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Colmare i deficit di conoscenza: stime dei lungo sopravviventi oncologici in Europa

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ISTITVTO SVPERIORE DI SANITA

BETTER CANCER INFORMATION TO IMPROVE CANCER CARE

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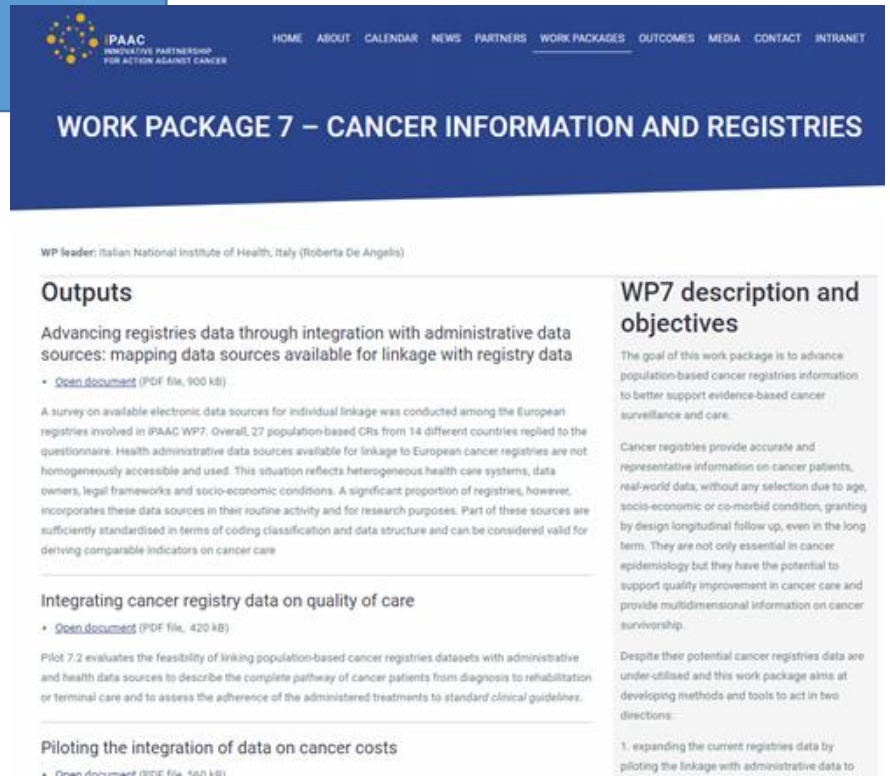
Work Package 7

Actions to enhance population-based cancer information systems to better support cancer control

1. **Enriching current registries datasets → piloting integration with multiple data sources to derive indicators for cancer care and management**

2. **Better use current registries datasets → cancer prevalence in European countries**



https://www.ipaac.eu/en/work-packages/wp7/

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IMPORTANZA DEGLI INDICATORI DI PREVALENZA DEI TUMORI

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La popolazione di persone che vivono con una pregressa diagnosi di tumore (*casi prevalenti*) è:

- **in continuo aumento** a causa dell'invecchiamento demografico e dei progressi terapeutici
- molto **eterogenea** e con **bisogni diversi** a seconda della fase della malattia

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JOURNAL OF CLINICAL ONCOLOGY | COMMENTS AND CONTROVERSIES

Categorization of Cancer Survivors: Why We Need It

Antonella Surbone, *New York University Medical School, New York, NY*
Paolo Tralongo, *Umberto I Hospital, Siracusa, Italy*

Table 1. Categories of Patients With and Survivors of Cancer

Category	Description
Acute	Patients/survivors at first diagnosis or relapse, who require acute intervention
Chronic	Patients/survivors with cancer that slowly progresses or alternates between phases of remission and relapse, often accompanied by acceptable quality of life
Long term	Patients/survivors in clinical remission for long periods of time or for their entire life, who remain at risk for distant relapse or second tumors and who potentially can experience late treatment-related medical and psychosocial sequelae
Cured	Disease-free patients/survivors whose cancer-specific mortality and life expectancy years after years diagnosis equals that of sex- and age-matched members of the general population

Classificare i casi prevalenti per durata della malattia (2, 5, 10 o più anni) è un modo per individuare i gruppi con bisogni diversi e incrementa l'utilità delle misure di prevalenza

