

## Specific Privacy Statement

### The European Surveillance System (TESSy)

This processing operation is subject to Regulation (EC) N° 45/2001 of the European Parliament and of the Council of 18 December 2000 (<https://ecdc.europa.eu/en/legal-notice>) on the protection of individuals with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data<sup>1</sup>. The information in this communication is given pursuant to Articles 11 and 12 of the Regulation (EC) N°45/2001.

#### **What is the purpose of the processing operation?**

The purpose of this processing operation is to collect, analyse and disseminate surveillance data on [56 communicable diseases](#) and related special health issues from all 28 European Union (EU) Member States, candidate countries for EU membership, the European Economic Area (EEA) countries (Iceland, Norway and Liechtenstein) and other international organization in the field of health.

#### **Who is the data controller?**

Vicky Lefevre, Acting Head of the Surveillance and Response Support Unit (SRS).

ECDC - Gustav III:s Boulevard 40 16973 Solna, Sweden

#### **What personal data do we process and through which technical means?**

##### **1. Patient data**

Surveillance data collected at the European level are predominantly case-based and comprise demographic, clinical, epidemiological and laboratory information. They are reported annually (for most diseases and special health issues), quarterly (for salmonellosis and infection with enterohaemorrhagic E. coli), monthly (for measles and rubella), weekly (for influenza and West Nile fever) or daily (for travel-associated Legionnaires' disease), as required for specific objectives, outputs and ensuing public health actions.

These personal data are collected and submitted under the applicable national personal data protection law by TESSy users. All personal identifiers will be removed from the dataset

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<sup>1</sup> OJ L 8, 12 January 2001, p.1

by the TESSy user prior to uploading case-based data into TESSy. Where unique record identifiers are used to report case-based data, they must be anonymised and must not be traceable to individuals by ECDC. ECDC should not be able to use the information in its possession to identify any persons.

The patient related data, which is anonymized in the manner described above, include data related to health on the subjects and variables included in the metadata files.

## **2. TESSy user data**

- a. Any **identification data** will be stored in the ECDC's Customer Relationship Management (CRM) System. For further information on personal data protection, please check the CRM Specific Privacy Statement.
- b. 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. Therefore, your browser must be configured to accept "cookies". Additionally, the IP address, operating system, browser and its version are collected in the log files for statistical purpose.

### **Who has access to the data and to whom is it disclosed?**

ECDC and nominated Member State surveillance experts are the default users of patient case-based EU/EEA surveillance data, but data access may also be granted to third parties upon request. Any member of the public has a right to access to the data, with the exception of data for which one of the exceptions in Article 4, paragraphs 1 to 3 of Regulation 1049/2001, applies.

The principles and terms of the access to TESSy data are stated in the "Policy on data submission, access, and use of data within TESSy" available on the ECDC website.

### **How do we protect and safeguard your information?**

Patient data is kept anonymized towards the TESSy user and all data are stored according to the security measures of the ECDC Information Systems.

### **How to access to your data?**

The person concerned has the right to access, erase, block, update or rectify his/her personal data in the cases foreseen by Articles 13, 14 and 16 of Regulation (EC) N°45/2001 by sending a written request to the TESSy data access team at [data.access@ecdc.europa.eu](mailto:data.access@ecdc.europa.eu).

Because there are no instances in which persons can be uniquely identified from patient data held in TESSy, requests from these data subjects will be referred to the relevant national authority (the data source), who may be able to retrieve the information.

More information on how to access a TESSy user's identification data is available at CRM Specific Privacy Statement. This statement is distributed to all TESSy users together with their TESSy credentials.

### **Recourse**

In the event of conflict, complaints can be addressed to the European Data Protection Supervisor at [edps@edps.eu.int](mailto:edps@edps.eu.int).

#### **What are the legal foundations for processing these data?**

- [ECDC founding regulation](#)
- [Decision No 1082/2013/EU](#)

#### **How long do we keep your data?**

##### **1. Patient data**

- Record IDs as provided by data providers<sup>2</sup> are kept up to 10 years;
- The rest of variables will be retained anonymized for an indefinite period of time. Access will be limited and secure.

##### **2. TESSy user's**

- Identification data – as stated in the CRM Specific Privacy Statement.
- Technical data – according to the retention policy of the ECDC Information Systems.

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<sup>2</sup> These Record IDs do not necessarily correspond to the ones used in the data provider's national surveillance systems.