healthwatch Staffordshire

Deep Dive - Women's Health Issues: Uncovering the Reality Behind Gynaecological Conditions

March 2026

Contents

Introduction **3**

Foreword 3

Purpose of this Deep Dive Study 3

Background 3

Local Context **5**

Health Harmonie Services 6

UHNM Pathways and Service Challenges 7

University Hospital Derby & Burton (UHDB) Pathways 9

Methodology **10**

Results of Survey and Case Studies **11**

Conditions 11

Duration of Condition and Time to Diagnosis 13

Impact on Day-to-Day Life 16

Diagnosis - Role of Professionals and Organisations 19

Funding of Diagnosis 20

Barriers to Getting a Diagnosis 21

Surgery 22

Impact of Diagnosis and Surgery on Quality of Life 24

Care Received 25

Suggestions for Improving Gynaecological Care 27

Themes Identified **29**

Recommendations **32**

Acknowledgements **36**

Useful Resources **37**

Appendix 1 - Glossary of Terms **38**

Introduction

Foreword

About language in this report

This report often uses the term *women* in line with national policy, clinical guidance and published research. However, Healthwatch Staffordshire recognises that some trans men, non-binary and intersex people also experience gynaecological and reproductive health conditions. Where we refer to women, this should be understood as inclusive of all those affected by the issues discussed in this report.

Purpose of this Deep Dive Study

The feedback received through Healthwatch engagement events, and through our website, from women and those with female physiology living in Staffordshire, highlighted that they have had painful gynaecological issues ignored, misdiagnosed and mistreated, often for many years, resulting in them losing their jobs and affecting their relationships, mental health and wellbeing.

It is against this background that Healthwatch Staffordshire embarked on this deep dive study to ascertain whether the local and national picture aligns. Our aim was to find out about the experiences of people in Staffordshire accessing services, getting a diagnosis and treatment. Our study looked at waiting times for getting an appointment and diagnosis, through both primary and secondary care services, and found out from women and others who experience female physiology what they would like to see happen to improve their experience and that of others going forward. We also wanted to find out what could be learned from any good practice they encountered on their journey through diagnosis and treatment and share that information with the commissioners and providers of services.

Background

Reproductive health conditions are very common. For example, endometriosis is estimated to affect 1 in 10 women and others of reproductive age who experience female physiology, while the prevalence of heavy menstrual bleeding in the adolescent population is estimated at 37%. www.nice.org.uk/guidance/ng73

'Women's health conditions' is terminology often used in studies and reports to describe conditions that are unique to female reproductive systems, more

common in female physiology than male physiology, or that affect those with female physiology differently and more widely than they do those with male physiology (Gjellestad et al., 2023).

Female physiology specific conditions such as endometriosis, fibroids, and menopause, along with gender disparities in diagnosing and treating general illnesses such as heart attacks, significantly affect the health and wellbeing of women and others who experience these conditions in many aspects of their lives.

Over the past 5 years, there have been extensive studies undertaken around women's experience. A recent House of Commons Committee on Women and Equalities published a report in December 2024, entitled 'Women's Reproductive Health Conditions' in which it stated:

"Women's reproductive health conditions, such as endometriosis, adenomyosis and heavy menstrual bleeding are highly prevalent in the UK. Yet many who experience them find their symptoms dismissed and normalised by those they turn to for help. For some conditions, accessing diagnosis and treatment can take years, leaving women and girls to "suck it up" and endure pain that interferes with every aspect of their daily lives, while their conditions worsen. Women and girls are missing out on their education, career opportunities, relationships, social lives and are having their fertility impacted because of neglected reproductive health conditions. Many are resorting to expensive private healthcare".

Women are being told symptoms such as heavy, painful bleeding and incontinence are "normal", that they are either too young to have a condition, or too old to expect treatment. As a result, women and girls are making repeat GP visits and ending up in A&E as their conditions worsen and become more complicated to treat

Similarly, the Royal College of Obstetricians and Gynaecologists (RCOG) produced a report 'Waiting for a way forward' published in November 2024. This was a follow-up report to their previous report 'Left for Too Long' (April 2022). Between the publication of these reports, waiting lists (to July 2024) for gynaecology in the UK have increased by a third and that there were three quarters of a million women waiting for gynaecology treatment. This figure is not including the thousands more women likely to be waiting for diagnostic tests to confirm their condition in the first place.

The RCOG report highlights that the continued lack of prioritisation of women's health by Government – and gynaecology by extension – explains why

gynaecology is so challenged as a speciality. Gynaecology has historically been perceived as less important in wider elective recovery, and this has resulted in an increasing number of complex cases, disease progression, emergency admissions and women living in pain and distress: all of which are preventable.

Based upon these findings, the RCOG have made several recommendations which will help professionals enhance their skills and capacity to deliver better care, will improve patient experience and improve the support offered to women who often experience years of pain and distress whilst waiting for diagnosis and treatment.

As a result of this and other supportive research data, the Government has agreed with the overarching aims of the findings and recommendations for improving women's health outcomes and experiences and acknowledged the impact that reproductive health conditions have on women's lives, relationships, and participation in education and the workforce.

The Health Secretary, Wes Streeting, commented;

"Whether it's being passed from one specialist to another for conditions like endometriosis or PCOS, the lack of proper pain relief during procedures, or unacceptable gynaecology waiting lists - it's clear the system is failing women, and it shouldn't be happening. We are committed to improving women's health as we reform the NHS, and women's equality will be at the heart of our missions. This report will support the government to consider what further action can be taken to ensure that the health needs of women and girls are prioritised, particularly as we develop the 10 Year Health Plan".

As the 10-year plan is developed, the government has committed to working with the sector to identify the right actions and interventions that will deliver the required changes for women and babies. It is acknowledged that whilst some of these will require time to implement, they will also identify immediate actions to drive forward change now.

Local Context

From the feedback we have gathered, it is apparent that for many women and others who experience female physiology in Staffordshire and beyond, heavy and painful periods are not "just a period". They are a source of profound distress, health deterioration, and social exclusion. Recent local investigations by University Hospitals of North Midlands NHS Trust (UHNM) parallel national findings, revealing that women are often dismissed, delayed, or denied adequate menstrual healthcare support.

On average, women wait 22 months from the onset of symptoms before consulting a healthcare professional about menstrual concerns. Even after seeking help, 84% receive no diagnosis and 81% are not referred to specialists, resulting in years of undiagnosed suffering. Conditions such as endometriosis take an average of 8 years and 10 months to diagnose, with Black women 50% less likely to be diagnosed than their White counterparts, raising urgent questions around racial bias and healthcare equity.

These delays were corroborated by Staffordshire-based findings that aligned with national data, suggesting that women across the region experience similar systemic neglect.

As part of our study, we engaged with the gynaecological services provided at University Hospital North Midlands (UHNM) and University Hospitals of Derby and Burton (UHDB). We carried out visits to outpatient services in Samuel Johnson Hospital (Lichfield), Robert Peel Hospital (Tamworth) and Queen's Hospital (Burton upon Trent).

We also spoke to managers at Health Harmonie Healthcare who provide local NHS gynaecological services within Staffordshire.

Our aim was to seek the views of a range of professionals across all parts of gynaecological care and treatment pathways, to understand their experiences of providing services, and perceptions of gaps and barriers in service delivery.

Health Harmonie Services

Health Harmonie has operated for 7 years in North Staffordshire and Stoke-on-Trent and provides NHS-funded gynaecology services in the community. They are now an accredited provider of gynaecology services across the whole of Staffordshire, commissioned by the Staffordshire and Stoke-on-Trent Integrated Care Board. These services cover a wide range of conditions, including heavy menstrual bleeding, polycystic ovary syndrome (PCOS), and menopause. Late in 2025 they were commissioned to provide an additional unscheduled bleeding pathway for patients on HRT.

Access to their service is available through referral from a GP. The service includes a comprehensive assessment, diagnosis and management of a wide range of women's gynaecological conditions. Pathways are delivered with specialist triage with average waiting time being 6-8 weeks. The service receives around 600 referrals per month, 7000 per year, and operates a patient initiated follow up service if required. This is an ongoing arrangement which is expected to continue until at least the end of March 2027.

This service allows many women to access specialist care more rapidly than if they are referred directly to hospital services. Some patients may need onward referral for surgical intervention at UHNM. Acute trust processes can then cause delays with treatment, as patients are currently required to undergo repeat triage.

Approximately only 20-25% of patients are onward referred to hospital services; the majority are retained in the community/discharged back to primary care (GP).

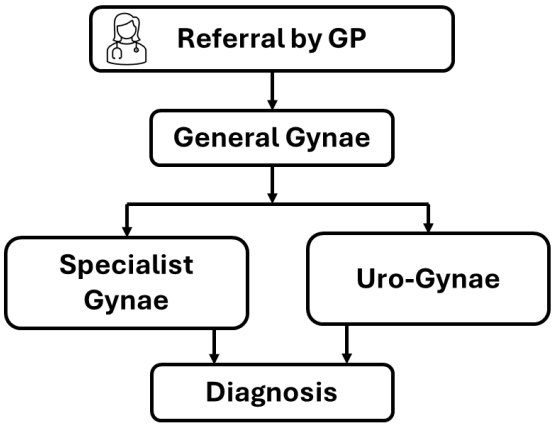
UHNM Pathways and Service Challenges

We spoke to two consultant gynaecologists at UHNM, at different times, and it was explained that waiting times vary depending on the type of referral. On average, patients wait around 26 weeks for an initial consultant appointment. The service is delivered by the gynaecology consultant team across two surgical and medical specialties, supporting both pregnant and non-pregnant women.

They identified several barriers affecting women's access to timely care. A key issue is the limited gynaecology training within general medical education, which can result in inappropriate or incorrect referrals. Specialist training opportunities are also limited, meaning GPs without a specific interest in gynaecology may lack the necessary expertise.

Referral pathways were described as inconsistent and sometimes confusing.

University Hospitals North Midlands Pathway for Gynaecology



For example, if the referral has gone through the Health Harmonie pathway and further surgical treatment is required - for example laparoscopy - then the patient would have to repeat the assessment process through the standard general gynaecology pathway. This should be resolved with the introduction of new nationally mandated referral processes, with all patients being clinically triaged and patients able to access straight to test or outpatient procedures.

100% of patients are seen for their first appointment at Health Harmonie within 10 weeks whereas the average wait times for a first appointment in general gynaecology in acute trusts are 24 weeks.

The following points were raised during these discussions:

- UHNM gynaecology generally does not accept diagnoses from consultants in other Trusts, due to varying clinical standards and the need for direct assessment (except where clinicians also work at UHNM).
- Referrals by Health Harmonie to UHNM for procedures requiring general anaesthetic (e.g. laparoscopy) often require further triage by the treating hospital, due to hospital policy and the need to manage existing waiting lists fairly.
- Patients assessed by Health Harmonie for straightforward issues—such as hysteroscopy, fibroids, or polyps—may proceed without further triage if no invasive surgery is required.
- There is significant concern regarding proposed virtual gynaecology consultations, particularly around patient safety and accessibility.
- Waiting times and patient outcomes are influenced by the referral pathway and can vary depending on the patient's diagnosis. For example, in menopause-related cases, consultants have been actively supporting GPs to deliver first-line treatments such as HRT, reducing the need for referral to gynaecology. When referrals are made for conditions that can be managed in primary care with HRT, national guidance is returned to GPs to avoid unnecessary delays. If patients still wish to see a specialist, they may be referred to Health Harmonie.

It was reiterated that endometriosis care is not a separate service at UHNM but has been part of the specialist gynaecology for the past 10 years. Since the summer of 2025, 3 new consultants have been appointed. One has created weekend surgery opportunities which has brought down the waiting list for general gynae, though specialist and uro-gynae lists remain higher (no figures available).

