

PRIVACY POLICY – FINNISH HEMATOLOGY REGISTRY AND CLINICAL BIOBANK

The Finnish Hematology Registry and Clinical Biobank (FHRB Biobank)'s register is maintained by the Finnish Association of Hematology (SHY), the Finnish Red Cross Blood Service (FRCBS) and the Institute for Molecular Medicine Finland (FIMM). In processing personal data, the FHRB Biobank complies with existing legislation on data protection and other related legislation and ensures that the security of personal data is at an appropriate level. In this privacy policy, we provide details on how your personal data is processed in the FHRB Biobank.

Why is my data being collected?

The FHRB Biobank collects your personal data in connection with the samples you have donated for purposes of medical research and research and development. Biobanking is long-term work that aims at promoting health and preventing diseases by providing samples and data for studies that identify disease mechanisms or develop of treatments and diagnostics. The Biobank processes the personal data of sample donors for the purpose of carrying out tasks provisioned under the Biobank Act (688/2012). The purpose of the Biobank Act is to support research that utilises human biological samples and protect the rights of donors. The legal grounds for processing under the EU General Data Protection Regulation is the performance of a task carried out in the public interest. The task carried out in the public interest that is being pursued is to enable scientific research as referred to in the Biobank Act. The FHRB Biobank only collects samples and data from persons who have given biobank consent in writing.

What data is collected about me?

- name, personal identity code
- date of giving biobank consent
- permissions specified in the biobank consent (permission to report possible incidental findings, permission to contact concerning possible further sample requests)
- Clinical data about the sample donor: data from laboratory, imaging and clinical findings required to make a diagnosis; treatments administered on the basis of the diagnosis; data from laboratory and imaging examinations and clinical findings necessary to assess the response to treatment; data from laboratory, imaging and clinical findings providing the basis for the maintenance or loss of response to treatment; other diseases affecting the implementation of treatment, and information relating to the time and cause of death
- quality, number, and dates of samples stored in the Biobank
- research projects to which the samples and data have been disclosed and the quality and number of disclosed samples
- results of the research projects received by the Biobank

How are my data obtained?

The Biobank stores personal data that you have provided upon registration, in other words when you signed the consent form for the FHRB Biobank. Clinical data is collected from your patient record onto the Finnish haematological register, from where it is transferred to the FHRB register to be connected to samples. In addition, data analysed from your samples during Biobank research is returned to the Biobank.

On a case-by-case basis, the material provided by the FHRB Biobank to research projects may require to be supplemented with data about the data subject's state of health, past medical treatment or examinations obtained from patient registries, national social welfare and health care registries such as the statutory Care and Cancer Registries maintained by the National Institute for Health and Welfare, Statistics Finland, the Digital and Population Data Services Agency, or from registries maintained by the Social Insurance Institution (e.g. registry on the special reimbursement of medicine expenses), and with data from other biobanks. The

FHRB Biobank does not store this information; instead, the data are made available to the project for the purposes of research for a specified duration, after which they are erased from the research project registry.

For what purposes are my personal data used?

Samples and data stored in the Biobank's register may be transferred or released for the purpose of biobank research. Researchers apply for material by describing the objective of research and the intended use of the samples and data. Samples and data from the FHRB Biobank are released to research projects focusing on haematological diseases. The Scientific Advisory Board evaluates all applications related to the use of biobank material and gives or withholds its favourable opinion to the Biobank's management team. In its assessment, the Scientific Advisory Board uses criteria defined by the management team, which consider the requirements of the Biobank Act and the objectives of the FHRB Biobank, the usability of research results in patient care, the scientific significance, level, challenges, and financial and intellectual resources of the research group.

Data is only released for applications that demonstrate that the data recipient has the right to process the data under the Biobank Act and otherwise meet the conditions for processing required by law and the FHRB Biobank. The material may be transferred for research purposes to researchers representing domestic and international universities, hospitals, and research institutions, as well as to health care companies (for example, pharmaceutical companies and diagnostic and analytical laboratories).

Any data transferred or released to research projects are in a coded form, in other words, with any identifying information removed (pseudonymised). In special cases, data that includes identifiers may be transferred, for example to another data controller for the purpose of combining data. Even in such cases, directly identifiable information is removed after combining the data and before the samples and data are released for use in research. In each disclosure, the provided material is limited to only that necessary for conducting the research.

Before the transfer or release of the requested samples and data, the FHRB Biobank signs an agreement with the recipient on the research use, the permitted period of use, restrictions on disclosure to third parties, and the obligation to return the data to the Biobank. Any subcontractors used are required to employ sufficient technical and organisational measures to protect personal data and sign a data processing agreement.

Upon request, you can receive information on to which research project the FHRB Biobank has released your data and samples, and from which registries or studies data has been collected.

Can my personal data be shared with parties outside of the EU?

The samples and data in the FHRB Biobank may be transferred or disclosed outside the EU and EEA for the purposes of research and product development, in compliance with the appropriate security measures, and only if the country in question can guarantee an adequate level of data security. The basis for transfer and security measures are assessed on a case-by-case basis. In these cases, too, the Biobank refrains from releasing personally identifiable information on the sample and data.

In all cases, the FHRB Biobank signs an agreement with the recipient on the intended use of the samples and data in research, the period of permitted use, restrictions on disclosure to third parties, and obligation to return the data to the Biobank.

How are my personal data protected?

The employees of the Biobank's owner organisations are under an obligation to non-disclosure. The registers are password-protected and can only be accessed by authorised members of staff. Registry browsing and the addition, editing and deletion of data are restricted to those with access rights. Log data on the use of the

register is saved. Printed documents that contain personal data are stored by the Blood Service in locked premises with controlled access. The samples and data are released only to research projects assessed by the FHRB Biobank to be ethically acceptable and trustworthy. The samples and data are released to research projects in a coded form to ensure that all personally identifiable information on the sample and data remains undisclosed.

Is my data used for profiling or automated decision-making?

No.

For how long is my data stored?

Your data are stored in the Biobank until further notice, and the necessity of storage is assessed periodically.

How can I review my data and rectify any inaccurate information?

You can check the data collected about you by completing, printing, and signing the Request for data form from the FHRB Biobank's website and submitting it to the Blood service. The Blood Service will send your data that is in the data file to you by post. You can request the rectification of inaccurate information in writing using the Rectification request form found on the Blood Service's website.

Can I request the erasure of my data or object to the use of my data?

Yes, you can always withdraw your consent to the Biobank.

If your samples stored in the Biobank have not yet been released to any research projects, you can request the erasure of all your data from the Biobank's register. If your samples have already been released to a research project, your data cannot be erased completely. Instead, your original consent must be stored together with your later withdrawal of consent., and or example, it may sometimes be necessary to store the material used in research to verify the accuracy of research results. After you have withdrawn your consent to the Biobank, your samples and data will no longer be disclosed to further analyses or other research projects.

If you wish to withdraw your consent, please fill out and sign the biobank consent withdrawal, and send it by post to the FHRB Biobank.

Can I lodge a complaint with the authorities?

If you feel that your personal data has not been lawfully processed, you may lodge a complaint with the competent supervisory authority.

Person responsible for the register

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