

ORIGINAL ARTICLE

Mapping population-based cancer registries in Europe: coverage, data availability, and capacity for real-world data generation

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Background: Population-based cancer registries (PBCRs) are essential for cancer surveillance and control yet their capacity and coverage vary across Europe. This study presents the first descriptive results of a survey mapping European PBCRs, with a particular focus on registry coverage, data availability, timeliness, and selected aspects of readiness for real-world data (RWD) generation.

Materials and methods: A cross-sectional survey was conducted in early 2026 within European Union Joint Action CancerWatch. A comprehensive questionnaire (>700 items, 15 sections) was distributed to 192 European PBCRs across 45 countries, covering organisational, legal, and technical aspects.

Results: A total of 175 (91.1%) PBCRs completed the survey. Of these, 151 were general registries collecting data for all cancer sites and age groups, representing 39 countries. Most countries have national registries or integrate data from multiple regional registries into a national dataset; however, population coverage remains incomplete in some regions. Data timeliness could be improved, as only 69% of countries provide cancer incidence data within 2 years. European PBCRs show substantial variability in digital infrastructure and data integration capacity, ranging from basic data linkage systems to partially or fully automated infrastructures. Over 60% operate within fragmented data exchange systems and one-third reported no/limited awareness of European Health Data Space (EHDS) requirements.

Conclusions: This survey provides the first comprehensive overview of European PBCR coverage, data availability, timeliness, and selected organisational and technical characteristics relevant to RWD generation. Although European PBCRs provide broad population coverage, they remain heterogeneous in digital maturity, data integration capacity, and timeliness, limiting their ability to support the generation of RWD and to meet EHDS requirements. Strengthened infrastructure, interoperability, and coordinated European action are needed, alongside a standardised, publicly accessible PBCR inventory.

Key words: cancer surveillance, data availability, population-based cancer registries, real-world data, registry coverage, timeliness

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INTRODUCTION

Population-based cancer registries (PBCRs) systematically collect data on all new cancer cases within defined populations and geographic regions, providing comprehensive and unbiased information on cancer incidence, prevalence, and survival. By capturing data at the population level,

PBCRs enable robust epidemiological analyses and are essential for monitoring cancer burden, evaluating screening and prevention programmes, assessing outcomes of cancer care, and supporting evidence-based decision making in cancer control.¹⁻³ Furthermore, their ability to link individual-level registry data with other health and administrative data sources enables the generation of real-world data (RWD), defined as data routinely collected during the delivery of health care or through other administrative systems rather than in controlled research settings. This linkage capacity supports the production of real-world evidence for oncology research, health services evaluation, and policymaking.⁴⁻⁷

In Europe, the harmonisation and comparability of PBCR data are supported by the European Network of Cancer Registries (ENCR), which provides standards and guidance on data collection, coding, quality control, and data protection.⁸ The ENCR is supported by the Joint Research Centre (JRC) of the European Commission, which manages the European Cancer Information System (ECIS), integrating data from national and regional PBCRs to produce comparable cancer indicators across countries.⁹ These coordinated efforts are central to monitoring and benchmarking cancer burden and control at national, regional, and international levels.¹⁰⁻¹²

Despite this well-established infrastructure, important challenges remain. PBCRs across Europe differ substantially in coverage, data completeness, variables collected, and capacity for data linkage, reflecting broader heterogeneity in digital infrastructure and interoperability. As demands for timely, integrated, and reusable health data increase—particularly in the context of initiatives such as the European Health Data Space (EHDS)¹³—there is a growing need to better understand and strengthen the digital maturity and interoperability of PBCRs.

