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Date: 06 May 2022  
Our ref: K: FOI/Ref: 2022-000093  
Direct Line: 0131 275 6807  
Email: [nss.pcf-foi@nhs.scot](mailto:nss.pcf-foi@nhs.scot)

Dear [REDACTED]

**Freedom of Information Reference: FOI-2022-000093 – Paper produced by National Services Directorate for regional directors of planning**

I refer to your freedom of information request that we received on 18 April 2022 requesting the following information.

**A copy of the paper produced by the National Services Directorate for regional directors of planning, highlighting the issues and service gaps encountered by people with Ehlers-Danlos Syndrome and hypermobility spectrum disorder.**

**This paper is referenced in the Rare Disease Scotland progress report (p.34) published on 28 February 2018 in relation to the work carried out in Scotland against the 51 Commitments in the UK Strategy for Rare Diseases.**

I can advise you that we have now completed the search of our records and can provide you with the following information:

On review, the paper you have requested was never actually produced. The reason was that NSSC were unsure whether this was a service, network or pathway and felt unclear with where the remit would fit. 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 was required.

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. NHS National Services Scotland does not hold this information.

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



**Headquarters**

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

Chairperson Keith Redpath  
Chief Executive Mary Morgan

Head of Information and Cyber Security  
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or at the email address [nss.foi@nhs.scot](mailto: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

