

## Privacy policy under articles 13 and 14 of EU Regulation 679/2016

### Premise

The EU Regulation 679/2016 (hereinafter, "**GDPR**") aims to ensure that the processing of personal data is carried out in compliance with fundamental rights and freedoms and the dignity of the data subject, with particular reference to confidentiality and the right to data protection. Under GDPR "processing" means any *"operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction"*.

In accordance with GDPR, Fondazione Istituto Nazionale di Genetica Molecolare - INGM with registered office in Milano (MI), Via Francesco Sforza, 35, Fiscal Code and Vat Number 04175700964 (hereinafter, "**Foundation**" or "**Data Controller**"), informs the data subjects that will process their personal data (hereinafter, "**Data**") in pseudonymised form, obtained from universities, hospitals, foundations, laboratories and research centres which are the Foundation partners in its scientific research (hereinafter, "**Scientific Partners**"), for the purposes set out in paragraph 1.

The Controller, in compliance with applicable, designated its Data Protection Officer (hereinafter, "**DPO**"), which can be contacted at the following e-mail: [rpd@ingm.org](mailto:rpd@ingm.org).

### 1. Purposes and lawfulness of data processing:

a) for scientific research purpose and other directly related purposes, on the basis of the data subject's consent given to the Scientific Partner for the processing of his/her data for this purpose, also through third party research institutes and bodies, such as the Foundation, pursuant to Art. 9.2(a) GDPR;

b) for the submission of research data - in such a form as to prevent the direct or indirect identification of the subject to whom they relate - in dedicated certified public databases, to promote Open Science and the public sharing of research data in order to foster scientific progress, in application of the provision of Legislative Decree 36/2006, as amended by Legislative Decree 200/2021, transposing Directive (EU) 2019/1024 et seq. mm. ii, pursuant to Art. 9.2(j) GDPR and the Prescriptions regarding the processing of genetic data set forth in Provision no. 146/2019 of the Italian Data Protection Authority

For more information on the Foundation's mission, laboratories, groups and research projects, please consult the "about INGM" and "research" sections of this website.

### 2. Consequences of any refusal to communicate the personal data

The provision of the Data for the purposes referred to in the previous paragraph is discretionary. However, any refusal to such processing may jeopardize the scientific research. The data subject has the right to withdraw its consent at any time, without affecting the lawfulness of processing based on consent before its withdrawal.

### 3. Manner of data processing and communication of personal data

The Data will be processed through computerized, automated manual systems, with logic strictly related to the purposes outlined above and, in any case, by persons authorized to perform these tasks, properly aware of the constraints imposed by the GDPR, equipped with security measures aimed to ensure the confidentiality of personal data and to prevent unauthorized access to third parties or unauthorized personnel.

The Data may be communicated, to the extent strictly necessary for the purposes referred to in paragraph 1, to employees, collaborators, professionals and companies in charge of specific data

processing. These suppliers, if operating in non-EU countries, offer their services on the basis of standard contractual clauses or on the basis of adequacy decisions adopted by the European Commission. These subjects will process the personal data necessary for the performance of their functions and may use these data only for the purpose of performing these services on behalf of the Data Controller or to comply with legal requirements. The Data may also be communicated to police bodies, judicial authorities, and individuals who can access them under law or secondary or European legislation. For the purposes of promoting Open Science, research data - in a form that prevents the direct or indirect identification of the subject to whom they refer - may be communicated, in compliance with the regulations in force, to: the providers of certified databases (such as, for example, the European Nucleotide Archive and ArrayExpress, managed by the EMBL European Bioinformatics Institute (EMBL-EBI) and to research bodies and institutes, associations and other public and private organisations whose research purposes are directly related to those for which they were originally collected.

The Data Controller will process the Data in compliance with GDPR, the Legislative Decree 196/2003, as amended by Legislative Decree 101/201, and the deontological rules applying to the processing of personal data for statistical and scientific research purposes provided by the Italian supervisory authority on 19 December 2018. The Data Controller will process the Data in a lawful and correct manner, collecting and recording them for specific, explicit and legitimate purposes, ensuring that they are relevant, complete and not excessive in relation to the purposes for which they are collected or subsequently processed.

#### **4. Data retention**

The processing will last, even by automated means, only for such period of time that is necessary for achieving the scientific research purpose, and after such period, in compliance with art 5, § 1 lett. e) of GDPR and art. 11 of and the deontological rules applying to the processing of personal data for statistical and scientific research purposes provided by the Italian supervisory authority on 19 December 2018 and/or in compliance with the legal obligations provided by the applicable laws and/or for defensive purposes.

#### **5. Data subject's rights**

As per Articles 15 et seq. of GDPR, each data subject has the right to receive from the data controller information on the existence of the processing of his/her personal data, on the data retention period as well as to access his/her own data, to obtain a copy of his/her data, the rectification, integration, updating, erasure of such data.

The data subject will also have the right to obtain the limitation of the processing, to oppose against processing, as well as the right to receive his personal data in a structured, commonly used and machine-readable format.

In order to exercise the aforementioned rights, it is necessary to write to the Data Protection Officer at the following e-mail address [rpd@ingm.org](mailto:rpd@ingm.org) and/or to the Data Controller at the following e-mail address [privacy@ingm.org](mailto:privacy@ingm.org) specifying "Privacy - exercise of the data subject rights" as object.

The data subject has the right to bring a complaint with the Italian supervisory authority and/or any other competent supervisory authority.

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This privacy notice was updated on 25-06-2024. Updates in case will be always published on this page.