

Received: 20.02.2024/Accepted: 20.03.2024/ Published online: 30.03.2024

УДК 617.7-007.681:616-036.86(574.13)

DOI: [10.26212/2227-1937.2024.41.67.008](https://doi.org/10.26212/2227-1937.2024.41.67.008)

L.S. Yermukhanova¹, ORCID: <https://orcid.org/0000-0001-7703-9649>
M.K. Taushanova¹, ORCID: <https://orcid.org/0000-0002-0165-9312>
V.Y. Baisugurova², ORCID: <https://orcid.org/0000-0003-0182-7598>
S.K. Balmagambetova¹, ORCID: <https://orcid.org/0000-0003-4080-5383>
S.T. Tazhbenova¹, ORCID: <https://orcid.org/0000-0002-4073-0070>
P.Zh. Aitmagambet¹, ORCID: <https://orcid.org/0000-0002-1958-0493>
K.B. Turdalina¹, ORCID: <https://orcid.org/0000-0002-1665-2578>
M.B. Kurganbekova¹, ORCID: <https://orcid.org/0000-0002-0165-9312>
A.U. Bekbauova¹, ORCID: <https://orcid.org/0000-0002-3795-1024>
G.S. Kuspangaliyeva¹, ORCID: <https://orcid.org/0000-0002-2679-1176>

¹West Kazakhstan Marat Ospanov Medical University, Aktobe, Kazakhstan

²Asfendiyarov Kazakh National Medical University, Almaty, Kazakhstan

CREATION OF AN ELECTRONIC REGISTER IN THE HEALTHCARE SYSTEM: IMPROVING THE EFFECTIVENESS OF GLAUCOMA MANAGEMENT AND TREATMENT

Resume: Glaucoma represents one of the major global health issues, being the second leading cause of irreversible blindness worldwide. Insufficient early diagnosis and lack of long-term monitoring lead to the progression of the disease, thereby exacerbating the public health issue. In Kazakhstan, the incidence of glaucoma and related disabilities have significantly increased, especially among the working-age population, underscoring the need for improved ophthalmological care. The article highlights the importance of creating electronic patient registries as a universal tool for improving the quality of medical care and disease management. Electronic registries allow for the assessment of the real course of the disease, therapy effectiveness, treatment safety, and impact on patients' life expectancy. In Kazakhstan, registries for other diseases are already operational, but there is no specialized registry for patients with glaucoma.

Keywords: glaucoma, electronic registry, patient monitoring, dynamic observation, patient database, blindness

Л.С. Ермуханова¹, М.К. Таушанова¹, В.Ю. Байсугурова², С.К. Балмагамбетова¹, С.Т. Тажбенова¹, П.Ж. Айтмаганбет¹, К.Б. Турдалина¹, М.Б. Курганбекова¹, А.У. Бекбауова¹, Г.С. Куспангалиева¹

¹«Марат Оспанов атындағы Батыс Қазақстан медицина университеті» КеАҚ, Ақтөбе қ., Қазақстан

²«С.Ж. Асфендияров атындағы Қазақ ұлттық медицина университеті» КеАҚ, Алматы қ., Қазақстан

ДЕНСАУЛЫҚ САҚТАУ ЖҮЙЕСІНЕ ЭЛЕКТРОНДЫҚ ТІРКЕЛІМДІ ЕНДІРУ: ГЛАУКОМАНЫ БАСҚАРУ ЖӘНЕ ЕМДЕУ ТИІМДІЛІГІН АРТТЫРУ

Түйін. Глаукома әлемдегі қайтымсыз соқырлықтың екінші жетекші себебі болып табылатын денсаулық сақтаудың негізгі жаһандық мәселелерінің бірі болып табылады. Ерте диагностиканың жеткіліксіздігі және ұзақ мерзімді бақылаудың болмауы аурудың өршуіне әкеліп, нәтижесінде қоғамдық денсаулық мәселесі нашарлайды. Қазақстанда глаукомамен аурушандық және мүгедектік, әсіресе еңбекке қабілетті жастағы адамдар арасында айтарлықтай өсті, бұл офтальмологиялық көмекті жақсарту қажеттігін атап көрсетеді. Мақалада медициналық көмектің сапасын жақсарту және ауруларды басқарудың әмбебап құралы ретінде науқастардың электрондық тізілімдерін құрудың маңыздылығы көрсетілген. Электрондық тізілімдер аурудың нақты ағымын, терапияның тиімділігін, емдеу қауіпсіздігін бағалауға мүмкіндік беріп, науқастардың өмір сүру ұзақтығына әсер етеді. Қазақстанда басқа аурулар бойынша тіркелімдер жұмыс жасайды, бірақ глаукомамен ауыратын науқастар үшін мамандандырылған тіркелім жоқ.

