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All Party Parliamentary Group
on Endometriosis

Endometriosis in the UK: time for change

APPAG on Endometriosis
Inquiry Report 2020

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Introduction



Sir David Amess MP,
Chair, All Party Parliamentary
Group on Endometriosis

We are delighted to present this report by the All-Party Parliamentary Group on Endometriosis, with support from Endometriosis UK.

This report is a long-overdue account of how those with endometriosis throughout the UK deserve better when it comes to their healthcare. It provides recommendations on how care and support need to be improved, and what practical changes the Government can make to ensure the voices of the 1.5 million people with endometriosis are heard.

We are extremely grateful to the patients, clinicians, charities and NHS workers who took the time to contribute evidence to the inquiry. We received an overwhelming response, and over 10,000 people shared their experience of endometriosis with us via a survey, with 75 people sharing their experiences in oral hearings in Parliament, or online following the outbreak of COVID-19.

We have been humbled and sometimes shocked to hear the stories of people affected by endometriosis as part of the inquiry. On behalf of all the members of the APPG on Endometriosis, our thanks go to all of those who bravely shared their experiences, and provided recommendations on what they would like to see the Government do to ensure they get the support they need to manage this often-debilitating condition.

When we planned the Inquiry and launched the survey in February, we had not anticipated that we would be conducting our research in the midst of a global pandemic, and with all scheduled NHS appointments and surgeries cancelled. We expanded the remit to hear accounts of experiences during lockdown and of the difficult challenges in navigating changes to healthcare. The APPG recognises the uncertainty and anxiety the COVID-19 pandemic has brought to many, and will be urging the Government, as part of this report, to ensure that people are not left in the dark about when their care will resume.

The APPG on Endometriosis would also like to take this opportunity to thank all the healthcare workers who have been at the forefront of supporting those with endometriosis during this difficult time. We had planned to conduct further oral sessions with healthcare practitioners alongside a survey, but recognising the huge burden COVID-19 has brought to the NHS, this was not possible.

The report has highlighted the devastating impact endometriosis can have on people's lives. 95% of people said that endometriosis has impacted their wellbeing in a negative manner, and the results show that diagnosis in the UK takes on average an unacceptable 8 years.

We have heard of the many challenges that can be faced by those with endometriosis, and that within some communities, endometriosis can be particularly complex. We have learnt of the cultural challenges many face, and for those with endometriosis who do not identify as female. The APPG is dedicated to ensuring that everyone's voices are heard within the group, and look forward to hosting meetings in the future that specifically discuss some of these challenges.

The report demonstrates that without investment in research, a reduction in diagnosis time, and appropriate NHS pathways, those with endometriosis will continue to face huge barriers in accessing the appropriate support at the right time.

The APPG now looks forward to working with the Government to ensure this report is the start of real change for those within the endometriosis community. We will not rest until tangible improvements are delivered to all those people who unfortunately suffer from this condition.



Emma Cox,
Chief Executive,
Endometriosis UK

Thank you to Sir David Amess MP and all members of the APPG on Endometriosis for their determination to make a difference for those with endometriosis, and their resolve for this Inquiry to continue despite the outbreak of Covid-19.

Their commitment in ensuring the voices of those with endometriosis are heard in Parliament offers a real opportunity to make a lasting difference in driving down diagnosis times and improving endometriosis care across the UK.

Getting access to the right treatments and support, at the right time and in the right place with access to skilled and experienced healthcare practitioners, gives the best chance for endometriosis to be managed effectively. We want to make sure that's the experience for all those with endometriosis. Whilst it is for some, sadly many experience a much more circuitous route, as the research for the Inquiry shows. Symptoms may not be recognised, attributed to other conditions, or taken to be 'normal' resulting in lengthy diagnosis times. Access to healthcare practitioners who specialise in endometriosis is limited, and often a post code lottery. When symptoms are recognised, effective care pathways have not yet been implemented within the NHS and can make it challenging to get patients to the right place in hospitals, along with limited availability of specialists with expertise in recognising and treating the disease.

The NICE Guideline on Endometriosis were issued in 2017 and adopted across the UK, but haven't been implemented. Implementing these and the associated NICE Quality Standards on Endometriosis would be a significant, positive step change in improving endometriosis diagnosis, treatment and care. Streamlining the diagnosis process will reduce wasted appointments with GPs, in hospitals and in A&E, and save many years of suffering and distress for the undiagnosed.

Education is also pivotal to decreasing diagnosis time. Including Menstrual Wellbeing in the new Health & Wellbeing school curriculum in England from this year is a big step forward in overcoming the taboos of talking about periods, and ensuring understanding about menstrual wellbeing and how to seek help around periods and menstrual conditions. The same needs to be adopted and implemented in Northern Ireland, Scotland and Wales to ensure nobody is left behind.

Endometriosis UK is pleased to provide the Secretariat to the APPG on Endometriosis, and to have supported the Inquiry and development of this report. We hope that as a result of all the incredible people who shared their experiences as part of the Inquiry, the Government will take bold action to ensure provision of the care and support needed, and endometriosis does not prevent the next generation achieving their potential and living the lives they want. Working together, let's ensure that stories of people being ignored, dismissed, and told pelvic pain is normal, or even 'in your head' become a thing of the past.

It is not yet known what long-term impact COVID-19 will have on the NHS, and this has been a distressing time with appointments and surgery cancelled, and the subsequent impact this has had on an individual's life. We ask that those with endometriosis are given due priority in the resumption of services, and are not forgotten nor the impact of their symptoms overlooked or underestimated, as has happened in the past.

Executive Summary

The APPG on Endometriosis found that those with endometriosis are waiting an average of 8 years for a diagnosis, despite over 58% visiting their GP 10 or more times with symptoms, 53% visiting A&E with symptoms, and 21% seeing doctors in hospital 10 or more times with symptoms.

The APPG survey received over 10,000 responses from those with a confirmed diagnosis of endometriosis living in the UK, and found the diagnosis time the same as it was a decade ago – an average of 8 years. Delays in diagnosing and managing endometriosis can affect quality of life and result in disease progression¹. As well as impacting on physical health, 81% said endometriosis has impacted their mental health negatively or very negatively, and 90% would have liked access to psychological support but were not offered this.

Only 19% knew if they had been seen in an endometriosis specialist centre, yet 84% of respondents reported bowel symptoms due to endometriosis. All those with suspected or confirmed deep endometriosis, for example involving the bowel, should be seen in an endometriosis specialist centre where there are the necessary skills and expertise from multidisciplinary teams to treat these patients. Over 60% of respondents may be being seen in hospital settings where there is not necessarily the expertise to operate on or treat them effectively.

NICE Guideline [NG73] on Endometriosis: diagnosis and management (2017) sets out the NHS baseline for endometriosis care. Despite being adopted by the NHS in each nation of the UK, the NICE Guideline has not been implemented. Many with endometriosis are left feeling that they are being failed by the system, and even when they have a diagnosis feel unable to access the care they need – 54% were not very or not at all confident they could get an appointment with a gynaecologist about their endometriosis symptoms if they felt they needed to (pre Covid-19).

Key findings from the APPG survey are given below. The survey was undertaken in February/March 2020, prior to the onset of the pandemic and lockdown.

Diagnosis

It takes 8 years on average from onset of symptoms to receiving a diagnosis, the same length of time as it did a decade ago. Prior to receiving a diagnosis of endometriosis, due to their symptoms:

- **58%** visited the GP over 10 times
- **21%** visited doctors in hospital 10 times or more
- **53%** went to A&E; 27% went to A&E 3 or more times

Endometriosis is common, affecting 10% of women from puberty to menopause² – although the impact may be felt for life. That's over 1.5 million in the UK. The APPG also acknowledges that not everyone who lives with endometriosis will identify as female.

As well as greatly supporting those with the disease to access the treatment and care they need, streamlining the process and reducing diagnosis time could save the NHS time and money with reductions in visits to GPs, hospitals and A&E.

¹ <https://www.nice.org.uk/guidance/ng73/chapter/Recommendations#organisation-of-care>

² Rogers PA, D'Hooghe TM, Fazleabas A, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. *Reprod Sci* 2009;16(4):335-46.

Access to treatments

- **26%** found their GP(s) helpful or very helpful, whilst 46% found their GP(s) unhelpful or very unhelpful.
- **43%** found their gynaecologist(s) helpful or very helpful, whilst 32% found their gynaecologist(s) unhelpful or very unhelpful.
- **54%** were not very or not at all confident they could get an appointment with a gynaecologist about their endometriosis symptoms if they felt they needed to.
- **Only 19%** knew if they were seen in an endometriosis specialist centre.
- **58%** would have liked fertility support and treatment but were not offered it, despite endometriosis doubling the risk of infertility¹.
- **72%** were not given any written information when diagnosed, leaving them without the knowledge and advice they need to make informed choices about their healthcare.

Impact

As well as the physical impact, the survey demonstrated the impact endometriosis and its symptoms can have on all aspects of life including education, career, relationships and social life, as well as mental health.

- **95%** said that endometriosis/the symptoms of endometriosis had impacted their wellbeing negatively or very negatively.
- **90%** would have liked access to psychological support, but were not offered this.
- **89%** felt isolated due to their endometriosis.

- **81%** said endometriosis has impacted their mental health negatively or very negatively.
- **42%** said they often, or very often, had time off school because of endometriosis symptoms, with 12% missing exams at school often or very often.
- **38%** were concerned about losing their job, whilst 35% had a reduced income due to endometriosis.

(Please note all figures are pre Covid-19)

90% would have liked access to psychological support but were not offered this.

¹ Endometriosis can double the risk of infertility in under 35s. A prospective cohort study of endometriosis and subsequent risk of infertility. J. Prescott, L.V. Farland, D.K. Tobias, A.J. Gaskins, D. Spiegelman, J.E. Chavarro, J.W. Rich-Edwards, R.L. Barbier, S.A. Missmer. Hum Reprod (2016) 31 (7): 1475-1482.

Key recommendations

Based on the evidence gathered, the APPG is making a series of recommendations throughout this Inquiry Report. Key recommendations include:

1. A commitment to drive down diagnosis times

Untreated, the disease may progress and impact on quality of life. Diagnosis time must decrease to support those with endometriosis access the treatment they need, when they need it. The APPG is seeking a commitment from Governments in all four nations to reduce average diagnosis times with targets of 4 years or less by 2025, and a year or less by 2030.

2. Ensure access to appropriate care

- The NICE Guideline on Endometriosis Treatment and Management was issued in 2017 and has been adopted across the UK, but not implemented. The APPG is calling for Government and NHS commitment in each nation for implementation of the Guidelines and the corresponding NICE Quality Standards on Endometriosis (2018), to provide a baseline for endometriosis diagnosis, treatment and management across the UK. As a first step, a gap analysis of endometriosis services should be undertaken.
- There are no NHS care pathways for endometriosis outside the pelvic cavity, despite it affecting up to 10% of those with endometriosis. The APPG is calling for NICE to ensure that care pathways for those with endometriosis outside the pelvic cavity are developed and implemented, starting with thoracic endometriosis.
- The APPG recognises the additional complexities and barriers that those from black, Asian and minority ethnic communities may face in talking about menstrual health and accessing support, and is committed to addressing health inequalities for all, and ensuring everyone has a voice in Parliament. We must do

more to understand the inequalities faced for those with endometriosis from black, Asian and minority ethnic communities, and come together to find the right policy solutions, which the APPG is committed to doing. The APPG is calling for the Government to address health disparities for black, Asian and minority ethnic people with endometriosis and the APPG commits to investigating this as a priority for the APPG's work going forward.

- Recognition from UK Governments that more needs to be done to ensure inclusivity and equality of access to endometriosis services. Proactive work is needed to identify issues faced and how these can be overcome, including understanding the barriers and additional needs faced by all those who need to access endometriosis care.
- Work with the NHS to ensure nobody faces additional barriers in accessing healthcare due to their race, gender, sexuality, ability or social status, and ensure that those with additional needs such as learning disabilities have access to appropriate patient information and resources.

3. Awareness

- Those with endometriosis have to recognise that what they are experiencing are symptoms, in order to seek help. Too many think the sometimes debilitating pain and symptoms they are experiencing is 'normal' and they have to live with it. The APPG would like to see Menstrual Wellbeing included as compulsory in the school curriculums across the UK, as it now is in England, to overcome the taboo of talking about periods and ensure all adolescents understand what a 'normal'

period is and when to seek help.

- It is vital for healthcare practitioners to recognise the symptoms of endometriosis, to be able to support diagnosis and ongoing treatment and care. The APPG are calling on the Royal College of GPs, Royal College of Obstetricians and Gynaecologists and Royal College of Nursing, to review how to ensure their members gain the knowledge, training and experience they need to recognise the symptoms of endometriosis.

4. Investment in research

- Historically, with limited investment in research into women's health in general, there's been so little investment in research into endometriosis that we don't even know what causes it, and without knowing the cause a cure cannot be found. To improve options for diagnosis, care and support, and to enable those with the disease to best manage living with endometriosis, the APPG is seeking commitment for vital investment in research into the cause of endometriosis, treatment and management options, and diagnosis.
- The APPG recognises from its own work that there are data gaps in research for assessing health outcomes for those from black, Asian and minority ethnic backgrounds. The APPG is committed to investigating and ending the ethnicity gaps in research for those from black, Asian and minority ethnic backgrounds.

A full list of recommendations can be found on page 67.

It is vital for healthcare practitioners to recognise the symptoms of endometriosis, to be able to support diagnosis and ongoing treatment and care.

Key statistics – a summary

Statistics given are from a survey which ran from the 10th February until the 24th March 2020, prior to the impact of the Covid-19 pandemic.

The survey was advertised widely on social media, and 10,783 responses were received that were eligible for this report (those with a confirmed diagnosis of endometriosis, living in the UK). Respondents to the survey were self-selecting, it was not a random sample.

Diagnosis

The average length to diagnosis from onset of symptoms was found to be 8 years in the UK. By nation the average varies:

- England – 8 years
- Scotland and Northern Ireland – 8.5 years
- Wales – 9 years

Prior to diagnosis, due to their symptoms:

- 58% visited the GP over 10 times, and 41% over 15 times
- 43% visited doctors in hospitals over 5 times, and 21% visited 10 or more times
- 53% went to A&E with symptoms, with 27% visiting A&E 3 or more times.

Treatment

- 46% found their GP(s) unhelpful or very unhelpful
- 32% found their gynaecologist(s) unhelpful or very unhelpful
- Only 19% knew that they were seen in specialist centres. All those with suspected or confirmed deep endometriosis, for example involving the bowel, should be seen in an endometriosis specialist centre where there are the necessary skills and expertise from multidisciplinary teams to treat these patients. 84% of respondents reported bowel symptoms due to endometriosis, meaning over 60% may be being seen in hospital settings where there is not necessarily the expertise to operate on or treat them effectively.

- 30% are waiting 6 months or more for surgery, from when their gynaecologist said they needed surgery (pre Covid-19)
- 54% are not very or not at all confident they could get an appointment with a gynaecologist about their endometriosis symptoms if they felt they needed to (pre Covid-19)
- 72% were not given any written information when diagnosed, leaving them without the knowledge and advice they need to make informed choices about their healthcare.

Impact

Respondents said that endometriosis/symptoms of endometriosis had:

- 95% – impacted their wellbeing negatively or very negatively.
- 81% – impacted mental health negatively or very negatively.
- 89% – affected their ability to lead life as they want to negatively or very negatively
- 90% – would have liked access to psychological support, but were not offered this.

When asked about the impact of different symptoms affected their ability to lead the life as they wanted to (figures for negative and very negative impact):

- Pelvic pain – 95%
- Fatigue – 93%
- Heavy menstrual bleeding – 85%
- Painful bowel movements – 84%
- Pain during or after sex – 83%
- Difficulty getting pregnant – 73% (of 6600 responded for whom this was relevant)
- Urinary symptoms – 60%

Methodology

The data used within this report came from:

- A survey which ran from the 10th February until the 24th March 2020, prior to the impact of the COVID-19 pandemic. The survey was advertised widely on social media, with over 13,000 responses received. 10,783 responses were found to be eligible for this report, having a confirmed diagnosis of endometriosis and living in the UK. Respondents to the survey were self-selecting, it was not a random sample.
- The breakdown of the numbers that answered questions is included in **Appendix 3**. Not all questions were compulsory and not everyone answered all questions. All answers referred to in the report received over 9,000 responses, unless otherwise stated. A full breakdown of number of responses per questions can be found in **Appendix 3**. The vast majority of respondents had recent experience of endometriosis diagnosis and/or treatment, with 81% seeing a gynaecologist between 2018–2020 and 88% seeing a gynaecologist between 2015–2020.
- Four oral evidence sessions were held to gather evidence, three focusing on those with experience of endometriosis (two in Westminster and one held virtually in Scotland) plus one on the impact of Covid-19. Due to the onset of the pandemic, a session with healthcare practitioners scheduled in March 2020 could not be attended by MPs from the APPG and the information was collated by Endometriosis UK. A further oral evidence session had been arranged in late March with the relevant Ministers, but had to be cancelled.
- Oxford University, working with Endometriosis UK, undertook an additional survey in May/June 2020 to identify the impact of Covid-19 on those with endometriosis.

The APPG had planned further activity to hear from more healthcare practitioners, including a survey of healthcare practitioners in the NHS in April, and Freedom of Information (FOI) requests from the NHS April/May. These were not undertaken due to the pandemic, recognising the significant pressures on the NHS and staff.

Chapter 1

Diagnosis

Endometriosis affects 10% of women from puberty to menopause. That is over 1.5 million in the UK and 176 million globally. The APPG also acknowledges that not all with endometriosis will identify as female.

Associated with the hormonal menstrual cycle, the disease can be active from puberty to menopause, although the impact may last for life. The cause is not known. Treatments include

surgery, hormones and pain management, but there is no cure. Endometriosis costs the UK economy £8.2bn a year in treatment, loss of work and healthcare costs¹.

Endometriosis and symptoms

Endometriosis is the name given to the condition where cells similar to the ones lining the womb (the endometrium) are found elsewhere in the body. Each month these cells react in the same way to those lining the womb, building up and then breaking down and bleeding. Unlike the cells lining the womb that leave the body as a period, this blood has no way to escape. This can cause inflammation, pain and the formation of scar tissue.

It is a chronic and sometimes debilitating condition.

The main symptoms of endometriosis² are:

- pain in your lower tummy or back (pelvic pain) – usually worse during your period
- period pain that stops you doing your normal activities
- pain during or after sex
- pain when peeing or pooing during your period
- feeling sick, constipation, diarrhoea, or blood in your pee during your period
- difficulty getting pregnant
- many with endometriosis also have heavy periods

Where the endometriosis grows varies person to person, so the range and severity of symptoms experienced and extent of the disease also varies for each individual. For some, symptoms may be mild and have little impact, whilst others may experience symptoms that are severe and debilitating. However, the symptoms experienced do not correlate with the extent of endometriosis found, and the disease may progress over time. Endometriosis is often classified into three types for treatment:

- Peritoneal or superficial endometriosis – found on the surface of the peritoneal lining of the pelvic cavity or organs. (Superficial in this medical context means 'on the surface', **not** fake or shallow which is an alternate meaning of the word).
- Deep endometriosis – found below the surface. Sometimes referred to as deep infiltrating or recto-vaginal endometriosis.
- Endometriomas – cysts on the ovary.

The majority of endometriosis is found within the pelvic cavity, however up to 10% of those with the disease may have endometriosis elsewhere in the body, for example on the diaphragm or in the chest cavity (thorax).

Despite being so common, and severe chronic pelvic pain being the most common symptom, our survey showed diagnosis time currently takes on average 8 years in England, 8.5 years in Scotland and Northern Ireland, and 9 years in Wales.

¹ <https://www.endometriosis-uk.org/endometriosis-facts-and-figures>

² <https://www.nhs.uk/conditions/endometriosis/>

The reasons for this include pain from endometriosis being normalised and dismissed as 'period pain' by family or friends, symptoms are not recognised by healthcare practitioners, or sometimes the level of pain is simply not believed. Cultural taboos may restrict discussions around menstruation. Adolescents may not have the words or understanding to describe what they are experiencing and may grow up suffering but not realising that what they are experiencing is not normal.

Radha was told the pain she was experiencing was normal:

“

In my teenage years, I always had quite heavy periods, but was told not to think anything of it and that painful periods are normal, including by my friends and family. In my early 20s I started taking the pill to help with irregular bleeding. Then one evening I was taken to A&E due to abdominal pain. I had investigations for appendicitis, UTI, kidney infection, and countless internal investigations. After numerous doctor's appointments and hospital visits, I was referred for a laparoscopy and was diagnosed with endometriosis.”

Sunaina said:

“

There are many cultural taboos and barriers when it comes to talking about menstrual health conditions including endometriosis, which can prevent people from seeking help and getting a diagnosis. For decades, many women have had to suffer in silence due to misinformation, mainly stemmed from cultural barriers and conditioning.

In certain cultures, menstruation is still considered as dirty, and many are subject to missing out on aspects of their daily lives such as family occasions or visiting religious institutions because they are menstruating. This can lead to young people growing up with limited knowledge

of menstruation because their families shy away from discussing the issues with them, and thus delay seeking medical help or treatment.

“The general consensus within the Support Group, which I run, is that there is an unconscious bias within certain communities and women consequently find the condition to not only impact home and work life but their mental health too. Women do not have the knowledge, or feel they have the voice, to talk openly to even their parents or guardians because of these cultural barriers. Some women do not attend regular support group meetings due to fear of being caught or judged for going to a support group about menstruation”.

