online survey)

> *“The doctor I spoke to was unwilling to prescribe HRT despite my concerns about perimenopause. I was told that it was ‘all the rage’ and told of the cancer risks associated with HRT. I came away very upset with a prescription for even more antidepressants.”* (online survey)

> *"I was immediately told I should go on statins for high cholesterol (which I declined) but when I mentioned the possibility of HRT for hot flushes etc., was told we shouldn't throw chemicals at things straight away and I should consider wearing baggier clothes."* (online survey)

We also heard about the impact of HRT medication shortages on people going through menopause.

8. Screening and procedures

In our online survey, we asked people about their experiences of cervical screening (smear test) and breast screening (mammogram).

- **Cervical screening** checks the health of the cervix and helps prevent cervical cancer. It is offered to women and people with a cervix aged 25-64. It is provided by GP practices.
- **Breast screening** helps prevent breast cancer and is offered to women and people with breasts aged 50-70. After the age of 71, women can continue to request breast screening is available every three years. In Oxfordshire, breast screening takes place at the Churchill Hospital and at mobile units across the county.

Additionally, many women told us about their experiences of other diagnostic gynaecological procedures, including hysteroscopy, colposcopy and laparoscopy. We also heard about experiences of routine fittings for contraceptive coils or intrauterine devices (IUDs). We heard about:

- **Positive experiences** of screening and procedures
- **Negative experiences** of screening and procedures.
- **Barriers to screening** - things that stop people from attending
- **Enablers for screening** - things that help, or could help, people to attend screening.

8.1 Positive experiences

We heard that things that contributed to a positive experience of screenings and procedures included:

- Being able to **attend screening locally**

"Screening outreach in a van at Millets Farm. I hate going into hospital, so it was brilliant to be able to be able to go closer to home and they were so good with me, I couldn't fault it." (online survey)

- A **straightforward booking process**

  "The cervical screening is very organised and efficient. I got the letter through, rang for an appointment later in the day and was offered a time/date in the near future. The experience at the surgery was punctual and the nurse was very friendly, informative and put me at ease."

- Being able to have **several tests done at the same time**

  "The one stop breast clinic at the Churchill was amazing - the ability to see consultant, have scans and mammogram and then get results the same day was fab." (online survey)

- Health and care professionals **explaining what was happening and why**

  "[Name of staff member] fully explained why they did the smear test what was being tested and the full list of potential outcomes. Really helped understanding and potentially unnecessary stress." (Feedback Centre review)

- Being given **choice** – for example being offered a chaperone or being able to insert the speculum themselves.

  "It was very straightforward. The nurse administering the smear was male and I was asked in advance if this is something I wouldn't mind. I was also offered a female chaperone on the day. It was really an excellent experience." (online survey)

  "I had a cervical screening which I always find very uncomfortable/painful. I asked the health professional if I could insert the speculum myself, which she agreed to and really helped me." (online survey)

8.2 Negative experiences

Unfortunately, we also heard from several people about negative and painful experiences, particularly of diagnostic procedures. Issues people told us about included:

- A lack of **accessible options for disabled people**
- Not feeling treated with **respect or compassion**

- **Difficulty making appointments**
- Pain and **a lack of pain relief**
- A need for **sensitive, trauma-informed care**.

A lack of accessible options

People told us there was a lack of accessibility or reasonable adjustments for people with additional mobility needs.

> *"Much better UTI screening for the over 85s, including developing a better way for collecting urine for those who cannot easily squat etc and home collection of samples."* (online survey)

> *"Registered as housebound but still had to attend the surgery."* (online survey)

Not feeling treated with respect and compassion

Some people felt they had not been treated with respect or compassion by health and care professionals around the procedure.

> *"I had a mammogram earlier this month. The nurse was very unsympathetic. She suggested I leave my walking stick and glasses in the outer room 'Unless you need them', which was absurd since I obviously don't use either for mere decoration. She made me feel small when I asked her to use my preferred name not my legal one. She pushed and pulled me about in front of the scanner instead of letting me step where she wanted in my own time: I have a [knee injury] and am unsteady on my feet, hence my use of a walking aid. She made the whole experience far more stressful than it needed to be."* (online survey)

Difficulty making appointments

We heard about the difficulty making an appointment outside of working hours, and the impact of having to travel for an appointment during an already stressful time.

> *"Great difficulty in getting a suitable appointment for a cervical smear as I work full time. These are important and should be more easily accessible at a variety of locations."*

> *"I know it's minor in your world, but in mine, "pre-cancerous" symptoms are worrying. Please don't treat me like just another task to be completed.*
> *It takes me half a day off work, an unnecessary pregnancy test, and a LOT of anxiety for a ten min max "check up" post-colposcopy appointment at the JR. Could you consider other locations for check ups?"* (online survey)

Pain and lack of pain relief

The most common theme we heard around screening and procedures was how painful they were, and in many of these cases, people had not been offered pain relief or modifications, such as a smaller speculum for cervical screening. Some people felt there had been a lack of information about potential pain before the procedure.

> *"My friend had a polyp on her uterus removed, and was told she wouldn't need pain relief. It was so horrendously painful that she had to ask them to stop and in the end they did it under general anaesthetic. She wasn't told at the outset how bad it would be but she didn't want to complain."* (feedback collected from outreach)

> *"I had my IUD implanted a few years ago. It was the most painful, traumatic experience of my life. I am terrified of having it removed. Why doesn't the NHS offer pain relief for this procedure?"* (online survey)

> *"It was horrific- it was on my notes that I find them uncomfortable but the nurse still persevered with a normal sized speculum and only when I cried in pain did she stop and try a smaller size. I don't understand why they don't start with a smaller size first."* (online survey)

A need for sensitive, trauma-informed care

We heard that people who had experienced trauma sometimes found it hard to make sure that health and care professionals understood how to support them through potentially triggering procedures. In some cases, people said they did not attend cervical screening because of these challenges.

> *"I don't have periods and that's a very sensitive subject to me because I'm struggling with infertility. When I schedule my cervical smears, reception at my GP goes on an automatic spiel about requiring the appointment to be at a particular point in my cycle. I don't have a cycle and having to explain that is upsetting. I also want my husband to attend the appointments because I have panic attacks during cervical exams [due to traumatic experiences]. I have to explain and push for this every time which is a huge barrier for me even making the appointment let alone attending."* (online survey)

> *"Smear test was due over a year ago - first one. Haven't had a single reminder from my GP practice. I have experienced rape and sexual assault so a smear is a huge thing for me and will require more time/ preparation*

> *than a normal appointment, GP receptionists refusing to book an extended appointment/ be flexible. Means I haven't been able to face having my smear done, risking my own health."* (online survey)

8.3 Barriers to screening

People told us about what would stop them getting cervical or breast screening. These included:

- Being excluded by age criteria, or misconceptions about eligibility
- Fear and embarrassment
- Difficulty making or attending appointments
- A lack of accessibility or reasonable adjustments
- Unclear communication and misconceptions about needing screening.

Eligibility

We heard from people who were excluded by age criteria but felt they should be eligible due to their own or family history of cancer. We also heard that there was a misconception that women cannot have breast screening after age 71.

Fear and embarrassment

Some people told us that feelings of shame, fear, embarrassment or gender dysphoria could prevent them from getting cervical screening. These could be exacerbated by previous distressing experiences of health or care services, or experiences of pain and discomfort during screening.

> *"I will never get a smear test because I will never be comfortable being that exposed in front of someone."* (online survey)

> *"Fear of procedure due to childhood sexual abuse and recent rape. A longer appointment time at the GP with someone I trust and can go at my pace/ talk me through it. Being able to take someone with me to support me."* (online survey)

> *"Virginity and I am scared of the procedure."* (online survey)

Difficulty making or attending screening appointments

We heard some people had problems making or attending appointments – for example, getting to a mobile breast screening unit without access to a car.

> *"I would like there to be easier ways to book appointments for routine tests like this. Often you get a letter of invitation and then have to contact the GP surgery on the phone to book in, but it is difficult to get through my*

> *phone, surely an email or online booking system would be more efficient and easier for everyone to use."* (online survey)

> *"It was fine, but where it was parked was not on a bus route so was difficult to get to easily."* (online survey)

Accessibility

We heard about experiences of access needs not being met, making it hard for some disabled people to get screening.

> *"Disabled women need access to cervical cancer screening. Many women are missing out because GP surgeries do not have hoists or other equipment to help people transfer to the bed."* (online survey)

Communication and misconceptions about who needs screening

Some people said they did not believe they needed cervical screening – including younger people who had received the HPV vaccine and people who had not been sexually active. This may be linked to another barrier we heard about – unclear communication about who is eligible for screening and why it is important to attend (see also Healthwatch England's 2024 report on improving invitations to cervical screening [3]).

> *"I have had the vaccine against cervical cancer. Some of my female friends who have had this vaccine and are not very sexually active are reluctant to attend smear tests."* (online survey)

> *"I was told by a trusted GP that don't need one because I have never been sexually active. However I still keep getting letters inviting me and I want to know for certain if I should still have one or not, I can't find consensus online."* (online survey)

8.4 Things that help, or would help

People also told us about what would make them more likely to attend screening and have a good experience. These included:

- **Training health and care professionals in techniques** that make screening easier or less painful

  "It has sometimes been too painful for them to actually succeed in taking the swab, but I think I'm getting techniques to deal with that now.

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[3] Healthwatch England blog: Barriers and inequalities to cervical screening

For people performing the procedure, being relaxed and patient is so important and being aware of different approaches or things that might help. For instance, I've found tilting my hips up makes a difference and seems to make it work. Not lecturing or talking to you like you're a "silly young woman", being calm and friendly like you're equals." (online survey)

- Enabling people to carry out their own cervical screening (**self-testing**)[4]

"Make smear tests much more comfortable and / or allow home tests. I hate them - SO uncomfortable every time, it never improves. And nothing is done to try and make it even slightly better. Just thinking about it gives me pain in my stomach." (online survey)

- Making sure professionals are trained in **trauma-informed care**

"It would help if the nurse was aware of issues affecting survivors of rape/abuse. So that they were sensitive to a patient's emotions etc." (online survey)

"I disclosed to the health professional that I was a survivor of sexual abuse and that I was very anxious about the procedure. The nurse was amazing; I could tell she had been trained to support survivors in a specific way. It didn't make the procedure easier, but it helped my anxiety enormously." (online survey)

- Making sure **care is person-centred** and considers different needs

"Pain due to vaginismus. I would feel more comfortable having a cervical screening in the future if I knew I had a female practitioner who understood my vaginismus." (online survey)

"Please don't tell us to relax, it is not helpful. Instead maybe ask, how can I help you relax today. What would make you feel more comfortable. And talk to us about what is happening and why." (online survey)

- Providing people with **relevant information** – including why it's important, and what to expect

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[4] See also Healthwatch England's report on cervical screening, which heard that nearly three quarters of 2,444 women who were hesitant about cervical screening said they would use a home testing kit if it was available for free.

> *"Excellent. Brilliant communication and support throughout. Leaflet about what to expect. Welcoming environment. Sensitive approach. Procedures done carefully, treated me like a human being. Explained all stages step by step. Did not rush. Provided results within 2 weeks."* (online survey)

- Offering **pain relief**

> *"Pain relief being offered to people who need it. For me, I have to take a days annual leave to attend these appointments as they cause extreme pain. Having a companion helped, and I was able to have a receptionist who is trained as one help me through it. I think that GPs are wrongly told that these screenings do not hurt. They often do not of course, but that does not mean that they do not."* (online survey)

- **Seeking feedback** from survivors and other patients.

