IEO
European Institute of Oncology

Protection of Personal Data

Information to be provided in accordance with art. 13
General Regulation on Data Protection (EU Regulation 2016/679)

Dear Sir/Madam,
The institute makes use of standard information about you. You have the right to be informed as to what this is, for what purpose and according to what procedures it will be used, who might have access to it, and how you can exercise your rights.

Which information about you will be acquired and used by the Institute?

The Institute acquires and uses generic information (personal data, postal addresses, telephone numbers, images, etc.), information regarding patients' health condition, including genetic information in the case of certain services. All information may be provided by you or acquired from your health records during the course of assessments or consultations, and will be used for various purposes. If your specific consent needs to be provided, this, if granted, will be considered valid for all further access unless withdrawn or amended.

What will the acquired information be used for?

1. **For the purpose of prevention, diagnosis and treatment** (including subsequent monitoring) and related activities concerning administration, statistics, improvement of the quality and safety of clinical and healthcare procedures. Management activities are regulated by additional national and/or regional legislation, regulations, recommendations and guidelines.

2. **For the purpose of scientific research in the medical and biomedical fields**. IEO is a Scientific Institute for Treatment and Research (IRCCS). All clinical activities are therefore instrumental to the pursuit of scientific research, which seeks to establish possible relationships between information on your health condition and the results of the treatments you undergo. The ultimate purpose is to achieve constant improvement in diagnostic capability and the treatment of diseases using ever more effective and less invasive methods, also improving patients' quality of life. The results may contribute towards the progress of research into the fight against cancer, and may only be made public if your anonymity is ensured.

3. **For the purpose of communication** for fundraising and clinical-scientific initiatives (new treatments, studies, prevention programs, etc.); carried out by the IEO and/or the IEO-CCM Foundation. Personal data is used in the pursuit of these goals.

Whether or not consent is required!

1. For the **purpose of prevention, diagnosis and treatment** your consent is mandatory. Failure to provide consent will make it impossible to provide any type of service, except, obviously, in situations of urgency, provided for by law, in which case the information needed to perform essential health procedures will be used even without consent. Specific consent to the use of genetic data will be requested only if health care involving the use of such information must be carried out (consultation with a geneticist and/or tests for the detection of genetic mutations).

2. For the **purpose of scientific research** there is a need for your consent (without which it is not possible to proceed), in the case of research projects concerning: clinical trials of drugs and medical devices; use of genetic data; all studies in general that involve patient participation and active involvement over time (observational prospective studies). For so-called retrospective studies, for example when a group of doctors or researchers decides to use information already acquired in the past for clinical purposes, to carry out a research project, then because the IEO is a Scientific Research and Treatment Institute (IRCCS) , it is possible to carry out research projects even without consent (in prespecified cases), following an authorisation process involving: Clinical Studies and Regulatory Activities Office, Scientific Committee, Personal Data Protection Manager, Legal Department and Ethics Committee, which aims to ensure scientific and methodological rigour and compliance with current regulations.

3. For the **forwarding of communication** regarding fundraising and clinical-scientific initiatives on the part of the Institute, your consent is optional and failure to grant consent will have no consequences with regard to prevention, diagnosis and treatment.

Who can access and use the information (recipients)?

1. **Institute personnel working** in various areas, units and services, research and management clinicians, on the basis of specific authorisation commensurate with their role (for example: for an administrative officer managing staff presence/absence or processing payroll envelopes, IT applications that make it possible to access patients' clinical documentation, etc. are not enabled).

2. **Personnel of external companies (suppliers)** who may sometimes be involved in information processing (for example: for the digitisation and archiving of medical records, or support for IT applications, etc.). In these cases, the Institute will also insert specific provisions for the protection of personal data into the contractual agreement with these companies.

3. **Researchers and staff of other centres or companies within the context of possible collaborative research projects, or in which the Institute is involved** in a national, European or non-European context. If the transfer of information outside of the Institute is required, compliance with current legislation must always be ensured (for non-European countries, protective measures similar to those covered by European legislation must be ensured).

