

Privacy policy for biobanks

1 Data controller

National Committee on Medical Research Ethics (Tukija)

Visiting address: Finnish Supervisory Agency, Ratapihantie 9, 00520 Helsinki

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Other contact details: tel. +358 295 254 000 (switchboard), info@tukija.fi

2 Contact person for the register

Outi Konttinen, outi.konttinen@tukija.fi

3 Contact details of the Data Protection Officer

Jukka Tuomela, tietosuoja@lvv.fi

4 The personal data processed

The registered data is intended for Tukija's operations. For the purpose of the opinion issued by Tukija, the register will process, where applicable, the following information about the persons in charge of the biobank and its contact persons:

- name, date of birth and role in the biobank
- address and contact information
- employer or company
- educational background
- professional information (work experience, publications) and other information provided in the CV submitted
- the name of the processor and the presenter, contact details.

5 Grounds for processing personal data

Tukija's duty is to issue an opinion on the establishment plan of a biobank and notifications of changes. To fulfil this purpose, Tukija processes the personal data provided in the applications.

The processing of personal data is based on compliance with a legal obligation under Article 6(1)(c) of the EU General Data Protection Regulation (2016/679).

Personal data is processed in duties assigned to Tukija in sections 6 and 9 of the Biobank Act (688/2012).

Personal data will not be processed for any purpose other than that for which it has been collected. Tukija will not use personal data for automated decision-making or profiling.

6 Retention period of personal data

The retention period of personal data depends on the retention period of the document containing said data:

- Applications for opinions and their annexes (retained for 25 years from the biobank's end of operations notification).
- Tukija's minutes and record extracts, opinions, decisions (retained permanently).

7 Regular sources of data

Tukija receives the data from the applicant submitting an application for an opinion on the establishment of a biobank or a notification of changes.

8 Data processors

Tukija operates in connection with the Finnish Supervisory Agency. The data is also processed by the agency's system administrators.

9 Disclosure of data

Data can only be disclosed and the processing of personal data outsourced in compliance with valid legislation.

The opinions issued by Tukija under the Biobank Act are disclosed to the Finnish Medicines Agency (Fimea), which is responsible for the guidance and supervision of biobank operations in accordance with section 31(1) of the Biobank Act.

Data is disclosed to others only upon request in accordance with the Act on the Openness of Government Activities (621/1999) and the data protection legislation.

Personal data will not be transferred outside the EU or the European Economic Area.

10 Rights related to the processing of personal data

This is a register required by law. In this case, the data subject has the right to:

- Obtain access to personal data concerning them in accordance with Article 15 of the General Data Protection Regulation. This request is addressed to the party in section 2.

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- Demand the rectification of erroneous data in the register concerning them in accordance with Article 16 of the General Data Protection Regulation. This request is addressed to the party in section 2.
- Request restriction of processing of personal data in accordance with Article 18 of the General Data Protection Regulation.

Due to the fact that the register is required by law, the data subject does not have the right to:

- Have the data controller erase the personal data concerning the data subject without undue delay in accordance with Article 17 of the General Data Protection Regulation.
- Transfer their personal data from one system to another or have their data transferred directly from one controller to another in accordance with Article 20 of the General Data Protection Regulation.

If the data subject considers that data protection legislation has been violated in the processing of personal data, the data subject has the right to lodge a complaint with the Office of the Data Protection Ombudsman.

Further information on the rights of the data subject can be found on the website of the Office of the Data Protection Ombudsman: <https://tietosuoja.fi/en/know-your-rights>

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