> *"I was particularly impressed that there was notification in the outpatients suite asking for survivors to provide feedback on their experiences."* (online survey)

9. Ideas for improvements

9.1 What would you like to see?

We asked people who responded to the online survey what would support them to use health services and look after their health and wellbeing. We provided options based on conversations with women and health services and commissioners. The most popular option was **'being able to get support for several different things in one appointment'** (257 people, 77%). Other popular options included:

- 'Appointments at times and locations that suit me' (207 people, 62%);
- 'Being offered the choice to see a female health professional' (185 people, 56%)
- 'More time for the appointment' (168 people, 52%)
- 'Being able to attend a drop-in clinic without having to make an appointment' (160 people, 48%).

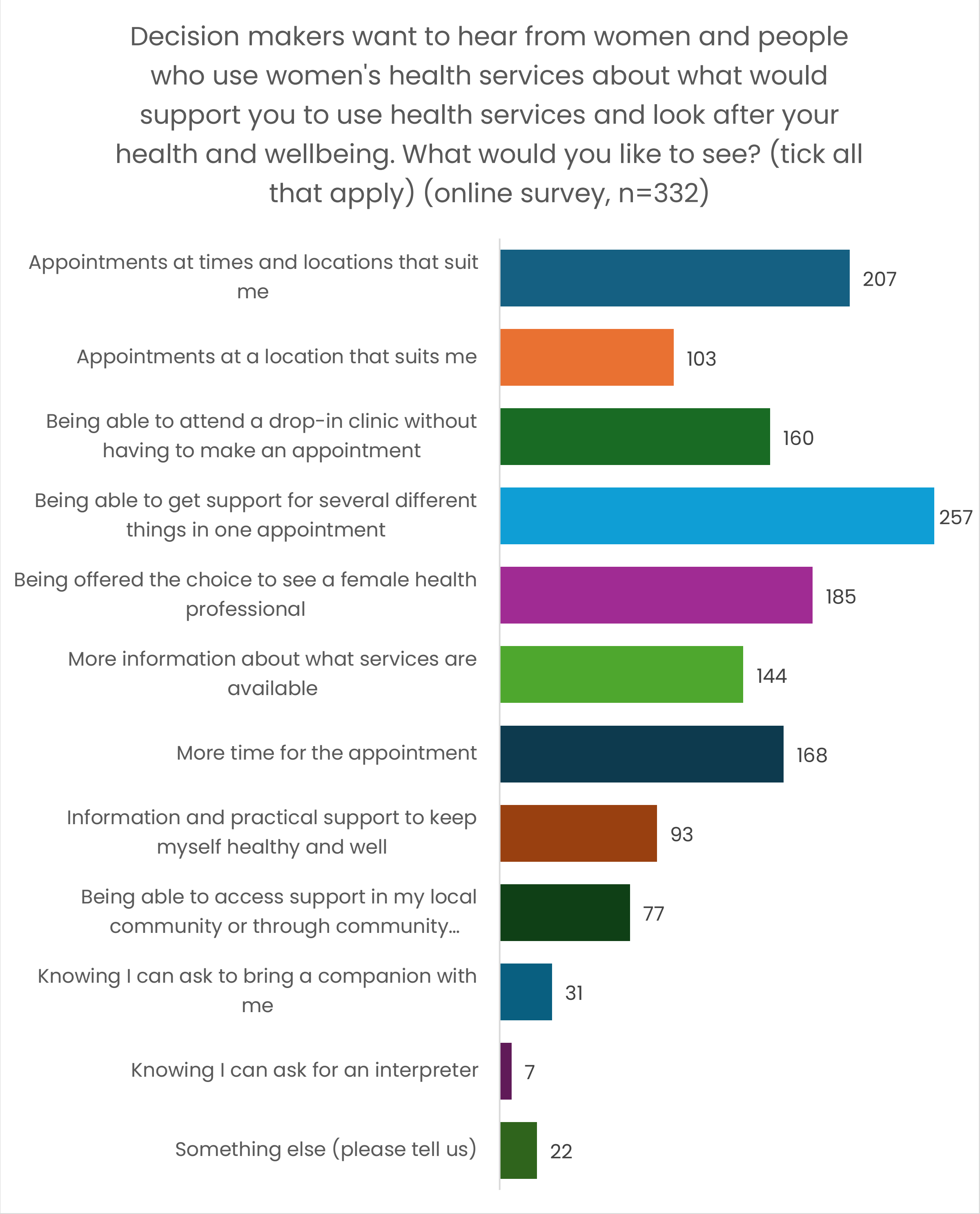

Figure 12: Bar graph showing responses to online survey about what people would like to see from women's health services (n=332).

Other suggestions included:

- Trauma-informed care
- Being able to book routine appointments
- Being able to see the same health or care professional each time

- Being able to see a professional face to face
- Being able to access services without needing a referral from a GP
- Ensuring access needs are met, for example providing hoists or the person knowing they can bring their assistance dog to appointments.

9.2 Your suggestions and ideas

Through the surveys and our conversations with women and people who use women's health services, we also heard suggestions and ideas about how health services could better meet people's needs. These fell into five main themes:

- Improving **public understanding and awareness** of women's health issues
- Improving **health and care professionals' understanding** of women's health issues, and **support for people living with women's health issues**
- **Joining up care** and making sure it is person-centred and high quality
- **Tackling barriers** to accessing health and care services
- **Listening** to women and people who use women's health services.

Improving public understanding and awareness

People suggested developing community networks and informational campaigns to improve public understanding awareness of menopause, menstrual disorders and other women's health concerns. This would help make sure that people are equipped to notice symptoms, seek help where needed, and look after themselves, and tackle the idea that pain is 'just part of being a woman'.

> *"In an ideal world girls would be educated about endometriosis and PCOS so if they experience very painful periods regularly or have other unusual symptoms they come forward. This gives them time to investigate the problem because it seems to affect so many people, takes years for a diagnosis and affects women's fertility later in life."* (online survey)
>
> *"Better understanding of menopause, discovering if you're in it and what can be done about it."* (online survey)

To make sure everyone has access to this information and is able to act on it, people suggested making sure **information was accessible** and that health and care services **go to where communities are**.

> *"There needs to be more outreach work done, perhaps small hubs in community centres in deprived areas to encourage women with protected characteristics to seek the help they deserve."* (online survey)
>
> *"More accessible information on where to go to for help."* (online survey)

Health and care services could continue to build on the ‘**making every contact count**’ model and ensure that, in their interactions with services, people are offered information that helps them make informed decisions.

> *“Health services for women can be improved, particularly when it comes to consultations for contraception, by taking the care and consideration to talk patients through all side effects and possible options of contraception and to explain what actually will happen to your body and mental health.”* (online survey)

Several people pointed out the importance of **building community** between women of similar ages and of different generations, for example through **support groups**, to encourage people to talk about women’s health issues, share knowledge and support each other with conditions like PCOS or through menopause.

> *“In many of our communities people don't have access to trusted older women who can share experiences - we need support to grow that and can learn from models in developing countries who encourage this. I believe these initiatives/resources should be targeted to those whose health is most at risk due to inequality and multiple disadvantage.”* (online survey)

> *“Many women are ashamed of some conditions. Let’s talk and raise issues and encourage all women to speak up.”* (online survey)

> *“Regular perimenopause and menopause groups covering different aspects at each session and support groups.”* (online survey)

Healthwatch Oxfordshire will be holding a **webinar on menopause**, hearing from an Oxford Community Champion and a representative of the Community Gynaecology Service, in June 2025.

Improving health and care professionals’ understanding of women’s health issues, and support for people living with these issues

People said they felt that more research and support was needed for women’s health issues, including the impact of hormones and experiences of pain.

> *“More research and education for NHS re women’s health and hormones.”* (online survey)

> *"More research and support about issues affecting women specifically such as endometriosis and adenomyosis, and the pain that is experienced through gynaecological issues being taken seriously and treated well."* (online survey)

People suggested that health and care professionals should receive more training in women's health issues, as well as improvements to pathways to care such as faster referrals and diagnosis.

> *"Train GPs in perimenopause support. Provide faster referrals to women who are struggling with their mental health as a result of physical symptoms. Ensure women are not just dismissed as perimenopausal when their symptoms are also indicative of more serious conditions such as cancer."* (online survey)

> *"Respect when we say we are in pain/ something's not right. Don't continually dismiss us for anxiety/ weight issues. Value our health as much as men's. Training particularly for male doctors, to stop being so dismissive. Reminding doctors of the need to advocate for patients, rather than dismiss us."* (online survey)

> *"There needs to be a much greater depth of understanding of how trauma (including birth trauma, sexual abuse and domestic violence) can continue to affect and impact us as women tens of years down the line - it isn't something that just disappears when the children have grown up or when the abuse might have come to an end."* (online survey)

Joined-up, person-centred, high-quality care

We heard that improvements could also be made to the ways that health and care services **work together** to provide care.

> *"Joined up conversations - for health practitioners to speak to each other if a patient has multiple issues (to see where there may be contraindicators on treatment plans)."* (online survey)

People suggested that being able to have a **designated or named health or care professional** would improve their experience of care. For example, being able to see the same clinician and build up trust and understanding over time or having a clinician who is designated as the lead on women's health, trauma-informed care or domestic abuse for a GP practice or primary care network.

> *"Make clear at GP practices who the menopause, women's health/ gynae specialist interest GPs are and continuity in that care. This would save many GP appointments."*

We heard that people would appreciate **timely, compassionate follow-up** from health and care services, particularly following traumatic experiences such as miscarriage, or while living with distressing symptoms.

> *"To feel you matter. Not forgotten or you have to chase the service."*

We heard that being able to have **longer appointments** and **face-to-face appointments** would help, particularly for important milestones such as the 6-week post-partum check-up.

> *"See us - some of these conversations are not fit for phone calls. You need to see us."*

> *"Women's check ups and time to speak openly about wide ranging issues, not just one problem per appointment."*

Tackling barriers to health and care services

People suggested ways of making women's health services more accessible. These included making **reasonable adjustments** for disabled people and considering this at every step of someone's care journey.

> *"Disabled access must be considered. Most places are wheelchair accessible in terms of being level and having ramps, but things like space in consulting rooms for larger powerchairs and hoists and transfer boards are needed as well. Access doesn't just mean you can get a manual wheelchair into the building."* (online survey)

Several people suggested **regular, routine check-ups** for women, particularly during perimenopause. More could be made of existing touchpoints – for example, health checks available to people 40 and over could be a timely moment for a conversation about menopause, or cervical screening could also be an opportunity for other health checks.

> *"The check you get when you're 40 could be a lot more useful - the one I had was just a tick box exercise, I gained nothing from it. This check might be a useful opportunity to start talking to women about menopause and giving them information on how to manage this."* (online survey)

> *"Overall health of the vulva, vagina, ovaries could be checked at the same time, e.g. with ultrasound. But it was just a cervical swab."* (online survey)

We heard that **greater flexibility around appointment times**, and support to bring children to appointments, would reduce barriers to health services for people who have caring responsibilities.

> *"They need to acknowledge that a higher proportion of women are also carers (to either adults or children) and need more flexible timings and remote options to allow them to access services around these roles."* (online survey)

> *"It would be nice if GP surgeries had more toys to keep kids entertained so mothers actually had time to discuss needs without interruption. Or even better, try to schedule all the mums around the same time and provide a bit of childcare so they can focus on their appointment uninterrupted."* (online survey)

As an alternative to trying to get non-urgent appointments, people suggested having **drop-in clinics**, such as menopause clinics, or **'one-stop-shop' appointments** where people can do several things at once. Clinics could even be provided in a mobile unit.

> *"More drop-in centres where you don't need an appointment just to talk to someone and get reassurance."* (online survey)

> *"One stop hub with drop-in services available with women's services - contraception, sexual and pelvic health, cervical screening, menopause."* (online survey)

> *"I think there could be a 'well woman' bus (like the mammogram lorry) that travels the area and does mammograms & smears & general health check all in one session by appointment."* (online survey)

We also heard that some people would like to be able to **self-refer** for more conditions and treatments.

Listening to women

Finally, we heard the importance of **listening to women and people who use women's health services** – both when they attend appointments, and in the design and delivery of services.

