



Menstrual and Menopausal Health Findings

September 2024

CONTENT WARNING

This report mentions suicide, self-harm and psychosis. **This warning relates to pages 35–36.**

Glossary

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Endometriosis - a chronic medical condition where tissue similar to the lining of the uterus grows outside the uterus, often on the ovaries, fallopian tubes, and other pelvic organs. This condition can cause severe pain, especially during menstruation, and may lead to fertility issues.

Hormone Replacement Therapy (HRT) - a medical treatment used to relieve symptoms associated with menopause by replenishing estrogen and, in some cases, progesterone levels in the body. HRT can help alleviate symptoms such as hot flashes, night sweats and vaginal dryness, and may also provide long-term benefits for bone health.

Menopause - the natural biological process marking the end of a woman's menstrual cycles, typically occurring between the ages of 45 and 55. It is diagnosed after 12 consecutive months without a menstrual period and is associated with symptoms like hot flashes, night sweats, mood changes, and vaginal dryness due to a decline in estrogen levels.


Perimenopause - the transitional phase leading up to menopause, during which hormone levels fluctuate, causing changes in menstrual cycles and the onset of menopausal symptoms such as hot flashes, sleep disturbances, and mood swings. This stage can last several years until menopause is reached.

Polycystic Ovary Syndrome (PCOS) - a hormonal disorder common among women of reproductive age, characterised by irregular menstrual periods, excess androgen levels, and the presence of multiple small cysts on the ovaries. PCOS can lead to symptoms such as acne, weight gain, and fertility challenges.

Premenstrual Dysphoric Disorder (PMDD) - a severe form of premenstrual syndrome (PMS) characterised by significant mood disturbances, such as depression, irritability, and anxiety, occurring in the luteal phase (after ovulation) of the menstrual cycle. These symptoms can severely impact daily functioning.

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Please note that all quotes included in this report are presented verbatim unless otherwise indicated. Only filler words such as 'um' and 'you know' have been omitted for clarity and brevity

Executive Summary

- For our first campaign of 2024, we focused on menstrual and menopausal health. As part of the Government's Women's Health Strategy, each Integrated Care Board (ICB) will have a Women's Health Hub. One aim and hope is that these hubs will improve diagnosis times, treatment and support for a range of menstrual health conditions including endometriosis, polycystic ovary syndrome (PCOS) and those going through menopause.
- Currently, little is known about the experiences of those in Lincolnshire who have these conditions or are going through perimenopause or menopause. Therefore, to explore this we launched two online surveys: one for service users and the other for professionals. We also held four focus groups for professionals.
- In total 450 service users and 18 professionals shared their views. Service users shared their views on the following:
 - Endometriosis – 17%
 - PCOS – 16%
 - Menopause – 26%
 - Perimenopause – 26%
 - Other – included post-menopause, PMDD, fibroids – 13%
- Common themes persist throughout the report, spanning areas such as endometriosis, PCOS, menopause, perimenopause and other menstrual health conditions. Both service users and professionals raised many of the same issues.
- According to the data collected, experiences did not appear to differ based on whether the individual was a carer, neurodiverse or which area of the county they lived in. The data did suggest there was a postcode lottery but not in the sense that one area of the county was having very positive experiences, it was much more random with variation within the same primary care network (PCN).
- **By far the biggest issues highlighted were not being listened to, not being taken seriously and a lack of interest and knowledge around menstrual health conditions and menopause.**

Executive Summary

Key headlines include:

Diagnosis

- Symptoms being ignored and/or normalised.
- Women not being listened to or taken seriously.
- A lack of knowledge or interest in menstrual and menopausal health among healthcare professionals.
- Long waiting times to be diagnosed.

Mental Health

- The impact of menstrual and menopausal health is poorly understood and rarely acknowledged.
- There is also a need for more emotional and wellbeing support for those navigating menopause and/or menstrual health conditions.

Treatment and Management

- Symptoms were mainly managed via medication. Access to HRT and effective pain relief for endometriosis were highlighted as issues.
- Service users also highlighted a need for more holistic support to complement the use of medication. There were calls for more emotional and wellbeing support and information on alternative therapies and lifestyle changes.

What works well?

For a minority of respondents, the following was highlighted as working well:

- Quick and easy access to appointments (however, this was not the experience for the majority).
- Interested, knowledgeable and supportive professionals.
- Being listened to and referred when needed.

What could be improved?

The majority of respondents highlighted the following as needing improvement:

- Listening to service users and taking them seriously.
- Quicker access to diagnostic tests.
- Review the training for healthcare professionals, on menstrual and menopausal health, especially for those in primary care who are the first port of call for many on menstrual and menopausal health issues.
- Information on how to cope with their symptoms and condition(s) while waiting for additional tests.

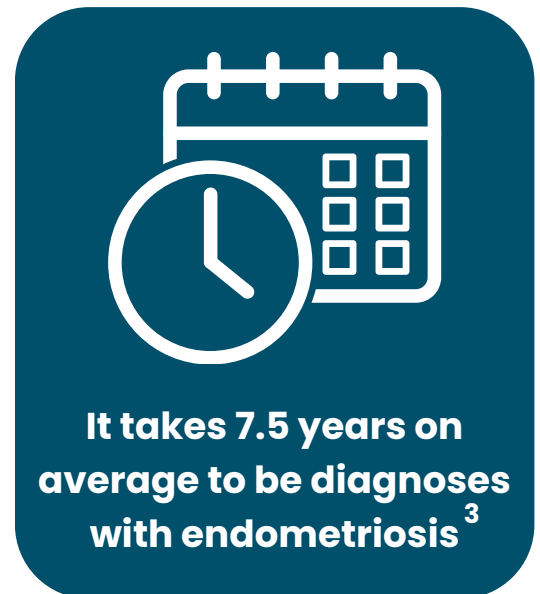
The findings of this work have already been used to support the development of the Women's Health Strategy and Health Hub for Lincolnshire.

Background

For our first campaign of 2024, we decided to focus on menstrual and menopausal health. As part of the **Government's Women's Health Strategy**, each Integrated Care Board (ICB) will have a Women's Health Hub.¹ One aim and hope is that these hubs will improve diagnosis times, treatment and support for a range of menstrual health conditions including endometriosis, polycystic ovary syndrome (PCOS) and those going through menopause. It is important to note that menopause is not a disease, disorder or condition. It is a natural stage of life but some can experience symptoms that affects their quality of life.²

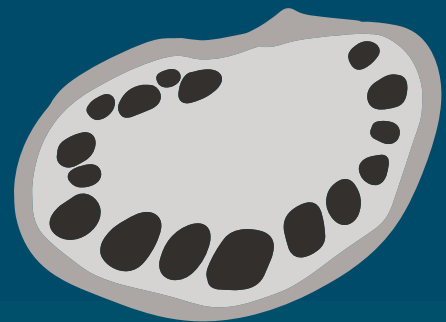
Endometriosis

1 in 10 women have endometriosis. This is the same as the number of people who have diabetes. Symptoms of endometriosis include chronic pain, fatigue, depression and fertility problems. There is currently no cure and on average women have to wait 7.5 years to be diagnosed. Endometriosis costs the UK economy £8.2 billion a year in treatment, loss of work and healthcare costs.³ NHS Lincolnshire ICB is one of only seven ICBs to not to have an accredited endometriosis centre.⁴



Polycystic Ovary Syndrome (PCOS)

Around 1 in 8 women have PCOS, but 70% are undiagnosed. Symptoms include irregular or no periods, weight gain, excessive hair growth on the body and hair loss from the head. The National Institute for Care Excellence (NICE) outlines it is the single most common cause of infertility. Those with PCOS have a higher risk of cardiovascular disease, hypertension, diabetes, depression and anxiety. They are also at higher risk of pregnancy complications and endometrial cancer. There is no cure.⁵



1 Department of Health and Social care (2022). [Women's Health Strategy for England.](#)

2 World Health Organisation (WHO) (2022). [Menopause.](#)

3 Endometriosis (2020). [Endometriosis Awareness Month.](#)

4 [Endometriosis UK Response to Health & Social Care Committee Call for Evidence on DHSC Integrated Care White Paper \(2021\)](#)

5 National Institute for Care Excellence (NICE) (2024). [Polycystic Ovary Syndrome.](#)

Menopause

NHS England outlines that menopause is when periods stop. It usually affects women aged 45 to 55 but can also happen after certain surgeries or cancer treatments.⁶ Symptoms can have a huge impact on daily life and include mood swings, brain fog, hot flushes, and joint and muscle stiffness. 8 out of 10 experience some symptoms, for around four years after the last period.⁷ Indeed, 1 in 10 women working during their menopause have left their job due to symptoms.⁸

Perimenopause refers to when you have symptoms of menopause, but your periods have not stopped.⁹

The main medication used to help menopause symptoms is hormone replacement therapy (HRT).¹⁰ A study by the Fawcett Society highlighted only 4 in 10 are offered HRT in a timely fashion. Nationally and locally there have been shortages of HRT.¹¹¹²

Endometriosis, PCOS and perimenopause and menopause are just a few examples of areas associated with menstrual and menopausal health. Currently, little is known about the experiences of those in Lincolnshire who have these conditions or are going through perimenopause or menopause. By exploring menstrual health, we hoped to involve more people in conversations about their health. This decision was part of our ongoing efforts to address health inequalities in Lincolnshire and ensure that everyone's needs are heard and considered. We were also keen to hear from health and care professionals about their experiences of diagnosing and supporting those navigating these conditions, perimenopause and menopause.*

**While we primarily focused on gathering service user and professionals feedback from these three areas, we still welcomed feedback about other menstrual health conditions such as adenomyosis, fibroids and premenstrual dysphoric disorder (PMDD).*

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6 NHS England (2022). Menopause.

7 Patient Info (2022). Menopause.

8 Fawcett Society (2022). Menopause and the workplace.

9 NICE (2022). When should I suspect a menopause or perimenopause diagnosis?

10 NHS England (2023). Hormone Replacement Therapy (HRT).

11 Fawcett Society (2022). Menopause and the workplace.

12 Gov. UK (2022). Further action taken to improve supply of HRT.



Engagement (Methodology)

To gain this insight we launched two surveys, one for service users and one for professionals. Individuals were also given the opportunity to share their experience over the phone, email or in any format that best suits them. The team, including our amazing volunteers, also distributed paper copies of the survey to those who preferred to engage this way* and to groups such as those with learning disabilities and living in rural areas. We linked into local menopause support groups, the local branches of Endometriosis UK and Verity (for PCOS).

We also ran four focus groups with health and care professionals to gain greater insight into their experience of supporting patients to navigate these conditions.

**The survey could be sent back to us using our freepost address.*

Engagement (Methodology)



Both forms of engagement covered the same topics:



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Acknowledgments

We would like to thank:

- Everyone who took the time to share their views.
- Your experiences are invaluable.
- The HWLincs team, including our amazing volunteers, local support groups and menopause champions for their support.
- The Director of Strategy and Partnerships for Boston Primary Care Network, for helping facilitate the focus groups.



Disclaimer

We recognise and acknowledge that the experiences shared may not be fully representative of:

- All service users who have accessed health and care for their menstrual and/or menopausal health and all professionals diagnosing and supporting those with menstrual health conditions or going through menopause in Lincolnshire.

