

ENDOMETRIOSIS IT'S TIME TO END THE STIGMA

Understanding the true impacts
of endometriosis through patients'
lived experiences



HEARING FROM THE EXPERTS, THE PATIENTS THEMSELVES

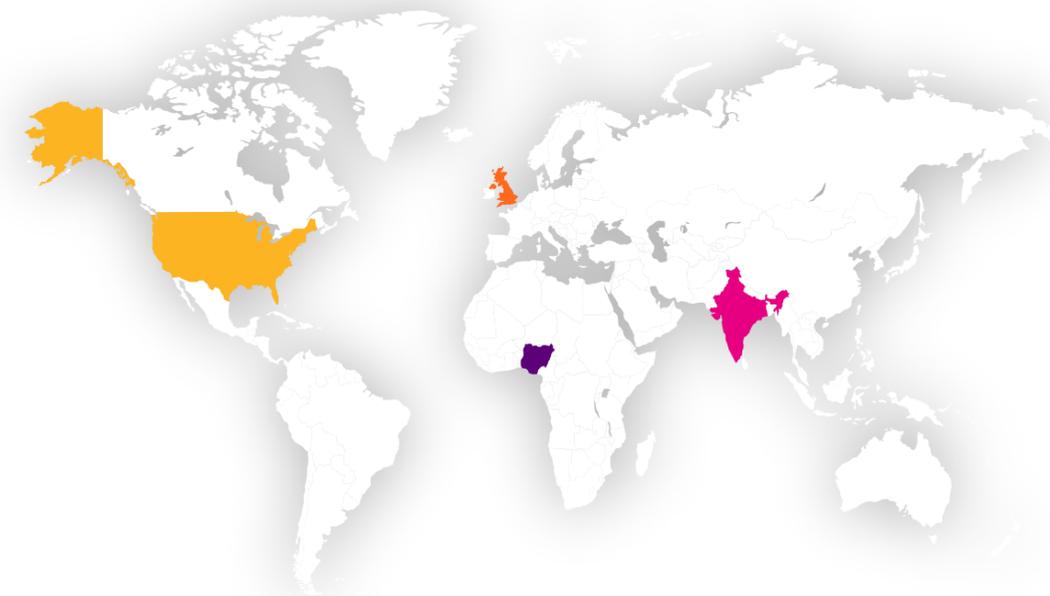
Over 190 million people across the globe have endometriosis.¹ Yet, people with endometriosis are rarely given the opportunity to express their experiences to the healthcare industry, leaving valuable insights unheard. The experts themselves, the patients, are the ones who best understand the patient journey and how their lives have been impacted by the condition, making their views crucial for improving care.

COUCH Health carried out a mobile ethnography study to get true insights into the realities of living with endometriosis. This included the most severe symptoms from the point of view of those living with endometriosis, the difficulties in obtaining a diagnosis and getting appropriate treatment, and the impacts of endometriosis on a person's social life and career.

Participants were encouraged to share insights through various interactive modalities, including video content, drawings, and detailed discussions. The insights shared were truly invaluable.

This eBook explores the findings of the study and discusses how the findings can be used to improve healthcare for people living with endometriosis.

190 million people globally have endometriosis
that's 10% of women of reproductive age





People with endometriosis are rarely given the opportunity to express their experiences to the healthcare industry

TABLE OF CONTENTS

Conducting a mobile ethnography study with people living with endometriosis	4
What's your endometriosis diagnosis story?	6
How do you feel in the morning and evening?	8
How has endometriosis impacted your life?	9
What is your worst symptom?	10
If endometriosis was an object, what would it look like?	12
How would you describe the perfect ally?	14
What can we do to improve endometriosis diagnosis and care?	15
The lessons learnt throughout the study	17
References	19

CONDUCTING A MOBILE ETHNOGRAPHY STUDY WITH PEOPLE LIVING WITH ENDOMETRIOSIS

This study aimed to gain true insight into the impacts of endometriosis on everyday life, from the lesser-known symptoms and their impacts, to the support people with endometriosis receive.

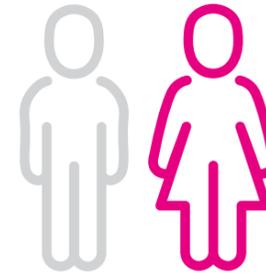
To obtain a more holistic view of the condition, a mobile ethnography study was conducted. Ethnography studies are used by researchers to gain valuable context for specific conditions.

