



# WP 7 Cancer Information and Registries

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## 1. **General introduction** on WP7 activities (*R. De Angelis*)

### **State of play of the different Tasks**

- 2. **Task 1-4** Piloting the integration of data sources (*R. De Angelis*)
- 3. **Task 5** ICT model in the Czech Rep to integrate multiple data sources to the National CR (*O. Majek*)
- 4. **Task 6**- Cancer prevalence in Europe (*E. Demuru*)

# 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 Tasks 1-5**

Piloting the *integration with administrative health data sources* to derive key indicators for cancer care management

## **2. To better use current registries datasets Task 6**

Promoting the use of indicators on *cancer prevalence* in Europe at MS level

# FROM EPAAC and CANCON to iPAAC



## Previous JA recommendations



- **European Cancer Information System (ECIS)**

Better coordination to overcome fragmentation of information in Europe and deliver comprehensive indicators on cancer incidence, mortality, survival and **prevalence**

- **Cancer survivorship care**

Collecting data on **clinical follow up and quality of life of cancer survivors** at the population level to improve survivorship and prevent late effects



**Need to enhance cancer information on the whole patients pathway**



# POTENTIAL OF POPULATION-BASED CANCER REGISTRIES



- ✓ well-established surveillance systems
- ✓ objective, accurate, representative
- ✓ indispensable for epidemiological research, for cancer plans and quality of care assessment

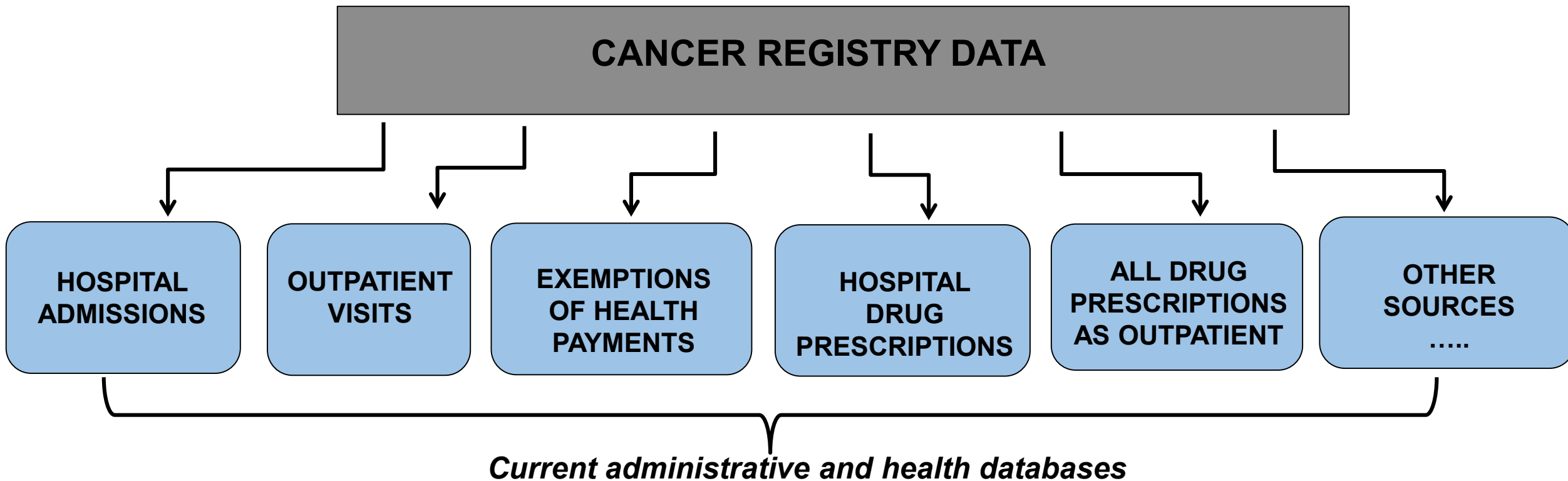


- ✓ partial population and scarce timeliness
- ✓ poor information on care details (*stage, first treatment, type of surgery,...*)<sup>1</sup>
- ✓ poor information after care (late effects & comorbidity)<sup>1</sup>

**Room to improve the potential of cancer registries and to strengthen their support to comprehensive cancer control**

<sup>1</sup> Siesling et. al. EUROCOURSE Project , Eur J Cancer 51 (2015) 1039-49

# INTEGRATION WITH ADMINISTRATIVE AND HEALTH DATABASES



**AIM : Methods and means to advance registry data through linkage with current health data flows**

# TASKS 2-5 EXPECTED OUTCOMES

Standardised procedures and requisites to integrate administrative health data with European cancer registries datasets and derive more advanced indicators

