

FOI request

Requester - [REDACTED]

Our Ref: DP-5470

Request and GE response

We are writing regarding the Genomics England projects. In order to ensure global privacy of sensitive genetic information, we are seeking clarification on your data sharing policies

1. We note that the project involves industry partners. We thus seek clarification on who else may register for data access, if this includes additional law enforcement or immigration services.

Our response:

Information around access to genomic information can be found here - [Joining our research community | Genomics England](#)

The Department of Health and Social Care 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.

2. We further seek clarification on what privacy protections are in place to prevent access to identifiable genetic information (including re-identifiable) in the hands of the project and third parties, by law enforcement and immigration services, including what policies are in place to prevent and monitor data breaches by your organisation or third party collaborators.

Our response:

Direct identifiers, such as name and date of birth, are held in a separate part of the data infrastructure. This part of the data infrastructure is more secure, in the sense that it is not accessible to researchers; nor, indeed, is it be 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.

Genomics England has a suite of policies designed to address data protection and data security within the organisation. These policies include:-

Data Protection Policy

Data Security and Data Breach Policy

3. We note that your website says that participants and researchers should be made aware of and breaches, and thus request information on any known breaches to have taken place already.

Our response:

Genomics England has not had any breaches requiring the need to inform affected individuals (participants or researchers included).

4. We note that withdrawal forms state that access to data and samples for research use will be stopped following withdrawal, but we seek clarification on whether data already transferred to third parties can continue to be used.

Genomics England does not transfer personal data to third parties. Our research environment operates as a reading library where de-identified personal data cannot be removed or downloaded. To protect patient data, access to the research environment is controlled and secure, and only results of analysis can be exported.

Sent on behalf of Nick Maltby

Data Protection Officer/Legal Counsel

Genomics England

21 June 2021