



Healthcare

ENDOMETRIOSIS MATTERS

Examining the distressing impact of
endometriosis and the pressing need to
improve diagnosis and care pathways



Visit our Endometriosis Matters hub

2020



#EndometriosisMatters

CONTENTS

Foreword by BMI Healthcare COO Karen Prins	Page 3
Survey overview	Page 4
SECTION 1:	Page 6
LIVING WITH ENDOMETRIOSIS	
The physical symptoms of endometriosis	
The impact of endometriosis on mental wellbeing	
The social impact of living with endometriosis	
Endometriosis and the workplace	
SECTION 2:	Page 15
PATIENT PATHWAYS AND TIME TO DIAGNOSIS	
Time to diagnosis	
The specialist's view: Mr Elias Kovoor	
The healthcare experience	
My journey to diagnosis: Laura Connelly	
SECTION 3:	Page 22
AWARENESS, UNDERSTANDING AND EDUCATION	
The state of awareness	
The importance of endometriosis support communities	
Why I founded a support group: Keisha Meek	
Conclusions	
Acknowledgements	

FOREWORD BY BMI HEALTHCARE COO KAREN PRINS



Endometriosis is frequently referred to as an invisible illness; it goes undiagnosed or misdiagnosed and many women across the world simply suffer in silence, unaware that help is available.

One in ten women of reproductive age are afflicted by this painful and debilitating condition.

Worse still, for those who don't seek, or can't access, treatment, the consequences can be life changing: infertility, crippling pain and severe repercussions for mental wellbeing.

Despite many years of research, the medical community hasn't been able to identify what causes endometriosis or how to cure it, but they have made great leaps in its treatment. More work needs to be done on raising awareness of this common, yet frequently misunderstood condition.

I am delighted that BMI Healthcare is joining this conversation and has begun to engage with a wider audience.

I was grateful to the many thousands of people – men and women – who participated in our recent research. The invaluable feedback, particularly on sufferers' experience of debilitating symptoms which prevent them from doing normal activities, will help us continue to improve both the service we offer and the information we provide to patients and those that care for them.

With the right support, women suffering from endometriosis can achieve a better quality of life and the burden this condition places on them can be lifted.

A handwritten signature in dark ink, appearing to read 'K. Prins', located at the bottom right of the page.

SURVEY OVERVIEW

OBJECTIVE

To gather primary data on & raise awareness of:

- The physical and emotional impact of living with endometriosis
- How endometriosis affects a person's social life, relationships and career
- Time to diagnosis and experience of healthcare, including response of primary care professionals

METHOD

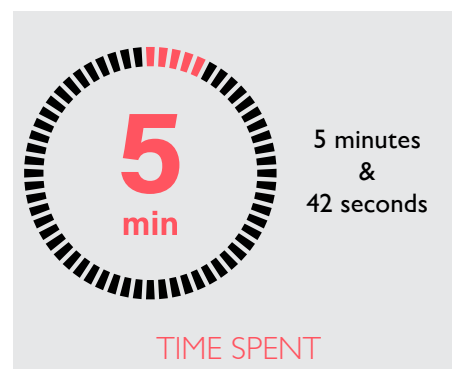
An online survey, 'Living with Endometriosis', promoted via:

- bmihealthcare.co.uk and its health blog
- BMI Healthcare email newsletters, both internal and external
- Social media (both paid and organic)
- Outreach to endometriosis-related online communities and key opinion leaders (KOLs) / influencers

The survey featured a combination of closed and open-ended questions in order to gather a combination of statistics and more qualitative data. There were **33** questions altogether.

The survey was **100% anonymous**.

The survey opened on 03/01/2020 and closed on 09/03/2020 (inclusive). **2,120** people took part.



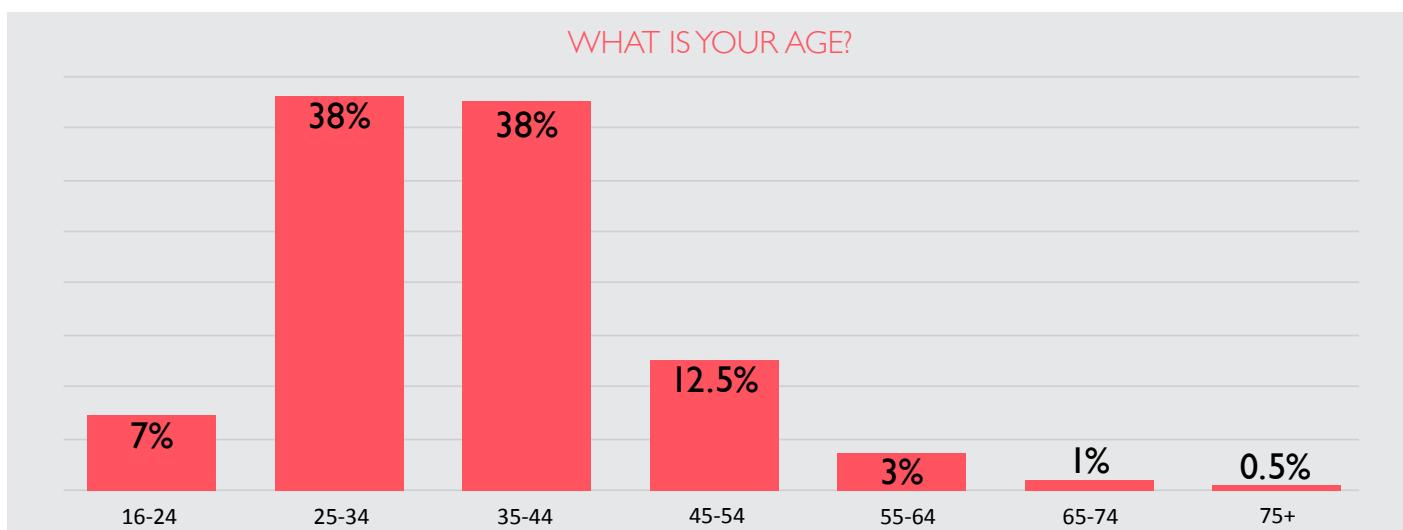
RESPONDENTS - DEMOGRAPHICS

Of the **2,104** respondents who gave their age range, the majority (around **75%**) were between **25-44** with an almost equal split between the **25-34** and **35-44** brackets. The next most prevalent age range was **45-54**. **78.8%** of respondents were living in the UK.

