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REVIEW

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Modern healthcare model in the Russian Federation

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ABSTRACT

Modern healthcare in the Russian Federation is built on the principles of the Semashko healthcare system while integrating contemporary organizational and digital solutions. The article analyzes the current healthcare model as a key instrument for achieving the National Development Goal “Preservation of population, health promotion and improvement of people’s well-being.” The governance structure is described at federal and regional levels, including the roles of the Ministry of Health, federal regulatory and insurance institutions, national medical research centers, and regional health authorities. Particular attention is paid to the vertically integrated network of public healthcare providers and the three-tier system of medical care organization, ensuring stepwise accessibility of primary, specialized, and high-tech care across 89 regions of the country. The mixed budget-insurance financing model, with compulsory health insurance as a core mechanism, and the State Guarantees Program are presented as key tools for securing free medical care and program-target management of resources. The preventive orientation of the system, including measures for the working population, and the rapid development of digital health technologies are highlighted as essential drivers of efficiency and quality. The article concludes that the modern Russian healthcare model combines continuity with historic principles and innovative approaches to meet current demographic and epidemiological challenges.

Key Words: model; healthcare system; principles of health protection; program-target (program-based) management; federal and regional levels

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"There is no task or problem that domestic medicine cannot solve."
N.A. Semashko, the first People's Commissar of Health of the RSFSR

Introduction

The modern healthcare system of the Russian Federation is based on principles established more than a century ago during the formation of the world's first national healthcare system, which was later named after its founder, the first People's Commissar of Health, Nikolai Alexandrovich Semashko [1]. These principles include universal coverage of the population with medical care, a preventive focus on care (dispensary observation, early detection of diseases), priority in providing care to socially vulnerable groups, and alignment between medical science and practice. The consolidation of disparate medical institutions into a single network, the introduction of the principle of district-based territorial service, and the provision of free medical care for all social groups have made it possible to optimize the use of resources and improve access to care at all stages.

Thus, the Semashko model of healthcare system became the basis for the current model of Russian healthcare.

The strategic objectives facing the healthcare system at the present stage are defined by the National Development Goals set out in Decree No. 309 of the President of the Russian Federation dated May 7, 2024, "On National Development Goals of the Russian Federation for the Period Until 2030 and for the Future Until 2036." The objective of "preservation the population, strengthening health and improving the wellbeing of people, supporting families" has the greatest impact on the development of medical care. The achievement of this objective is determined by a number of target indicators and depends on the coordinated work of all components of the healthcare system, the rational use of human, material, technical, and information resources, and the advanced development and application of health-saving technologies, preventive medicine, and personalized medicine.

As discussed subsequently in the article, the modern healthcare model of the Russian Federation is considered as the successor to the principles of the Semashko healthcare system and, at the same time, as one of the key instruments for achieving the specified National Development Goal.

Governance structure and key stakeholders

In accordance with Russian Federation legislation[1], the healthcare model includes state, municipal, and private healthcare systems.

State regulation in the healthcare sector is a key element in ensuring the sustainable functioning of the healthcare system, based on the principle of separation of powers between federal, regional, and municipal levels of government to achieve effective management and optimal use of healthcare system resources.

The Russian Federation's public healthcare system meets the basic needs of the population providing affordable, high-quality medical care, which is organized and provided in accordance with medical care procedures, taking into account medical care standards and based on clinical guidelines.

[1] Федеральный закон от 21.11.2011 г. № 323-ФЗ. Об основах охраны здоровья граждан в Российской Федерации (с изменениями на 23 июля 2025 года) [Russian Federation. Federal Law No. 323-FZ of November 21, 2011. On the Fundamentals of Citizens' Health Protection in the Russian Federation (as amended on July 23, 2025)] (in Russian). Accessed 24.11.2025. http://publication.pravo.gov.ru/Document/View/0001201111220007/

The current model of the Russian Federation's public health care system is represented at the federal and regional levels, each of which has its own structure (Figure 1).

The federal level of the model is represented by federal executive bodies in the field of health care:

- The Ministry of Health of the Russian Federation, which is empowered to implement a unified state policy in the field of health care, protect human and civil rights and freedoms, and ensure state guarantees of free medical care;
- The Federal Service for Surveillance in Healthcare (Roszdravnadzor), whose aim is to improve the efficiency, quality, and safety of the health care system for citizens of the Russian Federation and ensures control in the field of health care.