## Three pilots in Europe

**Task 2 – Quality of Care** - care pathways and adherence to standard guidelines - *INT- M. Sant*

**Task 3 – Costs of Care** - direct costs related to diagnosis, care and follow up along the entire disease pathway  
*ISS- S. Francisci*

**Task 4 – Long-term clinical follow up** - late effects in Adolescents and Young Adults (AYAs) cancer survivors -  
*INT- A. Trama*

## Task 5 Pilot in the Czech Republic

Complex ICT model integrating the **National Cancer Registry** with multiple data sources to support cancer care management

*MUNI-UZIS – L. Dusek*

# 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 administrative health data sources* to derive key indicators for cancer care management

## 2. To better use current registries datasets Task 6

Promoting the use of indicators on ***cancer prevalence*** in Europe at MS level



# WHY PREVALENCE INDICATORS ?

- Cancer survivors, a **growing** population in **ageing** societies
- Increasing costs of therapies challenges the **sustainability**
- Indicators quantifying health care demand are needed **BUT are not systematically available** in Europe

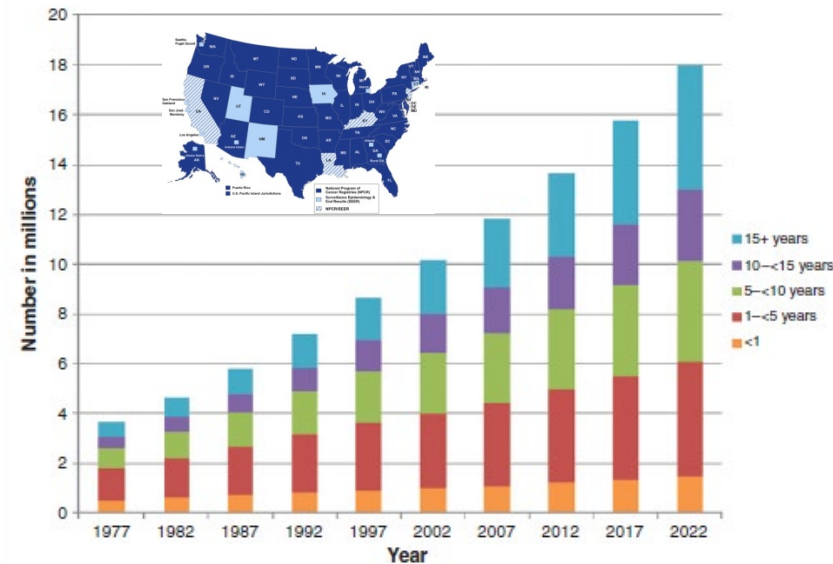
Published OnlineFirst March 27, 2013; DOI: 10.1158/1055-9965.EPI-12-1356

## CEBP Annual Report

### Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care

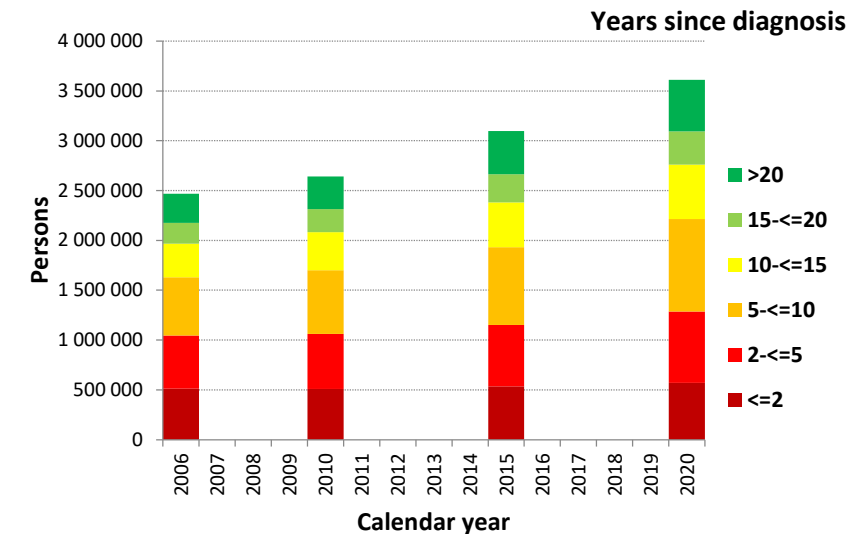
Janet S. de Moor<sup>1</sup>, Angela B. Mariotto<sup>2</sup>, Carla Parry<sup>3</sup>, Catherine M. Alfano<sup>1</sup>, Lynne Padgett<sup>3</sup>, Erin E. Kent<sup>4</sup>, Laura Forsythe<sup>5,6</sup>, Steve Scoppa<sup>7</sup>, Mark Hachey<sup>7</sup>, and Julia H. Rowland<sup>1</sup>

