A service based on kindness and respect

The health experiences of women with long term conditions in York

September 2026

healthwatch York

Contents

Content warning: These stories include references to misogyny, mental ill-health, distress, self-harm, violence and discrimination. Please only read these when you feel able to.

Acknowledgements:
Thank you to all the women who shared their stories with us and allowed us to share them in this report. Thanks to the organisations who circulated the information and shared anonymous feedback they had heard.

Where names have been used, they have been changed.

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Executive Summary

This report builds on our 2025 report, Women's health: stories of health experiences in York[1]. In that report we brought together the experiences of women shared with Healthwatch York directly or through partner organisations about any contact with a healthcare provider. As a result of what we heard, we wanted to explore the experience of women with long term conditions, especially those that particularly affect women including ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome), endometriosis, osteoporosis, PoTS (Postural Orthostatic Tachycardia Syndrome), PMOS (polyendocrine metabolic ovarian syndrome) also known as PCOS (polycystic ovary syndrome), fibromyalgia, EDS (Ehlers-Danlos Syndromes) and more.

This report shares women's experiences of these, and other, conditions to identify themes in the health care and support they received.

Overall, what needs to change can be summarised as follows:

1. Listen to women, believe them and treat them with dignity
2. Improve the knowledge and understanding of women's long-term health conditions
3. Reduce delays in diagnosis and treatment
4. Deliver co-ordinated, person-centred care for complex conditions
5. Improve support for self-management and improved quality of life
6. Improve access and make services more accessible
7. Strengthen specialist services and reduce postcode variation

[1] https://www.healthwatchyork.co.uk/seecmsfile/?id=120

As with our earlier report, we heard that women want to be listened to, believed and taken seriously by healthcare professionals with knowledge of their condition, understanding and kindness.

We heard from women where their diagnosis had taken from months to more than 20 years and about long waiting times to see specialists or receive treatment if there is treatment for their condition.

We also heard from women who were told their physical health condition was mental ill health and experienced medical misogyny leading to significant distress before an eventual diagnosis.

Some women described excellent care from clinicians who listened, showed empathy and worked in partnership with them to provide care and treatment.

We finished the data collection for this report as the government's renewed Women's Health Strategy for England was published. The information in this report echoes the information shared as part of the development of that strategy, which included large scale consultations and feedback from local and national Healthwatch, including our earlier report on women's experiences of local health services. If that renewed strategy is fully implemented many women in the future may not experience the challenges, mis-diagnosis, ignorance and misogyny that the women we heard from have experienced.

However, we will continue to listen to and share women's experiences of healthcare, to call for change and hold providers to account.

A message from our Chair

It is good to see women's health being taken seriously nationally and locally with the launch of the renewed Women's Health Strategy for England and City of York Council's recent women's health needs assessment.

That said, while it is good to have this focus on women's health and recognition of the work needed to empower women to get the care they need, the proof of the strategies and plans will be the actions that do, or don't, follow. The women we have heard from and those we know are struggling in silence need action to come quickly.

It is amazing that in 2026 a women's health strategy and action plan are needed; that women are still experiencing poor or non-existent healthcare, particularly for women-specific conditions or those that are more likely to affect women; that there is so little research, data collection or accountability for improving women's health.

Following our previous report, we were delighted to be involved in Nimbuscare[2] organised training for GPs and other primary healthcare professionals on ME/CFS. The high levels of attendance at these sessions illustrates that there is a real demand among professionals for improved knowledge and understanding of these areas. It would be wonderful to see training taking place in relation to other conditions mentioned in this report.

We also look forward to seeing changes in the way healthcare for women is delivered, supported by funding for services and research that prioritises the needs and interests of women. Hopefully the next time Healthwatch York writes a report about women's health, it is to celebrate the positive changes and applaud the actions that have happened nationally, regionally and locally.

[2] https://www.nimbuscare.co.uk/

Background

Women make up 51% of the UK population. They generally live longer than men but spend more time in ill health. It is widely accepted that there is not enough focus on health conditions that only impact on women, or how conditions that affect both men and women may present differently and have different outcomes depending on who you are.

Renewed Women's Health Strategy for England

In April 2026, the UK Government published the Renewed Women's Health Strategy for England[3]. In the report, Secretary of State for Health and Social Care when launching the strategy said: "The NHS has a problem with basic, everyday sexism and an appalling culture of medical misogyny … Being ignored, gaslit, humiliated and disrespected are all-too-common experiences for far too many women."
The renewed strategy reflects the 2022 Women's Health Strategy[4].
The Renewed Women's Health Strategy should be seen within the context of the NHS 10 year plan for England[5]. This includes three shifts: emphasising prevention; moving more care to the community (neighbourhood health) and an increasing use of technology.

The Renewed Women's Health Strategy is structured around four commitments:

- To make women's voices and choices central in healthcare.
- To transform NHS performance and services that matter most to women.
- To support all women to lead healthy, prosperous lives.
- To create an approach to research and development that works for and empowers women.

[3] https://www.gov.uk/government/publications/renewed-womens-health-strategy-for-england
[4] https://www.gov.uk/government/publications/womens-health-strategy-for-england/womens-health-strategy-for-england
[5] https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future

In total 117 action points are listed under the above headings. A new national director of patient experience will oversee the collection of enhanced patient and carer feedback.

The Renewed Women's Health Strategy includes promises relevant to women with long term conditions including:

- Shorter waits for gynaecological care.
- Fewer painful procedures without informed consent or a choice of pain relief.
- Women to have better information and more control over their health through digital services.
- Women being listened to and taken seriously at the first time of asking.
- Fewer cases of women repeating their story.
- Women to have more control of their health through the course of their life.
- Reducing years-long diagnostic journeys with single points of access and redesigned referral pathways.
- More joined-up and co-ordinated neighbourhood-based care with multidisciplinary teams closer to home.
- Better management of chronic pain and long-term conditions.
- Greater use of data, patient feedback and accountability mechanisms to drive service improvement.

NICE

NICE has recently updated guidelines for endometriosis and included a fertility treatment pathway[6]. In July 2026, NICE approved the use of new technologies to help speed up the diagnosis of endometriosis in primary care[7]. It has updated the guideline on identification and management of menopause[8]. NICE is also currently updating

[6] https://www.nice.org.uk/news/articles/nice-recommends-new-dedicated-fertility-treatment-pathway-for-endometriosis
[7] https://www.nice.org.uk/news/articles/new-technologies-for-endometriosis-diagnosis-in-primary-care
[8] https://www.nice.org.uk/guidance/ng23

guidelines on ectopic pregnancy and developing guidance on PMOS (polyendocrine metabolic ovarian syndrome)[9].
Currently there are no NICE guidelines for EDS (Ehlers-Danlos Syndromes), PoTS (Postural Orthostatic Tachycardia Syndrome), fibromyalgia or MCAS (Mast Cell Activation Syndrome).

Medical misogyny and reproductive health

In December 2024, a report by the Women and Equalities Committee[10] (a Parliamentary Committee) warned that "women experiencing painful reproductive health conditions such as endometriosis, adenomyosis and heavy menstrual bleeding are frequently finding their symptoms 'normalised' and their 'pain dismissed' when seeking help." The report painted a damning picture of stigma, medical misogyny, poor education, and limited, often painful options for treatment.

Long term conditions and their impact on women

As part of this report we have heard from women with a range of conditions that either only affect or disproportionately affect women. These include ME/CFS, osteoporosis, Ehlers-Danlos Syndromes (EDS), rheumatoid arthritis, endometriosis, PMOS (polyendocrine metabolic ovarian syndrome), fibromyalgia and PoTS (Postural Orthostatic Tachycardia Syndrome).

Myalgic Encephalomyelitis also known as Chronic Fatigue Syndrome (ME/CFS)

ME/CFS affects 400,000 people in the UK, increasing to 1.35m when people with Long Covid who meet diagnostic criteria for ME are included[11]. Women are nearly four times more likely to be affected than men.

An independent report by the University of Exeter in 2025[12] highlighted significant delays in the diagnosis of ME, low satisfaction in specialist

[9] https://www.nice.org.uk/guidance/indevelopment/gid-hub10001
[10] https://committees.parliament.uk/publications/45909/documents/228040/default/
[11] https://www.actionforme.org.uk/supporting-you/what-is-me/#h-how-many-people
[12] https://news.exeter.ac.uk/faculty-of-health-and-life-sciences/earlier-diagnosis-and-better-care-needed-for-me-and-long-covid-patients-report-finds/

services and a need for improved self-management resources and better-coordinated care. 2025 research at the University of Edinburgh[13] has identified a 'lottery' in care for the disease, with a 50-fold variation in diagnosis rates. Researchers at Edinburgh University, reported in the Times, found people with ME "felt invisible and ignored" by the NHS, with many struggling to access support[14]. The report also highlighted the significant barriers to getting a diagnosis and ongoing help, as there is no diagnostic test and no cure.

In April 2026 the Department for Health and Social Care announced that it had paused commissioning a specialised service for very severe ME/CFS until April 2027[15] at the earliest. An NHS template service specification for mild and moderate ME is in development to guide care commissioners.

NHS England has developed three e-learning modules about ME/CFS for healthcare practitioners. However, these are voluntary and uptake has been minimal.

Due to significant research developments, such as the 2025 Decode ME study which identified genetic differences linked to the immune and nervous systems, understanding of ME and how people with the condition can best be supported continue to evolve.

Osteoporosis

More than two million women in England and Wales have osteoporosis. Its prevalence increases markedly, from approximately 2% at 50 to almost 50% at 80.[16]

The Royal Osteoporosis Society project, 'Tackling inequalities in osteoporosis care'[17] proposes that Fracture Liaison Services (FLS) are the

[13] https://link.springer.com/article/10.1186/s12889-025-22603-9

[14] https://archive.ph/56ero

[15] https://meaction.org.uk/news/2026/03/very-severe-service-planning-paused

[16] https://cks.nice.org.uk/topics/osteoporosis-prevention-of-fragility-fractures/background-information/prevalence/

[17] https://theros.org.uk/research/our-strategy-and-projects/supported-research-projects/

world standard model for systematically identifying and assessing people aged 50 and older who have had a fragility fracture and delivering a personalised treatment plan to prevent further fractures.