UHNM have developed new procedures to maximise efficiency, to get people seen quicker and home quicker, though they are still well supported, not just 'out the door'. There are also more robotic surgeries which have been introduced by one of the new consultants.

At a glance:

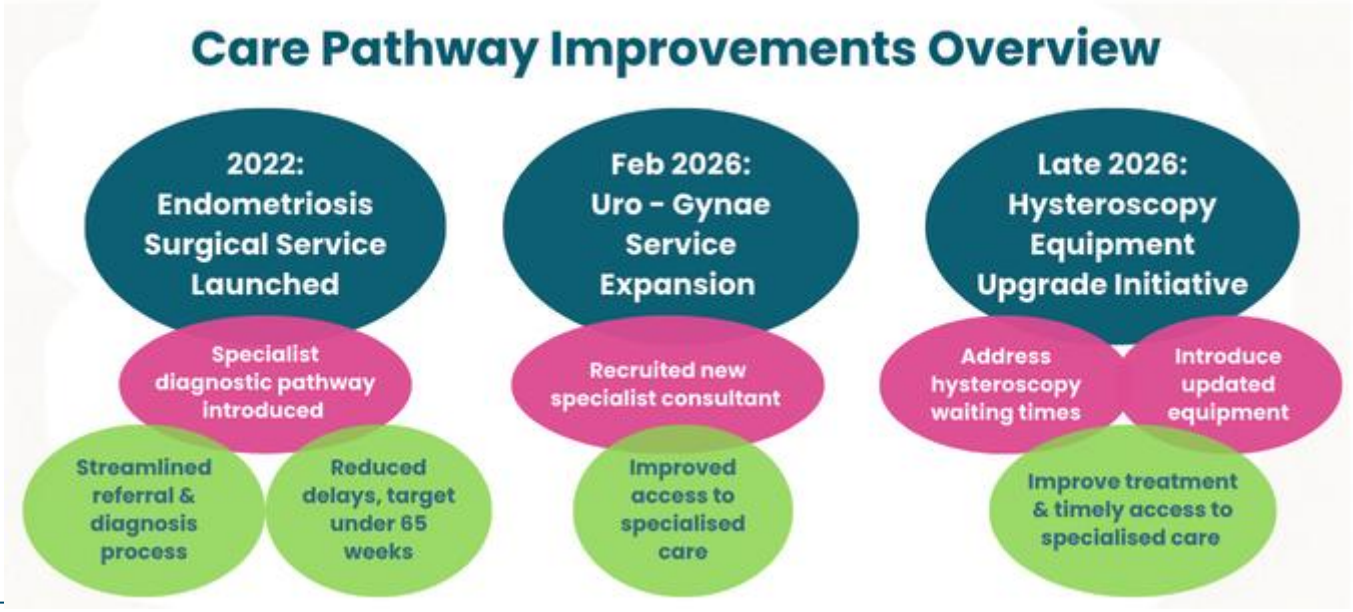
Consultants also highlighted poor communication and a lack of coordination between commissioners and providers - including GPs, UHNM, Health Harmonie, and MPFT—as a major source of inefficiency. Combined with low awareness in primary care and increasingly well-informed patients with higher expectations, these issues contribute to greater frustration and dissatisfaction. They stressed the need for a fundamental redesign of women's health services, with better integration between primary and secondary care to reduce waiting times and improve patient outcomes.

University Hospital Derby & Burton (UHDB) Pathways

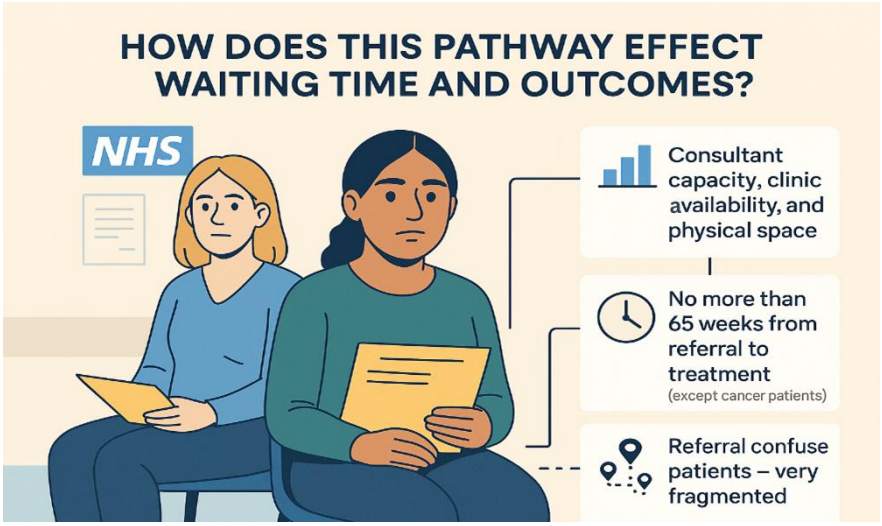
Triage Pathway Steps Process for Diagnosis through UHDB Trust

GP Referral through Patient Access Systems → Triage through Meditech (UHDB electronic Health Record system) → Consultant Review (depends on Key Words in referral) → Appointment & Diagnostics (would be carried out) → Treatment Pathway (Patient would start on that Journey).

We were told that the endometriosis surgical service launched in 2022 and is accessed through a GP referral. In February 2026 the Uro-Gynae service expansion was launched to help bring down the waiting list.



The team have specialised skills and will be based at Queen's Hospital (Burton upon Trent). In late 2026 there is an initiative planned to upgrade hysteroscopy equipment, as the current equipment is dated. There is also an initiative to improve the waiting time for patients requiring a hysteroscopy procedure.



Methodology

We used a multi-faceted approach to gather comprehensive feedback.

An online survey explored women's experiences of seeking a diagnosis and treatment, identifying key concerns and barriers. It was widely promoted across Staffordshire through our website, social media, community posters, and our e-Bulletin.

We also held five creative, activity based- focus groups with around 25 women, producing three detailed case studies that illustrate their varied journeys from symptoms to diagnosis and treatment.

In addition, we visited outpatient clinics at Samuel Johnson Hospital, Queen's Hospital, Sir Robert Peel Hospital, and University Hospital North Midlands. We spoke with staff, including two consultant gynaecologists, and met the manager of Health Harmonie to understand the scope and scale of local gynaecology services.

Results of Survey and Case Studies

Conditions

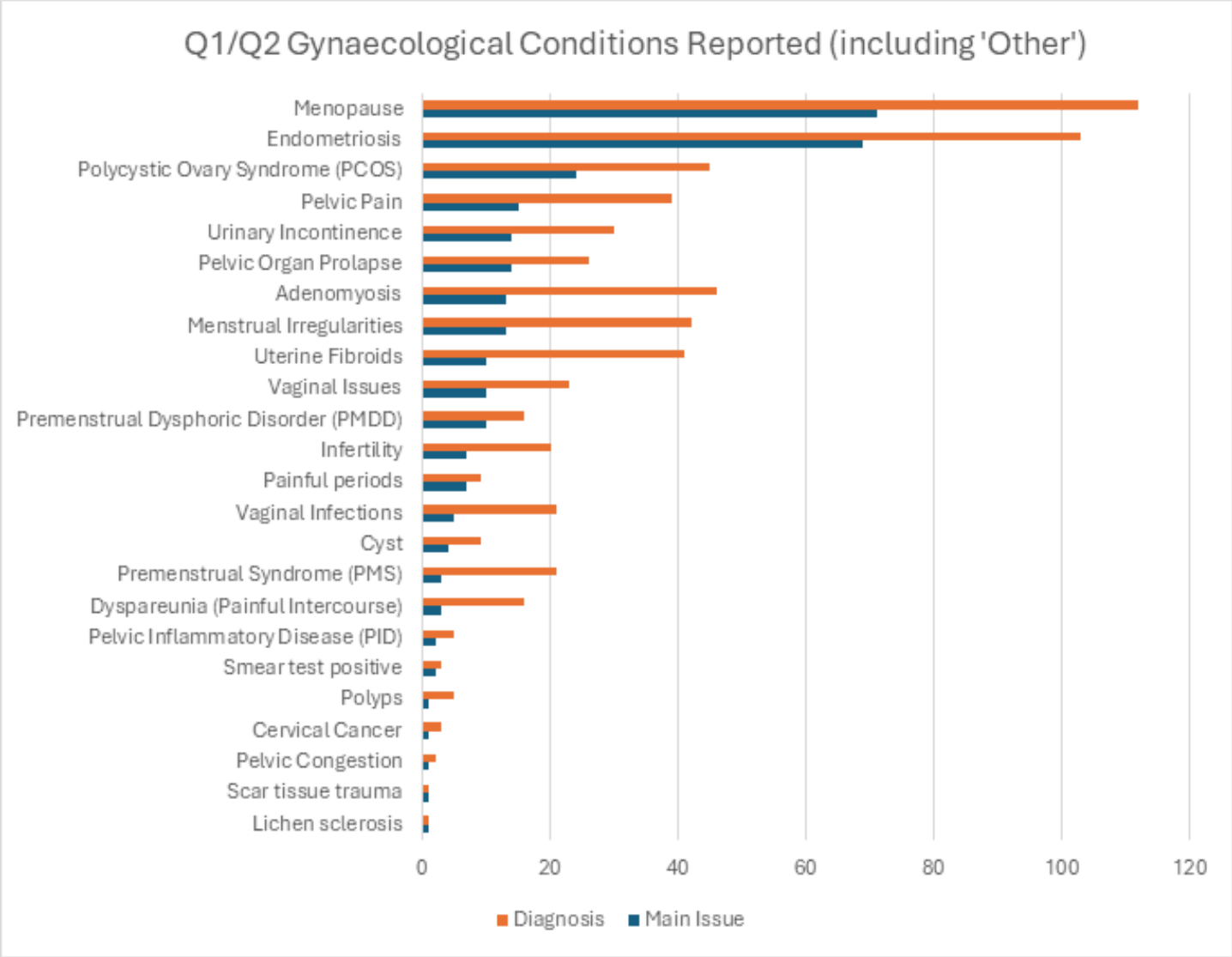
Our survey produced 304 responses. The top 6 conditions that **women were diagnosed with** were:

- Menopause
- Endometriosis
- Polycystic Ovary Syndrome (PCOS)
- Adenomyosis
- Menstrual irregularities
- Uterine Fibroids

Appendix 1 contains a glossary of terms, which explains these and other gynaecological conditions.

