УДК 616.61-002.2-047.36-07-082
https://doi.org/10.20538/1682-0363-2026-2-184-190

Chronic Kidney Disease Registries as a Tool for Monitoring, Diagnosis, and Quality Improvement in Medical Care

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ABSTRACT

Chronic kidney disease (CKD) is a leading cause of morbidity and mortality worldwide. CKD registries serve as an effective tool for the systematic collection and analysis of data, facilitating early detection, monitoring, and improvement in the quality of medical care. This lectute presents international and Russian experience in using CKD registries, analyzing their structure, variables, and data sources. Particular attention is paid to the organizational and methodological aspects of implementing CKD registries at the regional level. The results of the analysis make it possible to identify key directions for the development and implementation of regional registries. Their maintenance will contribute to increasing the effectiveness of follow-up and, consequently, to improving the epidemiological indicators of socially significant diseases.

Keywords: chronic kidney disease, patient registry, healthcare organization, quality of medical care, epidemiological monitoring

Conflict of interest. The authors declare the absence of obvious or potential conflicts of interest related to the publication of this article.

Source of financing. The authors declare they received no funding for the study.

For citation: Yurastova K.A., Yarovoy N.D., Bespalova I.D., Teteneva A.V. Chronic Kidney Disease Registries as a Tool for Monitoring, Diagnosis, and Quality Improvement in Medical Care. *Bulletin of Siberian Medicine.* 2026;25(2):184–190. https://doi.org/10.20538/1682-0363-2026-2-184-190.

Регистры хронической болезни почек как инструмент мониторинга, диагностики и улучшения качества медицинской помощи

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РЕЗЮМЕ

Хроническая болезнь почек (ХБП) является одной из ведущих причин заболеваемости и смертности во всем мире. Регистры ХБП служат эффективным инструментом для систематического сбора и анализа дан-

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ных, что способствует раннему выявлению, мониторингу и повышению качества медицинской помощи. В лекции представлен международный и отечественный опыт использования регистров ХБП, проанализированы их структура, переменные и источники данных. Особое внимание уделено организационно-методическим аспектам внедрения регистров ХБП на региональном уровне. Результаты анализа позволяют определить ключевые направления для разработки и внедрения региональных регистров, ведение будет способствовать повышению эффективности диспансерного наблюдения, и, как следствие, улучшению эпидемиологических показателей социально значимых заболеваний.

Ключевые слова: хроническая болезнь почек, регистр пациентов, организация медицинской помощи, качество медицинской помощи, эпидемиологический мониторинг

Конфликт интересов. Авторы декларируют отсутствие явных и потенциальных конфликтов интересов, связанных с публикацией настоящей статьи.

Источник финансирования. Авторы заявляют об отсутствии финансирования при проведении исследования.

Для цитирования: Юрастова К.А., Яровой Н.Д., Беспалова И.Д., Тетенева А.В. Регистры хронической болезни почек как инструмент мониторинга, диагностики и улучшения качества медицинской помощи. *Бюллетень сибирской медицины.* 2026;25(2):184–190. https://doi.org/10.20538/1682-0363-2026-2-184-190.

INTRODUCTION

Chronic kidney disease (CKD) is a major public health concern, with a prevalence ranging from 11% to 13%, with most cases occurring at stage 3 of the disease [1]. In 2017, the global prevalence of CKD was estimated at 9.1%, corresponding to approximately 700 million cases worldwide [2]. From 1990 to 2017, global mortality attributable to CKD increased by 41.5%, highlighting the need for more active control and preventive strategies [3]. Progression of CKD is associated with a high risk of cardiovascular complications and premature mortality, making it one of the leading causes of death worldwide [3]. The main risk factors for CKD development are diabetes mellitus and arterial hypertension, which account for the majority of cases [4].

In addition, genetic factors, environment, lifestyle, and the availability and quality of healthcare also play a significant role. CKD registries are organized databases that systematize information on this patient population. They play a crucial role in studying epidemiological indicators of the disease, analyzing trends, evaluating treatment effectiveness, and developing preventive strategies. In Russia, as in several other countries, the true prevalence of CKD may be underestimated due to the absence of a unified national registry, which highlights the importance of data systematization and the implementation of regional registries within the healthcare system.

