



iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

iPAAC Work Package 7

Cancer information and Registration

Cancer Control in Europe: Finding Sustainable Solutions

13 - 14 December 2021

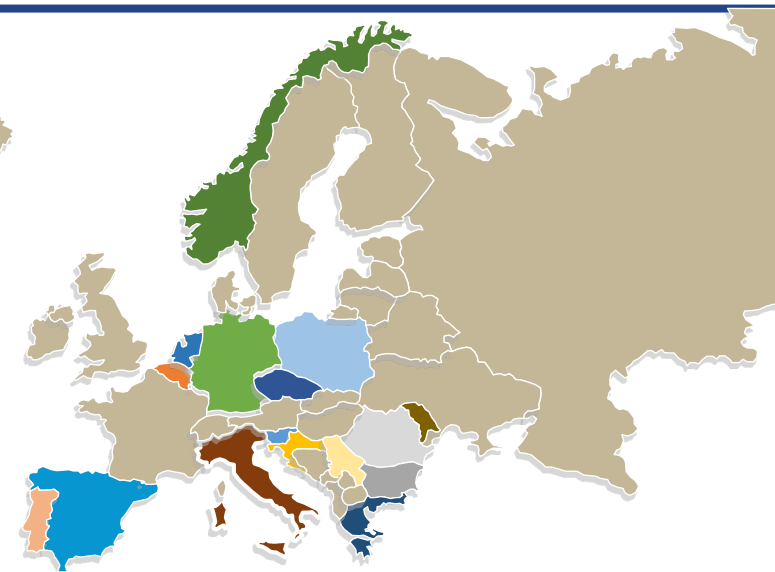


Co-funded by
the Health Programme
of the European Union

CANCER INFORMATION AND REGISTRATION

Italian National Institute of Public Health (ISS)

PARTICIPATING PARTNERS IN WP 7 (17 Countries)



Italy

- Istituto Superiore di Sanità, **ISS**
- Istituto Nazionale dei Tumori, Milano, **INT**
- Centro di Riferimento Oncologico, Aviano, **CRO**
- Istituto Studio Prevenzione Rete Oncologica, **ISPRO**
- Università di Foggia, **UNI-FG**
- Ministero della Salute, **MoH**

Czech Republic

- Ústav Zdravotnických Informací a Statistiky České Republiky, **UZIS**
- Institute of Biostatistics and Analyses, Masaryk University, **MUNI**

Belgium

- **SCIENSANO**
- Belgian National Cancer Registry

Norway

Oslo Universitetssykehus HF, **OUS**

Poland

Narodowy Instytut Zdrowia Publicznego Państwowy Zakład Higieny, **NIZP-PZH**

Slovenia

- Nacionalni inštitut za javno zdravje, **NIJZ**
- Institute of Oncology Ljubljana, **OIL**

