



Dear Sir/Madam,

We are writing regarding your Japan Genomic Medicine Project. In order to ensure privacy of sensitive genetic information at a global level, we are seeking clarification on your data sharing policies.

We note that the project will involve some pooled data access for commercial users. We thus seek clarification on exactly what data will be shared with third parties including commercial companies, and any potential insurance companies, law enforcement or immigration agencies. We also seek information on exactly what privacy protections are in place to prevent access to identifiable genetic information (e.g. pseudonymised or de-identified data) by law enforcement and immigration services. This includes what policies are in place to prevent data breaches by your organisation and any third parties. Further, we seek clarification on whether any data is sold to third parties.

We were unable to find information on what may happen to data once a participant withdraws from a project, and whether it will be retained or deleted. We were also unable to find a consent form online, and request that you may send a copy to us.

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,

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