

[REDACTED]

25 July 2017

Dear [REDACTED]

Your email of 4 July 2017

I refer to your request of 4 July 2017 under the Freedom of Information Act 2000 (FOIA). This has been passed to me to deal with. I set out our responses to your questions in the Annex to this letter:

If you have any queries about this letter, please contact me. If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Grant Stapleton
Senior Information Responsible Officer
Genomics England

Email: grant.stapleton@genomicsengland.co.uk

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the Department. The ICO can be contacted at:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Kind regards

Yours sincerely

[REDACTED]

GENERAL COUNSEL AND COMPANY SECRETARY

[REDACTED]

Annex

Response

Under what circumstances will GeL assist Police with genetic information?

This question is included in the FAQ Page on our website. "The Department of Health has had confirmation from the Home Office and the Association of Chief Police Officers that they will not seek access to Genomics England's data." See <https://www.genomicsengland.co.uk/the-100000-genomes-project/data/faqs/> In addition section 9.3.2 of our Protocol confirms that any such applications in the form of Court Orders will be referred to Genomics England's Legal Counsel as promptly as possible, so that all representations may be made to the court, for example to limit the information requested.

Are there any circumstances in which such assistance will be provided without the prior notification of the data subject and opportunity to prevent such assistance through injunction action?

Our Protocol, which is available to read on our website at <https://www.genomicsengland.co.uk/100000-genomes-project-protocol/>, sets out the permissible uses for data held by the 100,000 Genomes Project. In particular section 9.3.2 defines the uses of data that will typically be refused outright following consideration. In particular you should note that "Requests in the form of Court Orders will be referred to Genomics England's Legal Counsel as promptly as possible, so that all representations may be made to the court, for example to limit the information requested." This question is also addressed in the FAQ section of our website at <https://www.genomicsengland.co.uk/the-100000-genomes-project/data/faqs/>. In any event should we not refuse the request we would notify the data subject so they could make representations.

As another example of an area of concern, with what other organisations is personal genetic data, as opposed to aggregated data shared with for example financial organisations that have no "need to know" yet are listed in the DPR Entry for GeL?

Section 9 of our Protocol describes the types of organisations we share data with and this is further explained on our web site at <https://www.genomicsengland.co.uk/the-100000-genomes-project/data/research/>. For specific information on our industry partners please see our website at <https://www.genomicsengland.co.uk/working-with-industry/>. In any event researchers only have access to de-identified data and then only within our data centre subject to the approval by the Access Review Committee.

If any, please disclose the information security obligations placed upon those parties in full, together with the due diligence and compliance requirements.

As described in the FAQ section of our website all research users must sign an electronic data access agreement and submit this to Genomics England's independent Access Review Committee along with their research application for approval. Only when their research study has been approved will they be granted remote access to only those de-identified datasets they need for their specific and approved research study. Clinicians will not have to sign a data access agreement as by the very nature of their profession

they will already have to abide by certain professional standards and adhere to their NHS Trust's data governance policies when dealing with a patient's data.

As an obvious third example of an area of concern, what is the patch to deployment period for GeL systems storing genetic information, and b) did the GeL systems /service shut down in response to the recent ransomware cyber attack that affected around 40 trusts?

Genomics England has protocols in place to ensure its systems are appropriately protected. It would be inappropriate to comment further on the measures we take to protect ourselves. Genomics England was not affected by the recent ransomware attacks.

How many staff are employed on a full time (perm or contract) basis to support cyber security defence of the GeL systems?

Genomics England has a number of permanent staff and contract staff who support the cyber security work. We work with external partners across the private and public sector to ensure we have an appropriate set of measures in place. It would not be appropriate to comment further on cyber security defence capabilities.

Assurance is often risk based against a level of threat actor capability. Please confirm whether it is the case that GeL systems for storing and processing personal genetic data are designed to withstand attack from FIS threat actors?

Genomics England considers threat actors across the diverse range of products and services we deliver and uses industry-standard tools and techniques to prevent unauthorised access. All Patient Identifiable Data is held in a secure UK Data Centre and all data travels from the NHS Genomic Medicine Centres to the Genomics England data centre over the dedicated NHS N3 network. Our systems are regularly tested by external security experts and we work with market leaders to continually refine and adapt our technologies to respond to these threats. Once the data arrives in our Data Centre direct identifiers, such as name and date of birth, are separated into another part of the data infrastructure. This part of the data infrastructure is not be accessible to researchers; nor, indeed, is it accessible to the majority of Genomics England staff. Given the sensitive nature of the health and genome data, similar expectations of security apply across the whole of the data infrastructure.

In the rare cases where Genomics England staff need access to identifiable data, access is only granted following explicit approval from Genomics England's Senior Information Risk Owner (SIRO). Access to identifiable data is strictly limited and protected. Finally, as described in the FAQ section of our website research users are only able to download the anonymised results of their analysis, provided that these results do not reveal the identity of any of the participants. The data systems that Genomics England have in place will not allow users to 'cut and paste' data into their own systems. As threat actors evolve Genomics England will continually adapt to respond to these threats.