Cancer  
Epidemiology,  
Biomarkers  
& Prevention



## INCREASING CANCER PREVALENCE IN ITALY PROJECTIONS TO 2020

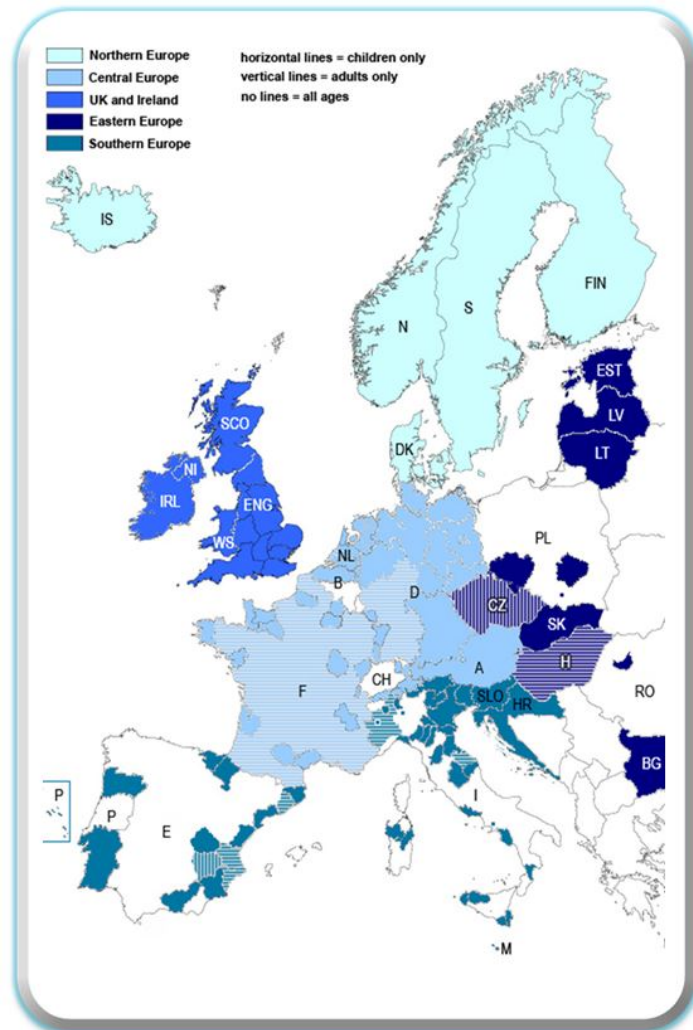
Guzzinati et al. BMC Cancer 2018



# TASK 6: EXPECTED OUTCOMES

- Promoting dissemination and use of comprehensive indicators on **cancer prevalence** in Europe at MS level (*ISS, R. De Angelis*)
  - by disease duration and complete (observed + **un-observed**)
  - time projections (**timeliness**)
  - prevalence by phase of care (initial, terminal, intermediate)
  - prevalence of cured patients, cure fraction and time to cure
  - life expectancy of cancer survivors
- Integrate the **European Cancer Information System (ECIS)** managed by ENCR-JRC with systematic cancer prevalence indicators by country/region in Europe