2,102 participants answered a question on gender identity, and while the vast majority selected 'female', **1.7%** of respondents selected 'male', 'other' or 'prefer not to say'.

We would like to highlight here that despite references to 'women' and 'women's health' we are cognizant that the issues covered in this report can also affect intersex, transgender and gender non-binary people.

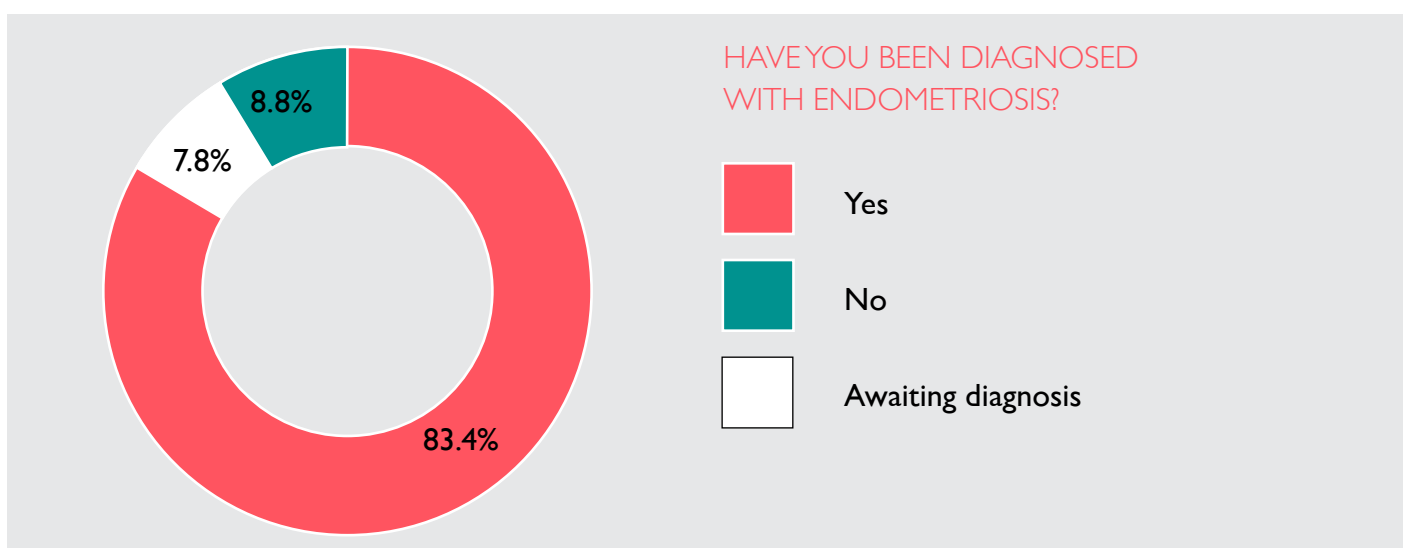




STAGE OF DIAGNOSIS

Of the **1,884** responses to the question 'Have you been diagnosed with endometriosis?' **83.4%** answered yes and a further **8.8%** selected 'I am awaiting diagnosis'.

Of the **7.8%** (147 respondents) who selected 'no', most nonetheless reported many of the symptoms associated with endometriosis and some even noted specifically that they had related conditions – for example adenomyosis – so felt the survey was relevant to them.



The decision was made to interpret results from all **2,120** respondents.

44.0% of respondents had been referred to an endometriosis specialist. Of the other participants, **46.4%** had been referred to a general gynaecologist and the remaining **9.6%** had not yet been referred. **74.0%** had already had some form of hormone treatment and/or surgery.

THE PHYSICAL SYMPTOMS OF ENDOMETRIOSIS

The symptoms of endometriosis can be hard to pin down. They differ from person to person and their severity is not necessarily relative to the severity of the condition.

This variation is evident in our findings, as is the prevalence of multiple symptoms, many of which aren't immediately identifiable as endometriosis-related.

Variations aside, there is one common thread that runs through the responses: **pain.**

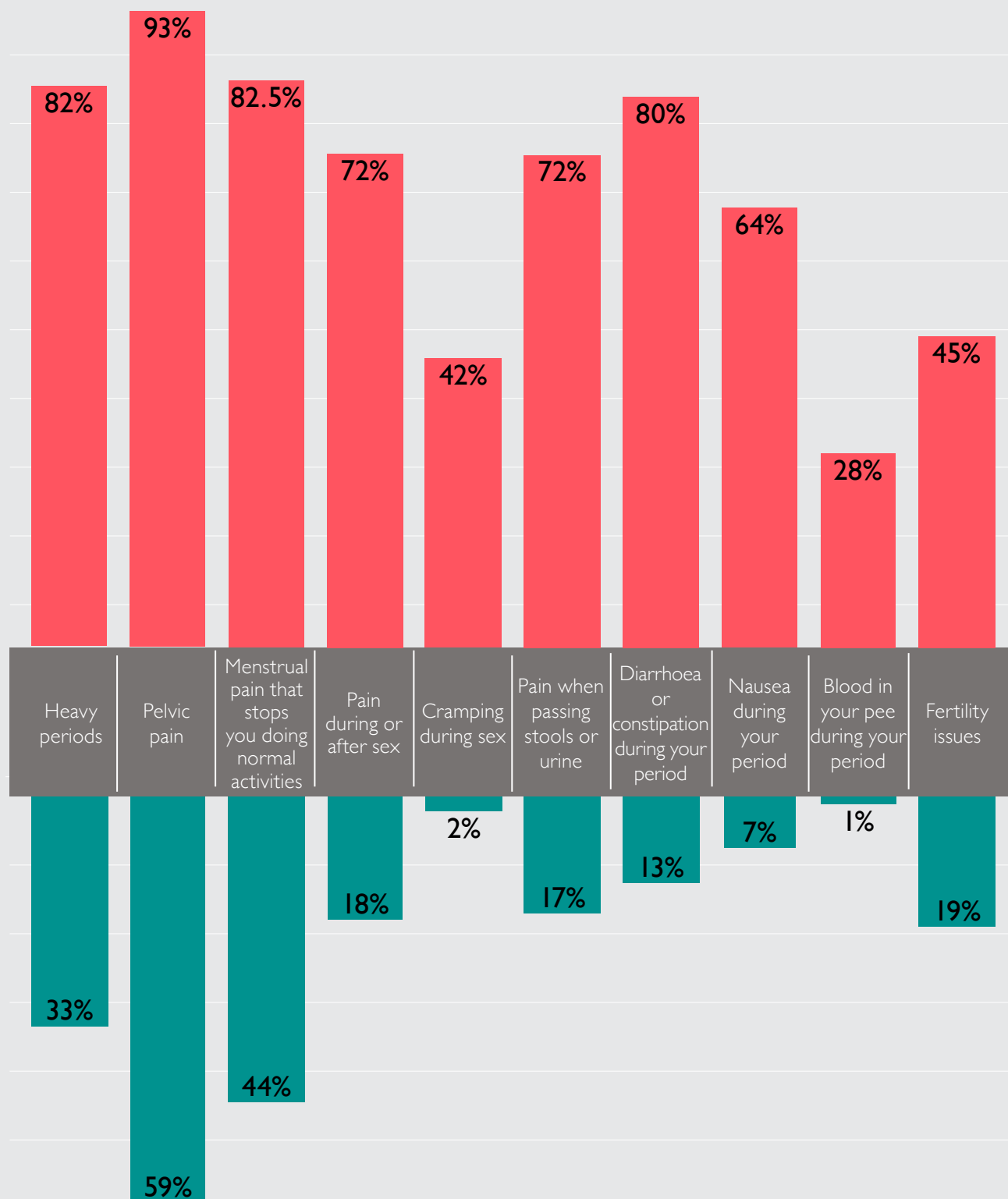
“Trust your instincts,
you know your body
better than anyone.”