“Listening to the woman and don't discredit what she is saying. They live with there bodies every minute of everyday, so just listen to them and don't leave them worse off and in more pain than they were.” (online survey)

“Seek feedback from women and listen to it.” (online survey)

Useful links

- NHS women’s health webpage
- NHS screening for trans and non-binary people
- Further support for cervical screening – NHS webpage
- NICE resources on menopause
- NICE guidance on endometriosis
- Women’s Health Concern
- Menopause matters
- Queer menopause
- Healthwatch Oxfordshire webpage – support for domestic violence and sexual assault
- Healthwatch Oxfordshire webpage – support for migrants, asylum seekers and refugees

Healthwatch Oxfordshire’s previous work on women’s health:

- Women’s views on maternity care (film)
- Maternal mental health in Oxfordshire

Support services

- **Domestic abuse:**
  Oxfordshire Domestic Abuse Helpline: 0800 731 0055 (M–F 10:00 – 19:00)

- **Mental health and suicide:**
  - If you, or someone close to you, requires emergency mental health support dial 999. Call 111 if you need medical help quickly, but it’s not an immediate risk, or if it is out-of-hours for your doctor’s surgery.
  - Call **Samaritans** for emotional support on the phone, 24 hours a day 365 days a year by dialling **116 123** free from any phone
  - **Oxfordshire Mind** – for information about mental health and services www.oxfordshiremind.org.uk or 01865 247788

  - **Oxfordshire Safe Haven** - open every day for people experiencing a mental health crisis. Call 01865 903037 or email osh@oxfordshiremind.org.uk

- **Sexual abuse, rape and harassment:**
  Survivor Space Oxfordshire

- **Gender dysphoria, homophobia and issues affecting LGBTQIA+ people**
  Switchboard - National LGBTQIA+ Support Line

- **Baby loss and pregnancy loss:**
  - Sands
  - Cruse
  - Tommy's
  - Petals

Appendix 1: In depth stories

Story 1: "I'm having to go armed with research"

I was referred to gynaecology 2 years ago after 10 years of menstrual problems. I've had 3 previous referrals to gynae in that time. Every time, they do an ultrasound, find some abnormalities, then tell me that because I'm a young woman I should just wait for things to settle and try a different contraceptive. This means I've been on 7 different forms of contraception, none of which work to resolve my symptoms. I feel I'm being dismissed because of my age and not being heard when I tell clinicians how debilitating this is. The outcome of the referral last year was being told that 'lots of people have bad periods' and being put on a different contraception, without any exploration of why I experience these symptoms which often stop me from being able to attend work, cause me to pass out, and cause significant pain. This treatment plan did not work, and my symptoms have worsened so I've since been re-referred and am awaiting an initial appointment- but this appointment has been rearranged 5 times with 3 different doctors in the space of a month. In the upcoming appointment, I'm having to go armed with research and clinical guidelines to really push for diagnostic tests (surgery to determine if I have endometriosis) and treatment because I can't bear being fobbed off with yet another form on contraception when I'm spending every day in agony. I asked my GP for this referral in January and it's taken until August to get an appointment because of having to wait for a STI screenings and then scan before a referral could be made. I have no idea how long the wait will be if I am referred for diagnostic surgery.

Story 2: "I could have saved probably 2 years of waiting, if I had just been given the right information"

I'll start at the beginning, which is going back to my teenage years. I noticed when I was probably 16 or 17 that my periods were very heavy, the pain was unmanageable, and I couldn't go to school if it was the time of the month. It wasn't just like have a hot water bottle and take paracetamol and get on with it. It was debilitating. I kept going to the doctors and my doctor at the time was an old man, probably a bit of a dinosaur – lovely, but as a young girl, you're more comfortable speaking to a woman. But at the same time, we often couldn't get those appointments, so my mum would encourage me to go and go through my troubles. I just kept getting told, "Oh, it's just women's problems," being made to feel as though I was a nuisance for being there, as if I was just being a hypochondriac. "All women have these problems, just get on with it, stop being such a wuss," and really I just wasn't listened to at all.

So then I just did, I put up and shut up and just dealt with the pain, from A Level time onwards, really. When I got my first job, I couldn't go to work on those days because of the pain, it wasn't just normal time of the month pain. And even when I went to uni it was the same thing. I went to a different doctor up in [city] and was still very much told similar things, just “get on with it”. I think it's changed a lot more recently. I think there's more awareness of it now.

[Q: Did they offer you anything like pain relief or contraception?]
Absolutely nothing. That was the only thing, at uni I was asked if I wanted to go onto the pill, but I'm very hormone sensitive so when I used to go on the pill, for want of a better word, it used to make me really emotional and angry. So I chose personally that the pill wasn't for me. It didn't mix with me. I was on it off and on, thinking it was the only thing that would help with the heavy periods and the pain. But it wasn't worth it for me. So ultimately in my early 20s I came off the pill completely.

I kept going back to the doctors, “this pain is just unbearable, is there anything else you can give me?” Because paracetamol wasn't cutting it. I was having to have the max amount of paracetamol and ibuprofen daily, for the period of four days. And it was just horrific. But even that didn't cut through. When I say about pain, I'm talking about having to run a bath at 3 o’clock in the morning and sit in the bath and take 2 paracetamol and 2 ibuprofen, crying, until I can sort of get it under control to reasonable amounts. And that was monthly. I couldn't do anything. It was horrific. That sort of carried on all the way through to my 30s.

Since we got married, we had tried to have a baby and that didn't happen. Year after year was going by and you just think, “Oh it'll happen, it'll happen.” We were thinking, “Oh, maybe we need to go and have some sort of fertility investigations,” then Covid happened and put a bit of a stall on it. We thought, “Oh, maybe it'll happen now because we're not stressed,” and that type of thing. So we started with, go to the doctor, explain that you've been trying for more than X years, it hasn't happened. Then they go, “Do all the blood tests,” and all my blood tests were fine. But what they noticed when I went for my first scan with the gynaecologist after that referral went through, was that I had a cyst on one of my ovaries, which was an endometrial cyst. And they also noticed from the scan that I had adenomyosis, which they call “the evil sister of endometriosis”. It's endometriosis that grows inside the lining of your uterus, like the muscles within the uterus and then they shed inside, in the wall of your uterus. So that explained why all these years I've been saying this isn't normal. I was just kind of made to feel like, “No, it is, you're just being a wuss,” but actually it’s adenomyosis. From my point of referral it took me about a year and a half to actually get to see the gynaecologist.

I suppose there were couple of issues, going into it. One was obviously the fact that I've never been diagnosed with this and actually, had the GPs taken me seriously in in the past, maybe this could have been treated earlier or I could have had at least maybe some pain relief. Because the first thing the gynaecologist said to me was, “Have you ever been offered pain relief for this?” And I explained then, “Well, no. Because every time I've gone to the GP, I just get told, ‘you're just being a nuisance. Basically, just get on with it.’” She straight away prescribed me [a medication] which reduces the amount you bleed and also codeine as well. She said to me, obviously they don't like to prescribe codeine willy nilly, but at the end of the day, for me to take two or three codeine once a month is a lot better than me taking so much ibuprofen. So I finally managed to get some tablets which actually have majorly helped me. All that I needed was for them to do an internal ultrasound and that's where they saw the cyst as well. That was a bit of a scare because they saw the cyst and they didn't know straight away – their feeling was that it was endometrial type cyst that would probably just disappear on the next cycle, which it did, but they couldn't be sure. So they had to send me in for a blood test for cancer markers, and actually that came back really elevated. So of course the whole of Christmas, I was petrified. The doctor was like, “Don't panic, because if you've got lots of inflammation in that area, that marker can be high anyway and can give you a false positive.” Thankfully when I went and had a scan two cycles later that cyst had completely disappeared, and then they knew it was an endometrial type cyst which can come and go, which then suggested I had endometriosis as well.

All these things impact your ovarian reserve as well. I suppose I felt really angry that this wasn't investigated at least earlier. Had I known I had endometriosis and adenomyosis when in my 20s and known the implication of that on fertility, it could well have changed my mind, rather than waiting till 35 to think about having a family. Not that it's necessarily impossible, but it's a lot harder now. Hence the IVF route. Had I have known, that's something I could have discussed with my husband and thought, “We're not ready for a family now, but actually I could have my eggs frozen” and would have had a lot more eggs to choose from than I have now. I think also there would have been different options. I know one of the things that can help with endometriosis is going on the pill, but it's almost too late an option for me now.

When I’d been passed on to the hospital for the referral for the IVF, I was talking to my GP and I said to her, “Please can you give me the prescription that the gynaecologist has recommended?” She looked and she was hesitant at first. She said, “Oh, she's prescribed you three things. Well, I'll just give you one of them for now and see how you go.” Bear in mind they all did slightly different things: the codeine obviously was the pain relief. The other one was to sort of make the bleeds light, and then the other one, she said, “This is like a very strong ibuprofen.” The idea was if I had them all, I could manage what I do. I wasn't just going to take them all, but she was so reluctant. I felt like even then I had to fight just to get the prescription that, within the blink of an eye, the gynaecologist just went “Right. You need this, that and the other.” Maybe that is because they are reluctant to prescribe opiates or things like that, but I had seen a specialist. Obviously, my GP didn't know a great deal about it, and she sort of very nonchalantly said, “Well, to be honest, the most ideal thing would be is if you just got pregnant, then the adenomyosis would sort of recover a bit on its own, wouldn't it?” And I just had this moment where I didn't know what to say, to be honest, because it was just like, “Well, yeah, obviously that would help. But I'm about to go through IVF, we put a referral through for me!” It just felt really insensitive.

My issue I suppose has been with the GPs. I just felt that they haven't listened or they’re just maybe not trained well enough in women's health. It seemed like I said she didn't really know what adenomyosis is.

Going back to when I was at that gynaecology appointment, so I'd waited probably a good year and a half from the point of getting the fertility referral from my GP to the appointment with the gynaecologist. After she prescribed me the sort of pain medications and things, I was literally told in that same appointment that “Oh, you're over 35. You're not eligible for NHS IVF treatment.” I sat there and burst into tears. I was with my husband and I'm in front of this lady and I'm trying to keep it together. I also thought she was joking at first or I'd misheard something. I was upset at first, but then afterwards I was angry because why had I even been put forward? Why didn't my GP say something?

I was 35 when I went to speak to my GP. Then I had all of the tests done. It was only after the tests were all done that then she put the referral through, and I was actually 36 at that point. Even at that point, she didn't say, “Oh, well, we can put this through. But in terms of the IVF NHS treatment, you're not actually eligible.” So I was told that, and I was devastated because we weren't really in a sort of financial position then to self-fund. It isn't cheap, especially with all the medications as well, you often you see the package prices online and they don't include the medications, so it’s often almost double the price of what you see online. So of course, I just felt in shock and angry and upset about a million things, you know, why wasn't I diagnosed with all of this stuff earlier? Why have I only just now found out that I'm not eligible in Oxfordshire for IVF? Which completely goes against the sort of the NICE guidelines, which say that women up to the age of sort of 42 can be offered IVF. I'm thinking, “I'm 36. I went to see my GP when I was 35. And you're telling me I'm too old? Isn't this what this is here for? For people like me, in my position!”

I got home and all of a sudden I was like, “Well, what do I do now?” So hence that's why the only option we really then had was to actually move [out of county]. In a way, it was lucky that we were just renting because it was easier for us then to sort of look geographically, where was close enough that it won't disrupt our lives with our families and things like that, but where we'll have access to IVF, obviously. So here I have two rounds of IVF on the NHS. It's a postcode lottery. That's what we're back to again, how in different areas people have such different access. Don't get me wrong, moving here has ended up being amazing and we love the house and I'm so glad we did move, but I would have rather have moved because I wanted to, rather than just to access healthcare. If we weren’t as financially secure we wouldn't have been able to, or even if we owned a house, to have to sell your home is not a quick process and not really the type of thing you'd want to do before IVF anyway, because moving is incredibly stressful.