Түйінді сөздер: глаукома, электронды тіркелім, науқастарды бақылау, динамикалық бақылау, науқастар базасы, соқырлық

Л.С. Ермуханова¹, М.К. Таушанова¹, В.Ю. Байсугурова², С.К. Балмагамбетова¹, С.Т. Тажбенова¹, П.Ж. Айтмаганбет¹, К.Б. Турдалина¹, М.Б. Курганбекова¹, А.У. Бекбауова¹, Г.С. Куспангалиева¹

¹ НАО «ЗКМУ имени Марата Оспанова», Актөбе, Казахстан

² НАО «Казакский Национальный медицинский университет имени С.Д. Асфендиярова», Алматы, Казахстан

СОЗДАНИЕ ЭЛЕКТРОННОГО РЕГИСТРА В СИСТЕМУ ЗДРАВООХРАНЕНИЯ: ПОВЫШЕНИЕ ЭФФЕКТИВНОСТИ УПРАВЛЕНИЯ И ЛЕЧЕНИЯ ГЛАУКОМЫ

Резюме. Глаукома представляет собой одну из основных глобальных проблем здравоохранения, являясь второй ведущей причиной необратимой слепоты в мире. Недостаточная ранняя диагностика и отсутствие длительного наблюдения приводят к прогрессированию болезни, в результате чего усугубляется общественная проблема здоровья. В Казахстане заболеваемость глаукомой и связанная с ней инвалидность значительно возросли, особенно среди лиц трудоспособного возраста, что подчеркивает необходимость улучшения офтальмологической помощи. В статье подчеркивается важность создания электронных регистров пациентов как универсального инструмента для улучшения качества медицинской помощи и управления заболеваниями. Электронные регистры позволяют оценивать реальное течение болезни, эффективность терапии, безопасность лечения и влияют на продолжительность жизни пациентов. В Казахстане уже функционируют регистры по другим заболеваниям, но отсутствует специализированный регистр для пациентов с глаукомой.

Ключевые слова: глаукома, электронный регистр, мониторинг больных, динамическое наблюдение, база пациентов, слепота

Introduction: Glaucoma is a serious global health issue and the second leading cause of irreversible blindness worldwide [1-4]. Without proper early diagnosis and treatment, particularly at the level of primary healthcare, and frequent long-term observation by an ophthalmologist, glaucoma can progress and cause irreversible vision loss and blindness, exacerbating an already serious public health problem [5].

In Kazakhstan, glaucoma is one of the main causes of blindness and visual impairment, with a rising trend in incidence [6]. The incidence of glaucoma in the Republic of Kazakhstan has increased by 25% over the last 10 years, and disability has increased by 3.7 times, moving from the fifth to the second place. Every fifth visually impaired person due to glaucoma (21.6%) is of working age, moreover, almost a third of glaucoma patients are recognized as first-group disabled due to complete or near-complete vision loss at their initial assessment [7, 8]. The demographic characteristics of the population of the Republic of Kazakhstan are marked by an increasing proportion of elderly people in the population and an increase in the share of glaucoma as the population ages. Analysis of the absolute incidence and prevalence of glaucoma over the years, as well as the calculation of these indicators per 1000 population, confirms the growth of glaucoma in Kazakhstan - against the background of an aging population.

Improving the quality of ophthalmological care that takes into account the needs of both patients and ophthalmologists is a sound strategy. One of the universal tools of the healthcare system is the patient registry [9, 10]. A registry is an observational study that serves four purposes: describing the real course of the disease; determining the effectiveness of therapy and/or defining the cost-effectiveness ratio; assessing the safety of therapy; evaluating the effectiveness of therapy and the life expectancy of patients [11-14]. It is conducted over a long period, allowing for the assessment of long-term outcomes. In the Republic of Kazakhstan, such observational studies can contribute to rational planning and budget use, and to the improvement of preferential drug provision for patients with costly and rare diseases. Currently, in Kazakhstan, there are registries such as: the registry of pregnant women and women of childbearing age, the National Registry of Diabetes, the electronic registry of cancer patients, and the record of patients with chronic kidney disease. According to our observations and preliminary research, there is no electronic registry for glaucoma patients in our country. There are reports of glaucoma patient registries in many European countries, Australia, New Zealand [15], the Russian Federation [16], and in Uzbekistan [17]. In our country, there has been an increase in disability and disease rates across all indicators over the last 5 years. Therefore, the formation of a glaucoma patient registry for the Republic of Kazakhstan is necessary for accounting and effective analysis.

