Beyond the Pain:

An Overview of Endometriosis & Adenomyosis Care

April 2025

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healthwatch
East Riding of Yorkshire

Contents

Disclaimer

All the views, opinions, and statements made in this report are those of the residents who participated in our survey.

The analysis of this report included the experiences of individuals of the East Riding of Yorkshire region in relation to their access to Endometriosis & Adenomyosis care and services, and their journey of receiving a diagnosis.

Due to this, the perception may not fully reflect the actual quality and availability of gynaecology services in the local area. Although, it is the opinion of the participants whose information Healthwatch East Riding of Yorkshire have collected.

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About Healthwatch East Riding of Yorkshire

Healthwatch provides an independent voice for the residents of the East Riding of Yorkshire. We listen to peoples lived experiences of health and social care services and report these experiences back to service providers. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

Our vision

Equitable Health and Care services that meet the needs of every person within our community.

Our mission

To give every person in East Riding of Yorkshire the opportunity to have their voices heard and empower them to play an active role in shaping services in their community.

Our values are:

- We are proud to be **independent**, and not afraid to speak up and **challenge decisions** that do not meet the needs of our communities.
- We operate a culture of **transparency** and **openness**, ensuring we are accountable to the communities in which we serve.
- Our work is **evidence** based – led by **public voice** and need.
- We are **collaborative**, working with organisations that share our vision of **equitable health and care services** that meet the need of every person within our communities.
- **Partnering** with the Government, health and care services and the voluntary and community sector to make care better whilst retaining our independence.

Why this Subject?

Healthwatch East Riding of Yorkshire (HWERY) received enquiries and information about the support and services available for people with Endometriosis and Adenomyosis in the East Riding region. With both **positive and negative experiences impacting on the health and wellbeing** of patients, a further look into healthcare surrounding these conditions was carried out.

During this research, evidence was found to suggest that there is a **lack of awareness of these conditions** on a regional and national scale. Waiting times for consultations and delays in treatment have been highlighted as a concern, as the impact to quality of life could be detrimental and potentially cause symptoms to worsen.

The Women's Health Strategy (2022) highlighted that there are gaps in knowledge of health conditions that only affect women. The strategy was formed and proposed adjustments to be made in the following 10 years to improve the health and wellbeing of women and girls in England and a further goal of improving access to care.

Another theme discussed by individuals with HWERY was the number of times people seek support for their symptoms at a primary care level, such as GPs, before being diagnosed. People are often waiting months or years after the initial contact with a general practitioner. The delay in receiving advice or treatment at a primary care level could form barriers to specialist healthcare treatment for patients, such as pain management teams.

Additional to this, there could also be an impact on the time it takes for an individual to receive a diagnosis for their condition.

It was acknowledged in the Women's Health Strategy (2022) that these conditions consist of severe symptoms that have been normalised, such as chronic pain and pelvic organ prolapse. Alongside this, the stigma around menstruation and period pain has caused a negative impact on education and workplace settings for women where there are limited policies implemented to support students and the workforce.

Considering these topics, specifically the investigative and diagnostic stages of a patient's journey, adjustments were made to the **NICE Guidelines** on 11th November 2024. This ensured that patients would be offered transvaginal ultrasound scans if their GP suspected Endometriosis rather than just an abdominal examination, where abnormalities can often be missed.

These adjustments to legislation and healthcare systems are what we strive to promote on behalf of the public to ensure that their health and social care needs are met. The recommendations formed from this report will help support individuals of the East Riding region with Endometriosis and Adenomyosis alongside the national strategies that have been implemented.

Aims and Objectives

- Raise awareness of Endometriosis and Adenomyosis with the goal to increase education of these conditions for the public and healthcare professionals.
- Highlight the services available to the residents of East Riding of Yorkshire who have been diagnosed with these conditions.
- Offer an opportunity to those who have experienced or are currently experiencing Endometriosis and Adenomyosis to share their journey to and after receiving a diagnosis.
- Emphasise the importance for a specific Endometriosis and Adenomyosis Centre in East Riding of Yorkshire that offers accessible specialist treatment.
- Highlight the need for specialist mental health support for patients with these conditions.
- Reduce health inequalities for women.

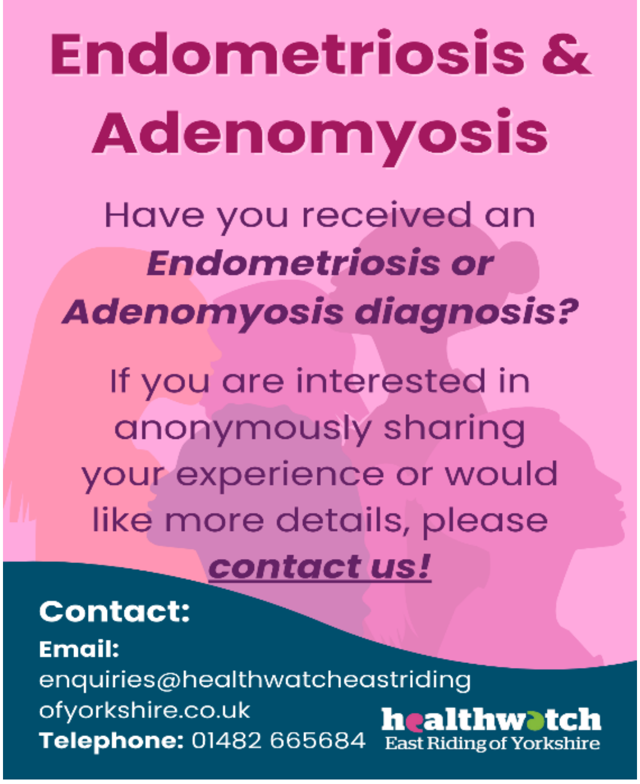
Methodology

Public Engagements

Healthwatch East Riding of Yorkshire (HWERY) spoke with local residents when we attended health and social events across the region. An opportunity for those who had experiences of Endometriosis and Adenomyosis to discuss their journey was provided. A HWERY representative was available to document these experiences with the consent of the individual. All experiences and feedback were kept anonymous.

Social Media

To recruit case studies for this project, social media posts were created and distributed across HWERY Facebook, Instagram, and TikTok platforms. This was successful as HWERY were contacted by people across all sites who have given their stories to contribute to this project.



Endometriosis & Adenomyosis

Have you received an ***Endometriosis or Adenomyosis diagnosis?***

If you are interested in anonymously sharing your experience or would like more details, please ***contact us!***

Contact:
Email: enquiries@healthwatcheastriding ofyorkshire.co.uk
Telephone: 01482 665684

healthwatch East Riding of Yorkshire

An information video of Endometriosis and Adenomyosis was created and distributed across all social media platforms, with a further opportunity for individuals who have experiences of these conditions to get involved with the project.

Case Studies

The approach of gathering the patient voice through the form of case studies was deemed most appropriate due to sensitivity of the project topic. Like any health condition, Endometriosis and Adenomyosis journeys are extremely personal, where a one-to-one discussion or confidential email gave individuals space to explain their care and treatment with as much or as little detail as they felt comfortable with sharing.

The people who have shared their journeys to receiving treatment and a diagnosis were fully informed of the aims of this project. All individuals have given consent for the information they have shared to be included in this project.

The right to remain anonymous was given to all individuals when they expressed an interest in being a part of this project. Alternative names have been given to protect the decision of those who chose to remain anonymous, which were generated for the purpose of allowing for the written experience to reflect a person rather than a number.

All case studies have given consent for their ages to be included with their stories to give a better understanding of the range of people affected by these conditions.

Local Support Services

Endo Buddies are a local charity that offer support to anyone with Endometriosis. HWERY reached out to the charity to discuss more about the condition and the physical and emotional support available in the East Riding region for those who have symptoms of the condition. Endo Buddies equally value the importance of support for people with Endometriosis and strive to support as many people as they can. In doing this, Endo Buddies have conducted a survey to gather responses on a national scale into the journeys that people have taken to gain specialist treatment and mental health support. As a community

Endo Buddies

Supporting the Wellbeing of People with Endometriosis

Registered Charity No. 1205532

partner with HWERY, Endo Buddies have shared the data gathered from this survey, which has been included in this project report.

NHS Humber Health Partnership

The patient experience team at NHS Humber Health Partnership shared the compliments and complaints of the Gynaecology and Endometriosis services from their patients. This has been most beneficial in gaining more intelligence directly from patients about the care and treatment available in the region and the outcome of their appointments.

As a part of gathering an overview of services available for patients, North Lincolnshire and Goole NHS Foundation Trust (NLAG) was contacted. The Consultant Obstetrician and Gynaecologist provided HWERY with valuable information about the staff to deliver the services available at the Northern Lincolnshire Endometriosis Centre. This included the following:

Accreditation

Nationally accredited Endometriosis Centre for the past 4-5 years.

Team Leaders

- Consultant Gynaecologist with expertise in complex endometriosis and complex Laparoscopic surgery, Lead of the Endometriosis Service at this centre.
- Endometriosis Clinical Nurse Specialist (CNS)
- Colorectal Surgeon with a special interest in endometriosis.
- Consultant Urologist with special interest in endometriosis.
- Consultant for Pain Management

- Consultant Radiologist with interest in endometriosis.

Services Offered

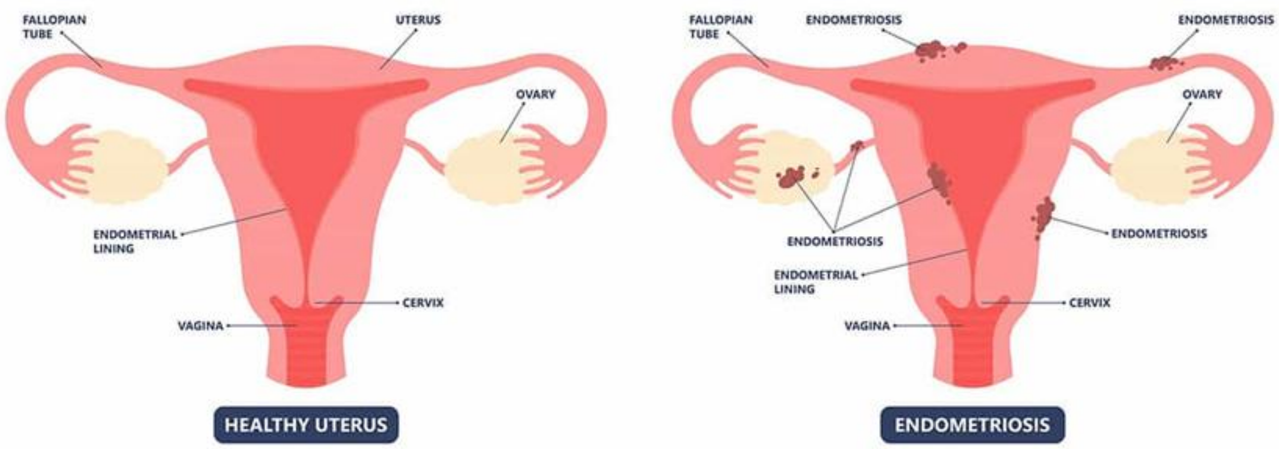
Management of complex endometriosis cases, including:

- Bowel resection and anastomosis
- Bladder endometriosis excision and repair.
- Ureteric surgeries (e.g., uretero-uretero anastomosis, neo-uretero implantation).

The Centre performs the highest number of complex endometriosis surgeries in the Humber and Yorkshire region, averaging over fifty cases annually.

What is Endometriosis?

Endometriosis is a chronic systemic inflammatory condition, where tissue similar to the lining of the womb grows elsewhere around the body. This includes extra tissue growth in areas around the Uterus, such as the Fallopian tubes and Ovaries. The diagram below compares a 'healthy uterus' to a uterus affected by Endometriosis.



The condition is found to affect around 1 in 10 women and adolescents of reproductive age, equating to approximately 1.5 million individuals. Symptoms consist of the following:

- **severe, life-impacting pain during periods**
- **pain during sexual intercourse**
- **pain during bowel movements and/or urination**
- **chronic pelvic pain (CPP)**
- **abdominal bloating**
- **nausea**
- **fatigue**
- **impacted mental health** such as depression, anxiety, and infertility.

Endometriosis can be separated into three types: **Superficial (Peritoneal), Cystic Ovarian (Endometrioma), and Deep Endometriosis.**

Superficial Endometriosis

This form of Endometriosis can also be referred to as Peritoneal Endometriosis and is known as **the most common form of the condition.** This is categorised as a growth on the surface of the peritoneum, which is the lining of the abdominal cavity.

Cystic Ovarian (Endometrioma)

Ovarian and tubal adhesions, which are bands of tissue that form across two surfaces. Often, they are described as internal scar tissue connecting tissue that isn't usually bonded.

Deep Endometriosis

This is an advanced form of Endometriosis, where the endometrial tissue spreads to surrounding organs located in or near the pelvic region.

What is Adenomyosis?

Adenomyosis refers to the **abnormal growth of Endometrial tissue growth** in the muscle layer of the Uterus, which is known as the **myometrial layer.** Due to this growth, the walls of the Uterus thicken and can cause symptoms of pain and heavy bleeding.

Further symptoms of this condition include the following:

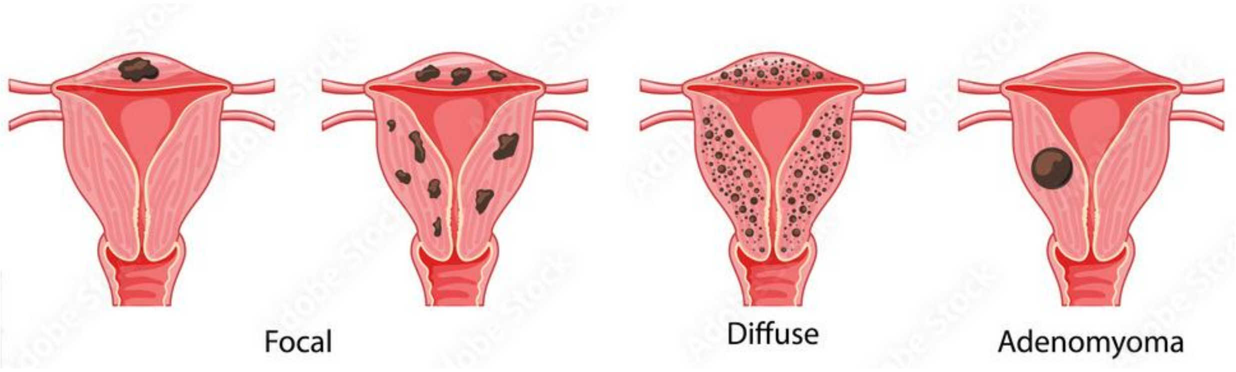
- **painful periods (dysmenorrhea)**
- **painful sexual intercourse (dyspareunia)**
- **chronic pelvic pain**
- **abnormal bleeding (metrorrhagia) or prolonged periods**
- **infertility**
- **an enlarged uterus**

The cause of Adenomyosis is not clear according to recent studies, but it has been found that women over the age of 30 and have given birth are more susceptible to the condition.

There are three different types of Adenomyosis:

- Focal
- Diffuse
- Adenomyoma

Below is a diagram that shows the different types of adenomyosis and the different areas of the muscular wall of the uterus that abnormal Endometrial tissue can grow.



It is essential that the correct type of this condition is diagnosed to ensure that the most appropriate and efficient treatment can be carried out. For example, some surgeries required to treat Focal Adenomyosis may not be best suited to a Diffuse Adenomyosis patient.

Focal Adenomyosis

This type of adenomyosis is determined when the abnormal growth of endometrial tissue is found in one area of the myometrium. Enlargement of the uterus is often the result of this.

(Uterine) Adenomyoma

This is a form of focal adenomyosis, as it refers to one area of the myometrium. However, it is more substantial as this tissue growth is a uterine mass or benign tumour, which can often be mistaken for a uterine fibroid. While there is still uncertainty and lack of understanding of the cause of adenomyoma, research has found that chronic uterine contractions can result in tissue injuries and inflammatory changes. It is suggested that these changes may induce the growth of endometrial tissue.

Cystic Adenomyosis

This is a rarer form of adenomyosis that is determined by the presence of small cysts, and often the route cause for chronic pelvic pain in those with this condition.

Diffuse Adenomyosis

When endometrial tissue is found in various places of the myometrium, this is categorised as diffuse adenomyosis. This type of the condition can often result in an enlarged and more rounded uterus.

Impact on health

Physical health

Endometriosis and Adenomyosis can both significantly impact a person's physical health with most common symptoms presenting as chronic pelvic pain (CPP), heavy bleeding that can occur at any time during the menstrual cycle, and fatigue. People who have these conditions can also experience fertility issues, pain during sexual intercourse, and bloating.

The total number of women who experience CPP are a part of the 30-50% of women who have endometriosis. Research has shown that those with Endometriosis who experience CPP as a symptom are at greater risk of experiencing psychological distress, specifically depression, than those who don't have CPP. It is important to acknowledge that individuals who have these conditions that don't experience CPP, may still have mental health challenges as a result of their symptoms and should be equally supported in improving their health.

Symptoms of fatigue can also heavily impact on an individual's physical health. This symptom often develops due to the heavy bleeding during menstrual cycles over a prolonged time, sometimes resulting in chronic anaemia.

Mental health

Individuals who have suspected or diagnosed Endometriosis and Adenomyosis often express that their mental health has been impacted as a result of their condition. Feelings such as depression, anxiety and stress can develop around managing the physical symptoms of the conditions alongside the time it takes to receive a formal diagnosis. With these factors impacting on an individual’s energy and drive to lead a fulfilling life, they become more at risk of developing psychological challenges.

The reoccurring nature of physical symptoms often poses a negative effect on mental health as many people who undergo surgery to resolve symptoms such as pain, must have multiple surgeries. Individuals who have multiple surgeries often express that post-surgery there can be a period of time where symptoms are resolved, improving their quality of life significantly. When symptoms have returned after this time, which can be as short as weeks or months post-operation, the emotional toll that this can cause is considerable.

Another contributing factor that can impact mental health is infertility stigma. Around 30-50% of women with infertility have endometriosis, with increased risk of miscarriage or having a premature baby for those with adenomyosis. The stigma surrounding infertility is seen to be universal, where regardless of culture, the norm is for humans to reproduce. Education levels and a lack of fertility awareness can cause this stigma to form and create a psychological burden on the people with these challenges.

Fatigue can impact both physical and mental health as the disruption to their lifestyle can cause people to avoid participating in activities that they may have previously enjoyed before their condition. This can lead to declines in mental health and coincide with a restricted social life.

Social health

As previously mentioned, Endometriosis and Adenomyosis can both influence a detrimental impact on the emotional wellbeing of individuals. This relates to the impact that these conditions have on peoples' social health. With symptoms such as CPP and chronic fatigue, people can find it difficult to engage in their hobbies that they may have been taking advantage of to improve their physical and mental wellbeing. Without the outlet of something that these individuals can dedicate their time to and create a sense of achievement from, there could be further isolation created if conditions such as anxiety and depression arise.

A strain can be put on relationships at the expense of complications such as infertility or withdrawing from social events due to the severity of symptoms. The levels of awareness and understanding of these conditions can also put further strain on relationships with partners as there may be a lack of understanding why certain procedures may be deemed more appropriate than others for example, a hysterectomy, causing induced menopause.

Additionally, lack of understanding of symptoms and the impact of these conditions can also lead to a strain on family life. Parental roles within families who are deemed as having a duty of care may experience parental burden when there are extreme symptoms in their children that may require specialist treatment. Similarly, this burden may be felt by other family members when the parental role of the family has these conditions. The lack of ability to support their loved ones through the physical impact of these conditions can strain these relationships.

Something that can positively impact the social health and mental wellbeing is through getting involved with support groups in the area. Those who share similar experiences of these conditions can offer a support network to others that may be feeling socially excluded.

Local charities that have a focus of Endometriosis, Adenomyosis and other gynaecological conditions are a great place to expand on knowledge and understanding of the conditions. Endo Buddies, founded in Kingston-Upon-Hull, is one of these charities that offer a range of different services. Their Care Package project for Endometriosis patients' post-surgery, emotional wellbeing tips, and knowledge of specialist support groups are just some of the services that can help boost social and mental wellbeing significantly.

Economic factors

External factors relating to education and work environments can also play a role in the impact on health. For individuals who have Endometriosis and Adenomyosis at school, college or university, there is often impact on their education alongside their social life as an adolescent with a long-term health condition. Individuals may feel isolated due to being misunderstood by their peers for requiring medical arrangements or class adjustments for conditions that have a lack of awareness.

Policies can be implemented by education and workplace settings to support their students and workforce with Endometriosis and Adenomyosis. An example of this would be allowing for flexibility of working hours such as increased breaks. Some medications prescribed by healthcare services for these conditions can require a medical professional to administer them, resulting in people potentially having to schedule these during the working day depending on appointment availability.

There may be an impact on wellbeing in the form of financial burden for individuals having to take time off work to attend medical appointments. These medical appointments could be treatment for themselves or for someone in their care, such as their child. With wait times and availability of specialist care, appointments that are scheduled take priority to prevent waiting longer to receive treatment.

Anxiety can also form around professional work environments for those with endometriosis or adenomyosis with future career goals. The inevitable anxiety around an interview process may be heightened due to arrangements being made to support that individual when attending. There may be additional worries around whether a new employer will implement the same policies made by previous employers to support their medical needs and whether this could affect their chances of a successful interview.

Diagnosis

Currently, the average waiting time to receive a formal diagnosis of Endometriosis is 8-10 years from an initial appointment with a medical professional. There is a lack of research available to identify the average time it takes people to gain a diagnosis of Adenomyosis. A person can have either condition, but they are most commonly seen to occur at the same time.

Delay in diagnosis can be devastating for patients and lead to escalation of their symptoms, a prolonged time of poor quality of life, and a risk to their fertility. With knowledge of the risks delay in diagnosis and treatment can have on an individual's physical and mental wellbeing, the NICE Guidelines were updated on the 11th of November 2024.

For individuals who have suspected Endometriosis or Adenomyosis, a referral should be made to paediatric and adolescent gynaecology team or a specialist endometriosis centre.

There is an NHS England target for 92% of patients to receive referral-to-treatment time of fewer than 18 weeks. During this time, investigative procedures can be carried out by medical professionals to find evidence and signs of these conditions.

Investigative Procedures

Pelvic Examination

To determine whether there is an enlargement of the uterus and whether there is any pain or discomfort for the patient, a doctor will perform a pelvic examination. The vulva, cervix, and vagina are also examined during this consultation to try find any underlying causes of the presence of symptoms.

Transvaginal Ultrasound Scan

Suspected patients of these conditions should be offered a transvaginal ultrasound scan to promote a quicker diagnosis time and the locating of abnormalities. This will give a better insight into the anatomy of the patient's uterine and pelvic anatomy.

Laparoscopy

This involves a camera, called a laparoscope, being passed through a small incision to access the inside of the abdomen and pelvic area. This is less invasive than other surgeries and known as a keyhole surgery and carried out under general anaesthetic. Gas is pumped into the abdomen using a tube, which allows for the surgeon to operate more efficiently.

The surgeon is able to use the camera to examine whether there are any signs of endometriosis. If this procedure results in a diagnosis, the surgeon may treat or remove the endometriosis during the laparoscopy.

Treatment

There are no treatments available at this time that can cure Endometriosis or Adenomyosis, however there are medicines, treatments, and procedures available can help manage symptoms of these conditions.

Medicines

General practitioners and other healthcare professionals often prescribe or advise patients to take specific medications to help ease symptoms. For pain management, paracetamol and ibuprofen are highly recommended.

Hormonal treatment options are available and recommended to reduce the production of oestrogen in the body as it is this female hormone that can induce growth of Endometrial tissue. They include the following:

- Combined oral contraceptive pill (‘the Pill’)
- Intrauterine System (IUS) often referred to as 'the coil’.
- Progestogens
- GnRH analogues

All of the treatments listed above are temporary and any changes to symptoms that are caused by these medications are reversed if the patient stops taking them.

Surgery

Different types of surgery can be offered if other treatments are not working or there is a large scale of endometrial tissue present. The opportunity to undergo surgery allows for patients to try these methods of treatment to help severe symptoms such as fertility challenges.

Surgery may be needed to remove the areas of endometrial-like tissue or cysts, such as ovarian cysts that occur with Ovarian Endometriosis. Some surgeries can include the removal of parts of the bladder or bowel if the endometrial tissue is affecting these areas. Often, further surgeries are needed if symptoms return after the patient's first surgery.

Conservative Surgery

This type of surgery is intended to be the least invasive and is often recommended to patients who wish to preserve their fertility functioning and avoid major surgeries such as a hysterectomy.

For patients with an Endometriosis diagnosis, conservative surgery would remove the endometrial-like tissue growing outside of the uterus whilst preserving the functioning of the uterus and ovaries.

Conservative surgery for individuals with Adenomyosis may include removing only the affected areas as opposed to removing the entire uterus. This is often referred to as an Adenomyomectomy.

Research shows that this method of surgery allows for fertility to improve, relieves pain, and reduced the severity of other symptoms without the need for the patient to have major surgery.

Complex Surgery

Where conservative surgery may not provide the most efficient and long-lasting relief of symptoms for patients, complex surgery may be needed.

This refers to more extensive procedures such as the removal of endometriotic cysts (endometriomas) for patients who have Endometriosis. For these patients, complex surgery can also be used to investigate surrounding areas that have been affected by the condition such as the bladder and bowel.

When an individual with severe Adenomyosis has exhausted other treatment methods that have been unsuccessful in resolving symptoms, a hysterectomy is often considered the most definitive option. If the ovaries are not affected by the adenomyotic tissue, surgeons can preserve them to protect and maintain hormonal balance.

Generally, complex surgery is recommended for patients whose conditions have a significant impact on their quality of life, with severe symptoms, and have had failed conservative treatment procedures.

Radical Surgery

This type of surgery is often the last method used for treating Endometriosis and Adenomyosis cases after other treatments have failed to resolve symptoms. These cases are typically severe and treatment-resistant, where this extensive surgical approach is most appropriate to improve the patient's quality of life.

When radical surgery is needed for a patient with Endometriosis, this can involve a total hysterectomy, referring to the removal of the uterus. This procedure can be performed with or without a bilateral salpingo-oophorectomy, which is the removal of the ovaries and the fallopian tubes. As this procedure is the most extensive, it is usually only considered when the patient is experiencing deep infiltrating endometriosis that is affecting multiple organs with no symptom relief from alternative surgery techniques.

Similar to patients with Endometriosis, radical surgery to treat patients with Adenomyosis usually involves a total hysterectomy due to the nature of the condition. As the Adenomyotic tissue grows in the uterus, removal of the tissue would be difficult without complete removal of the organ. However, if the ovaries are healthy, they can be preserved to prevent surgical menopause.

Further Support

Mental Health

Mental health support is crucial for individuals living with these conditions. Symptoms of persistent pelvic pain can often lead to emotional exhaustion, increasing the susceptibility of anxiety and depression. Additional to this, chronic pain can also lead to significant stress and fear due to the unpredictability of flare-ups. This subsequently makes it difficult for individuals living with these conditions to plan their daily activities.