This approach enables more emotive data to be collected, helping to effectively show the reality of day-to-day life with endometriosis and, importantly, identify crucial areas for improvement within the patient journey.

Opposite is a summary of the participant demographics.

18-41

All participants were between 18 and 41 years of age.



All participants identified as female.



7 people identified as White, 2 people identified as Black Caribbean, 1 person identified as Black African, and 1 person identified as Mixed (White and South Asian).

~50%
Black women

Black and Hispanic women were ~50% less likely to be diagnosed with endometriosis

~50%
Hispanic women

Research shows that compared with white women, black women were around 50% less likely to be diagnosed with endometriosis. Hispanic women were also approximately 50% less likely to be diagnosed with endometriosis, compared to white women.²

The study participants were asked to engage in a total of **9 tasks across 6 days**. All of the tasks were purposefully created to gain deep insights into the lived experiences of those living with endometriosis. Here is a summary of the tasks the participants were asked to complete throughout the study.

“Introduce yourselves”

Participants were asked to introduce themselves to each other on an online platform.

“How did you feel this morning?”

Participants were asked to share how endometriosis impacts them in the mornings by recording a short video.

“What’s your diagnosis story?”

Participants were asked to share their diagnosis stories by recording a short video.

“What is your worst symptom?”

Participants were asked to share their worst symptom through either an abstract or literal drawing.

“How does endometriosis impact you in the evenings?”

Participants were asked to share their experiences of endometriosis in the evenings by recording a short video.

“If endometriosis was an object, what would it be?”

Participants were asked to share a drawing or photo of endometriosis as an object.

“Where do you find the latest information and support about endometriosis?”

Participants were asked to share where they found trusted information, and what support groups they were part of.

“How has endometriosis impacted your life?”

Participants were encouraged to share their endometriosis experiences on the online platform.

“How would you describe the perfect ally?”

Participants were asked to describe their ‘perfect’ endometriosis ally.

WHAT'S YOUR ENDOMETRIOSIS DIAGNOSIS STORY?

Despite endometriosis being a common condition, all of the participants in the study shared a familiar difficulty in obtaining a diagnosis — with a number of participants reporting that they had waited up to 25 years for a diagnosis. While there are likely many factors that contribute to this length of time, one factor was mentioned repeatedly by participants — medical gaslighting. Medical gaslighting is similar to gaslighting, but it is strictly contained in a healthcare environment.

Average lifespan of a woman (in years)

0

25 years

74

| Reported time waiting for a diagnosis |

Medical gaslighting leads patients to question their own reality and induces doubt in the validity of their own symptoms. When asked about their experiences of getting a diagnosis, many participants highlighted that they first learnt about endometriosis online, and had to use their own research to be taken seriously by doctors.

“I’ve seen 20 GPs over 20 years across the UK who dismissed me and laughed me out the surgery.”



GASLIGHTING

The action of tricking or controlling someone by making them believe things that are not true, especially by suggesting that they may be mentally ill.³

MEDICAL GASLIGHTING

When a doctor refuses to take their patient seriously, either by ignoring the patient's symptoms, misleading the patient about a diagnosis, or accusing the patient of lying or fabricating information about symptoms.⁴

Yet, getting a clinical diagnosis is only half of the story for people with endometriosis. After experiences with medical gaslighting, it's clear that many healthcare professionals (HCPs) often aren't aware of how common endometriosis is, or how it manifests itself in terms of symptoms.

This lack of awareness translates over to post-diagnostic care too, preventing people with endometriosis from accessing appropriate care, which was highlighted by the participants.

One of the participants also shared the role that racism plays in finding the right care, highlighting that access to appropriate care may be influenced by racial bias and prejudices exhibited by HCPs. She described her experience of being denied a diagnosis, where HCPs had informed her that endometriosis is a 'White woman's disease'.

This is yet another dangerous misconception about endometriosis that is simply untrue, as endometriosis can affect anyone from any gender or ethnic background.

Despite all of the participants identifying as female, many of the participants discussed the intricacies of endometriosis care for people who have a uterus but do not identify as a woman, including transgender men and non-binary people. The participants stated that the lack of awareness around the impacts of endometriosis on transgender and non-binary people is a key contributor to the barriers in receiving care.

“Despite having a diagnosis, I then had to deal with jumping through hoops to try and see a specialist.”