The creation of electronic registries will allow for an objective assessment of the growth in disease incidence both in specific regions and at the country level, taking into account the characteristics of the disease's course, and to have information on statistical indicators in real-time [18-21]. Making correct and timely management decisions affects the further tactics of patient management and the reduction of disease rates. The electronic registration of patients is especially important

for optimizing the process of providing high-tech care to the population, as well as for accounting for expensive drugs [22]. The automation of electronic patient records, i.e., the creation of automated registry systems for glaucoma patients for Kazakhstan's healthcare system, is a relatively new tool for modernizing healthcare organization.

The creation (and in many aspects, the revival) of a system for the early detection of primary glaucoma is a pressing task in Kazakhstan today. The main aspects of dynamic observation of a glaucoma patient include selecting adequate therapy to achieve treatment goals, timely identification of indications for other treatment methods, overall health improvement, treatment of comorbidities affecting the course of glaucoma, educating the patient on self-monitoring techniques, the methodology of instilling drops and taking other medications, and optimizing work and lifestyle regimes.

Making correct and timely management decisions impacts the further tactics of patient care and reduces the rates of disease, disability, and premature mortality. One such important tool for addressing this issue is the creation of an electronic registry of patients with glaucoma.

Modern medicine is aimed at increasing the effectiveness and safety of treatment. For this purpose, the healthcare sector is standardizing the services provided and treatment methods. The introduction of patient registries for various nosology's can be a tool that allows addressing these tasks. In the Republic of Kazakhstan, the creation of patient registries can contribute to rational budget planning and the improvement of drug provision for patients with rare diseases and/or expensive treatments. Moreover, maintaining a patient registry facilitates dynamic observation of patients with chronic diseases to timely detect recurrence or evaluate the effectiveness of different treatment methods. The development of a patient accounting system can be used and implemented at any level of medical care, regardless of the patient's location, to ensure continuity in the activities of medical institutions.

A patient registry is a system for collecting information about patients with specific diseases, in a particular clinical status, or having received/are receiving the necessary treatment and are registered in the healthcare system [15, 23]. The most accurate definition of "patient registry," from the perspective of pharmacoepidemiology, is as follows: it is a prospective observational (cohort) study of patients with a specific disease, certain risk factors, or the same clinical condition [24].

In the modern world, amidst a vast amount of information, there arises a need for systematization and simplification of data acquisition. In neighboring countries of Kazakhstan, there is information about the implementation of various patient registries for different nosology depending on the need to control the effectiveness of treatment and the course of the disease. In ophthalmology, the issue of creating patient registries for glaucoma remains current to this day. However, there are still no unified approved protocols for managing patients with many ophthalmological diseases. This is because most eye diseases result from changes in the body as a whole. Therefore, to assess the local ophthalmological status, it is often necessary to analyze information about the condition of other organs and systems.

In many countries, studies have been successfully conducted on creating electronic registries for patients with glaucoma (in the Republic of Uzbekistan, there is a "Glaucoma Patient Dispensary Card," designed to record and analyze the main clinical and statistical indicators of this disease [17]; in Europe - Open Eyes; in the Russian Federation [25], and in the Republic of Bashkortostan – an automated registry for patients with glaucoma [10]). Unfortunately, the overall situation with registries in Kazakhstan remains complex. To date, there is no unified database for patients with glaucoma. The reasons can be attributed to the lack of "network" exchange and analysis capabilities and the presence of only data on local prevalence. The issue of implementing the start of data entry at the local level to create adequate and timely patient routing is of current importance.

A registry for patients with glaucoma will increase patients' knowledge and awareness of glaucoma and its associated risks, improve access to glaucoma screening through early detection and treatment at the community level, enhance subsequent ophthalmological care, and potentially reduce unnecessary suffering and disability. It will also influence health-related behaviors in patients with glaucoma and ensure the continuity of ophthalmological care for adults under dynamic observation [26]. As a result of monitoring the effectiveness of outcomes, the registry will provide valuable information about the value of the targeted glaucoma detection program at the community level in urban settings.

Utilizing public health strategies, the registry will aim to mobilize local institutions for planning, development, implementation, and evaluation of an integrated targeted intervention at the level of primary healthcare, with the goal of improving the detection, management, treatment, and subsequent ophthalmological care for people at high risk of glaucoma.

