

EU2022.CZ

Czech Presidency of the Council  
of the European Union



**iPAAC**  
INNOVATIVE PARTNERSHIP  
FOR ACTION AGAINST CANCER



# Secondary use and linkages of cancer data: iPAAC pilot studies

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**Future of cancer registries and European Health Data Space**

Roberta De Angelis, Italian National Institute of Health, Leader iPAAC WP7 on Cancer Information



Co-funded by  
the Health Programme  
of the European Union



# BETTER CANCER INFORMATION TO IMPROVE CANCER CARE



**Work Package 7** **Actions to enhance information from population-based cancer registries** to better support cancer surveillance and care

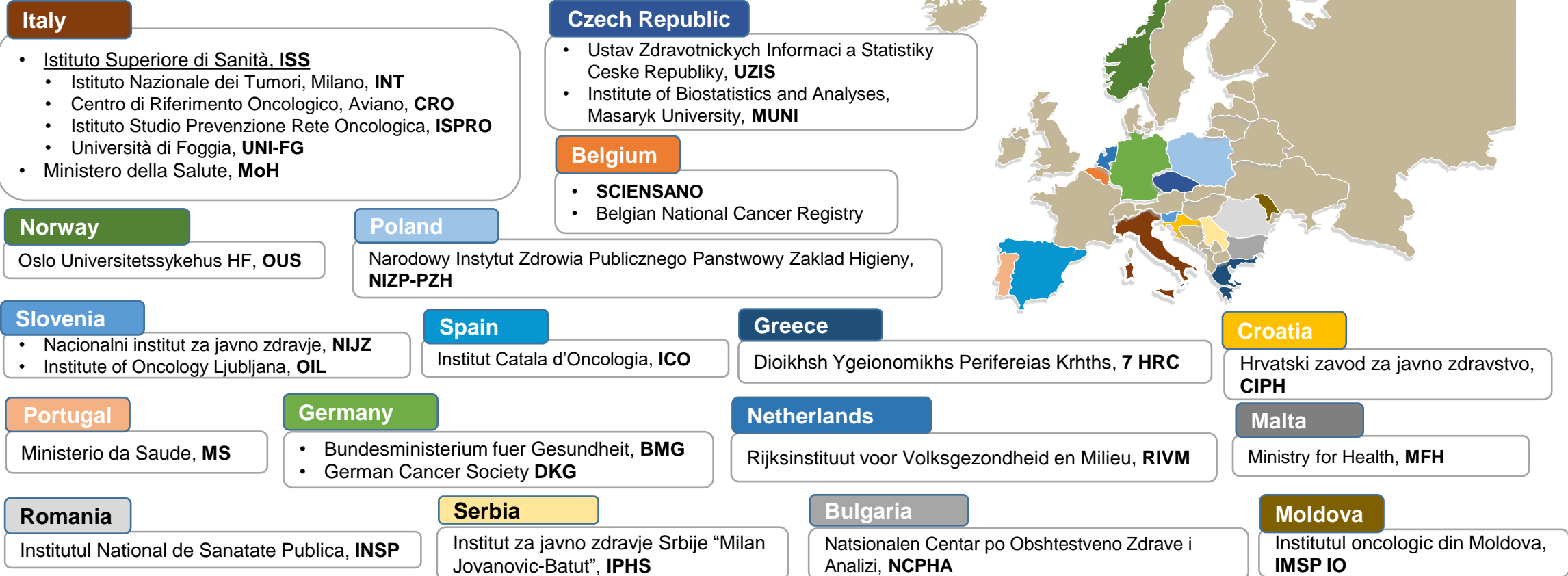
**1. Better use current registries datasets → actions to foster dissemination and use of cancer prevalence estimates in Europe**

**2. Enriching current registries datasets through secondary use of data → piloting linkage with multiple data sources to derive key indicators for cancer control**



