

Information Governance

Medical Directorate
NHS Grampian
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BY EMAIL
Peter Murtagh
[request-824552-
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Date 17 February 2022
Our Ref FOI/2022/056
Enquiries to Information Governance Team
Extension 51319
Direct Line 01224 551319
Email gram.foi@nhs.scot

Dear Mr Murtagh

Freedom of Information (Scotland) Act 2002

I refer to your e-mail dated 21 January 2022, requesting:

"I would like to obtain information regarding the treatment regime for known haemochromatosis patients in the care of your health authority.

Specifically

- 1) *Between 1st March 2019 and 1st March 2020 how many known haemochromatosis patients were receiving venesection treatment ?*
- 2) *Between 1st March 2020 and 31st December 2021 how many known haemochromatosis patients, previously receiving venesection, have received no venesection treatment for their condition?*
- 3) *Between 1st March 2019 and 31st December 2021 how many known haemochromatosis patients, previously receiving venesection, have received 1-4 venesection treatments for their condition?*
- 4) *Before 1st March 2020 what criterion/criteria was used to triage haemochromatosis patients for venesection treatment ?*
- 5) *Between 1st March 2020 and 31st December 2021 what criterion/criteria was used to triage known haemochromatosis patients for venesection treatment ?*
- 6) *Between 1st March 2020 and 31st December 2021 what procedure/ methodology was used to ensure that any clinical database of haemochromatosis patients' blood levels was accurately maintained and updated?"*

I can now respond as follows:

1) Between 1st March 2019 and 1st March 2020 how many known haemochromatosis patients were receiving venesection treatment ?

AND

2) Between 1st March 2020 and 31st December 2021 how many known haemochromatosis patients, previously receiving venesection, have received no venesection treatment for their condition?

AND

3) Between 1st March 2019 and 31st December 2021 how many known haemochromatosis patients, previously receiving venesection, have received 1-4 venesection treatments for their condition?

In relation to the above questions NHS Grampian can advise that it does not routinely record this information; s.17 of the Act refers – Information not held. The only way this may be obtained is by manual examination of every patient record which is impractical and would grossly exceed the limit allowed under the Act; s.12 of the Act refers – Excessive cost of compliance.

4) Before 1st March 2020 what criterion/criteria was used to triage haemochromatosis patients for venesection treatment ?

Ferritin of above 50 ug/l (sometimes tailored for individual patients who do not tolerate venesection).

5) Between 1st March 2020 and 31st December 2021 what criterion/criteria was used to triage known haemochromatosis patients for venesection treatment ?

The same as answer 4 above. Venesections had to be interrupted for a short period during peak COVID waves when many treatments were cancelled.

6) Between 1st March 2020 and 31st December 2021 what procedure/ methodology was used to ensure that any clinical database of haemochromatosis patients' blood levels was accurately maintained and updated?

The database automatically flags any patients who have not had blood tests for more than their specified review period (typically 3 months for stable maintenance patients) and they can be alerted to book blood tests (patients book their own blood tests at blood hubs across the region).

Under section 20 (1) of the Act, if you are dissatisfied with the way NHS Grampian has dealt with your request, you have a right to request a review of our actions and decisions in relation to your request, and you have a right to appeal to the Scottish Information Commissioner.

A request for review must be made within 40 working days and should, in the first instance, be in writing to: Directorate of Corporate Communications, Foresterhill House, Foresterhill, Aberdeen, AB25 2ZB or by email to gram.foi@nhs.scot

Requests for appeal can be made by using the Scottish Information Commissioner's online service at www.itspublicknowledge.info/Appeal or should be made in writing to: Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife, KY16 9DS Telephone: 01334 464610, Fax: 01334 464611.

If you remain dissatisfied following an appeal to the Scottish Information Commissioner your recourse is to the Court of Session on a point of law.

Yours sincerely

A handwritten signature in black ink, appearing to read 'R. Bains', with a horizontal line underneath.

Roohi Bains
Information Governance Manager & Deputy DPO
NHS Grampian