IEO
Istituto Europeo di Oncologia
Clinical Research Hospital (IRCCS)
Via Ripamonti 435 20141 Milan

Confidentiality and Data Protection
Notice - art. 13 of the Code concerning Personal Data Protection (Legislative Decree 196/03)

Why read this notice?
The institute will use some information about you and you have the right to be informed as to which it is, for what purposes and according to what procedures it will be used, to whom it might be communicated, etc. Most importantly, it will be you, through your consent, who chooses whether or not to authorise the institute, after having been informed about the mandatory or optional nature of the consent and about the consequences of a lack of consent.

What information about you will be acquired and used by the Institute?
It will be both general information (personal details, postal addresses, phone numbers, images, etc.) and information regarding your state of health, the latter being defined by the regulations as "sensitive" data, including genetic data**. This information can be provided by you or acquired through health documents during check-ups and visits. In particular, "sensitive" data can be used only with your consent or with that of authorised entities***, through a written request. Consent will be considered valid for every further access until a possible revocation or amendment.

What aims shall be pursued with the acquired information?
Prior to your kind consent for any stated purpose, information will be used:

- for **diagnosis and treatment purposes** (included subsequent controls) and for related activities of the institute concerning administration, statistics, improvement of the quality and security of clinical and healthcare procedures. In particular, genetic data can be used also for protecting the health of another person in your same genetic line, even in case your consent had not been obtained or could not be obtained due to physical impossibility, inability to act or to lacking a sound mind, memory, or understanding; this concerns exclusively previously gathered genetic information, and in case the processing of this information were to be indispensable to allow another person to make a conscious reproductive choice or were justified by the availability of preventative or therapeutic interventions;
- for **scientific research purposes** in the medical and biomedical fields (with the exclusion of genetic data). In particular, to determine possible relations between the information on your state of health and the results of the treatments you have undergone or will undergo. The results could contribute to the progress of Research in the fight against cancer (and potentially also for your own direct benefit), and can be made public only if your anonymity is guaranteed.
- Furthermore, the personal details, postal, phone and email addresses can be used to **forward further communication** by the institute (fund-raising initiatives to support research conducted by IEO and/or by the IEO-CCM Foundation, scientific information in relation to new therapies, clinical studies, etc.).

What happens in case consent is denied for the stated purposes?

- For **diagnosis and treatment purposes**, it is essential to consent to the use of personal and sensitive data and lack of consent entails the impossibility to access any type of service, except obviously from urgent situations, set out by the regulations, for which even without consent one proceeds to processing the personal data that are necessary for the performance of indispensable health operations. If the diagnosis and treatment purposes entail the use of sensitive genetic data, the lack of consent results solely in the impossibility to access diagnostic / therapeutic services that require the use of genetic data. Thus, it follows that you can anyhow decide, if possible, to pursue the diagnostic and treatment aims through non-genetic data.
- For **scientific research purposes** and for the Institute to **forward further communication**, the consent is optional and lack of consent does not entail consequences as for what the diagnostic and therapeutic fields are concerned.

How will information be treated?
Either in paper or electronic form, in accordance with the current provisions regarding personal data protection and with the adoption of appropriate security measures. The data storage period will depend upon the type of document that they are contained in (e.g. unlimited for the medical records concerning the hospitalisation

period). To find out the storage time for the different documents one must contact the Personal Data processing manager indicated below.

Who will receive information concerning your state of health?
Such information will not be communicated to a third party, unless this was necessary or pursuant to the law. Information on your state of health can be given to family members and acquaintances only under your express authorisation.

Who is Responsible for data processing?
The Responsible entity is the European Oncology Institute (Istituto Europeo di Oncologia) with registered office in Via Filodrammatici 10, 20121, Milan and with operational branches, also in Milan, in Via Ripamonti 435, Via San Luca 8.

Whom should you approach to assert your rights?
You can approach the Personal Data Processing Manager of the Institute (Via Ripamonti 435, 20141 Milan) to find out about the data that concern you, find out how they have been acquired, verify whether they are exact, complete, up to date and assert your rights on the matter. In particular, with reference to the specific use of genetic data, we also inform you that you have the right to:

- be informed by a health professional regarding the attainable results and possible unforeseen finding that could arise following the investigations performed;
- oppose the processing of genetic data for legitimate reasons;
- limit the sphere of communication of genetic data and transfer of biological samples, as well as any use of these for purposes that are beyond those of the requested investigation;
- know the storage times for genetic data and biological samples.

