European Commission

EUROPEAN CANCER INEQUALITIES REGISTRY (ECIR)

ECIR data tool roadmap

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Roadmap

for the European Cancer Inequalities Registry (ECIR) data tool

Background

The European Cancer Inequalities Registry (ECIR)[1] is a flagship initiative of the Europe's Beating Cancer Plan[2]. It aims to highlight disparities, gaps and inequalities between and within EU countries (EU27 plus Iceland and Norway).

The ECIR consists of three elements:

- A **Data Tool** to explore and compare indicators on cancer.
- Cancer **Country Profiles**, published in even years to help Countries understand their strengths and weaknesses in cancer prevention and care.
- **Analytical Reports**, published in odd years, to compare a Country's performance at EU level.

Country Profiles and Analytical Reports are prepared by the Organisation for Economic Cooperation and Development (OECD).

This roadmap focuses on the planned developments of the **ECIR Data Tool.**

What does the ECIR Data Tool include?

The Data Tool, structured along the pillars of the Europe's Beating Cancer Plan[2], presents data and indicators on inequalities in cancer. It covers the whole cancer continuum, from prevention, screening, diagnosis and treatment to survival and quality of life, as well as indicators quantifying the burden of cancer.

[1] https://cancer-inequalities.jrc.ec.europa.eu/ ECIR is governed by Commission services, the Directorate-General for Health and Food Safety (DG SANTE) and Directorate-General of the Joint Research Centre (DG JRC), together with the Organization for Economic Cooperation and Development (OECD).

[2] https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-life/european-health-union/cancer-plan-europe_en

The primary target audience of the Data Tool is decision makers at national and regional levels, although citizens, researchers, healthcare providers and other stakeholders also stand to benefit from this new, unique resource. First and foremost, the ECIR Data Tool compiles quantitative data along (currently) six 'inequality dimensions': by country, sex, education level, income, urbanisation and age.

The data included should originate from authoritative sources that are independent of private, commercial or national interests (i.e. fostering patient- and citizen-centricity).

The Tool will NOT include individual, country-specific data that requires data harmonisation or large-scale collection.

Data Sources

While the primary source of data will be population-based (registries or household surveys), institution-based sources may also be considered (e.g. medical records).

The data source starting point for developing the Data Tool was Eurostat[3]. Other data sources[4] currently considered include data collected by EC agencies and systems (European Cancer Information System), international organisations (OECD, UN specialised agencies like the World Health Organisation, International Agency for Research on Cancer), data collected by cancer societies and data generated through EC funded projects (see Annex for details).

The Data Tool will be a **'living website'**, regularly updated and enriched as new evidence becomes available. All stakeholders and potential data providers are invited to submit data through a portal that will be available on the ECIR website. However, only data complying with the Data Quality Criteria (p.6) can be included in the Data Tool.

Data not compliant with these criteria, but yet considered relevant and of EU added-value, may be made available on the website via ''links to external sources''.

[3] https://ec.europa.eu/eurostat/data/database

[4] https://cancer-inequalities.jrc.ec.europa.eu/other-data-sources

Data Quality Criteria

The ECIR Data Tool accepts quality-checked data[5] from authoritative sources that fulfil the FAIR (findable, accessible, interoperable, reusable) principles for data quality[6].

The data considered should be:

- available for at least 65%[7] of the 29 European countries (n=19),
- authorised to (re-)use,
- standardised within and between population groups,
- collected using harmonised data collection techniques,
- containing detailed, quality descriptions of the data collection process (metadata),
- relatively recent, representing the last 6 years (i.e. for the last available data point or estimate).

The variables and indicators presented in the data tool have to be evidence-based, specifically relevant to cancer inequalities and analytically sound[8]. The choice of data categories presented is driven by evidence-based guidelines for cancer prevention, screening and care (e.g. European Code against Cancer[9], European Guidelines for cancer screening, diagnosis and care[10], World Cancer Research Fund[11], etc.).

Given the scarcity of data for some dimensions of the cancer care continuum, qualitative data or data with limited coverage (less than 65% of the countries) may exceptionally be considered for integration in the data tool in the future.

