

Data protection challenge for sharing cancer registries data



TYPE
STATUS

Pilot legal framework

LAST
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EUROPE • CANCER REGISTRIES
Cancer monitoring & epidemiology

PROBLEM & OBJECTIVE

PROBLEM Cancer disease surveillance requires up-to-date figures to monitor the burden of cancer and allows the understanding of risk factors and inequalities. To this purpose, appropriate aggregations and analyses of cancer occurrence(s) at patient level are needed, as resulting from the archives of the cancer registries across European countries and regions.

OBJECTIVE Developing appropriate legal framework for processing and sharing data, taking into account the General Data Protection Regulation (GDPR), is crucial for epidemiological cancer research at European level.

CONTACT

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KEY COMPONENTS / STEPS

- The procedures regulating data collection and processing centrally at the JRC, and related data safeguards are described in the ECIS data protection (DP) record.
- A collaboration agreement including the agreement on transfer of personal data (where applicable) is concluded between the cancer registries and the JRC, as subsidiary to the ECIS.
- Signing the agreement is mandatory for submitting data to the JRC, for participation to the JRC-ENCR and possibly other international research projects (as detailed in the DP record).

KEY CONTEXTUAL FACTORS

- The Joint Research Centre of the European Commission (JRC) supports the European Network of Cancer Registries (ENCR) in the harmonization of data and registration processes.
- Building on population-based cancer registries data, the JRC developed and maintains a public website - the European Cancer Information System (ECIS) - disseminating statistics on temporal and geographic trends of cancer incidence, mortality, prevalence and survival indicators.
- The JRC processes data on individual cancer occurrence(s) at patient level. This data relate to identifiable natural persons, and are therefore personal data. When collecting and processing cancer data, both the JRC as well as the cancer registries must ensure compliance to the data protection rules.

MAIN IMPACTS / ADDED VALUE

- Population-based cancer registries' data is essential for the understanding of the cancer burden in the European population and to provide tools to drive policy decisions for cancer control. Moreover, such data is also an important contributor to address and tackle inequalities in cancer prevention and care, identified as one of the key challenges in the Europe's Beating Cancer Plan.
- The process to sign the collaborative agreement between the JRC and ENCR registries is ongoing, paving the way for a smoother process of updating ECIS with the most recent cancer burden indicators.
- Addressing in a common way the data protection issue helps the scientific community to perform collaborative studies at European level.
- Collaborative studies also foster data harmonisation and progress towards common standards at EU level.

LESSONS LEARNED

- The implementation of the new data protection regulation (GDPR) implies a higher scrutiny on the safeguards put in place by data controllers regarding the acquisition, storage and sharing of individual-level cancer data. While aiming to prevent identification of patients, the applied measures should still allow the safe use of patients' data for research purposes.
- Some difficulties in sharing individual data were raised by some registries, where sparse populations in some regions increase the risk of identification of individuals. Specific measures are needed to accommodate those cancer registries data and allow the computation of comparable cancer indicators between European countries.

REFERENCES & DOCUMENTATION

- 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)
- Data Protection Record
- Europe's Beating Cancer Plan
- ENCR
- ECIS web application

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