WP 7 Cancer Information and Registries

Roberta De Angelis, MSc, Scientific coordinator iPAAC WP 7

Italian National Institute of Health- Istituto Superiore di Sanità (ISS),IT

Co-funded by
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BETTER CANCER CARE BASED ON BETTER CANCER INFORMATION

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INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

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

1. **Better use current registries datasets→ prevalence**

2. **Piloting integration of registries datasets with multiple data sources to derive indicators for cancer care and management**
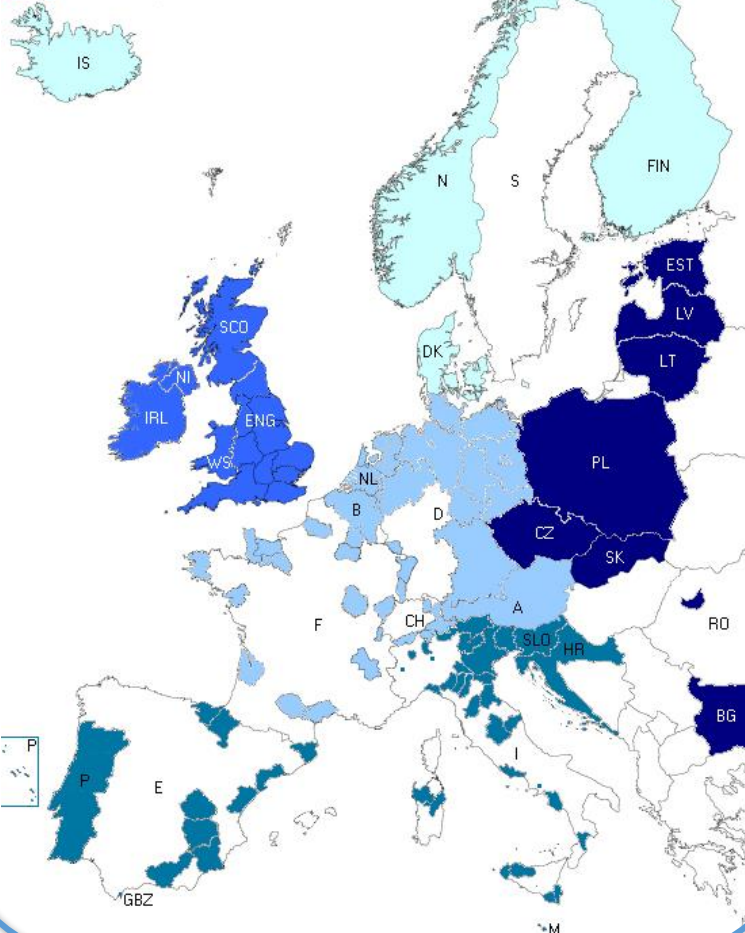
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- **Providing methods and means to deliver systematic information on cancer survivors in Europe at MS level**

  i) **complete prevalence and prevalence by disease duration**
  ii) **time projections to 2021**
  iii) prevalence by phase of care (initial, terminal, intermediate)
  iv) prevalence of cured/uncured patients, cure fraction and time to cure
  v) life expectancy of cancer survivors

- Action in collaboration with the EUROCARE network

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CANCER REGISTRIES IN EUROCARE-6

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Legend:
- Northern Europe
- Central Europe
- UK and Ireland
- Eastern Europe
- Southern Europe

110 CRs from 29 countries

23 National CRs

6 Regional CRs:
France (16), Germany (7), Italy (40), Portugal (3), Spain (11), Switzerland (5)

Incidence and follow up data on 25 million cancer patients diagnosed in Europe to 2013-2014