“Even after diagnosis, they told me I was too young at 20 to have the surgery. It took my lung collapsing to finally get the support I needed.”

“I was told women of my colour don't get endometriosis.”



HOW DO YOU FEEL IN THE MORNING AND EVENING?

Many people affected by endometriosis experience a different set of symptoms in the mornings and evenings. To further understand the differences, the participants were asked to share their morning and evening symptoms, highlighting how each one is affected by their condition.

Participants described both physical and mental impacts of endometriosis, including vivid recollections of painful experiences and anxiety that spurred from the thought of another day filled with pain.

“The other thing that is quite bad in the morning is the anxiety, what’s my pain like? Is it going to be bad today? Is it going to be worse?”



“I really struggle most mornings because of the medications I take in the evenings, it makes me really drowsy.”

When participants described their evenings, it was clear that their mental symptoms evolved from feelings of anxiety to feelings of depression, with participants describing a loss of ability to be productive, socialise, or sleep.

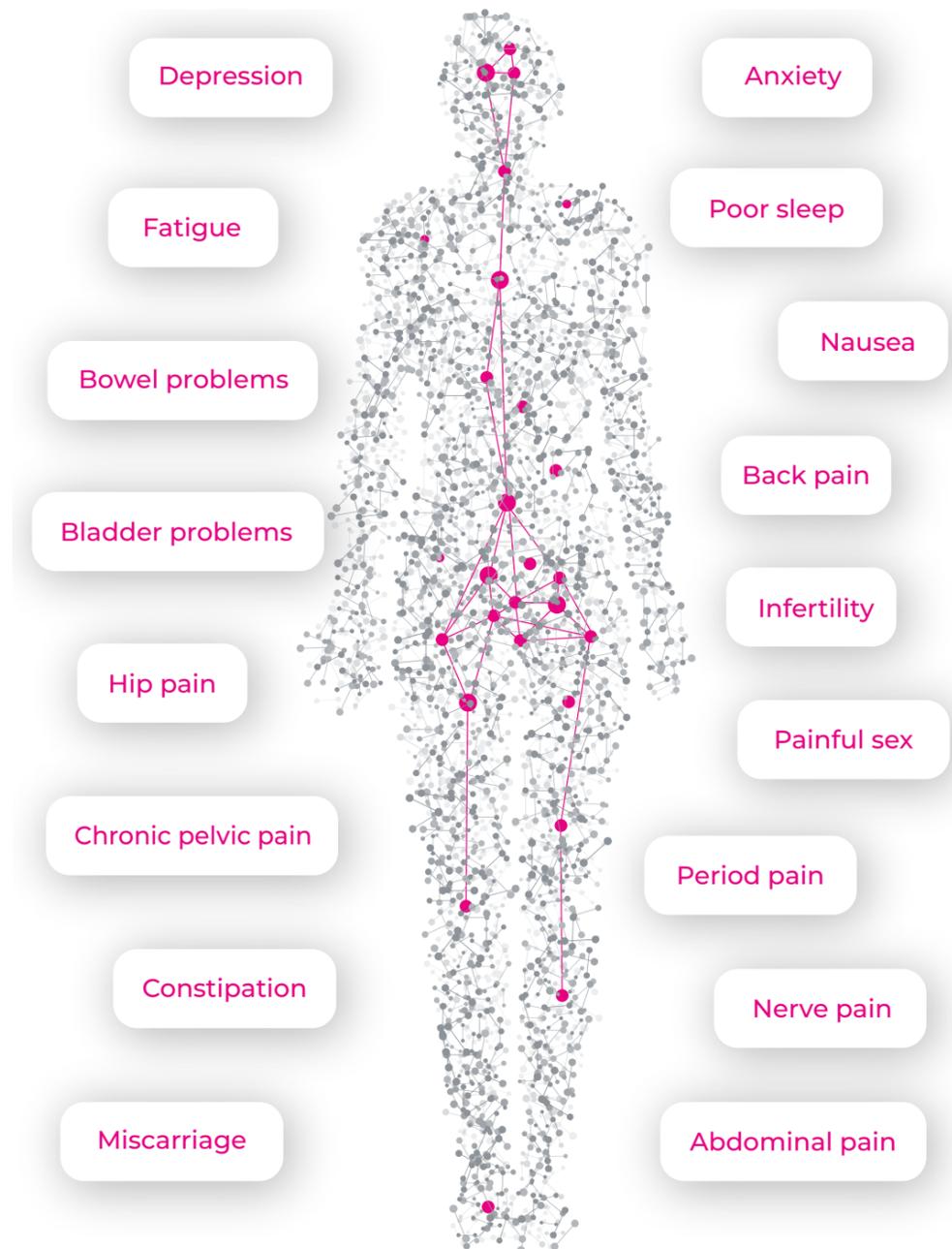
“Sometimes my bowels and my bladder wake me up and then I’ll pass out on the toilet from the pain.”