[5] In this context data refers to data collected via surveys or studies, as well as statistical calculations and estimates computed based on collected data

[6] https://www.intechopen.com/online-first/79580

[7] https://knowledge4policy.ec.europa.eu/publication/your-10-step-pocket-guide-composite-indicators-scoreboards_en

[8] https://www.oecd.org/sdd/42495745.pdf
https://ec.europa.eu/eurostat/documents/64157/4373903/05-Handbook-on-data-quality-assessment-methods-and-tools.pdf/c8bbb146-4d59-4a69-b7c4-218c43952214

[9] https://cancer-code-europe.iarc.fr/

[10] https://knowledge4policy.ec.europa.eu/cancer/topic/cancer-screening-diagnosis-care_en

[11] https://www.wcrf.org/diet-activity-and-cancer/cancer-prevention-recommendations/

This distinction will be clearly indicated on the website. Furthermore and if deemed relevant (in the case of limited or difficult to measure data), proxy or composite indicators (index of several indicators) may also be computed and presented.

Data Presentation

Data is presented in ways that are comprehensible to a wide and varied audience, using different visualisation techniques, depending on the most appropriate way to represent each inequality dimension, data type and structure. Data visualisation makes use of maps, bars or line charts, tables for individual indicators, as well as heatmaps/matrices for presenting multiple variables. Presentation techniques and modalities will also evolve according to stakeholder requirements and emerging technologies.

First version of the Tool

The first version of the data tool was developed based on Eurostat datasets.

The presentation started with only the geographical dimension (step 1) and then (step 2) expanded to disparities in sex and socioeconomic and spatial dimensions (education, income, and urbanisation), subject to data availability.

Step 3 incorporated data on **time trends** over the last 10 years (for computed tomography scanners, gamma cameras, magnetic resonance imaging units, mammographs, PM10 and PM2.5 microns) or trends between 2014 and 2019 (for cervical smear test, colorectal cancer screening, fruit & vegetable consumption, obesity, physical inactivity, passive smoking and smoking) for only geographical dimensions.

Step 4 will include **age inequalities**. The primary focus will concentrate on the most common, preventable cancers but will be gradually extended to other cancer sites in the future.

