

## Freedom of Information request 37-22

---

### Request

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?

### Response

1. This information is not held electronically. The data may be held in a patient's record, but to extract this data would require a manual trawl of all patient records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the Freedom of Information (Scotland) Act 2002 and under Section 12 we are not required to provide.
2. This information is not held electronically. The data may be held in a patient's record, but to extract this data would require a manual trawl of all patient records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the Freedom of Information (Scotland) Act 2002 and under Section 12 we are not required to provide.
3. This information is not held electronically. The data may be held in a patient's record, but to extract this data would require a manual trawl of all patient records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the Freedom of Information (Scotland) Act 2002 and under Section 12 we are not required to provide.
4. Before 1 March 2020 Ferritin > 50 was used to triage known haemochromatosis patients for venesection treatment.
5. Between 1 March 2020 and 31 December 2021 Ferritin > 500 was used to triage known haemochromatosis patients for venesection treatment.

6. While there is currently no comprehensive database of haemochromatosis patients' blood levels at NHS Border, planning for a monitoring and treatment service for haemochromatosis is ongoing between Primary and Secondary Care

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or [foi.enquiries@borders.scot.nhs.uk](mailto:foi.enquiries@borders.scot.nhs.uk).

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **37-22** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.