Spain

Institut Català d'Oncologia, **ICO**

Greece

Dioikhs Ygeionomikhs Perifereias Krhths, **7 HRC**

Croatia

Hrvatski zavod za javno zdravstvo, **CIPH**

Portugal

Ministerio da Saude, **MS**

Germany

- Bundesministerium fuer Gesundheit, **BMG**
- German Cancer Society **DKG**

Netherlands

Rijksinstituut voor Volksgezondheid en Milieu, **RIVM**

Malta

Ministry for Health, **MFH**

Romania

Institutul National de Sanatate Publica, **INSP**

Serbia

Institut za javno zdravje Srbije "Milan Jovanovic-Batut", **IPHS**

Bulgaria

Natsionalen Centar po Obshtestveno Zdrave i Analizi, **NCPHA**

Moldova

Institutul oncologic din Moldova, **IMSP IO**

Key Stakeholders: ENCR, JRC

Subcontracts: AIRTUM, ECPC, OECI

CANCER INFORMATION AND REGISTRATION

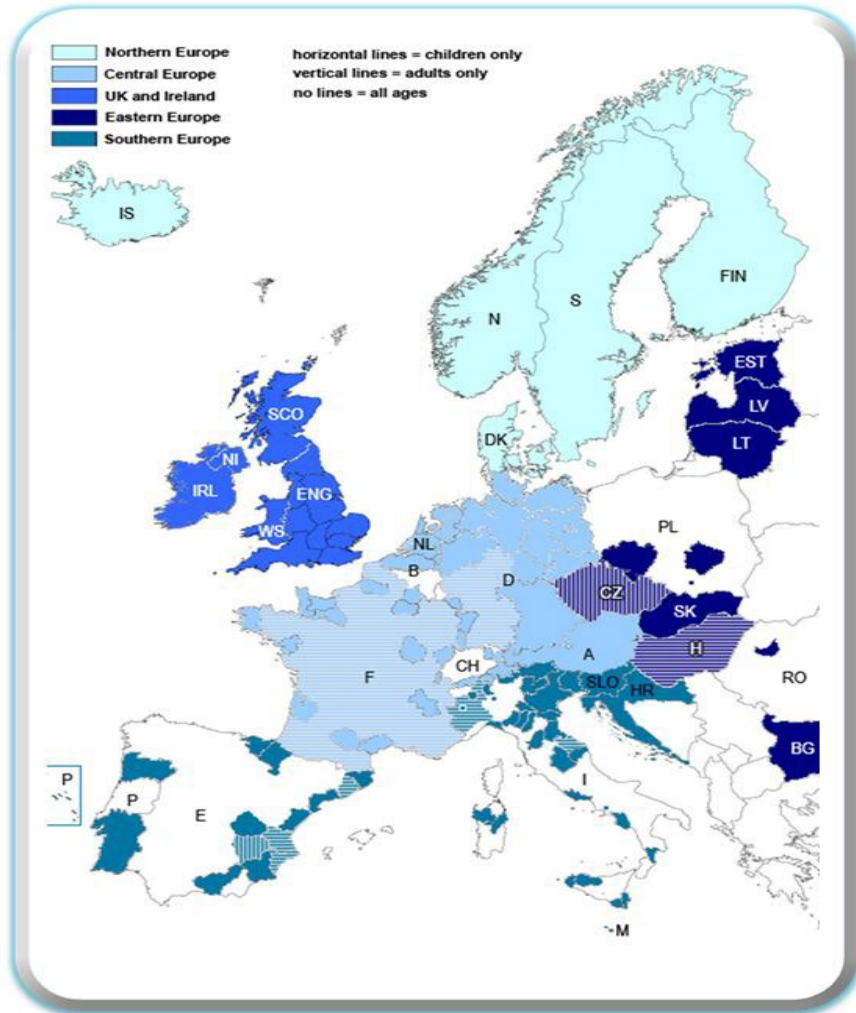
Italian National Institute of Public Health (ISS)

KEY OUTPUTS & OUTCOMES COMPLETED

Actions to enhance information from population-based cancer registries to better support cancer care and management

- 1. Better use current registries datasets in cancer epidemiology**
 - actions to foster dissemination and use of **complete cancer prevalence estimates by country** which are not systematically provided in Europe

CANCER PREVALENCE ESTIMATES IN EUROPE 2020



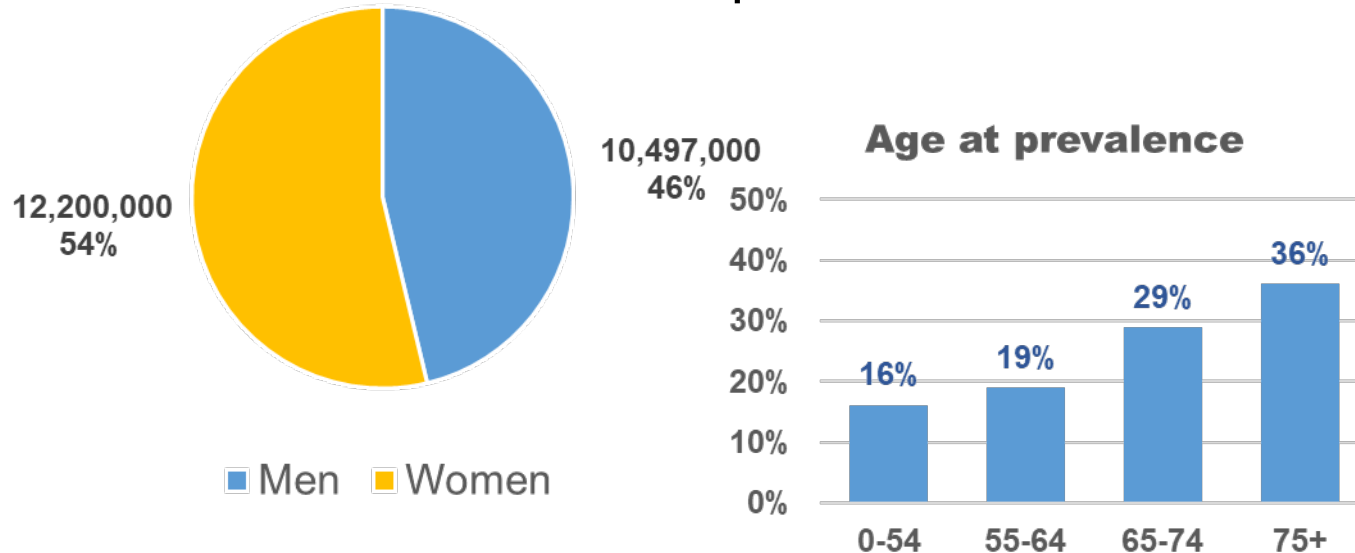
EUROCARE-6 : the widest collaborative study on cancer survival and prevalence in Europe Joint ENCR-JRC DataCall