HOW HAS ENDOMETRIOSIS IMPACTED YOUR LIFE?

Endometriosis has a substantial impact on people's lives. To gain a deeper understanding of the symptoms experienced, participants were asked to share the symptoms they had encountered throughout their time with endometriosis.

The participants explained that they experience these symptoms almost every day, unlike the common misconception that symptoms are only present during periods of menstruation.

“Initially the pain was on and off, but now I suffer every single day. I feel like it dictates everything I do. From movement, to sleep, and even how I eat. Endo really sucks. I feel like my life has just been stripped away.”



The symptoms of endometriosis have serious secondary complications. The debilitating pain experienced by those with endometriosis can affect their ability to work and sleep, leaving them feeling lethargic and inactive. Often, the knock-on effects from symptoms can be described as cyclical, with one symptom leading swiftly onto the next.

“Currently I am working less hours due to my condition, and have had to step down from a promotion. I am off work a lot, and despite them being supportive, this is really hard to deal with.”

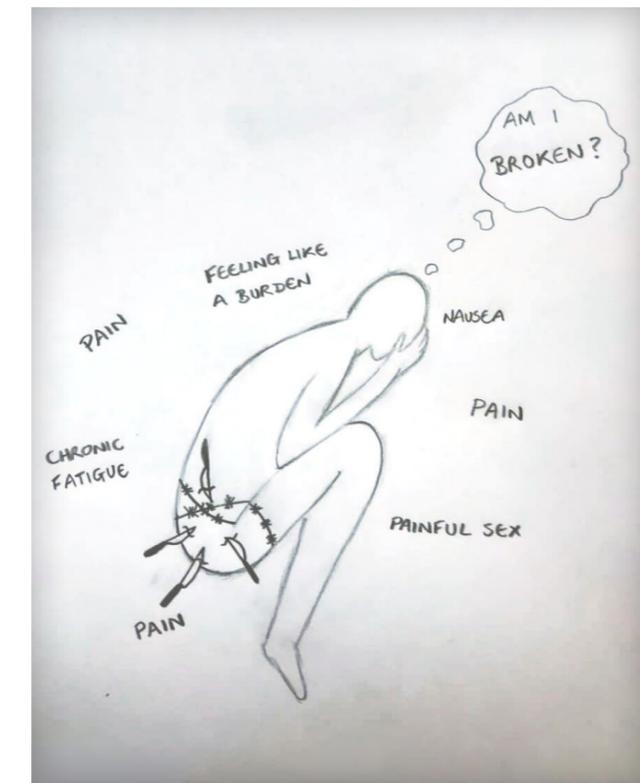
WHAT IS YOUR WORST SYMPTOM?

Imagery is a powerful tool, so the participants were asked to create a drawing that they think accurately depicts their worst symptoms of endometriosis.

As you can see, endometriosis is clearly an isolating condition. The participants exemplified their thoughts and feelings towards endometriosis using metaphors such as drowning, or feeling like a black hole. These drawings help us better understand and empathise with the realities of endometriosis outside of a clinical setting.

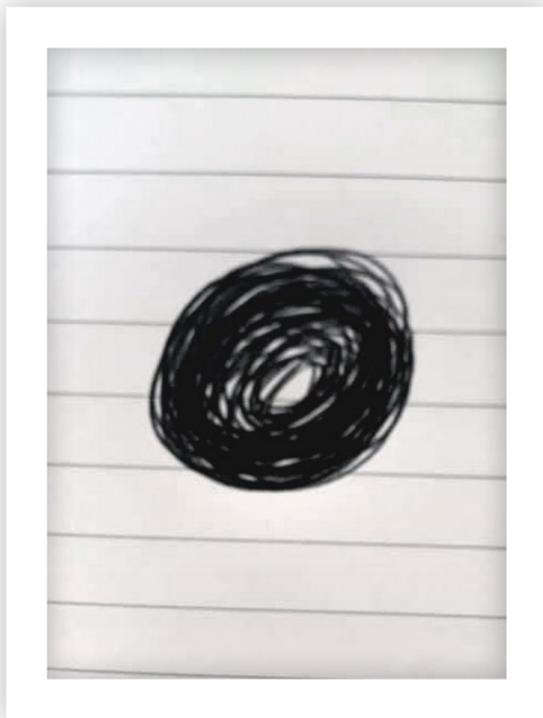


"Constantly having your thoughts constrained and dominated by your health, whether that be worries or pain."