The CancerWatch Joint Action (JA)¹⁴ is a EU4Health initiative (September 2025 to August 2028) coordinated by the Norwegian Institute of Public Health and involving 92 partner organisations from 29 European countries. Its overall objective is to improve the quality, timeliness, and usability of PBCR data for research and policy by strengthening cancer registration processes and supporting the ECIS and the EHDS. The present survey was conducted within Work Package 5 (Operations and Digitalisation; Slovenian Cancer Registry, Ljubljana, Slovenia) and Task 5.1 (Cancer Registry Assessment and Development; Slovenian Cancer Registry, Ljubljana, Slovenia), which aims to map all European PBCRs using a standardised assessment tool to characterise their organisational, legal, financial, and technical frameworks and identify opportunities for strengthening registry infrastructure and harmonisation.

This study presents the first results from a survey designed to map European PBCRs, providing an overview of geographic coverage, data availability and timeliness. It also addresses selected technical and organisational aspects relevant to capacity of registries to generate and integrate RWD through linkage with other health and administrative data sources, thereby supporting epidemiological research, cancer surveillance, and evidence-informed policymaking. To

our knowledge, the survey represents the most comprehensive and up-to-date assessment of the European PBCR landscape.

METHODS

Survey design, piloting, and implementation

This study was based on a cross-sectional survey conducted in the framework of the European Union JA CancerWatch in early 2026, from January 14 to February 28. The survey was coordinated by the Slovenian Cancer Registry, which also led the development of the questionnaire and the overall survey implementation.

A comprehensive questionnaire in English, comprising >700 items was developed with input from CancerWatch consortium partners. The survey included quantitative and qualitative questions. Response formats comprised numerical fields, predefined single-choice and multiple-choice options, and open-text fields for additional explanations or comments. Conditional branch logic was used to display follow-up questions according to previous responses. The survey was designed to capture key domains of PBCRs functioning, including legal frameworks, funding, staffing, data collection processes, information technology (IT) infrastructure, data quality procedures, and dissemination practices. The questionnaire also included elements related to registry maturity and their capacity to support RWD generation. It was primarily based on the 2023 survey conducted by the European Commission's JRC, which covered 122 PBCRs within ENCR.¹⁵ Additional questions were developed based on other available surveys, including those by Mihor et al.¹⁶ on childhood cancer registration practices in Europe, Van Eycken et al.¹⁷ on the global perspective of cancer registration, the International Atomic Energy Agency self-assessment questionnaire for cancer registries,¹⁸ and the survey by Znaor et al.¹⁹ on cancer registration practices in Eastern Mediterranean Region. The draft questionnaire was reviewed by CancerWatch consortium partners and further refined to ensure relevance for the implementation of CancerWatch activities.

The survey was implemented using research electronic data capture (REDCap), a secure, web-based platform designed for research data collection.²⁰ The questionnaire was structured into 15 thematic sections (Table 1) using the REDCap Survey Queue feature, enabling respondents to complete the survey in stages and allowing different team members to contribute to specific sections according to their expertise. This was essential given the length of the questionnaire and the time needed to prepare the input information. Survey submission did not require completion of all questionnaire items. The platform also enabled centralised monitoring of survey completion and automated notifications by e-mail upon submission.

Before full deployment, the questionnaire underwent pilot testing involving 11 PBCRs and 10 regional survey coordinators. Each pilot registry provided structured feedback, including identification of unclear questions and technical issues. A postpilot consolidation meeting was

Table 1. Response rates by sections of the CancerWatch survey

Section	No. (%) of registries that responded to at least 90% of questions	No. (%) of registries that responded to 70% to 90% of questions	No. (%) of registries that responded <70% of questions
Identification and consent	36 (20.6)	89 (50.9)	50 (28.6)
Registry framework	155 (88.6)	20 (11.4)	0 (0.0)
Regulations and funding	164 (93.7)	8 (4.6)	3 (1.7)
Sustainability capacity	158 (90.3)	3 (1.7)	14 (8.0)
Data sources	167 (95.4)	6 (3.4)	2 (1.1)
Data items	175 (100.0)	0 (0.0)	0 (0.0)
Data registration operation	164 (93.7)	8 (4.6)	3 (1.7)
IT system for cancer registration	153 (87.4)	4 (2.3)	18 (10.3)
Registry personnel	144 (82.3)	24 (13.7)	7 (4.0)
Data quality	164 (93.7)	9 (5.1)	2 (1.1)
Data check software	163 (93.1)	0 (0.0)	12 (6.9)
Knowledge production	152 (86.9)	11 (6.3)	12 (6.9)
Data dissemination	141 (80.6)	28 (16.0)	6 (3.4)
Communication	166 (94.9)	7 (4.0)	2 (1.1)
Future plans and recommendations	88 (50.3)	58 (33.1)	29 (16.6)
Total CancerWatch survey	154 (88.0)	20 (11.4)	1 (<0.1)