There is a substantial impact on quality of life for people who live with endometriosis and adenomyosis as people often experience symptoms of fatigue, sleep disturbances, and difficulty maintaining work, relationships, and social activities. Through a holistic care approach, comprehensive care can be ensured for patients.

The mental health of individuals living with Endometriosis and Adenomyosis may also be impacted through treatments that can affect hormones. Side effects to these medications such as mood-swings, depression, and anxiety can make living with these conditions more difficult without mental health support. This further emphasises the need for this support to be established and accessible.

Therapy and Counselling

When people living with these conditions experience a delay in receiving a diagnosis, this may result in anxiety forming around seeking support for their symptoms. The likelihood of anxiety and distrust developing towards services providing care and treatment can be increased if people have repeated negative experiences with services.

Support Groups

Uncertainty about pregnancy outcomes and the emotional toll fertility treatments can burden people with can be an extremely overwhelming time. By connecting with others who share similar experiences in settings like support groups, feelings of isolation can be reduced.

Mind-Body Techniques

Mindfulness, meditation, and cognitive behavioural therapy (CBT) has been seen to improve pain management for people living with these conditions and boost resilience.

Pain Management

TAP (Transversus Abdominis Plane) Nerve Block

For people living with Endometriosis and Adenomyosis that have been referred to a pain clinic may be offered a TAP (Transversus Abdominis Plane) nerve block. This is a type of regional anaesthesia often used to manage chronic pain for people living with these conditions. A TAP nerve block involves injecting a local anaesthetic into the space between the abdominal muscle layers to target and numb the nerves supplying the lower abdomen.

The procedure is usually assisted with an ultrasound scan, making it easier to direct the injection with precision. Once completed, the pain relief provided can last for hours to days, where repeated TAP blocks are often needed to provide long-term relief.

TENS (Transcutaneous Electrical Nerve Stimulation)

A treatment that can offer patients experiencing pain from their conditions with a temporary relief is making us of a TENS machine. This involves the passing of a weak electrical current to the patient’s nerves, resulting in a decrease of pain. Natural painkillers, most commonly known as endorphins, are released and prevents pain signals generated by nerves reaching the brain. Unfortunately, this method of treatment is not successful for everyone.

Neuromodulators

Central sensitisation can be caused by Endometriosis and Adenomyosis, which results in the nervous system becoming overly sensitive to pain signals. Through the use of Neuromodulators such as Amitriptyline, overactive nerves can be calmed and pain perception reduced. Symptoms such as pelvic pain, nerve pain, and hypersensitivity can be eased and often resolved.

There is also a muscle relaxing effect that occurs when taking Amitriptyline, where people living with these conditions can have an ease in their symptoms of pelvic spasms and tension. Similarly, this medication can assist with symptoms such as irritable bowel syndrome (IBS) related pain.

Physiotherapy

For some individuals muscle-related pain can be a symptom of their condition, where pelvic physiotherapy can help. This type of physiotherapy can also support patients in post-surgery rehabilitation.

Multi-Disciplinary Approach

For more severe cases of Endometriosis and Adenomyosis, where pain persists despite engaging with alternative treatment methods, a referral to a multi-disciplinary team may be needed. Gynaecologists, pain specialists, physiotherapists, psychologists can work together to tackle the patient's pain.

Living with Endometriosis & Adenomyosis

Case Studies

To gain a better understanding of the impact that these conditions have on peoples' lives, patient experiences were gathered in the form of case studies.

Listening to the stories and journeys that were shared with HWERY helped create a better understanding of what extent people go to regarding treatment and investigations to gain a formal diagnosis.

Included in this section, quotes have been added directly from the case studies to allow for the voices of lived experience to be heard.

For a full account of the case studies, please see Appendices 1.0-1.6.

Impact to health

The following themes have been drawn directly from the experiences of people living with endometriosis and adenomyosis, linking specifically to the impact of the conditions to their physical health.

Chronic pain

The symptom of chronic pain and the impact that this has on health was something discussed by all of the individuals who shared their journeys.

> *“Severe pain, and bad periods”* and *“horrendous pain.”* -Darcie
>
> *“I was in severe pain… I was almost double over in pain, felt as bad as contractions.”* -Emma

“Severe abdominal pain and chronic constipation” as mentioned by Bella’s parent, is something that some individuals can experience. Often the investigations carried out for people who have symptoms of multiple conditions result in additional procedures. This includes scans such as ultrasound scans to rule out any issues relating to the bowel.

Chronic and constant pain can become *“debilitating”* as discussed by Katy. When she was 15 years old, she consulted a GP about severe pain.

Katy was told that she was experiencing sciatica as she *“could hardly walk some days.”*

Similar comments were made about the impact that persistent chronic pain can have on a person’s quality of life. Darie elaborated beyond this, with emphasis on the barriers that pain can cause, such as the impact to her social life when she cannot participate in her hobbies, such as running.

“Some days I could barely stand up.” -Emma

“Pain during/after intercourse.” -Sophie

“I did take an overdose… I started to feel so low and couldn’t stand the pain.” -Emma

The symptom of chronic pain is evidently one that impacts physical health and mental health. It is essential to understand this to provide the most appropriate psychological support to help people through their physical symptoms.

“Bowel issues, endometriosis bloat” -Sophie

“Pain and irregular bleeding” -Anna

“Bella cannot walk for more than a few minutes.”

-Bella’s parent

Bleeding

Severe symptoms of bleeding were discussed with some case study individuals. Marie recalled multiple times where this symptom was more prevalent for her than other symptoms. For a full account of Marie's experience, please refer to the Appendices 1.5.

> *"In the 20mins since I last went to the toilet, I bled through my clothes and into my shoes"*- Marie.

Significant blood loss can often result in additional abnormalities occurring for patients, such as anaemia. This is something that was explained by Marie along with the challenges that she faced with this.

> *"My bleeding was so bad over the summer that my iron levels were the lowest they've been for many years (below 3), and I was struggling to function."*
>
> -Marie

Marie described severe bleeding as *"flooding"*, which could occur some days, *"other days just a little, but either way, it's debilitating."* Marie also said, *"I have to wear pads all the time and have no sex life. The days I flood are unmanageable and come out of nowhere."*

The severe bleeding resulted in Marie’s Mirena coil becoming dislodged, which was something she experienced on more than one occasion. *“The pain was intense, and the clots were enormous.”*

Fertility Issues

Challenges with fertility issues is a topic discussed by these people of lived experience with extreme sensitivity.

Katy said during 2014-2016, she underwent two failed rounds of IVF treatment. When she enquired with the specialists if this could be related to her Endometriosis, they assured her that this was not the case and that she should continue with the treatments.

Katy experienced a further two failed rounds of IVF before making the decision to stop with this treatment as it was *“emotionally draining.”*

To consider alongside the physical difficulties of fertility challenges is the psychological impact this can have on people. Support needs to be in place to assist these people through the emotional journey of fertility treatment and conversations about outcomes.

It is equally important to note that fertility treatments often have an expense and cost the individual their time to attend appointments and consultations. Marie mentioned this:

> *“Let’s not even get into how hard it was to actually get pregnant, and how many hospital appointments*

for fertility investigations we went through, without ever being asked about my periods or given a scan." -Marie

Following the birth of her first child, Emma experienced two miscarriages and an ectopic pregnancy during the first few years of her symptoms developing.

Ectopic pregnancy was also experienced by Darcie, who was *"dismissed"* by her GP when raising her concerns about the symptoms she was having.

Reoccurring symptoms

Despite surgery and other methods of treatment, symptoms of Endometriosis and Adenomyosis reoccurred for the case study individuals. This can often be the case for people living with these conditions due to the tendencies of the tissue growth.

"The pain was still persistent." -Darcie

"...it's likely that I will need to have a stoma due to my bowel being attached to my uterus again." -Sophie

> *"I had returning symptoms several times each year but always got told that it was just something I would have to live with as the operation to remove scar tissue creates more scar tissue."* -Emma

Katy shared that her symptoms returned after a third surgery, resulting in questions surrounding the possibility that she may have Adenomyosis alongside Endometriosis.

Darcie also told us that her pain symptoms returned after some time being asymptomatic following her hysterectomy.

It is essential to set expectations with patients before their treatments of the outcomes to these procedures or medications. This will help protect the mental wellbeing of people living through the treatments and allow them to create a better understanding of their health outcomes.

Fatigue

Chronic fatigue was mentioned by these individuals as a symptom that can affect their concentration, motivation, social interaction and attendance in education settings. This should be considered by education and workplace providers if their staff or student is experiencing fatigue due to Endometriosis or Adenomyosis. Reasonable adjustments should be made to help support these individuals in their working environment to achieve the most effective work of which they are capable.

"Chronic fatigue around the time of my GCSE's"

-Sophie

It is essential to also consider that fatigue has an impact on self-esteem in individuals that may gain weight due to a reduced amount of physical activity. This was commented on by Emma:

"Was in so much pain it made me tired, miserable and put weight on… they kept saying to exercise, the pain was too much, and I was too tired and depressed to do it. From my experience, exercise did not help at all." -Emma

Side effects to medication

As medication was a topic of discussion for many of these individuals, there were also conversations surrounding the side effects that have occurred for some.

Darcie told us that when she was switched to a cheaper alternative medication from Prostap, she experienced severe and *"horrendous"* side effects. When taking this medication, Darcie said that she felt suicidal at times.

Prostap was prescribed to Katy a number of times by an Endometriosis Specialist consultant. This resulted in symptoms of *"horrific pain"* and *"endo belly",* which is often referred to as severe bloating of the abdominal area.

This highlights how people can respond differently to treatment methods than others, which is something that should be considered by health professionals when prescribing medication.

There are side effects to some medications such as Prostap that can cause chemical menopause. This was something experienced by Sophie:

> *"He put me on Prostap to put me in a chemical menopause... this was just before my 30th birthday".*
>
> -Sophie

Also mentioned by the people we spoke to with lived experience was the amount of medication they would be given or advised to take to ease their symptoms of pain. This was something that Darcie helped shed light on when she was referred to the Gynaecology department at Hull Royal Infirmary. She was told that she was:

> *"Overdosing on paracetamol and codeine"* by taking *"over three times the recommended amount."*
>
> -Darcie

This was previously recommended to her by healthcare professionals as a way to tackle her pain.

To prevent this from happening and best support people, pain management plans are needed for each patient to suit their specific needs.

Additional to experiencing side effects from taking medication, some people may experience no change in their symptoms. Discussed by some individuals, many different medications were prescribed, each having no effect or improvement of symptoms.

> *"Trialled multiple contraceptives to see if these helped (they did not)."* -Anna
>
> *"The GP put me on norethisterone three times per day, but it didn't stop my bleeding."* -Marie

Positive outcomes to taking medication were also discussed by Darcie. She told us that she was able to *"live a normal life"* and enjoy sports activities once again. This had a positive impact on her overall wellbeing.

Education

It became apparent from the discussions with people living with Endometriosis and Adenomyosis that there is an urgent need for increased education of these conditions. In addition to raising awareness of these conditions, there is also a need for education surrounding women's health and menstrual health.

This section summarises the misunderstood areas where lack of knowledge of the topics has led to inequality in patients receiving care and treatment.

Endometriosis and Adenomyosis

Darcie said that there seems to be a lack of education and understanding of endometriosis and adenomyosis as the Gynaecologist said that she was *"cured"* of endometriosis after a hysterectomy.

When discussing her symptoms with her GP, Marie was told:

> *"This will get better when you've had children."*

"You need to get pregnant," was advice given by a gynaecologist to Katy to ease her symptoms. This was emotionally damaging for Katy as she had just experienced four failed rounds of IVF treatment.

Women's Health

Darcie said that there was patient who was also in the waiting area *"visibly having a miscarriage,"* with no support or privacy for their dignity. This traumatic experience is something that should have been managed with sensitivity and the wellbeing of that person as a priority. This includes the mental wellbeing of that individual, who may have needed mental health support. This is also a distressing situation for anyone around this person as they were visibly in need of medical assistance and support.

With this considered, there needs to be increased acknowledgement of women's health in the region, additional to increased education of Endometriosis and Adenomyosis to prevent medical negligence.

The need for more education surrounding women's health was reiterated by Anna. She told us that when she reached out to her GP for support for the symptoms she was experiencing, she was told, *"Maybe it's just the way your body is.".* With education of these conditions, primary care providers may be better equipped to tackle initial symptoms in a timely manner.

Menstrual Health

It is evident from the following experiences that people have shared with us about menstrual health, there is a need for education of this topic to be promoted in the East Riding. There is a misconception surrounding menstrual health, which has led to the normalisation of severe symptoms. By raising awareness of menstrual health, delays in receiving support and treatment could be prevented.

Katy took ibuprofen and paracetamol to tackle menstrual pain at 11 years old. Katy said, *“I was always told that it’s just how it is.”* from family members and the school nurse after *“passing out in the lunch queue”* from the pain.

When period pains were worsening for Katy, with pain before, during, and after menstruation, leaving her in constant pain, the GP practitioner at Hedon GP Surgery told Katy that these symptoms were “normal.”

When symptoms of severe pain were present and these individuals consulted with medical professionals, the following comments are what was received as advice and support:

“It’s just a period.” -Katy

“You just must get on with it, and we all have to deal with it so may as well get used to it.” -Marie

“The pain was that bad, I thought it might be my appendix, to again be told there was nothing wrong so it must be period pains.” -Emma

“I was in that much pain I couldn’t stand up and was convinced that I was in labour as really felt like my insides were going to drop out… the pressure was so severe it felt like my womb had dropped out. I am pretty good with pain, but this was unbearable. I was left in A&E for 9 hours with no pain killers only to be told by the doctor when I eventually saw one that it was probably period pains.” -Emma

Chronic Symptoms

This section emphasises the importance of awareness and education of Endometriosis and Adenomyosis to prevent the normalisation of chronic symptoms.

Darcie was told by her GP at Greengate’s Cottingham General Practice to *“live with it,”* when consulting her doctor 5 times following the return of her pain symptoms after a hysterectomy.

Similar advice was given to Bella when she saw a Gynaecologist in December 2024 at the Women and Children’s Hospital, Hull Royal Infirmary to discuss her symptoms of pain that has not been relieved with medication.

“The consultant simply told Bella to alter her diet, stop taking her painkillers as she was on too many and told her she will see her again in one year!!” -Bella’s parent

Communication between service providers and healthcare professionals with patients

The case studies of this project discussed how the communication between services and themselves can be *“very limited”* and *“pretty much non-existent”* in relation to services and departments communicating with each other.

> *“I was discharged from HRI after going through two procedures… I was also discharged at this point from Castle Hill as I was under the care of HRI.”* -Sophie

Misdiagnosis, delays in treatment, and the language and terminology used by healthcare professionals has been highlighted in this section.

Misdiagnosis and Delay in Treatment

Endometriosis and Adenomyosis are conditions that can have many symptoms that may overlap into the criteria of different diagnoses. Due to this, Sophie and Katy said that they both received a misdiagnosis of irritable bowel syndrome (IBS) before their correct diagnoses.

Due to a misdiagnosis, specialist treatment for their symptoms of Endometriosis and Adenomyosis were delayed. A way to prevent this from happening could be to raise awareness of the conditions on a clinical level, where clinicians will recognise the early symptoms as a cause for concern.

Darcie said that she had a *"confusing"* interaction with an Endometriosis nurse, who suggested the use of the medication Prostap for the second time. Darcie found this *"Upsetting and frustrating,"* as she had been previously told that she was only eligible for two years of medication during her lifetime.

Further discussions around delays in treatment occurred with Darcie who said that she had bloods taken to test for ovarian cancer. This occurred after 8-10 GP visits and A&E visits requesting support for her chronic symptoms. 18 months later, Darcie had a laparoscopy at Hull Royal Infirmary, where she was diagnosed with Stage 4 "aggressive Endometriosis and Adenomyosis".

Delaying the treatment of specialist support, such as surgery, has been damaging for these individuals living with Endometriosis and Adenomyosis as other patients have been prioritised over their chronic pain.

> *"My operation was cancelled 4 times this year as classed as non-emergency, one of the times I actually got as far as being put in the gown and just about to be given the anaesthetic and then was informed there was an emergency come in so mine had been cancelled again! At this point I just broke down in tears and was so depressed."* -Emma

Paediatric Assessment Unit (PAU)

As Bella was experiencing bowel issues, tests were carried out at Hull Royal Infirmary to establish whether these symptoms were related to an underlying abdominal condition, such as Chron's disease. Clinicians told

Bella and her parents that this could be a gynaecology problem and was assured that a referral would be made to investigate this.

After this, Bella was discharged with no confirmation of the referral to gynaecology from the Paediatric Assessment Unit (PAU) to Gynaecology. This was due to there never being a referral made. The error in not making the referral led to a prolonging of pain symptoms for Bella to experience, with no further contact from PAU.

Language and Terminology

> *"Made to feel I was making up or exaggerating the pain by almost all of the medical people I went to see."* -Emma

It has become apparent after speaking to these individuals about their experiences that appropriate language and terminology is essential to be used by medical professionals when discussing their conditions. This would help strengthen the trust that patients have for healthcare professionals who are delivering care and treatment.

It is essential to recognise the importance of this for people living with these conditions as the correct and sensitive terminology can result in better understanding of their own medical condition. This can result in a better healthcare outcome for the individual as they may feel better supported.

This section highlights the language used to discuss patient journeys by different medical professionals.

General Practitioner

When Darcie attended Haxby Group Hull GP for an examination to check the positioning of the coil, Darcie said that she was *"dismissed"* and told she *"[can't] be pregnant as the coil was in the correct position."* No referral or further investigations were made, which resulted in the ectopic pregnancy Darcie was living with was discovered after a prolonged period of time. Darcie moved GP surgeries to Greengate's Cottingham General Practice.

> *"My doctor kept telling me to exercise and that it was period pains."* -Emma

Comments like these from Primary Care settings need to be acknowledged and improved upon to prevent delays in treatment and a decline in quality of life for patients.

Interactions with a doctor at North Beverley Medical Centre were described as *"wonderful"* by Bella's parent as they were the only consultant that discussed the symptoms in depth.

Gynaecologist

> *"He gave me my Endometriosis diagnosis by saying "you told me you didn't want any more children; I suggest going home, go on holiday if you have one*

booked, then come back for a hysterectomy." I was 29 at the time."

-Sophie, Goole Hospital

> *"When I went to my appointment, the gynaecologist did not attend."*

-Sophie, Castle Hill

Endometriosis specialist

Katy said that an Endometriosis specialist she saw was *"very dismissive"* and *"didn't think there was anything there."* Katy felt that the Laparoscopy referral was only made to confirm that she was wrong about her symptoms, rather than to investigate the symptoms she was experiencing.

On a different occasion, Katy saw another Endometriosis Specialist at Castle Hill Hospital, who she said was *"really kind"* and went into details about what Endometriosis is and the next steps.

Hull Royal Infirmary- Emergency Department

Bella's parent described the staff as, *"very dismissive"* of Bella's pain as she was prescribed "3 days' worth of codeine" before being discharged.

Darcie spent around 17 hours in chronic pain at the emergency department, where morphine was administered in the waiting area with a lack of privacy.

Orthopaedic Surgeon

During investigation for the symptoms that Katy was experiencing, MRI scans and “many tests” were performed. Katy was told by the orthopaedic surgeon that she was *“making it up”* as there was *“nothing there”* on the scans that were a cause for concern.

Pain Management Team

During an investigative procedure, Katy was asked, *“let’s see if it’s a boy or girl… tell me about your children”* following four failed rounds of IVF treatment. There conversations resulted in severe anxiety for months following the procedure as there was little consideration that this may have been a recent trauma for Katy.

Pain Management & Treatment

This section highlights the experiences people have had when engaging with pain management services and additional treatment for their symptoms, including the following: medication, surgery, pain management programmes.

Pain management team/clinic

It was discussed by Bella’s mum that when requesting for support from a pain management team, this was denied due to Bella’s age. They were told that she must be at least 16 years old to be referred to pain management.

“We hit a lot of brick walls because of her age but as her Mum, I need her pain to be managed, and the cause identified…. Nobody seems to be trying to establish where her pain is coming from and how to get it under control.”

Katy said that she had never been seen by the pain management team until she experienced pain on her lower, left side. This caused her to have restricted movement due to the intensity of the pain, where she was administered morphine.

Medication

Discussed in this section as ways to tackle symptoms of pain and excessive bleeding are Prostap injections, Opioids (Codeine, Morphine), Paracetamol, Ibuprofen, Contraceptive Pills, the Mirena coil, Provera, Norethisterone, and Tranexamic acid.

At the age of 14, the GP prescribed Katy the contraceptive pill, which would help her symptoms of pain and heavy bleeding for around 6 months before they would return and worsen. This led to being prescribed different types of the contraceptive pill every time symptoms returned.

> *"I just managed the pain myself with Cuprofen and Co-codamol."* -Emma

Despite an initial positive impact to Darcie's life being pain free following her hysterectomy, the pain symptoms returned. She returned to the GP approximately 5 times, where the GP advised her to take double the dose of the over-the-counter pain medication.

Marie's GP recommended going on the contraceptive pill to tackle the severe bleeding she experienced during her period. This allowed symptoms to settle for around two years until she began to bleed for two weeks, have two weeks with no bleeding, and then it would return. Marie stopped taking this medication and was given an alternative, where her symptoms settled until around three years ago, where Marie said she was *"bleeding all the time."*

Marie's symptoms progressed, resulting in her GP prescribing her iron tablets for her "constant anaemia" and norethisterone to be taken three times per day. Marie said that this still did not stop her severe and constant bleeding.

When Marie had a Mirena coil fitted, this was in place for less than a month before her *“heavy bleeding dislodged it, so it was removed and replaced”.*

During a visit to Hull Royal Infirmary, morphine was administered and an MRI Scan given to Darcie to rule out the possibility of Bowel restrictions. This was the first time she had been prescribed pain medication rather than being advised to take paracetamol or codeine. After being referred from the emergency department to Gynaecology, she was told that she was “overdosing on paracetamol and codeine” by taking “over three times the recommended amount.” Further tests were needed to check liver functioning.

Darcie consulted her GP at Haxby Group Hull GP, who recommended the Mirena coil (intrauterine device) as the first method of pain management following her diagnosis of Endometriosis and Adenomyosis.

Bella, who is 13 years old was given *“3 days’ worth of codeine”* and a *morphine patch* to treat her pain symptoms.

Surgery

As *“all options of treatments had been exhausted,”* Katy made the decision to go ahead with a hysterectomy. Katy described this as a *“tough journey”* both mentally and physically.

Darcie described the experience of a Laparoscopy procedure at Hull Royal Infirmary as a *"cattle market,"* where patients are *"in and out with their procedures"*.

Darcie was admitted to Hull Royal Infirmary as a result of the pain. A scan was carried out that found a large cyst on the ovary, which was haemorrhaging. Despite the severity of this and the persistent pain, the hospital said that Darcie *"didn't fit the criteria to remove the cyst.,"* and that the cyst was *"too small to operate".* Darcie was not prescribed any pain medication at this point and was advised to double to dosage of codeine purchased over the counter.

> *"[A gynaecologist] referred me for a hysterectomy. Thank the lord!!!"* -Marie

This comment highlights how severe the impact to quality of life is when people living with these conditions for a prolonged period of time are celebrating being referred for extremely invasive surgery. It is also important to consider the impact to quality of life that these surgeries can have post operation as sometimes, patients do not always receive the outcome that they wanted.

> *"I lost my right ovary, putting me in surgical menopause at 35."* -Sophie

Gynaecology Ward

The specialists told Darcie that it was only possible for her to have access to Prostap injections for a limited time of two years. During this time, Darcie said that she was able to *"live a normal life"* and enjoy sports activities, including running. The pain returned when she stopped taking the Prostap injections.

Pain management programme

Katy was denied access to the Pain Management Programme during the assessment stage as *she was told that she was "in too much pain to be on the programme."* When she was finally given a place on the programme, she said that it was *"amazing,"* and the techniques provided by the psychologist were beneficial.

Waiting Time for Specialist Endometriosis or Adenomyosis Appointments

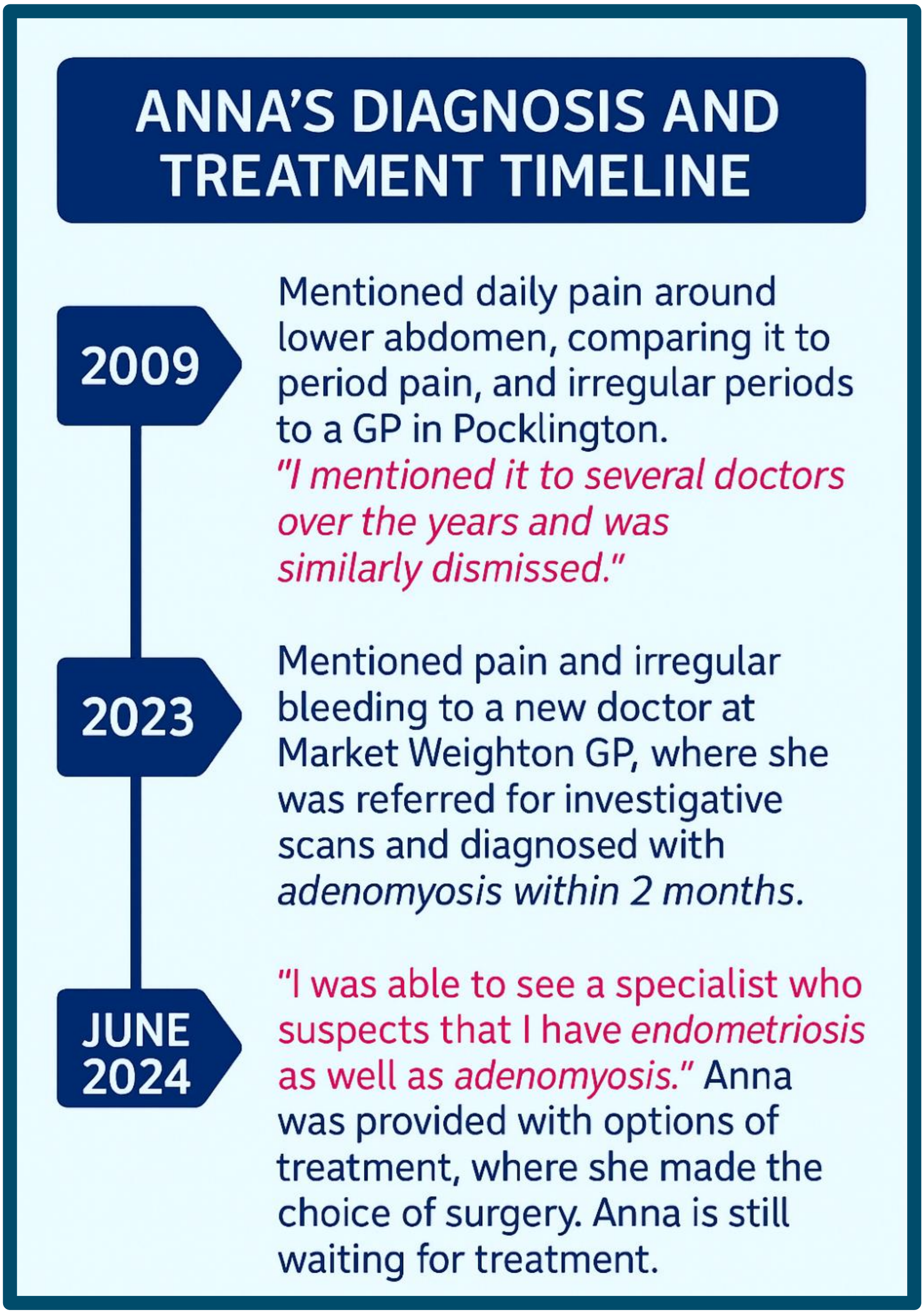
It was communicated through these case studies that the waiting time for patients to receive specialist appointments and referrals is of a significant length. This section highlights the number of times patients have had to contact their GP to receive a referral or support for their symptoms.

