

# Participation of **SLOVENIAN CANCER REGISTRY**

at

**iPAAC Joint Action**

**Work Package 7: Cancer Information and Registries**

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**OBVLADOVANJE RAKA V EU – KAKO NAPREJ**  
Ljubljana, 31 May



**iPAAC**  
INNOVATIVE PARTNERSHIP  
FOR ACTION AGAINST CANCER

# WP 7 Cancer Information and Registries

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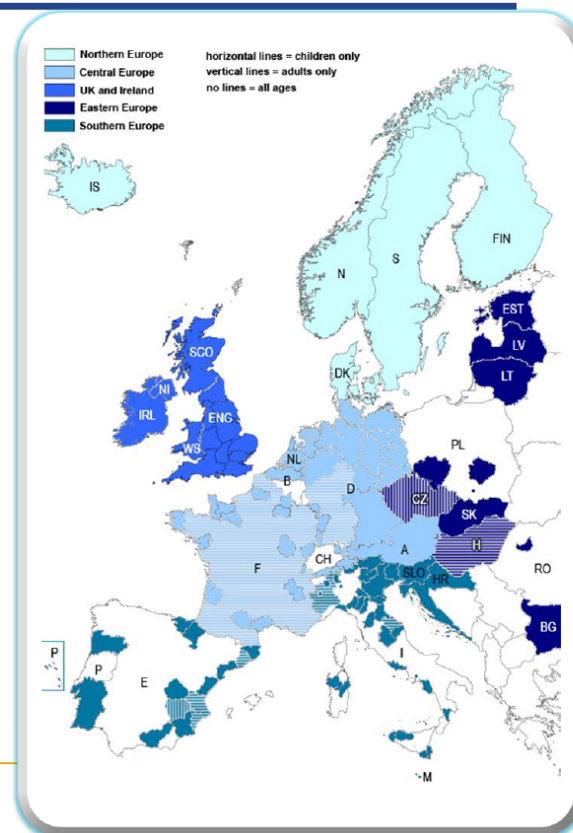


Co-funded by  
the Health Programme  
of the European Union

## CANCER REGISTRIES: A KEY INFORMATION SYSTEM FOR CCC



- Un-biased, accurate, representative data. Indispensable for epidemiological research and evidence-based cancer control
- **Integration with other health data to collect clinical information on the entire pathway of care is still a challenge**
- Room to improve the potential of CR in most MS and to strengthen their support to address clinically relevant issues



## WP-7 OBJECTIVES



Actions to enhance population-based cancer information systems to better support evidence-based comprehensive cancer care

### 1. To advance current registries datasets Task 1-5

Piloting the integration with *clinical and administrative electronic data* in order to derive key indicators on cancer care pathway and costs

### 2. To expand information available from current registries datasets Task 6

Promoting the use of more informative epidemiological indicators on cancer prevalence at European MS level

# 1. ADVANCING REGISTRIES DATASETS



Task 1 **Mapping key administrative and clinical data sources**  
to integrate registries data

## Task2

Pilot study to  
integrate data on  
**cancer pathways**

## Task3

Pilot study to  
integrate data on  
**cancer costs**

## Task 4

Pilot to integrate  
data on **long term**  
**follow up of**  
**cancer survivors**

## Task 5

ICT model piloting a  
national cancer care  
information system by  
**integrating multiple**  
**data sources**