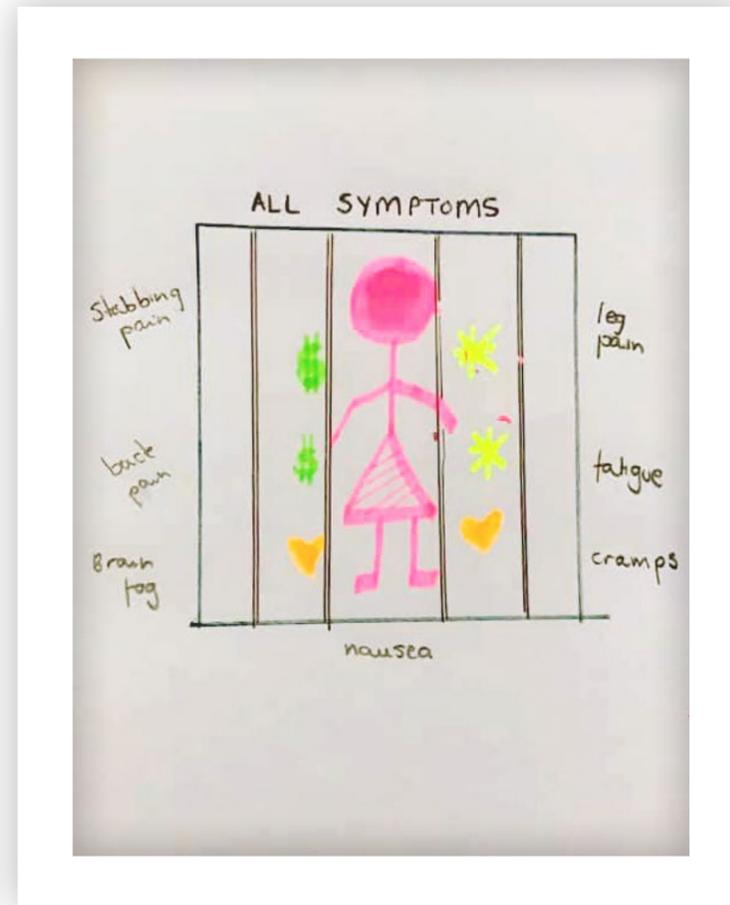


"When the pain hits it feels like knives stabbing me. It feels like someone is tightly grabbing my organs and twisting them. The pain is enough to send anyone insane."

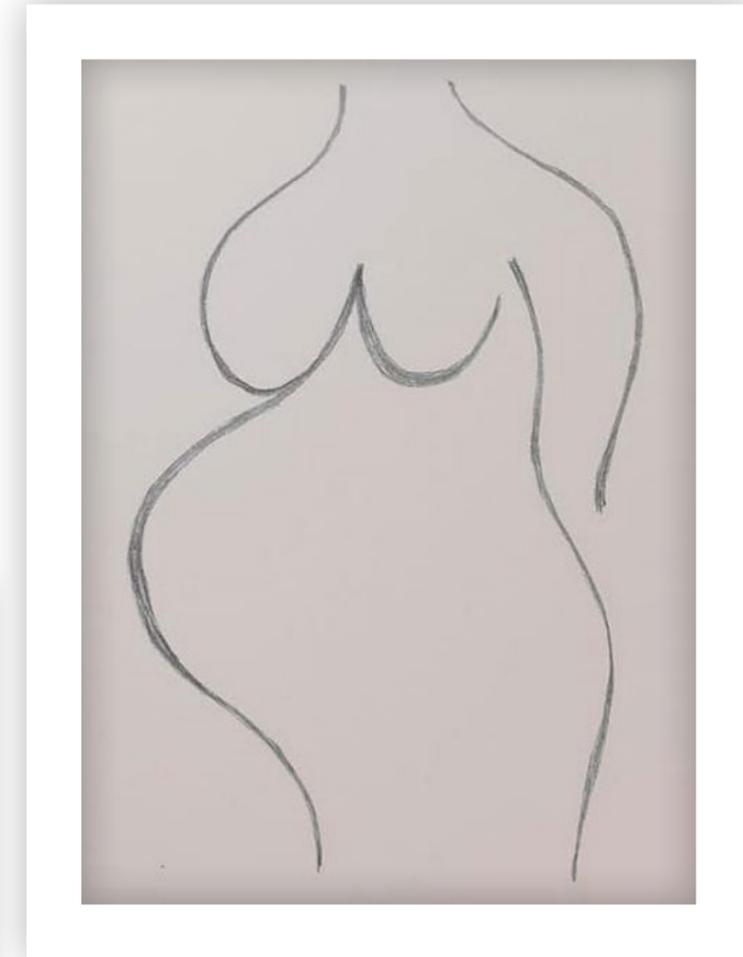
WHAT IS YOUR WORST SYMPTOM?