Contact with GP

Based on the experiences that we have gathered from these individuals; numerous GP appointments have been made for each person to gain investigative scan referrals or referrals to specialist gynaecology practitioners. It is clear from the following quotes and stories, that access to specialist appointments for these conditions is limited and is an area that requires improvement.

> *"Went to the doctors multiple times each year and had 4 visits to A&E as the pain was that bad."* -Emma

> *"I was back and forth to my GP with [symptoms of] pain during and after intercourse."* -Sophie



ANNA'S DIAGNOSIS AND TREATMENT TIMELINE

2009

Mentioned daily pain around lower abdomen, comparing it to period pain, and irregular periods to a GP in Pocklington.
"I mentioned it to several doctors over the years and was similarly dismissed."

2023

Mentioned pain and irregular bleeding to a new doctor at Market Weighton GP, where she was referred for investigative scans and diagnosed with *adenomyosis within 2 months.*

JUNE 2024

"I was able to see a specialist who suspects that I have *endometriosis* as well as *adenomyosis."* Anna was provided with options of treatment, where she made the choice of surgery. Anna is still waiting for treatment.

Referral consultations

When individuals have been referred to specialist appointments or departments after seeking advice from their GP, the waiting time to be seen by the specialist and the time to receive treatment has been raised as a concern.

> *"I was granted this referral after a 6-to-12 month wait… I was then waiting around another 6 months for surgery."*
>
> -Sophie

> *"By the time I saw the consultant in gynaecology outpatients, I'd been dealing with it for so long that it felt like it would never end. He referred me for a hysterectomy… it would be a 70-90 week wait."* -Marie

> *"January 2024, I was referred back to Castle Hill from the Community Menopause Clinic. I got an appointment to see [Endometriosis Specialist] on the 1st of March. He asked for some scans, and I went back to see him on the 25th of October."* -Sophie, Castle Hill Endometriosis Specialist

Darcie made the decision to have a hysterectomy as this is often a treatment recommended for people who experience endometriosis and adenomyosis. Darcie was told that there would be a two year wait for this surgery.

Gynaecology- Hull Royal Infirmary

The Gynaecology ward attempted to refer Darcie to the Gynaecology department at Castle Hill, but this was denied as she is currently waiting for the endometriosis specialist. The Gynaecology ward at Hull Royal Infirmary wrote a letter to Darcie's GP. Darcie also sent an appointment request form to her GP but did not receive a call back for this appointment.

6 days later, Darcie emailed the GP to chase up the appointment request, where she received a response summarising how the request will be actioned, but the GP surgery is currently very busy.

Darcie joined the waiting list for the Castle Hill Endometriosis Specialist Centre in May 2024 and is currently waiting to receive support in November 2024.

Bella attended an appointment with a Gynaecologist at the Women & Children's Hospital on 3rd December 2024, despite experiencing chronic pain since September 2024.

Marie's GP made a referral to gynaecology, but after hearing nothing from them and waiting a significant amount of time, the GP contacted the department for advice. They recommended a transvaginal scan and a Mirena coil.

From the experiences shared, it can be suggested that communication between primary and secondary care is needed along with improved communication between different hospital departments. This will prevent patients from being discharged with no support and a reduction in any confusion of where patients expect to be receiving their support. Ensuring communication will also prevent patients being on multiple waiting lists.

Aftercare and Follow Ups

One of the main themes that all case studies of this project have contributed to is that of aftercare and follow up appointments. This includes follow up appointments and care plans after a surgery or procedure required to alleviate the patient's symptoms.

> *"No care plan or pain management was put in place, which was ridiculous as even after I attempted suicide (with pain killers I bought and sleeping tablets and antidepressants I had been prescribed), I was still then given another prescription for the same medication with no consultation or advice or support from a doctor or medical professional."* -Emma

Castle Hill Hospital

An email two years after the operation (May 2024) was the only check-up Darcie received after a hysterectomy performed by Castle Hill Hospital. Darcie disclosed to the Endometriosis nurse that things were far from okay in terms of pain and ongoing symptoms of endometriosis and adenomyosis. The nurse suggested being referred to the specialist centre, where Darcie told the nurse that she was never made aware that this was an option as it had never been communicated with her.

Endometriosis Specialist Lead, Castle Hill Hospital

Katy said that they consultant was *“really kind”* and went into details about what Endometriosis is and next steps. Katy said that this was the first time that a clinician had taken time to explain and inform her of the possible causes of the condition and the involvement of sciatic nerves.

Goole Hospital

> *“Sent to Goole Hospital due to there being a 10-centimetre endometrioma (blood filled cyst) on my left ovary… When I came around from the surgery, the gynaecologist was going to tell me what he had done in the surgery. I asked for him to tell when I come around a little more.”* -Sophie

From Sophie’s experience after her surgery, it may be useful to promote more education of the recovery process of these procedures to clinicians to ensure better care of patients.

Waiting Time for a Diagnosis

This section discusses the lengths of time people living with suspected endometriosis and adenomyosis waited to receive an official diagnosis for their condition. Whilst these individuals have been waiting for their diagnosis, symptoms have been ongoing. For some, a shorter wait than others, but still limited support during the investigative period.

- 15 years wait for a diagnosis in total for Sophie, whose symptoms started at the age of 14 years.
- Katy's symptoms started 14 yrs of age, diagnosis at the age of 32.

"Since I was 15." -Marie

"I mentioned the pain and irregular bleeding to the doctor on an initial appointment, and was immediately referred for scans, where I was diagnosed within 2 months with adenomyosis." -Anna

Bella is aged 13, with symptoms of severe abdominal pain and chronic constipation since January 2024. These symptoms progressively got more severe, resulting in chronic pain for Bella, who is unable to attend secondary school due to this. Investigative scans have been carried out including ultrasound scans, MRI, and X-Rays in attempt to locate the suspected endometriosis during October 2024.

These scans did not confirm a diagnosis of Endometriosis. This process is currently still ongoing for Bella, with the inability to attend school as a result of the chronic symptoms.

After many years of severe and constant bleeding, Marie received a transvaginal scan, which confirmed a diagnosis of Adenomyosis.

Mental Health & Psychological Support

Whilst primary symptoms of Endometriosis and Adenomyosis are well documented, the mental health challenges that people living with these conditions are often faced with are overlooked. Mental health support is essential, as coming to terms with the physical and emotional aspects of these conditions can significantly improve overall well-being and quality of life.

This section discusses the ways that the mental health of people with lived experience of these conditions have been impacted. The effect on mental well-being at the expense of limited support and information about the health conditions is also included.

Anxiety and Depression

The dismissive comments from GP practitioners caused Katy's mental health to decline rapidly, where Katy said that she often had thoughts of *"not having a purpose anymore. That was difficult to deal with"* and question *"Why me?"*

Katy also felt that people were never understanding of the symptoms she was experiencing as she was told to *"just get on with it."* This resulted in worsened mental health and an increased feeling of being *"caged in"* and *"no one believes you."*

When Bella's parent shared their daughter's experience of needing support for her symptoms, she said:

> *"Bella's mental health is suffering from all of this."*

Emma explained how symptoms of chronic pain began to affect her emotional wellbeing:

> *"I started to suffer from depression as some days I could not stand the pain."*

Darcie is currently taking medication for anxiety- something that she had never experienced to this extent before her symptoms started. When Darcie was asked about whether she had received any support and if so, what type, she responded:

> *"Absolutely nothing. Zero support."*

> *"I did get put on antidepressants and was diagnosed with depression, I did keep explaining to my doctor that the only reason I felt so low was due to the pain, but this just seemed to be ignored."* -Emma

Consideration for the mental health of individuals living with endometriosis and adenomyosis is needed. Although often, in cases like Emma's, symptoms of depression are being treated with lack of consideration of the pain that has impacted her mental wellbeing.

If physical and psychological

symptoms were treated with consideration of the other, this could improve quality of life for patients and have a feeling of support from all aspects of their health.

Isolation

Feelings of isolation were mentioned by some individuals, relating to the lack of knowledge provided to them about their condition. Sophie highlighted what she felt after being diagnosed with Endometriosis:

> *"I went away feeling really confused, very alone, and upset."* -Sophie

Isolation has also been experienced by Bella, whose parent said their daughter:

> *"Hasn't been to school for months."* -Bella

This could have a significant impact on Bella’s mental wellbeing as she is missing out on education and social development that children experience by attending school.

Support for children living with suspected or diagnosed Endometriosis and Adenomyosis is vital. Ensuring that there is sufficient support for children with chronic pain can help them continue school attendance and remain included in social situations with their peers and friends.

By tackling symptoms of chronic pain with an early intervention approach may prevent children like Bella from missing out on school and other activities. This would support the positive boost of mental wellbeing in these individuals and improve their health outcomes significantly as their feelings of isolation and loneliness would be reduced.

Emotional support would be additionally useful in education settings for Bella and others with health conditions to offer them a safe space to make sense of what they are experiencing.

Lack of Support and Information

This was a theme discussed by all individuals who came forward as case studies. Based on these experiences, there is an urgent need for improved communication of what information is provided to those who live with Endometriosis and Adenomyosis.

Improving the information that is given to patients could prevent incorrect messages being presented to the general public about how symptoms should be managed. This is something experienced by Marie, where her symptoms were normalised and suggestions of integrating them into everyday life were made:

"I was always told that you just must get on with it, and we all have to deal with it so you may as well just get used to it." -Marie

By spreading the correct messages and information about these conditions can help set realistic expectations of health outcomes after a treatment procedure. Feelings of confusion can be reduced by promoting correct and useful information about the conditions and prevent individuals from finding their own answers using research methods that may be promoting the wrong information.

"I was devastated as I thought my operation would cure things finally." -Emma

"Confused… this made me do my own research into Endometriosis and found that Castle Hill was a BSGE Specialist Centre." -Sophie

"2008- I finally had my operation to remove "scar tissue" it was only the nurse that actually said to me that it was Endometriosis and told me what it was and that it would just keep coming back, she explained things so well and gave me more information any doctor or specialist had." -Emma

The following responses are what was provided after people were asked about what type of mental health support was offered and provided to individuals during the investigation process of symptoms and after a formal diagnosis:

> *"No mention of mental health support at any of the appointments, or any discussions about my wellbeing."*
>
> -Anna

> *"I was never offered any mental health support during any time during the consultations/GP visits."* -Emma

Katy said that the only support she had received in relation to her mental health before the Pain Management Programme was the mandatory counselling needed for IVF treatment.

After receiving a diagnosis of Adenomyosis, which Marie had no knowledge of prior to this, she said that she was not given any information about the condition.

Support groups and Local Charities

From those who shared their experiences, Darcie said that the support she received from a local charity in East Riding, Endo Buddies, was *"Heartwarming and caring."*

With raised awareness of which groups and charities are available in the region individuals may feel more supported, especially from support groups who have people of lived experience sharing their journeys. This should be considered with the overall wellbeing of individuals, with a goal to offer social support when they may be in a time of need of a caring group.

Impact on work life

Some individuals who shared their health journey highlighted the impact that endometriosis and adenomyosis symptoms can have on their working life. This specifically relates to symptoms of chronic pain and severe bleeding.

It is important to consider that the working life of all those who have lived with or are currently living with these conditions may be affected. Secondary to this, family or carers of these individuals may also be impacted if time away from work is needed to help get their loved one to their healthcare appointment.

The following experiences highlight the missed opportunity of work life enjoyment when individuals have had to leave work early or miss work entirely.

> *"My boss told me I had to go see a doctor, as I was ill every month. I would often get halfway through a shift and not manage to stay upright as the pain was so extreme. I'd end up bleeding through my uniform and having to go and get changed. On the day I could manage the pain, I'd still need to go to the toilet every hour."* -Marie

Katy said that she worked on a campsite in France as a summer job. Unfortunately, due to the intensity of pain and other Endometriosis symptoms, she had to return home early.

> *"I work in a school and was on a trip to the park with a class. In the 20 minutes since I last went to the toilet, I bled through my clothes and into my shoes. I had to leave the other staff members with the children and go through the disabled toilets to wash my dungarees out in the sink and dry them under the hand dryer."* -Marie

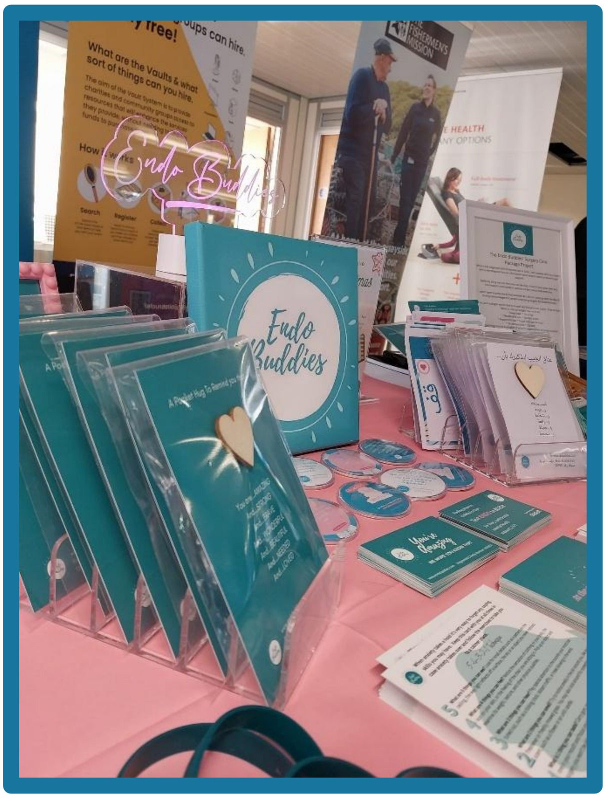
Endo Buddies- Survey 2024

Who are Endo Buddies?

Endo Buddies are a local charity in East Riding that offer support to individuals living with suspected and diagnosed Endometriosis. They have a range of different tools and resources, including a pain management help sheet and an anxiety toolkit.

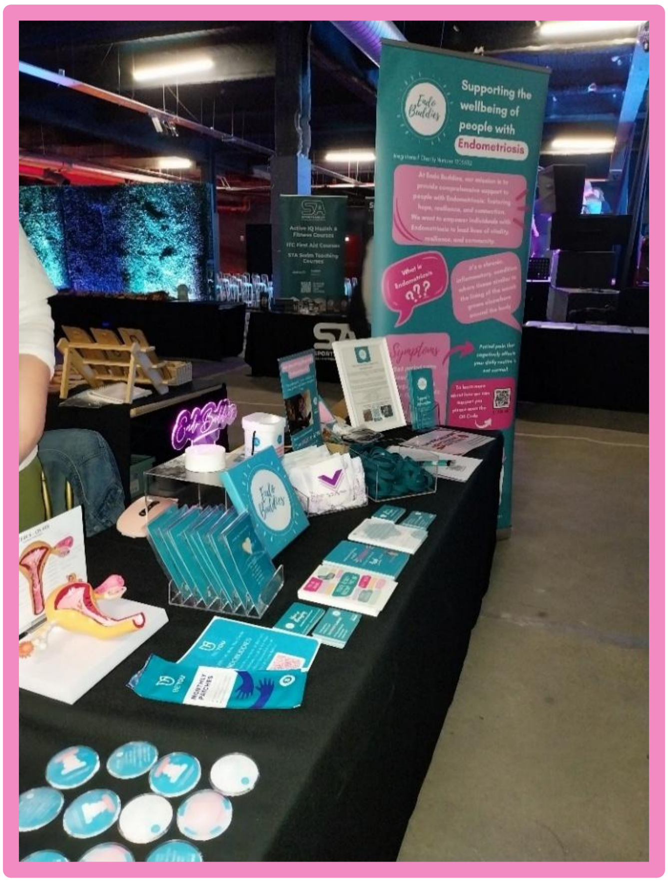
The Endo Buddies' Surgery Care Package Project was launched in 2020, that contains useful items that may help people who have undergone surgery for Endometriosis. This includes items such as:

- Sleep mask, ear plugs, and menstrual pad.
- Peppermint Tea
- Under eye mask, moisturiser, and lip balm
- Mints and throat lozenges
- Hair bobble and nail file
- Information leaflets and cards for other organisations
- Something for anxious hands and anxious minds



Endo Buddies have a stall set up that they take around local communities to help spread awareness, offer support, and educate on the condition. Pictured to the left are some "Pocket Hugs" that provide people with positive affirmations.

Also pictured are Endo Buddies' contact cards, offering free, confidential mental health support from their partnership with Shout.



Pictured on the right are some of the educational materials that Endo Buddies take with them for their stall set ups.

In addition to raising awareness in person, Endo Buddies have created an awareness video on their website. The video goes into detail about what it is like to live with Endometriosis by hearing from those with lived experience.

General Survey

For a complete record of the survey responses that were gathered in 2024 and included in this section of the report, please see Appendices 1.7

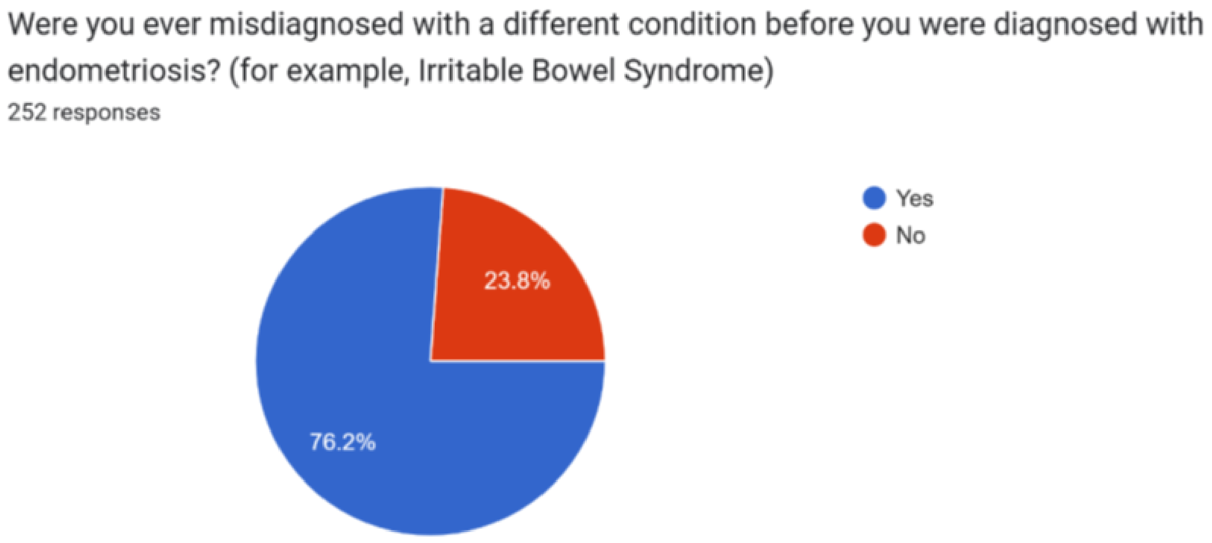
A total of 252 responses were gathered for the general survey conducted by Endo Buddies, where responses from Yorkshire and Humber residents equated to 10.3%.

55% of the total respondents said that the **length of time to receive a formal diagnosis** of Endometriosis was between **3-12 years.** The average wait time of 6-8 years received 22.3% of the survey responses.

When respondents were asked about the number of times they visited their GP for support when seeking a diagnosis, **27%** said that they visited **"more than 20 times".**

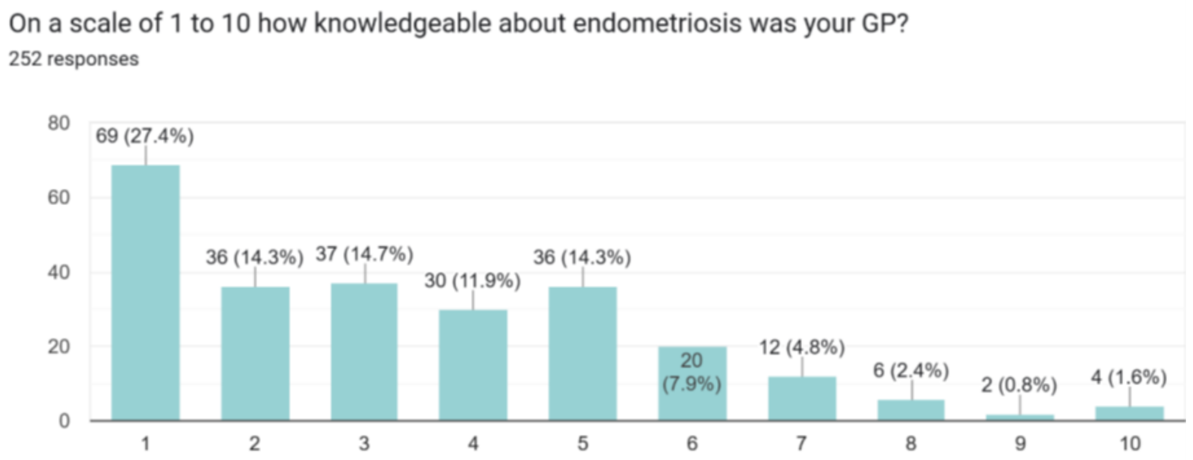
When individuals were receiving investigative care and treatment from healthcare providers prior to their formal diagnosis, 93.7% of individuals said that an **Ultrasound Scan** was carried out. However, people said that they had to have multiple ultrasound scans before there was a confirmation of abnormal results. **39.7%** said that they had **8-11 scans.**

76.2% responded **"Yes"** when they were asked if they had ever been **misdiagnosed** before given a correct diagnosis of Endometriosis, which can be seen in the diagram below.



Were you ever misdiagnosed with a different condition before you were diagnosed with endometriosis? (for example, Irritable Bowel Syndrome)
252 responses

A Likert scale of 1-10 (1 being the least knowledgeable, and 10 being the most knowledgeable) was given to participants to score their **GPs knowledgeability on Endometriosis**. Most individuals gave an answer of 1, equating to 27.4% of respondents. 1.6% of answers attributed to the score of 10; a total of 4 people.

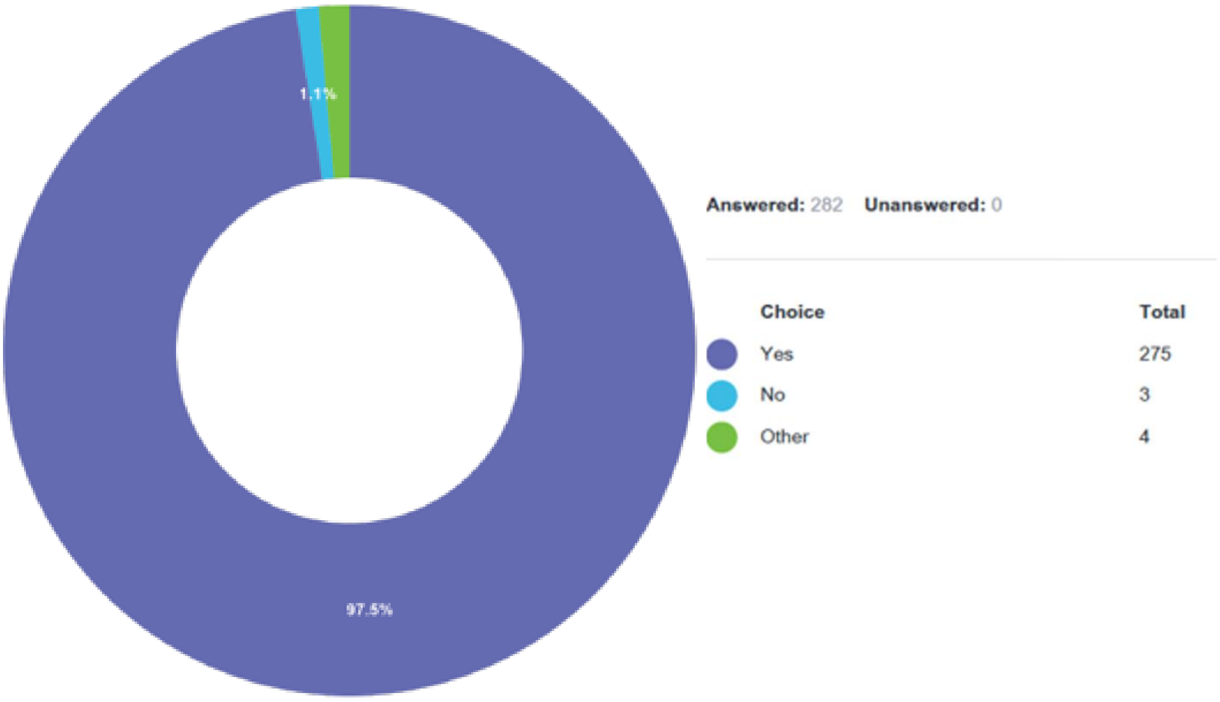


On a scale of 1 to 10 how knowledgeable about endometriosis was your GP?
252 responses

Mental Health Survey

A complete record of the responses that were recorded in 2024 and included within this section are included in Appendices 1.8, where topics of conversation were the same as those who responded to the survey in 2023.

In a mental health survey that was carried out by Endo Buddies, respondents were asked if the effects of Endometriosis have had a **negative impact** on their mental health. **97.5% responded with "Yes,"** equating to 275 individuals.



92.2% of respondents said that there were **delays in being seen by a medical professional** in relation to their symptoms of Endometriosis, where 33.3% said that the average waiting time was 1-2 years. A further 14.2% said that their wait was 2-3 years.

When respondents were asked if they had received **any support during the referral wait time** for appointments or surgery, **251 individuals (89%) said "No".** Of the 6.7% of responses that did receive support, this included an information leaflet, access to an Endometriosis Specialist Nurse, access to an information website, information of local support groups, counselling, cognitive behavioural therapy (CBT).

Respondents were asked **what support they would find beneficial during waiting times** for appointments, treatment, or surgery. The following three were deemed as most beneficial:

- "Support Groups Available"
- "In Person Mental Health"
- "Online Mental Health Support"

The majority of survey respondents said that they had **never been offered a consultation with a Pain Management Team,** which was a total of 214 individuals **(75.6%).**

Question 15 of the survey asked respondents if they have ever had any thoughts of ending their life due the impact of Endometriosis. **53.5%** responded to this with **"No,"** highlighting the extreme impact of the condition on individuals' mental health.

