
PRIVACY NOTICE

Introduction

This privacy policy is subject to:

- I. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (“GDPR”);
- II. The Belgian Data Protection Act of 30th July 2018 on the protection of privacy in relation to the processing of personal data (as amended) (the “Privacy Act”); and/or
- III. All other applicable legislation regarding the protection of privacy and the processing of personal data.

The privacy legislation

In this Privacy Policy any use of “DIGICORE”, “we”, “us”, “our” refers to the Digital Institute for Cancer Outcomes Research, a European Economic Interest Grouping headquartered at Rue d’Egmont 11, 1000, Brussels, Belgium; registration number 0766.541.015 under the Crossroads Bank of Enterprises.

For the purpose of the “Privacy Legislation” DIGICORE acts as data controller of your personal data. This means:

The “Digital Institute for Cancer Outcomes Research – DIGICORE” is a pan-European research network built to accelerate the implementation of precision oncology in Europe. DIGICORE promotes and equips cancer centres in their use of routine electronic health records (EHR) and molecular diagnostic information (MDX) for trial automation, real world outcomes research, digital diagnostics and care quality management.

The ultimate goal is to shape a digital research infrastructure based on digital interoperability between its Members. Network membership supports them to improve data quality and completeness, develop new data sources and tools, share digital best practices and promote novel, digitally enabled research methods.

DIGICORE is set-up as a European Economic Interest Grouping including several prominent cancer centres, two cancer networks, UNICANCER and Alleanza Contro il Cancro, and two commercial partners allied in this challenge.

1. What type of personal data does DIGICORE collect?

- I. Identity: first name, last name, (date of birth, ID and/or passport details only for the Board Members);
- II. Picture(s);
- III. Professional details: professional title, curriculum-vitae;
- IV. Contact details: e-mail address, postal address, phone and/or mobile number.

The Personal data are obtained:

- directly from you; or
- indirectly through third parties, such as your organisation.

2. For which purpose(s) and on which legal basis can DIGICORE process personal data

Members

2.1 Identity details of the legal representative of the applicant institution are used:

- to process the membership application of the applicant Centre/Institution to the DIGICORE Membership;
- to manage the general administration and the DIGICORE Membership;
- to comply with our obligations related to the DIGICORE governance (e.g. organisation of general assemblies and board meetings).

Such processing is based on the legitimate interest of DIGICORE (GDPR art.6.1) which commits to strictly limit its collection of data and information to the above-mentioned purposes.

2.2 Identity and professional details of individuals appearing on the organigramme of each Member (General Director, Medical Director, Scientific Director or any other position in each Member Institution) are processed:

- to be deposited in the database or restricted area managed by the DIGICORE Liaison office;
- to be used for communication and dissemination purposes;
- to promote and increase the collaboration of the Members in the various DIGICORE activities;
- to highlight the DIGICORE presence and visibility with worldwide cancer organisations and stakeholder groups in cancer-related matters.

Such processing is based on the free, specific, informed and unambiguous consent given through the annexed consent form to DIGICORE.

2.3 The contact details of each Member-designated contact person are processed:

- to facilitate your access to member-only content;
- to provide you relevant and updated information about DIGICORE and its activities;

Such processing is based on the free, specific, informed and unambiguous consent given through the annexed consent form to DIGICORE.

Non-members

2.4 DIGICORE processes personal data of representatives and contact persons of third party entities with which DIGICORE has a contractual relationship (e.g. services providers or consultancies).

2.5 DIGICORE processes contact details of journalists, Members of European Parliament, officials from the European Commission and from EU Member States, academics, consultants and industry experts and European affairs stakeholders, European and International Cancer Organisations in order to carry out its research, advocacy activities, publications and educational events. Such processing is based on the legitimate interest of DIGICORE which commits to strictly limit its data and information collection to the purposes described in this paragraph.

2.6. For event organisation: DIGICORE processes identification details of individuals who register to participate to events and conferences it organises for the purpose of managing the registration and participation to such events under the general terms and conditions that are expressly accepted by the individuals and/or based on consent for certain personal data.

