ONCODAILY MEDICAL JOURNAL

Article

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**Published:** August 11, 2025

doi.org/10.69690/ODMJ-001-0811-4701

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## ABSTRACT

Systematic collection and analysis of comprehensive, high-quality, population-based cancer data are crucial for monitoring progress and informing cancer control policies. National and regional population-based cancer registries (PBCRs) serve as the primary source of these data, offering information on cancer incidence, survival, prevalence, and mortality. In Europe, PBCRs contribute to national and regional cancer control efforts, informing initiatives such as the European Cancer Information System, the European Cancer Inequalities Network, and Europe's Beating Cancer Plan. However, PBCRs encounter challenges, including data quality issues, suboptimal standardization and comparability, limited treatment data availability, data privacy concerns, restricted data linkage, interoperability issues, and funding constraints. These obstacles hinder the full utilisation of registry data for robust policy evaluation and decision-making. Opportunities to enhance PBCRs' capacity include promoting standardised data collection, improving data linkage through secure platforms, navigating data privacy issues through stakeholder engagement, leveraging new technologies such as artificial intelligence to support cancer registration, strengthening collaborative networks, increasing funding, and fostering training. Addressing these challenges is crucial for generating high-quality evidence to shape effective, equitable, and patient-centred cancer care policies.

## INTRODUCTION

Cancer is a major determinant of loss of health in populations. Only optimal access to cancer care can ensure that individuals live productive lives. However, there are wide disparities in outcomes worldwide, which depend on stark inequities in cancer care provision. Systematic collection and analysis of comprehensive, high-quality, population-based cancer data are key to monitoring progress and informing cancer control plans. National and regional cancer registries serve as the bedrock of this data collection, as the primary source of population-based information on cancer incidence, survival, prevalence, and mortality[1,2]. High-quality registry data are essential for assessing the effectiveness of healthcare services in managing cancer. Population-based cancer registries (PBCRs) help identify opportunities for implementing screening programs, evaluate the impact of therapeutic advancements, and inform resource allocation. They are key to public health and health governance as they aim to register all new cancer cases in a defined geographic area, providing unbiased metrics for an accurate assessment of the cancer burden[3],[4],[5].

## PRINCIPLES OF CANCER REGISTRATION

Cancer registration is the systematic collection of data on patients diagnosed with cancer in a given country or territory covered by a cancer registry, over time, using defined standards for data collection and coding.

Data collected by a cancer registry are patient-related, disease-related, and treatment-related. The availability and granularity of these data vary between registries. The variables comprise information on demographics: age, sex, race/ethnicity, place of birth, and place of residence. Diagnosis: date of diagnosis, primary anatomical site (coded using classifications such as the International Classification of Diseases for Oncology – ICD-O)[6], histology/morphology code, basis of diagnosis (histology, cytology, clinical, death certificate only). Stage at diagnosis: extent of disease defined using staging systems such as the tumour, node, and metastases (TNM) system, or simplified classifications (localised, regional, distant). Initial treatment: summary information on the first course of treatment received (surgery, radiotherapy, chemotherapy). Follow-up information: vital status of the patient (alive/dead), date of last known vital status, cause of death[7].

Data sources for cancer registries are diverse and usually include hospital records, pathology and cytology reports, specialised clinical registers, outpatient facilities, and death certificates. The process for data collection can be active or passive, with most high-quality registries employing a combination of methods to ensure completeness and accuracy.

Quality indicators for cancer registration include completeness, namely capturing all eligible cases in a defined population. High completeness is essential for accurate estimation of cancer burden. Accuracy: ensuring the recorded data is correct and reflects the source records. This requires rigorous data validation procedures. Timeliness: data should be collected and made available for analysis within a reasonable timeframe. Significant data lag is a common challenge that impacts the relevance of analyses for policy needs. Comparability: using standardised coding systems, definitions, and data collection protocols is crucial to enable robust international comparisons and monitor data over time[7]. International classifications such as ICD-O, or data dictionaries promoted by the International Association of Cancer Registries (IACR), the European Network of Cancer Registries (ENCR), or the North American Association of Central Cancer Registries, (NAACCR) are important, but differences in cancer registry coding practice (ICD-O-3, ICD-10, Site Recode ICD-O 3/WHO 2008 Definition for SEER data) may persist[6],[8],[9],[10]. Confidentiality and privacy: protecting sensitive patient information is crucial. Strict protocols for data handling, anonymisation or pseudonymisation, and access must be followed to align with ethical guidelines and legal requirements, such as the General Data Protection Regulation in Europe[11].

