Nottingham and Nottinghamshire Integrated Care Board

04/09/2026

NN-ICB/26-1672

Dear Requestor

Re: Freedom of Information Request

Thank you for your request for information, received on 23 June 2026, regarding endometriosis and adenomyosis services and pathways. We have processed your request in accordance with the Freedom of Information Act 2000 (FOIA).

Under the FOIA, public authorities like ours are required to respond to requests for information within 20 working days. In response to your request, I can confirm that we partially hold the information requested.

Please find below our response to your request:

1. Please provide the number of patients recorded with a diagnosis of endometriosis within datasets available to the ICB, by financial year, for each of the last five financial years. If exact figures are not held, please provide any estimates available.

   The ICB has access to GP clinical data which records patients currently coded with an endometriosis diagnosis. At the date the data was extracted, 13,295 patients were recorded as having an endometriosis diagnosis.

   The ICB does not hold this information broken down by financial year and is, therefore, unable to provide the yearly figures requested.

2. Please provide the number of patients recorded with a diagnosis of adenomyosis within datasets available to the ICB, by financial year, for each of the last five financial years. If exact figures are not held, please provide any estimates available.

Diagnosis	2021/2022	2022/2023	2023/2024	2024/2025	2025/2026	TOTAL
Adenomyosis	55	50	68	82	93	348

3. Please provide the number of referrals for suspected endometriosis received within the ICB area, by financial year, for each of the last five financial years.

   The ICB does not hold this information for suspected endometriosis referrals. The level of referral data held by the ICB relates to gynaecology referrals as a whole and cannot be reliably disaggregated to suspected endometriosis referrals.

   You may wish to contact individual providers to request this and how to submit a Freedom of Information request to each provider can be found on their website links below:

   - Nottingham University Hospitals NHS Trust - https://www.nuh.nhs.uk/freedom-of-information
   - Sherwood Forest Hospitals NHS Foundation Trust - Freedom of Information | Sherwood Forest Hospitals

- Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust - https://www.dbth.nhs.uk/contact/freedom-of-information/.

4. Please provide the average waiting time from referral to a first specialist gynaecology appointment for patients with suspected endometriosis during the most recent complete financial year. If available, please also provide data for the previous four financial years.

   The ICB holds waiting time information at specialty level for gynaecology services. Information relating to local gynaecology waiting times is referenced within the attached briefing document 'Support for Endometriosis in Nottingham and Nottinghamshire' – see attachment A.

   Further endometriosis-specific information may be held by the relevant providers, who you may wish to contact directly (see response to question 3).

5. Please provide the average waiting time from referral to diagnostic laparoscopy for suspected endometriosis, where recorded. If this information is not held centrally, please provide any available waiting-time data relating to diagnostic investigations for suspected endometriosis.

   The ICB does not hold this information. You may wish to contact the relevant provider organisations directly (see response to question 3).

6. Please provide the names of the specialist endometriosis centres and providers to which patients within the ICB area are routinely referred.

   Patients within the Nottingham and Nottinghamshire ICB area are routinely referred to:

   - Nottingham University Hospitals NHS Trust
   - Sherwood Forest Hospitals NHS Foundation Trust
   - Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust.

   Where complex or deep infiltrating endometriosis is suspected, patients may be referred to British Society for Gynaecological Endoscopy (BSGE) accredited specialist endometriosis centres. The most common referral centre for Nottinghamshire patients is Royal Derby Hospital, although referrals may also be made to centres in Leicester, Sheffield, Birmingham and Peterborough.

7. Please provide copies of any current care pathways, service specifications, policies or guidance documents relating to endometriosis.

   The ICB holds referral optimisation pathways and prescribing guidance relevant to endometriosis, see below:

   - Referral Optimisation: Gynaecology; - see attachment B
   - Support for Endometriosis in Nottingham and Nottinghamshire - Briefing for Nottinghamshire Health Scrutiny Committee (November 2025); - see attachment A.
   - Ryeqo® and Linzagolix Prescribing Information Sheet; - see link found here - Ryeqo and linzagolix prescribing guideline.

   These documents contain information relevant to referral pathways, clinical management and prescribing arrangements for endometriosis

8. Please provide details of any digital tools, mobile applications, websites or self-management resources that are currently recommended, commissioned or signposted by the ICB for patients with endometriosis or adenomyosis.

   The ICB does not commission any digital tools or mobile applications specifically for endometriosis or adenomyosis. The attached clinical guidance (see response to question 7) signposts clinicians and

patients to a range of nationally available resources and support materials relevant to these conditions

9. Please provide details of any **funding, investment programmes, service development initiatives or allocated budgets specifically intended to improve** endometriosis services during each of the last three financial years.

   The ICB holds information relating to implementation of NICE-approved treatments for endometriosis, including development of shared-care prescribing arrangements, commissioning discussions, pathway development and associated financial considerations. Relevant information is contained within Area Prescribing Committee (APC) meeting minutes and prescribing guidance documents, which are available in the public domain.