IT, information technology.

held to review and harmonise feedback, leading to refinement of questionnaire content and structure.

A letter of intent was sent to all identified PBCRs 1 month before survey initiation. At the time of distribution, each participating registry received a personalised survey link along with instructions for completion. During the survey period, several reminders were sent to non-responding registries.

Twelve regional survey coordinators from prominent CancerWatch partner organisations were appointed to support survey implementation. They were selected based on their expertise in population-based cancer registration and their experience with the established PBCRs. Their role included facilitating registry participation, assisting with questionnaire completing, addressing language-related issues, and contributing to the clarification of collected responses and consistency in interpretation.

Geographical coverage

The survey targeted all PBCRs within the United Nations geographical definition of Europe, including nonmetropolitan France, Cyprus, and the Mediterranean part of Turkey and excluding Russia and Belarus. Given the specific historical context of cancer registration in the United Kingdom, we considered England, Scotland, Wales, and Northern Ireland as separate countries.

A comprehensive list of PBCRs was compiled by the Slovenian Cancer Registry using the ENCR membership list as the primary source. The list was further validated in collaboration with regional coordinators to confirm coverage and up-to-date contact information. Survey invitations were sent to the designated professional contact person for each registry. Registry representatives were identified solely for survey administration purposes and only the contact information required for communication with the registry was processed in accordance with applicable data protection (General Data Protection Regulation) requirements.

Analytical approach

In this initial analysis, descriptive analyses of survey responses were carried out as follows:

- Registry characteristics were described by registry type and nonresponding registries were identified.
- Population coverage across European countries was estimated by summing the coverage reported by regional general PBCRs.
- Data timeliness was assessed by calculating how many years before 2025 the most recent incidence data were available and by comparing these with the most recent data submitted to ECIS. Further, for each country, the earliest and latest years of available cancer incidence data were determined using the widest time span reported by contributing regional general PBCRs (i.e. the earliest first year and the most recent last year reported by any registry).
- Capacity for RWD generation was summarised using seven selected survey questions.

Descriptive analyses were limited to questions applicable to all registries. Conditional questions, free-text responses, and additional comments were excluded.

RESULTS

Survey participation and database characteristics

The survey was distributed to 192 European PBCRs from 45 countries. Of these, 181 (94.2%) initiated the survey and 175 (91.1%) completed it.

The questionnaire comprised 764 items organised into 15 thematic sections. The number of items per section ranged from 20 to 199, with a median of 50 items per section. The survey included single- and multiple-choice questions, numerical fields, and open-text fields. The total excludes the 192 open-text fields that were displayed only when respondents selected an 'other' response option. Of the total of 764 items, 352 core items were intended for all registries, while the remaining items were displayed conditionally according to registry characteristics or responses to preceding questions.

For example, after a registry identified their geographic coverage as regional rather than national, they were asked about the percentage of national population coverage, whether their databases are regional, pan-regional, or national, and whether they are represented by a national coordinating body; those questions were not applicable to national registries. Consequently, the number of questions presented varied between registries and only the core items are presented in the descriptive analysis.

Of the 352 items applicable to all registries response completeness was high across most sections, with the majority exceeding 90%; only the first and the last sections had completion <80% (Table 1). The number of missing responses on questions related to capacity for high-quality RWD is shown in Figure 1.