Representation of the 4 steps of the ECIR tool development

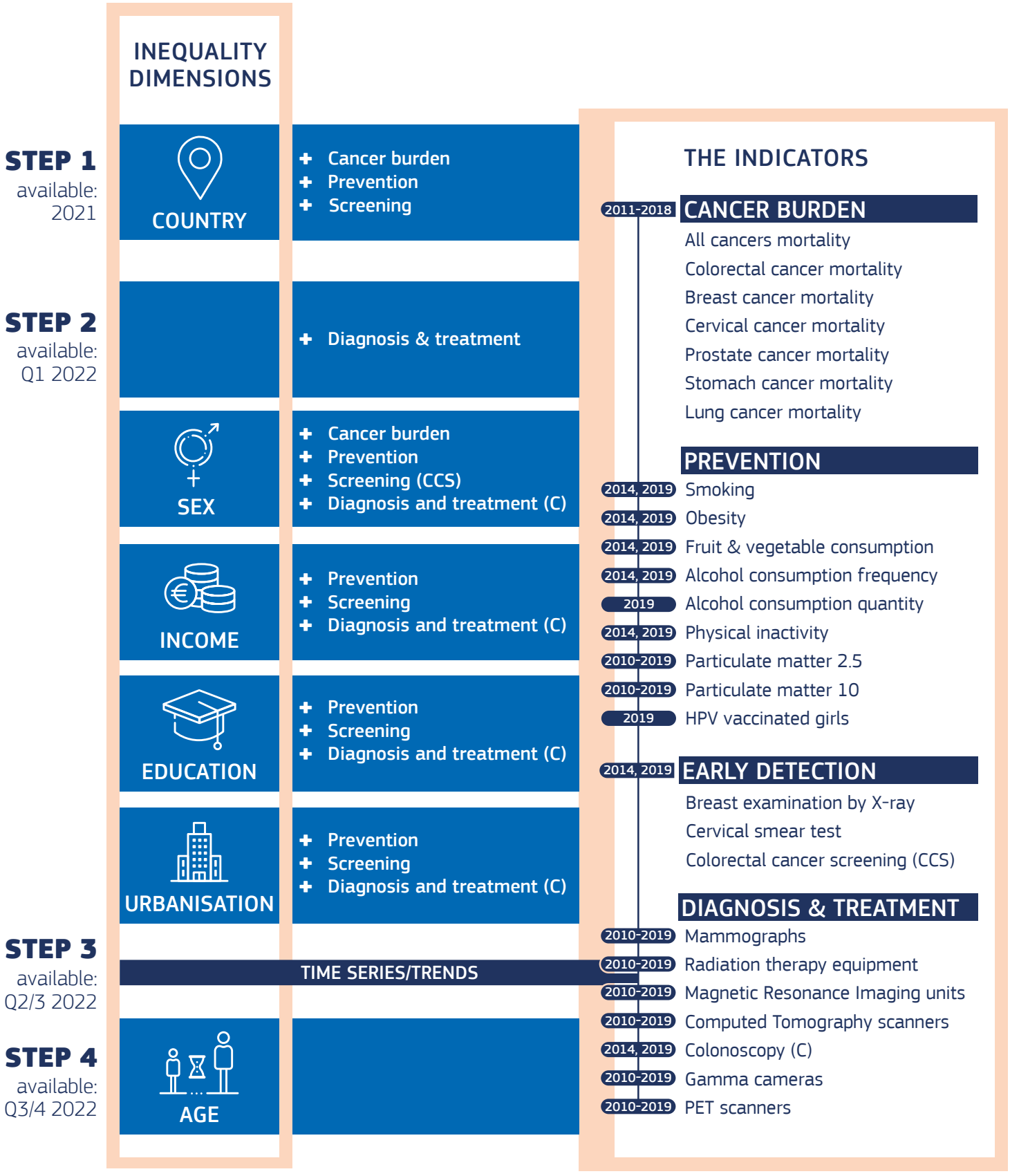


Figure 1. Represents the first four steps of the Data Tool's development.

Future evolution of the ECIR Data Tool

Building on the first version of the tool, its evolution will now proceed in an **inclusive, transparent and democratic way**. This Roadmap will be publicly available on the ECIR website, it will be open to all for comments and we particularly expect active contributions from EU Member States, Iceland and Norway, stakeholders, cancer societies and organisations, patient advocacy groups, patients and citizens.

The **guidelines and criteria** for proposing data sources have been described in 'What does the ECIR Data Tool include?' section of this document. Furthermore, data presentations, interactivity aspects and visualisations will be constantly enhanced by the internal IT team while always open for external proposals and suggestions.

Specific details about what indicators will be published next, their source, availability, aspects that can(not) be included and projected timelines will be documented in the **Annex**, categorised under (1) Cancer Burden, (2) Prevention, (3) Screening, (4) Diagnosis and Treatment, (5) Improved Quality of Life, (6) Outcomes and (7) Policies. Next will be the inclusion of the age inequality dimension (Quarter 3 and 4, 2022). Variables related to healthcare, treatments and national control plans will follow in 2023.

Another important evolution will be coordination and alignment with the **Cancer Country Profiles** (prepared by the OECD) by making the Country Profile Graphs directly accessible on the ECIR Website (Quarter 4, 2022).