¹The 10 symptoms¹ were chosen based on symptoms most frequently listed on some of the top-ranking online sources for (reliable) endometriosis information in the UK, including endometriosis-uk.org and nhs.uk

Our survey put forward 10 symptoms¹ of endometriosis and asked respondents to select all they had experienced, with no limit to how many they could select. On average, each participant identified 6.6 symptoms.

HAVE YOU EXPERIENCED ANY OF THE FOLLOWING?



WHICH TWO SYMPTOMS AFFECT YOU MOST?

- Pelvic pain' was the most prevalent symptom, identified by **93%** of participants. The next most frequent answer was 'menstrual pain that stops you doing normal activities' at **83%**
- 7 of the 10 symptoms were identified by more than **50%** of respondents, with even the least frequent – 'blood in your pee during your period' – chosen by more than a quarter of respondents (**28%**).

“ I hate that symptom profiles and awareness focus on period pain. Not migraines, sciatica, dyschezia, dysuria etc. ”

Participants were then asked to choose which two of the above symptoms affected them the most.

- 'Pelvic pain' was again the most common selection, experienced by **59%** of respondents. And again 'menstrual pain that stops you doing normal activities' was the second most frequent response, selected by **44%** of people.
- 'Heavy periods', a symptom experienced by **82%** of women, was identified as one of the two most difficult symptoms by **33%** of respondents.
- 'Fertility issues' were noted by **45%** of people. **19%** of respondents also chose this answer as one of the two symptoms that affected them the most.
- While 'blood in your pee' was chosen by only **1%** of respondents as one of the worst symptoms, all answers were chosen by at least one participant.

“ They don't understand how intense the pain is and that it's not just normal period pain, it affects my whole body. ”

So, pain was the most frequently reported symptom among respondents, as well as the symptom that affected them the most. And open-ended answers showed that pain was not restricted to the options offered in the survey.

Respondents referenced menstrual and ovulation pain as well as general pelvic pain, pain during sex, pain while urinating or passing stools, back pain, hip pain and more.

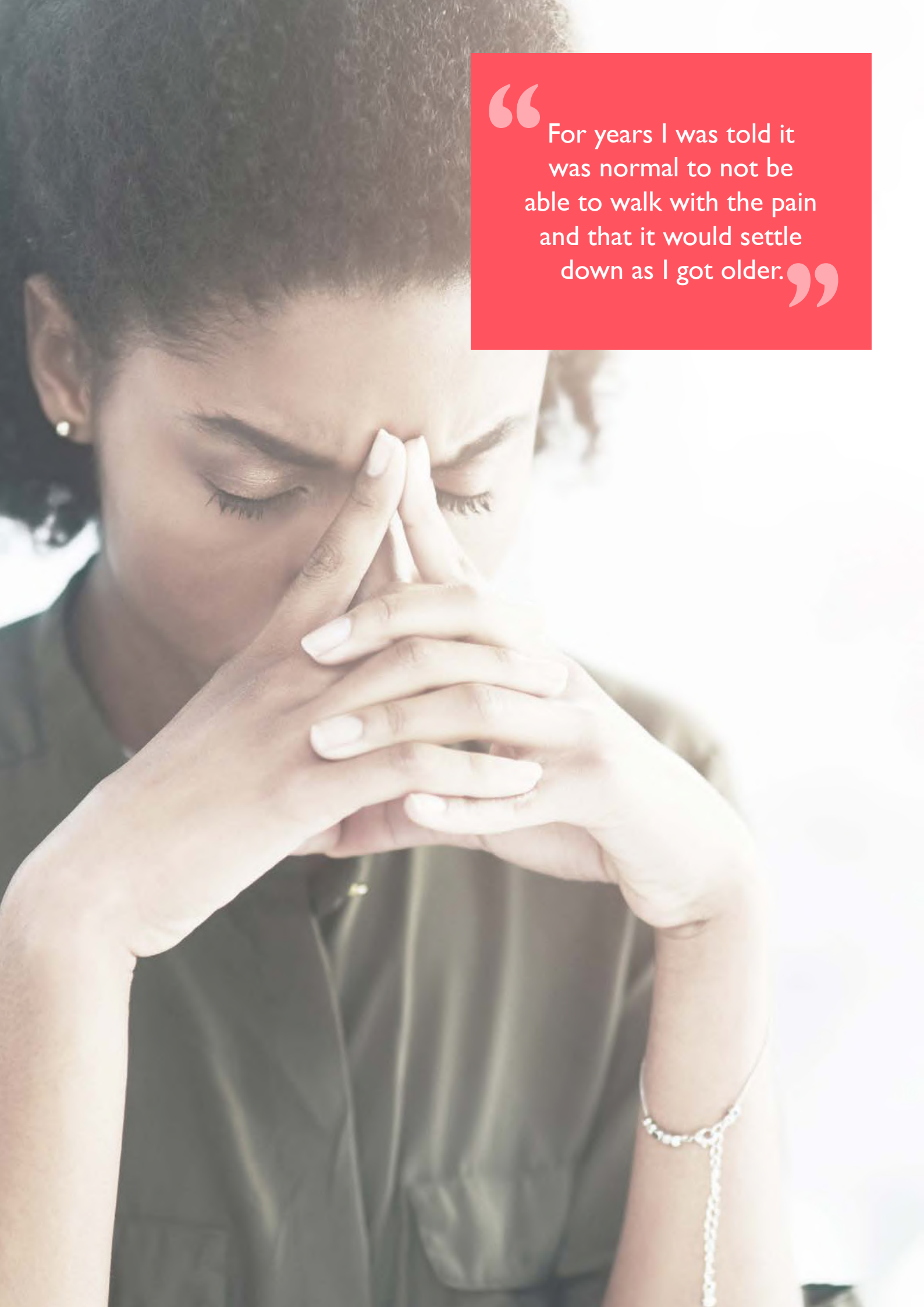
“ It's not just 'period pain', it's so much more than that. It affects the whole body and mind. ”

