



# WP 7 Cancer Information and Registries

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# BETTER CANCER CONTROL THROUGH BETTER **CANCER INFORMATION**



**Work Package 7: Actions to enhance population-based cancer information systems** to better support evidence-based comprehensive cancer care

- 1. Better use current registries datasets**
- 2. Advance cancer registries datasets through better integration with clinical and administrative data sources**



Work Package 7: **Actions to enhance population-based cancer information systems** to better support evidence-based comprehensive cancer care

## 1. Better use current registries datasets

### Expected outcome

Disseminating and promoting the use of informative epidemiological indicators on **cancer prevalence at European MS level (Task 6)**

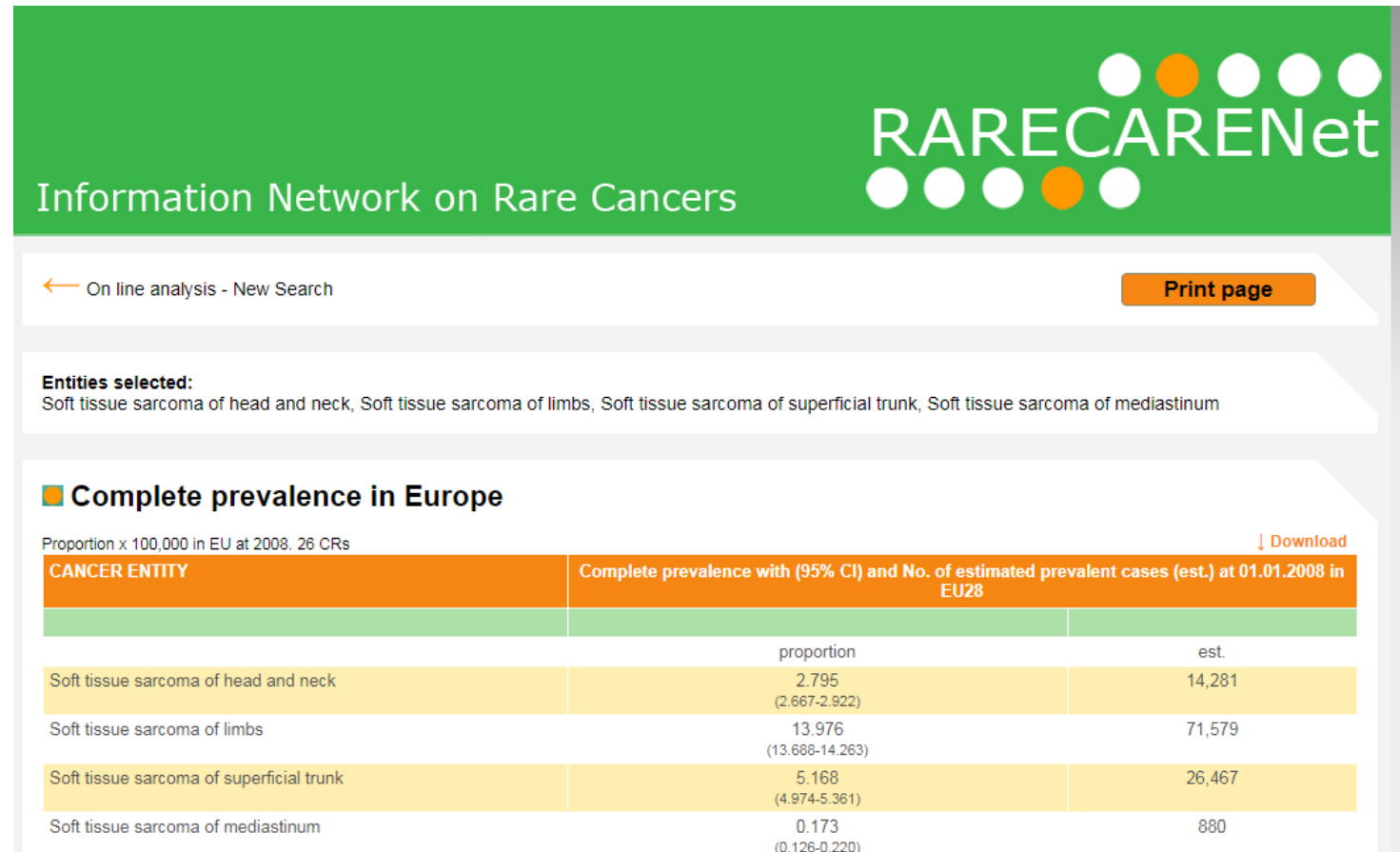
# TASK 6: EXPECTED OUTCOMES

- **Disseminating comprehensive population based indicators on cancer survivors in Europe at MS level**
  - i) complete prevalence and prevalence by disease duration
  - ii) prevalence by phase of care (initial, terminal, intermediate)
  - iii) prevalence of cured/uncured patients, cure fraction and time to cure (*cure models*)
  - iv) life expectancy of cancer survivors
  - v) time projections to 2020
- This activity relies on the **EUROCARE-6** study dataset

# COMPLETE PREVALENCE APPLICATIONS IN EUROPE

<http://www.rarecarenet.eu>

- Complete prevalence for **rare cancers** in Europe
- **RARECARE** project  
Eur J Cancer 2011
- **RARECARE-net** project  
Lancet Oncol 2017



