

Fundamental rights protection of persons with disabilities living in institutions

The European Union Agency for Fundamental Rights (FRA or Agency) processes the personal data of a natural person in compliance with Regulation 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, and repealing Regulation (EC) No 45/2001 and Decision No 1247/2002/EC.

This data protection notice explains FRA's policies and practices regarding its collection and use of your personal data, and sets forth your privacy rights. We recognise that information privacy is an ongoing responsibility, and we will update this notice where necessary.

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1. Why do we process personal data?

The purpose of the processing of the personal data is to collect information and data for the purpose of a research project titled “*Fundamental rights protection of persons with disabilities living in institutions*”.

The research responds to a request contained in the [EU Strategy for the Rights of Persons with Disabilities 2021-2030](#), calling on FRA to examine the situation of persons with disabilities living in institutions regarding violence, abuse, and torture. The project builds upon FRA’s previous work on [victims’ rights](#) and on the [rights of persons with disabilities](#) and contributes to the Agency’s activities as member of the [EU Framework for monitoring the UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#).

This project consists of desk research (Service Request 23) and fieldwork research (Service Request 24) in the form of interviews with [experts](#) and [key stakeholders](#), as well as with [persons with disabilities](#), in Croatia, Germany, Ireland, Italy, Latvia, Malta, Poland, Portugal, Slovenia and Slovakia carried out by [FRANET¹ contractors](#) across the aforementioned 10 Member States. The information from the interviews will feed into the preparation of a report to be published in 2025.

The objective of the expert interviews and the narrative in-depth interviews with people with disabilities is to complement the data gathered through the national desk research (SR 23) and provide FRA with primary country specific data on fundamental rights implications, gaps, challenges and promising practices in the implementation of policies, programmes and related measures for the protection from and response to instances of violence and abuse of persons with disabilities in institutions.

In order to carry out the interviews, and collect information on national responses for the protection of and the response to violence in institutions of persons with disabilities, the contact details of experts, key stakeholders and persons with disabilities will be collected.

2. What kind of personal data does the Agency process?

We will collect only the following personal data necessary for the processing operation described above.

(a) General personal data:

- Personal details (name, surname, sex).
- Contact details (email address, phone number).
- Family, lifestyle and social circumstances, which might be revealed during the interview.

¹ FRANET contractors covering all EU Member States have been selected by FRA following a public procurement procedure to provide data collection and research services on fundamental rights issues.

- Other:
 - If the interviews with the relevant persons take place online, IP addresses, cookies, metadata or information about participants' devices might be collected by the online tools used to carry out the interview.
 - As the interviews will be video and/or audio recorded (upon consent) for accuracy and note-taking purposes, voice and/or image of the participant will be processed.

(b) Special categories of personal data:

- Since the purpose of the interviews is to examine the situation of people with disabilities living in institutions, genetic and/or biometric data, or data concerning health might be revealed during the interviews.
- Information regarding and individual's sex life or sexual orientation as well as racial or ethnic origin, political opinions and/or religious or philosophical beliefs might also be revealed during the interviews.
- Should the interviews and meetings with the relevant persons take place online, racial or ethnic origin, political opinions and/or religious or philosophical beliefs might be incidentally revealed by the image when participants switch on their cameras, which might also be recorded.

3. How do we collect and process your personal data?

FRANET contractors will use information gathered through the desk research component of the project (SR 23) to identify persons to be interviewed.

3a. Information you provide us:

We collect your personal data mentioned above directly from you through the consent form that will be provided to you before the interview, and during the interview, which will be conducted by FRA's ten FRANET contractors through digital channels (e.g. video call) or face-to-face, in the countries covered by the research (see Section 1 above). For accuracy and note taking purposes, interviews will be audio- and/or video-recorded upon your consent. Interviewees will enjoy anonymity and FRA will not include any names in the final report. All recordings will be destroyed as indicated in section 10 below. Moreover, at any point during the interview, interviewees can indicate that they do not wish to be recorded.

3b. Information we collect about you:

Your IP address, connection details, cookies, and/or device information might be collected if the interviews take place online, as indicated in Section 2 above. In this context, FRANET contractors are requested to inform interviewees before the interview takes place about which online conferencing tool they will use for the interview and to provide a link to the tool's website where the tool's data protection policy can be found. IT servers used by FRANET contractors to collect and process the data are located within the EU.

3c. Information we receive from other sources:

FRANET contractors may undertake research and find the contact details of the persons to be interviewed via FRA, lawyers, prosecutors, social services and institutional facilities, civil society and victim support organisations, organisations of and for persons with disabilities, national human rights bodies or other organisations and authorities of the respective EU Member State.

4. Who is responsible for processing your personal data?

The Agency is the legal entity responsible for the processing of your personal data and determines the objective of this processing activity. The Head of the Equality, Roma and Social Rights Unit is responsible for this processing operation.

The ten [FRANET contractors](#) will act as FRA's data processors and will collect the data on behalf of FRA as specified under section 3 above.

5. Which is the legal basis for this processing operation?

The processing operation is necessary to achieve the Agency's goal, as stated in Article 2 of its founding Regulation (EC) No 168/2007, amended by Council Regulation (EU) 2022/555 (FRA's founding regulation), to provide its stakeholders, including Union institutions and EU Member States, with assistance and expertise relating to fundamental rights, including its tasks described in Article 4 (1)(a), (c) and (d).

Therefore, the processing is lawful under Article 5.1.(a) of the Regulation (EU) No 2018/1725.