4. **Health Protection Companies, Regional institutions, Ministry of Health, Insurance companies, etc.** Some information flow is expected according to specific provisions of the law, regulations, etc. (for example: SDO hospital discharge sheets are summaries of hospitalisation that are periodically communicated to institutional organisations and bodies for appropriateness checks, to obtain reimbursements of the services carried out under the regional healthcare system, for the results of the AGENAS national project, etc.). Other flows, such as those relating to health policies, are regulated by specific agreements between patients, insurance companies and/or an intermediary, and the Institute.

Who is Responsible for data processing and what do they do?

The data controller is the **European Institute of Oncology (Istituto Europeo di Oncologia)** with registered office in Via Filodrammatici 10, 20121, Milan and operational branches, also in Milan, in Via Ripamonti 435, Via San Luca 8. Within the limits permitted by law, the data controller decides how and for what purposes the information is used, and is required to establish adequate, effective measures to ensure the protection of personal data. The Institute is a structured, complex organisational reality with a **specific organisational model for the protection of personal data**. It aims to review and reorganise all work processes by balancing the need to use information to pursue the stated purposes with the safeguarding of rights regarding personal data protection. Specific information on the organisational model can be obtained by contacting the Personal Data Protection Manager, as shown below.

How long is information stored?

The institute stores information relating to clinical documentation for an indefinite period, both in response to the specific regulations/legislation of the sector, and to the needs of scientific research arising from its nature as an Institute of Scientific Research and Treatment (IRCCS). Specific information on this subject can be obtained by contacting the Personal Data Protection Manager, as shown below.

Whom should you approach to assert your rights?

To exercise any of your rights in terms of access, amendment, cancellation, limitation, storage time, opposition, transferability of personal data; to find out the name of the companies or third parties processing your personal data, or for details of your right to complain to a supervisory authority, you can contact the **Personal Data Protection Manager** directly, using the following contact details:

- Tel +39 02 57489285
- Email privacy@ieo.it / direzione.sanitaria@ieo.it
- PEC direzionesanitariaieo@pec.it

Further guarantees relating to "confidentiality"

Call in communal waiting areas. Once you have checked in at reception and you are waiting for your appointment in the communal area, the staff will call you by name when it's your turn. This is to provide a warmer approach right from the initial stages of your interaction with us. If you so wish, you may request, upon reception, to be called such that that your name is not spoken, in order to ensure greater confidentiality.

Delivery of reports. The results of exams and/or consultations performed at the Institute can only be issued to you or to people authorised by you, using the appropriate delegation form provided by the Institute, properly filled in. Those who have activated their patient dossier at the Institute can consult and download reports directly from the website, using appropriate credentials.

Consultation without the patient. The institute may carry out consultations in the absence of the patient. In such cases a trusted individual with the appropriate delegation form, completed by you, may submit the clinical documentation relating to your disease to the specialist.

Communicating your attendance at the Institute to a third party. Communicating your attendance at the Institute to a third party. In the event of a hospital stay, the staff at the Institute will confirm your presence to persons that might request it (to enable communication with and/or visits from relatives and friends), unless you indicate otherwise on the appropriate form, which the Institute will provide.

Some definitions under the European Data Protection Regulation (EU Regulation 2016/679)

- ***Personal data***: *any information regarding an identified or identifiable individual person ('interested party'); the identifiable individual person can be identified, either directly or indirectly, with particular reference to identifying data such as a name, identification number, location data, online identifier or one or more characteristic elements of the his/her physical, physiological, genetic, psychological, economic, cultural or social identity.*
- ***Health related data:*** *personal data relating to the physical or mental health of an individual person, including the provision of health care services, which reveals information relating to his or her health condition.*
- ***Genetic data***: *personal data relating to the hereditary or acquired genetic traits of an individual person that provides unique information on the physiology or health of that individual, particularly that which results from analysis of a biological sample taken from the individual person in question.*

DCM.DO.6676.B

For further clarification, or to exercise your rights regarding the protection of personal data, please contact the Personal Data Protection Manager:
T +39 02 57489285 M: direzione.sanitaria@ieo.it — privacy@ieo.it