

Online survey of ENVR experts for FRA's project on the '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 from European Network on Victims' Rights (ENVR) experts to complement the research carried out under the 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 \(CRPD\)](#).

For the project, two different research methods and processes are taking place:

(a) The core data collection process is carried out by FRA's research network FRANET through desk research in the 27 EU Member States and in North Macedonia, Serbia, Albania, and fieldwork research in 10 EU Member States. For this first component of the research, and especially for protection of personal data collected and processed through interviews, kindly refer to the relevant [Data Protection Notice](#).

(b) Separate research, covered by this data protection notice, will take place in parallel and complementary to the FRANET research, with a specific focus on access to protection and support for victims of violence and abuse who are persons with disabilities living in institutionalised settings. This research component is carried out in cooperation with the [European Network on Victims' Rights \(ENVR\)](#), established in 2016 by Council conclusions (Amsterdam Conclusions, 9997/16) and operating under the aegis of the Justice Programme of the European Union.

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).
- Other:
 - IP addresses, cookies, metadata, or information about respondents' devices might be collected by the online tool used to carry out the survey. Please, refer to Section 3 below.

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

ENVR will launch, on behalf of FRA, an anonymous online questionnaire (survey), prepared in cooperation with FRA, that will be disseminated to its members (generic network) before the Spring Expert Meeting to be held in May 2024. All responses to the questionnaire will be collected and processed only by ENVR. A consolidated file with the collected expert's input will be shared with FRA in an aggregated and anonymised format to further analyse and use for (i) preparing a dedicated workshop focusing on the protection of

fundamental rights of persons with disabilities living in institutions at the ENVR Spring Expert Meeting, and (ii) providing complementary data to be used for FRA's comparative report on the protection of fundamental rights of persons with disabilities living in institutions, as final output of [FRA's project on the matter](#).

FRA will not collect, save, process, or have access to any personal data of the respondents to the questionnaire. The consolidated file transmitted to and shared with FRA will not contain any personal data of the respondents of the questionnaire or other technical information (email addresses or IP addresses) that could be traced back to the respondents.

In order to disseminate the survey, for identifying the potential respondents ENVR has collected and processed the personal data indicated in Section 2 above from its generic network of members who had registered and designated as members of the network and who have agreed to be contacted for and to participate in ENVR's research activities.

Your IP address, connection details, cookies, and other metadata might be collected when connecting to the online tool used to conduct the survey ([SurveyMonkey](#)). Please, note that advertising cookies will never be used on survey-taking pages (unless the respondent has already visited the webpage and accepted the use of such cookies), and that the IP addresses and other metadata collected from respondents' devices are processed only for functional purposes and to make sure that the same person does not complete the survey twice.

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.

To carry out the processing operation, ENVR will collect and process 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 box to be ticked by the respondents at the beginning of the survey, and always after an explanation of the project's objective and purpose, the respondents will be requested by the online tool used to conduct the survey to provide their explicit consent for the processing of their personal data as indicated in this data protection notice and therefore to participate in the questionnaire before starting to fill it online.

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

6. Who can see your data?

Your data can only be accessed by designated ENVR staff responsible for conducting the survey. The same staff also have access to ENVR's account for the SurveyMonkey online tool, and therefore to the responses provided by the respondents.

The Agency will only have access to aggregated and anonymised data resulting from the survey responses, which will be provided by ENVR to FRA after the survey has been carried out, as indicated in Section 3 above.

7. Do we share your data with other organisations?

Personal data is processed by ENRV (on behalf of 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.

However, the online tool used to carry out the survey, SurveyMonkey, is a US based company that is subject to US surveillance laws. Therefore, international transfers of limited personal data (refer to Section 3 above) cannot be completely discarded. Such transfers, if any, fall under the adequacy decision for the [EU-US Data Privacy Framework](#) adopted by the European Commission on 10 July 2023.

9. When will we start the processing operation?

The processing operation will start in March 2024.

10. How long do we keep your data?

The aggregated and anonymised datasets resulting from the survey responses will be kept by the Agency and ENVR indefinitely.

The IP addresses, connection details, and other metadata collected from respondents' devices for functional purposes as specified in Section 3 above will be deleted once the surveys have been completed.

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 questionnaire is not mandatory, you will be required to confirm that you are willing to start filling in the questionnaire, and therefore that you consent to the processing of your personal data as explained above. Consent will be collected by the online tool. You have the right to withdraw your consent at any time, and we will restrict processing of your data. 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 ENVR acting on its behalf 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, located in the EU, with limited access to a specified audience only. You can also access the ENVR privacy policy [here](#).

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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