- 109 Cancer Registries
- 29 countries
 - 23 national CRs
 - 6 regional CRs
(Italy, France, Spain, Portugal, Germany, Switzerland)
- 50% of EU population covered
- 26 million cases diagnosed to 2013
- 45 different cancer types

COMPLETE CANCER PREVALENCE IN EUROPE 2020

Estimates of **complete prevalence** on 1/1/2020
Pool of 29 European countries

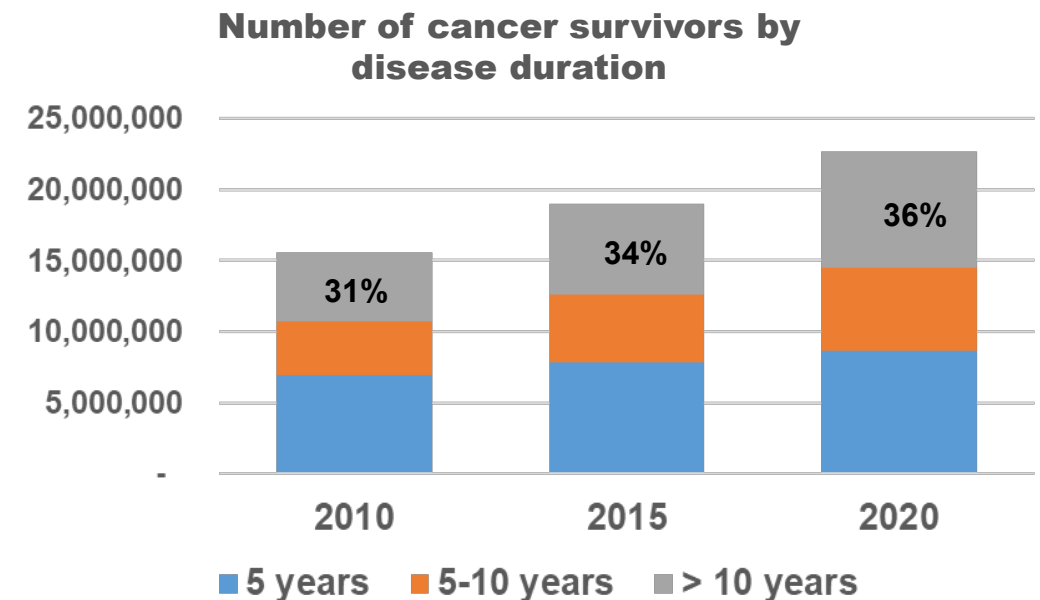


22.7 million cancer survivors

- 4.7% of total resident population
- 54% women
- 65% over 65 years of age

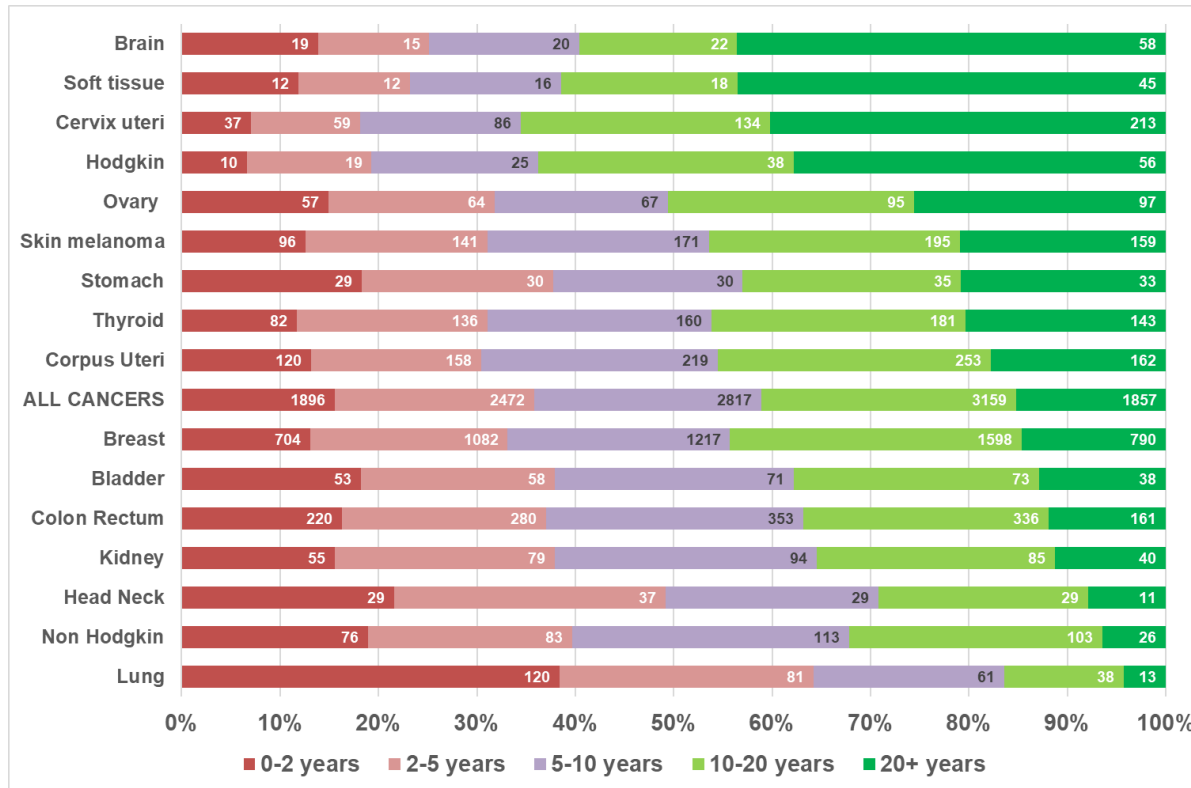
2010-2020 INCREASE: from 15.5 to 22.7 million → + 46%

