Lothian NHS Board

Lothian NHS Board
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www.nhslothian.scot

Date 24/06/2026
Your Ref
Our Ref 11520

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

Dear

FREEDOM OF INFORMATION – NEURODEVELOPMENTAL ASSESSMENT

I write in response to your request for information in relation to neurodevelopmental assessment and East Lothian Health and Social Car Partnership (ELHSCP).

Question:

1. Policy Documentation
   Formal and informal written policy documents relating to the practice of writing to patients to advise that will be removed from the neurodevelopmental assessment waiting list if they fail to respond, including the date of introduction, the name and role of the person or body who approved it, and any subsequent reviews.

Answer:

Scottish Government Policy document – Waiting Times Guidance:-
https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2023/12/nhsscotland-waiting-times-guidance-november-2023/documents/nhsscotland-waiting-times-guidance/nhsscotland-waiting-times-guidance/govscot%3Adocument/nhsscotland-waiting-times-guidance.pdf

NHS Lothian Waiting Times Guidance – Local Access Policy refers to National Guidance as above
https://www.nhslothian.scot/wp-content/uploads/sites/7/2024/06/Local-Access-Policy-V-5.0-May-2024-Final.pdf

This information is exempt under Section 25 of the Freedom of Information (Scotland) Act 2002 - Information otherwise accessible

(1) Information which the applicant can reasonably obtain other than by requesting it under section 1(1) is exempt information.

Question:

2. Projected Impact
   Any analysis, modelling, briefing, or other documentation relating to the anticipated or projected impact of the policy, including:

   (a) the number of patients expected to be removed from the waiting list as a result;
   (b) the basis on which that figure was considered acceptable;
   (c) any assessment of whether patients removed would genuinely no longer require assessment, as opposed to having simply failed to respond to correspondence;
   (d) consideration of how to ensure that patients have actually received the letter or text message.

Answer:

a. No expectations or assumptions were made.
b. As (a.)
c. East Lothian HSCP, by local arrangement, wrote to all patients on our waiting list to warn them that the validation process was happening. We then actively telephoned patients who have had contact through validation process. This was in addition to standard Validation process to ensure patients have received the validation contact and responded appropriately, correcting any errors due to miscommunication or misunderstanding.
d. As (c.)

Question:

3. Aim of policy
   Any documentation setting out the operational, clinical, or administrative problem the policy was intended to solve, and the benefit it was expected to deliver.

Answer:

Provided within documents accessible via links at Point 1.

Question:

4. Equalities
   Any equalities impact assessment (or equivalent) carried out before or after the introduction of the policy, including any consideration of the specific impact on patients with neurodevelopmental conditions, for whom challenges in communication and executive functioning can be key disabling features of their condition.

Answer:

As at 2. (c)

Question:

5. Scope of policy

Any information confirming whether this policy applies to other waiting lists or clinical specialties within NHS Lothian, or whether it is specific to the neurodevelopmental assessment waiting list.

Answer:

Applies to all NHS Out Patient Waiting Lists

Question:

6. Outcomes to date
   The number of patients who have been removed from the neurodevelopmental assessment waiting list under this policy since its introduction, and the total number contacted.

Answer:

110

Question:

7. Internal correspondence
   Any internal emails, minutes, briefings, or other communications discussing the rationale for introducing the policy or any concerns raised about it prior to or following implementation.

Answer:

Please see enclosed.

Question:

8. Parliamentary Inquiries
   Any consideration of the recommendations of Scottish Parliament inquiries from the past year. For example, consideration of how this policy can be reconciled with the following statement of the Equalities, Human Rights and Civil Justice Committee in early 2026:

Answer:

This should be taken up with the Scottish Government. ELHSCP is following government and NHS Lothian policies.

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
Enc.

East Lothian Health & Social Care Partnership | colleague briefing

DATE

Recovery plan to improve neurodiversity assessment and treatment times

East Lothian's Adult Neurodevelopmental Service has commenced an ambitious service redesign to reduce adult neurodiversity assessment waiting times from 4+ years to 12 weeks within the next 18 months.

Current position

Demand for neurodiversity assessment has risen sharply across the UK. In East Lothian, the waiting list currently includes 2149 people (March 2026). Individuals are waiting 4+ years for an assessment.

Many additions to the waiting list come from transfers from CAMHS, children and teens who have reached adulthood before they have been assessed. The delay of diagnosis in childhood, and lack of support in education and/or early employment can have significant negative life changing implications.

