

**DATA PROTECTION NOTICE FOR
SCIENTIFIC RESEARCH**
General Data Protection Regulation of the EU
Articles 12–14
Date: September 18th, 2023

Information on the processing of personal data in canine and feline genetic studies

The canine and feline genetic studies in the Lohi group involve processing of personal data. The purpose of this data protection notice is to provide information on the personal data to be processed, from where they are obtained and how they are used. Detailed information on the rights of data subjects will be provided at the end of this notice.

Your participation in the research project and provision of personal data are voluntary. If you do not wish to participate in the project or you wish to withdraw from it, you can do so without negative consequences.

1. Data Controller

University of Helsinki
Address: PO Box (Fabianinkatu 33), 00014 University of Helsinki, Finland

2. Contact person and principal investigator

Contact person in matters concerning the research project:

Name: Hannes Lohi

Faculty/department/unit:

- Faculty of Veterinary Medicine, Department of Veterinary Biosciences
- Faculty of Medicine, Department of Medical and Clinical Genetics

Address: Haartmaninkatu 8, Box 63, 00014 University of Helsinki, Finland

Phone: +358 2 941 25085

Email: hannes.lohi@helsinki.fi

3. Contact details of the data protection officer

You can contact the University of Helsinki data protection officer via email at tietosuoja@helsinki.fi.

4. Description of the research project and the purpose of processing personal data

The research group investigates diseases in dogs and cats and their causes. Pet health information, behavioural data, and biological samples are collected. The owners' data is collected to identify pets, collect pet data, report research results, and other communications.

The personal data related to the study are processed by the current members of the Lohi group at the Faculty of Medicine and Veterinary Medicine of the University of Helsinki. The research group is responsible for the practical management of the data, such as the minimization of the data to be processed, the accuracy and the determination of storage periods and the use of appropriate systems/applications. The risks related to the treatment are assessed in cooperation with the supervisor. The University guides and supports the processing of personal data from planning to the publication of the final work and provides the necessary infrastructure and tools to carry out the research.

5. Personal data included in the research data

The following **pet owner information** is stored and used in the register:

- Name of owner: identification of owners and pets
- Email address and telephone number: in contacts regarding pet health information and other important information for research, reporting of results
- Street address: to distinguish owners of the same name during sample reception and health information update
- Postal code: to study the geographic distribution of pets in relation to environmental factors affecting pet health
- IP address: to check internet server log files for identification and prevention of cyber attack and hoax

The following **pet information** is stored and used in the register:

- Sample form (when the sample is sent)
 - Name of the pet
 - Breed
 - Registration number and ID marking
 - Date of birth
 - Gender and information on castration/sterilization
 - Possible time and cause of death
 - Results of official health examinations (hip joints, elbow joints, shoulder osteochondrosis, spine, patellar luxation, cardiac examinations, eye examinations)
 - Names and registration numbers of sire and dam
- Additional data collected through voluntary surveys on pet health and behaviour (the surveys are located on the secure REDCap platform on the University of Helsinki server)
 - E.g., Health Update Form (possible hereditary diseases and behavioral problems), Epilepsy and Dyskinesia Survey, Behavioral Questionnaire

6. Sources of personal data

The information is provided by the pet owners voluntarily participating in the study via electronic or paper forms used in the study.

7. Sensitive personal data

No special categories of personal data (i.e., sensitive data), as defined in Article 9 of the GDPR, will be processed in this research.

8. Lawful basis for processing personal data

Personal data are processed on the following basis (Article 6(1) of the GDPR):

- Task carried out in the public interest:
 - Scientific or historical research purposes or statistical purposes
 - Archiving of research material and cultural heritage material
- Consent by the research subject
- Compliance with a legal obligation to which the controller is subject
- Legitimate interests pursued by the controller or by a third party
Specify the legitimate interest:

If the processing of personal data is based on the research subject's consent, they can withdraw that consent at any time. The withdrawal of consent does not affect the lawfulness of processing based on consent before its withdrawal.

9. Recipients of data

Pet owner information

Pet owner information (listed in section 5 above) will not be transferred outside the research group, except in exceptional cases with the owner's separate permission.

