

Auria Biobank's info sheet and consent form

You are being asked for your consent to allow samples and personal data to be used for biobank research. A biobank is a unit, per the Biobank Act (688/2012), that is supervised by a regulatory authority and which collects and stores human biological samples and related data for medical research. The biobank allows access to samples and data for domestic and international research projects. The biobank's collections may also include material intended for more restricted use. Once the projects are completed, the results obtained from the samples are returned to the biobank for use in new research.

Biobank samples and data. Samples may be collected during treatment or while taking part in a medical study, and sometimes specifically for the biobank. Previously taken samples can also be transferred to the biobank. Auria Biobank operates within the hospital districts who are its founders and who also own the samples, unless otherwise has been agreed on in the transfer of the samples. Samples may consist of, e.g. tissue (biopsy; fine-needle, bone marrow and exfoliative cytology samples; surgical tissue samples), blood, bodily fluids (urine, saliva, mucus, stool) or DNA or cells isolated from samples. Data related to the sample and the donor is attached to the sample: i.e. general information (age, sex), as well as health information (diagnoses, medical procedures, treatment, lab results, imaging records) and sample-based data, such as genome information (genetic information). The data requested can come from the donor, patient records, national social and healthcare registers (i.e. Care Register for Social Welfare and Health Care, Cancer Registry, Social Security Institution's special reimbursement register), medical and Statistics Finland's registers or data collected in a research project.

Voluntary nature of consent and duration of consent. Giving consent is voluntary. Healthcare services will be available to you as usual, even if you do not give your consent. Given consent is valid until further notice, but can be cancelled at any time without giving a reason.

Giving, cancelling and refusing consent. You can give, cancel or refuse consent by sending the signed consent form or refusal of consent form to Auria Biobank or by returning it to the medical treatment or research staff. The forms can be found at www.auria.fi/biobank or they can be mailed to you. Adults can also give their biobank consent online at www.suostumus.fi. It may be possible to restrict consent by contacting the biobank. The consent, or its cancellation, restriction and refusal, will enter into force when the biobank receives information thereon. After the biobank has received your notice of cancellation of consent (refusal), your samples and data will no longer be used nor will they be accessed for new research. Auria Biobank's consent and refusal of consent apply only to Auria Biobank.

Benefits and drawbacks for the donor.

Generally, no immediate treatment benefits are to be expected by granting the biobank consent to access samples and data, as the biobank exists primarily for research purposes. The biobank cannot guarantee the quality of the data from the analyzed samples or that the research will reveal information that is significant for you or which can be used by you or by health care.

There is an extremely small risk of the samples and data being misused. The biobank handles the samples and data in compliance with the data security requirements for confidential information. The name and other identifiers of the donor of the sample are replaced by a code, and the code key is stored separately. It is nearly impossible to identify an individual based on the coded data. Identifiable samples and data can only be assigned if there is a justified need for it, for example, in order to combine previous data collected by a researcher with the biobank's samples or data. Samples and data can also be assigned for research in countries outside the EU and EEC, in which case the level of statutory data security may vary. Data security is ensured by coding samples and data and by drawing up detailed contracts regarding how they are handled.

The biobank's samples and data cannot be used in criminal investigations, in administrative or other decision-making involving the donor, in evaluating or determining the donor's capacity to work or in decision-making by credit and insurance institutions. Unauthorized use is a crime.

Consent to the processing of samples and data by Auria Biobank

I confirm that I have read and understood the info sheet and, accordingly, I give my consent to Auria Biobank. My samples, my personal data and data related to my health can be transferred to Auria Biobank, combined with samples and stored there. Auria Biobank can assign them for biobank research. I can cancel my consent by sending the biobank a completed refusal of consent form.

In addition, I consent to Auria Biobank contacting me in the following circumstances:

To inform me of findings from my samples which are of significance to my health Yes No

To discuss whether I would like to provide additional samples or participate in some form of research that is not covered by this consent Yes No

Personal identity code

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Full name of person giving consent

Address

Date and Signature

Send the consent form to:
Auria Biobank
P.O. Box 52, FI-20521 Turku

You can also return
the consent form when
you visit the hospital

VSSHP's internal address
(for VSSHP staff only)
Auria Biobank, MD4C
Pneumatic post 542

Receipt of the consent form (to be filled in by Auria Biobank)

Name, date, signature: _____

You have the right, upon request, to receive information on the use of your samples and data for research. Requests for information, requests about follow-up studies and contacts: See contact details below.

Bioholvi is Auria Biobank's mobile story game aimed at children and adolescents. The game is available at Google, Microsoft and Apple app stores.

Auria Biobank was established by the University of Turku and the hospital districts of Southwest Finland, Satakunta and Vaasa. The biobank's area of research encompasses promoting people's health, identifying factors that influence the mechanisms of disease, preventing diseases and developing products and treatment practices that promote health or which are used in medical care.

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Telephone + 358 (0)50 578 0815

www-address www.auria.fi/biobank
Email info@auria.fi
Online consent www.suostumus.fi