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TASK 6: ACHIEVEMENTS M1-18

M9   Preliminary EUROCARE-6 dataset
- **27 / 29 countries**

M12 Study design agreed
- **Indicators**
- **Methods**
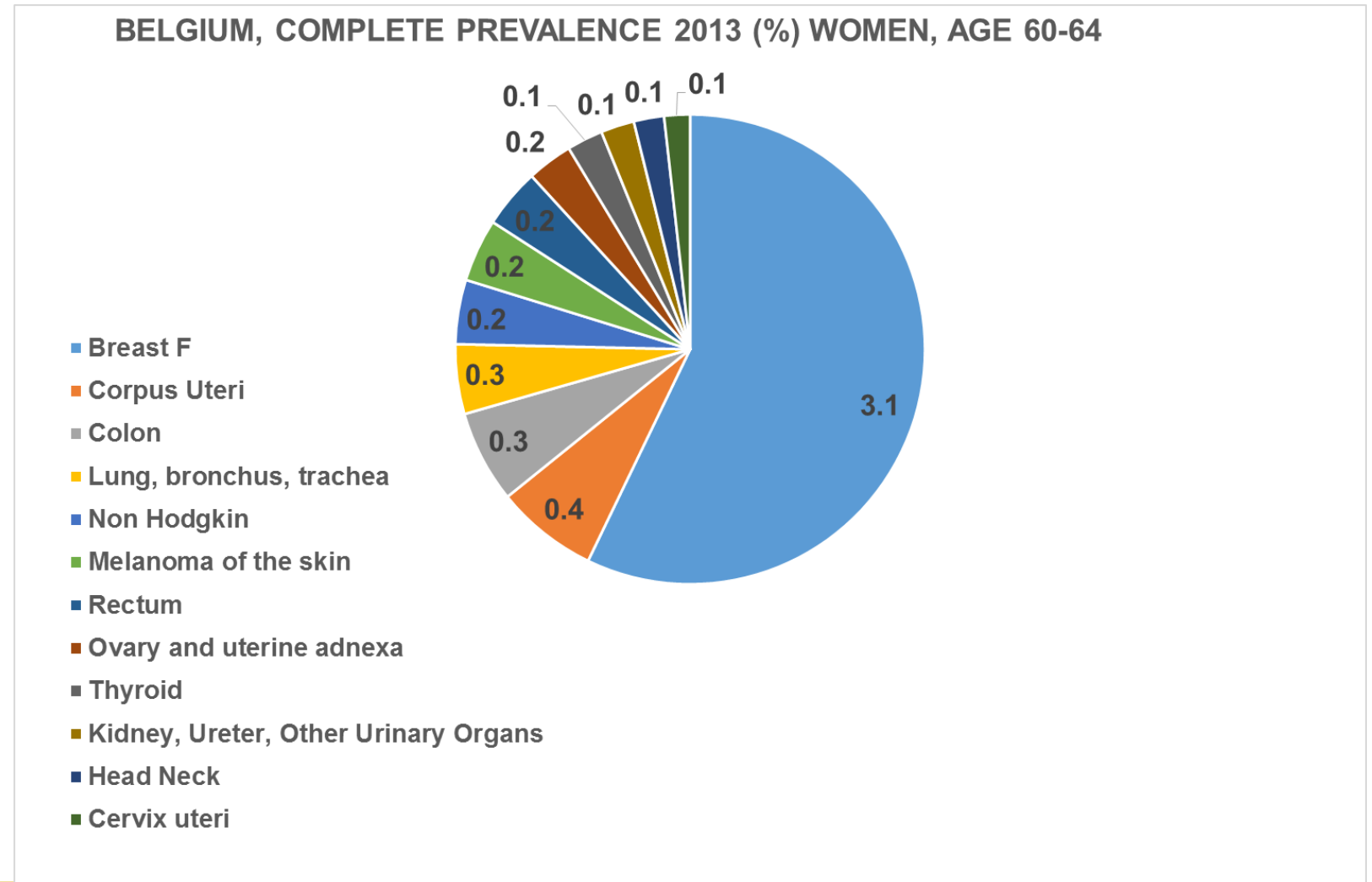- **Index cancers**
- **Time projections**