Of the 175 registries that completed the survey, 151 were general PBCRs (collecting data for all ages and all tumours), while the remaining registries were classified as childhood cancer registries (12 registries), hospital-based registries (2 registries), or site-specific cancer registries (10 registries). The 11 nonrespondents comprised five national and six regional registries. Thus, no feedback was received within the study timeframe for six populations (Table 2).

Assessment of PBCR coverage and data availability across Europe

These analyses include information from 151 general PBCRs across 39 European countries. As shown in Table 2, a total

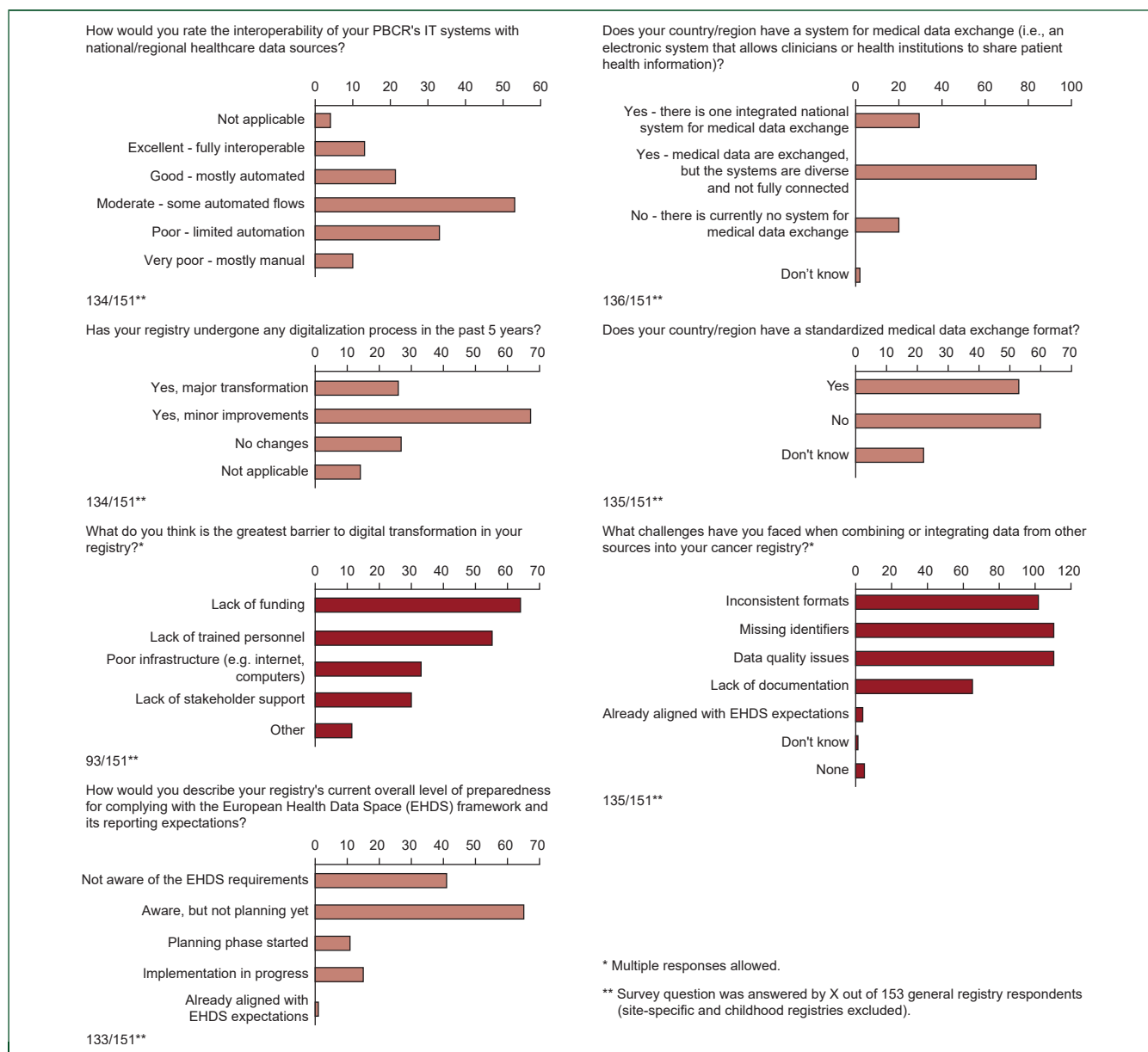


Figure 1. Distribution of responses to selected questions on capacity for high-quality real-world data generation by cancer registries. Analyses include 151 general PBCRs that completed the survey. Bars represent the number of registries selecting each response category. Missing responses indicate unanswered questions and do not include 'not applicable' or 'Don't know' responses. The ratio shown below each panel indicates the number of registries with a recorded response out of the eligible registries included in the denominator. For multiselect questions, registries could select >1 response; therefore, response counts may exceed the number of responding registries. EHDS, European Health Data Space; IT, information technology; PBCRs, population-based cancer registries.

Table 2. Coverage, incidence data availability, and reporting timeliness by European countries based on survey responses from national and regional general registries.

Country	No. PBCRs contacted	No. general PBCRs: responded ^a	Availability of a national dataset	Population coverage (%)	Incidence data available		Incidence reported to ECIS		Data availability delay (years back from 2025)	Reporting to ECIS delay (years)