People surviving >10 years after diagnosis
→ from 4.9 to 8.2 million (31% to 36%)

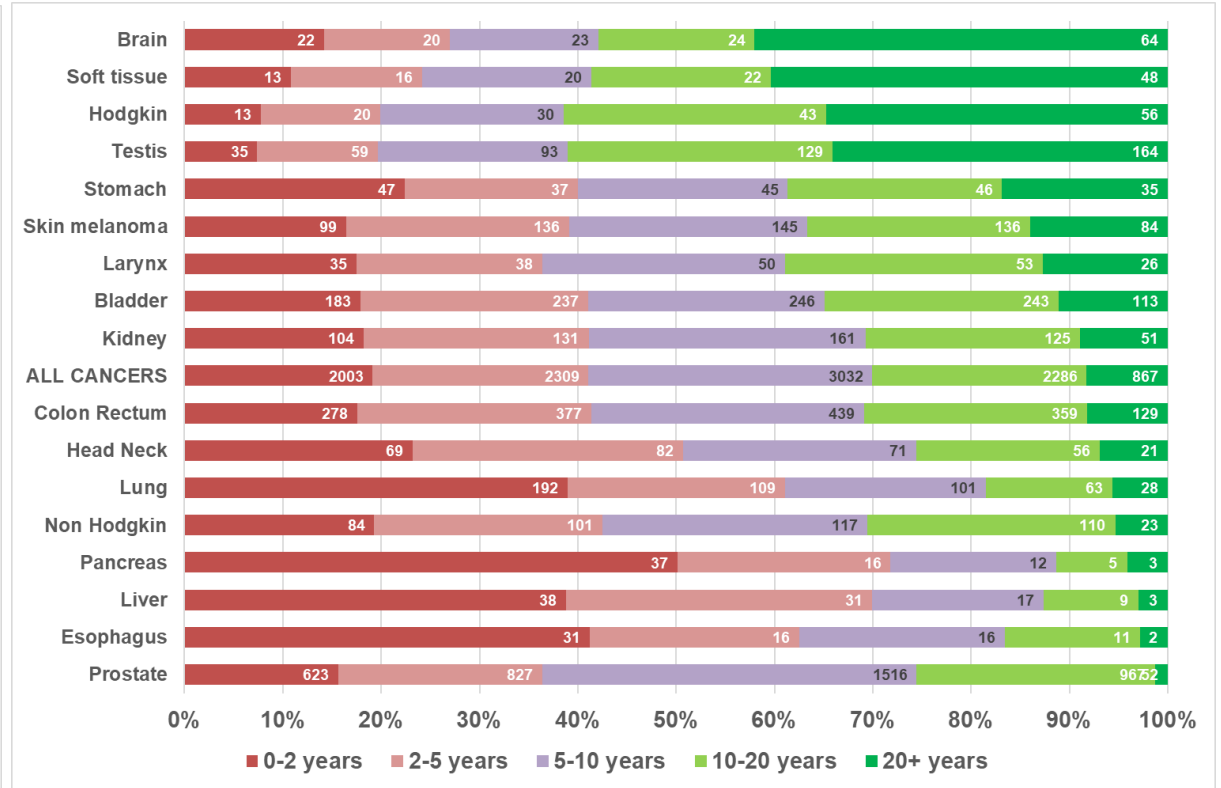


IMPACT OF LONG TERM SURVIVORS VARIES WITH CANCER TYPE AND SEX

Complete number of prevalent cases (in thousands) by disease duration in years (2, 2-5 , 5-10, 10-20, 20+) in EUROPE (Pool 29 countries) on January, 1st 2020



