

DATA PROTECTION INFORMATION

The processing and the protection of personal data at Semmelweis University (Semmelweis Egyetem in Hungarian) are in compliance with the relevant legislation and safety regulations. Legislation and safety regulations governing data processing and the protection of data are comprised at the website of Semmelweis University: <https://semmelweis.hu/english/data-protection/>

I. Introduction

The TEHDAS Joint Action project develops European principles for the secondary use of health data. TEHDAS is being carried out by 25 European countries and co-ordinated by the Finnish Innovation Fund, Sitra. The project started in February 2021. It is based on the European Commission's Health Programme 2020. Work Package 8 (WP8) of TEHDAS focuses on citizens' participation and data altruism. The National Directorate General for Hospitals (in Hungarian Országos Kórházi Főigazgatóság – OKFŐ) and Semmelweis University are responsible for the deliverable D8.2 "Recommendations on lessons learned and recommendations for data altruism practices in national and European health data spaces". As part of D8.2, OKFŐ and Semmelweis University organise online workshops with national and EU stakeholders, including the WP8 Advisory Group (WPAG8) to discuss and identify new definitions, good practices of data altruism in the EU Health Data Space, with a focus on use cases. Semmelweis University is responsible the technical organisation of the workshops. Semmelweis University (hereinafter referred to as "Data Controller"), abiding by the provisions of the European Union and Hungarian regulations, provides the following information regarding the processing of personal data acquired during online registration for the following events:

Health data altruism and citizens' control TEHDAS WP8 ONLINE WORKSHOPS 17-19 JANUARY 2022

Dates and times:

10:00-12:00 CET, 17 Jan 2022

14:00-16:00 CET, 18 Jan 2022

14:00-16:00 CET, 19 Jan 2022

The provision of your data takes place via a web application on the Internet. The registration form for the events is available at the following website:

REGISZTRÁCIÓS LINK

The confidentiality, the integrity (inviolability), the authenticity and the availability of personal data can be guaranteed at this website as it is available and stated in its FAQ, Support, Privacy statement and Terms of Service.

II. The laws creating the framework of data processing policy

Legislation:

1 "The REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data and repealing Directive 95/46/EC (General Data Protection Regulation, hereinafter referred to as GDPR),

2 Hungarian national legislation: Act CXII of 2011 on the Right of Informational Self-Determination and on Freedom of Information (hereinafter referred to as “Information Act”)

Further legal guidance:

3 The guidelines set by the European Data Protection Board created based on Article 68 of GDPR and the former Article 29 Working Party

4 The recommendations of the Hungarian National Authority for Data Protection and Freedom of Information

III. Guidelines and definitions

The definitions related to the data processing activities of the Data Controller and the guidelines of data processing are to be understood and applied as defined by GDPR.

IV. Name and contact information of the Data Controller

- Name: Semmelweis Egyetem (Semmelweis University)
- Address: 1085 Budapest, Üllői út 26.
- Controller contact: László Bencze, e-mail: bencze.laszlo@emk.semmelweis.hu
- Data protection officer: Dr. Sára Trócsányi, e-mail: adatvedelem@semmelweis-univ.hu

V. Legal basis of data processing

The legal basis of data processing is the consent of the persons concerned. Consenting to data procession is voluntary. Consent is given on the registration page.

The personal data of the registered person are processed on the legal basis of and in line with Art. 6 (1) of the General Data Protection Regulation (GDPR).

The personal data are collected from the data subject on the legal basis of and in line with Art. 13 of the General Data Protection Regulation (GDPR).

VI. Purpose of data processing

Personal data of registering persons are only processed when this is necessary to receive the registration for the events described in Section I. of this Data Processing Information document (hereinafter referred as “events”), and to organise the events, and to communicate with the registered person about the events.

Please be advised that video and audio recordings will be taken for use in TEHDAS reports. Communication and dissemination materials on the TEHDAS website and in other online media such as LinkedIn, Facebook, and twitter may also be based on the video and audio recording but the recordings will not be published.

VII. The types of processed data

Following data are requested during registration at the form for information, contact and aggregated statistical purposes under the legitimate interest of consent:

Mandatory:

1. Registration for the events (3 options /multiple choice) – mandatory
2. First Name - mandatory
3. Last Name - mandatory
4. Email address – mandatory
5. Sector:
 - Scientific Community (Higher Education, Research)
 - Industry
 - Civil Society (Patient, health, professional association/society/other organisation)
 - Policy Makers, Government, Public authority, EU
 - Media
 - Investors
 - Customers (individual patients, professionals, scientists, non-professionals)
 - General Public
 - Other

Non-mandatory:

6. Country
7. Position
8. Organisation
7. Participation in a pre-event online survey regarding the topics of the workshops (YES/NO)
8. Interest in making a pitch (a short presentation) at one of the events, max. 5 minutes (YES/NO)
9. Date and topic of the pitch

Aggregated statistics will not contain personal data. Please be advised that aggregated statistics will be made for use in TEHDAS reports, and communication and dissemination materials on the TEHDAS website and in other online media such as LinkedIn, facebook, and twitter. Recording of pictures, notes, chats and speeches appearing at the online platform used for organising the events are requested during the events in the form of audio and video recordings for the purposes of preparing summaries of the events. The legal basis of audio and video recording is consent. Participants give their agreement to the recording by joining the events.

VIII. Transmission of data

The personal data acquired during registration are not transmitted to third countries or international organisation by the Data Controller, they are only used for the purposes as defined by Section VI. and Section VII. of this Data Processing Information document.

If the registered person wishes to receive the TEHDAS newsletter, the subscription page is available at:

<https://www.sitra.fi/en/projects/joint-action-towards-the-european-health-data-space-tehdas/#newsletter>

If the registered person wishes to receive further information about the activities and results of TEHDAS, and ask to add her/his name, e-mail and organisation to the stakeholder list of TEHDAS, requests can be sent to: csizmadia.istvan@okfo.gov.hu and bencze.laszlo@emk.semmelweis.hu .

IX. The duration of data processing

The duration necessary and reasonable for realising the purposes of data processing is a period of 1 year counted from the data of the last of the events. Consents may be revoked any time, however, revocation of consent will not affect the validity of data processing prior to revocation.

X. Recipients or categories of recipients of the personal data

Your personal data will be transmitted to:

- the employees of OKFŐ and Semmelweis University who are in charge of organising and operating the events,
- speakers of the events,
- participants of the events,
- security and safety administrations,
- service providers for the technical support of registration and provision of the events.

XI. Rights of data subjects

The data subject has the right to request information from the Data Controller regarding his/her personal data processed by the Data Controller and may request to correct, complement, limit the processing and delete the data.

The data subject is aware of the:

- Right to access personal data;
- Right to rectify personal data;
- Right to obtain erasure of personal data.
- Right to object to the processing of her/his data;
- Right to withdraw consent at any time;
- Right to lodge a complaint with a supervisory authority.

You have the right to be informed, the right of access, the right of rectification, the right to erasure and the right to restrict processing of the personal data that we hold about you within the limits of the current data protection legislation. Please contact us via email if you would like a copy of your personal information. You may ask us to correct or remove personal information you think is inaccurate. Please contact us should you wish to exercise any of these rights. We will check the legal requirements for the exercise of this right.

XII. How to raise a complaint

For privacy claims, you may contact the relevant authority:

Name: Nemzeti Adatvédelmi és Információszabadság Hatóság (National Authority for Data Protection and Freedom of Information, Hungary)

Mailing address: 1363 Budapest, Pf. 9

Email address: ugyfelszolgalat@naih.hu

web: <http://naih.hu>