When asked which single gynaecological condition most affected their day-to-day life, 298 respondents reported 307 diagnoses. The top 6 conditions that **most affected women** were:

- Menopause
- Endometriosis
- Polycystic Ovary Syndrome (PCOS)
- Pelvic Pain
- Urinary Incontinence
- Pelvic Organ Prolapse



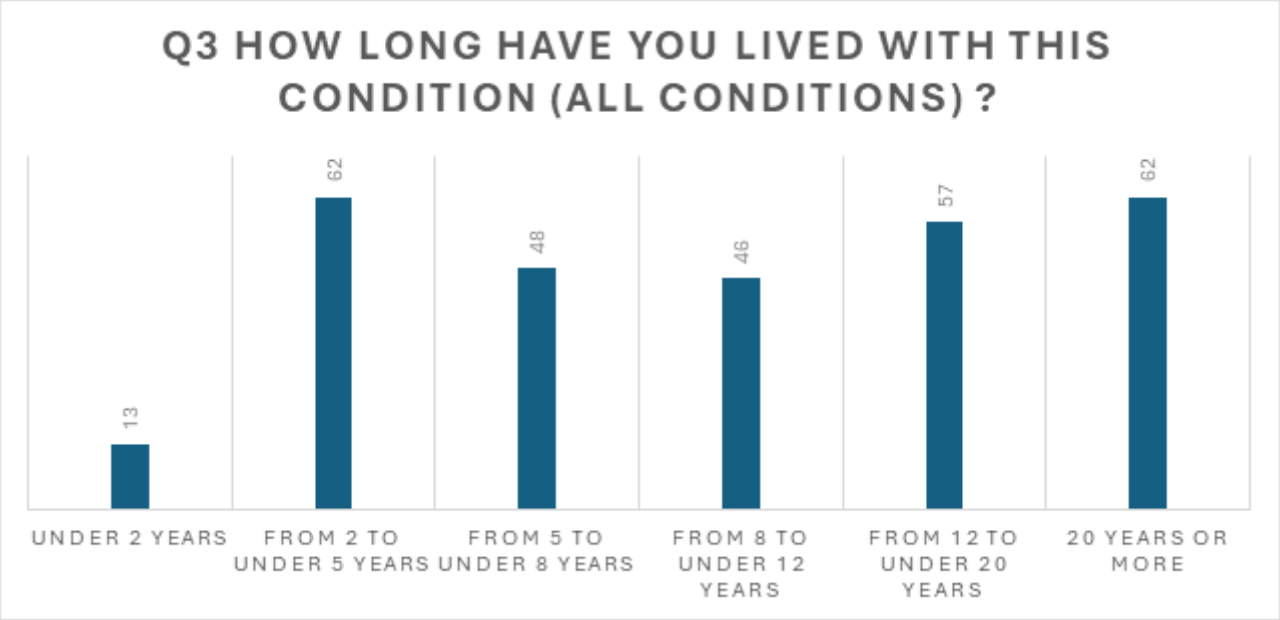
Nine respondents were unable to identify a single condition, citing multiple conditions instead, for example: *"Endometriosis and pelvic congestion syndrome equally, as one aggravates the other."*

Several respondents reported that one condition led to another; for instance, one individual required a hysterectomy, which subsequently resulted in early menopause with a whole new set of symptoms.

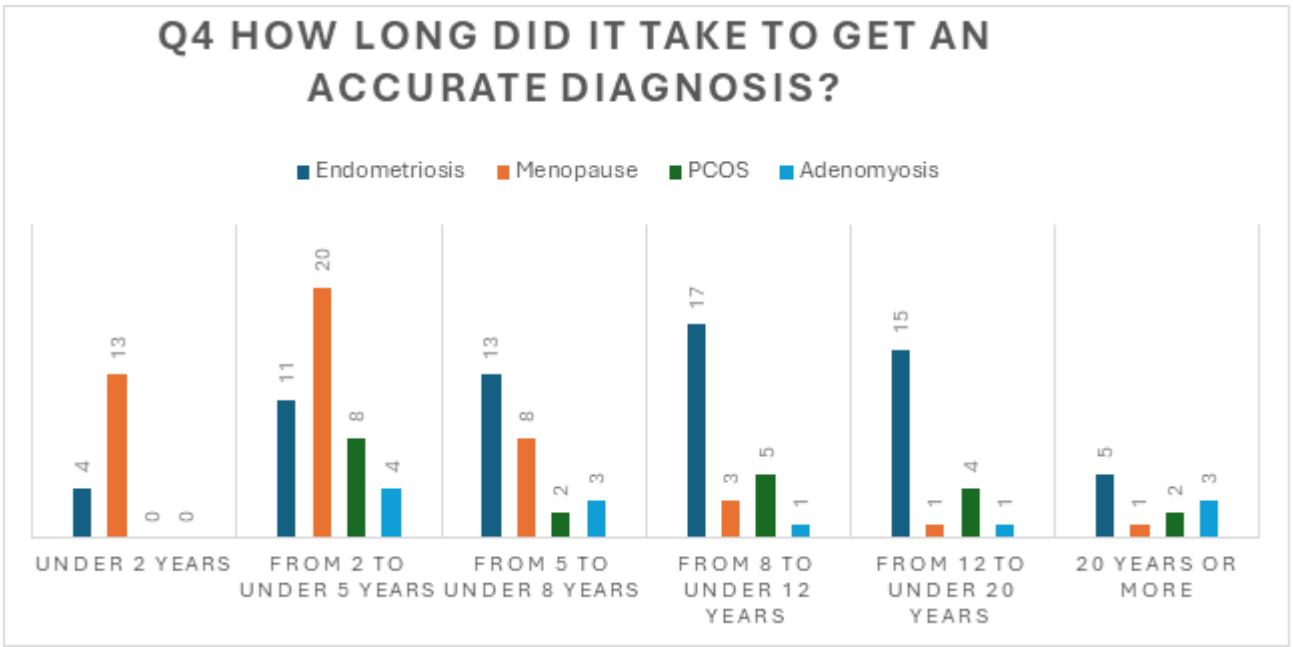
Duration of Condition and Time to Diagnosis

Respondents had lived with their condition from under two years to over 20 years. Among the 62 who had lived with a condition for 20 years or more, nine had experienced symptoms for over 38 years.

Menopause generally has a shorter duration, while endometriosis is often long-term.

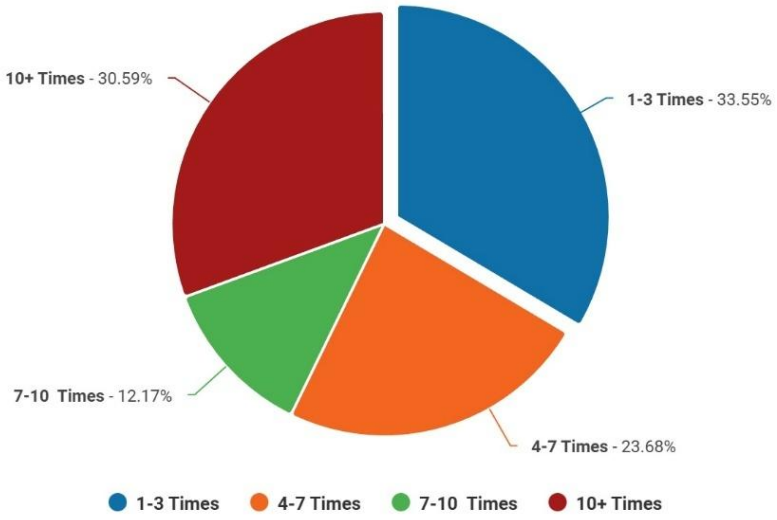


The most common diagnosis timescale was 2–5 years, varying by condition. Endometriosis had the longest delays, typically taking 8–12 years to diagnose, while PCOS and adenomyosis took at least two years.

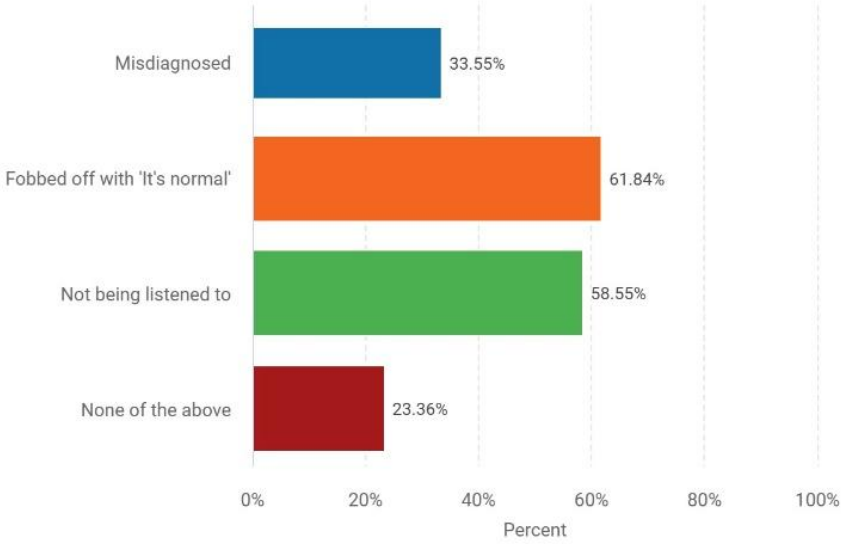


The longest reported wait was 32 years for endometriosis in someone aged 50–65, although better examples included eight months for someone aged 25–49 with the same condition.

Survey respondents were asked how many times they visited their GP with symptoms before receiving a diagnosis or specialist referral. Most reported attending 1–3 times; however, a notable number attended 10 or more times.



Before receiving a diagnosis, many respondents reported feeling dismissed and fobbed off by professionals, often being told that their symptoms were "normal." This was frequently followed by a sense of not being listened to, and a smaller proportion experienced misdiagnosis. Only a limited number felt that none of these issues applied to their situation.



Case Study 1

In the following visual, you will be able to see the lived experience of one of our case studies in trying to get a diagnosis.

Ask Yourself! How Many Women Resonate with Lydia's Story?

Symptoms

From 16 years of age

Heavy painful Periods

Missed periods

Unable to conceive

10 Years of suffering to be taken seriously

Diagnosis

GP being the blocker

GP not taking symptoms seriously

Inconsistency with not seeing the same GP

GP not referring to a specialist

Lockdown not able to see a GP

Condition worsening Forcing issue with GP

The Trauma

Fobbed off

Marginalized

Not Listened to

Unnecessary Pain

Adverse effects on life

Impacts Physical & Mental Health

No work - life balance, No LIFE!

Years of persistence finally got GP to refer to consultant

FINALLY seen and diagnosed by consultant within months

Ultrasound & Hysteroscopy

Few months later surgery to remove several large fibroids & pain free

Professional Excuses

"It's Normal"

"It's Anxiety driven"

"It's Hormonal"

"It's just a period"

"It's Depression"

Impact on Day-to-Day Life

When asked about the impact of their condition on different aspects of their lives, it was clear that gynaecological conditions affect almost every area of daily functioning, with the level of impact varying by condition and severity.

More than 200 respondents talked about the negative impact of their condition on their mental health and 180 women said it had impacted negatively on their physical health and relationships. Many individuals endure years of unnecessary suffering, highlighting significant inequalities in gynaecological healthcare and reinforcing the importance of bringing these issues to the forefront to drive change.

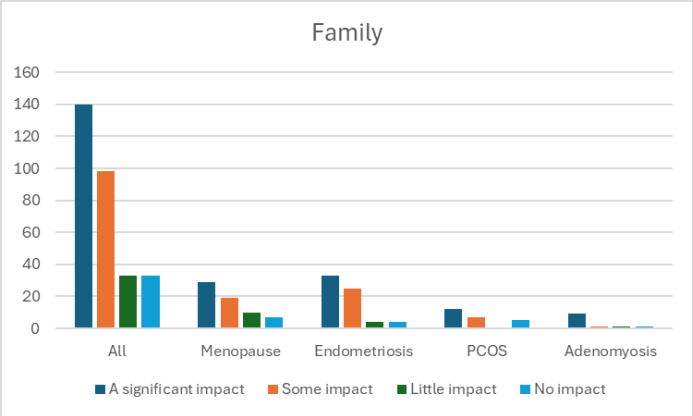
The following comments are a small sample of the 274 received:

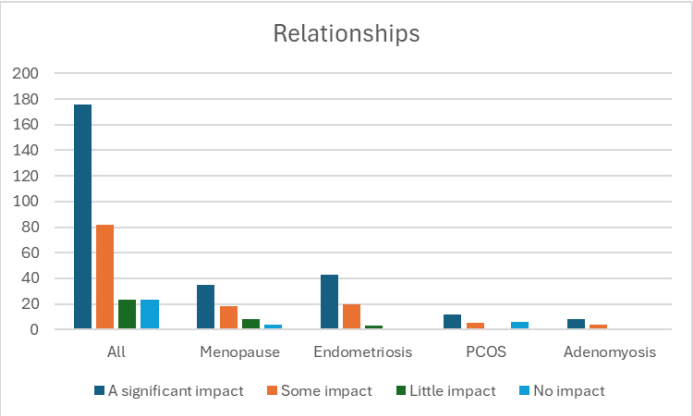
"I experienced mental health issues which included OCD type behaviour and feelings of anxiety and depression. Loss of sex drive, and irregular periods caused confusion and uncertainty as to whether I would have a period, how long it would last and how heavy it would be. Physically experienced pain, including joint pain, increase in headaches and weight gain".