Question 16 asked individuals to **describe their experience of endometriosis,** or suspected endometriosis, and its' **impact on their daily life and mental health.** The following quotes have been extracted from the responses to this question relating to mental health, where the full responses can be found when referring to Appendices 1.8, question 16.

"unbearable"

"Alone"

"I'm very depressed and anxious".

"My pain is so bad I have attempted to take my life twice".

"I experience suicidal thoughts, and self-harm urges every period".

"I take antidepressants".

"Unable to cope"

"The constant pain and hormone issue made my life unbearable".

"Loss of confidence and feeling inadequate".

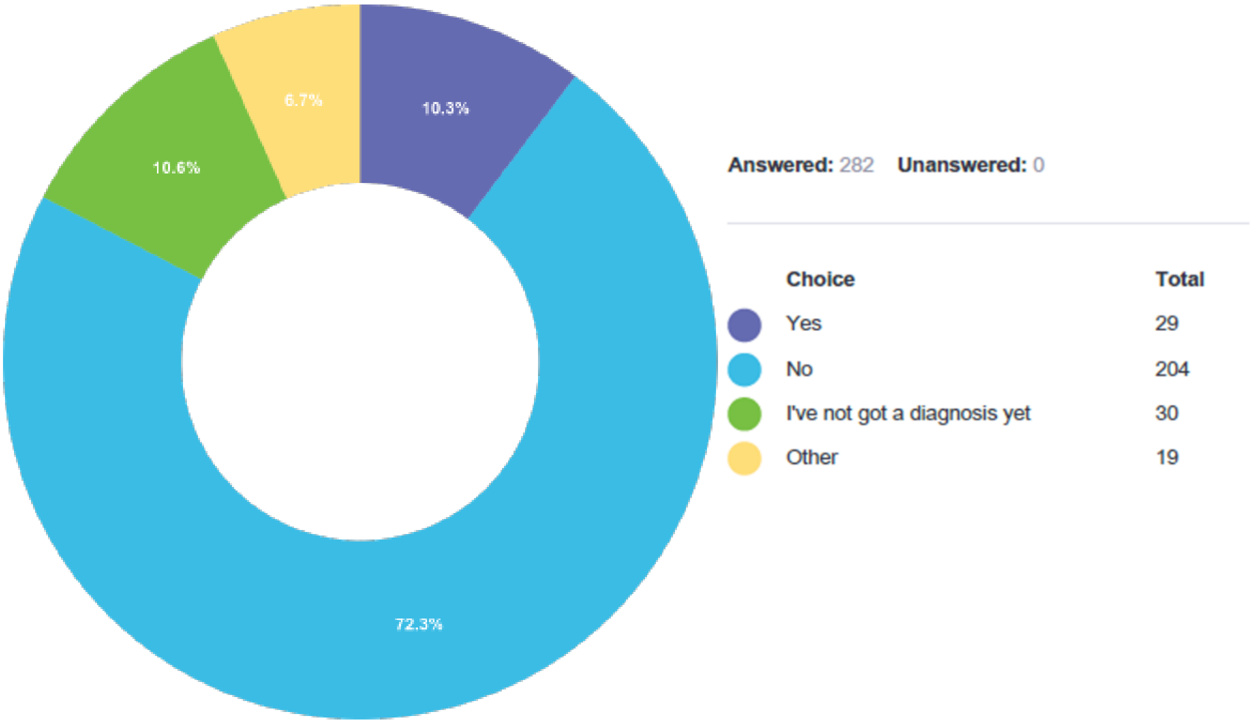
"Very overwhelming, and hard to find the joy".

The suggestions of **what could make a difference to individuals' mental health** whilst living with Endometriosis or Suspected Endometriosis that received the most responses were the following:

- "Being taken seriously by medical professionals" **(21.3%)**
- "Employers knowing about Endometriosis and taking necessary steps to support you" **(19%)**
- "Being told where to go for support when you were diagnosed" **(18.6%)**
- "Having access to mental health support".

Responses to questions 18 and 19 of the survey suggest that individuals feel they are **“left to ‘just get on with it’”** whilst both waiting for a diagnosis and after receiving a diagnosis.

The responses were supported in the following question of whether respondents had ever been given **a care plan by a medical professional,** where 204 individuals **(72.3%) said “No”.**



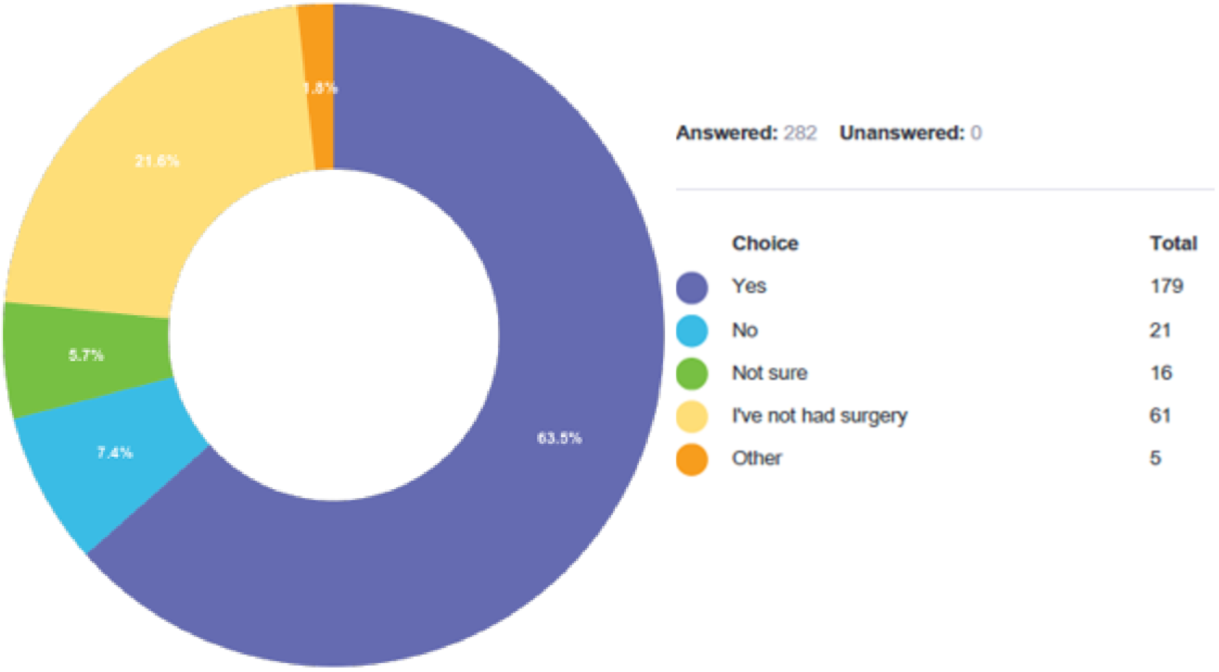
Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	29
●	No	204
●	I've not got a diagnosis yet	30
●	Other	19

A care plan tailored to the specific needs of the individual was something that **89.7%** of the survey respondents said would be **beneficial.**

When individuals were asked what their **preferred type of mental health support** was, **“In person therapy/support”** received the majority of responses with a total of **55%.**

Individuals who have received **surgery as treatment** for their Endometriosis were asked if they ever experienced feelings of **depression,** where **63.5% said "Yes."**



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	179
●	No	21
●	Not sure	16
●	I've not had surgery	61
●	Other	5

Participants of the survey were asked if there was anything more that they would like to add to complete their response. Some of the responses included the following:

"My consultant told me that my depression was not related to my endometriosis."

"Having a diagnosis shouldn't be the end of endo treatment and support. It should be the start of personalised care."

"Long waiting lists for operation. Sent home with a endo box and info about support groups. Still feeling like I don't know much about it, and it's left to me to find out."

"Once I was referred to my endometriosis specialist, he was brilliant. A busy man who did his best to see me in a timely fashion. The registrar and GPs I saw were not supportive at all."

"I think endo needs to be more known, and support needs to be improved. I was fobbed off for 7 years till they started doing something about it, and for others it's longer. My main issue was I was young, so doctors didn't listen and told me it's normal."

For a complete copy of responses to this question, please refer to Question 30 of Appendices 1.8.

Patient Experiences

Patient experiences of those who have received Gynaecology and Endometriosis treatment were shared with HWERY from the Hull University Teaching Hospital's Patient Experience team at Humber Health Partnership.

Treatment, attitude, and care and comfort were noted by patients of the Gynaecology department of Hull Royal Infirmary in their feedback, which can be seen in *Appendices 1.9.*

General themes have been gathered from the complaints made by those who received Endometriosis care, where lack of communication and information being shared was highlighted.

> "[Patient] feels that her symptoms are being ignored and that she has not received guidance on how to manage her condition."

> "Gynaecology consultant that pregnancy is a treatment option for endometriosis rather than surgery."

For a complete record of this feedback, please refer to the Appendices 2.0.

Conclusions

Information gathered from the feedback of patients, data collected through case studies, and public engagements has provided an insightful overview of what life is like living with Endometriosis and Adenomyosis.

Common themes that have been highlighted through the voices of people living with these conditions are as follows:

- There is **limited accessibility to Endometriosis and Adenomyosis specialised services** for diagnosed patients and those who are yet to receive a diagnosis.
- There is a **lack of support and information** provided to patients following diagnosis of both Endometriosis and Adenomyosis.
- **Mental health support is extremely limited** and rarely offered to patients living with Endometriosis or Adenomyosis.
- There is a **limited availability of appointments** with specialist care services (services only being available one day a week, between limited hours from Castle Hill).
- **Awareness and understanding of these conditions** are limited from general population (families, workplace) to medical professionals (GPs, A&E staff) perspective.
- **Stigma** around menstrual health and chronic pain conditions exists in the East Riding region and on a national scale.

- **Repeated bad experiences** has resulted in women having **a lack of trust in the services,** with many feeling that their condition and symptoms do not matter.

The information and lived experiences in this report allows for potential areas of improvement to be acknowledged with the hope that healthcare services will recognise these challenges as an opportunity to improve patient satisfaction.

Addressing the concerns raised and working towards implementing positive change through developing strategies would be most beneficial to the population of people living with suspected or diagnosed endometriosis and adenomyosis.

The passion and willingness of the people living with these conditions to feed back about their support and treatment of the services to gain positive change in their healthcare experiences has been reflected in this report. All of the individuals involved have provided HWERY with valuable information that highlights both positive and negative experiences.

This report aims to focus on the opportunities this information will provide to healthcare services with a goal of improving early intervention, access to care, and promote improved health outcomes for those living with Endometriosis and Adenomyosis.

Our Recommendations

Recommendation 1: Hull & East Yorkshire Endometriosis Centre, Primary Care Networks
Continuity of care following diagnosis and medical procedures Procedures for developing care pathways for patients after they have received a diagnosis, or post-surgery should be reviewed to prevent unmonitored escalation of conditions' severities.

Recommendation 2: Hull & East Yorkshire Endometriosis Centre, Primary Care Networks
Monitoring patients of suspected and diagnosed Endometriosis and Adenomyosis Developing a primary care pathway could lead to less appointments being needed to update GPs on changes after a patient has been discharged. Long-term health could benefit in identifying issues as they arise as opposed to waiting for a notable change in symptoms before requesting urgent treatment.

Recommendation 3: Hull & East Yorkshire Endometriosis Centre, Hull University Teaching Hospitals
Pain Management Programmes and Clinics The criteria to receive pain management treatment should be reviewed, relating to the age of the patient and degree of pain to ensure equal access to this service.

Recommendation 4: Hull & East Yorkshire Endometriosis Centre, Primary Care Networks

Pain Management Treatment

A review of pain management plans and programmes is needed, where treatment should be tailored specifically to each individual patient rather than as a collective approach.

Recommendation 5: East Riding of Yorkshire Public Health, Primary Care Networks

Raise awareness of symptoms and treatments of Endometriosis and Adenomyosis

Education of the symptoms and where to receive support should be promoted on a regional and national level to empower people to seek help from appropriate medical professionals.

Recommendation 6: City Health Care Partnership, East Riding of Yorkshire Public Health

Education of menstrual health

Additional education is needed in schools, colleges, universities and workplaces to tackle the stigma around menstrual health and gynaecological conditions.

Recommendation 7: East Riding of Yorkshire Public Health

Support for mental health

A review of existing support pathways is needed for people with diagnosed and suspected Endometriosis and Adenomyosis. An integrated care model that includes accessible and targeted mental health services for those affected should be implemented.

This report was distributed to stakeholders on 10th July 2025. As of 11th August 2025 we **have not** received any responses from stakeholders or service providers.

If we receive any formal response following publication, the relevant stakeholders will be updated and the responses added to the report on our website:

www.healthwatcheastridingofyorkshire.co.uk/our-reports

Next Steps

What will happen next with this report?

This report will be submitted to local commissioners and providers under the Healthwatch power that allow for reports and recommendations to be made. Services have 20 days from receipt to respond before the report is published.

The report will be added to the Healthwatch archive and the Joint Strategic Needs Assessment (JSNA). From there, the public will have full access to the report.

Healthwatch East Riding of Yorkshire will monitor responses to our recommendations. Members of the public and stakeholders will remain informed of progress and actions to deliver improved services.

Acknowledgements

Healthwatch East Riding of Yorkshire (HWERY) would like to thank all the people who took their time to share their stories and journeys of Endometriosis and Adenomyosis with us. We appreciate that this is a sensitive and extremely personal topic for people to discuss and be open about. The contribution of the **patient voice and those with lived experience** to this project is extremely valuable and helps raise awareness of chronic health conditions.

The support that HWERY have received from **our Community Partner, Endo Buddies,** has been greatly appreciated. The work and support that they offer people is incredible, with the dedication of data collection on a national scale emphasising the impact of these conditions of women in the UK. The data shared with HWERY has been most insightful and an impactful contribution to this project- thank you!

Hull University Teaching Hospital's Patient Experience team at NHS Humber Health Partnership have been of much help in sharing patient voices communicated through their feedback services.

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Websites

Endo Buddies: www.endobuddies.com

Endometriosis.net: https://endometriosis.net/clinical/ovarian-endometriomas

Endometriosis UK: https://www.endometriosis-uk.org/

International Society of Ultrasound in Obstetrics and Gynecology:

https://www.isuog.org/clinical-resources/patient-information-series/patient-information-gynecological-conditions/superficial-endometriosis.html

Mayo Clinic: https://www.mayoclinic.org/diseases-conditions/adenomyosis/symptoms-causes/syc-20369138

National Institute for Health and Care Excellence (NICE): https://www.nice.org.uk/guidance/ng73

NHS (Endometriosis): https://www.nhs.uk/conditions/endometriosis

NHS (Adenomyosis): https://www.nhs.uk/conditions/Adenomyosis/

Seckin Endometriosis Centre (SEC) https://drseckin.com/adenomyosis/

Women’s Health Strategy (2022): Women’s Health Strategy for England - GOV.UK

World Health Organisation: https://www.who.int/news-room/fact-sheets/detail/endometriosis

Appendices

1.0 Darcie’s Story

Darcie, aged thirty-nine

This individual disclosed that they have received a diagnosis of Endometriosis and Adenomyosis on a telephone call with Healthwatch East Riding of Yorkshire. A fake name has been generated to protect the individual’s anonymity and consent was received to disclose the correct age of the individual.

Darcie’s symptoms of Endometriosis began around 1 year after a C-Section procedure, which included “severe pain, and bad periods”.

She had bloods taken to test for ovarian cancer after 8-10 GP visits and further A&E visits.

18 months later Darcie had a laparoscopy at Hull Royal Infirmary. She described the experience as a “cattle market,” where patients are “in and out with their procedures.” After the laparoscopy, Darcie was diagnosed with Stage 4 “aggressive Endometriosis and Adenomyosis”. Adhesions were removed by surgery after receiving this diagnosis.

The pain returned a few months after the surgery.

Haxby Group Hull GP:

After the diagnosis of Endometriosis and Adenomyosis, the pain was still persistent, so Darcie contacted her GP for advice. The GP recommended the coil (intrauterine device). This was suggested to Darcie before any mention that there was an endometriosis specialist at Castle Hill, who could provide specialist support and treatment for these gynaecological conditions.

Darcie received multiple positive pregnancy tests, despite being on the coil. She contacted the GP immediately as she was experiencing symptoms of ectopic pregnancy. The GP carried out an examination to check the positioning of the coil, where Darcie said that she was "dismissed" and said that she "[can't] be pregnant as the coil was in the correct position." She also said that she had "no dignity" during the assessment as she was asked to remove her clothes without the curtain drawn across to protect her privacy.

As Darcie was still experiencing the symptoms of ectopic pregnancy, she contacted the Cedar Ward at Hull Royal Infirmary, who carried out a urine sample. It was confirmed that she was pregnant.

The patient said that it took from a Friday to the following Monday to locate the pregnancy, where the Head of Ultrasound was the only clinician that could find it. During this time, Darcie was told that this was a "life or death" situation, where emergency surgery was then carried out.

Darcie moved GP surgeries after this experience to Greengate's Cottingham General Practice.

Castle Hill Endometriosis Specialists:

Darcie said that multiple ultrasound scans were carried out at Castle Hill hospital.

Suggested Prostap injection, which is administered once every three months. Whilst taking this medication, the functioning of the ovaries is frozen.

The specialists told Darcie that it was only possible for her to have access to Prostap for a limited time of two years.

During the time on this medication, Darcie said that she was able to "live a normal life" and enjoy sports activities, including running.

After Darcie had completed the two-year treatment period, the pain returned. At this point, Darcie made the decision to have a hysterectomy as this is often a treatment recommended for people who experience endometriosis and adenomyosis. Darcie was told that there would be a two year wait for this surgery. The decision to go on a private waiting list for this surgery was made.

Darcie was informed that she would be waiting for a further three months additional to a two and a half year wait.

During the time on the waiting list for private treatment, the endometriosis centre at Castle Hill called Darcie to ask if she would like to be removed from the NHS waiting list despite there being an availability for the surgery in the following few weeks. Darcie made the decision to stay with the NHS waiting list and accept the hysterectomy surgery date as it would mean less time with "horrendous pain" and saving her a great expense.

The surgeons completed the surgery and left Darcie with one ovary. This decision was made with Darcie's age in mind, as early menopause symptoms can be a side effect of removing ovaries.

After the surgery, Darcie said that she was able to take up running again. However, the "horrendous pain" returned putting another stop to "normal life." She returned to the GP around five times, where the GP advised her to take double the dose of the over-the-counter pain medication, and to "live with it." Prescription pain medication was still not offered to Darcie at this point in time.

Darcie was admitted to Hull Royal Infirmary as a result of the pain. A scan was carried out that found a large cyst on the ovary, which was haemorrhaging. Despite the severity of this and the persistent pain, the hospital said that Darcie "didn't fit the criteria to remove to cyst," and that the cyst was "too small to operate." Darcie was not prescribed any pain medication at this point and was advised to double the dosage of codeine purchased over the counter.

Follow up after Hysterectomy: Castle Hill Endometriosis Specialist

Darcie only received one check-up after the hysterectomy performed by Castle Hill Hospital, which was an email two years after the operation in May 2024 from the endometriosis nurse.

Darcie disclosed to the Endometriosis nurse that things were far from okay in terms of pain and ongoing symptoms of endometriosis and adenomyosis.

The nurse suggested being referred to the centre. Darcie told the nurse that she was never made aware that this was an option as it had never been communicated with them. She joined the waiting list in May 2024 and is still currently waiting to receive support in November 2024.

During contact with the endometriosis nurse in May 2024, the Prostap medication was suggested to be taken. This was “confusing” for Darcie as she had previously been told that there was a lifetime limit of this medication of two years. The endometriosis nurse explained that things had changed in relation to time frames that people can take the medication for, however this was never communicated with Darcie. This was upsetting and frustrating for Darcie as she said that Prostap was the only medication that had worked prior to operations and allowed for her to live a functioning life with no pain.

Darcie told us that Prostap is no longer available in the East Riding of Yorkshire area, and that there is a cheaper alternative medication. She said that this medication must be collected from the GP, but an appointment is needed with a GP for them to administer to drug. Darcie said that this is a massive inconvenience as there is already a “struggle to get a GP appointment most of the time.”

Unfortunately, Darcie experienced severe side effects to this type of medication, which resulted in her feeling suicidal. The experience was described as “horrendous” and that she had got to a point where she would rather be experiencing the severe pain of the condition than living with the declined mental health.

Hull Royal Infirmary A&E

Darcie was not given any pain medication; she was only recommended to take over the counter medication such as paracetamol.

W/C 18th November 2024- Greengate’s Cottingham GP and Hull Royal Infirmary, A&E:

Darcie attended the GP for advice regarding pain management for the symptoms that she was experiencing despite taking the recommended “double dose” of codeine and paracetamol. She had an abdominal evaluation that confirmed there are still symptoms of endometriosis and adenomyosis despite the surgeries.

Darcie attended Hull Royal Infirmary Emergency Department where she received morphine and an MRI scan to rule out possibilities of bowel restrictions. She was then referred to the Gynaecology ward, where she was told that she was “overdosing on paracetamol and codeine” by taking “over three times the recommended amount.” As a result of this, Darcie was sent for further tests on liver functioning, which came back positively with no lasting damage.

This visit was the first time in the Endometriosis and Adenomyosis journey where Darcie had been prescribed medication for pain rather than being advised to take paracetamol or codeine.

The ward attempted to refer the Darcie to the Gynaecology department at Castle Hill, but this was denied as she is currently waiting for the endometriosis specialist.

This was “frustrating” for Darcie to hear as although she is on a waiting list to see a specialist, she hasn’t yet received any support. With knowledge of this, Castle Hill Gynaecology department refused to accept the referral.

The Gynaecology ward at Hull Royal Infirmary wrote a referral letter to Darcie's GP. She also sent an appointment request form online to the GP but did not receive a call back for this appointment. Six days later, Darcie emailed the GP to chase up the appointment request as she still hadn't heard anything. She then received a response summarising how the request will be actioned, but the GP surgery is currently very busy.

The length of time spent at this A&E visit was around 17 hours, where Darcie said that there was a lack of privacy for when the morphine was administered, as this was in the waiting area of the department. Darcie said that there was a patient who was also in the waiting area "visibly having a miscarriage," with no support or privacy for their dignity.

Endo Buddies:

Darcie received a care package from Endo Buddies after a surgery. She described the charity as "heartwarming and caring." Darcie also said that it's reassuring to know that there are people out there willing to "support others out the kindness of their own heart."

Additional Comments:

Darcie said that there seems to be a lack of education and understanding of endometriosis and adenomyosis as the

Gynaecologist said that she was "cured" of endometriosis after a hysterectomy.

Darcie suggested that an on-call endometriosis doctor/nurse would be useful for patients to ask questions and get urgent support when needed.

It was mentioned that clinicians often refuse to see patients if they are on a different waiting list.

Darcie is currently taking medication for anxiety, which is something she said sha has never experienced to this extent in the past. She said that there has been no mental health support offered or put in place during any of the referral wait times or treatments. "Absolutely nothing. Zero support."

Date experience was received: 27/11/2024

1.1 Sophie's Story

Sophie

This individual said that have an official diagnosis of Endometriosis on a telephone call with the project lead. They also provided the following information using email. A fake name has been generated to protect the individual's anonymity and consent was received to disclose the correct age of the individual.

"My endometriosis symptoms started when I was a teenager, around the age of fourteen.

My main Endometriosis symptoms were/are chronic fatigue, bowel issues, endometriosis bloat, pain during/after intercourse.

I had investigations for the chronic fatigue around the time of my GCSEs. This was put down to being relaxed as I had normal blood results for things such as diabetes, B12, etc.

When I was around the ages 18-20, I used to have bleeding after intercourse. Investigations found I had endometrium on my cervix. This was cauterised at Doncaster Royal Infirmary, but no further investigations were done.

After this, I moved to the East Riding of Yorkshire. I was back and forth to my GP with pain during and after intercourse. This went on for serval years. In between this, I had my daughter 12 years ago. She arrived 7 weeks premature (not sure if this was due to Endometriosis as I was diagnosed after).

I was eventually sent to Goole hospital due to there being a 10-centimetre endometrioma (blood filled cyst) on my left ovary. I was expecting for the cyst to be aspirated and to carry on with life as normal.

When I came around from surgery, the gynaecologist was going to tell me what he had done in the surgery. I asked for him to tell when I come around a little more.

The next day before I was discharged to go home, he gave me my diagnosis of Endometriosis by saying "you told me you didn't want any more children; I suggest going home go on holiday if you have one booked, then come back for a hysterectomy". I was twenty-nine at the time and no information was provided as to what endometriosis is.

I went away feeling really confused, very alone, and upset. This made me do my own research into endometriosis and found that Castle Hill was a BSGE Specialist Centre. I asked for a referral there to see Mr Philips. I was granted this referral after a 6-to-12 month wait. I had my first appointment with Mr Philips. He put me on Prostap to put me in a chemical menopause... this was just before my 30th birthday.

I was then waiting around another 6 months for surgery, which resulted in me losing my left ovary. This surgery also involved removing my uterus from my Bowel, and emotions from Pelvic wall, Pouch of Douglas, And ureters.

I was then ok for around 8 months. My symptoms then reoccurred. I was referred back to see Mr. Phillips, which resulted in the same as the surgery regarding waiting times and treatment. This time I lost my right ovary putting me in the surgical menopause at 35.

At this time, I asked for my uterus to be removed, but it was left in due to complications. This was March 2020.

I have had issues since this point due to my body not tolerating HRT, I bleed roughly a week, then have 10-14 days off then bleed again. I was referred by my GP to community HRT specialist. They referred me back to Castle Hill with the request/advice on having my uterus removed so I could be prescribed just oestrogen.

When I went to my appointment. The gynaecologist did not attend. This was April 2023. It was down as Mrs Jane Allen… but it could have been one of her team.

In May 2023, I had a referral to Hull Royal Infirmary (HRI) with an endometrium cancer scare. I was discharged from HRI after going through two procedures, where for one I had to go under general anaesthetic. At this point, I tried to argue them to take my uterus out at this time. They refused. I was also discharged at this point from Castle Hill as I was under the care of Hull Royal Infirmary.

January 2024, I was referred back to Castle Hill from the Community Menopause Clinic. I got an appointment to see Mr Cunningham on the 1st of March. He asked for some scans, and I went back to see him on the 25th of October.

He had agreed to take out my uterus but it's likely that I will need to have a stoma due to my bowel been attached to my uterus again. He advised that I would need to have an opponent with the bowel team before surgery.

I am also currently not taking any HRT to the excessive bleeding."

Date experience was received: 02/12/2024

1.2 Bella's Story

Bella, aged thirteen

The information in this case study was provided by a parent on behalf of the individual, who gave consent for their daughter's first name and age to be included with her experience in this project. They told Healthwatch East Riding of Yorkshire that their daughter, Bella, has suspected Endometriosis and hasn't yet received a formal diagnosis.

Symptoms

- Bella has been experiencing symptoms of severe abdominal pain and chronic constipation since January 2024. Over the last 4 months, this has become chronic pain, causing Bella to be unable to attend secondary school since September 2024. Bella's parent told us that the care and support her daughter has been receiving for these symptoms is "really disappointing."