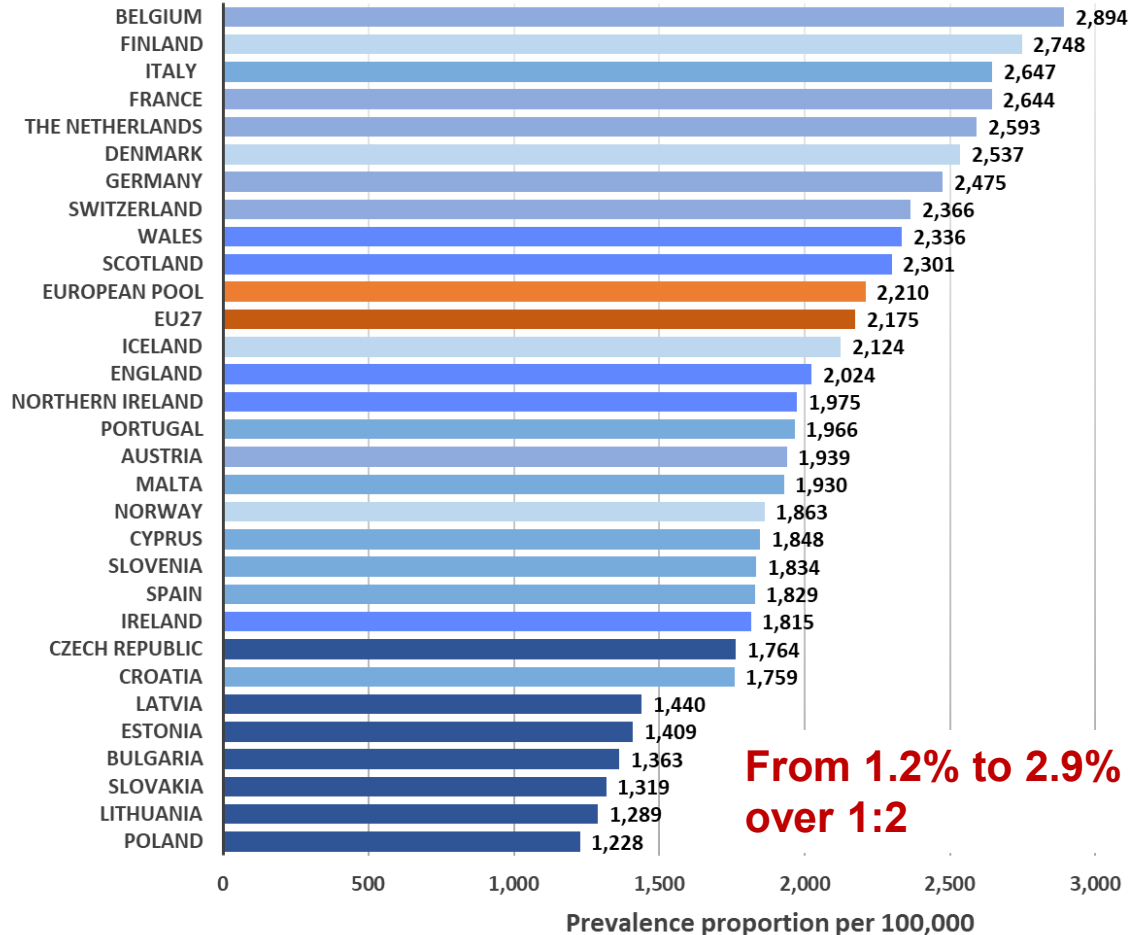
Women



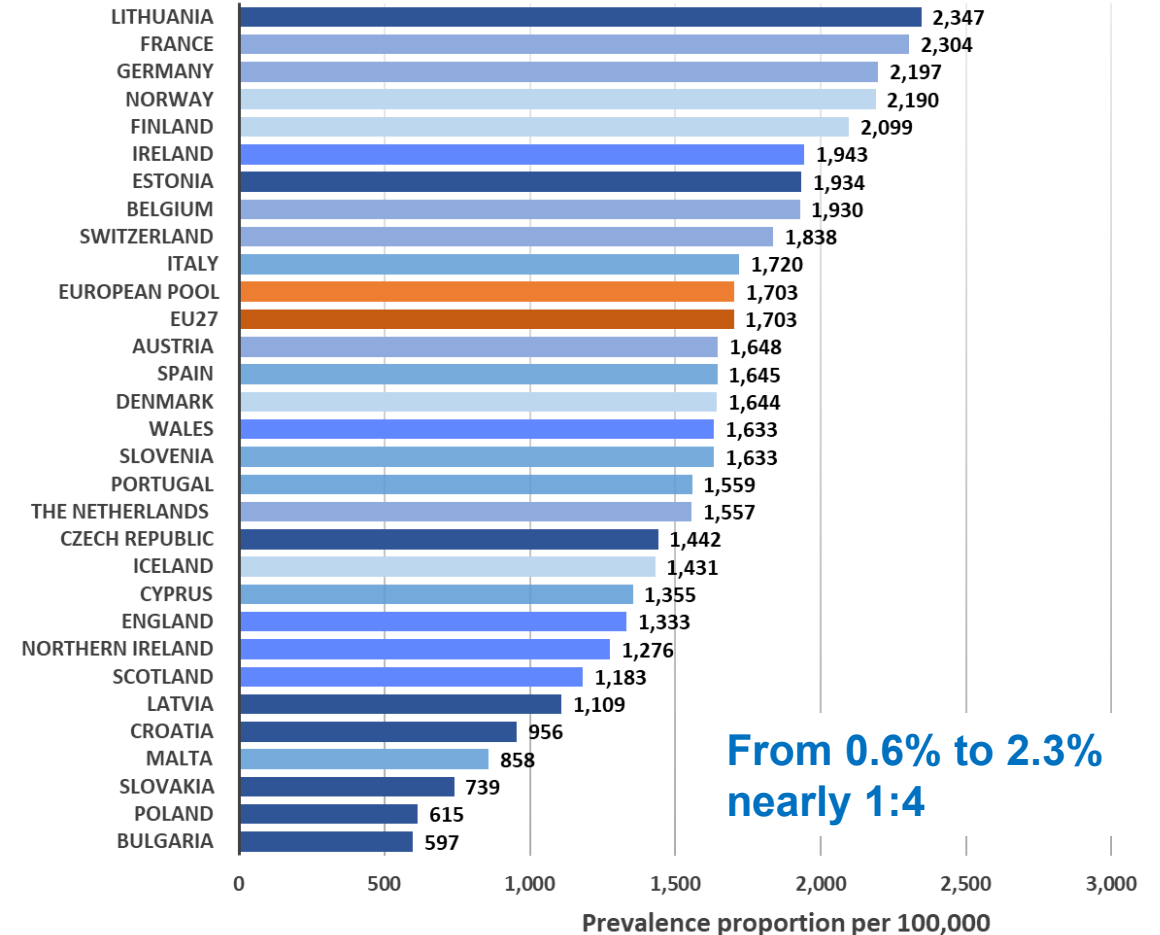
Men

GEOGRAPHICAL VARIATIONS IN PREVALENCE PROPORTIONS ARE WIDE

Breast, women



Prostate, men



Integrating prevalence estimates into the ECIS

ECIS - European Cancer Information System

Measuring cancer burden and its time trends across Europe



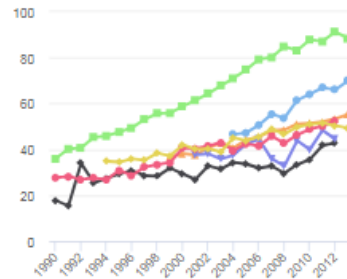
ECIS provides the latest information on indicators that quantify cancer burden across Europe. It permits the exploration of geographical patterns and temporal trends of incidence, mortality and survival data across Europe for the major cancer entities.

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**.



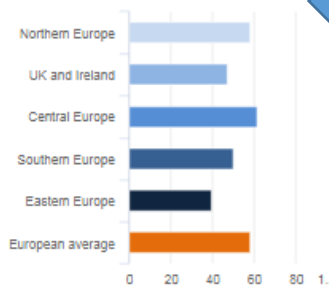
Incidence and mortality estimates 2018

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 Estimates

Survivors by



- cancer type
- disease duration
- sex, age
- EU 27, European Pool
- country, region

EUROCARE-6 Study



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

iPAAC Distance Training on cancer prevalence estimation



- E-learning on *Methods and Software for estimating Complete Cancer Prevalence from registries data. Theory and Applications*
- June 2021, 2 days
- Target: epidemiologists & statisticians from European Cancer Registries
- **92 participants** from 21 countries

DISTANCE TRAINING ON POPULATION-BASED CANCER PREVALENCE

22-23 JUNE 2021

ORGANISED BY **ISTITUTO SUPERIORE DI SANITÀ - ISS**
IN COLLABORATION WITH THE **ENCR-JRC**

Distance training on population-based cancer prevalence indicators addressed to statisticians and epidemiologists working in the European Cancer Registries. The course was developed within the framework of the *Innovative Partnership for Action Against Cancer (iPAAC)* Joint Action, an initiative co-financed by the European Commission involving 24 European countries. Promoting the dissemination and use of epidemiological indicators on cancer survivors is part of the iPAAC Work Package 7 activities.

