



Ministero della Salute

Info Webinar 8 May 2024

**Nuove Joint Actions Programma EU4Health
2^a fase 2024**



CR-g-24-40 Direct grants to Member States' authorities

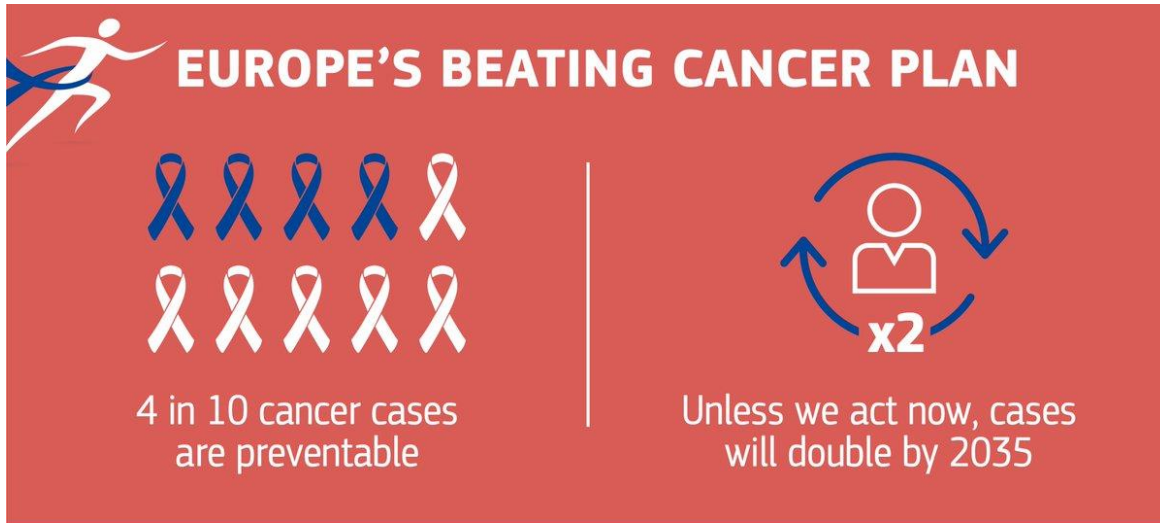
**Support quality improvement of cancer registry data
feeding the European Cancer Information System**

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Why a JA on cancer registries information



Strategy for health data

Help *researchers to exchange findings* across Member States, and to improve access to *crucial health data* for medical staff and hospitals, health care planners, for patients and citizens

Horizontal topics

1. Innovation: data, digitalization, research and training
2. Reducing inequalities across UE
3. Special focus on Childhood cancers

THE KNOWLEDGE CENTRE ON CANCER

An **independent** data broker **providing support** while expanding the EC's IT systems, gateways, portals, platforms and databases



Evidence-clearing house
for policy making



Prevention



Early
detection



Treatment
and survivorship



European Cancer
Information System



European guidelines
and quality assurance
schemes



Cancer
screening



Diagnosis



Care

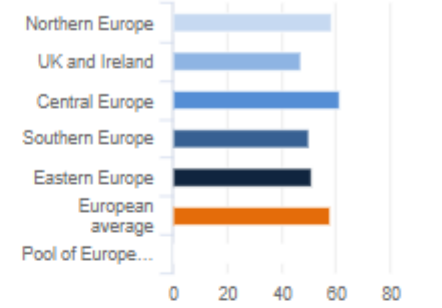
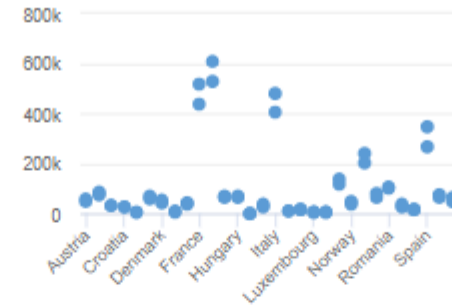
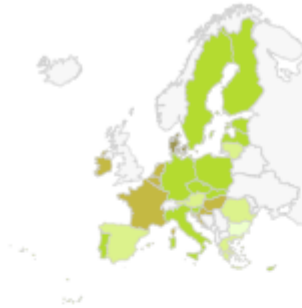
ECIS - European Cancer Information System