# DATA FROM THE EUROCARE-6 STUDY



**29 Countries**

**23 National Registries**

**102  
Cancer  
Registries  
- Adult cases -**

**6 Countries with local  
coverage (79 CRs)**

France, Germany, Italy,  
Portugal, Spain, Switzerland

# WP-7 OUTCOMES FOR THE ROAD MAP

## 1. ADVANCING REGISTRIES DATASETS

Task 1 **Mapping data sources** to  
integrate registries data

Task2 Pilot  
study on  
**cancer  
pathways**

Task3 Pilot  
study on  
**cancer costs**

Task 4 Pilot  
on **long term  
follow up of  
cancer  
survivors**

Task 5  
Piloting  
**integration  
of data  
sources** in a  
ICT model

## 2. BETTER USING REGISTRIES DATASETS

Task 6

P  
inf  
canc

### WP 7 Road Map

**Recommendations and strategies to  
implement policies to advance cancer  
information systems in MS**

## 1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

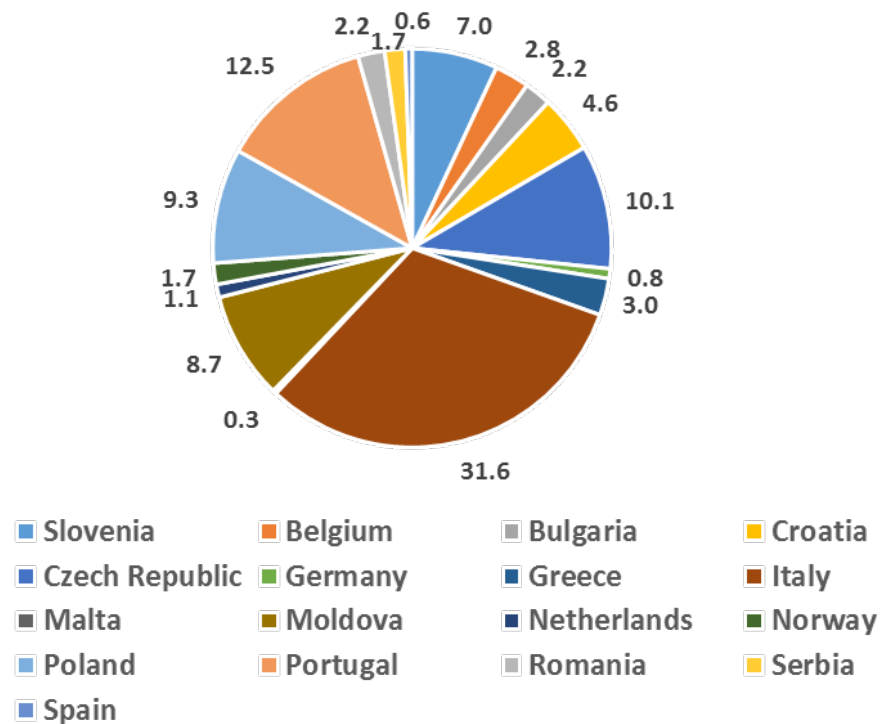
- Task 1 - Survey to map administrative data sources available to integrate cancer registry data
- Task 2-4 - Workshop to agree on the study protocols of the pilots to integrate data sources with registry data
- Task 5- Legal background approved for National ICT model integrating multiple data sources in the Czech Republic
- Task 6 - Validated methodology to derive first core cancer prevalence indicators by country in Europe

## 2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- Task 2-4 Standardised procedures to derive comparable indicators on quality of care, direct costs of care, and disease patterns of AYA survivors, through integration with administrative data sources (3 rd milestone meeting)
- Task 5 Implementation and validation of the National Health Information system integrating epidemiological, administrative and clinical records to support quality improvement in cancer care in the Czech Republic
- Task 6 Systematic delivery of up-to-date population-based indicators on cancer prevalence in MS to boost the European Cancer Information System (ECIS)

# WP-7 PARTNERSHIP: 17 COUNTRIES

## Staff effort per applicant (%)



## 3. Collaborating partners and stakeholders

- European Network of Cancer Registries (ENCR) and National Associations (ReDeCAN, AIRTUM)
- Joint Research Center (JRC) European Commission
- Patients Associations
  - ECPC, Pancreatic Cancer Europe-PCE
- National Research Institutions and Universities
  - Tor Vergata, CNR (IT)
  - Tampere (FI)

## 4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

- Common standards and procedures to advance registry-based information on the whole cancer pathway
- Legal requirements to access additional data sources and enhance the scope of cancer registration
- How to increase the interoperability between epidemiological, administrative, clinical data sources



## Tasks 1-4

# Advancing registries datasets through integration with multiple data sources

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G. Tagliabue, M. Sant, A. Trama Istituto Nazionale dei Tumori, Milan IT (INT)

S. Francisci, R. De Angelis Istituto Superiore di Sanità, Rome IT (ISS)



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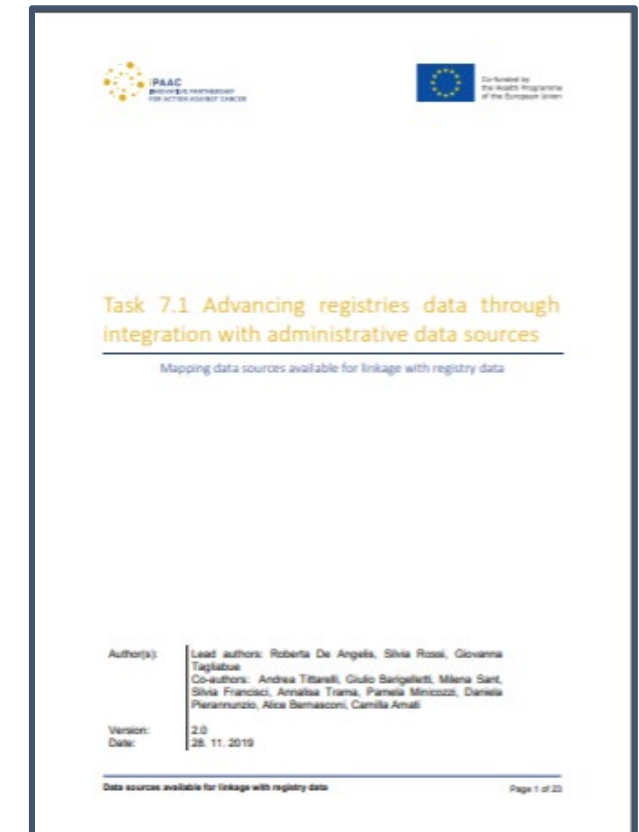




## KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

### Task 1

- Survey to map data sources available to cancer registries in Europe
- Final Report / November 2019



# TASK 1: MAPPING DATA SOURCES

## SURVEY QUESTIONNAIRE on accessible data flows and on legal procedures to access, link, share patients microdata

### 4. DATA SOURCES

a) INFORMATION ON DATA SOURCES IN USE TO THE CR (indicate which are used by the CR and specify their characteristics)

#### LEGEND:

[@] Relevance. Please indicate in which percentage the source contributes to the definition of CR cases. If not routinely calculated, please indicate an estimated value, based on your experience.