"It's like a black hole sucking all the light and life out of you."



"My whole life is dictated by endometriosis. It takes away future opportunities from me."



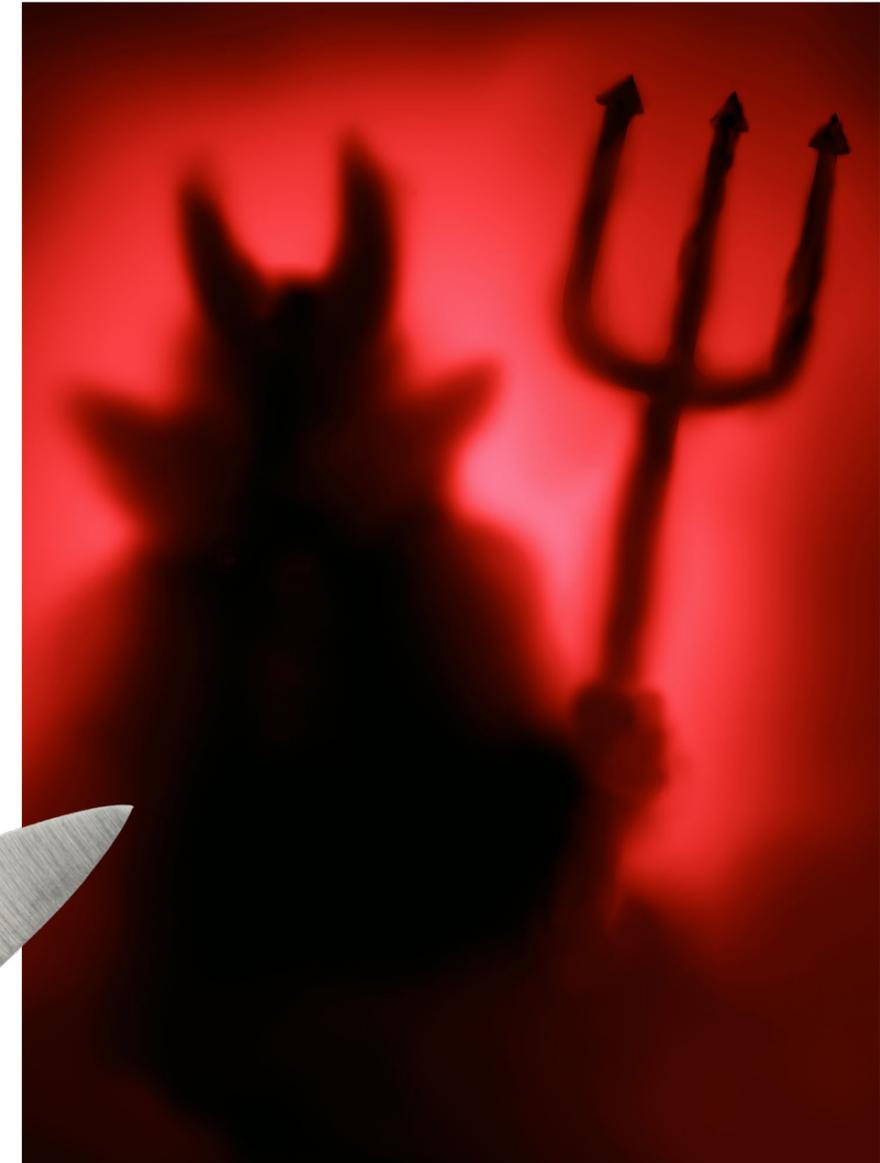
IF ENDOMETRIOSIS WAS AN OBJECT, WHAT WOULD IT BE?

