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Date: 7 July 2022
Our ref: K: FOI/Ref: 2022-000138
Direct Line: 0131 275 6807
Email: nss.pcf-foi@nhs.scot

Dear [REDACTED]

Freedom of Information Reference: FOI-2022-000138 – Paper relating to Ehlers-Danlos Syndrome

I refer to your freedom of information request that we received on 09 June 2022. I can advise you that we have now completed the search of our records and can provide you with the following information:

The Stage 3 application to NSSC for service designation referenced in your response as well as the relevant Stage 1 and Stage 2 applications

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSSC did not support the progression to a Stage 3 application for service designation as stated in FOI request ref 000093 – “NSSC did not support a Stage 3 application for service designation and advised it should be passed back to the clinical community, to propose a different solution”. Please find the following attached appendices for the Stage 1 & Stage 2 Applications & Cover Papers in which some redactions of personal/sensitive information may have been made in line with Section 38 1(b) of the FOISA:

- Appendix 1 - NSSC 2018-77A EDS Stage 1 Application_Redacted
- Appendix 2 - NSSC 2018-77 EDS Stage 1 Cover Paper
- Appendix 3 - NSSC 2019-36A - EDS Stage 2 Application_Redacted
- Appendix 4 - NSSC 2019-36 EDS Stage 2 Cover Paper

The minutes from the meeting in which the decision was made by NSSC not to support the Stage 3 application along with any relevant decision paperwork (report, letter, etc.)

Please find attached the minutes from the meeting, information relating to this is on pages 3 & 4 in which some redactions of personal/sensitive information may have been made in line with Section 38 1(b) of the FOISA:



Headquarters

Gyle Square, 1 South Gyle Crescent, EDINBURGH EH12 9EB

Chairperson Keith Redpath
Chief Executive Mary Morgan

Appendix 5 - 2019-09-18 NSSC Mins_Redacted

The minutes from the meeting which took place in May 2017 in which information was gathered and reviewed regarding the needs of patients with EDS in Scotland and their current options (also referenced on p.34 of the Rare Disease Scotland progress report published on 28 February 2018

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. We have searched our records for a meeting that took place in May 2017 and cannot locate any information relating to that meeting; however, upon searching our records we have located a meeting that took place in July 2017 with the subject being Ehlers-Danlos Syndrome (EDS) Pathway Discussion. Please find attached the draft of the minutes for this meeting in which some redactions of personal/sensitive information may have been made in line with Section 38 1(b) of the FOISA:

Appendix 6 - 2017-07-07 EDS Pathway Discussion draft minute_Redacted

I trust you will find the information of assistance and if you require any further information please do not hesitate to contact me.

If you are unhappy with any aspect of how we have dealt with your request, you can make representations to us asking us to review the handling of your request. Please write to the

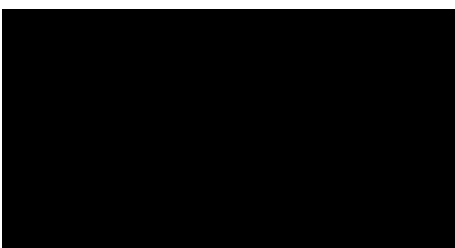
Head of Information and Cyber Security
Digital and Security
NHS National Services Scotland
Headquarters
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

or at the email address nss.foi@nhs.scot within 40 working days of the date of this correspondence.

If after a review you are still unhappy, you also have the right to apply to the Scottish Information Commissioner, who can be contacted at Kinburn Castle, St Andrews, Fife, KY16 9DS, or via their [online application form](#).

If you have any queries about this letter, please contact me at the above address.

Yours sincerely



ENCS