North Beverley Medical Centre

- The support Bella has received from Dr Martin at North Beverley Medical Centre has been "wonderful." Bella's parent said that he has been the only clinician in this process to discuss the symptoms in depth with Bella, allowing her to "feel believed" for what she is experiencing. The parent said that this has helped to ease the doubt in Bella's mind from being passed between healthcare professionals with a lack of investigations or support for the extreme pain.

GP Referral for Investigative Scans

- Bella was referred by her GP at North Beverley Medical Centre for Ultrasound scans, an MRI, and further X-Rays to try to locate the suspected endometriosis and rule out any suspected abdominal conditions.

- These scans were carried out in October 2024, but they didn't show any abnormal growth of endometrial tissue.

Hull Royal Infirmary- Emergency Department

- Bella has attended Hull Royal A&E on numerous occasions, where the care has been described as "terrible" and staff being "very dismissive" of Bella's pain. Bella's visits to the hospital have resulted in being prescribed "3 days' worth of codeine" and discharging her.

- Bella was also using a morphine patch, which her parent said she stopped taking due to there being no ease of her pain symptoms.

Hull Royal Infirmary- Paediatric Assessment Unit (PAU)

- Bella has been to the PAU unit twice, where on 11th September 2024, the experience was described as "better" than the Emergency Department.
- As Bella has been experiencing bowel issues, tests were carried out to establish whether these symptoms were related to an underlying abdominal condition, such as Chron's disease. When these tests presented with no concern for bowel conditions, the clinicians told Bella and her parents that this could be a gynaecological problem.
- Bella was told that a referral to gynaecology would be made to investigate this, with the details being sent to her soon. They discharged her after this. However, there was no confirmation of the gynaecology referral as there was never one made. There was no further contact from the PAU.

Hull Royal Infirmary- Women & Children's Hospital

- Bella attended an appointment with a Gynaecologist at the Women & Children's Hospital on 3rd December 2024.

Additional Comments from Bella's Parent

"Due to my frustration at Bella just being lost in the system, despite being in so much pain, I contacted Graham Stuart. He was amazing and helped me to get an appointment with a Gynaecologist. I have also submitted two complaints via PALS."

"However, we had this appointment on Tuesday, and it was so disappointing. The consultant simply told Bella to alter her diet, stop all her painkillers as she was on too many and told her she will see her again in one year!!"

"Bella cannot walk for more than a few minutes. She is pretty much house bound. Hasn't been to school for months. Her mental health is suffering from all of this, and nobody seems to be trying to establish where her pain is coming from and how to get it under control."

"We hit a lot of brick walls because of her age but as her Mum, I need her pain to be managed, and the cause identified."

Date experience was received: 17/12/2024

1.3 Katy's Story

Katy, aged thirty-nine

Katy disclosed with Healthwatch East Riding of Yorkshire that they have received a diagnosis of Endometriosis on a video call with the project lead and gave consent for their first name and age to be provided in this report.

Childhood Experience:

Katy was diagnosed with abdominal migraines at the age of 8-9 years. There is no certainty whether this is linked to Endometriosis as a possible connection between the two diagnoses as this has never been discussed with a clinician.

Menstruation began when Katy was 11 years old, which was described as *"horrendous"*. With a lack of knowledge and understanding from parents, the Katy took ibuprofen and paracetamol to tackle the pain.

Lack of understanding and awareness of menstruation and conditions like Endometriosis became more apparent when Katy said, *"I was always told that it's just how it is."* Comments like this came from family members and the school nurse after having to visit due to *"passing out in the lunch queue"* from the pain and trying to get out of participating in physical education sessions. Another phrase that Katy said she was often told was *"it's just a period."*

At the age of fourteen, Katy attended the GP for some support and advice regarding her period. The GP prescribed the contraceptive pill, which would help symptoms of pain and heavy bleeding for around 6 months before they would return and worsen. This led to being prescribed different types of the contraceptive pill every time symptoms returned.

At the age of fifteen, Katy went to the GP and was told that she was experiencing sciatica. She said that she *"could hardly walk some days."*

Orthopaedic Surgeon:

During investigations for the symptoms that Katy was experiencing, MRI scans and *"many tests"* were performed. The orthopaedic surgeon told Katy that she was *"making it up"* as there was "nothing there" on the scans that caused concern.

Effect on work life:

Katy said that she worked on a campsite in France as a summer job. Unfortunately, due to the intensity of pain and other Endometriosis symptoms, she had to return home early.

Hedon GP Surgery:

After Katy experienced persistent cold and flu symptoms, where recovery would be for a week before symptoms returned, she made and attended a GP appointment. Period pains were worsening at this time, with pain before, during and after menstruation. This left the Katy in constant pain.

The GP practitioner told Katy that these symptoms were *"normal."*

Impacted Mental Health:

The dismissive comments from GP practitioners caused Katy's mental health to decline rapidly, where they said they often had thoughts of *"not having a purpose anymore. That was difficult to deal with."* Katy also found herself questioning *"Why me?"* and felt that people were never understanding of the symptoms she was experiencing as she was told to *"just get on with it."* This individual described this time as a "battle inside [her] head."

This resulted in worsened mental health and an increased feeling of being *"caged in"* and *"no one believes you."*

Symptoms of fatigue, *"heavy painful legs,"* bowel issues, intolerance to certain foods, and nausea were present at this time. Katy also experienced nose bleeds around the time of menstruation but was told by her GP that this was a *"coincidence."*

Misdiagnosis of Irritable Bowel Syndrome (IBS):

A diagnosis of IBS occurred when Katy was 30 years old.

Katy received a referral from her GP around one year after this to the Gynaecology department. Katy said that this referral was only made after she discussed with her GP about having issues with conceiving not due to the symptoms that she was experiencing at the time.

Katy discussed that this was a really difficult time for her emotionally.

Hedon GP Surgery:

A referral was made whilst Katy was thirty-one to have her first surgery, which was a Laparoscopy and took place at the age of 32. This was made by the Endometriosis specialist at Hedon GP surgery, where Katy was in the outpatient's department.

The endometriosis specialist was *"very dismissive"* and *"didn't think that there was anything there."* Katy felt that the Laparoscopy referral was only made to confirm that she was wrong, rather than to investigate the symptoms she was experiencing.

As Katy was experiencing bowel issues alongside the Endometriosis symptoms, the procedure was referred to Castle Hill.

A diagnosis of Endometriosis was then given after the surgeons found evidence of the condition. This gave Katy the reassurance she needed to *“feel like [she] was being taken seriously.”* Katy discussed how she felt that “people shut doors on you to access the treatment and investigations that you need.” Katy also said that being treated as if she wasn’t to be believed made her understand why people’s mental health take such a decline.

Post Operation- Hedon GP Practice:

2-3 weeks after the procedure, Katy experienced a sharp pain in her right side, under her ribs.

When enquiring about this with her GP, they said that it was symptoms of IBS, despite this previously being a misdiagnosis. Katy said that the practice would not take this misdiagnosis off the system.

Follow Up after Surgery with Endometriosis Specialist lead- Mr Phillips

Katy said that when she discussed with him the symptoms of sharp pain on her right side with Mr Phillips, he was *“really kind”* and went into details about what Endometriosis is and next steps. Katy said this was the first time that a clinician had taken the time to explain and inform her of the possible causes of the condition and the involvement of sciatic nerves. Mr Phillips told Katy that a second surgery would be needed, which he made a referral for.

It was emphasised here the *"misconception and lack of knowledge about Endometriosis,"* and how the GP didn't provide her with any information. She discussed how when you *"look physically well,"* there can be a presumption that there is nothing wrong with a patient.

2nd Surgery- 2013

Katy said that she felt angry at this stage as it was confirmation again that the GP had been wrongfully diagnosing her with IBS symptoms, despite the Endometriosis diagnosis.

IVF Treatment 2014-2016

Katy said during 2014-2016, she underwent two failed rounds of IVF treatment. When she enquired with the specialists if this could be related to her Endometriosis, they assured her that this was not the case and that she should continue with the treatments.

Katy experienced a further two failed rounds of IVF before making the decision to stop with this treatment as it was *"emotionally draining."*

Gynaecology Referral

Due to the ongoing issues with conceiving and persistent Endometriosis symptoms, a referral to gynaecology was made. This was described by Katy as *"just awful."* Katy said that there were two staff members in the consultation room, where one of them didn't introduce themselves.

A solution suggested by the gynaecologist to ease the symptoms that Katy was experiencing was *"you need to get pregnant."* This was emotionally damaging for Katy as she had just experienced the failed rounds of IVF and there was a lack of sensitivity of the subject.

Consultation with Endometriosis Specialist Lead- Mr Phillips

After discussing symptoms of Endometriosis with Mr Phillips, the decision to have a third surgery was made. This occurred in 2017.

Unfortunately, symptoms returned after the surgery and sparked the question as to whether this was symptoms of Adenomyosis too. At this point, Katy said that she made suggestions of having a hysterectomy, where Mr Phillips said that other treatments may work before a procedure that major.

He prescribed Katy with Prostap a number of times, however this resulted in symptoms of *"horrific pain,"* and *"endo* *belly,"* which refers to severe bloating of the abdominal area.

Katy tried Provera (medroxyprogesterone) and the Mirena coil was suggested to her as treatment, but she declined this due to preference.

Hysterectomy operation

Mr Phillips said that *"all options of treatment had been exhausted"* at this stage, with only the hysterectomy option remaining. The decision to go ahead with this surgery was made, despite being an extremely *"tough journey."*

Since the operation, Katy said that she has received no support regarding menopause.

Urology diagnosed Katy with Neurogenic Bladder, which refers to the damage of nerves that disrupt the correct functioning of the bladder. This diagnosis occurred after experiencing symptoms of urinary incontinence and urinary tract infections (UTIs) on a frequent basis.

Katy was self-catheterising to treat these issues, which started as something she would do around three times per day but increased to whenever she needed to urinate.

As a result of the symptoms, Katy attended A&E where it was confirmed that she had a kidney infection. She said that she was prescribed the wrong medication by A&E, prolonging symptoms further.

HRT Review- 2022

During a HRT review with her GP, Katy was told that she had low levels of oestrogen. Katy received a repeat prescription of oestrogen, which resulted in her never experiencing UTIs since.

Pain Management Team

Katy said that she had never been seen by the pain management team until she experiences pain on her lower, left side. This caused her to have restricted movement due to the intensity of the pain. She was given morphine for this pain.

It was confirmed at a later point that this was due to adhesions being present.

A TAP (transversus abdominis plane) block was administered to treat the pain, although this was unsuccessful in resolving such symptoms. During this procedure, Katy said that she was struggling with her emotions, and that the consultant was *"rude."* She discussed that she had an anxiety attack, and it was evident that the nurse and other clinicians had not read her medical notes as one of them said *"let's see if it's a boy or a girl."* Comments similar to this of *"tell* *me about your children"* were made again by other staff after the procedure.

This experience caused Katy to have severe anxiety for months following the procedure.

Private Pain Management

Katy decided to go down the private healthcare route to receive further pain management treatment, where another TAP was provided. This, again, was unsuccessful in resolving the symptoms of pain. Katy was told here that there was *"nothing else"* that could be done.

There was a one year wait for acupuncture treatment, where Katy said that after three weeks she had noticed a dramatic difference. She said that she was able to complete small tasks again, such as emptying the dishwasher with no pain.

Pain Management Programme

Originally, Katy was denied access to the Pain Management Programme during the assessment stage as she was told that she was *"in too much pain to be on the programme"* and the clinicians said that she wouldn't be able to engage with the activities.

When Katy had finally been given a place on the Pain Management Programme, she said that it was *"amazing,"* and the techniques provided by the psychologist were beneficial. Katy said that the only support she had previously had in relation to mental health was the mandatory counselling needed for IVF treatment.

Katy said that she had previously disclosed to her GP about struggles with mental health, who told her on a telephone consultation that she was experiencing pain because of stress.

Additional Comments

"I was just left to get on with it."

"The way I've been treated, it's so bad. It's so unnecessary."

"I've never been asked how my mental health is- not once. Nothing at all."

Date experience was received: 09/12/2024

1.4 Anna's Story

Anna, aged thirty-five

Anna disclosed with Healthwatch East Riding of Yorkshire that they have received a diagnosis of Adenomyosis through an email to the project lead. Consent was received to include Anna's first name and age in this report.

“In 2009 I went to my GP in Pocklington about daily pain around my lower abdomen, comparing it to period pain, and irregular periods. I was told 'maybe it's just the way your body is'.

I mentioned it to several doctors over the years and was similarly dismissed. Trialled multiple contraceptives to see if these helped (they did not).

On transferring to Market Weighton doctors, in 2023, I mentioned the pain and irregular bleeding to the doctor on an initial appointment, and was immediately referred for scans, where I was diagnosed within 2 months with adenomyosis. I was then placed on a waiting list for the gynae specialist, however received the phone call offering me an appointment when I was 6 months pregnant in 2024 so was removed from the waiting list and told to ask for a re-referral if still an issue after birth.

I was able to see a specialist who suspects that I have endometriosis as well as adenomyosis in June 2024 and was given options for treatment. I have opted for surgery. I am still waiting for treatment; I have received three surveys (one 24 hours after agreeing to surgery) asking if I want to remain on the waiting list and checking if I have opted to go private instead.”

Additional Comments:

When Anna was asked whether she had ever received or been offered any mental health support in relation to her ongoing journey of Adenomyosis and suspected Endometriosis, she responded:

"There has been no mention of mental health support at any of the appointments, or any discussions about my wellbeing."

Date experience was received: 24/01/2025

1.5 Marie's Story

Marie

This individual disclosed that they have received a diagnosis of Endometriosis through an email to Healthwatch East Riding of Yorkshire. A fake name has been generated to protect the individual's anonymity.

"I have suffered from very heavy periods since I was fifteen. I have always been violently sick and had diarrhoea the day before my period started.

I was always told that 'you just must get on with it,' and 'we all have to deal with it so may as well get used to it.'

When I was seventeen, my boss told me I had to go to see a doctor as I was ill every *month. I would often get halfway through a shift and not manage to stay upright as the pain was so extreme. I'd end up bleeding through my uniform and having to go and get changed.*

On the days I could manage the pain, I'd still need to go to the toilet every hour.

So, I went to see my lovely, elderly male GP. He told me 'This will get better when you've had children' … Because of course it was a given that I planned on doing that. And let's not even get in to how hard it was to actually get pregnant, and how many hospital appointments for fertility investigations we went through, without ever been asked about my periods or given a scan.

Then after my children eventually came along, my periods were still as bad as ever and my new GP recommended going on the pill.

Brilliant… I had quite a few years with no periods at all. Amazing!

That is until it wasn't. And I was bleeding for about 2ks, off 2wks then on again.

I came off that pill and went on to another. And it carried on like this until around 3yrs ago when I was bleeding all the time. Some days flooding, other days just a little, but either way it's debilitating. I have to wear pads all the time and have no sex life. The days I flood are unmanageable and come out of nowhere.

I work in a school and was on a trip to the park with a class. In the 20mins since I last went to the toilet, I bled through my clothes and into my shoes. I had to leave the other staff members with the children and go through the disabled toilets to wash my dungarees out in the sink and dry them under the hand dryer. Luckily, they are thin, multicoloured fabric and it was a hot day.

But that's beside the point really.

By this point, my GP had me on iron tablets for my constant anaemia and had referred me to gynaecology. The GP put me on norethisterone three times a day, but it didn't stop the bleeding. My GP contacted gynaecology for advice, as the wait to be seen is so long. They recommended a transvaginal scan and a Mirena coil.

The scan confirmed adenomyosis, which I'd never heard of. I was given no information about it either.

I had the coil fitted. And less than a month later, my heavy bleeding dislodged it, so it was removed and replaced.

I was sent for a biopsy and hysteroscopy. The biopsy was clear, so I got a letter to say it was being discharged. My GP challenged that as they'd referred me to deal with the endless bleeding.

By the time I saw the consultant in gynaecology outpatients, I'd been dealing with so long that it felt like it *would never end. He referred me for a hysterectomy. Thank the lord!!!*

That was April last year. It would be a 70-90wk wait.

My bleeding was so bad over the summer that my iron levels were the lowest they've been for many years (below 3), and I was struggling to function.

My GP wrote to the consultant and asked for my referral to be expedited. They agreed and I was added the urgent list in August.

Last week, I lost such a lot of blood one night. It was every 15mins for about 4hrs. The pain was intense, and the clots were enormous. It was so bad that I took a photo as I feel like nobody really understands what my normal is. It wasn't until I looked at the photo that I saw my coil strings in it.

I rang the consultant the next morning and asked for advice. He said it might have all come out, but if not, they'll remove it when I have my hysterectomy.

He suggested I have tranexamic acid as well as the three norethisterone a day. I've had tranexamic acid and mefenamic acid before, so I'll try it again.

My hysterectomy is booked for the end of March, and I can't wait.

I feel like, if this were a male problem, it would have been solved years ago. And also, that it's impossible to know what is *abnormal when it comes to periods because we don't discuss what normal looks like. We've only just got to a point were adverts use red liquid on pads. I've had clots the size of my fist, every month since I was fifteen. And no one ever told me that isn't normal, until I was at a point where I couldn't function properly.*

It shouldn't have to come to this."

Additional Comments:

When Marie was asked if she had ever received or been offered any support for her mental health surrounding her Adenomyosis symptoms and diagnosis, she responded with the following:

"I have never been offered mental health support in relation to my adenomyosis but have been put on antidepressants because of perimenopause."

Date experience was received: 26/01/2025

1.6 Emma’s Story

Emma, aged fifty-one

Emma shared her journey to an Endometriosis diagnosis to Healthwatch East Riding of Yorkshire by emailing the project lead. Consent of her first name and age to be included in the final report was received.

Emma provided a timeline of relevant information about the journey of her diagnosis and treatment.

“1991 - Had my first child.

1992 - Went to my doctors as I was in severe pain and was told it was period pains and to take paracetamol - at this point I was almost doubled over in pain, felt as bad as contractions. UK- Leeds

1993 - Back to doctors several times this year to be told there was nothing wrong and was PMT. I also had a miscarriage this year. UK- Leeds

1994 - 1998 Went to doctors multiple times each year and had 4 visits to A&E as the pain was that bad, I thought it might be my appendix; to again be told there was nothing wrong so it must be period pains and to take paracetamol and ibuprofen. In 1985 I had another miscarriage and also an ectopic pregnancy - UK - Leeds & Salisbury

1998 - Had my second child

1999 - 2000 - The symptoms were at their worst, some days I could barely *stand up, my doctor kept telling me to exercise and that it was period pains, at this point I started to suffer from depression as some days I could not stand the pain. I just kept being told to take pain killers. Uk Salisbury*

2001 - I moved to Germany with my Husband who was in the forces and spoke to a GP over there and they immediately sent me for a scan and a laparoscopy, finally!! It was then that they found I have an Ovarian cyst and booked me in for an operation to remove it. Germany - Osnabruck

2002 - After a few months, the pain returned and seemed worse than before I had my operation, so they booked me in for more scans and tests and then diagnosed I had some scar tissue, and I had a further operation to remove some of the tissue. Germany

2003- I had to be sterilised as they said this would help with the pain as again; I had an issue but this time they found it was with my fallopian tubes. While doing the operation they found another issue with one of my ovaries and also more scar tissue. At this point I was only 30 years old. Germany

2006 - I moved back to the UK and was rushed into Pinderfields hospital as was in that much pain I couldn't stand up ad was convinced that I was in labour as really felt like my insides were going drop out, I know that probably sounds really dramatic, but the pressure was so *severe it felt like my womb had dropped. I am pretty good with pain, but this was unbearable. I was left in A&E for 9 hours with no pain killers only to be told by the doctor when I eventually saw one that it was probably period pains. UK Wakefield*

2007 - I went to see a new doctor (female) and luckily for me she had suffered from very similar symptoms so could understand the pain I was describing and for the first time asked me if I had heard of endometriosis? At this stage no one had mentioned that to me. I was then sent for more scans, laparoscopy and internal examinations and booked for an operation to remove what they said was scar tissue. My operation was cancelled 4 times this year as classed on non-emergency, one of the times I actually got as far as being put in the gown and just about to be given the anaesthetic and then was informed there was an emergency come in so mine had been cancelled again! At this point I just broke down in tears and was so depressed. Uk Pinderfields

2008 - I finally had my operation to remove "scar tissue" it was only the nurse that actually said to me that it was endometriosis and told me what it was and that it would just keep coming back, she explained things so well and gave me more information any doctor or specialist had. I was devastated as I thought my operation would cure things finally. Uk Dewsbury

2008 - 2020 - I had returning symptoms several times each year but always got told that it was just something I would have to live with as the operation to remove scar tissue creates more scar tissue, so I just managed the pain myself with Cuprofen and Co-codamol.

2021 - I started to go through the menopause (which I think I am finally at the end of). I have found that my symptoms have got less and less over the years."

"I do think there was a huge lack of information in the UK about endometriosis and was made to feel I was making up or exaggerating the pain by almost all of the medical people I went to see. I am so glad that it is a recognised medical problem now and that people like you are taking your time to research and help improve things as so many women have been through and are still going through what I did, and some have had a worse experience than me."

"For a huge chunk of my life it stopped me from just functioning like a normal person as was in so much pain it made me tired, miserable and put weight on because even though they kept saying to exercise the pain was too much and I was too tired and depressed to do it

and from my experience exercise did not help at all.”

“I was never offered mental health support at any time during the consultations/GP visits - to be honest back in the 90s and 2000s mental health was still something that people didn't really acknowledge or talk about. During this period, I did get put on antidepressants and was diagnosed with depression, I did keep explaining to my doctor that the only reason I felt so low was due to the pain, but this just seemed to be ignored. I did take an overdose in 2006 as I started to feel so low and couldn't stand the pain. Now I realise I am so lucky that I didn't succeed and am happier than I have ever been and feel very selfish and ashamed for even thinking about it and putting my family through it.”

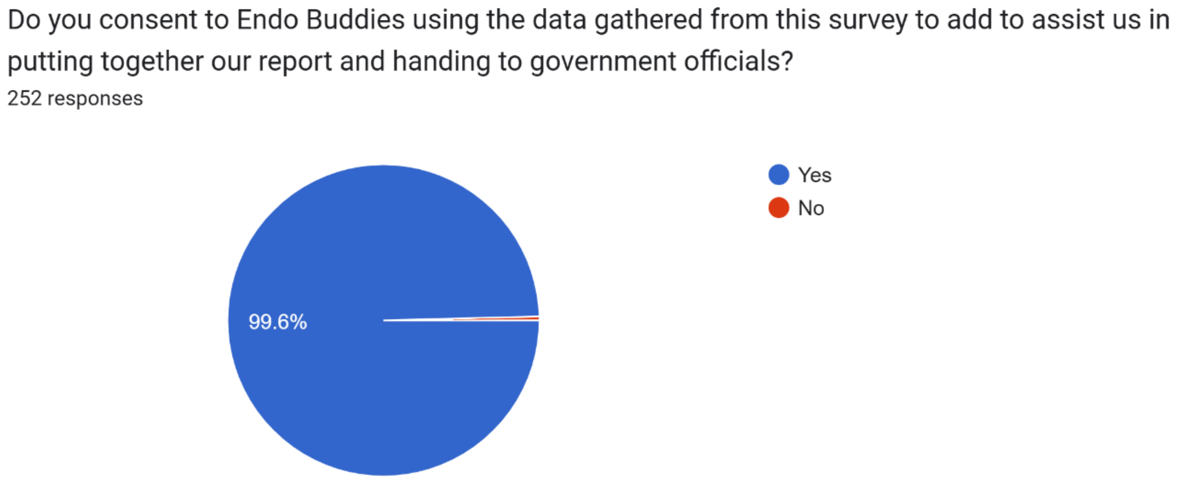
“Communication was pretty much non-existent between the care services; each time I went to see someone the whole process would start again as no information was passed on and Pinderfields hospital actually lost all my records at one stage. The communication and information passed on to me was also very limited, it was only really the nurses at the hospital at Dewsbury that gave me information, and

a diagnosis for all those years was certainly not discussed with me."

"No care plan or pain management was put in place which was ridiculous as even after I attempted suicide (with pain killers I bought and sleeping tablets and antidepressants I had been prescribed), I was still then given another prescription for the same medication with no consultation or advice or support from a doctor or medical professional."

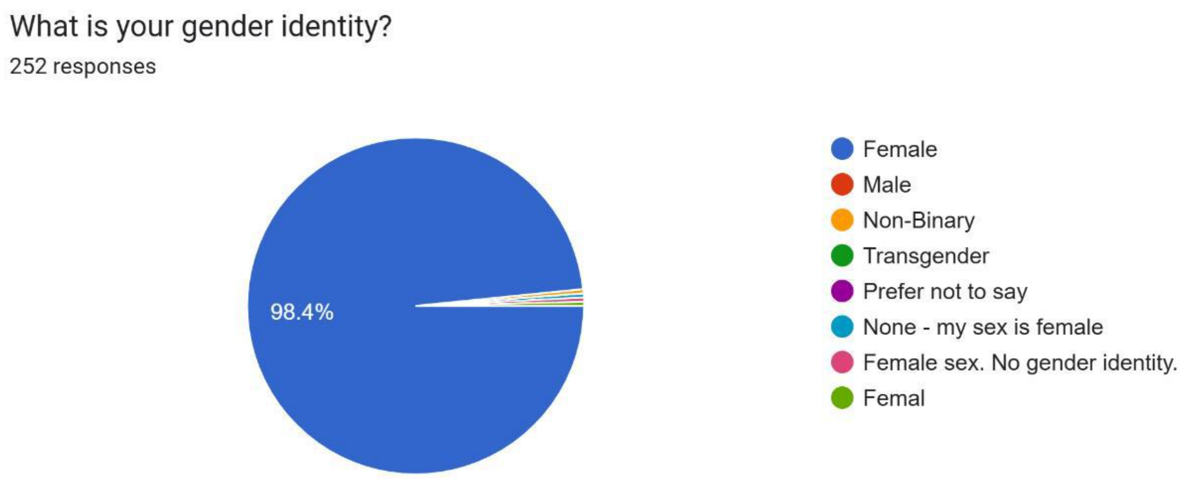
Date experience was received: 13/02/2025

1.7 Endo Buddies- General Survey



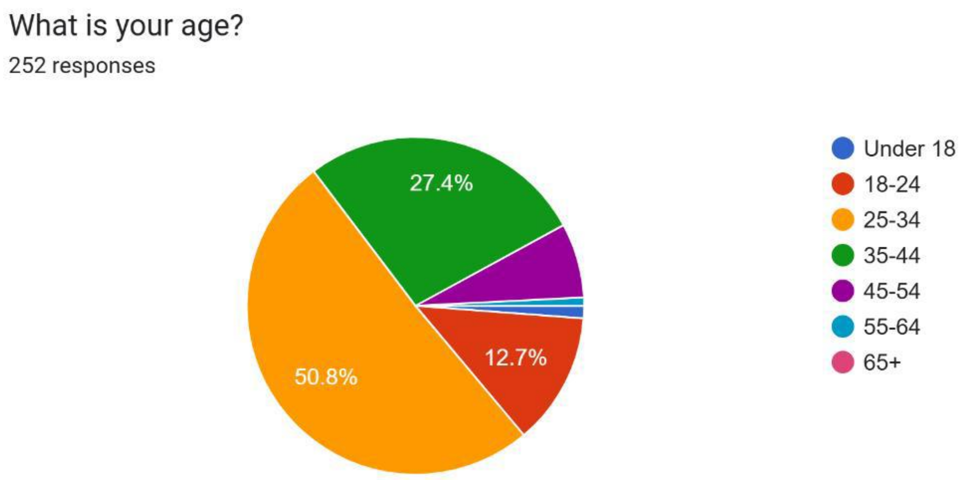
Do you consent to Endo Buddies using the data gathered from this survey to add to assist us in putting together our report and handing to government officials?