M18 Data Analysis
- **Preliminary results available**

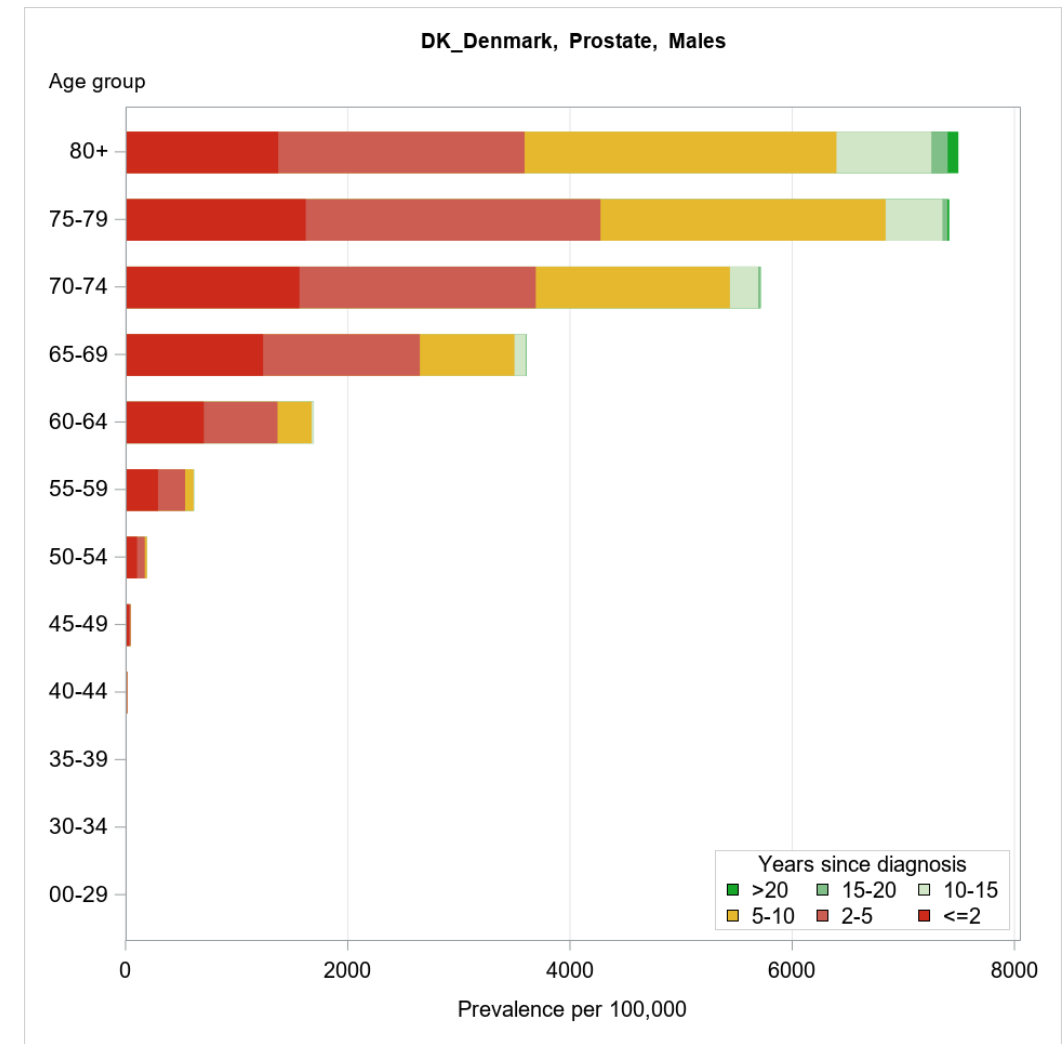