Summary of the main consents required for the processing of personal, sensitive and genetic data.
You will be asked to produce in writing the following consents that will be considered valid for any further access until a possible revocation or amendment:

- consent to treatment of personal and sensitive data, for diagnostic and treatment purposes and for related activities of the institute concerning administration, statistics, improvement of the quality and security of clinical and healthcare procedures;
- consent to the processing of genetic data for diagnostic and treatment purposes;
- consent to the treatment of personal and sensitive data (with the exclusion of genetic data), for scientific research purposes in the medical and biomedical fields. The results could contribute to the progress of Research and can be made public only if your anonymity is guaranteed;
- consent to the processing of personal data for forwarding further communication from the Institute (fund-raising initiatives to support research conducted by IEO and/or by the IEO-CCM Foundation, scientific information in relation to new therapies, clinical studies, etc.).

Further guarantees relating to "confidentiality"

Call in the communal waiting areas.
With regard to services accessed personally at the Institute, we inform you that after you have registered at reception, while you are waiting in the communal areas to access a service, when your turn comes the staff will call you by your name, for a warmer approach right from the initial phases of your interaction with us. Anyhow, if you so wish, in order to guarantee a higher degree of confidentiality, you can request at the time of registration at reception to be called in way that your name is not spoken.

Delivery of reports
The results of exams and / or visits performed at the Institute can be issued only to you or to people authorised by you, with the appropriate delegation module set up by the Institute, properly filled in.

IEO
Istituto Europeo di Oncologia
Clinical Research Hospital (IRCCS)
Via Ripamonti 435 20141 Milan

Consultation without patient
The institute performs consultations in the absence of the patient, in which case a trusted individual with the appropriate delegation form filled in by you, can submit the clinical documentation relating to your pathology to the specialist.

Communication to a third party of your presence in the Institute
In case of hospitalisation, the staff at the Institute will confirm your presence to the people that might request it (to allow the communication with and/or visit by relatives and friends), unless you state otherwise in the appropriate form that will be provided to you by the Institute.

Useful references
We remind you that for any clarification pertaining the protection of your personal data and confidentiality, you can contact the Personal Data Processing Manager at the Institute's Health Directorate (Direzione Sanitaria), Via Ripamonti 435, 20141 Milan
Tel. +39 02 57489.1 Fax +39 02 94379212 Email direzione.sanitaria@ieo.it

** We use the term sensitive data to refer to "personal data that can reveal the racial and ethnic origin, religious, philosophic or other forms of belief, political opinions, membership to parties, trade unions, associations or organisations with a religious, philosophical, political or trade-unionist agenda, as well as data that can be used to reveal the state of health and sexual life" (paragraph d, subsection 1, art. 4 of the Code concerning Personal Data Protection).*

*** We use the term genetic data to refer to the result of genetic tests and any other information that, regardless of its type, identifies the inheritable genotypic traits of an individual in the context of people belonging to the same family.*

**** Were the affected party not to give his consent due to inability to act or to lacking a sound mind, memory, or understanding, consent is given by the person with legal authority, by a next of kin, a family member, a partner or, in their absence, by the director of the facility where the affected party lives (paragraph b, subsection 4, art 26 and subsection 2, art. 82 of the Code concerning Personal Data Protection)*

IEO
Istituto Europeo di Oncologia
Clinical Research Hospital (IRCCS)
Via Ripamonti 435 20141 Milan

The undersigned (*)

Name and surname: _____ **Data of birth:**____/____/_____

(*) If you are not the directly affected party (patient) score out one of the checkboxes listed below:

□ Legal representative (not a parent)
□ Parent (Underage)
□ Representative of the facility where the affected party lives

Details of the directly affected party:
Name and surname: _____ Data of birth:____/____/_____

Having acquired the information provided by the responsible entity for data processing according to art. 13 of the Code concerning Personal Data Protection (Legislative Decree no. 196 dated 30 June 2003) and also aware that such consent will be considered valid for any further access until a possible revocation or amendment by the affected party, consents

- to the processing of personal and sensitive data **for diagnostic and treatment purposes** (included subsequent controls) and for related activities of the institute concerning administration, statistics, improvement of the quality and security of clinical and healthcare procedures.

- to the processing of genetic data for diagnostic and treatment purposes. Yes □ No □

- to the processing of sensitive data **for scientific research purposes** in the medical and biomedical fields (with the exclusion of genetic data). In particular, to determine possible relations between the information on your state of health and the results of the treatments you have undergone or will undergo. The results could contribute to the progress of Research in the fight against cancer,(and potentially also for your own direct benefit), and can be made public only if your anonymity is guaranteed. Yes □ No □
- to the treatment of personal details (postal, phone and email addresses) to **forward further communication** by the Institute (fund-raising initiatives to support research conducted by IEO and/or by the IEO-CCM Foundation, scientific information in relation to new therapies, clinical studies, etc.). Yes □ No □

Date____/____/_____ **Signature** _____