



Review Article.

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National Electronic Oncology Registry in Kazakhstan: Patient's Journey

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Creative Commons Attribution 4.0 International License Abstract: The burden of non-communicable diseases (NCDs), particularly cancer, is steadily increasing in Kazakhstan alongside socioeconomic development, highlighting the urgent need for effective national management and control strategies. The Electronic Registry of Oncological Patients (EROP) is a key initiative designed to support this goal by enabling comprehensive surveillance of cancer patients across the country. This review examines the patient journey that informs EROP's data collection process and explores its potential as a foundation for local cancer epidemiology research. Analysis of the registry reveals extensive coverage of dispensary, outpatient, and inpatient visits, capturing detailed socio-demographic information, diagnoses, treatments, and mortality outcomes. EROP provides valuable insights into cancer morbidity, mortality, and quality of life across spatial and temporal dimensions in Kazakhstan. The review also addresses current limitations and underexplored aspects of the registry, emphasizing the importance of careful interpretation to ensure robust, evidence-based research.

Keywords: Oncology; Cancer; National registry; Epidemiology;

Introduction

Over the past three decades, global health has shifted from being dominated by communicable diseases to facing a rising burden of non-communicable diseases (NCDs). This shift was primarily driven by factors such as urbanization, aging populations, lifestyle changes, and improvements in infectious disease control, which have been especially pronounced in lowand middle-income countries (LMICs). According to the World Health Organization (WHO), NCDs account for over 70% of global deaths, with a significant proportion occurring in developing regions [1]. In Central Asia, this transition mirrors global trends but is shaped by unique regional dynamics. Following the dissolution of the Soviet Union in 1991, Central Asian countries faced economic instability, healthcare system disruptions, and a legacy of underinvestment in chronic disease management [2]. During the 1990s, infectious diseases remained a primary concern in the region [3], which remained so in the following 30 years, thanks to advancements in health policy, which made CDs less prominent. By the 2010s, cancer had become a significant public health challenge in the region, reporting increasing incidence rates linked to smoking, dietary shifts, and environmental exposures [4]. This epidemiological transition necessitated an appropriate reorientation of health systems to resolve emerging challenges of chronic conditions like cancer.

In Kazakhstan, the transition from infectious diseases to non-communicable diseases (NCDs) has been particularly notable. In the post-Soviet era, the country grappled with infectious disease outbreaks and a fragmented healthcare infrastructure [5]. However, beginning in the early 2000s, economic growth largely driven by the energy sector - enabled substantial improvements in healthcare infrastructure and access [6]. Paradoxically, this socioeconomic progress also facilitated behavioural and environmental changes that elevated NCD risks, including increased alcohol and tobacco consumption, sedentary lifestyles, and dietary shifts [1]. Lung, stomach, and colorectal cancers are among the most prevalent malignancies, influenced by both genetic predispositions and modifiable risk factors [7].

Considering these developments, robust data systems became essential for understanding cancer trends, informing policy strategies, and shaping evidence-based interventions. The Electronic Registry of Oncological Patients (EROP) represents a critical step in Kazakhstan's efforts to modernize cancer surveillance and research.

This review aims to explore the research potential of EROP, emphasizing its value as a foundational data

source for advancing cancer epidemiology, monitoring clinical outcomes, and supporting strategic health policy planning in Kazakhstan and comparable LMIC contexts. By examining the structure, content, and analytical possibilities offered by EROP, this work seeks to underscore its significance in the broader landscape of digital health transformation and non-communicable disease control.

Registry forms

The Electronic Registry of Oncological Patients (EROP) contains collective data on oncology patients across all regions of Kazakhstan from 2014 to 2023. This information has been gathered from four standardized forms used for documenting and tracking medical information and compiled throughout an oncological patient's journey (Figure 1).

Form 034/u - "Notice": When a patient is first diagnosed with an oncological disease or identified as at risk of developing one, Form 034/u is filled out to document this initial notice.

Form 030-6/u - "Control Card of Dispensary Observation (Onco)": Following diagnosis, the patient is registered at the local oncological dispensary for monitoring and surveillance. At this stage, Form 030-6/u is completed for each patient, including details such as registration and deregistration dates.

