

PRIVACY NOTICE FOR SCIENTIFIC RESEARCH PARTICIPANTS EU GENERAL DATA PROTECTION REGULATION ART. 12-14 ART.

Date: [21.5.2025]

Information for Research Participants

You are taking part in a scientific study organised by the University of Oulu. This notice describes how your personal data will be processed in the study.

Participation in the study is voluntary. There will be no negative consequences for you if you choose not to participate in the study or if you withdraw from the study. However, if you withdraw from the study, data collected prior to your withdrawal may still be used in the study.* For more information on your rights and how you can affect the processing of your personal data, please see section 17 of this notice.

*If you withdraw from the study or withdraw your consent to participate in the study, the data collected prior to either withdrawal may still be used in the study unless you specifically request the erasure of your data or the restriction of its processing in accordance with the rights described in section 17.

1. Data Controller

The data controller of the study is the University of Oulu, which is responsible for the lawfulness of the processing of personal data taking place in connection with the research.

Address: University of Oulu, P.O. Box 8000, FI-90014 University of Oulu (Pentti Kaiteran katu 1, Linnanmaa)

Contact person responsible for matters relating to the research:

Name: Katri Kukkola

Address: Optoelectronics and Measurement Techniques research unit, Faculty of Information Technology and Electrical Engineering, University of Oulu, P.O. Box 8000, FI-90014 University of Oulu (Erkki Koiso-Kanttilankatu 3, Linnanmaa)

Telephone: +358 29 4487 694

E-mail: katri.kukkola@oulu.fi

E-mail: lupaloikata@oulu.fi

2. Description of the study and the purposes of processing personal data

The aim of the study is to enable the use of remote services in oral health care, especially in preventive work. The study prepares and tests a concept and tool for a remote service.

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The study examines whether a remote oral health care service based on virtually collected data and machine learning is capable and suitable as a tool for identifying the risks of the most common oral diseases and dental phobia, customising self-care guidance and providing an initial recommendation for a treatment path without the participation of experts.

The purpose of processing personal data is to develop the risk assessment and prevention of oral diseases. The observations and conclusions made from the survey responses and dental images will be compared with oral and dental health data (oral health examination data) from the patient register by statistical methods and machine learning. The data collected in the study will be used to create a system based on machine learning (using artificial intelligence). The suitability and desirability of virtual services are examined by means of a separate survey.

Direct personal data is used only for extracting patient records concerning oral health from the patient register (the extraction and linking is done by the Finnish Social and Health Data Permit Authority Findata). Only personal data necessary in view of the purpose of the study will be recorded in the study register. In the study, prior to analysis, direct personal identifiers will be removed, and documents and research results will only refer to you by an identifier code. When processing images, background information is removed and cropped so that the face is not visible. As a result, the results cannot be linked to an individual.

3. Parties and their responsibilities in research collaboration

The University of Oulu is the controller of this study, which determines the purposes and means of the processing of personal data. The Mid Sweden University participates in the development of machine learning solutions.

4. National Coordinator or responsible research group

Name: Marja- Liisa Laitala

Address: Unit of Oral Health Sciences, Faculty of Medicine, P.o. Box 5000, 90014
University of Oulu (Aapistie 3, Kontinkangas)

Telephone: 029 4485 423

E-mail: marja-liisa.laitala@oulu.fi

5. Contact details of the Data Protection Officer

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Contact details of the Data Protection Officer: dpo@oulu.fi.

6. Persons performing the study

The research is carried out by researchers and research assistants of the Unit of Oral Health Sciences of the Faculty of Medicine of the University of Oulu, the Optoelectronics and Measurement Techniques research unit and the Biomimetics and Intelligent Systems Group of the Faculty of Information Technology and Electrical Engineering

Researchers and research assistants from the Sensible Things that Communicate (STC) Research Centre of the University of Central Sweden (Mittuniversitet) are involved in the development of machine learning.

7. Name, nature and duration of the study

Name of the study: Digital Leap in Oral Health – Towards a Virtual Reception

☒ One-time research

☐ Monitoring study

Duration of the study – how long your personal data will be processed for this study: The study is expected to last until the end of 2030, but it may be longer if required by the research-related publishing or doctoral thesis. It is also possible that further research according to the same purpose will be carried out on the basis of the data.

8. Lawful basis of processing

Personal data is processed on the following basis, which is based on Article 6(1) of the General Data Protection Regulation:

☐ Participant's consent

☐ Compliance with a legal obligation to which the data controller is subject

☒ Scientific or historical research, statistics or the exercise of official authority in the public interest

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☐ Legitimate interests pursued by the data controller or by a third party (if so, please specify:)

9. Sensitive personal data

The following sensitive personal data will be processed in the study:

- ☐ Racial or ethnic origin
- ☐ Political opinions
- ☐ Religious or philosophical beliefs
- ☐ Trade union membership
- ☐ Genetic data
- ☐ Biometric data for the purpose of uniquely identifying a natural person
- ☒ Health
- ☐ A natural person's sex life or sexual orientation

Sensitive data is processed on the following basis, which is based on Article 9(2) of the General Data Protection Regulation:

- ☐ Consent of the participant
- ☒ Scientific or historical research purposes or statistical purposes
- ☐ The sensitive data has been made public by the participant
- ☐ Other: Please specify

☐ Personal data relating to criminal convictions or offences will be processed in the study.