					First year	Last year	First year	Last year		
Albania	1	1	—	100.0	2015	2024	—	—	1	—
Austria	8	5	Yes	100.0	1983	2024	1983	2024	1	0
Belgium	1	1	—	100.0	1999	2023	2004	2020	2	3
Bosnia and Herzegovina	2	2	No	40.0	2001	2025	—	—	0	—
Bulgaria	1	0	—	—	—	—	—	—	—	—
Croatia	1	1	—	100.0	1968	2023	2001	2022	2	1
Cyprus	1	1	—	100.0	1998	2022	1998	2022	3	0
Czechia	1	1	—	100.0	1977	2023	1994	2023	2	0
Denmark	1	1	—	100.0	1943	2024	1978	2024	1	0
England	1	1	—	100.0	1995	2023	—	—	2	—
Estonia	1	1	—	100.0	1968	2023	1968	2023	2	0
Faroe Islands	1	1	—	100.0	1955	2023	—	—	2	—
Finland	1	1	—	100.0	1953	2023	1953	2023	2	0
France ^b	30	18	Yes	34.3	1975	2023	2008	2013	2	10
Germany	17	15	Yes	86.6	1956	2025	1995	2024	0	1
Gibraltar	1	0	—	—	—	—	—	—	—	—
Greece	2	0	—	—	—	—	—	—	—	—
Hungary	2	1	—	100.0	2000	2023	—	—	2	—
Iceland	1	1	—	100.0	1955	2024	—	—	1	—
Ireland	1	1	—	100.0	1994	2022	1994	2022	3	0
Italy	42	38	No	100.0	1976	2023	1976	2022	2	1
Latvia	1	1	—	100.0	1980	2024	2000	2024	1	0
Liechtenstein	1	0	—	—	—	—	—	—	—	—
Lithuania	1	1	—	100.0	1978	2023	—	—	2	—
Luxembourg	1	1	—	100.0	2013	2021	—	—	4	—
Malta	1	1	—	100.0	1980	2022	—	—	3	—
Moldova	1	1	—	100.0	2016	2023	—	—	2	—
Montenegro	1	1	—	100.0	2013	2014	2013	2013	11	1
Netherlands	1	1	—	100.0	1989	2024	1989	2023	1	1
North Macedonia	1	1	—	100.0	1979	2023	—	—	2	—
Northern Ireland	1	1	—	100.0	1993	2022	—	2019	3	3
Norway	1	1	—	100.0	1953	2024	1970	2022	1	2
Poland	18	16	Yes	97.3	1967	2023	2000	2022	2	1
Portugal	5	5	Yes	100.0	1988	2023	1997	2022	2	1
Romania	2	1	No	13.3	2008	2018	2008	2016	7	2
Scotland	1	0	—	—	—	—	—	—	—	—
Serbia	1	1	—	100.0	1999	2024	2019	2023	1	1
Slovakia	1	1	—	100.0	1978	2015	—	—	10	—
Slovenia	1	1	—	100.0	1950	2022	1983	2022	3	0
Spain	15	11	No	22.9	1973	2022	1975	2020	3	2
Sweden	1	1	—	100.0	1958	2024	1960	2023	1	1
Switzerland	15	11	Yes	81.8	1968	2024	1980	2022	1	2
Turkey	2	1	No	5.4	1993	2020	—	—	5	—
Ukraine	1	0	—	—	—	—	—	—	—	—
Wales	1	1	—	100.0	1972	2022	—	2020	3	2