Form 012/u - "Statistical Card of a Patient Discharged from Hospital": If the patient undergoes hospitalization, whether planned or urgent, Form 012/u is finalized and uploaded upon discharge. This form records data for all oncology inpatients, covering both 24-hour and daytime stays and including information on the diagnostic and therapeutic services received during the hospitalization. **Form 052/u - "Medical Record of an Outpatient":** Information about ambulatory oncology patients in the registry is sourced from Form 052/u, which documents the details of outpatient care. The form records data on ambulatory services patients received.

For each form, the data is entered by attending physicians during respective patient encounters through authorized medical portals called healthcare or medical information systems (HIS or MIS) [8]. As part of UNEHS, the recorded forms from medical organizations all over the country are then accumulated at the Republican Center for Electronic Health (RCEH) for healthcare statistics. For epidemiological studies, raw data separately provided for each form is securely transferred to the local servers of a research facility, such as a university, with access strictly limited to authorized personnel [8]. For this review, the end data of EROP collected throughout this patient journey were grouped and discussed for potential use in healthcare research. The study was approved by the Institutional Review Board of Nazarbayev University (protocol code: NU-IREC 651/24112022 and date of approval: 28 November 2022), with exemption from informed consent.

Registry description

The data provided on EROP

The information provided on EROP spans from simple demographic information to details of cancer progression and treatment received at medical facilities. The data variables available in EROP are provided in Table 1 and grouped into seven categories.



Figure 1. Oncological Patient Journey in EROP.

Identification numbers

Each patient in UNEHS, including EROP, is assigned with unique identification number, called RpnID. RpnID helps to connect information of individual patients from different registries of UNEHS without using patient-identifiable information and compromising the confidentiality of patients. This variable also helps to connect EROP data with other databases of the UNEHS. For example, in extracting information on the death status of the patient or comorbidities he or she has, alongside the main disease of interest. For example, in extracting information on the death status of the patient or comorbidities he or she has alongside with the main disease of the interest.

Provider information

Provider information as an oncological dispensary, where oncological patients were assigned for surveillance or treatment, as well as the medical clinic providing primary medical care, is available in EROP. These variables help to assess the oncological service across regions of Kazakhstan and to evaluate the regional burden of disease.

Demographic information

Demographic information in EROP includes birthdate, sex, ethnicity, residency, and region. The birth date variable given in Day/Month/Year format helps to calculate the age of patients at the moment of diagnosis, treatment and death. The derived age variables can help to see the trend of morbidity, mortality and quality of life estimates for oncological patients across age strata. Information on sex and ethnicity aids in stratifying the burden of oncological diseases across different demographic categories. Certain forms in the EROP include details about the patient's living region, based on the administrative structure of Kazakhstan for the corresponding year, encompassing oblasts and administrative cities. Furthermore, residency variables provide additional insights into whether patients reside in urban or rural areas.

Diagnoses

Each diagnosis in EROP forms is recorded using International Classification of Diseases 10th Revision (ICD-10) codes, enabling the extraction of specific oncological diseases from the database. Additionally, certain EROP forms include diagnosis data based on the International Classification of Diseases for Oncology (ICD-O) codes, which provide detailed information on the morphology and topology of oncological diseases. Further diagnostic details are captured using variables for staging, based on the TNM system. This includes information on the stage of the disease, provided separately, along with details on tumor (T), lymph nodes (N), and metastasis (M). The date of diagnosis is recorded in Day/Month/Year format, allowing for the analysis of temporal trends in disease burden. Some forms also contain information about the circumstances under which the disease was identified, facilitating the evaluation of screening effectiveness, where it is applicable.

Stay in medical organization

The 012/u form of EROB provides comprehensive details about hospital stays. It includes admission and discharge dates formatted as Day/Month/Year, alongside information on the unit and bed profile associated with each hospitalization and discharge event. Furthermore, it specifies whether the hospitalization was planned or urgent, and provides information about the purpose of the hospitalization. This information offers significant insights into the burden that oncological diseases place on healthcare facilities. They also aid in analyzing patient flow within hospitals, contributing to a better understanding of operational dynamics and resource allocation.



Table 1. EROP framework.