We do however believe that all individual experiences are important and should be reflected on where and when possible. A strength of this data is that common themes persisted throughout responses from service users and professionals.

- At Healthwatch Lincolnshire, we champion inclusivity and equality in all we do. Most menstrual and menopausal health service users who shared their views via this survey identified as a woman. Therefore, we have primarily used the term 'women' in this report, but we also recognise the experiences of diverse gender identities.
- **Common themes persist throughout the report, spanning areas such as endometriosis, PCOS, menopause, perimenopause and other menstrual health conditions. Both service users and professionals raised many of the same issues.**
- **According to the data collected, experiences did not appear to differ based on whether the individual was a carer, neurodiverse or which area of the county they lived in. The data did suggest there was a postcode lottery but not in the sense that one area of the county was having very positive experiences, it was much more random with variation with the same primary care network (PCN).**

Findings – Who shared their views?

450

**service users
shared their views**

18

**professionals
shared their views**

The following relates to service users:



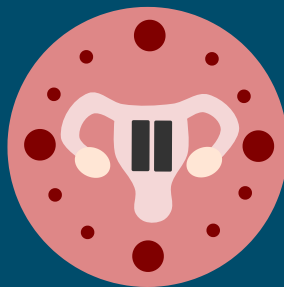
**17% (76)
Endometriosis**



**16% (70)
Polycystic Ovary
Syndrome (PCOS)**



**7% (33)
Other***



**26% (117)
Menopause**

**28% (126)
Perimenopause**

**6% (27)
Post-menopause**

- **37% (167) work in health and/or social care**
- **13% (59) considered themselves neurodiverse**
- **10% (46) were carers**
- **3% (14) belonged to the LGBTQ+ community**
- **3% (12) were serving members of the armed forces or veterans**
- **2% (11) work in farming or agriculture**

*Other conditions included Premenstrual Dysphoric Disorder (PMDD), fibroids, adenomyosis and other conditions. A full breakdown of who shared their views can be seen in the demographics section of this report.

Diagnosis

Overall

Overall, there was an even split in the number of respondents who had been diagnosed correctly the first time and those who had previously been diagnosed with something else.

- Endometriosis had the highest percentage of respondents who were initially diagnosed incorrectly (63% [48]). Some respondents shared they were at first diagnosed with Irritable Bowel Syndrome (IBS) or other gastrointestinal issues which have some overlapping symptoms with endometriosis.¹³
- PCOS had the highest percentage of people being diagnosed correctly the first time (56% [39]).
- Correct, first-time diagnosis for perimenopause was 29% (36) compared to 46% (39) for menopause. This was supported by the additional comments where respondents who suspected they were going through perimenopause were frequently told they were “too young” to be experiencing their symptoms and as a result often had to wait months or even years to be diagnosed.
- 17% (75) were trying to get diagnosed or had tried previously. This group was mainly made up of those going through suspected perimenopause, post-menopause and those who selected “other condition” including PMDD.
- 12% (54) shared they had not tried to get a diagnosis and 65% (28) of these individuals were navigating suspected perimenopause, menopause or post-menopause. Reasons for not seeking a diagnosis included not being able to access an appointment at primary care, fears of not being taken seriously or not feeling there was a need as symptoms were manageable.

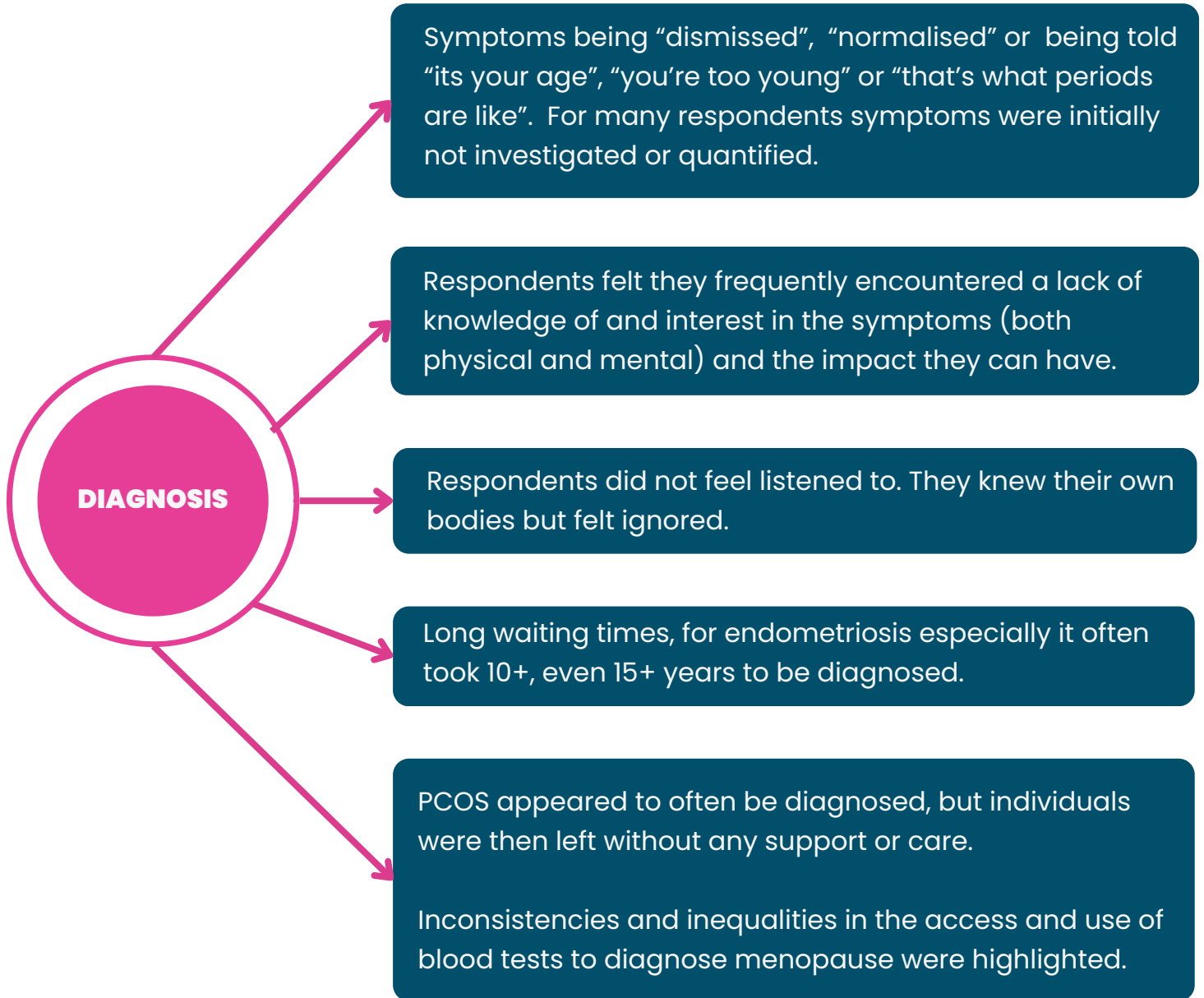
Don't feel I can fight for an appointment

“Can hardly get into see a GP when I really need to. Don't feel I can fight for an appointment when not sure myself.”

I won't be taken seriously

“Time and effort involved in seeking diagnosis. It's hard to think about my own needs when my caring role takes up all my headspace. Fear that I won't be taken seriously. Concern about shortages of medications to treat menopause.”

There were many commonalities in the experiences of trying to get diagnosed, regardless of whether it was PCOS, endometriosis, perimenopause or PMDD. The following were raised by both service users and professionals:



You give up looking for help

“I feel like women’s pain and symptoms, especially surrounding periods, are played down and I have always been almost gaslighted about experiencing such severe problems three out of four weeks of each cycle. I was not only not encouraged to have the conversation, I was actively discouraged from having it when I brought it up. After years of this treatment and attitudes you learn how to cope with your symptoms and give up on looking for help as it feels like there isn’t any and you begin to blame yourself for not being brave or strong enough to deal with your symptoms like other people do.”

Endometriosis

Those with endometriosis shared that their symptoms often started in their early to late teens. When presenting at their GP practice with their symptoms, respondents shared they were frequently “ignored”, “dismissed” and told their symptoms were normal or “all in your head”. The latter even occurred for some when they finally got their referrals to and appointments at secondary care.

The journey to getting a diagnosis for many respondents was a very long one, often waiting over 10 years, in some cases 15+ years to be diagnosed. The journey was described by some as “traumatic”. Whilst waiting for a diagnosis some respondents were left in excruciating pain and unmanageable menstrual cycles. This in turn contributed to a decline in their mental health, ability to work and relationships. By the time some had got diagnosed, the condition was in its advanced stages.

The long waiting times with unbearable, unmanaged symptoms forced some to seek a diagnosis privately.

A lot of pain and nothing was done

“My concerns were definitely not taken seriously, I felt like I was not believed and was completely dismissed. Was in a lot of pain and nothing was done. Made me feel like I was imagining my pain and was convinced there was nothing wrong with me.”

Considerable damage

“The diagnosis took approximately 10 years. My problems were continually dismissed despite me taking time off school/university and work. The diagnosis was only made once I finally had diagnostic surgery by which time the endometriosis had caused considerable damage.”

I am now infertile

“It took 13 years and six hospitals; multiple misdiagnoses and gaslighting. I was never taken seriously due to having another health condition even though I ticked all of the endometriosis symptom boxes. Because of this I am now infertile, am too high risk for egg freezing, have now issues with my existing condition and surgical intervention due to endometriosis now growing on a manmade organ, will be having major surgery which would not have been necessary. Due to no Lincolnshire specialists having the skillset to treat me I travel three and a half hours for care, and have been in chemical menopause throughout this creating spinal issues and bone density loss. No emotional, social or practical support has ever been offered.”

In one of the focus groups, an attendee highlighted good practice about exploring a diagnosis for suspected endometriosis. They highlighted many areas of good practice such as a supportive and knowledgeable GP who listened and referred when needed. They sadly too highlighted that this was not always the experience for everyone seeking such a diagnosis.

How many women don't have the resources? You feel for that group

"My daughter was written off – we took her privately because we just didn't know what to do in the end. She was seen for like 15 minutes for £250 – wasn't even examined. The doctor tried to indicate that it was her mental health, which that was really, really upsetting. I mean, I'm a mental health nurse and so is her father. We've both been nurses for many years. And absolutely, if one of us have a mental health problem, you know that it can affect anyone. But we knew that this was something different. She was rolling around on the ground writhing in pain, it was horrific, really traumatic. And so to be dismissed in that way was really difficult.

Our GP was brilliant and when we thought all the symptoms aligned with endometriosis, he listened to us.

Our GP stuck with us the whole time. He believed us. He researched stuff himself, outside of our appointments. I could go on about all of the things that he did in terms of providing that kind of trauma. Informed care really. It was amazing.

We went to Nottingham and had a quite a difficult experience with them and we hadn't wanted to come to Lincolnshire. We then found somebody who was specialist in Manchester, specialist within endometriosis for adolescents and our GP referred us there which was just outstanding really. I think without that GP we could have gone off sick because, I don't know how we actually, she wasn't at school. We were trying to navigate the education system. We're trying to navigate the health system. We were trying to work. We've got two other children and it was like a really difficult time. I think without him I absolutely do not know what we'd have done. So I don't know what the solution is but I used to think gosh we're really lucky. We've got a lot of resources and again we can navigate some of this not easily but we can. How many women out there just don't have the resources to be able to do that? You feel for that group of people."

