

04 August 2026

Endometriosis and Adenomyosis Services and Pathways

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.

Note: We are a Health and Social Care Trust not an ICB and this response is based on Belfast Health and Social Care Trust information only.

- 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.**

Under Section 1(1)(a) of the Freedom of Information Act 2000, Belfast Trust cannot provide data about diagnosis at outpatients, as this is not coded.

Referrals are received for many clinical concerns and accurate diagnosis cannot be given until investigations are completed.

- 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.**

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

- 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.**

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

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- 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.**

We do not hold waiting time information specifically for patients with suspected endometriosis. Patients referred with suspected endometriosis are managed within the wider Gynaecology waiting list. The current waiting time for a first Gynaecology outpatient appointment is approximately 3 years.

The Trust does not hold the requested average waiting-time information by condition.

- 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.**

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

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

Regional commissioning of endometriosis services is ongoing with the Strategic Planning and Performance Group (SPPG). Until this has been completed, Belfast Trust has not sought formal accreditation.

However, Belfast Trust operates under the same parameters as the British Society for Gynaecological Endoscopy (BSGE) requirements with an MDT, specialist nurse and multi-disciplinary surgery

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

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

- 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.**

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Patient Information Leaflets are provided electronically as a thumbnail / QR code on patients 'after visit' letter

Please see attachments 1 to 4.

- 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.**

This is a question for commissioners. You will need to redirect this question to the Strategic Planning and Performance Group of the Department of Health (SPPG) - Email: FOI@health-ni.gov.uk

- 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.**

For information regarding Northern Ireland Health & Social Care
Email: FOI@health-ni.gov.uk

- 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.**

For information regarding Northern Ireland Health & Social Care
Email: FOI@health-ni.gov.uk

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

See response to Question 6.

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

For information regarding Northern Ireland Health & Social Care
Email: FOI@health-ni.gov.uk

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

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For information regarding Northern Ireland Health & Social Care
Email: FOI@health-ni.gov.uk

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

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

Email: FOI@health-ni.gov.uk. There is work ongoing for a regional endometriosis pathway

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.

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.

Email: FOI@health-ni.gov.uk.

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.

Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested

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.

As advised above, questions about commissioning should be directed to the Strategic Planning and Performance Group of the Department of Health for Northern Ireland -
Email: FOI@health-ni.gov.uk