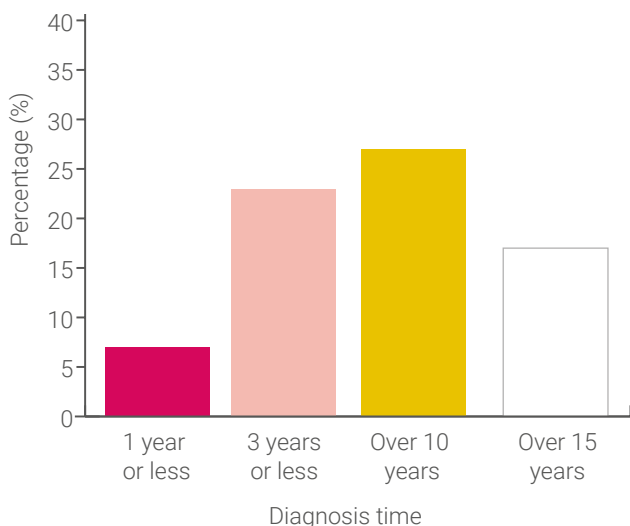
Natalie, has continuously not had her pain believed:

“

I was diagnosed with stage 4 endometriosis three years ago. Diagnosis has been incredibly difficult, with GPs not believing my pain, or telling me it's "all in my head". I've had pains in my chest which could be indicative of thoracic endometriosis, yet am constantly told "I've got anxiety" or "it might be a panic attack". I know my own body, and I am a personal trainer, yet am constantly undermined and dismissed by healthcare practitioners.

Even now I have had my diagnosis, I still feel I am fighting to be heard for my pain to be taken seriously. A lot of women of colour who I know, who have gone to A&E with endometriosis symptoms, or even diagnosed endometriosis, they have been told to have CBT therapy instead. It seems that we constantly have to justify our pain and fight for a diagnosis and support”.

The average length of time to diagnosis masks a huge variation in diagnosis times. For the 10,783 respondents to the survey, the average diagnosis time was 8 years. 38% of respondents said they had symptoms for 10 years or longer before receiving a diagnosis.



Andrew Kent, Consultant Gynaecologist and Vice President of the BSGE (British Society for Gynaecological Endoscopy) said:

“

Delay in diagnosis defers definitive treatment. If suspected on the basis of symptoms and non invasive investigations, medical treatment can be given, but that does not remove the disease. Definitive diagnosis is by laparoscopy which also allows removal of the endometriosis.”

Morgan was diagnosed quickly after visiting a new GP:

“

I consider myself extremely lucky. It took 3 years from going to my GP back in 2016 with pain, being told in this time it's likely to be IBS or PCOS, to eventually having a consultation with a new doctor and a laparoscopy and diagnosis within two months of visiting a new GP. The doctor initially ruled out other conditions with several different tests, and as they were all clear, he suggested I went for

a laparoscopy as my symptoms were suggesting I could have endometriosis. The doctor gave me information to research about endometriosis and having a laparoscopy, and following surgery it was confirmed I had endometriosis”.

Others told the APPG:

“

I had an extremely quick diagnosis. I had a lot of family history with endometriosis. I was offered a laparoscopy and it was confirmed I had endometriosis”.

“I was lucky to be diagnosed quickly with endometriosis, but left the hospital with no information about endometriosis whatsoever”.

“I'm currently waiting for a treatment plan – my endometriosis was discovered by accident during a different pelvic operation. I was told when I woke up, then no information followed. This followed years of being ignored, referrals “lost”, no information provided, and no treatment options discussed”.

“After I was diagnosed with endometriosis, no information was provided. I was told to just go on the pill with no further information about other treatments.”

“It's difficult to find someone who understands about the different treatment options. Often GPs have little understanding and you are left in limbo and in the dark with no information. There needs to be more understanding of what treatments are available”.

At present the only definitive way to diagnose endometriosis is by a surgical procedure called a laparoscopy (key-hole surgery), which involves a general anaesthetic and a camera being inserted through a small cut in the abdomen, and a biopsy of tissue is taken. Endometriosis may be suspected through other methods, for example through the history of symptoms, symptoms decreasing with hormonal treatments, or with ultra-sound or MRI scans – although endometriosis does not always show up on scans and a negative

scan does not exclude endometriosis. Endometriosis shares symptoms with some other conditions which may be ruled out first, using non-surgical tests. The APPG is calling for further research into a non-invasive diagnosis test for endometriosis, which had help people access a diagnosis more quickly and easily.

Whilst a definitive diagnosis cannot be made immediately with one visit to a GP or with one test, it is vital that GPs are educated to recognise the symptoms of endometriosis, and follow the NICE Guideline on Endometriosis: Diagnosis and management (2017) and NICE Quality Standard on Endometriosis (2018), including suspecting endometriosis when a patient presents with one or more of the common symptoms. The APPG were pleased to hear that the Royal College of General Practitioners (RCGP) has been working with Endometriosis UK to develop a menstrual wellbeing toolkit and e-learning for GPs. They would be keen to see this valuable resource for GPs being built on, and ensuring improved education to ensure recognition of the symptoms of endometriosis and other menstrual conditions by all GPs.

The NICE Guideline and Quality Standards on Endometriosis state that endometriosis should be suspected with one or more of the following symptoms:

- Chronic pelvic pain
- Period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- Deep pain during or after sexual intercourse
- Period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements
- Period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- Infertility in association with 1 or more of the above.

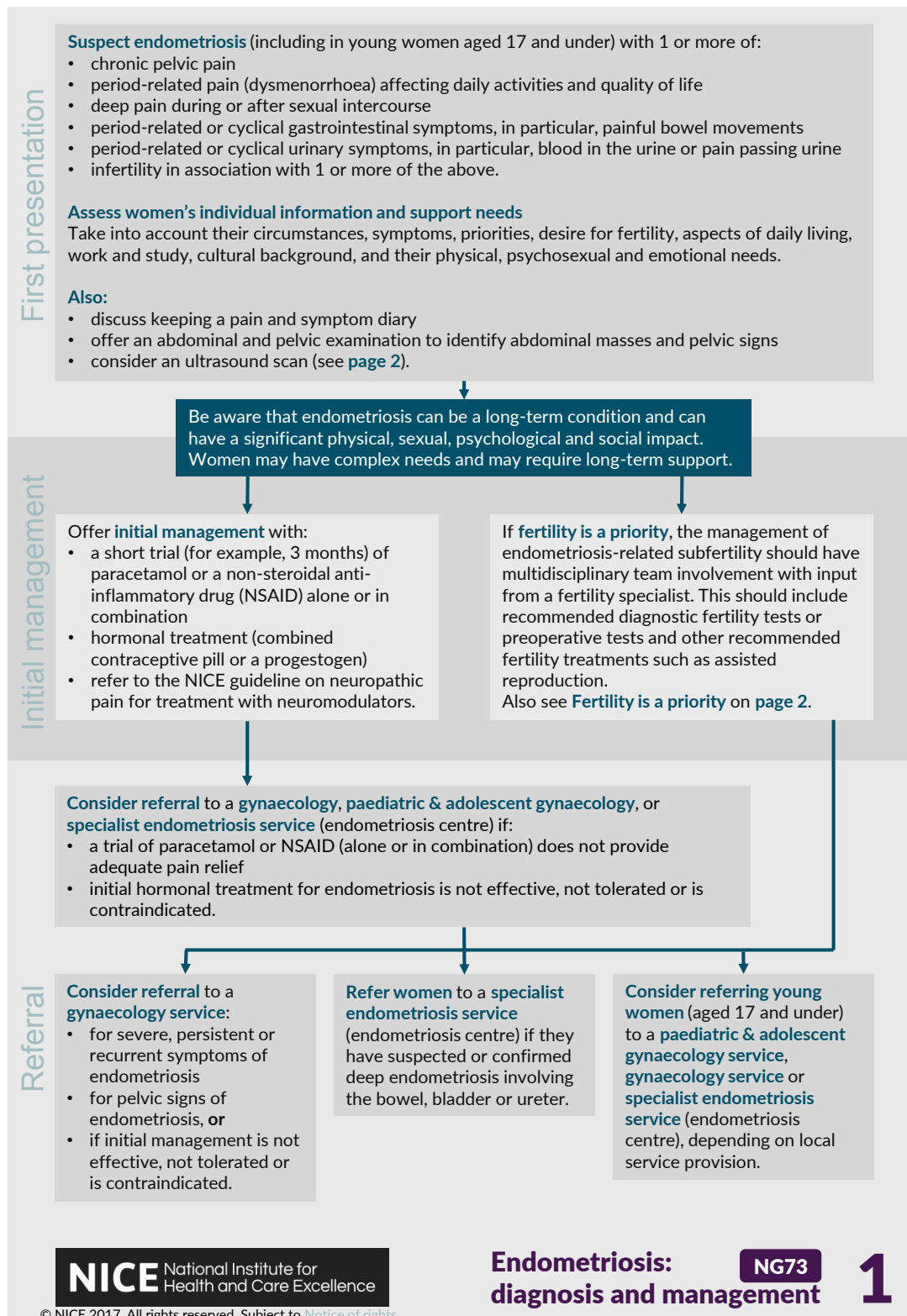
The NICE Guidelines present a care pathway for diagnosis, summarised as a flow chart in their document *Algorithm for diagnosing and managing endometriosis*, reproduced on the following two pages.

The APPG is calling for further research into a non-invasive diagnosis test for endometriosis

NICE guideline

Algorithm for diagnosing and managing endometriosis

<https://www.nice.org.uk/guidance/ng73/resources/algorithm-for-diagnosing-and-managing-endometriosis-pdf-4595719645>



Continued...

Algorithm for diagnosing and managing endometriosis continued.



The NICE Quality Standards on Endometriosis state that all healthcare practitioners should recognise the symptoms of endometriosis. The 8 years average time to diagnosis, along with oral evidence gathered as part of this Inquiry, indicate there is significant inconsistency of recognition of symptoms and suspecting endometriosis. Far too many report endometriosis never being mentioned despite long diagnosis journeys and multiple investigations for their symptoms.

Andrew Kent, Consultant Gynaecologist and Vice President of the BSGE said:

“

Recognising the signs and symptoms of endometriosis is key. Once considered, then a referral can be made but there is considerable variance in care at the present time. The possibility of endometriosis as the cause of pelvic pain needs to be discussed at the outset.”

In the Inquiry the APPG asked respondents what would improve your experience of getting a diagnosis for endometriosis and the most common theme was ‘being listened to’, ‘believed’ and ‘taken seriously’ by healthcare professionals, primarily GPs and gynaecologists.

Alice told the APPG:

“

When I first went to the doctor, I was tested for a lot of different STIs. Sex was painful, I was experiencing a lot of pain in my pelvis, and my periods were painful and difficult to manage. All the STI tests came back negative, but they were sure that this is what it was. I was sent on my way with some antibiotics, and left explaining to my partner that I’d been tested for STIs, but with no answers as to what this pain could be. I was left feeling confused, upset and embarrassed. A week later following a lot of pain I was rushed to hospital with suspected appendicitis. After this was ruled out, I was yet again left with no answers. I was years later diagnosed with endometriosis, after my friend had

mentioned the word to me, I’d looked at the symptoms, found the Endometriosis UK website, and it was like a lightbulb moment. I then underwent a laparoscopy and was diagnosed with endometriosis”.

Responses to the survey also included:

“

My age was held against me. I was 14 when my symptoms started, and I was told I would grow out of them. It was only when I had trouble conceiving that endometriosis was investigated”.

“It has been previously suggested by a GP that I might have an STI before even asking if I was sexually active. I was referred to gynaecology and endometriosis wasn’t mentioned until I was diagnosed”.

The Inquiry found that due to their symptoms but prior to diagnosis:

- 58% visited the GP 10 or more times
- 43% visited doctors in hospitals 5 or more times, and 21% 10 times or more
- 53% went to A&E, and 27% went 3 or more times

The APPG heard from many people who were referred to hospital but to the wrong type of doctor (not a gynaecologist), or for different tests, as endometriosis was not suspected. Common areas included to colorectal or gastroenterology departments, and for sexual transmitted diseases. In some cases, patients had even suggested endometriosis after their own research, however it was still not considered.

Several people told the APPG that they had to have their appendix removed prior to being diagnosed. One person told the APPG:

“

I was told to have my appendix removed just in case, and it was then they found a large cyst which needed removing along with my fallopian tube, at 18 years old”.

These figures highlight how individuals have struggled with the symptoms of endometriosis and often failed to secure a diagnosis after trying to engage with the healthcare system often on multiple occasions.

Many reported to the APPG the difficulty they had experienced trying to navigate a pathway to a diagnosis of endometriosis. The findings in our APPG survey highlight that much more needs to be done to support those living with endometriosis. The UK Governments should work closely with the NHS to ensure that the NICE Guideline and NICE Quality Standards on Endometriosis are followed, so that people have access to the right pathways to help manage their condition. Access to pain management services should be made available to all those suffering from endometriosis-associated pain, so that they do not unnecessarily end up in A&E.

Awareness

Lack of awareness of endometriosis was a major theme highlighted throughout the Inquiry, and covered three key areas:

- Lack of awareness of what a normal menstrual cycle is. Many said that this was due to societal taboos in talking about menstruation, and a historic lack of menstrual wellbeing education in schools. Cultural issues may create a taboo around discussing this pain and seeking help.
- Lack of public awareness of endometriosis. Recent research by Endometriosis UK shows that 54% of people do not know what endometriosis is, increasing to 74% of men. 62% of women between the age of 16–24 don't know what endometriosis is¹. With low awareness of endometriosis, those with the disease may not recognise the symptoms they are experiencing, or link them to the same condition. The lack of public awareness can have an impact on how employers and colleagues treat those experiencing endometriosis symptoms.

- Apparent lack of awareness of symptoms with some healthcare practitioners, resulting in those with endometriosis having to make multiple GP visits, gynaecology visits, A&E visits, and in investigations and sometimes surgery for other conditions.

A common issue that many respondents identified in this Inquiry through comments sections was the lack of awareness of what was a 'normal' period and level of pain, when to seek help, and how all too often people put up with pain and other endometriosis symptoms without seeking help. This flags to the APPG that more awareness is needed around endometriosis, and what normal pain and symptoms are, so individuals are encouraged to seek help when they need it. In addition, the most common theme from respondents when asked about what would help diagnosis was being believed by healthcare professionals, and the APPG is calling for more HCP professional awareness of endometriosis to help this issue.

Many who took part in the APPG oral evidence sessions explained how they learnt to live from a young age with severe, sometimes debilitating pain and other symptoms including bowel and bladder issues. The APPG Inquiry found that 42% of respondents stated that they often or very often, had time off school because of endometriosis symptoms.

Awareness of what constitutes 'normal' menstruation is low in school aged children and adolescents. The APPG were pleased to see, following campaigning by Endometriosis UK, Menstrual Wellbeing is included in the new mandatory relationships and sex education (RSE) and health education for schools in England, commencing September 2020. The APPG will continue to support and advocate for age appropriate, effective menstrual wellbeing education to be included as compulsory in the school curriculums for all children in both primary and secondary schools, and recommend this education is expanded into Scotland, Wales and Northern Ireland. We need to do more to break down

¹ The research was conducted by Censuswide, with a nationally representative sample of 2,000 adults (aged 16+) between 22.01.20-24.01.20 on behalf of Endometriosis UK

taboos that are present from an early age that prevent discussion or raising concerns about menstruation, and when they are raised, for them to be taken seriously.

Periods can start as young as 8 years old, and understanding of menstrual wellbeing from an early age will result in earlier recognition of symptoms of a range of menstrual conditions including fibroids, PCOS, heavy menstrual bleeding, adenomyosis and PMDD. As well as help being sought at an earlier stage, adolescents will have the knowledge and language to describe their experiences to help healthcare practitioners support a diagnosis. It is important this is delivered, age appropriately, at both primary and secondary school, so no child is scared about having periods rather it is done in a constructive way.

The more people willing to talk about periods, pain and what is normal, the more we can help remove stigma and the more quickly people will understand when to seek help and feel comfortable raising the issues with friends, family, teachers and employers.

Shaunee said:

“

My school years suffered massively due to endometriosis, but because I wasn't taught any different at school, I assumed it was normal. I thought it was part of growing up and being a woman. I missed out on school days and my education suffered massively. It wasn't until years later that I trained as a midwife that I sought help. It's vital menstrual wellbeing is taught in schools across Scotland, so that young people do not grow up suffering in silence thinking what they are experiencing is normal”.

Diagnosis

The Inquiry found that that there is an average of 8 years between individuals experiencing symptoms to the time when they receive a diagnosis. This is a significant period of uncertainty and doubt, without a name for symptoms and no clear treatment options as the condition has not been diagnosed and

may not even be suspected. Prior to diagnosis, treatment and support cannot be accessed and the disease may progress.

There are a variety of reasons patients may be delayed in securing a diagnosis. Individuals can be reluctant to seek help initially. This can stem from a lack of information around what constitutes a 'normal' period, normalisation of symptoms by family or peers, or their levels of pain not being believed. They can be put off from seeking help following a dismissal early on in their experience from a healthcare professional and then many encounter delays once they do enter the system, if symptoms are not recognised, or due to waiting times.

At the oral evidence session Anita explained how her experience as a teenager put her off seeking help again in her twenties and she did not go back to see the doctor until she saw a friend's post on social media when she was almost 30:

“

I was 14 was when I started seeing the doctors about my period pain, and was told that some women or some girls have more painful periods than others, and that's it. The thing is, at a vulnerable age when you're 14 you don't question a doctor, or you don't question what you're told ... I didn't have the confidence to go back to the doctor and ask any questions, nor did I even want to be put in that situation. It's just like you've been told so many times, why am I going to waste my time waiting at the doctors to then be told this is normal.'

Potential cultural barriers may deter people from accessing help. This was highlighted in the hearing on the impact of Covid-19, with examples of those finding it difficult to take phone appointments from healthcare practitioners in front of family, right through to difficulties in accessing services and stigma around menstruation that may be felt in some communities.

The first stage of seeking diagnosis is typically with a GP appointment to discuss the symptoms being experienced. As noted,

there is no simple test for endometriosis and the symptoms may overlap with those of other conditions and require investigation. The pathway recommended by the NICE Guideline on Endometriosis is shown on **pages 16–17**.

Throughout the inquiry, we heard of those who felt they'd 'got stuck' in a cycle of seeing healthcare practitioners, sometimes over many years, but unable to get an answer for what was causing their symptoms.

Prior to the Inquiry, a common theme heard by the APPG was the large number of GP, and sometimes hospital, appointments over many years, with no mention of endometriosis and not receiving a referral to gynaecology where this is needed to get a diagnosis. This was backed up by the survey results which showed that of the individuals who responded:

- 58% had 10 or more GP appointments with their symptoms before their diagnosis of endometriosis, with 41% having over 15 appointments prior to diagnosis.
- 21% visited doctors in hospital 10 times or more with their symptoms before their diagnosis of endometriosis.
- 53% went to A&E with symptoms before their diagnosis, with 27% going to A&E more than 3 times.

The APPG recognise that generally more than one appointment will be needed prior to diagnosis, with both a GP and gynaecologist usually needing to be seen, and tests or possibly treatments tried prior to a laparoscopy. There were good examples of GPs recognising symptoms, providing excellent support, and prompt referral to gynaecologists to achieve a diagnosis. However, a recurring theme from the inquiry was of multiple GP appointments, often over many years, and difficulties in getting a referral to a gynaecologist. The APPG would not anticipate so many needing 10 or more appointments before receiving a diagnosis for endometriosis, which many reported. Unnecessary GP, hospital and A&E appointments can cause capacity issues in both primary and secondary care and cost the

NHS time and money, as well as impacting the individuals' experience and the possibility of the disease progressing if left untreated.

The NICE Guideline is clear that there should be a prompt diagnosis, and the NICE Quality Standard reinforces this, identifying 6 months as the time period for onward referral for those with symptoms of endometriosis.

The NICE Guideline states that endometriosis should be suspected, including in women aged 17 and under, with one or more of the symptoms listed. Evidence from the Inquiry demonstrates that this is often not the case. The impact of not getting a diagnosis nor being able to access help to manage endometriosis can have on both physical and mental health is clear. From the survey undertaken and evidence heard, GPs can do more to ensure the NICE Guideline and NICE Quality Standard on Endometriosis are being followed, and that those presenting with symptoms of endometriosis are recognised and supported for a prompt diagnosis.

“

There was no mention of endometriosis despite me saying I do not have regular periods but am still in agony all the time. Endometriosis was only explored when I researched my symptoms online and found a support group”.

“My GP initially didn't refer me – I was told that the pain I was experiencing was normal. It was only after a second opinion from a different GP that I had a diagnosis”.

It is recognised that some individuals may choose not to get a secondary care referral and are content to be treated at a GP level, for example if endometriosis is suspected, good information is provided including on the potential long term impact and fertility, and initial hormonal treatment is effective. However, for those who seek a confirmed diagnosis and access to secondary care treatment, more needs to be done to ensure they can get this referral in a prompt and effective manner.

Appropriate investigations and wider symptoms

A further theme from the inquiry hearings was of those who'd been 'put on the pill', often as adolescents, due to severe pelvic or pain, but with no explanation or investigation about what the cause of the pain might be. The impression they received is it was 'normal' pain and they had no idea it could be a symptom of a long term condition. If pain increased over time, different types of hormonal contraception might be tried, or some felt it was 'their lot' to have very painful periods and nothing could be done. Other endometriosis symptoms such as bowel problems were not related to their pelvic pain, and often investigated for other conditions. It was only when they came off the pill, sometimes after many years to have a break from it or with a desire to get pregnant, their symptoms came back 'with a vengeance', and they pursued a diagnosis. Some felt this lack of knowledge had cost them their opportunity to succeed in education and career, or to have children.