ECIS, European Cancer Information System; PBCRs, population-based cancer registries.

^aNumbers in column 1 are excluded childhood and site-specific PBCRs and all general PBCRs that did not initiate or complete the survey.^bFour PBCRs from French overseas territories where identified, three completed the survey but are not included in the information on coverage.

of 28 European countries reported operating a single national PBCR covering their entire population. In addition, Austria, Switzerland, Germany, France, Portugal, and Poland integrate data from multiple regional registries into a national dataset, enabling estimation of national cancer burden indicators from a single source. The national datasets of Switzerland, Germany, and Poland are population wide. However, the coverage shown in Table 2 is <100% because some regional registries in these countries did not respond to the survey. In Italy, the entire population is also

covered by regional registries; however, a consolidated dataset is not yet available. According to the survey results, 34% of the population in France and 23% in Spain are covered by regional PBCRs. Two cancer registries in Bosnia and Herzegovina cover ~40% of the population, while the Cluj Cancer Registry covers ~13% of Romania. However, Romania also maintains a national childhood cancer registry with full population coverage. The Izmir Cancer Registry is the only PBCR reporting for the Mediterranean part of Turkey, covering ~5% of the national population.

According to PBCR survey responses (Table 2), 87% of countries publish incidence data within 3 years after the diagnosis, 69% within 2 years, and 31% within 1 year. For countries represented by multiple regional registries, the country-level delay was calculated using the most recent incidence year reported by any responding regional PBCR. This value does therefore not imply that all regional PBCRs within the country had the same reporting delay. In Slovakia and Montenegro, the most recent published incidence data are less recent than in other countries.

For ECIS reporting status, apparent discrepancies identified during data review were reviewed against publicly available ECIS information. Based on this verification, approximately two-thirds of European countries have sufficiently developed cancer registration systems to enable reporting to ECIS. In most of these countries, data are reported either immediately or within 1 year after becoming available at the national level. Registries from Albania, the Faroe Islands, Hungary, Luxembourg, Moldova, North Macedonia, Slovakia, and Turkey have not yet submitted data to ECIS, with all but North Macedonia indicating an intention to do so.

Evaluation of PBCRs' capacity for RWD generation

Across Europe, PBCRs show substantial variability in digital infrastructure and data integration capacity, ranging from basic data linkage systems to partially or fully automated infrastructures (Figure 1).

Approximately one-quarter of European general PBCRs rate the interoperability of their IT systems with national or regional health care data sources as good or excellent, with data exchange being fully or largely automated. Most registries (64%) report partially automated data flows, while a small proportion (7%) still rely mainly on manual data linkage, whereby records are matched with sources such as hospital databases and mortality registries through comparison of individual identifiers. These findings are consistent with reported developments in digital capacity over the past 5 years. Substantial transformation was reported by 19% of registries, including full migration to automated systems, integration with external databases, or implementation of AI-based data validation. In comparison, more than half of the registries reported only incremental improvements, including clearer forms, automated alerts, or enhanced dashboards. By contrast, 20% reported no changes in digitalisation. Among the main barriers to digital transformation, lack of funding was most frequently reported, followed by shortages of trained personnel, inadequate infrastructure, and limited stakeholder support.