# IPAAC WORK PACKAGE 7 PARTNERSHIP

## 17 European countries



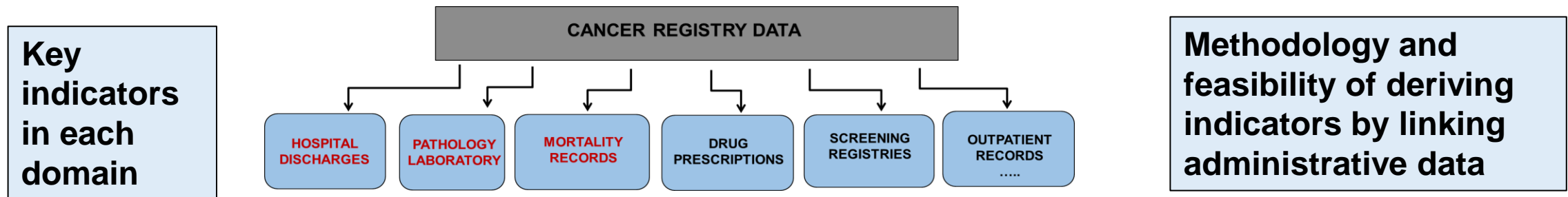
**Key Stakeholders: ENCR, JRC**

**Subcontracts: AIRTUM, ECPC, OECI**

# THREE EUROPEAN PILOTS

## Advancing cancer registries data through linkage with multiple data sources

- 3 pilots involving European registries from different countries (national or regional population coverage: IT, NO, PL, BE, SLO, GR, SP)
  - **Quality of care and adherence to standard protocols** ([Task 7.2](#)) M.Sant, INT IT
  - **Cost profiles by phase of care** ([Task 7.3](#)) S. Francisci, ISS IT
  - **Long-term care and late effects in AYAs survivors** ([Task 7.4](#)) A. Trama, INT IT



# IMPLEMENTATION OF WP 7 PILOTS

## Pilots 7.2-4 implementation steps

1. Feasibility and adaptation to country-specific data sources

2. Individual linkage of registries patients data

3. Data analysis : Quality Checks and indicators

4. Validation

- A **survey** to CRs to census accessible data flows and contents
- A specific **study design** was developed: i) **cross-sectional** for quality and costs of care, ii) **longitudinal** for AYA survivors
- **Common methodologies/standards** were agreed and **adapted** to country-specific data sources
  - a. **Centralised applications**: registries sent linked data to the leading task teams for the analyses
  - b. **De-centralised applications** : data linkage and analyses performed in-house by the registries





**Tasks 2-3**  
**CROSS SECTIONAL DESIGN**  
*Prevalent cases are linked to detect cancer related events occurring in a definite time interval*

**Task 4**  
**LONGITUDINAL DESIGN**  
*AYAs survivors cohorts are linked prospectively to detect all events marking late effects*

# MAIN OUTCOMES: STANDARDISED INDICATORS AND METHODOLOGY

|                       | Indicators                                | Data source           |
|-----------------------|---|-----------------------|
| <b>skin melanoma</b>  | SIR of multiple cancers                   | multiple and of       |
|                       | — Percent                                 |                       |
|                       | — Percent (Breslow)                       | Inform diseases AYA c |
|                       | — Percent thickness                       | Mortal cancer         |
| <b>pancreatic can</b> | RR of low education                       | Inform survive        |
|                       | — Percent                                 |                       |
|                       | — Percent resecta                         | Inform and fo         |
|                       | — Percent status; unskilled working class | Inform class t popula |
| — Percent commo       | RR of using social/financials benefit     | Inform AYA c          |

Co-funded by the Health Programme of the European Union

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**Results of the iPAAC Work Package7 pilots: enriching cancer registry data**

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Author(s): Lead author: Annalisa Trama, Silvia Francisci, Milena Sant  
Co-authors: Alice Bernasconi, Simone Bonfaruzzo, Laura Botta, Roberto Lillini, Anna Gigli, Stefano Guzzinati, Tania Lopez, Sandra Mallone, Daniela Pierannunzio, Andrea Tavilla