When I finally got that appointment with the gynaecologist in Oxford, she said to me, “What’s your priority? Is it to solve your women's problems? i.e. help for the adenomyosis or the endometriosis, that type of thing? Or is it fertility?” And obviously at that point, it was like, “Well, fertility is my number one goal here.” And then I was told that, well, that road was closed anyway. When I then had my referral put through in [the county where I now live], the gynaecologist there is head and shoulders better in terms of the information I was given, compared to Oxford. She explained everything perfectly. I read journals on IVF now, so now I would know what anyone was talking about. But in that early stage I didn't, it was all very new to me. She explained it to me in layman's terms and I understood everything. But she also said to me, “There are other options.” Things like laparoscopy, so what they could have done was before I had IVF, they can go in with keyhole surgery to remove any endometriosis in the uterus, to clean out the fallopian tubes, things like that. So they could have done that, and she would have done that first. She said that would help with the endometriosis, that would reduce my pain and make my periods more manageable, all of those things.

I chose not to have that initially because there was a waiting list of just about a year to have that, and to pay privately was about £5000, which is just crazy. What she did do was a test to check my tubes and they were completely clear. She was then happy for me to just move on. But going back to when the lady in Oxford said to me, do you want to focus on? Because quite a lot of women, after they have a laparoscopy, actually end up falling pregnant naturally, because if there were tubal issues or because of the removal from endometriosis within the uterus can make it a nicer environment for an embryo to implant. I just felt really upset with Oxford because that wasn't explained to me. This was in the summer and by Christmas we had moved [out of county]. So that's six months. And then I was being told that even if I wanted this operation, it would be another year. So it's such a long period and we'd already waited a year and a half.

I just felt had Oxford have said to me, “Unfortunately, so sorry, you aren't eligible for IVF here, but what we can do is, we can do this in the meantime or we can put you on the waiting list for this surgery, because not only will it make your periods better and more manageable, but actually it can increase your likelihood of falling pregnant naturally as well,” and I would have jumped to that opportunity then, but I wasn't even told about it, you know, she didn't even suggest it. It was just a case of, “Oh, no, you're not eligible for fertility. That's what you said you wanted. Door closed. Goodbye.” So when [my new gynaecologist] explained all of this to me, I was like, “Well, why, why didn't they just tell me that?” Because in the meantime, I could have been on that waiting list. I felt sort of at every angle. I just felt like I was sort of not misguided or not told things or things weren't explained to me. When I went back to my GP and said to her, “Can you put in a referral to [another area’s service] because we're just about to move house?” and explained to her what had happened, she was like, “Well, what do you mean you're not eligible?” So my GP in Oxfordshire didn't even know the criteria and I just thought that was poor, because she might have gone, “Oh, I can see you're 35 now, but by the time the referral goes through…” I could have saved probably 2 years of waiting for IVF, if I had just been given the right information.

I’m much more aware now, but back then I was just going to the doctors, and I was just listening to them and going on their advice and thinking they know best, I didn't think to question or to query or to push for things. Like I said, the laparoscopy, I didn't even know that was an option. I just thought, “Oh, I've got these painkillers, that will help.” I didn't know there was an operation which would have really helped remove the endometriosis. I think personally, from my teenage years until now, I just feel like honestly, it's been an absolute nightmare, but I am lucky now that I'm sort of in the system. And the ironic thing is, since I've [moved out of county] - this is what just makes my head spin, I know it's about funding and all of that – I live [out of county] but the treatments my for my IVF, I travel to Oxford for. So I go to the same place, literally, that I would have gone if I was 34 in Oxford. The same doctors, the same nurses, the same embryologists.

[What has been positive about your recent experiences?]
I think just the fact that everything has just been really clearly explained to me from start to finish, my options have been outlined for me. It's very detailed. The gynaecologist could have just said, “Yeah, we'll just quickly pass you through. You

have a quick tube test, then get straight onto IVF." Everything was explained to me. She explained that, "However, if you have this operation, this might be good for removing the endometriosis. But it can further affect your ovarian reserve." For me that was something, so I decided to just do the tube test because it was quicker. Had the tubes have been blocked then I probably would have had to have taken a step back and then gone on the waiting list for the operation. I just think more transparency and I think also for the GPs to just be a little bit more in the know of the referral process, and I know they can't know every bit about eligibility criteria, but surely just age. I was just flabbergasted that my GP didn't know.

And in my gynaecology appointment, where I was given the choice, this door or that door. And I said "this door" and she said, "uh-uh, no". Nothing was then explained to me, like what other options I had in my situation. It was just a case of go away and think about it. There was no, "We'll give you a follow up for your other problems" or "we'll have a follow up call to see how you're getting on with the medications". Absolutely nothing. I just get my medications on prescription and that's it, just get on with things. There's been no follow up at all. When I moved here and my GP actually looked at them, I said to them, "Can you add these prescriptions?" and they literally just added all three of them without question, because they obviously looked at the specialist notes and thought, "This is what they think is best for her. They're the specialists." They didn't even question or query. Whereas in Oxfordshire, it was a fight just to get some codeine.

[Is there anything that would have helped you at any stage in terms of having access to information or anything?]
Even when I was told I had adenomyosis, I wasn't given a leaflet or told where to go or any sort of print outs. I had to come home and I didn't even know how to spell it. So it's only because I have the NHS app that I could quickly look on, go on and sort of see my consultation notes and go, "OK, that's what it is." And then I did my own research. But I just felt like I wasn't given anything like "You've got this, but don't worry. This is what it is. And this is how it happens. And these are the things we could do, these are your options." With endometriosis as well, I wasn't given, like, "These are the treatment options." I know that a TENS [Transcutaneous Electrical Nerve Stimulator] machine is supposed to be quite good for people who suffer with really bad stomach cramps or endometriosis. But I wasn't told about any of this. Just a little leaflet to say, do you have adenomyosis and endometriosis? Just like a primary school guide would have been alright, you know. But yeah, nothing, even from my GP. Because she didn't even know what adenomyosis really was. She was aware of it, but she didn't really know, she had to look into it.

[Is there anywhere that's been particularly useful as a source of information?]

There is a website which is geared around adenomyosis. I mean yes, there's a bit of blurb on the NHS website. I found a lot more information from assorted different websites. But there is definitely one that was geared around that cause they went into all of the options for treatment. But again that was only through research and things like that.

Like if I had just known about the laparoscopy, if I'd have just known about that years ago, if my women's issues would have just been looked into in my 20s, or in my teens, and they had realised and just sent me in to have a couple of scans. They would have known this. I could have had a laparoscopy years ago, or other things. I just feel a little bit let down, really. I chose to wait to have kids later, and that was my decision, and that's ended up slightly backfiring on me. But I just feel had these things been investigated, had I known that I had adenomyosis in my 20s, it would have changed how I thought about things. Rather than just being told, “No, no, it's perfectly normal, you know, not don't worry about it,” which didn't cause me to worry about it.

If I could advocate for other women, it would be, if there could be an advert on TV to go, “Don't just wait till you're 35, because actually all of these things could happen,” which I just don't think anyone knows about.

If I was just taken seriously and listened to, or had a GP said to me in my mid 20s, “OK, you’re having a lot of problems with your periods, if you're considering a family in the future, maybe we should get this checked out now, just to get ahead of the curve type thing,” it would have made such a difference to me and could be the difference between me ever falling pregnant and having a child or not. I just think if more women were made aware of those things it would be useful. Yeah, it's actually made me a little bit teary talking about it because it does make me just feel a little bit let down and that's the main word, it’s just “let down”.

Story 3: “Surgical menopause banged into me like hell”

I always had loads of problems with my period, quite a heavy period since I was a very young age. But I obviously never took much attention of that. When I had my youngest son, I experienced a totally different pain and it was always in one place. It was always in one side and I felt that was really weird. So the suspicions started that something was not normal, and I always constantly came to my doctor and said, “Look, I have something wrong. I have massive periods and I'm always with this pain on my left side.” But my doctor never paid attention to any of that, so it took me seven years to be diagnosed with endometriosis.

I don't think [my GP] knew. I think he ended up referring me when I was massively desperate, one day that I just said, “This can't happen anymore,” was when he sent me to the gynaecologist clinic at the JR and I had the first scan. That first scan showed loads of different things, and they thought it was cancer instead of endometriosis. So I had to do scans at different times of the month to see if the scans would show a totally different pattern, which they did so they immediately thought OK, this [must be endometriosis].

As I said, it took me probably 7 years to be diagnosed with endometriosis, of constantly going to the doctor and suffering. And not only that but having to miss work because I couldn't there were certain days of the month I couldn't literally come out of bed because the pain was absolutely terrible. It was so much, because literally, if I was standing, if I would move, I would literally be covered with blood. Possibly for a lot of women, what they think is period pains is not.

I had to go private because on the NHS, sadly no one was listening to me and in conversation with the with a friend, she said, “Oh, I have this amazing doctor at the Manor.” Because he was a specialist in endometriosis. I sent an email to his secretary and explained the situation, and she was quite sweet and said, “You don't need to come to private because the doctor is the director of the Endometriosis Clinic at the JR.” So she immediately put me through the JR without having to go through my GP and so on. I was diagnosed with endometriosis and adenomyosis or something like that. When I was diagnosed I was in stage 4 endometriosis. It was glued to my bowels, my bowel was covered, that's why I had the pain that I constantly had, that cycle of pain.

You might think, “OK, she was diagnosed and now it's fine.” But even being diagnosed, it took a long time. They started me on this hormonal treatment to see if it will be able to clear out and then they put me on the coil, and they put me on something in my arm to see if I would stop with my periods and if it would help. So it took probably three years to the point that I said “No, this is not working.” I was putting a lot of weight. I put maybe two stones on with that hormonal treatment that I was put on and it wasn't helping at all, I was still in pain to the point that the doctor said, “I think the best option is surgery.” But obviously you have to remove everything to be able to get rid of endometriosis and in some cases it's still not possible. Because it was so infiltrated already and my bowel and my cervix were glued together with endometriosis, there was the risk of me having to have part of the bowel removed, to be able to remove everything. But thankfully, no, they managed to take everything out and that bit was sorted.

I took the decision: “I have three kids, let's go for a total hysterectomy.” I had a total hysterectomy, and I got rid of the endometriosis and everything else. But then I started a massive surgical menopause, which banged into me like hell.

When I said, “this is not working. It's not working. What should we do next?” and they said, “The only option after this is surgery,” that was when came the question, “OK, what does surgery involve?” I don't think I ever had anyone saying to me, “Look, you're gonna remove your ovaries, but this is gonna happen to you. You're gonna massively bang into menopause.” I remember someone said, “You're gonna start on menopause,” but no one said what is menopause, what is gonna happen to you, to your body and to everything. For me it was a very light thing. I can take this tea or blah blah and that will support me with the symptoms. Oh my God, I was so wrong.

[Did you get any support with menopause?]
No, not at all. No support at all from the JR, from my GP, from the consultant. It took me a long time, because obviously having a surgery you can't start immediately on HRT and because it’s a surgical menopause you can't have just any HRT. So they put me on gel for the beginning, which wasn't working at all. I was still being followed at a clinic and at the JR, but he was always like, “Try this and see if it works,” you know? So the support wasn’t amazing. I read a lot. I researched a lot about endometriosis and the surgical menopause coming from that, and what could I do? What could I use and not use to be able to support myself? Because it was quite difficult at the beginning. I think it took me probably two years to be able to be in the situation that I am now - way more stable, but still very forgetful. I think the worst for me was the pain that I was feeling, quite a lot of pain in my joints, my wrists, my knees, the lower back. It was really crazy pain. It took me a little bit till I got put on the HRT that I am today. I was the one that suggested to the doctor, “Should I put my dose up?” So at some point I ended up going private.