The screenshot shows the RARECARENet website interface. At the top, there's a green header with the RARECARENet logo and the text 'Information Network on Rare Cancers'. Below the header, there's a navigation bar with a link to 'On line analysis - New Search' and a 'Print page' button. The main content area displays the 'Entities selected' as 'Soft tissue sarcoma of head and neck, Soft tissue sarcoma of limbs, Soft tissue sarcoma of superficial trunk, Soft tissue sarcoma of mediastinum'. Below this, there's a section titled 'Complete prevalence in Europe' with a 'Download' link. The table below shows the proportion and estimated number of cases for each cancer entity in EU28 as of 01.01.2008.

Proportion x 100,000 in EU at 2008. 26 CRs			Download
CANCER ENTITY	Complete prevalence with (95% CI) and No. of estimated prevalent cases (est.) at 01.01.2008 in EU28		
	proportion	est.	
Soft tissue sarcoma of head and neck	2.795 (2.667-2.922)	14,281	
Soft tissue sarcoma of limbs	13.976 (13.688-14.263)	71,579	
Soft tissue sarcoma of superficial trunk	5.168 (4.974-5.361)	26,467	
Soft tissue sarcoma of mediastinum	0.173 (0.126-0.220)	880	

# COMPREHENSIVE PREVALENCE INDICATORS

## APPLICATIONS IN ITALY

### AIRTUM Monographs 2011, 2015

- Systematic estimates of complete and by disease duration prevalence in Italy,
- Including indicators on cured survivors
- All cancer types, by sex, geographical area and age



Pool of Italian Cancer Registries - 1 January 2010

### LINFOMA NON-HODGKIN

### NON-HODGKIN LYMPHOMA

(ICD-10 C82-85,96)

**AIRTUM- Report 2014,  
Epid&Prev 2015**

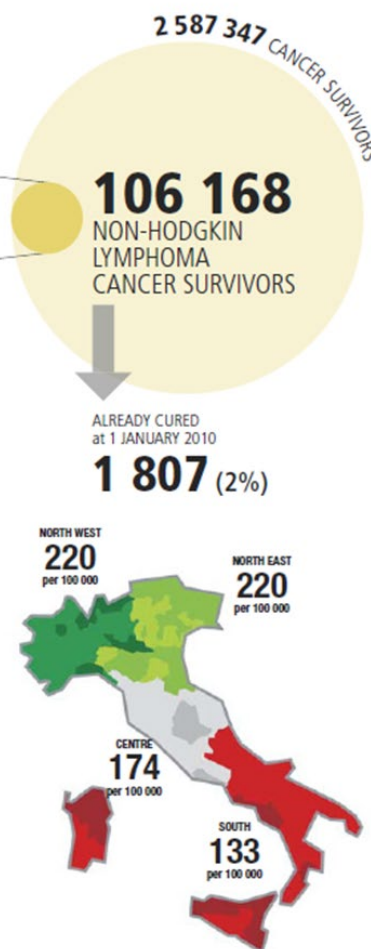
**COMPLETE PREVALENCE BY YEARS SINCE DIAGNOSIS**

YEARS →	≤ 2	(2 - 5]	(5 - 10]	(10 - 15]	(15 - 20]	> 20
No. →	18 577	23 331	25 656	16 826	9 333	12 444
% →	17%	22%	24%	16%	9%	12%
PROPORTION PER 100 000 →	33	41	46	30	17	22
	MALE 51%			FEMALE 49%		