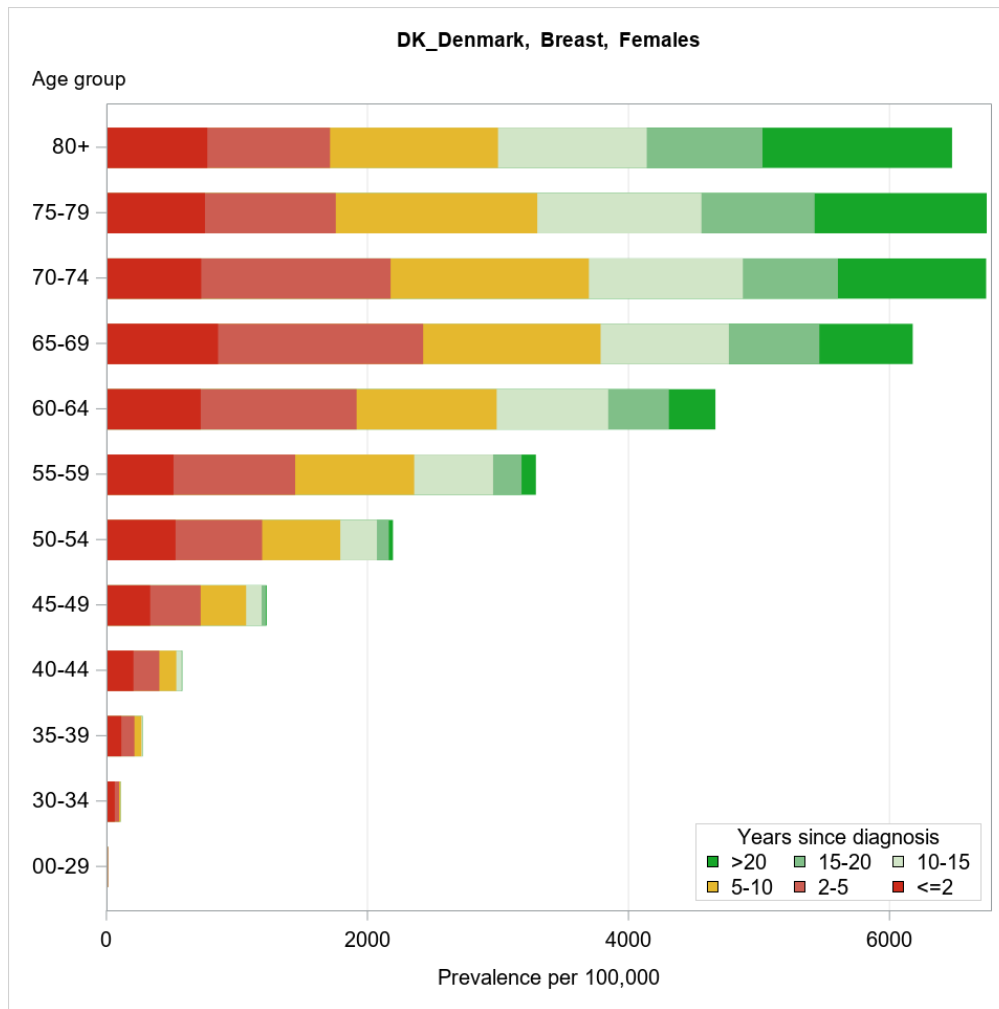# COMPLETE PREVALENCE RANKING BY CANCER SITE, WOMEN