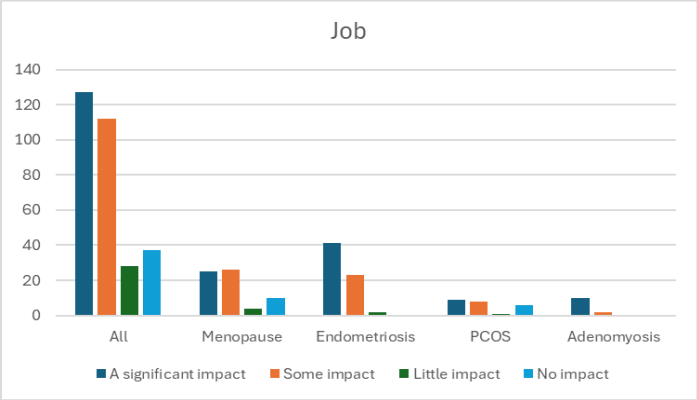
"I have become a shell of a person. Very withdrawn and struggling to do normal day to day things. I had to quit my Senior Manager job role in July 2024 and had to wait until I was prescribed medication to help in March 2025 and for that to start working for me to start to feel better and return to work part time in June 2025. Even now I don't feel 100% because my Prostap injections only work for part of the month."

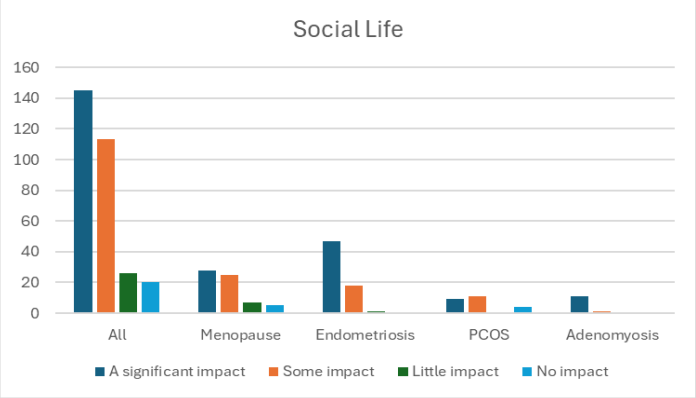
"Endometriosis impacted my physical health as the condition is very painful. It would cause painful intercourse which would often affect my relationships, the pain would affect my work life as I would be in a lot of pain at work. The condition is also very unpredictable so it would cause flare ups at work or when out with friends and family."

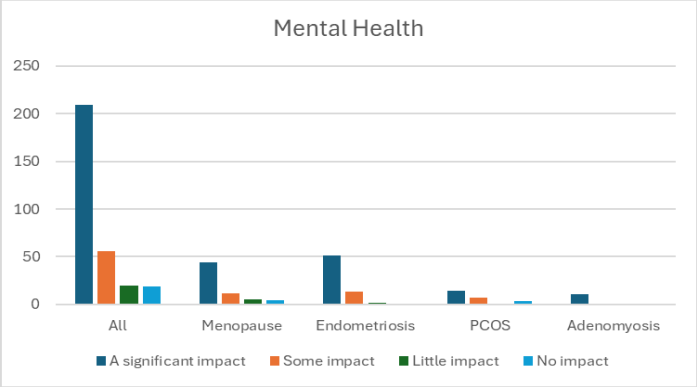
The accompanying graphs show how the impact varies across conditions, highlighting differences in both the extent and severity of their effect on quality of life.

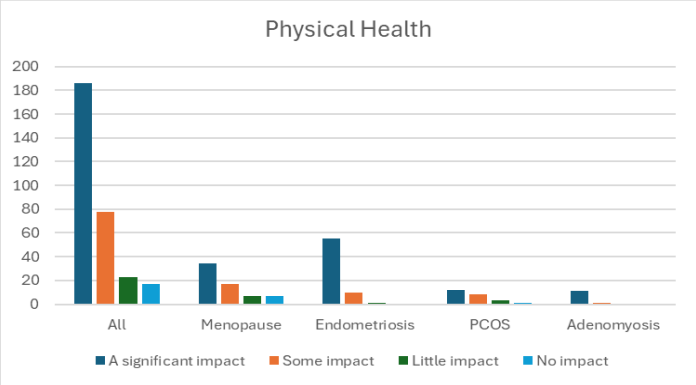






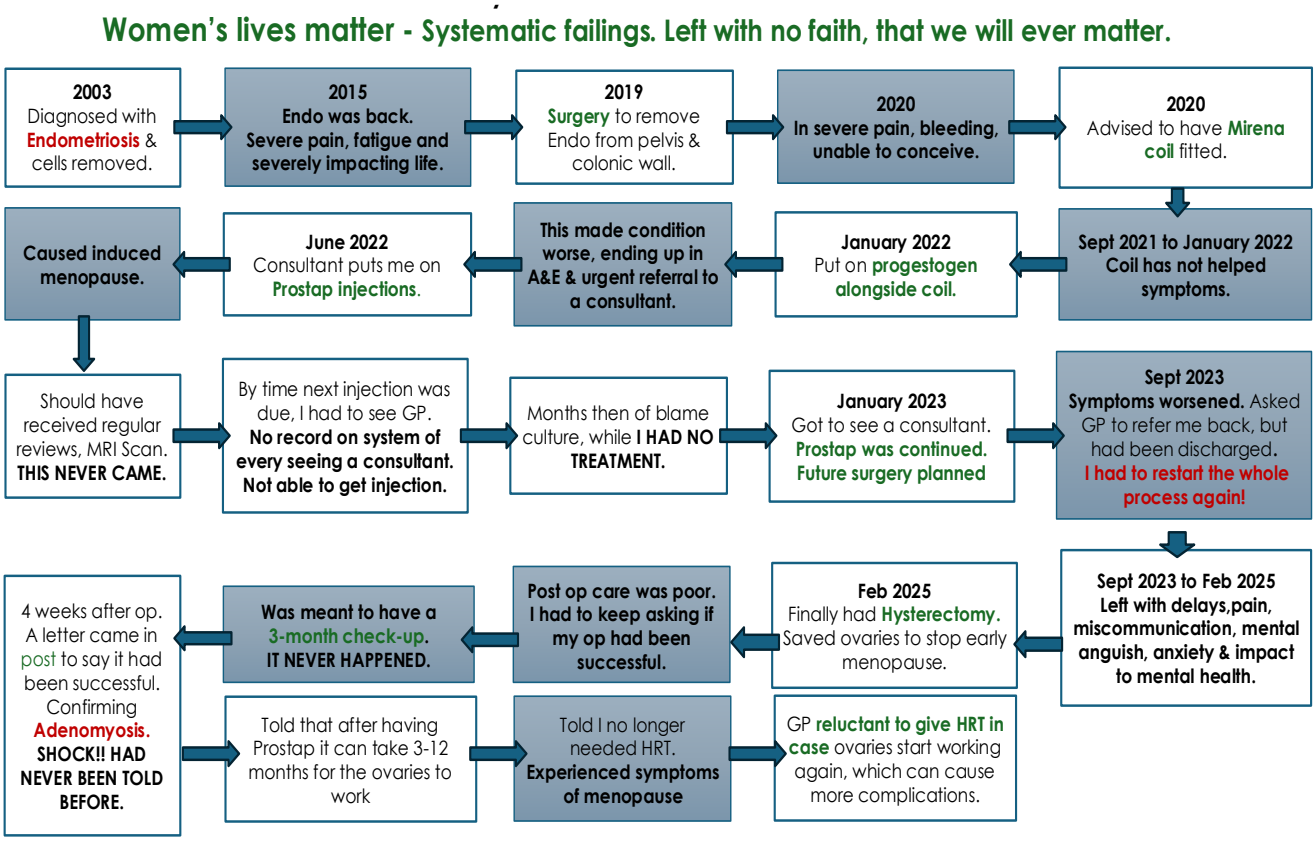




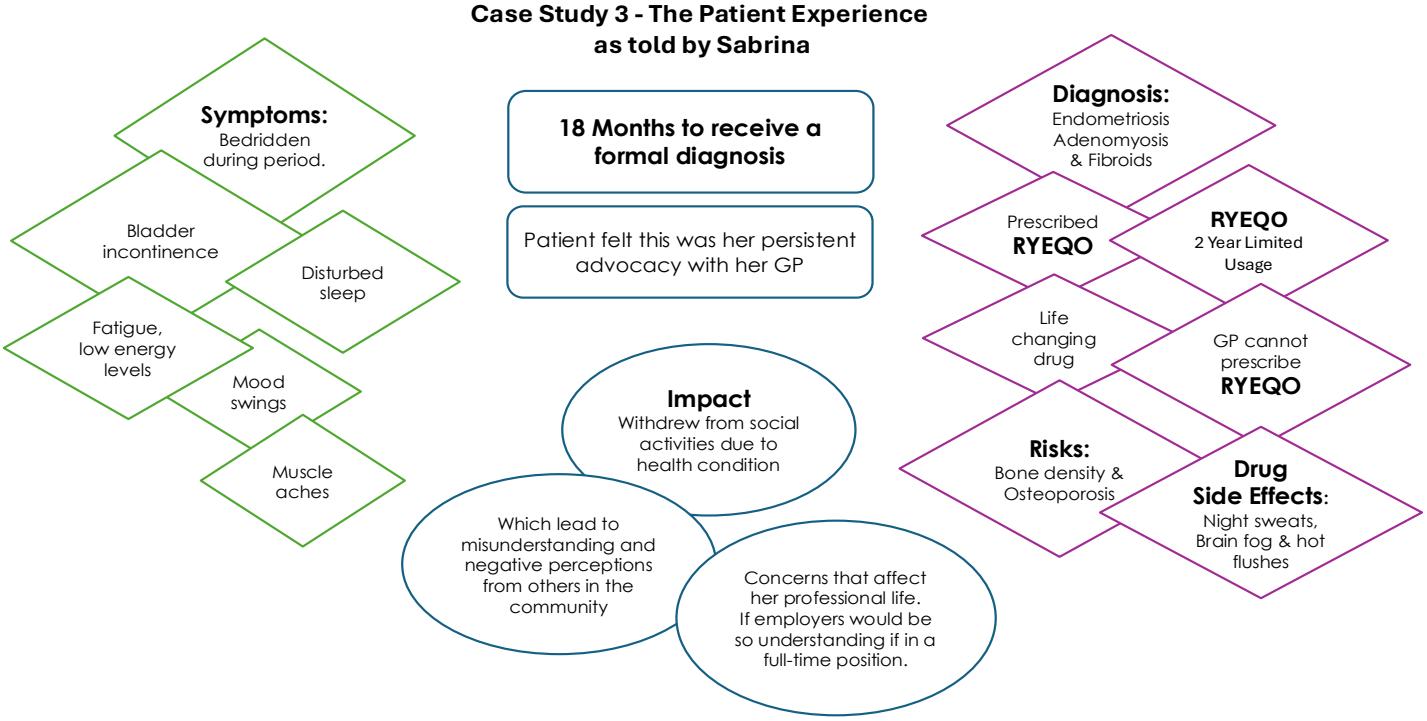


We also have the following case studies regarding one lady's lived experience of Endometriosis, and another's battle with Endometriosis, Adenomyosis & Fibroids. These include their journeys to getting diagnosed and receiving treatments.

