

Freedom of Information request 114-23

Request

- a. For the period 1st January 2022 to 31st December 2022 (or the most recent 12-month period available), the number of patients diagnosed with Genetic Haemochromatosis under your care.
- b. For the period 1st January 2022 to 31st December 2022 (or the most recent 12-month period available), the average time in days from first referral from Primary Care to the patient's first appointment within your trust.
- c. A copy of your protocol and/or patient pathway applicable to the care of people with Genetic Haemochromatosis.
- d. The date that your protocol/patient pathway for Genetic Haemochromatosis was last reviewed or revised.
- e. A copy of your clinical protocol(s) for Therapeutic Venesection.
- f. The date that your protocol(s) for Therapeutic Venesection were last reviewed or revised.

Response

- a. NHS Borders treated <5 patients with a Diagnosis of E831 Genetic Haemochromatosis (extracted from SMR1 data in any diagnostic position) in the period 1st Jan to 31st Dec 2022.
- b. 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.
- c. Please see attached document below which is the protocol that covers Genetic Haemochromatosis and Therapeutic Venesection.
- d. The protocol/patient pathway for Genetic Haemochromatosis was last reviewed or revised in June 2020 and is due for review in December 2023.
- e. Please see attached document below which is the protocol that covers Genetic Haemochromatosis and Therapeutic Venesection.
- f. The protocol(s) for Therapeutic Venesection were last reviewed or revised in June 2020 and is due for review in December 2023.



Venesection SOP for
patients with haemocl

As the number of events in some areas are very small and in accordance with the Code of Practice for Official Statistics any number that is less than five, actual numbers and potentially identifiable information is withheld

to help maintain patient confidentiality due to potential risk of disclosure. Further information is available in the [ISD Statistical Disclosure Control Protocol](#).

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.

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 **114-23** 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.