When integrating data from external sources into cancer registry databases, registries frequently encounter data quality issues at the source level, particularly missing patients identifiers. Additional challenges include inconsistent data formats and inadequate documentation. More than 60% of general PBCRs in Europe operate within national medical data exchange systems that are partially

interconnected and characterised by heterogeneous database and IT infrastructures. A standardised data exchange format is defined in 39% of cases, while 14% of European PBCRs are not integrated into any medical data exchange system. Finally, awareness of the EHDS Regulation,¹³ is limited, with approximately one-third of European PBCRs reporting no familiarity with its operational requirements and nearly half reporting no related actions to date.

DISCUSSION

The recently completed CancerWatch survey provides a comprehensive overview of PBCR characteristics across Europe, enabling the classification of registries according to their operational and digital maturity and the assessment of their capacity to support high-quality RWD. Initial analysis indicates that, although registry coverage is generally well established across Europe, substantial heterogeneity persists in digital maturity and data integration capacity. Further analyses of the large and comprehensive survey dataset have already been planned within the CancerWatch project.¹⁴

The questionnaire contained >700 items because it was designed to support the wider objectives of the CancerWatch JA rather than only the analyses presented in this article. It covered multiple domains of PBCR organisation, governance, legal frameworks, data collection, data management, interoperability, and technical infrastructure. Extensive branch logic ensured that registries were shown only questions relevant to their organisation and workflows. Nevertheless, the length and scope of the questionnaire increased the burden on participating registries and may have contributed to nonresponse or partial completion.

Population-based cancer incidence data have been available in Europe for >80 years. The field was historically led by the Nordic countries, with the Danish registry established in 1942 and other national PBCRs following in the 1950s.²¹ Outside the Nordic region, one of the earliest PBCRs was established in Slovenia, with incidence data available since 1950.²² Today, PBCRs are established widely across Europe. Information on cancer registration activities was not available from six populations through the survey. However, cancer registration activities also take place in these settings. The Scottish Cancer Registry and the Cancer Registry of Eastern Switzerland, which provides data for Liechtenstein, report regularly to ECIS with full population coverage.⁹ In Greece, plans to establish a national PBCR in 2026 have been reported. A childhood cancer registry that had operated in the previous decade has since been discontinued and no data from Greece are currently available in ECIS. In Bulgaria, cancer registration activities have recently undergone organisational changes, with data now published by the Ministry of Health.²³ Cancer incidence data from Bulgaria are available in ECIS, although they refer to earlier years.⁹ The National Cancer Registry of Ukraine initiated the survey but did not complete it; however,

cancer incidence data are available in ECIS, although they relate to earlier years.⁹

A broad catalogue of European PBCRs was developed for inclusion in the survey, representing, to our knowledge, the most comprehensive and up-to-date inventory of PBCRs in Europe. This represents a substantial increase compared with the previous pan-European PBCR survey, which included 122 respondents including 106 general cancer registries across 32 European countries.¹⁵ Despite the length of the questionnaire, we obtained a notably high response rate exceeding 90%, reflecting strong engagement of participating registries and supporting the representativeness and reliability of the findings. The high response rate is likely due to effective coordination and communication led by the Slovenian Cancer Registry, with strong support from the CancerWatch consortium, as well as the active involvement of regional survey coordinators. Sustaining comparable response rates in future surveys will likely require a similarly well-coordinated approach, effective follow-up procedures, and clear communication with participating registries.

Despite an excellent response rate, several limitations should be considered when interpreting the findings. Firstly, the data are based on self-reporting by participating registries, which may introduce reporting bias or inconsistencies in how information was provided. Secondly, nonresponse from a small number of populations may have resulted in incomplete coverage and potential nonresponse bias. Thirdly, variation in the interpretation of survey questions across registries may have affected the comparability of responses, particularly for more complex or less standardised items.