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LE MISURE DIRETTE DI PREVALENZA SONO PARZIALI

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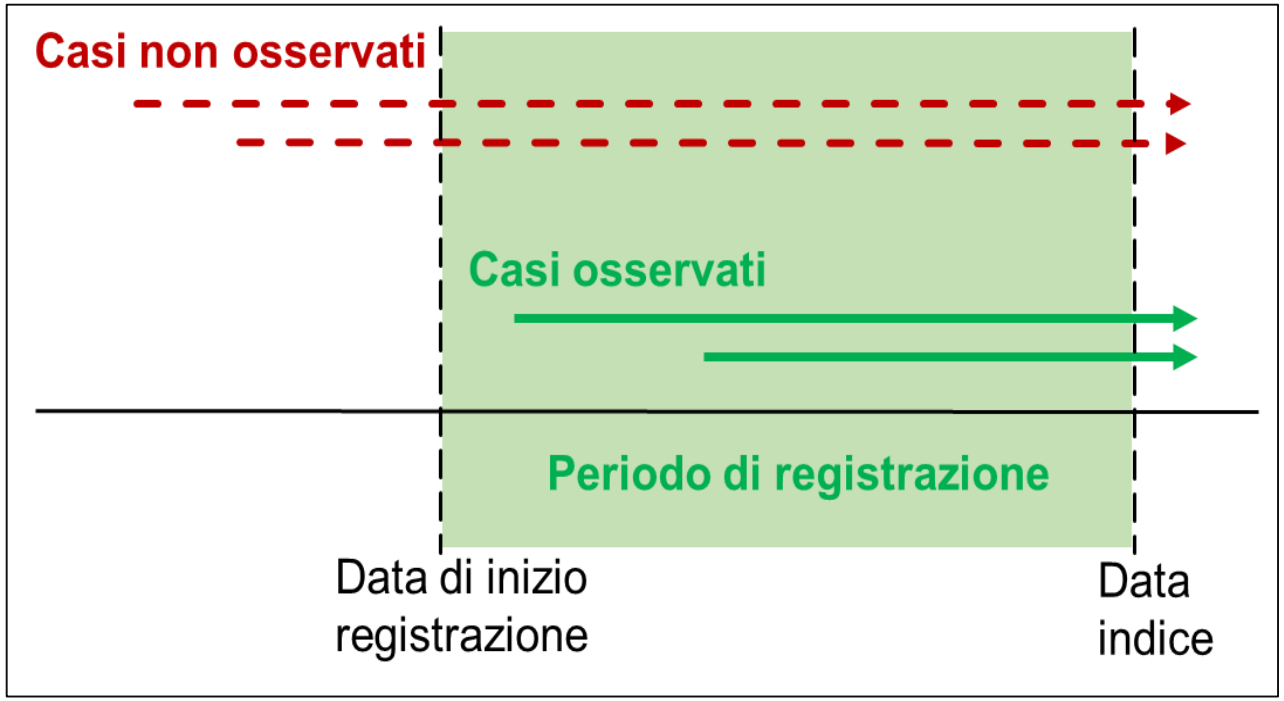
- I casi diagnosticati prima dell'avvio della registrazione **NON** sono osservabili
- La **prevalenza osservata**, cioè quella calcolata direttamente dai dati dei registri è **incompleta**



- Bisogna stimare con metodi statistici la quota di casi non osservati per ottenere la **prevalenza completa**
- La necessità di competenze tecniche e software specifici ostacola la produzione sistematica di indicatori di prevalenza in molti paesi europei

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STIMA DELLA PREVALENZA SUI DATI EUROCARE-6