[#] Completeness. Please indicate the percentage of completeness of the source, i.e. in which percentage all the events monitored by the source that occur to a patient are included in the data flow received by the CR. For example, suppose a patient experiences 20 hospitalizations, in which percentage are they recorded in the Hospital Discharge flow? If not routinely calculated, please indicate an estimated value, based on your experience.

[\$] Pathway. Is this data source relevant to reconstruct the complete therapeutic pathway of patients?

[+] Linkage feasibility. Is it possible for the registry to identify patients' records in the data source through linkage with their tumour cases?

[\*] Transmission to iPAAC. Are you legally permitted to provide case data linked to other data sources in anonymized format to the iPAAC study? If you answered No please specify in: Section 5 SUGGESTION Box if it is possible to overcome the ban through appropriate procedures and how the iPAAC project can help you.

[^] Record Track. Please provide the record track file of the data source in English (see the example given in Section 6) and indicate here its name. Accepted file formats are: .txt, .doc(x), xls(x), csv.

Source Name	Availability			Usability and Quality			Linkage Feasibility	Transmission to iPAAC	Record Track file name
	From Year	To Year	Type of diseases	Relevance (in %) [ @ ]	Completeness (in %) [ # ]	Pathway (in %) [ \$ ]			
I. <input type="checkbox"/> Hospital discharges			<input type="checkbox"/> all diseases <input type="checkbox"/> only cancer			<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input type="checkbox"/> Yes <input type="checkbox"/> No	
II. <input type="checkbox"/> Private hospital / Clinical facilities			<input type="checkbox"/> all diseases <input type="checkbox"/> only cancer			<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input type="checkbox"/> Yes <input type="checkbox"/> No	
III. <input type="checkbox"/> Hospital oncology registries			<input type="checkbox"/> all diseases <input type="checkbox"/> only cancer			<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input type="checkbox"/> Yes <input type="checkbox"/> No	
IV. <input type="checkbox"/> Pathology laboratories			<input type="checkbox"/> all diseases <input type="checkbox"/> only cancer			<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input type="checkbox"/> Yes <input type="checkbox"/> No	