GENERAL SCOPE AND LEARNING OBJECTIVES

The course aims at providing a general overview of the methods and means to derive cancer prevalence estimates from observed incidence and survival data, balancing theory and practical applications.

At the end of the course participants will be able to:

- 1) Identify basic prevalence measures, determine their scope and interpretation
- 2) Identify the appropriate methods to compute complete and limited-duration prevalence
- 3) Select the appropriate software and input information needed to calculate each indicator
- 4) Plan the steps needed to derive prevalence estimates from their cancer registry data

PROGRAM CONTENTS

Prevalence definitions, measures, main applications and interpretation

Statistical methods: counting method, prevalence completeness index, cure survival models

Software to derive prevalence indicators: SEER*Stat Prevalence session, ComPrev

Guided exercises and examples of application using a test dataset



CANCER INFORMATION AND REGISTRATION

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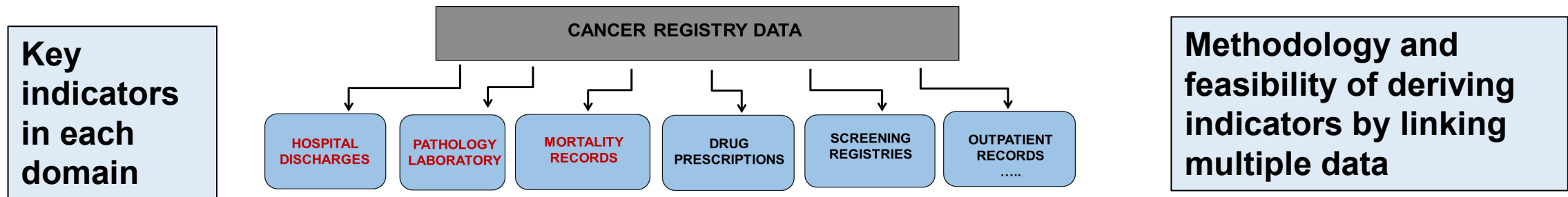
KEY OUTPUTS & OUTCOMES COMPLETED

Actions to enhance information from population-based cancer registries to better support cancer care and management

- 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 care and management**

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, GR, PT, 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



WP7 PILOTS IMPLEMENTATION

Pilots 7.2-4 implementation steps

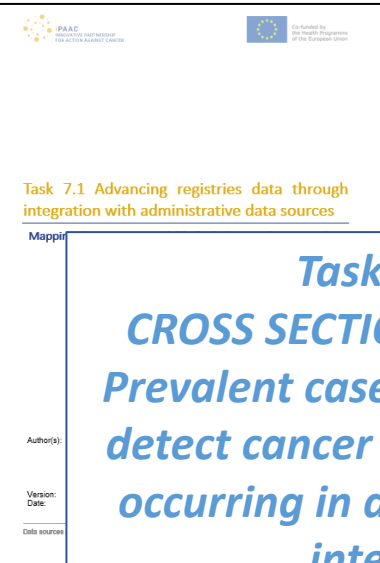
1. Feasibility and
adaptation to
country-specific
data sources

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
- Pilots **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
- Technical documentation released in the upcoming **iPAAC deliverables** for Tasks 7.2-7.4