One person told the APPG:

“

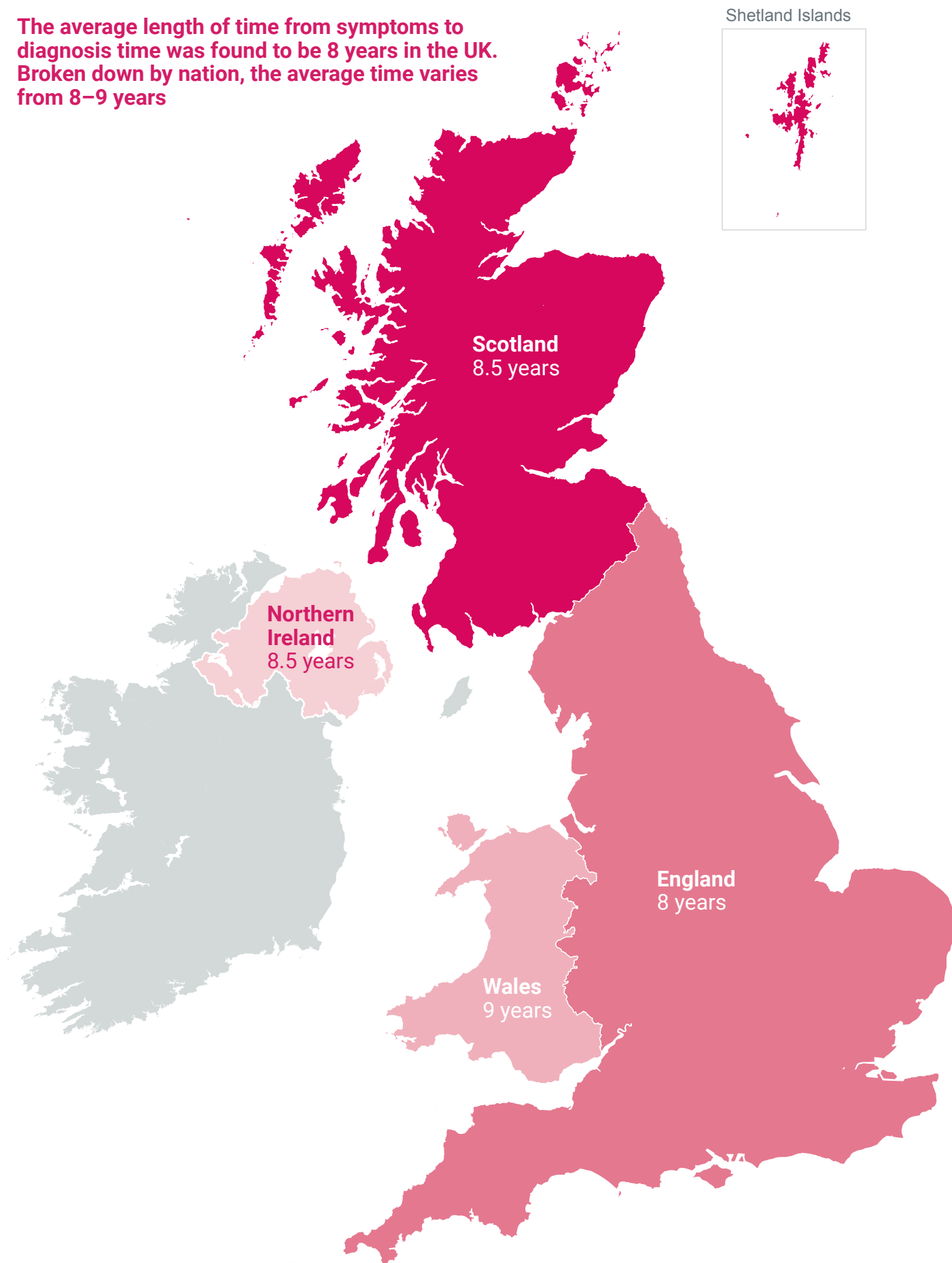
I wish I'd had my symptoms investigated rather than being put on the pill to mask the pain, as the endometriosis then damaged my fertility”.

The inquiry results demonstrate the need for pelvic pain that is impacting on day to day living to be taken seriously, including in adolescents. If symptoms are severe enough for long-term medication, the possible cause and implications should be discussed. Healthcare practitioners should be aware of symptoms of endometriosis to be able to join up the dots for those that were put on pill due to pelvic pain and later present with other symptoms. The APPG encourages the RCGP to look at ways to share best practice in supporting the diagnosis of endometriosis and implementing the NICE Guideline and Quality Standards on Endometriosis.

The 8 year average diagnosis time is the same as a decade ago. This has to change. The APPG recommends a target for diagnosis time, an average of 4 years by 2025 and under 1 year by 2030 in order to make the significant improvements that are needed.

The 8 year average diagnosis time is the same as a decade ago. This has to change.

The average length of time from symptoms to diagnosis time was found to be 8 years in the UK. Broken down by nation, the average time varies from 8–9 years



Wales has only one endometriosis specialist centre, in Cardiff. The inquiry heard about long delays in getting hospital appointments for those living in Wales, and sometimes refusals for patients to be referred to endometriosis specialist centres rather than their local hospital where there may be no endometriosis expertise. Whilst there are cross border agreements for treatment, for example for those in North Wales to attend the endometriosis specialist centre in Liverpool, this does not always happen. Instead, referrals may be to local general gynaecology, even for deep endometriosis which the NICE Guideline is clear must be seen in a specialist centre. The Welsh Government undertook a review of provision of endometriosis services in Wales, which recommended an enhanced service to provide good care for all those with endometriosis in Wales. The recommendation is currently being considered for implementation.

In Scotland, three endometriosis specialist centres exist and were planned to provide specialist endometriosis coverage for the whole of Scotland. However, these are currently being commissioned as local services and for local capacity, and it has been difficult to get a referral if you live in a different health board area. For some, this can mean no access to specialist treatment even if suffering from deep endometriosis. The Scottish Governments *2019 – 2020 Programme for Government Women’s Health Plan*, work being led by the Chief Medical Officer’s Directorate of the Scottish Government, is currently considering the funding of the three specialist endometriosis centres in Scotland to provide a national service, along with reducing diagnosis time, improved care pathways, and improving menstrual health and endometriosis care throughout Scotland. Endometriosis has specifically been included in one of the 5 sub groups of the Women’s Health Group, the Menopause and Menstrual Health including Endometriosis Sub Group.

Northern Ireland has one provisional BSGE accredited centre. We have heard of very long waiting times for diagnostic laparoscopies and accessing general gynaecology and specialist endometriosis care, with some waiting over 2 years.

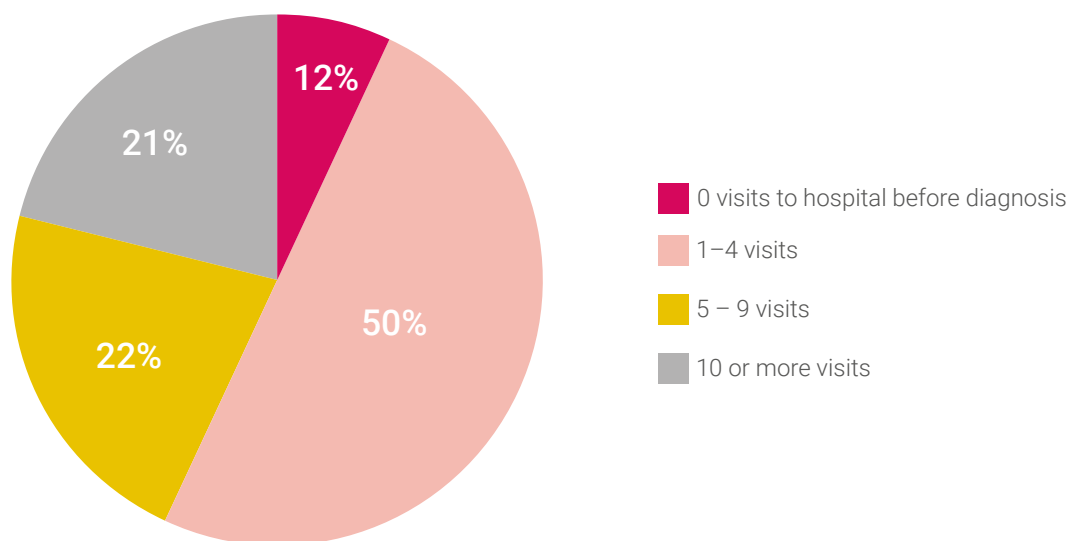
The APPG is calling for equitable access for all individuals, regardless of where they live in the UK.

Through our survey we found that 21% needed 10 or more visits to doctors in hospital before receiving a diagnosis – this may, for some, include being seen not by a gynaecologist but by other specialists if endometriosis wasn’t initially suspected.

The APPG were surprised at the number of respondents who, prior to diagnosis, had symptoms so serious that they had to attend A&E. 53% of all respondents visited A&E prior to receiving a diagnosis, with 27% having been to A&E three or more times prior to diagnosis. Of those who identified as being from a black, Asian or minority ethnic group, 31% reported attending A&E 3 or more times prior to diagnosis. A similar pattern was found in each nation, and it is clear that more needs to be done across the UK to improve the time to diagnose for people, and how many times they have to seek help for their symptoms.

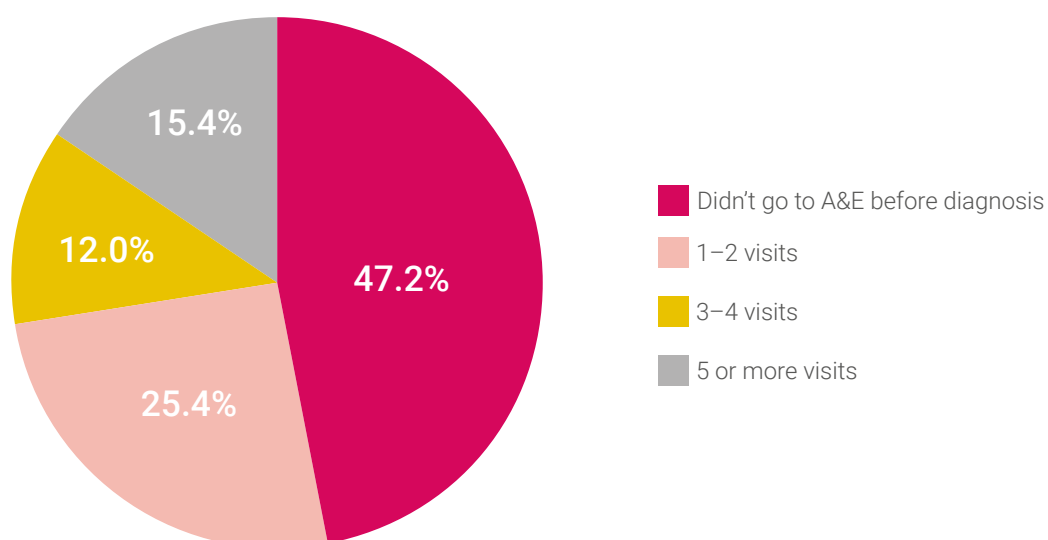
53% of all respondents visited A&E prior to receiving a diagnosis

If you have been diagnosed, approximately how many times did you visit the Doctors in hospital with your symptoms of endometriosis, before you received a diagnosis for endometriosis?



If you ever went to A&E with your symptoms before receiving a diagnosis, please tell us how many times

England, NI, Scotland, Wales



Waiting times

An additional challenge that those with endometriosis face is the waiting times for gynaecology appointments – already an issue prior to the pandemic. Following this there may be further tests, sometimes repeats of those done in primary care, and waits for a diagnostic laparoscopy appointment. Resource is an issue in this area with a limited number of gynaecology appointments available on the NHS and limited access to those specialists diagnosing and treating endometriosis.

Prior to Covid-19, it was found that in the UK 30% of patients were waiting 10 or more months for surgery. However, by nation there was significant disparity. In England 17% of patients were waiting 10 months or longer for their surgery, in Scotland this was less at 13%, whilst in Wales it was 32%, and in Northern Ireland 42%. The APPG call on all Governments to ensure that waiting times are minimised.

Linda told the APPG:

“

I was told I'd have to wait up to two years for a laparoscopy in Northern Ireland, despite being in severe pain. This was having already waited a year to see a consultant for an initial appointment. I ended up travelling to England to see a BSGE specialist privately, which has led to financial issues. It has also been emotionally draining to have to push for treatment away from home, and then having to recover from surgery away from family and friends”.

Pathways should include streamlining the diagnosis process, reducing GP appointments, avoiding unnecessary referrals to the wrong specialty and stopping A&E presentations. This would save both time and money for the NHS and greatly improve the experience for those with endometriosis.

The APPG is calling for more training, awareness, and support in primary care along with appropriate referral pathways being implemented, to ensure a more streamlined and effective diagnostic process, and avoiding

unnecessary GP visits, presentations to A&E and unnecessary referrals prior to receiving a diagnosis.

Diagnosis experience

The APPG asked those who responded to the survey ‘what would have improved your experience of getting a diagnosis for endometriosis?’ The main themes that came through in the comments section were:

- Many specifically quoted ‘being listened to’, ‘believed’ and ‘taken seriously’ by healthcare professionals, primarily GPs and gynaecologists
- Quicker referrals and reduced time to diagnosis
- More empathy and understanding from GPs and gynaecologists
- More support from healthcare professionals throughout the diagnosis process, including more information being given at an earlier stage on what the disease is, potential treatments and impact
- Better understanding of what a ‘normal’ period is and being able to identify if the pain and symptoms experienced are not ‘normal’

The next stage of the pathway after seeing a GP will most frequently be to see a gynaecologist, but often these referrals can be to those who are not specialists, which can cause further delay and concern for patients. In the APPG survey 32% of respondents found their gynaecologist unhelpful or very unhelpful, whilst 46% found their GP unhelpful or very unhelpful. This signposts that more support and care needs to be given to patients throughout the pathway.

Whilst some secure a prompt diagnosis of endometriosis, demonstrating it can be done, it is clear that for many it can be a lengthy and difficult process. It is recognised that symptoms vary, and diagnosis is not as straightforward as those conditions where there is a simple, non-surgical diagnostic test. However, much more needs

to be done to ensure GPs, practice nurses and gynaecologists follow the NICE Guideline and NICE Quality Standards on Endometriosis in terms of recognising symptoms and suspecting endometriosis, securing appropriate referrals to gynaecologists with expertise in endometriosis. Lindsey, 42, was diagnosed with thoracic endometriosis in 2020, after a 20 year battle to get diagnosed, and being sent to various specialists:

“

I started my period in 1991, which were always very painful, and I was told and dismissed for years that this was “normal”. It wasn’t until 2009 that I received an official diagnosis of endometriosis via a laparoscopy, following previous surgeries and scans. 11 years later in 2020, I was also officially diagnosed with thoracic endometriosis. This has followed years of ending up in A&E regularly, and being misdiagnosed with asthma.

In November 2019 I was referred for my first lung CT scan, and in the February had my second, where I was told there was no change in abnormalities and was referred to a chest specialist at the hospital. I have seen by various specialists over the years, but it took over 20 to be seen by the right one and get the thoracic endometriosis diagnosis that I had been waiting for. It is terrifying to think what damage is done to your body during this time without the right course of treatment”.

Doctors can find it challenging supporting patients to get to the right place to for a diagnosis and support. Anne Connolly, Clinical Champion for Women’s Health at the RCGP and Chair of the Primary Care Women’s Health Forum, explained some of the challenges:

“

We need good referral pathways, so we get it right first time. Using Choose & Book can be very clear for many conditions, for example for fertility there will be a local fertility clinic, or for cataract surgery it is clearly signpost where this is being done and who to book with, there are

limited choices. But if I’m trying to refer for suspected endometriosis it’s just ‘gynaecology’ with loads of options to pick from. There’s no signposting as to who may have experience or where is an endometriosis specialist centre. Better pain management options are also required, so GPs are able to refer patients with endometriosis and chronic pelvic pain to where they can get help.”

The APPG were pleased to hear of the work the RCGP is doing to develop GP awareness and knowledge of endometriosis and other menstrual health conditions. The RCGP has, in partnership with Endometriosis UK, developed an online Menstrual Wellbeing Toolkit for GPs, as part of their Women’s Health Hub. This includes resources to help with consultations, e-learning units eg on endometriosis and heavy menstrual bleeding, and podcasts with patients to understand the patient journey. Within the Woman’s Health Hub, a Covid-19 section is being developed, to help GPs support their patients during these difficult times.

The APPG will be following up with the RCGP as to what is needed to enable and support effective diagnosis in primary care.

Rapid Diagnostic Centres for cancer – any learning for diagnosing endometriosis?

The NHS has committed to roll out Rapid Diagnostic Centres (RDCs) to “deliver faster and earlier diagnosis and improved patient experience” specifically for cancer¹. The ambition for the RDCs is to have a single place where patients with symptoms that could indicate cancer can go to and have all the tests done, by experts with good quality equipment. The APPG are keen to see if there are learnings from RDCs improving pathways and efficiency of diagnosis that could be applied to endometriosis.

¹ <https://www.england.nhs.uk/wp-content/uploads/2019/07/rdc-vision-and-1920-implementation-specification.pdf>

Recommendations

1. A commitment from the NHS's across the UK to drive down diagnosis times

Diagnosis time is not decreasing; this must be improved to support those with endometriosis. The APPG recommends a target for diagnosis time be adopted across the UK, an average of 4 years or less by 2025 and under 1 year by 2030. The APPG recommends the following actions to support this reduction in waiting times:

- Implementation of the NICE Guideline on Endometriosis: Diagnosis and Management (2017) and NICE Quality Standard on Endometriosis (2018) across the UK.
- Endometriosis and menstrual conditions training at medical schools to be reviewed and improved.
- Support the RCOG (Royal College of Obstetricians and Gynaecologists) and RCGP (Royal College of General Practitioners) to ensure appropriate training and education within their curriculums and experienced based training.

2. The NHS and Governments across the UK to recognise the scale of endometriosis

and commit the resources needed to diagnose, treat and manage the disease effectively; acknowledging it is a chronic condition and long-term support is needed.

3. Increase healthcare practitioner awareness of endometriosis signs and symptoms,

as stipulated within the NICE Quality Standards.

4. Build NHS capacity to appropriately diagnose those with endometriosis

- Prompt referrals from primary to secondary care, including for diagnostic laparoscopy, by ensuring capacity within gynaecology departments and endometriosis specialist centres.

- Identify learning from the Rapid Diagnostic Centres being implemented to reduce times for diagnosing endometriosis.

5. Awareness

- Raise awareness with the general public of what a 'normal' period is, the symptoms of endometriosis and other menstrual conditions, and when to seek help.
- UK Governments and all departments not to use the words 'sanitary' or 'hygiene' when referring to period products, as this gives and reinforces the message that periods are dirty.

6. Education

- Scotland, Wales and Northern Ireland to mandate teaching of menstrual wellbeing within the school curriculum.
- Ensure education on menstrual wellbeing is adopted by all schools in the UK, and teachers are given sufficient support and resource to ensure all young people have access to the same level of menstrual wellbeing education.
- Endometriosis symptom awareness with school nurses and other healthcare practitioners in educational establishments.

Chapter 2

Treatment and care pathways

The APPG has heard that there is some excellent care and support provided across the UK, including prompt diagnosis and effective treatments, however unfortunately this is not the case for all with endometriosis.

The Inquiry heard that there is a wide variation in the standard of care that those living with endometriosis experience across the country, and the APPG will push to make sure that everyone living with endometriosis has access to the best possible care. Whilst there are a variety of experiences that respondents have gone through, what is clear is the bespoke measures needed for individuals, and how

different people need access to different treatments and therapies.

After often a long diagnosis process, the inquiry heard that many were disappointed they could still not access specialist care or the help they would like once they had a firm diagnosis of endometriosis.

What is an endometriosis specialist centre?

For classification as a British Society for Gynaecological Endoscopy (BSGE) endometriosis specialist centre, the following specialisms are needed:

- A dedicated consultant lead endometriosis service run within a specialist outpatient clinic.
- Appropriate workload: the requirement is for a minimum of 12 cases annually per named gynaecologist for each centre.
- A named colorectal surgeon is required to support the service.
- A support network is required which includes urologists and pain management specialists who declare that they will provide active support to the service when needed.

- Written agreement from the lead Gynaecologist in the Centre that all cases of rectovaginal endometriosis (as defined by dissection of the pararectal space) will be entered on to the BSGE database, and will be followed up for two years post-surgery.
- Endometriosis Specialist Nurse.
- Submission of an exemplar video of surgery for laparoscopic excision of severe recto-vaginal endometriosis.

Specialist endometriosis services, often referred to as an endometriosis centre, are not as some people assume, a physical building with dedicated staff. Rather, it refers to a grouping of clinicians in a hospital offering support and integrated care, provided by a 'multidisciplinary' team as outlined above. The size of teams, the amount of time they work on endometriosis, and the amount of scheduled operating time they have varies, and some centres may undertake less than 20 operations a year.

Endometriosis specialist centres are in place to ensure patients with deep endometriosis, 20% of those with endometriosis, can have access to specialist knowledge, surgery and support. There are currently 63 centres in the UK, however the capacity in each centre varies significantly, with some having capacity to undertake surgery on less than 20 patients per year. The APPG welcomes the introduction of these centres in 2008 and the step change in care that these provided to patients. However, as outlined in the data, and the oral evidence heard from patient advocates, not all those who should be seen in a specialist centre are able to access care, and many have not even heard of the specialist centres.

Only 19% of respondents knew that they were seen in endometriosis specialist centres. Yet 60% reported urinary symptoms and 84% bowel symptoms, possible indications of deep endometriosis. The NICE Guideline states that all those with suspected or confirmed deep endometriosis should be seen in an endometriosis specialist centre.