AIM → to support pilot studies



To assess the feasibility of registry participation

To define the protocols for data integration

Task 7.2

Cancer care pathways

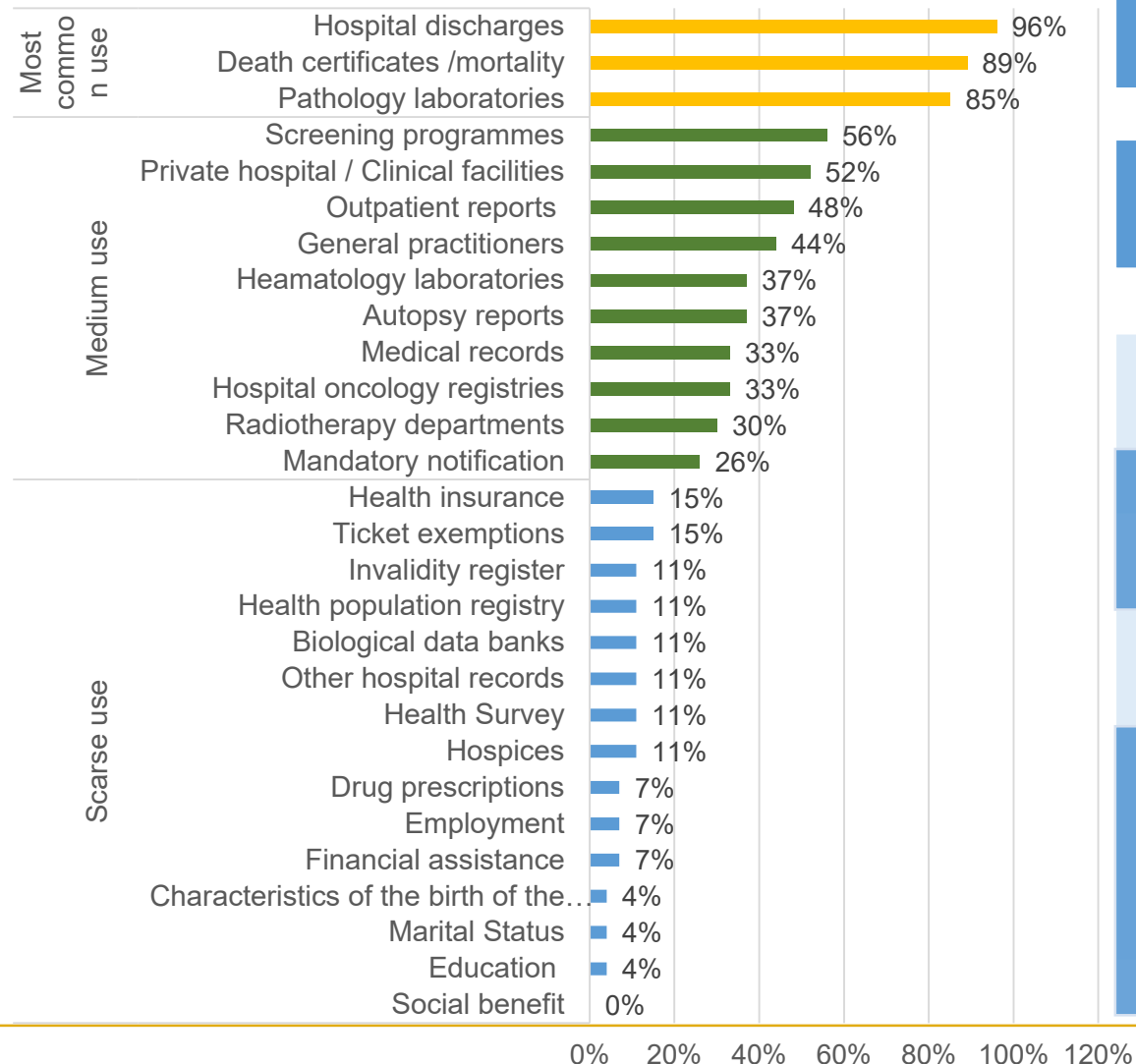
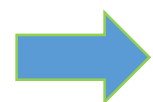
Task 7.3

Cancer care costs

Task 7.4

Long term survivorship

# TASK 1 - SURVEY RESULTS



**33 registries were contacted**

**27 CRs (82%) from 14 countries replied**

## Data sources file formats

**17 CRs (63%) supplied the structure of data sources**

3 CRs (11%) did not supply for complex structure

7 CRs (26%) did not supply for other reasons

## Data sharing with iPAAC

**17 CRs (63%) legally authorised to link and share data**

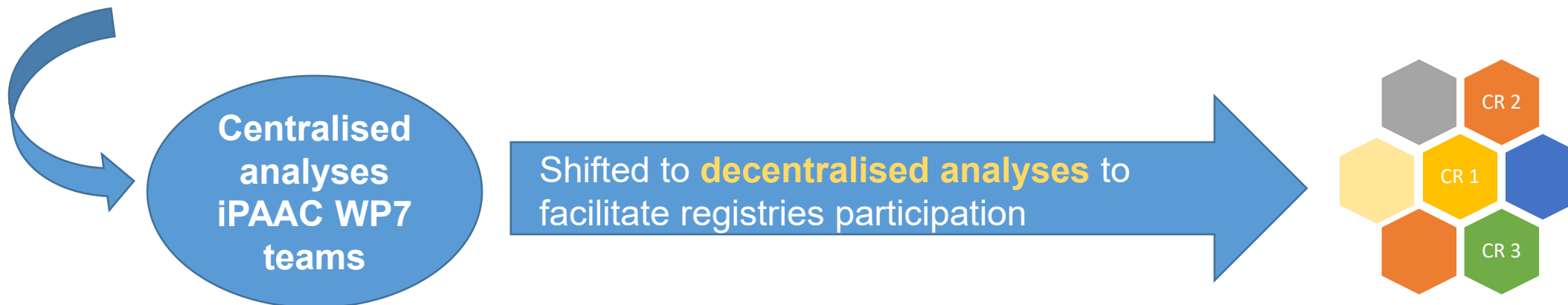
**Data sources that can be shared:**

- Screening programmes data (93%)
- Death certificates (71%)
- Hospital discharges (65%)
- Pathology laboratories records (57%)

# TASK 1: HIGHLIGHTS

## There is considerable variability between countries

- In most countries the integration is feasible (varying data flows spectrum)
- In some countries not all relevant data sources are electronic
- All pathologies occurring to cancer patients are not always accessible (lack of legal mandate). Accessibility reflects registries' institutional mandate.
- Accessing and sharing data is usually possible upon specific permissions or agreements (varying complexity and time needed)



## KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

### Task 1

- Survey to map data sources available to cancer registries in Europe
- Final Report / November 2019