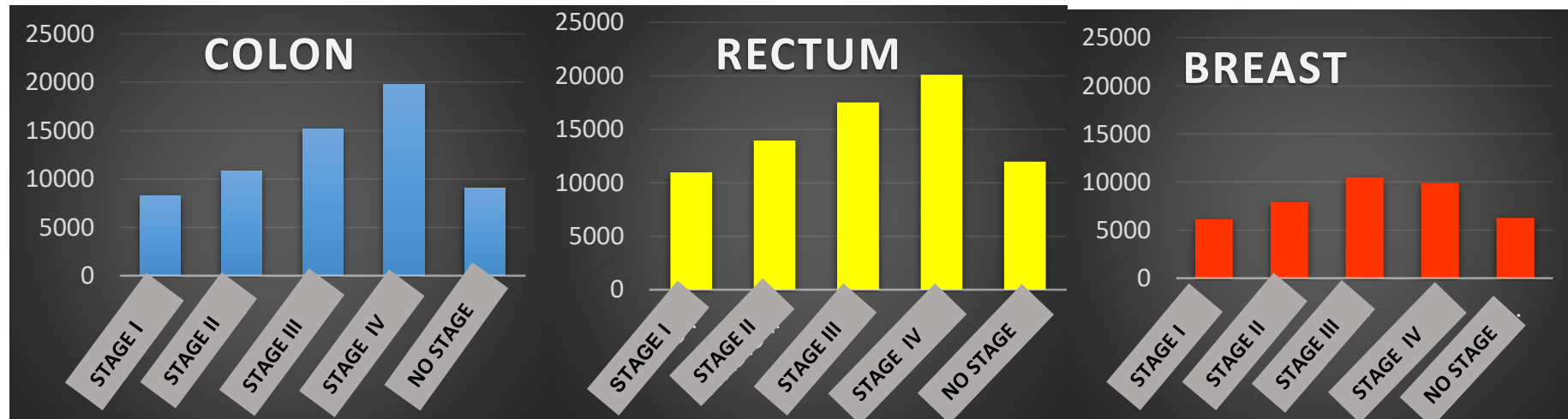
Version: 2.0  
Date: 21. 12. 2021

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Results Tasks 7.2; 7.3; 7.4 Page 1 of 22

| Source  |
|---|
| registry database   |
| discharge records: hospitalisation for a specific proxy of the disease occurrence (standardised hospitalisation ratio).   |
| registry  |
| Education ISCED classification  |
| Marital status classified as: married, not married, widowed, single   |
| Occupational conditions classified as Employed, unemployed/looking for first occupation, Housewife, Student, ; occupational class classified as Bourgeoisie, Middle class, Self-employed with employees, Self-employed without employees, Skilled working class, Unskilled working class. |
| INAIL/INPS (collaboration in progress). In other cases to be defined.   |

# ANNUAL AVERAGE COST PER PATIENT BY STAGE AND CANCER - ITALY



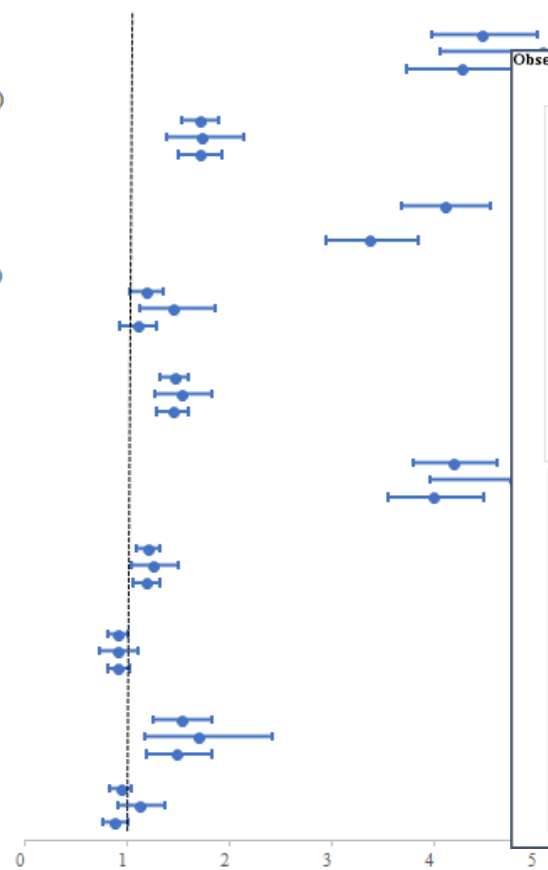
- **COSTS (€) related to HOSPITAL ADMISSIONS ONLY and to FIRST YEAR AFTER DIAGNOSIS (Initial Phase)**
- **COSTS ARE HIGHER FOR ADVANCED STAGES (especially for COLORECTAL cancers)**



