

## Privacy Policy art. 13 of GDPR 679/16

The Data Controller is **the Italian Multiple Sclerosis Foundation – FISM ETS** – with registered legal office in Rome (Italy), Via Cavour 181/A, with its national headquarter in Genoa (Italy), Via Operai 40, who can be contacted through the following channels:

- Phone: 010/27131
- PEC: presidenza@pec.aism.it
- Mail: richiesteprivacy@aism.

The Data Protection Officer (DPO) is Liguria Digitale S.p.A., legal office in Genoa (Italy), Via Enrico Melen, 77, who can be contacted through the following channels

- Phone: 010/65451
- mail: dpoaism@aism.it

This privacy policy is valid exclusively for the purpose of the “**A Delphi Study on Patient Reported Outcomes for Multiple Sclerosis**”, hereby named “**the Study**”, distributed online by the Data Controller.

### Purpose of Data collection and Legal basis

Your data will be collected in order to carry out the Study in compliance with the GDPR data protection regulations.

The purpose of the data collection is to create a panel of experts who will participate to conduct the Study (Study Protocol approved by ethics committee n° 2023/0052095, 26/04/2023)

Personal data provided for the purposes indicated above will be processed exclusively on the basis of your express consent (art. 6 par. 1 lett a) GDPR), which you may revoke at any time. Any withdrawal will only be valid for the future, the processing carried out up to that point remaining valid.

### Type of Data

The Data collected by the Data Controller throughout the whole duration of the Study refer to personal data e.g. name, surname, mail address, institution and gender of the contact person addressed to fill out the survey as central core of the Study.

Other information relies on general data related to the professional field, which then can be shared in aggregated form.

### Processing Modality

The Data provided by you will be collected through the PROMS website ([www.proms\\_initiative.org](http://www.proms_initiative.org)) for the whole duration of the Study. Data will be processed by computerised or telematic means and the following processing operations may be carried out: collection, recording, organisation, structuring, storage, extraction, communication, consultation, use, comparison or interconnection, restriction, deletion or destruction.

### Data Storage

The Data processed for the purpose set out in point 1 will be kept in the Controller's archives for a maximum period of 10 years from the end of the project. The data may be kept for a different period of time in order to document our activity or to assert a right in court. Finally, we would like to remind you that once the storage periods defined above have ended, the data may be stored in aggregate and anonymous form for statistical purposes.

### **Data Sharing**

The Data Controller may communicate the data to governmental authorities or subjects to whom communication is compulsory by law, as well as to collaborators, suppliers or, more generally, to third parties who provide services for FISM connected or instrumental to the management of the Study, who will be suitably instructed of the constraints imposed by the GDPR (e.g. digital tools for surveys, etc.).

The results of the Study may be diffused in anonymized and aggregate form and only for the purposes of the Study, as well as presented in the context of Conferences or published on the Owner's websites and in the various communication channels without ever permitting the precise identification of the participants. Still in anonymous and aggregate form, the results of the Project may also be communicated to Public Authorities or other Partners for study and research purposes.

Personal Data will be stored on servers located within the European Union. Your data will not be transferred to non-EU countries or in any case not subject to the GDPR regulations.

### **Rights of the data subject**

As a Data subject, you may exercise your rights under Articles 15-22 and ex art. 7 par. 3 of the GDPR at any time.

In this regard, we remind you that you have the right to:

- request the update, rectification, integration, withdrawal, transformation into anonymous form, or blocking of data processed in violation of the law, including data no longer necessary for the purposes for which they were collected
- receive information on the processing method;
- receive the data in a structured, commonly used and machine-readable format;
- withdraw any consent you may have given regarding the processing of your data at any time and object, in whole or in part, to the use of your data

### **How to exercise your rights**

You may exercise your rights at any time by contacting the FISM reference at [proms.programmanagement@aism.it](mailto:proms.programmanagement@aism.it)

DPO for FISM is Liguria Digitale, with headquarter in Genoa Science and Technology Park, Via Melen 77, 16152 Genoa, email [dpofism@aism.it](mailto:dpofism@aism.it).

**In receiving the above information, you express your consent to the processing of your personal Data.**