Case Study 2



Case Study 3



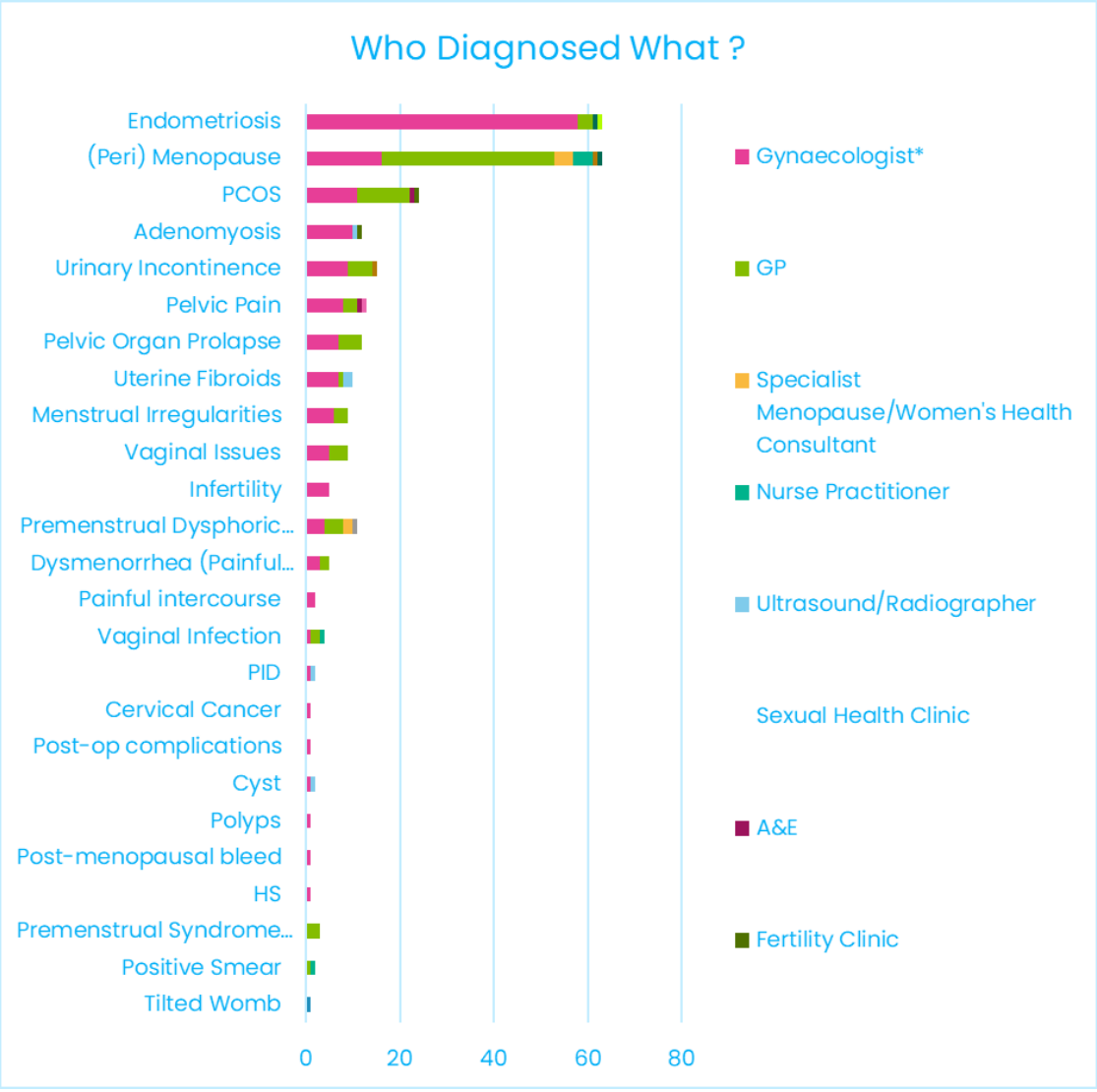
Diagnosis – Role of Professionals and Organisations

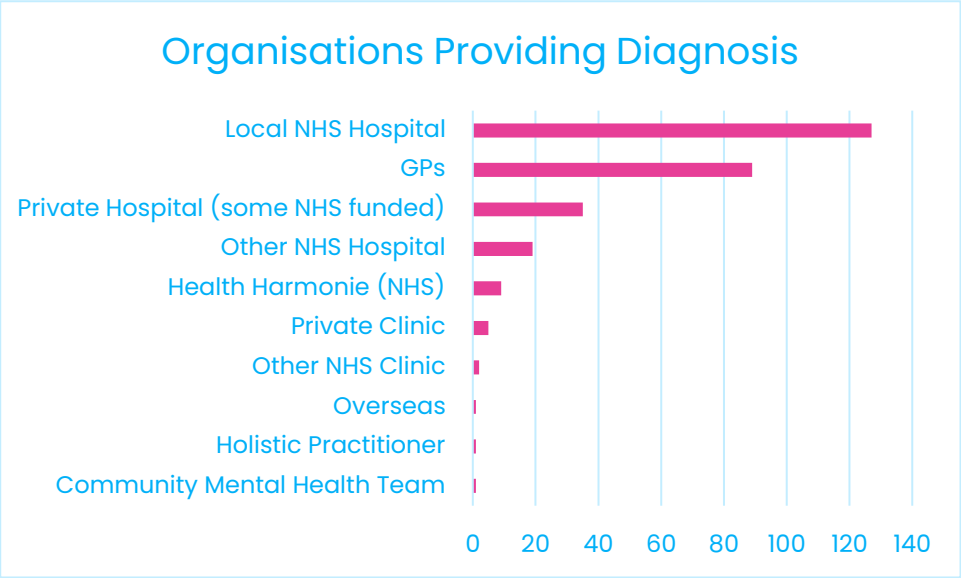
A total of 84 respondents were diagnosed by a GP, 159 by a consultant gynaecologist, and 2 by a sexual health clinic.

The additional respondents reported alternative pathways including:

- private diagnoses
- self-diagnosis
- undiagnosed

Most people were diagnosed via the NHS, either in hospital or through GP surgeries. However, a significant number reported alternative or fragmented pathways, including some who sought private diagnoses. A further number were diagnosed via Health Harmonie.

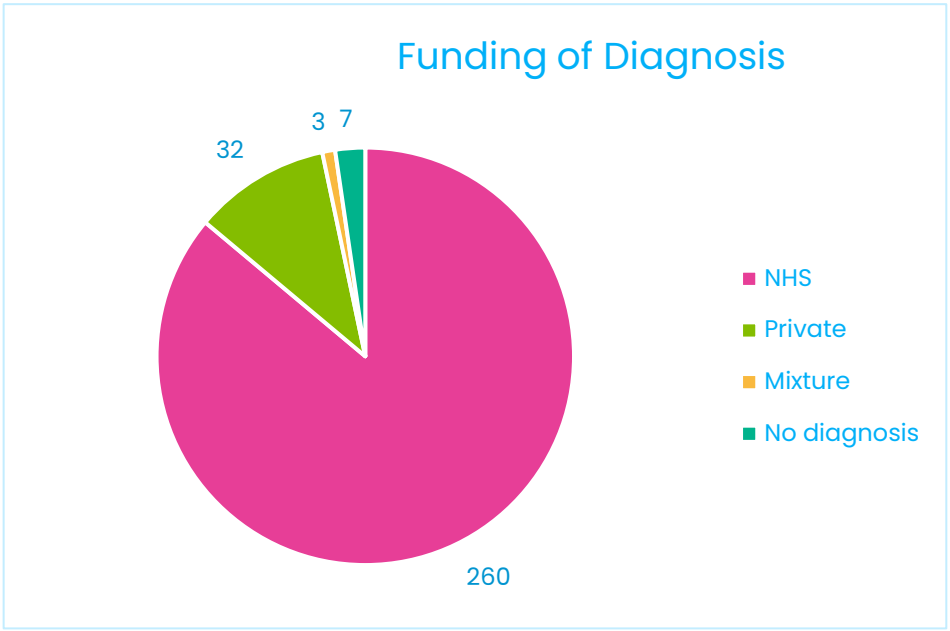




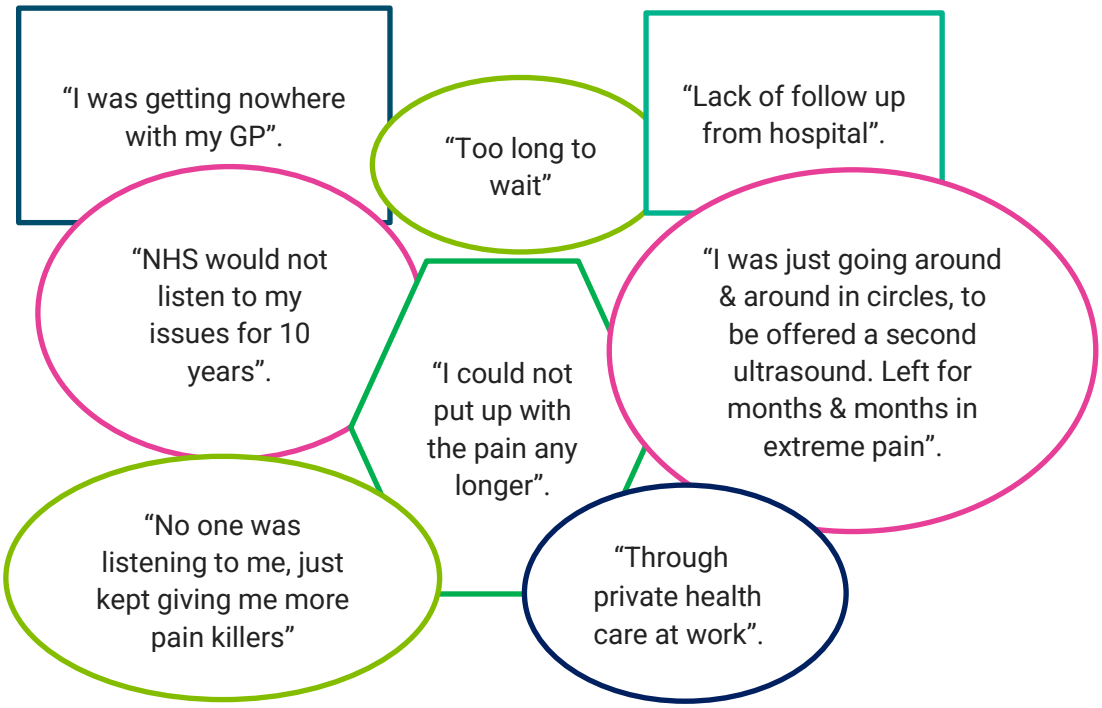
Funding of Diagnosis

Of those paying privately, two reported getting funding through work and one through health insurance shared with their parents.

The NHS paid for visits to 11 private hospitals.

