

ECIR Roadmap Survey 2022

Fields marked with * are mandatory.

1 Personal Information

Name

Sara

Surname

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* Organisation

Association of European Cancer Leagues

* Institution type

- International Organisation
- Governmental/National Organisation
- Non-governmental Organisation (NGO)
- Academia
- Private company
- Other

* 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)

Our organisation is an umbrella association of cancer leagues and societies across Europe, and I am a policy officer.

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Date

02/12/2022

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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?

- Robust data on survivorship and quality of life of individuals, as well as data on access to and availability of services for cancer patients and survivors, such as rehabilitation, psycho-oncology and onco-sexology services;
- Data on countries having initiatives in place that effectively facilitate the return to work of cancer survivors;
- Data on the availability of specialists in supportive and palliative care;
- A clear overview of the process through which eligible stakeholders can submit data.

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

1= bad, 2= fair, 3= good, 4= very good, 5= excellent	<input checked="" type="radio"/> <input checked="" type="radio"/> <input checked="" type="radio"/> <input type="radio"/> <input type="radio"/>
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* 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 type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Access/reimbursement for innovative screening schemes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Support schemes for cancer patients and survivors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Regional differences in cancer care provision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Health care workforce characteristics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Cancer prevalence by cancer site	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
5-year-survival rate by cancer site	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

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

- Yes
 No

Please elaborate

i) Socio-economic inequalities in psychosocial quality of life of cancer survivors

ECL welcomes the planned inclusion of data regarding country-level initiatives to implement the Right to be Forgotten, as this is a key source of social inequalities and psychological harm for cancer survivors. Building on this endeavour, we find that the tool should grow to include data on countries having initiatives in place that effectively facilitate the return to work of cancer survivors - another aspect that is closely linked to social inequalities and psychological distress for cancer survivors.

ii) Socio-economic inequalities in access to cancer rehabilitation, psycho-oncology, onco-sexology, and palliative care

iii) Data on regional differences in service and workforce availability for effective survivorship and palliative care

ECL calls for including data on the availability of specialised services and workforce for cancer rehabilitation, psycho-oncology, onco-sexology, and palliative care.

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?

The Association of European Cancer Leagues welcomes the Cancer Inequalities Registry and is determined to contribute to shedding light on cancer inequalities.

ECL is pleased to see indicators for Prevention, Early Detection, Diagnosis and Treatment. Another area where there are large inequalities are related to survivorship and quality of life, especially with the growing number of cancer survivors. ECL calls for the inclusion of robust data on survivorship and quality of life of individuals, as well as data on access to and availability of services for cancer patients and survivors, such as rehabilitation, psycho-oncology and onco-sexology services.

The ECIR should shed light on existing inequalities not just on physical health outcomes but also on the psychosocial wellbeing of cancer survivors, as outlined above. ECL welcomes the intention to include data on workforce characteristics in the near future. It would be of particular value to include data on the availability of services and trained specialists in supportive and palliative care.

As cancer societies and other stakeholders independent of private, commercial or national interests could contribute to the tool by sharing data they collected, ECL recommends adding to the website a clear overview of the process through which stakeholders can submit data.

When data matching the ECIR's quality criteria is not available - such as in the case of data on return-to-work initiatives - the Commission should strive to foster its creation and collection through EU-funded projects, foreseeing inclusion of newly generated data in the medium-term.

We further recommend to:

i) Consider ways to make the data more accessible to the public, therefore making the tool more inclusive. ECL suggests to further build the tool in a way that supports both the health literacy and the ability of the population to navigate (health) data – a key aspect to consider given Europe's ongoing digital transformation, in particular in the health sector. This could be achieved by adding more accessible visual presentations, integrating links or a short learning platform to explain the terminology used in (health) data analysis (i.e., rate, prevalence, etc.), as well as narrative summaries interpreting the data presented.

ii) Better link the ECIR and ongoing EU policy initiatives. If made more accessible to the public, this tool has a great potential to bring European initiatives in the realm of cancer and public health closer to citizens. In addition, the tool can be used to track advancements towards the goal laid down by said initiatives.

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](#)