IMPORTANCE OF REGISTRIES FOR THE HEALTHCARE SYSTEM

CKD registries play a crucial role in healthcare systems by enabling systematic collection and analysis of patient data, which contributes to improving medical care, developing prevention strategies, and increasing treatment effectiveness. One of the key objectives of registries is monitoring the epidemiological situation, including assessing the prevalence and trends of CKD across different regions and population groups. This allows for identification of major risk factors and causes of disease development, as well as detection of geographic and socio-demographic differences in morbidity, which is particularly important for developing targeted preventive measures [5].

In addition to epidemiological monitoring, CKD registries provide in-depth analysis of clinical outcomes and trends, enabling tracking of disease progression from early stages to end-stage renal disease. An important task is the evaluation of the effectiveness of different treatment approaches and their impact on patient survival, allowing healthcare professionals to develop optimal management strategies. For example, registry data help determine how successfully patients with different stages of CKD respond to conservative therapy, when initiation of dialysis or kidney transplantation becomes necessary, and how treatment strategies affect prognosis [6].

Furthermore, registries serve an important function in supporting clinical decision-making and healthcare planning. They provide an evidence base for the development of clinical guidelines and standards of care, facilitate optimization of healthcare resource allocation based on real-world patient needs, and support the development of early detection and prevention programs for CKD. For instance, registry data can help identify patient groups at higher risk of rapid disease progression and enable the development of targeted monitoring and treatment strategies for these populations [7].

Comprehensive analysis of registry data and the resulting timely management decisions form the foundation for improving the quality of medical care, including through the implementation of personalized treatment approaches. Patient data allow clinicians to select evidence-based strategies, reducing the risk of complications and improving treatment effectiveness. The implementation of electronic medical registries and integration of big data into clinical practice have made it possible to improve CKD diagnosis and management, identify patients at earlier stages of disease, and adjust therapy according to individual characteristics. These systems also help assess the impact of various treatment approaches on long-term outcomes and improve patients′ quality of life [8].

Thus, CKD registries represent a powerful tool for improving the effectiveness of diagnosis, treatment, and prevention of this condition. They enable identification of risk factors, development of optimal therapeutic strategies, improved planning of healthcare resources, and establishment of an evidence base for informed healthcare management decisions. Through these systems, it becomes possible not only to improve the quality of medical care but also to reduce the overall burden of CKD at the population level, which is particularly important given the increasing global prevalence of the disease.

INTERNATIONAL AND NATIONAL EXPERIENCE IN THE USE OF REGISTRIES FOR CHRONIC KIDNEY DISEASE

One of the most well-known international registries is the United States Renal Data System (USRDS), a national data collection system for patients with end-stage renal disease (ESRD) in the United States. This registry provides valuable information on the prevalence, treatment patterns, mortality, and economic burden of CKD, as well as evaluates the effectiveness of different therapeutic strategies. USRDS data are widely used in scientific research and healthcare policy development, supporting programs for early detection and prevention of the disease [9].

Another major international initiative is the European Renal Association − European Dialysis and Transplant Association (ERA-EDTA) registry, which includes data on patients with CKD across Europe. This registry tracks outcomes in patients undergoing dialysis or kidney transplantation and analyzes factors affecting disease progression. ERA-EDTA actively collaborates with national registries, creating large-scale databases that enable international comparisons and contribute to the development of unified standards of care [10].

CKD.QLD, the chronic kidney disease registry in Australia, should be highlighted among national registries. It was designed to collect data on patients in the pre-dialysis stages of CKD and served as the foundation for the establishment of the Center for Kidney Disease Research in Australia. The registry supports assessment of disease prevalence, identification of risk factors, and development of treatment strategies aimed at reducing the burden of CKD [11].

In Romania, the ReNal national CKD registry collects demographic and clinical data on patients at all stages of the disease. The registry is used to improve the quality of medical care, analyze causes of CKD, and develop prevention programs. Preliminary data indicate that the main causes of CKD in Romania are arterial hypertension and diabetes mellitus, which is consistent with global trends [7]. In the United States, electronic health record-based registry systems are also actively developing, integrating CKD patient data at a national level. Such approaches allow healthcare providers to exchange information efficiently, monitor disease progression, and optimize patient management [8].

