

Written Evidence from Nottingham Women's Centre [WRH0032]

Introduction

In the summer of 2021, the policy team at Nottingham Women's Centre released its quarterly Campaigning Issues Paper which highlighted the challenges and experiences of women suffering endometriosis in Nottingham due to the lack of a specialist NHS endometriosis clinic in Nottingham.

Summary

Several our staff and service users are suffering due to the lack of a specialist NHS endometriosis clinic in Nottingham. Women are being forced to travel to Leicester, Peterborough, Birmingham, and other parts of the country for treatment. This is particularly difficult for women with caring responsibilities and those who do not have cars. This has caused undue financial burden on women both for travel costs as well as childcare costs. Women who access social security can claim back travel costs, but women on low wages cannot claim financial support for travel.

We ran a poll through our social media platforms and found that 45% of respondents with endometriosis (7 out of 15 women) said they had to travel to other parts of the country for treatment. Women unanimously agreed that it was "extremely important" that Nottingham gets a specialist endometriosis treatment centre through NHS.

Since 2021, NWC's policy team have pursued this campaign, lobbying for change through social media, to set up a specialist endometriosis by running polls, organising awareness workshops and engaging with MPs, Integrated Care System(ICS which replaced the Clinical Commissioning Group), , co-production teams on women's health, as well as local organisations including Endometriosis UK, Notts Make our NHS Public and university research networks. In May 2023, we hosted the event, 'All About Endometriosis', an awareness workshop with two health professionals and over 50 women registered. As part of the event, we included a question bank which gave women the opportunity to tell their story and experiences through questions. In total, we received over 40 questions. Their questions revealed their struggles of women with lived experiences of endometriosis and provided useful insights into the challenges of the current services for women's reproductive health. This submission therefore presents information from the workshop/question bank, social

media poll conducted, cases from our case workers and our various engagements with local organisations and ICS NHS Nottingham.

Specifically, this submission provides evidence to the following questions

- What are women's experiences of being diagnosed with undergoing procedures and being treated for gynaecological or urogynaecological conditions?
- What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?

To tackle the current barriers to women's reproductive health, it is important for the government to consider the following:

- The importance of cross ICS cooperation for people needing referral to an endometriosis specialist centre who live in an integrated care system without such a centre cannot be over emphasized. Steps need to be taken to ensure there is sufficient capacity at centres that receive cross ICS referrals to ensure that people with endometriosis receive the care they need, regardless of where they live.
- Provision of free psychological support within the NHS for women suffering from endometriosis.
- Funding allocation for a specialist endometriosis clinic in Nottingham. There are an estimated 16,000 women who suffer with endometriosis in the city.
- Better training and diagnosis education about endometriosis in Nottingham's GP practises.
- Launch a wider awareness campaign on endometriosis to encourage women to get diagnosed and improve public understanding of the condition.
- Funding research on the condition and diagnosis education for better health outcomes.

1. What are women's experiences of being diagnosed with undergoing procedures and being treated for gynaecological or urogynaecological conditions?

Endometriosis is a condition where cells similar to the ones in the lining of the womb (uterus) are found elsewhere in the body. Each month these cells react in the same way to those in the womb, building up and then breaking down and bleeding. Unlike the cells in the womb that leave the body as a period, this blood has no way to escape. In the UK, around 1.5 million women and those assigned female at birth are currently living with the condition, regardless of race or ethnicity.¹ Endometriosis can affect you from puberty to menopause, although the impact may be felt for life.

According to the story of one woman,

“I was diagnosed with endometriosis in 2018 after suffering from cripplingly heavy periods, chronic pelvic pain and fatigue for over 12 years. The gynaecologist who diagnosed me did not have the special interest in endometriosis required by the NICE guidelines and told me that I had mild endometriosis which she had removed during my diagnostic surgery. This turned out to be a misdiagnosis I’ve now been diagnosed me with severe endometriosis, which requires a different level of treatment.

My second round of treatment has been delayed due to Covid. My symptoms are worsening all the time and I am now in constant pain. I have gained two stone and I am no longer able to run (due to pain from the endometrioma) which was something which was very beneficial for my mental as well as physical health. Because I rely on strong painkillers to get through the day, I am now opiate dependant and when I do have the surgery I am waiting for (assuming it is successful) I will need to go through an opiate withdrawal programme.