252 responses



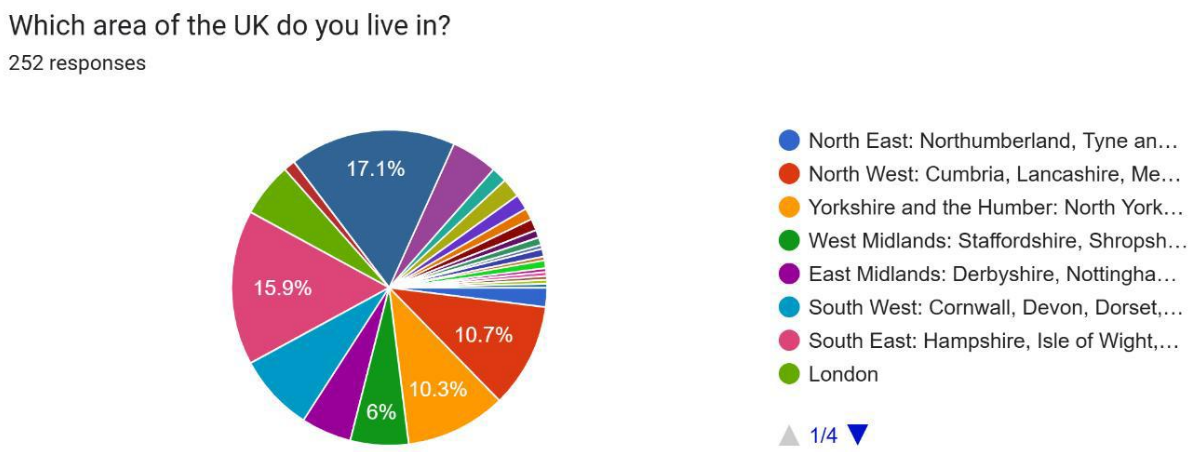
What is your gender identity?

252 responses



What is your age?

252 responses

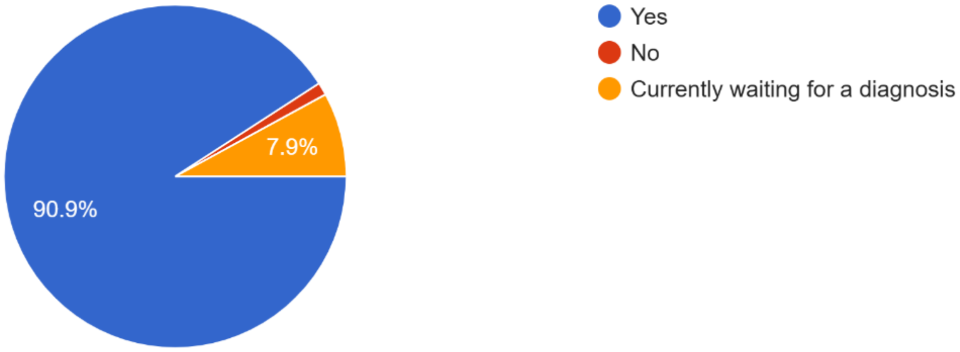


Which area of the UK do you live in?

252 responses

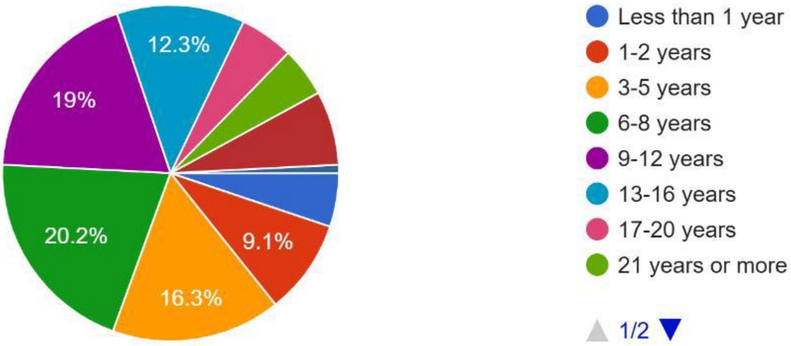
Have you been diagnosed with endometriosis?

252 responses



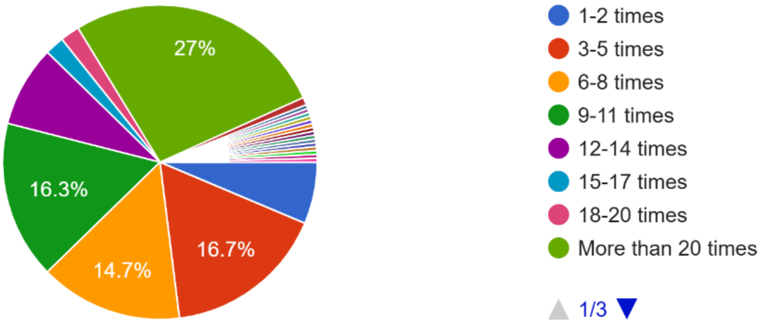
How long did it take for you to get a diagnosis of endometriosis?

252 responses



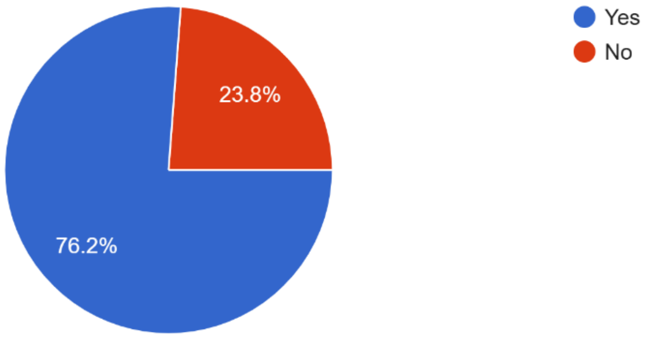
How many times did you visit your GP for help when you were trying to get a diagnosis? (how many times did you visit them before you were referred to a gyanecologist)

252 responses



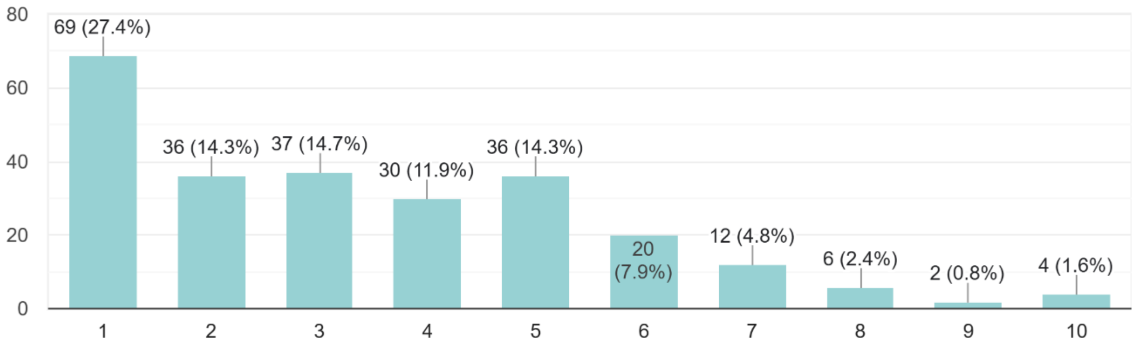
Were you ever misdiagnosed with a different condition before you were diagnosed with endometriosis? (for example, Irritable Bowel Syndrome)

252 responses



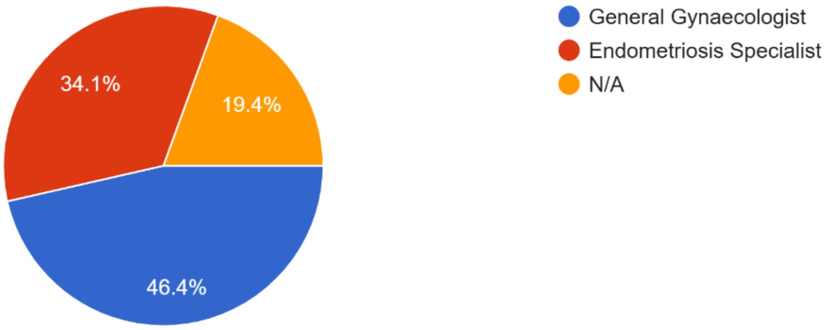
On a scale of 1 to 10 how knowledgeable about endometriosis was your GP?

252 responses



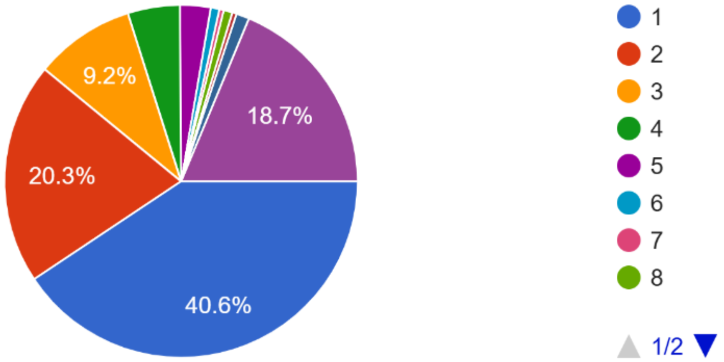
If you have had surgery to diagnose endometriosis, was this with a general gynaecologist or an endometriosis specialist?

252 responses



How many surgeries have you had for Endometriosis?

251 responses

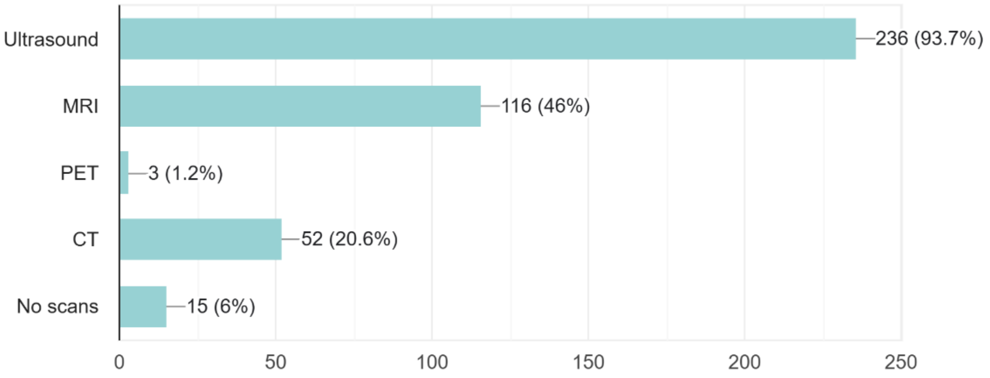


If your surgery was with a general gynaecologist did you have to have more surgery with an endo specialist?

252 responses

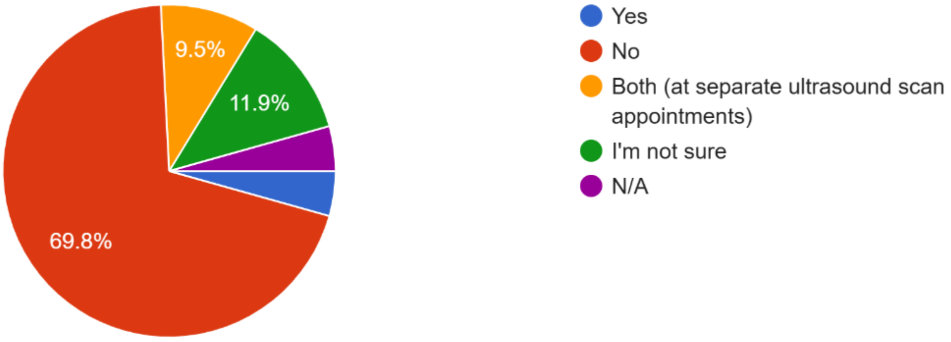
Prior to being formally diagnosed with endometriosis, did you have any scans? Please tick all that apply

252 responses



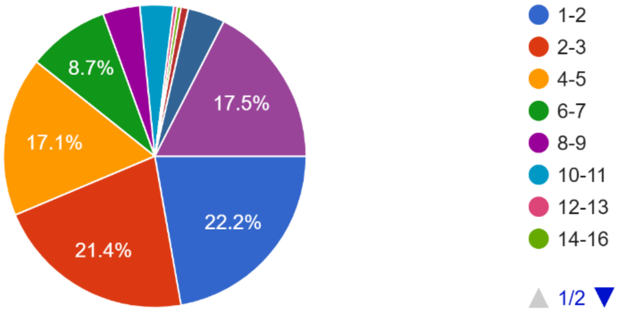
If you had ultrasounds, were these by an endometriosis specialist sonographer?

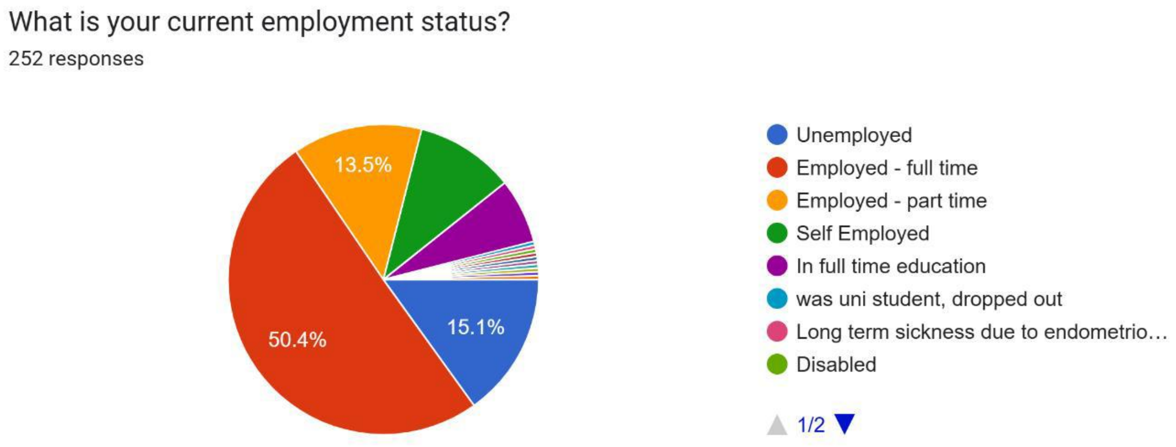
252 responses

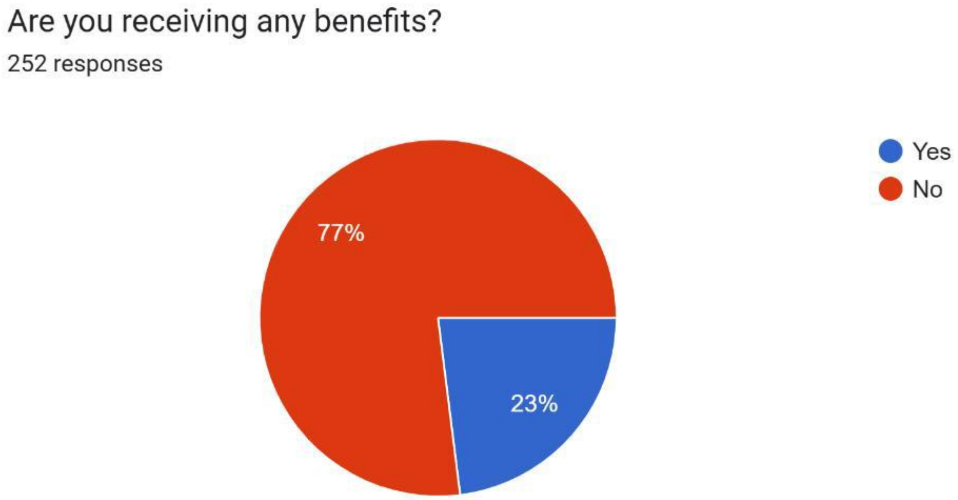


How many ultrasound scans have you had where you were told that they couldn't find any thing wrong with you?

252 responses

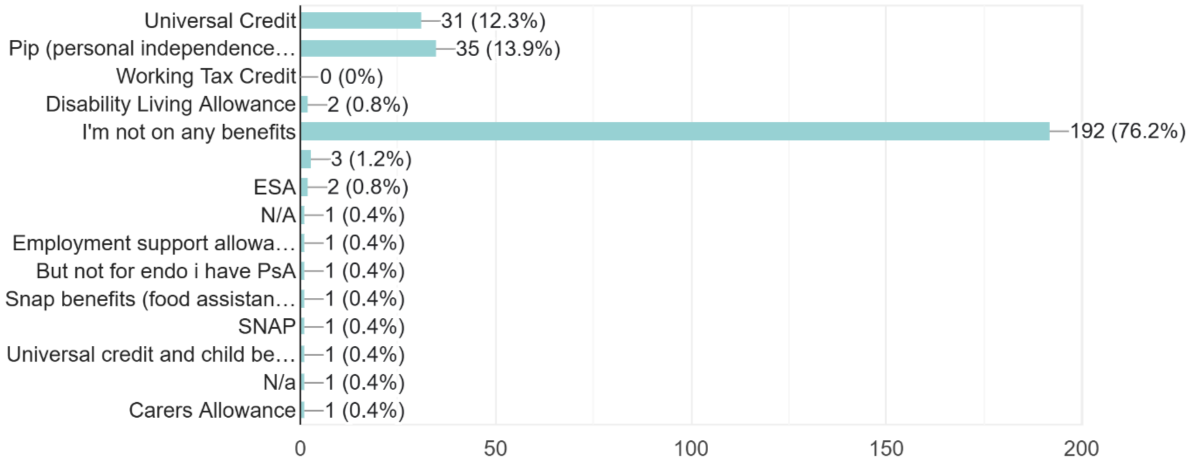



What is your current employment status?
252 responses
13.5%
50.4%
15.1%
Unemployed
Employed - full time
Employed - part time
Self Employed
In full time education
was uni student, dropped out
Long term sickness due to endometrio…
Disabled
1/2


Are you receiving any benefits?
252 responses
77%
23%
Yes
No

Which benefits are you in receipt of? Tick all that apply.

252 responses

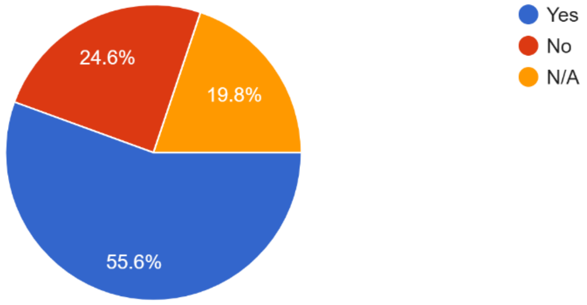


If you have had surgery for endometriosis, did you have a follow up consultation after your surgery?

252 responses

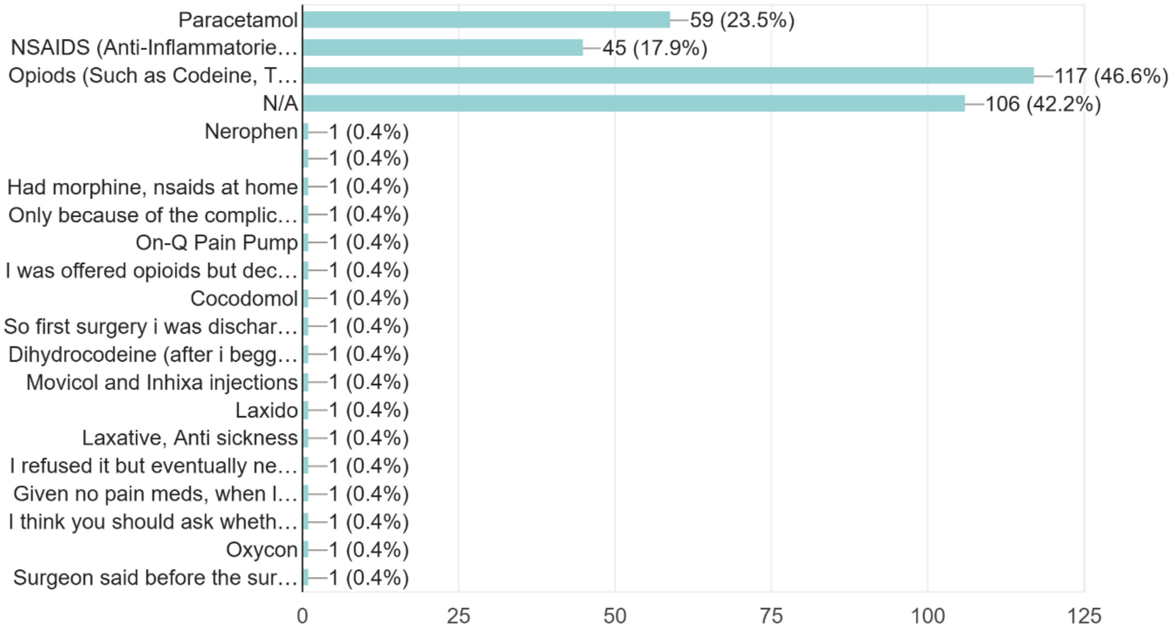
If you have had surgery, were you discharged with medication to help with the pain?

252 responses



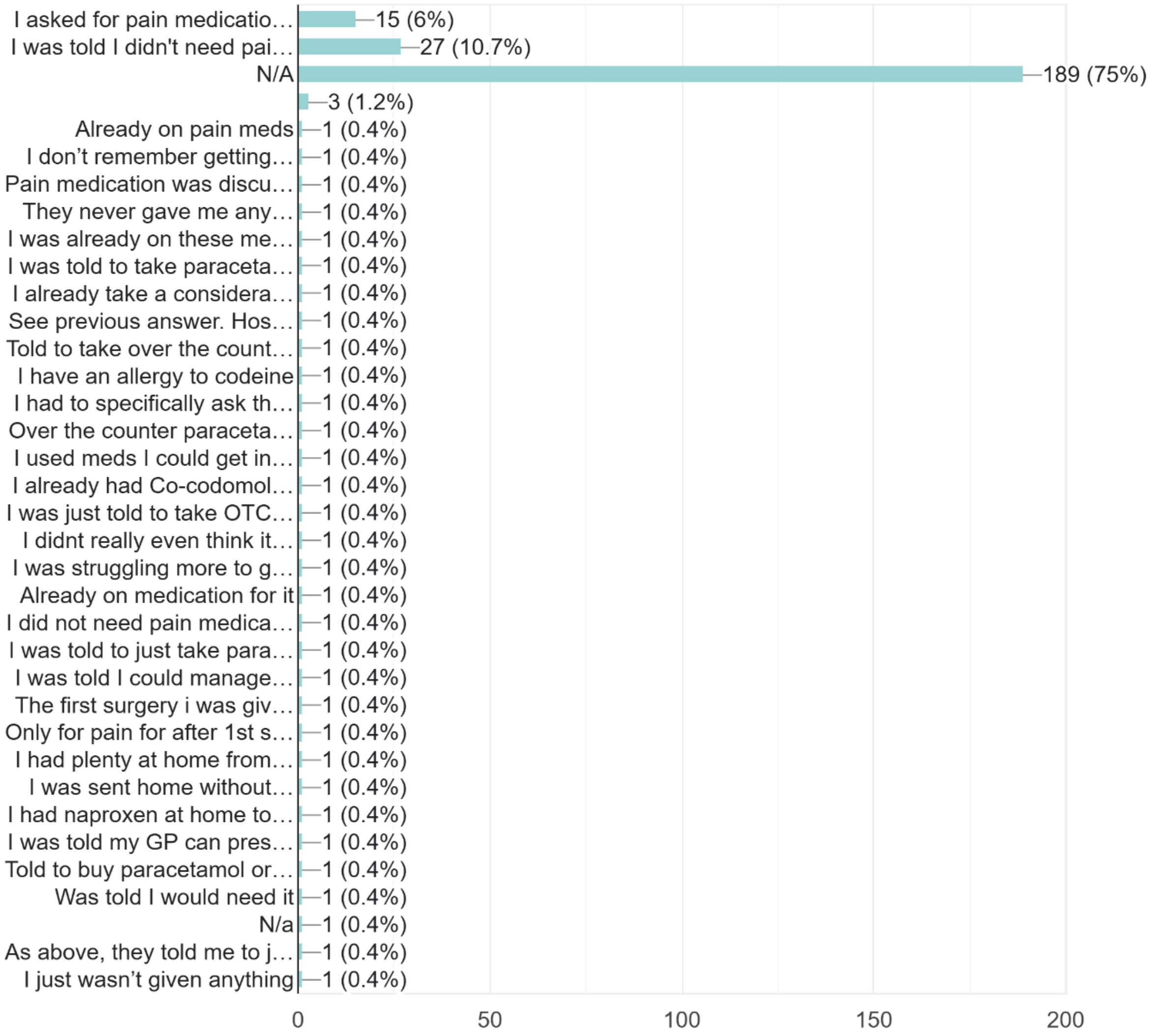
If yes, what medication were you discharged with? Tick all that apply

251 responses



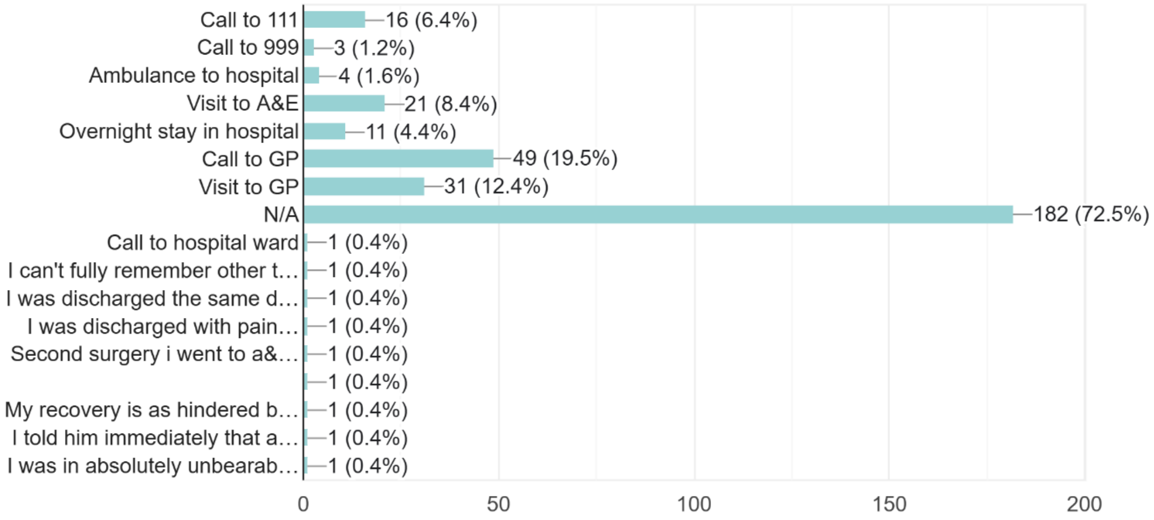
If you were not discharged with pain medication, please go into more detail about that. Did you ask for pain medication? Were you refused medication?