Participants were asked to share their thoughts and feelings about endometriosis through imagery.



"It doesn't care what's in its way, it'll burn through it all, especially during my periods I feel like my insides are on fire."

"I literally feel some days like there is a knife in me. The pain makes me feel that I'm not in control and it's extremely painful."



"It's as if the devil lives in your body and travels from one area to another causing issues. They get angry if you do the wrong thing then take the anger out on your body!"

IF ENDOMETRIOSIS WAS AN OBJECT, **WHAT WOULD IT BE?**



"Searing-sharp, big claws latching onto and digging into the abdomen and uterus. Yanking it down and in every direction."

"A ticking time bomb, constantly counting down to a new flare of pain, not knowing when exactly it is going to go off."



Endo for me has got to be a hot water bottle and 🍷s. It's how I spend the majority of my life."

HOW WOULD YOU DESCRIBE THE PERFECT ALLY?

It's essential that people with endometriosis have the right support in place. Yet, for some people with endometriosis, this support is hard to come by.

The top three criteria for excellent support were identified as:

1 To be present and non-judgemental of the symptoms.

2 To understand that even when people look healthy on the outside, they can be in agony on the inside.

3 To be an advocate for the condition.

“People who take time to listen and not try to offer suggestions on how to ‘fix’ me. They do their own research and never judge if you have to cancel plans.”

“They would help me advocate for myself and would understand that endo is a dynamic disability.”

“That our symptoms occur whether we eat well, exercise, or take vitamins. That yoga or eating avocados doesn't cure these symptoms.”



WHAT CAN WE DO TO IMPROVE ENDOMETRIOSIS DIAGNOSIS AND CARE?

When asked how long it took to get a diagnosis, the group's answers ranged from 5–25 years. Unfortunately, this is reflected worldwide too, with it taking an average of 7.5 years to be diagnosed with endometriosis.⁵

Numerous times throughout the study, the participants highlighted that endometriosis doesn't just affect women, and that transgender people and men should be involved in the conversation too. There are many case studies and interviews that highlight the additional barriers in place for those who have endometriosis that do not identify as a woman. Transgender men, non-binary people, and people of other genders often face hardships that are unique to them. The truth is that endometriosis exists outside of the binary confinements of cisgender identity, yet healthcare systems are often not designed to cater for these people.



One participant revealed that transgender men can be subject to differential treatment. In the interview, a transgender man described the mistreatment they received as a result of coming out as transgender — they were previously offered a hysterectomy as a woman, then their motives were questioned after coming out as a transgender man.⁶

“What was previously an open invitation to receive a hysterectomy, is now being scrutinised as something that I am potentially abusing the medical system for as part of my gender identity, and not my long struggle with endometriosis, and the physical, mental, and emotional anguish I have experienced as a result.”⁶

The participants often highlighted that many people have incorrect misconceptions about the symptoms of endometriosis, with a lot of people believing that symptoms are only present during their period. As demonstrated in this study, the symptoms of endometriosis vary greatly. Yet, one part of the condition that is often overlooked is the knock-on effect of these symptoms. Research suggests that there are links between endometriosis and an increased risk of anxiety and depression disorder,⁷ with up to 50% of women with endometriosis having contemplated suicide.⁸ Similarly, 51% of people with endometriosis say that the condition has negatively impacted their personal relationships,⁹ and 51% say their career has suffered as a result of the condition.¹⁰

“It does affect my mental health. So, when I’m really having a bad flare and it’s the evening, it’s just like, when is this going to end? When am I going to feel okay? And yeah, I just feel quite depressed to be honest.”

Many participants described difficulty in receiving the right care after being diagnosed with endometriosis. While a hysterectomy is the closest thing endometriosis patients have to a cure, it brings many challenges for people living with endometriosis — including infertility and early menopause, meaning patients who decide to have this procedure do not make this decision lightly. Yet, there are occasions where women are actively denied a hysterectomy due to their childless status¹¹ — where a person’s ability to produce children is prioritised over their health.