ECIS is a main pillar of KCC

Latest information on cancer burden across EU

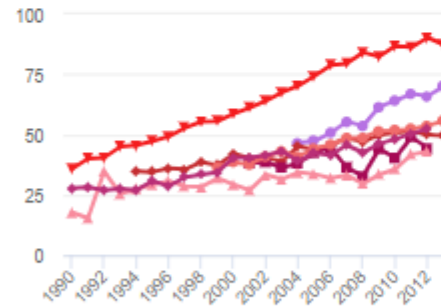
Aim: to support research, public-health decision making, and inform European citizens

Explore the data



Incidence and mortality estimates 2022

National estimates of cancer incidence and mortality in 2022, for the major cancer sites in European countries.

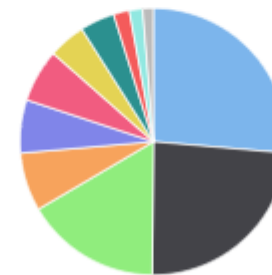


Incidence and mortality historical data

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

Long-term incidence and mortality estimates up to 2040

National estimates of cancer incidence and mortality up to 2040, for the major cancer sites in EU and EFTA countries, according to different projected populations.

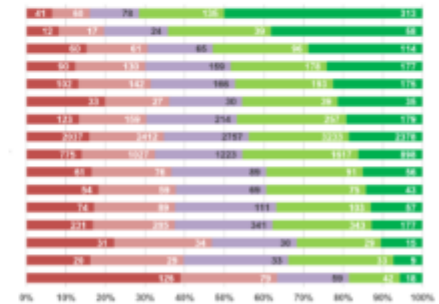


Childhood incidence historical data

Childhood incidence statistics by diagnostic group in European cancer registration areas.

Survival estimates

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



Prevalence estimates 2020

Estimates of cancer prevalence in 2020 for major cancer entities in European countries and regions.

Welcome to ENCR

The European Network of Cancer Registries (ENCR), established within the framework of the Europe Against Cancer Programme of the European Commission, has been in operation since 1990.

The ENCR promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on incidence and mortality from cancer in the European Union and Europe.

[Read more](#)

External links

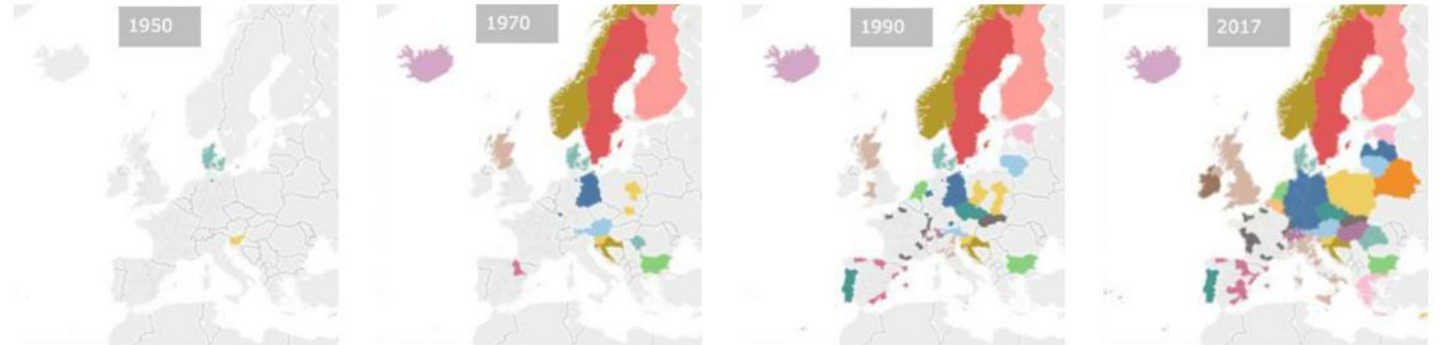
ECIS-European Cancer Information System

Visualisation of European statistics on cancer burden
[Read more about the ECIS web application](#)