Tasks 2-3

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

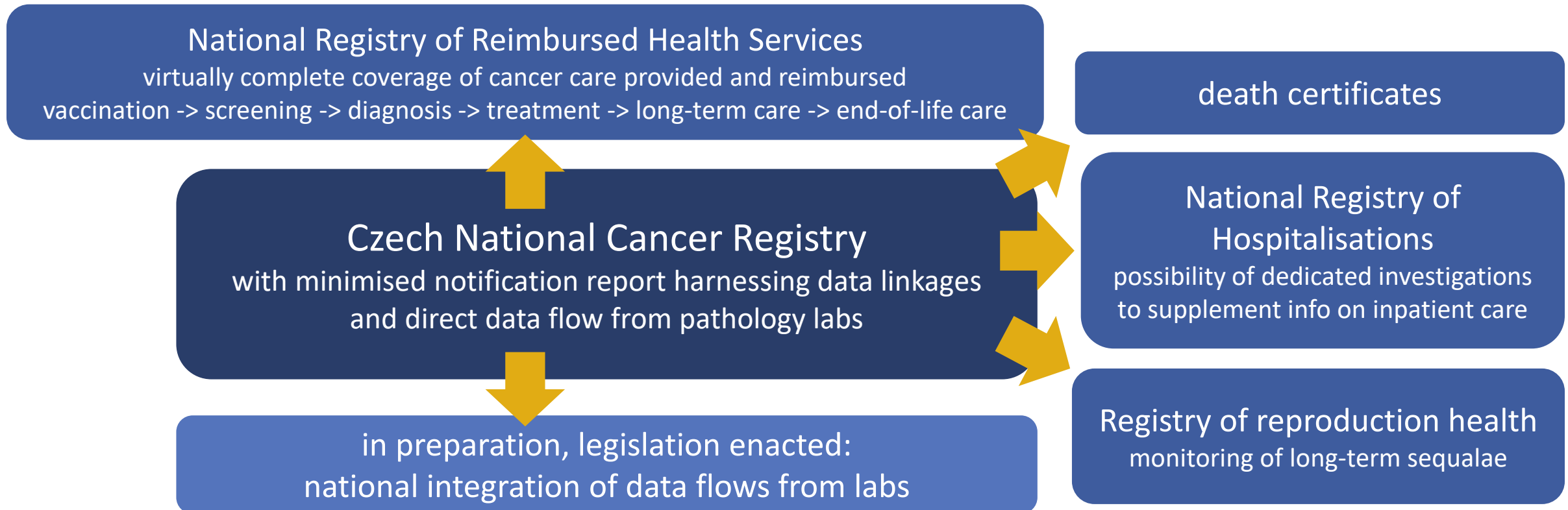
Task 4

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

PILOTING 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

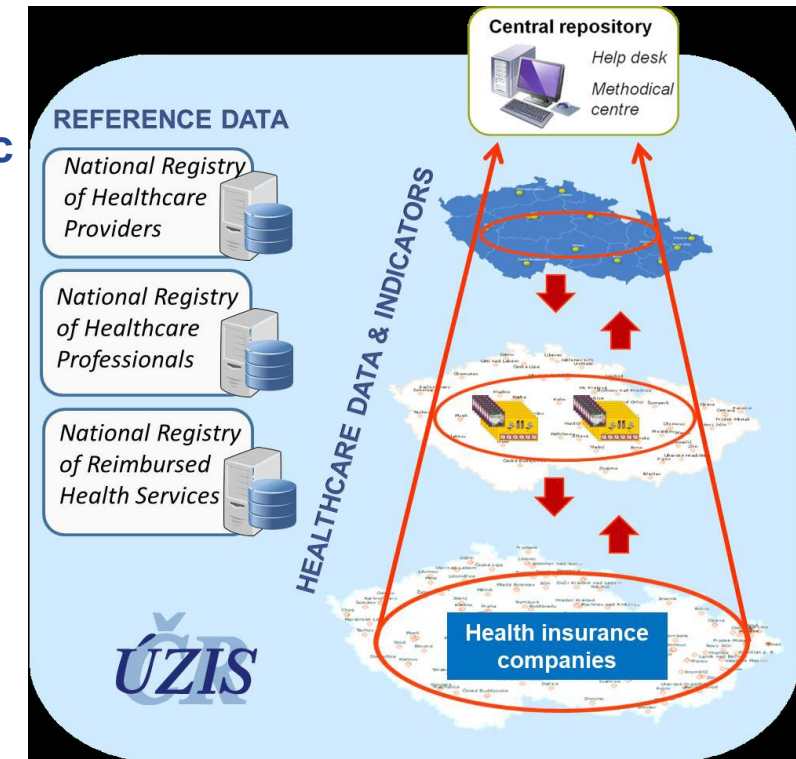
- Czech comprehensive ICT model integrating multiple data sources**



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



Promoting the use of indicators on Cancer Prevalence in EU

POTENTIAL FOR FUTURE USE/VALUE OF OUTPUTS/LESSONS LEARNED

Integration of iPAAC outputs in the ECIS web-portal :**collaboration JRC-EUROCARE-ENCR to design & implement the prevalence section planned for 2022**

Sustainability of regular prevalence updates in ECIS: **data availability granted by next ENCR-JRC Data Call, support to epidemiological research to feed the ECIS is needed**

Building capacity at European level: **Training Module on Methods and Software for Cancer Prevalence estimation → EU registries interested to move forward**

Link to EBCP initiatives: **prevalence is a key epidemiological indicator for the Inequality Registry and to inform initiatives targeting cancer survivors and survivorship, such as the Right to be Forgotten (*prevalence of cured people*)**

Enriching
Registries
Information

through

optimised
secondary-
use of data

POTENTIAL FOR FUTURE USE/VALUE OF OUTPUTS/LESSONS LEARNED

Standardised methods to enrich registries data through data re-use:
guidance and recommended key indicators for implementation in MS

Lessons learned:

- legal background **for registration and data re-use** → regulations on registration **should cover survivorship and cancer care monitoring amongst the scopes;**
- digitalisation and integration → **innovative ICT models incorporating the registries in comprehensive cancer care information systems** (registries as information-hub)

Future use in Czech Rep: ICT model supporting complex bodies managing and delivering care (like CCCNs) and national systems for comprehensive cancer surveillance (including long-term surveillance)

THANK YOU!