IEO
Istituto Europeo di Oncologia

Personal Data Protection and Privacy Safety

Duty to inform - art.13 Code on Personal Data Protection (D.lgs.196/03)

Why should you read this information?
The Institute will use some information about you and you have a right to be informed which information it is, for what purpose and how it will be used, to whom it may be given etc. Most of all, by giving your consent, you will choose whether you want to authorize the Institute, after being duly informed whether giving your consent is mandatory or optional and what consequences you might incur by not giving your consent.

What information about you will the Institute acquire and use?
Both general information (personal data, address, telephone numbers, photos, etc) and information on your health, the latter defined as "sensitive data" by the law *, including genetic data **. This information may come directly from you or be acquired from the reports of exams and visits. "Sensitive" data In particular can only be managed if yourself or any authorized parties *** give a written consent which will be considered valid for all following contacts until you cancel or repeal it.

For what purposes will gathered information be used?
After acquiring a separate consent for each of the specified objectives , all information will be used:

- for **diagnosis and treatment** (including follow up) and for all correlated institutional activities (administration, statistics, improvement of quality and clinical pathways safety. Genetic data in particular may be used to safeguard the health of others of your genetic line, even when you did not give your consent or it cannot be acquired due to physical or mental incapacity; this only applies to already collected genetic information, when handling is indispensable to allow for the other party to make an informed reproductive choice or for preventive or curative procedures;
- for **scientific research** in medicine and biomedicine (excluding genetic data). In particular to determine any relations between information on your health status and the results of the treatments you have undergone or will undergo. Such results may contribute to the progress of Research against cancer, even for yourself, and can be published only by safeguarding your anonymity.
- Furthermore, personal data, postal and e-mail addresses, may be used to **send you further communications** by the Institute (e.g. fundraising campaigns pro Research by IEO and/or IEO Foundation, scientific information related to new treatments, clinical studies, etc.).

What happens if you refuse your consent for the above-mentioned purposes?

- For **diagnosis and treatment**, your consent to the management of personal and sensitive data is mandatory; if you do not give your consent IEO will not be able to perform any procedures for you, except for emergency situations, as defined by current laws, when data necessary for life-saving procedures can be managed even without consent. However, if diagnosis and treatment entail the use of genetic sensitive data, your refusal to give your consent only entails the impossibility to perform diagnostic/therapeutic procedures requiring the use of genetic data. It follows that you can decide, if possible, fo pursue diagnosis and treatment through non genetic data.
- For **scientific research** and for **further communications** by the Institute**,** your consent is optional; if you do not give it there will be no consequence regarding your diagnosis and treatment.

How will information be managed?
On paper and through IT tools, within the current law on personal data protection , by applying sufficient safety measures. Data will be stored for a period varying according to the type of documents they are in (e.g. unlimited for hospitalizations records). If you wish to know for how long the different documents will be kept, you have to contact the person in charge of persona data management (see below).

Who can be informed about your health status?
Such information will not be given to any third parties unless necessary or required by law. Family members and friends can be given information on your health only if you give your written authorization.

Who is the Data Controller?
It is the European Institute of Oncology with legal headquarters in Via Filodrammatici 10, 20121 Milano and operation offices in Milano, Via Ripamonti 435, Via San Luca 8, Via Ramusio 1.

Who should you contact to assert your rights?
You can contact The Institute data Processor (Via Ripamonti 435, 20141 Milano) to know all your data and how they were acquired, to verify if they are correct, complete, up to date and to assert your rights. In particular regarding the specific use of genetic data, we inform you that you have the right to:

- Be informed by a health professional regarding available results and any unexpected knowable information derived from the performed procedures;
- Deny your consent to the management of genetic data for legitimate reasons;
- Limit the communication spread of genetic data and transfer of biological samples, as well as their use for purposes other than the required procedure;
- Know how long genetic data and biological samples will be stored.

Modality to acquire patient's consent to the management of personal, sensitive and genetic data
Registration personnel will ask you to give the following written consents which will be considered valid for any further contact until you revoke or repeal them:

- For the management of personal and sensitive data, for diagnosis and treatment and for all correlated institutional activities (administration, statistics, improvement of quality and clinical pathways safety);
- For the management of genetic data for diagnosis and treatment;
- For the management of personal and sensitive data (excluding genetic data), for scientific research in medicine and biomedicine. Such results may contribute to the progress of Research against cancer and can be published only by safeguarding your anonymity.
- For the management of personal data for further communications by the Institute e.g. fundraising campaigns pro Research by IEO and/or IEO Foundation, scientific information related to new treatments, clinical studies, etc.).

Further guarantees on "privacy"

Additional information –Electronic Health File (Regione Lombardia)
We inform you that:

- When you give the Institute your consent for the management of personal data for diagnosis and treatment, IEO will make all clinical information regarding any health procedure you received available in your FSE (Fascicolo Sanitario Elettronico – Electronic Health File);
- You can ask the Institute that such information be available in your FSE in "blocked" mode, so that it can only be accessed if you give your consent each and every time, by keying in your CRS-SISS PIN;
- Both the communication of your health event to your General Practitioner, and the use of your clinical information through your FSE, can only occur if you have given specific written consent, as requiredin the document "Information on personal data management via Electronic Health File (FSE)"that Regione Lombardia has made largely known.
- For any further details, please check www.crs.lombardia.it

Patient's call in communal waiting areas
After administrative registration, while waiting to undergo a procedure in a communal waiting area, the Institute personnel will call you by name to guarantee higher humanization since the beginning. If you wish, in order to ensure your privacy, when performing your administrative registration, you can ask to be called anonymously.

Report delivery
The results of exams and/or visits performer at IEO can only be given to you personally or to third parties authorized by you, when showing the specific proxy form, duly filled in.

Second opinion consultations in absentia
The Institute performs second-opinion consultations in absentia. In this case, a third party with a proxy duly signed by you, can show a specialist your clinical records.

Communication to third parties of your presence in the Institute
In case of hospitalization, the Institute personnel will confirm your presence to anyone who asks (in order to allow communications with and/or visits by relatives and friends), unless you deny your consent on the appropriate form which will be handed to you by the Institute.

Useful references
We remind you that for any further detail regarding your personal data protection and privacy safety you can address the Data Processor care of the Institute Chief Medical Office, Via Ripamonti 435, 20141 Milano
T +39 02 57489.1 F +39 02 94379212 E direzione.sanitaria@ieo.it

** by sensitive data we mean: "All personal data that can reveal race and ethnical origin, religious, philosophical or other beliefs, , political opinions, membership to political-parties, trade unions, religious, philopsphical political or labor associations or organizations, as well as all data that can reveal a person's health status or sexual behavior" (letter d, comma 1, art.4 of the Italian Code on Personal Data Protection).*

*** by genetic data we mean the result of genetic tests or any other information, whatever it is, that can identify a person's genotype characteristics transmissible within a group of people related by blood (Item 1, letter a, Authorization to genetic data management - 24 June 2011 and following modifications/additions) .*

**** In case the interested party cannot give his/her consent due to physical or mental incapacity, the consent is given by a legal guardian, next of kin, relative, cohabitee or, in their absence by the head of the facility where the interested party lives (letter b, comma 4 art. 26 and comma 2, art 82 of the Italian Code on Personal Data Protection)*