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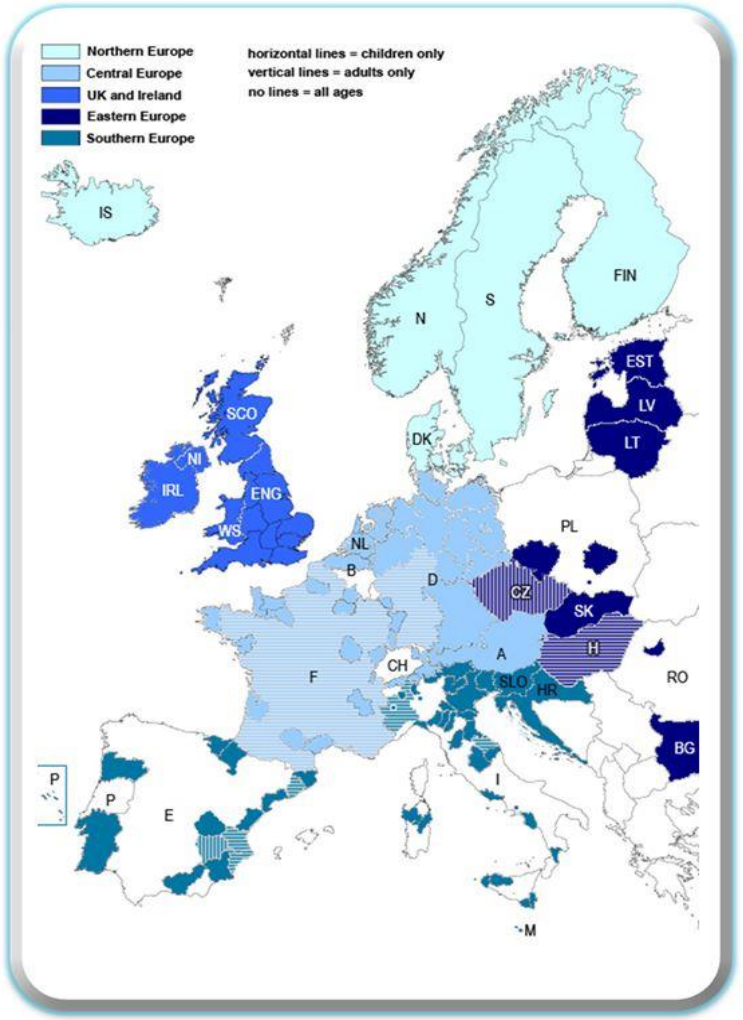

Sopravvivenza e prevalenza dei tumori in Europa

- 50% della popolazione europea
- 26 milioni di casi diagnosticati fino al 2013
- 29 paesi, 109 Registri Tumori
- Copertura nazionale in 23 paesi
- Copertura parziale in 6 paesi
  Italia, Francia, Spagna, Portogallo, Germania, Svizzera
- 45 tipologie di tumore

EUROCARE
Survival of cancer patients in Europe

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METODOLOGIA

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1. Calcolo prevalenza osservata per registro/paese/area, tipologia di tumore, sesso, età, durata della malattia e anno di calendario fino al 2013

2. Completamento della prevalenza osservata tramite gli *indici di completezza*

3. Proiezioni della prevalenza completa al 2020 tramite modelli di regressione lineare

Software utilizzati: SEER*Stat, ComPREV (NCI-NIH) & SAS Statistical Package

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PREVALENZA DEI TUMORI IN EUROPA 2020

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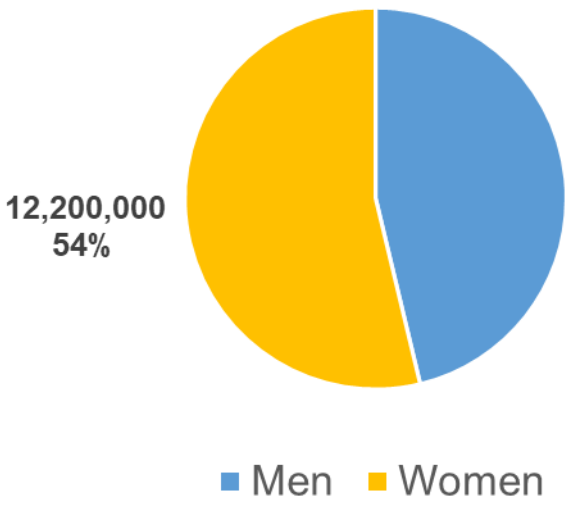
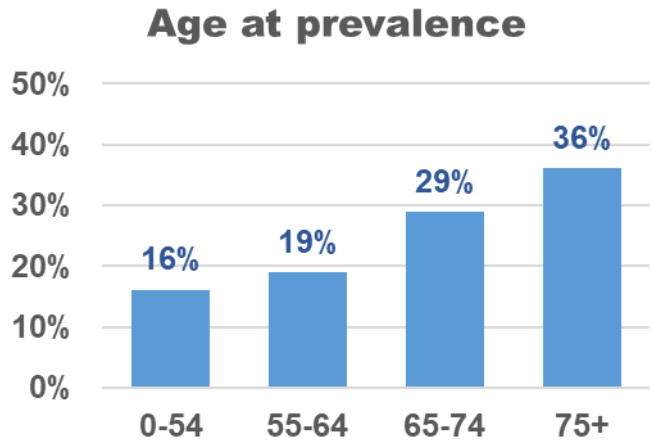
Stime della prevalenza completa nel pool dei 29 paesi EUROCARE-6 al 1/1/2020



