

Date: 17 April 2024
Our ref: K: FOI/Ref: 2024-000141
Email: nss.pcf-foi@nhs.scot

Dear [REDACTED]

Freedom of Information Reference: FOI-2024-000141 – Duchenne Muscular Dystrophy (DMD).

I refer to your freedom of information request that we received on 26 March 2024. We have now completed the search of our records and can provide you with the following information:

Under the Freedom of Information Act 2000, I would like to request the following information in regard to the treatment of Duchenne muscular dystrophy (DMD) by your organisation:

Does your organisation commission any services for people with DMD?

NHS National Services Scotland (NSS), National Services Division (NSD) does not commission clinical services for patients with Duchenne Muscular Dystrophy (DMD) as these are the responsibility of individual territorial Health Boards (HBs).

NSD does however manage the Scottish Muscle Network (SMN). This is a National Managed Clinical Network for children and adults with neuromuscular disorders, including DMD. The role of SMN is to raise awareness of neuromuscular disorders and to promote the delivery of equitable, high-quality services to all patients with a neuromuscular disorder across Scotland.

You may wish to contact each territorial HB for any information that they hold in relation to your request, as under the terms of Freedom of Information (Scotland) Act, 2002 (FOISA) we are unable to transfer this request on your behalf. Please find attached Appendix 1 - Health Board FOI Contact Details.

If no, does your organisation expect to commission services for DMD in the future?

At the present time there are no plans for NSS to commission services for DMD.

If yes, what services for people with DMD does your organisation commission?

Not applicable.

How many people with DMD does your organisation serve?

NSS does not serve any people with DMD directly as this is the responsibility of individual territorial Health Boards. I would suggest that you contact the HBs listed in Appendix 1 - Health Board FOI Contact Details for any information that they hold in relation to your request, as under the terms of FOISA we are unable to transfer this request on your behalf.



Chair
Chief Executive
Director

Keith Redpath
Mary Morgan
Susi Buchanan

*NHS National Services Scotland is the common name of the
Common Services Agency for the Scottish Health Service*

Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?

Our policies and guidance can be found on the SMN website, here: [Guidelines – Scottish Muscle Network \(nhs.scot\)](#).

Do any of your organisation's strategies, objectives, plans, performance indicators, audits, inspections, or similar, cite DMD (or any muscle-wasting disease) or use either as a metric?

The SMN provides an Annual Report to NSD on a range of metrics relating to neuromuscular disease, as laid out in the Network's Service Agreement.

Is your organisation aware of the work of DMD Care UK (<https://dmdcareuk.org/>)?

NSS, NSD is aware of the work of DMD Care UK.

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

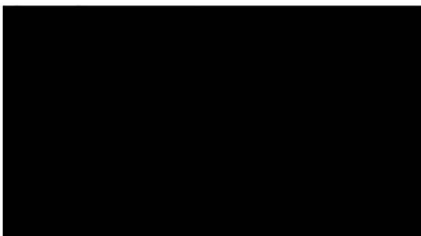
Head of Information and Cyber Security
Digital and Security
NHS National Services Scotland
Headquarters
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

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



Chair
Chief Executive
Director

Keith Redpath
Mary Morgan
Susi Buchanan

*NHS National Services Scotland is the common name of the
Common Services Agency for the Scottish Health Service*