I saw a specialist and they were the ones that really supported me and said, “Look. Let's do a blood test to see what is your oestrogen levels and all of that.” My GP weren’t really understanding me. The lack of knowledge about menopause was crazy. You would expect your GP to be able to support you with that, isn't it? But I think what really helped me was talking with the other women that were in the same situation as I was. So there's an amazing group on Facebook for surgical menopause, where you are able to ask questions and people really answer back and give their opinions and what happened to them and examples, and what should you take to support you with all the symptoms that we have. Because obviously natural menopause you start it, and you slowly feel everything, and new symptoms are coming. With surgical menopause it's automatic. It just bangs you, it literally just comes like “ooff!”

But I think the fact that I was able to talk with other women about it and reading a lot about it as well, the research and so on. At some point I felt I was getting mad, crazy, literally because my mood was absolutely horrendous. My family at that point really supported me. I'm much better nowadays, but I think the lack of knowledge that the GPs and everyone has is still a lot.

[Were you given any resources or information?]
No resources at all. I had friends saying, “Oh, ask your GP to go to the menopause clinic at the JR.” I’ve never gone to the menopause clinic at the JR at all, I don’t even know what it is. So it was just trying what is gonna work, what was working for me, what is not working, over the years, and yeah, I'm finally way more stable than I was. I still forget about things a lot, simple things like your name or my best friend's name. But yeah, I'm much better, I don't wanna scare anyone about what menopause is, but it's quite a challenge for women.

[Is there anything that you would want health services to know or anything that you think would have helped if it could be done differently?]
I think if they came, if they listened more to people actually. I know the training for them is not much, but at the gynaecologist clinic at the JR they should listen to everything because it's like we are constantly having to ask for things. And the fact that COVID happened, everything was on the phone, so there wasn't that personal one to one that you could really say to the person, “Look, I'm massively struggling with all of these.” So it's quite impersonal as well, isn't it? And obviously that is not their fault, it's the circumstances of what happened to all of us, but I really struggled with all of that, to the point that one of the times I said, “Look, this is not working. I really need to talk with someone and see someone and I don't remember the last time I saw anyone.”

And they even suggested that I should see a psychologist at the JR and to be able to be supported. I was like, “Why do I need to see a psychologist? I don't think I need a psychologist.” I said several times, “Look, this is not in my head, this is clearly happening to me.”

I don't think we should have to be going private or paying a private specialist in menopause to be able to be diagnosed with or to be able to be supported with whatever HRT we need and so on. I think there's quite a lot of people who struggle in the same way I do, and obviously the fact that we now can't have an appointment with our GP as easily as it used to be, it was even more complicated. I moved house three years ago and I have never met [my GP]. It’s been everything on the phone. It's just the fact of being able to have an appointment with the same person, that is so important, isn't it? Because you develop that relationship with them. You have one GP available today, if you see one tomorrow you see a different one and it tends to not be personal anymore. It's just like they see you as anyone else that comes in through the doors, isn't it? So, yeah, that's different. But I think something that we're gonna have to learn to deal with, isn't it?

There's always questions, if there's a different symptom that comes, which is always happening, or if you are very itchy, “Why am I very itchy?” It's things like that, you know, “Is it normal to be itchy?” You end up Googling it, which can be quite bad. As I said, this menopause support group on Facebook, it was lovely because you could actually ask, “Are you feeling the same thing, is your scalp really itchy?” Or suddenly you develop these rashes all over the place and you don't know why, and the doctor looks at you like, “Oh, that's an allergy.” But it’s an allergy that you suddenly just started to your deodorant that you've been using for years. It's things like that that we obviously need to learn to live with and understand our own body in a totally different way. But yeah, I'm pretty sure for some women it's way more complicated, mentally especially. The fact that I put a lot of weight on, that struggle that I had at the beginning of, I don't like to see myself like this and so on. I think I learned to love my body in a totally different way.

But then there's loads of questions of, “Till when I'm gonna be in menopause. Till when I'm gonna have to have HRT?” I have no clue. I don't know. I don't know still how long am I gonna have to have it or am I going to ever stop having symptoms?

For quite a long time the [HRT medication] was totally out of stock. Which for me in my case was a good thing, because I ended up being changed to a totally different one, which worked better for me, which was the patches. But then obviously the pharmacist will not change it for you, it needs to be the GP doing it. But then for you to be able to see the GPs, it's quite a difficult thing. I was lucky that one of the GPs who was on that day said, “Oh, I can see that woman,” and she was one that changed it for me and the pharmacist gave me the new HRT. Because otherwise I would probably go without it.

But there's always this trial of, “Oh, try this one and see if it works. Let’s try this one and see if how you feel, if you feel well or not with it.” Even having a test to see how are my testosterone levels. A lot of people tell me, “Oh you if you had testosterone, you probably will feel much better.” We always have to seek to try finding new alternatives and new answers for the symptoms we have. I did ask several times [to have my hormone levels tested] and they said, “Oh yeah, but you know, the levels can change depending on the day and the time of the day.” And I said, “OK, so maybe we could try different dates, different times?” but then obviously that's a cost for the NHS.

If I ever want a clear answer, I'll have to go and pay £200 to be able to be seen, which is not affordable, is it? A very good friend just started with crazy symptoms. And I said, look, “If you want to be diagnosed and if you really want to know what is going on with you, I think you're gonna have to go private, unless you're very lucky to have a GP that listens to you and really understands what is menopause." I think if it's a woman it is easier. I think women pay attention in a totally different way that men don't, and most of them don't have a clue what menopause is.

[Has that been your experience than when you've seen a female GP?]
Yeah, I think they listen to us in a totally different way, especially if they are a little bit older, they've probably gone through it.

Appendix 2: Background

Why women?

Although women generally live longer than men, they spend more years in ill health, and are more likely than men to have experience of living with lower back pain, depression, headaches, musculo-skeletal disorders, dementia and HIV.[5] This has a significant negative effect on the UK economy[6], as well as, more crucially, the wellbeing of women, girls and people who use women's health services.

Women and people who use women's health services are more likely to need medical help in the ordinary course of their lives – for things like contraception, pregnancy and around the menopause – as well as when they are ill. They are also more likely to be caregivers and support those they look after to get help from health and care services. They often play a key role as connectors, sharing health information with others.[7] Healthwatch Oxfordshire hears from more frequently from women than from men – but what we hear is rarely about women's health services, and more often in relating to caring responsibilities for someone else e.g. a child, partner or parent.

However, there are significant health inequalities experienced by women and people who use women's health services. Five key inequalities are around:

- **Access to women's health services**, particularly gynaecology. This was highlighted by the parliamentary Women and Equalities Committee's report, *Women's reproductive health conditions*, published in December 2024.[8] Waiting lists for gynaecology appointments doubled between February 2020 and November 2024,[9] with a 'devastating impact' on women waiting for care.[10] Increasing numbers of women are turning to private

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[5] Guardian article on Lancet report: women live more years in ill health than men, May 2024

[6] NHS Confederation article: The economic case for investing in women's health revealed, October 2024

[7] Kings Fund podcast: What women want – addressing women's health inequalities, March 2022

[8] Women and Equalities Committee report, *Women's Reproductive Health Conditions*, December 2024

[9] BBC article – 'Gynaecology waiting lists double, leaving women in pain'

[10] RCOG press release about their report on the "Gynaecology care crisis"

providers for treatment, and costs of private hysterectomies have soared.[11] Demand for contraceptive and other reproductive services is likely to continue to grow over the next decade, as women become sexually active earlier and have children later than in previous generations.[12]

- **Lack of training in women's health issues** and **unconscious bias** in how women are treated by health and care services – meaning that women are not always listened to or their pain or symptoms are not taken seriously. The Birth Trauma Inquiry found that "Women complained they were not listened to when they felt something was wrong, were mocked or shouted at and denied basic needs such as pain relief."[13] The Women and Equalities Committee highlighted a "clear lack of awareness and understanding of women's reproductive health conditions among primary healthcare practitioners."[14] This can discourage women from seeking help, particularly for non-urgent but debilitating conditions such as some perimenopausal symptoms.[15]
- Historical and ongoing **bias in medical research**, meaning there are gaps in understanding of women's health issues and around diagnosis and treatment of other conditions in women and people who use women's health services, such as diabetes and heart attacks.[16] Some steps are being taken to reduce this gap. For example, in Wales, a new Women's Health Research Centre, supported by Welsh Government funding, is due to open in 2025.[17]
- Access and **barriers to cancer screening**, such as cervical screening (smear test) and breast screening (mammograms). In 2024 the NHS launched a campaign to encourage greater uptake of cervical screening, with reports that 5 million women and people with cervixes were not up to

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[11] Guardian article – 'Women paying up to £11,000 for a hysterectomy amid NHS delays'

[12] Faculty of Sexual and Reproductive Healthcare report 'Fixing the System: Reducing Women's Reproductive Inequalities'

[13] BBC news article about Birth Trauma Inquiry: 'Poor maternity tolerated as normal, inquiry says', May 2024

[14] Women and Equalities Committee report, *Women's Reproductive Health Conditions*, December 2024

[15] Katie Barber and Alexandra Charles (2023) 'Barriers to Accessing Effective Treatment and Support for Menopausal Symptoms: A Qualitative Study Capturing the Behaviours, Beliefs and Experiences of Key Stakeholders.' *Patient Preference and Adherence.* 17: 2971—2980.

[16] Alice Witt, Kate Womersley, Sophie Strachan, Jane Hirst and Robyn Norton (2024) Women's health needs beyond sexual, reproductive, and maternal health are missing from the government's 2024 priorities. *British Medical Journal 384*: *q679.*

[17] National Health Executive article – 'Women's health research gets major boost', February 2025

date with their cervical screening, which usually takes place every 5 years from ages 25-64.[18]
- **Intersections of gender inequality with other factors**. There is a growing recognition that women from ethnic minority backgrounds are more likely to experience health inequalities and face additional barriers to getting the care they need than their white counterparts. For example, in 2021-23, maternal mortality rates were twice as high for Black women as for white women.[19] Similarly, Black women experience endometriosis at the same rate as white women but receive a diagnosis 50% less frequently. [20] People from ethnic minority backgrounds may also be more likely to experience some gynaecological conditions, such as fibroids.[21] Other kinds of inequality, such as socio-economic inequality and disability, can also affect different women's experiences.

What is happening?

Recent years have seen a growing public and policy awareness of the need to tackle gendered health inequalities. This has included some strategic direction:

2020	Community Gynaecology service Oxfordshire pilot commenced Jan 2020 in Oxford City with expansion to whole of Oxfordshire at the end of 2020
2022	10-year ***Women's Health Strategy for England*** Launched. Aim to improve health outcomes for women and girls and "radically [improve] the way in which the health and care system engages and listens to all women and girls."[22] The strategy aimed to take a 'life course approach' and ensure joined up working to support.
2023	Integrated Care Boards (ICB – commissioner of health services in their area) in England funding to pilot **women's health hubs**, to bring together services for support with heavy periods, menopause, prolapse and incontinence, and contraception.[23]

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[18] NHS England press release: 'NHS makes fresh uptake appeal as five million women not up to date with cervical screening', November 2024

[19] Kings Fund long read: The health of women from ethnic minority groups in England

[20] Faculty of Sexual and Reproductive Healthcare report 'Fixing the System: Reducing Women's Reproductive Inequalities'

[21] London School of Hygiene and Tropical Medicine webpage: Findings from the 2023 Reproductive Health Survey for England published in the British Journal of Obstetrics and Gynaecology

[22] UK government – Women's Health Strategy for England, 2022

[23] Healthcare Leader article: 'How ICBs are setting up women's health hubs', October 2024

2025	• NHS England announced a roundtable on 'procedural pain' in Spring 2025, to reduce the number of people experiencing pain during hysteroscopies, cervical screening and other procedures. • The Department of Health and Social Care may introduce pain as a new measure for patient experience, based on the findings of the Women and Equalities Committee's report.