### COMPLETE PREVALENCE BY SEX, MACRO-AREA, AND AGE

(PROPORTION PER 100 000)

AGE CLASS →	0-44	45-59	60-74	75+	ALL AGES
<b>MALE</b>					
NORTH WEST	59	240	499	672	228
NORTH EAST	53	253	521	775	232
CENTRE	48	222	356	550	178
SOUTH	53	182	344	395	145
POOL	54	225	451	619	199
<b>FEMALE</b>					
NORTH WEST	40	191	441	499	212
NORTH EAST	43	195	431	540	208
CENTRE	40	185	349	423	170
SOUTH	34	153	278	292	122
POOL	39	180	384	453	178
<b>BOTH SEXES</b>					
NORTH WEST	49	215	468	561	220
NORTH EAST	48	224	474	625	220
CENTRE	44	203	352	472	174
SOUTH	43	167	309	333	133
POOL	47	202	416	515	188



# TASK 6:

## IMPACT AND EUROPEAN ADDED VALUE

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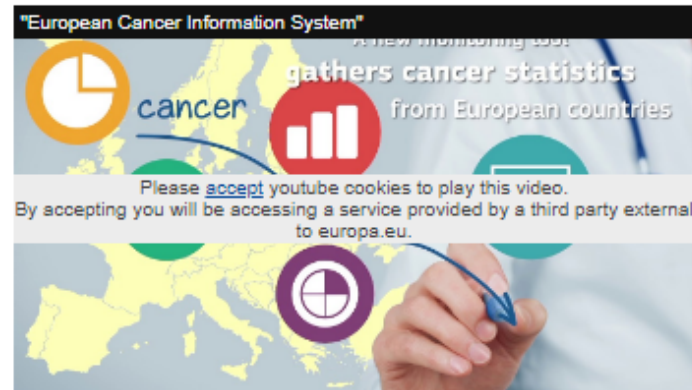


- 1. Integrating the European Cancer Information System (ECIS)**  
Comprehensive and comparable indicators on cancer prevalence in EU by country will feed the EC **web-site** managed by the **ENCR-JRC**



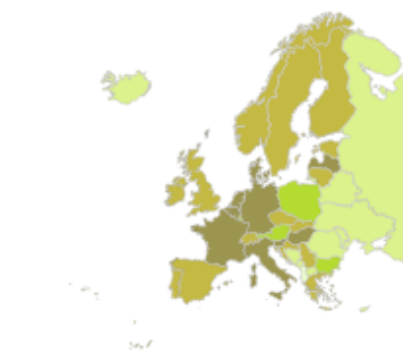
# ECIS - European Cancer Information System

Measuring cancer burden and its time trends across Europe



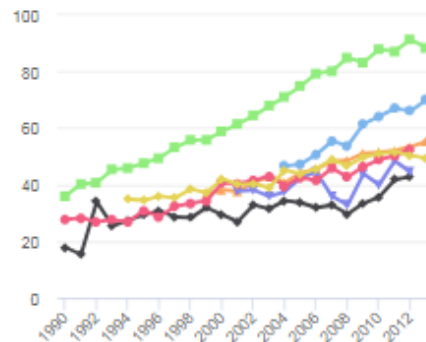
ECIS provides the latest information on indicators that quantify cancer burden across Europe. It permits the exploration of geographical patterns and temporal trends of incidence, mortality and survival data across Europe for the major cancer entities.

The purpose of the web-application is to **support research** as well as public-health decision-making in the field of cancer and to serve as a point of reference and information for **European citizens**.



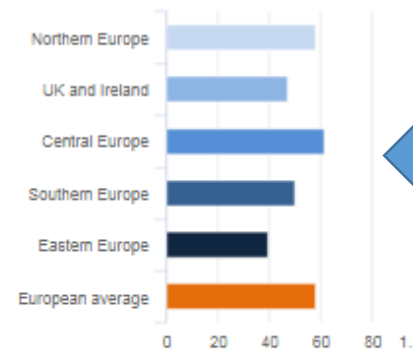
## Incidence and mortality estimates 2018

National estimates of cancer incidence and mortality in 2018, for the major cancer sites in 40 European countries.



## Incidence and mortality historical data

Incidence and mortality statistics over time by cancer site and demographic variables, in European cancer registration areas.



