



Dear Sir/Madam,

We are writing regarding the genome project, the Australian Genomics Health Alliance. In order to ensure global privacy of sensitive genetic information, we are seeking clarification on your data sharing policies.

We note that your project involves data sharing with commercial companies, with tiered access to data for secondary use. This will include tier 2 data that is de-identified and thus presents the possibility of re-identification of participants.

We thus seek clarification on exactly what data is shared, and what privacy protections are in place to prevent access to identifiable genetic information by 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 or third party collaborators. Further, we seek clarification on whether such data is sold to third party companies.

While your information on Policy on Data Access and Sharing for Secondary Use refers to data breach processes, it only refers to an alert system whereby someone alerts the project when there is suspicion that a breach has occurred. However, we seek further clarification on whether additional policies are in place to monitor and protect against breaches occurring in the first place.

We further request access to the consent forms that are not publicly available on the website. We also could not find any information on what occurs to data following withdrawal of participants and whether data is retained or deleted.

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]