TESSy data protection notice

1. PURPOSE OF THE PROCESSING OPERATION

ECDC processes the personal data collected in accordance with Regulation (EU) 2018/1725. The purpose of the processing is to collect, analyse and disseminate surveillance data on communicable diseases and related special health issues from European Union (EU) Member States, candidate countries for EU membership, the European Economic Area (EEA) countries and other international organizations in the field of public health.

2. IDENTITY OF THE DATA CONTROLLER

The Data Controller is the European Centre for Disease Prevention and Control (ECDC), Gustav III:S Boulevard 40, 16973 Solna, Sweden. The Public Health Function Unit within ECDC is responsible for the processing operation. The Head of Unit is Ms Vicky Lefevre, vicky.lefevre@ecdc.europa.eu

You can contact ECDC to exercise your rights as data subjects under Regulation (EU) 2018/1725 and to request information about the data processing operations.

For most of the processing operations, the Member States and other data submitters act as joint controllers.

ECDC also stores in TESSy pseudonymised personal data from non-EU/EEA countries on behalf of the WHO. For such processing operation, ECDC acts as processor on behalf of the WHO.

3. LEGAL BASIS FOR THE PROCESSING

ECDC processes personal data in TESSy based on the following legal basis:

- Article 5(2) of Regulation (EC) 851/2004 establishing a European centre for disease prevention and control
- Articles 13 and 14 of Regulation (EU) 2022/2371 of the European Parliament and of the Council of 23 November 2022 on serious cross-border threats to health

European Centre for Disease Prevention and Control (ECDC)
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Phone: +46 (0)8 58 60 10 00 - Fax: +46 (0)8 58 60 10 01
www.ecdc.europa.eu

4. CATEGORIES OF PERSONAL DATA COLLECTED

a) Patient data

Surveillance data collected at the European level are predominantly case-based and comprise demographic, clinical, epidemiological and laboratory information. These personal data are collected and submitted under the applicable national personal data protection law by TESSy users. Where unique record identifiers are used to report case-based data, they have undergone pseudonymisation by the data providers (in most cases, the Member States). ECDC is unable to use the information in its possession to re-identify any data subject. The pseudonymised patient related data include data related to health on the subjects and variables included in the metadata files.

b) TESSy user data

Any identification data will be stored in the ECDC's Stakeholder Relationship Manager (SRM) system.

TESSy also collects some technical information from TESSy users. The system uses cookies for authentication, session cookies to ensure communication between the respondent and the server, and cookies containing information about previous searches in Query data. Additionally, the IP address, operating system, browser and its version are collected in the log files for statistical and security purposes.

5. WHO HAS ACCESS TO THE PERSONAL DATA AND TO WHOM IS IT DISCLOSED?

ECDC and nominated Member State surveillance experts are the default users of pseudonymised patient case-based surveillance data.

Data might be made available to other EU institutions, provided that the transfer is compliant with Regulation (EU) 2018/1725..

6. HOW LONG DO WE KEEP YOUR DATA?

a) Patient data

Record IDs as provided by data providers are in principle kept up to 10 years, unless an extension is necessary for public health reasons.

The rest of variables are retained anonymized for an indefinite period of time.

b) TESSy users

Personal data is retained for as long as the respective data subject maintains his/her position granting access to TESSy. Thereafter, the data will be deactivated with a retention period of three years and accessible only to authorised ECDC staff. After three years retention, deactivated data will be deleted automatically in SRM.

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7. HOW DO WE PROTECT AND SAFEGUARD YOUR DATA?

In order to protect your personal data, a number of technical and organisational measures have been put in place. Technical measures include appropriate actions to address online security, risk of data loss, alteration of data or unauthorised access, taking into consideration the risk presented by the processing and the nature of the data being processed. Organisational measures include restricting access to the data to authorised persons with a legitimate need to know for the purposes of this processing operation.

Personal data is pseudonymised. Third parties are required to sign a data sharing agreement.

8. WHAT ARE YOUR RIGHTS AND HOW CAN YOU EXERCISE THEM?

The Controller may be contacted at any time by the data subjects for exercising the right of access, to rectify, to block, to erase, to transmit or to object to the processing of the data, pursuant to Articles 17 to 24 of Regulation (EU) 2018/1725. However, where such data refers to pseudonymised patient data, the data subject will need to contact the data providers (joint controllers), as it would be impossible for ECDC to identify a data subject and therefore to enable the data subject to exercise his/her rights. Where the legal basis to the processing is consent, this consent can be withdrawn at any time.

The rights above are not absolute, and they can also be restricted pursuant to Article 25 of Regulation (EU) 2018/1725.

For those operations where ECDC acts as controller, the controller can be contacted at:

data.access@ecdc.europa.eu

Data subjects can contact the data controller to exercise their rights. The data controller will act within one month from receiving the request.

Data subjects can also contact the ECDC Data Protection Officer (DPO) in case of any difficulties or for any questions relating to the processing of their personal data at the following email address: dpo@ecdc.europa.eu. The data subject has the right of recourse at any time to the European Data Protection Supervisor: www.edps.europa.eu

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