   Please see the shared care information for endometriosis treatment, here: Ryeqo and linzagolix prescribing guideline.

   The Area Prescribing Committee (APC) meeting minutes that relate to the discussion around this are here: 4-apc-formulary-minutes-august-2025.pdf and 5-apc-formulary-minutes-december-2025.pdf.

10. Please provide details of any **funding, investment programmes, service development initiatives or allocated budgets specifically intended to improve** adenomyosis services during each of the last three financial years.

    The ICB does not hold records identifying any dedicated funding allocation, investment programme or ring-fenced budget specifically for adenomyosis services during the period requested.

11. Please provide **copies of any service reviews, audits, needs assessments, gap analyses or evaluation reports relating to endometriosis or adenomyosis that have been undertaken** or commissioned within the last five years.

    The ICB does not hold any service reviews, audits, needs assessments, gap analyses or evaluation reports specifically relating to endometriosis or adenomyosis within the scope of your request.

12. Please provide the number of specialist endometriosis services currently commissioned by the ICB and the nature of those services.

    The ICB commissions secondary care gynaecology services through:

    - Nottingham University Hospitals NHS Trust
    - Sherwood Forest Hospitals NHS Foundation Trust
    - Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust.

    These services provide assessment, investigation, diagnosis and treatment for patients with suspected or confirmed endometriosis.

    Where complex or deep infiltrating endometriosis is suspected, patients may be referred to BSGE-accredited specialist endometriosis centres in line with regional pathways.

13. Please provide copies of any documents, reports, meeting minutes, audits or analyses that identify factors contributing to **delays** in the diagnosis of endometriosis.

    The ICB holds information relevant to this request within the attached document *Support for Endometriosis in Nottingham and Nottinghamshire - Briefing for Nottinghamshire Health Scrutiny Committee (November 2025)* - see Attachment A.

    The document includes information relating to delays in diagnosis, waiting times, access to specialist services, referral challenges and patient experiences of the diagnostic pathway.

Please see the minutes of the Health Scrutiny Committee meeting where this item has been discussed - Health Scrutiny Committee 11.11.2025.

14. Please provide copies of any documents, reports, meeting minutes, audits or analyses relating to **barriers** to the timely diagnosis of endometriosis or adenomyosis.

    The ICB holds information relevant to this request within the attached document *Support for Endometriosis in Nottingham and Nottinghamshire - Briefing for Nottinghamshire Health Scrutiny Committee (November 2025)* - see Attachment A.

    The document includes discussion of barriers reported by patients and stakeholders, including diagnostic delays, referral challenges, access to specialist services and wider women's health inequalities.

    Please see the minutes of the Health Scrutiny Committee meeting where this item has been discussed - Health Scrutiny Committee 11.11.2025.

15. Please provide copies of any referral templates, referral guidance documents, triage criteria or audits relating to referrals for suspected endometriosis.

    Please see response to question 7.

16. Please provide copies of any standardised symptom assessment tools, questionnaires or patient-reported outcome measures used across commissioned services for patients with suspected endometriosis.

    The ICB does not hold this information. Please refer to the response to question 3 for provider website links.

17. Please provide copies of any patient information forms, questionnaires, checklists or guidance documents that set out the information routinely requested from patients prior to their first specialist appointment for suspected endometriosis.

    The ICB does not hold this information. Please refer to the response to question 3 for provider website links.

If you are unhappy with the way in which your request has been handled, NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) has an internal review procedure through which you can raise any concerns you might have. Further details of this procedure can be obtained by contacting Lucy Branson, Director of Corporate Governance and Assurance via lucy.branson@nhs.net or by writing to FOI Team at NHS Nottingham and Nottinghamshire ICB, Sir John Robinson House, Sir John Robinson Way, Arnold, Daybrook, Nottingham NG5 6DA.

If you remain dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office (ICO), who will consider whether the organisation has complied with its obligations under the Act and can require the organisation to remedy any problems. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Nottingham and Nottinghamshire ICB. You can find out more about how to do this, and about the Act in general, on the Information Commissioner's Office website at: https://ico.org.uk/for-the-public/.

Complaints to the Information Commissioner's Office should be sent to:

FOI/EIR Complaints Resolution, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Telephone 0303 123 1113 or report a concern via https://ico.org.uk/concerns/.

Yours sincerely

Freedom of Information (FOI) Officer on behalf of NHS Nottingham and Nottinghamshire Integrated Care Board nnicb-nn.foi@nhs.net

All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the Open Government Licence (OGL) a request to re-use is not required, but the license conditions must be met. You must not re-use any previously unreleased information without having the consent of NHS Nottingham and Nottinghamshire Integrated Care Board. Should you wish to re-use previously unreleased information then you must make your request in writing (email will suffice) to the FOI Lead via nnicb-nn.foi@nhs.net. All requests for re-use will be responded to within 20 working days of receipt.