It says that "the FLS model is a proven game-changer, reducing the risk of re-fracture by between 30-40%. However, we know that a fifth of women who have broken a bone, break three or more before even being diagnosed. This is because after the first fracture there is a postcode lottery for access to a FLS. Having access to an FLS is not the whole solution. The effectiveness of the FLS model depends on the quality of the service provided and accessibility to treatments, and like coverage, this is also a postcode lottery." In York there is a local bone protection service pathway[18] which aims to identify patients who have had a bone fracture and reduce their risk of subsequent fractures.

Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD)

A 2019 study found that in Wales the prevalence of EDS is 70% women and 30% men[19]. The research also found there was a pronounced gender difference of eight and a half years in the mean age at diagnosis with women diagnosed later than men.

A 2017 report by Helen Harte, 'The experience of diagnosis with hypermobile Ehlers Danlos Syndrome: a narrative review'[20] explored current research to understand women's experience of being diagnosed. Its findings were similar to the feedback we received and included:

- People presenting with pain being greeted with scepticism, treated with suspicion and left feeling rejected by the medical community.

[18] Bone protection service - York - HNY Policy and Pathway Repository

[19] https://www.hdruk.ac.uk/resources/diagnosed-prevalence-of-ehlers-danlos-syndrome-and-hypermobility-spectrum-disorder-in-wales-uk-a-national-electronic-cohort-study-and-case-control-comparison/

[20] https://world.physio/congress-proceeding/experience-diagnosis-hypermobile-ehlers-danlos-syndrome-narrative-review

- Women graft to maintain self-esteem and credibility. Attempting to not appear too assertive nor too meek was effortful.
- "Diagnosis should be considered as a socio-political process rather than biomedical practice representing a shift in the balance of power."

Endometriosis and Polycystic Polyendocrine Metabolic Ovarian Syndrome (PMOS and previously known as PCOS)

Endometriosis UK in a 2023 diagnosis survey found that the current average diagnosis time is eight years and 10 months in the UK[21]. The data from their 2025 diagnosis survey is not available yet.

Endometriosis UK, Cysters and the Nuffield Department of Primary Care Health Sciences at the University of Oxford are working together on a study about using experiences of endometriosis to improve healthcare. The ongoing research aims to understand UK patients' experiences of endometriosis alongside the perspectives of healthcare practitioners involved in their care and use this learning to support improvements[22]. While the report is not yet available, we expect the research to reflect the experiences we have heard.

On 12 May 2026, PCOS changed to PMOS (Polyendocrine Metabolic Ovarian Syndrome). It is a very common condition that affects one in every eight women in the UK[23]. There is little research into PMOS in the UK, something that Verity (the PCOS/PMOS UK Charity) and Cardiff University are hoping to address. Together they have led work to identify the top ten research priorities[24]. Those priorities include looking at optimal care pathways for people with PMOS and how to improve the knowledge and clinical management skills of healthcare professionals to better meet the needs of people with PMOS.

[21] https://www.endometriosis-uk.org/endometriosis-uk-launch-new-diagnosis-survey
[22] https://www.phc.ox.ac.uk/research/groups-and-centres/health_experiences/Experiences-of-endometriosis
[23] https://www.verity-pcos.org.uk/
[24] https://www.verity-pcos.org.uk/jlapcos.html

Postural Orthostatic Tachycardia Syndrome (PoTS)

PoTS mostly affects younger women and children. It was estimated that there were over 95,000 people in England living with PoTS before the COVID19 pandemic. As 7-14 % of people with Long COVID have PoTS this number is likely to have increased since pre-pandemic levels[25].

In April 2026, PoTS UK met with representatives from the Department of Health and Social Care and other MPs to raise key issues people with PoTS are facing. This included the lack of care pathways and specialist services. Only four out of 42 Integrated Care Boards reported having a specialist service for adults (Humber and North Yorkshire does not have a specialist service, but does have a pathway[26]) and there is no service for children.

The briefing for MPs[27] outlines responses to a 2025 survey which found:

- 85% of respondents had difficulty accessing healthcare.
- 52% were misdiagnosed with a mental health condition.
- 34% said their GP has not heard and/or does not believe in PoTS.
- 41% had to seek private healthcare for diagnosis or management of their PoTS.

This reflects what we heard.

Fibromyalgia

Fibromyalgia is a chronic pain condition, affecting 2–4% of the general population. It is twice as common in women as men[28]. Research by the University of Liverpool said: "Historically stigmatised and its existence still doubted by some physicians, patients often experience substantial diagnostic delays." Patients describe a 'revolving door' of referrals between pain, gastroenterology, and surgical

[25] https://www.potsuk.org/pots-uk-raises-urgent-need-for-improved-nhs-services-at-westminster-meeting

[26] Postural tachycardia syndrome - York - HNY Policy and Pathway Repository

[27] https://www.potsuk.org/wp-content/uploads/2026/04/Access-to-Healthcare-in-England-Apri-2026.pdf

[28] https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913(26)00051-2/fulltext

specialties, with high personal costs, difficulty navigating care, and poor outcomes for their working lives[29].

The University of Liverpool's research hopes that new information showing the biological basis for the condition and can address some of the health inequalities associated with fibromyalgia[30].

Rheumatoid arthritis (RA)

About 1% of the population in the UK has RA – more than 450,000 people in the UK. It affects more women than men, roughly two to three times as many women[31].

Much of the research into RA is about treatment, but the National Rheumatoid Arthritis Society outlines healthcare essentials for anyone diagnosed[32]. As we heard, the treatment and support for rheumatoid arthritis in York is generally good.

Local picture

Women's health in York – women's health needs assessment

In July 2025 City of York Council published its women's health needs assessment[33]. This was informed by our earlier report on women's health in York[34]. The assessment is wide ranging and covers health and wider issues including menopause, period poverty, cancer screening, maternal health and accessibility of primary care services including medical misogyny. The assessment also includes a number of recommendations and action areas including early intervention and prevention and a public health approach to gender inequality. The latter includes addressing women's health issues as systemic challenges, not niche concerns.

[29] https://www.bbc.co.uk/news/articles/c3d0xex4078o
[30] https://www.liverpool.ac.uk/research/unlocking-mystery-of-fibromyalgia/
[31] https://nras.org.uk/resource/what-is-ra/
[32] https://nras.org.uk/resource/10-healthcare-essentials/

[33] https://democracy.york.gov.uk/documents/s184406/Vs.11%20updated%20format%20Final%20draft%20WHNA%20002.pdf
[34] https://www.healthwatchyork.co.uk/seecmsfile/?id=120

Why we did this project and what we did

When reviewing the feedback we received for our 2025 report about women's health[35], we noticed common themes for women who have long term conditions. This project heard from more people to better understand the commonalities as well as condition-specific experiences.

We launched the project with a VoICeS meeting to listen to women's thoughts and experiences to help shape the work. While the women attending had a range of conditions, they outlined similar experiences from seeking support for their symptoms to diagnosis and treatment (if available). We worked with some of the people who attended that meeting to develop the survey we used to gather feedback.

We launched the survey in December 2025 and closed it at the end of March 2026. We also gathered feedback through ongoing conversations, responses to Healthwatch York in general and through partner organisations. In total we heard from more than 110 women including 78 people who responded to the survey.

Of those survey respondents:

Condition	Number of respondents
ME/CFS	18
Osteoporosis	12
EDS/HSD	10
Rheumatoid arthritis	8
Endometriosis	8
Fibromyalgia	8

[35] https://www.healthwatchyork.co.uk/seecmsfile/?id=120

PoTS	7
PMOS / PCOS	5

Many survey respondents had more than one condition with some people listing as many as five different long-term conditions. Some conditions are interconnected. For example, some people with ME/CFS often have PoTS, EDS and hypermobility spectrum disorders.

We asked people to describe their symptoms:

- Nearly half (49%) mentioned pain.
- More than a third (37%) said fatigue.
- 14% said brain fog.
- Other symptoms mentioned included sleep problems and mental ill health as a result of coping with a long-term condition or trying to navigate the health service.

Respondents were asked how long they had had the condition(s). This varied from less than a year (6% of respondents) to 20+ years (31%) and everything in-between.

We asked survey respondents about the general impact of their condition(s):

- Not at all – 3%.
- Mild – 8% (it affects me but I can maintain a mostly normal life).
- Moderate – 38% (I have had to make some changes to my life).
- Severe – 50% (it has significantly changed my life and I need help from others).
- Very severe – 6.5% (I have to rely on others for most of my care and daily living needs).

We also asked about the specific impact for people (in this instance they could select more than one response):

- Reduced mobility – 62%
- Reduced quality of life – 79%
- Impact on mental health – 68%
- Impact on family life – 51%
- Impact on personal relationships – 55%
- Reduction in working hours/going part time – 27%
- Give up work – 37%
- Financial impact – 46%
- Lost trust in healthcare professionals – 56%

What we heard

A strong theme from the feedback received was about the attitudes and actions of healthcare professionals. These were evidenced in how they treated women going to them for diagnosis, treatment and support, what support people were given both to support their needs but also in terms of signposting and the healthcare professionals' knowledge of particular conditions.

Listen to us and believe us

More than half (55%) of respondents to our survey said that healthcare professionals did not listen to them. Two fifths (39.5%) said that they were not believed. One third of respondents (33%) said they were first told they had a mental health issue.

Comments included:

- "I've had very mixed experiences of seeking help for FND [functional neurological disorder]. The first time, it was awful. I was asked to compile evidence (e.g. recording of a non-epileptic attack) but before I could even hand them in, I was discharged because the blood tests found nothing and the neurologist felt it was 'just panic attacks'. You know, panic attacks that lasted for five hours and sometimes sent me to A&E."
- "The first GP dismissed my experiences and tried to fit them into an anxiety box (I'm a psychologist and know it wasn't anxiety related). He said he didn't know what ME was."
- "I am constantly dismissed as having nothing wrong, belittled, fobbed off with 'mental health must be the cause', told it is all in my head, usual aches and pains, hormones, … therefore they fob me off with 'functional', caused by emotions. It is ridiculous, as all females suffer the same medical narcissism, dismissed as

psychosomatic/mental/emotional because we are female, and age discrimination whatever age we are."