Pet information

Pet information (listed in section 5 above) may be transferred for scientific research to the following entities:

- Partner universities and other research organizations
- Co-operating companies
- Subcontractors and service providers (e.g., company providing analysis or transcription services, company providing online survey platform service, etc.)

10. Transfer of data to countries outside the European Economic Area

Pet owner information

Pet owner information (listed in section 5 above) will not be transferred to countries outside the European Economic Area. They are processed only within the EEA.

Pet information:

Pet information (listed in section 5 above) may be transferred for scientific research to the following countries outside the European Economic Area: United States, Canada, United Kingdom, China, Japan

Data may also be transferred to recipients in other countries during the research project. The groups of recipients are mentioned in section 9 above.

The transfer of data is based on the European Commission's adequacy decision or standard contractual clauses (https://ec.europa.eu/info/law/law-topic/data-protection/international-dimension-data-protection/standard-contractual-clauses-scc_en), whereby recipients of personal data agree to comply with the data protection requirements outlined in the clauses.

11. Automated decision-making

The research project involves no automated decision-making that has a significant effect on data subjects.

12. Protection of personal data

Personal data included in the research dataset will be processed and kept protected so that only those who need the data can access them.

The data processed in data systems will be protected using the following:

- Username and password
- Registration/log of use
- Access control
- Encryption
- Two-factor identification
- Other, please specify:

Physical material (e.g., data in paper form or other tangible form) is protected by being kept in a locked space accessible only to the appropriate persons.

Processing direct identifiers:

- The controller collects the personal data without direct identifiers.
- Direct identifiers will be removed during the analysis stage and kept separate from the analysed research data.
- The data will be analysed using direct identifiers because (give grounds for preserving the direct identifiers):

13. Duration of the processing of personal data in this research project:

This study is a follow-up study. The research started in August of 2006 and will continue until further notice.

14. Processing of personal data when the research project ends

- The research data will be deleted
- The research data will be kept for the purposes of validating or replicating the results of this research project:
 without identifiers identifiers included
- The research data will be kept for later, compatible scientific research in accordance with the requirements of the GDPR:
 without identifiers identifiers included

The storage of the research data is based on Article 5(1)(b) and (e) of the GDPR. Data subjects will receive a new data protection notice on the new use of the research data, unless the controller can no longer identify the subjects from the data.

In addition, the data subjects will not be informed of the new research if delivering this information to them is impossible or involves a disproportionate effort or renders impossible or seriously impairs the achievement of the research objectives (Article 14(5)(b) of the GDPR).

Where and for how long will the data be stored: After the end of the research, the research register will be archived with identifiers on a secure server of the University of Helsinki for possible further use until further notice.

15. Rights of data subjects and derogations from those rights

The contact person in matters related to research subjects' rights is stated in section 1 of this notice.

Rights of data subjects

Under the General Data Protection Regulation, data subjects have the following rights:

- Right of access to their own data
- Right to rectification of their data
- Right to the erasure of their data and to be forgotten
- Right to the restriction of processing of their data
- Right to data portability from one controller to another
- Right to object to the processing of their data
- Right not to be subject to automated decision-making

However, data subjects cannot exercise all their rights in all circumstances. The circumstances

are affected by, for example, the legal basis for processing personal data.

Further information on the rights of data subjects in various circumstances can be found on the website of the Data Protection Ombudsman: <https://tietosuoja.fi/en/what-rights-do-data-subjects-have-in-different-situations>.

Derogations from rights

The General Data Protection Regulation and the Finnish Data Protection Act enable derogations from certain rights of data subjects if personal data are processed for the purposes of scientific research and the rights are likely to render impossible or seriously impair the achievement of the research purposes.

The need for derogations from the rights of data subjects will always be assessed on a case-by-case basis.

Right to appeal

If you consider that the processing of your personal data has been carried out in breach of data protection laws, you have the right to appeal to the Office of the Data Protection Ombudsman.

Contact details:

Office of the Data Protection Ombudsman
Street address: Ratapihantie 9, 6th floor, 00520 Helsinki
Postal address: PO Box 800, 00521 Helsinki
Phone (switchboard): 029 56 66700
Fax: 029 56 66735
Email: tietosuoja(at)om.fi