Data protection safeguards in the European Cancer Information System

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28 May 2021

Joint
Research
Centre

Data protection regulations

- General Data Protection Regulation (GDPR) (EU) 2016/679
  - on the processing by an individual, a company or an organisation of personal data relating to individuals in the EU.
  - updates the existing Data Protection Directive of 1995 to a Regulation
  - enforcement date: May 25th 2018
- For EU institutions: Regulation (EU) 2018/1725 (applicable to cancer data processing in ECIS)
  - on the protection of natural persons with regard to the processing of personal data by the Union institutions, bodies, offices and agencies and on the free movement of such data

Data protection principles

- Refers to any information relating to an identified or identifiable natural (living) person such as:
  - name, date of birth, phone numbers, e-mail address
- Pseudonymisation can mitigate the risk of disclosing information on an identifiable natural person.
- The definition of “identifiable” considers all means reasonable likely to be used to identify the natural person directly or indirectly – taking cost, time and technology into consideration.
- Data protection does not apply to anonymous data, nor if the data subject is dead.

Data protection principles

- Health-related data are considered sensitive:
  - The processing of personal data, revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of **genetic data, biometric data** in order to uniquely identify a person or **data concerning health** or sex life and sexual orientation shall be prohibited.
- Processing personal data is generally prohibited, unless:
  - it is expressly allowed by law
  - or the data subject has consented to the processing,
  - or the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Regulation (EU) 2018/1725

- ‘**personal data**’ means any information relating to an identified or identifiable natural person (‘data subject’); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;

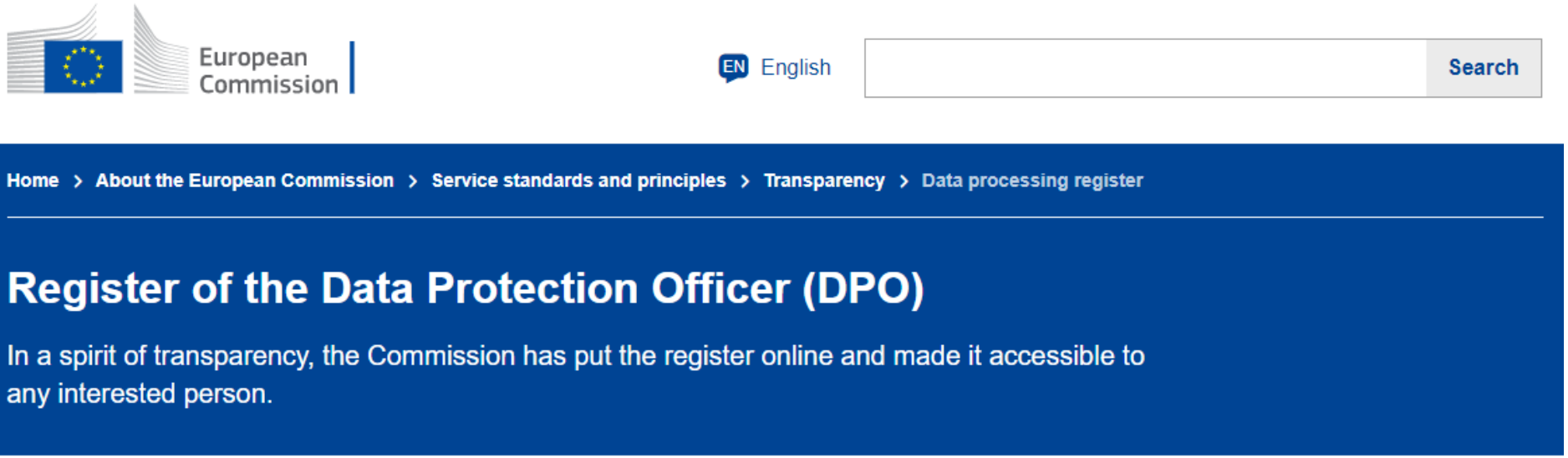
- ‘**processing**’ means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;

Hosting and processing of data in the European Cancer Information System

- DP Register for the EU Institutions
  - ✓ https://ec.europa.eu/dpo-register/detail/DPR-EC-00417