BELGIUM

60-64, 2013

1. Breast
2. Colon – Rectum
3. Corpus uteri
4. Lung
5. Non Hodgkin

BELGIUM, COMPLETE PREVALENCE 2013 (%) WOMEN, AGE 60-64

Legend:
- Breast F
- Corpus Uteri
- Colon
- Lung, bronchus, trachea
- Non Hodgkin
- Melanoma of the skin
- Rectum
- Ovary and uterine adnexa
- Thyroid
- Kidney, Ureter, Other Urinary Organs
- Head Neck
- Cervix uteri

Values shown on pie: 3.1, 0.4, 0.3, 0.3, 0.2, 0.2, 0.2, 0.2, 0.1, 0.1, 0.1, 0.1

COMPLETE AND LIMITED DURATION PREVALENCE
DENMARK BREAST & PROSTATE

TASK 6: NEXT STEPS
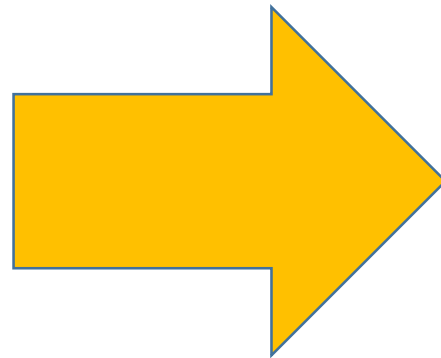
M 20 Finalise EUROCARE-6 dataset
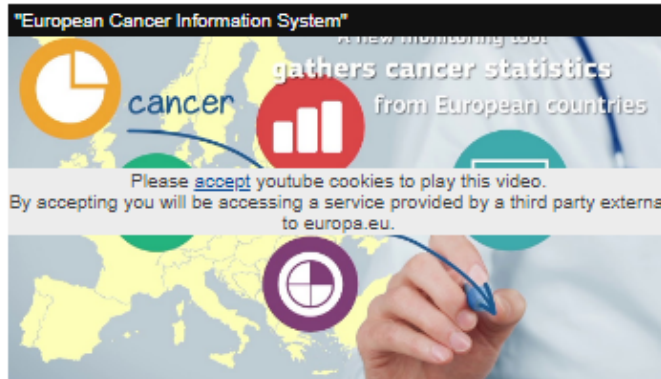- **29 European countries**

M 25 Data analysis progress
- **Complete prevalence**
- **Limited duration prevalence**
- **by cancer-sex-age-area**
- **time projections to 2021**

M 28-32 Dissemination
- **Methods and softwares**
- **Publications**
- **Training & web tool (ENCR-JRC)**

ECIS - European Cancer Information System

Measuring cancer burden and its time trends across Europe

"European Cancer Information System"

gathers cancer statistics from European countries

cancer

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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**.
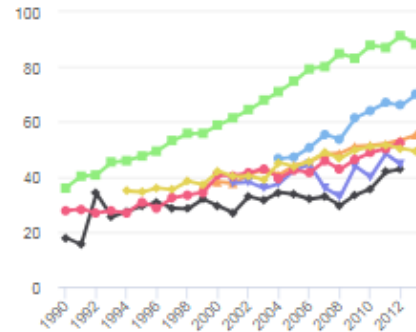
Prevalence Session

Survivors by
- cancer type
- disease duration
- sex
- age
- country
- region

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.
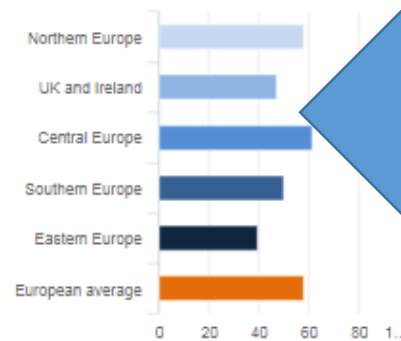
Survival estimates