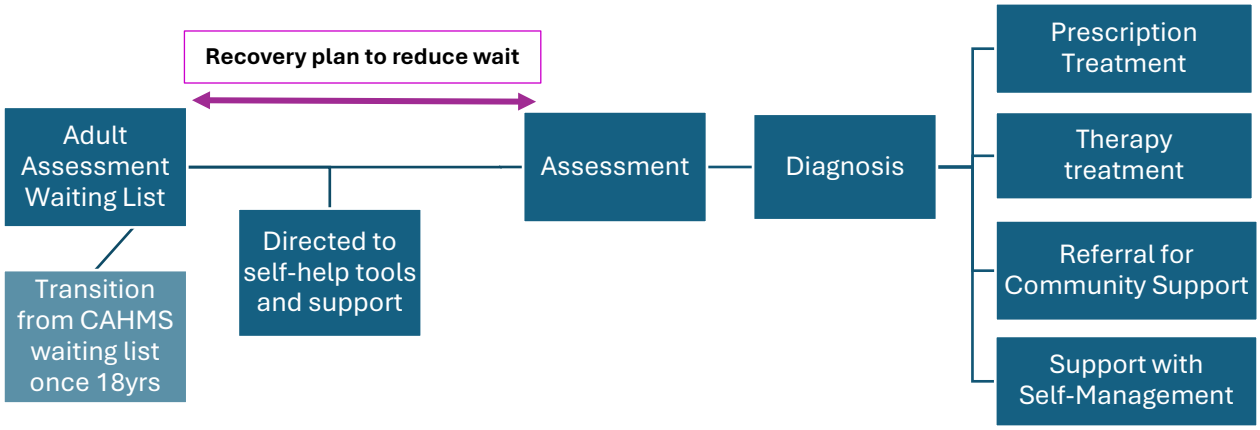
There is also a misunderstanding that private diagnosis can lead to faster NHS treatment. This is not the case. Patients who receive private assessments, still require to be reviewed by the East Lothian assessment team before GPs can take over prescribing.

Our goal

Over the next 18months, our goal is to reduce waiting time for neurodevelopment assessments to 12weeks. Doing so will ensure we:

- ✓ Align East Lothian's assessment times with Scottish Government targets.
- ✓ Deliver on NHS Lothian's objectives to provide equitable, efficient care and reduced waits.
- ✓ Support ELHSCP's vision to support people to live healthy lives and achieve their potential to live independently, exercising choice over the services they use.
- ✓ Work towards delivering the IJB core objective to reduce health inequalities.
- ✓ Support the delivery aims of The Scottish Parliament's 2026 ADHD & Autism Pathways Report that calls for urgent action and consistent national adult pathways for ADHD and autism.

Patient pathway



Recovery plan essentials

Staff recruitment: we will expand the Neurodevelopment Service Team from 2.6 WTE t 12.3 WTE for an initial 18 months to address the waiting list backlog. Thereafter we will maintain a team comprising of 7.4 WTE to maintain delivery of assessment, medication titration and reviews.

Staff training and development: we will be delivering a robust training scheme to upskill current skills gaps in neurodiversity assessments.

Use of digital tools: we will explore and make effective use of emerging tools to suppo pre-assessment information gathering, triage, assessment, dictation, and report generation. Digital tools will also be used to prescribing of medication to increase safet and governance.

Support from Queen Margaret University's National Autism Implementation Team
As well as using the research obtained through the NAIT, they are supporting East Lothia in the development of radical plans for new assessment pathways. The implementation and recovery project delivered in East Lothian will go onto the inform national advice.

Supporting patients to 'wait well'

Communication: we are keeping in contact with the individuals on the waiting list. Confirming they still want to be retained on the waiting list and advising them of the service developments about to commence.

Employment support: we are directing people to accessible support services to access occupational therapy support while employment.

Community organisations: we signpost people to local community organisations who can offer advice and support and activities to support mental wellbeing.

Update GPs on progress: we liaise with local GP practices to support them with patient enquiries, referrals and reviews, and are keeping them informed of service developments taking place so they can advise patients.

Further information

This recovery project is being led by Guy Whitehead and Jamie Morris.

Should you have any enquiries about the proposals, or wish to enquire about the upcoming vacancies within the neurodevelopment assessment team, please contact:

Jamie Morris on Jamie.morris@nhs.scot

East Lothian Health & Social Care Partnership

Thank you for taking the time to read this ELHSCP staff briefing.
Contact the ELHSCP Communications Team here.

East Lothian Health and Social Care Partnership
East Lothian Community Hospital, Alderston Rd
Haddington EH41 3PF

Telephone : 01620 642905
Date : April 2026

Dear [Name],

YOU DO NOT NEED TO RESPOND TO THIS LETTER

We are sorry that you have been waiting a long time for neurodevelopmental assessment, and we want to acknowledge the frustration and uncertainty this can cause. We also want to be open about the work happening to improve the service and what will happen next.

Why we are writing to you

East Lothian Health and Social Care Partnership is beginning a major redesign of neurodiversity assessment and support services.

As part of this process, NHS Lothian will send you separate communication. This message will:

- Ask you to confirm whether you still want to be on the waiting list

- Explain clearly how to provide that confirmation

- Tell you what you need to do next – **YOU MUST RESPOND TO NHS LOTHIAN'S MESSAGE**

This request will come directly from NHS Lothian in the coming months.

Support you can access while you wait - these services are optional and will not affect your position on the assessment waiting list.

NHS Lothian Work Support Services

This NHS service can provide functional employment support for people in employment.
Website:
https://services.nhslothian.scot/lothianworksupportservices/

Changes Community Health Project

Changes run activities that you can self-refer for.
Website: https://www.changeschp.org.uk/

EastSpace

This is a database of information about organisations in East Lothian.
Website: https://eastspace.org.uk/

We want to improve our communication with you and will be in touch again soon to let you know more about what we are doing.

You do not need to respond to this letter to stay on the list.

Thank you for your patience.

With best wishes,

East Lothian Adult Neurodevelopmental Service