European Commission

Register for the EU Institutions



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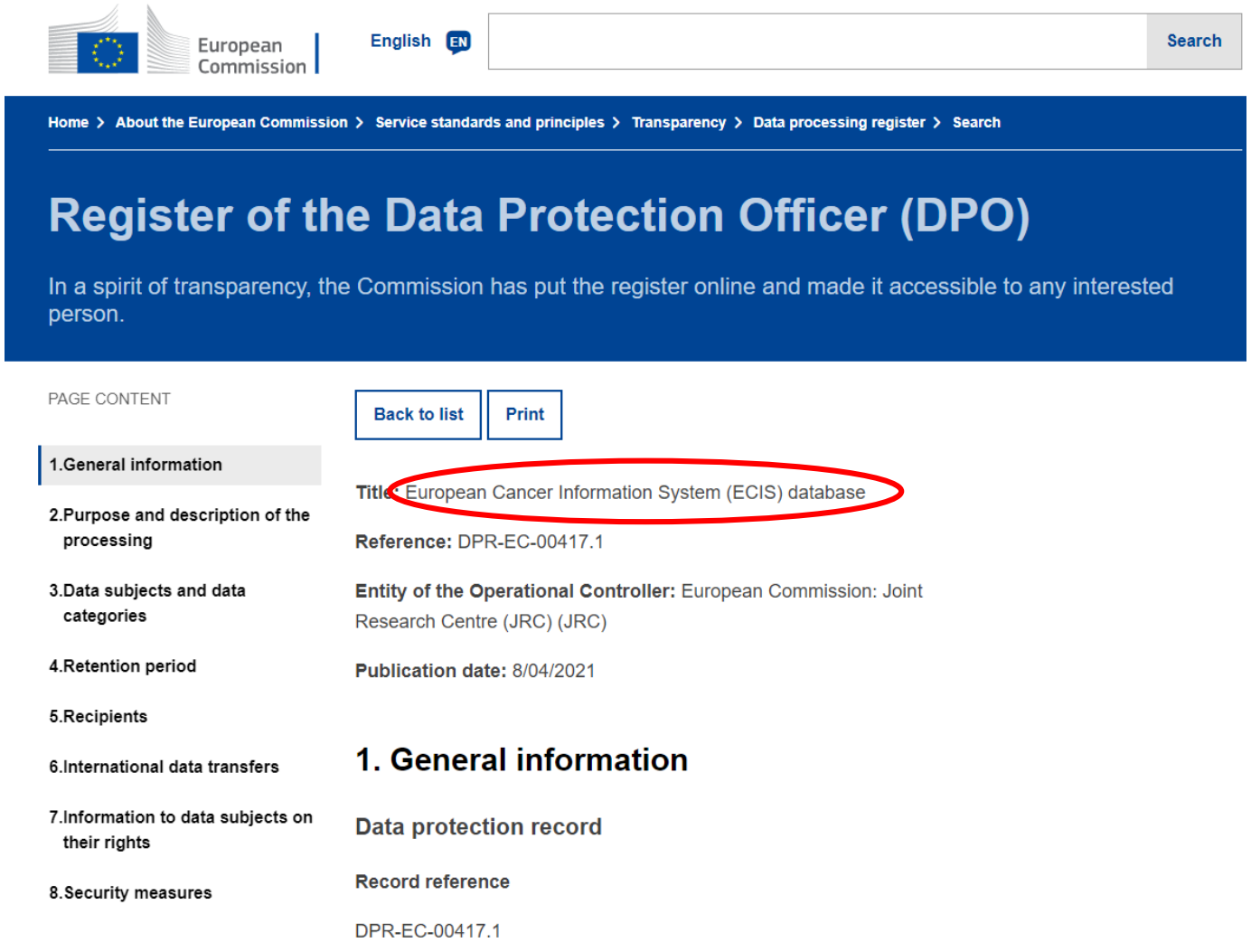

European Commission

https://ec.europa.eu/dpo-register/detail/DPR-EC-00417

1.General information

2.Purpose and description of the processing

3.Data subjects and data categories

4.Retention period

5.Recipients

6.International data transfers

7.Information to data subjects on their rights

8.Security measures

In the context of these activities, the JRC process data on individual cancer occurrence(s) at patient level (henceforth 'cancer data') provided by population-based cancer registries affiliated to ENCR. Cancer data can be considered to be information relating to identifiable natural

JRC processes cancer data exclusively for scientific research purposes.

