

ECIR Roadmap Survey 2022

Fields marked with * are mandatory.

1 Personal Information

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* Institution type

- International Organisation
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- Non-governmental Organisation (NGO)
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* Please specify your organisation (e.g. cancer society, cancer organisation, patient organisation, cancer registry, research institute) and role (e.g. policy maker, health professional, patient, researcher, student)

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Date

30/11/2022

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2 Introduction

BACKGROUND

[The European Cancer Inequalities Registry \(ECIR\)](#) aims to identify trends, disparities and inequalities in cancer prevention and care between Member States and regions, as well as inequalities due to age, sex and inequalities associated with socio-economic factors. Alongside regular qualitative assessments of the country-specific situation, the Registry will identify challenges and specific areas of action to guide investment and interventions at EU, national and regional level under [Europe's Beating Cancer Plan](#).

It is governed by the European Commission Directorates-General for Health and Food Safety (DG SANTE) and the Joint Research Centre (JRC) together with the Organisation for Economic Cooperation and Development (OECD).

The Registry consists of three elements: (1) a data tool, (2) biennial reports focusing the assessment of the country-specific situation, and (3) biennial analytical reports comparing performance at EU level.

[The ECIR Data Tool](#) was launched by President von der Leyen in February this year. It currently integrates and presents data available from authoritative sources, such as Eurostat, the World Health Organisation, OECD health databases, the European Cancer Information System, etc. The Data Tool will be further enhanced and expanded according to a Roadmap developed by JRC.

AIM

The aim and scope of this survey is to gather feedback and insights from organisations represented in the Cancer Stakeholder Contact group on the existing [ECIR website](#), [Data Tool](#), and the Roadmap document (indicated below).

FILES

[ECIR Roadmap with Annex.pdf](#)

3 Questions

* 1. Do you think anything is missing on the [ECIR website](#)?

- Yes
 No

Please specify what was missing on the website?

ECIR data tool:

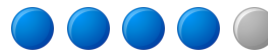
- For most data variables, the latest data available is 2019. The tool would be useful to also reflect the impact of the pandemic, in view of the wider inequalities faced in (access to) cancer prevention and care.
- Inequalities are currently grouped by country. Given the varying inequalities faced within each Member State, the tool could provide additional value by adding an option to display inequalities at sub-national/local level per country, where feasible.
- data variable: obesity indicator could be complemented with consumption levels of red and processed meat, plant-based diets and/or whole grains consumption; treatment component could be completed with access to mental health support/services;

Additional sections:

- More links can be made around what is being done at EU level to tackle cancer across different disciplines. For example, links to existing funding mechanisms (EU4Health, Horizon Europe and its EU Cancer Mission), present and past EU-funded projects, as well as links to networks, such as the EU Stakeholder Contact Groups, SGPP etc. and cancer focal points to contact. A section on good practices/case studies would also be beneficial.

2. How do you rate the usability/format of the [ECIR Data Tool](#)?

1= bad, 2= fair, 3= good, 4= very good, 5= excellent



* 3. The following **Data Quality Criteria**, based on the [FAIR principles for data quality](#), apply to the data displayed on the [ECIR Data Tool](#).

The data considered should be:

- available for at least 65% 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).

* EU27 + Norway and Iceland

Do you have suggestions for additional criteria to be potentially included?

- Yes
 No

* 4. For some (prevention/screening) indicators the [Data Tool](#) currently presents one data category that, based on available scientific evidence, may be linked to altered cancer risk (e.g. proportion of daily smokers). Other data categories (e.g. proportion of non- & occasional-smokers) can be accessed by clicking on the '*Link to data*' at the bottom of the ECIR Data Tool webpage, which redirects to the data source (e.g. [Smoking of tobacco products](#)).

Do you agree with this approach?

- Yes, I prefer that only one evidence-based data category indicating altered cancer risk (e.g. proportion of daily smokers) is presented on the ECIR Data Tool (as it is now) with access to other data categories by clicking on the link to data source.

- No, I prefer that all other data categories (e.g. additionally to proportion of daily smokers also proportion of non- & occasional-smokers) are also visible on the ECIR Data Tool, as well as being available in their original data sources.

5. Next enhancements of the Data Tool will be to include age inequalities and data on cancer treatments, policies, and quality of life of patients and survivors, depending on data availability and quality. It will also aim to collect and display data from vulnerable population groups.

As for some of these aspects there is currently no or only scarce data available, new studies or data collection exercises would be needed to close the data gaps. In which of these areas do you see an important need to collect more evidence. Please rate on a scale from **1=not important** to collect new data to **5=extremely important**:

	1	2	3	4	5
Access to cancer prevention and care for vulnerable or marginalized groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Socio-economic inequalities in cancer survival	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Access to innovative cancer treatments	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access/reimbursement for innovative screening schemes	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support schemes for cancer patients and survivors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Regional differences in cancer care provision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Health care workforce characteristics	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer prevalence by cancer site	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5-year-survival rate by cancer site	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you think it is important to collect data for any other areas not listed above?

- Yes
- No

6. The ECIR Roadmap Annex (attached above) summarises indicators to be included in the Data Tool in the course of 2022/2023.

Do you have suggestions for any additional indicators to be included (bearing in mind the Data Quality Criteria presented in Question 3)?

- Yes
- No

7. Any other comments and/or suggestions?

- 1) The tool can generate valuable data to guide activities supported by EU funding mechanisms, such as the Horizon Europe Mission on Cancer and the Resilience and Recovery Facility (eg. resilience of healthcare systems dashboard/environmental determinants), ensuring that the action undertaken to address cancer inequalities is strongly evidence-based.
- 2) The tool can highlight its links with non-health related EU tools and surveillance systems, such as for example the Social Scoreboard of the European Pillar of Social Rights and the monitoring of the SDGs Agenda implementation.
- 3) The data tool can also expand beyond reporting inequalities - it can additionally present the impact of successful interventions in the reduction of inequalities (by, for example, centralising information on evaluated, good practices which promoted health equity in cancer prevention, control and care).

Thank you for taking the time to complete this survey.

Useful links

[European Cancer Inequalities Registry \(https://cancer-inequalities.jrc.ec.europa.eu/\)](https://cancer-inequalities.jrc.ec.europa.eu/)

Contact

[Contact Form](#)