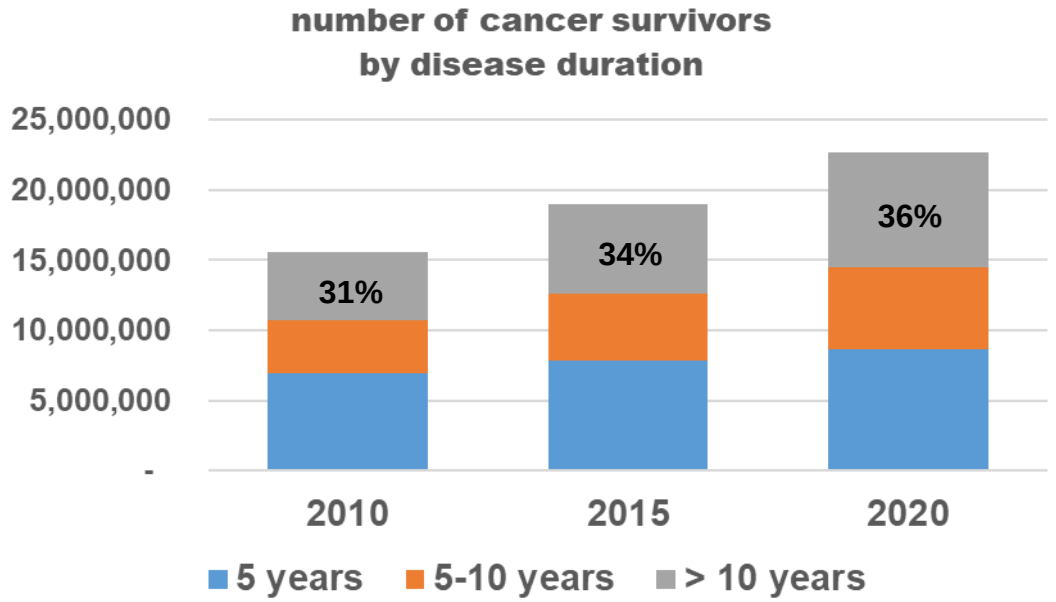


22.7 milioni di persone con una pregressa diagnosi di tumore

- **4.7%** della popolazione residente
- **54%** donne
- **65%** over 65 anni

AUMENTO 2010-2020 : da 15,5 a 22,7 milioni
→ + 46%

dal 31% al 36% di lungo-sopravviventi
(diagnosi da più di 10 anni)



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PREVALENZA DEI TUMORI IN EUROPA
DONNE, 2020

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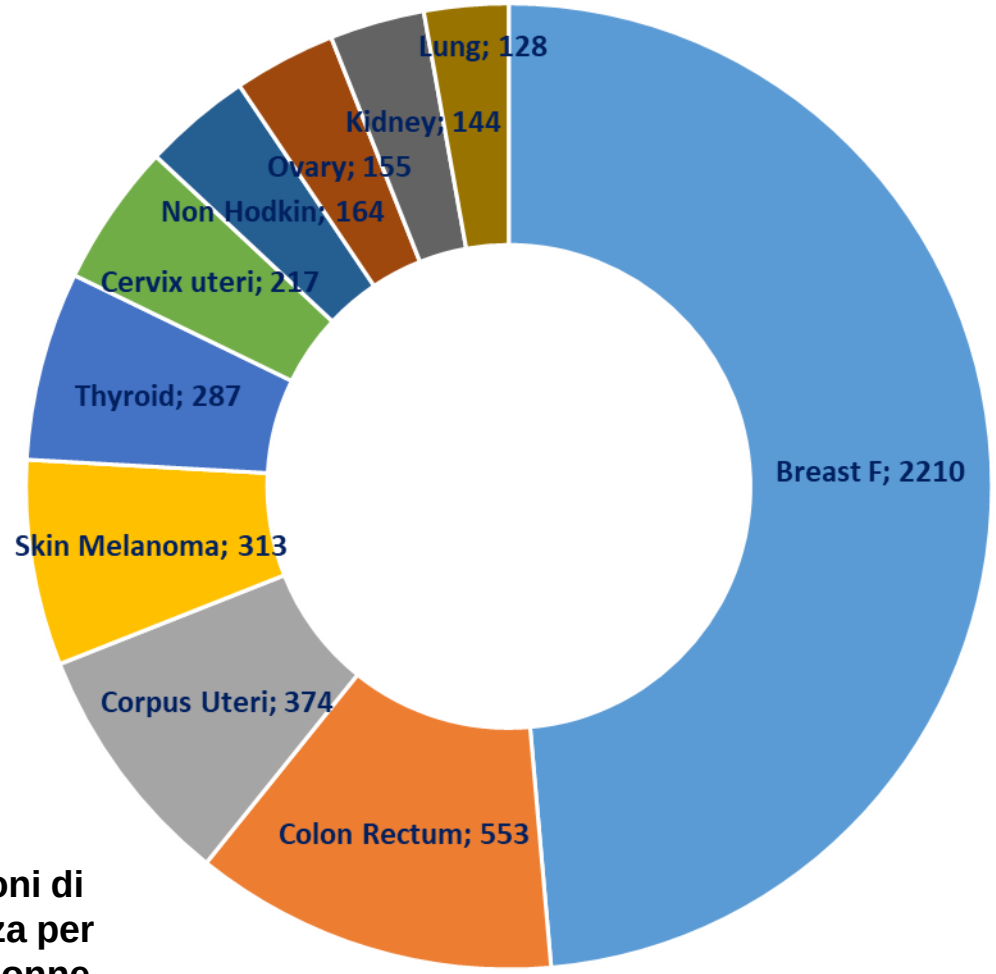