2025	• March 2025, the current government also recognised that "much more needs to be done to support women with reproductive health conditions, particularly around:
	  • listening to women
	  • improving information and education
	  • improving access to healthcare services"[24]
	  • BOB ICB developing local women's health strategy

As the NHS 10 year plan is developed, along with a move to **'neighbourhood health'**, there is potential to develop more joined up ways of supporting women and people who use women's health services, for example with focus on care closer to home, integrated care, prevention, and using technology to help monitor symptoms as part of the 'digital shift'.[25]

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[24] Government Response to the Women and Equalities Committee Report on Women's Reproductive Health, March 2025

[25] See, for example, King's Fund blog on potential for digital shift to support women

Appendix 3: Women's health services in Oxfordshire

- **Gynaecology services** at Oxford University Hospitals – these include:
    - Colposcopy and vulval clinics at the Churchill Hospital
    - Specialist clinics including endometriosis, menstrual clinic, menopause and early menopause, pelvic pain, Polycystic Ovary Syndrome (PCOS), post-menopausal bleeding and hysteroscopy, recurrent miscarriage at the John Radcliffe Women's Centre
    - Gynaecology Day Surgery Unit at the John Radcliffe Women's Centre
    - Early Pregnancy Assessment Unit at Rose Hill Community Centre
    - Oxfordshire Sexual Health – services available at clinics across the county
    - General gynaecology clinics at the John Radcliffe and Horton hospitals
    - Oxford Rose Clinic for women with female genital mutilation or cutting (FGM/C), at the John Radcliffe Hospital
    - John Radcliffe Fertility Clinic
    - Gynaecological Oncology and breast cancer care at the Churchill Hospital

- **Community Gynaecology Services** – intermediate service provided by Principal Medical Limited, access by referral from GP

- **Cervical screening**, commissioned by Public Health and provided at GP practices across the county

- **Breast screening** provided by Oxford University Hospitals at the Churchill Hospital and mobile units across the county

- **Community pharmacies** and **Pharmacy First** provide some treatment and support including access to emergency contraception and treatment for uncomplicated urinary tract infections (UTIs) in women aged 16-64

Appendix 4: Additional data

What stops you from getting the help you need?

We asked people who responded to the online survey about what reasons might stop them from getting help with a women's health issue (see Figure 7 below). Just over a fifth of people (65 people, 21%) said that 'nothing' would stop them from getting help with a women's health issue. The most common barriers people told us about were around appointments: not being able to get an appointment at a time that suits them (89 people, 29%) or finding it difficult to get to the appointment (72 people, 23%).

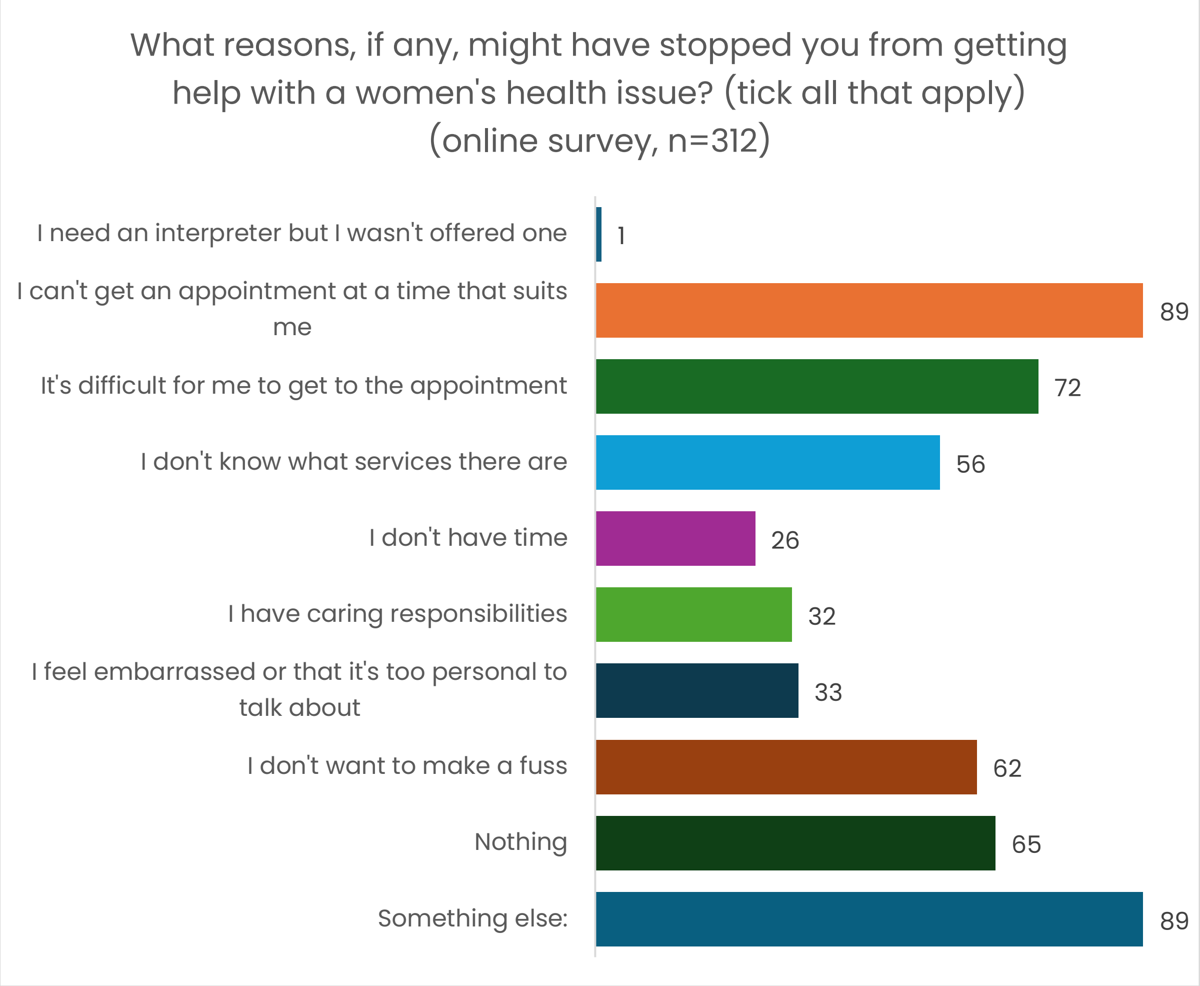

Figure 13: Bar graph showing responses to online survey question about what reasons might have stopped people from getting help with a women's health issue (n=312).

Other common barriers included:

- Not wanting to make a fuss (62 people, 20%)
- Not knowing what services there are (56 people, 18%)
- Feeling embarrassed or that it was too personal to talk about (33 people, 11%)
- Having caring responsibilities (32 people, 10%)
- Not having enough time (26 people, 8%).

Importance of face-to-face appointments

> *"Sometimes it is hard to put symptoms into words online and explain where and how pain and discomfort is and feels. When I was seen face to face, out of hours, I felt there was a better understanding, and it was easier to explain (by showing exactly how and where problems were)."* (online survey)

Positive impact of convenient appointments and home visiting

> *"There has been a huge difference in health visiting between pre and post covid, it's slowly improving again. This puts more burden on the NHS. I didn't take my daughter to the GP for 3 years because the Health Visitor was regularly visiting my house." (feedback from Oxford Community Champion)*

Emotional, social and cultural barriers

> *"Worries about bothering health services so don't follow up."* (online survey)
>
> *"It can feel embarrassing, I am an autistic woman and some of the questions that get asked and asked again about the possibility of STIs or pregnancy are embarrassing when I am not sexually active- I feel like a weirdo."* (online survey)
>
> *"Ability to speak to a GP and get an appointment. When you are menopausal you are suffering from so many things and simply running out of energy to keep ringing for help."* (online survey)
>
> *"I would like to book an appointment but I'm nervous about how I'll be treated."* (online survey)

Getting referrals to specialist services

> *"Going round in circles/ having to tick every separate box repeatedly before GP's will consider a referral elsewhere- yet they aren't doing anything about the issue in the meantime."* (online survey)
>
> *"It is very difficult if you go to GP and try to get a referral to a specialist."* (online survey)

"I was referred to community gynaecology in the first instance via the phone. It felt like they were reading from a script 'oh yes this is normal - if it continues for another 12 months we'd perhaps do something'. I had to cry before they referred me to the Menopause Clinic who at least understood I had to work, I had migraines and 3+ weeks of heavy bleeding probably was problematic." (online survey)

Experiences of care

Getting help and support

"I have repeatedly told clinicians involved in my care that I want to have conversations about trying to conceive (but I have a long-term health condition which complicates this). I have personally not found it possible to get support for this and services only appear to be geared towards identifying and addressing acute crises." (online survey)

"There are no alternatives being offered. I'm not stopping myself getting help, the system is stopping me getting help." (online survey)

"*A few years ago I went to my GP about possible Pre Menstrual Depression Disorder. It took a lot of courage to make and attend the appointment. My GP did no tests or examinations, told me there was nothing they could do and sent me away with a suggestion of buying evening primrose oil. I was devastated."* (online survey)

"I was also told to go to a health food shop and try red clover supplements by a menopause specialist nurse." (online survey)

Listening well and making every contact count

"My second birth was much better as I did feel they listened to me more, and I got the water birth I wanted first time - my midwife then was amazing." (online survey)

"You get a say, you are not pushed into any decision and are given time to think about it." (online survey)

"When I have an appointment, they take the time to listen to me and refer for further help as appropriate." (online survey)

"Amazing to have a menopause nurse and GPs who take female issues seriously." (online survey)

"My GP was lovely and really took the time to listen and try and help. She made me feel like I wasn't wasting her time/faking it etc like some health professionals can." (online survey)

"The clinicians I spoke with were caring and compassionate. They listened to my concerns, and even the less major ones such as side effects to medications that are uncomfortable rather than extreme." (online survey)

"The care and interactions with health professionals were all exemplary. They anticipated my needs, involved me in decision making, were empathetic and kind." (online survey)

"The nurse who fitted an IUD for me suggested oestrogen when I'd not really considered myself to be perimenopausal yet. She asked a lot of questions and really listened to what was going on for me and was very helpful." (online survey)

Not feeling listened to or taken seriously

"Every time I have been to the doctor I have felt that my symptoms are not bad enough to seek help." (online survey)

"My last appointment was my best yet and was immediately listened to, and helped. Even booked me an ultrasound to check up on me. This needs to be the case every time. Otherwise we feel unheard and don't bother to go then things get worse without help." (online survey)

Being told that pain or other symptoms are normal

"My daughter always misses school because of her period, it's not like me or my other daughter. The GP said to give paracetamol and do exercise but it's not made her any better." (feedback from Oxford Community Champion)

"I have been suffering abdominal pain, had to go through a sexual health clinic first before I got referral for ultrasound. At the sexual health clinic male doctor suggested pelvic inflammation as an effect of 'overexcitement'. Then had to wait 3 months for ultrasound that detected a uterine fibroid." (online survey)

"GPs always act like you're just making it up. even if you have things like unexplained weight loss that if evident, they're like oh it's nice to not be overweight." (online survey)

Feeling dismissed because of age, weight or other factors

> *"Please be more aware that some people […] might not be sexually active, or have ever been sexually active, and […] explain what that means in terms of things like HPV / cervical cancer risk. People sometimes seem baffled about this and my first smear test was a really unpleasant and upsetting experience because I felt the nurse didn't seem to get why I was there or why I might have made the choices I have."* (online survey)
>
> *"I was referred to gynaecology 2 years ago after 10 years of menstrual problems. I've had 3 previous referrals to gynae in that time. Every time, they do an ultrasound, find some abnormalities, then tell me that because I'm a young woman I should just wait for things to settle and try a different contraceptive. This means I've been on 7 different forms of contraception, none of which work to resolve my symptoms. I feel I'm being dismissed because of my age and not being heard when I tell clinicians how debilitating this is. […] I think they only way I can get people to listen is to say that I'm trying to conceive."* (online survey)