Because I have severe endometriosis, I have to be treated by a specialist endometriosis centre, however Nottingham does not have such a centre so I need to travel to Leicester for my care. This is also where my surgery will take place meaning it is unlikely that any friends or family will be able to visit me while I'm in hospital.”

This is one amongst several cases recorded by our case workers at Nottingham Women's Centre since 2021. Recorded cases of women's experiences highlight these key points:-

¹ Endometriosis UK <https://www.endometriosis-uk.org/what-endometriosis>

- **Lack of/ Limited information from GPs and Health professionals on the condition**

Women have often reported inconsistency in the medical advice they receive from GPs and health professionals throughout their reproductive health journey. Information relating to the symptoms, causes, treatment and management of the condition are often piecemeal, contradictory, inaccessible, and limited. This has left women with no autonomy over their bodies and uncertainty about their lives, causing more stress and anxiety. In the words of one woman, *'Is there any hope for the future of endo? Many doctors and gynos seem to have no answers for me'*

'I don't know at which stage I am and what is the possibility that it could cause fertility/miscarriage issues (an experience that I would prefer to prevent rather than have it).'

As outlined in [NICE Guidelines](#), anybody who is suspected to be suffering from endometriosis should be seen by a gynaecologist who has a special interest in endometriosis (i.e. specialist training). Our research within the city shows that there are currently no gynaecologists with a special interest in endometriosis in Nottingham.

- **Delay in diagnosis**

According to Endometriosis UK, on average it takes 8 years from onset of symptoms to get a diagnosis. Most of our service users report that they started experiencing symptoms from age 14+. Symptoms include chronic pain and fatigue which has often interrupted their education or work life and overall quality of their lives. This prolonged time without a diagnosis leaves women with prolonged experience of chronic pain, treatment delay, risk of disability, and significant impact on the quality of their lives. Women say,

*'I have been suffering since i was 14 years old, got diagnosed when i was 23...I am also disabled due to endometriosis so limited mobility in right leg, due to waiting too long to finally have a operation.'*²

'I believe I may be pre-diagnosis... do you have any tips or recommendations to shorten the wait to getting to the point where the pain can be more easily and predictably managed?'

Delay in diagnosis of endometriosis could be attributed to a lack of awareness of the condition amongst the general public. In our engagement with the Centre for Reproductive

² <https://www.endometriosis-uk.org/support-group/45403>

Health, De Montfort University, researchers highlighted the need for public awareness and their focus on the impact of endometriosis on couples and relationships. This lack of public awareness has led to women not recognising early symptoms of the condition as well as family and friends not certain on how to manage their loved ones with the condition. A woman said, *What is the best way to support a colleague with endometriosis? What adjustments should be made in the workplace?*

Some women are entitled to certain rights and adjustments in the workplace under the Equality Act 2010 due to endometriosis-related disability but they are unable to access such rights due to the lack of public understanding of the condition amongst employers. Pre diagnosis (which could take up to 8 years), women face apathy, distrust and risk of redundancy from their employers as they struggle to prove their need for entitlements such as sick leave at work. According to the question by a woman, *How can I find a workplace that is supportive of my endometriosis?*

- **Lack of psychosocial support/pain management service within the NHS**

90% of the women we polled with endometriosis said they would have liked psychological support, but they have not been offered this as part of their treatment. The mental health impact of endometriosis is often neglected in the treatment journey. Endometriosis pain, though indescribable, is often described by women with lived experiences as, amongst others, *the feeling of a barbed wire fence running across my abdomen. It's sharp, fire-hot pain that comes in waves.*³ Words such as stabbing, debilitating, relentless, insides on fire are only a few amongst the intense words used to describe endometriosis pain. To manage the pain, women are becoming more and more addicted to painkillers, which is impacting their mental health. Some women with endometriosis are unable to partake in physical exercises, due to the condition, which is one way to maintain their mental health. Some of the questions women asked through the question bank highlight this point:

'What help and support is out there for people that are living with endometriosis on a daily basis and if there is how is this accessed?'

'Is there any holistic approaches I can take to alleviate symptoms? I always get referred back to taking a pill but don't think it's the most effective way of helping my symptoms'

'What are good resources (books etc) for Endometriosis and related health conditions?'