Data elements and	Description	Potential application in research	Presence in EROP		
variables			forms		
Identification numbers					
RpnID	Unique identification number assigned to every patient in UNEHS	Interconnection of UNEHS databases	012/u, 030-6/u, 052/u,		
			034/u		
Provider information					
Oncological dispensary	One of 24 facilities in Kazakhstan where patients are registered for	Region identification and assessment of regional burden	012/u, 030-6/u, 052/u		
	oncological care and surveillance				
Registered clinic	Clinic where patients are registered and get primary medical care	Region identification and assessment of regional burden	012/u, 030-6/u		
Demographic information					
Birth date	Recorded date of birth in format of Day/Month/Year	Calculation of age at diagnosis, age at death and age-	012/u, 030-6/u		
		specific estimates of burden of disease			
Sex	Male/Female	Sex-specific estimates of burden of disease	012/u		
Ethnicity	Ethnic identity like Kazakh, Russian and others	Ethnicity-specific estimates of burden of disease			
Region	Administrative region of Kazakhstan, where patient is from	Regional burden of disease	012/u		
Residency	Type of residence, such as urban (republican or regional cities) or rural (villages and small towns)	Residency-specific estimates of burden of disease	012/u		
Diagnoses					
ICD-10 code	ICD-10 code for main oncological disease and comorbidities	Extraction of specific oncological diseases from database	012/u, 030-6/u, 052/u		
ICD-10 code name	Description of diagnosis	Distinction of types within oncological diseases			

Diagnosis date	Recorded date of diagnosis in format of Day/Month/Year	Identification of temporal estimates of disease incidence	012/u		
Cancer stage	The level of cancer progression, classified using the TNM system,	Stage-specific stratification of oncological disease cases	012/u, 030-6/u, 034/u		
	from stages I to IV				
Т	Tumor size	Analysis of progression and treatment outcomes	012/u, 030-6/u		
Ν	Number of affected lymph nodes	Tracking of disease spread and staging	012/u, 030-6/u		
М	Presence of metastasis	Study of dissemination and impact on survival	012/u, 030-6/u		
ICD-O morphology code	Code representing the histological structure and cellular	Classification of oncological diseases based on histological	030-6/u		
	characteristics of the oncological disease	characteristics			
ICD-O topology code	Code indicating the anatomical site of the oncological disease	Classification of oncological diseases based on their	030-6/u		
		anatomical locations			
Diagnosis identification	How a disease was diagnosed, such as during screening, check-up,	Understanding of patient pathways to diagnosis and the	030-6/u		
	or self-initiated consultation	impact on treatment outcomes			
Stay in medical organization					
Hospital admission date	Recorded date of hospitalization in format of Day/Month/Year	Identification of unique hospital stay cases	012/u		
Hospital discharge date	Recorded date of hospital discharge in format of Day/Month/Year	Identification of unique hospital stay cases	012/u		
Type of hospitalization	Planned/Urgent	Comparison of planned and urgent care usage, assessment	012/u		
		of emergency and preventive care systems			
Purpose of hospitalization	Reasons for hospital stay, such as examination, treatment,	Insights into reasons for hospital stays supporting analysis	012/u		
	continuation of care, or rehabilitation	of treatment trends and resource use			
Admission unit	Hospital unit where the patient was admitted	Usage patterns of oncological care units	012/u		
Discharge unit	Hospital unit from which the patient was discharged	Patient flow in oncological care units	012/u		
Admission bed profile	Assigned bed at admission	Bed allocation for oncological care	012/u		
Discharge bed profile	Bed assigned before discharge	Bed usage and turnover in care units	012/u		
Therapy					
Type of therapy	Types of therapy as chemotherapy, radiotherapy, surgery, and immunotherapy	Analysis of effect of therapy types on disease outcomes	012/u		

Type of chemotherapy	Type of chemotherapy as adjuvant (preventive, therapeutic), neoadjuvant, independent	Analysis of effect of chemotherapy types on disease outcomes	012/u		
Side effects of chemotherapy	Side effects as gastrointestinal, hematological, hepatitis, infectious, other or absent	Analysis of side effects of chemotherapy	012/u		
Type of radiotherapy	Types of radiotherapy as beta therapy, gamma therapy, combined radiation therapy, photon radiation therapy	Analysis of effect of radiotherapy types on disease outcomes	012/u		
Complications of radiotherapy	Complications as local, on regional lymph nodes, systemic, without	Analysis of side effects of radiotherapy	012/u		
ICD 9 code for surgical procedures	Code indicating performed surgical procedures	Analysis of surgical procedures on disease outcomes	012/u		
Chemotherapy start date	Recorded date for the initiation of chemotherapy in format of Day/Month/Year	Calculation of chemotherapy duration	012/u		
Radiotherapy start date	Recorded date for the initiation of radiotherapy in format of Day/Month/Year	Calculation of radiotherapy duration	012/u		
Medical procedure date	Recorded date for the performance of medical procedure in format of Day/Month/Year	Calculation of days after surgical procedures	012/u		
Outcomes					
Death date	Recorded date of death in format of Day/Month/Year	Survival analysis of oncological patients	030-6/u		
Outcome of hospital stay	Outcome of hospital stay like discharge, death, transfer	Insight into hospital performance and patient survival rates	012/u		
Treatment outcome	Outcome of received care during hospital stay as improvement, no change, deterioration, death	Evaluation of care effectiveness and disease progression	012/u		
Financial costs	•	•	•		
Cost of medical services	Total cost of services provided per one hospital stay or ambulatory visit in KZT	Analysis of economic burden of oncological diseases	012/u, 052/u		
Funding source	Sources of funding like social health insurance, out-of-pocket expenses, and sponsorship contributions	Evaluation of financial resource distribution and utilization	012/u		

