

FOI 3857

20th July 2026

FREEDOM OF INFORMATION ACT 2000 – INFORMATION 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.**

Response: This information is not recorded centrally and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

Furthermore, under Section 16 of the Freedom of Information Act, we can advise that it would require an extensive manual review of all Gynae outpatient attendances and admissions just to ascertain if information relevant to your request is held. As such, we advise that there is no way to refine this request to bring it within the appropriate limit.

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.

Response: This information is not recorded centrally and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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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.

Response: This information is not recorded centrally and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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Furthermore, under Section 16 of the Freedom of Information Act, we can advise that it would require an extensive manual review of all Gynae referrals and outpatient attendances just to ascertain if information relevant to your request is held. As such, we advise that there is no way to refine this request to bring it within the appropriate limit.

- 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.**

Response: The Acute Information Team can only provide the average wait for gynae speciality – not broken down by specific diagnosis so therefore we are unable to provide any data.

- 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.**

Response: The Acute Information Team can only provide the average wait for laparoscopy – not broken down by specific diagnosis so therefore we are unable to provide any data.

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

Response: Patients who meet the criteria for surgery in a tertiary centre to the GSGE accredited Endometriosis Centre in the Western Trust and have established referral pathways with this centre.

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

Response: A regional approach to endometriosis care within Northern Ireland is currently in advanced stages of development through the Regional Endometriosis Task and Finish Group, of which the Southern Trust is an active member.

Please refer to Attachment 1 - ESHRE guidance on Endometriosis management; We would reference the NICE guideline (NG 73) which forms the basis of endometriosis care.

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.

Response: This Information is not held, currently there are no commissioned resources.

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.

Response: Northern Ireland is progressing the development of endometriosis services through the adoption of a regional hub-and-spoke model, aligned with the NHS England framework. This work is being taken forward by a regional Endometriosis Task and Finish Group, with representatives from across Health and Social Care organisations, including the Southern Trust.

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.

Response: Please see response above to Q9.

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.

Response: All patients undergoing excisional surgery for deep disease have been audited since March 26. End points are symptom improvement (assessed by Quality of Life Questionnaire) and surgical outcomes. Please refer to Attachment 2 – BSGE Pelvic Pain Questionnaire, which has been adapted for use in the Southern Trust.

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

Response: The Southern Trust currently offers a dedicated local endometriosis service which provides investigation and medical and surgical management for all patients with endometriosis.

Excisional endometriosis surgery is provided for all women.

Those with severe deep infiltrating endometriosis are discussed with the BSGE Accredited Centre in the Western Trust and referred to this centre for surgery if felt to be required.

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

Response: This information is not held.

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

Response: As above, this information is not held.

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

Response: This information is not held.

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.

Response: Please refer to Q11 response alongside Attachment 2.

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.

Response: Please refer to previous response above.

Email: Foi.Team@Southerntrust.hscni.net