Proporzioni di prevalenza per 100,000 donne

Pool EUROCARE-6, Prevalenza completa al 1/1/2020

Prevalenza completa tra le donne:

- 12.2 milioni
- 5% della popolazione femminile residente

Tumori a più alta prevalenza:

- **mammella (2.2% della popolazione femminile, 5.4 milioni)**
- colon-retto (0.6%, 1.4 milioni)
- corpo dell'utero (0.4%, 0.9 milioni)
- melanoma della pelle (0.3%, 0.8 milioni)
- tiroide (0.3%, 0.7 milioni)

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PREVALENZA DEI TUMORI IN EUROPA UOMINI, 2020

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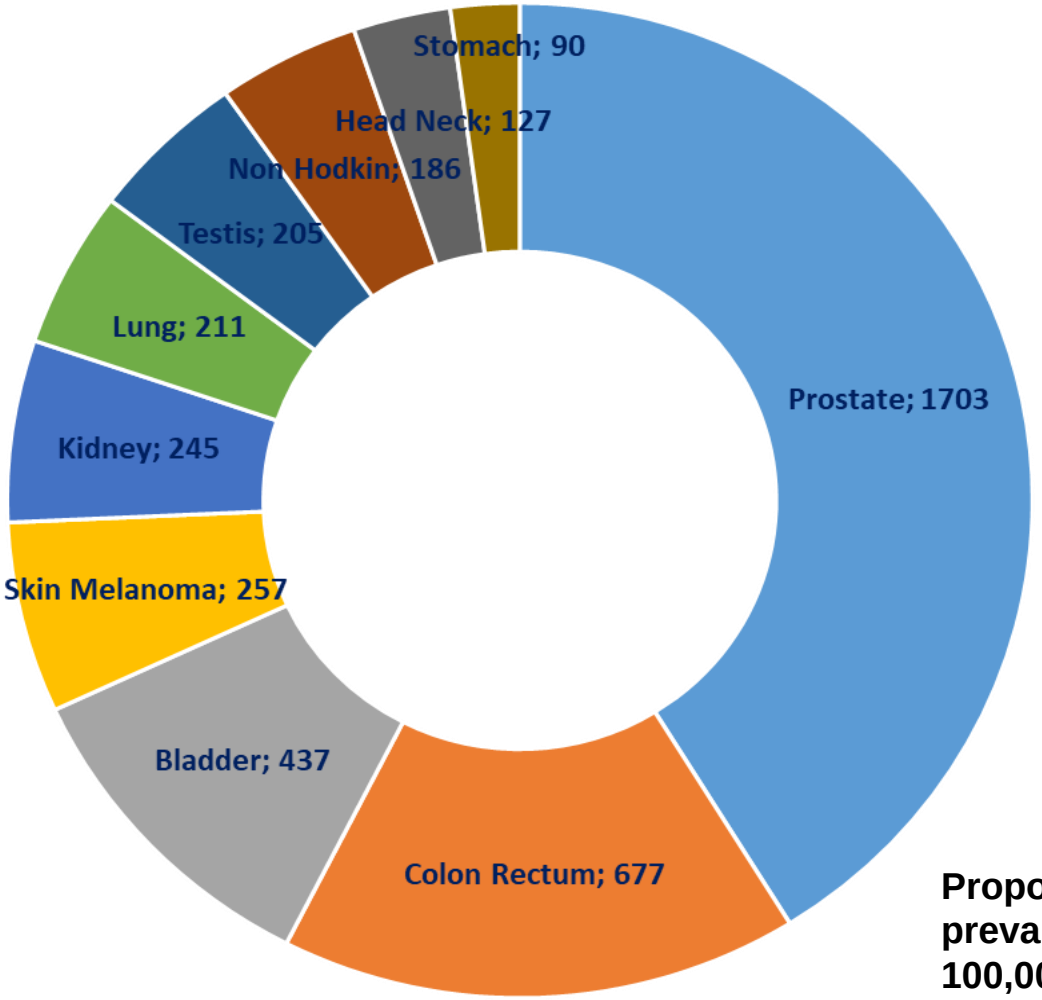
Pool EUROCARE-6, Prevalenza completa al 1/1/2020