## PBCRS IN EUROPE

Europe has a long history of cancer registration, with some of the earliest PBCRs established in the mid-20th century. Today, PBCRs cover a significant proportion of the European population. ENCR, established in 1990 and hosted by the Joint Research Centre (JRC) of the European Commission, plays a crucial role in enhancing collaboration and data comparability among the European PBCRs. ENCR sets guidelines for data collection and quality, promotes training, and facilitates data calls for collaborative research projects and European-level reporting[8].

A key output based on data submitted by European PBCRs is the European Cancer Information System (ECIS). Hosted by the JRC, ECIS aggregates data from ENCR participating registries, presenting key indicators on cancer incidence, prevalence, and mortality across Europe[12]. The ECIS goal is to make European cancer statistics more accessible to policymakers, researchers, healthcare professionals, and the public. These statistics inform evidence-based decision-making and increase awareness across the continent.

Other regional stakeholders leveraging data from PBCRs include the Organisation of European Cancer Institutes (OECI)[13]. OECI is a network of tertiary-level cancer centres and research institutes in Europe. These centres do not primarily collect data, but may complement cancer registry data with additional clinical information. Moreover, OECI relies on registry data for research and performance benchmarking.

Key assets of European PBCRs include coverage of a remarkable proportion of the European population; high data quality in most registries; a robust basis for European-level statistics, presented through ECIS; collaborative research, such as EUROCARE, measuring population-based survival trends in Europe to highlight possible disparities[14]; evaluation of initiatives for cancer control, including population-based screening programmes.

European PBCRs are also an important component of global research collaborations such as the CONCORD programme. In 2015, CONCORD-2 established global surveillance of cancer survival trends[15]. Its last cycle, CONCORD-3, included over 37 million patients diagnosed during 2000-2014 with one of 18 common cancers in adults, and brain tumours and haematological malignancies in children, in 70 countries worldwide[16]. Survival estimates from CONCORD have become the benchmark for assessing health system capacity to deliver high-quality cancer care. The Organisation for Economic Co-operation and Development (OECD) is in partnership with the CONCORD programme to develop healthcare quality indicators of cancer care. Survival estimates from CONCORD have been included in OECD's Health at a Glance since 2017[17]. CONCORD results have also been used in the European Union's Country Health Profiles as part of the State of Health in the EU initiative[18].

Despite these strengths, there are differences in the variables collected and in the level of their granularity. Data on stage are available in many PBCRs with wide variability in completeness, and treatment data are still sparse. This affects comparability and restricts the scope of analyses, especially for the evaluation of treatment effectiveness at a population level[19]. Worldwide, population-based clinical cancer registries or high-resolution chapters of national or regional cancer registries exist. Examples are the Swedish National Register for Breast Cancer, the specialised registry of the Surveillance, Epidemiology, and End Results Program in the US, and the Netherlands Cancer Registry[20],[21],[22]. Large international collaborations such as CONCORD and EUROCARE have also conducted international comparative studies using high-resolution data[23],[24],[25].

## The role of PBCRs in cancer policy

The data collected by PBCRs underpin the formulation, implementation, and evaluation of effective cancer care policies at national and regional levels[26]. Their role is integral to a comprehensive approach to cancer control, particularly within the framework of European initiatives such as Europe's Beating Cancer Plan (EBCP)[27]. PBCRs' activities may act in the following domains.

**Quantifying the cancer burden and identifying priorities.** PBCRs provide accurate and unbiased estimates of cancer incidence, mortality, prevalence, and survival. These data enable policymakers to understand the magnitude of the cancer burden, identify populations or geographic areas with poorer outcomes to prioritise interventions, and allocate resources.

**Monitoring trends and evaluating interventions.** By collecting data over time, registries enable the monitoring of trends in cancer incidence, mortality, and survival. These metrics help assess the impact at the population level of primary prevention interventions, screening programs, or new treatment protocols or guidelines. Registry data enable the evaluation of implemented policies and programs using real-world evidence (RWE). RWE is crucial for informing clinical decision-making because it is based on data from an unselected patient population, which may differ from the population seen in clinical trials. High-resolution, population-based studies provide robust RWE and assist in assessing the effectiveness of a health system in managing cancer. RWE may translate into actionable evidence and inform national and international cancer treatment guidelines. This is also related to the definition of monitoring and evaluation framework indicators in the context of Europe's Beating Cancer Plan. These indicators are derived from high-quality cancer registry data to track progress towards the EBCP's aim, which is reducing inequalities in access to cancer care across the EU.

**Highlighting and addressing cancer inequalities.** PBCR data help identify inequalities in cancer outcomes. This information is the basis for initiatives such as the European Cancer Inequalities Network (ECIN)[28]. ECIN uses data from various sources, including PBCRs, to map cancer inequalities across the EU, explore their determinants, and tackle these inequalities by promoting the exchange of best practices.