Cancer data are collected by registries at national/regional level, and processed in accordance with national legislation regulating their activities. The collection and processing of the data by the registries is

The JRC is the recipient of pseudonymised cancer data collected by the registries, and, as a recipient, has no role under the GDPR to ensure compliance by the controller with its own obligations.

Scientific Collaboration Agreements will be concluded between the Registries and the JRC as well as Personal Data Transfer Agreements to frame the transfer of cancer data from a controller (each regional / national registry) to the JRC as recipient and new controller for the further processing. In those Agreements, Registries will warrant and

https://ec.europa.eu/dpo-register/detail/DPR-EC-00417

The system includes data concerning health, a special category of data that falls under Article 10 of Regulation (EU) 2018/1725. The health data include medical diagnosis and tests results, medical treatment, medical classifications.

- Information about the area of residence of the patient (such as region or subregion);
- Medically relevant data on the patient (such as month of birth, year of birth, gender and age at diagnosis);
- Clinical data about the cancer (such as tumour identifier, month of incidence, year of incidence, topography, morphology, stage at diagnosis, type of treatment received and other clinically relevant information);
- Variables related to follow up (such as vital status, duration of survival, and cause of death).

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Cancer data shall be kept for a maximum total storage period of 10 years from the moment of submission by the registries. Cancer data shall be kept for the purposes of carrying out the processing activities described above for a maximum period of 5 years. Subsequently, cancer data will be kept for archiving purposes in order to perform data verification and audits in case inaccuracies, inconsistencies or incompleteness are detected. The additional storage period for such secondary, compatible purposes will be for a maximum of 5 years from the moment of publication of the statistical indicators, or until a new set of statistical indicators produced on the basis of a new set of cancer data submitted by national registries is published, whichever date comes first. After a maximum total storage period of 10 years from the moment of submission by the registries, the cancer data will be destroyed.

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JRC may disclose cancer data to researchers for the purpose of scientific studies, and to national and international bodies in the field of cancer epidemiology, prevention and treatment, subject to the provisions of Art. 9 of Regulation (EU) 2018/1725.

In addition to the requirements of such provisions, the approval of the registry at the origin of the cancer data will be sought before data is disclosed to the third party.

Possible external recipients of cancer data are:

- Istituto Nazionale Tumori di Milano (Italy) and Istituto Superiore di Sanità (Italy) for the EUROCARE (EUROpean CAncer Registry based study on survival and care of cancer patients) project: a collaborative research project on cancer survival in Europe, http://www.eurocare.it/;

- IARC (WHO's International Agency for Research on Cancer), for their project on "Cancer Incidence in five continents" http://ci5.iarc.fr/Default.aspx;

- London School of Hygiene & Tropical Medicine (United Kingdom) for the CONCORD study - a global programme for world-wide surveillance of cancer survival, led by the https://csg.lshtm.ac.uk/research/themes/concord-programme/;

- Other external applicants (e.g. for scientific research) to be assessed on a case-by-case basis.

https://ec.europa.eu/dpo-register/detail/DPR-EC-00417

Data is transferred to international organisation(s)

Yes

The names of the international organisation(s) to which the data is transferred

International Agency for Research on Cancer (IARC), specialized cancer research agency of World Health Organisation.

Legal base for the data transfer

The legal base for the data transfer

- Transfer subject to appropriate safeguards (Article 48.2 and .3)
  - Standard data protection clauses adopted by
    - The Commission
- Transfer based on an International agreement (Article 49)

The International agreement(s) which is/are the legal basis for the data transfer

Agreement with IARC.

Keep in touch

EU Science Hub: ec.europa.eu/jrc

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Thank you

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