"Too young for menopause"

> *"Have also been experiencing perimenopause symptoms. GP says I am too young and closed down the conversation, despite sonographer at hospital appointment suggesting I might need HRT and to see my GP."* (online survey)
>
> *"Said I was too young to be experiencing perimenopause symptoms despite me experiencing lots of symptoms consistent with perimenopause."* (online survey)

Having to advocate for yourself or do your own research

> *"In 2021 I had been struggling with undiagnosed health symptoms for a number of years and was having frequent contact with 111, 999 and A&E due to not being given any answers for what could be causing these symptoms. I did my own research and came across the term [for my condition] online. I booked a GP appointment with my doctor at the time and showed up with two pages of notes explaining why I thought I might have it and asking to be referred. My GP simply said no and blamed it on hypochondria which was the only diagnosis I had regarding my physical health at the time. After 4 more years of relentless hospital visits and doctors' appointments where my symptoms were dismissed and blamed on anxiety, I finally received a diagnosis for [condition] last week. Had my doctor listened to me all those years ago it would have saved me a lot of*

time, energy and trauma." (Feedback submitted to Healthwatch England about an Oxfordshire GP practice)

"Prenatal care was good however I had a short period of poor mental health during that time and was advised to self-refer. I felt I needed someone to advocate for me instead of leaving me to reach out myself after already reaching out to midwives." (online survey)

Limitations of tests currently offered by NHS services

"I went privately and had an MRI which diagnosed cancer. I had the result of the hysteroscopy at the same time as the MRI result. [The hysteroscopy] was clear and I was being discharged. Had I not gone privately for an actual consultation my ovarian cancer would have been missed and given the appalling survival rate for ovarian cancer my health and potentially life could have been very severely impacted." (online survey)

Having to advocate for yourself or do your own research

"I was prescribed HRT but I had to ask for the Bijuve pill which suits me better as an older woman & met some resistance at first but after bad experience with the progesterone pill & oestrogen gel - I was experiencing severe vaginal irritation & was told to use more gel which made it worse - I was finally 'allowed' to have the one pill which has been 100% better." (online survey)

"In terms of the GP care I have received around self-diagnosing my auto-immune issue, I often felt very stuck - they were unwilling or unable to take my symptoms seriously and take further action but they also seemed unwilling to accept and work with the actions and evidence I had been working on myself (several years of food, symptom and medication diaries plus results from tests that I had ordered privately)." (online survey)

"My experience of a gynaecological issue I sustained during childbirth was never taken seriously. I had to chase for someone to pay it due attention and by then I was told they wouldn't offer corrective surgery. I felt disregarded and the fact it was birth trauma was ignored. I have had to persevere with this for a second opinion due to the functional limitations it has for me." (online survey)

"Re Perimenopause, there is a long list of symptoms I have learned from books such as Davina or I've just finished Dr Newson's Perimenopause and Menopause book. So many ah-ha moments following a few years of using up NHS time on individual symptoms." (online survey)

“The lack of understanding of women’s health conditions”

> *“GP was sympathetic, understood my concern, but couldn't do anything to help me understand why it had happened and if it might happen again because it had already ended.”* (online survey)
>
> *“The GP did not have sufficient knowledge of contraceptive options and their impact on PMT and peri menopause to advise me. The sexual health clinic telephone advice was better, but I still didn't feel that there was a lot of expertise related to PMT. Finally, I saw a consultant in a sexual health follow up clinic who gave the most individualised advice.”* (online survey)
>
> *[Q: What would help?] “More understanding in the urology department of Interstitial cystitis and bladder pain syndrome. A female consultant, not just men who specialise in prostate cancer.”* (online survey)

Informed choice

> *“I asked my GP to help with getting a vaginal ring pessary fitted. She was very understanding and prescribed various types of pessary of different sizes for me to bring along see which fitted me.”* (online survey)
>
> *“For my first time experiencing labour and birth it was made such a positive experience. The care team were absolutely amazing checking on me every 15 minutes or staying with me to labour through. Offering positive encouragement and plenty of tea and toast if that’s what I wanted. I was able to take control of my choices. Afterwards the care team was amazing and because of this we were able to go home 5 hours later - again this was our choice made possible by them.”* (Feedback centre review)

Other sources of information and advice

We heard about the role that community groups, both online and locally, could play in supporting people with women’s health issues, particularly menopause. We also saw this in action at the Oxford Community Champions meeting we attended. One woman was drinking star anise and sage tea, and explained to the other women that it helped with perimenopausal symptoms: “It is good for estrogen and makes you calmer”.

> *“Talking to other women - comparing symptoms - comparing treatments - reading books, blogs and webpages by women with lived experience and/or health care training.”* (online survey)

> *"The internet and special interest groups have been a life saver for me. Hearing so many other people's similar stories and reading books and books on these subjects has helped me understand what I can do to support myself."* (online survey)

Waiting for referrals, appointments and results

> *"First tried to get GP appointment, only slot was two weeks away. Was directed to Oxford sexual health who also had no appointments but suggested a clinic at the JR where I would have to turn up an hour before opening to even potentially get a slot, and could be waiting for several hours on a weekday to be seen."* (online survey)

> *"I was experiencing perimenopausal depression and palpitations and it took 12 months to be put on HRT. Because I wasn't having hot flushes peri menopause was not considered as a cause for my worsened depression. I was sent for a battery of heart tests which whilst reassuring took a long time."* (online survey)

> *"Booking the appointments, waiting to receive letters which had to be chased, and referrals which had to be chased was ridiculous. It felt archaic and open to serious mistakes."* (online survey)

> *"I had a miscarriage and they don't want to see me neither to do a scan to check what my current status is. Basically I had a miscarriage and their answer is to rest. If I continue to bleed heavily maybe to contact them."* (Feedback Centre review)

> *"I had to wait for an appointment so long my issue just stopped by itself after six/seven weeks of bleeding."* (online survey)

The impact of waiting

> *"My daughter had a tummy ache for two years, she was told it was her period. She's been on a waiting list since December last year and the appointment is in December this year. They just gave her paracetamol. When we went to A&E they said they could put her on hormones but I wasn't sure about that as she's only 13. It's disruptive to have to go to [hospital] when her school is in [another city] – but the GP sent her there because of issues with [hospital] not sending the test results, and I'm a migrant woman so I just take what I'm given."* (feedback from Oxford Community Champion)

"My daughter has endometriosis and adenomyosis. She had a Mirena coil fitted to help with her symptoms, on the advice of a specialist, who also said that when she wants to start a family, she can have it removed. Now my daughter wants to have it removed, but her GP says it has to be done by the sexual health clinic, and there is an 18-month waiting list! My daughter would never have had the coil fitted if she had known she would have to wait 18 months to have it removed." (signposting call)

Waiting well or not having to wait long

"The wait list for my first appointment to address my pain (now diagnosed as vaginismus) was around two years on the NHS. Oxfordshire Sexual Health were fantastic in that they could start to address my concerns straight away and the wait list for full therapy was a year." (online survey)

Joined-up, holistic and person-centred care

"I am non-binary and have panic attacks [so] I had to have a [procedure] done under general anaesthetic. All the staff on the day ward were considerate, friendly, sympathetic, and treated me with respect." (online survey)

"I had a really difficult journey through several miscarriages. I was very grateful to have access to the Early Pregnancy Assessment Unit and really appreciated the fact that this was separate from the main maternity care pathway. The staff were incredibly sensitive and caring, it was clear they understood that patients were facing anxiety and uncertainty and spoke with this in mind, e.g. unlike in the main maternity care pathway where the expectation is that you will be joyful and excited. It was also clear that there is specialist expertise in dealing with miscarriage which is very reassuring." (online survey)

Lack of person-centred care

"I would prefer not to be in a clinic with women who or are either pregnant or trying to get pregnant. I have never wanted children and it is frustrating to hear nothing else."

"The pre-op team said I could stay in for a few days after my hysterectomy because I had no help at home. The post-op surgical team sent me home the day after my operation even though they knew I had no help." (Feedback received by Healthwatch Oxfordshire at Didcot Play Day)

"Having had both my fallopian tubes removed at a very young age due to endometriosis - I get fed up with being asked 'is there a chance you could

be pregnant' or a pregnancy test being carried out without telling me. There should be somewhere on the health record that states my medical history above so that these questions cannot be asked and avoid any upset." (online survey)

Lack of joined-up working

"There is a real disconnect between sexual health services, who I initially approached about my symptoms, primary care and gynaecology services." (online survey)

"Conflict between hospital and GP about information and testing and I ended crying when it was not my argument." (online survey)

"I wish that maternity services were better integrated with Oxfordshire Breastfeeding service." (Feedback received by Healthwatch Oxfordshire at Didcot Play Day on 22nd June 2024)

Symptoms being treated in silo

"I felt that every issue I had was attributed to pregnancy and miscarriage, even when the symptoms were unusual - it seemed the preference was to believe that I was imagining them or overreacting rather than consider that there could be something else to investigate." (online survey)

"Treat the whole body - I'm very happy that the NHS offers regular cervical cancer screenings, but why isn't there a full exam of things like hormones, which have a massive impact on women's health. Also, as someone who, because of birth control, hasn't had a period in over a decade, it would be helpful to have some way of telling where in my menopause journey I am. But the only question asked is 'when was your last period?'" (online survey)

"I find dealing with GPs or even gynaecologists on these issues soul destroying. 10 mins with someone who only ever wants to talk about 1 symptom at a time is infuriating. Weight gain is a symptom of a much wider issue and if I have guilt weight shaming turned on me one more time by a GP, I think I might explode." (online survey)

Lack of follow-up

"It took two years for GPs in my health centre to listen to me and my symptoms, even to do basic needed tests to treat my migraines and hormonal fluctuations (which still are affecting me in various ways- premenopausal symptoms). I had to really insist that I was not well and

keep asking for appointments to be listened […] GP only insisted that I took antidepressants (for two years was the only option offered). I even tried some of them but still the GP didn't even follow up on how I was getting along." (online survey)
"My initial contact was very positive and I felt my concerns were listened to however I have never received any feedback from the scans I was referred to." (online survey)

Finding alternative sources of support

"I have used other self-help that I have found on the internet." (online survey)

"I saw reviews for herbal supplements online and tried these. They seem to work, though I still don't know what's happening to my body." (online survey)

"Still finding my way in adjusting the HRT by myself (GPs gave the general guidance but does not offer follow ups if I don't insist on telephone appointments). HRT and some medication for migraines is what I am taking now. Still, I don't feel 100% well." (online survey)

"I was concerned that my HRT wasn't the correct strength. I therefore discussed it with a male GP who increased the dose. After one month a wasn't feeling very well so I stopped taking the higher dose and started to feel okay again. I did not return to the GP to discuss the initial problem as I didn't feel that the GP's had enough knowledge to help me any further." (online survey)

"I ended up having to save money and go privately because I could never get an appointment with the GP specialising in women's health." (online survey)

"Significant gynaecology problem that went undiagnosed for 10+ years despite repeated GP consultations. In the end, I had to seek private treatment which resulted in major open abdominal hysterectomy." (online survey)

Sexism

"I have had a doctor call me a 'delicate little flower' and said I couldn't handle the medication another doctor said I should go on." (online survey)

"My experience was not the same as for the men who came to A&E with a similar issue. I really had to push to get the care I needed." (online survey)

"When we were having infertility investigations at the JR, the consultant asked me if I was really trying hard enough to get pregnant because sometimes professional women just don't make the time. We had been trying for 3 years, and had made that a priority before seeking investigations. I refused to attend any further infertility appointments without my partner because I knew they wouldn't say something like that with him there." (online survey)

"Told I'm tired because I'm a "working mother". I don't expect any fathers get told they're "doing too much" by trying to have both a job and children." (online survey)