The survey identified significant variation across the UK. Whilst the percentage of respondents who knew that they had been seen in an endometriosis specialist centre was 19% for the UK, by nation this was:

- England 20%
- Wales 17%
- Scotland 15%
- Northern Ireland 10%

This again highlights the potential gaps in service that those with endometriosis face when trying to access specialist treatment, and the urgent need to ensure the provision of endometriosis specialist care is planned and put in place for each nation.

The data highlights the wider problem identified within this report that the system is not working in terms of how capacity is allocated. It is clear that people who need it are being left without specialist treatment, and the APPG recommends that everyone with suspected or confirmed endometriosis should be seen by a specialist who has received

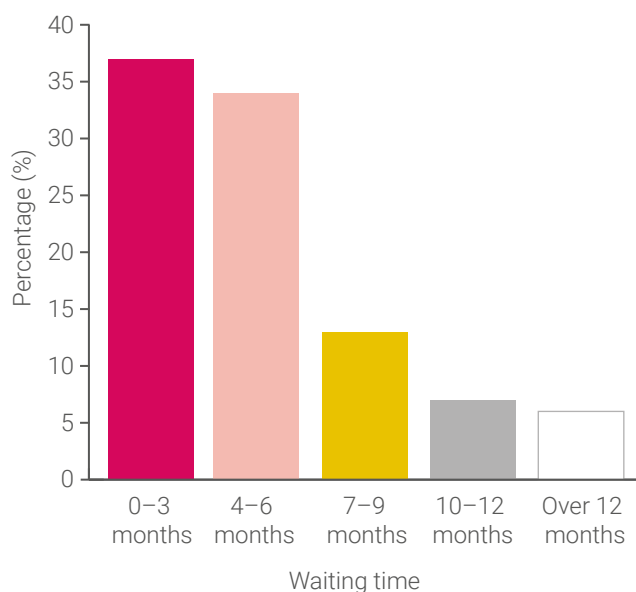
specialist training as per the NICE Guideline; this is not currently happening.



I had to fight for a diagnosis and to be seen by a specialist. At first I was operated on by a general gynaecologist and was told I didn't have endometriosis. I then sought a second opinion and was seen by an endometriosis specialist and was diagnosed via a laparoscopy with endometriosis, and it was excised. It's so important people are seen by a specialist so people are not having surgery unnecessarily".

Waiting times

The APPG survey, undertaken before the Covid-19 pandemic, found that the waiting time from when someone was referred to see a gynaecologist to when they had their appointment was:



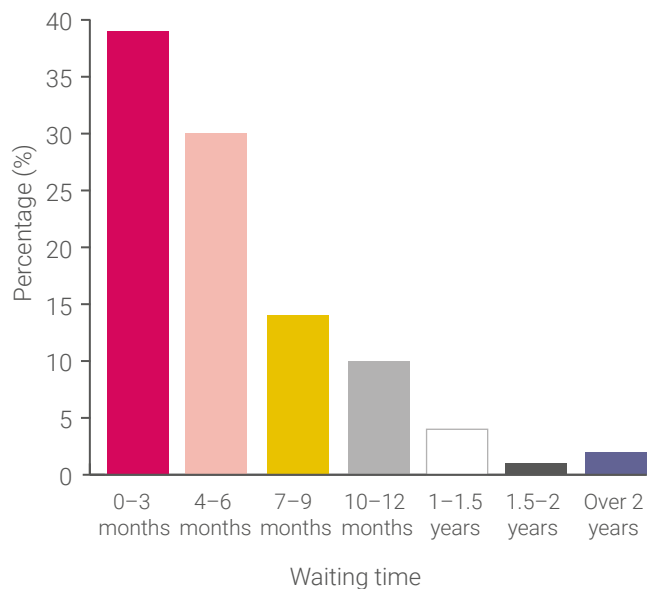
The NICE Guideline on Endometriosis expects endometriosis specialist centres to have the capacity to see the 20% of those with endometriosis that have deep endometriosis¹. Even if it was being achieved, which our survey indicates is not happening, it means that 80% of those with endometriosis – 1.2 million – will not be able to be receive diagnosis and care from a healthcare practitioner with the specialist training to recognise and treat the disease. It is crucial that the NICE Guideline recommendation for every gynaecology department to have a gynaecologist with specialist training in endometriosis is implemented as soon as possible.



I wish I'd had an immediate referral to a specialist rather than a general gynaecologist. These mis-referrals took several months and slowed down the process of putting me on the waiting list for surgery. Meanwhile my symptoms were worsening”.

As endometriosis may grow in various locations within the body, its impact will be different for different people. Whilst for some their symptoms will be minimal, for others it can have significant, wide ranging and sometimes debilitating impact. Expertise and cross disciplinary teams are needed in order to provide the treatments and advice that those suffering with certain symptoms and forms of endometriosis need. Endometriosis may also progress over time, making timely diagnosis and treatment important.

The APPG asked in relation to responders’ last surgery, how long did it take from when you and your gynaecologist agreed you should have surgery to you having that surgery, the answers were



Whilst the APPG welcomes the news that 39% of respondents had surgery within 3 months of it being agreed, there are concerns that 61% are waiting over 3 months for necessary surgery to help alleviate symptoms from endometriosis. This was prior to Covid-19 and the additional delays that has brought.

Not all will have surgery for endometriosis, however some have had multiple procedures. In this survey, 27% of individuals have had 3 or more operations; and 10% had 5 or more operations. The APPG is calling for more research into treatment and management of endometriosis to ensure effective options for treatment can be provided, the efficacy of surgery for different situations is known, and to enable informed choice about future treatment options and their impact.

People should be given the appointments they need to manage their condition, and this will vary from individual to individual in terms of the symptoms they experience, and any recurring symptoms.

Some with endometriosis may need multiple appointments with their gynaecologist as treatments are tried to manage the condition,

¹ <https://gynecologysurg.springeropen.com/articles/10.1186/s10397-019-1065-9>

or if symptoms return. However, the Inquiry found that even those with a confirmed diagnosis could experience difficulties in getting a referral to gynaecology if symptoms recur. Despite being a chronic condition, the APPG heard frequent examples of those with previous diagnosis having to go through a range of procedures again to get a referral to a gynaecologist. The APPG is recommending that endometriosis is treated like the chronic condition that it is so that it is easier to access specialists, if necessary, once diagnosed.

One person told the APPG:



Following my surgery I was discharged from my gynaecologist straight away. This meant that when symptoms returned I had to be re-referred and started with the process again”.

Type of Treatments

The type of treatment a patient receives for endometriosis should be decided in partnership with the healthcare professional. Access to specialists is key for those with more complex cases of endometriosis in order to gain expertise to treat the condition. Different treatments will work for different people, and may vary for an individual over time. For example, 25% thought the surgery they received was extremely effective or very effective, whilst 17% thought it was not at all effective and 30% thought it was only slightly effective. No treatment was deemed extremely effective or very effective by over 30% of responders, highlighting some of the issues in treating endometriosis and the need for further research in this area.

The APPG is calling for further research into treatments, management, causes of and, ultimately, a cure for endometriosis to help those affected by the condition find help to live with the condition, which they are currently struggling to do.

In discussion of treatments that were offered, the key themes from respondents to the Inquiry were:

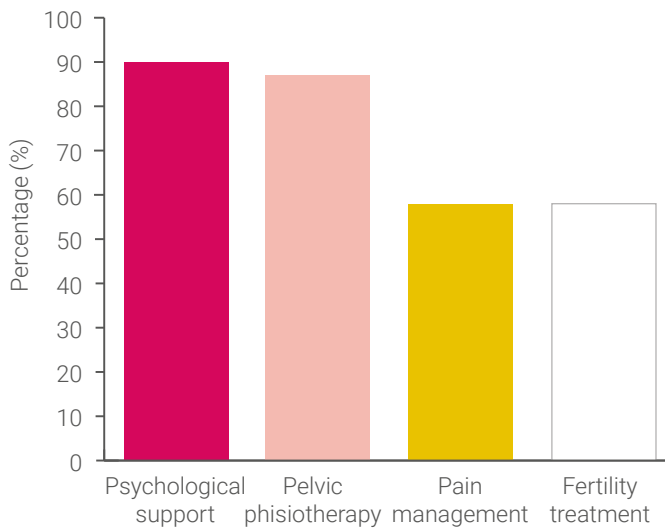
- The prominent concern was around pain and a lack of pain management support
- Lack of access to treatments
- Concern around treatments reportedly failing to help with symptoms
- The wish to access treatments that they were not offered
- A lack of clarity around what treatments were available
- More information on the impact of treatments that were offered

Some respondents indicated that what was offered as a treatment was not fully explained and may have failed to help or they had not been aware of side effects. Several examples were heard of being recommended and given hormonal injections that induce a medical menopause, without any understanding of the possible side effects this may have.

When asked what treatment you would have liked to have accessed but were not offered:

- 90% would have liked access to psychological support
- 87% would have liked access to pelvic physiotherapy
- 58% would have liked access to pain management
- 58% would have liked access to fertility treatment, but were not offered it

Treatments that people would have liked access to but were not offered



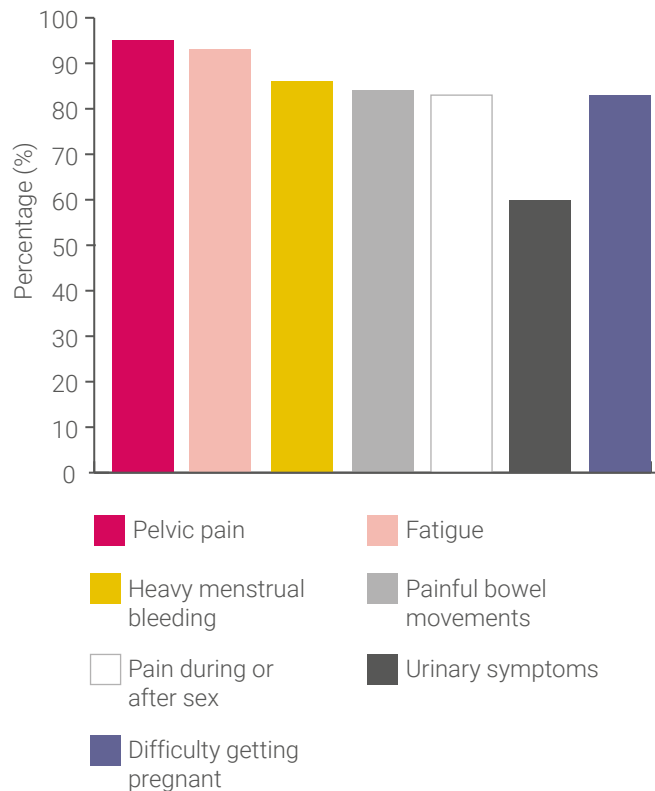
Other treatments such as surgery, hormones and prescribed painkillers were more likely to be offered.

Endometriosis is a chronic pain condition however the inquiry highlighted that it is seldom treated like this in the NHS, resulting in the majority of those diagnosed not being offered pain management or interventions such as pelvic physiotherapy. As these figures show overwhelmingly people want access to these services, and this should be a priority part of the pathway moving forwards.

Regarding which endometriosis symptoms had the worst effect, the APPG found that survey respondents stated the following symptoms had a negative or very negative impact:

- Pelvic pain – 95%
- Fatigue – 93%
- Heavy menstrual bleeding – 86%
- Painful bowel movements – 84%
- Pain during or after sex – 83%
- Urinary symptoms – 60%
- Difficulty getting pregnant (for those for whom this was relevant) – 83%

Endometriosis symptoms that had a negative or very negative impact



These results highlight the importance of wider care and treatment for those with endometriosis in order to support individuals in managing symptoms such as pain and fatigue. As well as appropriate investigations, support for these symptoms should be provided. The APPG heard of individuals being put on the pill due to chronic pelvic pain with no investigations. If someone is in enough pain to receive medication, the cause should be investigated.

Professor Andrew Horne, University of Edinburgh and Trustee of Endometriosis UK, said:



To deliver well-designed, large scale, collaborative research requires money. To see real progress, we need significant financial investment into endometriosis research and for that we need support from politicians and governments. Research is pivotal to understanding the cause of the disease, better treatment options, and one day a cure. Without research, people with endometriosis will continue to face huge barriers in accessing the right treatment”.

The APPG is calling for more research and investment into treatments for endometriosis to help those who find current treatments have minimal effectiveness and to help those in the future manage and treat their condition. Areas for research include:

- Effective treatment and management
- Diagnosis
- Lifestyle and wellbeing
- Cause

Treatment experiences

The APPG asked those who responded to the survey ‘What would improve your experience of ongoing treatment for endometriosis?’ The answers predominantly were themed around the below points, listed in order of priority:

- Help with pain, either in terms of formal pain services or advice on management of pain
- More support – including access to specialists, and wider support in terms of pain management and psychological support
- Shorter waiting times for referrals and appointments
- Regular appointments and check-ups

- More information on diagnosis
- More knowledge and awareness from the healthcare professionals speaking to
- More understanding and compassion from healthcare professionals
- Mental health and psychological support
- Increased access to specialists – at accredited specialist centres or endometriosis specialist nurses

The APPG asked those who responded to the survey ‘What would improve your experience of managing living with endometriosis?’ The answers predominantly were themed around the below points and are listed in order of priority:

- Help with pain management
- More support from healthcare professionals
- More help to manage the symptoms
- More understanding
- Mental health and psychological support
- More understanding from employer
- Access to specialists and care
- More awareness
- More information
- Physiotherapy

pain management support understanding pain work
hysterectomy better understanding disability psychological support
support group employer people endometriosis information symptoms
conditions awareness time pain relief access mental health surgery options doctor
pain killer emotional support better pain management better pain relief workplace gp cure options
fatigue disease mental health support work place pain medication treatment options financial support
regular check ups public awareness better access better support quality of life chronic pain

Vicky told the APPG that she has received a good pathway of support for diagnosis and treatment for her endometriosis:

“

I hadn't heard of endometriosis until I was diagnosed in 2017. I initially had an MRI scan which showed suspected endometriosis, and was subsequently referred for a laparoscopy and was diagnosed with endometriosis. I have since been seen by an endometriosis specialist, and have tried various treatments to find what has worked best for me. I was initially offered to go into temporary menopause, which I didn't want to do, and my specialist supported me in finding a treatment option that worked best for me”.

Supporting Healthcare Practitioners

At present, the NICE Guideline on Endometriosis states that endometriosis specialist centres – virtual multi-disciplinary teams within a hospital setting, as specified by the BSGE – should see all those with suspected or confirmed deep endometriosis, an estimated 20% of patients. This leaves 80% of patients to be seen in general gynaecology clinics, where there may be seen by someone with no expertise in diagnosing or treating endometriosis.

The NICE Guideline states that all general gynaecology departments should have a gynaecologist with a special interest in endometriosis. This should be a competency and skills based qualification, however requiring a lower level of experience than required at a specialist centre. This

competency based qualification has not yet been developed, and as far as we are aware there have been no appointments to this role.

It is recommended that the BSGE work with the RCOG to develop and accredit the 'special interest in endometriosis' competency, including setting the training experience initially and on an ongoing basis, along with time spent in specialist centres to develop skills including excision surgery; becoming a member of the BSGE, and demonstrating keeping up with new developments and best practice. Not every gynaecology department should be a specialist centre, but every gynaecology department should have an allocated post of a gynaecologist with a special interest in endometriosis, who can ensure that those with suspected or confirmed deep endometriosis are referred to an endometriosis specialist centre, along with a formal link to an endometriosis specialist centre.

Having this two-tier system would support GPs in referring to the right place as referrals via Choose and Book would only be to those qualified in endometriosis. This is comparable with other specialties.

Andrew Kent, Consultant Gynaecologist and Vice President of the BSGE, highlighted the importance of skills and experience in treating endometriosis:

“

Recognising the signs and symptoms of endometriosis is key. Once considered, then a referral can be made but there is considerable variance in care at the present time. The possibility of endometriosis as the cause of pelvic pain needs to be discussed at the outset.”

From the Inquiry, the APPG believe there is not enough capacity planned within the NHS to treat the numbers with endometriosis in secondary care. Specialist endometriosis centres, as specified by the BSGE, have developed in locations where individuals with an interest in endometriosis are based, and if the individual leaves or retires there is a risk the centre may cease to exist. It's a postcode

lottery as to where specialist centres are and if patients can access them, with many reports of those with deep endometriosis not being seen in by endometriosis specialists. With the exception of Scotland where it was decided at a national level there should be 3 specialist centres, there seems to have been no overall strategy or planning within the NHS to provide this needed specialist service. Recommendation: the NHS in each nation to ensure specialist centre provision to meet the demand is planned, commissioned and funded. Succession planning is needed to ensure continuation of experience.

In order to develop and improve services, more data is needed. An audit and QA programme would enable understanding of the challenges faced by the NHS in delivering an effective endometriosis service, and how these can be addressed. An endometriosis registry should be set up to collect and collate data on treatment and management.

Recommendations

1. Governments and NHS' recognising endometriosis as a chronic condition

and having a pathway so if symptoms recur individuals can access the care they need.

2. Governments and NHS' to plan and provide a specialist service available to all that need it,

including planning a endometriosis specialist centres to meet the needs of patients in their country.

3. Access to pain management services

are made available to all those suffering from endometriosis-associated pain that include a range of interventions, not just being offered painkillers.

4. Funding for research

for better treatment and management options, to discover the cause of the disease, and one day a cure. Without investment in research, future generations will continue to suffer and not get the care and support they deserve.

Care Provision

Endometriosis is a chronic and sometimes debilitating condition, requiring support and care from healthcare practitioners in order to diagnose, treat and manage the condition. Care may be required from a range of healthcare professionals, including GPs, practice nurses, gynaecologists, specialist nurses, fertility specialists, colorectal specialists, physiotherapists and pain management specialists.

In the APPG survey respondents were asked how helpful they found their GP in supporting them with endometriosis/symptoms and 46% of responders said that their GP had been unhelpful or very unhelpful. The majority of responders, 63% stated that if they wanted to speak to a medical professional about their endometriosis symptoms they would go to their GP first, identifying how difficult many people find the system in accessing useful support and help.

Whilst gynaecologists were deemed more helpful, 32% stated that they had been unhelpful or very unhelpful in supporting them. In addition, 54% were not at all confident or not very confident that they would be able to get an appointment with a gynaecologist about endometriosis or symptoms if they felt they needed to.

21% said if they needed to access specialist care they would go to their gynaecologist. 10% said their first point of contact would be their Specialist Endometriosis Nurse, highlighting the importance of this role.

The role of Clinical Nurse Specialist in Endometriosis is a key part of the team at endometriosis specialist centres. Often referred to by patients as the 'Endometriosis Nurse', they have a key role in managing and supporting those with endometriosis. Extensive experience and training is required, and as defined by the Royal College of

Nursing¹, the role has been designed to take account of the need to:

- lead and develop services
- ensure these services are linked with primary care
- support a better understanding of this condition among all nurses coming in contact with those with endometriosis.

Under the NICE Guideline on Endometriosis, an Endometriosis Nurse Specialist should be available to everyone with endometriosis. However, in July 2020 there were only 66 such postholders, all within endometriosis specialist centres, and the majority of those were part-time². Additionally, the post holders are often focused towards administration around data gathering and inputting, rather than focused on directly supporting patients.

These responses highlight the challenges experienced in accessing specialist care and support, vital for managing endometriosis. The fact that 63% would seek help from their GP initially highlights the importance of GP awareness of symptoms, treatment and referrals pathways. Responses overwhelmingly showed that individuals would like to access specialists, however a high percentage of respondents flagged that there are long waiting lists and difficulties in accessing specialist healthcare practitioners.

The Inquiry evidence highlights that individuals are struggling to access the professional care that they need and deserve. This seemed to be predominantly due to a lack of expertise in recognising symptoms, not knowing where to refer to, and a lack of capacity within the NHS. This lack of capacity to see the right experts resulted in either referrals to non-specialists, the wrong specialty, or long waits.

NHS's and Governments across the UK need to recognise the scale of endometriosis and commit the resources needed to diagnose, treat and manage the disease; acknowledging

¹ <https://www.rcn.org.uk/professional-development/publications/pub-007239>

² <https://onlinelibrary.wiley.com/doi/full/10.1002/nop2.574>

it is a chronic condition and that long-term support is needed in order to help improve the care that individuals are currently receiving. This will result in more efficient pathways and decrease unnecessary appointments in primary care and A&E or with the wrong specialist.

NICE Guideline on Endometriosis diagnosis and management

The APPG welcomes the work of the National Institute for Health and Care Excellence, in producing their Guideline and Quality Standards on Endometriosis. These offer an opportunity to provide a minimum standard of care across the UK. However, the Inquiry found these have not yet been implemented.

NHS's and Governments across the UK need to recognise the scale of endometriosis and commit the resources needed to diagnose, treat and manage the disease

NICE Guideline and Quality Standards on Endometriosis

The National Institute for Health and Care Excellence (NICE) provides guidance and advice to improve health and social care. Decisions on how NICE guidance applies in Wales, Scotland and Northern Ireland are made by the devolved administrations, who are often involved and consulted with in the development of NICE guidance. The NICE Guideline on Endometriosis has been adopted across the UK, but is yet to be implemented.

NICE Guideline [NG73] – Endometriosis: diagnosis and management¹, issued September 2017

The Guideline covers diagnosing and managing endometriosis and aims to raise awareness of the symptoms of endometriosis, and to provide clear advice on what action to take when those with signs and symptoms first present in healthcare settings. It also provides advice on the range of treatments available. Produced to improve care and care pathways in the NHS, they can also be used by patients to understand what to expect with the treatment and management of endometriosis.

The Guideline covers the whole of the care pathway, including:

- Highlighting that delays in diagnosis can affect quality of life and result in disease progression.
- Organisation of care to ensure prompt diagnosis and treatment, and coordinated care.
- Everyone with endometriosis should have access to:
 - a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery;
 - a gynaecology specialist nurse with expertise in endometriosis;
 - a multidisciplinary pain management service;
 - a healthcare professional with an interest in gynaecological imaging;
 - fertility services.