ENCR-JRC data portal

Data submission and participation in projects
- reserved to ENCR members

Timeline of cancer registration in Europe



ECIS is fed with the data provided by the European Network of Cancer Registries (ENCR)

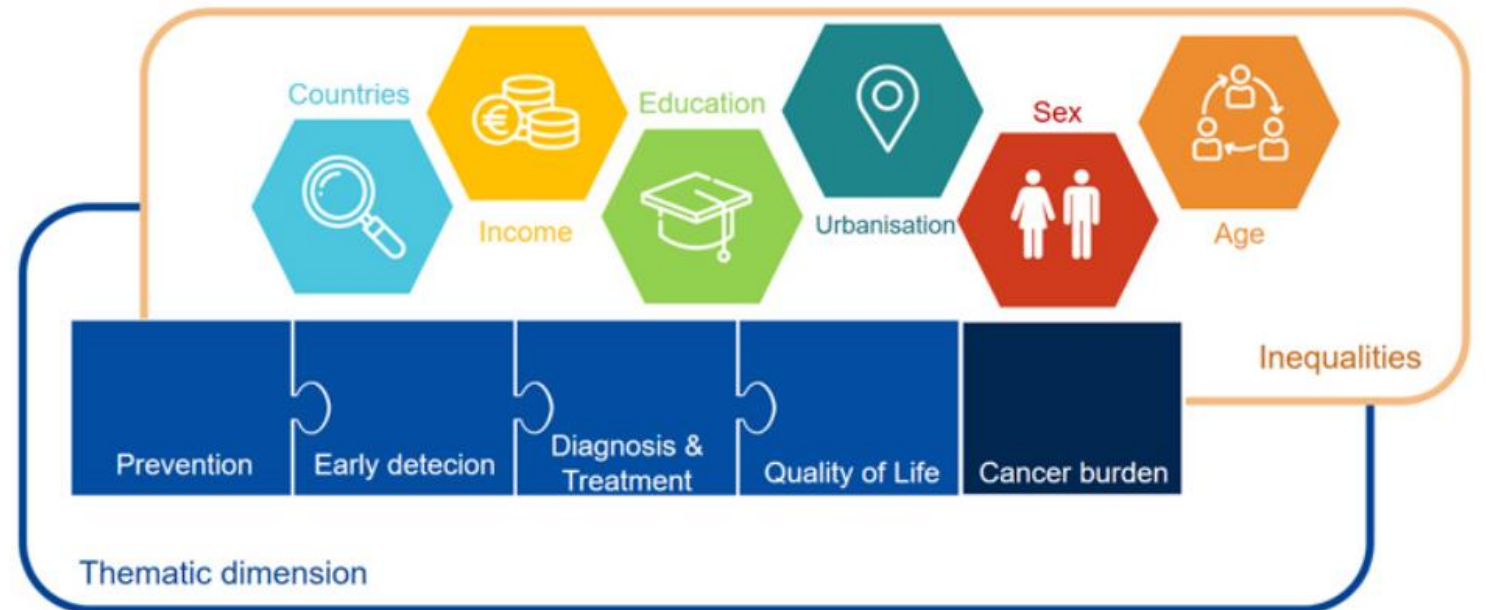
European Cancer Inequalities Registry (ECIR)

- Flagship initiative of EBCP to understand, address and reduce cancer inequalities between Member States.
- **Better and timelier CRs data** from the ECIS will feed the ECIR