In Russia, several registries collect and analyze CKD data at both national and regional levels. However, a unified federal registry focused on early detection and case monitoring of CKD patients is currently lacking. The Russian Dialysis Society maintains a federal registry of patients with end-stage renal disease receiving kidney replacement

therapy (KRT) (https://nephro.ru/index.php?r=site/main). In addition, regional initiatives for CKD monitoring have been implemented. For example, in Yekaterinburg, the Registry of the Kidney Disease and Dialysis Center at City Clinical Hospital No. 40 provides data on CKD prevalence in the region [12].

CKD REGISTRY VARIABLES

CKD registries include a wide range of variables that allow for monitoring of patient status, disease progression, and treatment effectiveness. Demographic data typically include age, sex, ethnicity, body mass index (BMI), and health insurance status [9]. Clinical and laboratory parameters include glomerular filtration rate (GFR), serum creatinine, proteinuria/albuminuria, and concentrations of urea, sodium, potassium, calcium, and phosphorus, as well as hemoglobin levels, blood glucose, and lipid profile indicators [13]. Patient medical history commonly includes the presence of diabetes mellitus, arterial hypertension, cardiovascular diseases, obesity, hyperphosphatemia, and mineral and bone disorders [14].

Information on treatment includes data on medication use (angiotensin-converting enzyme inhibitors, angiotensin II receptor blockers, diuretics, and erythropoiesis-stimulating agents), their dosages, and duration of therapy, as well as information on the use of hemodialysis or peritoneal dialysis and history of kidney transplantation [15]. In addition, CKD registries often capture risk factors, such as smoking status, family history of kidney disease, level of physical activity, and patient-reported quality of life [3]. Collection and analysis of these data allow clinicians and researchers to better understand disease progression, predict outcomes, and develop more effective strategies for treatment and prevention.

DATA SOURCES FOR CKD REGISTRIES

CKD registries are typically developed using information obtained from multiple medical, laboratory, and administrative systems. The primary data sources include healthcare institutions and clinical databases, such as electronic health records, inpatient and outpatient records, and hospital information systems containing patient medical histories, including diagnoses, results of laboratory and instrumental examinations, prescribed treatments, and other clinical information [16]. Laboratory and diagnostic sources include blood and urine test results, such as glomerular filtration rate (GFR), serum creatinine, urea, electrolytes, and the presence and level of albuminuria, as well as data from ultrasound examinations and kidney biopsy findings [13]. Governmental and insurance medical databases also represent important sources of information, providing data on treated patients, prescribed medications, and drug reimbursement programs [3].

Specialized registries of patients receiving dialysis treatment or undergoing kidney transplantation provide detailed information on treatment modality, frequency of procedures, complications, and use of immunosuppressive therapy [15]. Databases on prescribed medications and pharmacotherapy monitoring play an important role in assessing treatment effectiveness, including its impact on creatinine levels and blood pressure control [9]. In addition, patient-reported data and lifestyle information collected through validated questionnaires are increasingly incorporated into registries, along with data obtained from mobile health applications and wearable devices that monitor blood pressure, blood glucose levels, and physical activity. Scientific studies and clinical trials also provide valuable data for evaluating new treatment approaches and understanding epidemiological characteristics of CKD [16]. Comprehensive analysis of these diverse data sources enables not only monitoring of disease progression but also development of personalized treatment strategies and improvement of the quality of healthcare provided to patients with CKD.

CHALLENGES AND LIMITATIONS

Chronic kidney disease registries play an important role in patient monitoring, development of treatment strategies, and healthcare policy planning. However, their implementation and maintenance face several challenges, including issues related to data quality, ethical considerations, and funding. One of the major limitations is incomplete or unreliable data. Studies have shown that registries often suffer from insufficient data standardization and data entry errors [17]. Limited integration with electronic health records may result in duplication of information and inconsistencies across databases [8].

In low- and middle-income countries, maintaining accurate and up-to-date registries is particularly challenging due to limited resources and a shortage of trained personnel [18]. Ethical considerations also represent an important challenge. Issues related to patient data confidentiality and protection of personal information are critical when developing registries. For example, the European pediatric registry CERTAIN maintains high standards of data protection, but this requires substantial resources [19]. Ethical concerns may also arise due to inequalities in access to treatment for patients with CKD in underfunded healthcare systems [20]. Patient participation in research and obtaining informed consent may be difficult, particularly in settings with limited health literacy [21].