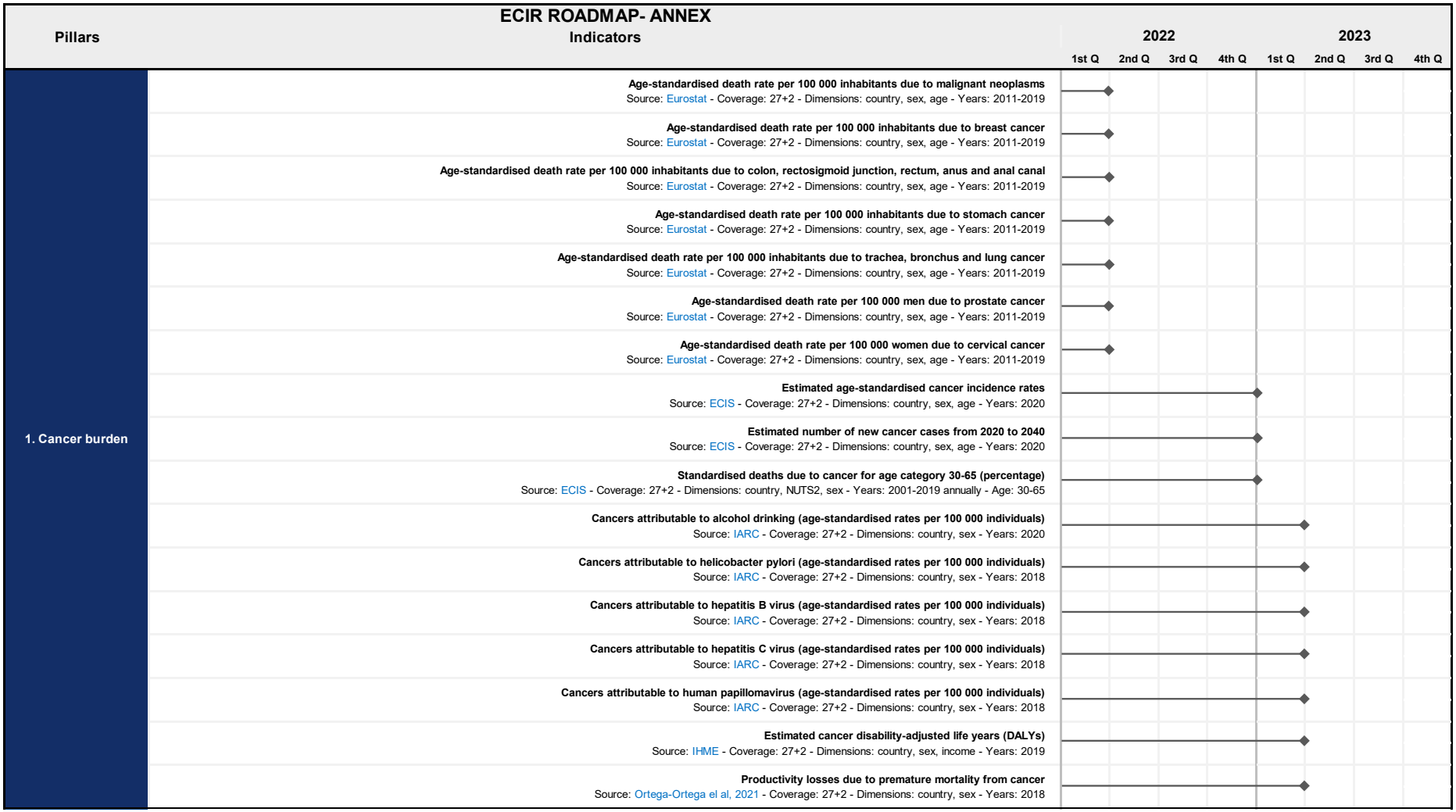
In terms of coordination with the **Zero Pollution Action Plan** (Flagship 1: Reducing health inequalities through zero pollution), data on airborne particulate matter (PM2.5 and PM10) is already integrated in the Data Tool. Other readily available air pollution data sets will be checked and published (Quarter 4, 2022), possibly including health impacts from exposure to certain environmental pollutants. This will lead to tackling the more ambitious challenge of linking geo-positioned environmental exposure (carcinogens) data sets with cancer data, which will be explored in liaison with the team working on the European Cancer Information System in 2023.

Initial data on **education inequalities in cancer mortality** is expected to be available and included in the Data Tool for a restricted number of European countries by the end of 2023. By the end of 2024, this data set should be completed for all EU Member States, Iceland and Norway.

In terms of **overarching principles**, the ECIR will also aim to provide additional evidence on inequalities in cancer prevention and care, including the consideration of vulnerable or marginalised population groups, aiming to advance knowledge on the extent, causes of, and possible solutions for inequalities in cancer. Fulfilling these aims will naturally depend on data discovery, availability, quality and fitness for purpose.

Annex

The Annex to the ECIR Roadmap presents indicators which will be included in the European Cancer Inequalities Registry (ECIR) Data Tool in the course of 2022/2023 (version 1, October 2022).