Up to 50% of women contemplated suicide



51% say that the condition has a negative impact in their personal relationships



51% say their career has suffered as a result of the condition



THE LESSONS LEARNT THROUGHOUT THE STUDY

There are numerous misconceptions about endometriosis that need to be corrected. Here's a summary of the lessons learned throughout this study.

ENDOMETRIOSIS IS NOT...

...JUST A PAINFUL PERIOD

It affects people's lives daily, not just during menstruation.

...A CONDITION THAT AFFECTS ONLY THE PELVIC ORGANS

The condition has numerous symptoms, many of which are located around the body. The condition is a full-body disease.

...MILDLY DISCOMFORTING

The condition has many secondary impacts that can affect people's jobs, social life, and mental health.

...A 'WHITE WOMAN'S DISEASE'

It can affect people from any ethnic background.

...WELL UNDERSTOOD BY HCPs

Many people have a hard time getting diagnosed, and even getting the right treatment.

...JUST FOR WOMEN

It can affect transgender men, people outside the gender binary, and in rare cases, people assigned male at birth.

MOVING FORWARD, WE MUST:

1

Improve education about endometriosis among HCPs.

Often, people wait years to be diagnosed due to the lack of understanding around the condition, and are often subjected to medical gaslighting. If this is to change, HCPs must be made more aware of the condition, and how they approach diagnosing and treating it.

2

Implement cultural safety training among HCPs.

The condition is thought to be a 'White woman's disease', which is a dangerous myth that must be challenged by those delivering care.

3

Initiate more support groups.

With more support groups available for those with endometriosis, people can work together to raise awareness of the condition and provide the attentive support that these people desperately need.

THANK YOU

People's insights are essential to the work we do to make health more human. By listening to communities and patients, we're able to learn more about people's needs, and create change in clinical research, to make it more inclusive.

COUCH Health would like to thank the participants who took part in this study and helped to generate these invaluable insights into their lived experiences with endometriosis.



REFERENCES

1. World Health Organization [ONLINE]. Available at: <https://www.who.int/news-room/fact-sheets/detail/endometriosis> [Accessed February 2023]
2. Bougie, O. et al, 2022. Revisiting the impact of race/ethnicity in endometriosis. *Reprod Fertil*, 3(2), R34-41.
3. Cambridge Dictionary. [Online] Available at: <https://dictionary.cambridge.org/dictionary/english/gaslighting> [Accessed June 2021].
4. Hayes, A., 2020. Let's talk about medical gaslighting. [Online] Available at: <https://themighty.com/2020/02/talk-about-medical-gaslighting/#:~:text=Medical%20gaslighting%20is%20what%20happens%20when%20doctors%20refuse,patient%20of%20lying%20or%20fabricating%20information%20about%20symptoms.>
5. Endometriosis UK. Endometriosis facts and figures. [Online] Available at: <https://www.endometriosis-uk.org/endometriosis-facts-and-figures> [Accessed June 2021].
6. Solomon, S., 2020. Endometriosis twice as hard for trans teenage man. [Online] Available at: <https://www.stuff.co.nz/life-style/well-good/300172187/endometriosis-twice-as-hard-for-trans-teenage-man> [Accessed June 2021].
7. Fox, L., 2014. Endometriosis and being a Trans Person: Beyond Gendered Reproductive Health. [Online] Available at: <http://www.hormonesmatter.com/endometriosis-transgender-beyond-gendered-reproductive-health/> [Accessed June 2021].
8. Bode, L., 2019. Study finds 50% of women with endometriosis have contemplated suicide. [Online] Available at: <https://www.womenshealth.com.au/endometriosis-suicide> [Accessed June 2021].
9. Fagervold, B. et al, 2010. Life after a diagnosis with endometriosis – a 15 year follow up study. *Obstetrics and Gynaecology*, 88(8), pp. 914-919.
10. Grant, R., 2020. This was supposed to be Endo's big moment. What happened?. [Online] Available at: <https://www.cosmopolitan.com/health-fitness/a30779164/endometriosis-cure-treatment-research-government-funding/> [Accessed June 2021].
11. BBC, 2021. Endometriosis: young woman 'pleading' for hysterectomy. [Online] Available at: <https://www.womenshealth.com.au/endometriosis-suicide> [Accessed June 2021].





COUCH Health
2nd Floor
5 Richmond Street
Manchester, M1 3HF
United Kingdom

www.couchhealth.agency



© COUCH Health, 2023. All rights reserved.