## Survival estimates

Estimated indicators of survival, by cancer sites and sex, across European countries and regions.

## Prevalence Session

Estimated indicators on cancer survivors by cancer type, sex, age, and European country

Including information on disease duration, cure, phase of care, life expectancy



# TASK 6:

## IMPACT AND EUROPEAN ADDED VALUE

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- 1. Integrating the European Cancer Information System (ECIS)**  
Comprehensive and comparable indicators on cancer survivors in EU by country will feed the EC **web-site** managed by the **ENCR-JRC**
- 2. Capacity building at EU MS level:** promoting the use of prevalence indicators will help to address information needs of relevant stakeholders (health professionals, patients, decision makers and research community)



# TASK 6: STATE OF PLAY

Month		Meetings	Milestones	Deliverables
M3	Jun-18	Kick-off Meeting		
M9	Dec-18		EUROCARE-6 Database available	
M12	Mar-19	2nd WP-7 Workshop	Agreement on: study design, indicators, working group, trainings (topics and organization)	
M18	Sep-19		Preliminary results available	
M18	Sep-19			Road Map: Draft Report
M24	Mar-20		Training to promote use of prevalence indicators	
M28	Jul-20	3rd WP 7 Workshop	Final results agreement	
M32	Nov-20		Draft publications, dissemination strategy	
M34	Jan-21			Road Map: Final Report

# EUROCARE-6 PRELIMINARY DATASET POPULATION AND TIME COVERAGE

## Quality checks

Data were collected, harmonised and quality checked in collaboration with the JRC and ENCR

## Time coverage

Prevalence estimates are derived from incidence and follow up information to 2013 or 2014

27 National CRs

22 General

5 Childhood

83 CRs with partial coverage

Countries	Period of Diagnosis										Follow up time				
	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	31-12-12	30-06-13	31-12-13	31-12-14	31-12-15
AUSTRIA															
BELGIUM															
BULGARIA															
CROATIA															
CYPRUS															
CZECH REPUBLIC															
DENMARK															
ESTONIA															
ICELAND															2015
IRELAND															
LATVIA															
LITHUANIA															
MALTA															
NORWAY															
POLAND															
SLOVAKIA															
SLOVENIA															
THE NETHERLANDS															
UK-ENGLAND															
UK-NORTHERN IRELAND															
UK-SCOTLAND															
UK-WALES															
France childhood															
Greece childhood															
Germany childhood															
HUNGARY childhood															
Switzerland childhood															
France (16)						13	1	2							
Germany (8)								6	2		5		2	1	
Italy (42)						16	4	11	11		6		12	24	
Portugal (3)						2		1					2		1
Spain (9)						2	1	5		1			8		1
Switzerland (5)								1	4				3	1	1

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Work Package 7: **Actions to enhance population-based cancer information systems**  
to better support evidence-based comprehensive cancer care

## 2. Advance cancer registries datasets through better integration with clinical and administrative data sources

- ***In Europe:*** 3 pilots to integrate population based cancer registries with health/administrative data to derive key indicators on :
  - cancer care and pathways (**Task 2**)
  - cancer costs (**Task 3**)
  - late effects in Adolescents and Young Adults (**AYAs**) survivors (**Task 4**)
- ***In Czech Republic:*** piloting a complex ICT model integrating epidemiological, clinical and administrative data at national level to support cancer care and management (**Task 5**)

# PILOTING DATA SOURCES INTEGRATION

## KEY DELIVERABLES



**Conceptual framework and tools** to derive **population based standardized indicators** in three different domains

1. **Quality of care: adherence to clinical guide-lines over the entire pathway\***
  2. **Cancer costs: direct costs along the entire pathway (cost profiles)**
  3. **Long term follow up of AYAs survivors: adverse and late effects**
- Cancer specific indicators (pancreas, colorectal, melanoma)\*
  - Ensuring common definitions, classification and comparable results by country