PCOS

Experiences of trying to get a PCOS diagnosis can be split into two broad groups:

1. Those who had long-standing concerns around irregular periods, heavy bleeding, weight gain and difficulty losing weight.
2. Those diagnosed when presenting with fertility difficulties.

Respondents in the first group shared that their symptoms often started in their mid-teens but had to wait years, often 5+ years to get diagnosed. Repeatedly, stories were shared, where respondents had been to their GP surgery with their concerns but were “dismissed”, “ignored” and told to “just lose weight”. The latter put some off from going back with their concerns. It appeared to be common to have multiple appointments, over multiple years before receiving a diagnosis. In the meantime, respondents shared they were left with unmanageable symptoms including heavy menstrual bleeding, pain and anxiety. In some cases, undiagnosed conditions and untreated symptoms led to life-changing consequences.

The relief of a diagnosis was short-lived when frequently no subsequent care was provided unless respondents were looking to have children. If they were not, some were prescribed a contraceptive but for many, they were left without any care or guidance. It was down to them to do their research and try and manage their condition the best they could. The little support available to those with PCOS and the apparent reliance on patients to manage their own condition, especially those who do not want to have children, was raised by professionals in two of the focus groups.

The female GP was mortified

“In my late twenties, my periods were sporadic, perhaps occurring four to five times a year, but were incredibly painful, heavy and lasted around 14 days. I returned to the doctor once again and voiced that something didn't feel right, but was faced with, “It's nothing to worry about” again. I argued that I wanted to have some tests done to check as I felt something was wrong but the GP (male) refused. At this point I changed GP practices and asked to have a female doctor. I explained my situation and the female GP was mortified that for nearly a decade I'd been told not to worry and left without even any investigation being done. I was immediately referred for an ultrasound, which showed up that I had large clusters of cysts on both ovaries and was diagnosed with PCOS at this point. I was 30.”

Had I been taken seriously sooner I may not be having fertility struggles

“As a result of being left for so long without intervention, I had suffered with weight gain, hirsutism, depression and anxiety, low immunity and sometimes extreme pain. I am now 38 and been trying to have a baby for several years but not able to conceive. The impression I have been given by gynaecology was that had I been taken seriously sooner, I may not be having the level of fertility struggles I am.”

A large cyst was missed and killed my ovary

“I was diagnosed when I was 11. Diagnosed very quickly. I was referred to endocrinology at Boston Hospital. Sadly after that there was no treatment except lose weight. When I was 24 I had a large ovarian cyst and resulted in me losing my ovary and fallopian tube. This was missed by Boston till it got too big and killed my ovary.”

Care has been virtually non-existent

“I was diagnosed in 2010 and, in all honesty, as I presented most of the obvious symptoms of PCOS I wasn't particularly difficult to diagnose. However, the 'care' provided afterwards has been virtually non-existent despite PCOS being the root cause of many health problems.

After diagnosis, concerns weren't taken particularly seriously. I was 'only' 17 and was told that I'd 'probably never have children'. Perhaps not too much of a concern at that age but I still think it should be handled carefully.

The mental impact of that one sentence has become more apparent over the last few years when thinking about starting a family.”



Perimenopause and Menopause

There were many commonalities in the experiences shared around being diagnosed with either perimenopause or menopause. For those who had positive experiences of being diagnosed, good practice included:



Healthcare professionals being aware of the symptoms and not just the “cliché” symptoms such as hot flushes



Healthcare professionals listening to patients, being empathetic and showing understanding



Quick access to diagnostic tests and results

This good practice appeared to relate to individuals rather than systems and processes. This, in addition to comments raised throughout the survey and focus groups suggests a “postcode lottery” exists: the quality of care received depended on the knowledge and interest of individuals. The latter appeared to be especially significant in regard to access to blood tests to diagnose menopause.

However, good experiences according to the data collected through this work were a minority. On their journey to a diagnosis respondents shared they frequently faced the following:

- Being told they were “too young” to be perimenopausal or menopausal.
- Their symptoms being put down to “being a women” or “their age” with no further exploration/quantifying.
- Healthcare professionals being uninterested and uninformed of the symptoms of perimenopause and menopause, especially those who are presenting with the less “stereotypical” symptoms. Despite knowing their own bodies, some respondents felt their symptoms were ignored.
- Being told to research their own treatment.

- Being prescribed antidepressants not HRT, despite the NICE guidelines outlining that antidepressants “should not be routinely offered as a first-line treatment”.¹⁴ The antidepressants not helping their symptoms.
- Inconsistencies and inequalities in the use of blood tests to confirm menopause and the knowledge and interest of healthcare professionals.
- Conflicting clinical opinions.
- Long waiting times to be diagnosed and to be referred to specialists if needed.

What did the professionals say about diagnosis?

Professionals raised many of the same issues as service users. They highlighted women not being listened to and a lack of knowledge among both professionals and the public about what is “normal” in terms of symptoms when it comes to menstruation and menopause. Some felt it had become “normalised” that periods were painful, when this is not necessarily the case. They too felt that as a result of this lack of knowledge about symptoms and bad experiences when trying to access support for menstruation and menopause, some women were deterred from going back.

A lack of exploring and quantifying symptoms was also discussed. One participant felt that symptoms were very quickly put down to periods but when there was something ‘abnormal’ about their periods, there was a reluctance to explore this and seek a diagnosis. Inequalities were also highlighted.

A conversation from a focus group:

Person 1 – “What I’ve found is, personally if I go to the doctors and I were to say, ‘My eye’s twitching,’ they’re very quick to go, ‘It’s to do with your periods.’ But for someone who does have symptoms of endometriosis they’re like, ‘Let’s hold back a little bit and we’ll diagnose you later. We’ll pop you on a waiting list.’ So I do find just a little bit my own opinion coming in there: as soon as we think there’s something wrong with our bodies and we know what it is, we just need that diagnosis. They’re very quick to say, ‘Whoa, whoa, whoa, I’m the professional here. I’ll do a diagnosis when I’m ready.’”

Person 2 replies – “I agree with what you said about it often being a blame thing about, ‘Well you’re obviously a woman and so you are expected to be in immense pain once a month.’ But actually, we know that isn’t right. That isn’t the way that periods work, people shouldn’t be experiencing that.”

Pretty much always a no

“I run a wellbeing hub and as part of that, we have groups where people from the community can come in and get support for their mental health and wellbeing. What I've found is actually women aren't getting necessarily a diagnosis. They are getting support, I say support, usually medication if I'm honest about their mental health. When they talk about their symptoms, if I ask if the GP has explored anything around their hormones it is pretty much always a no.

That's the bit. It's the lack of curiosity and looking at it deeper. For some people, they're quite vulnerable and they're not thinking that or haven't got the information or aren't really sure about what's going on with their bodies. I suppose my frustration is that sometimes that lack of empowerment as a woman and some women anyway.”

Postcode lottery

“The problem is you're a bit of a postcode lottery and how invested your GP is. They get such conflicting advice in terms of what they can and can't do, what they should be doing and that.”



Case Study – A GP shares their views

What common challenges do you face in diagnosing menstrual health conditions?

“The age old one is that women don’t necessarily know it is a problem or that they don’t know to come and ask about it. I think as women we have our own individual experiences of menstrual cycles, if that’s just what it’s always been, they don’t necessarily know that is it abnormal or potentially improvable. I fit mirenas. One of my favourite things is when I see a 42-year-old women and they come back and tell me I’ve changed their life because they’ve had 20 years of awful periods and suddenly they’ve got none at all and they didn’t know it was possible. It is such an easy thing to do.

I think that is part of the thing that women don’t know to ask. There is still a very, very patchy service when they do ask and so I think women come and are told once ‘It is a period, what do you expect?’ Of course you are going to feel tired and of course it is going to painful and of course... Sometimes it is normalised by people without doing any quantifying, like the Royal College of General Practitioners (RCGP) questionnaires and stuff like that, which can be really useful. Also in other areas of life, we tell people if acne scars cause cosmetic distress we do something about it whereas with periods women are often told it’s a period, crack on. I think there is a real variability in the quality they get when they do come and that obviously often means they come once and they never come again because they’ve been told to get on with it or been shamed or life is just too busy so they don’t get to come again. So that’s a problem.

Unless you have a GP who is particularly interested in women’s health it just doesn’t get done. Particularly at the moment but historically, its been largely the same I think is the back up from secondary care and access to investigations and what do we do next? We’ve tried these things, what can we do? It is a broader question about the outsourcing of simple procedures to non-doctors and I say this without any disrespect to our nursing colleagues or advanced clinical practitioners or anything else, but very often when we send women to hospital now (not just gynae) they see a technician who has experience and has been taught to do a procedure but doesn’t actually give a clinical assessment or clinical advice. We send women for a hysteroscopy and they get it and it is normal, go away and there back to us. We could do with some specialist input and we’re not getting any. We are getting a procedure with a result and nothing else. It is helpful in some ways, it’s nice to know they don’t have endometrial cancer but even so they are having all these problems, what do we do next? So that’s really frustrating and I think it is really frustrating for women when they’ve been waiting for months and months and they just get told their biopsy’s normal, go see your GP.

Cont...

“Then I suppose there is all that PMDD and psychiatric disorders to do with menstrual health and again I think part of the problem is just everyone being really busy. I’ve been doing the job for 20 years, things like PMDD didn’t exist 20 years ago. It certainly was not recognised. So actually the concept for the GP is I recognise it’s here but do I have the time, the energy or anything else to find out about it? It is difficult to do when you are already fighting all these other fires. I think there is a knowledge gap and again if you referred someone to psychology for that they would probably be waiting a year and a half for that and that is difficult as well. As with so many things in psychiatry if you’re not suicidal, bad luck, keep going kind of thing, there aren’t really services available for that.

Although slightly out of the scope of menstrual health, copper coils for emergency contraception are supposed to be first line gold-standard. Who can get one of those? It is almost impossible unless all the stars align. You’ve got no hope of being able to offer gold standard contraception like that. Again, if you could ring up and there was a hub somewhere who could see them tomorrow that would be amazing and so much better for women.

There is too much work and not enough supply and what that means is at the moment, I think women are missing out very badly.”

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Waiting Times

We asked:

“Are you currently waiting for any tests, treatment or additional diagnosis relating to your condition?”



Overall

- Endometriosis had the highest proportion of respondents waiting for additional tests, treatment or additional diagnosis, with 47% (35) still waiting.
- 1 in 5 with PCOS and going through menopause and 28% (35) going through perimenopause were waiting.

We asked:

“Please tell us about your experience of waiting for this. (E.g. how long have you been waiting, have appointments been cancelled, have you been given any support whilst waiting?)”

Regardless of the condition, the same issues around waiting times were raised:

- The length of time, waiting months or even years for referrals to gynaecology or specialist endometriosis support.
- Lack of communication from services while waiting.
- Waiting well – such as how symptoms can be managed whilst waiting, what support is available for both physical and mental health concerns.

My GP laughed

“I’ve been waiting over a year for gynaecologist appointment. My GP laughed and said I will probably be in menopause before I get an appointment.”

Zero support

“I’ve been waiting nearly three years now and I’ve had ZERO support whilst waiting. I am struggling.”