252 responses



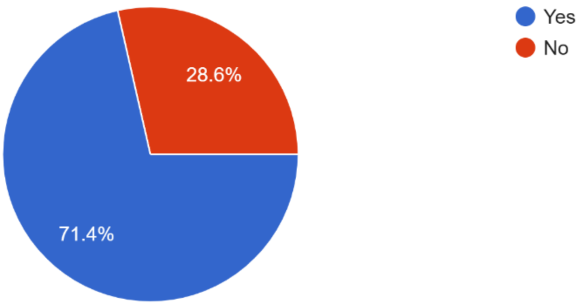
Did the lack of pain medication on your hospital discharge result in any of the following? Tick all that apply

251 responses



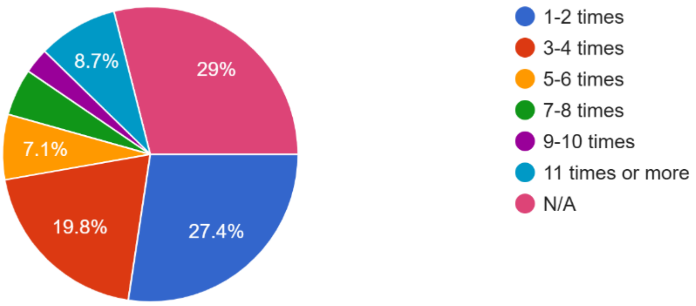
Have you ever had to attend A&E because of your endometriosis symptoms?

252 responses



How many times have you attended A&E because of your endometriosis symptoms?

252 responses

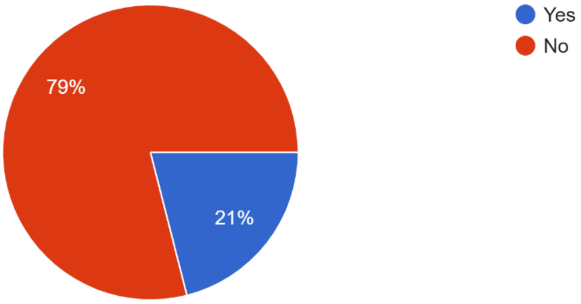


If you went to A&E because of your endometriosis symptoms did you feel that you were listened to and taken seriously or did you feel unsupported?

252 responses

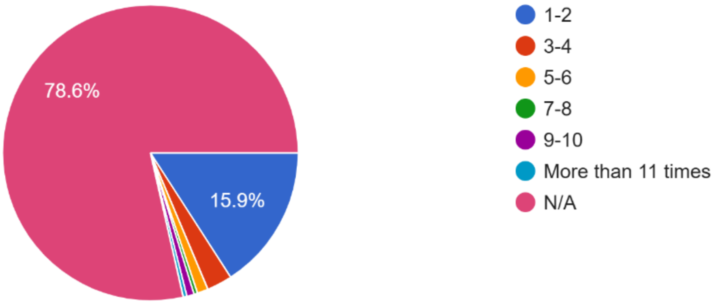
Have you ever needed an ambulance to transport you to A&E because of Endometriosis symptoms?

252 responses



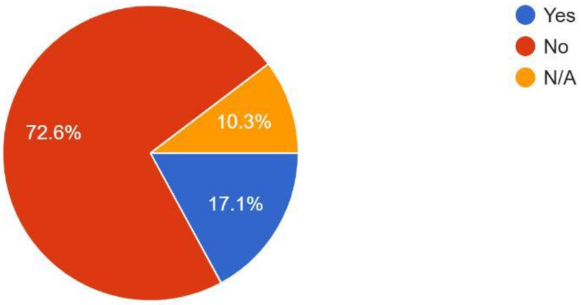
How many times have you needed an ambulance to transport you to A&E because of Endometriosis?

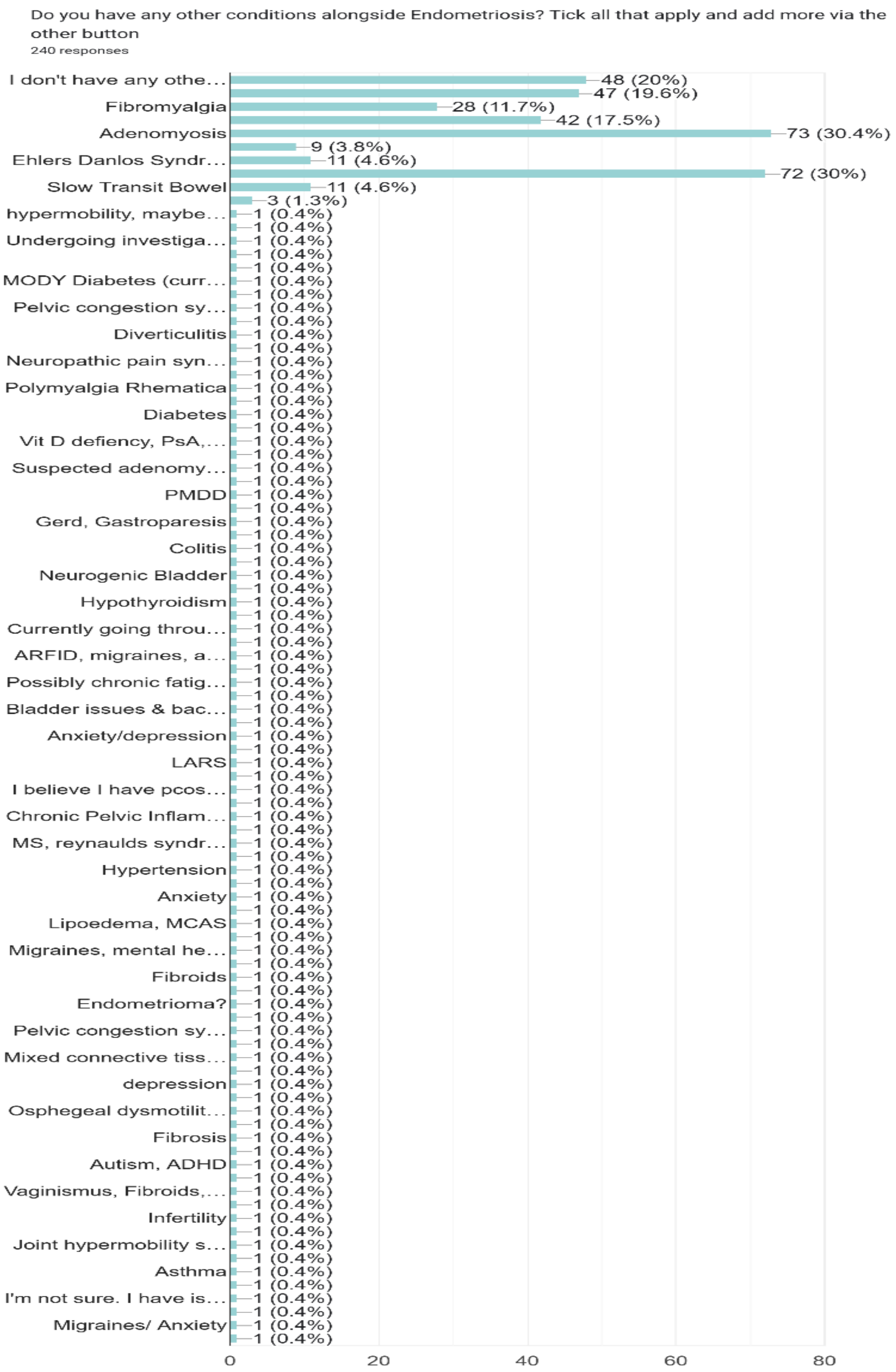
252 responses



Have you ever been given a care plan post endometriosis diagnosis?

252 responses

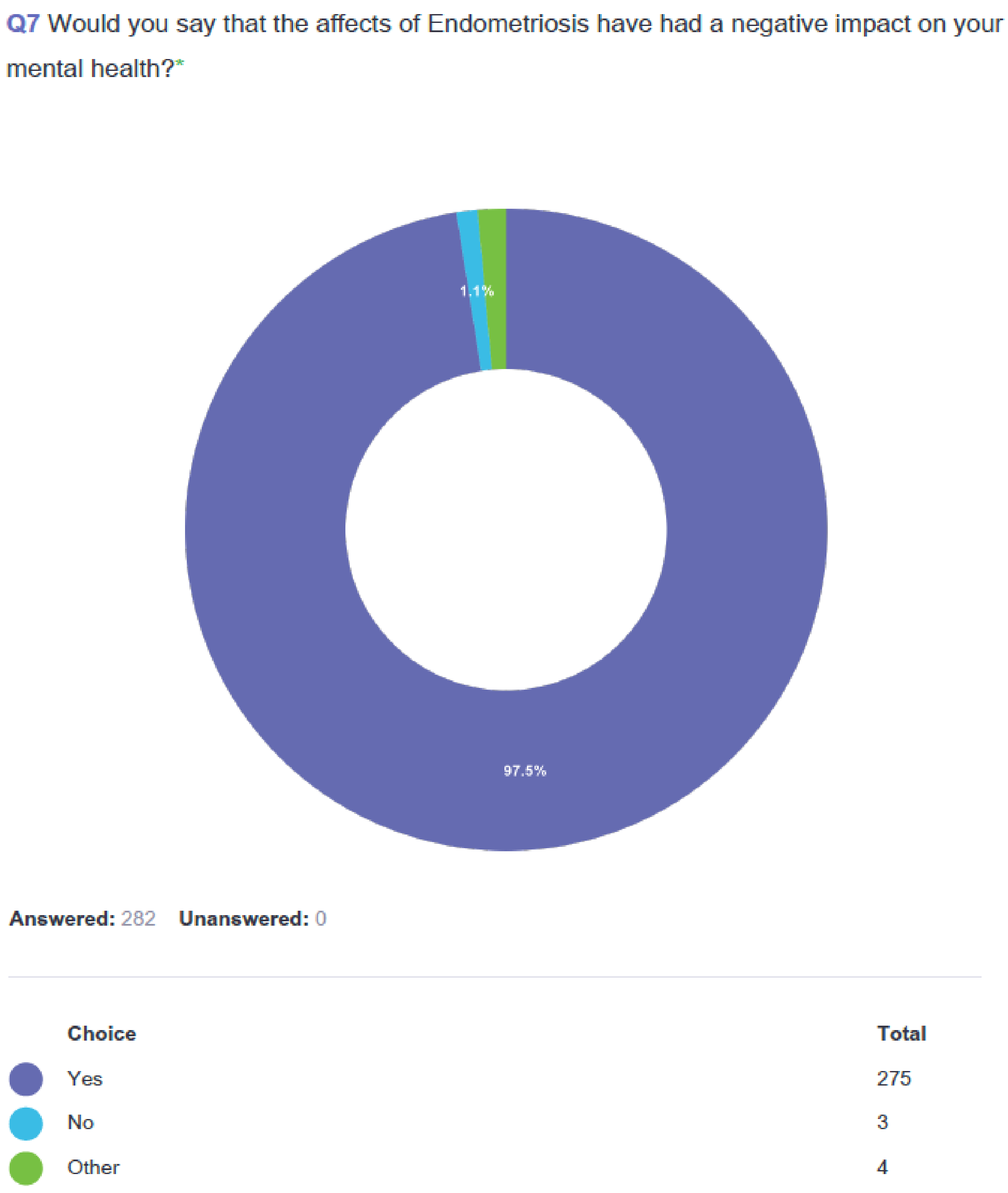




Do you have any other conditions alongside Endometriosis? Tick all that apply and add more via the other button

240 responses

1.8 Endo Buddies- Mental Health Survey

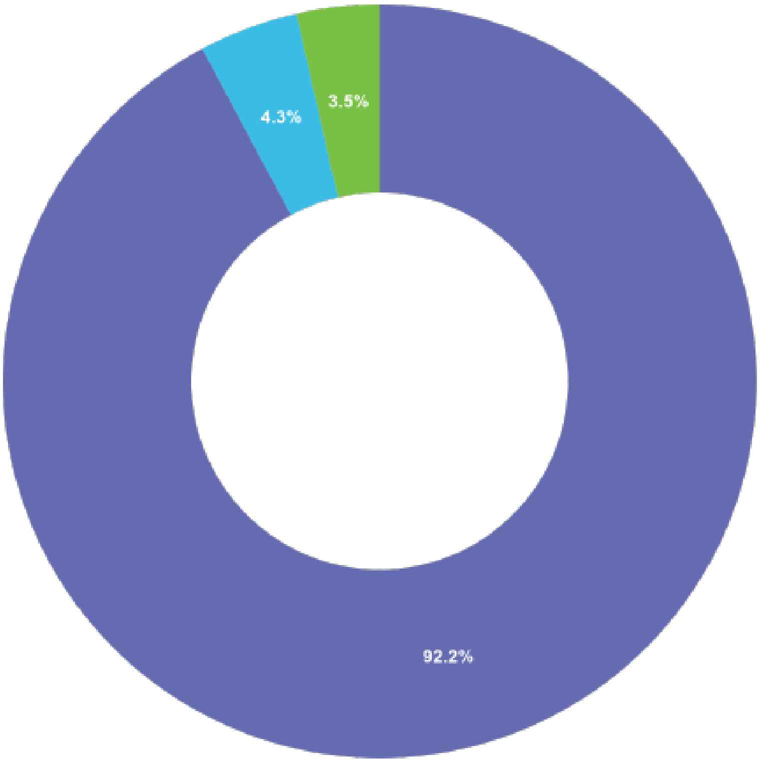


Q7 Would you say that the affects of Endometriosis have had a negative impact on your mental health?*

Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	275
●	No	3
●	Other	4

Q8 Have you had any delays in being seen by a GP, Gynaecologist, Endometriosis Specialist or Surgery?*

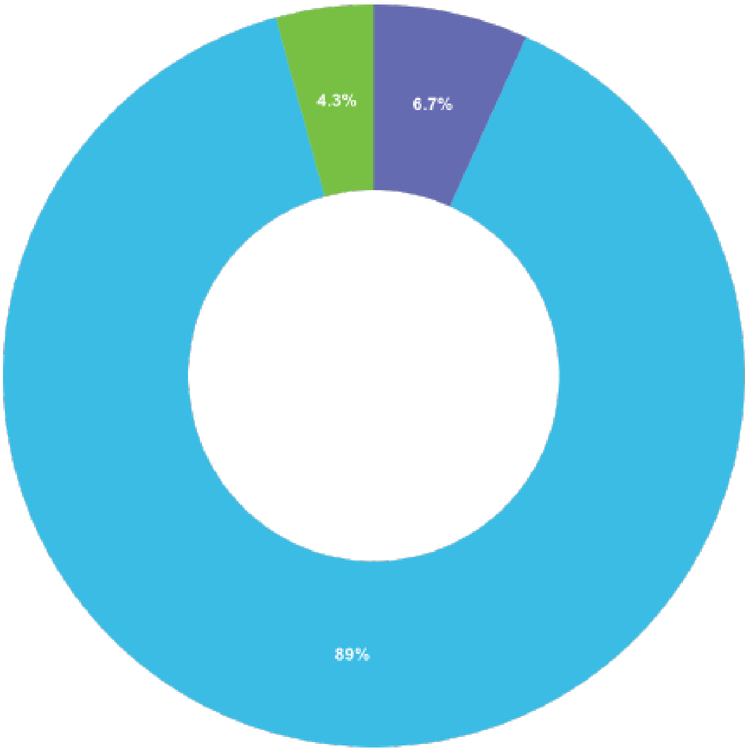


Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	260
●	No	12
●	Other	10

Q10 Whilst you were waiting for your appointment/surgery, were you offered any kind of support?*

Please type N/A if you didn't experience any delays

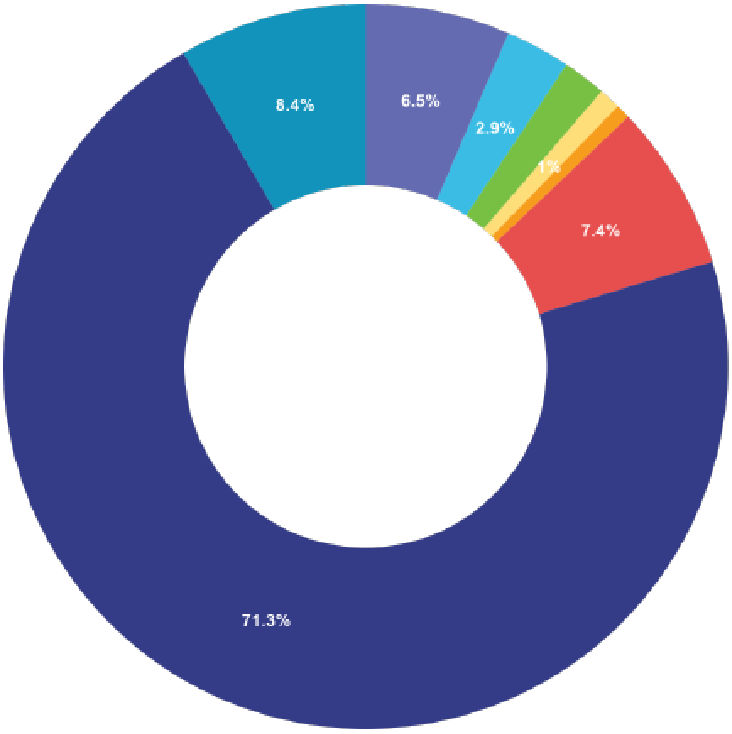


Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	19
●	No	251
●	Other	12

Q11 What support were you offered?*

Please type N/A if you didn't experience any delays.

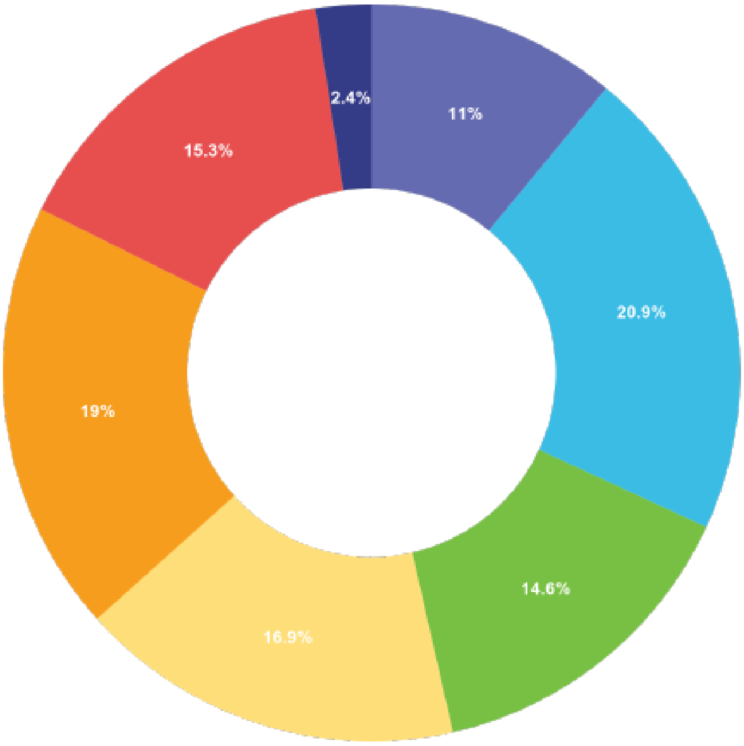


Answered: 282 **Unanswered:** 0

	Choice	Total
●	Information leaflet	20
●	Given a Website to look at	9
●	Information about local support groups	6
●	Counselling	3
●	Cognitive Behavioural Therapy	2
●	Access to an Endometriosis Specialist Nurse	23
●	Nothing offered	221
●	Other	26

Q13 What support do you think would have been beneficial whilst you were waiting for appointments/treatments/surgery?*

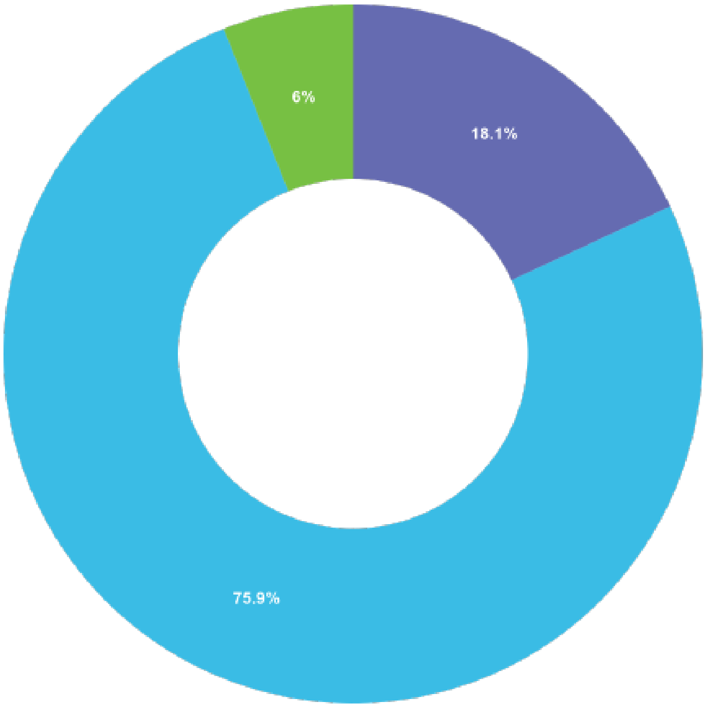
Please add other options in the box below if there is something else you could have benefited from.



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Information leaflet	113
●	Support Groups Available	215
●	Sign posting to other services	150
●	Online Mental Health Support	174
●	In Person Mental Health Support	195
●	A Guide to Self Manage Your Mental Health	157
●	Other	25

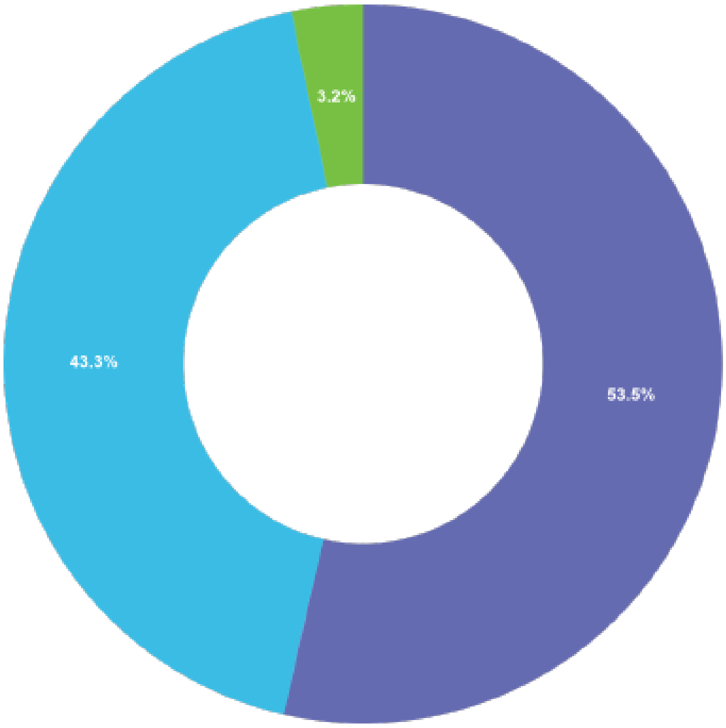
Q14 Have you ever been offered a consultation with the Pain Management Team?



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	51
●	No	214
●	Other	17

Q15 Have you ever had any thoughts of ending your life because of Endometriosis? (this can include because of your pain/symptoms, being fobbed off by medical professions and the negative affect Endo has had on your life in general)*



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	151
●	No	122
●	Other	9

Question 16 - Please describe your experience with endometriosis, or suspected endometriosis, and its impact on your daily life and mental health.

Apr 17, 2024	constant fatigue, constant pain which becomes unbearable whilst having a period, period no longer regular.
Apr 17, 2024	Painful periods, heavy periods Abdominal pain all times of the month. Tired, exhausted.
Apr 5, 2024	I wasn't offered support. I had two labial cysts and always complained to my GP about painful periods since I first had them at the age of 15. Then I went to a private professional who referred me for an MRI scan, that's when further findings of Endometriosis and Adenomyosis was found. I have had one surgery already but need a further two surgeries to remove the cysts. This impacted my mental health massively as I was just told it was health anxiety and nothing to worry about, after several misdiagnoses of IBS and other conditions and being told to go on the pill again after the pill messed my periods up.
Apr 5, 2024	Like it's all in my head, like I'm normal but not normal. Like I'll be ignored about my endo. That doctors just want us to crack on and shut up moaning. Not listened

	too. Alone. Like no one really understands. Scared. Nervous. Anxious.
Apr 5, 2024	My social life has been impacted massively I no longer make plans or have the energy to do things and scared to make plans in case I have a flare up. Work has also been affected I'm lucky I work for the NHS therefor the support from work has been fantastic however it has significantly impacted this.
Apr 4, 2024	I'm very depressed and anxious
Apr 4, 2024	I experience daily pain, I feel like a burden, I am trying to lose weight, but the fibroids are not helping, the fact that there is no cure affects me daily. I have random thoughts of ending it all.
Apr 4, 2024	Cannot get through daily life without being in awful pain. Feel very deflated and like can't cope. Constantly asking why me.
Apr 4, 2024	daily struggle, it's affected my work, my social life and my relationship!
Mar 31, 2024	It took so long to be diagnosed and yet I am still gaslit by medical professionals in regard to my pain. My pain is so bad I have attempted to take my life twice and yet I still am waiting months for appointments with persistent pain clinics etc.