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

https://ecis.jrc.ec.europa.eu/

2. Advancing registries datasets through integration with multiple data sources

- *In Europe:* 3 pilots integratingadministrative health data to derive key indicators on :
  - **Quality of care** (**Task 2**)
  - **Costs of care** (**Task 3**)
  - **Late effects** in Adolescents and Young Adults (**AYAs**) **survivors** (**Task 4**)
- *In Czech Republic*: piloting a complex ICT model integrating the National Cancer Registry with multiple clinical and administrative data sources at national level to support cancer care and management (**Task 5**)
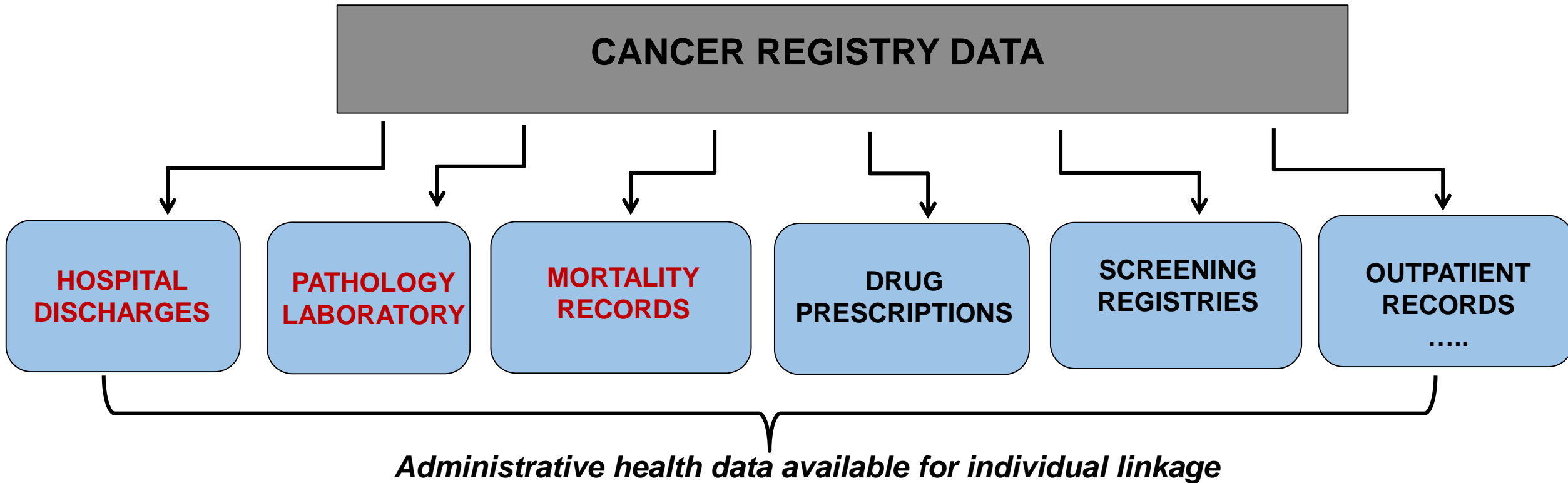
TASKS 2-4 : PILOT STUDY PROTOCOLS DESIGNED AND AGREED