Just told to wait

“No support, just told to wait for an appointment to come through. Months ago!”



Medication

Overall

- Overall, 52% (227) of respondents were taking medication for their condition.
- 61% (44) of respondents were taking medication for endometriosis, 53% (64) for perimenopause and 66% (77) for menopause.
- 76% (51) of those with PCOS were not on any medication.
- Overall, 70% (160) of those who took medication for their condition shared they had faced challenges getting the medications that worked for them. There was little variation in this figure across endometriosis, perimenopause and menopause.

Endometriosis

Access to effective pain relief was the main concern for those taking medication for endometriosis. This included being prescribed appropriate pain relief by primary care and access to specialist relief prescribed by specialist centres when back in the community.

PCOS

For those with PCOS, access to Metformin was discussed by some. Metformin can be prescribed “off-label” to those with PCOS.¹⁵ Some experiences shared by respondents highlighted the inconsistencies and inequalities in access to the treatment. These included being prescribed the treatment by one professional or in other areas of the country and it helping them managing their symptoms. However, when they saw a different professional or moved to another area, they were no longer prescribed the treatment.

Perimenopause and Menopause

For those accessing medication for perimenopause and menopause, the following were raised as issues:

- Supply issues and shortages of HRT. This was a nationwide issue. Some were left without medication and some felt healthcare professionals were uncertain what to prescribe as a replacement. As a result, some individuals drove miles to try and get their prescription. Some resorted to paying privately.
- Prescription order limits.
- Access to testosterone.
- Access to Mirena.

Professionals in the focus groups discussed access to HRT.

In one of the focus groups a GP discussed access to Mirena coils (hormonal coil), especially in the context of treatment for heavy menstrual bleeding. Sexual health services are not commissioned to fit mirenas for heavy menstrual bleeding (this is a nationwide issue).

“Historically we could possibly bend the truth slightly and overemphasise the need for contraception. Now that has changed to eight years for contraception and five years for HRT. It is very apparent we are not going to be able to get sexual health to do Mirena changes at five years instead of eight. I think that is a real problem it is such a barrier and I do GP appraisals and speak to GPs all the time who have women who have heavy menstrual bleeding and want to go on HRT. They cannot get a mirena because no one in the practice can do it and there is nowhere for them to go other than gynae which is a two-year waiting list. That’s not good for anyone. It is a waste of a gynae clinic appointment because really they shouldn’t be putting in routine mirenas, that’s nonsense but it is also a real problem for that women who has come and asked for help and the help is not available.

There are fewer and fewer GPs doing Mirenas. The recompense to the practice is poor, so if you are overworked and demand outbids supply. These sorts of things where it has always been nice to do those sorts of things for patients are the kind of things that will stop being done and you then lose people that can do it and that skill set which means they will then be referred on. Even then if they announce this sort of hugely beneficial contract the skill has gone anyway. There is a national shortage of fitters and trainers.”

Access to testosterone was also discussed in another focus group.

“I think the biggest thing in Lincolnshire is the testosterone issue. It has to be secondary care [prescribing it] and that will be low on the priority for referral to gynae. So ladies are sourcing it through private clinics and they get charged thousands with little backup on how it’s going to affect.”

Difficulties accessing testosterone was also a driving force in seeking private care for some.

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Mental Health

Professionals' perspective: a closer look menstrual, menopausal and mental health

While not asked about directly via the survey, a recurring theme throughout responses from service users was the impact that endometriosis, PCOS and other menstrual health conditions, perimenopause and menopause can have on mental health and wellbeing.

Many respondents felt that this impact on mental health was rarely acknowledged, understood or considered. The impact on mental health appeared to be exacerbated when symptoms were being “ignored” and “normalised” and there were long waits for diagnosis, tests and treatment, frequently leaving symptoms unmanaged. As a result for some it affected their ability to work, their social circle and relationships.

The link between menstrual, menopausal and mental health was explored in depth by several professionals who participated in the focus groups. Many of these individuals worked for our local mental health trust Lincolnshire Partnership NHS Trust (LPFT). They felt that while progress had been made in terms of linking menstrual, menopausal and mental health, there was still a long way to go and a need for more research. However, finding funding for such research was often challenging, and some felt it was deemed unimportant by society as it was a 'women's issue'.

They highlighted a need to link menstrual health, menopause and mental health, and that early diagnosis and management of menstrual and menopausal symptoms could improve mental health.

Oh my gosh, we've never considered this

“I've been a mental health nurse for 23 years and currently and for a long time have worked with people with what's classed as severe mental illness. So, psychosis and complex needs, secondary care type presentation. But then I have had some personal experiences. My daughter was very, very poorly and we thought she had endometriosis. I'm perimenopausal. So it came on my radar from a personal point of view. I started to read more about things and become far more aware. I think we have anyway, it was timely. They talk about the Davina effect. And there are lots of people now talking about this. I just wonder what the heck women have done in the past.

What it made me really reflect upon was the fact that throughout my career I've worked predominantly with severe mental illness, I've worked in Child and Adolescent Mental Health Services with young girls, I've worked in learning disability, I've worked across lots and lots of different places and I was appalled because I thought, oh my gosh, we have never considered this. The only thing we ever really considered was when we were working with teenage girls, we might consider vitamins and iron, but that was it. It was so limited. With lots of the women that we're starting to work with in community rehab, we are finding that lots of these women have menopausal symptoms, PMDD.

We advocated for a lady that was going to be returned to secure care and it's really difficult to unpick what's trauma, what's seen as their mental health experiences, which is often linked to trauma, what's now the reproductive health issues and it isn't easy but we must be thinking in that way. I've got an incredible team and lots of ladies and the males. There are lots of male allies in there as well. We're really really enthusiastic about always including that in our reflections and trying to develop our knowledge and skills. But often women, the most vulnerable women, the women that are diagnosed with severe mental illness, for many of us it's dismissed for those women it is absolutely put down to whatever is going on for them and never considered. So that's something that I'm hoping over the next kind of 12 to 24 months we would like to really develop a project around that. And we have lots of support right up to the chief executive role in our LPFT."

"What I really noticed was the strong link between people with first-episode psychosis hitting menopause. I think probably having a vested interest in that has made me pick up on that. There's not that link in with your GPs and that it's not something people are giving consideration to when people are becoming unwell at a certain age, mid to late 40s into early 50s that first episode. You get presentations coming through and they don't know where this is coming from (with no mental health history). They've never had any kind of mental health issues and background and then we're getting this first episode and people are ending up hospitalised.

There's not enough going on around early intervention for people to prevent this then ending up in hospital. The problem is, once you get into hospital, you're then medicated, then you think about the side effects for the medication, your weight gain. People going through menopause struggle anyway with weight gain and losing weight. We then start them on an antipsychotic or something like that it impacts on other factors in terms of their motivation, their mobility."

“We’ve had somebody that we’ve done a lot of work with around that. They’ve been in and out of hospitals for most of their adult life, last 12 or 13 years. But we started noticing there was a strong link with their cycles. So we were doing a lot of work around that, supporting her outside when she was in the community and then she’s ending up in hospital and the consultants are not interested in the diary around her menstrual cycles and just stick her on some more meds.

We’ve done loads around empowering her and keeping diaries. It’s checking it through the whole month looking at the changes in mood, in terms of her suicidal thoughts linking it all in. It was all very apparent. And then she goes into hospital you hand it over and then don’t even look at it and you think, ‘Well it doesn’t feel good for them.’ Then it’s like, ‘Just go on more meds,’ and don’t think that’s the answer.

“There’s another thing around endometriosis. There is a lot of work being done around that now and a lot more awareness around that, which is really good. Because again, I think that’s something that’s been dismissed from really early on in people. Like teenagers just saying its periods, just how it is. That’s what they’re told. That’s what they go on to believe. Actually, it should be being diagnosed a lot earlier than it is. People are being left for years with it, in horrendous amounts of pain. With any kind of pain, you’re trying to function and go, it’s going to impact on your mood. When you can’t function at a normal ability, it then has an impact on your mood because you don’t feel that you’re that you’re the same as most of the people in society. So you are feeling very different to others.

You’re losing your network. You should be out with your friends, investing in those relationships when you’re young, as you should be as a young adult teenager that they’re not, they’re being stuck in the bedroom in pain and it’s unrecognised. Your social skills, and your personal skills are impacted.”

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Treatment and Management

This section discusses treatment and management outside of medication.

Overall

- Respondents had mainly (85% [322]) received care from their GP practice.
- Endometriosis had the highest percentage of people receiving hospital care as both in- and outpatients at 31% (43). This was followed by 27% (30) for those with PCOS.
- 19% (13) of respondents with endometriosis shared they had been referred to a British Society for Gynaecological Endoscopy (BSGE) Accredited Endometriosis Centre. The locations they had been referred to included:
 - Norwich and Norfolk University Hospital
 - Sheffield
 - Castle Hill – Hull
 - Birmingham
 - Peterborough – Ramsey
- 1 in 10 respondents going through confirmed or suspected perimenopause accessed care from an NHS pharmacist.
- Overall, 18% (70) shared they had accessed private care. More than 1 in 10 had received private care for endometriosis, menopause and perimenopause.
- Only 13% had been offered or received any other treatment besides medication.
- Endometriosis had the highest proportion of respondents sharing they had been offered or received treatment outside of medication. 39% (28) had been offered care outside of medications and this mainly took the form of surgery.
- As discussed previously, respondents with PCOS highlighted repeatedly that they were often only diagnosed and then left without support to manage their condition.

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Treatment and Management

While the importance and benefit of medications to help control and manage symptoms were highlighted, respondents shared a need/wish for more holistic care. Similar suggestions were raised by respondents on what other treatment they believed would be beneficial regardless of whether they were experiencing e.g. perimenopause or PCOS. These suggestions included:

More and better mental health and wellbeing support

Empower individuals to support themselves

Peer-support groups

Trusted information on symptoms, management strategies including lifestyle changes, alternative therapies and mindfulness that could help manage symptoms. Those with PCOS wanted more sensitive and realistic guidance on weight management

For PCOS especially, respondents highlighted that there is a need for more support for those who do not want to have children

Left to deal with the disease alone

“Yes it would be helpful. There isn't much on offer; it is very much a case of being diagnosed and then left to deal with the disease alone. Most people who have the disease join online support groups and you learn more from these than from medical practitioners. The majority of people are told to “lose weight” and that's that, which is very difficult because of how the condition affects the body. I would like to see some real interventions to help people.” – A PCOS patient

I'd love to be listened to

“I'd love to just be listened to by a professional.” – An endometriosis patient

I've suffered all these years

"I was refused a hysterectomy when I was mid thirty's because I was too young. I was not getting pregnant, and I was adopting. I was mentally at a point where I was ready to accept that it wasn't going to happen. I was just palmed off, no help, no-one to talk to about it. I still stress now that I've suffered all these years with periods etc and not got pregnant. I think during my times of knowing what my condition was I've not had much emotional support." – An Endometriosis patient

- "Lack of knowledge around other treatment/management options both patients and professionals
- Follow-up appointments to discuss ongoing treatment
- Mental health impact – mindfulness
- Education for more understanding
- More time with clinicians to go through tests etc
- Someone to talk to peer support group – professional drop in?
- Help empower people to look after themselves
- Recognise that everyone's symptoms are different – no one size fits all
- Mindfulness etc. should not replace meds
- Bad experiences putting people off from going back, symptoms have worsened
- Better public health messaging, and health promotion start early and make it for everyone
- Menopause clinic
- I have read lots of information and made as many lifestyle changes as possible. I already exercised regularly and eat balanced diet. I have reduce alcohol and take cold shower or ice bath. No information was given to me about making positive changes." – An individual going through the menopause

Not one size fits all

"I would love to see that more specialist focus offer. You've got that access for everyone to that level of information so women can make an informed decision. And also support for around relationships as well, because it does have a massive impact. I don't think it is just about educating women either. I also teach yoga and because I've had issues with my hip. I've also had issues with cortisol. So I've been doing some work with women on somatic movements and getting into that deep cell work. I found I tried lots of things and I've needed HRT but I've got other tools in the box that are helpful and I've had to find what works for me. A tailored, individual approach, so it is not just one size fits all – that is what I would love to see."