³ <https://endometriosis.net/living/pain-description>

Existing support groups outside the NHS through local organisations such as endometriosis UK support groups lack the technical and financial resource to provide sustainable quality support for the number of women who need this support as they are often run by volunteers , who themselves have lived experience of the condition. Therefore, integrating a psychological and mental health support system within the NHS for women with endometriosis, will provide women with early support and mental strength to survive this condition, which in itself has a daunting and traumatic treatment journey.

2. What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?

- **Lack of specialist endometriosis clinic in Nottingham**

According to Endometriosis UK,⁴ 1 in 10 women (an estimate of over 16,000 women in Nottingham) suffer from endometriosis - a condition where tissue similar to the lining of the womb starts to grow in other places, such as the ovaries and fallopian tubes.⁵ Women often need specialist support to manage extreme pain and associated symptoms but there is no specialist clinic in Nottingham, which forces women to travel to Leicester, Peterborough, Birmingham, and other parts of the country for essential treatment.

Women suffering endometriosis are not only required to travel significant distances to receive medical help, but are also being passed around a confusing bureaucratic system spanning across ICS areas, ultimately impeding their access to vital care. This is generally discomforting for women in such painful condition and disproportionately affects women with care responsibilities, women with low income as public transportation and accomodation expenses are unaffordable especially if they are frequent, women who are single parents, women with disabilities and women who suffer several and multiple disadvantage (SMD).

Through our research and engagement with ICS Nottingham and Endometriosis UK, we found that though the British Society for Gynaecological Endoscopy (BSGE) is the professional body which accredits endometriosis specialist centres, the geographic

⁴ Endometriosis UK <https://www.endometriosis-uk.org/endometriosis-facts-and-figures>

⁵Office for National Statistics

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationandhouseholdestimatesenglandandwalescensus2021>

distribution and capacity of these centres has not been planned or overseen, but has instead arisen due to the strong interest of an individual clinician or clinicians. Endometriosis specialist centres are not physical centres, but virtual groups of clinicians and other staff (who are suitably qualified and willing to support the project), which operate a clinic within a hospital setting. Based on this, for the past 3 years, we have lobbied for clinicians in Nottingham; who are willing and qualified; but our efforts have been met with futility. Subjecting women with this debilitating condition to an undue burden to travel miles for treatment due to lack of qualified and interested clinicians in the area makes health care inaccessible and further exacerbates health inequalities.

- **Long waiting times for treatment**

Long waiting times for the first consultation after referral to gynaecology/endometriosis specialist centre is a chronic barrier to women's access to reproductive health services. Over 50% of participants at the Endometriosis workshop held at Nottingham Women's Centre report a waiting time of up to 6 months and more. During these waiting times, women struggle with persisting symptoms such as excessive bleeding that most often incapacitates their ability to live their normal lives. . In the past year, our casework team have reported the influx of several women requesting assistance for a shorter waiting time as their symptoms get worse. One woman asked,

I'm on the waiting list for a laparoscopy and have been waiting 7 months, can they please give an estimate as to how much longer it will be?

It is important to highlight that delayed appointments leading to delayed referral and diagnosis can have serious 'avoidable' implications for women (and children in the long run) as prognosis may significantly differ if they had been seen swiftly. Several women have developed endometriosis-related disability and deep trauma issues as a result of the impact of long waiting times.

About Nottingham Women's Centre

Nottingham Women's Centre (NWC) was established in 1971, making us one of the oldest and largest women's centres in the country. Today we are a charity and community space that empowers women by providing financial and employment support, counselling, training, social activities and activism in a women's building in central Nottingham. With approximately 500 women coming through our doors each month and our connection to over 162 organisations through our Women's Organisations Network, we have recorded a 60% increase in skills by women between April 2021 and March 2022.⁶ Besides, our Ministry of Justice project which works with women within the criminal justice system, we run several projects that provides case work support to women in Nottingham and Nottinghamshire on a variety of themes such as housing and accommodation; employability & training; finance, benefits & debt; dependency & recovery; family & relationships; lifestyle and purpose; health & wellbeing; social inclusion and belonging.

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⁶ <https://www.nottinghamwomenscentre.com/in-the-space-of-one-year-heres-what-we-achieved/>