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Date: 31 January 2024
Our ref: K: FOI/Ref: 2024-000048
Email: nss.pcf-foi@nhs.scot

Freedom of Information Reference: FOI-2024-000048 – Sarcoma Patients

I refer to your freedom of information request that we received on 12 January 2024 requesting the following information.

I am contacting you from Sarcoma UK, the bone and soft tissue cancer charity, regarding a project that we are currently running that is looking to build a picture of when sarcoma patients are being given access to genomic testing by the NHS across the four nations of the UK; and to identify when they are not and to understand what barriers need addressing.

Please can I therefore ask if you would be able to provide or facilitate a response from the network about the following topics? As a charity, we hope that by undertaking this project there will be a much clearer picture about current practice on genomic testing, what barriers may exist, as well as potential opportunities, which we hope can lead to improved health outcomes for sarcoma patients.

- What data do you have on (a) the proportion of sarcoma patients currently being offered and (b) consenting to genomic testing?
- What feedback are you gathering from sarcoma patients or their families about their experience of being offered genomic testing, giving consent and non-take up?
- How is the Network working with healthcare providers, researchers or other organisations to promote and raise awareness about the benefits of genomic testing for sarcoma patients, to increase patient take-up?

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

- What data do you have on (a) the proportion of sarcoma patients currently being offered and (b) consenting to genomic testing?



Headquarters

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

Chairperson Keith Redpath
Chief Executive Mary Morgan

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 it. NHS National Services Scotland (NSS) does not hold this information as there is no specific data regarding this. Since all sarcoma patients eligible for genetic testing in Scotland are offered targeted testing as part of their standard care routine diagnostic testing pathway as detailed in the Scottish Cancer Genomics Test Directory (<https://www.genomics.nhs.scot/test-directories/cancer/>). This testing is targeted for known genomic abnormalities associated with sarcoma and patients are therefore not consented for testing. Whole genome sequencing is not currently available to sarcoma patients in Scotland.

- **What feedback are you gathering from sarcoma patients or their families about their experience of being offered genomic testing, giving consent and non-take up?**

Under section 17 of the FOISA, NSS does not hold this information as we do not gather feedback from sarcoma patients or their families regarding genomics testing since all available testing is routine standard of care testing.

- **How is the Network working with healthcare providers, researchers or other organisations to promote and raise awareness about the benefits of genomic testing for sarcoma patients, to increase patient take-up?**

The Scottish Strategic Network for Genomics Medicine (SSNGM) works across Scotland to promote the work of the network and the Genomics Laboratory Services with healthcare providers, researchers, and other organisations where appropriate. The Scottish Cancer Genomics Test Directory has been published (<https://www.genomics.nhs.scot/test-directories/cancer/>) and clear lines of communication are now in place across Scotland with our regional and national cancer networks, including the Scottish Sarcoma Network. The SSNGM publishes a quarterly cancer newsletter for our stakeholder which details the cancer genomics work in Scotland. We have recently established a Patient Involvement and Advisory Group (PIAG) which will be key at considering our patients in Scotland.

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



