



Dear Sir/Madam,

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.

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. 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. 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.

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.

The information that is provided, or not provided to us, will be shared with the public in order to promote transparency and to inform on the privacy implications of growing genetic databases. We thus thank you for any information that you can share with us to facilitate this process.

Yours sincerely,

Dr [REDACTED]  
Policy Officer  
Email: [REDACTED]

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