With these considerations in mind, the timeliness of data availability in European PBCRs remains suboptimal. Less than one-third of registries are able to report incidence data within 1 year of diagnosis, while a comparable proportion require >2 years to complete their databases. An additional delay is observed in some countries when aggregating data from regional registries into national estimates. Similarly, Giusti et al.²⁴ reported, based on data from 49 European PBCRs, a median interval of 610 days from cancer incidence to registration.

Eleven countries reported that they have not submitted data to ECIS; however, for Iceland, Lithuania, Bosnia and Herzegovina, Malta, and England, incidence data are available in ECIS, although not for recent years.⁹ Almost all registries that do not currently report to ECIS indicated plans to do so in the near future.

Digital maturity can improve the timeliness and efficiency of data transfer, linkage, and validation supporting more sustainable registry operations and enabling more effective integration of routinely collected health data. However, achieving these benefits requires common standards, appropriate governance, and specialist expertise. European PBCRs vary widely in digital maturity and are increasingly expected to INTEGRATE registry data with electronic health records, clinical platforms, genomic data, and other routinely collected sources.

Such integration expands opportunities for more comprehensive RWD generation and precision oncology while preserving the unique advantages of population-based cancer registration.

Registries in other regions face similar challenges, including reporting delays, fragmented systems, and workforce constraints. Although some are adopting automated case finding, natural language processing, and machine learning, these technologies and staffing issues were not assessed in the present survey and should be examined in future CancerWatch analyses.

The role of PBCRs within the EHDS has not yet been defined in a uniform way. Possible functions include contributing validated population-based cancer data, supporting data linkage, facilitating secondary use, and acting as national or regional cancer data coordination points. However, the appropriate model will depend on national governance, legal mandates, technical infrastructure, and relationships with other health data holders. The current findings support the need for PBCRs to be included in these discussions but they do not provide a basis for recommending a single organisational model.

Advances in medical knowledge and the growing importance of precision oncology are increasing demand for more detailed and timely cancer data.^{17,25-27}

Addressing the gaps identified in this survey will require coordinated investment in several priority areas. Strengthening workforce capacity, including expertise in data management and digital technologies, is essential to support increasingly complex registry activities. Investments in digital infrastructure, interoperability, and secure data linkage is needed to improve the timeliness and integration of registry data. Closer collaboration among PBCRs, clinical communities, and other health data providers will also be necessary to facilitate efficient data exchange and maximise the value of routinely collected health data. Together, these developments could help PBCRs meet emerging demands while retaining their population-based surveillance role. Continued coordination through CancerWatch and related European initiatives will be needed to clarify priorities, assess additional aspects of registry capacity, and determine how PBCRs should contribute to the evolving European health data landscape.

Conclusions

While PBCRs across Europe achieve broad population coverage, they remain highly heterogeneous in terms of digital infrastructure, data integration capacity, and timeliness of data availability. These differences may limit their ability to support RWD generation and to meet the emerging requirements of the EHDS. The findings highlight the need for sustained investment in workforce capacity and technological infrastructure, alongside stronger collaboration between clinical and registry communities, to improve interoperability, data integration, and the timeliness of cancer registration.

This study provides an important evidence base for prioritising targeted investments and coordinated European action to strengthen the role of PBCRs within the evolving European health data ecosystem. The establishment of a continuously updated, standardised, and publicly accessible inventory of PBCRs—detailing their characteristics and selected organisational and technical capabilities—would support transparency, benchmarking, and strategic planning. Such a platform would require central coordination, clear governance, and long-term sustainability. While initiatives such as CancerWatch represent an important step forward, further sustained efforts will be required to achieve a more integrated and harmonised European cancer surveillance.

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DATA AVAILABILITY

The data that support the findings of this study are not publicly available due to restrictions related to confidentiality and the terms under which the data were collected. Aggregated data may be available from the corresponding author upon reasonable request and with permission of the participating institutions.

DECLARATION OF AI AND AI-ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

During the preparation of this work, the authors used ChatGPT-5.3 to improve readability and language use. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

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DISCLOSURE

The authors have declared no conflicts of interest.

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