

Dear

FREEDOM OF INFORMATION – SHARED CARE AGREEMENTS

I write in response to your request for information in relation to shared care agreements for ADHD treatment in NHS Lothian.

Question:

1. Shared Care Agreements – Autism

- The total number of GP practices within your territorial health boards.
- The number of GP practices currently operating under any form of shared care agreement (SCA) relating to autism.
- Of those, how many shared care agreements include prescribing of medication.
- A breakdown of the type of shared care provided (for example: medication prescribing, physical health monitoring, behavioural support, or other specified responsibilities).

2. Shared Care Agreements – ADHD (Private Diagnosis Context)

- The total number of shared care agreements requested in relation to ADHD diagnoses made by private providers within the last five years (if available).
- The number of GP practices currently operating under any form of shared care agreement (SCA) relating to ADHD.
- A breakdown of the shared care provided including medication prescribing and behavioural support.
- The number of those requests that were accepted.
- The number and of those requests that were refused.
- The proportion (percentage) of shared care requests relating to private ADHD diagnoses that were refused.
- If recorded, the most common reasons for refusal.
- If recorded, the number of complaints from each GP trust

3. Policy Framework

- A copy of any current territorial health board policy, guidance, or position statements regarding shared care agreements for autism and/or ADHD.
- Confirmation of whether GP participation in shared care agreements within your territorial health board area is mandatory, recommended, or voluntary.

Answer:

1. Shared care agreements - Autism:

- NHS Lothian has 115 GP practices of which 113 are traditional practices, we have a Challenging Behaviour Practice (formerly violent patient practice) and our Access Practice that serves the homeless population.
- NHS Lothian does not have shared care agreements for autism but has a well-established patient pathway that can be found on our RefHelp system that supports GPs and other referrers. There are two distinct pathways for adults: [Autism \(Adult\) – RefHelp](#) and children and young people: [Autism Spectrum Disorder \(CAMHS\) – RefHelp](#)

2. Shared Care Agreements – ADHD (Private Diagnosis Context)

- GP practices in Lothian are independent contractors, and the board does not hold information relating to their relationships with private providers. The board is therefore unable to answer your questions that you have posed under the heading **Shared Care Agreements – ADHD (Private Diagnosis Context)**.

3. Policy Framework

- Please find attached:
- Guidance for GPs and specialist teams around all shared care agreements in NHS Lothian. This guidance applies to those in use for ADHD medication. It is located on the NHS Lothian intranet.
- Procedure for the shared care of medicines NHS Lothian
- Shared care agreement participation in Lothian is voluntary as it is across NHS Scotland.

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 <https://www.foi.scot/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 reviewer at the address at the top 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>

Yours sincerely

ALISON MACDONALD
Executive Director of Nursing Midwifery and AHPs
Cc: Chief Executive
Enc.

ADHD and shared care with private providers

NHS Lothian has shared care agreements for some of the drugs used to treat ADHD in children and young people over 6 and adults. These agreements are between NHS Lothian specialist services and GP practices in Lothian. **These agreements are designed to support GPs and specialist teams in providing safe and accessible care for patients.** The agreements details what part of the care should be provided by specialist/hospital consultant teams and which parts are the responsibility of the General Practitioner and their team and are agreed by representatives of the specialist service, GPs, and pharmacists.

There are no similar agreements between GP practices and private providers. As independent contractors GP practices can choose to share care with private providers but there is no requirement to do so.

If a practice chooses to share care with a private provider, they will normally require the private provider to provide the same level of specialist input as the NHS specialist services; in other words, to follow the NHS Lothian shared care agreement. This is sensible as the shared care agreement is there to support safe and effective care.

Details of the NHS Lothian shared care agreements for AD(H)D medicines:

For patients under 6 years of age

- All of the care would be provided by specialist services including prescribing and they are not part of the shared care arrangements.

For patients over 6 but under 18

- The specialist team (usually CAMHS) is required to undertake, assessment, diagnosis, titration of medicine dosage **and all monitoring including – height, weight, pulse, BP at baseline, 3 monthly, then 6 monthly in the longer term.**
- **Only prescribing is done by GPs** and then only if the CAMHS have confirmed that the ongoing monitoring is in place and supports continued prescribing of the medication.
- When the young person reaches 18 and is transferred to adult services the specialist team are required to facilitate this transfer.

For adult patients

- The specialist team (usually adult mental health teams) is required to undertake, assessment, diagnosis, titration of medicine dosage including - height, weight, and family history of cardiovascular disease at baseline and refer patient for ECG if required, monitor BP and pulse during dose titration.

- The specialist team are also responsible for a re-evaluation of continued need for medication beyond one year.
- The GP is responsible for 6 monthly monitoring of weight, pulse, and blood pressure every 6 months once the patient is stable and for prescribing. The GP would require the 12 months re-evaluation by a specialist to take place to continue the monitoring and prescribing in primary care.

Common issues that arise between GPs and private providers and difficulties for patients:

- Not all private providers are able to offer the monitoring required.
- Not all private providers offer the 12 months re-evaluation.
- It is often extremely expensive for patients and parents who need to pay for the private part of the care.
- There has been doubt cast on the validity of diagnoses made in the private sector. Many private providers are providing a high-quality service, but it is difficult for GP teams to identify concerns of this nature when they have such limited contact with the providers. This has led many GPs and GP practices to decline to enter into shared care arrangements with private providers.
- Recent publicity and some negative local experiences have increased this concern. The BMA, that represents doctors, has advised doctors not to enter into these arrangements and it is likely that the number of practices willing to do so will fall even further if the current difficult situation remains unchanged.
- Often private providers work across a number of regions of Scotland or indeed the UK where subtly different shared care agreements will be in place. This can cause confusion for patients, parents and the clinicians involved.

Waiting times in NHS Lothian for specialist assessment and care in this area are long and this is a pattern seen across the UK. Representatives of both specialist services and General Practitioners have argued that much greater resource is needed, in both sectors, for significant improvements in this situation to be made.

NHS Lothian, and the GP practices we work with, recognise the extreme challenges faced by patients and their families who are concerned about the possibility of an ADHD diagnosis. GP practices work very hard with colleagues in other specialist services using shared care agreements that have been carefully designed to provide high quality care, but do not have the capacity to enter into multiple bespoke arrangements with other providers. NHS Lothian is working hard to continue to improve the quality and accessibility of ADHD care but like other regions of Scotland and the UK is struggling with an unprecedented increase in need in this area.

Dr Jeremy Chowings
Deputy Medical Director Primary Care NHS Lothian
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