

Dear

FREEDOM OF INFORMATION – EHLERS DANLOS SYNDROME

I write in response to your request for information in relation to treatment of Ehlers Danlos Syndrome in NHS Lothian.

Question:

1. How many patients with any Ehlers Danlos Syndrome variant have any of your spinal or neurosurgeons operated on in the last five years?

Answer:

Fewer than five patients with Ehlers Danlos Syndrome variant have been operated on by a spinal or neurosurgeon in NHS Lothian in the last five years.

I am not able to give the exact number as due to the small numbers this information could lead to the identification of the individuals involved. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

Question:

2. How many of your neuro surgeons and how many of your spinal surgeons have operated on any patient with any Ehlers Danlos Syndrome variant in the last five years?

Answer:

1 neurosurgeon and 3 spinal surgeons have operated on a patient with Ehlers Danlos Syndrome variant in the last five years.

Question:

3. How many patients had cervical stabilisation surgeries has the trust performed in the last five years? How many of these were for patients with craniocervical and for patients with atlantoaxial instability (or both)? How many of these patients had any Ehlers Danlos Syndrome variant? Did any of the patients also have a documented PMP 22 deletion?

Answer:

345 cervical stabilisation surgeries have been performed in NHS Lothian in the last five years. None of the patients operated on had Ehlers Danlos Syndrome variant.

Information on whether the patients operated on had craniocervical or atlantoaxial instability or whether they had a documented PMP 22 deletion is not recorded centrally. Information will be held in individual patient records, but in order to provide the information you request it would be necessary to review each patient record over the period you have specified, requiring significant resources. Under section 12 of the Freedom of Information (Scotland) Act 2002, NHS Lothian is not required to respond to your request if the resources required to do so equate to more than £600 in 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 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