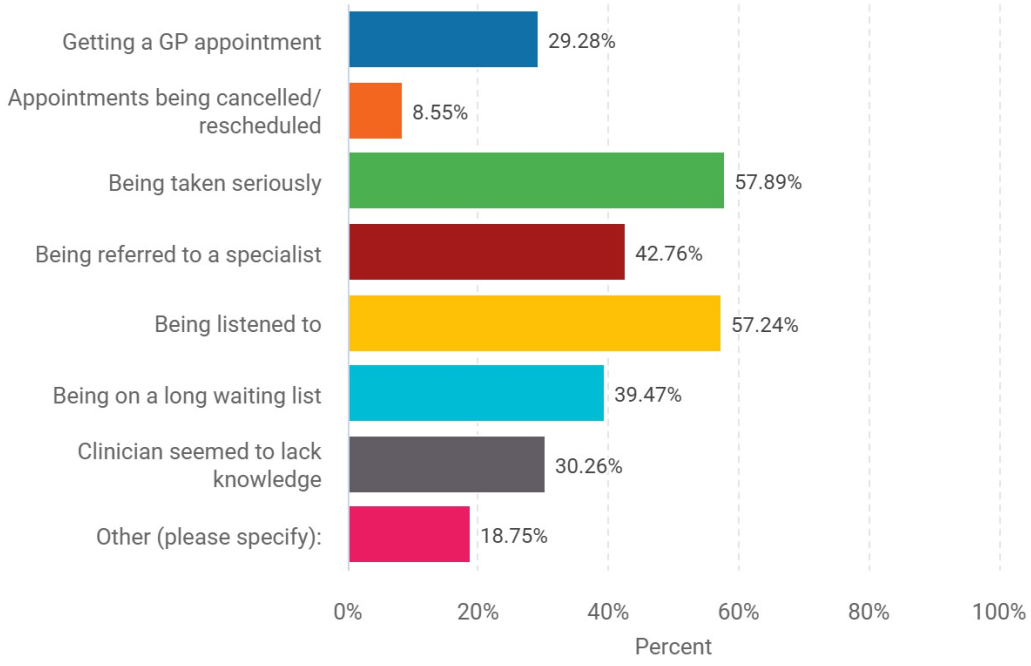


Reasons for people paying privately included:



Barriers to Getting a Diagnosis

This graph shows how women felt about the barriers we suggested. Out of the 304 people who feedback on this question 57 commented that there were other reasons for barriers which included another 18 people saying they were not being listened to.



Surgery

People were asked about surgery - was it necessary, was it successful and how long did you have to wait?

Over 40% of respondents had surgery and 16% thought that they might need more in the future or are still waiting. Comments included:

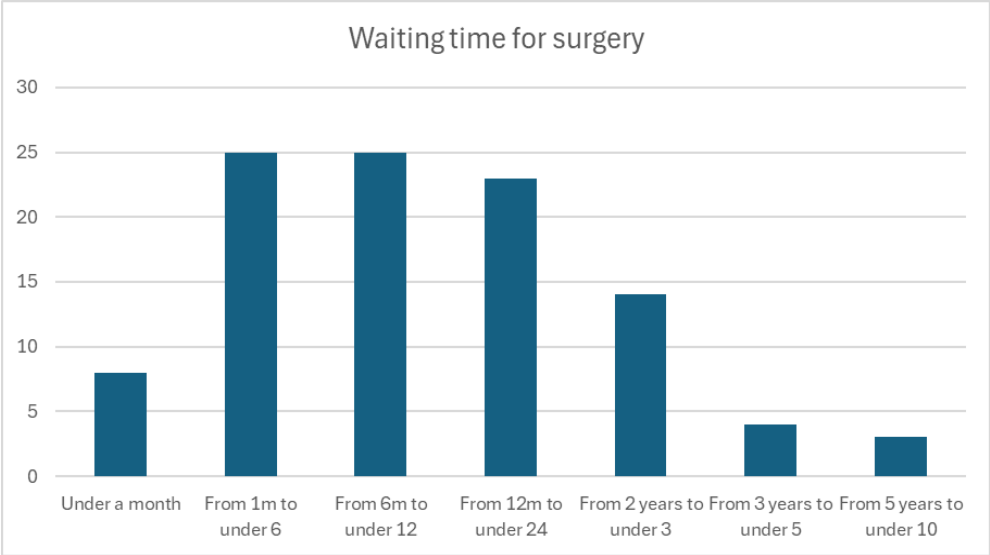
"Only just got my first appointment at the hospital, seen GP in October 2024 and got my first hospital appointment in September 2025".

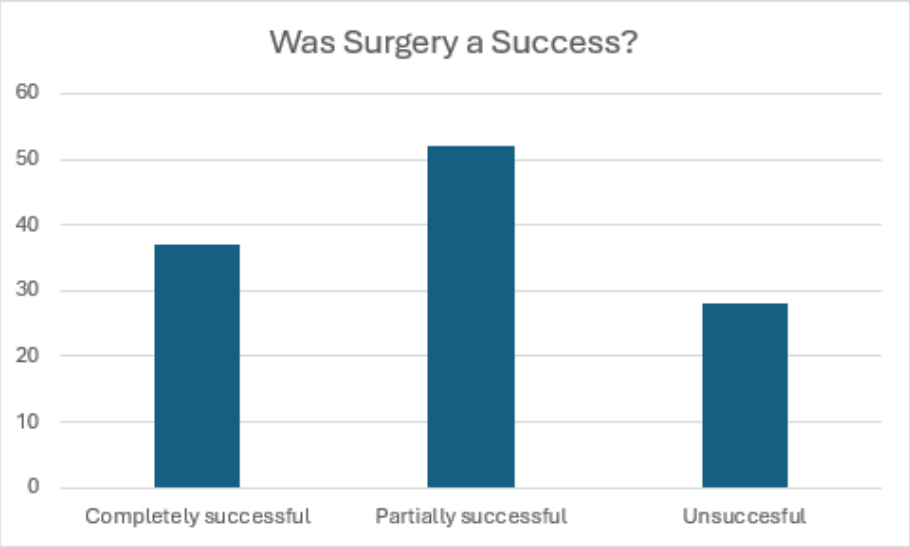
"Still waiting, I was referred for surgery in 2020. Then put on hold due to Covid. I contacted the hospital after the pandemic to be told they had decided not to offer the surgery anymore & have discharged me".

"Over 12 months for unnecessary surgery that left me needing a hysterectomy that I paid privately for due to the pain".

"I was able to make an appointment within a week of my visit to the GP and referred to Burton Hospital. I was seen & had minor surgery to remove the Polyp on the same day as my appointment".

"As I was privately funded, I was scheduled for an operation within 6 weeks".





Additional comments were made, examples of which are shown below.

Was successful in diagnosing and treating bowel symptoms but not in treating pain

I have to be really careful with what I do. Limited aspects of exercise and no sex. Successful in removing fibroids. Feel better in myself physically.

Offered temporary relief and confirmed was not mad. Now require hysterectomy due to severity of symptoms.

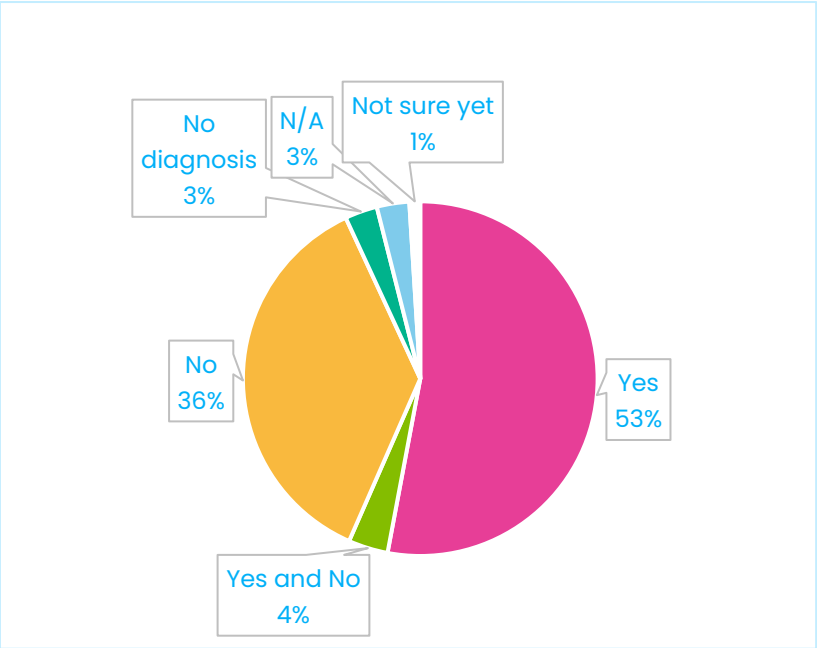
I had surgery to find what the concern was.

The cyst keeps growing back

Impact of Diagnosis and Surgery on Quality of Life

Diagnosis

304 people answered this question. 145 gave a clear Yes and 29 gave a clear No. The remaining 103 answers were descriptive.



Of these, 9 reported a lot of improvement, 7 a little improvement, 11 had mixed effects, 49 stayed the same and 32 were worse or had new symptoms. Nine were still awaiting a diagnosis and three had only just had treatment and were waiting to see whether life improved or not.

There were both positive and negative impacts following diagnosis.

One of the positive benefits of a diagnosis was that people felt validated, that it wasn't: *"all in their head".*

Those suffering infertility or miscarriage often had to deal with the low moods this caused. Difficulties staying in work or running around with their children were other frustrations mentioned. A few people had struggles getting hormone tests or treatment, which was surprising. Those who hoped for relief from their symptoms became depressed when there was no improvement after treatment.

Surgery

Of the 187 respondents, 31 reported that surgery significantly improved their lives, 34 reported some improvement, and 26 reported no improvement. A further 96 provided additional comments.

Two people had complications with surgery that left them with new problems, others started early menopause following surgery leading to issues like brain fog and low bone density. In some cases, surgery created scar tissue that caused extra pain. For some endometriosis sufferers things improved initially, only for symptoms to return later with a vengeance. Several people had undergone multiple surgeries.

Care Received

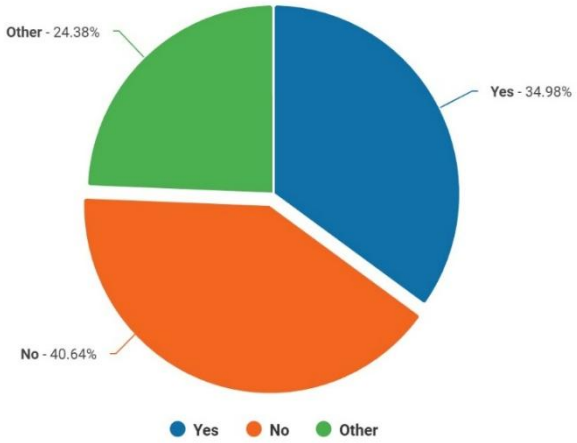
Follow Up Care

Women were asked "Are you receiving the ongoing treatment or monitoring that you need?"

- 99 of 283 respondents were receiving ongoing treatment or monitoring.
- 115 were no longer receiving support.

Of the remaining 69:

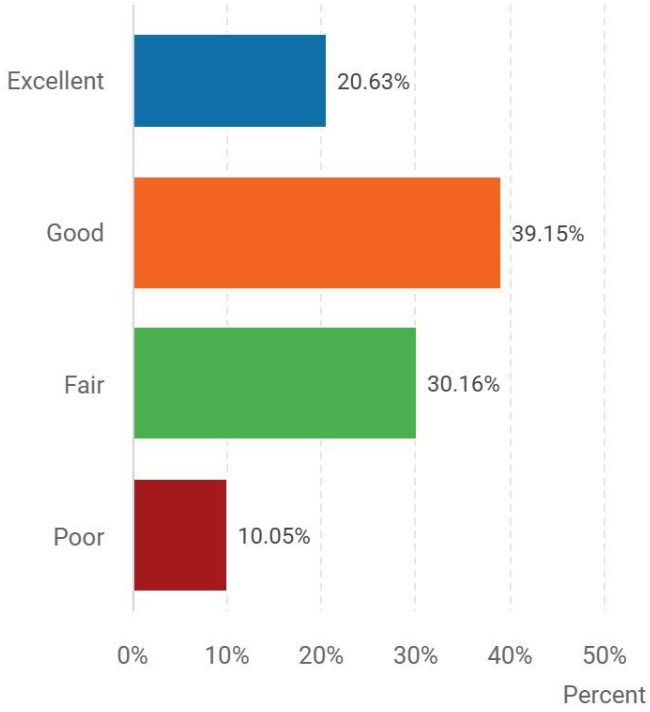
- 12 had no follow-up care.
- 11 were waiting for surgery.

