Every cancer patient counts: strengthening European population-based cancer registries to improve cancer control

Gijs Geleijnse,[a,b,*] Claudine Backes,[c,d] Maria Dolores Chirlaque,[e,f] Matthijs Sloep,[b] Esteve Rodon Navarro,[g] Mario Šekerija,[h,i] Liesbet van Eycken,[j] and Giske Ursin[a,k,l]

[a]The Cancer Registry of Norway, Norwegian Institute of Public Health, Oslo, Norway
[b]Department of Research & Development, Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, the Netherlands
[c]Registre National du Cancer du Luxembourg (RNC), Luxembourg
[d]Cancer Epidemiology and Prevention Group (EPICAN), Department of Precision Health (DoPH), Luxembourg Institute of Health (LIH), Luxembourg
[e]Centro de Investigación Biomédica en Red de Epidemiología y Salud Pública (CIBERESP), Madrid, Spain
[f]Department of Epidemiology, Regional Health Council, IMIB-Arrixaca, Murcia University, Murcia, Spain
[g]Catalan Institute of Oncology, Catalonia, Spain
[h]Croatian Institute of Public Health, Zagreb, Croatia
[i]Andrija Stampar School of Public Health, University of Zagreb School of Medicine, Zagreb, Croatia
[j]Belgian Cancer Registry, Brussels, Belgium
[k]Department of Nutrition, Institute of Basic Medical Sciences, University of Oslo, Oslo, Norway
[l]Department of Preventive Medicine, University of Southern California, Los Angeles, CA, USA

The Lancet Regional Health - Europe 2026;70: 101855

Published Online xxx https://doi.org/10.1016/j.lanepe.2026.101855

Population-based cancer registries (PBCRs) systematically and continuously collect data on all cancer cases within defined populations following international standards to ensure harmonization, data quality and complete coverage. They operate on regional or national level and inform us of the burden of cancer in terms of incidence, survival and prevalence. Together with mortality, these three indicators are considered the essential elements of population-based cancer control.[1]

Through the European Cancer Information System (ECIS), the PBCRs in the European Network of Cancer Registries (ENCR) reveal cancer inequalities in and between geographies in Europe, they show where progress is made and where attention is required. With cancer spending expected to rise 59% by 2050,[2] PBCRs are uniquely positioned to support the effective allocation of resources and effective implementation and evaluation of cancer prevention, early detection and quality of care.

Many European countries have national legislation on cancer registration. However, in practice PBCRs face persisting challenges in the collection of timely, relevant and high-quality population-based cancer data.[3] Despite investments in digitalization in healthcare and the preparation of the European Health Data Space (EHDS), the infrastructure of PBCRs is frail: coverage of Europe is still suboptimal, timeliness of data publication is varying and PBCRs mention resource limitations as barrier to invest in innovation.[4,5] European regulation on PBCR-based statistics is lacking. This contrasts with regulation on (cancer) mortality statistics,[6] which are delivered by national statistics bureaus and Eurostat, which ensure timely and comparable collection of cause of death data on Europe.

The 192 European PBCRs follow the EU Commission's Joint Research Centre (JRC)/ENCR guidelines for registration, but there is a large variation in their ability to collect timely, high-quality data and record elements such as stage at diagnosis and treatments.[7,8] The Joint Action CancerWatch (2025–2028), with participation of 92 organisations from 29 countries, aims to improve the timeliness and quality of the PBCR data feeding into ECIS. With incomplete geographic coverage and limited availability of timely indicators on ECIS, the project addresses a pressing issue.

The European Court of Auditors has called for a monitoring framework for the European Commission's Beating Cancer Plan.[9] Although the ECIS was established with the purpose of monitoring the cancer burden in Europe, the current limitations in PBCR data infrastructure undermine ECIS' ability to fulfil this monitoring role. Stronger coordination is required to provide Europe with more timely and high-quality cancer burden indicators. The following policy options on EU-level, member state level and PBCR-level can strengthen Europe's ability to monitor its cancer control plans.

On the *EU level*, a formal recognition of PBCRs as core components of public health systems will support their mandate. Such a formal endorsement dedicated to PBCRs would be in line with the council recommendation for screening programs.[10] The European Commission should publish criteria for data quality and timeliness for PBCR data on the ECIS, such that quality and progress of cancer registration in member states can be monitored and managed. Following the European Health Data Space Regulation, a data usage fee

*Corresponding author. The Cancer Registry of Norway, Norwegian Institute of Public Health, Oslo, Norway.
E-mail addresses: g.geleijnse@iknl.nl, gijs.geleijnse@fhi.no (G. Geleijnse).