Please note it is a living document that will be continuously updated on the ECIR website (https://cancer-inequalities.jrc.ec.europa.eu/roadmap)

ECIR ROADMAP- ANNEX

Pillars	Indicators	2022 1st Q	2022 2nd Q	2022 3rd Q	2022 4th Q	2023 1st Q	2023 2nd Q	2023 3rd Q	2023 4th Q
2. Prevention	**Daily smokers of cigarettes** Source: Eurostat - Coverage: 27+2 - Dimensions: country, sex, age, urbanisation, education - Years: 2014, 2019	◆							
	People affected by obesity Source: Eurostat - To be replaced.	◆							
	Daily consumption of at least 5 portions of fruit and vegetables Source: Eurostat - Coverage: 27+2 - Dimensions: country, sex, age, urbanisation, education - Years: 2014, 2019	◆							
	Percentage of people not performing any aerobic physical activity Source: Eurostat - Coverage: 27+2 - Dimensions: country, sex, age, urbanisation, education - Years: 2014, 2019	◆							
	Annual mean concentration (µg/m3) of particulate matter 2.5 (PM2.5) at urban background stations in agglomerations Source: Eurostat - Coverage: 27+2 - Dimensions: country - Years: 2010, 2019	◆							
	Annual mean concentration (µg/m3) of particulate matter 10 (PM10) at urban background stations in agglomerations Source: Eurostat - Coverage: 27+2 - Dimensions: country - Years: 2010, 2019	◆							
	Frequency of alcohol consumption Source: Eurostat - Coverage: 27+2 - Dimensions: country, sex, age, urbanisation, education - Years: 2014, 2019	◆	◆						
	Alcohol consumption (15+ years), total per capita (in litres of pure alcohol) Source: WHO - Coverage: 20+2 - Dimensions: country - Years: 2016, 2018	◆	◆						
	Girls aged 15 years old that received the recommended doses of HPV vaccine Source: WHO -Coverage: 27+2 - Dimensions: country - Years: 2012-2020	◆	◆						
	Daily exposure to tobacco smoke indoors Source: Eurostat - Coverage: 27+2 - Dimensions: country, sex, age, urbanisation, education - Years: 2014, 2019	◆	◆	◆	◆	◆			
	Percentage of overweight and/or obese population among total population aged 18+ (self-reported) Source: Eurostat (1)(2) - Coverage: 27+2 - Dimensions: country, sex, age, education - Years: 2014, 2019	◆	◆	◆	◆	◆			
	Estimated cancer deaths attributable to ambient particulate matter pollution Source: IHME - Coverage: 27+Norway - Dimensions: country - Years: 2019	◆	◆	◆	◆	◆	◆		
	Estimated cancer deaths attributable to household air pollution from solid fuels Source: IHME - Coverage: 27+Norway - Dimensions: country - Years: 2019	◆	◆	◆	◆	◆	◆		
	Estimated cancer deaths attributable to occupational carcinogens Source: IHME - Coverage: 27+Norway - Dimensions: country - Years: 2019	◆	◆	◆	◆	◆	◆		
	Estimated cancer deaths attributable to residential radon Source: IHME - Coverage: 27+Norway - Dimensions: country - Years: 2019	◆	◆	◆	◆	◆	◆		
	Hepatitis B (HepB3) immunization coverage among 1-year-olds (percentage) Source: WHO - Coverage: 27+2 - Dimensions: country - Years: 2019	◆	◆	◆	◆	◆	◆	◆	
3. Early detection	**Women that self-reported to have never had a breast examination by X-ray** Source: Eurostat - Coverage: 27+2 - Dimensions: country - Years: 2019	◆							
	Women that self-reported to have never had a cervical smear test Source: Eurostat - Coverage: 27+2 - Dimensions: country - Years: 2019	◆							
	People that self-reported to have never had a colorectal cancer screening test Source: Eurostat - Coverage: 27+2 - Dimensions: country - Years: 2019	◆							
	Coverage of a national cervical cancer screening program (percentage) Source: WHO - Coverage: 27+2 - Dimensions: country - Years: 2019	◆	◆	◆	◆	◆	◆	◆	