**Informing screening policies.** PBCRs are essential for evaluating the population coverage and impact of cancer screening programs. By linking registry data with screening records, it is possible to assess participation rates, stage distribution, and survival outcomes among screened versus unscreened populations. This evidence is critical for evaluating the cost-effectiveness of existing screening programs and informing decisions about implementing or modifying screening policies[29].

**Facilitating resource planning and allocation.** Accurate data on cancer incidence and prevalence, broken down by age, sex, and geographic region, is fundamental for planning healthcare infrastructure and workforce needs, aligning with the EBCP's focus on integrated care pathways[27,30,31,32].

**Providing insights into the quality of care at the population level.** Population-level statistics derived from registries, such as stage at diagnosis distributions and population-based survival, offer insights into the quality of the cancer care pathway and the effectiveness of healthcare systems.

**Benchmarking.** National and regional cancer reports based on cancer registry data enable benchmarking of cancer outcomes against internal targets or international standards.

**Advocacy and public awareness.** Presenting data from cancer registries regarding the burden, trends, and disparities helps advocate for increased investment in cancer control, raising public awareness, and mobilising support for policy changes.

**Follow-up strategies and "right to be forgotten" for cured patients.** Cure indicators of PBCRs help to inform clinicians, patients, and healthcare policy makers about strategies of survivorship care[33,34].

## CHALLENGES

Cancer registries may face challenges hampering their ability to collect, process, and disseminate data effectively.

**Data Quality.** Incomplete reporting from data sources can lead to underestimation of incidence, impacting the reliability of burden estimates used for policy. Inaccuracies in coding can bias results and undermine the validity of international comparisons. A too long time lag between diagnosis and data availability reduces the relevance of analyses for policy needs[19].

**Comparability and standardisation.** While international standards exist, their implementation and the interpretation of coding rules can vary between registries. Differences in methodologies for data collection, the definition of certain variables, and the data granularity can make comparisons between registries or countries less robust[35,36].

**Availability of treatment data.** While the collection of data on stage is generally well established, data collection on treatment is not. An analysis of the 2015 ENCR-JRC data call questionnaire revealed that only 49% of responding PBCRs reported collecting treatment data, with national registries more likely to do so than regional ones. The most commonly reported sources were hospital discharge records and clinical records. This heterogeneity in treatment data collection limits the ability of registries to conduct robust population-based analyses of treatment patterns, evaluate the real-world effectiveness of specific treatments across populations, and assess adherence to clinical guidelines[19].

**Data privacy and integrity**. The implementation of GDPR in the European Union has introduced complex challenges for cancer registries[37]. Stringent data protection regulations can restrict access to registry data or linkage across datasets, hampering the use of registries for essential public health research and evidence-based policymaking. There are differences across Europe in the practical implementation of these rules, with some countries facing greater barriers to the use of cancer registries for research than others. Balancing individual privacy rights with the societal benefits derived from using registry data for public health research and cancer control is an ongoing challenge that requires input from all stakeholders, including patients, researchers, policymakers, and registry professionals. Data protection regulations may also impact the ability to conduct collaborative research[11].

**Data linkage capabilities.** Robust data linkage with other relevant health datasets (e.g., prescription datasets, administrative claims, pathology reports) is key to informing European initiatives such as ECIN and to conducting high-resolution, clinically relevant research. However, there are technical barriers and legal restrictions imposed by data protection regulations[38].

**System integration and interoperability.** The lack of system integration and interoperability standards between disparate healthcare information technology (IT) systems and registries will require manual data abstraction, which is inefficient, costly, and prone to errors. Creating automated data flows remains a significant technical and organisational challenge[38].

**Funding and resources.** Several registries operate with limited budgets, impacting staffing levels, IT infrastructure development, and the ability to invest in training and quality improvement initiatives needed to address challenges such as data quality and data content expansion[2].

**Skilled Workforce.** A high-quality cancer registry requires a skilled workforce. Recruiting and retaining staff with the necessary expertise (coding, data management, epidemiology, IT) is challenging and impacts the registry's ability to provide high-quality data for policy and initiatives[2].

These challenges are interconnected and impact the entire data ecosystem supporting European cancer control, from individual registries to collaborative platforms and policy frameworks like ENCR, ECIS, and ECIN. The heterogeneity in data collection, particularly for treatment data, is an example of how these challenges may limit the use of data for policy evaluation and research.

## OPPORTUNITIES FOR IMPROVEMENTS

Despite the challenges, there are opportunities to enhance the capacity and impact of cancer registries in informing cancer care policies, based on technological advancements and evolving data landscapes.