- Defining the multidisciplinary team and facilities needed by specialist endometriosis centres.

The NICE guideline specifies that it only covers endometriosis found within the pelvic cavity.

Please also see **pages 16–17**, the flowchart describing the care pathway laid out in the NICE Guideline.

NICE Quality Standard [QS172] – Endometriosis², issued August 2018

NICE Quality Standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements, and are intended to drive up the quality of care.

For the endometriosis quality standard, three quality statements were developed with the aim of improving diagnosis and ensuring prompt and appropriate referral to secondary care:

Statement 1: Women presenting with suspected endometriosis have an abdominal and, if appropriate, a pelvic examination.

Statement 2: Women are referred to a gynaecology service if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated.

Statement 3: Women with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter are referred to a specialist endometriosis service

For successful implementation, the Quality Standards state that:

- service providers – eg GP practices, school health services, sexual health clinics, emergency departments – ensure staff know the symptoms and signs of endometriosis;
- healthcare professionals who might come into contact with women who could have endometriosis – eg GPs and practices nurses, school health services, sexual health clinics, and emergency departments – consider endometriosis as a possible diagnosis when women present with signs or symptoms that suggest endometriosis.

² <https://www.nice.org.uk/guidance/qs172/chapter/quality-statement-1-presentation-with-suspected-endometriosis#quality-statement-1-presentation-with-suspected-endometriosis>

¹ <https://www.nice.org.uk/guidance/ng73>

The APPG is calling for the NICE Guideline and NICE Quality Standards on Endometriosis to be implemented across the UK. Through this Inquiry the APPG has found a lack of awareness of the NICE Guideline and Quality Standard on Endometriosis, and overwhelmingly that these are not being followed. The APPG will continue to work with stakeholders to support implementation of the NICE Guideline and Quality Standards on Endometriosis, and to raise the profile of these.

Whilst the NICE Guideline and Quality Standards set minimum standards across the UK and with implementation would make a significant improvement for those with endometriosis, they have gaps. The following need to be reviewed and included:

- Endometriosis outside the pelvic cavity is wrongly referred to as 'rare'. It might only be a small percentage of those with endometriosis, it's estimated that up to 10% of those with endometriosis have it outside the pelvic cavity – but this equates to 150,000 in the UK. The most common type of endometriosis outside the pelvic cavity is thoracic endometriosis, on the diaphragm or within the chest cavity. Pathways for care for those with endometriosis outside the pelvis, starting with thoracic endometriosis, need to be developed and implemented.
- Pathways for supporting and treating those post hysterectomy or who have gone through menopause, and still have symptoms or complications from endometriosis or the surgeries they have had for endometriosis. The Inquiry heard examples of patients being 'dropped' from gynaecology post hysterectomy, and unable to get support if they had ongoing problems as there is no pathway for them. This could include for long term complications post surgery, eg bladder issues following bladder surgery for endometriosis, or if they were still experiencing pain.
- Details on non-pharmacological management of pain. 95% of responders stated that pelvic pain symptoms had a negative or very negative impact, and a key theme that came from the survey was a desire for help with pain, either in terms of formal pain services or advice on management of pain. Despite being a chronic pain condition, the NICE Guideline does not contain any details on non-pharmacological ways to manage of pain. The positive impact of interventions such as exercise programs and psychological therapy on chronic pain were highlighted in the recent (September 2020) draft consultation on the NICE Guideline on Chronic Pain: assessment and management.

Case study:

It took 24 years for Emma to eventually be diagnosed with endometriosis in the pelvic cavity and on the diaphragm. Emma says that without NICE amending their guidelines to include pathways for those with endometriosis outside the pelvis, thousands of people will be left without a diagnosis and the specialist care they need.

“It took 24 years for me to be diagnosed with endometriosis. I not only have endometriosis extensively throughout my pelvis, I also have it on my diaphragm (known as thoracic endometriosis). I had difficulties immediately after starting my periods, at 12 years old. Within six months I was being treated for heavy periods, and at 14, was prescribed the combined pill. As a young teenager, I had over twenty appointments, and my first referral to a gynaecologist was at aged 16. No action was taken and I was told these problems would improve as I got older. They didn’t. I was prescribed several different medications by the time I was 18, but the problems persisted.

During those years, I was also being treated for constipation-like and diarrhoea-like symptoms. My bowel movements were always normal yet I struggled to pass them. In 2002 (aged 19), I was referred to a colorectal clinic. I’ve since had two rectal surgeries, and multiple appointments with no answers.

By 2009, aged 26, my periods would last anywhere between 15 and 60 days. A locum doctor suggested it might be endometriosis, but my main doctor did not investigate further. I was told I most likely had “unexplained pelvic pain” and it was “just one of those things”. By the age of 28, I’d had over 100 appointments for painful, heavy prolonged periods. By the age of 33, alongside a feeling of upper abdominal pressure, I started to experience the symptoms of what I now know to be endometriosis on my diaphragm. I was prescribed indigestion tablets, despite explaining I didn’t have indigestion.

In December 2018, at the age of 37, one GP at my practice finally decided to investigate my symptoms of long term menstrual problems, right shoulder pain with onset of menstruation and the symptoms of varying from constipation to diarrhoea during menses. I researched the symptoms of thoracic endometriosis, and asked my GP if they thought this might be the cause of some of my symptoms. They dismissed the suggestion, and I sought a second opinion with a private specialist who directed me towards a surgeon who had an interest in diaphragmatic endometriosis.

I finally had pelvic surgery in October 2019 where endometriosis was confirmed and removed, followed by diaphragm surgery in February 2020 and a confirmation of thoracic endometriosis.

Nobody should have to wait 24 years to be diagnosed with endometriosis. Since surgery, I have had to take 8 months off work and have been unable to do my job as a teacher. The condition has significantly impacted my emotional and physical well-being, my relationships and the way I live my life. The NICE Guideline does not give a pathway for those with endometriosis outside of the pelvis. Without this change, thousands of women will be left without the specialist care they need.”

Clare, 33

“

I had a hysterectomy at 31, with adenomyosis as well as endometriosis. As I was leaving the 'Reproductive Health' department, a nurse said 'Well, we won't be seeing you here again!'. I don't think she meant it unkindly, but the message to me was 'now you can't have babies there's no point in us seeing you'. There was no support or follow up, turns out I should have been referred to a menopause clinic but that fell between that cracks and I wasn't, and now I have issues with my bone density."

Countless responders to the APPG Inquiry and at the oral evidence session outlined how impactful additional areas of care had been to them in their life. Pain management and physiotherapy may also offer cost saving to the NHS and society if they allow people to help manage their condition and symptoms more easily. This in turn can help individuals live their life to the full, get back to school, university or work and reduce their interactions with the healthcare system.

Bhavni told the APPG:

“

It took 15 years of treating me to finally refer me to pain management, which feels like an afterthought process in the system. They shouldn't just look at what medications you take, but should also look for alternative support such as physiotherapy and psychotherapy or counselling to help you manage your condition. I find it ironic that it took 20 years since my diagnosis to refer me to pain management. Equipping us to be able to have the tools to live a really full and healthy life as best we can under the confines of what we have needs to be a priority".

Helen added:

“

I've had to pay out £1,000 for pelvic physiotherapy. It's an investment that not everyone can afford, and I think everyone should have access to it. I think it's disgusting that I have a spinal problem, and I can go to the doctor with backache and I'll be referred immediately to physiotherapy, yet for women's health barely any endometriosis patients have heard of pelvic physio and the benefits it can have".

Pain management and physiotherapy may also offer cost saving to the NHS and society

Recommendations

1. Effective implementation of NICE Guideline on Endometriosis: diagnosis and management (2017) and NICE Quality Standard Guidelines on Endometriosis (2018),

including but not limited to:

- Endometriosis symptoms to be recognised by all healthcare practitioners, and endometriosis to be suspected with one or more of the symptoms.
- Ensure processes in place for prompt diagnosis.
- Ensure endometriosis specialist centres available to all who need it, not a postcode lottery.
- All with suspected or confirmed deep endometriosis must be referred to an endometriosis specialist centre for the diagnosis process and treatment. Non specialist gynaecology units must not 'try' to treat these patients.
- Developing and appointing to the role of a gynaecologist with a Special Interest in Endometriosis, including defining the role and competencies, training programme and recruitment to all gynaecology departments. This role is vital to support those with endometriosis seen in general gynaecology rather than specialist endometriosis centres.
- Championing and embedding the NICE Quality Standard. Ensuring all healthcare practitioners recognise symptoms of endometriosis; embed into RCOG and RCGP training and work with fellow Royal Colleges to do the same.
- Access to a Specialist Endometriosis Nurse for all those with Endometriosis.
- Access to prompt fertility support for those with endometriosis, should they require it.
- Access to pain management services for all those suffering from endometriosis-related pain, so relying on strong

prescription painkillers or strong opioid drugs is not the only option, and that other interventions, such as pelvic physiotherapy, can be accessed.

2. Pathways to support diagnosis, treatment and management need to be put in place, including:

- To include all endometriosis, including that outside the pelvic cavity. Pathways for care for those with endometriosis outside the pelvis, starting with thoracic endometriosis, need to be developed and implemented.
- Ensure a pathway for non-pelvic endometriosis to be in place across the UK by end of 2021.
- To include pathways to ensure all those with, or suspected, endometriosis are always seen in hospital settings by a gynaecologist with specialist training and experience in endometriosis.
- To ensure pathways and support for all aspects of endometriosis. These would include: ongoing management once diagnosed including access to specialists in secondary care if needed; access to fertility preservation and fertility services; and pathways for those who have had hysterectomies however whose disease or treatments may have resulted in ongoing complications or need for support – rather than them being 'dropped' as they are no longer considered by gynaecology.

3. The APPG calls for NICE to reconsider its decision not to support the use of Visanne, a Dienogest, by the NHS.

Visanne is used to treat endometriosis pelvic pain and is widely available in the rest of the world including Europe, Australia and the US.

Lack of information

Informed choice and consent is vital for those with endometriosis, alongside the need for clear, explained information that individuals can go away and consider before committing to a treatment. In the APPG oral evidence session the group heard of several examples of individuals not being told the impact of the treatment they were advised to enter into, such as a chemically induced menopause, or feeling pressurised into a hysterectomy whilst not understanding this might not resolve their symptoms. Others were told to 'get pregnant' or 'have a baby' – sometimes at quite a young age – which the APPG did not feel is an acceptable treatment recommendation.

Jackie-Doyle Price MP, Vice Chair of the APPG on Endometriosis and chair of an APPG oral evidence sessions, outlined the issue around the lack of informed consent around endometriosis treatments, stating that:

“

Without sufficient information about treatments and how to manage what is a chronic condition, people are not able to make informed choices about their healthcare. It's absolutely key that patients are given the full facts about different treatment options including the side effects, so people can decide what course of treatment is right for them, in line with any other considerations that individual patient has, such as their fertility”.

Whilst a variety of evidence based information exists on the condition, treatment, and management options, all too often people are not signposted to relevant areas and not provided with any information or choice in their care.

Anecdotally the APPG heard from individuals who had been told to 'go home and google it'. Data from the APPG survey found that 73% of responders to the APPG Inquiry said that they were not given any written information when they were diagnosed with endometriosis. Of those that did receive information when they were diagnosed, 54% of individuals were either dissatisfied or very dissatisfied with the information.

The NICE Guideline on Endometriosis explicitly comments on the need to provide information around endometriosis, and the APPG is calling for this guidance to be followed. Information and choice are vital to appropriate management and treatment of endometriosis. Individuals have different symptoms, respond differently to treatments and have different priorities for symptom management. Individuals' different priorities in terms of symptoms they find most difficult, and their most appropriate treatments, should be explored by healthcare professionals whilst having an open conversations about what is needed.

Those living with endometriosis deserve to be given all the information available about their condition so that they can make an informed decision about what they want to do to manage it.

Recommendations

1. Informed choice:

ensuring patients understand their treatment options and can make their own informed choice through providing effective information and communication around endometriosis and treatment options, and appropriate time for a decision to be made.

2. Provision of patient information,

so patients are not left in the dark about their disease.

Fertility

Whilst many with endometriosis will be able to conceive naturally, the disease does double the risk of infertility¹. The inquiry heard that for many, issues around fertility can cause huge anxiety and concern, and understandably, fertility frequently featured in both the oral evidence and survey.

Concerns were raised in five areas:

- 1 Trying to understand the impact of endometriosis on fertility and what your own situation might be
- 2 Accessing fertility services
- 3 How those who did not want children or for whom it was not a priority felt their pain, symptoms and treatment were ignored or considered less important as not related to having a child
- 4 Insensitivity around the impact of being told that you cannot have children
- 5 Presumptions that those not in heterosexual relationships did not want children

These different concerns were raised throughout the evidence gathering session for this Inquiry and it became clear that many were particularly affected by the treatment or comments they had received around fertility through their endometriosis journey.

Regarding those people who were concerned with their fertility, there are clear concerns around discussions with healthcare professionals at an early stage and access to treatments. Many comments that were received through the APPG survey highlighted the mental anguish that people struggling to have a family experienced throughout this process.

However, only 44% of responders were asked if their fertility was important to them by any medical practitioner.

Many commented on waiting times for accessing information and fertility services. Of those that had accessed or tried to access fertility treatment, 2,818 respondents, when asked how long did it take to get first appointment:

- 45% – within 6 months
- 19% – 7–12 months
- 10% – 1–2 years
- 22% – gave ‘other’ as an answer, including responses such as being refused a referral, still waiting, having to pay privately to speed up the process and some never receiving the referral despite being told they would be given one

In addition, 20% of 2,393 who answered the question stated that they had to pay privately for fertility services. Quotes from the APPG survey highlighted some of these issues:

“

I was not even offered fertility help by the NHS and I have had to fund this myself at a private clinic despite my extensive medical history of endometriosis.”

“I have never been referred even though I have raised the concern.”

“I was in post-op recovery. The surgeon said I had endometriosis – my first reaction was relief they’d found something, it hadn’t been in my head; I was actually pleased! Then he said ‘I hope you didn’t want to have children’ and left. That was it, no explanation. I was devastated.”

Those from LGBTQ+ communities may face challenges in accessing fertility support. The Inquiry heard from lesbians who highlighted the assumptions that may be made about their views on fertility, and lack of support in accessing fertility treatment on the NHS.

¹ A prospective cohort study of endometriosis and subsequent risk of infertility. J. Prescott, L.V. Farland, D.K. Tobias, A.J. Gaskins, D. Spiegelman, J.E. Chavarro, J.W. Rich-Edwards, R.L. Barbier, S.A. Missmer. *Hum Reprod* (2016) 31 (7): 1475-1482.

“

I'd taken my partner to the appointment, and introduced her. At one point the doctor said 'it's a good job you're a lesbian and don't want children.' I was shocked, I do want children, they didn't even ask."

"I feel as a lesbian it would be nice to have help to have a child from the NHS. Its easy for them to tell me I may need a hysterectomy but have no support to have a family with my wife. This has caused me depression and anxiety which makes it hard to live a normal life with a poor expectation of having a child or it costing up thousands of pounds."

For those with endometriosis who are concerned about fertility or are trying to get pregnant, the NICE Guideline on Fertility should be followed so that an immediate referral is made to fertility services if an individual has a recognised condition that impacts on fertility. In addition, as has been widely covered in the media, there are a range of CCG restrictions on IVF meaning the additional stress depending on location in terms of accessing the IVF treatment.

NICE Clinical Guideline: Fertility problems: assessment and treatment [CG156]

These NICE Guidelines¹ state:

“Offer an earlier referral for specialist consultation to discuss the options for attempting conception, further assessment and appropriate treatment where:

- the woman is aged 36 years or over
- there is a known clinical cause of infertility or a history of predisposing factors for infertility.”

Endometriosis is a known cause of infertility.

There should be parity with other conditions. The APPG would like those with endometriosis to have access to the same levels of fertility and fertility preservation support as those with other conditions that impact on fertility. For example, in one area fertility preservation was not funded by the NHS for ovarian removal due to endometriosis, when it is for ovarian removal due to cancer.

The Inquiry heard about cultural considerations there may be in relation to fertility, when some cultures place an emphasis on families, resulting in additional challenges for those with the condition from certain religious or minority ethnic backgrounds.

Bhavni told the APPG:

“

“As a South Asian woman there is a certain expectation, culturally and within your community, that you will get married, bear children and continue the family line. Having some kind of ‘women’s’ problem is not something that is widely talked about and any murmur of such things seem to bring with them an element of shame and personal failing not only on the individual but their families.

I remember going through various surgeries and my parents feeling like they could not tell the extended family the true extent of what I was going through or the reality of my condition and diagnosis. This was due to the cultural stigma associated with discussing such ‘taboo’ subjects and also their worry of how this would reflect on the family. The irony is that if they were able to talk more openly as a wider family, we may have been able to realise a lot sooner that a number of us cousins were going/will go through similar journeys in our life.

Breaking these cultural barriers and addressing these topics head on so that they become normal vocabulary in all communities is so important. Perceptions of families and family life need to shift to ensure what is a difficult journey with this condition, does not become harder still”.

¹ <https://www.nice.org.uk/guidance/cg156/chapter/Recommendations#principles-of-care>

Support to those when fertility isn't a priority

It was not just fertility treatment access that was a concern. The APPG heard from many how they did not want to be treated for endometriosis just in terms of improving their fertility or having children, for example some wanted to focus on improving their quality of life or getting back to work. Others did not want children. Respondents told the APPG that they wanted to be treated as individuals, not just as a baby making machine, and wanted their own needs and symptoms addressed. Those who do not want children should be afforded the same level of care as those that do.

Lucy:

“

I think communication, education is obviously key, but actually I was too ill to even think about the possibility of having a child.

It felt like my fertility was taking priority over my own health and pain. Often the woman or the person gets lost, because the condition is so focused on menstruation and fertility, and actually it's about your ability to function and manage your pain and your life.

I have been told too many times to have a baby, and I literally need to be able to function and manage my pain to get to work. Women with endometriosis are often being left out of the conversation if it's not in relation to fertility”.

As with many menstrual conditions, endometriosis is commonly put under 'reproductive health'. This gives out the message that the priority is fertility and reproduction, with implications that 'women ought to be having children'. Those not considering reproduction, either due to age (young or old) or because they cannot or do not want to have children, may think this does not apply to them or feel excluded. Whilst this term is widely used by healthcare practitioners and within the NHS, it can be unhelpful for patients. The APPG recommend

the NHS look to move away from using the term 'reproductive health' as short hand for menstrual health.

Pregnancy is not a 'treatment' for endometriosis

The myth that having a baby will cure endometriosis still persists, even in clinical settings. Many respondents reported that they have been told by healthcare practitioners 'to have a baby' to treat or sometimes even cure their endometriosis, even as teenagers. Having a child should not be suggested as a 'treatment' for a medical condition, and again highlights the importance of education for healthcare practitioners.

Rhea:

“

I had a young nurse with me when I was sat crying in pain. She leaned against me and said "Why don't you just have a baby?" Just have a baby, I thought. First of all, I'm not in a relationship, and secondly, it highlighted to me the issue that people aren't taken seriously and women's pain is often only recognised in relation to fertility. And of course, having a baby is not a cure”.

Quote from survey:

“

When I was diagnosed my doctor told me it was my own fault (because I am a lesbian) because most women of my age (then 28) had already had babies!!!”

Recommendations

1. The APPG recommends that there is a need to look holistically at the individual including their desires or concerns around fertility.

It should not be assumed that individuals only care about the ability to have children, however for those who are concerned around fertility there should be support in accessing appropriate information and care. Nor should it be assumed that those not in heterosexual relationships do not want children.

2. Recognition from Governments, NHS's and healthcare practitioners that there can be significant emotional impact of not being able to have children.

3. NICE Guideline: Fertility problems: assessment and treatment (CG156) should be followed,

including early referral for specialist consultation for those with endometriosis.

4. Those for whom having children is not a priority should still be afforded the same level of care, treatment and support

to manage their symptoms and live their lives.

5. If an individual's endometriosis, or the treatments they are receiving, could impact on their fertility, they should have access to NHS treatment for fertility preservation.

Chapter 3

Living with Endometriosis

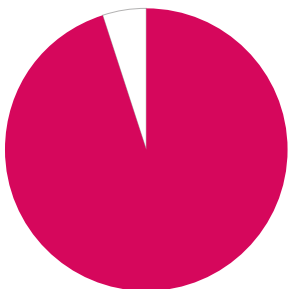
The APPG Inquiry investigated the wider issues around the impact endometriosis can have on an individual's life. This section will cover:

- Mental health
- Employment
- Benefits
- Education

Endometriosis is a chronic and sometimes debilitating condition and can have a significant impact on a person's life in a number of ways, for example through chronic pain, depression, problems with relationships and difficulty in fulfilling work and social commitments.

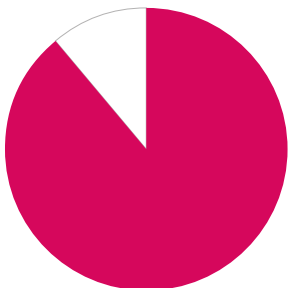
The survey results starkly demonstrate the significant extent and negative impact endometriosis can have on an individual's wellbeing and ability to live their lives, and on their mental health.

