

# Integrating cancer registry data on care with administrative and health information sources in Europe



TYPE  
STATUS

Guidance for implementation  
Pilot

LAST  
UPDATE

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ITALY • NATIONAL • REGIONAL  
Cancer care

## PROBLEM & OBJECTIVE

**PROBLEM** Data on care are differently available to population based cancer registries (CRs), they are poorly standardized and expensive to collect. The time lag between data collection and analyses impairs the use of results by clinicians or health planners. Within and between country differences in legislation framework impairs exchange of data for common analyses.

**OBJECTIVE** This pilot evaluates the feasibility of linking individual patients' data with current administrative and health data in order to:

- describe the complete pathway of cancer patients;
- assess the adherence to standard clinical guidelines.

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## KEY COMPONENTS / STEPS

- Identification of relevant indicators of cancer care.
- Definition of study protocols and approval by ethical committees.
- Engagement of cancer registries.
- Discussion with other stakeholders (e.g., oncologists, cancer registries).
- Identification of health databases accessible to CRs and of the most suitable approach to be used (e.g., centralized vs. decentralized data analyses with local databases).
- Centralization in a common repository tested using Italian CR data.
- Selection of the relevant health data to be linked under each individual patient's record.
- Development of algorithms to derive key indicators of cancer care and adherence to clinical guidelines, based on the ICD9-CM, ATC codes and EPICOST lists of procedures, interventions, treatments.

## KEY CONTEXTUAL FACTORS

- Computerised sources of information are available to all European CR, but with different extent.
- CR based "high-resolution" studies, collecting more detailed clinical data than those routinely available (on stage at diagnosis, diagnostic procedures and treatment), have been conducted in Europe to explain reasons of outcomes differences and assess the adherence to standard clinical guidelines [1-4].
- The linkage of CR data with current administrative and health data enlarges the potentiality of CR information on care and shortens the interval between data collection and delivering results.
- In Italy we obtained indicators of cancer care in different disease phases (diagnostic, treatment, end of life) by linking individual patient's records with multiple health data sources (hospital and emergency admissions, exemption files, ambulatory services, drug prescriptions) [5].

## MAIN IMPACTS / ADDED VALUE

- Pilot WP7.2 developed a model to study different phases of the entire pathway of cancer care, replicable in other countries where similar health databases are available.
- Information to tackle inequalities in cancer care and outcomes can be enhanced by this approach.
- Data collection would be less expensive and time-frame for obtaining results shortened.

## LESSONS LEARNED

- CR data should cover cancer care monitoring.
- Methods to ensure interoperability of different dataset within and across countries should be developed and promoted, provided the willingness of data providers and competent authorities.
- There is need to develop procedures to access health data based on a common legal framework.
- Need to harmonize GDPR interpretation and country-specific implementations of data protection.

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