



European Cancer Registration

**Commission's Expert Group on Health Information
Luxembourg, 19 May 2015**

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Population-based cancer registries and their role in providing accurate and comparable data

Record all new cancers diagnosed in the population of a well-defined geographic area, within a specific time interval

→ To assess the magnitude of the cancer burden and its evolution

→ To evaluate the impact and effectiveness of cancer control measures and for policy implementation (both ex ante and ex post)

↓
INCIDENCE

↓
PREVALENCE

↓
SURVIVAL

↓
MORTALITY

→ To provide a basis for research on cancer causes and outcomes

Situation prior to 2013 at EU level

- Project-based – leading to continuity and infrastructural issues;
- Stakeholder fragmentation;
- Non-harmonisation of data-cleaning standards;
- Plurality of databases;
- Information system servicing only quite specific needs;
- Lack of means for supporting European Network of Cancer Registries (ENCR);
- Outdated information at European level.

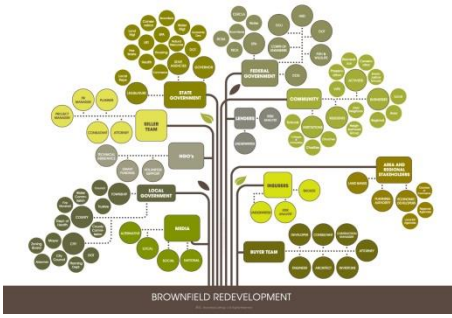
Work in progress

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- Establishment of revamped basic infrastructure (data portal; harmonised data-quality check protocol; data cleaning software tools) – critical for the imminent call for updated European cancer data (May 2015);
- Further harmonisation of registration practices;



- Rationalisation of data-submission process and more streamlined process for handling data-usage permissions;
- Stakeholder inclusion and coordination of stakeholder initiatives and activities.



Near-term objectives



- Broadening the data-usage base;
- Agreement on extended European metadata set and associated quality standards;
- Establishment of ethical committee to agree statistical usage;
- Development of statistical-analysis and data-visualisation tools for comparison between regions;
- Collection and preparation of standardised European cancer data to serve as comprehensive EU data for global use (e.g. within the cancer incidence in five continents WHO-IARC)
- Preparing the groundwork towards a European Cancer Information System (ECIS) in follow up of the European Partnership for Action Against Cancer (EPAAC).

Challenges

- Some countries do not have well-functioning population-based cancer registries, and some regions have no registries at all . . . ;
- Some cancer registries are often under-funded and many face loss of continuity in funding. Previous well-functioning, active cancer registries have become mediocre registries as a result with sub-optimal data quality;
- Tighter EU regulations on personal data may well impede cancer registration if specific provision is not made for them. Hot topic in light of the current discussions on the proposed new EU regulation on data protection;



Realising ECIS

Important infrastructural elements to address

- Development of a concept for a sustainable business model for registries (not confined solely to cancer registries) and raising political awareness of importance of registries for steering evidence-based health policy;
- Agreement on overall framework/ architecture (c.f. the INSPIRE model) in full liaison with wider stakeholder groups (WHO, environmental institutes, Eurostat, etc.);
- Addressing the quality and reliability of primary data-feed processes;
- Interface mechanisms with other data sources (environmental, socio-economic, contagious diseases, other disease registries . . .);
- Issues requiring political input as well as technical.





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