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ECIR ROADMAP- ANNEX

Pillars	Indicators	2022 1st Q	2022 2nd Q	2022 3rd Q	2022 4th Q	2023 1st Q	2023 2nd Q	2023 3rd Q	2023 4th Q
4. Diagnosis and treatment	**Dedicated mammography machines** Source: Eurostat - Coverage: 24+2 - Dimensions: country - Years: 2010-2019		◆						
	Machines used for treatment with x-rays or radionuclides Source: Eurostat - Coverage: 19+2 - Dimensions: country - Years: 2010-2019		◆						
	Magnetic Resonance Imaging units (MRI units) Source: Eurostat - Coverage: 21+2 - Dimensions: country - Years: 2010-2019		◆						
	Computed Tomography scanners (CT units) Source: Eurostat - Coverage: 23+2 - Dimensions: country - Years: 2010-2019		◆						
	People that self-reported to have never undergone a colonoscopy Source: Eurostat - Coverage: 27+2 - Dimensions: country - Years: 2010-2019		◆						
	Number of Gamma cameras Source: Eurostat - Coverage: 21+2 - Dimensions: country - Years: 2010-2019			◆					
	Number of Positron Emission Tomography (PET) scanner units Source: Eurostat - Coverage: 24+2 - Dimensions: country - Years: 2010-2019			◆					
	Number of oncologists (per 100 000 inhabitants) Source: Mathew, 2018 - Coverage: 24+Norway - Years: 2018						◆		
	Number of radiotherapy machines per million population Source: IAEA - Coverage: 27+2 - Dimensions: country - Years: 2021						◆		
	Access to oncology clinical trials (indicator to be defined) Source: EU Clinical Trials Register - Coverage: 27+2 - Dimensions: country, age, sex - Years: 2012-2021					◆			
	Access to essential anticancer medicines for adults (indicator to be defined) Source: ESMO - Coverage: 27+2 - Dimensions: country - Years: 2016						◆		
	Access to essential anticancer medicines for children and adolescents (indicator to be defined) Source: ESMO - Coverage: 27+2 - Dimensions: country - Years: 2021						◆		
5. Quality of life	**Countries with legislative initiatives concerning the "Right to be forgotten" to access to financial services for cancer survivors** Source: ECPC - Qualitative indicator - Coverage: 27 - Dimensions: country - Years: 2022						◆		
6. Outcomes	**Cancer five-year net survival** Source: OECD Stat - Coverage: 21+2 - Dimensions: country, sex - Years: latest period - Age: 15+						◆		
	Cervical cancer five-year net survival Source: OECD Stat - Coverage: 21+2 - Dimensions: country - Years: latest period - Age: 15+						◆		
	Years lost per 100 000 population aged 75 years old due to colorectal cancer Source: OECD Stat - Coverage: 22+2 - Dimensions: country - Years: 2018 or 2019						◆		
	Years lost per 100 000 population aged 75 years old due to stomach cancer Source: OECD Stat - Coverage: 22+2 - Dimensions: country - Years: 2018 or 2019						◆		
7. Policies	**Information within Cancer-related plans (3)** Source: ICCP/EPAAC(4) - As a qualitative variable							◆	

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(1) Educational attainment level: https://ec.europa.eu/eurostat/databrowser/bookmark/0c1d3fad-ccc9-4622-81a9-3fca0aedabf4?lang=en

(2) Degree of urbanisation: https://ec.europa.eu/eurostat/databrowser/view/HLTH_EHIS_BM1U__custom_1930681/bookmark/table?lang=en&bookmarkId=25535fe6-54ac-4f04-b864-adef8cd54e33

(3) Some possible qualitative (dichotomous) country-related variables: Plan published in the last 10 years. Existence of physical activity and obesity reduction programmes. Specification of Pain management. Existence of specific strategy to ensure availability of and accessibility to oral morphine. Inclusion of focus on vulnerable populations, indigenous populations and lesbian, gay, bisexual, transgender and intersex (LGBTI) people. Mention of Oncology nursing. Existence of a specific national cancer research strategies and priorities.

(4) The joint action EPAAC developed a European Guide for Quality National Cancer Control Programmes and they mapped the European plans.

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