



Dear Sir/Madam,

We are writing regarding your Genome Denmark and FarGen Projects. 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. We thus seek further clarification on what data will be shared with third parties. We also seek clarification on whether data will be shared with other third parties including 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.

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,

Dr [REDACTED]
Policy Officer
Email: [REDACTED]

53 Milton Road ♦ Cambridge ♦ CB4 1XA ♦ UK
Phone: +44 (0)330 0010507 ♦ E-mail: mail@genewatch.org
Website: www.genewatch.org

GeneWatch International is a trading name of GeneWatch UK (Trade Mark No: UK00003281756).

GeneWatch UK is a company limited by guarantee. Registered in England (No. 03556885). EU Transparency Register ID: 00705635730-

53 Milton Road ♦ Cambridge ♦ CB4 1XA ♦ UK
Phone: +44 (0)330 0010507 ♦ E-mail: mail@genewatch.org
Website: www.genewatch.org

GeneWatch International is a trading name of GeneWatch UK (Trade Mark No: UK00003281756).

GeneWatch UK is a company limited by guarantee. Registered in England (No. 03556885). EU Transparency Register ID: 00705635730-