

ECDC Data Protection Notice

SPF

Data Protection Notice for EpiPulse 03 December 2025, Stockholm

I. Introduction

This data protection notice explains how ECDC processes your personal data in the context of the operation of its surveillance platform, EpiPulse.

II. Who is responsible for processing your personal data?

The European Centre for Disease Prevention and Control (ECDC) is the data controller for processing your personal data. You can find ECDC's contact details <u>here</u>.

III. For which purposes does ECDC process your data? And under which legal basis?

Personal data are processed for the purposes of collecting, analysing and disseminating 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.

The legal bases for processing are the following:

- Articles 5(1) and 10(2)(i) of Regulation (EU) 2018/1725 on the protection of natural persons
 with regard to the processing of personal data by the Union institutions, bodies, offices and
 agencies and on the free movement of such data
- 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

Your personal data will not be subject to automated decision-making.

IV. Which data is ECDC processing in this context?

The **categories of personal data** processed include the following:

a) Data of individuals exposed to or affected by a disease under surveillance

All personal data processed by ECDC are pseudonymised. Surveillance data collected at the European level are predominantly case-based and comprise demographic, clinical, epidemiological and

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laboratory information, as well as information regarding the health of the individual. For description of events, also travel history and information about family might be processed. These personal data are collected and submitted under the applicable national personal data protection law by EpiPulse 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).

b) Data of EpiPulse users

Any identification data are stored in the ECDC's Stakeholder Relationship Manager (SRM) system. A specific data protection notice is provided for SRM.

EpiPulse also collects some technical information from its users. The platform 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.

EpiPulse also processes the data that the users themselves have included in the platform with the purpose of sharing information.

The categories of data subjects include the following:

- Individuals exposed to or affected by a disease under surveillance
- Users of the EpiPulse platform

Processing operations include in particular collection, storage, analysis and transmission.

Data is collected from you as a data subject.

V. Who has access to your personal data?

Recipients of the data are:

- ECDC staff working on surveillance
- Nominated national experts in the EU/EEA Member States
- Nominated experts from non-EU/EEA countries, but only to the data that they have themselves reported
- In certain circumstances, WHO where it is necessary to avoid double reporting by the EU/EEA Member States

Your personal data might also be processed by the service providers that provide the technical solutions used by ECDC to store and use the data for the purpose of the organization of the meeting and the recording of it provided that appropriate technical measures are in place to safeguard the confidentiality, integrity, and availability of data.

VI. How long will ECDC process your personal data?

National record identifiers are deleted after 10 years.

Data of nominated users that are necessary to access the platform are kept for three years after the expiration of the nomination.

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VII. What are your rights as data subject?

As the individual to whom the personal data relate, you can exercise the following rights:

- access to your personal data under Article 17 of Regulation (EU) 2018/1725;
- rectify your personal data under Article 18 of Regulation (EU) 2018/1725;
- erase your personal data under Article 19 of Regulation (EU) 2018/1725;
- restrict the processing concerning yourself under Article 20 of Regulation (EU) 2018/1725;
 or
- exercise the right to data portability under Article 22 of Regulation (EU) 2018/1725.
- withdraw the consent at any time to process your personal data, for those processing operations whose legal basis has been identified as your consent

These rights are not absolute rights, which means that some exceptions may apply.

Please note that, in certain cases, as provided in Article 25 of Regulation (EU) 2018/1725, restrictions of data subjects' rights may apply. These restrictions are applied on a case-by-case basis.

Please also note that all data processed by ECDC has been pseudonymised before transmission to ECDC. It means that ECDC will not be able to identify you as data subject in case you wish to exercise your rights. We will however liaise with the data providers and make our best effort to ensure that you are able to exercise your rights.

VIII. Who can you contact in case of questions or to complain about the processing of your personal data?

In case of questions related to the processing of your personal data, you can contact the data controller at surveillance@ecdc.europa.eu

You can also contact the Data Protection Officer of ECDC at dpo@ecdc.europa.eu

Should you wish to lodge a complaint, you may do so at the European Data Protection Supervisor (EDPS) at edps@edps.europa.eu

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