# WP-7 PARTNERSHIP BY TASK



	<b>Task 1: Mapping data source</b>	<b>Task 2: Pilot care pathways</b>	<b>Task 3: Pilot cancer costs</b>	<b>Task 4: Pilot long-term follow-up</b>	<b>Task 5: Pilot ICT model</b>	<b>Task 6: Indicators on cancer prevalence</b>
<b>Task Leader</b>	<b>INT, Italy</b>	<b>INT, Italy</b>	<b>ISS, Italy</b>	<b>INT, Italy</b>	<b>UZIS, Czech Rep</b>	<b>ISS, Italy</b>
<b>Partners</b>	<ul style="list-style-type: none"> <li>ISS, UNI-FG, ISPRO, Italy</li> <li>UZIS, MUNI, Czech Rep</li> <li>IPHS, Serbia</li> <li>NIPH – NIH, Poland</li> <li>NIJZ (OIL), Slovenia</li> <li>NCPHA, Bulgaria</li> <li>MFH, Malta</li> <li>IMSP, Moldova</li> <li>RIVM, Netherlands</li> </ul>	<ul style="list-style-type: none"> <li>ISS, UNI-FG, ISPRO, Italy</li> <li>NIJZ (OIL), Slovenia</li> <li>7HRC, Greece</li> <li>RIVM, Netherlands</li> <li>ICO, Spain</li> <li>NIPH – NIH, Poland</li> <li>INSP, Romania</li> </ul>	<ul style="list-style-type: none"> <li>INT, ISPRO, Italy</li> <li>BMG, Germany</li> <li>HZJZ, Croatia</li> <li>NIPH – NIH, Poland</li> <li>RIVM, Netherlands</li> <li>WIV-ISP, Belgium</li> <li>DGS, Portugal</li> </ul>	<ul style="list-style-type: none"> <li>ISS, Italy</li> <li>NIJZ (OIL), Slovenia</li> <li>BMG, Germany</li> <li>CRN (OUS), Norway</li> <li>RIVM, Netherlands</li> <li>INSP IOCN), Romania</li> <li>DGS, Portugal</li> <li>ICO, Spain</li> </ul>	<ul style="list-style-type: none"> <li>ISS, MoH, Italy</li> <li>IPHS, Serbia</li> <li>IMSP IO, Moldova</li> <li>HZJZ, Croatia</li> </ul>	<ul style="list-style-type: none"> <li>INT, CRO, ISPRO, MoH, Italy</li> <li>WIV-ISP, Belgium</li> <li>NCPHA, Bulgaria</li> <li>HZJZ, Croatia</li> <li>RIVM, Netherlands</li> <li>CRN (OUS), Norway</li> <li>NIPH – NIH, Poland</li> <li>INSP, Romania</li> <li>ICO, Spain</li> </ul>
<b>Sub-contracts</b>	<ul style="list-style-type: none"> <li>AIRTUM</li> </ul>	<ul style="list-style-type: none"> <li>OECI</li> <li>AIRTUM</li> </ul>	<ul style="list-style-type: none"> <li>AIRTUM</li> </ul>	<ul style="list-style-type: none"> <li>AIRTUM</li> </ul>	<ul style="list-style-type: none"> <li>ECPC</li> <li>AIRTUM</li> </ul>	<ul style="list-style-type: none"> <li>ECPC</li> <li>AIRTUM</li> </ul>

## Task 1 Mapping key administrative and clinical data sources to integrate registries data



*Information gathering form for the Cancer Registries (CR) participating in the Project iPAAC WP7*  
***TASK 1: mapping key data sources to integrate registries data***

(After filling out, save and send via email to: support.cr@istitutotumori.mi.it)

### 1. CR FEATURES

#### a) General Data

I. Name of the Cancer Registry

Cancer Registry of Republic of Slovenia

II. Country Slovenia

III. Full address Epidemiology and Cancer Registry, Institute of Oncology Ljubljana, Zaloška cesta 2, SI-1000 Ljubljana, Slovenia

IV. WEB Site http://www.slora.si/en/ and https://www.onko-i.si/eng/crs/

V. Director Vesna Zadnik, MD, PhD, professor of public health

# **SLOVENIAN CANCER REGISTRY**

## **proposal for participation**

**iPAAC Joint Action**

**Work Package 7: Cancer Information and Registries**

assoc. prof. Vesna ZADNIK, MD, PhD

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Rome, 12-13 March 2019



## Slovenian Cancer Registry

General cancer registry

Population-based

Compulsory notification

Follow-up through Central Population Registry

## Slovenian Cancer Registry: data sources

Notifications from all hospitals

Death Certificates, screening registries

Hospital IS: Institute of Oncology Ljubljana

National clinical melanoma registry



**NO  
AUTOMATIC  
LINKAGE**

**AUTOMATIC**

## Task2

### Pilot study to integrate data on cancer pathways

#### AIMS OF THE PILOT STUDY - TASK 7.2

This pilot study will evaluate the **feasibility of linking individual patient's data included in the participating population-based CRs, with administrative and health data**, in order to:

- 1) describe the complete pathway of cancer patients from diagnosis to rehabilitation or terminal care, including the use of health care resources at the end of life;
- 2) assess the adherence of the administered treatments to standard clinical guidelines.