Funding is another significant challenge. The development and maintenance of registries require considerable financial investment. In many countries, funding for clinical research and registry maintenance remains limited. For example, in some African countries, only about 7% of research funding is allocated to nephrology-related studies [22]. Unequal distribution of financial resources across regions may lead to disparities in access to high-quality healthcare services [23]. In low-income countries, registry implementation and CKD patient management are often supported primarily through charitable organizations and international grants [24]. Thus, despite the importance of CKD registries in improving the quality of healthcare, their implementation and sustainability require addressing challenges related to data quality, ethical issues, and funding. Improving data standards, strengthening personal data protection, and expanding financial support will contribute to making these registries more effective and accessible.

FUTURE PERSPECTIVES

Modern technologies are opening new horizons for the development of CKD registries, improving diagnosis, monitoring, and personalized treatment of patients. Key perspective directions include digitalization, the application of artificial intelligence, and global initiatives. The implementation of digital healthcare solutions, such as electronic registries, cloud-based platforms, and telemedicine services, significantly simplifies patient monitoring and disease management [25]. Intelligent mobile health applications allow patients to track their health status, receive personalized recommendations, and communicate with healthcare professionals in real time [26]. The development of remote monitoring technologies for patients with CKD improves disease control, reduces the burden on healthcare institutions, and increases access to medical care [27].

The use of artificial intelligence (AI) in data analysis and CKD diagnostics also provides new opportunities. Advances in machine learning and deep learning algorithms enable prediction of renal function decline and support early adaptation of treatment strategies [28]. AI-based systems can analyze kidney biopsy and ultrasound findings to improve CKD staging and increase diagnostic accuracy [29].

Global initiatives in CKD management also play an important role. The creation of international databases and standardized approaches to medical data exchange contributes to more accurate monitoring of disease prevalence and development of effective treatment strategies [30]. Several countries are already implementing national and regional CKD patient registry systems, improving healthcare resource planning and allocation [31]. In the future, global AI-supported monitoring systems for CKD patients may help predict disease burden trends and improve healthcare delivery worldwide [32]. The future of CKD registries is connected with digitalization, the use of AI, and the development of global initiatives. These technologies will facilitate improvements in diagnosis, enhance prognosis accuracy, and make treatment personalized. International cooperation and data standardization also play a crucial role in establishing effective kidney disease management systems.

Analysis of international and Russian experience in maintaining CKD patient registries demonstrates that registries as structured systems for data collection, storage, and analysis represent an effective tool for monitoring patient health status and providing evidence for evaluation of quality of care, healthcare costs, scientific research, and health policy development. They enable not only analysis of disease trends but also the development of personalized treatment approaches, which is particularly important given the increasing global prevalence of CKD. Future research directions include integration of artificial intelligence and machine learning into registry data analysis,

enabling early prediction of disease progression and prevention of adverse outcomes.

Further digitalization and automation of data collection processes will improve data quality and ensure accessibility for the medical community. Global initiatives aimed at data harmonization and development of international registries will enhance comparative analyses across countries and regions, facilitating more efficient healthcare resource management. The establishment and development of regional CKD registries in the Russian Federation may improve long-term patient monitoring, enhance prognosis, and support rational healthcare planning. Thus, the continued development of CKD registries, implementation of advanced technologies, and international collaboration will contribute to improved diagnostics, higher quality of care, and reduction of the overall burden of CKD for both patients and healthcare systems.

CONCLUSION

Characterizing the chronic kidney disease course should become an integral part of the clinical diagnosis based on an appropriate classification system. Such a classification can be an effective tool in clinical practice only if the terms it includes have clear definitions and well-defined boundaries for their proper application. However, despite ongoing discussions regarding the delineation of key concepts and repeated attempts to develop unified positions, experts from leading international professional communities have not yet reached full consensus, and definitions of terms used to describe the course of CKD differ across clinical guidelines.

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Received on February 6, 2026;
approved after peer review on February 17, 2026;
accepted on February 26, 2026