



Privacy policy in accordance with Art. 13 and 14 of EU Regulation 679/2016 Data processing SMA screening

1. Preface

It is necessary to recall that:

- **personal data** is any information that is capable of identifying - directly or indirectly (i.e. also by using further information) - a natural person, the so-called **data subject** (hereinafter, when reference is made to the prerogatives of the data subject, in the case of infants, reference will be made to those of the parents who represent them);
- the term '**processing of personal data**' refers to any operation carried out on personal data;
- the **Data Controller** is the entity (including the public sector) that uses such data for its own purposes and identifies the means (i.e. the methods of implementation, both from a technical and organisational point of view) with which to carry out the processing;

In order for a data processing to be lawful, it must comply with certain conditions, assumptions and purposes provided for and permitted by current legislation on personal data protection

Information on the processing is a right of the data subject and an obligation for the data controller.

This information refers to both Art. 13 (personal data collected from the data subject) and Art. 14 (personal data not obtained from the data subject) of the General Regulations as there are two data controllers, and the data are collected by the first data controller directly from the data subject (or rather from the person exercising parental responsibility) and communicated to the second, who has no direct contact with the data subject.

2. Context of the processing

The processing of personal data that is the subject of this information sheet concerns Your data and the data and biological samples of Your son/daughter that are indispensable for carrying out SMA screening. Screening includes a test and a possible subsequent diagnostic investigation.

With reference to the data processing functional to this pathway, the Azienda Ospedaliero Universitaria Meyer of Florence (as Lead Company) and the Health Authority of the Birth Point you went to (as Company of first contact) are qualified as autonomous Data Controllers (autonomous in the sense that they have a specific legitimacy and responsibility for the processing activities of their competence).

In the event that an external party carries out data processing activities on behalf of a Data Controller, as in the case of services entrusted to external parties in the field of laboratories, the external party is identified as the Data Processor in accordance with the procedures set out in art. 28 of the General Regulations, and is brought within the scope of the data processing of the Data Controller (almost as if it were an internal branch, from the point of view of data processing, of the Data Controller).

The Università Cattolica Sacro Cuore of Rome, which will be able to carry out the analysis on the biological sample, is appointed, pursuant to art. 28 of the General Regulation, as Data Processor.

3. Purposes of the processing

It has been observed that a Data Controller may lawfully process personal data only when the processing has a specific legal basis, i.e. when it is functional to activities that are included among its institutional purposes (or are not incompatible with them) and meets certain general conditions, in compliance with the applicable legislation.

The processing in question is carried out in compliance with art. 9 par. 2 letter h ("purposes of preventive medicine, diagnosis, assistance or health therapy") and art. 9 par. 2 letter g ("reasons of relevant public interest", for administrative activities related to health care) of the General Regulations as well as article 2-sexies paragraph 2, letter t) of the Code. The processing concerns the following categories of personal data:

- common data (e.g. personal data and contact data);



- special categories of personal data pursuant to Art. 9 of the General Regulations (in this case, data relating to the state of health and possibly genetic data).

The provision of data does not require the consent of the person concerned as it is necessary for the lawful purposes mentioned above.

4. Processing methods

The processing involves the collection, recording, storage and management of personal data using paper and computer tools, with logic strictly related to the purposes and, in any case, so as to ensure the security and confidentiality of the data in accordance with art. 32 of the General Regulations.

5. Storage of personal data

The data will be stored for the time provided for by current legislation; in particular, in the event of a positive outcome of the test in question, the data will be stored indefinitely. The extracted DNA will be destroyed at the end of the analysis.

6. Transfer of personal data outside the EU

The data will not be processed in countries outside the European Union.

7. Exercise of rights

The interested party has the right, if he/she so desires, to:

- access his/her personal data;
- request their rectification, integration and, where applicable, erasure (erasure of data is not envisaged where processing is necessary for the performance of a task carried out in the public interest: even in these cases, erasure of non-essential data with respect to the prescribed documentation obligations is still possible);
- request, where applicable, the restriction of processing (i.e. the temporary submission of data, in particular cases exhaustively listed in art. 18 of the General Regulations, to the sole operation of storage, pending checks to be carried out or to ensure particular claims of the person concerned).
- oppose the processing of personal data.

Requests relating to the exercise of these rights may be submitted to the Data Protection Officer by writing to the email address linked to the various autonomous Data Controllers and indicated in point 8 below.

Finally, if you believe that the processing of your personal data is in breach of the provisions of current legislation, you may lodge a complaint with the Authority, as provided for in art. 77 of the General Regulations (Data Protection Authority, www.garanteprivacy.it, e-mail garante@gdpd.it, switchboard tel. 06696771), or take legal action (art. 79 of the General Regulations).

8. Contact details

Data controllers:

- Birth point _____
- Azienda Ospedaliero Universitaria Meyer, with registered office in Viale Pieraccini n. 24, 50139 - Florence, PEC meyer@postacert.toscana.it, as Lead Agency and coordinator of the Region of Tuscany. Pursuant to art. 37 of the GDPR, a Personal Data Protection Officer (DPO) has been appointed at Azienda Ospedaliero Universitaria Meyer, who can be contacted for any clarification at the following e-mail address: privacy.dpo@meyer.it.