The survey then asked patients about the link between symptoms and the monthly cycle.

Endometriosis is often associated with menstrual or cyclical pain, but anecdotal evidence suggested that this link wasn't widely accepted among sufferers.

37% of respondents did note a change in symptoms depending on their monthly cycle, and **17%** reported different experience of symptoms from one month to the next.

However, **46%** of people reported that their symptoms were consistent throughout the month, suggesting no relation between menstrual cycle and severity or presentation of symptoms.

A close-up photograph of a woman with dark skin and curly hair. She is looking down with her eyes closed, and her hands are clasped together over her forehead and nose, suggesting a state of distress or pain. She is wearing a dark green or olive-colored shirt and a thin silver chain bracelet on her left wrist. The background is bright and out of focus.


“ For years I was told it was normal to not be able to walk with the pain and that it would settle down as I got older.”

THE IMPACT OF ENDOMETRIOSIS ON MENTAL WELLBEING

With any chronic illness, especially one that is associated with significant pain, there is a considerable chance that it will affect the sufferer's mental health.

When speaking directly to women with endometriosis, they all spoke of the psychological difficulties that came with the condition.

This was echoed in our survey responses, which spoke of the life-altering effects of living with the illness and the mental toll this took. From chronic pain and infertility, to feelings of isolation and worries about being a burden, the emotional impact of endometriosis can be just as difficult as the physical.



“Living with endometriosis has felt like more than I can bear. I have tried to take my life multiple times.”



Dr Babu Karavadra is a Specialty Registrar in Obstetrics & Gynaecology at the Norfolk & Norwich University Hospital. He is currently writing his PhD thesis on the delays to diagnosis of endometriosis. Here he analyses our open-ended survey questions to shed light on the far-reaching and life-changing impact the condition has on the lives of sufferers.

ANALYSIS BY DR BABU KARAVADRA

The impact endometriosis has on sufferer's lives can be devastating. Participants were asked to provide insight into the way endometriosis influenced their mental wellbeing.

- **90%** of participants said endometriosis had negatively affected their overall wellbeing.
- 84% of respondents said that endometriosis impacted their mood negatively. This resulted in social isolation, taking time off work and impact on relationships.
- 69% said their self-esteem was affected through worsening symptoms and as such negatively impacted on their personal relationships with partners and children.
- One woman recalled a moment where she "looked pregnant due to the bloating" and "therefore did not go outside for days".
- Women described their illness as "devastating", "debilitating" and "depressing". These are of course strong and profound words.
- Symptoms of pain were the biggest areas that women reported to be troublesome. It was the impact of pain on other areas of life that subsequently affected women.
- A lot of women tried multiple measures to "control the pain", but sometimes the side effects of these medications had a negative impact on quality of life. One woman described it as a "Catch 22 scenario".
- Concerns about fertility were also discussed in varying detail. Many women felt it was "unfair" to have to self-fund cycles of IVF based on current rules and regulations. Women were very worried about the way the disease might impact on future

fertility. This was exacerbated by waiting times to see a gynaecologist and the time taken to operate.

- **87%** of respondents felt that endometriosis made them feel negatively about their future. Sadly, **27%** also said that they had considered self-harming or self-harmed as a result of endometriosis.

“One woman described endometriosis as a silent life sentence of pain and worrying how you will wake up feeling.”

Women detailed multiple aspects of endometriosis that influenced their daily lives.

- The key areas discussed were persistent pain, unpredictable pain, tiredness, not knowing how the illness would behave and "sacrificing other areas of life".
- Participants also mentioned the difficulties they experienced with healthcare workers and the feeling of "not being heard".
- Constant tiredness and fatigue massively influenced the way women perceived their illness.
- These symptoms were often linked with other problems such as unpredictable pain and heavy menstrual bleeding.
- A number of women were only managed by their GP, despite worsening symptoms, and therefore had concerns that their condition was not being taken seriously.
- Relationships were impacted in a negative way; participants spoke of excruciating pain during sexual intercourse, and how this led to avoidance of sexual contact with their partners. This in turn affected emotional relationships.



Self-esteem
Health
Sleep
Pain
Diagnosis
Relationships
Problems
Career
Struggle
Everything
Destroyed
Life
Physical
Bloated
Suffer
Flare up
Weight
Family
Ruined
Children
Sex
Life
Impact
Diagnosis
Fatigue
Marriage
Cycle

87% of respondents felt that endometriosis
made them feel negatively about their future

THE SOCIAL IMPACT OF LIVING WITH ENDOMETRIOSIS

Our survey found that the impact of endometriosis extended beyond the purely personal to affect social lives, careers and relationships.

64% of respondents said they had felt embarrassed or ashamed to talk about what they were going through.

31% felt they couldn't speak to friends and family openly. **59%** said they felt unable to speak to their manager or employer openly.

The difficulties of living with endometriosis are enhanced by a lack of understanding among non-sufferers. Additionally, the lack of openness around gynaecological and menstrual subjects holds women back from being able to talk openly about what they're going through.