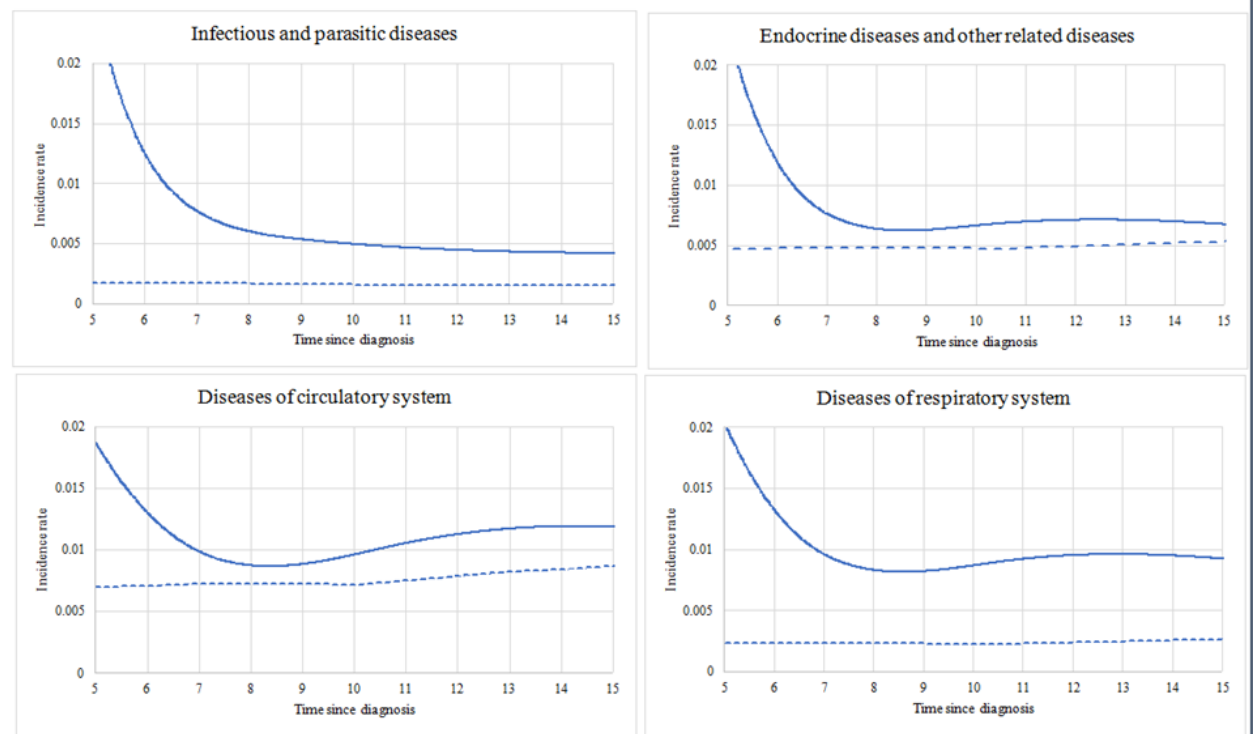
# EXCESS HOSPITALISATION RISK IN AYA SURVIVORS OF HAEMATOLOGICAL CANCERS

## Standardized Hospitalization rate Ratios

|   |                   |
|---|-------------------|
| Infectious and parasitic diseases             | 4.46 (3.97; 5.01) |
| Leukemias                                     | 5.05 (4.06; 6.29) |
| Lymphomas                                     | 4.27 (3.73; 4.89) |
| Endocrine diseases and other related diseases | 1.70 (1.53; 1.90) |
| Leukemias                                     | 1.72 (1.38; 2.13) |
| Lymphomas                                     | 1.70 (1.50; 1.93) |
| Diseases of blood-forming organs              | 4.10 (3.69; 4.55) |
| Leukemias                                     | 6.48 (5.45; 7.70) |
| Lymphomas                                     | 3.36 (2.94; 3.84) |
| Diseases of nervous system and sense organs   | 1.18 (1.03; 1.35) |
| Leukemias                                     | 1.45 (1.13; 1.86) |
| Lymphomas                                     | 1.09 (0.93; 1.29) |
| Diseases of circulatory system                | 1.46 (1.33; 1.60) |
| Leukemias                                     | 1.52 (1.26; 1.83) |
| Lymphomas                                     | 1.44 (1.29; 1.60) |
| Diseases of respiratory system                | 4.18 (3.79; 4.62) |