10. What personal data does the research data contain

The personal data collected in the study includes the participant's name, personal identity code, telephone number and e-mail address.

The research data includes the collected risk survey data, images of teeth, data from the customer experience survey, findings and conclusions found on the basis of the data, customer satisfaction survey data and dental status data (for example, fillings and extracted teeth, incipient and manifested caries, tooth wear, visible plaque, tartar and gum bleeding by teeth), index data on oral health status (for example, data on the number of teeth and dental surfaces that have cavities, indices describing the amount of plaque,

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the condition of gums and erosive wear) and the data on the need for treatment and examination intervals from the patient register. Of these, dental status data and dental images may in some cases be unique identifying data if combined with other data (from outside the study registry).

11. Sources of personal data

The data is collected from you in the research situation (survey responses and pictures) and from the patient register of the dental service provider (Kuusamo or other municipality or city, Kallio municipal basic services consortium or another dental foundation, group or company offering dental care, such as the Finnish Student Health Service, Mehiläinen, Terveystalo, Plusterveys, Oral Hammaslääkärit, Coronaria or Pihlajalinna) (information describing the oral and dental health).

12. Transfer and disclosure of the personal data to third parties

In the study, the data collected from you will be disclosed to the Finnish Social and Health Data Permit Authority Findata, so that Findata can combine the collected data with the data extracted from the patient registers according to Section 14 of Act on secondary use of health and social data (552/2019) for the use of the research team in a data-secure operating environment. Data transfer to Mid Sweden University for development of machine learning consists only the needed parts of images that have markings of the findings observed from them. The presentation of the results of the study may be accompanied by the publication of all or part of the images collected in order to clarify the study and its results.

13. Transfer or disclosure of personal data to countries outside the European Union/European Economic Area

No transfer or disclosure.

14. Automated decisions

No automated decisions.

The study will create and study a system aimed at automatic risk assessment and the making of treatment recommendations, but they will not affect you in any way, as the

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study that is not directly associated with health care and its data is not communicated to health care.

15. Safeguards to protect personal data

☒. The data is confidential.

Protection of manual material: The paper consent forms are stored in PDF format.

Personal data processed in IT systems:

☒ username ☒ password ☐ logging ☐ access control
☒ other, please specify: encryption

Processing of direct identifiers:

☒ Direct identifiers will be removed in the analysis phase

☐ The material to be analysed includes direct identifiers. Reason: (reason for retention of direct identifiers)

16. Processing of personal data after the completion of the study

☐ The research material will be deleted
☒ The research material will be archived
☒ without identifiers ☐ with identifiers

Where will the material be archived and for how long: University of Oulu, estimated archiving period 10 years.

17. Your rights as a data subject, and exceptions to these rights

In accordance with data protection legislation, the subject has certain rights with which the subject can ensure privacy protection, which is a fundamental right. **If the**

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subject wishes to exercise the right mentioned in this section 17, contact the study contact person mentioned in section 1.

Withdrawing consent (GDPR Article 7)

You have the right to withdraw your consent, provided that the processing of the personal data is based on consent. The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal.

Right of access (GDPR Article 15)

You have the right to obtain information on whether or not personal data concerning you are being processed in the project, as well as the data being processed. You can also request a copy of the personal data undergoing processing.

Right to rectification (GDPR Article 16)

If there are inaccuracies or errors in your personal data undergoing processing, you have the right to request their rectification or supplementation.

Right to request erasure of data or restriction of processing, right to object to the processing request to transfer data from one system to another (Articles 17, 18, 20, 21 GDPR)

You may also request the erasure or restriction of the processing of your personal data used in the study and you may object to the processing or request the transfer of your data from one system to another.

Derogating from rights

The rights listed above in section 17 **Your rights as a data subject, and exceptions to these rights** are not absolute and therefore do not apply in every case, and exceptions to these rights may be made under data protection legislation, for example, where these rights impede or severely impair the achievement of a scientific or historical research or statistical purpose. The need for derogations will always be assessed on a case-by-case basis.

18. Right to lodge a complaint

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You have the right to lodge a complaint with the Data Protection Ombudsman's Office if you think your personal data has been processed in violation of applicable data protection laws.

Contact information:

Data Protection Ombudsman's Office

Address: Lintulahdenkuja 4, 00530 Helsinki

Postal address: PL 800, 00531 Helsinki

Tel (switchboard): 029 56 66700

Fax: 029 56 66735

E-mail: tietosuoja@om.fi