- "Nothing went or is going well. I have fibromyalgia, ME, costochondritis and hemiplegic migraines. I live in so much pain that I regularly collapse and spend up to 20 hours a day in bed. I am diabetic, I have had mini strokes and use a wheelchair. I asked my GP for a sick note, so that I could go on the correct level of Universal Credit. She replied that there must be some work that I could do! I honestly feel that I don't have a GP for care or support, just a prescription dispensing service."
- "My daughter died three years ago. She didn't feel well and went to the GP but they kept saying she was depressed and giving her anti-depressants. … In 2022 she felt very ill, wasn't sleeping and had lost weight. They did a blood test and diagnosed her with hemochromatosis. Her serum ferratin levels were 8,000 when normal is 200. Over 1,000 means someone will have liver damage and she did and had kidney damage. Eventually she was taken to hospital with a gastric bleed. It was during Covid and they were trying to keep me away, but I was with her when she died the next day. Hemochromatosis can't be cured, but if it is caught early, it can be managed. As a result, her GP practice has trained staff to be aware of the condition, but it is too late for my daughter. … When I complained about it I was told that nothing could have been done and it 'was just one of those things.'"

We also heard from someone who was diagnosed with FND in a different area and moved to York. They experienced a number of seizures leading to them going to A&E on many occasions. However, in York their condition was not acknowledged and their symptoms dismissed.

When we asked what a good health service would look like, the responses reflected the overwhelming request for people to be listened to and believed. People told us:

- "We just need to be listened to and not dismissed and particularly not told it's part of the ageing process when it happens overnight."
- "Symptoms and concerns being taken seriously immediately. No comments disregarding or excusing symptoms as normal or blaming mental [ill] health."
- "If they don't know what is wrong with a patient it is not because there is nothing wrong, the patient is not faking and it should not be assumed that the issue is psychological…"
- "Belief in your symptoms. A good understanding of the condition - that its biological not psychological."

Understanding and awareness

More than half (54%) of respondents to our survey said that healthcare professionals had limited understanding of their condition.

They told us:

- "Due to Ehlers Danlos being a rare condition, my GP and other health professionals at the time didn't know much, if anything about it. I had to do my own research and get help from support groups and others with the condition so I knew not only what to ask for but who to be referred to."
- "Utterly depressing to look back and realise every single bit of support I got from healthcare professionals only came about through my own advocacy and private clinics."
- "There is little understanding on behalf of GPs. The NICE guidelines were updated in Oct 2021, but GPs are not educated about the condition [ME/CFS] or worse still have unfounded and inaccurate assumptions that ME is a psychological illness. In fact, dismissal by healthcare professionals is a key point mentioned in the NICE guidelines."

Most of our respondents had done a lot of research during and after diagnosis as they felt they were not getting the treatment, support or care they needed. For some, this led them to private healthcare, although others could not afford this. Many found charities, voluntary sector organisations and peer support groups, which they felt were often as helpful as, if not more useful than, healthcare professionals.

- "I researched more about my conditions and other impacts that they can have on your health and how to help reduce symptoms by things like diet, exercise and supplements. To receive actual treatment I would have to go private which I cannot afford."
- "I use social media for help and support (non-medical) which do make me feel more supported and less alone with it all."
- "Paid for another scan (REMS - radiofrequency echographic multispectrometry), joined the Royal Osteoporosis Society which is very helpful. Talked to others with the same condition, did extensive Internet research."
- "Yes, I have done endless research on the internet and reading research papers. I joined internet forums to ask for help and ideas of what to try to get well. I have paid thousands and thousands of pounds for supplements.
- "I have done my own research, but without the help from the GP to refer me for the appropriate tests and examination, and history taking of my symptoms, signs, and monitoring etc, I am in limbo."
- "I've had to do most of my research alone and that's given me more advice and ideas than any support I've been given from doctors."

When we asked what a good health service would look like, the responses included healthcare professionals at least being aware of their condition and preferably knowing and understanding it. People told us:

- “GPs educated on women’s health and how PCOS affects women.”
- “GPs have training on signs and symptoms of endometriosis.”
- “Medical professionals who have heard of ME - one doctor told me he'd only done his training ten years ago, seeming to imply that this is a new condition so he can't be expected to know about it. I don't expect them to be experts, but at least do a little online research, or contact the Yorkshire Fatigue Clinic for advice - don't just send me away with a shrug.”
- “Physiotherapists dealing with arthritis need to learn that exercise intolerance is a big part of having ME and fibromyalgia - this has been a recurring issue as my arthritis affects other joints.”
- “Good would be my GP practice has a GP with special interest in ME - but there are none in the York area!”
- “Also, consider the medical background of the patient before prescribing or suggesting medication to them. For example, I get recommended certain drugs for my epilepsy that are known to make people depressed and extremely tired all the time, even though I am already on medication for depression and I'm constantly tired already.”
- "I think it's important that all staff at the surgery are aware of ME/CFS, not just the doctors, as it's horrible to try and explain things to the receptionist and for them to not be very understanding.”

Many respondents talked about reasonable adjustments - healthcare professionals understanding symptoms and the impact of a condition and reflecting that in how they support people:

- “I feel that [GP practice] is denying me fair access to healthcare and exploiting the fact I am disabled. I have ME and struggle with the phone, particularly before 11am, and I take time to answer. I spoke to a lovely GP who added that information to my patient record. However, this week I had a call from someone … at 9am and a further

phone call that rang off before I got chance to answer the phone. I then got a message to say as I hadn't engaged and answered the phone, I would have to start again if I needed help. I just want to be able to access medical care and for them to take into account what I need which is on my patient record."

- "I have multiple disabilities including ME. In line with the 2021 NICE guidelines for ME, I requested somewhere else to wait as my appointment was already late and being in the waiting room was making me feel ill. This was not provided and I had to wait for almost an hour for my appointment going between standing which I can only do for a few minutes and sitting in the lobby on a cold hard floor."
- "Reasonable adjustments for other health services. Priority triage at GP. Porter service for outpatients. There's a sort of passport for people with learning disabilities. Why not for us? A trip to the hospital is exhausting. Look at how to make that less tiring."
- "Adjustments such as being able to access services via video link as too exhausting to go to multiple appointments and telephone appointments are only helpful in limited way."
- "It would be good if GPs checked in regularly, so it didn't feel like we're just left to muddle through ... it would be good if home visits were offered before you are physically housebound, as the exertion of attending an appointment can be too much."

Take issues seriously

More than half (54%) of respondents felt they were not taken seriously:

- "My GP in late 2024 told me that poor lifestyle was to blame for a complex mix of symptoms."
- "It took two scary A&E crises to be taken seriously."

- “I was told there was nothing medically wrong with me so there was nothing they could do.” (Person was later diagnosed with ME/CFS).
- “I still think women's health is bottom of the list for priorities and the one or two professionals who are specialists and do listen are so few and far between that they are overwhelmed trying to help people.”
- “I look OK, but no-one knows what it is like to live in my body. Doctors just roll their eyes if you tell them you have ME. They don’t want to know.”
- “Some healthcare professionals still see ME/CFS as a made up condition.”
- “I’ve had a variety of experiences with doctors over the years, mostly negative. This has included doctors being openly hostile, making snide and sarcastic comments about ME, me being accused of making it up and lying etc. I now feel scared about seeing any doctor. I only contact the GP for other medical issues.”

When we asked what a good health service would look like, the responses included being taken seriously when talking about symptoms.

People told us:

- “Services need to treat women's medical problems with the same respect as anything else and not act like you should ‘just get on with life’.”
- “Healthcare professionals taking their time to make sure that you understand and aren’t left confused or with more questions.”
- “I would like to see longer appointments available and used so that doctors can take a thorough medical history. This would make a massive difference in ordering the right tests and getting a correct diagnosis. It would save time in the long run!”

- “Good would be that my GP listens and takes seriously the impact of the complex range of symptoms that I am dealing with and which have had a fundamental impact on my quality of life - instead of asking ‘have you managed to get away on holiday?’"
- “Good would be the ability to book follow-on appointments for chronic conditions that are not treated as lower priority 'routine' by comparison to "urgent" requests that are often far less impactful on a patient's health.”
- “I would really like an annual review of my ME to be automatic and compulsory, in the same way that diabetes patients have a yearly review. It would be a chance to inform the doctor, explain any improvements or setbacks and describe how the illness is affecting me.”

It’s not ‘normal for women’

Almost a third (31%) of respondents to our survey said they were told that their symptoms were normal for women or they experienced misogyny.

We heard:

- “Ableism, misogyny, gaslighting, and ignorance are common experiences for me. I have to spend so much time rehearsing what to say in my appointments, bringing my own evidence, including professional guidelines, to appointments. Afterwards I am often overwhelmed by the experience and rarely feel a sense of relief that I have got the help I need.”
- “I just think women are ignored because we are women, we are born that way and we should deal with it. I have lived in pain for 20 years and am no closer to a proper treatment plan/cure than I was when I started. It has impacted on every aspect of my life.”
- “I had a traumatic birth with my son, who is now 31. But it means that I have PTSD with anything to do with gynaecology. I once had a

positive smear and had to go back to find it was a male gynaecologist and I panicked. I complained and now for any cervical screening people get a choice of whether to see a man or woman."

When we asked what a good health service would look like, the responses included not dismissing things as 'women's problems' and giving women the same time, respect and courtesy that other patients receive. People told us:

- "Communication is key, measure patient journey and patient outcomes from patients with full transparency of medical records and ability for the patient to contribute about her health, to improve patient outcomes and efficiency and effectiveness throughout. Stop the bias against females."
- "Consistent support, national pathway as there is for other conditions like diabetes or heart disease. I know men also have osteoporosis but it is largely a disease of menopausal women and I feel because so many older women have it that it is not given the recognition it needs."
- "An understanding service rather than just having an attitude of 'it's just women's problems'. The fibroids affected my work, they were so large my whole uterus was pushed out of place. The doctor who did the first internal examination at the hospital said she didn't need to examine me internally, she could see my uterus as it was being pushed so low. I couldn't have sex with my husband for years. I felt so alone and unhappy but the health service made me feel like I was complaining about nothing. Any kind of support or advice would have helped but it seemed they were more interested in how much it cost and who would pay."
- "I also think more regular check-ups for things like period, smear tests, hormones would spot problems earlier and avoid issues further down the line."

