

Freedom of Information (Scotland) Act 2002

DATE RECEIVED	25/01/2022	SUBJECT	Treatment Regime for known Haemochromatosis Patients		
PASSED TO	Information Medical Director	DATE PASSED	25/01/2022	RESPOND BY	15/02/2022
CATEGORY	Private	FoI NUMBER	2022-030		

Question/s to be Answered

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?

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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?

2, one had left Shetland (and the UK) the other had died

9 were venesected in this period

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?

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One of these had previously been treated with venesection elsewhere and moved to Shetland recently and has been venesected in May, June and November 2021. Another had been treated with venesection in General Practice but referred to hospital for treatment in 2021 and was venesect in May and August 2021. I am not aware how often prior to that in General Practice. One has left Shetland (and the UK) One has had died

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

Treatment is based on achieving the dual targets:

Ferritin < 50 microg/l

Transferrin Saturation < 50%

Other than for one patient with a rare variant known as ferroportin disease in whom, on the advice of the haematologists, the target is Ferritin <200 microg/l

5) Between 1st March 2020 and 31st December 2021 what criterion/criteria was used to triage known haemochromatosis patients for venesection treatment?

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The same criteria continued to be used

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?

Dr Fryer manages the care of eight of the current nine patients being treated with venesection for haemochromatosis. His practice has been to check iron studies (ferritin and transferrin saturation) at the time of a venesection session, if this is the last of a planned sequence, or to provide the patient with a lab form to have testing done two to three months after venesection, whichever seems most clinically appropriate (the therapeutic effects of venesection takes many weeks to months fully to manifest in the test results). On receipt of such blood test results he makes an assessment of further venesection need and arranges this or further blood testing after an appropriate interval. Due to the unreliability of some patients performing such tests he has, in the last few months, moved to sending out such lab forms at around the time he wants the tests done. This has all been done in conjunction with his secretary who has a table of patient and relevant dates. He has now taking over the management of the ninth, recently referred, patient to ensure they are monitored and treated in the same manner.