Data protection for cancer registries

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Functions of the cancer registry and confidentiality

- Cancer registry (CR): collection, recording and analysis of data relating to the lifetime of identified individuals with cancer
- Use: tool for public health surveillance, including the planning and evaluation of health services
- CR must maintain the same standards of confidentiality as apply to the doctor–patient relationship

Confidentiality of data at the cancer registry level

- International Association of Cancer Registries (IACR) – a formal code of conduct for cancer registries in 1991
- EU Directive on the protection of individuals with regard to processing of personal data (Directive 95/46/EC, 1995)
- European Network of Cancer Registries (ENCR) first revision in 2002 – Guidelines on confidentiality for Cancer Registries

Confidentiality of data at the cancer registry level

Under the auspices of EUROCOURSE project (2009–2012) a Working Group was formed including specialists in epidemiology, screening, biobanks and clinical databases

(a) To update the Guidelines on Confidentiality in the Cancer Registry published by the European Network of Cancer Registries in 2002

(b) To include ethics and linkages to other databases.

(c) To examine to what extent these guidelines could be used in cancer registries outside Europe, and to identify areas in the guidelines where difficulties may arise.

Confidentiality of data at the cancer registry level

ENCR and IACR – new revision 2011

Guidelines on Confidentiality and ethics for population-based cancer registration and linked activities in Europe

Confidentiality of data at the cancer registry level

Aims of 2011 revision - updated guidance on:

- Definition of terms for cancer registration and confidentiality, with reference to the European Directive
- Articles in the Directive that are of particular relevance to cancer registration
- Need for a code of conduct in the maintenance of confidentiality in cancer registration, and the definition of what should be considered confidential
- Objectives of confidentiality measures in cancer registration, and their legal basis
- Principles of confidentiality, including the measures to maintain and survey security procedures
- Guidelines for the preservation of confidentiality and ethical standards, for the use and release of registry data in accordance with these principles

General principles

- The purposes for which data collected by the cancer registry are to be used should be clearly defined
- The legal basis of cancer registration should be clarified and it should be ensured that all reporting bodies have legal authority to report cancer, whether registration is compulsory or voluntary
- The cancer registry must maintain the same standards of confidentiality and ethics as customarily apply to the doctor-patient relationship; this obligation extends indefinitely, even after the death of the patient
- Identifiable data may be transferred to a collaborating or central registry for the purposes of complete and accurate cancer registration
- Confidentiality rules apply to all data regardless storage or transmission media
- Data on deceased persons should be subject to the same procedures for confidentiality as data on living persons

Data protection measures

- The Director of the registry is responsible for data security
- The staff is aware about the data protection rules (signed declaration, in force even after cessation of employment)
- Controlled access to the registry (files, databases etc.), both physical and electronic, and a list of persons authorized to enter the registry
- Safe disposal of confidential waste
- Precautions should be taken for both physical and electronic security of confidential data sent on electronic media. This could be by separating identifying (ID) information and tumour-related data, or via encryption of the ID

Release of the data

- The registry should develop procedures for use and release of data that ensure the maintenance of confidentiality and ethical standards
- Access to data needed for the management of the patients by physician, in accordance with the national law
- The data subjects should be given access to their own data on request, unless a national law exempts such a release
- Requests for identifiable data to be used for research should include a detailed justification with a commitment to adhere to the registry's guidelines on confidentiality
- Cross border transfers
    - If allowed by national law, cross-border transfer of identifiable individual data should only be carried out if required for the conduct of a research project and if the level of protection is satisfactory