- "A chance to reconsider the original refusal of the consultants to operate and any other options. Some sort of hope that I am just not going to continue to slide down the slippery slope of constant pain."
- "Ideally an automatic referral for a DEXA scan to all post-menopausal women so that the condition could be caught at the earliest possible stage. Failing that a referral should automatically occur to all post-menopausal women after a bone fracture occurs."

Good is possible

Nearly half (47%) of our survey respondents said they had come across at least one sympathetic and understanding healthcare professional. We also heard from others who talked about good healthcare and reflected on their experience as a positive one.

Comments included:

- "When I did get a hospital appointment the first person I saw was very understanding and listened to me. She stopped an internal exam as she could see my pain and recommended a hysterectomy."
- "Most of the healthcare professionals have been brilliant and I have not had to wait too long."
- "My initial doctor was very supportive and thorough. Even though it took a year to be diagnosed, I'm glad my doctor checked other possibilities first before diagnosing me with ME."
- "The female GP who diagnosed me was lovely and listened and seems to have a good understanding of it. But she then needed to refer me to chronic fatigue clinic to confirm diagnosis and she referred me to the cardiologist for PoTS which at the time I didn't know really what it was. And I'm so thankful she did."
- "I am now on to the seventh GP I have spoken to and he has been good. I have ME and he admits he doesn't know about it.

But he is good at listening and is a mental health specialist so helpful about my mental health issues. He has now prescribed me new medication which has really helped with my anxiety and other mental health issues. While my ME hasn't changed, the new medication has helped as I can now cope better as I don't have the same mental health issues as I did before."

- "I've had ME/CFS for five years … I wanted to commend my GP for their help and reassurance. Though they admit to knowing very little about my condition, they still listen to my concerns and come up with suggestions that might help. … Having someone who seems to genuinely care and tries to help makes a huge difference."
- "I cannot suggest an improvement for the way my osteoporosis has been handled."
- "The rheumatology department has a phoneline for patients who are experiencing flare ups or have medication issues, and when I have phoned them in the past, I have usually received a response within a few days."

While much of this report reflects on the bad experiences for women, it is interesting to note the good experiences are often a mirror image of the bad. We are reassured to hear that there is good practice in York from which better services can developed.

System issues

Another theme of our feedback was systemic issues that were not necessarily to do with staff attitudes. For example long waiting times and lack of continuity of care.

Waiting for referrals

More than a third (41%) of respondents felt they had waited a long time (more than six months) for a referral to a specialist and just less than a quarter (23%) had to be referred to more than one specialist.

One respondent said: “It was a long wait to see a sleep consultant here, and when I did it was a locum who put me on one treatment then left. Then it was a long wait for follow up with the local consultant who could see treatment wasn't working and wanted to switch it. Everything is waiting, waiting.”

When we asked what a good health service would look like, the responses talked about quicker referrals and appointments and something to support people while they are waiting. People told us:

- “Better initial screening and advice from physiotherapy straight away before condition becomes chronic.”
- “Faster diagnosis and initial referral.”
- “Early intervention and not always focusing upon the money. My daughter needed a new knee at 24, due to an accident. She’s still waiting at 38 and is in chronic agony every day.”
- “I understand that scans and other tests cost a lot of money, but if the NHS would do these tests first, in my case I believe it would save huge amounts of money and professional time in the long term.”
- “The initial wait that I had for my first appointment was awful, and the efforts of my GP made all the difference. An urgent referral should be dealt with urgently, preferably within a couple of weeks, people shouldn't have to wait for months whilst in pain.”
- “One standard screening - I could give the list of everything I've been tested for. Do it all - all the bloods, the CT, the weird adrenal test, the questionnaires, the sleep study. Not over 20 years, over one year.”
- “During these long wait times, some kind of check in or stop-gap treatment, such as signposting to networks or charities or even books to read would be helpful.”
- “Staff… able to give defined timescales of when treatment may happen. Information on what to expect and when this may happen.”
- “Good would be my GP has support from experts to whom they can refer me for more detailed investigations.”

Continuity of care

Just under a third of respondents (29%) said that they never saw the same healthcare professional.

Comments included:

- "Continuity of care (ie one or two GPs who really know the patient) is really, really important in severe ME - particularly because of the interconnectedness of symptoms."
- "I contacted my local surgery about a women's health issue…women's health doctor… been very supportive…. However, no mention was made of my chronic illness or mental ill health even though I thought they could be linked. I ended up having to see two different doctors over a number of months for separate symptoms."

When we asked what a good health service would look like, the responses included seeing the same healthcare professional, particularly GPs. People told us:

- "Longer appointments for complex cases with the same GP for continuity of care."
- "A service to provide a 'same and always' GP instead of one of 35 possible and rarely the same one. Someone who could keep me up to date on my specialist referrals and when I might hope for any."

Coordination of care across multiple conditions

We heard a call for care to be better coordinated across conditions, rather than each being treated separately. Respondents talked about holistic, person-centred care across physical and mental health and multi-disciplinary teams (MDTs).

- "Holistic approach to both physical and mental health with social circumstances also looked at… No online or telephone triage of

having to limit to one symptom as multiple symptoms and health conditions are all related and need addressing at once as one symptom often worsening many others."

- "An MDT to cover conditions that come under the same umbrella - PoTS, MCAS (Mast Cell Activation Syndrome), HEDS (Hypermobile Ehlers-Danlos Syndrome) etc so that it could all be handled under one clinic and not require separate referrals and appointments."
- "... better multi-agency working/being able to signpost for non-medical support as well."
- "Since a lot of these conditions overlap, co-occur, have a hereditary component and share generic symptoms it would make total sense for patients and the service, to have multi-speciality clinics that assess that all things at once instead of treating discrete body systems."

The impact of neurodivergence

Some people raised challenges of healthcare professionals not being aware of or understanding the impact of neurodivergence on people's other health conditions. This is not a women-only issue. However, there are still delays for some women in being diagnosed with neurodivergent conditions as they do not present in the 'typical' way.

- "More understanding and awareness of neurodivergence in women, including screening, as well as considering this in appointments."
- "I'm also AuDHD (autistic and ADHD) and coping with that on top of my medical condition can be extremely hard."
- "Stress, mental health, trauma and neurodivergence needs to be fully understood and treated as part of the complexity of these illnesses. The role of the nervous system is central to all these conditions but is rarely considered in the current system."

Condition-specific responses

As well as the similar experiences that many women outlined, we heard about condition-specific experiences. The information below includes responses from people who have one or more of the specific conditions, including quotes and personal stories.

Note that we have changed the names of the people who provided personal stories. Where the same name is used for stories under different conditions, it is the same person who has a number of conditions with information shared under the appropriate condition.

For each condition, we have included a link to the NHS Conditions A – Z website[36].

ME/CFS

https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

We heard from 18 people in our survey who have ME/CFS and 20 people through our ongoing work and contributions to a Protected Learning Time session for healthcare professionals about the condition.

Much of the feedback we heard reflects that outlined above, but people also told us about experiences and issues that are specific to ME/CFS. Debilitating fatigue and chronic pain were symptoms mentioned by most of the people we heard from and most said that the impact on them was severe where the condition had significantly changed their life and they now had to rely on others.

One person said: "My life is so constrained. I have a limited social life. I can't network to grow my business. I can't cook or clean or get the house in order... We're just here, existing. I'm left here, coping, just, wondering if this is just my life now. Seeing a grief counsellor on the NHS for eight weeks

[36] https://www.nhs.uk/conditions/#nhsuk-nav-a-z

to try to come to terms with that seems like a drop in the ocean to be honest."

While we heard from people with severe ME, some who have very severe ME couldn't engage with this project or with healthcare professionals:

"There is no support for people with serious or very serious ME/CFS who often struggle to get out of bed."

One key aspect of ME/CFS is that there is no treatment for the condition. The support that exists focuses on managing symptoms. Currently the specialist NHS support available in York is through the Yorkshire Fatigue ME/CFS Service (also known as the fatigue clinic). We heard from people who found this service invaluable and others who had not found the support and care at all helpful. One person felt it had made their symptoms worse.

Someone reflected: "People are still being referred to a physio or told to do exercise when it is clearly stated that this is not appropriate in the NICE guidelines. My daughter went to the fatigue clinic and was encouraged to exercise – there needs to be a common approach to say that this is not helpful and can be harmful."

The Humber and North Yorkshire Integrated Care Board assured us that the Yorkshire Fatigue ME/CFS service follows NICE guidelines.

Another said: "The fatigue clinic … changed my life. I don't know how I would have got through without them. They taught me how to live with ME."

Most of the people with ME/CFS we heard from had done their own research about the condition and many had sought support from national charities and local support groups.

A number of people we heard from were frustrated that GPs often attribute other symptoms to ME/CFS:

- “The GPs I have seen attribute every single symptom I have to ME, and as they think that I am causing that myself by failing to address my alleged 'emotional problems', they have not helped me. I had to get sleep apnoea diagnosed privately - literally, this should have been ruled out before any ME diagnosis was given. It has been very, very hard to keep fighting against the NHS for basic care. I feel utterly traumatised and any contact I have to have with my surgery leaves me feeling like a nervous wreck, with very high levels of anxiety.”
- “If you have an ME diagnosis there is a tendency to put other things down to ME. I don't think other illnesses/symptoms are taken as seriously. Symptoms like pain, sleep problem and IBS can be treated even if the cause is ME.”

People particularly felt that often initial ME symptoms are put down as mental ill health:

- “My daughter … has severe ME, PoTS and is very restricted in what she can do, including not being able to leave the house in most circumstances… She feels she is treated as if she has mental ill health, when she feels she doesn't at all, and that this is on her medical record. … My daughter is seen by the [practice] complex care team and has seen two doctors and a paramedic. However, she feels that none of them has listened or understood either severe ME or PoTS and not asked about her symptoms and experience of the conditions…”

We also heard from women about their experiences of menopause and ME/CFS:

- “ME has two peaks of occurrence for women - during puberty and menopause. For me, the ME arose around menopause. This is

because there are interactions between hormones and the physical processes involved in ME. Seeking treatment for menopause … has helped some of the shared symptoms. There needs to be greater appreciation of this and greater proactive access for women to these hormone treatments."