# Slovenian Cancer Registry Pilot 7.2

- Skin melanoma cohort - *Slovenian CR*
  - Prevalence on date 31.12.2017
  - Diagnosed within last two years (from 1.1.2016 to 13.12.2017)
  - Follow up till 31.12.2018
- Clinical Melanoma Registry:
  - Details on melanoma treatment, all indicators on standard care (entire pathway; general and site specific)
  - Molecular status, mutation testing
  - Details on staging (eg. Breslow)
  - End of life QI:
    - Chemotherapy use in the last 2 weeks of life
    - Death in acute care hospital

## Slovenian Cancer Registry Pilot 7.2

- Causes of death - *Slovenian CR (already obtained from National Public Health Institute)*
- Vital status - *Slovenian CR (already obtained from Central Population Register)*
- EDI (SES) data – available estimation on small geographical level
- Hospital admissions (DRG) – unavailable

# Task2

## Pilot study to integrate data on cancer pathways

### For each tumour under study

- Type of hospital (oncological, general hospital, oncological department within general hospital) where patients received the main treatments

- **Indicators of quality of care at the end of life:** in this phase high hospitalisation or anticancer drugs use are considered indicator of inappropriate care (*Barbera et al. Quality of end-of-life cancer care in Canada: a retrospective four-province study using administrative health care data. Curr Oncol. 2015;22:341-55*):

At least one among

- a new hospital admission in the last 30 days of life,
- intensive care unit (ICU) admission in the last 30 days of life,
- chemotherapy use in the last 2 weeks of life,
- death in an acute care hospital

**Indicators of standard care for skin melanoma** (*Dummer R et al. Cutaneous melanoma: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. Ann Oncol 2015;26: v136-132.*)

At least one indicator among the following ones:

- Percentage of stage IV melanomas receiving mutation testing
- Percentage of melanomas with information on the maximum thickness in millimetres (Breslow)
- Percentage of melanoma patients with a tumour thickness of >1 mm receiving sentinel lymph node biopsy
- Percentage of metastatic melanoma patients treated with immunotherapy

## Task 4

Pilot to integrate  
data on **long term  
follow up of  
cancer survivors**

The **pilot 7.4** will focus on AYA (15-39 years at cancer diagnosis) cancer survivors (alive at least 5 years from the cancer diagnosis) with the following **objectives**:

- to define, in each country involved in this pilot, a cohort of AYA cancer survivors,
- to estimate the burden of late effects using data sources available and/or accessible by cancer registry,
- to assess the feasibility of comparing late effect indicators across the different countries involved in the pilot.

# Slovenian Cancer Registry Pilot 7.4

- All AYA cancers - *Slovenian CR*
  - Incidence cohort from 1980 to 2014
  - 5-years survivals
- Secondary primary cancers for AYA survival cohort - *Slovenian CR*
- Causes of death - *Slovenian CR (already obtained from National Public Health Institute)*
- Vital status - *Slovenian CR (already obtained from Central Population Register)*
- Primary treatment (not drugs)
- Late effects of cancer treatment for childhood cancer (0-14) – Late affect database
- Hospital admissions – unavailable
- SES data - unavailable

## Task 4

### Pilot to integrate data on **long term follow up of cancer survivors**

**Late effects that will be studied** include clinical and socio economic outcomes

#### 1) Clinical outcomes


- Multiple subsequent malignant neoplasms (overall and by cancer specific groups)
- Hospitalizations (overall and by cause specific such as: Infectious and parasitic diseases, Endocrine nutritional and metabolic diseases, and immunity disorders, Diseases of the blood and blood-forming organs, Diseases of the nervous system and sense organs...)
- Mortality (all cause and by specific cause such as Diseases of the nervous system and sense organs, Diseases of the circulatory system, Malignant neoplasms...)
- Infertility and/or complications of pregnancy, childbirth, and the puerperium
- Congenital anomalies

#### 2) Socio-economic outcomes

- Education level
- Marital status
- Household organization/social network (living independently; living alone, living together (partner in unmarried couple with and without children, partner in married couple with and without children); one-parent household and people living with relatives or others who are not partners).
- Utilisation of social/financial benefit (for unemployment, for disability)
- Occupation

In addition, we will check with CR the availability of sources with information about the treatment as a possible explicative variables of late effects.

#### **Indicators**

- 
- standardized mortality ratio (SMR)
  - standardized incidence ratio (SIR)
  - standardized hospitalization ratio (SHR)
  - odds ratio of attaining a low education level, of not getting married, of not benefiting of a social network, of being financially dependent, of being unemployed.