

Our Reference North East and North Cumbria ICB\
FOI ICB 26–145

North East and North Cumbria ICB
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By Email

16 July 2026

Dear Applicant

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received on 24 June 2026 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000. The ICB covers the areas of County Durham, Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley.

Please find the information you requested on behalf of the ICB as follows.

Your Request

I am writing to make a request for information under the Freedom of Information Act 2000 in relation to endometriosis and adenomyosis services within your ICB.

The purpose of this request is to better understand the current diagnostic pathways, service provision and support available for individuals living with these conditions. The information gathered will contribute to work focused on supporting people affected by endometriosis and adenomyosis through improved symptom monitoring, self-management and understanding of patient experiences.

I would be grateful if you could provide the following information, where held:

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.
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.
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.

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.
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.
6. Please provide the names of the specialist endometriosis centres and providers to which patients within the ICB area are routinely referred.
7. Please provide copies of any current care pathways, service specifications, policies or guidance documents relating to 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.
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.
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.
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.
12. Please provide the number of specialist endometriosis services currently commissioned by the ICB and the nature of those services.
13. Please provide copies of any documents, reports, meeting minutes, audits or analyses that identify factors contributing to delays in the diagnosis of endometriosis.
14. Please provide copies of any documents, reports, meeting minutes, audits or analyses relating to barriers to the timely diagnosis of endometriosis or adenomyosis.
15. Please provide copies of any referral templates, referral guidance documents, triage criteria or audits relating to referrals for suspected endometriosis.
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.
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.

If any of the requested information is not held by your ICB but is held by another organisation, I would be grateful if you could advise accordingly or transfer the request where appropriate.

Our Response

1. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. However, we have determined that the information is held by the acute hospital NHS foundation trusts (FTs) within the North East and North Cumbria region.

In accordance with our duty under s.16 of the FOIA to provide reasonable advice and assistance to an individual requesting information, we have provided the FOI contacts for those foundation trusts.

NENC Acute Hospital FTs	Email/Online portal
County Durham and Darlington NHS FT	cdda-tr.cddftfoi@nhs.net
Gateshead Health NHS FT	ghnt.foi.enquiries@nhs.net
North Cumbria Integrated Care NHS FT	foirequest@cumbria.nhs.uk
North Tees and Hartlepool NHS FT	nth-tr.foi@nhs.net
Northumbria Healthcare NHS FT	foi@northumbria.nhs.uk
South Tees Hospitals NHS FT	stees.foi.admin@nhs.net
South Tyneside and Sunderland NHS FT	stsft@infreemation.co.uk
The Newcastle upon Tyne Hospitals NHS FT	https://www.newcastle-hospitals.nhs.uk/help/foi/

2. Please refer to the response to question 1.
3. Please refer to the response to question 1.
4. Please refer to the response to question 1.
5. Please refer to the response to question 1.
6. Please refer to the response to question 1.
7. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested. However, this is publicly available on the Northern Treatment Advisory Group website: <https://ntag.nhs.uk/?s=endometriosis>. In accordance with s.21 of the FOIA, we are not required to provide information in response to a request if it is reasonably accessible to you by other means.
8. Please refer to the response to question 1.
9. Costs relating to endometriosis would be in the contracts with foundation trusts but would be included in the Obs and Gynae speciality. ICB records show £6.15m spent in 2024/25 and £8.49m in 2025/26 where the primary diagnosis is endometriosis. There is no record held where adenomyosis is the primary diagnosis.
10. Approximately 300,000 people living in Middlesbrough, Redcar and Cleveland and adjacent areas of North Yorkshire receive access to commissioned [specialist endometriosis centres](#), as part of our Gynaecology commissioned services.
11. There has been no specific commissioned work relating to endometriosis or adenomyosis. To enhance the ICB's insight and intelligence across the previous five years, the following needs analysis and evaluations were carried out to inform strategic decision-making for Women's Health, which includes key considerations for menstrual health and gynaecological conditions:
 - North East and North Cumbria Women's Health Programme: Regional Needs Assessment, July 2024
 - [Women's health profile: North East and North Cumbria data dashboard, March 2026](#)
 - The Big Conversation, in partnership with Healthwatch and Explain, the ICB commissioned independent research to engage with women across the North East and North Cumbria.
 - ICB Women's Health Plan 2025-2030, a collaborative system led plan, following extensive consultation with stakeholders, which outlines key actions and desired outcomes for endometriosis, within our Menstrual Health and Gynae conditions section

ICB clinical and commissioning leads continue to collaborate and support foundation trusts to enhance female patient pathways, for those suffering from these conditions.

12. We are aware of two specialist Endometriosis centres in the region:
 - [Endometriosis centre – Newcastle Hospitals NHS Foundation Trust](#)
<https://www.bsge.org.uk/centre/category/accredited-centres/united-kingdom/north-east/>
 - [Find BSGE Accredited Endometriosis Centres in the UK](#)

The detail of these services and the specific treatments delivered would be information held within the remit of these departments in the Foundation Trusts.

13. ICB Clinical and Commissioning leads have had conversations regarding information sharing and a patient leaflet for endometriosis, with strategic health partners. This has included conversations regarding heavy menstrual bleeding and chronic pelvic pain which are symptoms and sequelae of endometriosis but not relating to specific delays in the diagnosis of endometriosis.
14. Please refer to the response to question 13.
15. Please refer to the response to question 1.
16. Please refer to the response to question 1.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Information Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the ICB's complaints procedure.

The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or www.ico.org.uk.

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk. This will not affect your initial information request.

Yours faithfully

Information Governance Support Officer

**Information Governance Support Officer
North East and North Cumbria Integrated Care Board**