The initiative to create an electronic registry for patients with glaucoma in the Republic of Kazakhstan is aligned with global trends in medicine and healthcare. It focuses on developing and implementing advanced approaches and methodologies to combat non-communicable diseases, particularly glaucoma. It is important to note that the WHO European Regional Office places special emphasis on developing strategies to improve the expected lifespan and quality of life of the population, including disease prevention at the population level. A key aspect is the active involvement of groups and individuals at high risk, as well as the integration of policies and practices aimed at preventive measures against neurotic disorders.

The program for the early detection and treatment of glaucoma aims to determine the current prevalence of the disease among the population, focusing on high-risk groups. This includes taking into account racial, ethnic, gender, and age characteristics, as well as eliminating barriers to access ophthalmological care. In the long term, this initiative seeks to reduce the level of disability and the economic burden caused by vision impairment due to glaucoma, thereby reducing disparities in the population's eye health.

Objective: The creation of an electronic registry for patients with glaucoma is aimed at reducing morbidity and preventing cases of blindness by developing and implementing an effective strategy for controlling and managing public health. This involves providing comprehensive preventive and therapeutic services for

glaucoma patients. The implementation of such a registry is directed towards improving the monitoring and observation process for patients at the primary level of healthcare, thereby enhancing patients' quality of life, as well as the social, medical, and economic efficiency of the healthcare system through optimized resource management and coordination of the treatment process.

Results and discussion: In the modern view, the glaucoma registry is an automated information and analytical system for clinical and epidemiological monitoring of glaucoma throughout the country, which provides for monitoring the patient from the moment of his inclusion in the registry and throughout the entire period of the disease, registration of the stage, course options, the presence of concomitant diseases, diagnostic parameters of progression, evaluation of the effectiveness of therapy in dynamics, as well as analysis of dispensary observation. In addition to its practical significance as a basic statistical tool, the register provides a unique analytical platform for evaluating not only epidemiological information, but also many other medical, organizational and scientific aspects, including determining treatment costs, planning the provision of medicines and personnel.

To increase its effectiveness, the patient registry will allow:

- 1) automate the transfer of clinical data from patient to doctor;
- 2) provide the doctor with information about patients who have not received medical care that meets clinical guidelines and standards;
- 3) develop forms of operational reports containing information about the current state of medical care to the patient;
- 4) organize patient reminder systems;
- 5) identify patients with a high risk of disease progression and complications.

Patients with glaucoma under dispensary observation in the Republic of Kazakhstan will be included in the registry. Clinic doctors will fill out the data on an electronic medium. In addition to basic patient information (gender, year of birth) and disease information (stage for each eye, duration of the disease, presence of blood relatives with glaucoma), information about the therapy being conducted will be entered. Based on the National Guidelines for Glaucoma 2015, the Ministry of Health of the Republic of Kazakhstan will develop a registry for patients with glaucoma. The registry will consist of 6 parts. The first part will contain information about the patient, their personal data, social status; the second part will include data on dispensary observation; the third will present information about complaints, medical history, and data from conducted studies; the fourth part will include concomitant ophthalmological and somatic diagnoses; the fifth part will detail the prescribed treatment; the sixth part will provide information about ocular hypertension, which may progress to glaucoma. All clinical signs will be registered at the beginning of observation and during subsequent examinations, allowing for monitoring of the disease's progression.

The use of the registry will allow for the assessment of the disease progression dynamics, comparing past clinical data with current research outcomes. Utilizing the registry will simplify the work of primary healthcare providers and ophthalmologists in terms of selecting, sorting, and analyzing data, and allows for the

presentation of obtained results in a visually comprehensible form, such as diagrams. To save time in medical documentation, it will be possible to automatically print any information, including special consultative conclusions about each examined patient.

The program will be protected by access restriction passwords. The registry interface will be intuitive and will not require special computer skills, allowing even a novice user to operate it. The software will include contextual tips for each indicator. The registry software will offer the capability to work in both text and graphic modes. Key sections will be highlighted:

- A registration block with demographic (static) data;
- A registration block with clinical (dynamic) data: patient examination data, results of diagnostic procedures;
- Therapy monitoring (medication, laser, surgical treatment);
- Monitoring of dispensary observation with visit dates for dispensary examinations.

For data quality control, a protocol and instructions for working with the registry will be developed. A multi-level data quality control system will be established, enabling statistically sound analysis of the information.