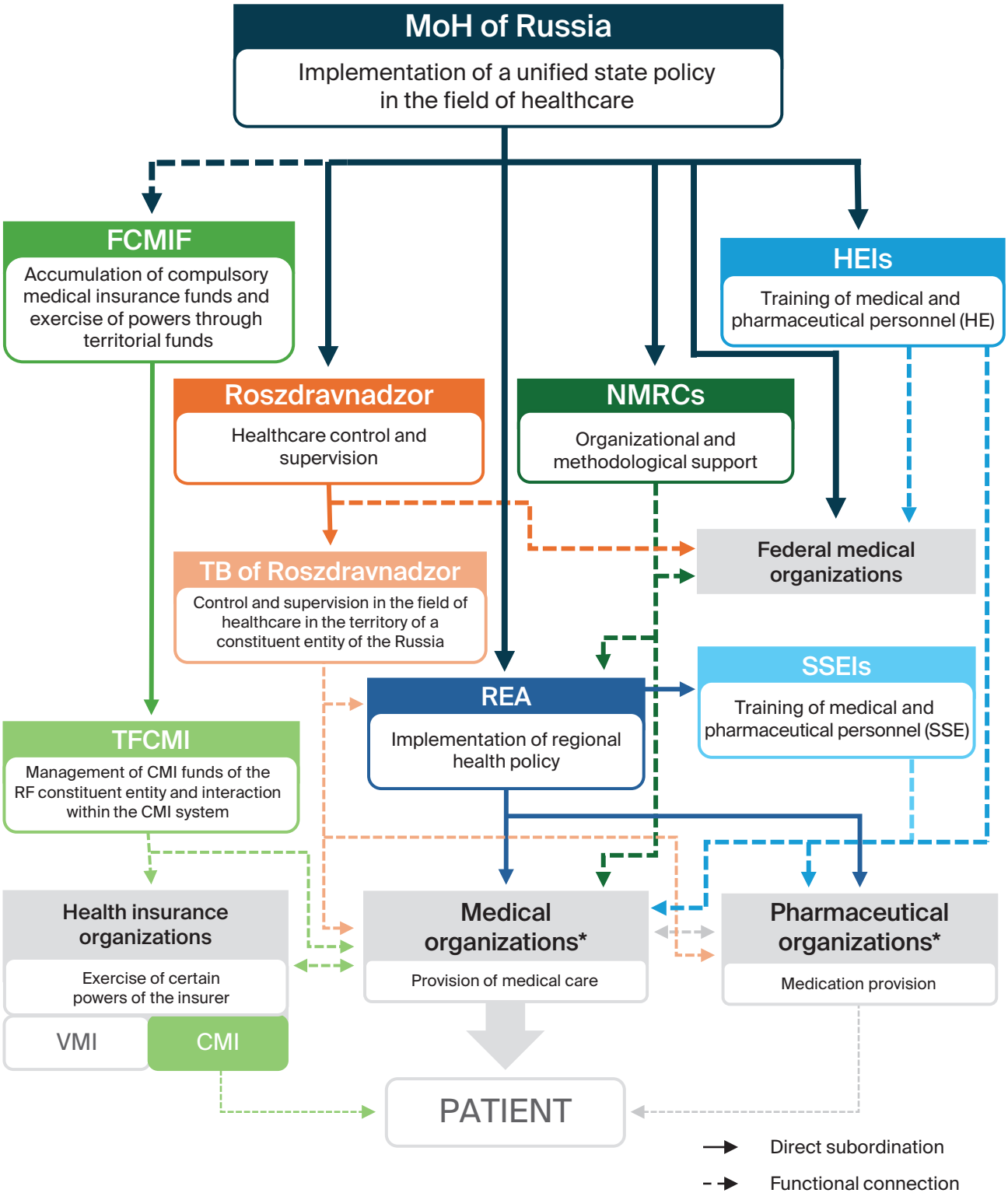
The Federal Compulsory Medical Insurance Fund, being a state extrabudgetary fund and performing the function of an insurer in the compulsory medical insurance system in the Russian Federation, also belongs to the federal level of the model and ensures the implementation of a unified state policy in the field of social protection of citizens. It is also responsible for coordinating the activities of entities and participants in the compulsory medical insurance system in the Russian Federation as well as ensuring the possibility of receiving medical care under a compulsory health insurance policy within the framework of the basic compulsory health insurance program in all the constituent entities of the Russian Federation.