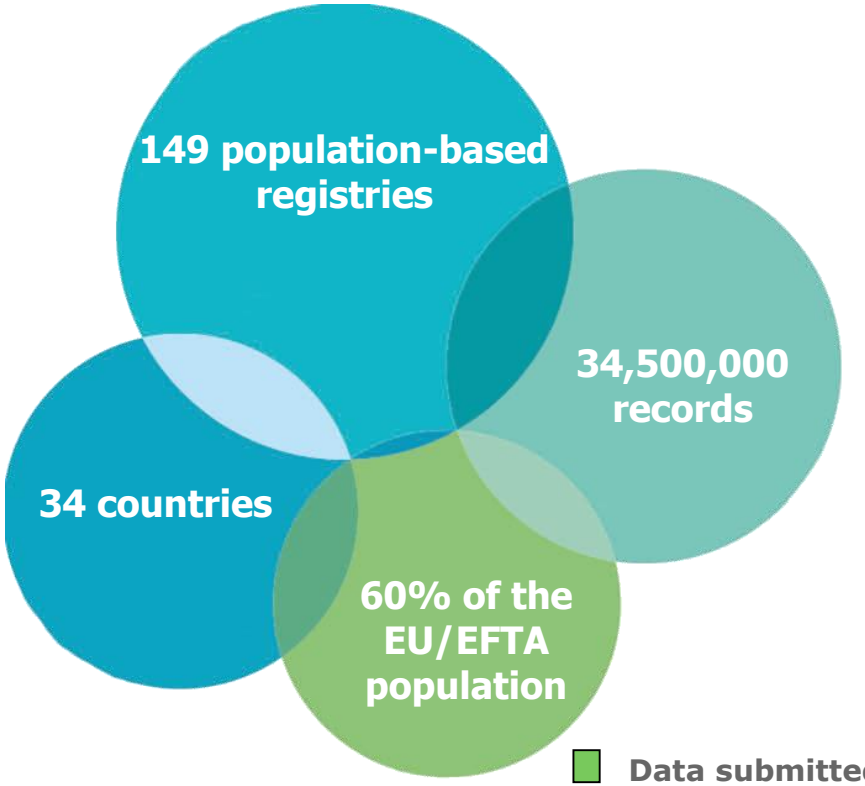
Confidentiality of data at the cancer registry level

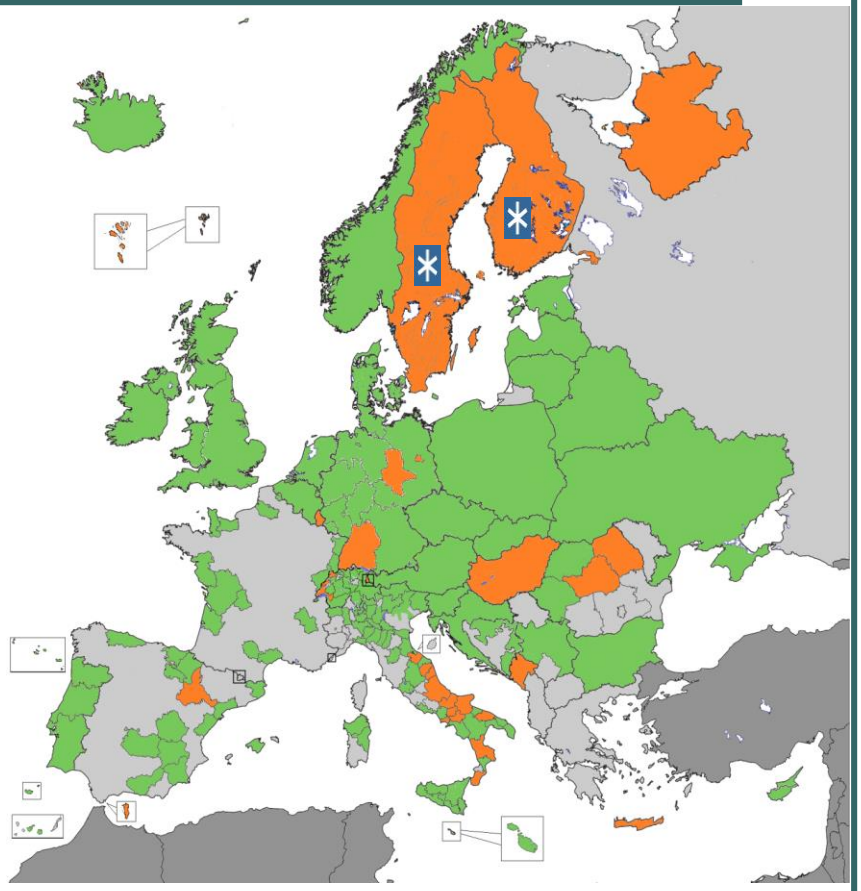
EUROCOURSE and ENCR Working Party

Position paper on the Commission's proposal for a General Data Protection Regulation - September 2012

"Research in public health is a fundamental pillar for the planning, management and evaluation of healthcare systems, as well as for disease prevention. The main roles for population-based cancer registries are measuring the public health impact and the burden of cancer, cancer survival and cancer control. During the last 50 years the benefits of collecting and using complete records on morbidity and mortality have been shown repeatedly. The importance of cancer registries is increasing in both planning and quality assessment of health care…"

…….. 2015 data call





General Data Protection Regulation (GDPR)

- Regulation (EU) 2016/679
  - update the existing Data Protection Directive of 1995 to a Regulation
  - harmonization of EU data protection legislation

- Valid since May 25th 2018