### Tasks 2-4

- Study protocols agreed in the 2° Milestone Meeting / March 2019
- Specific agreements with participating registries

### Tasks 2-4

- Internal Report defining pilot protocols / July 2019

# TASKS 2-4 : PILOT PROTOCOLS STUDY DESIGN

Example: **prevalent cases** at 1/1/2016

## Tasks 2-3

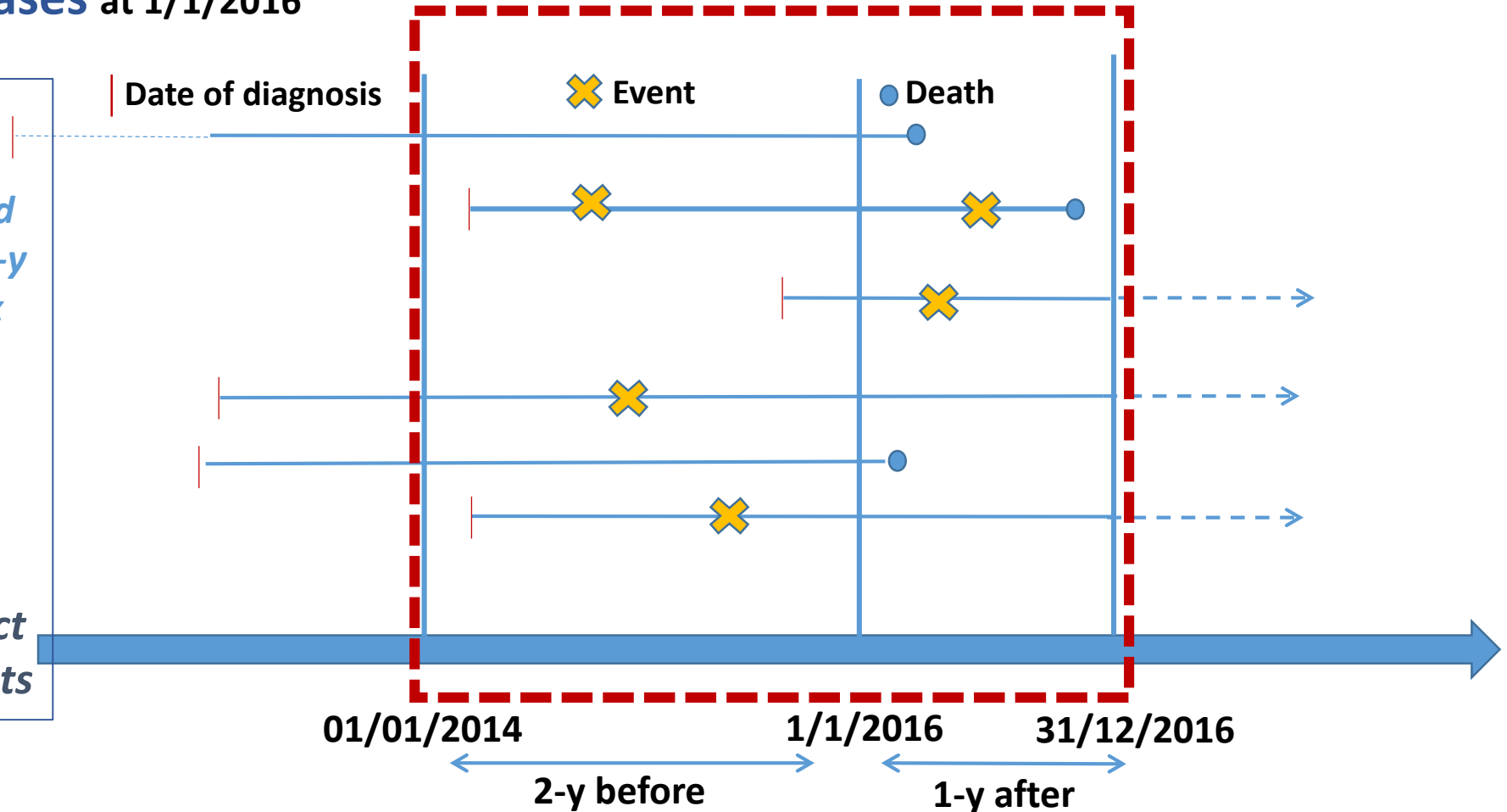
### CROSS SECTIONAL DESIGN

Prevalent cases data are linked  
to detect all events occurring 2-y  
before and 1-y after the index  
date

## Task 4

### LONGITUDINAL DESIGN

AYAs survivors cohorts are  
linked prospectively to detect  
all events marking late effects



# TASKS 2-4 : PILOT PROTOCOLS INDEX TUMOURS

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## Tasks 2-3: Cancer-specific indicators & procedures