Since 2018, as part of the implementation of the National Project "Healthcare," national medical research centers have become an important component of the federal model. Their organization and development became possible thanks to the federal project "Development of a network of national medical research centers and introduction of innovative medical technologies."

National Medical Research Centers are unique medical organizations under the jurisdiction of the Ministry of Health of the Russian Federation that integrate scientific, organizational, methodological, educational, and professional capabilities to improve the quality of medical care by developing innovations in healthcare and implementing them in practical healthcare. Between 2018 and 2024, 38 national medical research centers were established within the Russian Federation's healthcare system, covering various clinical profiles and areas of healthcare organization. Starting in 2025, in accordance with the instructions of the President of the Russian Federation, the network of national medical research centers is set to be expanded. As a result of the implementation of the project "Development of Federal Medical, Scientific, and Educational Organizations" during 2025–2030, continuity in the provision of specialized and high-tech medical care will be maintained by ensuring continuity of patient care, and the availability of remote, online consultations will increase. For doctors working in medical organizations in the constituent entities of the Russian Federation, it will become easier to discuss the treatment of specific patients with specialists from leading federal centers anywhere in the country, as well as to make quick decisions on hospitalizing patients, if necessary, in federal clinics. A socially significant result of the project will be the provision of medical care to 1.5 million citizens using advanced and unique medical technologies for diagnosis and treatment, regardless of their place of residence.

An important component of the federal level of the modern healthcare model of the Russian Federation is higher education institutions that provide training for highly qualified medical personnel. Currently, 48 higher

FIG. 1. Organizational and functional model of healthcare in the Russian Federation



Note: MoH of Russia – Ministry of Health of the Russian Federation; FCMIF – Federal Compulsory Medical Insurance Fund; TFCMI – Territorial Fund for Compulsory Medical Insurance; Roszdravnadzor – Federal Service for Supervision of Public Health and Social Development; TB of Roszdravnadzor – Territorial body of Roszdravnadzor; HE – higher education; HEIs – higher education institutions subordinate to the MoH of Russia; NMRCs – national medical research centers; Federal medical organizations – medical organizations subordinate to the MoH of Russia; REA – regional executive authority in the field of health care; SSEIs – secondary specialized education institutions; SSE – secondary specialized education; CMI – compulsory medical insurance; VMI – voluntary medical insurance; * state-owned and non-state-owned organizations.

education institutions under the jurisdiction of the Ministry of Health of the Russian Federation offer basic and additional education programs at the specialist, residency, postgraduate, professional retraining, and advanced training levels, forming and developing the healthcare system's main and most long-term resource: medical personnel.

Like most national healthcare systems, the Russian healthcare system faces serious challenges related to staffing issues in healthcare [2]. The medical training system in the Russian Federation is currently being successfully adapted to the real needs of the healthcare labor market, ensuring the integrative unity of educational policy and personnel policy in the healthcare system. Targeted measures are being developed and implemented to attract and retain medical personnel, including in the primary health care system.

Another completely unique component of the modern healthcare model of the Russian Federation at the federal level is the institution of chief external specialists of the Ministry of Health of the Russian Federation. This cohort of specialists comprise leaders in the relevant field of medical activity and represent the expert potential of the healthcare system of the Russian Federation. They determine the development strategy for the relevant field and tactical decisions for its implementation, aimed at improving medical care, studying and replicating new medical technologies. In addition, they participate in the development and implementation of personnel policy in the Russian Federation with regard to medical workers providing medical care in the relevant specialty (field, profile of activity).

The regional level of the model is a collection of regional healthcare systems that provide medical care in 89 constituent entities of the Russian Federation. The coordinating structure in each constituent entity is the regional executive authority in the field of health care, which is empowered to implement state social policy and ensure state guarantees of free medical care for the population of a particular region.

Despite the existence of uniform principles for the organization of medical care, it should be noted that there are specific features in the activities of regional health care systems, determined by the medical, demographic, climatic, geographical, and socio-economic characteristics of each specific constituent entity of the Russian Federation. The ratio of urban to rural populations, gender and age demographics, population density, transportation accessibility, and the geographical dispersion of settlements are factors that must be considered when planning a network of medical organizations. In addition, one needs to consider routing patients according to specific clinical profiles (e.g., routing patients with cardiovascular diseases, malignant neoplasms, injuries, etc.), planning the location of emergency medical stations and subunits to enable the provision of emergency medical care.

