

Begin forwarded message:

From: FinnGen info <finngen-info@helsinki.fi>

Subject: RE: Request for information on data sharing policies of genome project

Date: 4 June 2021 at 13:05:48 BST

To: [REDACTED] FinnGen info <finngen-info@helsinki.fi>

Cc: [REDACTED]

Dear Dr. [REDACTED]

thanks for your interest towards the FinnGen study! Data protection is an area that the FinnGen study takes very seriously and where we have an excellent track record. This is helped by the unique Finnish situation including specific legislation that has been enacted within Finland to address balance between privacy and benefits of medical research.

A lot of the information you request is already on our website, but we are in the process of updating some of the sections and will be including additional information about the Finnish legislation and regulatory environment for genetic research that will address the questions you pose. We believe that the best policy here is to make information available to everyone through our website, and it's in that spirit that we will respond to your questions.

The legislation most relevant for our project includes:

- [the Biobank Act](#), and
- [the Act on the Secondary Use of Health and Social Data](#)

All data processing in FinnGen takes place for the sole purpose of scientific research under our scientific plan approved by the local ethical board. Furthermore, we are following the instructions provided by the national Ombudsman. The genotype data produced by FinnGen is returned to the biobanks and owned by them. The research data in our possession can not be sold to any third parties in any circumstances. Biobanks can grant access to the genome data to the applications that fulfil the requirements of the Finnish Biobank Act.

Furthermore, based on the section 19 of the Biobank Act, data based on biobank samples may not be used by insurance companies, law enforcement or immigration services.

"Notwithstanding the provisions laid down elsewhere in law on the right of authorities to receive secret information, access to the samples stored in a biobank and the information associated with such samples may not be granted and they may not be used for the purpose of a criminal investigation or in administrative or other decision-making concerning the person. Samples and information stored in a biobank may not be used to assess or determine the work ability of an individual or for the decision-making of credit or insurance institutions."

From the technical point of view, the Secondary Data Act and the Social and Health Data Permit Authority Findata have set the conditions for a data secure environment in which permit holders may process data and we are following their regulations:

<https://findata.fi/en/uutiset/findata-has-issued-a-regulation-on-the-requirements-of-secure-operating-environments/>

<https://findata.fi/wp-content/uploads/sites/3/2020/10/048ba8a0-findata-regulation-1-2020-requirements-for-other-service-providers-secure-operating-environments.pdf>

Your e-mail drew our attention to some areas that were not covered in existing materials, and we see the opportunity to fill in these gaps as a positive contribution to the dialog. We'll let you know shortly when we have updated our public information to include the points you have raised more completely and will be glad to answer further question if there is more detail you would like to see.

On behalf of the FinnGen team and our Scientific Director [REDACTED]

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