3. Transfer of personal data to third parties

3.1 DIGICORE guarantees that it will not transfer your personal data to third parties, unless:

- I. There is a legal obligation to transfer such personal data;
- II. It is necessary for the achievement of one of the Purposes described here-above (e.g. subcontractors, partners or contracting parties);
- III. DIGICORE has a legitimate interest in doing so.

3.2 Third parties to whom DIGICORE may, or is obliged to, transfer personal data on the basis of the above categories, can be located within or outside the European Union. In such case, DIGICORE shall ensure that the personal data will be treated fairly and lawfully. This will include ensuring DIGICORE has a legal ground for sending the personal data outside the European Union and putting in place necessary safeguard for such arrangement.

3.3 DIGICORE cannot be held responsible for the transfer of personal data and cannot be liable for the further processing of the personal data by third parties.

4. Storage period

DIGICORE stores the personal data for as long as it is necessary to achieve the purposes described here-above. After that, the personal data will be deleted or anonymized.

5. Your rights

5.1 The Privacy Legislation provides you with a number of rights related to your personal data.

You are entitled to the following rights, free of charge:

- Right of access: you have the right to access and receive a copy of your personal data that DIGICORE holds;
- Right of correction: you have the right to have your personal data corrected in case errors occur;

in this regard please inform the DIGICORE of the changes occurred;

- Right to delete: you have the right to have your personal data deleted in case:
 - a. your personal data are no longer necessary to achieve the Purpose;
 - b. you withdraw your consent and there is no other legal ground for the processing of the personal data;
 - c. you object to the processing of the personal data and there is no other legal ground for the processing of the personal data;
 - d. the personal data have been unlawfully processed; i.e. there is a legal obligation to erase the personal data;
- Right to restrict the processing of your personal data;
- Right to transfer your personal data to a third party;
- Right to object against the processing of your personal data, in particular the processing related to direct marketing purposes;
- Right to withdraw your consent pursuant to which DIGICORE is allowed to process your personal data.

5.2 In case you want to exercise the above-mentioned rights you may send a written request by mail: info@digicore-cancer.eu.

Such request must be signed and dated and shall be accompanied by a proof of identity.

5.3 You also have the right to lodge a complaint with the Belgian Data Protection authority: <https://www.dataprotectionauthority.be/citizen/privacy/what-to-do-in-case-of-abuse> if you believe that the processing of your personal data breaches the Privacy Legislation.

5.4 By agreeing to this privacy policy, if you provide personal data of third parties (e.g. their employees, members, board members, staff, subcontractors, contracting parties) you must guarantee that the afore-mentioned data subjects are informed on the above-mentioned rights and how to exercise these rights.

6. Security measures

DIGICORE commits to take (or have) all reasonable measures (taken) to its best ability to safeguard the protection of the personal data through organisational and technical security measures.

Personal data are stored entirely on a server and on a digital platform managed by a processor through the DIGICORE website restricted area; only authorised users can download such data via Excel files.

Please acknowledge and accept that the transfer and storage of personal data is never without risk and consequently, the damage that you may suffer from the unlawful use of your personal data by third parties, can never be referred to DIGICORE.

7. Liability

DIGICORE can solely be held accountable for damage which directly results from the processing of your personal data due to a fault or negligence of DIGICORE.

DIGICORE cannot be held liable:

- I. In circumstances of force majeure; and/or
- II. For any indirect or consequential damage; and/or
- III. For damages that result from errors, faults or negligence by you or third parties.

DIGICORE's liability cannot exceed 1,000 euro (one thousand euro) for breaches regarding this privacy policy and/or Privacy Legislation.

8. Applicable law and competent court

8.1 You agree that all disputes between you and DIGICORE regarding personal data and privacy issues are exclusively subject to Belgian law, excluding any conflict of law principles.

8.2 Every dispute regarding personal data and privacy issues belongs to the exclusive jurisdiction of the courts of Brussels, Belgium, and exclude any other court.

9. Changes to the Privacy Policy

DIGICORE can modify this Privacy Policy at any moment.

The updated Privacy Policy will take effect as soon as it is updated.

Version dated 20 January 2023