



21 April 2023

Our Ref: RFI 49080

Dear

**Freedom of Information Act 2000
Information in Relation to Genetic Haemochromatosis**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to above which you requested on 7 February 2023. Please accept my apologies for the delay in responding to your request. Thank you for your understanding and forbearance.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Rebecca Manning
Information Governance Manager (Interim)

Q1. 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.

A1. The number of patients under the care of the Gastroenterology Medical Day case unit is 147. This is the current number on a local database. There are also a further 118 patients attend a clinic in Ards Outpatient's under the care of the Haematologists.

Q2. 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.

A2. The average referral time is approximately around 4 weeks (20 days).

Q3. A copy of your protocol and/or patient pathway applicable to the care of people with genetic haemochromatosis.

Q4. The date that your protocol/patient pathway for genetic haemochromatosis was last reviewed or revised.

A3-4. The Trust does not have a Haemochromatosis policy/pathway, the Trust refers to Venesection Policy.

Q5. A copy of your clinical protocol(s) for therapeutic venesection.

A5. Please see Attachment 1 - Trust Venesection Protocol Policy.

Q6. The date that your protocol(s) for therapeutic venesection were last reviewed or revised.

A6. The policy for Therapeutic Venesection was approved in August 2022 and will be for review 2025.