



LIVE
STREAM

CONFERENCE

Rare Diseases in the EU: Joint Action shaping the future of ERNs - JARDIN kick-off meeting

8 MARCH 2024
BRUSSELS, EESC, RUE BELLIARD 99, ROOM JDE62



Data Protection Notice

1. Who is responsible for the processing of your personal data?

The above event is organised by the European Economic and Social Committee (EESC), which is the data controller in charge of the processing of your personal data. The service responsible for processing your personal data on behalf of the controller is the Section for Transport, Energy, Infrastructure and Information Society's Secretariat (TEN), ten@eesc.europa.eu.

2. What is the purpose of the processing?

Your personal data will be processed in order to:

- register you for the above event
- provide access to the venue
- fulfil the communication objectives of the above event (with your consent only)
- share your name with the other participants (with your consent only)
- send you invitations to future events the EESC may organise (with your consent only).

The EESC is not responsible for recordings (such as photographs or videos) made by participants in a private capacity.

3. What is the legal basis for the processing?

[Regulation \(EU\) 2018/1725](#) applies to the processing of your personal data collected for the organisation and management of the above event. The legal basis for the processing of your personal data is Article 5(1)(a) of [Regulation \(EU\) 2018/1725](#), as the processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in a Union institution or body.

The processing of certain categories of your personal data as described in this privacy statement will be carried out based on your consent (Article 5(1)(d) of [Regulation \(EU\) 2018/1725](#)).

4. What personal data are processed?

The following personal data will be processed:

- information necessary for your registration: first name, last name, e-mail, phone number, job title, name of organisation, ID / passport number, nationality / citizenship stated in your ID

Your consent is required for:

- photos, audio and video recordings and web streaming related to the above event
- attendee list containing your name and affiliation, which will be shared among participants
- invitations to future events the EESC may organise

You can provide your consent via the registration form.

In addition to our contacts database, we have used publicly available sources in order to identify persons who might be interested in the event. If your contact is not in the EESC database, you are receiving this email because we believe that you might be interested to attend this event. Your personal data will be kept in the EESC database in order to send you future invitations to events organised by the EESC only if you agree. If you do not reply to this email or if you do not agree to have your contacts in the EESC database, your personal data will be deleted from the database.

If you have expressed the wish not to appear in pictures and/or videos, we would therefore ask you to get a "NO PHOTO" badge at the venue reception on the day of the event and to wear that badge during the whole duration of the event.

Please remember that without the NO PHOTO badge, the photographer will not be aware of your wish not to have your photos taken and/or not to appear in videos and therefore your image might appear in the above event pictures and/or videos.

5. Who are the recipients or categories of recipients of your personal data?

The recipients of your data will be the EESC staff in charge of the organisation, management and follow-up of this event.

Under certain conditions defined in law, we may disclose your information to third parties (such as the European Anti-Fraud Office, the Court of Auditors or law enforcement authorities) if it is necessary and proportionate for lawful, specific purposes

We will never share your personal data for direct marketing purposes.

Photographs and/or audio and video recordings could be published in the context of the above event and in the framework of EESC activities on the web, including via social media. If need be, the files containing the video materials may be slightly altered (for example, brightness and contrast) so that they can be used for the purposes for which they were taken.

We use social media to provide information about and promote the above event through widely-used channels: Facebook, X, LinkedIn, Instagram and YouTube. The use of social media does not in any way imply endorsement of their privacy policies. In the event that one or more social media are unavailable, we accept no responsibility for lack of service due to their downtime. We recommend that users read the [Facebook](#), [X](#), [LinkedIn](#), [Instagram](#) and [YouTube](#) privacy policies. Each company explains its policy of data collection and processing, its use of data, user rights and the ways in which users can protect their privacy when using these services.

6. Are your personal data transferred to a third country (non-EU Member State) or international organisation?

Your personal data will not be transferred to a non-EU member state and/or international organisation.

7. How can you exercise your rights?

You have the right to request access to your personal data. You also have the right to request rectification or erasure of your personal data or restriction of the processing of your personal data.

You also have the right to withdraw your consent at any time. Please note that withdrawal of consent will not have retroactive effect (processing of your personal data based on your consent before withdrawal is lawful up to the moment when you withdraw your consent).

Where applicable, you have the right to object to the processing of your data. Where applicable, you have the right to receive your personal data provided to the controller or to have your personal data transmitted directly to another controller (data portability).

You can direct your queries to ten@eesc.europa.eu. Your query will be dealt without undue delay and in any event within 15 working days of receipt of the request. That period may be extended by one further month where necessary.

You have the right to lodge a complaint with 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.

8. How long are your personal data kept for?

Your data (excluding photos, audio and video recordings that have been published and personal data provided for accreditation purposes) will be kept for a maximum period of 12 months after the end of

the event, unless you explicitly agree to your contact details being kept in order to receive invitations to future similar events organised by the EESC.

If you wish to delete these data at any time after you have given your consent, please contact us at ten@eesc.europa.eu and we will do so within 15 working days upon receipt of your request or after the latest correspondence with you about your request.

In accordance with Article 75 of Regulation (EU, Euratom) 2018/1046 of the European Parliament and of the Council of 18 July 2018 on the financial rules applicable to the general budget of the Union, financial data is kept for at least five years from the date on which the European Parliament gives discharge for the financial year to which the documents relate.

Your ID card or passport number provided for accreditation purposes will be kept for 12 months. For more details on how your personal data are processed for accreditation purposes, you can consult the accreditation privacy statement available on the [EESC data protection internet page](#).

Your photos, audio and video recordings that have been published (for example on the web or in publications) will remain in that format indefinitely.

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9. Are personal data collected used for automated decision-making, including profiling?

The EESC will not use your personal data to make automated decisions about you. "Automated decisions" are defined as decisions made without human intervention.

10. Will your personal data be further processed for a purpose other than that for which the data were obtained?

Your personal data will not be further processed for a different purpose than the ones mentioned above.

11. Who can you contact if you have queries or complaints?

If you have any further questions about the processing of your personal data, please contact the unit in charge of the processing of your personal data: ten@eesc.europa.eu .

You may also contact the Data Protection Officer of the EESC (data.protection@eesc.europa.eu) and/or the European Data Protection Supervisor (edps@edps.europa.eu) at any time.
