



EUROPEAN COMMISSION

PROTECTION OF YOUR PERSONAL DATA

This privacy statement provides information about the processing and the protections of your personal data

Processing operation: European Reference Networks (ERNs) Communication and Collaborative Platform (ECP)

Data Controller: European Commission, Directorate-General Health and Food Safety, Directorate B/ B3 Unit

Record reference: DPR-EC-00179

Table of Contents

1. Introduction
2. Why and how do we process your personal data?
3. On what legal ground(s) do we process your personal data?
4. Which personal data do we collect and further process?
5. How long do we keep your personal data?
6. How do we protect and safeguard your personal data?
7. Who has access to your personal data and to whom is it disclosed?
8. What are your rights and how can you exercise them?
9. Contact information
9. Where to find more detailed information?

1. Introduction

The European Commission (hereafter 'the Commission') is committed to protect your personal data and to respect your privacy. The Commission collects and further processes personal data pursuant to [Regulation \(EU\) 2018/1725](#) of the European Parliament and of the Council of 23 October 2018 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.

This privacy statement explains the reasons for the processing of your personal data, the way we collect, handle and ensure protection of all personal data provided, how that information is used and what rights you have in relation to your personal data in the context of **European Reference Networks (ERNs) Communication and Collaborative Platform (ECP)**. It also specifies the contact details of the responsible Data Controller with whom you may exercise your rights, of the Data Protection Officer and of the European Data Protection Supervisor.

2. Why and how do we process your personal data?

Purpose of the processing operations:

The Data Controller collects and uses your personal data in order to facilitate the communication between the members of the ERNs. The European Reference Networks Collaborative Platform (ECP) is an information system provided by the European Commission to European Reference Networks to support the ERNs collaboration activities, in particular in their on-line communication, document management, event organization as well as access to ERNs meetings recordings. The access to ECP requires the register via the European Union Authentication Service "EU Login". In a self-registration process, users are requested to create a user account using the EU-Login for the European institutions. The user account is then authorised by using e-service tool, the SAAS2 authorisation service, which is under the responsibility of the Commission's Directorate General for Health and Food Safety.

Your personal data will not be used for an automated decision-making including profiling.

3. On what legal ground(s) do we process your personal data

We process your personal data, because processing is necessary for the performance of a task carried out in the public interest (Article 5(1)(a) of Regulation (EU) 2018/1725). The Union act is the CrossBorder Healthcare 2011/24/EU which gives the Commission the mandate to support the ERNs' establishment, functioning and evaluation through the adoption of implementing measures. For these purposes the Implementing Decision (EU) 2014/287/EU provides criteria for establishing and evaluating European Reference Networks and their Members and for facilitating the exchange of information and expertise on exchanging and evaluating those Networks, whilst the Commission's Delegated Decision 2014/286/EU provides a list of specific conditions and criteria that must be fulfilled by European Reference Networks and healthcare providers wishing to join and become a Member of the Network¹.

¹ All legal acts regarding the ERNs are available here:
https://health.ec.europa.eu/european-referencenetworks/overview_en

4. Which personal data do we collect and further process?

ECP Processing operation:

The user account is authorised by using e-service tool, the SAAS2 authorisation service, which is under the responsibility of the Commission's Directorate General for Health and Food Safety. Only the following personal data relating to the user profile are collected in EU Login/SAAS via the ECP to authorise users and grant them access according to the authorisations:

- Identification data: EU Login, first name, last name
- Professional data: organization details (Health Care Provider Name), professional e-mail address, country, work telephone/fax, application/motivation letter and resume (in case of election procedures for the Chair of the ERNs Board of the MS)
- Contact data: personal email, personal phone number, M365 Teams Profile or social media accounts (Facebook profile, Twitter profile (X), LinkedIn profile, Google+)
- Other data: preferred language, picture

Personnel employed by the Commission, who are indicated as the responsible person for technical support to ECP users are included in the database amongst the users above; however, personal contact details are not disclosed to the ERN users. Instead, a functional mailbox is used for facilitating contact between users and users managing the support of the system. Personal data of data subject to the ERNs may be also cited in the documentation exchanged. In this case the following categories of data may be cited: first name, surname, professional email address, organisation details.

5. How long do we keep your personal data?

Contact data (EU Login username, first and last names, organisation details, professional email address), included in the documentation exchanged in the ECP as well as contributions to ECP (posts, documents) of the users and responsible persons of the ECP are kept in the system for as long as is necessary and the members retain their capacity as representatives of their healthcare providers in the ERNs and for five years after the end of this capacity. The personal data can be modified or deleted by the users directly in EU LOGIN2 and SAAS3. Instead, in the ECP, contact details and contributions made can be modified or deleted upon request by the user to the technical support staff at SANTE-ERN-ECP-ITSUPPORT@ec.europa.eu, via an email explicitly specifying his/her requests, and insofar as the relevant grounds in EDPR can apply. The user can also contact the technical support if there is any objection to the processing of his/her personal data.

