



Dear Sir/Madam,

We are writing regarding your Estonian Genome Project as part of the Estonian Biobank. 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 involves mixed funding, including from commercial companies, and that there will be restricted access to data by commercial companies. Your procedures for issuing de-pseudonymised DNA states that it may be issued to third parties. 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 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 such data is sold to additional third party companies, as the procedure for issuing samples states that there may be a fee for accepting samples.

We note that you have detailed processes for the destruction of data and samples, including all data that could be de-pseudonymised. We could not however, find information on whether destruction of data in the hands of third parties is also included, if someone wishes to withdraw from participating in the project. We could also not find a copy of the consent form on the website and kindly request that you may send us a copy.

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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