82% of respondents felt that the condition had impacted the people around them

83% believed endometriosis had affected their romantic relationships

85% had missed work because of the illness

88% said endometriosis had caused them to miss a social event

64% said they had felt embarrassed or ashamed to talk about what they were going through

31% felt they couldn't speak to friends and family openly

59% of participants said they felt unable to speak to their manager or employer openly

44% of respondents said they had suffered financial difficulties due to endometriosis

75% had felt ignored, dismissed, patronised or disbelieved by healthcare professionals

69% said their self-esteem had been impacted by endometriosis

90% believed their mood had been affected by the condition



ENDOMETRIOSIS AND THE WORKPLACE



Dr Babu Karavadra gives his analysis of open ended questions about the effects of endometriosis on work life and the response of employers.

Participants were asked to provide insight into how they felt that their employer could better support them. In summary, women provided the following responses:

- To be listened to.
- To have paid leave where possible.
- To understand that endometriosis can affect many different aspects of life, and this in turn can affect employment.
- To offer flexible hours where possible.
- To be believed when reporting symptoms.
- To be allowed to take flexible breaks when in pain at work.
- To be flexible with medical appointments and allowing time off for this.
- To have access to reliable resources about what endometriosis is.
- For management to have an understanding about endometriosis and subsequently incorporate this into any local employment policies.

Below are some quotes that reflect women's thoughts about the potential ways in which employers can support them:

- "It needs to be seen as a medical condition, not disregarded as normal period pain/symptoms."
- "Having more awareness of the impact the condition has on sufferers and how that can present and make things difficult for the employee on a daily basis."
- "By putting in a plan of action if I have a flare up day and need to go home or, if I stay at the workplace, having a plan of action about how to help me there."

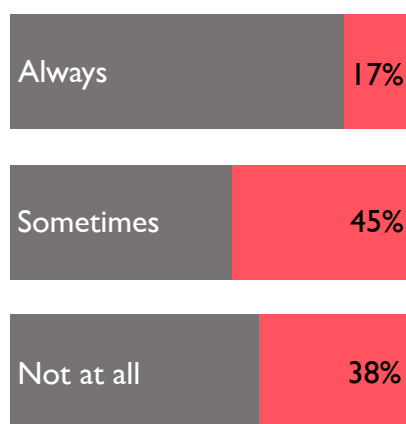
While participants provided insight into what their employer could do to help, they also spoke about some of the challenges they faced. Below are some quotes:

- "It's hard to speak to a manager about something like this. Before my diagnosis, I didn't even know what to call it so I had to just say I felt unwell. I have a male manager now so feel a little embarrassed to speak about it with him."
- "Not make you feel like you're making it up. It's pretty normal that most people just think you're overreacting to regular cramps."

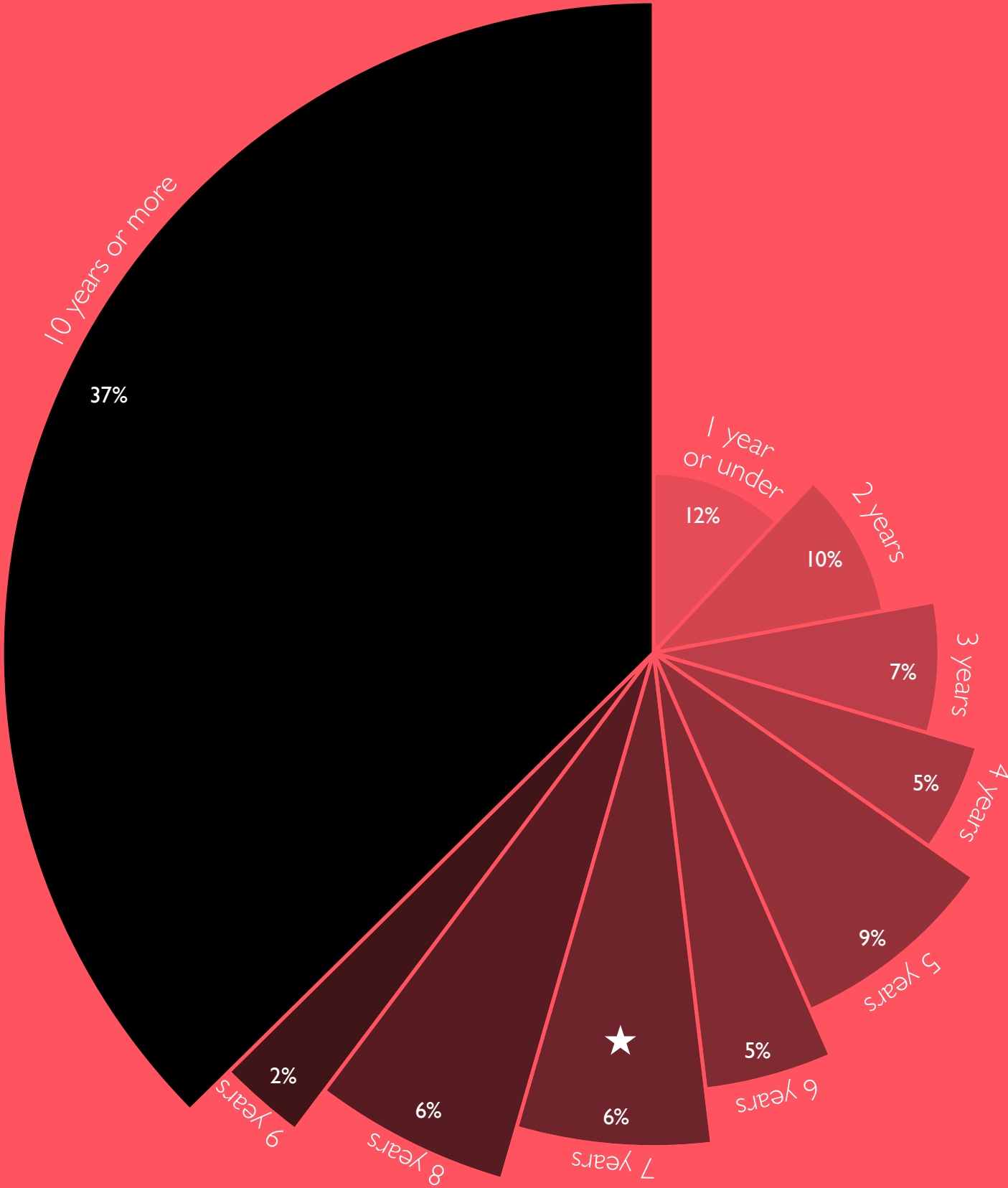
Some people did feel they had the support they needed. One participant spoke about the positive experiences she has had with her employer:

- "My current employer is fantastic and so understanding. They understand my condition and are really supportive. They allow me to work from home sometimes and any time off for endo related stuff doesn't count towards my sickness total. I'm the past I have lost my job due to too many days off even though I had two surgeries whilst employed there."