Prevalenza completa tra gli uomini:

- 10.5 milioni di sopravviventi
- 4.5% della popolazione maschile residente

Tumori a più alta prevalenza

- **prostata (1.7% della popolazione maschile, 4 milioni)**
- colon-retto (0.7%, 1.6 milioni)
- vescica (0.4%, 1 milione)
- melanoma della pelle (0.3%, 0.6 milioni)
- rene (0.2%, 0.5 milioni)



Proporzioni di prevalenza per 100,000 uomini

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DIFFERENZE GEOGRAFICHE: PREVALENZA DEL TUMORE DELLA MAMMELLA (DONNE), 2020

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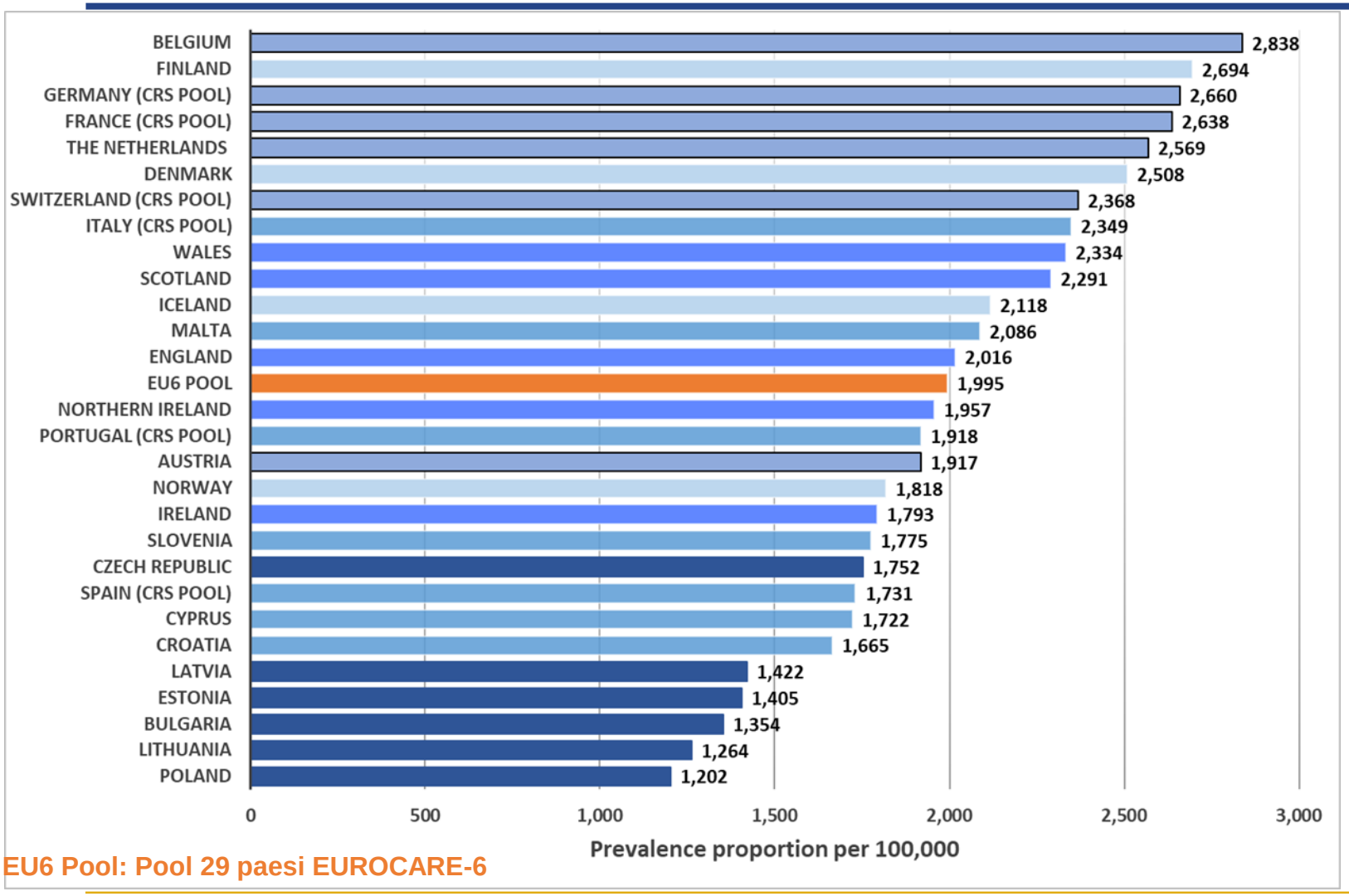