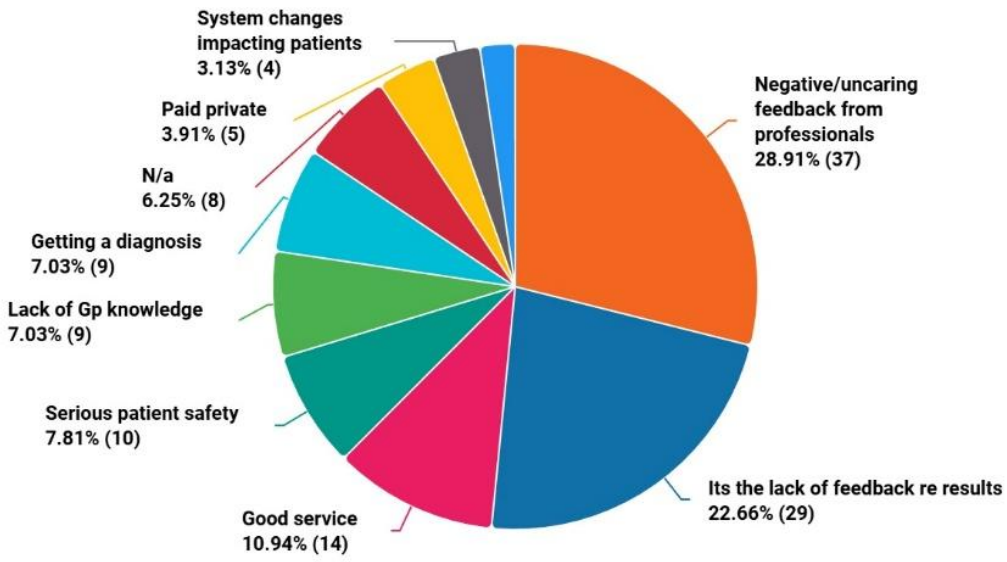


- 10 were unsure about their outcomes.
- 5 were receiving HRT.
- 5 required a GP referral to re-access gynaecology services.
- 4 were awaiting referral.
- 2 were receiving private care.
- 1 was being seen by Health Harmonie.
- 5 were N/A

Quality of Care

Among the 304 respondents, 39 rated their care following diagnosis as excellent, 74 as good, and 57 as fair. Nineteen reported poor care, while 115 provided additional comments outlining their experiences and areas for improvement. The accompanying graph shows the distribution of ratings and the key factors influencing perceptions of gynaecological care.



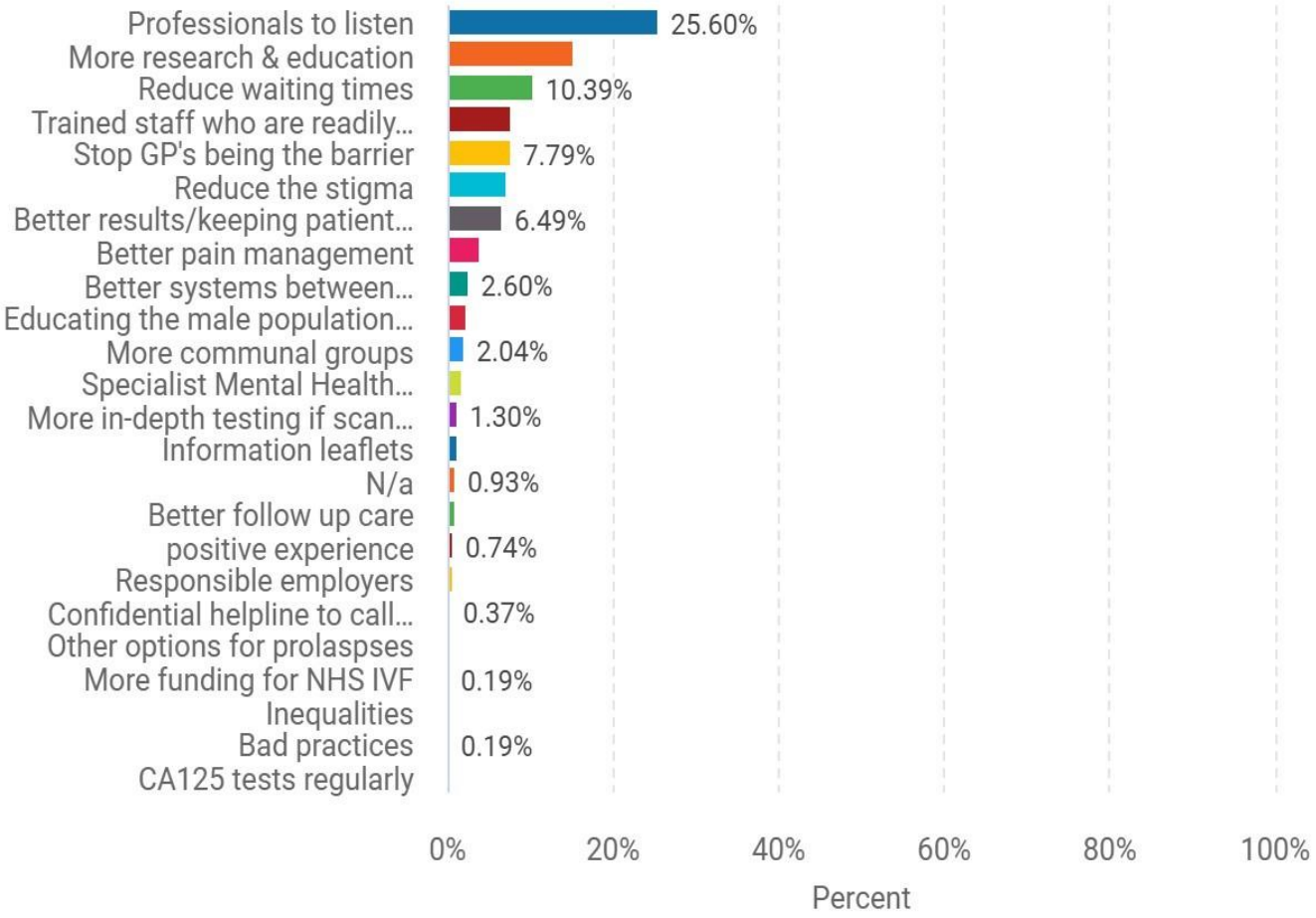


Suggestions for Improving Gynaecological Care

Among 273 participants, the most frequently suggested improvements were better listening to patients (138), increased research and education (82), and reduced waiting times (56). Other recommendations included improved staff training, fewer GP-related barriers, tackling stigma, clearer communication,

better pain management, integrated services, education for men, support groups, enhanced specialist mental health care, more in-depth scans, improved information and follow-up, expanded treatment options (including IVF and prolapse support), addressing inequalities, eliminating poor practice, and introducing routine CA125 testing.

The CA-125 test is a blood test that measures the level of cancer antigen in the blood. It is primary used to monitor ovarian cancer, assess treatment effectiveness, and detect recurrence. It can serve as a screening tool for individuals at elevated risk of ovarian cancer, such as those with family history or specific genetic mutations.


Professionals to listen
More research & education
Reduce waiting times
Trained staff who are readily...
Stop GP's being the barrier
Reduce the stigma
Better results/keeping patient...
Better pain management
Better systems between...
Educating the male population...
More communal groups
Specialist Mental Health...
More in-depth testing if scan...
Information leaflets
N/a
Better follow up care
positive experience
Responsible employers
Confidential helpline to call...
Other options for prolaspses
More funding for NHS IVF
Inequalities
Bad practices
CA125 tests regularly
25.60%
10.39%
7.79%
6.49%
2.60%
2.04%
1.30%
0.93%
0.74%
0.37%
0.19%
0.19%
0%
20%
40%
60%
80%
100%
Percent

Themes Identified

This deep dive into Women's gynaecological conditions was undertaken to highlight experiences of women across Staffordshire gaining access to and treatment for a range of gynaecological conditions. It also provided the opportunity to talk to professionals working in the area, hearing about some of the initiatives in place to improve services and some of the challenges to providing and improving them for patients going forward. The results have produced some rich and detailed feedback which can be summarised through the following key messages.

1. Severe and Debilitating Physical Symptoms

Women reported long-term physical effects, including:

- Extreme pain (pelvic, abdominal, back) limiting mobility and daily function
- Heavy, unpredictable bleeding causing fear of leaving the house
- Fainting, vomiting, exhaustion, anaemia
- Damage to organs (bowel, bladder, urethra) in advanced conditions
- Repeated surgeries, sometimes with complications
- Chronic infections (UTIs, thrush)
- Incontinence and prolapse, particularly after childbirth

Overall, symptoms significantly disrupted work, education, school, travel, exercise, and personal independence.

2. Major Mental Health Impacts

A huge proportion described emotional distress, including:

- Anxiety and depression
- Feeling dismissed, disbelieved, or "going mad"
- Loss of confidence and self-esteem
- OCD like behaviours or panic attacks
- Suicidal thoughts, sometimes repeatedly
- Mood swings, rage, or PMDD symptoms

Many explicitly linked mental health decline to being ignored or misdiagnosed.

3. Significant Impact on Work, Education and Daily Functioning

Common consequences included:

- Frequent absence from work or school
- Loss of jobs or forced career changes
- Working while in severe pain, often hiding symptoms
- Being unable to attend social events, holidays or normal activities
- Having to plan life around cycles, toilets, or pain flare-ups
- Financial strain from lost income or private healthcare

4. Long Delays, Misdiagnosis, and Feeling Unheard by Healthcare Providers

This is one of the strongest recurring themes.

- Many reported years or decades before correct diagnosis
- Being told symptoms were normal, IBS, anxiety, depression, weight related, or "in your head"
- Refused referrals, scans, or diagnostic procedures
- Dismissive or patronising encounters (e.g., "just get pregnant", "it's normal for your age")
- Incorrect or contradictory advice
- Patients having to research their own condition, chase appointments, or pay privately
- Lack of follow-up after surgeries or major complications

The system was often described as not believing women or not taking women's pain seriously.

5. Major Consequences for Fertility and Family Life

Many women described:

- Infertility or recurrent miscarriages
- Fear of pursuing pregnancy due to pain or risk
- Relationship breakdowns due to physical or emotional strain
- Loss of intimacy because intercourse was painful or impossible
- Feeling "broken", "inadequate", or grieving the family they hoped to have

6. Disrupted Relationships and Social Isolation

The symptoms and lack of support affected:

- Marriages and partnerships
- Friendships
- Engagement with family life and childcare
- Ability to participate in activities with children
- Willingness to socialise or exercise

Some described becoming withdrawn, housebound, or feeling like a "shell of a person."

7. Surgical or Treatment-Related Impacts

Many had undergone:

- Hysterectomies, sometimes with complications
- Multiple laparoscopies, bowel surgery, mesh repairs, and post-operative issues
- Hormonal treatments, often with side effects (weight gain, mood swings, hot flushes, loss of libido)
- Inadequate explanation of procedures or follow-up

Some felt forced into major surgery due to lack of earlier intervention.

There was inadequate pain relief—during investigations, procedures, and chronic pain. Comments frequently mention:

- Traumatic pain during IUD fittings, biopsies, screenings
- Dismissal of severe period or pelvic pain
- Being given only paracetamol
- Pain not taken seriously because "women cope with pain"

8. Overall Sense of Systemic Failure

A strong overarching message:

Women overwhelmingly feel not listened to.

- Women feel unheard, dismissed, and under-supported.
- Many experienced years of suffering that could have been prevented with earlier diagnosis and appropriate care.
- Lack of knowledge and training in women's health was mentioned repeatedly.

Many comments express anger, frustration, hopelessness, and a sense that the healthcare system is not designed with women's health in mind.

9. Poor communication and lack of follow-up

Women describe:

- No follow-up after surgery
- Being discharged with ongoing symptoms
- Inconsistent information
- Consultants not explaining findings or options
- Being left to manage alone between appointments

Some feel they fall "between the cracks" in the system.