HAVE YOU FELT SUPPORTED IN THE WORKPLACE?



HOW LONG DID IT TAKE YOU TO GET DIANOSED?



★Average time to diagnosis as identified by Endometriosis UK Diagnosis Survey, 2011

TIME TO DIAGNOSIS

A 2011 survey by Endometriosis UK found that the average time to diagnosis for people with endometriosis in the UK is 7.5 years. Difficulty getting diagnosed is one of the most profound issues facing people with endometriosis in the UK today.³

The same survey found that the **2,890** respondents waited an average of two years after the onset of symptoms before reporting them to their GP; that GPs took on average four years to refer the patient to a specialist; and that the average wait for diagnosis after that was another one year and nine months.

Our survey of **2,120** respondents supports the 2011 Diagnosis Survey, with **51%** reporting a wait of **seven years or more** for diagnosis. So it seems that there has been little or no progress over the intervening nine years.

In fact, the most common answer in our survey was **10+ years**, given by **37%** of participants, showing that many people are waiting much longer than the perceived average. And while the BMI Healthcare survey and Endometriosis UK survey are not direct like-for-like comparisons, they do demonstrate that more needs to be done to speed up diagnosis.

10+ years remained the most frequent answer among all age groups. This by a significant margin in all groups except the youngest, 16-24. Of this group, responses were split relatively equally across the different answers.

Some believe that the time to diagnosis is improving, due to factors such as increased awareness among both patients and primary care. Our youngest respondents showed the lowest wait times, which

could be said to support this. Nonetheless, **33%** reported a wait of seven years or more.

Encouragingly, **22%** of respondents to our survey reported getting diagnosed within two years. While this is only a small increase on the **20%** reported in the 2011 Endometriosis UK survey, it does indicate that things are moving in the right direction.



³ <https://endometriosis-uk.org/endometriosis-facts-and-figures>

THE SPECIALIST'S VIEW: MR ELIAS KOVOOR



Mr Elias Kovoor is a consultant gynaecologist specialising in endometriosis. He practices at BMI Chelsfield Park Hospital and at Dartford & Gravesham Endometriosis Centre.

There is no known cure for endometriosis, but **early diagnosis and treatment can vastly improve the quality of life of sufferers.** There are treatments available that can manage symptoms and slow the progression of the condition. Equally, the longer endometriosis is left untreated, the worse it can become.

Delayed diagnosis has a psychological impact, too. Women are made to feel they are exaggerating or even fabricating their symptoms, or that their pain is 'normal', and that they should simply deal with it.

That this survey shows time to diagnosis at more than seven years suggests **there is still a lack of understanding of endometriosis and its various clinical symptoms among non-specialists.** Some of the symptoms of the condition can be very non-specific and can be easily overlooked or misattributed.

Thankfully, NICE released guidance in 2017 that offers clear criteria for referring women to secondary care. This includes patients with persisting symptoms, non-response to standard medications, and ultrasound or clinical examination that leads to suspicions of endometriosis. These criteria apply to adolescent girls, too.

22% of respondents did report getting diagnosed within two years, and the average length of time does seem to drop as the age brackets decrease, which I hope indicates that more recent patients have had a less protracted journey to diagnosis. The better the education and awareness of endometriosis, in both patients and primary care, the faster the time to diagnosis should become.

More research needs to be done to confirm the current time to diagnosis, and to try to identify the reasons behind these delays. More importantly, work needs to be done to bring the average down. **If there has been an improvement, it is not yet enough.**

THE HEALTHCARE EXPERIENCE

Negative experiences with healthcare professionals are all too common among people with endometriosis. **59%** of survey respondents who had received their diagnosis said they were not satisfied with the process.

It is clear from the responses to our survey that the impact of endometriosis can be devastating on women's lives. It is also clear that more work is required to explore further the way in which endometriosis is diagnosed.



Dr Babu Karavadra gives his analysis of open-ended questions about experiences of healthcare.

Participants were asked about their experiences of being diagnosed.

- **50%** of women were not satisfied with the process of diagnosis.

The majority of women provided significant insight into the wait they had prior to being diagnosed.

- Participants described not being 'taken seriously' in medical consultations.
- The delay was often in primary care and involved problems with being referred to a gynaecologist. Some women decided to see a private gynaecologist for "quicker treatment".

“The consultant who initially diagnosed me with endometriosis and adenomyosis via lap surgery was very dismissive afterwards, saying ‘oh, it’s only very mild’. He found ‘inactive old endometriosis’, which he did not excise. When I started getting symptoms again he was adamant there was nothing wrong with me.”

- Most women explained that once they saw a gynaecologist, the process of being diagnosed with endometriosis was relatively quick.
- Some women were diagnosed with endometriosis through 'unconventional ways'. One woman described how she had appendicitis and the endometriosis was picked up by the general surgeons. Another woman said she was diagnosed "after an endometrioma burst and caused sepsis". Both of these women reported that they had the "classical symptoms" of endometriosis for a number of years prior to being diagnosed.



“My GP was very unhelpful and showed no empathy. They tried to make me believe it was ‘normal’ to experience painful periods and I just had to accept it. They tried to mask symptoms with pain relief and contraceptive pills, and never tried to get to the bottom of the issue. I had to change doctors and demand to be seen by a specialist, and this after collapsing and being hospitalised multiple times due to pain. It was a stressful and lonely experience. I would do anything to ensure other women don’t have the same journey to getting a diagnosis.”

