Reference:	FOI.20825.26
Subject:	Endometriosis and Adenomyosis services and pathways
Date of Request:	23 June 2026

Requested:

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.

Response:

Integrated Care Boards (ICBs) are a feature of the NHS in England. Hywel Dda University Health Board (UHB) is part of NHS Wales and is an integrated Local Health Board responsible for the health and well-being of its resident population of Carmarthenshire, Ceredigion and Pembrokeshire. The UHB plans and provides primary care, community services and in hospital services, together with mental health and learning disability services and population health, based on the needs of the local community across the three (3) counties. Therefore, the information relating to the UHB is provided below.

1. The UHB provides within the table overleaf, the number of patients with a diagnosis of Endometriosis, as recorded on the Welsh Patient Administration System (WPAS), during the 2021/22 to 2025/26 financial years.

Financial year	Number
2021/22	206
2022/23	238
2023/24	199
2024/25	214
2025/26	252

2. The UHB provides within the table below, the number of patients with a diagnosis of Adenomyosis, as recorded on the WPAS, during the 2021/22 to 2025/26 financial years.

Financial year	Number
2021/22	26
2022/23	51
2023/24	59
2024/25	76
2025/26	69

3. The UHB provides within the table below, the number of referrals received for suspected Endometriosis, as recorded on the WPAS, during the 2021/22 to 2025/26 financial years.

Financial year	Number
2021/22	8
2022/23	18
2023/24	32
2024/25	36
2025/26	38

4. The wait time from the date the referral is received to a first appointment for the clinical condition Endometriosis, is currently twenty-six (26) weeks.

5. The average waiting time from referral to diagnostic laparoscopy for suspected Endometriosis, is approximately eighteen (18) to twenty-four (24) months.

6. UHB patients diagnosed with Endometriosis are routinely referred to Swansea Bay University Health Board (SBUHB) for specialist care.

7. The UHB adheres to the National Institute for Health and Care Excellence (NICE) Endometriosis: diagnosis and management.

   As this information is accessible by another means, the UHB has applied an exemption under Section 21 of the Freedom of Information Act 2000 (FoIA). The guidance is available on the NICE website. For ease, a link to the relevant guidance has been provided below.

   Overview | Endometriosis: diagnosis and management | Guidance | NICE

8. The UHB provides links to the websites and resources it uses for patients with Endometriosis overleaf:

   - Endometriosis Cymru

   What are the symptoms of endometriosis? - Endometriosis Cymru

   - Endometriosis UK

   Ending endometriosis starts by saying it | Endometriosis UK
   Adenomyosis | Endometriosis UK
   pelvic exercise programmes web.pdf

   - LiveWell with pain

   Home - Live Well with Pain

   - Healthline

   Healthline: Medical information and health advice you can trust.
   10 Supplements That Fight Inflammation

9. The UHB received funding from Welsh Government (WG) for a Whole Time Equivalent (WTE) number of 1.00 for an Endometriosis Clinical Nurse Specialist (CNS), for the 2023/24 to 2025/26 financial years.

10. The UHB does not hold the requested information, as no funding is received for Adenomyosis services.

11. The UHB does not hold the requested information, as no analyses or evaluation reports relating to Endometriosis or Adenomyosis have been undertaken during the 2021/22 to 2025/26 financial years. The Endometriosis CNS position was only recruited to in 2021.

12. The UHB does not commission specialist Endometriosis services. Please see response to question 6.

13. The UHB does not hold reports, meeting minutes, audits or analyses that identify factors contributing to delays in the diagnosis of Endometriosis. However, the UHB's Patient Advisory Liaison Service (PALS) receive many patient concerns relating to delays in the diagnosis and treatment of Endometriosis.

    Copies of these concerns are being withheld under Section 40 of the FoIA as they relate to personal information of a third party. This decision has been made as it is not within the reasonable expectations of these individuals, that their personal information would be released into the public domain. This information is classed as personal data of a third party. Therefore, it is being withheld in accordance with the exemption set out in section 40(2) of the FoIA, by virtue of section 40(3)(a) of the FoIA, which permits a public authority to withhold personal data other than the requestor's where the disclosure would breach Data Protection principles.

    This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations (UK GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

    In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

14. The UHB does not hold the requested information, as it does not have documents, reports, meeting minutes, audits or analyses relating to barriers of the timely diagnosis of Endometriosis or Adenomyosis.

15. In addition to the NICE Guidance referred to in response to question 7, the UHB provides a copy of its Endometriosis CNS Referral Criteria, at Attachment 1.

16. & 17. The UHB provides copies of the questionnaires and assessment tools used for patients with suspected Endometriosis, at the following attachments:

    - British Society for Gynaecological Endoscopy (BSGE) Pelvic Pain Questionnaire - Attachment 2
    - London Orthopaedics Surgery EQ-5D Questionnaire – Attachment 3.
    - Patient Experience Survey - Endometriosis CNS appointment – Attachment 4.