

Central Finland Biobank information leaflet concerning consent and approval

We ask for your consent to collect and store your samples and related data in the biobank. This applies to samples already collected from you on previous occasions, samples collected in other contexts (e.g. studies and diagnostics), and samples collected in the future. With this form, you may also give your consent to be informed of clinically significant findings.

We also ask for your approval to attach to your samples information on the factors affecting your state of health and health, and this data may also be handed over from the biobank for research purposes. **Transferring the samples and associated data to the biobank is subject to your consent and approval.**

A biobank is a government-controlled unit under the Biobank Act (688/2012) where samples and related special categories of personal data (health and genetic data) are processed for the purposes of health science research. A biobank provides samples and data for national and international research projects. A biobank's collections may also include materials intended for more restricted use. Once the research has been concluded, the results obtained from the samples are returned to the biobank to be used in new research. Personal data shall be processed pursuant to Article 6(1)(e) and Article 9(2)(i) of the EU's General Data Protection Regulation (2016/679).

Biobank samples and data. Biobank samples may be collected in connection with treatment-related sampling or during participation in scientific research, or, in some cases, specifically for the biobank. Providing a sample is always voluntary. Previously collected samples may also be transferred to the biobank.

Central Finland Biobank is located in the Wellbeing Services County of Central Finland. The owner of the samples is the Wellbeing Services County of Central Finland, unless otherwise agreed. Samples include, for example, tissue (biopsies, fine-needle or bone marrow samples, samples from exfoliated cells, tissue extracted in surgery), blood, secretions (urine, saliva, sputum, stool), or DNA or cells isolated from samples. General information about the sample and the sample donor (e.g. age and gender), health information (e.g. diagnoses, medical procedures, treatments, laboratory results, imaging records) and data determined from the sample, e.g. genomic data, will be attached to the samples at the biobank. Furthermore, data about you may be collected on a study-specific basis and combined with biobank samples and data from national registers when biobank data is handed over for biobank research. Such registers include, for example, patient records, national social welfare and health care registers (such as the care notification, cancer, and Kela special reimbursement registers), Statistics Finland, Digital and Population Data Services Agency, or materials collected from previous research projects.

Giving consent and approval. You may give your consent and approval by providing a signed consent and approval form to Central Finland Biobank, or by returning the form to healthcare or research staff. The forms can be found on the website www.hyvaks.fi/biopankki or they can be posted to you. On our website, you can also give your consent/approval electronically. Giving your consent for sampling and approval for the attachment of data is voluntary, and healthcare services will continue to be available to you as before even if you decide not to provide your consent and approval. The consent and approval for Central Finland Biobank only applies to Central Finland Biobank.

v01.01.2024

Withdrawal of consent and exercising of the right to object. You may withdraw consent and/or exercise the right of objection under Article 21 of the EU General Data Protection Regulation by submitting the signed refusal form to Central Finland Biobank or by returning it to a member of healthcare or research staff. The forms can be found on the website www.hyvaks.fi/biopankki or they can be posted to you. You may withdraw your consent prior to sampling, or, at the latest, before the sample and associated data are handed over to the biobank. By exercising the right to object, you can manage and prohibit the use of your own data in biobank operations. If you object to the use of your personal data, neither your samples nor your data will be handed over any more from the biobank for further research. Withdrawal of consent given to Central Finland Biobank and exercising the right to object only apply to Central Finland Biobank.

Advantages and disadvantages for the sample donor. There is generally no immediate therapeutic advantage to be expected from providing samples and data for biobank research, since the biobank is primarily intended for research purposes. The biobank cannot guarantee the quality of the data analysed from the samples, nor can it guarantee that the research will reveal information significant to you, or that said data would be made available to you or to your health care system.

The risk of misuse of samples and data is extremely low. The biobank processes the samples and data in accordance with the data protection requirements for confidential information. The name of the sample donor and other identification data are replaced by a code, the decryption key for which is stored separately. It is nearly impossible to identify an individual on the basis of the coded information. Access to identifiable samples or data can only be granted where there is a justified need, such as the need to link the samples or data in the biobank to other data, such as data already collected by the researcher. Samples and data may also be transferred for research purposes to countries that are not members of the EU or the European Economic Area and that therefore may have different statutory levels of data protection. Data protection is safeguarded by coding the samples and data and by making detailed agreements on their processing. Samples and data from the Biobank may not be used in criminal investigations, administrative or other decision-making concerning the sample donor, assessing or determining fitness for work, or decision-making by credit or insurance institutions. Unauthorised use of samples and data is a criminal offence.

Central Finland Biobank was founded by the Central Finland Health Care District (the Wellbeing Services County of Central Finland as of 1 January 2023) and the University of Jyväskylä. Our research area covers biological, medical, sports and health science research and product development. Central Finland Biobank has a research focus on population health promotion, identification of factors impacting disease mechanisms, disease prevention, and the development of products and treatment practices that promote the population's wellbeing and health or are used in medical care.

Consent and approval for the processing of samples and data at Central Finland Biobank

By signing below, I confirm that I have read and understood the above information and, accordingly, I give my consent and approval to Central Finland Biobank. My samples may be processed at Central Finland Biobank. I also give my approval for data and information on my health status and health determinants to be associated with the samples. Central Finland Biobank may grant access to the samples and data for purposes of biobank research. I can withdraw my consent or object to the processing of my personal data at the biobank by signing a refusal form.

I also consent to Central Finland Biobank contacting me for the following purposes:

- To report a significant health finding revealed by a sample
Yes No
- To enquire about my willingness to give additional samples or participate in research not covered by this consent.
Yes No

Personal identity code

Full name _____

Street address _____

Postal code and town _____

Date and signature _____

You may return the form on your arrival or by post without a postage stamp (postage paid).

Address:
Wellbeing Services County of
Central Finland
Biobank
Tunnus 5007650
00003 VASTAUSLÄHETYS

**In-house mail
(for staff only)**
Biobank M-1

Recipient (to be filled in by the biobank or another staff member of the wellbeing services county):

Date, name and signature
or the stamp of the biobank: _____

You are entitled to request at any time to receive information on the research use of your samples and data.

For information requests and to get in touch, please use the above contact details.

v01.01.2024