– An individual going through perimenopause

A real inequality

“It’s incorporating some of the holistic approaches, attending a clinical reflexologist and that’s been so incredible. It really helps with my symptoms, not saying it does everything but it really really helps. But again it is really lovely that I can go and do that, but I think these women we see at work, we cannot offer those things. Very often it is a tablet and those kind of solutions first. For me I am more than happy to consider HRT at some point, but I really want to look at the other things first, so my diet, exercise, reflexology all of those things. Then once I’ve got to the place I want to be then, I’ll consider it. I just feel like I am in a really privileged position to be able to do that. I feel there is a real inequality there.” – An individual going through perimenopause

Private Care

- More than 1 in 10 shared that they had chosen to access private care for their endometriosis, perimenopause and menopause.
- The reason for accessing private care for endometriosis was often out of desperation due to feeling ignored by the NHS in terms of their symptoms being underestimated and long waiting times to access specialist care. However, this has been a very difficult and costly decision. For others, it is not a possibility.
- Those who accessed private care for their perimenopause and menopause did so due to:
 - Long waits to be seen.
 - Not being taken seriously by their GP practice.
 - Not being able to access testosterone on the NHS.
- Concerns were raised by professionals around the inequalities this is creating.

I feared I would take my own life

“NHS waiting list was nine months for surgery and the pain was so severe I feared I would take my own life. I remortgaged my house and had to go private for surgery.” – An endometriosis patient

I was not taken seriously.” – An endometriosis patient

“No funding. Lack of access to NHS services or wait times. No availability of the services in Lincolnshire. Desperation due to pain.” – An endometriosis patient

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I thought I was going to have some kind of breakdown

“I ended up going private because I wasn't getting what I thought I needed from my GP, whether that's down to lack of resource or whatever. I literally thought I was going to have like some kind of breakdown, and to feel like you're that poorly that you're not sure whether you can come into work anymore or you doubt everything that you do. I have to say, I feel very privileged that I've been able to make that choice and it is the best thing that I've ever, ever done. I said to my partner, I don't care. I've got no money left at the end of the month. My health is the most important thing.”

- An individual going through perimenopause

My GP refused to listen

“Because my GP refused to listen to my concerns about what was happening to me despite the fact that I did a lot of research and advised him that NICE does not recommend antidepressants as the first line for menopause and that women requesting HRT should be prescribed HRT. He also tried to tell me that as I was still having periods I couldn't take HRT until I was post menopause.”

- An individual going through menopause

Going private, I was seen straight away

“Speed of consultation and treatment. I didn't want to wait over six months for an appointment and going private I was seen straight away. Treatment was given immediately and this was fantastic. Plus I was never going to get testosterone on the NHS.” - An individual going through menopause

I thought I may have early onset dementia

“Had been prescribed different medication that quickly became ineffective and felt physically and mentally awful, it was a last resort! I was at university and finding it difficult to recall information or think straight, I thought I may have early onset dementia.” - An individual going through menopause



CONTENT WARNING

The next two pages mention suicide and self-harm.

Premenstrual Dysphoric Disorder (PMDD)

A closer look:

Eight people shared their experiences of accessing services for PMDD in Lincolnshire. They highlighted difficulties getting diagnosed due to not being listened to, a lack of understanding and knowledge around the condition.

It took four years of going to gynae before I was diagnosed

“Took me years to diagnose me with Premenstrual Dysphoric Disorder. From the age of 16 I was on and off antidepressants and told I had anxiety. This was linked to my hormones and took me to attend counselling for a counsellor to notice the ups and downs with my moods were linked to my hormones. I thought premenstrual syndrome (PMS) was only a few days so struggling for two to three weeks each month didn't dawn on me it could be my body's reaction to my hormones. It then took four years of going to gynae before I was diagnosed.”

I don't feel I can fight

“Can hardly get into see a GP when I really need to. Don't feel I can fight for an appointment when not sure myself.”

Same old excuses

“Yes. Any treatment or testing would be nice but unfortunately you get the same old excuses of 'just lose weight', 'it's all in your head' or 'it's just normal for us women to be in constant pain and suicidal'.”

No end in sight

“It took 20 years to be diagnosed. I was diagnosed with depression, had counselling was put on antidepressants I was sent several times to Peter Hodgkins Centre for regular appointments. I was told it's just something that women have to deal with. Thankfully 2 years ago a GP took me seriously and I kept a diary of my symptoms which made it easier to diagnose me with PMDD. It has been debilitating. I was so pleased to finally have an answer but getting help is ridiculous. I have been waiting over a year for an appointment with gynecologist with no end in sight.”

I'm still struggling

"Have been diagnosed with generalised anxiety instead and later ADHD which has a high comorbidity with PMDD. Have said I have painful periods and the week before I feel suicidal and can't do focus/flu symptoms but was just told to take Ibuprofen. I have ended up having to look online for ways to treat and now take magnesium and inositol supplements and take antihistamines in the week leading up to my period. I'm still struggling a lot and wondering if I may need to pursue the diagnosis route again but have not bothered asking my GP about it yet because I'm not prepared to have my concerns diminished again."

Strong urges to cut myself

"I tracked my PMDD symptoms for four months to highlight patterns. It was getting bad and I was having strong urges to cut myself so knew it wasn't normal. With all my evidence I wrote to askmyGP. The GP called me back and told be not to be offended but it was because I was overweight. If I lost a stone then he would prescribe me weightloss meds (I was three stone overweight) I complained about him to another GP who sent me a link to the NHS weightloss page. They wouldn't prescribe me the pill – because of my weight even though I requested the progesterone only pill which is fine. I bought the pill online, it helped so much, I was able to lose three stone and I'm ok-ish now. Symptoms have begun to creep in though (like the pre-menstrual three-day migraines) I joined a support group on facebook who say that this normally happens. I'm not sure what my next steps will be, I can't imagine that I'll get any help from my doctor."

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Menstruation, Menopause and the Criminal Justice System

A closer look:

An individual who attended one of the focus groups shared their experience of menstrual health and menstruation within the criminal justice system.

We're still in the Dark Ages

"I work in the criminal justice field. So I've talked to a lot of women, particularly about PMS, emotional dysregulation, and menstrual times because that sometimes can be not a rationale but a contributory factor to why they're actually in the criminal justice system.

I do talk to them an awful lot about their menstruation and they look at me sometimes, I think some of the women look at me gone out because I go, do you think that has an impact? And it can take quite a while for people to line it up. I think it's because not enough is said about it. I've educated myself. I still wouldn't say I'm particularly great, but I don't think there's enough information out there about what it feels like, what the symptoms are.

I'm old enough to remember the Claire Rayner video of sanitary towels. We're still really in the Dark Ages, it's still something that gets pushed to one side or it's a women's own issue or a non issue."

Thinking about the justice system, what happens there?

"It gets very complicated. They are quite forward thinking. In the female area we do have sanitary products but what we don't have, which we've kind of raised a few times and we haven't really had a resolution, is we don't have changes of clothing. So what we do sometimes have is women will have come through the system and have bled over their clothing. There's nothing – we don't have anything within the court area. So people are being released into the community, with very little dignity and it makes it really, really difficult. It makes it extremely difficult. Prison is not much better. It's very much because the female population within the criminal justice service isn't huge. It's not something that has a lot of weight. It's very much a well as long as we provide sanitary products, we're doing our bit. Yeah, that is literally it. We've done our bit. We've told them where it is. That's it."



Emergency and Urgent Care

Respondents were asked “In the past 12 months, have you ever needed to access emergency or urgent care for your condition?”.

Overall

- 8% (35) shared they had accessed emergency or urgent care.
- Endometriosis had the highest percentage of people sharing they had needed to access emergency care for their condition at 17% (12). The reason for this appeared to primarily be due to unmanaged/uncontrolled pain.
- Some went on to discuss their experiences further with one respondent sharing a very positive experience they had at Louth Urgent Treatment Centre (UTC).
- For others, they did not have a positive experience, sharing they felt they were again “dismissed” and it is “just period pain”.

Did everything they could

“I accessed the urgent care at Louth hospital and I don’t have a bad word to say about them. At four in the morning despite not being able to do a lot for me regarding my endometriosis pain, and not having a gynaecologist there, they were reassuring and did everything they could and were so friendly in doing so. I don’t have a bad word about Louth’s urgent care.”

Scared doctors won’t believe me

“I had to contact 111 due to really intense pain that made me pass out. I didn’t end up going to A&E as the pain eventually went down and I wanted the comfort of my home. I get scared doctors won’t believe me.”

“Told its just period pains and to go and go see my GP.”

“Very dismissive attitude...its period pain... Lack of understanding of the condition.”

Some respondents with suspected PCOS had to access emergency and urgent care due to their undiagnosed, unmanaged symptoms which then resulted in them finally being diagnosed.

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Emergency

Overall

All service users were then asked to reflect on their experience and rank a series of areas from very good to very poor.

Overall	Very good	Good	Poor	Very poor	N/A or prefer not to say	Overall
Being able to access care for your condition when you need to	7% (27)	22% (85)	30% (116)	33% (130)	8% (33)	POOR 63% (146)
Listening to you	7% (29)	23% (89)	28% (108)	36% (138)	6% (23)	POOR 64% (246)
Explaining tests and treatment	7% (26)	27% (107)	27% (105)	28% (108)	12% (45)	POOR 55% (213)
Involving you in decisions about your care	10% (37)	31% (119)	25% (97)	24% (93)	11% (41)	POOR 49% (190)
Offering you different forms of treatment not just medication	3% (12)	11% (43)	24% (92)	44% (171)	18% (70)	POOR 68% (263)
Treating you with care and concern	10% (39)	27% (104)	29% (111)	26% (100)	9% (34)	POOR 55% (211)
Addressing your needs or making plans to do so	7% (27)	21% (82)	34% (132)	29% (111)	9% (35)	POOR 63% (243)

Overall

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Communicating with you clearly about your care	8% (31)	24% (94)	31% (121)	27% (107)	9% (37)	POOR 58% (228)
Providing you with information about your condition, treatment and care	6% (24)	15% (58)	34% (132)	35% (135)	10% (40)	POOR 69% 267
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	3% (11)	13% (51)	23% (87)	33% (126)	29% (111)	POOR 56% (213)

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What works well?