In addition, by means of the relevant consent form, and always after an explanation of the project's objective and purpose, its methodology, the data items to be collected and the rights the data subjects are entitled to, the participants will be requested by FRANET contractors to provide their explicit consent to the processing of their personal data, and therefore to participate in the interviews before they take place. Moreover, interviewees will be requested to provide consent to the audio and/or video recording of the interviews, for accuracy and note-taking purposes.

Therefore, the processing of the personal data is also in accordance with Article 5.1.(d) of Regulation (EU) No 2018/1725.

Moreover, the processing of special categories of personal data as indicated in Section 2 above is lawful under Article 10.2.(a) of Regulation 2018/1725, as specific consent has been given by the data subjects and it is stored.

6. Who can see your data?

Your data can be accessed by the designated staff of the FRANET contractors carrying out the interviews. Furthermore, the data can be accessed by staff members of FRA's Equality, Roma and Social Rights Unit and FRA staff working on that project. Access is restricted to authorized staff members and only these members have access rights to open the files.

FRANET contractors are bound by specific contractual clauses for any processing operations on behalf of FRA, and by the confidentiality obligations deriving from Regulation (EU) 2018/1725).

7. Do we share your data with other organisations?

Personal data is processed by the Agency only. In case that we need to share your data with third parties, you will be notified to whom your personal data has been shared with.

8. Do we intend to transfer your personal data to Third Countries/International Organizations?

No

9. When will we start the processing operation?

We will start the processing operation in April 2024.

10. How long do we keep your data?

The personal data referred to in section 2 above, as well as the consent forms, will be kept for 24 months after the final date of implementation of the project as indicated in the respective FRANET contracts. All data held by FRA and contractors will then be deleted. Anonymised research material, e.g. reporting templates, will be kept indefinitely.

11. How can you control your data?

Under Regulation 2018/1725, you have rights we need to make you aware of. The rights available to you depend on our reason for processing your information. You are not required to pay any charges for exercising your rights except in cases where the requests are manifestly unfounded or excessive, in particular because of their repetitive character.

We will reply to your request without undue delay and in any event within one month of receipt of the request. That period may be extended by two further months where necessary, taking into account the complexity and number of the requests.

You can exercise your rights described below by sending an email request to: ARNDSector@fra.europa.eu.

11.1. The value of your consent

Since your participation in the interviews is not mandatory, you will be required to confirm that you are willing to start the interview before it takes place, and therefore that you consent to the processing of your personal data and to the audio and/or video recording of the interview. Consent will be collected via a separate consent form. You have the right to withdraw your consent at any time, and we will delete your data or restrict its processing. All processing operations up until the withdrawal of consent will still be lawful.

11.2. Your data protection rights

a. Can you access your data?

You have the right to receive information on whether we process your personal data or not, the purposes of the processing, the categories of personal data concerned, any recipients to whom the personal data have been disclosed and their storage period. Furthermore, you can have access to such data, as well as obtain copies of your data undergoing processing.

b. Can you modify your data?

You have the right to ask us to rectify your data you think is inaccurate or incomplete at any time.

c. Can you restrict us from processing your data?

You have the right to restrict the processing of your personal data. If you do, we can no longer process them, but we can still store them. In some exceptional cases, we will still be able to use them (e.g. with your consent or for legal claims). You have this right in a few different situations: when you contest the accuracy of your personal data, when the Agency no longer needs the data for completing its tasks, when the processing activity is unlawful, and finally, when you have exercised your right to object.

d. Can you delete your data?

You have the right to ask us to delete your data when the personal data are no longer necessary for the purposes for which they were collected, when you have withdrawn your consent or when the processing activity is unlawful. In certain occasions we will have to erase your data in order to comply with a legal obligation to which we are subject.

We will notify to each recipient to whom your personal data have been disclosed of any rectification or erasure of personal data or restriction of processing carried out in accordance with the above rights unless this proves impossible or involves disproportionate effort from our side.

e. Are you entitled to data portability?

Data portability is a right guaranteed under Regulation 1725/2018 and consists in the right to have your personal data transmitted to you or directly to another controller of your choice.

In this case, this does not apply for two reasons: I) in order for this right to be guaranteed, the processing should be based on automated means, however we do not base our processing on any automated means; II) this processing operation is carried out in the public interest, which is an exception to the right to data portability in the Regulation.

f. Do you have the right to object?

When the legal base of 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 the Union institution or body*” which is the case in most of our processing operations, you have the right to object to the processing. In case you object, we have to stop the processing of your personal data, unless we demonstrate a compelling reason that can override your objection.

g. Do we do automated decision making, including profiling?

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

12. What security measures are taken to safeguard your personal data?

The Agency, as well as the ten FRANET contractors acting on its behalf as processors within this processing operation, have several security controls in place to protect your personal data from unauthorised access, use or disclosure. We keep your data stored on our internal servers with limited access to a specified audience only.

13. What can you do in the event of a problem?

- a) The first step is to notify the Agency by sending an email to ARNDSector@fra.europa.eu and ask us to take action.
- b) The second step, if you obtain no reply from us or if you are not satisfied with it, contact our Data Protection Officer (DPO) at dpo@fra.europa.eu.
- c) At any time you can lodge a complaint with the EDPS at <http://www.edps.europa.eu>, who will examine your request and adopt the necessary measures.

14. How do we update our data protection notice?

We keep our data protection notice under regular review to make sure it is up to date and accurate.

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