Framework to monitor disparities

Inequalities dimension

Thematic dimension



JA on cancer registries to support the implementation of the ECIS

- **CR-g-24-40 Direct grants to Member States' authorities**

Support quality improvement of cancer registry data feeding the European Cancer Information System

Objective 1: fostering quality improvement of cancer registry data

Objective 2: Improving survival and prevalence indicators in the ECIS

Aim 1 - Quality improvement of CRs data

Timeliness, accuracy and completeness

- Improving compliance with **data quality standards** according to the European Network of Cancer Registries ('ENCR') guidelines, JRC-ENCR protocol and **minimum standards on data quality indicators**;
- improving **completeness of cancer records**, increasing **access to primary data sources** and **standardisation and harmonisation of data collection** and extraction processes whenever not yet available (*hospital discharge records, pathological reports, etc.*); possibly taking advantage of the *European Electronic Health Record exchange Format*;
- improving **completeness of cancer variables**, accessing **additional data sources** to retrieve missing information (i.e., *clinical variables such as **treatment, stage, etc.***) possibly taking advantage of the *European Electronic Health Record exchange Format*;

Aim 1 - Quality improvement of CRs data

Interoperability and alignment with EHDS

- aligning **access and exchange of electronic health data** from cancer registry data with the relevant frameworks envisaged in the proposed EHDS, and particularly health data access bodies;
- exploring the **use of the data quality and utility label** developed in the context of the proposed EHDS;
- aligning cancer registries' specifications for datasets with the **proposed EHDS Regulation**, including, at least, **data elements, controlled vocabularies, quality requirements**;
- exploring the **interplay and alignment** between the ECIS and the relevant EHDS infrastructures;

Aim 1 - Quality improvement of CRs data

Linkage with screening data

- linking **cancer registries and screening registries data**, using Union tools and guidelines supporting the **harmonisation of screening information** at Union level building on the outcomes of the CanScreen ECIS project;
- establishing a **sustainable** mechanism for **regular provision of aggregated screening data and information to ECIS**;

Aim 2 – survival and prevalence in ECIS

Improve indicators provided in ECIS

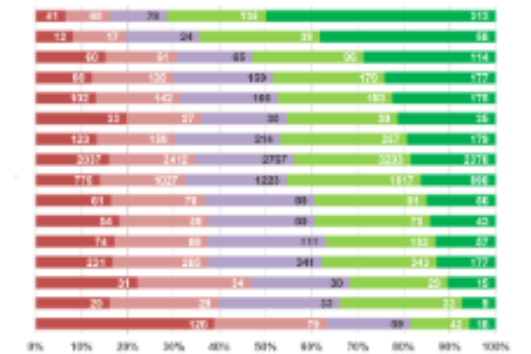
- Survival and Prevalence indicators currently available in the ECIS are those estimated by a wide European study on population-based cancer survival and prevalence in Europe (EUROCARE, 120 CRs)
- Results on cancer prevalence on 2020 in Europe from the EUROCARE-6 study are on-line in ECIS (Jan 2024) – outcome of iPAAC JA 2021

ECIS - European Cancer Information System



New ECIS module with 2020 prevalence estimates for EU-27 and European countries!

Look at the [news](#) announcing the release and the publication of the [new study published in the Lancet Oncology](#), and consult the [ECIS prevalence estimates page](#).



Prevalence estimates 2020

Estimates of cancer prevalence in 2020 for major cancer entities in European countries and regions.

Aim 2 – Survival and Prevalence indicators

Improve indicators provided in ECIS

- a) building on the already available mechanism in Member States to feed the ECIS with **aggregated data held by cancer registries**. This part of the action should consist in validating and processing data collected via data calls to European registries and **deriving up-to-date survival and prevalence indicators** in alignment with the current ECIS settings for incidence and mortality figures, in terms of **geographical detail, cancer sites definition, age range availability and timeliness**;
- b) including **pseudonymised and anonymized data sets**, subject to data availability, **computing survival and prevalence indicators for countries associated to the EU4Health Programme**.