Other women also told us about the lack of understanding of ME by some healthcare professionals and them being given advice that is contrary to NICE guidelines:

- "I've had problems walking for nearly five years, so my doctor referred me to the neurologist at York Hospital… I waited 15 months then managed to get a last-minute appointment in March. I explained my mobility issues to the neurologist, as well as the leg pain and cognitive issues, and was asked to do some physical activities, like hopping on the spot. I was told my brain and spine were fine, and to use graded exercise to improve my walking (with no mention of the other issues), in what I felt to be quite a patronising manner (I'm sure they would have spoken to an older male patient differently). I've tried so hard to exercise more but it leaves me exhausted and in more pain (in fact, I've read in ME books and online that graded exercise shouldn't be used). I felt unable to reply to the neurologist, and left feeling very disappointed, alone, and afraid. I know ME is a difficult condition to treat, and I'm not expecting a cure, but it would be nice if medical experts took it more seriously. It worries me to think there are other ME patients on the waiting list for the neurologist who will likewise leave disappointed."

Personal stories

We heard from a number of people with ME/CFS who shared their experiences in more detail:

Bethan's experience

"I became ill in March, then really ill in June. I went to see a private GP who said I had ME. I then went back to my NHS doctor who said 'I don't think you have ME because you want to work!' Then I had more blood tests and was sent to the Yorkshire Fatigue Clinic.
I can no longer work on a good day. I can go out and meet friends for coffee. On a bad day I struggle to take my dog out, cook, make a drink and I spend most of my time in bed. … I don't go to the doctor with my ME because they don't understand."

Laura's story

"I was diagnosed in 1991. It took around two years. I was doubted, dismissed, accused of being lazy etc. I was diagnosed by a GP whose mother had ME so he had a little bit of understanding.

This illness has devastated my life. I have never been able to work, I'm housebound 99% of the time. On most days my main focus is on feeding myself on a shoestring and little more. On a good day I can go out of the house for two hours. That happens once every few weeks and then it takes seven to ten days to recover.

I want GPs to know how utterly debilitating ME is. How doing the slightest task (cleaning my teeth or making a cup of tea) is exhausting. People only see me when I am well enough to be seen, they don't see how ill I am afterwards. Being understood and accepted is so important, especially as a lot of us have had bad experiences with doctors."

Jane

"I was diagnosed with ME in May 2023. I first suffered symptoms in November 1984, when I lost strength and slept for a fortnight. Afterwards I didn't recover to my previous level of health. I was living in a small, seaside town and my GP didn't diagnose me with ME. He thought it wasn't 'a real illness'…

… in January 2019 I had a blood test for what the GP called TATT (Tired All the Time). It showed nothing except pre-diabetes. At some point, I saw another doctor to ask if I had ME. She seemed interested but said that if I didn't have joint or muscle pain, that couldn't be the diagnosis.
In October 2021, new guidelines for ME were published by NICE in co-operation with the ME Association, who shared a patients' version with members, including me. In November the following year I saw a GP who said, 'You've probably got ME,' which sounded too vague to be a diagnosis. She recommended Graded Exercise Therapy (GET), which I knew from the NICE guidelines had been discontinued because it made some patients worse. Being non-assertive, I only managed to say I'd heard it wasn't helpful for some. The doctor simply went on to discuss pre-diabetes, which she seemed more interested in.

In 2023, after 39 years, I finally got a diagnosis of ME. It was another GP, who also referred me to the Yorkshire Fatigue Clinic… However, the issues didn't stop there. I asked why I had been getting worse in the last few years. The doctor pointed out that the problem with ME is that we don't know much about it, but he thought it was because of age (I was 72). When I started the course at Yorkshire Fatigue Clinic, I was told it was due to overdoing it, so I felt confused.

It turned out the clinic was right. I unwittingly overdid it in August 2024 and slept for a week. When I recovered, I was able to do significantly less than before because of post-exertional malaise (PEM). It happened again the following spring.

At present I only have the afternoons to get things done and I also lose time because of having frequent rests. I am therefore constantly behind with everything.

I can sleep for 10 hours or not till 6am. If I crouch or bend, such as when taking washing out of the machine, my legs feel immediately fatigued and achy and I can't continue. I get the same effect if I lift my hands above my

head when I'm holding anything with any weight, so can't put the washing on the line.

...I can't walk to the bus stop, so have to get a taxi or lift. I am isolated because of all this, which I hate, and it has emotional and practical consequences.

I have poor concentration and brain fog (cognitive dysfunction), which means I may have difficulty taking in information or finding the right word in conversation. It affects thinking and writing..."

Margaret's experience

"In 2002 my GP suspected I had coeliac disease and told me to stop eating gluten. I did, but then he said I should carry on eating gluten until I had an endoscopy. I did and my health drastically spiralled... and I became extremely fatigued with brain fog, extreme anxiety and I was unable to tolerate any level of stress. ME was suspected but couldn't be confirmed until six months had elapsed. During this time I wasn't given any advice on how to manage it. I was signed off sick and ... I pushed myself to walk several miles a day which gradually made the ME considerably worse ... After six months I was given the ME diagnosis and was put on a waiting list for a short course which generally covered pacing activity... This was helpful, but it wasn't enough ...

The pacing stopped me from worsening but ... I lost my job of 25 years. I was left to manage until 16 years later when I heard about the Fatigue Clinic in York and asked to be referred there. The first thing they said was that the earlier they saw people, the better the outcome, which was very upsetting to hear.

I was also diagnosed with depression after losing my job... I had to wait 18 months to see a counsellor and despite saying I needed to see someone who understood the limitations of ME ... They were unwilling to see me every other week to allow me time in-between to recover ... and

concluded that I was only depressed because I didn't go out enough. When I explained … they wrote to my GP to say that I was unwilling to try their suggestion.
Over the years, having ME has caused difficulties accessing other healthcare due to a lack of understanding of the condition.
For example, my GP practice has many surgeries and routinely expects you to travel to one miles away. … My GP offers phone appointments … but no time of the day is given … which necessitates being awake all day when I need to have rest. Appointments at the hospital often require long waits in a busy environment which often means brain fog has set in before you are seen, making communication and understanding difficult …

… knowing appointments take up a lot of your energy resource, resting up for days before and after and knowing they often result in a relapse means you are often tempted to put off arranging them. During appointments they only want to discuss one illness, but without looking at your health holistically they miss things … This can result in poorer outcomes and complications.

In 2002 my periods stopped and I told the GP I thought I was menopausal… he thought I was too young at 42. They never started again and he never followed it up. … Consequently, I was not offered HRT and because coeliac disease causes malabsorption of calcium and I was unable to do any exercise because of the ME, I was subsequently diagnosed with osteoporosis."

Rebecca's story
"I find email much easier than speaking, particularly when trying to explain something complex. Telephone appointments can be helpful, but it's really important to have advanced warning and a set time because I need to budget so many spoons [of energy] for a conversation and rehearse it lots before speaking to a doctor. So, if they ring two hours late that massively affects my energy. And if they ring out of the blue, I usually can't get my brain into gear quickly enough to explain the problem/forget lots of

important bits, and it's a real issue with confidentiality if I haven't had advanced warning to get someone to shut my door, etc, to avoid being overheard by carers/family (as I can't just take myself outside, etc, like other people might).

When in a 'good place' I can converse fluently (albeit with huge energy costs), but when my health is worse, my ability to communicate (particularly verbally) declines. In particular, if there is sensory overwhelm/ emotional upset, it can make me almost mute/monosyllabic. This is not a choice, but it can be misconstrued as being behavioural/passive aggressive, which can put extra strain on already strained relationships.

...I think it's important to stress how interconnected symptoms are - and what a fine balancing act it becomes. I think of it like spinning plates: focus on adjusting one, and the others all start to fall... e.g. adding in a new medication (risk: side effects will affect other systems). Also, when my state of health is this precarious, it's very easy for things to go south very quickly - e.g. add in social/emotional stresses, and the associated immune response can affect gut absorption/nausea etc ...

I know how stretched primary care is, and how resource intense home visits are, but it's important to recognise that surgery waiting rooms (and worse, A&E!) can have a massive detrimental impact on severe ME - the bright lights, noise, exposure to viruses, exposure to perfumes/air fresheners, temperature changes, sitting upright, etc, etc... not to mention all the issues with travelling to the surgery.

...GPs are very skilled at managing risk, but particularly when services are overwhelmed, the knee-jerk response of triaging/signposting certain 'standard' presentations to A&E comes at a huge risk/energy cost. ... We really, really need to fight for GPs to be able to directly admit [people with] severe ME onto a ward (i.e. side room). Sadly, York hospital is essentially refusing direct admissions and insisting everyone goes via A&E. Last time I

spent 29 hours awaiting a bed despite my GP fighting really hard for direct admission."

Osteoporosis

https://www.nhs.uk/conditions/osteoporosis/

We heard from 12 people in our survey who have osteoporosis and also heard from the York Royal Osteoporosis Society.

Much of our feedback echoes that above and is included above. Half of our respondents with osteoporosis also have at least one other long term health condition.

Some people said they did not have any symptoms and were not aware of the condition until they broke a bone. Others talk about fatigue and aches and pains as well as symptoms related to other conditions. Survey respondents had a mix of experiences from people with mild impact to very severe. More than half of respondents had reduced mobility and reduced quality of life.

We received many comments on the impact of not being listened to or taken seriously before diagnosis:

- "My friend had a bad back and contacted the GP. She was told to wait and she did, for months. Eventually she rang again and was told that she had been overlooked. She was given an appointment with a physiotherapist who was horrified that nothing had happened. The physiotherapist referred her for a scan which showed a broken vertebrae and osteoporosis."
- "I went to the GP with awful back pain. It took me three months to see a GP. I had seen a Physician Associate who was useless, he and three other GPs I spoke to by phone just told me to take pain killers. I asked for an x-ray but didn't get one. I went privately for an MRI scan which found four spinal vertebrae fractures and I was diagnosed with osteoporosis. … GPs need to have better training so when they

see a post-menopausal woman with back pain, they should immediately think it could be osteoporosis."

In terms of treatment, respondents mentioned physiotherapy, joint replacements and alendronic acid.

- "I have osteoporosis. I went to talk to my GP about it in December and they said they would refer me to the hospital for a medication review. I have been on the same medication without a review for five years and want to see if it is possible to have infusions instead. I heard that the appointment was in June. I contacted outpatients at the hospital and they have managed to get me a cancellation in April. But it is a phone appointment with a specialist nurse in rheumatology and I don't know if they will be able to help me get on to infusions."

