

Fostering cancer prevalence estimates in Europe to boost the European cancer information system



TYPE
STATUS

Implementation plan – Guidance for implementation
Fully implemented and ongoing

LAST
UPDATE

January 2022

EUROPE • CANCER REGISTRIES
Survivorship • Epidemiology

PROBLEM & OBJECTIVE

PROBLEM Cancer survivors are a growing population with heterogeneous health needs depending on the phase of care. Unlike incidence or survival, complete cancer prevalence information is only sparsely available in Europe since its estimation requires specific expertise and resources.

OBJECTIVE To promote systematic provision of complete cancer prevalence indicators in Europe through collaborative studies and training programs involving population-based cancer registries in different MS.

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KEY COMPONENTS / STEPS

- EUROCARE-6 study dataset reporting data from 109 European cancer registries in 29 countries. Finalization of quality checked and standardized dataset.
- Estimated target prevalence indicators: i) limited-duration prevalence ii) complete prevalence iii) time projections to 1/1/2020.
- Target prevalence indicators were estimated for 32 cancer entities by sex, age, year, disease duration (2,5,10,15, 20, 25+ years), country, European Pool (29 countries) and EU-27 [8].
- Validation of the methodology to derive complete prevalence projections against observed prevalence data from the long term established Nordic cancer registries [9].
- An e-learning on methods and software to estimate complete cancer prevalence starting from observed limited-duration prevalence was offered to the European cancer registries. The course was organised in collaboration with ENCR and the JRC [10].

KEY CONTEXTUAL FACTORS

- Country-specific regulations on population-based cancer registration (national or regional).
- European Network of Cancer Registries (ENCR) and Joint Research Center (JRC) acting as scientific secretariat of ENCR [1].
- EUROCARE network aimed at monitoring cancer survival and prevalence by country in Europe [2].
- Joint Call for Data of ENCR-JRC addressed to European cancer registries to serve European studies on cancer incidence, survival and prevalence [3].
- European Cancer Information System (ECIS): web-portal managed by ENCR-JRC and reporting indicators on cancer epidemiology in Europe [4-7].
- Prevalence by disease duration identifies groups with different health care needs.

MAIN IMPACTS / ADDED VALUE

- Policy makers, health professionals, patients and citizens will benefit of a wider spectrum of representative indicators on cancer burden. Standardised information on cancer survivors at population level is needed to design and assess cancer control plans, to best allocate health resources and for Health Technology Assessment (HTA).
- Estimates on cancer survivors provide evidence to promote patients' social inclusion and rehabilitation, survivorship plans and quality of life assessment.
- Systematic prevalence information by country contributes to assess disparities in the Cancer Inequality Registry [11] and also inform initiatives to tackle patients' discrimination, such as the legislation on the Right to be Forgotten.
- iPAAC prevalence estimates will contribute to feed the European Cancer Information System (ECIS), the web portal managed by the JRC [4]. This is a first step to reach a more systematic dissemination in Europe.

LESSONS LEARNED

- Unlike incidence and survival, complete cancer prevalence can only be estimated through statistical methods (to recover long-term survivors beyond the limited observed follow-up). This represents a major obstacle for the registries in terms of expertise and resources.
- Joint analysis of European datasets increases data quality and allows to better exploit the big potential of cancer registries data which is often under-utilised for lack of resources and technical skills at the local level.
- Systematic provision of standardised and comparable indicators on cancer survivors at EU level is feasible through pan-European collaborative studies. Dedicated resources to collaborative studies and increasing capacity building at MS level are crucial to ensure a sustainable implementation.

REFERENCES & DOCUMENTATION

- European Network of Cancer Registries – ENCR
- EUROCARE study
- ENCR-JRC Call for Data 2015
- ECIS - European Cancer Information System
- ECIS - EPAAC book chapter 9
- 2009 Decision European Commission to adopt EPAAC recommendation to develop the ECIS
- EPAAC Consensus Document on ECIS "Roadmap for a Cancer Information System"
- Demuru E et al. Oral presentation. ENCR Scientific Meeting 2021 Conference Book
- NORDCAN: Cancer Incidence, Mortality, Prevalence and Survival in the Nordic Countries, Version 8.2 (26.03. 2019). Association of the Nordic Cancer Registries. Danish Cancer Society
- E-learning on population-based cancer prevalence
- European Cancer Inequality Registry

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