Public healthcare providers network structure

The key components of the state healthcare system are medical and pharmaceutical organizations subordinate to federal and regional executive authorities, as well as healthcare organizations responsible for supervising consumer rights and human welfare, forensic institutions, other organizations and their separate divisions operating in the field of healthcare.

Educational institutions offering secondary vocational education programs in the medical field also play an important role in the Russian Federation's public health care system, meeting the practical health

care needs for specialists with secondary medical education. Most organizations of this type are regionally subordinate, which allows educational organizations to respond quickly to the changing needs of the labor market in the relevant constituent entity of the Russian Federation, and to focus on the practical training of students in regional medical organizations. This is particularly relevant in the context of the growing role of personnel with secondary medical education in the direct provision of medical care to the population, especially with regard to preventive measures.

Types and levels of medical care

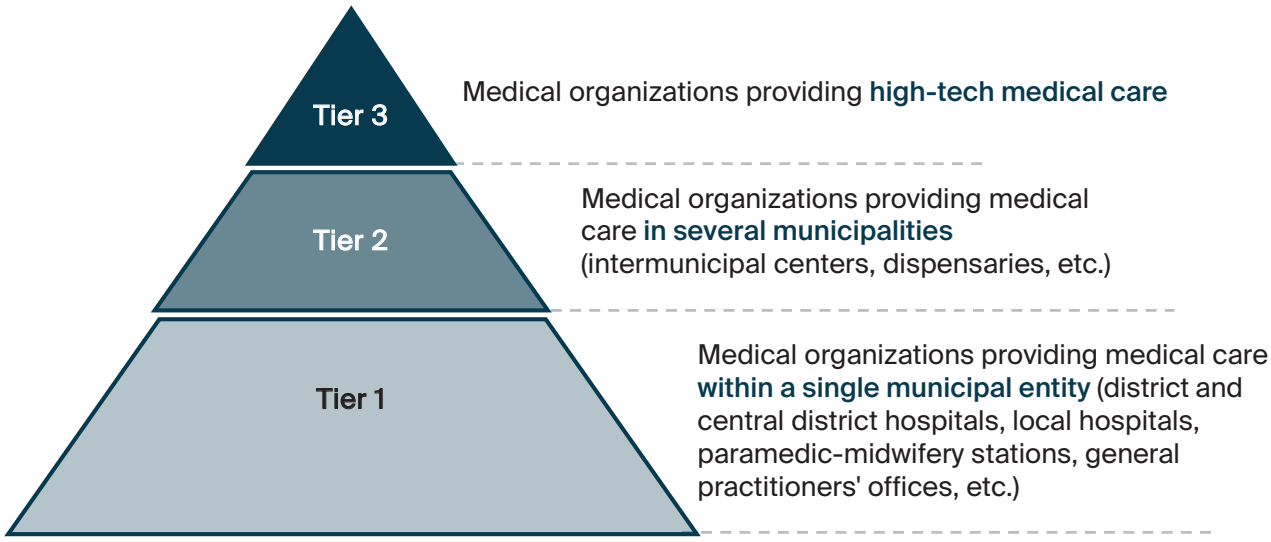
In accordance with legislation of the Russian Federation[2], there are four types of medical care:

- primary healthcare;
- specialized care, including high-tech care;
- emergency care, including specialized care;
- palliative care.

To ensure that the population has access to affordable, high-quality medical care, a hierarchical system for the provision of medical care based on a three-tier model has been introduced nationwide (Figure 2). This system has been successfully adapted to the needs of each of the 89 constituent entities of the Russian Federation, ensuring the effective functioning and interaction of medical organizations at all levels.