"A year ago my partner enquired about being referred for a vasectomy and the GP asked him why his wife just wouldn't take the birth control pill. This made him very uncomfortable. He hasn't received the service and as a result, I don't believe our contraceptive needs are managed." (online survey)

"Always feel unsafe and talked down to by male staff." (online survey)

"I have had mostly positive experiences of healthcare within the last year, with a noticeable improvement in doctors' attitudes towards women's health." (online survey)

Caregiving responsibilities

"Women are often the primary carers for children. Our younger generation are struggling with mental health challenges which has a significant impact on women's mental health - to improve access to CAMHS for young people would have a positive impact on women's mental health too." (online survey)

"I am the power of the house, who will look after me if I fall?" (feedback from outreach with Refugee Resource women's group)

"I go to Connect Health. I was told, "We are full, no appointments." They asked me to go to another site – but I don't drive and can't afford a taxi and need to pick up my children from school." (feedback from outreach with Refugee Resource women's group)

> *"Being offered face-to-face meetings instead of always on the telephone for a brief time that never allows me to speak fully about my needs (as distinct from my husband's)."* (online survey)

> *"I feel my mental and physical health needs as a full-time carer of someone with a serious and challenging disease are being ignored. Sometimes I feel completely alone and abandoned. The system needs to improve hugely on this front."* (online survey)

Menopause

> *"No-one told me about the menopause until I came to women's group and learned about the symptoms. Before menopause I used to say "my period, what time will it finish? I want to fast in Ramadan." But now I say, "I wish my period would come back!""* (feedback from outreach with Refugee Resource women's group)

> *"I have a good relationship with my doctor, and I could talk to him about my menopause quite easily."* (outreach survey)

> *"I'm in my 50s. HRT keeps me sane. I know several women who suffered as they entered the menopause and were put on various antidepressants rather than HRT because they thought the symptoms of menopause were restricted to physical changes like hot sweats and weight gain. Proper nurse-led support groups at GP practices would stop people doing all their research on facebook!"* (online survey)

> *"Menopause is dehumanising… If men went through it, more money would be made available to research & treat."* (outreach survey)

> *"With post menopausal problems I'd have liked to think there was some help available other than just having to live with hot flushes etc. There is a menopause clinic run by Dr Katie Barber in Oxfordshire but nobody seemed to know anything about this. I felt I was dismissed somewhat brusquely when I raised the idea of treatment."* (online survey)

Screenings and procedures

Positive experiences

> *"My visit to the breast clinic at the Churchill hospital for a 2 week wait appointment was managed professionally and compassionately by all of the staff. I had an ultrasound, a mammogram, a 3D mammogram and a*

biopsy and finally saw the breast physician who explained the imaging results and the next steps and crucially reassured me." (signposting call)

Negative experiences

"More dignity required. We are asked to undress to the waist down then walk around as if it's normal to be around strangers baring your breasts." (online survey)

"There was little privacy. Instructions for an insertable anaesthetic were given loudly in a corridor outside a loo that had not been flushed, I felt rushed. No leaflet telling me what to expect was provided. The consultant barely engaged with me at all prior to performing the procedure other than to express irritation that I was tensing all my muscles. The nurse present tried to engage me so as to help me relax. The consultant dropped part of the instrument on the floor. She did not explain what was happening, the consultant spoke very quietly and did not make eye contact with me, this increased the difficulty as I could not hear her instructions or tell if she was talking to me or the nurse. She did not make eye contact on ending the session. The results took 2 months to reach me." (online survey)

Painful procedures and a lack of pain relief

"Automatically offering better pain relief for every single woman attending for a hysteroscopy. Gas & air would be a good option, and is offered in other hospitals routinely. Sedation would be another option if a general anaesthetic is not recommended." (online survey)

"I had to have three hysteroscopies and the final two they failed to get sufficient cells. I was also told I should have done the final one without anaesthesia even though I had tried that and been unable to complete it due to pain." (online survey)

"I had a colposcopy that was a horrendous experience, when the results came back as unknown, I asked them for anaesthetic, when asked to have a womb biopsy, I also opted for general anaesthetic. I believe this should be offered at the very first opportunity because the cervix and the womb are very sensitive areas. I believe this would be very different for male patients." (online survey)

"The ultrasound procedure happened very quickly; I hadn't realised that I would have an internal ultrasound as well as an external one, which put me in the position of having to disclose the potential for me being

> *triggered. I would have appreciated having some information beforehand which prepared me for the possibility that that might happen. The hysteroscopy procedure was excruciating; I experienced spasms of pain for 2 hours afterwards. The consultant did explain beforehand that as I had had a colposcopy, the scar tissue on my cervix might cause discomfort, but it was actually quite distressing. The pain was searing and constant. Both the consultant and nurses were amazing. The consultant explained what he was doing and once he was happy with my womb lining ended the procedure as quickly as possible. One of the nurses held my hand throughout. I felt very well looked after, but if I were to have the procedure again, I would request an anaesthetic; the thought of experiencing that again is triggering."* (online survey)

> *"It was awful and wasn't successful. They didn't compete the procedure. I have talked through with GP many times but not decent or suitable alternatives have been offered."* (online survey)

A need for sensitive, trauma-informed care

> *"I have gender dysphoria and have a visceral dislike of having anything inserted into my vagina. Additionally, I have panic attacks [in certain situations] so such an appointment would be extremely stressful for me on two levels."* (online survey)

> *"Very difficult and frustrating to make the appointment and make them let me bring someone with me to avoid panic attacks. Very upsetting for me with the assumptions that I have periods."* (online survey)

Barriers to screening

> *"Guidelines should change in relation to cervical screening for women with history of abnormal results. I appreciate that normally it takes years for cervical cancer to develop (hence current guidelines are set up the way they are), but more resources and investigation should be made for women with history of abnormal smears (checks to happen more often then currently recommended)."*

> *"I am considered too young despite my mother dying from breast cancer at a young age. I strongly feel screening should be lowered to 45."* (online survey)

> *"I would like breast screening but as I am 76, I no longer get this opportunity."* (online survey)

> *"Being entitled to breast / bowel cancer screening after NHS cut off dates. Women over these ages still get those diseases and hopefully have 10 or 20 years left."* (online survey)

> *"I found breast screening excruciating, but know how important it is to have done."* (online survey)

Enablers to screening

> *"Nurse was friendly and approachable given it was my first screen. The process was uncomfortable but over with quickly. I did have some minor spotting after, so patients could be warned about this."* (online survey)

> *"Very nice and gentle nurse but am sure the technology could have been improved more by 2024!"* (online survey)

> *"It's not my favourite thing to do early on a Tuesday morning but I know the consequences if I don't go. I have also had colposcopy treatment in the past following a test that showed cell changes. It is always painful but all the nurses I have ever had (and I have always gone for my smear test) have been courteous, as quick as they can be and apologetic! Perhaps the only thing that could be made better is to have longer to chat any concerns or worries through prior to the test and to know that the person doing it has heard those concerns and if possible answered your queries."* (online survey)

> *"Ovarian cancer is difficult to diagnose as the symptoms often don't show until the condition is relatively advanced. Why are women over a certain age not offered an annual CA125 blood test as a screening option? I would gladly pay towards an annual CA125 + Blood sugar + cholesterol blood screen which will catch and highlight ovary changes, type 2 diabetes risk and cholesterol risk. Simple, cost effective to prevent rather than treat as far as the NHS goes, and would be as reassuring to as many women as the breast screening is."* (online survey)

Ideas for improvements

Improving public understanding and awareness

> *"Information targeted at premenstrual tension (PMT) management and peri menopause contraception."* (online survey)

> *"Mental health awareness around our hormones it's very common for us women to suffer during different stages and I believe this needs to be*

more talked about especially for the younger women who need to know they aren't alone right away and to report changes that aren't normal for them." (online survey)

"In relation to menopause - access to information and advice on dealing with menopause BEFORE the symptoms require a GP visit. A more holistic approach to menopause." (online survey)

"More information on menopause symptoms and (importantly) when does menopause end? Will I feel better once it ends? Very little information or optimism about post-menopause or how you know you've reached that stage!" (online survey)

"More honesty & information. Maybe champions in a particular area that can give proper experiences, so you are better prepared/informed. Also stop lumping everything under the umbrella of 'women's problems'. Women go through an awful lot from periods, pregnancy, smears, menopause etc & I truly feel it still isn't given enough recognition of all the changes /procedures women go through." (online survey)

"I would like to see more of a public health/population health management approach to tackling inequality, stigma and bias around women's health at all life stages, in a similar way to how the Time to Change campaign had (at least some!) success in tackling mental health stigma. This plus more informal & formal education for women of all ages and demographics would be good - one of the most useful things I've had was a talk from a brilliant woman who was instrumental in creating the first menopause-friendly police force [that] was arranged by [my employer] in our work time." (online survey)

Improving health and care professionals' understanding of women's health issues and support for people living with these issues

"Upskilling GPs to recognise the symptoms of menopause and offering equal consistent care to all patients. GPs being trained on listening to patients, regardless of the patient not fitting into the 'normal' age of menopause." (online survey)

"Training for all GPs on menopause and gynaecological issues. Frightening how often I seem to know more or am more aware of up-to-date treatment guidance than most of the medical professionals I meet." (online survey)

> *"Much better clinical training needed including of specialist consultants - menopause and especially surgical menopause is almost entirely absent from some conversations where it should be front and centre. Work to change the culture around attitudes to female pain, expectations of poor health, not listening to us."* (online survey)

More joined-up working between services

> *"It would help a lot if different specialty groups would communicate with each other more and worked things out between them rather than being told different things from different teams and having to explain what other teams have said."* (online survey)

> *"Slightly complex that different services for same thing due to different rules for me originally sent to family planning for coil exchange but as was to be used as HRT this is commissioned to be looked after by community gynaecology."* (online survey)

Designated women's health GP

> *"Because issues e.g. around perimenopause and menopause are complex, it is helpful to see a dedicated GP or Healthcare professional, the same one each visit, so they can get a more holistic picture"* (online survey)

> *"I am a victim of domestic abuse and an advocate for victims. There should be a designated practitioner in GP surgeries who victims can liaise with for female services and mental health. Victims of domestic abuse will be far more reluctant to schedule appointments for female services if they do not know and trust the practitioner."* (online survey)

> *"There should be a designated doctor to discuss women's issues and this should be an advertised service so that women are not afraid to ask for appointments and the service should be transparent as to what exams you are entitled to and when."*

Follow-up and aftercare

> *"Provide aftercare for miscarriage - at the very least a follow up to check on mental health afterwards. Ideally support would be similar to that provided throughout and after pregnancy - resources and information about healing and next steps, support groups to help with isolation, physical therapy for those who have experienced complicated miscarriages. Bring more awareness of the impacts of pregnancy loss into maternity care - previous experiences have a huge impact on how you experience a pregnancy yet there is still an overwhelming sense through*

> *all pregnancy services that miscarriage is something that you don't talk about, which makes no sense at all as it is highly relevant."*

Women's health checks

> *"Routine perimenopause checks for women over 40."* (online survey)

Drop-in clinics and one-stop-shop appointments

> *"A one stop shop type clinic appointment in gynaecology, where all necessary tests and scans and consultations could be arranged in 1 day to avoid delays in having to wait for several appointments before then having to wait for a referral to be accepted."* (online survey)

> *"One designated hub that sends patient to a right service, instead of patients being sent from a service to a service."* (online survey)

> *"Being able to combine procedures such as smear and coil insertion would be such a relief instead of having to go through the intimate appointment twice."* (online survey)

> *"I think there should be far more menopause clinics, so that women can get medical advice regarding menopause symptoms."* (online survey)

> *"Specific clinics for female related health issues e.g. menopause, menstrual issues etc. that are not specific to one particular practice. This would be a safe space with more expertise in women's' health and perhaps prescribe HRT, antibiotics for UTI, etc."* (online survey)

> *"Local clinics could consider running sessions on perimenopause, signs and symptoms."* (online survey)

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