

## PARTICIPANT BULLETIN

### What are FinnGen and its new research sections?

FinnGen ([www.finngen.fi](http://www.finngen.fi)) is a research project covering the whole of Finland, that aims to increase our understanding of the factors affecting illnesses and to provide new information for improving health care and medical care. FinnGen was launched in 2017 and is planned to last until 30th April 2027. The research is led by the University of Helsinki. You have already supported the study through your biobank consent and sample.

FinnGen utilises the genome data (genetic data) generated from biobank samples and health-related data from social and healthcare registers. By analysing both genome data and health data together, we can research what genetic factors (variation that occurs in our genes) affects risk of becoming ill, either protecting from or increasing risk of illnesses. Because national health registers collect data about how citizens use health care services throughout their whole life course, we can also investigate what genetic factors affect disease progression. In addition to genetic contributors, health and illnesses are also affected by numerous environmental and lifestyle factors as well as personal features and preferences. It is important to understand how these factors, together with genetics, affect risk of diseases and their progression. However, not all information that is relevant to health research is available from national registers. For this reason, FinnGen now invites its participants, including you, to take part in new research sections. In these research sections, issues related to the different aspects of life are examined in more detail. Our goal is to make it easy and interesting for you to participate.

Using the new information gathered in these research sections, we aim to understand what lifestyle factors, personal features and preferences together with genetic factors affect risk of becoming ill and the progression of possible diseases. The information collected from you will be combined with the information of all other participants in a secure analysis environment. In this environment, named researchers will then look for correlations between genetic data, data collected about lifestyle and personal features, and the risk of becoming ill as well as disease progression.

The research methods and questions posed in these new FinnGen research sections are the same as in other FinnGen research, namely, they are based on the statistical analysis of genetic variation and disease and health information.

### How can I participate?

**You can participate by logging in online to the MyBiobank service at:  
[www.omabiopankki.fi](http://www.omabiopankki.fi).**

To use the service, copy and paste the address [www.omabiopankki.fi](http://www.omabiopankki.fi) to your internet browser. The service can be accessed using a smartphone, computer, laptop, tablet, etc. Log in using suomi.fi authentication. If problems occur during the authentication process, please delete cookies from your browser and try again. If the problems persist, please get in touch by email [finngen-info@helsinki.fi](mailto:finngen-info@helsinki.fi) or call 0503228106 or 0294125788 (Mondays 9.00-12.00 and Thursdays 15.00-18.00). Once you have logged in, you can familiarise yourself with and participate in the new research sections available to you. These include a health and well-being survey and a collection of functional tests. Both sections can be filled in

online via MyBiobank whenever you have the time and at your own pace. These sections are available until 31.7.2021. If you do not wish to participate in the new research sections, you do not have to do anything. Participation is entirely voluntary.

## **How do I suspend or cancel my participation?**

You can abort a questionnaire or test that you have already started. However, the data collected by the date of the suspension may be included in the research section unless you specifically prohibit their use in the manner described below.

If you do not want the data collected in the research sections described in this bulletin or any other data concerning you to be processed in the FinnGen study or in other biobank studies, you may withdraw your Biobank Consent at any time by contacting your biobank. The contact details of your biobank are available in the invitation letter you received. After your withdrawal has been received, your information will no longer be used in the study. However, it may be necessary to use the research materials and research results already obtained from the data, as well as any data included in these that does not contain an identifiable information.

If you have any questions concerning the withdrawal of your consent, you can also contact the Data Protection Officer of the FinnGen study: [grp-finngen-dpo@helsinki.fi](mailto:grp-finngen-dpo@helsinki.fi). The privacy policy of the FinnGen study is available at [https://www.finngen.fi/en/data\\_protection](https://www.finngen.fi/en/data_protection).

## **Why am I being asked to participate?**

Until now, FinnGen has collected its research data from biobanks and registers. This is the first time FinnGen invites participants to provide information. All invitees are over 18 years of age and live in Finland. The FinnGen study already contains the genomic and health information of each invited person, and they have authorised their biobank to contact them in their Biobank Consent. FinnGen researchers do not know the identities or contact details of the invitees.

## **How will I benefit from participating?**

Participating in the FinnGen study or its new research sections may not provide you with any direct benefits. After performing the functional tests over the internet, you can see your own results if you wish.

## **Invitation to further studies**

From time to time, we contact you again through your biobank. We may ask you to renew the research sections so that we can get follow-up information over longer periods of time. We may also ask you to participate in other surveys or tests, or invite you to clinical measurements or sample collections that are part of the FinnGen study. We may also ask you to provide data using wearable technologies, such as activity bracelets. You would only receive a few invitations per year, and with these you will receive a bulletin for each research section. These will provide more detailed descriptions of the sections, and you will always be able to decide whether you wish to participate.

In the FinnGen study, we do not collect your identification or contact information, so the invitations will be delivered to you through your biobank or the MyBiobank service and the digital contact information you

have provided in it. If you do not wish to receive such messages, please notify your biobank. Your biobank's contact information is available in the biobank's invitation letter.