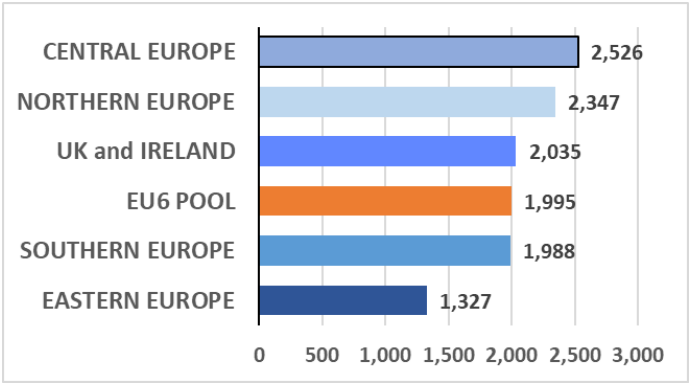
EU6 Pool: Pool 29 paesi EUROCARE-6

Ampie differenze tra i paesi europei

Proporzioni di prevalenza da 2,838 per 100,000 in Belgio a 1,202 per 100,000 in Polonia

Determinanti:

incidenza, sopravvivenza, struttura demografica e copertura dei programmi di screening



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DIFFERENZE GEOGRAFICHE: PREVALENZA DEL TUMORE DELLA PROSTATA (UOMINI), 2020

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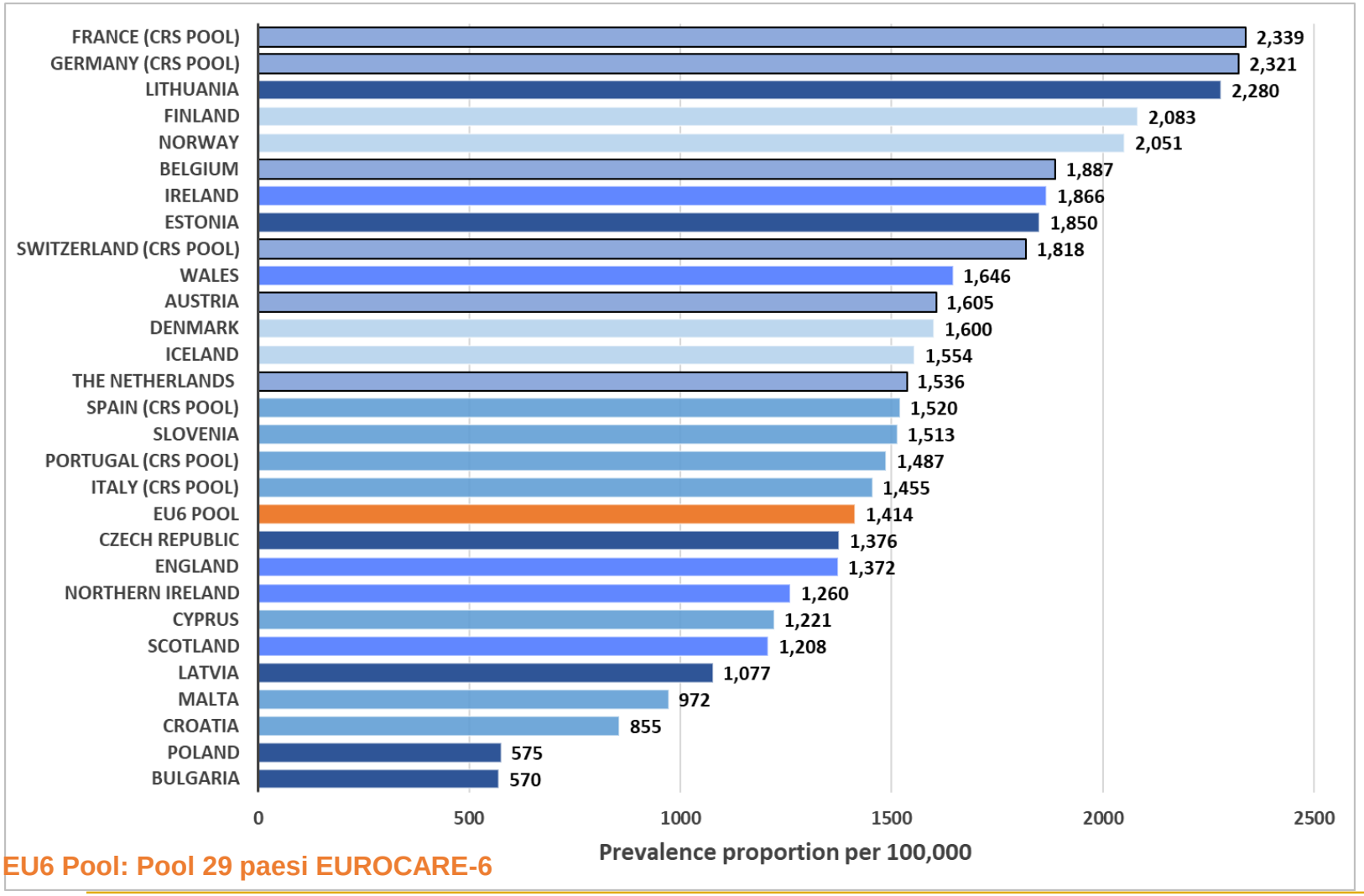


