

16 August 2019

Our Ref: RFI 29867

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 the above which you requested on 17 July 2019. I apologise for the delay in responding to you.

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

Jane McCormick
Information Governance Assistant

Q1. For the period 1st January 2018 to 31st December 2018 (or the most recent 12 month period available), the number of patients diagnosed with genetic haemochromatosis under your care.

A1. 482 patients.

Q2. For the period 1st January 2018 to 31st December 2018 (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 time is 30.7 weeks for a routine referral.

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

A3. Please find attached to your email a copy of the "Venesection Clinic – Care Pathway" document.

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

A4. July 2019.

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

A5. Please find attached to your email a copy of "Therapeutic Venesection Guidelines – September 2014".

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

A6. September 2014.