Some feedback also suggested that GPs are not referring people for DEXA (bone density) scans even when suggested by a specialist. And other feedback suggests that early identification (via a DEXA scan) is essential:

- "The hospital consultant that x-rayed my fracture wrote to my GP and suggested that I undergo a DEXA scan due to my age (68) and family history (sister with early diagnosed osteopenia). However, I was not referred by the GP … and after a few months I requested a DEXA scan myself."
- "So much more needs to be done around preventing osteoporosis. Screening all menopausal women but especially those with a family history would be beneficial."

We understand that current pathways support specialists requesting DEXA scans, rather than asking a GP to do a referral.

Members of the local Royal Osteoporosis Society committee outlined the situation in York and the impact of no local fracture liaison service:

“We should point out that osteoporosis is not an exclusive women’s health issue as men also can be diagnosed with it.

… Some years ago we did have a fracture liaison service at York hospital. Leeds has a newly developed fracture liaison service (FLS). Consequently our medical pathway could best be defined by the cliche ‘a postcode lottery.’

Many of us receive good medical help particularly if led by a consultant. However, many of us would comment that we self-manage our condition e.g. requesting a DEXA scan or asking the GP for different medication. We also rely on self-help within the support group and on the Royal Osteoporosis Society nurses for clear advice.

A fracture liaison service (FLS) has proven cost effectiveness. Capture the fracture - provides medication; offsets a secondary fracture; offsets the loss of independence and there is no extra costs for the care system.

We continue to hope that the Integrated Care Board (ICB) will re-instate a solid fracture liaison service (FLS) in the area soon.”

EDS (Ehlers-Danlos syndromes) and hypermobility spectrum disorders

https://www.nhs.uk/conditions/ehlers-danlos-syndromes/

We heard from 11 people in our survey who have EDS or hypermobility spectrum disorders issues and three people through our ongoing work.

Everyone we heard from with EDS or hypermobility spectrum disorders also had other conditions. Many mentioned joint problems, pain and fatigue as commons symptoms. All the survey respondents talked about the impact of their conditions as severe or very severe where it affects their daily living and means they have to rely on others for help.

The time for diagnosis varied and many people felt healthcare professionals did not understand the condition. One person said: "Due to Ehlers Danlos being a rare condition, my GP and other health professionals at the time didn't know much, if anything, about it. I had to do my own research and get help from support groups and others with the condition so I knew not only what to ask for but who to be referred to, i.e. specific medical professionals."

Another person said: "Many of the health issues I've had in earlier life can be explained by my EDS but due to no diagnosis no one could recognise the problem and no one knew what was wrong with me."

The main treatment or referral we heard about is for physiotherapy with varying waiting times to get support.

When we asked people with EDS or hypermobility spectrum disorders what a good NHS service would look like for them, they mentioned more awareness and understanding and "multi-systemic care for hypermobility conditions" with multi-disciplinary teams and recognition of the connections between a range of conditions.

Alison's experience

Alison has a number of conditions including EDS which she sees as her main condition.

"The main symptom was severe pain. Also, my toes dislocated when I walked and I experienced other dislocations more regularly than seemed normal.

When I went to the GP, I didn't know that the pain I experienced all of the time was not normal. I assumed that everyone had a similar experience. I was 21 or 22 before I realised that my level of pain was not normal. By that time my sister had also been diagnosed so we could compare symptoms.

I went to see a GP and was referred to rheumatology. They didn't do any tests and told me it was growing pains. They referred me to a physiotherapist but that wasn't helpful. I could not make my muscles do what they were telling me to do because of poor proprioception (later a private physio talked to me about actions that use muscles and that made much more sense and did help).

I went back to the GP two years later and again was referred to rheumatology. I saw someone else and they did the tests for EDS and said that it was EDS rather than hypermobility. However, they said that they wouldn't refer me to a specialist as there wasn't anything they could do. I was told to go back to the GP for pain management. The treatment I found was through a specialist physio including advice about pacing.

After another two years, I went back to the GP as I needed a formal diagnosis to get Access to Work support. I was referred to Newcastle and waited. I knew it would take a while so didn't worry. When I chased it up I was told the department I had been referred to in Newcastle didn't exist and no referral had been made. I went back to my GP and they referred me to London. That appointment, including blood tests, confirmed I had EDS and linked me with a physiotherapist in York. It was more helpful and better, but still not great.

I did get six weeks' hydrotherapy which was helpful, but there was nothing after that.

... I developed severe depression. I was put on a waiting list for mental health support. In the meantime, I was self-harming as a coping mechanism and developed anorexia, again as a coping mechanism. My mental health referral said that the underlying issues were physical health and I was referred to the pain clinic. But they said they couldn't help as I wasn't healthy enough (due to the anorexia). At the pain clinic there was a very helpful Occupational Therapist (OT) who explained pacing very well and talked to me about practical things I could

do including adaptations for my home. They were human and understanding.

I was struggling at work. I was working four days a week. All my non-working time was spent recovering so I could go to work. I had no life. The doctor I spoke to at the pain clinic said it wasn't a good idea to give up work as my pain would get worse. They said I didn't need all the pain medication as I just thought I was in pain.

I saw an OT at the hospital regarding advice for work. They told me to take a break every 15 minutes, but the work I was doing on a telephone advice line meant that was impossible. A physio told me to take my wrist splints off several times a day, but I couldn't do that by myself and without them I couldn't do many necessary tasks like having a drink. They had no practical understanding of my life. When I explained why things they suggested wouldn't work, they saw me as argumentative and that I didn't want to help myself.

...It felt like people thought I wanted EDS and to be in pain. I wasn't treated as a human being. I wasn't listened to, there was no empathy or understanding.

I started struggling to swallow properly and for five months I was struggling to eat and became ill.

I was admitted to hospital and had an awful experience. A nurse tried to insert a feeding tube. It didn't feel right and hurt when I moved or talked. When I explained, the nurse said that 'if I didn't want the tube I should eat.' They had seen anorexia on my notes and assumed that that was the problem rather than EDS.

Also, I am lactose intolerant and vegetarian and there was no food available at the hospital for me to eat. Again, I was seen as being difficult when I explained.

… The whole experience of hospital was not good. None of the healthcare professionals or nurses treated me well. They told me I would be in trouble if I didn't get up and walk round. But I couldn't do that.

Before discharge I asked for some stronger pain killers – similar to the opiates I was taking at home. I was told no as I would not be allowed those at home. They said that without checking that I had the same medication at home. I was discharged the week before Christmas but still wasn't able to eat or drink.

At the end of January I had an appointment with a gastro doctor. They said there wasn't anything physically wrong and said I should have some nutritional drinks. These were either milk or pork-fat based. I was told I would have to try and had to use the pork-fat based ones which were awful. I was sent home with them to try. I am lactose intolerant and vegetarian…

My friend contacted the best doctor I had seen once and said that if he didn't see me she'd have to come up to take me to A&E. I was throwing up every time I moved or drank. I was admitted but to a different ward and the doctor talked to me about a feeding tube (PEG). The staff on that ward were lovely. The experience was much better until the good doctor went on holiday and the previous gastro team were providing my care. Again, they raised my mental health issues and used some issues I was having with the feeding tube to say I was being defiant rather than seeing that it was just some problems with the tube. They contacted the emergency mental health team.

I was being given IV anti sickness medication and I could feel it going round my body and couldn't breathe properly. When I saw the mental health team, I explained how my anorexia was different from the current situation and they listened and understood.

Then the good doctor returned from holiday and a PEG was fitted. It made such a difference.

The better ward felt like it was a partnership. The good doctor had mentioned my situation to a colleague who was teaching medical students. They asked and I was happy to talk to the students who were learning about seeing the full picture for each patient. There was also a good nurse who treated everyone as an individual and adapted his approach and conversation to each person.

As well as all medical staff treating me like a human, it would be much better if it was clear on someone's notes when issues are historic and therefore not relevant to current care. It seemed like some healthcare professionals just saw my mental ill health and anorexia and assumed that was still the problem, when it wasn't."

Gynaecological issues – endometriosis and PMOS

https://www.nhs.uk/conditions/endometriosis/ and
https://www.nhs.uk/conditions/polycystic-ovary-syndrome-pcos/

We heard from eight people with endometriosis and seven with PMOS (polyendocrine metabolic ovarian syndrome) in our survey and fourteen more with these and other gynaecological issues through other feedback.

Much of the feedback we heard reflects that above, but people also told us about experiences and issues that are specific to endometriosis, PMOS and other gynaecological conditions.

We heard from people who had mild symptoms to those severely affected. Many in the survey told us that their condition had affected their mobility and quality of life. The symptoms most often mentioned were chronic pain, very heavy periods and fatigue. Several respondents mentioned the trauma associated with not being believed and one said they now have: "Loss of trust in medical profession to understand or address my problems."

People reflected that their diagnosis had taken between a few months and more than twenty-one years. We heard:

- "It took 21 years to get diagnosed with endometriosis. I had issues with extreme period pain from when I was 11 and was diagnosed with endometriosis at 32. I saw GPs approximately twice a year with issues and they told me it was in my head; I should get on with it; it was just a part of being a woman and I was over-reacting. I was put on the pill at 14 which did help a little. I was only taken seriously when I broke down in a GP's office and was referred to gynaecology, but that was to do with fertility issues, not the other symptoms I had experienced."
- "I know my story isn't unique. It was draining to know something is wrong but to have health care professionals say there was nothing wrong. I began to doubt myself. My symptoms came back two years ago and I still had to fight to get a referral despite having a diagnosis."
- "For my PMOS I was referred for an ultrasound. I asked for more support in the appointment for my CPTSD (complex post traumatic stress disorder). I was told there would be supportive nurses and extra time. However, in the appointment the nurses were rude and hostile and impatient when I was nervous. They told me to leave without doing the ultrasound, and then reported back to my GP that they had done the ultrasound and found nothing. I was diagnosed with PMOS after I had an ovarian cyst burst."
- "You can get sent for an ultrasound, but endometriosis doesn't show up."
- "I was referred for an ultrasound and the people doing the ultrasound were told I had once broken my wrist and had a verruca. They weren't told I had endometriosis and had had a bowel resection, so they had no idea what they were looking for."
- "I was also told it was an STI and that my boyfriend must be cheating on me. Being told you have an STI is particularly common for younger people."
- "My daughter (25) has had years of crippling periods and awful pain. It affects her mental and physical health. At the GP practice she was

told it was due to rough sex, which isn't true. They did refer her to the hospital and she had a laproscopy which found nothing, so they dismissed her even though the symptoms haven't changed. … She did have a coil fitted, but that hasn't helped. She tried different contraceptive pills but they all had different impacts for her, particularly on her mental health. At one point they tried to force her to take medication that she didn't want to - one of the side effects was anxiety, which she already was experiencing - and did not listen to what she was saying. We know she has a high pain threshold but it is getting to the stage where she is having to take time off work as the pain is so bad."