Of the over 10,000 respondents:



95%

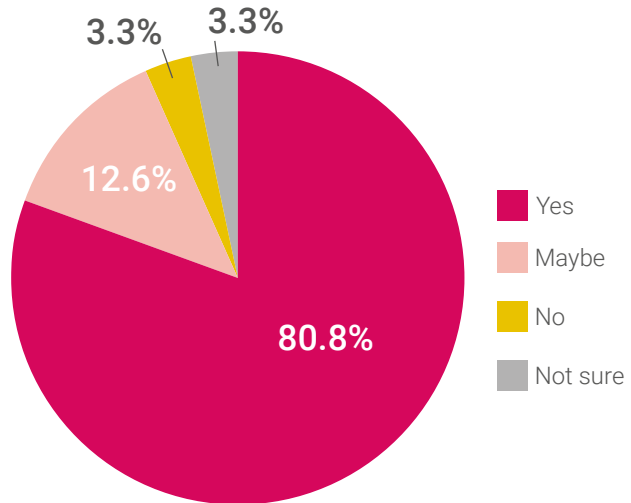
said endometriosis/symptoms have had a negative or very negative impact on their wellbeing.



89%

said endometriosis/symptoms had affected their ability to live their life as they wanted with a negative or very negative impact.

Has endometriosis had an impact on your mental health?



The APPG is calling for more recognition and consideration of endometriosis as a long term condition. There is no cure and it can have a significant, sometimes lifelong impact. It can be perceived that endometriosis 'goes away' after menopause, but there can be a lifelong impact for example from internal adhesions and scarring, or effects due to surgery. Endometriosis needs to be treated in a more holistic manner to help people live their lives as best they can, looking to mitigate the detrimental impact it may have.

The APPG asked for comments on living with endometriosis and the wider impact that this condition has. The quotes below highlight just what this can look like:

“

It's life changing, I used to have a life with a bright future, be active and social and now I am almost completely anti-social, tired and anxious in a vicious cycle.”

“Endometriosis has had a very negative impact on my life. I spend a lot of time feeling defeated and exhausted, mentally and physically.”



It is terrifying as no one really understands it and it can feel very lonely at times.

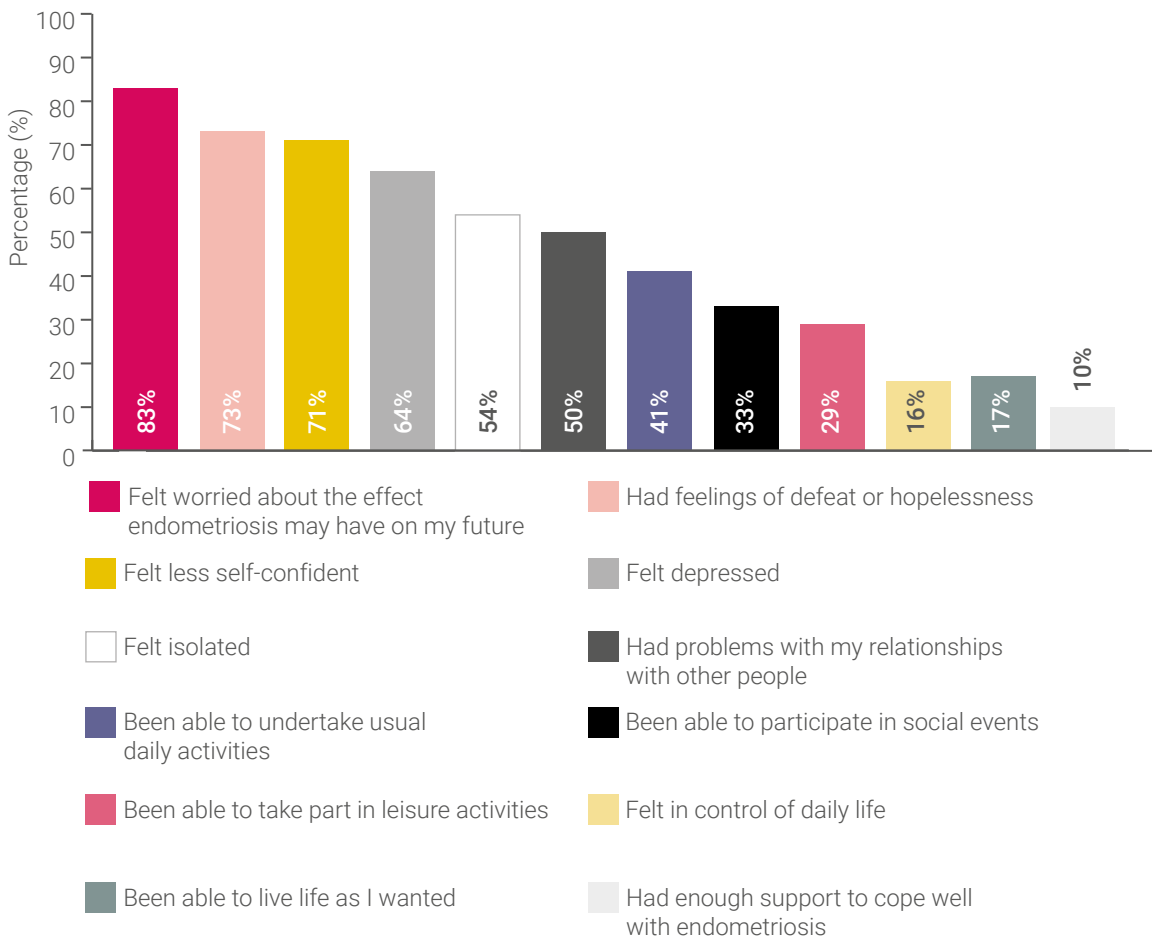
“Every day is a struggle.”

“It is devastating for both mental and physical health.”

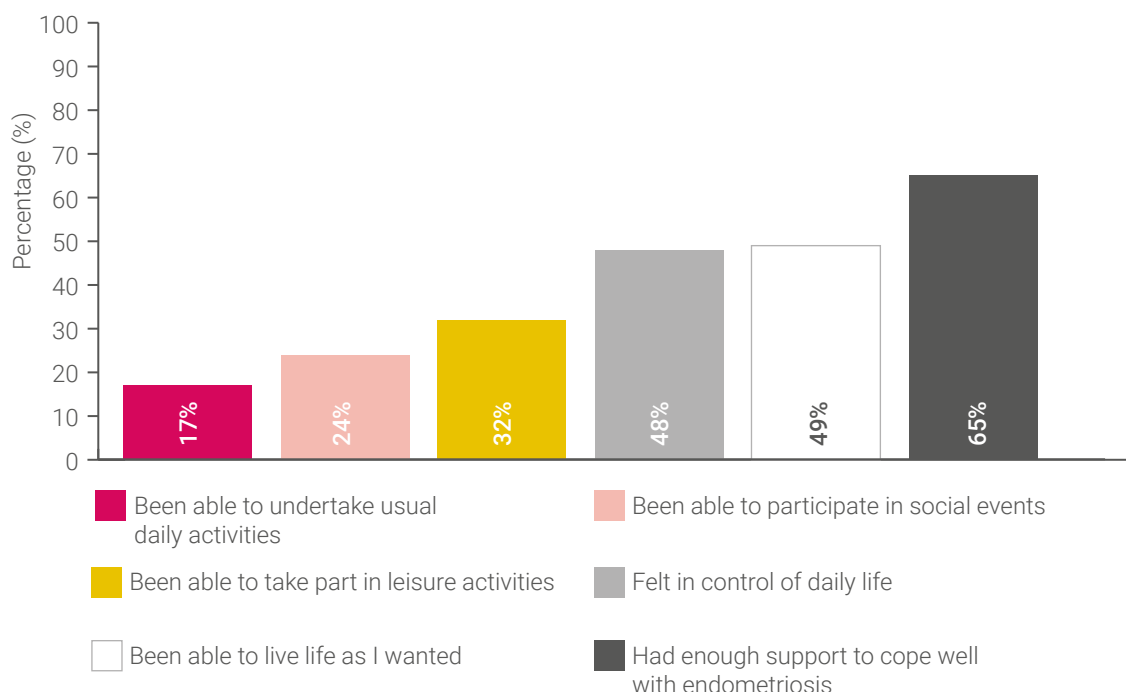
“Living with endo is an invisible disease. No one realises the pain you have every day. A lot of the time my back pain is so bad I can barely breathe or have to gasp for air. Because its unseen and not many people are aware of what it is, it feels as though your attention seeking or lying.”

The APPG also asked what was the biggest impact endometriosis had on their day to day life, the highest responses were feeling worried about the effect endometriosis may have on their future and feelings of defeat or hopelessness.

Due to my endometriosis, in the last three years, I have often or very often:



Due to my endometriosis, in the last three years, I have never or seldom:



The results highlight the breadth of support needed by those with endometriosis. It is a long term condition without a simple diagnosis – treat – cure pathway, it needs to be treated as such, with services planned accordingly. Individuals will have different experiences of endometriosis, and whilst some may only experience mild symptoms, others may find

it debilitating and require increased care and support for their health and wellbeing. Policy makers and those designing and planning services need to be aware that endometriosis, and long delays in diagnosis, can have a significant impact on wellbeing and mental health, in addition to physical health.

Recommendations

1. Recognition by NHS's, healthcare practitioners and the UK Governments of the detrimental impact endometriosis can have on mental as well as physical health,

and a commitment to develop holistic services to support those with endometriosis and the physical *and* mental health.

Mental Health

Physical health problems significantly increase the risk of poor mental health, and vice versa. Latest statistics show that having a long-term physical condition doubles a person's chances of having a mental health difficulty¹.

The links between physical and mental health were heavily reported throughout the APPG inquiry, with the outcomes of the patient survey highlighting the huge impact endometriosis can have on a patient's mental wellbeing. 81% said that endometriosis has badly impacted their mental health, and 90% would have liked access to psychological support, yet was never offered this.

Comments within the report and from the oral evidence hearings also echoed this, with several referencing that access to mental health services would offer significant improvement to their overall wellbeing and ability to manage their condition.

Many reported both the huge impact lengthy diagnosis and the symptoms of endometriosis can have on long-term mental health. The symptoms of endometriosis such as chronic pain and infertility can have a significant impact on mental wellbeing, yet 90% who stated they would have benefited from psychological support were never signposted to mental health services or offered any psychological support.

This is despite some of the symptoms of endometriosis such as chronic pain and infertility having a known impact on mental wellbeing and triggering mental health issues. For many, coming to terms with a diagnosis for an incurable condition after years of being dismissed by healthcare practitioners has also had a negative impact on their mental health. Depression, anxiety, OCD and suicidal thoughts were frequently referenced within the Inquiry.

Becca, 35, said:

“

I always feel that mental health is a double-edged sword when it comes to endometriosis. When I was growing up and first started going to the GP about my symptoms, I was told that perhaps I had mental health issues and that I needed counselling. Years later I was diagnosed with endometriosis, after years of being fobbed off and told it was all in my head. I never got referred for counselling, and was left alone to navigate the emotions of living with an undiagnosed condition, and the mental trauma of being told it was all in my head. At the time, it felt like my mental health was being used as a weapon to shut me up, whilst not even offering me any support to manage it. Counselling and mental health support should always be offered to those with endometriosis. Years of battling misdiagnosis and being told it's in your head can have a huge detrimental impact on your mental wellbeing, yet support is rarely offered”.

There is a clear need for people with endometriosis to have access to mental health support when needed as part of an integrated care pathway. For many, access to emotional and psychological support and treating endometriosis in a holistic way would give the opportunity to come to terms with their diagnosis and help manage their symptoms; potentially reducing the risk of long-term mental ill health. Mental health support may not be needed by all those with endometriosis, but many throughout the Inquiry referenced the need for a tiered approach to be offered depending on the individual needs of the patient.

¹ Kingsfund and Centre for Mental Health Report, Long Term Conditions and Mental Health: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf

Dr Katy Vincent, Consultant Gynaecologist at Oxford University says that people with endometriosis should be treated holistically, and have both their mental and physical needs met:

“

My view is that as well as surgery we should treat endometriosis holistically with physiotherapy and with psychotherapy”.

As well as those who spoke about the need for mental health support, many reported how mental health has been used as a barrier to receiving a diagnosis for endometriosis and further treatment for physical symptoms. Many have reported being misdiagnosed with a mental health condition such as anxiety, with physical symptoms dismissed and not further investigated. Many also stated that despite being told their physical symptoms were linked to ill mental health, no signposting was provided to mental health services, leaving people without support for either their physical or mental health. Without access to either physical or mental health support, it is clear from the Inquiry report the impact this can have on all aspects of life.

For those with a pre-existing mental health condition or history of ill mental health, many felt that this has also prevented them from accessing treatment and/or a diagnosis.

Jilly, 28, told the APPG that:

“

If you have a mental health issue then you don't get taken seriously. Medical practitioners presume that your condition is all in your head, resulting in delayed diagnosis. For women who have mental health issues and endometriosis, it is concerning that they are not having both their physical and mental health needs met, or that one is being used against the other”.

Brittnee, 27, told the APPG how experiences of past trauma should never be a barrier for accessing support for physical symptoms. She spoke of how at 19, she started to experience painful sex, which triggered repressed memories of sexual assault. Due to her experience of past trauma, Brittnee states that:

“

these symptoms were disregarded and seen as the reason for why she was experiencing pain, rather than looking into the cause of the pain itself.

I was nineteen when my endometriosis started impacting my daily life and relationships, though I had dealt with crippling period pain many years prior. The endometriosis symptom that is often dismissed by the medical community, pain during intercourse, was destroying my life. Until that point in my adult life, I had been in typical, healthy relationships with my partners, but at nineteen I started experiencing searing pain that resulted in bleeding and vomiting anytime I was intimate. When this started happening, it triggered repressed memories of sexual assault, just adding to the pain, shame, and embarrassment of the situation. The complication I faced then was having this pain disregarded by doctors, who then seemed to use this traumatic experience as a reason for why I was experiencing pain, rather than look into the cause of the pain itself.

Contrary to the narrative that endometriosis makes intercourse 'just not that fun anymore', it can actually create a very traumatic relationship with intimacy which can have a detrimental impact on mental health.

After being dismissed for several years, I started to receive therapy at my University counselling services, before being referred to a centre for complex-post traumatic stress disorder where I was evaluated and diagnosed with C-PTSD.

No one should have to fight for a diagnosis and treatment as much as those with endometriosis have to, and rather than approaching them with speculation as to their mental state, we should offer them support and validation. Finally having my pain and experience acknowledged in therapy has given me the tools to live a happy and healthy life as a woman in my 20s – it really is that simple. It should be standard practice that mental health services are available, and encouraged, for anyone undergoing diagnostic testing and treatment for endometriosis. Additionally, experiences of past trauma and mental health should absolutely not be exploited as a barrier to fair healthcare, as they have been for me”.

It is clear that the potential impact of endometriosis on a person’s mental health cannot be overstated, and that mental and physical health symptoms should always be taken seriously and investigated, and support, if required, should always be offered within an integrated pathway. Healthcare practitioners should assess patients in a holistic way, and look at the whole patient and their individual experiences, and not dismiss physical pain if someone has a pre-existing mental health condition or historical ill mental health.

Integrated pathways would also have a potentially positive impact on the economy, and reduce long-term costs to the NHS. According to a report by the Kings Fund and centre for mental health¹, psychological problems associated with physical health conditions, and vice versa, are costing the NHS more than £11 billion a year and care is less effective than it could be. They state that integrating physical and mental health care within the NHS can improve health outcomes, and save the NHS money.

Andy Bell, Deputy Chief Executive at Centre for Mental Health said:

“

Mental health difficulties should never be ignored. Yet for too many people receiving treatment for physical health problems or living with chronic pain, emotional and psychological wellbeing is not taken seriously. Likewise people being treated for mental health problems too often find their physical health needs are ignored. This carries a heavy cost and causes avoidable suffering. We must ensure women get the support they need, with compassion and respect, and break down the barriers between mental and physical health care.”

¹ Kings Fund Report, 'Bringing Together Physical and Mental Health (2016): <https://www.kingsfund.org.uk/publications/physical-and-mental-health>

Recommendations

The APPG is calling for

- 1. Integrated mental health support as part of the endometriosis pathway.**
- 2. Updating the NICE Guideline to ensure mental health support is provided to patients who need it.**
- 3. Ensuring the NICE Guideline on Endometriosis are followed so that patients are not waiting on average 8 years for a diagnosis,**

potentially leaving patients with long-term mental health issues.

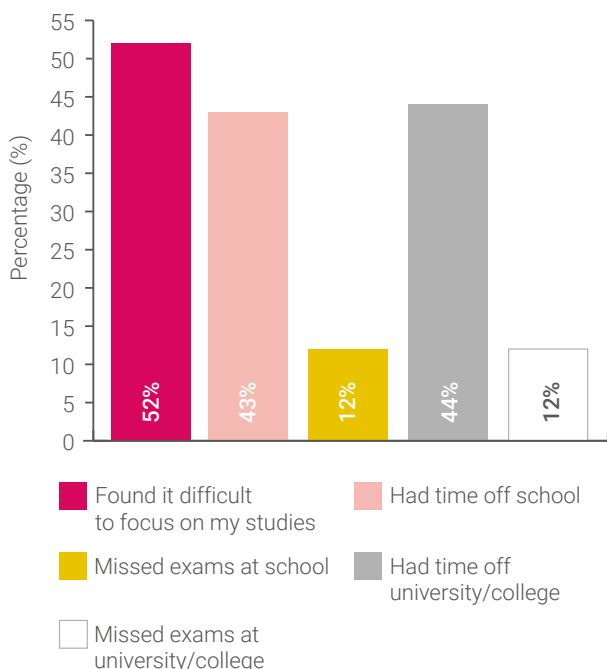
- 4. For the APPG on Endometriosis to investigate further the links between endometriosis and mental health,**

and work with partners including Endometriosis UK and the Centre for Mental Health to take this forward.

Impact on Education

Whilst not all those with endometriosis will experience symptoms whilst of school, college or university age, significant numbers of respondents to our survey did. 6,600-7,000 respondents answered questions about the impact of endometriosis on their education. The results show that, sadly, endometriosis can have a detrimental impact on education, both school and further/higher education.

Due to my endometriosis, I have often or very often



The correlation between missing days of school and endometriosis is significant, with over 40% of responders to this question confirming this. The impact that endometriosis can have at an early age cannot be underestimated. Without a diagnosis, time off will be considered as multiple, small issues and not taken into account in assessments or exams.

The impact of missing school and missing college can result in individuals not attaining their education potential. This can have a dramatic knock on impact on their employment and career options and

ability to earn money in the future. School is where most learn to develop strong social relationships with friend. Missing days of school can lead to breakdown in relationships and increase isolation.

With a diagnosis, endometriosis can be taken into consideration for missed school and assessments, however without a diagnosis there will be no understanding nor consideration and joining up of multiple absences. Missing school can have other consequences, such as fines for not having a valid reason for the absence.

Individuals who were affected at an early age by endometriosis gave evidence to the APPG through the oral evidence sessions.

Eloise, 21, told the APPG her story:



I had heavy periods from my 11th birthday. I probably went to the doctors about 100 times before I turned 17, and then just overnight I started getting pain every day, not just on my period and I was missing college and missing social events, and 17's quite a delicate age. So, I remember going to college and sitting in the toilet to eat my lunch because I didn't have any friends. I'm in so much pain. I don't know what to do.

I went to A&E. I was sent away from A&E a couple of times with just oramorph and expected to take that every day whilst driving and going to college. And, then I went to see a gynaecologist eventually. The gynaecologist did an internal scan and was like, "Oh, I think you might have endometriosis." I was like, "Oh, what's that? Never heard for that before." And, told me to go home and Google it. So, I went home and Googled it, and I don't know if anyone else has Googled it to know what it is, it's quite scary to Google. So, I did that and then they told me to just go on the pill and not come back for six months. I was like, "OK." And, then in that time I went through my A Levels which, obviously, doubled up in pain, trying to

take oramorph, all that kind of stuff. And, then in the end we saved up as a family to pay to go see a private gynaecologist, because the GP then wouldn't refer me back. The gynaecologist did a scan immediately and found a 17cm cyst on my ovary.

I had an operation a week later and he was like, "Oh, yes, you've got stage 3 endometriosis everywhere. All over your pelvis, your kidneys," But, considering it was private we were kind of expecting to find out more information, and even that was kind of, "Go home, research it," thing which, again I was, "Oh my God. What is this?" And, then whilst I was recovering I got my A Level results and I'd failed, and I was about to start an apprenticeship in that September and I couldn't because I was still recovering from surgery.'

The APPG found through the oral evidence session frequent examples of adolescents being dismissed at a young age by healthcare professionals and told that their symptoms were normal. This had the impact of individuals not wanting to seek help again, despite symptoms continuing or worsening, and individuals just continuing to take more time off education.

Mandatory RSE education in England will have a large role to play in supporting the dialogue around menstrual wellbeing, clarifying what is a 'normal' period, and encouraging adolescents to seek help should they need it. This will hopefully also improve teacher education and how educators can be more flexible to accommodate the needs of those living with endometriosis. The APPG is calling for Scotland, Wales and Northern Ireland to mandate the teaching of menstrual wellbeing

education in schools alongside England. It is vital this is taught in schools so that messages are delivered, age appropriately, to all.

Harriet, 24:

“

I missed school on a regular basis because of my periods, so my attendance was never great. It felt like I was always 'catching up' or sitting in class wishing the pain away so that I could actually listen and learn. To this day I vividly remember sitting in a GCSE French lesson drenched in sweat because of the pain in my stomach and I could feel the blood dripping onto my thighs and I had to excuse myself to go and be sick in the toilets. Another time, a member of school staff laughed at me whilst I was in tears waiting for my mum to pick me up from school as I could barely stand and was being sick from the pain. She said to me "oh you'd better get used to this – this is what it's like being a woman!" I was told by doctors, teachers and my family that this was normal and was what a period was like. I would tell my friends that I had a stomach bug and that's why I was off sick instead of my period – because I thought what teenager has to take time off for a period? What teenager can't go out with her friends because of a period? I wish so much that we had been taught what was absolutely not a 'normal' period. Menstrual wellbeing needs to be taught in schools so that no teenage girl ever has to sit in a school cubicle wondering if her life is worth living because of the pain she's in".