| Leukemias                                     | 4.77 (3.96; 5.75) |
| Lymphomas                                     | 3.99 (3.55; 4.48) |
| Diseases of digestive organs                  | 1.20 (1.10; 1.32) |
| Leukemias                                     | 1.25 (1.04; 1.50) |
| Lymphomas                                     | 1.18 (1.06; 1.32) |
| Diseases of urinary and genital organs        | 0.91 (0.82; 1.00) |
| Leukemias                                     | 0.90 (0.73; 1.11) |
| Lymphomas                                     | 0.91 (0.81; 1.02) |
| Diseases of skin and subcutaneous tissue      | 1.52 (1.26; 1.83) |
| Leukemias                                     | 1.68 (1.17; 2.42) |
| Lymphomas                                     | 1.47 (1.18; 1.82) |
| Diseases of bone, joint and soft tissue       | 0.93 (0.83; 1.04) |
| Leukemias                                     | 1.11 (0.90; 1.36) |
| Lymphomas                                     | 0.87 (0.76; 1.00) |



Observed (solid) and expected (dashed) hospitalization rates by time since diagnosis by type of hospitalisation



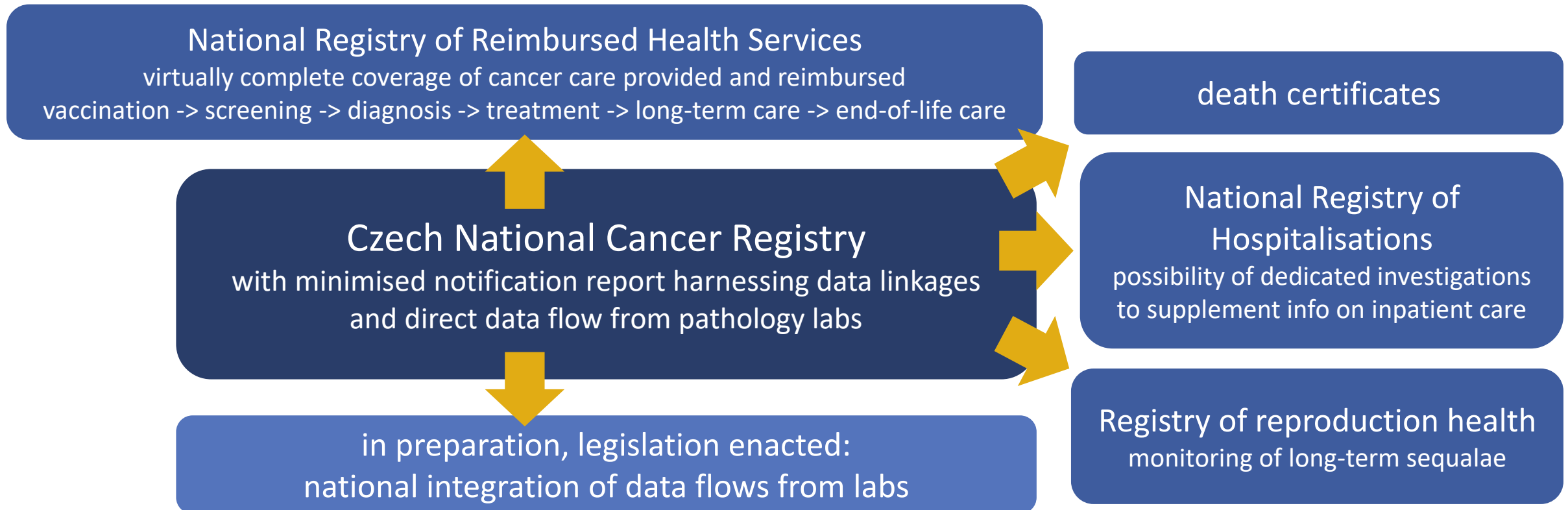


# CZECH PILOT ON CANCER DATA INTEGRATION AT THE NATIONAL LEVEL



Institute of Health Information and Statistics of the Czech Republic (UZIS) Task 7.5 L. Dusek, O. Majek

