Privacy notice of Biobank of Eastern Finland

This privacy notice informs about the processing of personal data in accordance with Articles 12, 13 and 14 of the EU General Data Protection Regulation. References in the form of "you" in the privacy policy refer to the data subject.

1. Data controller

Wellbeing services county of North Savo
P.O. Box 1711
70211 KUOPIO
kirjaamo@pshyvinvointialue.fi

The contact person concerning the processing of personal data: biobank director, arto.mannermaa@pshyvinvointialue.fi

Data protection officer’s contact information: tietosuoja@pshyvinvointialue.fi.

2. Name of the personal data registers

- Sample and Data register,
- Consent register,
- Code register and
- Event register.

3. Purpose of processing personal data

The purpose of data processing is biobank operations in accordance with the Biobank Act. This includes handling and storing registered persons' samples and data in the biobank and their transfer to biobank research as well as analyse samples and data. Biobank of Eastern Finland can deliver samples and data to scientific research or development projects that promote medical research and product development

The register maintains information on biobank consents and approvals, or those who have withdrawn consent and/or exercised their right to object, as well as whether old samples or data collected during health care or scientific research that have been transferred to the biobank

The biobank maintains sample and data register, consent register, code register and event register of biobank operations

4. Legal basis for processing of personal data

The legal basis for processing personal data in the biobank is the public interest related to public health under the Finnish Biobank Act and EU General Data Protection Regulation (GDPR) article 6(1)(e) and article 9(2)(i).

5. Personal data to be processed

Sample and Data register:

- Information about sample donor e.g. biobank code created for pseudonymisation, gender, date of birth,
- Data related to sample or its technical record e.g. sample code, type of sample, sampling time, processing history, statements, information analysed from samples,
- Health information concerning sample donor (e.g. diagnoses, medical procedures, treatment, hospital visits, results and records of laboratory analyses and imaging, treatment costs),
- Results obtained from biobank research.

Consent register:

- Your name and personal identity code,
- Information collected from biobank consent and approval form,
- Biobank refusal form,
- Data about old sample collections transferred to the biobank.

Code register:

- Your name and personal identity code,
- Biobank code,
- Project-based codes.

Event register:

- Your biobank code and personal data sources,
- Data about biobank research, data about samples and data assigned to research. Dates of these events,
- Information about recontacting data subjects for research purposes.

6. Regular sources of personal data

To the extent that personal data have not been collected from you, regular sources of personal data include:

- The healthcare patient registries of North Savo, South Savo (Eloisa) and/or North Karelia (Siun sote) wellbeing services counties.
- The research teams that have transferred so-called old research samples to the biobank.
- The health care units that have transferred so-called old research samples to the biobank.
- Research results obtained from biobank research.

Data are collected and processed only to the extent necessary and relevant for biobank operations and research.

7. Regular transfer or disclosure of personal data

The biobank assigns samples and information to research teams for biobank research. The Scientific Steering Committee of Biobank of Eastern Finland evaluates each biobank project according to the Biobank Act. Only the necessary number of samples or data are delivered to biobank research. Data security is ensured by encoding samples and data and by drawing up detailed contracts regarding how they are handled.

8. Transfer and disclosure of data outside the EU or the EEA

On some occasions, your personal data may be transferred to third countries outside the EU or the EEA in the context of biobank research. In such cases, the transfer of personal data is justified by a decision by the European Commission on an adequate level of data protection or by the standard contractual clauses adopted by the European Commission. We shall also protect your data on a case-by-case basis, for example, by encrypting or pseudonymising them.

9. Principles of data protection

We shall protect your personal data by implementing technical and organisational safeguards, such as:

- Personal data registers of the data controller are processed in data systems of North Savo, South Savo (Eloisa) and/or North Karelia (Siun sote) wellbeing services counties.
- Protecting data systems by means of a username and password. Access rights are only granted to the employees of the data controller who are entitled to use such data in their work tasks.
- Placing data systems in a secure environment protected with firewalls and maintained by applying appropriate data security practices.
- Storing any paper materials in appropriately controlled spaces, access to which is restricted by access rights.

- Storing archived materials in appropriately controlled spaces, access to which is restricted by access rights.
- Training employees and giving written instructions to them.
- By contractual means.

The biobank complies with North Savo, South Savo and Nort Karelia wellbeing services data protection and data security principles.

10. Profiling and automated-decision-making

Personal data will not be used for profiling and automated-decision-making.

11. Retention period for your personal data

Your data will be stored in accordance with the requirements laid down in the Biobank Act and other applicable legislation.

12 Rights of the data subject

Data protection legislation grants you certain rights to ensure the protection of privacy, which is a fundamental right. If you wish to exercise your right, please contact Wellbeing services county of North Savo, Registry, P.O. Box 1711, 70211 KUOPIO or kirjaamo@pshyvinvointialue.fi.

Not all of the rights of the data subject can be exercised in all situations, depending on factors such as the basis for the processing of personal data. If your rights can´t be exercised the data controller will implement the appropriate and necessary safeguards required by law.

12.1. Right to withdraw consent and object to processing of personal data

You have the right to withdraw consent and/or object to processing of personal data.

12.2. Right of access by the data subject

You have the right to obtain from the data controller confirmation as to whether or not personal data concerning you is being processed, and, where that is the case, access to the personal data. The data controller must provide you a copy of the personal data undergoing processing. The right to obtain a copy shall not adversely affect the rights and freedoms of others.

12.3. Right to rectification

You have a right to obtain from the data controller without undue delay the rectification of inaccurate personal data concerning you. The data controller assesses whether the data you have requested to be rectified is incomplete, inaccurate or incorrect.

12.4. Right to erasure

You have a right to obtain from the data controller the erasure of personal data concerning you.

12.5. Right to restriction of processing

You may have the right to restrict the processing of your personal data in cases provided for by law. The right of restriction may be relevant, for example, if you consider that the personal data concerning you are incorrect or they are being unlawfully processed, or you have objected to the processing of your data.

12.6 Right to object

You have a right to object processing of personal data concerning you.

12.7 Right to lodge a complaint with a supervisory authority

You can notify the Data Protection Ombudsman if you suspect that the data controller is processing. personal data in violation of data protection regulations.

Office of the Data Protection Ombudsman

Postal address: P.O. Box 800, 00531 Helsinki, Finland

E-mail: tietosuoja(at)om.fi

Switchboard: +358 (0)29 566 6700