Lothian NHS Board

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**www.nhslothian.scot**

Date 24/12/2025
Your Ref
Our Ref 10724

Enquiries to Richard Mutch
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loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

**FREEDOM OF INFORMATION – FUNCTIONAL NEUROLOGICAL DISORDER**

I write in response to your request for information in relation to Functional Neurological Disorder and cancer.

- Under the Freedom of Information Act 2000, I am requesting the following information held by NHS Lothian concerning oncology treatment delays, cases where Functional Neurological Disorder (FND) was initially diagnosed but later found to be cancer, and discharge safety regarding prophylactic anticoagulation.
    1. Most recent complete year: 2024
    2. Ten-year look-back: 2014 (or nearest available year)
    3. Optional: annual breakdown 2020–2024, if available without undue burden

Question:

**A. Oncology – Biopsy and Treatment Delays**

1. Average, median, and maximum turnaround time from **biopsy to pathology report**.
2. Number of patients whose **chemotherapy or treatment schedule was delayed** due to biopsy or pathology turnaround.
3. Total number of **biopsies processed** and number of **pathologists and lab technicians on staff** during these periods.

Answer:

| Timeline 31st March 2015 | Requests received | Specimens received | % of Histopathology cases reported in 7 days (168 hours) | Healthcare Science team (WTE) | Pathologists (headcount) |
|---|---|---|---|---|---|
| 1st April 2014 - 31st March 2015 | 62181 | 89411 | 35.78% | 56.35 | 41 |
| 1st April 2015 - 31st March 2016 | 62928 | 88032 | 42.92% | 53.94 | 34 |
| 1st April 2016 - 31st March 2017 | 56688 | 86519 | 44.96 | 53.7 | 33 |
| 1st April 2017 - 31st March 2018 | 57297 | 89976 | 16.97% | 53.64 | 34 |

| | | | | | |
|---|---|---|---|---|---|
| 1st April 2018 - 31st March 2019 | 60283 | 96158 | 44.85% | 47.24 | 37 |
| 1st April 2019 - 31st March 2020 | 59807 | 95732 | 20.74% | 45.22 | 31 |
| 1st April 2020 - 31st March 2021 | 40808 | 66860 | 32.12% | 50.7 | 39 |
| 1st April 2021 - 31st March 2022 | 52610 | 85401 | 20.69% | 64.07 | 40 |
| 1st April 2022 - 31st March 2023 | 54461 | 85458 | 23.22% | 54.14 | 40 |
| 2nd April 2023 - 31st March 2024 | 56722 | 91531 | 20.43% | 51.74 | 42 |
| 3rd April 2024 - 31st March 2025 | 54701 | 87724 | 22.08% | 51.48 | 42 |
| Specimens received used this is an indication of biopsy numbers i.e. cases have parts (sample pots) and more realistic of workload. We have provided % of cases reported in 7 days as this is the data we hold. We have provided 2014 onwards as requested. | | | | | |

We do not have data to answer question 2. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

Question:

**B. Neurology / FND Misdiagnosis Impacting Cancer Care**

1. Number of patients initially diagnosed with **FND** who were later confirmed to have **cancer**.
2. Diagnostic process prior to FND diagnosis, for example in a patient presenting with **limited or absent sensation in the lower limbs (paraplegic)**:
    - **Application of the Three Rules**:
        1. Rule out structural or organic neurological disease
        2. Rule out systemic/metabolic causes
        3. Rule out drug/toxin-related causes
    - **Tests that would normally be performed** according to standard guidance, including MRI, CT, EMG/nerve conduction studies, blood/metabolic panels, lumbar puncture, and specialist referrals.
    - Indicate which of these tests are **routinely performed prior to confirming FND**.
3. Typical steps taken before confirming FND – e.g., referrals, follow-up appointments, monitoring procedures.
4. **Delays caused in cancer care:** Average, median, and maximum time from initial presentation to:
    - FND diagnosis
    - Cancer diagnosis

- Start of appropriate treatment

5. **Safeguards to prevent misdiagnosis:** Policies or standard procedures in place to reduce the risk of incorrectly diagnosing FND when a serious condition such as cancer may be present.

Answer:

This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

We do not keep routine data on misdiagnosis of any condition in neurology. We carry out a morbidity and mortality meeting within Neurology three times a year where we discuss confidentially cases of misdiagnosis. There have been cases of FND discussed at that meeting, both where an alternative diagnosis was missed, but also where an alternative condition, such as cancer or Parkinson's disease, occurred alongside the diagnosis of FND, or where the diagnosis of FND was missed. There is no evidence that FND is overdiagnosed compared to other neurological conditions.

There is published data from Edinburgh on misdiagnosis rates in a consecutive cohort of patients with functional limb weakness related to FND showing a very low misdiagnosis rate at follow up of 14 years (see attached). Such studies require research time and funding

The FND research team within the department have published widely on this issue and advise clinicians regularly about diagnostic pitfalls both of overdiagnosis and underdiagnosis of FND'

Question:

**C. Discharge and Blood Thinner Protocols**

1. For patients who were **immobilised or had limited mobility** during a hospital stay (e.g., due to neurological symptoms, misdiagnosed FND, or cancer treatment):
   - Number of patients discharged **without prophylactic anticoagulants (blood thinners)** despite being at risk of thromboembolism.
   - Policies or guidance on prescribing **blood thinners at discharge** for patients at risk of clots.
   - Instances where **GPs were asked to continue or start prophylactic blood thinners** post-discharge, and whether refusals occurred.

Any **recorded delays or complications** (e.g.,

2. blood clots) linked to the absence of prophylactic anticoagulation at discharge

Answer:

This level of detail is not held in a centrally extractable format. Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: https://org.nhslothian.scot/FOI/Pages/default.aspx

Yours sincerely

**ALISON MACDONALD**
**Executive Director, Nursing**
Cc: Chief Executive