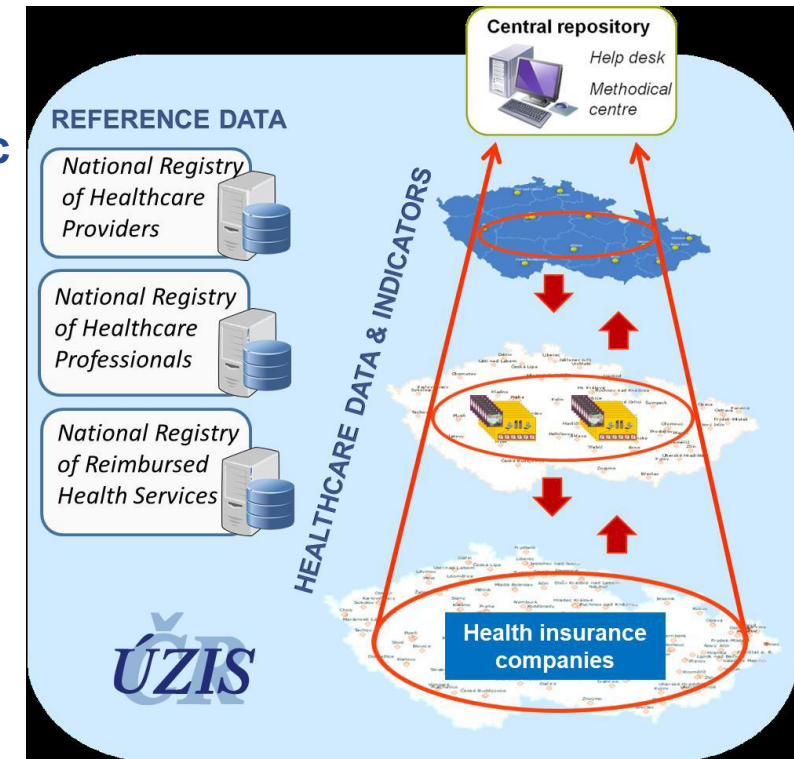
- **Czech comprehensive ICT model integrating multiple data sources**



# PILOTING CANCER DATA INTEGRATION AT THE NATIONAL LEVEL

## Institute of Health Information and Statistics of the Czech Republic (UZIS)

- Czech comprehensive ICT model integrating multiple data sources  
**DESCRIPTION AND IMPLEMENTATION GUIDE (iPAAC deliverable)**
  - Legislation to establish the comprehensive model
  - Organizational background for cancer control in the Czech Republic
  - Contents of the comprehensive ICT model
    - architecture of the National Health Information System
    - reference data background
    - Czech National Cancer Registry
    - other data sources and registries
  - Functionalities of the model: opportunities for producing relevant cancer information (key indicators recommended in iPAAC WP7)



# PILOTING CANCER DATA INTEGRATION AT THE NATIONAL LEVEL



## Institute of Health Information and Statistics of the Czech Republic (UZIS)

- **Czech comprehensive ICT model integrating multiple data sources**  
**STEPS FOR IMPLEMENTATION**
  - Legislation and associated documents: data governance and organization of cancer care
  - Establishing the technical infrastructure
  - National workshops and dissemination: planning and presenting results of pilot studies (distribution of cancer care, prostate cancer surgery, impact of COVID-19 on care, monitoring and evaluation of cancer screening programmes, etc.)
  - Use of the system for informing preparation of the Czech National Cancer Programme 2022-2030
  - Use of the system for monitoring of cancer centres and networks (stepwise implementation)
  - Future interlink with National Health Information Portal and open data platforms



