



Dear Sir/Madam,

We are writing regarding the genome project, the FinnGen Project. In order to ensure privacy of sensitive genetic information, we are seeking clarification on your data sharing policies.

We welcome protective privacy policies including the use of non-disclosure agreements, and pseudonymisation of data, as well as the limitation of data sharing with service providers.

However, we note that your project involves the collection of medical data, as well as partnerships with commercial companies and collaborations with third parties who will also process and store some of the data, including Google Ireland Ltd (with potential processing in the USA). Considering personal information will be shared with research partners, we thus seek clarification on exactly what privacy protections are in place to prevent access to re-identifiable genetic information by insurance companies, law enforcement and immigration services of data in the hands of the project and third parties. This includes what policies are in place to prevent data breaches by your organisation, partners or third party collaborators. Further, we seek clarification on whether such data is sold to third party companies.

We note that the participant rights to erase or restrict data following withdrawal from the project only applies to data that is not de-identified, so we seek clarification on what processes are in place for protecting identifying information, and whether re-identification of participants is possible. We also note that derogation from data protection rights will be assessed on a case-by-case basis and thus request information on which circumstances such exemptions would be made.

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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