One of the issues for women with gynaecological issues we heard about is being refused referrals to gynaecology or being told there isn't any treatment. We heard:

- "Refused due to not having infertility issues, (advised if tried for a baby for more than 12 months without success then to come back. But I do not want children)."
- "I was diagnosed with PCOS last year and have experienced a lot of debilitating symptoms. The GP's only advice has been permanent contraception until menopause and they won't acknowledge my requests for a gynaecology referral as all my conversations have been over text message which takes over a week for response. I have sent a complaint in as by the time the GP responds, they've forgotten everything I've told them and have to start again. It's been incredibly stressful."
- "I am still waiting for an appointment with gynaecology. I was told the wait list is 72 weeks, I have been waiting around 30 weeks."
- "My pain is constant and not controllable, as the more opiates I use, the less my digestive system functions, which causes me pain. So, I either have to chose more pain or more morphine, neither acceptable and I cannot get an effective balance…"

- "I was told to get pregnant and that would help! But it isn't a cure, there isn't a cure."
- "I had four failed rounds of IVF and went to the gynaecologist who said 'you need to get pregnant'. The insensitivity is horrific but isn't unique. I had so much anxiety as a result."

We heard from two people who had more positive experiences (eventually) thanks to healthcare professionals who listened:

- "With the neurogenic bladder I had UTIs for 18 – 24 months after I had a hysterectomy. I was seen by GPs and a urology nurse and they just kept prescribing antibiotics. I was on them for about two years until I went to one GP who listened and took me seriously. They listened to my symptoms and thought my oestrogen could be low. It was, the treatment has worked and I haven't had a UTI since."
- "I really struggled with fibroids in my uterus and cysts on my ovaries. I had irregular periods and pain. I also had a number of miscarriages and ectopic pregnancies. I saw GPs for years who said it might be IBS. But the treatment didn't help so I went back for years. I was eventually diagnosed when a new GP listened to me. They looked at my records and said they thought it was more than IBS and referred me to gynaecology. They were great and I had scans which showed fibroids and cysts. I got follow up from the hospital and the GP who was great. I saw them regularly and they worked with me on a plan to shrink the fibroids and got me blood tests to check my hormones and thyroid. They didn't want to do surgery. I was blown away by how well supported I felt. The GP was the second person I told when I found I was pregnant, part of it was I wanted to double check. She asked if I could see her that day to do another check and she was delighted for me. She shared my records with my midwife and made sure they understood what I would need. They made sure I was seen every two months to check on the fibroids and that I gave birth at 37 weeks due to risk. It was a traumatic birth and I had post partum depression. I had an amazing health visitor and they spotted the depression and referred me back to the same GP who got me

mental health support. When you get the help you need it is fantastic. My GP took time and listened to me, worked through my symptoms and got to the bottom of the cause. The information is there if GPs take time to find it and know who to refer you to."

Sarah's experience

"The biggest issue is the length of time taken to get a diagnosis. I had the first symptoms when I was 14 (low iron, pain, heavy periods) and wasn't diagnosed until I was 35.

At 14 I was offered anti-depressants and offered contraceptives and hormones. I was told I was unlucky with my periods. My experiences with periods shaped my life. I felt I couldn't go away to university, so stayed in York and lived at home. My life was lived around my periods, pain and fatigue.

Following an increase in pain eight years ago, I had a scan before I fell pregnant with my son (now seven) which found I had a blocked fallopian tube. I was told it could be the result of an untreated sexually transmitted disease. I told them this wasn't possible, but they didn't listen. As a result I felt shame.

When I was pregnant with my son and when I was breast feeding everything was much better. But when I stopped breast feeding, I had the worst experience I had ever had.

I had a miscarriage during Covid and had a lot of pain and awful periods. When I talked to healthcare professionals about wanting another child, they said I could have treatment or another child. I could not have both. … I eventually went to a private consultant who then saw me via the NHS. They did a laparoscopy which led to a diagnosis of endometriosis. I was then put on a waiting list as my fallopian tube was blocked due to endometriosis (not an STI!)

Six months later I was pregnant and am now breast feeding my baby. (It took six years to conceive). I don't know what will happen when I stop breast feeding. No one has talked to me about that or about longer term treatment."

Maria's experience

"Ten years ago I was diagnosed with pelvic inflammatory disease. I was finally diagnosed after years of pain that was dismissed as my bad mental health. It was beyond repair when they finally discovered it.

I had previously had problems with my periods, and had a procedure for that, but I was still left in pain. I had a number of laparoscopies with one consultant who continually found nothing wrong. Eventually he left and the next time I went there was a female consultant who did the procedure. After the procedure she told me that they had found end stage endometriosis, large cysts, and my bowel was compromised - basically there was nothing they could do.

I was offered a coil to help with my periods, but during the procedure they punctured my uterus and the coil had to be removed. I tried various contraceptive pills but they had no effect.

Eventually my GP referred me to a specialist in Hull who found endometriosis and adenomyosis. He said that at an earlier stage I could have had surgery, but now it was so high risk, potentially involving a seven-hour procedure and 15 clinicians, that it could be fatal or have life changing effects.

I receive injections every few weeks to induce early menopause and have therefore experienced symptoms of menopause. The medication I receive is off licence … There is no treatment, no surgery, I just have to hope that my bowel doesn't perforate.

Every three to four months I have to have steroid injections because the numerous laparoscopies I had previously resulted in scar tissue which was cut away, and in the process caused nerve damage. The steroid injection helps with the nerve damage pain that I experience. The consultant who does these injections is lovely and he knows me now which is really helpful. Because these jabs are an unusual treatment and were developed for a different purpose, I have agreed to be part of a research study he is conducting.

I was referred to a pain clinic last year and saw a senior physiotherapist who was terrible. She was not interested in my condition and was dismissive of my physical pain. She told me it was all in my head. I had previously been seen by a psychologist for a number of years (until a couple of years ago), and because of the problems I experienced getting help for my physical health, she took it upon herself to write to the various consultants I was seeing at that stage to tell them how to help me, just basic good patient care: listening to me and explaining what they were doing as they went along.

I feel like everyone thinks that this is all in my mind, but the consultant who eventually helped me reassured me it absolutely wasn't. In fact, if the earlier doctors had responded at a much earlier stage when I asked them about the pain I was experiencing, I don't think I would be in the position I am now – without any treatment options and adjusting to a life in pain."

Alison's experience

Alison has a number of conditions including endometriosis and vaginismus. This is her experience of those conditions:

"It took six to eight years to get diagnosed with endometriosis. The GPs just fobbed me off and said it was just periods, that I should take birth control but nothing worked.

I eventually spoke to a GP who had more understanding of EDS and the impact of progesterone and oestrogen on EDS. They felt a coil would be better for me. I explained about the vaginismus and was referred to the community team to fit the coil. I explained about the EDS and vaginismus but they tried to fit the coil twice. When it didn't work, they told me to come back in two months and take paracetamol. I managed to get a referral to gynaeocology. The first person I saw was the first person to ask if I wanted a family. They also said there was no need to examine me as it would be painful for me and not help. They said I would need a general anaesthetic to sort out the endometriosis and fit the coil. This happened.

The coil was due to be removed in December 2025. I went to hospital and was greeted by four nurses and a doctor. I was in the stirrups and they were planning to take the coil out in the normal way. … They tried a variety of things to remove the coil but eventually managed to saying that 'I don't think we're going to put another one in'.

I had asked about a hysterectomy but was told no. I am now waiting to see how I get on without the coil."

PoTS (Postural Orthostatic Tachycardia Syndrome)

https://www.nhs.uk/conditions/postural-tachycardia-syndrome/

We heard from seven people in our survey who have PoTS and three people through our ongoing work.

All survey respondents who said they have PoTS have one or more other long-term conditions. All of the respondents said that high heart rate was one of their symptoms, but many had multiple symptoms including pain, fatigue, dizziness and cognitive impact.

All respondents said the impact on the of their conditions was severe or very severe. Most experienced reduced mobility, impact on quality of life, impact on mental wellbeing and on ability to work full time. Almost all the respondents said they had to go private to get their PoTS diagnosis.

One person said: "My cardiologist in 2013 told me I just had a high heart rate because of my age. My GP in late 2024 told me that poor lifestyle was to blame for a complex mix of symptoms."

We heard from people that any local support for POTS had been withdrawn in 2025 and there is now no local service. We got in touch with PoTS UK, a national charity. The chair, Dr Lesley Kavi told us:

"PoTS can be complex and a difficult to manage condition, and cardiologists often tell us they do not have the time to see patients. Where services previously existed, we see them closed down. Sometimes it is because a clinician retired and there was no succession planning. No other consultant wants to take over seeing the patients. At other times the hospital management team tells the consultant that they are no longer permitted to see PoTS patients. They say a service was never commissioned (and the ICBs who have no knowledge of the prevalence or needs of their local PoTS patients do not wish to commission a service).

We hear of very complex unwell patients being discharged back to their GP and medication stopped. Adults and children return to being unable to work or attend school.

… The small number of services that exist are completely overwhelmed with referrals from outside their locality, and the staff are exhausted. Equally worrying, I have heard of consultant cardiologists with excellent services being told that they are the worst clinic in the hospital due to high new patient to follow up ratios or long waiting times, and for these reasons these desperately needed clinics have been threatened with closure in order to resolve waiting list issues."

Alison's experience

Alison also has PoTS/dysautonomia. This is her experience:

"I did my own research before diagnosis – my sister has the same condition and had been diagnosed before – to know that having my feet up and having salt helps. I was also already diagnosed with EDS [see above] and it is common to have PoTS and dysautonomia with EDS.