- First level (online input control): A program that operates during information entry, ensuring data input format restrictions, checks data for allowed values and boundaries.
- Second level (offline data compatibility check): A program that analyzes the entire volume of data to find discrepancies. At this stage, numerical and logical checks of the consistency of different parameters (database fields) are conducted. Integral characteristics of data completeness and quality are also calculated. This check analyzes the presence or absence of key parameters. The logical relationship of entered dates (consistency of dates) is verified.
- Third level: External selective data audit. Based on the results of the first two levels, if the data quality and completeness ratings are low, a decision may be made to investigate the reasons for the low level.

The research team will have different levels of access to the registry database:

- Database administrator – full access to the registry database (modifying the registry structure, changing the software);
- Workstation operator – glaucoma department ophthalmologist – reading, updating, deleting database records only of the corresponding department involved in the registry operation, processing data by department;
- Heads of departments involved in the registry operation – reading, analyzing records by a specific department or across the entire registry database.

Conclusion. The use of an electronic registry in the Republic of Kazakhstan will enable visual control over the dynamics of the glaucoma process (transition from stage to stage), improve the quality of dynamic observation of patients with glaucoma, and identify patients who have not appeared for their appointments in a timely manner. The Registry will allow for the documentation of the treatment methods used and their effectiveness, as well as the frequency of use of each method. At any time, it will be possible to conduct an accurate analysis of the number of dispensary patients, observation results, the dynamics of dispensary care (transition from group to group), and its effectiveness. The creation of an electronic registry for

patients with glaucoma will: enhance the effectiveness of dynamic observation of patients with glaucoma and their relatives at risk of developing this disease, standardize the information contained in the database, conduct statistical analysis of indicators with an assessment of the disease prevalence in the region, quickly and in any volume obtain necessary information, monitor the disease, maintain complete continuity in the management of dispensary work based on a unified, standard document, including when changing the place of residence, and use the information stored in databases for epidemiological, medical-environmental, and scientific research.

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Authors' Contributions. All authors participated equally in the writing of this article.

No conflicts of interest have been declared. This material has not been previously submitted for publication in other publications and is not under consideration by other publishers. There was no third-party funding or medical representation in the conduct of this work.

Funding - no funding was provided.

Авторлардың үлесі. Барлық авторлар осы мақаланы жазуға тең дәрежеде қатысты.

Мүдделер қақтығысы – мәлімделген жоқ. Бұл материал басқа басылымдарда жариялау үшін бұрын мәлімделмеген және басқа басылымдардың қарауына ұсынылмаған. Осы жұмысты жүргізу кезінде сыртқы ұйымдар мен медициналық өкілдіктердің қаржыландыруы жасалған жоқ.

Қаржыландыру - жүргізілмеді.

Вклад авторов. Все авторы принимали равное участие при написании данной статьи.

Конфликт интересов – не заявлен. Данный материал не был заявлен ранее, для публикации в других изданиях и не находится на рассмотрении другими издательствами. При проведении данной работы не было финансирования сторонними организациями и медицинскими представительствами.

Финансирование – не проводилось.

Information about authors:

№	Full name	Position, place of work	Phone	E-mail
1	Yermukhanova Lyudmila	Candidate of medical sciences, associate processor, head of the department: "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87022330465	aleka_2807@mail.ru
2	Taushanova Maiya	Senior lecturer of the department of "Public Health and Healthcare" West Kazakhstan Marat Ospanov medical university. Corresponding author	87475170280	maiona_93@mail.ru
3	Baisugurova Venera	PhD, Biostatistics and fundamentals of scientific research department. Asfendiyarov Kazakh National Medical University,	87017425714	vbaisugurova@mail.ru
4	Balmagambetova Saule	PhD, Department of Oncology. West Kazakhstan Marat Ospanov medical university	87055794637	sau3567@gmail.com
5	Tazhbenova Saule	PhD, department of "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87027895289	t.saule.t@mail.ru
6	Aitmaganbet Perizat	PhD, department of "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87023398577	piki.kz@mail.ru
7	Turdalina Kunzira	Senior lecturer of the department of "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87075101775	turdalina92@mail.ru
8	Kurganbekova Meruert	Senior lecturer of the department of "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87022406499	macosya@inbox.ru
9	Bekbauova Aimira	Senior lecturer of the department of "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87016681709	85_aimira_85@mail.ru
10	Kuspangaliyeva Galya	Senior lecturer of the department of "Public Health and Healthcare", West Kazakhstan Marat Ospanov medical university	87016107317	galya190976@mail.ru