For a minority of respondents, the following was highlighted as working well:



**Quick and easy
access to
appointments
(both primary
and secondary
care)**



**Interested,
knowledgeable
and supportive
professionals**



Being listened to



**Being referred
when needed**



**Follow-ups
and reviews**



**Responsive and
proactive care**

During the focus groups, the work LPFT has done around menopausal health was highlighted as well as ULHT's menopause clinic. Those working in LPFT highlighted the value of the henpicked training (menopause in the workplace training), greater awareness of menopausal symptoms and creating a supportive and understanding environment. They also highlighted the other positive work they've done around menstrual health such as their period dignity campaign. The following comments were shared during the focus groups:

"I know ULHT have got their menopause clinic which is amazing. But that needs to be like, for all women. I said to my mum you'll have to come and work for the NHS, for the menopause support. I mean it's a good recruitment drive for us. It's an amazing initiative."

"It's been that popular that they currently have a waiting list for 12 weeks and that's just for ULHT staff. So that's like how popular it is, how needed it is. You can imagine how big a team you'd need to cover the whole of Lincolnshire. The feedback has been astounding really."

"I think we as an organisation have done quite a lot and what we can in terms of we've got a menopause policy but also things like we're currently expanding we've got our period dignity campaign that we're doing so we have all of our products in there should be in every female toilet. We're looking to expand that and roll it out so it's in all toilets so, it includes our trans-community as well and also looking at it's not just about period dignity, but looking at continence underwear. I mean as a sideline we're looking at breast pads and things for our breastfeeding mothers. We're doing what we can but without the support of primary care and healthcare services outside for our women who are our staff there's only so much we can do." – LPFT

"As a trust, I feel that we are as a general rule quite understanding. We're doing a lot of work around and a lot of support and advice around it and I do think we're quite passionate about it. I do think as a trust, we've encouraged it as a whole it's fed down to us a lot to kind of role model that behaviour towards it anyway and be that be like that. So I would hope, I do feel this across the trust we really invest in time into it with I mean our well-being team is offering support groups and reasonable adjustments with we have we do offer them to staff." – LPFT

Moving forward, there should be a focus on amplifying this good practice across the system to ensure equitable experiences for everyone.

What could be improved?

Some improvements and suggestions have been explored throughout the report. Suggestions on how to improve menstrual and menopausal care in Lincolnshire included:



Listening to service users and taking them seriously



Quicker access to diagnostic tests e.g. blood tests and scans



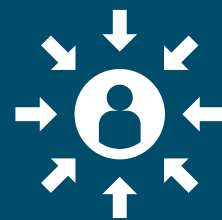
More emotional and well-being support for service users



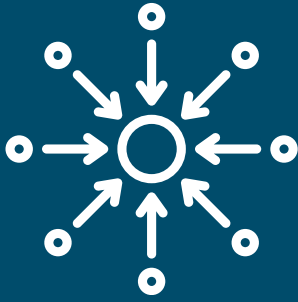
Review the training for healthcare professionals, on menstrual and menopausal health. Especially for those in primary care who are the first port of call for many on menstrual and menopausal health issues



Greater awareness and acknowledgement of the impact these conditions can have on mental health, wellbeing, work and relationships (in the healthcare system and beyond)



Person-centred, individualised care



A dedicated hub or “one-stop shop” for information about signs/symptoms and management strategies. A place to direct queries which don’t warrant a GP appointment



Stronger public health messaging around menstrual and menopausal health e.g. signs, symptoms, what is “normal” and how to stay well. This should be for everyone not just a specific age or gender

Area-specific improvements included:

- Endometriosis – more local specialist support. A professional also highlighted the lack of knowledge amongst other professionals in regard to the support available in Lincolnshire for those with endometriosis.
- Menopause – menopause clinics and less rigid diagnostic criteria i.e. people being told they are “too young”.
- PCOS – more sensitive and realistic support around weight management.

What did professionals say?

Patients travel hours out of county

“There is no specialist endometriosis centre in Lincolnshire, leading patients to travel hours out of county. The professionals at these hospitals are then unaware of the support available to Lincolnshire residents. Awareness of teams and support services of the complexity of endometriosis is extremely low leading individuals to rely on social media forums and groups for support.”

Working in silos

“Individually services such as the GP with special interest service, secondary care gynae service, Lincolnshire Sexual Health, continence service etc provide good quality evidence based practice but they are working in silos.”

A one-stop shop site

“We could do with a one-stop shop site. An internet site. There's a one stop shop that says these are all the pills and stuff you can use. These are all the things you need to know about the menopause. These are all the things you need to know about PMS, PMT, and PMDD.”

Unable to safely support patients

“GP, Nurse, Gynaecology consultant awareness of endometriosis and that it is not just a 'bad period' which so many Lincolnshire healthcare professionals have told me. We need better diagnostic services. We have to improve access to fertility treatment and those of us treated out of county are not eligible for fertility treatment there and the Lincolnshire ICB do not fund this. Fertility specialists in Lincolnshire are not aware of the extent of endometriosis and are therefore unable to safely support this cohort of patients which takes away the opportunity to conceive from people.”

So many women simply don't know enough about their bodies

“Add a tick box on to the Arden's template at point of smear and five-yearly NHS health check to have a conversation re menopause or perimenopause with the pt. So many women simply don't know enough about their bodies- they think that if they are still having periods they can't be perimenopausal - so they struggle with weight/carb craving, flushes, mental health etc etc. if they knew the signs and had support- life would be so much better for so many women!”

Lack of joined up working

“Accessing good quality assessment and management of these conditions is a challenge. Some of this is due to there not being enough specialist services and long waiting times for accessing the services that are available. Patient education and empowerment is also key to how women seek solutions to these conditions. There is a lack of joined up working between the various womens' healthcare providers in the county is a further challenge which leads to women seeing multiple providers for the same problem depending on how they present themselves to a first contact practitioner, be it a GP, sexual health service or secondary care specialists service. A one-stop service that has expert resources could address all the above challenges.”

Feels like men have written it

“I definitely think that there's more public health messaging that we could do. You just don't see it really, do you? You don't see it and whatever it is, is so cliché. I've not started going through the menopause, but what I've learnt its hell. I've loved doing the henpicked training because I've learned so much about it. And yeah, it prepares you as well. I feel more prepared but also you don't realise all of these different things that people experience. It's almost like we need like less cliché public health messaging. It just needs to be real. It feels like, I mean, I'm, I'm going to say it. It feels like men have written it, to be honest, not menopausal women.”

A one-stop shop would be amazing

“There is more and more going on with women’s health hubs. I think there would be great benefit in that in some ways because it would hopefully be a group of interested people and a one-stop shop to get scans and an opinion and treatment all in one place would be hugely beneficial. For these women of reproductive age, getting to clinics and getting stuff done is complicated we have busy lives, children and parents we are looking after, jobs and houses, and all this kind of stuff. Being able to go for your scan on one day, bloods on another is a right palaver and I’m sure that is a barrier in some ways as well. Having that one stop shop would be amazing, particularly if we could have interested professionals that could and would do everything all in one spot would be brilliant.”

We don’t have the resources or the time

“I do think it is sad that is kind of thing is moving away from GPs, because I think we do this kind of stuff really well as GPs if we are given the time and resources to do it but I don’t think we have the resources or time to do it. I think that is a real shame, things are being compartmentalised. You are going to see someone completely different for your PMDD, whereas that would be best done by your GP. But maybe there is a place for specialist help initially, then sending them back to their GP. A lot of this is about diagnostics and simple things that can be done and then continued. Idea of patients coming back for follow-up or multiple issues is proper general practice. That’s really valuable and how it should be for her and me to have that continuity of care. I’m inclined to think that the health hubs are the way forward because they would give quick and easy access to important things.” – A GP discussing the value of a “one-stop shop”

Single point of access

“A Women’s Health Hub that joins up the various services available across the county can be useful. Such a hub could essentially function as a single point of access for health professional and patients alike by not just being a repository of directory of services but as hub that can easily access expert opinion and services in the most effective manner for the benefit of the woman.” – A professional talking about the value of a “one-stop shop”

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Final Thoughts

We would again like to thank everyone who supported this project, especially the 450 service users and 18 professionals who shared their views on menstrual and menopausal health in Lincolnshire.

Common themes persist throughout the report, spanning areas such as endometriosis, PCOS, menopause, perimenopause and other menstrual health conditions. Service users and professionals raised many of the same issues.

Some of the key issues raised were:

Diagnosis

- Symptoms being ignored and/or normalised.
- Women not being listened to.
- A lack of knowledge or interest in menstrual and menopausal health among professionals.
- Long waiting times to be diagnosed.

Mental Health

- The impact of menstrual and menopausal health is poorly understood and rarely acknowledged.
- There is also a need for more emotional and wellbeing support for those navigating menopause and/or menstrual health conditions.

Treatment and Management

- Symptoms were mainly managed via medication. Access to HRT and effective pain relief for endometriosis were highlighted as issues.
- Service users highlighted a need for more holistic support to complement the use of medication. There were calls for more emotional and wellbeing support and information on alternative therapies and lifestyle changes.

What works well?

For a minority of respondents, the following was highlighted as working well:

- Quick and easy access to appointments (however, this was not the experience for the majority).
- Interested, knowledgeable and supportive professionals.
- Being listened to and referred when needed.

What could be improved?

The majority of respondents highlighted the following as needing improvement:

- Listening to service users and taking them seriously.
- Quicker access to diagnostic tests.
- Review the training for healthcare professionals, on menstrual and menopausal health, especially for those in primary care who are the first port of call for many on menstrual and menopausal health issues.

Final Thoughts

- Information on how to cope with their symptoms and condition(s) whilst waiting for additional tests.
- Greater awareness and acknowledgement of the impact these conditions can have on mental health, wellbeing, work and relationships (in the healthcare system and beyond).
- A dedicated hub or “one-stop shop” for information about signs/symptoms and management strategies. A place to direct queries which don’t warrant a GP appointment.
- Stronger public health messaging around menstrual and menopausal health e.g. signs, symptoms, what is “normal” and how to stay well. This should be for everyone not just a specific age or gender.

From the experiences shared, good practice appeared to relate to individual professionals and their knowledge and interest in menstrual and menopausal health. The positive work done by LPFT in regard to menstrual and menopausal health was highlighted and the ULHT menopause clinic.

However, comments made by both service users and professionals suggests a “postcode lottery” exists, with women in the same PCNs and friendship groups having vastly different experiences. In the future, work should focus on replicating good practice across the system to ensure more equitable experiences.

