Endometriosis Diagnosis and Treatment in Nottingham and Nottinghamshire
Briefing for Nottinghamshire Health Scrutiny Committee
November 2025

1. Introduction

The purpose of this briefing is to provide Nottinghamshire Health Scrutiny Committee with an overview of the support for endometriosis and the pathway from diagnosis to treatment for patients living in Nottinghamshire.

2. Background

Endometriosis is a long-term condition where tissue similar to the lining of the womb, known as endometrium, grows outside the uterus. In most cases, the extra endometrium grows on organs in the pelvic area such as the ovaries, fallopian tubes, and the lining of the pelvis. However, in rare cases, it can affect organs like the bladder, bowel, or even areas outside the pelvis. All endometrium is affected by the menstrual cycle, where in the womb they would build up before breaking down and leaving the body during the Menstrual period.

Endometriosis occurs when cells similar to the ones in the lining of the womb (uterus) are found elsewhere in the body. These cells can grow and change in response to hormones in the menstrual cycle, this can cause inflammation, pain and scar tissue. Endometriosis is most commonly found on the lining of the pelvis (peritoneum) and may occur in the ovaries and involve other pelvic organs, like the bowel or bladder. Less commonly, endometriosis can also be found outside the pelvis, such as in the chest.

Individuals with endometriosis often suffer from severe period pain, heavy or irregular bleeding, lower back and stomach pain, pain during or after sex, and discomfort when passing urine or stools. Some people experience fatigue, bloating, pain in the lower back and legs. or difficulty conceiving a child

Endometriosis affects 1 in 10 women and those assigned female at birth from puberty to menopause, although the impact may be felt for life. In the UK, that is more than 1.5 million from all races and ethnicities living with the condition. Nottingham Women's Centre estimates that around 30,000 people in Nottingham live with endometriosis[1], based on the national prevalence.

According to the Office for National Statistics[2], between March 2011 and December 2021, 4,285 women in Nottinghamshire were diagnosed with endometriosis by the NHS. It is not currently feasible to access more detailed data from individual GP records to explore the gap between this number and the 30,000 above.

3. Navigating the Pathway for Suspected Endometriosis in Nottinghamshire

When a patient presents with symptoms suggestive of endometriosis (such as severe cyclical pelvic pain, menstrual-related bowel or bladder issues, or infertility) the journey typically begins in primary care. The GP conducts a thorough history, rules out any red-flag symptoms, and initiates first-line management using analgesia or hormonal therapy. If symptoms persist or escalate, the patient is referred to a local general gynaecology service through the NHS electronic-Referral Service, usually at Nottingham University Hospitals NHS Trust (NUH) or Sherwood Forest Hospitals NHS Foundation Trust (SFH).

[1] Latest NWC campaigns.... - Nottingham Women's Centre
[2] Characteristics of women with an endometriosis diagnosis in England - Office for National Statistics

Diagnosis and management of suspected or confirmed endometriosis is provided through local general gynaecology and fertility services. Clinicians routinely request imaging, most commonly a pelvic ultrasound: an MRI scan will be organised if deep disease is suspected. If the condition appears superficial and confined to the pelvis, treatment will be provided locally, either through medical management or straightforward laparoscopic surgery. Multidisciplinary chronic pain services are available in both community and hospital settings, though access is limited due to demand exceeding capacity and not specific to pelvic pain or endometriosis.

However, if investigations and symptoms suggest deep infiltrating endometriosis (DIE) involving organs such as the bowel, bladder, ureters, or rectovaginal septum, the patient is referred to a British Society for Gynaecological Endoscopy (BSGE)-accredited Endometriosis Centre. For Nottinghamshire, this typically means the Royal Derby Hospital, although referrals may also be made to centres in Leicester, Sheffield, Birmingham, or Peterborough, depending on patient preference and capacity.

This pathway ensures that patients with suspected endometriosis receive timely, specialist-led care tailored to the complexity of their condition.

These specialist centres operate as regional tertiary services, commissioned under NHS England's specialised gynaecology pathways. Referrals are made via the NHS e-Referral Service (e-RS) under the category: "Endometriosis – suspected deep or complex (BSGE accredited centre)".

The referral package includes:

- Imaging reports (trans-vaginal ultrasound (TVUS)/MRI)
- Operation notes (if applicable)
- A summary of symptoms and their impact on the patient's quality of life

Care at the BSGE centre is provided through a Multidisciplinary Team (MDT) approach. The MDT meetings should include a core membership of all gynaecologists listed within the centre, an endometriosis clinical nurse specialist. a colorectal surgeon and a radiologist. Other members join meetings to discuss specific cases as required. A support network is required which includes urologists, fertility specialists and pain management specialists who can provide active support to the service when needed.

Over recent years there has been an increasing focus on the need for earlier recognition and diagnosis of endometriosis among both health care professionals and the public. This has been supported by the publication of updated NICE Guidelines on Endometriosis in 2024[3].