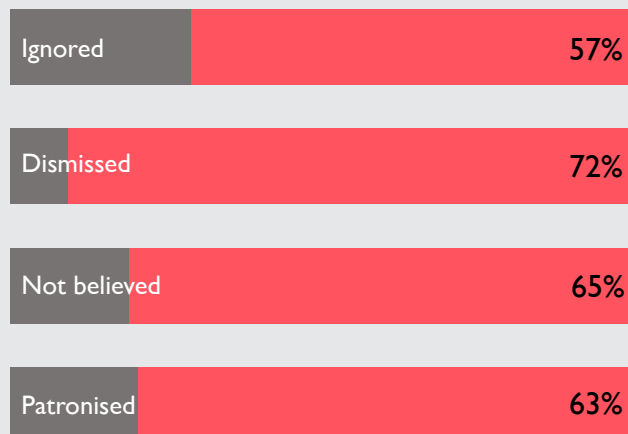
- While many women had a negative experience with their healthcare worker, some women described positive experiences.
- They explained the “quick process” of being referred to a gynaecologist. They felt listened to and understood.
- Women who spoke about fertility concerns to their GP also felt that their symptoms were taken more seriously and that they were provided with further support on this.
- Some participants described negative experiences with gynaecologists as well as primary care.

Overall, **37%** of participants felt that their GP did not take their symptoms ‘seriously at all’, and only **10%** felt they were taken ‘very seriously’. At some stage during their diagnosis or treatment journey, **58%** of women felt ignored, **72%** dismissed, **65%** not believed and **63%** patronised.

HOW SERIOUSLY DO YOU THINK YOU WERE TAKEN BY YOUR GP WHEN REPORTING YOUR SYMPTOMS?



HAVE YOU FELT ANY OF THE FOLLOWING DURING YOUR DIAGNOSIS OR TREATMENT JOURNEY?



“A very common response was ‘this is normal’. No explanation, support, referral to experts or support groups. Gynaecologists often felt dismissive.”

“Not properly diagnosed. Had to fight for a laparoscopy, which they did when I was on my period. Then was told I was fine and I didn’t have it. I was later told my symptoms still pointed to it and maybe the surgeon couldn’t see any evidence of it because it was well hidden. After that I had more pain due to scar tissue in my abdomen. I am 26 and was offered an injection to shut my ovaries down, which would put me in a menopausal state, yet I would like to have children. I just wanted a diagnosis and I just want proper treatment so I can get on with my life.”

“GPs not interested at all. Had to pay to be seen privately where it was then diagnosed.”

“Dehumanised when asking for pain relief, was treated as though I had drug dependency or substance abuse issues which I don’t.”

“It’s so important to know that endometriosis is not just a gynaecological disease. It can affect a lot of other organs and cause a lot of different symptoms. In fact, it often needs to be treated by a team of specialists. It’s so much more than just bad periods.”





MY JOURNEY TO DIAGNOSIS: LAURA CONNELLY

"I experienced a long list of debilitating symptoms from the age of 14, but I feel I wasn't taken seriously by doctors. I was told on more than one occasion that 'some women just get bad periods'.

"I saw countless GPs over the years but in the end, it was actually me who suggested endometriosis and pushed to be referred to a gynaecologist. By this point I was finding it incredibly difficult to cope.

"At home I relied on my partner for help with almost everything. At work I was struggling and having to take a lot of sick leave. Eventually I made the very difficult decision to go part time.

"Finally, at 27 I had a diagnostic laparoscopy. Since then, excision surgery and hormone treatments have made a huge difference to my life.

"I just wish I had known about the existence of endometriosis when I was younger. I wish I had been taught properly about menstrual health in school."

THE STATE OF AWARENESS

A recent survey by Endometriosis UK⁴ found that **54%** of people in the UK do not know what endometriosis is. This increases to **74%** among men.

62% of women aged 16-24 don't know about endometriosis, and **45%** of all female participants were unable to identify any symptoms of the condition.

This lack of awareness can add to a delay in diagnosis, meaning symptoms aren't reported or aren't correctly interpreted when they are.

It can also mean that women are misunderstood or disbelieved by those around them, and that adequate allowances aren't made in the workplace.

- Throughout the survey responses, open-ended answers called for greater understanding and awareness of the condition. Although many felt that awareness had grown in recent years, the resounding feeling was that more needed to be done.

“ I really appreciate that endo is starting to gain some exposure. Hopefully women of the future won't have to wait as long as I did for a diagnosis. ”

- **94%** of women felt that the situation had been affected by the fact it is (predominantly) a women's condition, linked to menstruation.

“ I have no doubt it is dismissed and diminished as a 'women's issue.' ”

- Women also spoke of the need for better education – in particular of menstrual health education from a young age – so that sufferers could understand their own symptoms earlier.

“ I wish I had been taught about endometriosis at school. If I had known, if it had been caught earlier... there's a chance I could be a mum by now. ”

- Respondents reported a lack of awareness as one of the most difficult aspects of living with endometriosis.

⁴ <https://www.endometriosis-uk.org/news/endometriosis-awareness-month-launches-tackle-fact-54-don%e2%80%99t-know-about-endometriosis-37621#.XmpqSKj7SUI>

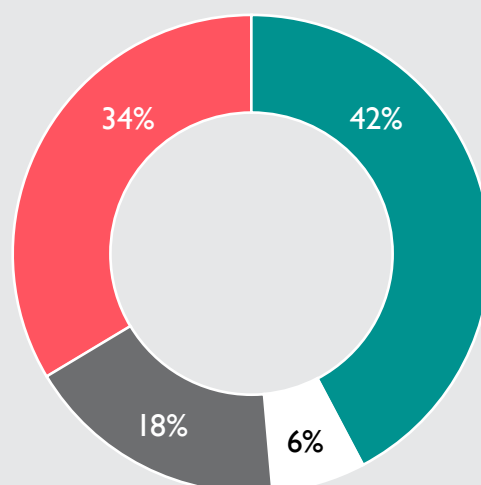
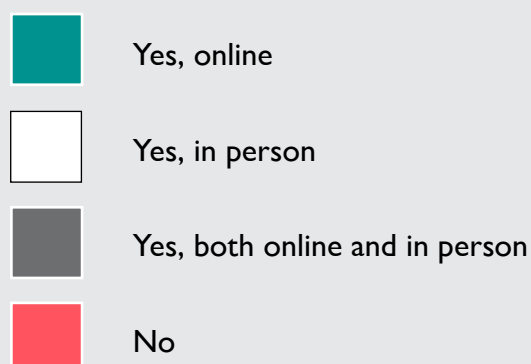
THE IMPORTANCE OF ENDOMETRIOSIS SUPPORT COMMUNITIES

Lack of awareness and support has been a major factor in the growth of endometriosis communities, where sufferers offer support to each other, share experiences and advice, and come together to campaign for their cause.