Medical organizations of the first tier provide medical care to the population of the municipal formation in which they are located. The list of these organizations and their structural units include paramedic (feldsher) and paramedic-midwife (feldsher-midwife) stations, where medical care is provided by mid-level medical personnel (paramedics and midwives), medical clinics, district hospitals, polyclinics, district hospitals, and central district hospitals. The list of types of medical care provided in medical organizations of the first

FIG. 2. Three-tier healthcare system



[2] Федеральный закон от 21.11.2011 г. № 323-ФЗ. Об основах охраны здоровья граждан в Российской Федерации (с изменениями на 23 июля 2025 года) [Russian Federation. Federal Law No. 323-FZ of November 21, 2011. On the Fundamentals of Citizens' Health Protection in the Russian Federation (as amended on July 23, 2025)] (in Russian). Accessed 24.11.2025. http://publication.pravo.gov.ru/Document/View/0001201111220007/

tier is determined by the type of medical organization and the size of the population served. Medical organizations of the first tier form the foundation of the healthcare system, as it is primarily these medical organizations that provide primary healthcare, including the organization and implementation of preventive measures and efforts to promote healthy lifestyles among the population. The legislation provides for standards that determine the territorial accessibility of medical organizations, the principles of district service and universal coverage of the population, which are not simply preserved historically, but expanded in the modern model. This takes into account the possibility of assigning citizens to a medical organization not only at their place of residence, but also at their place of study or work, which significantly increases the accessibility of this type of medical care, bringing the possibility of receiving it as close as possible to the place of actual residence, work, or study of the citizen.

Medical organizations of the second tier provide mainly specialized (except for high-tech) medical care to the population of several municipalities for a broader or specialized clinical profile (e.g., interregional hospitals, dispensaries).

Medical organizations of the third tier are represented by organizations that have structural divisions providing high-tech medical care, which is their distinguishing feature.

Currently, the state healthcare system meets all the basic healthcare needs of the population, including in rural areas and remote and hard-to-reach settlements across the country. This has been made possible primarily through the targeted development and strengthening of primary healthcare, which is the foundation of the entire healthcare system in the Russian Federation. To bring primary healthcare as close as possible to where people live, study, and work, the network of paramedic-midwifery stations and medical clinics has been expanded, mobile healthcare services and telemedicine technologies have been introduced. A targeted training of medical personnel who are able to work in rural areas is being carried out. Thus, the Russian state healthcare system is built on the principle of proximity-based accessibility of medical care, within which the patient's initial contact with the healthcare system takes place when primary healthcare is provided closest to their actual location. This allows most of the population's health-related problems to be solved at this level, relieving the resource-intensive inpatient sector and ensuring the implementation of the principle of preventive medical care.

As of December 31, 2024, the network of state medical organizations in the Russian Federation consists of:

- 4,076 hospital-based institutions;
- 14,253 polyclinic-type medical organizations, including structural divisions of hospital organizations providing outpatient medical care;
- 1,141 district hospitals;
- 6,156 medical clinics;
- 1,363 health post;
- 33,139 paramedic-midwifery stations;
- 3,222 paramedic stations[3].

The municipal healthcare system is represented by local government bodies exercising powers in the field of healthcare, as well as by separate municipal medical and pharmaceutical organizations in a number of constituent entities of the Russian Federation.

[3] According to data from the Federal State Budgetary Institution "Central Research Institute for Health Care Organization and Informatization" of the Ministry of Health of the Russian Federation.

The private healthcare system consists of privately owned medical and pharmaceutical organizations established by legal entities or individuals, as well as other organizations operating in the field of healthcare.

In summary, the organizational and functional model of the Russian healthcare system is characterized by a vertically integrated hierarchical structure with two types of relationships between the components of the system: direct (linear) and functional subordination. Despite the existence of organizations with different forms of ownership, the system has functional unity – all elements, including private medical and pharmaceutical organizations, operate within a single regulatory framework. State medical organizations have dual subordination at the regional level: on the one hand, they are subordinate to their direct founder, but at the same time they are required to comply with health protection legislation and interact with control and supervisory bodies. The modern healthcare system model is characterized by a clear division of functions among all components of the system, ensuring optimal efficiency. Strategic development management and control are concentrated at the federal level, while operational management is concentrated at the regional level.

Regulatory framework and standardization

The organizational model of the healthcare system is based on the principle of standardization from the perspective of regulatory control – the introduction of requirements for the organization of medical activities in accordance with the provisions on the organization of medical care of a particular type, procedures for the provision of medical care, based on clinical guidelines and taking into account medical care standards. This makes it possible to ensure an optimal degree of regulation by developing and establishing requirements for work, services, and technologies used in healthcare, as well as for the conditions for their provision [3, 4]. Regulations on the organization of medical care have been developed for each type of care and are enshrined in orders issued by the Ministry of Health of the Russian Federation. On September 1, 2025, updated regulations on the organization of primary health care, specialized medical care, and palliative care came into force, reflecting current trends and including innovative organizational technologies aimed at improving and increasing the availability of the relevant type of medical care.