GPs have access to a clinical information and referral guideline platform (known as "F12") which is integrated into the clinical systems. This contains links to national guidance on pelvic pain, local ultrasound guidance and pre-referral management guidelines for primary care clinicians. These are designed to support clinicians with early recognition and timely referrals. The ICB are finalising local pre referral guidelines for Gynaecology to complement national guidance and provide links to local services and information.

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[3] Overview | Endometriosis: diagnosis and management | Guidance | NICE

Nationally and locally, gynaecology waiting lists are large and many pathways exceed 18 weeks. Trusts publish specialty-level waiting time information on MyPlannedCare[4], which provides averaged waiting figures for each specialty, but this cannot be broken down into endometriosis pathway waits specifically. The publicly available average waiting time for a first outpatient appointment and treatment in the Nottingham and Nottinghamshire ICB local NHS Trusts for gynaecology services are shown in the table below.

Provider	Average waiting time for first outpatient appointment	Average waiting time for treatment
NUH	14 weeks	17 weeks
SFH	11 weeks	17 weeks
DBH	18 weeks	14 weeks

The British Society for Gynaecological Endoscopy (BSGE) holds data on the numbers of annual surgical cases for severe rectovaginal endometriosis requiring pararectal-space dissection, at accredited endometriosis centres, but it does not publish waiting list metrics for each centre. The table below summarises the annual surgical activity at six BSGE accredited centres most relevant to Nottinghamshire referrals: Derby, Leicester, Peterborough, Birmingham, Sheffield, and Rotherham[5].

BSGE Endometriosis Centre Activity: Midlands and Adjacent Regions (2018–2024)

BSGE Centre	2018	2019	2020	2021	2022	2023	2024	Total
Derby	13	15	5	12	19	24	47	135
Leicester	–	–	13	8	24	25	15	85
Peterborough	18	24	12	16	–	–	–	70
Birmingham	19	18	9	17	16	20	–	99
Sheffield	30	27	19	23	26	28	32	185
Rotherham	10	14	8	12	18	21	24	107

4. Women's Perspectives on the Endometriosis Pathway in Nottinghamshire

Recent engagement activities and reports in Nottinghamshire have provided valuable insight into how women perceive the current endometriosis diagnosis pathway and its effectiveness.

In May 2023, the Nottingham Women's Centre hosted an online awareness event titled "All About Endometriosis" where women shared their lived experiences and provided feedback on the diagnosis and treatment pathway.

Several key themes emerged from these discussions. Access to care was a prominent concern, with participants reporting difficulties in reaching specialist centres, particularly during episodes of acute pain. Long waiting times for procedures such as laparoscopy were frequently cited, with some women experiencing delays of up to eight or nine months. In some cases, referrals to gynaecology services were declined despite years of persistent symptoms, contributing to frustration and a sense of being dismissed.

The diagnosis pathway itself was described as lengthy and inconsistent. Many women reported delays in receiving a formal diagnosis, often spanning several years. Symptoms such as back pain, urinary issues, and abdominal pressure were not initially recognised as indicative of endometriosis, leading to misdiagnosis or inadequate treatment. As a result, self-advocacy became a necessary strategy, with women encouraged to raise the possibility

[4] My Planned Care NHS
[5] Data for BSGE Accredited Endometriosis centres | BSGE

of endometriosis directly with their GPs and to document their concerns through written correspondence.

Treatment experiences varied widely. Hormonal therapies, including the mini-pill and Mirena coil, were commonly prescribed, but responses ranged from effective symptom relief to reports of ineffectiveness and adverse side effects. Surgical interventions such as laparoscopy and hysterectomy were also discussed, with outcomes differing from patient to patient.

Collectively, these insights reveal a pathway that, while clinically structured, often falls short of meeting the needs and expectations of women experiencing endometriosis. The feedback highlights the importance of timely diagnosis, compassionate care, and inclusive service design.

Between October and December 2024, Nottinghamshire County Council ran a Women's Health Survey[6] to gather views from women across the county. The survey explored topics such as health and wellbeing, access to health information and services, and the impact of caring responsibilities and employment. Notably, the survey acknowledged that women's health conditions, including menopause and endometriosis, remain under-recognised and under-diagnosed within the broader health system. This recognition signals a growing awareness of the need to address gaps in service provision and information access for women experiencing these conditions.

The Director of Public Health Annual Report (2024-25)[7] further reinforced these findings. Drawing on feedback from approximately 1,000 local women, the report highlighted persistent health inequities and barriers to care. It underscored the importance of prevention, reducing stigma, and improving access to services. A key recommendation was the adoption of coproduction approaches, whereby women are actively involved in the design and delivery of services that affect their health and wellbeing. This emphasis on inclusive service development reflects a broader commitment to equity and responsiveness in healthcare planning.

5. Recommendations to Nottinghamshire Health Scrutiny Committee

The Nottinghamshire Health Scrutiny Committee is asked to note the contents of this briefing.

[6] womenshealthsurveydataanalysis.pdf
[7] Director of Public Health and Communities Annual Report | Nottinghamshire County Council