
Tampere Biobank consent information

Your consent is requested for biobank processing of your samples and personal data. A biobank is a regulated facility where samples and associated data are compiled, collected and stored for health science research needs in accordance with the Biobank Act (688/2012). A biobank discloses samples and data for domestic and international studies and product development projects. Biobank collections may also include material intended for more restricted use. When a study has ended, the results obtained from samples are returned to the biobank for use in future studies. The right to process samples and related data in a biobank is based on a biobank consent given by an individual and directly on public interest by virtue of the legislation (EU General Data Protection Regulation, Article 6(1e), Article 9(2g)). The use of data for studies is based on public interest (EU General Data Protection Regulation, Article 6(1e), Article 9(2g, i and j)).

Biobank samples and data Samples may be collected in the course of health care activities or participation in a scientific study. Sometimes samples are collected specifically for a biobank. As a general rule, samples are taken on a one-off basis. A person may be asked for new biobank samples if the biobank samples taken from them have been used up or if the samples have been damaged during transport or processing so that they cannot be used for biobank studies. In cases where the health status of a person is being monitored, biobank samples may be taken several times. Such samples may be used, for example, in studies relating to the monitoring of health status, disease or treatment. Donating samples is always voluntary. Samples may also be moved to a biobank after being collected previously. Tampere Biobank operates in the hospital districts that founded it. Samples are owned by Pirkanmaa Hospital District unless otherwise agreed. The samples may consist of tissue (biopsies, fine-needle aspirates, bone marrow aspirates, cell smears, tissue removed during surgery), blood, excretions (urine, saliva, sputum, stool), aspiration fluids (incl. cerebrospinal fluid, pleural fluid) or DNA or cells that have been isolated from samples. A sample is linked to information about it and the person who donated it, such as the donor's general information (age, sex) and health information (diagnoses, medical procedures, treatments, laboratory results, saved images) as well as data generated from the sample, such as genome sequencing (genotype information). Information may be requested from the donor or from patient documents, national social welfare and health care registers (such as the Care Register, Cancer Register, or Kela's register of drugs eligible for special reimbursement), Statistics Finland, the Population Register Centre, or material collected for a research project.

Voluntary nature and validity of consent: Giving consent is voluntary. Health care services will be available to you as usual even if you do not give consent. When consent is given, it is valid indefinitely but can be withdrawn at any time without stating a reason.

Giving, withdrawing or refusing consent: A biobank consent or refusal can be made electronically via OmaTays (www.omatays.fi). You need online banking credentials or the Mobile ID to use the service. You may also give, withdraw or refuse consent by submitting a signed consent or refusal form to Tampere Biobank or returning it to health care or research personnel. The forms are available at www.tays.fi/biopankki or they can be sent to you by post. It may be possible to restrict your consent by contacting the Biobank. When consent withdrawal (refusal) is received by Tampere Biobank, your samples and data will no longer be used or released for new studies. The Tampere Biobank consent or refusal applies to Tampere Biobank only.

Donor benefits and risks: Donating samples and data to the Biobank is not expected to help your treatment directly since it is mainly for research purposes. The Biobank cannot guarantee the quality of data obtained from analysed samples, that any information significant for you would be detected in testing, or that any such information would be available to you or health care services.

The risk of samples and data being misused is extremely low. The Biobank processes samples and data in compliance with the data security requirements for confidential information. The donor's name and other identifiers are replaced with a code, and the code key is stored separately. It is nearly impossible to identify any individual person from encoded data. Samples or data containing identifying information may be released only if there is a justified need for it, such as to pool biobank samples or data with other information that an investigator has collected previously. Samples and data may also be released for studies in countries outside the EU and EEA, where legal requirements for data protection vary. Data protection is ensured by encoding the samples and data and by preparing detailed agreements about how they will be processed. Biobank samples and data may not be used in criminal investigations, administrative or other decision-making concerning the donor, work capacity assessment or determination, or decision-making by lending institutions or insurance companies. Unauthorized use is a criminal offence.

Tampere Biobank was founded by Pirkanmaa Hospital District, the University of Tampere, and the hospital districts of South Ostrobothnia and Kanta-Häme. Its research scope encompasses promoting public health, identifying factors that affect disease mechanisms, preventing illnesses, and developing products or clinical practices that promote the well-being or health of the population.

Consent for sample and data processing at Tampere Biobank

My signature confirms that I have read and understood this information and give my consent to Tampere Biobank as described. My sample and my personal and health-related data may be transferred to Tampere Biobank, linked to an existing sample and stored there. Tampere Biobank may release these for biobank research. I may withdraw my consent by submitting a biobank refusal form.

In addition, I give my consent for Tampere Biobank to contact me in the following cases:

- To notify me of a finding from the sample that has health significance.
 yes no
- To ask about my willingness to provide additional samples or to participate in a study not covered by this consent.
 yes no

Personal identity code

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Consent given by
full name

Address

Date

Signature

**You may return
the consent to
the hospital
in person.**

Postal service (postage paid)

Tampere Biobank
Tampere University Hospital
Info: 924
TUNNUS: 5003897
00003 VASTAUSLÄHETYS

Internal post

(only for personnel)
Tampere Biobank
FM 1, 1st floor

To be completed by health care or biobank personnel
Received by (date, name, signature): _____

You have the right to obtain information about the research use of your samples and data at any time upon request.

Information requests and contacts: See contact information above.