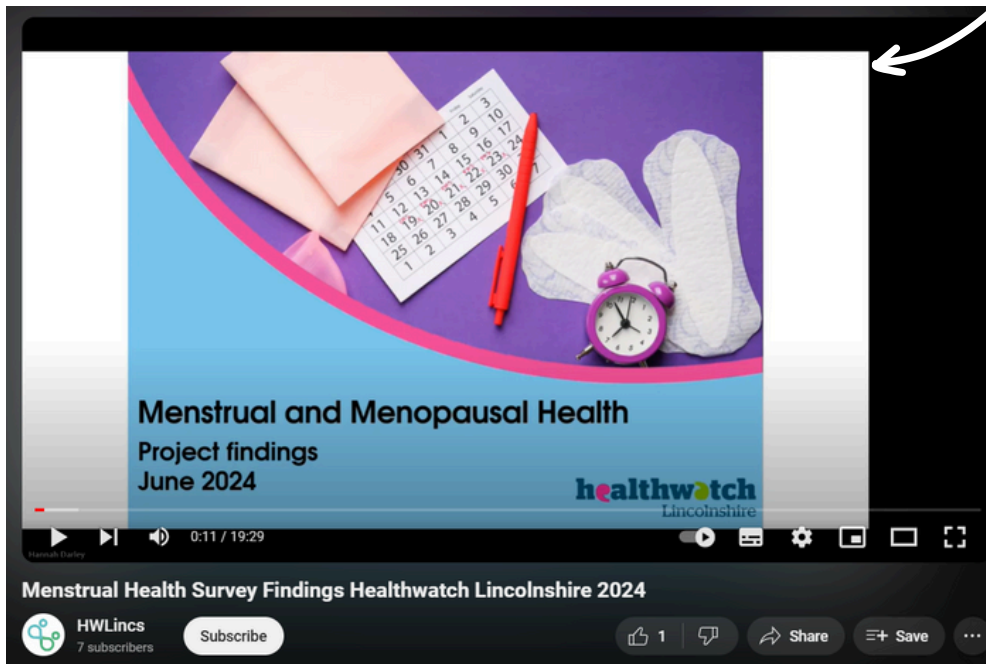
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Workshop

To share the survey results, we held a workshop with health and care professionals to foster a collaborative and co-production approach to enhancing menstrual health and overall wellbeing for women in our community. Attendees were invited to comment on our findings, as well as to share their insights and initiatives. The first part of the workshop was a presentation of our findings, which is available to watch on our YouTube channel HWLincs:

Click the picture to watch our presentation



Workshop attendees included health and care professionals from our local hospital, mental health and community health trusts, primary care, public health, and the voluntary and community sector. A national menopause support charity was also present.

The draft report was then shared with attendees as well as being sent to other key stakeholder in the health and care system, voluntary and community sector and beyond. The report was shared to allow various individuals and organisations to comment on the findings and share their own initiatives and work around women’s health.

Women's Health Initiatives

Every-One: The Peri Meri Menopause Moments Project

Project literature:

“A new and innovative project is being delivered across Lincolnshire by Every-One – The Peri Meri Menopause Moments Project started in February 2024. It is a fully funded three-year project supported by The National Lottery Community Fund and is being delivered across Lincolnshire.

Our ethos is to engage, encourage, support and inform... there is so much out there around menopause, that it is so difficult to find what is fact or fiction! We aim to ensure and encourage individuals to explore all the options and activities available to them, how diet and exercise can support their journey, recognising that it's not just one thing that suits individuals and that everyone is different...but ultimately giving them informed choices!

Our overall aim is to support the menopause journey through a variety of ways:

- A programme for individuals called Peri Meri Menopause Moments – which is delivered in the community, it is delivered over five weeks, covering symptoms, mental health, medications and health, wellbeing & holistic support.
- Working with employers to assess their organisational needs offering 12 hours free support and engagement, producing an action plan of their needs.
- We are working directly with partners; these organisations, professionals and individuals offer health, wellbeing, holistic therapies – to ensure we inform and signpost to the great work that is already out there across the county.
- We are also undertaking, three research areas; menopause and cancer; men and menopause and those that are experiencing early on-set menopause. This research will be co-ordinated and conducted through a co-production approach with professionals and those with lived experience.

We initially trialled the Peri Meri Menopause Programme utilising the Innovation, Shine Lincolnshire Managed Funds in 2023, delivering 3 cohorts. Feedback was amazing and very positive, we identified through such feedback that mental health support and referral is essential and was quite apparent just how much help is needed through the delivery process – Every-One was therefore successful in accessing and utilising Sustainability funding through Shine Managed Funding for 3 years, and will align alongside the Peri Meri Menopause Moments project and will also be raising awareness around menopause and mental health.

Women’s Health Initiatives

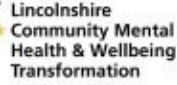
Every-One: The Peri Meri Menopause Moments Project

Project literature continued:

We are very early in the journey of assessment and how the project will develop, but it is very clear, so early on just how essential this menopause support is needed across the county (and beyond!).

If you would like to get involved, want to access the menopause programme, please go to our website [Peri Meri Menopause Moments - Every-One](#) for more information, or alternatively email us at memo@every-one.org.uk.

It’s very early days for our overall Peri Meri project model, but it does seem to be heading in the right direction... the main thing that is quite apparent is that people just want to know the facts and the various options available to them or others.. to be able to access professional advice around medications, but ensuring that also links up seamlessly to raise awareness of all the other health and wellbeing options that supports individuals not only physically but mentally on their menopause journey.”



Women's Health Initiatives

Gynaecology and Primary Care Services Integration (GPSI) – Dr Rama Mark

Project literature:

Gynaecology and Primary Care Services Integration (GPSI) involves collaborative initiatives that incorporate gynaecological services into primary care settings, providing comprehensive and accessible care for women's reproductive health while ensuring continuity of care. – [NHS England](#)

"The GPSI service has been running since 2005. It largely caters to women in the western part of Lincoln city and surrounding villages. The service manages women with gynaecological conditions such as PCOS, menstrual issues, pelvic pain, menopausal and perimenopausal issues. It also offers Insertions of Mirena for HRT, period control and contraception and supporting vaginal pessary insertions for prolapses and medical management of uro-gynaecological issues. The service is accessed via the EACH triage process.

The service has been very well received by patients and referring clinicians alike for offering short waiting times, easy accessibility, holistic management and being a good "listening service" for patients who have often struggled to get satisfactory answers to their women's health issues.

The service has limited funding and therefore has not been expanded to cover the larger geography of Lincolnshire."

Feedback for Dr Mark and the service:

"The doctor was very caring and proactive referring me to help with all aspects of my consultation. I would happily see her again. The nurse I saw and the doctor were a credit to the NHS. I am now awaiting a scan when a slot becomes available to hopefully bring me more information and peace of mind if nothing is found. The GP I saw definitely deserves an excellent rating and thanks for what she's doing. "

"Dr Mark was amazing I can not begin to explain the difficulties I have with getting a smear. I also am a serious sexual assault survivor and find the procedure triggering. I so nearly didn't go but the cancer worm was in my head. Dr Mark was amazing, got down to business, and wasn't going to be beaten. I felt supported and safe with Dr Mark and the outstanding nurse who literally held my hand. It's so hard to find my pesky cervix. Thank you both so much, I would not hesitate to come back next time."

"I felt I could talk to her, very happy with every visit. Wish all the doctors where like her, she made you feel more like a good friend."

Women's Health Initiatives

Gynaecology and Primary Care Services Integration (GPSI) – Dr Rama Mark

Project literature continued:

Thoughts on the findings from our work

"Inconsistencies and inequalities in the access and use of blood tests to diagnose menopause were highlighted."

"These inconsistencies and inequalities highlight the need for a uniform approach to be taken by clinicians across the spectrum of available services. This latter can be achieved by implementing robust evidence-based management pathways that healthcare professionals dealing with women's menstrual and menopausal health can access easily. It also requires easily accessible educational material that professionals can signpost patients to. This dual approach to educate healthcare professionals and patients alike can reduce both professional dissatisfaction in care provision by the healthcare professional and improve patient experience in how their concerns are managed without delay."

"A dedicated hub or "one-stop shop" for information about signs/symptoms and management strategies. A place to direct queries which don't warrant a GP appointment."

"With adequate funding such a service could have dedicated primary care health care professionals providing expert management of menstrual and menopausal problems and interventions such as Mirena insertions in primary care avoiding long waiting times in secondary care. Such a service along the lines of the GPSI service would therefore help reduce waiting times for those who do actually need secondary care intervention."



Women's Health Initiatives

Public Health

"We've recently reprocured our long-acting reversible contraception (LARC) services and the work we're engaged in now is to improve services and outcomes. We want to improve access and uptake of LARC in primary care (implants, copper coils and hormonal coils like Mirena). Two of the issues raised in the report – access to copper coils and Mirena – we are looking to address. For example, from today GPs will be paid for providing Mirenas for non-contraceptive/gynaecological purposes, whereas previously they weren't paid for this and would have referred women to secondary care."

A vision for women's health in Lincolnshire

"The difficulties faced by women in current healthcare settings are extensive, and many result from a lack of focus on women-specific issues. This hinders the ability of women to discover and prevent problems that will likely have a more significant impact later in life. To tackle the inequalities faced by women in healthcare, the government launched the first Women's Health Strategy (WHS) in 2021.

"The WHS sets out a 10-year timeline to improve how health and care systems listen and respond to women, the overarching aim being to improve the health of women and girls across their lifetime. The strategy was informed by the Call for Evidence, a large-scale survey of nearly 100,000 people in England, who offered their views and experiences as women and healthcare professionals."

"The survey found that women did not feel listened to in current healthcare services and felt that the system was failing them. The WHS therefore placed a strong focus on ensuring women's voices were heard and using female-oriented research to develop services that addressed the concerns and needs of women. The misconceptions surrounding women's health stem from a long history of male bias and female exclusion. Misunderstanding, misconception, and stigma still exist within today's society and have a strong impact on the care women receive. Empowerment and inclusion were also emphasised within the strategy, as well as addressing the difficulties women have with navigating health and care systems."

"Ensuring that local work addresses the issue of women not feeling listened to is key to promoting an inclusive health and care system that addresses health disparities and does not leave women feeling dismissed or disregarded. The development of local women's health hubs is an opportunity to change how women are listened to, empowered and included in the health and care system. This ambition, together with findings from a local needs assessment on women's health conducted by LCC Public Health, have guided the development of the following goals and actions for women's health in Lincolnshire. able to live well and pursue their ambitions."

Women's Health Initiatives

Public Health

Ambition

All Lincolnshire women and girls have choice and control over their health and feel able to live well and pursue their ambitions.

Goals to tackle women's health disparities:

1. Women and girls' voices are at the center of service design and delivery

- Develop platforms for women to talk about their needs and priorities, to feedback and have a say on how services are delivered.
- Conduct research and engagement with local women.

2. Women and girls are empowered to maintain their health and wellbeing

- Provide easily available information to support women and girls to support them in making decisions about their own health.
- Support the delivery of high-quality education on women's health in schools and higher/further education.
- Inclusive health promotion that addresses stigma and taboos associated with women's health.
- Explore the benefits of peer support models.

3. Women and girls feel listened to and have their concerns taken seriously

- Provide ongoing education, training and support to healthcare professionals regarding women's health conditions and delivering better care to women.

4. Women and girls have better access to and experiences of care

- Have a system-wide approach to women's health that strives to deliver care at the right time, in the right place, and by the right person; prevent unnecessary secondary care referrals; commission collaboratively to make best use of resources; prioritise holistic women's health in local strategies; and provide accountability for women's health outcomes.
- Develop a joint local women's health needs assessment and intelligence hub.
- Consider developing Lincolnshire's existing LARC model by supporting GPs to provide other services for menstrual health, gynaecological conditions and menopause.
- Review local systems and pathways to ensure that women from inclusion groups are not systemically discriminated against or excluded from care (for example, GP registration for women without a fixed address; processes for inviting people with learning disabilities and trans men for cervical screening)
- Develop a single point of access model.