Recommendations

1. Healthcare practitioners to recognise that endometriosis can start from the onset of puberty,

and that endometriosis should be suspected in adolescents with one or more symptoms, as per the NICE Guideline.

Impact on Employment

Endometriosis costs the UK economy £8.2 billion a year in treatment, loss of work and healthcare costs¹. More must be done to ensure those with endometriosis are given the support they need to thrive in the workplace.

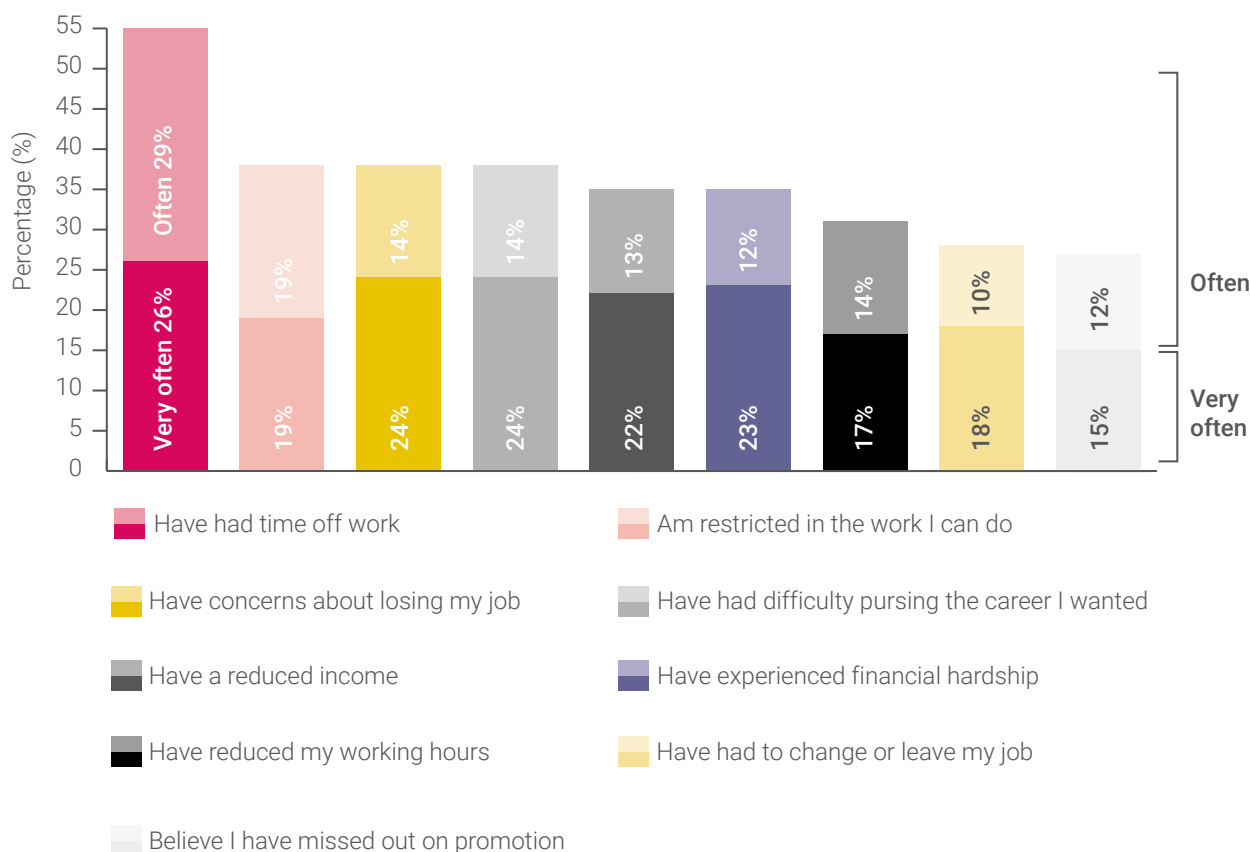
As has been discussed, everyone with endometriosis experiences different levels of symptoms and is affected differently. Not all those affected by endometriosis experience significant symptoms or require support, however those whose lives are significantly affected should be afforded the support they need to thrive in the workplace – as with any

other medical condition.

Respondents have reported to the APPG the positive benefits of being able to work flexibly, such as options to work from home and vary hours, and how this improves their ability to perform at work. All too often the APPG heard stories of where individuals have felt they had no option but to resign or move jobs due to the lack of support from some employers.

In this APPG Inquiry the group asked responders whether they had experienced endometriosis whilst working, and if it had an impact on their work?

Due to my endometriosis, I often or very often



¹ Simoens S, Dunselman G, Dirksen C, et al. [The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres](https://pubmed.ncbi.nlm.nih.gov/22422778/). Hum Reprod 2012;27(5):1292-9: <https://pubmed.ncbi.nlm.nih.gov/22422778/>

At an oral evidence session Endometriosis UK highlighted that patterns of sickness can penalise those with a cyclical condition like endometriosis. For example, the Bradford Score, used by some HR departments, applies a relative weighting to employee absences based on the principle that short, frequent absences have a greater operational impact, and are therefore considered worse than longer absences. This results in those with an intermittent condition like endometriosis being penalised. The APPG is calling for more understanding and education in workplaces so that appropriate measures can be implemented to support those living with endometriosis to fulfil their potential.

The APPG believes that more awareness and education in organisations around what endometriosis is and how businesses can provide support to employee is vital. In addition, flexible working options could provide a great advantage to those who are managing their condition. Endometriosis needs to be recognised and treated like any other condition an employee may have.

The Inquiry heard from Endometriosis UK about the *Endometriosis Friendly Employer* scheme, recently launched to support those with endometriosis in the workplace. Developed with the help of Standard Life Aberdeen, the scheme helps employers put in place the support employees with endometriosis need to thrive in the workplace. For many employers with good HR practices, this is often very straight forward, such as raising awareness of endometriosis with managers and ensuring relevant policies include endometriosis and intermittent conditions.

During the oral evidence sessions the APPG heard from attendees who outlined some of their personal experiences of working with endometriosis.

Rosie:

“

Endometriosis has had quite an impact on my career, I originally trained as a barrister, but have since taken a new job in training them instead. If I had developed endometriosis in my early twenties, I don't think I would have been able to qualify as a barrister at all.

I was lucky that I could do office-based work and be involved in criminal defence, but doing the prep to give someone else to go to court and do what I wanted and had trained to do, was pretty devastating. It was a really difficult decision having to take a step back, but I am glad I was able to change jobs. I have had mixed experiences with workplaces and endometriosis – there is an assumption that you have surgery and you are “cured”, and subsequent confusion because you still require time off. I've been pulled into HR meetings to discuss why I've had so much time off, and the statutory sick pay system isn't in favour of those with long term health conditions, although it can be at the discretion of your employer”.

Sarah:

“

I had four surgeries while I worked for one company, and one of them I had a resection of my bowel and I had a colostomy bag. During that surgery it caused me to suffer kidney failure. So, my recovery was three months until I came back to work. I came back to work, and I was told I was going to get a disciplinary because I'd gone over the company average for my sickness, even though they knew me. I'd been there for six years at this point. They knew me, they understood I had a diagnosis. And, this goes back to the lack of understanding of it's a chronic condition. And, in the end I just quit. I found another job while I was recovering from my last operation, to have my colostomy reversed. So, I just never went back.”

If some living with endometriosis feel that they are unable to work due to lack of understanding and adaptability from their employers, a section of the female population could be missing out on contributing to the UK economy. In the current Covid-19 economic recovery, it is even more important that employers take due consideration around measures that can help support their employees.

Recommendations

1. The UK Governments should adopt an open culture when it comes to talking about menstrual health.

Employers should be comfortable in talking about endometriosis with their staff, and in turn, help employees feel supported in talking about the impact it may have on their work. The UK Governments should lead by example in encouraging employers to become “Endometriosis Friendly”.

2. Governments to work with NHS's to ensure people with endometriosis have access to the right support at the right time to limit time needed off work.

Benefits

Whilst many with endometriosis are able to carry out day to day activities including work, for some their endometriosis is extremely debilitating and prevents them working. The Inquiry sought the opinion of those who had been affected in this way.

The definition of disability under the Equality Act 2010 states that you're disabled "if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities."¹ It is recognised that consideration needs to be taken when a condition is debilitating, including chronic conditions. However, the APPG heard of those for whom endometriosis is debilitating and prevented them working, yet were unable to access support. Those that have tried to access Personal Independence Payment (PIP) and other support have found it incredibly difficult.

PIP is a benefit available to people with long term ill-health or disability. To qualify for this payment, a person must be shown to have a substantial and long-term condition, meaning that it has impacted daily living for at least three months.² It is available to patients who suffer with variable and fluctuating conditions.

The APPG Inquiry found that of the 1,664 responders that answered positively the question, 'Have you ever applied for or received support for your endometriosis as a disability?', 29% were refused disability-related financial support. Of those that had been able to access support 20% had received universal credit, 22% PIP/Disability Living Allowance whilst 15% had received Employment and Support Allowance (ESA).

Of those that responded, when asked if they have applied for any form of disability support as a result of your endometriosis, 92% said the process had been difficult or very difficult.

“

I had an appointment, they came, and they gave me an assessment. First day of my period, I couldn't get out of bed, two hot water bottles, very shaken up. You could clearly see I was on lots of painkillers. Did the assessment. I got the letter, and I got told I'd failed every stage of the way because I knew a lot about my condition, which made me knowledgeable.'

Natasha told the APPG:

“

I failed my PIP assessment because I made the original journey to an appointment in the car, so they told me I was clearly well enough to get out of bed, so was well enough to work. This is despite years of relentless pain, time off work, and being unable to get out of bed some days. Endometriosis does not mean the same symptoms every day, and if you have your assessment on a better day, it shouldn't mean it affects how benefits are distributed. Awareness of endometriosis by those assessing your benefits is key”.

Others told the APPG:

“

I lost my job because of endometriosis”.
“I ended up having a hysterectomy because my employer wasn't happy about me having up to 4 days off work every month, and I was told this could ease the symptoms. I subsequently lost my job”.
“I wanted to be a freelance professional musician but have had to abandon that hope because there is no sick pay or provision for people with chronic illnesses in that industry. I had to rethink my whole career and the expectations for my life because of endometriosis”.

¹ <https://www.gov.uk/definition-of-disability-under-equality-act-2010>

² <https://www.gov.uk/pip/eligibility>

Even those that did manage to access support highlighted in their responses some of the issues they had faced:

“

Stressful and upsetting. I had to go to tribunal to get my PIP accepted.”

“The process is very difficult and often you are assessed by health care professionals who have no knowledge on the condition.”

“I was told I didn’t qualify for years.”

The APPG has noted that those people who are most severely affected by endometriosis and struggle to manage their treatment may encounter barriers within the system with accessing support that they should be able to access such as PIP and Universal Credit. The APPG recommends that the Department for Work and Pensions review their guidelines and

training for assessors to ensure understanding of endometriosis, and those who are severely affected by endometriosis and require support are able to access benefits they need.

Statutory sick pay (SSP) only applies when an employee has been off for at least four days in a row. Periods of sickness due to the same cause can be linked, if 8 weeks apart or less. You are not eligible for SSP if a series of linked periods last more than three years. Therefore if someone has 1–3 days off each month they will not qualify for sick pay during that time. If this happens some but not every month, they cannot be linked as the person will not fit official SSP criteria. Some suffering with endometriosis, or other menstrual conditions, may not have their time off sick covered by SSP compared to someone who may have the same, or more, days off sick in a year due to an acute injury, such as a sporting accident.

Recommendations

1. Ensure those with endometriosis have the statutory support they need and don’t face discrimination due to the societal taboos around menstrual conditions.

This includes PIP and other disability allowances – ensuring guidance around endometriosis and its impact on work is clear so that those assessing an individual’s application understand the debilitating impact endometriosis can have on a person’s life.

2. Ensure those with endometriosis have access to Statutory Sick Pay.

The current definition of Statutory Sick Pay fails to recognise long-term conditions like endometriosis. SSP is only available to an employee for a linked period of sickness for a maximum of three years – which penalises

those with chronic, long term conditions like endometriosis where the impact may be felt for life. As part of this, the APPG wants those with endometriosis to be supported through recognition in both guidance to employers and Statutory Sick Pay that chronic conditions may result in intermittent rather than continual symptoms. In this way, those with the disease will be able to thrive in the workplace without discrimination.

3. Recognition by UK Governments of the profound, long term negative impact the disease may have on all aspects of life,

including education and career, and that this can be compounded by long delays in diagnosis and being unable to access specialist care and support.

Chapter 4

Diversity and inclusion

Individuals needs are diverse and can vary such as their age, race, sex, sexual preferences, and socio-economic status. Failing to acknowledge people's needs can have an impact on the outcomes and access to health services.

From an education attainment perspective 54% of respondents had a degree or a higher degree. This is a higher proportion than the general population, 42%¹.

Of the respondents to the survey, 82% identified as white, compared to the 2011 census data which showed 86% of the UK population identifying as white. 5% identified as black, Asian and minority ethnic groups, compared to 14% of the UK population, with 13% leaving the question blank or answering 'other'. The survey results cannot be taken to be representative of all communities, and the APPG recognise there is more work to do to ensure the experience of those from black, Asian and minority ethnic groups are heard.

The APPG recognises the additional complexities and barriers that those from black, Asian and minority ethnic communities may face in talking about menstrual health and accessing support, and is committed to addressing health inequalities for all, and ensuring everyone has a voice in Parliament. We must do more to understand the inequalities faced for those with endometriosis from black, Asian and minority ethnic communities, and come together to find the right policy solutions, which the APPG is committed to doing.

The APPG heard through the Inquiry from those from black, Asian and minority ethnic communities who have faced additional barriers in seeking support and being diagnosed with endometriosis. For example, some reported that they have been misdiagnosed with fibroids, another menstrual health condition, due to higher occurrence of fibroids in African-Caribbean communities²,

meaning endometriosis investigations have been delayed.

The Royal College of Obstetricians and Gynaecologists (RCOG) have highlighted that "endometriosis is traditionally thought to affect more white people than black. However, it remains unclear if there is a biological basis for this difference, or whether it can be explained by social bias and the continued focus in medical research on the prevalence of the disease and not on the variation of presentations. This has resulted in delayed and missed diagnosis for those of other ethnic groups presenting with the disease"³.

Reports have also been made by those from black, Asian and minority ethnic groups who have not felt believed by healthcare practitioners. Nathalie told the APPG that she has often felt dismissed by healthcare

We must do more to understand the inequalities faced for those with endometriosis from black, Asian and minority ethnic communities

1. <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/articles/graduatestheuklabourmarket/2017#steady-increase-in-the-number-of-graduates-in-the-uk-over-the-past-decade>

2. NHS: <https://www.nhs.uk/conditions/fibroids/>

3. <https://www.rcog.org.uk/globalassets/documents/news/position-statements/racial-disparities-womens-healthcare-march-2020.pdf>

practitioners, and when presenting with symptoms, has been told she is suffering from “anxiety” or “panic attacks”.

Although there are commonalities for everyone affected by endometriosis with regards to misdiagnosis and lengthy diagnosis times, we know that there are health disparities and those from black, Asian, and minority ethnic communities can receive a lower quality of care. More needs to be done on this in respect to endometriosis diagnosis, treatment and care.

Historically, the reasons for these health disparities have been thought to be due to socioeconomic factors. Black, Asian, and minority ethnic women are more likely to live in areas of high deprivation, have lower incomes, experience language barriers and have poorer access to women’s healthcare services¹.

The impact of COVID-19 on black, Asian and minority ethnic communities has also been reported, and in particular the challenges around online consultations, with many from black, Asian, and minority ethnic backgrounds stating that they find it difficult, due to cultural barriers, to speak to healthcare practitioners whilst in the house with others such as their husband or family members. When re-assessing how endometriosis services should resume after the Covid-19 pandemic, factors such as this should be brought into play, and considerations should always be made for those who may struggle to access virtual appointments.

1 R. Garcia et al., Specific antenatal interventions for black, Asian and Minority Ethnic (BAME) pregnant women at high risk of poor birth outcomes in the United Kingdom (2015), K Newbigging et al., The role of advocacy and interpretation services in the delivery of quality health

Neelam Heera, Founder of Cysters, said:

“

Those from minority communities face challenges in accessing virtual appointments at home. A lot of people from BAME communities that we’ve spoken to feel that their own endometriosis care has been pushed aside to deal with other issues such as family life. Those from a South Asian background felt they had to put their own health aside because they effectively have to put the family first due to the traditional roles within these households. Online consultations have also been reported as difficult for those from black, Asian, and minority ethnic backgrounds, with many from minority communities stating that they find it difficult to speak to healthcare practitioners in private whilst in the house with others such as their husband or family members. When re-assessing how endometriosis services should resume, factors such as this should be considered and exceptions should always be made for those who may struggle to access virtual appointments”.

In order to eradicate health disparities for those with endometriosis in black, Asian and minority ethnic communities, more research must be done into the challenges and barriers that these communities face. As a next step, the APPG will commit to undergoing a series of meetings with women and those assigned female at birth, from black, Asian and minority ethnic backgrounds to greater understand these challenges.

Recommendations

1. Address health disparities for those from black, Asian and minority ethnic communities.

2. End the gender and ethnicity data gaps for those from black, Asian and minority ethnic backgrounds.

LGBTQ+

The APPG recognises the challenges faced by those within the endometriosis community who identify as LGBTQ+. A report by Stonewall, *LGBT in Britain: Health Report (2017)* highlights the general issues in healthcare that those within the LGBTQ+ community have faced, that are relevant in understanding how those with endometriosis may experience care and support. The report, *LGBT in Britain Health*¹ highlighted that:

- Almost one in four LGBT people (23 per cent) have witnessed discriminatory or negative remarks against LGBT people by healthcare staff.
- One in eight LGBT people (13 per cent) have experienced some form of unequal treatment from healthcare staff because they're LGBT. A third of trans people (32 per cent) have experienced unequal treatment. One in five non-binary people and LGBT disabled people (both 20 per cent) have experienced this at one time. Similarly, one in five black, Asian and minority ethnic LGBT people (19 per cent), including 24 per cent of Asian LGBT people, have experienced this.

- Three in five trans people (62 per cent) said they've experienced a lack of understanding of specific trans health needs by healthcare staff; 41 per cent had experienced this in the last year.

We have seen from our own findings and those reported by Endometriosis UK that there can be difficulties for those from LGBTQ+ communities, including accessing healthcare, experiences of discrimination, the use of gendered language and particular challenges around fertility. One woman, for example, was told her endometriosis was “invalid” due to being a lesbian, and that she didn't need to worry “because she wouldn't be having children” – even though she did indeed want children. Others have reported feeling even more alone due to the gendered language that health practitioners use in relation to endometriosis care.

Those who do not identify as female may find it distressing to attend appointments in a women's hospital or dedicated women's unit. The NICE Quality Standards on Endometriosis highlight that trans men with endometriosis may need to be seen in another clinic or setting, in line with their individual preference, and this should be implemented by the NHS.

¹ *LGBT in Britain: Health Report* – Stonewall (2017): https://www.stonewall.org.uk/system/files/lgbt_in_britain_health.pdf

Recommendations

1. Recognition from UK Governments that more needs to be done to ensure inclusivity and equality of access to endometriosis services, and proactive work to identify issues faced and how these can be overcome.

Chapter 5

The impact of Covid-19 on the endometriosis community

The onset of the Covid-19 pandemic meant an abrupt change in healthcare provision in the UK, in March 2020. Whilst the primary focus was on the care of those infected with SARS-CoV-2 and public health measures to prevent transmission/identify those most at risk, individuals with chronic conditions saw their treatments halted, cancelled or changed with very little warning, little information available and extremely limited access to clinicians (in primary or secondary care).

Many of those with endometriosis rely on regular medication, often requiring a face to face appointment for prescriptions or drug delivery (i.e. to check blood pressure before repeat prescriptions, provision of injections) and many others were on waiting lists for appointments, surgical procedures and/or fertility treatments.

The University of Oxford led a study in collaboration with Endometriosis UK and INSERM, Paris to identify the impact the pandemic has had on people with endometriosis. A key aspect was to understand what those with endometriosis consider should be prioritised both during the pandemic itself and as healthcare services begin to return to some form of “new normal”. Only UK respondents who met an inclusion criteria (aged 18 years old or over; previous diagnosis of endometriosis) are included in this analysis for the APPG Inquiry.