### **Recommendations to improve interoperability of cancer information systems**

- Specific actions varying by EU country
- Specific ICT model in Czech Republic

\*In coordination with WP8 and WP-10 to maximize synergies in iPAAC



# PILOTS ON DATA SOURCES INTEGRATION: STATE OF PLAY

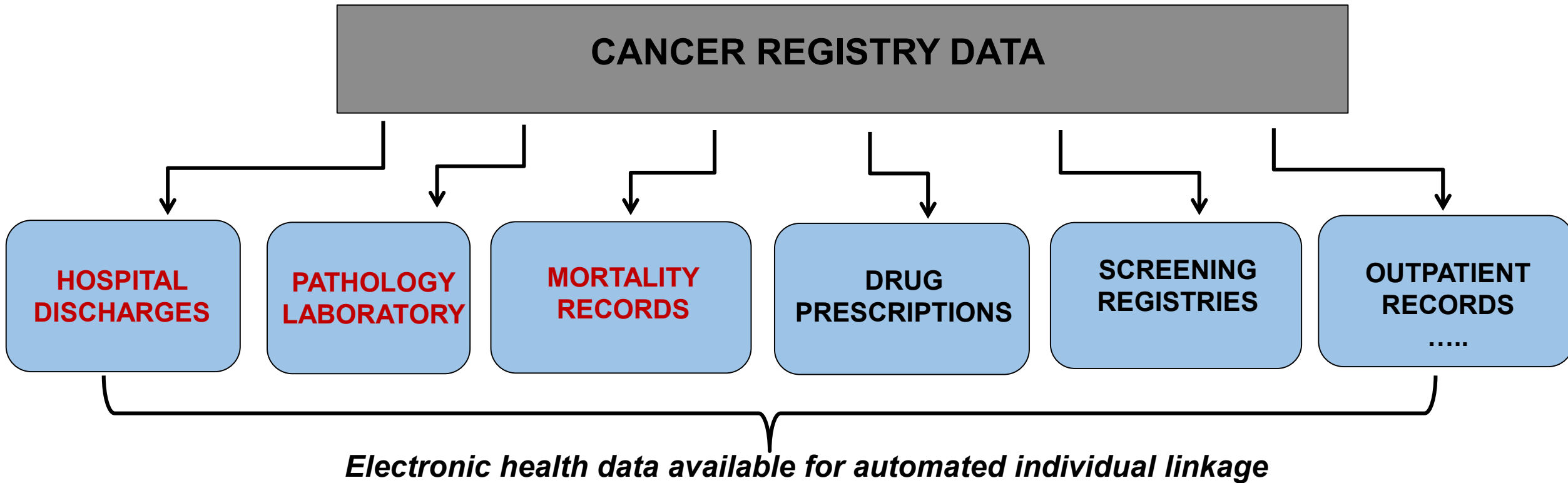
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M9	Dec-18		Survey launched, draft protocols ready		1
M12	Mar-19	2nd WP7 Workshop	Tasks 1-5: agreement on pilot data collection protocols, indicators, working group		all
M18	Sep-19		Pilot data sources integration and data collection completed by the CRs		2,3,4,5
				Road Map: Draft Report	all
M26	May-20		Data quality checks and data analysis completed		2,3,4
M28	Jul-20	3rd WP 7 Workshop	Pilots results agreed		all
M34	Jan-21			Road Map: Final Report	all

# TASK1: SURVEY ON DATA SOURCES INTEGRATION

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 [\$]			
I. <input checked="" type="checkbox"/> Hospital discharges	1987	2017	<input type="checkbox"/> all diseases <input checked="" type="checkbox"/> only cancer	10	99	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	<input checked="" type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	tracciato record SDO
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 checked="" type="checkbox"/> Pathology laboratories	1987	2017	<input type="checkbox"/> all diseases <input checked="" type="checkbox"/> only cancer	89	95	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	tracciato referti AP
V. <input type="checkbox"/> Outpatient reports			<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	
VI. <input checked="" type="checkbox"/> Autopsy reports	1987	2017	<input type="checkbox"/> all diseases <input checked="" type="checkbox"/> only cancer	0.6	95	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	tracciato referti AP
VII. <input type="checkbox"/> Medical records			<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	
VIII. <input type="checkbox"/> General practitioners			<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	
IX. <input checked="" type="checkbox"/> Death certificates /mortality	1987	2016	<input type="checkbox"/> all diseases <input checked="" type="checkbox"/> only cancer	1.3	99	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes In house <input type="checkbox"/> No <input type="checkbox"/> Yes, externally	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	tracciato record schede di morte
X. <input type="checkbox"/> Heamatology 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	
XI. <input type="checkbox"/> Radiotherapy departements			<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	
XII. <input type="checkbox"/> Screening programmes			<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	