I capitoli del piano Oncologico Italiano

1. Epidemiologia

- *Registri tumori e sistemi informativi sul cancro*

2. Prevenzione sostenibile del cancro

- *Primaria, secondaria e terziaria*

3. Il percorso del malato oncologico

- *Presa in carico, PDTA, Reti Oncologiche, Rete Nazionale Tumori Rari, Cure Palliative, Psico-Oncologia, Supporto nutrizionale, Riabilitazione, Follow up e Qualità della vita*

4. Uno sguardo al futuro in oncologia

- *Modelli Predittivi, Anatomia Patologica, Diagnostica molecolare avanzata, Imaging e Medicina nucleare, Chirurgia oncologica, Digitalizzazione*

5. Formazione e comunicazione in oncologia

6. Monitoraggio e valutazione



Ministero della Salute

**Piano Oncologico Nazionale:
documento di pianificazione e indirizzo
per la prevenzione e il contrasto del
cancro
2022-2027**

Registro tumori nazionale

Dare piena attuazione alla rete Nazionale dei Registri Tumori



OBIETTIVI Strategici

- Completare l'iter di istituzione della Rete Nazionale dei registri tumori
- Garantire il processo di costituzione e la piena funzionalità organizzativa in *tutte le aree* del paese della Rete dei Registri Tumori Regionali (legge 29/2019), valorizzando le esperienze esistenti anche attraverso la costituzione di reti regionali

- Definire gli *standard di funzionamento* dei registri tumori, locali e regionali, attraverso l'individuazione di **requisiti organizzativi, tecnologici e strumentali ottimali**, nonché dei flussi informativi necessari e delle modalità di accesso ai dati
- Migliorare la tempestività della produzione dei dati **potenziando la disponibilità dei flussi**, anche attraverso la predisposizione di **sistemi di interscambio dei dati tra Regioni**, per ridurre i ritardi associati alla *mobilità passiva extraregionale*



Linee strategiche

2. Formazione e Qualità

- Promuovere percorsi di **formazione continua** per gli operatori dei Registri
- Garantire ***l'accREDITamento e la valutazione degli standard qualitativi*** (continuo e de-novo) e la completezza e qualità dei dati attraverso la predisposizione di **strumenti condivisi di verifica**
- Garantire **omogeneità nelle procedure di classificazione e codifica** delle patologie oncologiche, attraverso la produzione e il costante aggiornamento di **manuali dedicati**



Linee strategiche | 3. Integrazione

- Promuovere l'integrazione dei registri nel *sistema informativo della rete oncologica regionale* anche ai fini della produzione di indicatori della qualità dell'assistenza e dell'erogazione dei LEA (volumi, esiti e indicatori relativi ai PDTA)
- Promuovere **l'interconnessione dei dati dei Registri** con i registri ospedalieri, gli archivi sanitari, amministrativi e statistici per rispondere alle *rinnovate finalità istitutive dei Registri* (ricerca e valutazione dei servizi per il miglioramento delle cure), garantendo contestualmente i relativi adeguamenti della normativa in tema di protezione dei dati

Considerazioni conclusive

- Gli obiettivi strategici del Piano Oncologico Italiano sono in linea con il Piano Europeo e con gli obiettivi della JA
- Linee strategiche del piano: prioritario garantire criteri organizzativi e di certificazione della qualità omogenei e standardizzati, migliorare l'integrazione con le fonti primarie e secondarie
- La proposta italiana potrebbe utilmente fare riferimento agli obiettivi strategici del PON e contribuire a dare piena attuazione alla Rete Nazionale dei Registri Tumori
- I registri e altri stakeholders italiani possono anche contribuire allo sviluppo di procedure per arricchire le informazioni disponibili (analisi stadio, trattamento, prevalenza e indicatori sui prevalenti guariti)