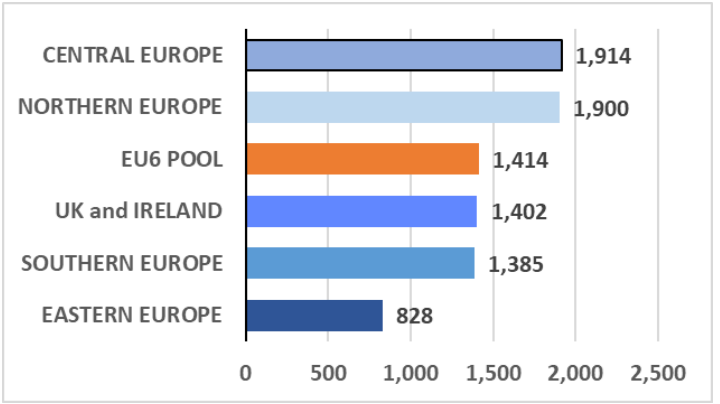
EU6 Pool: Pool 29 paesi EUROCARE-6

Ampie differenze tra i paesi europei

Proporzioni di prevalenza da 2,339 per 100,000 in Francia a 570 per 100,000 in Bulgaria

Determinanti:

incidenza, sopravvivenza, struttura demografica e diffusione del Test PSA



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INTEGRAZIONE DELLE STIME DI PREVALENZA IN ECIS

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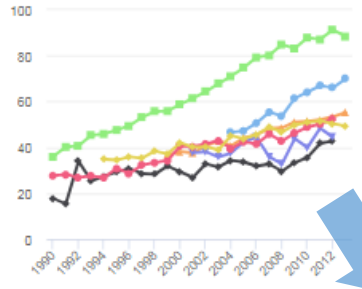
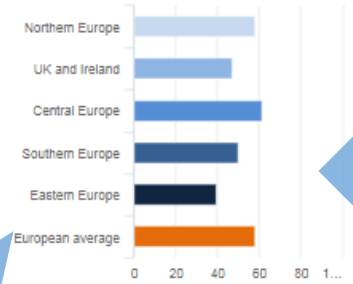
ECIS - European Cancer Information System

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.

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

European Network of Cancer Registries

Stime di prevalenza per

- Tipo di tumore
- Durata della malattia
- Sesso, età, anno di calendario
- Paese / Area

EUROCARE-6

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FORMAZIONE SU METODI E SOFTWARE PER LA STIMA DELLA PREVALENZA

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- Corso sui metodi di stima della prevalenza completa a partire dai dati dei Registri Tumori, teoria e applicazioni
- Giugno 2021, 2 giornate
- Target: epidemiologi/statistici dei Registri Tumori europei
- 92 iscritti

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

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Grazie per l'attenzione!

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