# SURVEY ON INTEGRATION WITH ADMINISTRATIVE AND HEALTH DATABASES



**PRELIMINARY SURVEY RESULTS: BIG VARIABILITY BETWEEN- and WITHIN-COUNTRY**

# TASKS 2-4 : STATE OF PLAY

## PROTOCOLS FOR DATA COLLECTION

Example: prevalent cases at 1/1/2016

### Tasks 2-3

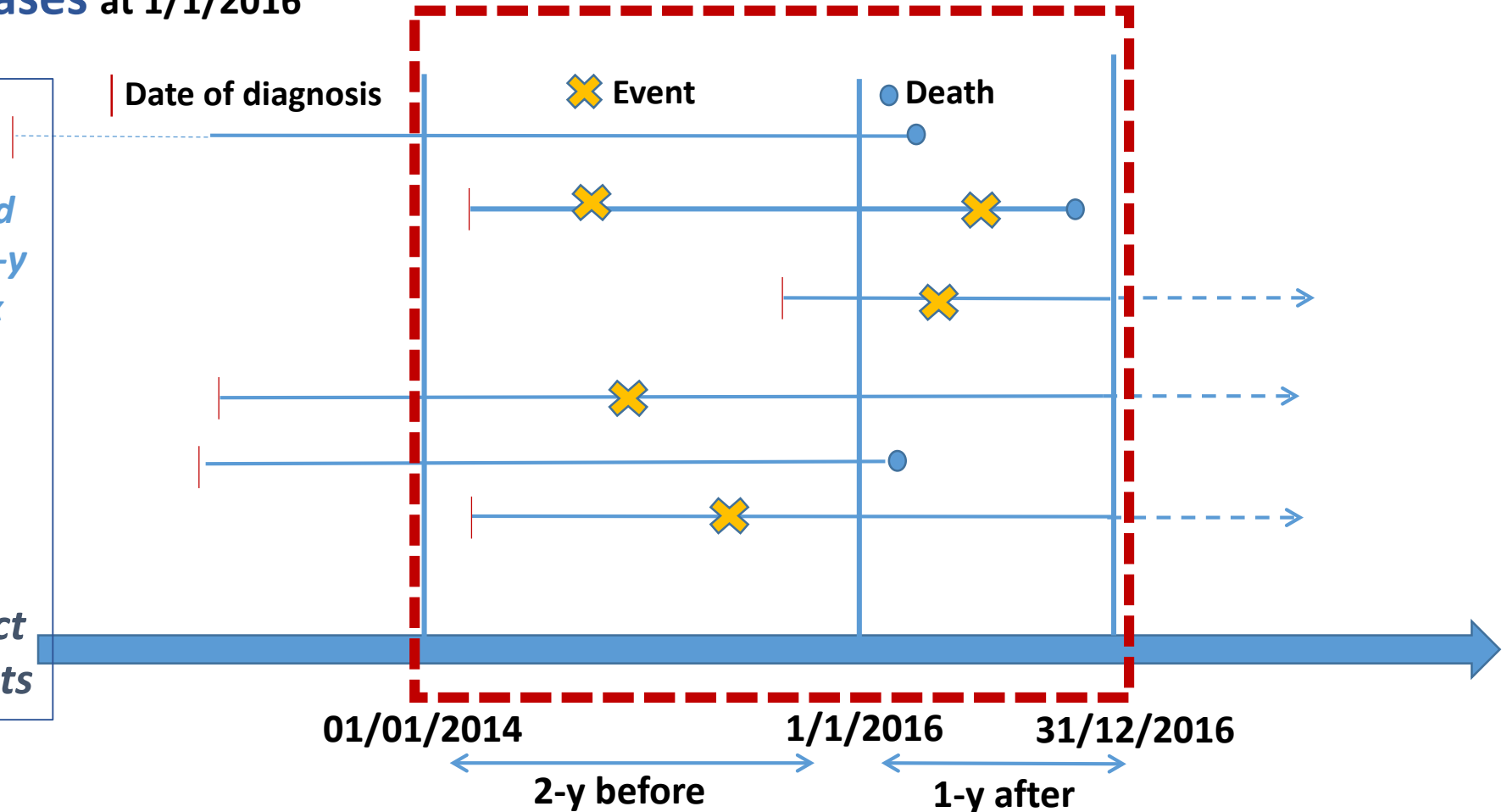
#### CROSS SECTIONAL DESIGN

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



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