

37 South Beach

Private & Confidential

Emmanuel Phillips

Date: 03/03/2022
Your Ref:
Our Ref: FOI Req 034-2022 amended

Enquiries to: Information Governance Manager
Extension: 3031
Direct Line: 01851 708031
E-mail: wi.FOI-requests@nhs.scot

Dear Sirs,

Request for information under the Freedom of Information (Scotland) Act 2002

Further to your recent enquiry under the Freedom of Information Act, received on 25 January 2022 please find our response below. In your request you asked for the following information:

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

Q1 Between 1st March 2019 and 1st March 2020 how many known haemochromatosis patients were receiving venesection treatment

A1 145

Q2 Between 1st March 2020 and 31st December 2021 how many known haemochromatosis patients, previously receiving venesection, have received no venesection treatment for their condition?

A2 <5

Q3 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?

A3 38

Q4 Before 1st March 2020 what criterion/criteria was used to triage haemochromatosis patients for venesection treatment ?

A4 Before 1st March 2020 the criteria used to triage hemochromatosis patients for venesection was prioritising on blood results and patients' symptoms.

Oifisean Bòrd na Slàinte
37 Mol a Deas, Steòrnabhagh, Eileanan Siar, HS1 2BB

Headquarters
37 South Beach, Stornoway, Western Isles, HS1 2BB

Cathraiche: G. NicCannon
Ceannard an Gníomh: G. MacSheumais

Chair: Gillian McCannon
Chief Executive: Gordon Jamieson



Western Isles NHS Board is the common name of Western Isles Health Board

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- Q5 Between 1st March 2020 and 31st December 2021 what criterion/criteria was used to triage known haemochromatosis patients for venesection treatment ?
- A5 **Between 1st March 2020 and 31st December 2021 the criteria used to triage known hemochromatosis patients for venesection was prioritising on blood results and patients symptoms.**
- Q6 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?
- A6 **Between 1st March 2020 and 31st December 2021 the procedure/ methodology used to ensure any clinical database of haemochromatosis patients' blood levels was accurately maintained and updated was the database was updated through SCI store blood results and nurses updating venesection therapy dates through E-form which automatically gets updated onto SCI store.**

Clarification provided:

For question 4 and 5 , could you advise what blood level values ie Ferritin mg/l and or TSAT % would be considered as the trigger thresholds requiring venesection procedure .

Response:

To trigger venesection therapy would be Ferritin over 100 and Transferrin Saturation over 50%. We would only use Transferrin Saturation's for monitoring if Ferritin increased dramatically for unknown reason or with co morbidities patients' ferritin can be increased and not a true reflection of Iron Overload.

If you are dissatisfied with the way NHS Western Isles has dealt with your request, you have a right to request a review of our actions and decisions in relation to your request within 40 working days and we will respond within 20 working days of its receipt. For this review you should write to Information Governance Manager, NHS Western Isles, 37 South Beach, Stornoway Isle of Lewis, HS1 2BB stating clearly why you wish a review to be carried out.

If, following the outcome of a request for review, you are still dissatisfied you have the right to make an application for a decision by the Scottish Information Commissioner under section 47(1) of the Freedom of Information (Scotland) Act 2002 within 6 months of receiving the response to review letter. The Commissioner can be contacted at Kinburn Castle, Doubledykes Road, St Andrews, Fife,

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KY16 9DS or by telephone on 01334 464610 or via the website
www.itspublicknowledge.info/Appeal.

If you have any further queries regarding this response please do not hesitate to contact me.

Yours sincerely



Carol Macdonald
Information Governance Manager

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