Mar 2, 2024	I have severe abdominal pain on a regular basis also constantly have cysts growing in my right ovary and have struggles to get pregnant.
Feb 19, 2024	Every flare up makes me feel like a burden. I experience suicidal thoughts, and self-harm urges every period.
Feb 17, 2024	Feeling really down. Unable to cope. Alone. Not believed.
Feb 15, 2024	Fatigue is unexplainable. It impacts your social life leading to isolation. Being ignored and gaslit by multiple medical professionals makes you think you are imaging the symptoms/being weak/making it up and are going mental. Pain is unbearable at times. But drs don't want to do surgery as it may be tricky but also don't want to give you pain relief as some people abuse them. So, we are left to suffer. How are we supposed to lead a fulfilling functioning life without the appropriate surgical and or medical treatments including effective pain relief
Jan 24, 2024	The constant pain and hormone issues made my life unbearable, I was moody to everyone, stopped going out, just about made it to work, but came home to bed. This affected my children's childhood. I've been on and off anti depression

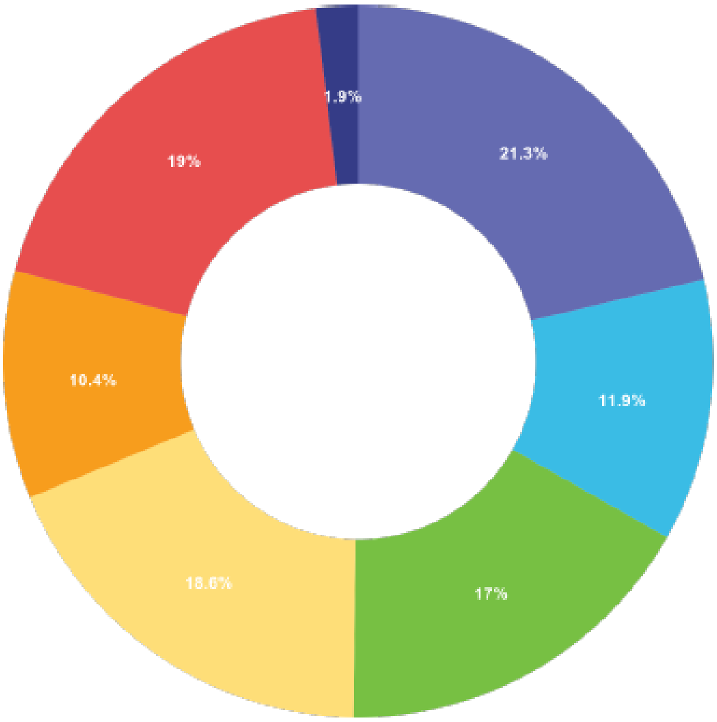
	medication for around twenty years or more.
Jan 22, 2024	Forever cancelling plans in daily pain
Jan 17, 2024	Loss of confidence and feeling inadequate. Self-esteem became very low, and I also found it too embarrassing to go out while on period.
Jan 17, 2024	It's a constant battle. Exhausting in every possible way and fighting constantly for pain relief and help while being treated like a drug addict for trying to get some kind of relief.
Jan 17, 2024	Debilitating pain, so much bleed, vitamin deficiencies because you can't keep up with you amount of blood loss, struggling getting up, back pain, curling over in public or having to sit down. Having ambulances come as you've had a fit on the floor because of the pain. The amount of shaking. The loneliness of surgery through Covid restrictions and having to deal with it.
Jan 17, 2024	It is relentless, broken sleep with pain and ongoing shooting and stabbing pains that nothing seems to touch.
Jan 16, 2024	In a word— devastating! If I had known the hell I was going to be put through, by people whose job it

	is to know, I think I would have ended my life. I chose to hang on and hold space so others will know they are not alone. If that’s all I can do, it’s enough to know someone seeing me hold space might encourage others to hold on too. I never imagined that in the 21st century we would have worse healthcare, yet here we are.
Jan 12, 2024	I experienced fertility issues and was never investigated properly. So, the effect of this was devastating on my mental health. We had IVF and it worked but not surprisingly I developed PND. My Endometriosis symptoms then got gradually worse for 10 years before I was diagnosed. I take anti-depressants; I left my nursing degree as I couldn't cope and just the worry of having horrible symptoms and not knowing why (while looking after twins) was difficult. A friend of mine was the one that told me I had Endometriosis; it had never even been suggested to me by Dr's. I then had to fight to get a gynae referral. That is all very hard to do when you are depressed and ill.
Jan 12, 2024	At times I was completely incapacitated die to pain. I also couldn’t have children and die to my age the wait for surgeries before stating IVF was agonizing

	and really took its toll on my mental health.
Jan 11, 2024	I developed symptoms at age 10 and eventually got diagnosed 17 years later following multiple A&E visits resulting in me screaming if they didn't help me, I'd pull everything out myself or end my life because the pain was so bad I couldn't even sit down.
Jan 11, 2024	Constant pain can make life very blue. Sometimes it's very overwhelming, and hard to find the joy.
Jan 2, 2024	These last 3 years have been really challenging, and I have really thrown everything at getting a diagnosis. At times I have thought I am losing my mind constantly being in pain. I have seen so many consultants in many fields all to try and have someone really take me on and help. Even now I have my diagnosis of Endo the help offered is still very disappointing being told to wait now 6 months from my surgery to see if the pain comes back. I've had no support offered in this period of 6 months just a wait and see. I feel if you don't advocate for yourself no one helps. I've been left exhausted and unable to concentrate at work it's left me feeling very lonely and although

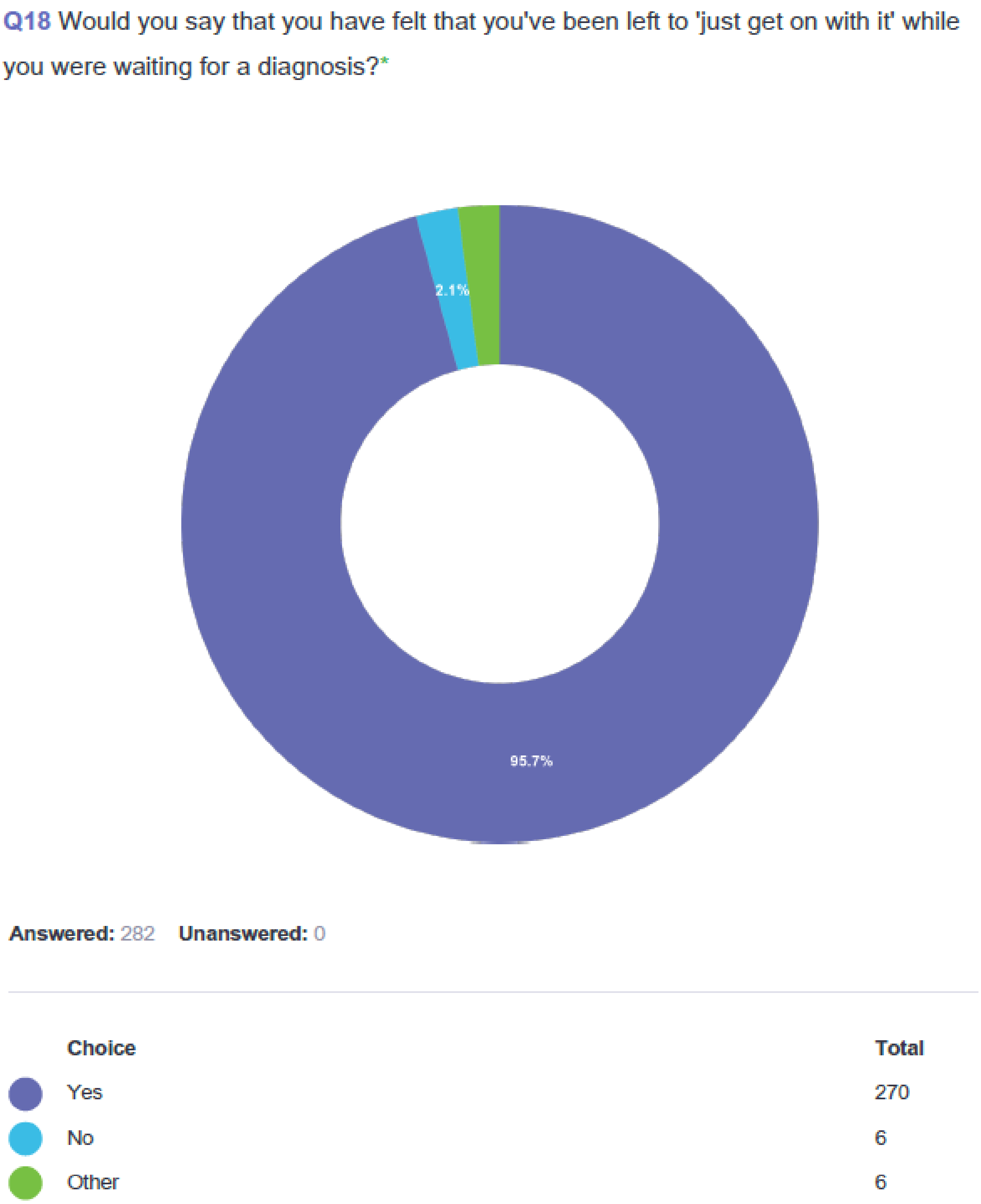
	friends and family always try to help it's not the same.
Jan 2, 2024	I get random sharp stabbing pains in right ovary, but they are very random. I have endometriomas which have been confirmed by private gynae are much smaller than NHS say. Not listening to me about AMH as we are currently going through infertility and about to start IVF.
Jan 1, 2024	Had my surgery on 20th November 2023. Stage 3 endo and also adenomyosis wasn’t given so much as a sheet of paper with info about either of these, no one I know has them, so all my research has been done myself, I’ve had a friend ask me why I keep "torturing myself by reading about it when "ITS JUST BAD CRAMPS" No one understands it

Q17 Throughout your experience of living with Endometriosis/suspected Endometriosis, what do you think could have made a difference to your mental health?*



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Being taken seriously by medical professionals	257
●	Having information leaflets about Endometriosis avaialble in medical settings	144
●	Having easy access to mental health support	205
●	Being told where to go for support when you were diagnosed	224
●	Family/friends/loved ones being more supportive	125
●	Employers knowing about Endometriosis and taking necessary steps to support you	229
●	Other	23

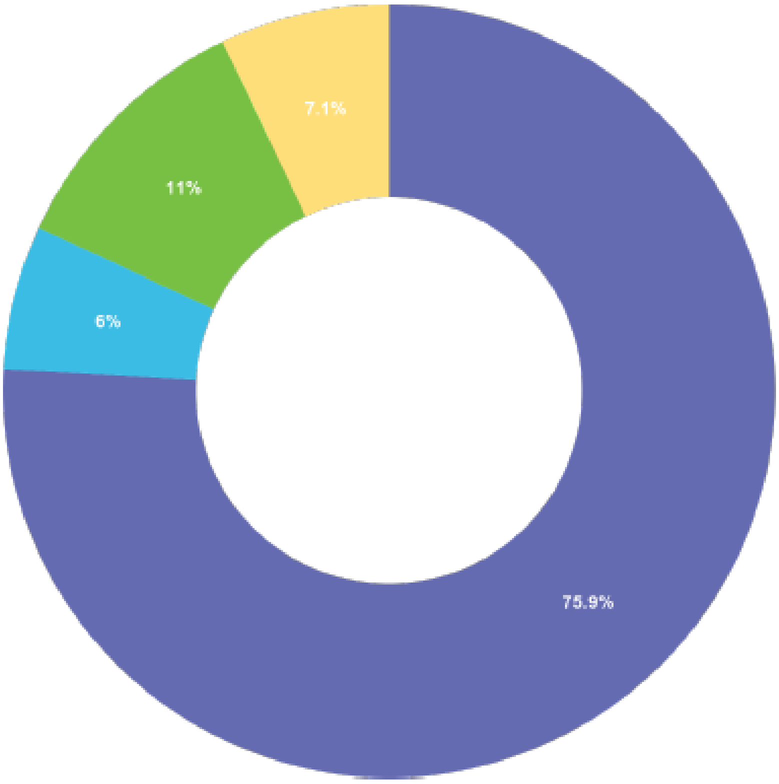


Q18 Would you say that you have felt that you've been left to 'just get on with it' while you were waiting for a diagnosis?*

Answered: 282 **Unanswered:** 0

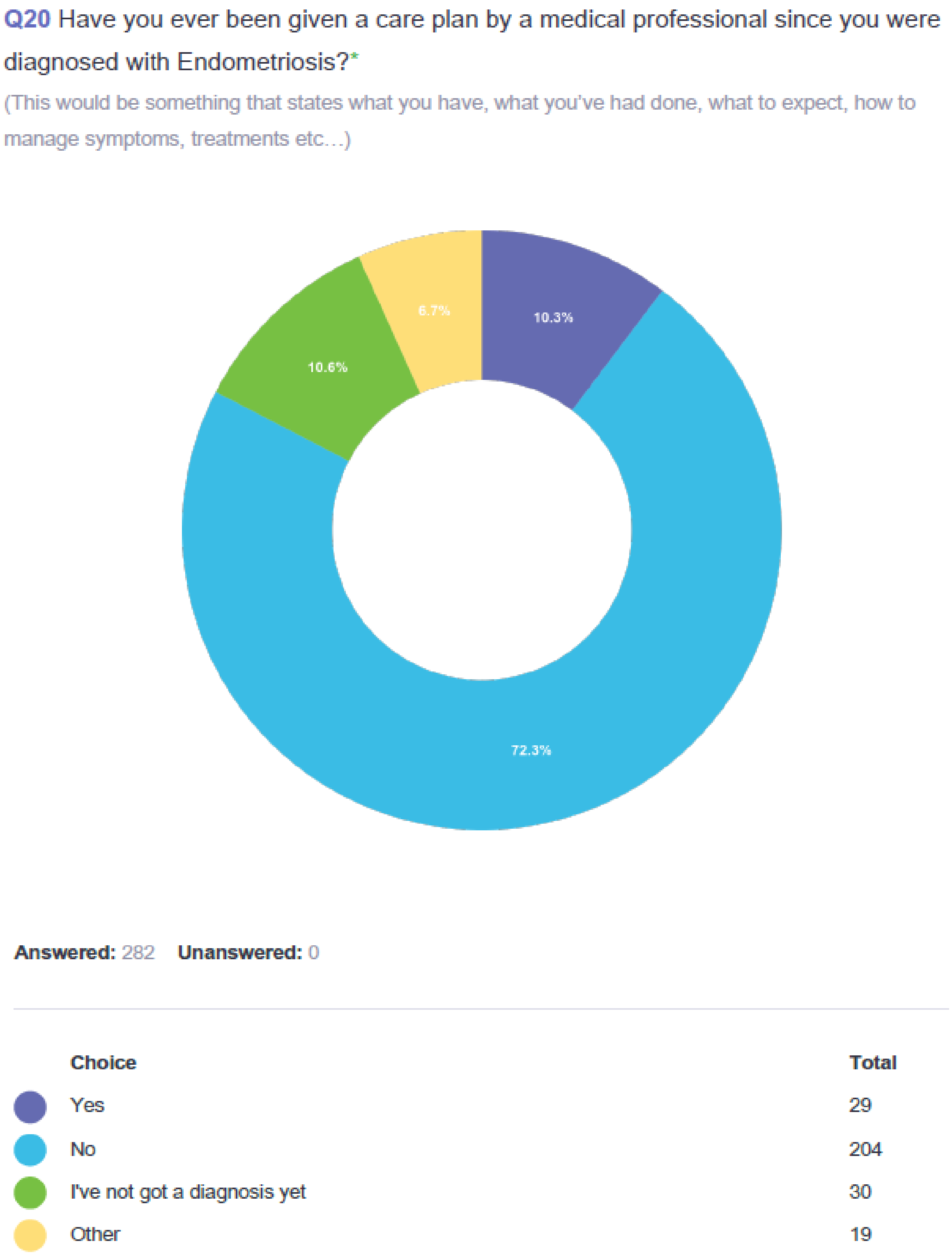
	Choice	Total
●	Yes	270
●	No	6
●	Other	6

Q19 Would you say you have felt that you've been left to 'just get on with it' since your diagnosis of Endometriosis?*



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	214
●	No	17
●	I've not got a diagnosis yet	31
●	Other	20



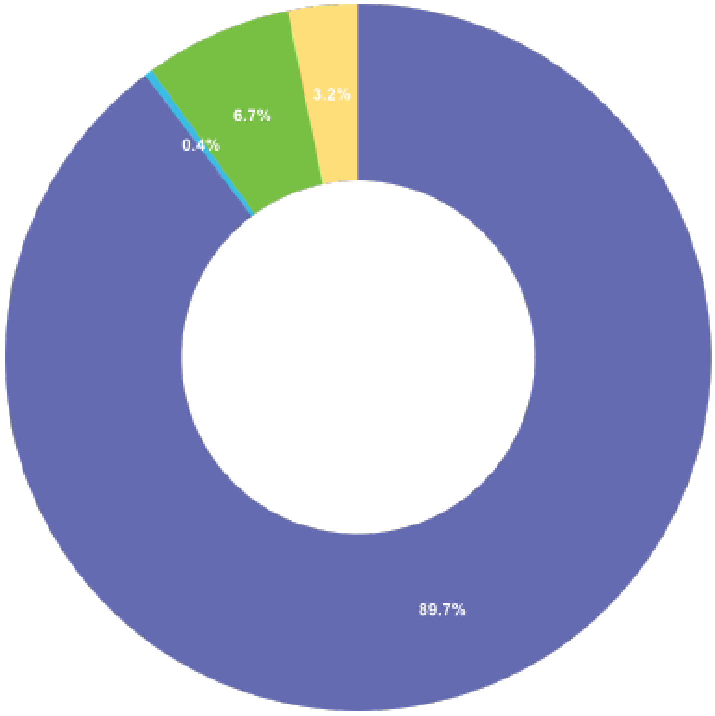
Q20 Have you ever been given a care plan by a medical professional since you were diagnosed with Endometriosis?*

(This would be something that states what you have, what you've had done, what to expect, how to manage symptoms, treatments etc…)

Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	29
●	No	204
●	I've not got a diagnosis yet	30
●	Other	19

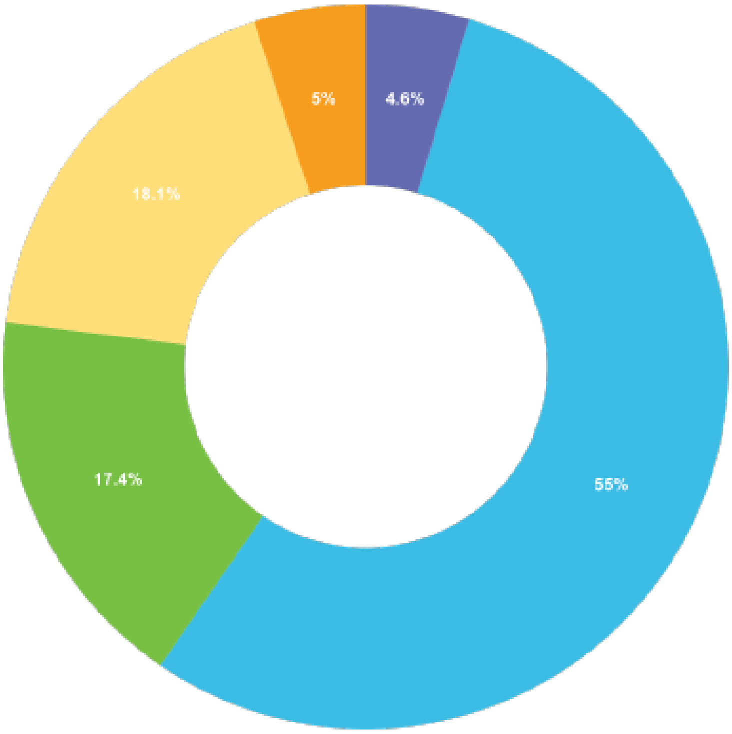
Q21 Do you think a personalised care plan would be beneficial for you and your care going forwards?*



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	253
●	No	1
●	Not sure	19
●	Other	9

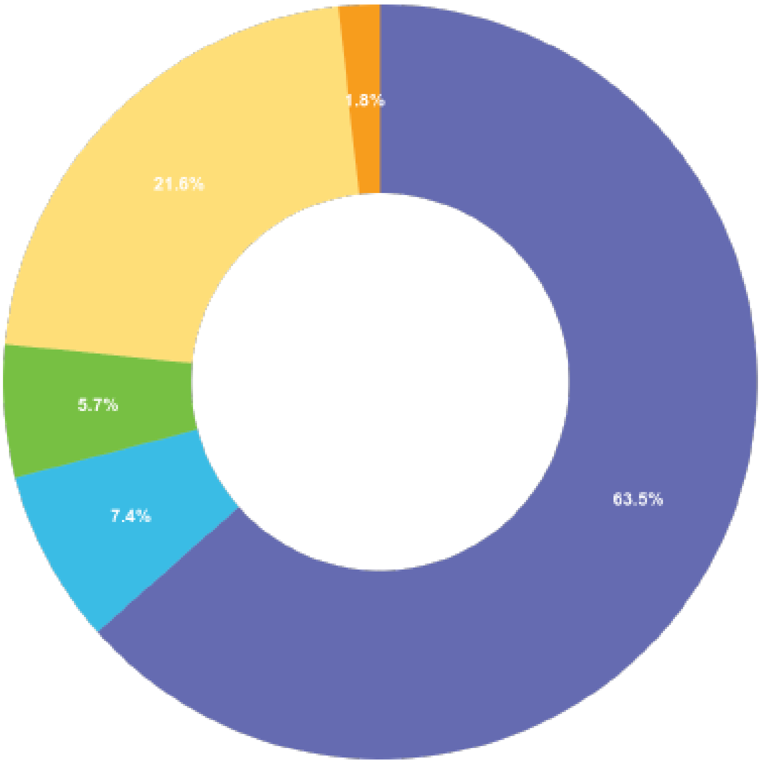
Q27 What type of mental health support do you prefer?*



Answered: 282 **Unanswered:** 0

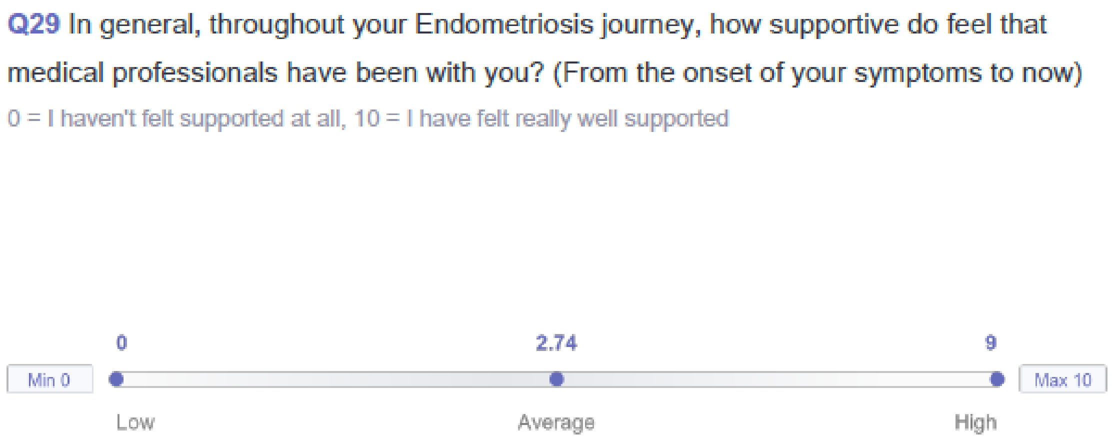
	Choice	Total
🟣	Self Help Books	13
🔵	In person therapy/support	155
🟢	Online support	49
🟡	Alternative Therapies (online or in person, such as Reiki, Acupuncture etc.)	51
🟠	Other	14

Q28 If you've had surgery for Endometriosis, have you experienced feelings of depression afterwards?*



Answered: 282 **Unanswered:** 0

	Choice	Total
●	Yes	179
●	No	21
●	Not sure	16
●	I've not had surgery	61
●	Other	5



Q29 In general, throughout your Endometriosis journey, how supportive do feel that medical professionals have been with you? (From the onset of your symptoms to now)

0 = I haven't felt supported at all, 10 = I have felt really well supported

Q30 Is there anything else you'd like to add?

Apr 17, 2024	Long waiting lists for operation. Sent home with a endo box and info about support groups. Still feeling like I don’t know much about it, and it’s left to me to find out.
Apr 5, 2024	I would love it if medical professionals could point me in the right direction and offer more support at universities for women struggling with this condition.
Apr 4, 2024	My consultant told me that my depression was not related to my endometriosis. He then said I was wrong when I told him it was.
Feb 15, 2024	Having a diagnosis shouldn’t be the end of endo treatment and support. It should be the start of personalised care.

Jan 17, 2024	I think endo needs to be more known, and support needs to be improved. I was fobbed off for 7 years till they started doing something about it, and for others it’s longer. My main issue was I was young, so doctors didn’t listen and told me it’s normal.
Jan 17, 2024	I wish Endo specialists would have the humility to admit when they don’t know something or don’t have experience in it rather than. Trying to blah it and risking life. A lot more respect would be given if they did explain what they cannot do and how to resolve it.
Jan 16, 2024	None of us expected abusive treatment by doctors or the abhorrent ignorance of our medical facilities—all due to glorification of an unproven, outdated 1927 theory. Imagine.
Jan 12, 2024	Once I was referred to my endometriosis specialist, he was brilliant. A busy man who did his best to see me in a timely fashion. The registrar and GPs I saw were not supportive at all.

1.9 Patient Compliments of the Gynaecology Department at Hull Royal Infirmary

Gynaecology Compliments	
Date	Topic
02/05/2024	Treatment
04/06/2024	Attitude
09/07/2024	Care & Comfort
15/07/2024	Treatment
22/07/2024	Treatment
19/09/2024	Treatment

2.0 Patient Complaints Relating to Endometriosis at Hull Royal Infirmary

Endometriosis Complaints		
Description	Specialty	Date
Patient admitted to Cedar Ward laparoscopic surgery for endometriosis. Questions at pre-op dismissed USS results not provided to patient/notes Patient left on her own in the ward/ staff had incorrect information about patient not wanting a Mirena Coil after surgery. Consultant had incorrect name of	Gynaecology	10/07/2023

patient and that she was to have coil fitted. Different type of surgery performed than explained to pt, no patient care, no follow up care		
Patient under Mr for endometriosis who advised it was IBS not endometriosis. Pt paid privately to see Mrs Gynaecology who sent for USS which revealed endometriosis and has planned surgery in September. Pt unhappy with misdiagnosis from Mr and with Endometriosis Nurse. **Pt declined a written response after verbal conversation**	Gynaecology	30/07/2023
Patient unhappy with lack of communication/information provided to patient regarding endometriosis surgery. Patient was provided with clinic opa 21.9.23 to discuss her concerns with the consultant, none of her concerns were addressed. Patient feels consent was not gained for when she was administered her Zolodex. **Cloverleaf - written response**	Gynaecology	09/10/2023
Complaint via Cloverleaf Written Response Patient informed by Gynaecology consultant that pregnancy is a treatment option for endometriosis rather than surgery or to have Prostap injections. Consultant very dismissive.	Gynaecology	21/11/2023
Patient unhappy with her treatment and care whilst under Gynaecology for	Gynaecology	12/12/2023

endometriosis.		
Patient attended ED post op Endometriosis surgery with severe pains. Delays in receiving pain relief, NIC rude to patient's mother, displaying threatening behaviour.	A and E	18/01/2024
The patient has been diagnosed with stage 4 endometriosis and had to wait 2 years for treatment for surgery. She had laparoscopy on 13 Feb 2020, following that she was then diagnosed with bilateral hydrosalpinx which she feels made her infertile. Patient feels due to delay in her treatment; she is now infertile. **** written response please ***	Gynaecology	05/06/2024
The patient is under Gynaecology Endometriosis in Castle Hill. She feels that her symptoms are being ignored and that she has not received guidance on how to manage her condition. ****** Verbal response *************	Gynaecology	21/06/2024

healthwatch
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