

Creating legal basis and harnessing the existing administrative datasets to produce cancer information effectively: example from the Czech Republic



TYPE	Legal framework	LAST UPDATE	December 2021	CZECH REPUBLIC • NATIONAL Cancer care
STATUS	Fully implemented and ongoing			

PROBLEM & OBJECTIVE

PROBLEM Functional cancer registry is an essential cancer control infrastructure. Unfortunately, traditional cancer registries often lack important clinical information on cancer care, don't offer optimal timeliness and demand extensive workforce.

OBJECTIVE Our aim was to establish legal and technical framework to optimize the use of the traditional cancer registry, strengthen secondary use of available administrative data from healthcare and establish national population-based integrated system harnessing data linkages.

KEY COMPONENTS / STEPS

- Approval of the amendment of the Act on Health Services, establishing legally and technically the National Registry of Reimbursed Health Services, which help to integrate reimbursement data through health insurance companies to the NHS.
- Enacting the new methodology of Czech National Cancer Registry considering integration of epidemiological, administrative, laboratory and clinical data collections.
- Approval of the Act on eHealth, strengthening the reference registries (of providers, healthcare professionals and patients) and interoperability of information systems.
- Establishing the essential universal technical infrastructure (Information and Data Departmental Interface).
- Establishing the data analysis process to support particular cancer control actions (e.g. cancer screening programmes, which greatly benefit from data linkages).

KEY CONTEXTUAL FACTORS

- The Czech Republic have long-term functioning high-quality traditional population-based national cancer registry. This registry is, according to the Act on Health Services, part of the National Health Information System (NHIS), a unified data framework allowing for data linkages. The NHIS is administered by the Institute of Health Information and Statistics of the Czech Republic (UZIS). Health care providers are obliged by the law to collect data, nowadays usually through sharing data from the hospital information systems, in line with the methodological documents issued by UZIS. Most of cancer care is reimbursed from public health insurance system, where health insurance companies and providers collect data describing the cancer care provided.

MAIN IMPACTS / ADDED VALUE

- Obtaining comprehensive cancer information (comprising the entire continuum from vaccination and cancer screening to end-of-life care) to steer national cancer control programme and assure the quality of the care, but at the same time minimizing the administrative burden stemming from creating new statistical investigations. The information system is being built and will be evaluated to ensure its optimal setting.

LESSONS LEARNED

- It is vital to include all stakeholders to reach consensus regarding the legal framework, obligations and benefits for all actors. Key stakeholders include the Ministry of Health, health committees of the Parliament, health insurance companies, healthcare providers, expert medical societies, office for personal data protection, patient advocate organizations. Key barrier is a potential concern about linkages of significant amount of data. Transparency and credibility of the data governing body and providing appropriate safeguards, data minimization principles, etc. is important. Moreover, the value of integrating the data must be demonstrated to stakeholders.

CONTACT

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REFERENCES & DOCUMENTATION

- General information about the Czech National Health Information System
- Description and implementation guide: Czech comprehensive ICT model integrating multiple data sources
 - <https://www.ipaac.eu/res/file/outputs/wp7/comprehensive-ict-model-multiple-data-sources.pdf>
 - <https://www.ipaac.eu/res/file/outputs/wp7/comprehensive-ict-model-multiple-data-sources-a1.pdf>
 - <https://www.ipaac.eu/res/file/outputs/wp7/comprehensive-ict-model-multiple-data-sources-a2.pdf>

- EPAAC, European Guide on Quality National Cancer Control Programmes
- Cancon Guide, Integrated Cancer Control
- Cancon Guide, Cancer Screening

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