- Colon (ICDO-3 C18)
- Rectum (C19-20)
- Skin melanoma ( C44, morphology codes 8720-8790)
- Pancreas (C25)

## Tasks 4: no cancer selections for AYA survivors

# TASKS 2-4 : PILOT PROTOCOLS

## TARGET INDICATORS

### Task 7.2

- Indicators of standard care
  - Example for rectal cancer: % screen detected, % endoscopy with biopsy, % neo-adjuvant radiotherapy in resected stage III, % metastatic treated with targeted therapy, peri-operative mortality (30/90 days)
- Indicators of quality of care at the end of life

### Task 7.3

- Monthly and annual average costs (overall and by phase of care);
- Total annual cost;
- Percentage of patients receiving at least one surgery treatment;
- Percentage of patients in initial phase of care receiving at least one chemotherapy
- Time occurring between surgery and chemotherapy.

### Task 7.4

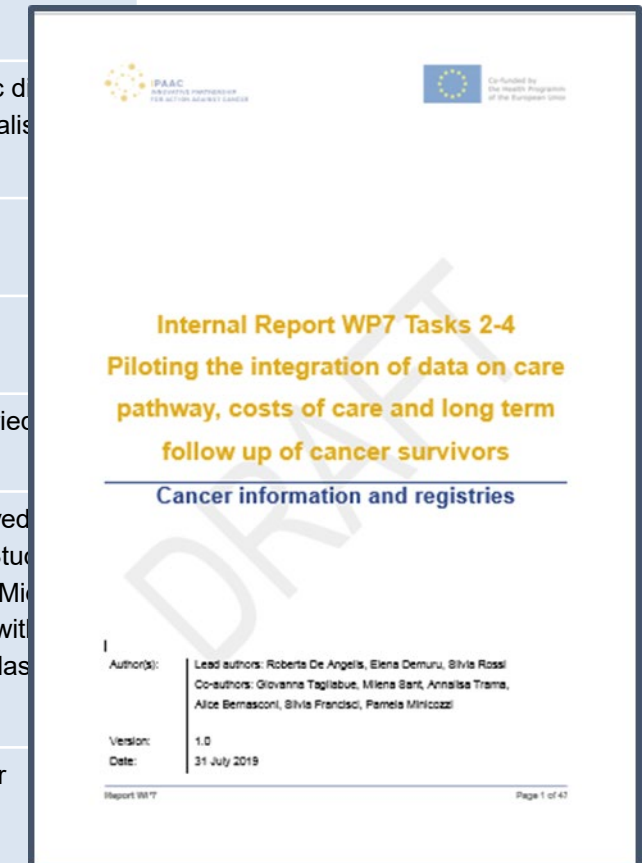
- Standardized incidence ratio (SIR) of cancer and other chronic diseases;
- Standardized mortality ratio (SMR);
- Risk ratio of attaining a low education level, of not getting married, of being financially dependent, of being unemployed.



# TASKS 2-4 : PILOT PROTOCOLS

## DATA REQUIREMENTS FOR EACH INDICATOR

Indicators	Data required	Data source
SIR of multiple cancers	multiple primary malignancies of AYA cancer survivors and of the not-AYA cancer population	Cancer registry database
SIR of chronic diseases	Information on cardiovascular, respiratory, endocrine diseases on infertility and pregnancy problems for the AYA cancer survivors and for the cancer-free population	clinical discharge records: hospitalisation for a specific disease as a proxy of the disease occurrence (standardised hospitalisation ratio).
SMR	Mortality (including cause specific mortality) for AYA cancer survivors and for the cancer-free population	Mortality register
RR of low education	Information on the attained education for AYA cancer survivors and for the cancer free population	Census. Education ISCED classification
RR of not being married	Information on marital status for AYA cancer survivors and for the cancer-free population	Census. Marital status classified as: married; not married; divorced; widowed; single
RR of being unemployed or being in an unskilled working class	Information on occupational conditions and occupational class for AYA cancer survivors and for the cancer-free population	Census. occupational conditions classified as Employed/Unemployed/looking for first occupation, Housewife, Student, Retired; occupational class classified as Bourgeoisie, Middle class, Self-employed with employees, Self-employed without employees, Skilled working class, Unskilled working class
RR of using social/financials benefit	Information on the use of social/financial benefit status for AYA cancer survivors and for the cancer-free population	In Italy INAIL/INPS (collaboration in progress). In other countries to be defined.



# NEXT STEPS



1. **Linkage** with available data sources
2. **Analysis:** quality checks, estimation and validation of the target indicators
  - Centralised vs de-centralised analysis option
  - Participating registries from 7 countries: BE, NO, IT, SP, PT, PL, GR
3. **Third Milestone Meeting** to discuss Pilots' results (Sept 2020)
4. **Road Map deliverable**
  - Recommended actions and standardised procedures to integrate CRs data