Medical care procedures are structural and organizational standards that contain requirements for the stages of medical care provision for a specific clinical profile, rules for organizing work at each stage, a list of equipment, and recommended staffing standards. The introduction of medical care procedures has ensured compliance with uniform requirements for the organization of medical care, which in turn has led to a systematic approach to the quality and safety of medical activities and the observance of the rights of Russian citizens in the field of healthcare [4].

Clinical guidelines contain evidence-based structured information on prevention, diagnosis, treatment, and rehabilitation, including patient management protocols (treatment protocols), medical intervention options, and a description of the sequence of actions to be taken by medical professionals, taking into account the course of the disease, the presence of complications and comorbidities, and other factors affecting the outcomes of medical care. The main purpose of creating

clinical guidelines is to provide information support for doctors' decisions that contribute to improving the quality of medical care for patients with a particular disease, condition (group of diseases, conditions), taking into account the latest clinical data and principles of evidence-based medicine.

Medical care standards are medical and economic documents that define a set of average indicators for the frequency of use of specific medical services, drugs, medical devices, blood components, and therapeutic diet for certain diseases. Medical care standards are based on current clinical guidelines.

Healthcare financing model

Based on the principle of the source of financial support for healthcare activities, it is traditional to distinguish between three types (models) of healthcare systems: predominantly state-run, predominantly market-based (private), and predominantly insurance-based. However, in practice, many countries, including the Russian Federation, operate mixed models.

The Russian model of healthcare financing is defined as a mixed, budget-insurance system characterized by a combination of state financing of healthcare, medical insurance, and private healthcare.

The key source of funding for the healthcare system is compulsory health insurance, which covers the majority of medical care, including inpatient care. Since 2014, high-tech medical care has been included in the compulsory health insurance program. Currently, the list of types of high-tech medical care guaranteed to the population free of charge through compulsory health insurance has been significantly expanded, which has increased the availability of medical care provided using complex, unique, and resource-intensive technologies.

A distinctive feature of the compulsory health insurance system in the Russian Federation is its non-commercial nature. Medical organizations participating in the compulsory health insurance program receive payment for medical care provided at an approved rate, which provides only for compensation of the costs incurred by medical organizations for providing medical care at cost, without setting a profit margin.

The financial stability of the compulsory health insurance system, as the main form of social protection of the population's interests in the field of health care, is guaranteed by the state. Federal legislation enshrines the principle that the state guarantees the rights of insured persons to the fulfillment of compulsory health insurance obligations under the basic program, regardless of the financial situation of the insurer.

Thus, the healthcare system of the Russian Federation is financed primarily through compulsory health insurance funds. Funds from the federal budget and the budgets of the constituent entities of the Russian Federation supplement the financial support for the state healthcare system by paying for certain types of medical care (specialized emergency care; high-tech care, except for the types included in the compulsory health insurance program; palliative care), medical care for certain socially significant diseases (sexually transmitted diseases caused by the human immunodeficiency virus, acquired immunodeficiency syndrome, tuberculosis, mental disorders, and behavioral disorders), subsidized medication, and a number of other medical measures.

The private healthcare system, in turn, provides citizens with the opportunity to choose non-state medical organizations, including for medical care that is not guaranteed under the state guarantee program (for example, in the field of cosmetology), or provided under different conditions (more convenient hours, priority appointments, etc.), with the provision of additional non-medical services (household, transportation, etc.).

The existence of various sources of funding for the healthcare system of the Russian Federation and medical organizations of all forms of ownership makes it possible to meet all of the population's healthcare needs, including citizens' constitutional right to free medical care, while the synergy of these components within a single legal and organizational structure ensures the functional unity of all elements of the healthcare system.

The financing of the Russian Federation's public healthcare system is carried out in accordance with the following principles:

- standardization of financial costs for providing free medical care;
- per capita principle of financing state obligations in the field of healthcare;
- combining social solidarity and fairness in the formation of financial support for state guarantees with targeted spending of financial resources when providing medical care for individual patients;
- payment for the actual volume of medical care provided per completed case (results-oriented financing);
- single-channel financing of medical organizations that carry out state tasks based on the insurance principle of paying all expenses (at the full rate);
- development of inter-budgetary relations with the aim of equalizing financial conditions in the constituent entities of the Russian Federation to ensure a full rate for the fulfillment of state obligations in the field of healthcare.