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
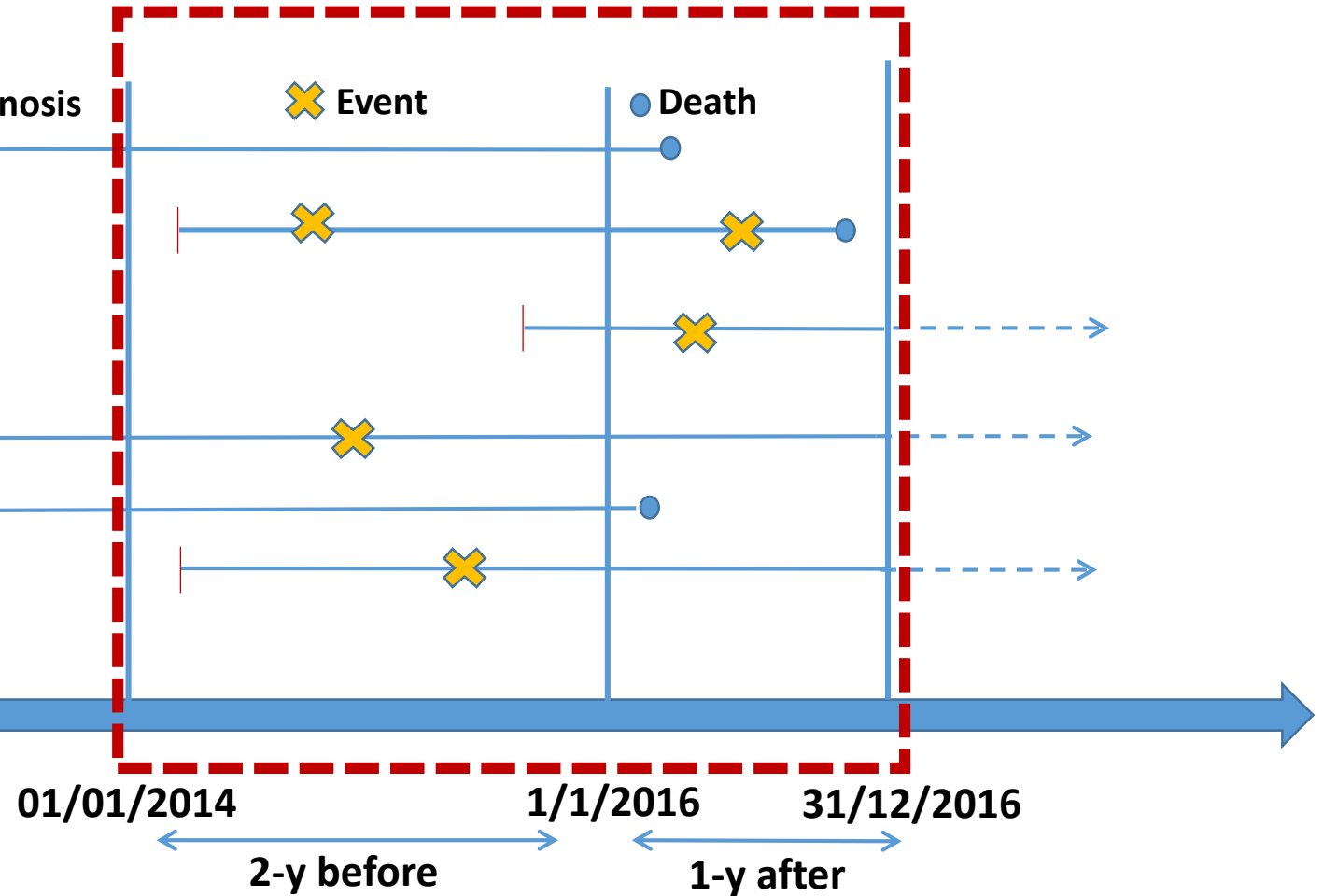
Task 4
LONGITUDINAL DESIGN
AYAs survivors cohorts are linked prospectively to detect all events marking late effects
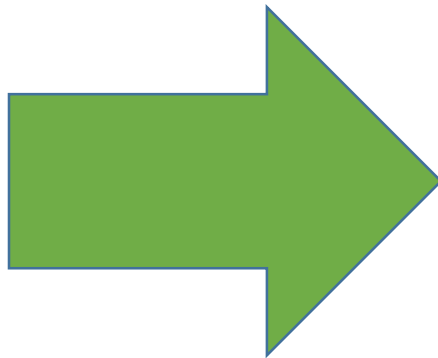
Date of diagnosis   Event   Death

01/01/2014   1/1/2016   31/12/2016

2-y before   1-y after

PILOTING INTEGRATION OF REGISTRIES DATA : NEXT STEPS

M 20 Mapping data sources Report

M 25 Linkage with data sources and analysis
- **Colon, rectum, pancreas, skin melanoma**
- **Centralised vs de-centralised analysis option**
- **Participating countries: BE, NO, IT, SP, PT, PL, GR**

M 28 Results discussion
- **Standardised procedures to integrate CRs data**

M 28-32 Dissemination
- **Recommended actions to improve interoperabilty**