## Research implementers

FinnGen is a joint research project between the public and private sector. The FinnGen study is led by the University of Helsinki, with Professor Aarno Palotie serving as its principal researcher. The FinnGen study includes all Finnish biobanks and their background organisations (hospital districts, universities, the Blood Service of the Finnish Red Cross, the Finnish Institute for Health and Welfare) and 12 international pharmaceutical companies (AbbVie, AstraZeneca, Biogen, Celgene, Genentech (a member of the Roche Group), GSK, Merck & Co. Inc., Pfizer, Sanofi, Jansen Global, Maze Therapeutics and Novartis). The study is funded by Business Finland (formerly TEKES) and the pharmaceutical companies participating in the study. Other parties may join the study at a later date. For all current and new information, see the study's website and privacy policy.

## How your personal data is protected and managed

The biobanks and the biobank cooperative FINBB are responsible for the MyBiobank-service. The biobanks can, if necessary, monitor who has participated in the study in the service. This information can be used, for example, to examine the impact of different invitation methods on participation rates (letters, emails, etc.). The research sections can be implemented with the help of external service providers. Your identification data will not be disclosed to these service providers. For more information, please see the privacy policy of the MyBiobank service, available at [www.omabiopankki.fi](http://www.omabiopankki.fi)

The biobanks and the Finnish Institute for Health and Welfare will transmit your responses and test results in an encoded format to the FinnGen researchers who can then use the code to link these to the data that is already in the study, including genome and health register data. This encoding is designed to protect your privacy, and your personal identification number or other identification data will not be disclosed to the researchers. The encoded research data in the FinnGen study may only be used for the implementation of the FinnGen study. FinnGen researchers may access the data only with the permission of the principal researcher. Your data will never be distributed from FinnGen to any parties outside the scope of the study.

Studies (e.g. surveys or tests) can be carried out through an external service provider, and participants will always be notified separately of this before the study is started. In these cases, FinnGen has entered into a data security agreement with the service provider, and identifiable personal data will never be transmitted to the service provider. The service provider will not use the data provided by participants, and all data copies will be removed from the service no later than after the collection phase of the research material. The data will be transferred to FinnGen researchers in a secure manner. For more information, see the FinnGen information security policy.

The legal basis for processing the research data in FinnGen is scientific research in the public interest, in accordance with the EU General Data Protection Regulation and the national Data Protection Act. For more detailed information on the grounds for processing and the processing of personal data in the FinnGen study, please visit the website of the study and its privacy policy, which can be found here: [www.finngen.fi/en/data\\_protection](http://www.finngen.fi/en/data_protection). In matters concerning data protection, you can also contact the Data Protection Officer of the FinnGen study at [grp-finngen-dpo@helsinki.fi](mailto:grp-finngen-dpo@helsinki.fi).

The research data collected through the MyBiobank service can also be saved to your biobank in accordance with your biobank consent and the Biobank Act, in which case the research data may, with the

permission of the biobank, be utilised by researchers other than FinnGen, in accordance with Finnish legislation. For more information about the data processing policies of your biobank, see the biobank's privacy policies and website. The contact details of your biobank are available in the invitation letter you received. The privacy policy of the MyBiobank service is available at [www.omabiopankki.fi](http://www.omabiopankki.fi).

## **Additional information**

For more information, visit [www.finngen.fi](http://www.finngen.fi) and its FAQ section at [https://www.finngen.fi/en/questions\\_and\\_answers\\_0](https://www.finngen.fi/en/questions_and_answers_0). If you cannot find the answers to your questions, you can send an email to [finngen-info@helsinki.fi](mailto:finngen-info@helsinki.fi) or call 0503228106 or 0294125788 (Mondays 9.00-12.00 and Thursdays 15.00-18.00). We try to respond to all email requests within two business days.

For more information on biobank activities, please contact your biobank. The contact details of your biobank are available in the invitation letter you received.

For more information on the use of social welfare and health care sector register data for scientific research and other secondary purposes, visit the website of Findata, the Health and Social Data Permit Authority, at [www.findata.fi](http://www.findata.fi).

## **List of social welfare and health care sector registers that provide information to FinnGen**

The FinnGen study combines genetic data with a wide range of health-related data. This data is retrieved from the following social welfare and health care sector registers:

- Statistics Finland (cause of death, education and socio-economic register data)
- Finnish Cancer Registry and Mass Screening Registry
- Register of Primary Health Care Visits (Avohilmo)
- Care Register for Health Care
- Kela (Medicinal products database and reimbursements for medicine expenses: The ATC code of the medicinal product and information related to the pharmaceutical package; the class of reimbursement paid for the medicinal product and information on the illness entitling to compensation; information related to the date of purchase of the medicinal product and the date of the prescription; information related to the price of the medicinal product; information related to the doses and distribution of the medicinal product; municipality of residence; reimbursement identifiers given to the pharmaceutical rights and the date and time-related information concerning the pharmaceutical right)
- Digital and Population Data Services Agency
- Finnish Register of Visual Impairment
- Care Register for Social Welfare
- Finnish Registry for Kidney Diseases
- Finnish National Infectious Diseases Register
- Medical Birth Register
- Register of Congenital Malformations
- Finnish National Vaccination Register
- Population Register Centre

- Biobank sample and data registers