Recommendations

What women told us would improve care locally

These recommendations reflect insights from 276 respondents on how to improve the overall experience of gynaecological services across Staffordshire.

1. Improve Diagnostic Pathways

- Increase the number of gynaecologists and specialists in endometriosis
- Standardise and streamline the diagnostic process for gynaecological conditions (e.g., fibroids, endometriosis, menopause).
- Reduce delays between scans/tests and communication of results.
- Ensure full and accurate reporting in letters and medical records.
- Introduce proactive follow up systems when tests recommend further appointments.
- Enable faster access to second opinions where symptoms persist despite "normal" tests.

2. Enhance GP and Primary Care Training

- Provide training on:
  - recognising gynaecological symptoms in combination rather than isolation.
  - understanding variations in menstrual health and what is *not* normal.
  - differential diagnosis when transvaginal scans are inconclusive.
  - early indications of prolapse, cysts, fibroids, and endometriosis.

- Improve GP awareness of referral criteria, including:
  - miscarriage support (removing/adjusting the "3 miscarriages" threshold).
  - when specialist blood tests *must* be arranged.

3. Address Systemic Bias and Gender Inequality

- Introduce mandatory training on:
  - sexism in healthcare.
  - dismissive attitudes.
  - gaslighting behaviours.
  - the impact of requiring male advocacy for women to be heard.

- Implement patient feedback loops to identify clinicians with recurring complaints.

- Establish guidelines ensuring symptoms are not minimised due to age, gender, or assumptions (e.g. "you're young", "are you pregnant?").

4. Improve Communication Between Services

- Strengthen interface protocols between:
  - GPs and specialists.
  - NHS and private providers.
  - different departments handling overlapping symptoms.

- Require GPs to action specialist-requested tests without unnecessary back and forth.

- Implement clearer accountability for referrals to avoid "passing the buck".

5. Expand Access to Services and Interventions

- Increase availability of:
  - Mirena coil fittings.
  - timely MRI and ultrasound appointments.
  - menopause related care pathways.
- Reduce waiting times for follow-ups, retests, and treatment escalation.
- Offer alternatives when transvaginal scans are inconclusive.

6. Improve Patient Experience During Diagnostic Procedures

- Improve transparency within the healthcare system.
- Reduce waiting times for diagnosis and treatment.
- Review procedures that patients describe as "humiliating".
- Provide clearer explanations before tests.
- Give patients options for chaperones, alternative procedures, or rest breaks.
- Improve communication of what the test is for and what results mean.
- Ensure timely return of test results to facilitate consultant appointments.

7. Strengthen Post Diagnosis Support

- Ensure patients receive:
  - timely follow-up appointments.
  - holistic explanations of all findings.
  - support to understand treatment options.
  - pathways to maintain continuity of care.

- Create systems ensuring no missed follow-up (e.g., automatic alerts when a follow-up is recommended).

- Address medication inconsistencies and eliminate health inequalities—access to treatment should not depend on luck or individual circumstances

8. Support Patients with Complex or Atypical Symptoms

- Develop guidance for clinicians on handling symptoms that don't fit a classic presentation.
- Consolidate examinations to minimise repeated invasive procedures, which are both physically and emotionally taxing.
- Encourage multi-disciplinary review where symptoms cross into gastro, pelvic, or hormonal domains.
- Reduce dependency on multiple rounds of failed treatments before escalation.

9. Ensure Equitable and Accessible Care

- Reduce financial barriers that push patients toward private investigations.
- Create safety net pathways for those on low incomes or with limited access.
- Promote awareness that self-reported pain or disruption to daily life should be taken seriously regardless of background.
- Consider gender equity in healthcare - would men face similar repeated internal examinations?

10. Increase Patient Education and Empowerment

- Provide resources helping patients understand:
  - what symptoms require escalation,
  - when continued pain is *not* normal,
  - what diagnostic steps to expect,
  - how to advocate for their needs.
- Encourage self-referral routes where appropriate.

11. Desire for more accessible, local support

Women want:

- Community-based clinics.
- Drop-in centres.
- Specialist nurses.
- Peer support groups.
- Safe spaces to talk openly.
- Better education at school and societal level.
- Promote the establishment of support groups and increase public awareness and education around gynaecological health.

Acknowledgements

Firstly, thank you to all the lovely ladies who have contributed their very personal stories through our engagement work, workshops and survey.

We would like to thank our volunteers Rebecca Ugwueze, Pearl Obiorah and Cecilia Chisom for their help with supporting research, the Glossary and other investigations and documents (see below).

We are also grateful to the following local Health organisations and support groups who have engaged with us:

- University Hospital North Midlands (UHNM)
- University Hospital Burton and Derby (UHDB)
- The Staffordshire and Stoke-on-Trent Integrated Care Board
- Health Harmonie
- Samuel Johnson Hospital
- Robert Peel Hospital
- Too Young to Pause
- Menopause Café Lichfield

Finally, a big thank you to local artists Ali Woolacott and Kate Dawes for the creative workshops they provided.

Useful Resources

During the research, we identified useful local voluntary, statutory and charitable organisations for support and these have been compiled into a directory which you can view here on our website.

At the start of our research, we were also helped by three of our volunteers who conducted initial research for us.

Cecilia Chisom produced two short reports which you can read on our website:

Research on Women's Health including GP barriers

Research on Mounjaro and its effects on symptoms of Endometriosis and Polycystic Ovary Syndrome.

Pearl Obiorah produced another report:

"Just a Period": Investigating Menstrual Health Inequities and Healthcare Barriers in Staffordshire.

The following Appendix was produced by Rebecca Ugwueze.

Appendix 1 - Glossary of Terms

Heavy Periods (Menorrhagia)

Menorrhagia is heavy or prolonged menstrual bleeding. If you need to change your pad or tampon every 1 to 2 hours, or have periods lasting over 7 days, you may have Menorrhagia, indicating a blood loss of 80ml or more. Heavy menstrual bleeding may affect your quality of life, interrupting daily activities. (References A, B and C)

Fibroids

Fibroids are non-cancerous growths that develop in or around the womb. Women who do have symptoms (1 in 3) may experience heavy periods, abdominal and lower back pain, constipation or pain during sex. Fibroids don't often cause symptoms, and the exact cause of fibroids is unknown. In some rare cases, fibroids may affect pregnancy and fertility. (References D, E and F)

Endometrial Biopsy

An Endometrial Biopsy is a medical procedure where tissue from the inner lining of the uterus is removed and examined. It is used to check the lining of the womb, most commonly to look at abnormal vaginal bleeding or other conditions, or it can also be done as part of infertility treatment. It is a quick test that takes 10-15 minutes and you will be asked to undress from the waist down. The sample is taken by a tube that passes through the vagina. It is unusual to have complications after this procedure, but occasionally there may be bleeding afterwards. (References G, H, I and J)

Adenomyosis

Adenomyosis is a condition that causes tissue in the lining of the uterus to grow into the muscular wall of the uterus. This uterus becomes enlarged, which may lead to heavy menstrual bleeding. There is no direct cause for adenomyosis, but certain groups are more at risk. This includes women 35-50, women who have given birth to more than one child, and women who have had uterine surgeries. Symptoms include heavy bleeding, painful menstrual cramps and pelvic pain. (Reference K)

Dyspareunia

Dyspareunia is pain before, during or after sex. It is most common in women and has different causes. Many of them can be treated. It can feel like discomfort, sharp pain, or burning in one spot or all over the vaginal area, inside, outside, or both. (Reference L)

Endometriosis

Endometriosis is a condition where cells similar to those that grow in the uterus grow outside of the uterus. This may cause severe period pain, heavy periods and pain when using the toilet. It may also cause fatigue, pain during or after sex and pelvic pain. Endometriosis can affect anyone who has their period and can be diagnosed from puberty to menopause. (Reference M)

Infertility

Infertility is when there is an inability to get pregnant despite 12 months or more of regular sexual intercourse. There are many causes of infertility, such as endometriosis or irregular ovulation, though

there is a 1 in 4 chance there is no identifiable cause. Those who are older, overweight or underweight, smoke or drink alcohol are at higher risk of infertility. (Reference N)

Menopause

Menopause is when periods stop and can happen naturally. It usually affects women aged 45-55, due to lower hormone levels. The first sign of menopause is irregular periods, which then stop entirely. It may cause mood changes and other physical symptoms such as hot flush, difficulty sleeping, palpitations, weight gain and headaches. Symptoms can last for years and change with time. (Reference O)

Menstrual Irregularities

The average time between periods is 28 days, but it can be a bit shorter or longer. Periods are called irregular if they come less than 21 days apart or more than 35 days apart. Anyone who gets periods can experience menstrual irregularities. Irregular periods can be caused by puberty, menopause, pregnancy, hormonal contraception, weight changes, stress, too much exercise, or conditions like PCOS and an underactive thyroid. (Reference P)

Pelvic Organ Prolapse

Pelvic organ prolapse happens when the muscles and tissues that support the pelvic organs (like the bladder, uterus, or rectum) become weak, causing one or more organs to drop and create a bulge in the vagina. This is often caused by pregnancy, childbirth, or menopause. This may result in symptoms such as pelvic or back pain, trouble keeping in a tampon, changes in urination or bowel movements, and pain during sex. (Reference Q)

Pelvic Pain

Pelvic pain is pain in the lower tummy that can be sudden and sharp (acute) or last for 6 months or more (chronic). It can feel like stabbing, burning, aching, cramping, or pressure, and may happen all the time or only during certain activities. Pelvic pain can be caused by infections or problems with organs in the pelvic area, like the bowel or bladder. (Reference R)

Polycystic Ovary Syndrome

Polycystic ovary syndrome (PCOS) is a common condition that affects how a woman's ovaries work. There is no direct cause. Its main features are irregular periods, high levels of male hormones that can cause extra hair growth and enlarged ovaries with many small fluid-filled sacs. You may be diagnosed with PCOS if you have at least two of these features. Signs of PCOS include irregular or no periods, trouble getting pregnant, weight gain, thinning hair or hair loss on the head, and oily skin or acne. (Reference S)

Premenstrual Dysphoric Disorder

Premenstrual dysphoric disorder (PMDD) is a very severe type of premenstrual syndrome (PMS) that causes strong emotional and physical symptoms during the week or two before your period. It may happen because some people are more sensitive to hormone changes during their cycle. Other things that might cause or worsen PMDD include genetics (family history), smoking, and stress or past trauma. (Reference T)

Premenstrual Syndrome

PMS (premenstrual syndrome) is a group of symptoms that can happen in the weeks before your period. It can affect mood, energy, sleep, and the body. It's common in anyone who has periods. PMS is caused by the natural hormone changes that happen during your menstrual cycle, especially changes in oestrogen and progesterone levels. Symptoms include mood swings, feeling low or anxious, tiredness, trouble sleeping, bloating, sore breasts, headaches, skin/hair changes, and food cravings. (Reference U)

Urinary Incontinence

Urinary incontinence is when you accidentally leak urine, and it affects millions of people. There are different types: stress incontinence happens when you leak during things like coughing or exercise because the muscles are weak; urge incontinence is when you suddenly feel a strong need to pee and can't always make it in time; overflow incontinence is when your bladder doesn't empty fully, so you keep leaking small amounts; and total incontinence is when you can't hold any urine at all, often due to health problems like birth defects or spinal injuries. (Reference V)

Vaginal Infections

Vaginal infections happen when bacteria, fungi, parasites, or viruses grow out of control in the vagina or vulva. Risk factors like being sexually active, using scented products, taking antibiotics, or having health conditions like diabetes or HIV can trigger an infection. Common vaginal infections include bacterial vaginosis, thrush, chlamydia and genital warts. It is possible to have more than one infection at a time. (Reference W)

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