Enriching  
Registries  
Information

through

optimised  
secondary-  
use of data  
and  
linkages

## Strategic role of Cancer Registries (CRs) data for cancer care and research

- Widening the **scopes of registration** to support quality of care improvement is feasible and cost-effective. This process already started in some countries and **mutual learning** is valuable.
- CRs present several **strengths**: **representative** population coverage, **accurate** selection of oncological diseases (strongly relying on pathology labs); experience in **quality certified** data collection according to international standards (IARC, ENCR, IACR); access to **multiple digitalized sources** to fulfill their present mandate; possibility to **follow up** cases in the long term
- CRs datasets provide representative patients cohorts suited for both *longitudinal* and *cross-sectional* studies and can be considered a *cornerstone* for comprehensive cancer information systems. Real-world and clinical datasets are not in competition they are **complementary** and should be **integrated**

# RECOMMENDATIONS


## Enriching Registries Information

through

optimised  
secondary-  
use of data  
and  
linkages

- **Legal background for registration and data re-use** is a key aspect. It limits/impairs/delays access to data (GDPR local application). **Data governance** at national/European level should be **supportive and open to data sharing** within and between countries. Discussion with national/European competent authority **to build trust** on data linkage and re-use
- **Increasing interoperability** is essential. Lack of common standards limits data interconnection. Innovative methods and common data models should be developed to ensure interoperability between multiple key data sources
- **EHDS initiative should incorporate the registries.** High added value: integrated registries support complex bodies delivering care (like CCCNs) and national systems for comprehensive (long-term) cancer surveillance

# FOR FURTHER REFERENCES



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## WORK PACKAGE 7 – CANCER INFORMATION AND REGISTRIES

WP leader: Italian National Institute of Health, Italy (Roberta De Angelis)

### Outputs

Advancing registries data through integration with administrative data sources: mapping data sources available for linkage with registry data

- [Open document](#) (PDF file, 900 kB)

A survey on available electronic data sources for individual linkage was conducted among the European registries involved in iPAAC WP7. Overall, 27 population-based CRs from 14 different countries replied to the questionnaire. Health administrative data sources available for linkage to European cancer registries are not homogeneously accessible and used. This situation reflects heterogeneous health care systems, data owners, legal frameworks and socio-economic conditions. A significant proportion of registries, however, incorporates these data sources in their routine activity and for research purposes. Part of these sources are sufficiently standardised in terms of coding classification and data structure and can be considered valid for deriving comparable indicators on cancer care

### Integrating cancer registry data on quality of care

- [Open document](#) (PDF file, 420 kB)


Pilot 7.2 evaluates the feasibility of linking population-based cancer registries datasets with administrative and health data sources to describe the *complete pathway* of cancer patients from diagnosis to rehabilitation or terminal care and to assess the *adherence* of the administered treatments to *standard clinical guidelines*.

### WP7 description and objectives

The goal of this work package is to advance population-based cancer registries information to better support evidence-based cancer surveillance and care.

Cancer registries provide *accurate* and *representative* information on cancer patients, *real-world* data, without any selection due to age, socio-economic or co-morbid condition, granting by design longitudinal follow up, even in the long term. They are not only essential in cancer epidemiology but they have the potential to support quality improvement in cancer care and provide multidimensional information on cancer survivorship.

Despite their potential cancer registries data are under-utilised and this work package aims at developing methods and tools to act in two directions:



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## Roadmap on Implementation and Sustainability of Cancer Control Actions

ROADMAP GUIDE LIST OF COUNTRIES LIST OF DOMAINS ABOUT ROADMAP

Use fulltext search, domain selection or interactive map to find an example, an implementation plan and related documents

Smoking



### Cancer registries and administrative databases to study the effects of cancer in AYA cancer survivors

TYPE: **STATUS** **UPDATE** January 2022 **EUROPEAN COMMISSION**

**PROBLEM & OBJECTIVE**

**KEY COMPONENTS / STEPS**

**KEY CONTEXTUAL FACTORS**

**MAIN IMPACTS / ADDED VALUE**

**LESSONS LEARNED**

**CONTACT**

<https://www.ipaac.eu>

