Finnish Red Cross Blood Service

Blood Service BIOBANK

Declaration regarding consent and data protection for persons providing samples for the Finnish Red Cross Blood Service's Biobank

We request your consent to the collection of samples, as well as personal and health-related information in the Blood Service Biobank for use in biobank research. This declaration contains information about the Blood Service Biobank's activities and what giving your consent involves in practical terms.

Summary

- The Biobank collects human samples and data for medical research and product development.
- Assisting the Biobank in these tasks is entirely voluntary and dependent on your consent. If you decide not to give your consent now or if you withdraw your consent at a later time, this will not affect your status as a blood donor in any way.
- Giving a sample to the Biobank usually happens at the same time as you donate blood at the Blood Service, and the sample is taken alongside the blood group and virus screening samples taken during this visit. Consenting to your blood sample being used by the Biobank does not mean that you will need to give more or less blood than usual.
- Consent may also relate to similar samples taken in connection with previous blood donations and data use, as well as to follow-up samples in the future.
- You have the right to know which studies your sample and information have been assigned to.
- The Biobank secures sample donors' privacy at all times when assigning samples and the related data for the purposes of biobank research.
- The data held in the Biobank on samples and sample providers can be stored for tens of years.

The Biobank and the significance of biobank research

A biobank is a unit compliant with the Biobank Act (688/2012), controlled by the relevant authorities, which processes human biological samples and the associated data and provides these resources to third parties for the purposes of medical research and product development projects. Among other things, biobank research is used to identify the causes of illness and the necessary prevention methods and to investigate the impacts of genetics, environmental factors, and lifestyle as causes of illness. The samples and the related data can be used for the purposes of various research projects, commercial cooperation, and product development projects that may even be based outside the European Union, as permitted by law. Researchers may be charged a fee for biobank services. Research results are returned to the Biobank for use in future studies.

The Blood Service's Biobank

The Blood Service established its Biobank as part of research into health promotion through studies that prevent diseases and identify the mechanisms of diseases. In addition, the Blood Service's Biobank specialises in the specific issues affecting transfusion medicine from the perspective of donors and patients alike.

Biobank samples and data

The Blood Service's Biobank is a subsidiary of the Finnish Red Cross Blood Service (FRCBS), and is responsible for the storing of samples and data in the Biobank. Biobank samples can be taken while giving blood as a donor, as part of participation in scientific research, or just for the purpose of a biobank. Samples previously taken during a blood donation can also be transferred to the biobank. Samples stored by biobanks consist of the donor's blood itself or specific parts of the blood, such as the serum or plasma, or even DNA and individual cells. Each biobank sample is identified by the information associated with the sample and the sample provider that is necessary for the study in question. This might be the age and gender of the sample provider, the sample type, and the date and time the sample was taken. The results of any biobank study, such as the data on an individual's genetics (genes), are then associated with the sample(s) and the sample provider(s).

In addition, data related to the samples and the sample provider may be requested from other registers, such as patient records, another biobank, national social and health care registers (e.g. THL's treatment notification register and cancer register), Statistics Finland, the Digital and Population Data Services Agency, or the registers of the Social Insurance Institution of

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Finland (e.g., Kela's special reimbursement register for medicines) and data collected by the research project itself, if the data are necessary for the implementation of the biobanking study. The information held on samples and sample providers may also be related to socio-economic status or data on relatives held in external registries if this is necessary to the biobank study in question. Information such as this, which is controlled by third parties, will not be stored in the Biobank, and will instead only be made available to the study or research project that needs it. Samples may be used for the purpose of investigating an individual genome and its impacts on health. The use of genomic information in research and everyday diagnosis is increasing dramatically. It is also now even possible to map an individual's entire genome – i.e., their genetic material.

You have the right to access information

Feel free to ask the Blood Service Biobank whether we hold your data and/or samples taken from you, about the reasons for this data storage (consent or notification procedure for old samples), how and where we obtained your information, and where your samples and information have been disclosed to. You can also ask what information about your health has been determined from your sample in the biobank study. However, the results of biobank research are rarely directly exploitable for the benefit of individual donors. If you wish, you may also obtain clarification of the significance of the results, but a fee corresponding to the expenses incurred by verifying and clarifying the information may be charged.

Possible further research requests and getting in touch

The consent form contains a separate question about whether we may contact you if the research has identified significant information about your state of health, such as a serious risk of illness for which there is effective treatment or the effects of which can be prevented. Although the Biobank cannot treat sample providers the Biobank staff will direct providers to the relevant healthcare services as needed. We also require a separate consent to be able to enquire about your willingness to participate in research or sampling that this consent does not allow. Such situations may include, for example, a request to participate in a drug study or to donate a new sample.

The benefits and potential disadvantages of biobank activities to sample donors

In most cases, individual health benefits cannot be expected from providing a blood sample and/or information for biobank research. Instead, the aim is to investigate and survey the causes of diseases and to find more effective treatments and disease prevention methods that benefit the wider population. The appropriate prerequisites for research are assessed in advance, so the risk of misuse of samples and data in the Biobank is very low. The Biobank processes samples and data in accordance with the data security requirements determined for confidential information. Data security is ensured by coding samples and by drawing up precise usage agreements. In countries outside the European Union, adequate levels of data protection are provided through special agreements, as the level of statutory data protection may vary. Research results and genome data can be shared with other researchers through international databases without an individual's data being identified. This makes it almost impossible to identify an individual person. Biobank's samples and information may not be used for the purposes of criminal investigation, administrative decision-making concerning the sample provider, or in the evaluation of an employment relationship or insurance contract. Unauthorised use is a criminal offence.

Voluntary consent, withdrawing consent, and the period of validity

Your consent is voluntary and valid until further notice. Acting as a blood donor is completely independent of your consenting to a sample being stored and used by the Biobank. You can withdraw your consent at any time. The consent, its withdrawal, modification, or prohibition will take effect as soon as the Biobank receives the related information. Withdrawal of consent or a prohibition do not retrospectively affect material transferred from the Biobank for biobank research prior to the prohibition or withdrawal. Withdrawal of consent does not always mean that the Biobank destroys a sample or that personal data is deleted. For example, in order to verify the accuracy of research results, it may sometimes be necessary to keep the samples and other documentation used in a specific study. You may grant consent, withdraw, or amend it by submitting the signed form directly to the Blood Service's Biobank or by handing it over to Blood Service personnel. The Blood Service website (www.bloodservice.fi) provides further information on the activities of the Blood Service's Biobank, as well as the details for contact persons and the abovementioned forms. You may also receive these by post if you so wish. The Biobank personnel will be happy to provide additional information.

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