When I went to the GP initially, I took a printout of the NHS information about PoTS /dysautonomia with my symptoms highlighted and information about treatment. The GP looked at the information, noted that one treatment was sertraline, which I was already taking, so said that my symptoms were in my head. Because of that, and the fact that I was managing my symptoms due to my research, I didn't bother to go back to the GP.

Now, if my feet are down for too long, I feel as if I can't get enough air to breathe. The situation has been made worse as a result of my hormones.

I felt that my concerns had been minimised, I was dismissed and the GP thought it was all about mental health. The communication was awful and I did not feel respected. One of the treatments is compression stockings and I could get those on the NHS if I had a diagnosis."

Fibromyalgia

https://www.nhs.uk/conditions/fibromyalgia/

We heard from six people in our survey who have fibromyalgia and one other person through our ongoing work.

All but one respondent had one or more other long-term conditions and particularly ME/CFS which five of our six survey respondents have. All our survey respondents say their condition(s) affects their mobility, all but one have had to give up work and now claim benefits.

All but one person said they had lost trust in healthcare professionals due to their experience. People told us:

- "... the point my GP diagnosed me [after 11 years of symptoms] was when it was realised there is a history of fibromyalgia in the female side of my family. Up until this, it felt like I wasn't believed."
- "I was diagnosed with fibromyalgia and a nurse said I had a neurogenic bladder. The only information I had about fibromyalgia was to pace myself. I tried to get referred to pain management but they said my pain was too bad and it took a year to get a referral. "

Only four respondents said they had been offered any treatment either immediately or at some point. One person said: "Many treatments suitable for arthritis, ME and fibromyalgia are not compatible with medication for my heart condition. Medication for that is lifelong as an ablation procedure was unsuccessful due to complications. Physio and steroid injections have had limited effect and I am still experiencing severe pain."

The experiences of people we heard from with fibromyalgia reflect those above in that people felt they weren't listened to, believed and there was not enough understanding of the condition. One person asked for healthcare professionals: "To be compassionate and understanding that this illness has destroyed normal life."

Rheumatoid arthritis (RA)

https://www.nhs.uk/conditions/rheumatoid-arthritis/

We heard from eight people in our survey who have rheumatoid arthritis.

Three of the respondents had at least one other long-term condition and more than half of respondents (five) said the condition has a moderate impact meaning they have had to make some changes to their lives as a result.

Most respondents (six) said they experience reduced mobility and all said their condition affects their quality of life.

The length of time to get a diagnosis varied from two or three months to four years.

This was the condition where most people (six out of eight) said they had a sympathetic healthcare professional and fewer people reported not being listened to or believed or not being taken seriously. However, some people did report all of these. The better experiences may be because rheumatoid arthritis is a better-known condition, with symptoms that are often typical for that condition and which can be diagnosed via one blood test.

One person reflected: "I had a lot of blood tests, initially every few weeks, and each time a different condition was written on the blood form. Sometimes it was RA, other times polymyalgia and fibromyalgia. When I ask the consultant he said it wasn't clear but in general terms 'inflammation'."

Generally, people didn't have to wait for treatment, initially prescribed via a hospital consultant. However, one person said: "My problem was that I really needed medication long before my appointment at the hospital as I was in a lot of pain and it was having a huge impact on my mobility. I went back to the GP a few times and they eventually sought permission from the consultant to prescribe steroids in advance of my hospital appointment. The steroids made a huge difference, but I had to wait three months for this. The consultant prescribed long term meds at my first hospital appointment."

The overriding comment when we asked what a better NHS service would look like was about speeding up the time for appointments. One person said: "The initial wait that I had for my first appointment was awful, and the efforts of my GP made all the difference. An urgent referral should be dealt with urgently, preferably within a couple of weeks, people shouldn't have to wait for months whilst in pain."

Recommendations

Recommendation	To
NHS England and successor organisation – implement the actions from the renewed women's health strategy for England.	NHS England
Review the actions from the renewed women's health strategy for England, set up a prioritised action plan and begin timetabled implementation.	Humber and North Yorkshire Health and Care Partnership; York and Scarborough Teaching Hospitals NHS Trust; Tees, Esk and Wear Valleys NHS Trust; Nimbuscare; GP practices
Introduce mandatory training on women's health inequalities, unconscious bias, medical misogyny and trauma-informed practice for all NHS staff. Training should include active listening and empathy.	Humber and North Yorkshire Health and Care Partnership; York and Scarborough Teaching Hospitals NHS Trust; Tees, Esk and Wear Valleys NHS Trust; Nimbuscare; GP practices

Develop continuing professional development programmes covering female-dominated and under-recognised conditions. This should include endometriosis, PMOS, other gynaecological conditions, osteoporosis, ME/CFS, fibromyalgia and other conditions that affect predominantly women. Such training should include making sure healthcare professionals are aware of the difference between symptoms for physical and mental health conditions to reduce instances of mental health misdiagnosis.	Humber and North Yorkshire Health and Care Partnership; Nimbuscare; GP practices.
Introduce, or raise awareness of if already in post, women's health specialists for each GP practice. Make sure patients are aware of these roles and can easily ask to see a fully trained women's health specialist as desired and appropriate.	Nimbuscare; GP practices
Actively encourage feedback about staff attitudes from female patients as part of feedback mechanisms. Collate, analyse and act on this feedback.	Humber and North Yorkshire Health and Care Partnership; York and Scarborough Teaching Hospitals NHS Trust; Tees, Esk and Wear Valleys NHS Trust; Nimbuscare; GP practices
Carry out analysis to better understand the reasons for the length	York and Scarborough Teaching Hospitals NHS Trust

of waits for gynaecological appointments and the reasons that referrals for some women are being rejected. Use the analysis to improve waiting times and ensure referrals are accepted where appropriate.	
Embed 'listen, believe, investigate' principles within primary and secondary care. Do not dismiss any woman's concerns about their gynaecological health, pain or other symptoms without investigation. Ask about family history and consider this in diagnosis or referral. If you are not sure what the problem is or can't identify a cause, do not dismiss the person, but seek specialist input or refer the person to a specialist.	Humber and North Yorkshire Health and Care Partnership; York and Scarborough Teaching Hospitals NHS Trust; Tees, Esk and Wear Valleys NHS Trust; Nimbuscare; GP practices
If you haven't already, implement Jess's Rule. This primary care initiative encourages GPs teams to rethink a diagnosis if a patient presents three times with the same symptoms or concerns, particularly if symptoms unexpectedly persist, escalate, or remain unexplained. This should be followed for women's health concerns.	GP practices
Make sure there is specialist information or advice readily available about women's health conditions, what symptoms might mean etc.	Humber and North Yorkshire Health and Care Partnership
Promote where they exist, or introduce, clear, patient-friendly diagnosis, referral and management pathways	Humber and North Yorkshire Health and Care Partnership

for women's health conditions including ME/CFS, endometriosis, PCOS/PMOS, other gynaecological conditions, endometriosis, POTS, EDS etc	
Ask women with multiple long-term conditions about the reasonable adjustments they need. Make sure these are recorded and adhered to for all future appointments. This could include the need for longer appointments, appointments at particular times of the day (for example afternoon), home visits, quieter spaces in waiting areas etc. This information should include non-medical information including caring responsibilities.	York and Scarborough Teaching Hospitals NHS Trust; Tees, Esk and Wear Valleys NHS Trust; GP practices
Investigate introducing a health passport for women with multiple long-term conditions in a similar way to those for people with a learning disability or those who are neurodivergent. If appropriate introduce and promote these options for appropriate patients.	York and Scarborough Teaching Hospitals NHS Trust
Develop multi-disciplinary teams (MDTs) and care coordination for care and treatment for women with multiple and/or complex long-term conditions where appointments are coordinated and they only have to attend once to see	York and Scarborough Teaching Hospitals NHS Trust

the different healthcare professionals for different conditions.	
Review data for patients who are returning with the same symptoms to understand who they are and what the issues are. Introduce approaches to address these needs to understand if those people have underlying health issues which could lead to those symptoms.	GP practices
Review information about women patients diagnosed with mental ill health, particularly where it is accompanied by symptoms including pain, heavy / painful / irregular periods and fatigue to make sure that there is not an underlying physical health condition that is resulting in symptoms of mental ill health.	GP practices; Tees, Esk and Wear Valleys NHS Trust
Make sure there is consistent coding for women's long-term conditions using the NHS SNOMED CT[37] across primary and secondary care. Use this coding to create and monitor data about women's health conditions.	Humber and North Yorkshire Health and Care Partnership, York and Scarborough Teaching Hospitals NHS Trust, GP practices, Tees, Esk and Wear Valleys NHS Trust.
Where possible endeavour to make sure that women with long-term conditions see the same healthcare professionals.	York and Scarborough Teaching Hospitals NHS Trust

[37] https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct

Provide structured information immediately after diagnosis including signposting to charities, support groups and community services.	York and Scarborough Teaching Hospitals NHS Trust; GP practices; Nimbuscare
Investigate social prescribing pathways tailored to people with chronic illness.	Humber and North Yorkshire Health and Care Partnership
Review ME/CFS care in York and make sure it aligns with the service template being developed for ICBs as part of delivery plan actions. Make sure that the service has a clear pathway and includes further investment in the Yorkshire ME/CFS fatigue service to reduce waiting times and enable ongoing support for patients. Also investigate other support and symptom management for patients either via the Yorkshire ME/CFS fatigue service or another provider.	Humber and North Yorkshire Health and Care Partnership
Review the local pathway for women's bone health including more frequent reviews for people with osteoporosis, priority scans for those with a family history of osteoporosis and investigating the cost and health benefits of a regional or local fracture liaison service.	Humber and North Yorkshire Health and Care Partnership

Response from Humber and North Yorkshire Integrated Care Board

NHS Humber and North Yorkshire Integrated Care Board welcomes this report and thanks the women who shared their experiences with Healthwatch York. The report raises important themes around listening to women, taking symptoms seriously, improving understanding of long-term conditions that disproportionately affect women, and making care more coordinated and accessible.

Several of the recommendations align with areas already being considered locally, including women's health inequalities within commissioning intentions, women's health integrated neighbourhoods, work underway on relevant pathways, and Single Point of Access work under development at the Trust.

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