The program state guarantees of free medical care to citizens

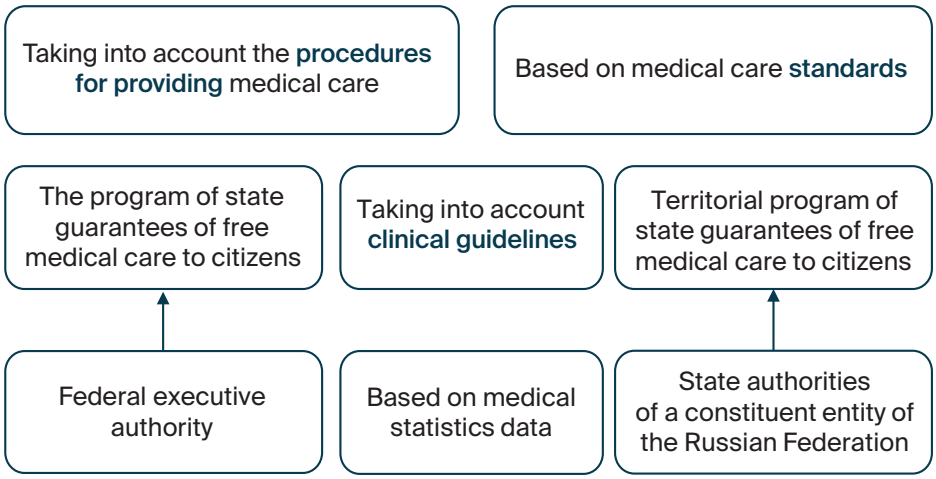
The main instrument for implementing the constitutionally guaranteed right to free medical care in the Russian Federation is the program of state guarantees of free medical care to citizens[4]. This document is developed and approved annually at the federal level by the Government of the Russian Federation. At the level of each constituent entity of the Russian Federation, territorial programs of state guarantees for the provision of free medical care to citizens are developed, adapting the conditions for the implementation of the program and the scope of medical care, taking into account the needs of the population of a particular region. Territorial programs are approved by the executive authority of the constituent entity of the Russian Federation and are valid in the territory of a specific region (Figure 3).

The main principles for developing the state guarantee program include:

- per capita planning of state medical care expenditure;
- a normative method for planning the volume of medical care;
- balanced regional state guarantee programs;
- uniform approaches to the pricing and payment of medical care using effective methods focused on the end result of the medical organization's activities;

[4] Постановленные Правительства Российской Федерации от 27 декабря 2024 г. № 1940 "О программе государственных гарантий бесплатного оказания гражданам медицинской помощи на 2025 год и на плановый период 2026 и 2027 годов" (в редакции от 04.09.2025) [Decree of the Government of the Russian Federation No. 1940 of December 27, 2024, "On the Program of State Guarantees for the Provision of Free Medical Care to Citizens for 2025 and the Planned Period of 2026 and 2027" (as amended on September 04, 2025)] (in Russian). Accessed 24.11.2025. http://pravo.gov.ru/proxy/ips/?docbody=&nd=608201774

FIG. 3. Principle of forming the program of state guarantees for the provision of free medical care to citizens



- uniform criteria for evaluating the effectiveness of the implementation of territorial state guarantee programs, reflecting the accessibility and quality of medical care.

The program of state guarantees of free medical care to citizens allows for program-targeted management of medical care provision to the population at the regional level[5], namely, to assess the accessibility and quality of medical care and the effective use of healthcare resources (Figure 4).

Preventive focus and working population health

A key feature of the Russian healthcare system is the preventive focus, which aims to actively identify diseases at an early stage, prevent the development of diseases and pre-morbid conditions, promote healthy lifestyles among the population, and educate people about hygiene [1]. The program of state guarantees of free medical care to citizens establishes[6] separate differentiated standards for the volume and financial support of medical care units for various types of preventive measures – comprehensive visits as part of preventive medical examinations, medical check-ups (including in-depth ones), dispensary observation to assess the reproductive health of women and men, visits to health centers for preventive purposes, and comprehensive visits to schools for patients with chronic diseases.