Social media has been a huge part of this, though support groups exist in offline as well as online spaces.

For many, these groups have been a consistent and necessary source of support in extremely difficult times. In our survey, a number of respondents credited these groups with helping them get access to the right treatment, even with saving their lives.

HAVE YOU REACHED OUT TO OTHER
ENDOMETRIOSIS SUFFERERS FOR SUPPORT?



WHY I FOUNDED A SUPPORT GROUP: KEISHA MEEK

“Reaching out to other people in the same situation changed my life.”

Keisha Meek is a founding member of National Endometriosis Sufferers Support (NESS), a community for people living with the condition. NESS has a strong online presence and organises meetups in person. Along with fellow members, Keisha campaigns for greater awareness of endometriosis.

“For a long time, I lived with endometriosis without knowing anyone else with the illness. I felt so alone. It felt like more than I could bear, and I tried to take my own life more than once.

“Eventually, I knew something needed to change and I started searching for support groups. I was amazed at how many people were out there, going through the same thing. Reaching out to other people in the same situation changed my life.

“Making friends with other sufferers felt like a breath of fresh air. Suddenly, I had endometriosis sisters, and together we were stronger.

“I couldn't bear to think of anyone else feeling like I had felt, so along with two other women, I decided to set up face-to-face meetings. NESS was born in December 2017, and today we have more than 2,000 members online and hold frequent meetups in person.

“As well as being a place for sufferers to connect and support each other, we also advocate for change. Without increased awareness and better access to specialists, people will continue to suffer more than they need to with this horrific condition.”



CONCLUSIONS

ENDOMETRIOSIS IS SO MUCH MORE THAN PAINFUL PERIODS

- Endometriosis can have a huge impact on the life of a sufferer, far beyond the common conception of 'just period pains'.
- **Symptoms are varied and they are many. Most of them are invisible. Often they continue throughout the month with no change in line with menstrual cycle.**
- The language used by participants was extreme. Endometriosis is "debilitating", "depressing", "devastating".

THE EFFECTS OF ENDOMETRIOSIS GO BEYOND THE PHYSICAL

- **Women are living with extreme pain, yet many of them feel embarrassed or even ashamed to talk about it.**
- Living with the difficult symptoms of a chronic illness, coupled with a feeling of being ignored or disbelieved by both loved ones and healthcare professionals, takes a serious toll on a person's mental health as well as their overall wellbeing.
- The effects can be profoundly isolating, negatively impacting all areas of a person's life.

“It is clear from the results of the survey that the impact of endometriosis can be devastating on women's lives. It is also clear that more work is required to explore further the way in which endometriosis is diagnosed.”

Dr Babu Karavadra, Specialty Registrar in Obstetrics & Gynaecology
at the Norfolk and Norwich University Hospital

MENSTRUAL EDUCATION NEEDS TO IMPROVE

- **Women have not been taught enough about menstrual health.** If women have not heard of endometriosis, they cannot recognise the symptoms. Some didn't know enough to realise their symptoms were anything but normal.
- As of 2020, menstrual health has been added to the curriculum in England. Endometriosis UK continues to campaign for the same decision to be made in Wales.
- Hopefully this change means that women will be better supported, and that the stigma around menstrual issues will begin to lessen.

LACK OF AWARENESS CAN HAVE DEVASTATING EFFECTS

- Women described losing relationships with friends and partners, even relatives, due to a lack of understanding. At work, less than half of them felt their illness was understood.
- **They spoke of stigma, of feeling like a burden, and of an intense loneliness.** It affected their mood and self-esteem.
- Our respondents, patients and consultants alike urge for greater understanding among non-sufferers – employers, friends and loved ones as well as primary care workers.

THE WAIT FOR DIAGNOSIS IS STILL TOO LONG

- Endometriosis is a progressive condition with no known cure. Early diagnosis and treatment is one of the best ways to manage its progression and potentially avoid its life-changing effects.
- Yet our survey found that the majority of people waited seven or more years for diagnosis, a figure backed up by anecdotal evidence as well as major studies.⁵
- The figure may be improving, but **with 33% of 16-to-24-year-olds still reporting a wait of seven years or more, it is not changing quickly enough.**

HEALTHCARE IS NOT RESPONDING THE WAY IT SHOULD

- Endometriosis sufferers are not satisfied with their experience of healthcare. Reaching diagnosis can be a protracted, complex and often upsetting journey.
- **Symptoms are overlooked, misdiagnosed or even dismissed. Patients are having to do their own clinical research and fight for their problems to be taken seriously.**
- Hopefully, things are already starting to get better. But there is still much to be done if we are to ensure satisfactory patient experiences and timely diagnosis across the board.

“More research needs to be done to confirm the current time to diagnosis, and to try to identify the reasons behind these delays. If there has been an improvement, it is not yet enough.”

Mr Elias Koor, Consultant Gynaecologist,
BMI Chelsfield Park Hospital

⁵ <https://endometriosis-uk.org/endometriosis-facts-and-figures>

ACKNOWLEDGEMENTS

This report could not have happened without the help of National Endometriosis Sufferers Support (NESS). The group, and especially members Keisha Meek and Amanda Ward, supported the project from the start and were integral to putting the survey together.

The Royal College of Gynaecologists and Obstetricians (RCOG) was kind enough to help us share our survey. We were also aided in our background research by the organisation's [Better for Women](#) report, a detailed proposal on how healthcare as a whole can better serve women and girls in the UK.

Our report would not be what it is without the statistics, supporting information and educational content provided by charity Endometriosis UK on its [website](#).

Another huge thank you goes to Dr Babu Karavadra MD, an endometriosis researcher whose work (including his PhD thesis) goes beyond purely clinical analysis of the condition and looks at the way it is experienced by real women and the impact it has on their lives.

Babu lent his expertise to this report, helping us analyse the qualitative data we collected through open-ended questions about living with endometriosis.

A number of our consultant gynaecologists provided insight along the way. Special thanks goes to Mr Elias Kovoor, one of BMI Healthcare's endometriosis specialists. He has shared the benefit of his experience to help us put our survey findings into context.

And of course, we would like to thank each and every one of the 2,120 people who took the time to fill in our survey.



Healthcare

ENDOMETRIOSIS MATTERS

0808 291 2480

Visit our Endometriosis Matters hub



1st Floor, 30 Cannon Street, London, EC4M 6XH

#EndometriosisMatters