

Date: 17 December 2025
Our ref: K: FOI/Ref: 2025-3192
Email: NSS.DevServicesFOI@nhs.scot

Dear [REDACTED]

Freedom of Information Reference: FOI-2025-3192 – Adult patients with inherited metabolic diseases and consultant numbers in Scotland.

I refer to your freedom of information request that we received on 20 November 2025 requesting the following information.

How many adults are were there in Scotland with Inherited metabolic diseases each year for the past 10 years?

How many metabolic specialist consultants for adult services were there in Scotland for the past five years?

We have now completed the search of our records and can provide you with the following information:

How many adults are were there in Scotland with Inherited metabolic diseases each year for the past 10 years?

Under Section 17(1) of the Freedom of Information Scotland Act, 2002 (FOISA) an organisation does not have to provide that information if it does not hold it. NHS National Services Scotland (NSS) does not hold the requested information. This is because the national service for inherited metabolic disorders was only formally designated in 2019. Prior to this, services were managed regionally, and as such, we do not hold data for the full 10-year period requested.

As commissioners of the national specialist service for Inherited metabolic disorders since 2019, NSS can you provide with the number of adults who accessed the national inherited metabolic disorders service since 2019.

Please see attached Appendix 1 – Inherited metabolic diseases numbers, detailing the available data from 2020 onwards. This data shows active patients by year and referrals by year since 2020. Please be aware that this data only includes patients referred to and managed within the national service.

We would advise you to contact each individual NHS Board who may be able to provide you with the information relating to years prior to 2019, email addresses are as follows:

NHS Ayrshire & Arran	foi@aaaht.scot.nhs.uk
NHS Borders	foi.enquiries@borders.scot.nhs.uk
NHS Dumfries & Galloway	dg.feedback2@nhs.scot
NHS Fife	fife.foirequestfife@nhs.scot
NHS Forth Valley	fv.freedomofinformation@nhs.scot
NHS Grampian	gram.foi@nhs.scot
NHS Greater Glasgow & Clyde	foi@ggc.scot.nhs.uk



Chair
Chief Executive

Keith Redpath
Mary Morgan

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Common Services Agency for the Scottish Health Service*

NHS Highland	nhsh.foirequestshighland@nhs.scot
NHS Lanarkshire	foi@lanarkshire.scot.nhs.uk
NHS Lothian	loth.freedomofinformation@nhs.scot
NHS Orkney	ORK.FOirequests@nhs.scot
NHS Shetland	shet.foi@nhs.scot
NHS Tayside	tay.foisa@nhs.scot
NHS Western Isles	wi.infogov-wihb@nhs.scot
NHS Golden Jubilee	FOI@nwtc.scot.nhs.uk

How many metabolic specialist consultants for adult services were there in Scotland for the past five years?

Please see attached Appendix 2 – Inherited metabolic consultant numbers, providing the number of specialist consultants for adult services in Scotland for the past five years. Please be aware that this data only includes consultants funded for the nationally commissioned service.

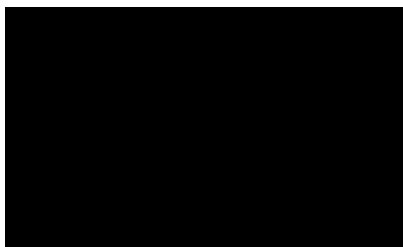
I trust you will find the information of assistance and if you require any further information, please do not hesitate to contact me.

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 Associate Director Governance and Board Services (Board Secretary) 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,



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