The EU Login username and his/her contributions to ECP (posts and documents) will be kept in the system for five (5) years for scientific purposes and to ensure business continuity.

Video recordings are kept for three years after the recording.

6. How do we protect and safeguard your personal data?

All personal data in electronic format (e-mails, documents, databases, etc.) are stored on the servers of the European Commission. All processing operations are carried out pursuant to the [Commission Decision \(EU, Euratom\) 2017/46](#) of 10 January 2017 on the security of communication and information systems in the European Commission². In order to protect your personal data, the Commission has put in place a number of technical and organisational measures. Technical measures include appropriate actions to address online security, risk of data loss, alteration of

² Personal data recorded through EU Login are retained for the duration foreseen by the system. In particular, the Identity&Access Management Service keeps the data for as long as the person is recorded as an active user and for a period of one year thereafter.

data or unauthorised access, taking into consideration the risk presented by the processing and the nature of the personal data being processed. Organisational measures include restricting access to the personal data solely to authorised persons with a legitimate need to know for the purposes of this processing operation. In addition, access to the ECP is controlled by two access layers, one for authentication to the system at EC level and the second as an authorisation layer at the application level. These are the EU Login for authentication to use European Commission applications and SAAS³ to provide authorisation to the ECP users. Both applications are hosted, and the data is stored, at the European Commission Data Centre⁴ with specific security protection measures (detailed in the DPO notification) and can be interrogated for necessary purposes pertaining to the operation of the system by the Commission and the Member States.

7. Who has access to your personal data and to whom is it disclosed?

Access to your personal data is provided to the Commission staff responsible for carrying out the processing operations and to other authorised Commission staff according to the “need to know” principle. Such staff abide by statutory, and when required, additional confidentiality agreements. In addition, the rest of the ENRs members can be considered as recipients of your personal data mentioned above in the context of your duties.

Please note that pursuant to Article 3(13) of Regulation (EU) 2018/1725, public authorities (e.g. Court of Auditors, EU Court of Justice, European Ombudsman) which may receive personal data in the framework of a particular inquiry in accordance with Union or Member State law shall not be regarded as recipients. The further processing of those data by those public authorities shall be in compliance with the applicable data protection rules according to the purposes of the processing. In addition, the information we collect will not be given to any third party, except to the extent and for the purpose we may be required to do so by law.

8. What are your rights and how can you exercise them?

You have specific rights as a ‘data subject’ under Chapter III (Articles 14-25) and Article 35 of Regulation (EU) 2018/1725, in particular the right to access your personal data and to rectify them in case your personal data is inaccurate or incomplete. Under certain conditions, you have the right to erase your personal data, to restrict the processing of your personal data, to object to the processing and the right to data portability.

You have the right to object to the processing of your personal data on grounds relating to your particular situation in accordance with Article 23(1) of Regulation (EU) 2018/1725.

You can exercise your rights by contacting the Data Controller or, in case of conflict, the Data Protection Officer. If necessary, you can also address the European Data Protection Supervisor. Their contact information is given under Heading 9 below.

Where you wish to exercise your rights in the context of one or several specific processing operations, please provide their description (i.e. their Record reference(s) as specified under Heading 10 below) in your request.

³ Personal data recorded though SAAS are retained for the duration foreseen by the system for the purposes of operating, administering and monitoring legitimate usage of the system.

⁴ The operation of which underlie the Commission's security decisions and provisions established by the Directorate of Security for the infrastructure, services and operations under the Commission Decision (EU, Euratom) 2017/46 of 10 January 2017, <http://eurlex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32017D0046&from=EN>.

9. Contact information

- The Data Controller

If you would like to exercise your rights under Regulation (EU) 2018/1725, or if you have comments, questions or concerns, or if you would like to submit a complaint regarding the collection and use of your personal data, please feel free to contact the Data Controller, the European Commission, Directorate-General for Health and Food Safety, Unit B3, at SANTE-ERN@ec.europa.eu.

- The Data Protection Officer (DPO) of the Commission

You may contact the Data Protection Officer (DATA-PROTECTION-OFFICER@ec.europa.eu) with regard to issues related to the processing of your personal data under Regulation (EU) 2018/1725.

- The European Data Protection Supervisor (EDPS)

You have the right to have recourse (i.e. you can lodge a complaint) to the European Data Protection Supervisor (edps@edps.europa.eu) if you consider that your rights under Regulation (EU) 2018/1725 have been infringed as a result of the processing of your personal data by the Data Controller.

10. Where to find more detailed information?

The Commission Data Protection Officer (DPO) publishes the register of all processing operations on personal data by the Commission, which have been documented and notified to him. You may access the register via the following link: <http://ec.europa.eu/dpo-register>.

These specific processing operations will be included in the DPO's public register with the following Record references: [DPR-EC-00179](#).