Therapy

The database includes detailed information on therapies administered during hospitalization. Specific details are provided for chemotherapy, radiotherapy, and surgical procedures. For chemotherapy, data includes the type, side effects, and start date (Day/Month/Year format). Radiotherapy information covers the start date, type, and associated complications. Surgical procedures are recorded with ICD-9 codes and performance dates. Additionally, data on medications administered as part of chemotherapy or immunotherapy are available. This comprehensive dataset facilitates the analysis of treatment patterns, effectiveness, and outcomes in oncological care.

Outcomes

Several outcomes of oncological diseases are documented in EROP, tailored to the type of form used. Treatment outcomes include improvement, no change, disorientation, or death for patients who received therapy. Hospital outcomes capture processes related to hospital stays, such as discharge, continuation, transfer, or death. Additionally, the death date (Day/Month/Year format) is recorded for patients whose death was registered. These variables enable

Discussion

The Registry serves as a comprehensive national oncology database. With near-complete coverage and systematic reporting from oncology centres across the country, EROP enables robust epidemiological surveillance and supports longitudinal and retrospective analyses. Its structure facilitates disaggregation by tumour site, age, sex, and geographic region, allowing researchers to assess patterns in cancer incidence, mortality, treatment, and survival.

Several studies have utilized EROP to examine cancer epidemiology, including incidence and diagnostic characteristics. Shatkovskaya et al. (2021) analyzed data from 2014 to 2019 to explore the local epidemiology of HR+/HER2– advanced breast cancer, focusing on stage diagnosis and treatment patterns. In a more comprehensive national study, Midlenko et al. [9] assessed breast cancer epidemiology among women aged 25 years and older, stratifying the findings by age group and geographic region. Pediatric oncology has also been investigated through EROP: Mussina et al. [10] conducted an age-specific cohort study of hematological malignancies in children under 18 between 2014 and 2021, confirming the registry's capacity for pediatric analysis of treatment effectiveness, patient outcomes, and healthcare processes.

Financial costs

Financial costs for services per hospital stay and an ambulatory visit are provided in KZT. Additionally, the funding sources for hospitalization services are detailed. This data facilitates the analysis of the economic burden of oncological diseases across various social demographic groups, spatial regions, and temporal periods.

The data provided on EROP

The data from EROP are accessed with permission of the study from the Institutional Review Board and a contractual agreement with the provider. The database does not contain identifiable elements as the name and national ID of the patient; instead, unique population IDs called RpnID used in the medical systems are available for data merge and connection. For additional protection of data, on the level of the data receiver, databases are uploaded and only accessed on restricted electronic servers, with access given to only authorized users.

cancer surveillance. In the field of gynecologic oncology, Sakko et al. [11] used registry data to examine the prevalence and temporal dynamics of major cancer-related surgeries, such as hysterectomies and adnexal procedures, linking surgical trends to diagnostic patterns.

In addition to incidence and prevalence, EROP has been instrumental in supporting analyses of survival and mortality. Its integration with death certificate data through the Patient Registry and hospital discharge records enables the estimation of in-hospital, 30day, 1-year, and 5-year mortality. Studies by Midlenko et al. [9] and Mussina et al. [10] applied Cox proportional hazards regression to identify clinical and sociodemographic predictors of mortality. Using a linked registry approach, Shatkovskaya et al. [12] estimated five-year overall survival in patients with metastatic urothelial cancer diagnosed in 2017, demonstrating the registry's applicability for long-term outcome evaluation. Similarly, Umurzakov et al. [13] investigated incidence, mortality, and survival among male reproductive cancers at the subnational level, highlighting the value of EROP in regional comparative studies.