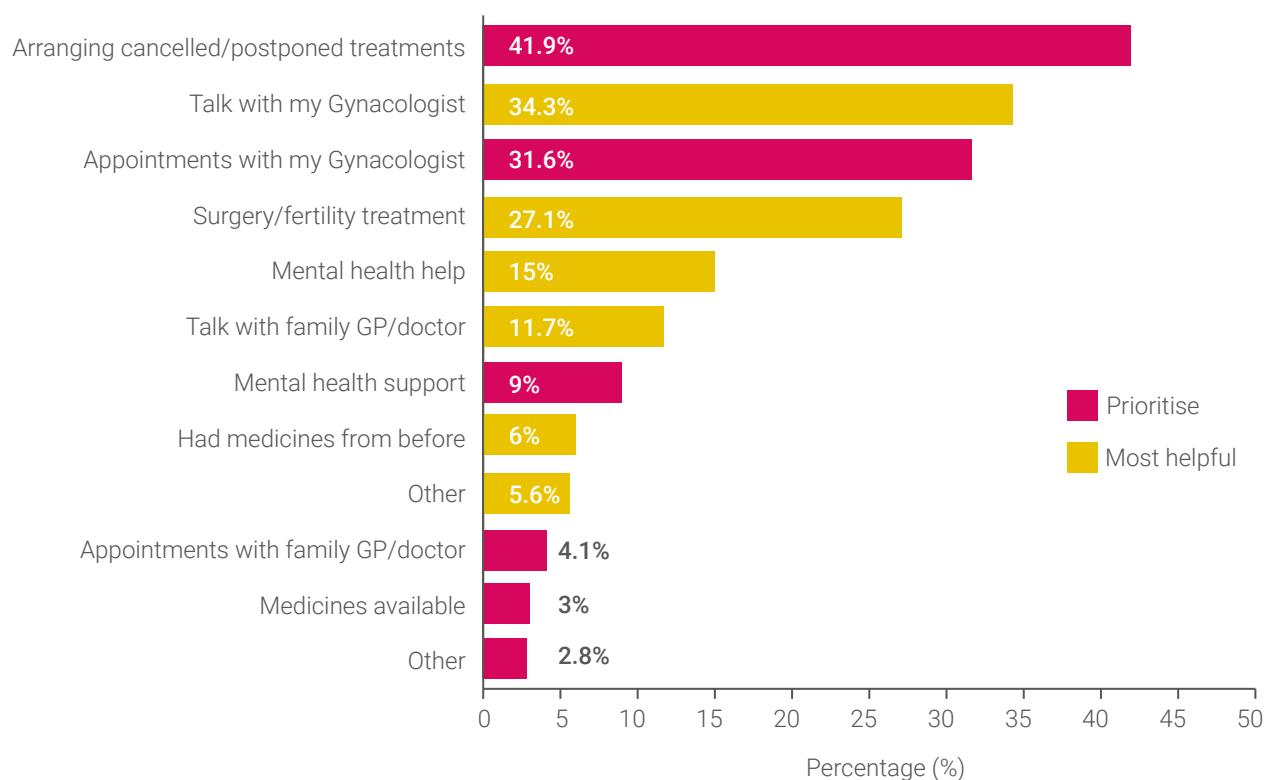
Q1: During the pandemic, what one thing would be most helpful to you, relating to endometriosis? 2071 UK respondents:

- 1 Being able to talk to my gynaecologist: 34.3%
- 2 Knowing when my surgery/fertility treatment will happen: 27.1%
- 3 Having some help with my mental health: 15.3%
- 4 Being able to talk to my GP/family doctor: 11.7%
- 5 Being able to have all the medicines I had before: 6.0%
- 6 Other: 5.6%

Q2: As restrictions begin to ease and healthcare starts to go back to normal, what one thing do you think should be prioritised with regards to endometriosis? 2098 respondents:

- 1 Arranging all treatments that were cancelled/postponed: 49.8%
- 2 Appointments with gynaecologists: 31.6%
- 3 Mental health support (counselling, psychology and/or medicines): 8.6%
- 4 Appointments with GPs/family doctors: 4.1%
- 5 Making medicines easily available: 3.1%
- 6 Other: 2.8%

How to help and what to prioritise in the UK during COVID-19



Both during and coming out of the pandemic those with endometriosis would prioritise speaking to their gynaecologist, rearranging treatments (surgical or fertility) or at least knowing when they will be rearranged, and support regarding their mental health. It is notable that mental health support ranks so highly given that this is not a key component of the majority of endometriosis services. However, its importance to those with endometriosis has been highlighted recently, including in the James Lind Priority Setting Partnership in 2017, and the BBC/ Endometriosis UK survey, October 2019.

As we look towards the autumn/winter with the risk of a second wave of cases and already pressurised health services, this information is going to be essential to ensure that those with endometriosis can access the care they need and want. Whilst surgical and fertility procedures may not be available, ensuring that gynaecologists are not redeployed to other

areas to allow telephone/video consultations is essential. Furthermore, mental health support initially in the form of online resources and virtual appointments should be developed to provide prompt support, whilst longer term solutions are developed and put in place. Whilst this may require significant investment from health service providers initially, in the longer term it can only be beneficial for those suffering with endometriosis and may reduce the burden of their symptoms and the negative impact on quality of life.

Summary of recommendations

Reducing diagnosis time

1. Untreated, endometriosis may progress. Diagnosis time must decrease to support those with endometriosis access the treatment they need, when they need it.

Currently, diagnosis time is an average of 8 years – the same as it was a decade ago. The APPG is seeking a commitment from Governments in all four nations to reduce average diagnosis times with targets of 4 years or less by 2025, and a year or less by 2030.

2. Building NHS capacity to appropriately diagnose those with endometriosis:

- Prompt referrals from primary to secondary care, including for diagnostic laparoscopy, by ensuring capacity within gynaecology departments and endometriosis specialist centres.
- Identify learning from the Rapid Diagnostic Centres being implemented to reduce times for diagnosing endometriosis

NHS pathways & access to specialist support

1. Governments and NHS's in the UK need to recognise the scale of endometriosis, and commit the resources needed to diagnose, treat and manage the disease; acknowledging it is a chronic condition and long-term support is needed.

2. That the UK Governments ensure the NICE Guideline and Quality Standards on Endometriosis are implemented.

This should involve undertaking a gap analysis, auditing and tracking where they are and

are not being followed. Areas that needed implementation include, but are not limited to:

- All areas to have a managed clinical network to coordinate endometriosis care.
- All with confirmed, or suspected, endometriosis having access to a gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery. Developing the role and appointing a Gynaecologist with a Special Interest in Endometriosis in all general gynaecology departments is vital to support those with endometriosis seen in general gynaecology.
- Access to a multidisciplinary pain management services, so relying on strong prescription painkillers or strong opioid drugs is not the only option, and that other interventions, such as pelvic physiotherapy, can be accessed.
- Access to fertility services to those with endometriosis who require them.
- Endometriosis symptoms to be recognised by all healthcare practitioners, and endometriosis to be suspected with one or more of the symptoms, including in adolescents.

3. Despite up to 10% of those with the disease having endometriosis outside the pelvic cavity, the NICE Guideline covers only endometriosis within the pelvic cavity.

Pathways need to be established for non-pelvic endometriosis, starting with thoracic endometriosis. These should be included in an updated NICE Guideline covering all types of endometriosis.

4. To ensure those with endometriosis have parity with treatment for other chronic conditions, and diseases that result in similar operations.

This would include a pathway for management in secondary care once diagnosed, access to fertility preservation, and pathways for those who have had hysterectomies however whose disease or treatments may have resulted in ongoing complications – rather than being ‘dropped’ as no longer considered by gynaecology.

5. Research is commissioned to discover the cause of the disease, better treatment and management options, and one day a cure.

Without investment in research, this condition will rob the next generation of women the education, care and support they deserve

6. The UK Governments must recognise the impact endometriosis has on people’s mental health as well as their physical health, and ensure psychological support becomes part of a person’s treatment plan.

7. Provision of patient information, so patients are not left in the dark about their disease.

8. The APPG calls for NICE to reconsider its decision not to support the use of Visanne, a Dienogest, by the NHS.

Visanne is used to treat endometriosis pelvic pain and is widely available in the rest of the world including Europe and Australia.

Awareness

1. Those with endometriosis have to recognise that what they are experiencing are symptoms in order to seek help.

Too many think the sometimes debilitating pain and symptoms they are experiencing is ‘normal’ and they have to live with it. The APPG would like to see Menstrual Wellbeing included as compulsory in the school curriculums across the UK, as it now is in England, to overcome the taboo of talking about periods and ensure all adolescents understand what a ‘normal’ period is and when to seek help.

2. It is vital for healthcare practitioners to recognise the symptoms of endometriosis, to be able to support diagnosis and ongoing treatment and care.

The APPG are calling on the Royal College of GPs, Royal College of Obstetricians and Gynaecologists and Royal College of Nursing, to review how to ensure their members gain the knowledge, training and experience they need to recognise the symptoms of endometriosis.

3. Awareness and education with the general public of what a ‘normal’ period is, the symptoms of endometriosis and other menstrual conditions, and when to seek help.

4. UK Governments and all departments not to use the words ‘sanitary’ or ‘hygiene’ when referring to period products, as this gives and reinforces the message that periods are dirty.

Fertility

1. There is a need to look holistically at the individual including their desires or concerns around fertility.

It should not be assumed that individuals only care about the ability to have children, however for those who are concerned around fertility there should be support in accessing appropriate information and care. Nor should it be assumed that those not in heterosexual relationships do not want children.

2. Recognition from Governments, NHS's and healthcare practitioners that there can be significant emotional impact of not being able to have children.

3. NICE Guideline: Fertility problems: assessment and treatment (CG156) should be followed, including early referral for specialist consultation for those with endometriosis.

4. Those for whom having children is not a priority should be afforded the same level of care, treatment and support to manage their symptoms and live their lives.

5. If an individual's endometriosis, or the treatments they are receiving, could impact on their fertility, they should have access to NHS treatment for fertility preservation.

Work and Benefits

1. Ensure those with endometriosis who need it have statutory support, and don't face discrimination due to lack of understanding and societal taboos around menstrual conditions.

This includes access to PIP and other disability allowances – ensuring guidance around endometriosis and its potential impact on work is clear to those assessing applications.

2. Ensure those with the disease who need it have access to Statutory Sick Pay.

3. Endometriosis should not be a taboo subject, and organisations and the UK Governments should adopt an open culture when it comes to talking about menstrual health.

The UK Governments should lead by example in encouraging employers to become "Endometriosis Friendly".

Mental health

1. Integrated mental health support as part of the endometriosis pathway.

2. Updating the NICE Guideline on Endometriosis to ensure mental health support is provided to patients who need it.

3. Ensuring the NICE Guideline is followed so that patients are not waiting on average 8 years for a diagnosis,

potentially leaving patients with long-term mental health issues.

4. For the APPG on Endometriosis to investigate further the links between endometriosis and mental health,

work with partners including Endometriosis UK and the Centre for Mental Health to take this forward.

Education

1. Devolved administrations to ensure menstrual wellbeing education is mandatory in all schools,

to ensure all young people across the UK have access to the same level of menstrual wellbeing education.

2. In England, the Government needs to ensure new education on menstrual wellbeing is implemented in all schools,

and teachers are given sufficient support and resource.

Diversity and inclusion

1. Recognition that more needs to be done to ensure inclusivity and equality of access to endometriosis services,

and proactive work to identify issues faced and how these can be overcome. Governments to work with the NHS to ensure nobody faces additional barriers in accessing healthcare due to their race, gender, sexuality, ability or social status, and ensure that those with additional needs such as learning disabilities have access to appropriate patient information and resources.

2. Address health disparities for black, Asian and minority people with endometriosis.

3. End the gender and ethnicity data gaps in research for those from black, Asian and minority ethnic groups backgrounds.

4. As identified in the NICE Quality Standards, those who don't identify as female may find it distressing to attend appointments in a women's hospital or dedicated women's unit, and may need to be seen in another clinic or setting in line with their individual preference.

5. Where possible, non-gendered language should be used by healthcare practitioners in relation to endometriosis and other gynaecological conditions.

Training should be provided by RCGP and RCOG for HCPs in providing care and support for those with gynaecological conditions who do not identify as female.

6. For those with pre-existing mental health conditions or disabilities (learning or otherwise), there may be additional barriers in accessing care.

Evidence should be gathered into the barriers faced by those with additional needs and ensure their additional needs are being met.

Acknowledgements

APPG Membership:

Chair:

David Amess MP

Vice-Chairs:

Jackie Doyle-Price MP,

Emma Hardy MP,

Dame Diana Johnson MP

Secretary:

Gill Furniss MP

A huge thank you to all the Members of the APPG on Endometriosis, and all who contributed to the Inquiry through the survey, hearings and submitting evidence

Endometriosis UK act as the group's secretariat.

Endometriosis UK commissioned PB Consulting to support this report.

Appendices

Appendix 1: Abbreviations

APPG: All-Party Parliamentary Group
BAME: Black, Asian and Minority Ethnic groups
Covid-19: SARS-CoV-2
ESA: Employment and Support Allowance
HCPs: Health Care Practitioners
NICE: The National Institute for Health and Care Excellence
PIP: Personal Independence Payment
RCGP: Royal College of General Practitioners
RCOG: Royal College of Obstetricians and Gynaecologists
RSE: Relationships and sex education and health education
SSP: Statutory Sick Pay

Appendix 2: Relevant Guidelines

NICE Guideline on Endometriosis: NG73 – <https://www.nice.org.uk/guidance/ng73>
NICE Quality Standard on Endometriosis: QS172 – <https://www.nice.org.uk/guidance/qs172>
NICE Guideline on Fertility: CG156 – <https://www.nice.org.uk/guidance/cg156>
RCGP Menstrual Wellbeing Toolkit – <https://www.rcgp.org.uk/menstrualwellbeingtoolkit>
RCOG Position Statement: Racial disparities in women’s healthcare
<https://www.rcog.org.uk/globalassets/documents/news/position-statements/racial-disparities-womens-healthcare-march-2020.pdf>

Appendix 3: Questions breakdown

Overview of data and analysis: figures used, broken down by individual question.

Responses from 02/10/2020 to 03/24/2020

Without non-UK residents 13,338

Minus 8 (n= 13,330) due to irregular age entry

Minus 1582 (n= 11,748) due to non-confirmed diagnosis

Minus 73 (n= 11,675) due to not answering "If you have been diagnosed with endometriosis, how long did you have symptoms before you got a diagnosis?"

Minus 892 (n= 10,783) due to conflicting answers from "If you have not been diagnosed with endometriosis, how long have you had symptoms?" (They confirmed diagnosis in previous answers)

For all questions those that skipped the question or listed N/A were removed from the results, hence the varying responses for each question.

Please find below the breakdown of number of responses for each quantitative question:

- Q1** Where do you live in the UK? 10,783
- Q2** How old are you? 10,783
- Q3** Please tell us about your diagnosis of endometriosis. 10,783
- Q4** If you have been diagnosed with endometriosis, how long did you have symptoms before you got a diagnosis? 10,783
- Q5** If you've not been diagnosed with endometriosis, how long have you had symptoms? (Not used in this report)
- Q6** If you have been diagnosed, approximately how many times did you visit the GP with your symptoms of endometriosis, before you received a diagnosis for endometriosis? If you are not sure, please give your best guess. 10,349
- Q7** If you have been diagnosed, approximately how many times did you visit the Doctors in hospital your symptoms of endometriosis, before you received a diagnosis for endometriosis? If you are not sure, please give your best guess. 10,219
- Q8** If you've ever went to A&E with your symptoms before receiving a diagnosis, please tell us how many times. 9,965
- Q9** Were you given any written information about endometriosis when you were diagnosed 10,027
- Q10** How satisfied were you with the information you were given on endometriosis when you received your diagnosis? 10,698
- Q11** Whilst the majority of endometriosis is found within the pelvic cavity, it sometimes grows elsewhere in the body. Have you been diagnosed with endometriosis outside the pelvis? 9,263 NB narrative responses showed that the term 'within the pelvic cavity' was not understood by many respondents, and results not used.
- Q12** To what extent has endometriosis/symptoms affected your wellbeing? 10,132
- Q13** To what extent has endometriosis/symptoms affected your ability to live your life as you want? 10,125

Q14 Considering this in more detail, to what extent have the different symptoms of endometriosis that you have experienced affected your ability to live your life as you want? Please tick all that apply.

- Pelvic pain 10,091
- Painful bowel movements 9,736
- Urinary symptoms 9,052
- Heavy menstrual bleeding 9,665
- Pain during or after sex 9,487
- Difficulty getting pregnant 6,633
- Fatigue 10,044

Q15 Have you seen a gynaecologist in a hospital about your endometriosis? 10,783

Q16 How many appointments have you had with a gynaecologist? 10,127

Q17 When was your last appointment with a gynaecologist? If you're not sure please give your best guess. 10,014

Q18 Thinking about your last appointment, how long did it take from when you were referred to see a gynaecologist to when you had your appointment? 10,008

Q19 If you have had surgery for endometriosis, how many operations have you had? 9,921

Q20 When was your last surgery for endometriosis? 9,172

Q21 Thinking about your last surgery, how long did it take from when you and your gynaecologist agreed you should have surgery to you having that surgery? 9,141

Q22 Considering all the treatments you have had for endometriosis, how effective do you think they have been in reducing the impact of your symptoms? Please tick all that apply to you:

- Surgery to remove endometriosis (including removal of ovarian cysts/ endometriomas) 8,569
- Hormonal contraceptives (eg the pill, Mirena coil) 8,251
- Hormones that put me into menopause 3,689
- Prescribed pain killers 8,557
- Pain management 6,861
- Pelvic physiotherapy 1,296
- Psychological support 1,978
- Fertility treatment 2,169

Q23 Are there treatments for endometriosis that you think would have improved your quality of life but you have not been offered?

- Surgery to remove endometriosis (including removal of ovarian cysts/ endometriomas) 7,796
- Hormonal contraceptives (eg the pill, Mirena coil) 7,709
- Hormones that put me into menopause 5,774
- Prescribed pain killers 8,127
- Pain management 8,255
- Pelvic physiotherapy 8,290
- Psychological support 8,475
- Fertility treatment 4,622

Q24 If you wanted to speak to a medical professional about your endometriosis / symptoms, who would you go to first. 10,012

Q25 Since you have been diagnosed, how helpful have you found you GP(s) in supporting you with your endometriosis/ symptoms? 9,651

- Q26** Since you have been diagnosed, how helpful have you found your Gynaecologist(s) in supporting you with your endometriosis/ symptoms? 9,321
- Q27** How confident are you that you would be able to get an appointment with a gynaecologist about your endometriosis or symptoms if felt you needed to? 9,950
- Q28** As part of your diagnosis or treatment, were you asked by a medical practitioner if fertility was important to you? 10,006
- Q29** Have you accessed, or tried to access, fertility services due to endometriosis? 3,394
- Q30** If you were referred to a fertility service, how long did it take from when you first tried to access fertility services until your first appointment? 2,818
- Q31** Were you referred to a fertility service that was free or you had to pay for? 2,963
- Q32** What fertility or fertility preservation treatments have you had, or are waiting for? Please tick all that apply.
- Intrauterine insemination (IUI) 819
 - In vitro fertilisation (IVF) 1,795
 - Surgery 1,541
 - Egg freezing 780
 - Embryo freezing 1,024
 - Ovarian tissue freezing 505
- Q33** What would have improved your experience of getting a diagnosis of endometriosis? (Free text)
- Q34** What would improve your experience of ongoing treatment for endometriosis? (Free text)
- Q35** What would help you to manage living with endometriosis? (Free text)
- Q36** Due to my endometriosis, in the last three years: (please tick all that apply)
- I was able to undertake usual daily activities 9,381
 - I was able to participate in social events 9,381
 - I was able to take part in leisure activities 9,378
 - I had enough support to cope well with endometriosis 9,375
 - I was able to live life as I wanted 9,380
 - I felt isolated 10,783
 - I had problems with my relationships with other people 9,368
 - I felt less self-confident 9,374
 - I felt worried about the effect endometriosis may have on my future 9,378
 - I had feelings of defeat or hopelessness 9,373
 - I felt depressed 9,373
 - I felt in control of daily life" 9,378
- Q37** Has endometriosis had an impact on your mental health? 9,461
- Q38** If you experienced endometriosis whilst at school, has it had an impact on your education? (Please go to next question if not applicable)
- I had time off school 6,800
 - I had time off university/ college 6,792
 - I found it difficult to focus on my studies 7,049
 - I missed exams at school 6,762
 - I missed exams at university/college 6,654

Q39 If you have experienced endometriosis whilst working, has it had an impact on your work? (Please go to next question if not applicable)

- I have had time off work 9,257
- I'm restricted in the work I can do 9,175
- I've reduced my working hours 9,056
- I believe I have missed out on promotion 8,845
- I have a reduced income 8,942
- I have concerns about losing my job 8,950
- I had to change or leave my job 8,914
- I had difficulty pursuing the career I wanted 8,985
- I have experienced financial hardship 9,018

Q40 Depending on the symptoms and severity experienced, some will consider their endometriosis as a disability, whilst others will not. Have you ever applied for or received support for your endometriosis as a disability?

- I have never applied for disability-related financial support" 7,921
- I receive universal credit" 336
- I receive Personal Independence Payment (PIP) or Disability Living Allowance (DLA) 365
- I receive Attendance Allowance 10
- I receive employment and Support Allowance (ESA)" 267
- I receive parking benefits – Blue Badge 127
- I receive a disabled persons bus pass or railcard 81
- I have applied for disability-related financial support due to my endometriosis but been refused 478

Q41 If you have applied for any form of disability support as a result of your endometriosis, how did you find the process?

Q42 Is there anything else you would like to add about the impact endometriosis has had on you? (Free text)

Q43

Which one of the following best describes your gender?	Total Respondents	Percentages
Female	7,628	70.74%
Male	4	0.04%
If you describe your gender in another term please provide it	22	0.20%
In another way	5	0.05%
Blank	3,122	28.95%
Prefer not to say	2	0.02%
Grand Total	10783	100.00%

Which one of the following best describes your ethnic group?	Total Respondents	Percentages
Arab	7	0.06%
Asian	51	0.47%
Asian British	169	1.57%
Black or Black British	96	0.89%
Blank	1319	12.23%
Mixed	210	1.95%
Other (please specify)	63	0.58%
White	8839	81.97%
Prefer not to say	29	0.27%
Grand Total	10783	100.00%

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What is your highest level of education qualification?	Total Respondents	Percentages
A levels, vocational level 3 or above	1604	16.94%
Degree or degree equivalent	2824	29.83%
Higher degree or post graduate qualifications	2306	24.36%
No qualifications	138	1.46%
Other (please specify)	108	1.14%
Other higher education below degree level	1157	12.22%
Other qualifications	296	3.13%
Other qualifications below A level, vocational level 3 and level unknown	790	8.34%
Prefer not to say	244	2.58%
Grand Total	9467	100.00%