© 2026 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

should be provided for PBCRs who prioritize delivery of data and statistics to ECIS. Moreover, PBCRs should be an integrated element of cancer screening programs and comprehensive cancer centers. Future EU project proposals on these topics should therefore require the involvement and adequate resourcing of PBCRs for planning, monitoring and evaluation.

On the *member state level*, a designated organization should be mandated with the responsibility to deliver national PBCR data to the ECIS. This organization should be the link between EU bodies and regional PBCRs and should be integrated in the design and monitoring of the national Cancer Mission Hubs. Besides adequate sustainable funding and resourcing for the PBCRs, national innovation funds allocated to artificial intelligence and digital sovereignty should support innovations in PBCRs.

The *PBCRs* should obtain a formal mandate from their government as a core component of public health and cancer control. They should allocate resources to increase efficiency of data collection and publication.

Policy action is required to strengthen PBCRs for effective, equitable cancer control. Timely, rich and high-quality population-based cancer data are essential for robust monitoring and evidence-informed European, national and local cancer policies. We need to count every cancer patient because every patient counts.

Contributors

GG developed and drafted the manuscript. GU reviewed the manuscript and contributed additional text sections. All authors reviewed the manuscript and contributed to the review and editing of the manuscript. GG and GU finalised the manuscript. All authors approved the final version for submission.

Declaration of generative AI and AI-assisted technologies in the manuscript preparation process

During the preparation of this work, the author(s) used Microsoft CoPilot for reviewing the text for clarity and readability. The author(s) reviewed and edited the output as needed and take full responsibility for the content of the published article.

Declaration of interests

This work was co-funded by the European Union through CancerWatch JA (Grant Agreement No. 101219450). Views and opinions expressed are those of the authors and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor HaDEA can be held responsible for them.

Gijs Geleijnse reports consulting fees from Westat for consultancy to the US National Cancer Institute and from Oslo University Hospital for scientific advice. He also received support for attending meetings from the Italian Association of Cancer Registries (AIRTUM), the European Commission, and the National Tumor Institute Milan.

Claudine Backes reports grants or contracts from the Ministry of Health and Social Security, Luxembourg.

Matthijs Sloep reports grants from KWF, ZonMw, NWO, Health Holland, and Health-RI; support for attending meetings from TMF e.V.; and an unpaid board membership with the Dutch Society for Medical Informatics (VMBI).

Giske Ursin, Maria Dolores Chirlaque, Esteve Rodon Navarro, Mario Šekerija, and Liesbet Van Eycken declare no competing interests.

Acknowledgements

This work was funded by the European Union (CancerWatch JA—Grant Agreement No 101219450). Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HaDEA). Neither the European Union nor HaDEA can be held responsible for them.

References

1 The Lancet. Cancer registries: the bedrock of global cancer care. *Lancet*. 2025;405(10476):353. https://doi.org/10.1016/S0140-6736(25)00189-8.
2 OECD, European Commission. *Delivering high value cancer care: european cancer inequalities registry analytical report*. OECD Publishing; 2026. https://doi.org/10.1787/060869fe-en.
3 Giusti F, Martos C, Carvalho RN, et al. Facing further challenges in cancer data quality and harmonisation. *Front Oncol*. 2024;14:1438805. https://doi.org/10.3389/fonc.2024.1438805.
4 Mousavi R, Derakhshani N, Sheikhtaheri A, Roshandel G, Hashjin AA. Challenges and solutions of cancer registries: a scoping review. *J Cancer Policy*. 2025;45:100607. https://doi.org/10.1016/j.jcpo.2025.100607.
5 Van Eycken LJ, Giannopoulos E, Tittenbrun Z, et al. Future of population-based cancer registries: a global perspective—A survey of population-based cancer registries. *Int J Cancer*. 2025;157(8):1566–1576. https://doi.org/10.1002/ijc.35516.
6 *Commission Regulation (EU) No 328/2011 implementing Regulation (EC) No 1338/2008 of the European Parliament and of the Council on Community statistics on public health and health and safety at work, as regards statistics on causes of death*. European Union; 2021.
7 Zadnik V, Duratović Konjević A, Jurtela M, et al. *Mapping population-based cancer registries in Europe: coverage, data availability and capacity for real-world data generation*. 2026. under review.
8 Bosetti C, Visser O, Van Eycken L, et al. Availability of stage information from cancer registries providing data to the European cancer information system for six selected cancers. *Int J Cancer*; 2026:1–12. https://doi.org/10.1002/ijc.70593.
9 *European Court of Auditors, special report 07/2026 "Europe's Beating Cancer Plan – a wide-ranging plan facing an uncertain future", Publications Office of the European Union*. 2026.
10 *Council Recommendation on strengthening prevention through early detection: a new EU approach on cancer screening replacing Council Recommendation, 2003/878/EC 2022/C 473/01*. 2022.