

Gillian Mathewson
gillian.mathewson@panspandas.scot

Date 04/12/2025
Your Ref
Our Ref 10793

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear Gillian Mathewson

FREEDOM OF INFORMATION – PANS AND PANDAS

I write in response to your request for information in relation to PANS and PANDAS.

Question:

1. **Actions Taken in Response to the PPSG Letter -**

What steps has NHS Lothian taken in response to the requests outlined in the PPSG letter, specifically:

- Distribution of information about PANS and PANDAS to GP practices.
- Circulation of this information to paediatric units.

Answer:

General paediatric, paediatric neurology and CAMHS teams are aware of the guidance. Primary Care have not circulated any separate information to GPs.

Question:

2. **Recognition of Updated Guidance**

Does NHS Lothian recognise that the 2023 PANS PANDAS Steering Group Statement supersedes the 2021 BPNA Consensus Statement?

Answer:

Clinicians in general paediatric, paediatric neurology and CAMHS teams feel that both statements provide valid and useful guidance to clinicians.

Question:

3. **Clinical pathways and referral options.**

The Cabinet Secretary stated that there are multidisciplinary services for PANS and PANDAS currently available in Glasgow and Edinburgh. Please confirm details of these services within NHS Lothian including:

- Referral pathways
- Eligibility criteria
- Whether referrals are accepted from other NHS Boards across Scotland

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
Lothian NHS Board is the common name of Lothian Health Board

Answer:

There is no specific referral pathway for suspected PANS/PANDAS. Instead, following referral, usually from a primary care clinician via SCI Gateway, children and young people presenting with acute onset neuropsychiatric symptoms may be initially assessed by a general paediatrician, paediatric neurologist or CAMHS clinician depending on the symptomology.

Where there is concern about an acute neuropsychiatric disorder then a multidisciplinary discussion between clinical teams (paediatrics, CAMHS, neurology) takes place to determine the best diagnostic and treatment approach, guided by the national guidance in the consensus statements referenced in the FOI request. There are no specific eligibility criteria for the referral process, but referrals are not routinely accepted from other NHS Boards across Scotland as the expectation would be that each Health Board could offer the same approach.

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.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive

