

Privacy Notice for cloud-based genetic next-generation sequencing (NGS) analysis carried out by NHS Greater Glasgow & Clyde Laboratory Genetics Service



Definitions

Under the definitions in the EU General Data Protection Regulation – (EU) 2016/679, NHS Greater Glasgow & Clyde Laboratory Genetics is the *Data Controller*. Any third-party vendors used to provide the laboratory with cloud-based NGS analysis solutions are *Data Processors*.

How your Personal Data will be processed

Due to the complex and resource-intensive nature of analysing genetic sequencing data, NHS Greater Glasgow & Clyde Laboratory Genetics uses specialist software provided as cloud-based analysis solutions by third-party vendors to analyse, annotate and interpret the sequencing data so that we can issue a useful clinical report to your clinician, where the results can be used to best manage your healthcare.

Our legal basis for using personal information

Under GDPR our legal basis for using your personal information is:

- Article 6 (1)(e) “processing is necessary for the performance of a task carried out in the public interest”
- Article 9 (2)(h) “processing is necessary for the purposes of preventative or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services”

Personal Data that will be processed by third-party providers

To carry out the analysis properly, we have to upload sequencing data, clinical data (eg your symptoms) and pedigree data (details of your family structure including any affected/unaffected relatives) to the cloud-based analysis software. All of this data is uploaded in a pseudo-anonymised fashion, where we only use a specific ID number to identify the data. This means that no-one outside of our laboratory can link these data specifically back to you.

How long we store your Personal Data

The sequencing data will be stored according to guidance from the Royal College of Pathologists (Retention and storage of pathological records and specimens; 5th Edition, April 2015) and Scottish Government (Records Management: NHS Code of Practice 2012). The current recommendation for storage is 30 years.

How we protect your Personal Data

We only use responsible, respected third party vendors, with a proven track record in cloud-based NGS analysis. The vendors must supply details of their data security measures and all vendors must be ISO 27001 certified (this is an industry standard certification regarding information security). Before we allow them to process any of our data, we carry out a risk assessment, a data protection impact assessment and sign a data processing agreement with them, to ensure that they keep all data secure and that they only use it in the manner for which we have authorised.

Your rights

You have the right to access your data by submitting a subject access request. However, sequence data files will be of no use to patients not expert in NGS analysis and without the specialist software tools required to process them. Access to the reported genetic test results can be obtained through the referring clinician or by submitting a subject access request.

You have the right to rectification. If the personal information we hold about you is inaccurate or incomplete, you have the right to have this corrected.

You have the right to restrict or object to NGS analysis. However, if you do this, it will not be possible to carry out the available clinical testing. This right will be upheld unless NHS Greater Glasgow & Clyde can demonstrate compelling legitimate grounds to continue processing your personal information.

Your data

Your data will not be transferred outside of the European Economic Area (EEA).

Further information on your rights and how NHS Greater Glasgow and Clyde use your personal information can be found at:

https://www.nhsggc.org.uk/media/248110/nhsggc_gdpr_data_protection_notice.pdf

If you have any queries regarding how your personal information is processed please contact the Information Governance Department at data.protection@ggc.scot.nhs.uk