



Information for participants of the research project “Inquiring Expert Opinions on the Problem Gambling Severity Index (PGSI)”

You are taking part in the research project Inquiring Expert Opinions on the Problem Gambling Severity Index (PGSI). 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. For more information on your rights and how you can affect the processing of your personal data, please see the end of this notice.

1. Data Controller

Finnish Institute for Health and Welfare, THL
PL 30 (Mannerheimintie 166)
FI-00271 Helsinki
puh. 029 524 6000

Contact person in matters concerning the project:
Name: Anne Salonen
Address: Mannerheimintie 166, FI-00271 Helsinki
Tel.: +358 29 524 8125
E-mail: anne.salonen@thl.fi

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

The purpose of this study is to inquire about both opinions and the use of the Problem Gambling Severity Index (PGSI) in both epidemiological studies and in clinical use. In addition, ideas and innovations for evaluating gambling-related harms in the future are inquired. The data is collected using a web survey. The target group of the survey consists of international experts working in the field of gambling research and in a clinical setting. The data will be used for research purposes, and the results are reported by the THL.

The participants can select whether they wish to stay anonymous or whether their name and email (personal data) can be used and stored for the future. The personal data of the participants is inquired about at the end of the survey. The participants can also specify the purpose of the use of their personal data, such as whether it can be used for the following: a) for the research group to deliver the summary of the preliminary results; b) for potential invitations for further studies and/or collaboration; and/or c) whether their contact information and responses can be combined in order to identify specific themes for potential future collaboration.

3. Parties and their responsibilities in research collaboration

This study involves no collaboration partners. This study and the daily work of the research group were funded by the Ministry of Social Affairs and Health, Finland, within the objectives of the [§52 Appropriation of the Lotteries Act](#).

4. Principal investigator or research group

In this study, the THL act as the controller, referred to in the General Data Protection Regulation (2016/679), and will be responsible for all of the obligations of the controller as laid out in more detail in the Regulation. All persons involved in collecting and processing the data are bound by a secrecy obligation. Research subjects can submit all requests to exercise the data subject's rights related to this study to the contact person below:

Name: Anne Salonen
Address: Mannerheimintie 166, FI-00271 Helsinki
Tel.: +358 29 524 8125
E-mail: anne.salonen@thl.fi

5. Contact details of the Data Protection Officer

The Data Protection Officer is Jarkko Reittu. You can contact him by sending an e-mail to the address: tietosuoja@thl.fi

6. Persons processing personal data in the study

The research group at the THL has the right to process the data during the course of the study. The research group will be expanded as needed. The personal data will not be transferred or disclosed to recipients outside the research group, and only Anne Salonen and Sari Castrén have access to the personal data.

7. Name, nature and duration of the study

Name of the study: Inquiring Expert Opinions on the Problem Gambling Severity Index (PGSI)

One-time research Monitoring study/longitudinal study

Duration of the processing of personal data:
This study will end in 2023. After the study has ended, the research data will be archived.

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 controller is subject
- performance of a task carried out in the public interest or in the exercise of official authority vested in the controller:
 - scientific or historical research purposes or statistical purposes
 - archiving of research materials or cultural heritage materials
- legitimate interests pursued by the controller or by a third party
description of the legitimate interest:

9. Personal data included in the research materials

The survey data collected do not include any personal data. The only background variables include the country of residence, current work, highest level of education and the duration of work experience.

A separate personal data register is formed of those who are willing to give their contact information (names and email addresses) and who confirmed that their information can be stored and used for invitations for potential further studies and/or collaboration. IP addresses are collected for the purpose of interval validity. The data will be stored at the THL.

10. Sensitive personal data

No sensitive personal data will be processed in the study.

11. Sources of personal data

All personal data are collected from the participants.

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

The survey data and the personal data will be stored apart from each other. A separate consent will be asked in order to use and store the personal data.

13. Transfer of personal data to countries outside the EU/European Economic Area

The data will not be transferred to recipients outside the EU/EEA.

14. Automated decisions

No automated decisions are made.

15. Safeguards to protect the personal data

The data are confidential.

Protection of manual material:

Personal data processed in IT systems:

user name password logging access control
 other: (please specify)

Processing of direct identifiers:

Direct identifiers will be removed in the analysis phase
 The material to be analysed includes direct identifiers. Reason: -

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

The survey data collected do not include any personal data, since direct identifiers will be removed before the analyses, and only a code number is used. A separate personal data register is formed of those participants who give consent in the survey to use and store the personal data. These data include the code number and contact information (name and email), but not the actual survey data. The material be archived at the THL until the end of the year 2031.

17. Your rights as a data subject and deviations from the rights

The contact person in matters concerning the rights of the participant is the person mentioned in section 1 of this notice.

Rights of data subjects

According to the General Data Protection Regulation (GDPR), data subjects have the right

- of access to their data
- to rectification of their data
- to the erasure of their data and to be forgotten
- to restrict the processing of their data
- to data portability
- to object to the processing of their data
- not to be subject to a decision based solely on automated processing.

Not all of these rights can be exercised in all situations, depending on factors such as the basis for the processing of personal data.

For more information on the rights of data subjects in different situations, please see the Data Protection Ombudsman's website: <https://tietosuoja.fi/en/what-rights-do-data-subjects-have-in-different-situations>

Exceptions to data subject rights

Under the General Data Protection Regulation and the Finnish Data Protection Act, certain exceptions to the rights of data subjects can be made when personal data are processed in scientific research, and fulfilling the rights would render impossible or seriously impair the achievement of the objectives of the processing (in this case, scientific research).

The need to make exceptions to the rights of data subjects will always be assessed on a case-by-case basis.

Right to lodge a complaint

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

Contact details:

Data Protection Ombudsman's Office (Tietosuojavaltuutetun toimisto)

Address: Ratapihantie 9, 6th floor, 00520 Helsinki

Postal address: P.O. Box 800, 00521 Helsinki

Tel. (switchboard): 029 56 66700

Fax: 029 56 66735

E-mail: tietosuoja(at)om.fi