

ECDC Data Protection Notice

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Analysis of pathogen genome data 06 March 2025, Stockholm

I. Introduction

This data protection notice explains how ECDC processes your personal data from the GISAID EpiCov and EpiFlu databases as well as the COVID-19 data portal for the purpose of detecting new pathogen variants and for following world-wide trends for known variants for epidemiological surveillance purposes.

II. Who is responsible for processing your personal data?

ECDC is the data controller for processing your personal data. You can find ECDC's contact details here.

The delegated controller is the Head of Public Health Functions Unit. You can contact the delegated controller <u>here</u>.

You can contact the Data Protection Officer of ECDC by writing to this address.

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

ECDC accesses and processes data from the GISAID EpiCov and EpiFlu databases and the COVID-19 data portal for the purpose of epidemiological surveillance – to detect new pathogen variants and follow global trends in known variants. This includes the processing of pseudonymised personal data.

The legal basis for processing are Art 5(1)(a) of Regulation 2018/1725 in combination with Art 3(2)(a) and Art 11(1a)(d) of Regulation 851/2004.

IV. Which data is ECDC processing in this context, and how?

Categories of data processed include:

- Gender
- Country of Residence
- Sample collection date, Patient age
- Patient data: pseudonymized identification number
- Pathogen genome sequence associated with case identifier

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Processing operations include collecting, storing, analysing personal data.

The sources from which your personal data originate are GISAID EpiCoV, GISAID EpiFlu, and the COVID-19 data portal.

V. Who has access to your personal data?

Your data comes from public sources. At ECDC, your data are processed by staff in the Macrobiology and Molecular Surveillance section.

VI. How long will ECDC process your personal data?

Data are kept for no longer than 90 days.

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

ECDC will respond to your requests to exercise your rights within one month from receiving the request.

Please note that these rights are not absolute rights, which means that some exceptions may apply.

Please also 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.

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 here

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)

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