Women's Health Initiatives

Public Health

Priority actions identified through local needs assessment

Preconception and maternal health

A. Discuss all methods of contraception with women during pregnancy and initiate their method of choice prior to discharge from maternity services.

Contraception

B. Improve access to the full range of contraceptive options and increase uptake of effective methods of contraception (including provision of LARC).

- Undertake a review of GP LARC provision in Lincolnshire, including training needs and capacity, following the outcome of GP LARC service reprocurement, and work with targeted areas to increase LARC prescription rates.

Menstrual health and gynaecology

C. Ensure every woman can access a practitioner in their area who is able to provide support, diagnosis and treatment for their menstrual health including pain, heavy bleeding and premenstrual mood disturbance.

- LCC and ICB to agree on a revised charging arrangement for non-contraceptive LARC, allowing all GPs with a LARC service contract to offer and be reimbursed for prescribing LARC for managing menstrual health conditions.
- Potential expansion of the GPwSI community gynaecology service.
- Provide training, education to GPs to increase confidence in the management of menstrual health.

D. Develop a community gynaecology service to manage non-emergency secondary care referrals in primary care.

- Potential expansion of the GPwSI community gynaecology service.

Abortion care

E. Abortion services should comply with NICE guidelines, with all women and girls seeking abortion having timely access to a choice of method (medical or surgical), including the option to self-refer directly to a service, as well as access to the full range of contraceptive methods.

- Undertake a review of abortion services in Lincolnshire and disparities in access.
- Consider introducing a remote telemedicine service for eligible woman at <9 weeks gestation.
- Consider increasing the gestation limit of surgical abortions in Lincolnshire to 14 weeks (as during Covid-19 pandemic) and expand the provision of MVAs offered at Lincoln.
- Ensure that the full range of reversible contraceptive options are available for women on the same day as their surgical or medical abortion.

Women's Health Initiatives

Public Health

Priority actions identified through local needs assessment

Menopause care

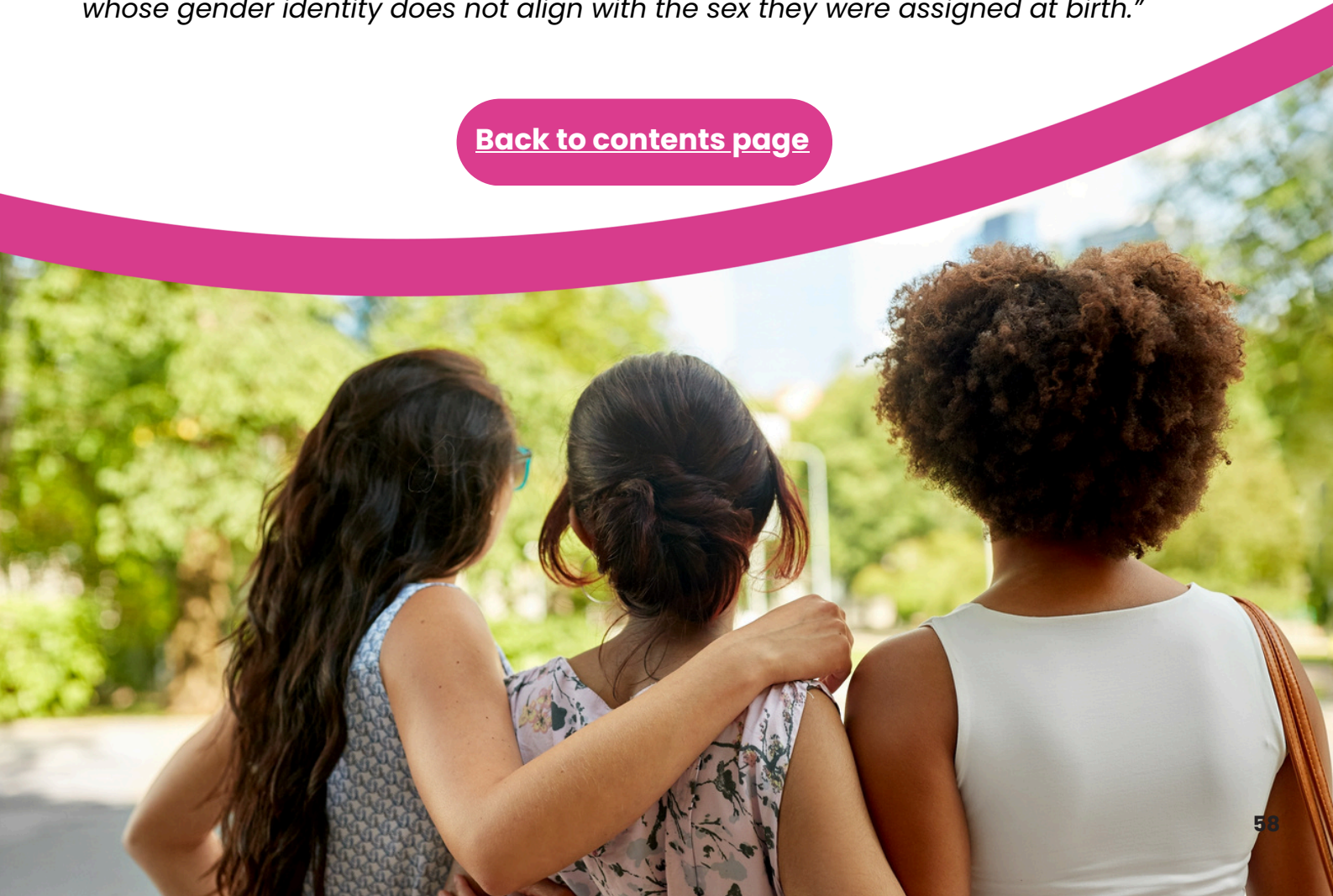
F. Ensure every woman can access a practitioner in their local area who is able to provide menopause care, support them to manage symptoms and choose appropriate treatment if required.

- Consider expanding the menopause service offered in Lincolnshire to ensure timely access to support and treatment.
- Provide training, education and support to GPs to increase confidence in the management of menopause, focusing initially on areas where HRT prescribing rates are lower.

A note on language:

Within this document, the terms 'woman' and 'women's health' are used. It is important to acknowledge that it is not only people who identify as women (or girls) who access women's health services. The terms 'woman' and 'women's health' are used for brevity, on the understanding that trans men and non-binary individuals assigned female at birth also require access to these services. Delivery of care must therefore be appropriate, inclusive, and sensitive to the needs of those individuals whose gender identity does not align with the sex they were assigned at birth."

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Recommendations

Key improvements that can be implemented across all services for short-term benefits to be seen by residents.

1. Improve listening and acknowledgement

- **Evidence from the report:**

- **Diagnosis issues:** Many respondents felt that their symptoms were dismissed or not taken seriously by healthcare professionals. Women reported hearing phrases such as "it's your age," "you're too young," or "that's what periods are like" (p. 13-14). Respondents mentioned they felt "gaslighted" or made to feel like their symptoms were "all in your head" (p. 14). There were multiple accounts of feeling ignored or not believed, especially around conditions such as endometriosis and PCOS.

- **Potential solutions:**

- Support professionals to better understand menstrual health conditions and menopause, incorporating symptoms and management.
- Create and share case studies with healthcare professionals who face these scenarios to promote best practice.

2. Increase awareness and knowledge of menstrual and menopausal health

- **Evidence from the report:**

- **Lack of knowledge among healthcare professionals and the public:**

The report highlights a significant lack of knowledge and awareness among healthcare professionals regarding menstrual and menopausal health conditions. Respondents frequently reported that professionals appeared "uninformed" or "uninterested," especially when presenting less common symptoms (p. 18-19). A lack of understanding of the signs and symptoms was also highlighted among the general public (p.33)

- **Potential solutions:**

- Launch an awareness campaign targeting healthcare professionals to bridge the knowledge gap regarding menstrual and menopausal health.
- Create an information resource for dissemination across health, care and community service providers.

Recommendations

3. Review how patients are supported while waiting for additional tests and treatment

- **Evidence from the report:**

- **Lack of support during waiting periods:** The report highlights an absence of support for patients waiting for diagnosis or treatment. Respondents indicated they often received no information on how to manage symptoms or access interim support (p. 23).
- **Mental health impact:** The lack of support while waiting contributed to worsening mental health for many patients, who felt isolated and without options (p. 27-29).

- **Potential solutions:**

- Review resources available to waiting patients and how they are communicated with during this time. If needed, collaborate with people who have lived or current experience to co-produce materials that will better support patients during their wait for tests and treatment.



Considerations

These are to inform future planning, development and improvement of services for long-term benefits to be realised for residents.

1. Review and develop training

- Establish comprehensive educational campaigns targeting the public, particularly in seldom-heard communities, using social media, print, and digital resources to raise awareness on these health conditions.
- Offer training for healthcare professionals directly or indirectly involved with people who may access services for their menstrual and menopausal health.
- Develop a toolkit with ongoing resources for professionals and the public, incorporating digital tools, webinars, and community workshops to ensure sustainable long-term impact.

2. Develop a consistent approach to providing accessible information and services

- Create a one-stop shop within women's health hubs where individuals can access information, diagnosis, and support for menstrual and menopausal health. This could include a signposting directory created by those with lived or living experience to cover information such as condition management, mental health support and alternative therapies. The directory could be on a webpage with copies in alternative formats to meet different needs. Professionals could direct individuals to this information.
- Launch an awareness campaign targeting the public regarding menstrual and menopausal health information and services.

Demographics

Demographic	Percentage (number)
Age 18 – 24 25 – 49 50 – 64 65 – 79	2% (7) 53% (197) 43% (161) 2% (8)
Gender Male Female Non-binary Prefer to self-describe	0.33% (1) 98% (367) 0.33% (1) 0.33% (1)
Have you gone through any part of a process, or do you intend to bring your physical sex appearance, and/or your gender role, more in line with your gender identity? Yes Prefer not to say	0.2% (1) 0.8% (3)
Ethnicity Asian/Asian British: Indian Asian/Asian British: Pakistani Mixed/Multiple ethnic groups: Asian and White White: British/English/Northern Irish /Scottish/Welsh White: Irish White: Any other White background Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic groups background Prefer not to say	0.84% (3) 0.28% (1) 1.11% (4) 88.30% (317) 1.67% (6) 5.57% (20) 0.84% (3) 1.39% (5)

Demographics

Demographic	Percentage (number)
I am a veteran I am a serving member of the armed forces	2% (11) 0.2% (1)
I work in farming/agriculture	2% (11)
I work in health and/or social care	37% (167)
I am a new parent	2% (8)
I am a carer	10% (46)
I belong to the LGBTQ+ community	3% (14)
I have a long-term health condition	26% (115)
I consider myself to be neurodiverse	13% (59)
I have a disability	8% (36)

Contact Us

Healthwatch Lincolnshire
Rooms 33-35, The Len Medlock Centre
St Georges Road
Boston
Lincs
PE21 8YB

www.healthwatchlincolnshire.co.uk

t: 01205 820892

e: info@healthwatchlincolnshire.co.uk

X: @HealthwatchLinc

[Facebook.com/healthwatchlincolnshire](https://www.facebook.com/healthwatchlincolnshire)

If you require this report in an alternative format, please contact us at the address above.

We know that you want local services that work for you, your friends and your family.

That's why we want you to share your experiences of using health and care services with us – both good and bad. We use your voice to encourage those who run services to act on what matters to you.