Akhmedullin et al. [7] conducted a national trend analysis of cancer-related mortality between 2014 and 2022, employing Jointpoint regression models to calculate Average Annual Percent Change (AAPC), as well as estimating mortality-to-incidence ratios (MIR) and proportionate mortality (PM). Their findings offer valuable insights into the evolving national cancer burden and the effectiveness of health policies over time.

Beyond epidemiological indicators, EROP has supported investigations into real-world treatment patterns and health system performance. Shatkovskaya et al. [14] analyzed the use of endocrine and targeted therapies in patients with HR+/HER2– metastatic breast cancer, documenting systemic therapy uptake and clinical decision-making. In gynecologic oncology, Sakko et al. [11] assessed operative trends and regional variations, identifying deviations from international recommendations and proposing updates to national clinical guidelines. Furthermore, EROP has been used to evaluate diagnostic delays, stage at presentation, and time to treatment initiation—indicators critical for assessing system responsiveness.

Finally, EROP facilitates the analysis of geographic disparities and health equity. Disaggregated data allow for comparisons across urban and rural settings, highlighting inequalities in cancer detection, treatment access, and outcomes. Studies by Midlenko et al. [9], Umurzakov et al. [13], and Akhmedullin et al. [7] collectively demonstrate the utility of the registry for identifying regional resource gaps, monitoring temporal trends, and informing national and subnational cancer control strategies.

The strengths and limitations of the database

The EROP database serves as a comprehensive national resource for oncological data, enabling robust epidemiological research through its standardized data collection forms, nationwide coverage, and multi-tiered quality control processes managed by governmental authorities. Its primary strength lies in the comparability of oncological indicators across regions, supported by uniform protocols and centralized oversight. The use of ICD-10 codes as the data entry basis further enhances the database's utility, allowing seamless alignment with international study designs and facilitating cross-border research collaborations.

Despite its strengths, EROP remains constrained by incomplete data capture in some regions, variability in reporting quality, and limited integration with nononcology clinical systems. Data on behavioural risk factors, socioeconomic determinants, and patient-reported outcomes are currently lacking, restricting opportunities for comprehensive risk modelling. Inconsistencies in data synchronization between EROP forms also create gaps in socio-demographic information when merging records from different care settings. For instance, patients receiving hospital or outpatient treatment may not appear in dispensary surveillance records, leading to fragmented datasets. Additionally, therapy documentation is limited to hospital-administered treatments, excluding at-home care, and resulting in an incomplete representation of therapeutic practices. Addressing these gaps-through standardisation, capacity building, and digital integration-will be critical for realising the full potential of EROP as a research platform. Future directions may include linkage to mortality registries, natural language processing for unstructured clinical notes, and patient-facing platforms to capture quality of life and treatment experience.

The EROP database is also subject to biases common to cancer registries. Sampling bias arises because the UNEHS system, which feeds into the registry, covers only 36.4% of Kazakhstan's adult population [8], meaning the registry's cases may not fully represent the country's oncological patient population. This partial coverage risks excluding demographic groups with limited healthcare access, potentially skewing socio-demographic analyses. Ascertainment bias further complicates the data, as the registry predominantly captures advanced-stage cancers linked to hospitalizations and outpatient visits, underrepresenting early-stage or less symptomatic cases managed outside formal care settings. The registry's large sample size, while enhancing statistical power, can amplify both biases and the likelihood of detecting statistically significant relationships, potentially leading to spurious associations or overinterpretation of minor effects without rigorous methodological safeguards [15]. Therefore, rigorous methodological designs should be employed when using EROP in epidemiological studies

Conclusion

In summary, EROP serves not only as a clinical database for managing patient information but also as a valuable research tool in cancer epidemiology, enabling the development of evidence-based, populationspecific health policies in Kazakhstan. It provides a unique opportunity to investigate regional determinants of cancer and to analyze oncological burden across spatial and temporal dimensions. Ensuring the ethical use of registry data and conducting validation studies of EROP and other UNEHS databases are critical steps in strengthening this resource. Ongoing improvements in data quality, data entry procedures,

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and registry coverage, combined with methodological rigor, will further enhance the value and effectiveness of the national cancer registry in supporting public health research and guiding cancer control strategies in Kazakhstan.

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