

Date: 24 April 2024
Our ref: K: FOI/Ref: 2024-000142
Email: nss.pcf-foi@nhs.scot

Dear [REDACTED]

Freedom of Information Reference: FOI-2024-000142 – Genetic testing for CACNA1C gene.

I refer to your freedom of information request that we received on 28 March 2024 requesting the following information.

How many individuals were identified by the Scottish Strategic Network for Genomic Medicine to have a CACNA1C gene change as a result of genetic testing during the years 2021, 2022 and 2023?

Ideally, your response would indicate the total for each year separately with the classification of the finding (according to ACGS Guidelines ie. Pathogenic, Likely pathogenic, Variant of Uncertain Significance, Likely benign, and Benign) alongside the number of individuals identified.

In your answer, it would be helpful to know which diagnostic test method ie. narrow and specific panel (CACNA1C is listed in 4 separate cardiac panels in the Scottish Genomic Test Directory for Rare and Inherited Diseases) up to whole genome sequencing, was used to examine the potentially causative loci.

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

Under section 17 of the Freedom of Information Scotland Act, 2002 (FOISA) an organisation does not have to provide that information if it does not hold that information. NHS National Services Scotland (NSS) does not hold the requested information. Genomic testing for CACNA1C gene variants is carried out in NHS Grampian's genomics laboratory, I would suggest that you contact gram.foi@nhs.scot 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.

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



Chair
Chief Executive
Director

Keith Redpath
Mary Morgan
Susi Buchanan

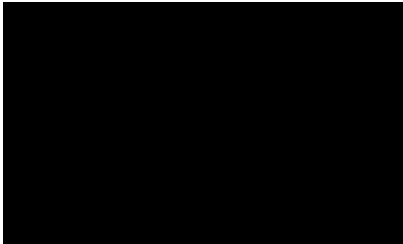
*NHS National Services Scotland is the common name of the
Common Services Agency for the Scottish Health Service*

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	Keith Redpath
Chief Executive	Mary Morgan
Director	Susi Buchanan