**Enhancing data content and standardisation.** Addressing the heterogeneity in collected variables, particularly treatment data, is a major opportunity. Promoting the systematic collection of high-resolution treatment information using standardised coding systems across all European PBCRs, potentially through revised ENCR guidelines and dedicated funding, would increase the ability to evaluate treatment effectiveness at a population level and provide crucial insights for policy[19].

**Improving data linkage.** Developing secure, robust data linkage platforms that connect cancer registry data with other relevant health datasets is key. While navigating GDPR complexities, establishing clear legal frameworks and technical solutions for secure linkage is essential for conducting comprehensive and relevant analyses. Creating integrated data environments or "health data spaces" in Europe could enhance the analytical potential while prioritising privacy[38].

**Navigating data privacy through collaboration and innovation.** Finding effective ways to balance individual privacy with the societal benefits of public health research using registry data is crucial. This requires an active dialogue between stakeholders, establishing robust governance frameworks for data access, and exploring avenues such as pseudonymisation. Collaborative efforts through ENCR and engagement with EU-level data initiatives can help establish best practices and common approaches to data sharing and access under GDPR[38].

**Leveraging technology.** Using AI, machine learning, and NLP offers opportunities to automate data abstraction, improve data validation and quality control, increase efficiency, and potentially analyse large, complex datasets, including unstructured clinical text[10].

**Real-time data collection.** Exploring strategies for more rapid or near real-time reporting of key data items can significantly improve the timeliness of data availability for policy monitoring, making ECIS more dynamic[12].

**Strengthening collaboration and data sharing networks.** Enhancing collaboration between registries, with researchers, clinicians, policymakers, and patient groups, is key. Developing secure data sharing platforms, using federated analysis, or defining clear governance frameworks that enable data access for public health purposes while fully complying with GDPR, can accelerate knowledge generation and translation.

**Increased investment and sustainable funding models.** Recognising cancer registries as an essential part of the public health infrastructure requires increased and sustained funding. Investments in modern IT systems, recruitment and retention of skilled personnel, training, and new technologies for data linkage are necessary to meet the demands of providing high-quality data for national policy and European initiatives[2].

**Capacity building and training.** Investing in training programs for registry staff, data analysts, and policymakers on data collection, analysis, interpretation, and the effective use of registry data for policy formulation is essential to maximise the utility of the collected information for all stakeholders.

Developing clear pathways for the translation of data into policy. Actively engaging with policymakers to understand their data needs and developing user-friendly data visualisations, reports, and policy briefs can address the gap between data generation and data implementation for policy purposes.

**Public engagement and trust.** Building public trust in how cancer registry data is collected, used, and protected is fundamental, particularly in the context of GDPR. Transparent communication about the purpose and benefits of registration for public health and research, including its role in supporting initiatives like Europe's Beating Cancer Plan, while safeguarding privacy, is crucial for public support[27].

Addressing these challenges, particularly those related to data quality, data heterogeneity, and data protection regulations, can help generate the evidence needed to shape effective, equitable, and patient-centred cancer care policies, ultimately contributing to reducing the burden of cancer and reducing inequalities across Europe.

To support PBCRs' long-term sustainability, the European Commission has announced a new joint action: Cancer Watch. This initiative, set to launch in September 2025, aims to improve the quality, timeliness, and coverage of cancer data across Europe.

# CONCLUSION

National and regional cancer registries, particularly population-based cancer registries, are an essential part of global efforts aimed at tackling the increasing cancer burden across populations. Cancer registries provide the epidemiological data required to measure the cancer burden, monitor trends, identify disparities, and evaluate the impact of interventions and policies at a population level.

In Europe, a network of well-established PBCRs contributes significantly to national cancer control efforts and informs European flagship initiatives. These include ECIS for disseminating comparable data and ECIN for identifying disparities. Collaboration with clinical networks such as OECI further translates population-based evidence into clinically relevant research and actionable evidence.

However, the operational environment for cancer registries is complex and challenging. Issues related to data quality, standardisation and heterogeneity of data, timeliness, data linkage capabilities, data protection regulations, system integration, and funding pose obstacles to leveraging the full potential of cancer registries in informing policy.

These challenges can be addressed by enhancing the standardisation of data collection, improving data linkage, embracing technological advancements, and strengthening collaborative networks. Closer collaboration between data producers (registries) and data users (policymakers, researchers, and clinicians) is also essential to translating registry data into policy and, ultimately, improving the lives of patients with cancer. The continued support of cancer registries is vital for the future of cancer control.

**Competing Interests:** The authors declare no competing financial interests.

**Funding:** This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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