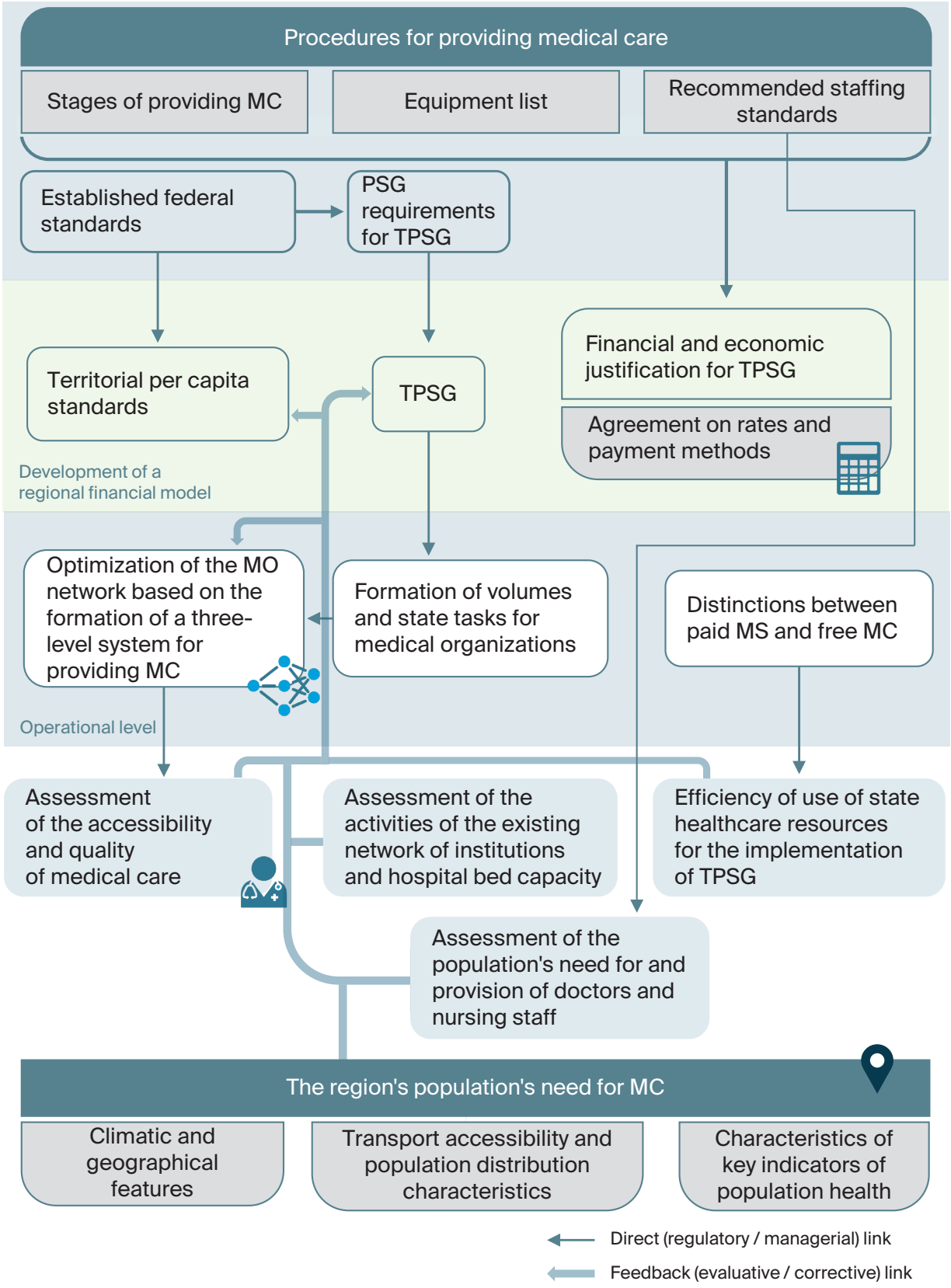
Special attention is paid to issues related to protecting the health of the working population. Measures are being developed and implemented to improve access to medical care for working citizens, including through interagency cooperation. Thus, from January 1, 2019, based on amendments to labor legislation[7], employees have been granted the right to take one working day off with full pay once every three years for the purpose of undergoing a medical examination. Medical organizations, in turn, strive to optimize the process

[5] Flek VO. Public Health and Health Care Management: selected lectures. Moscow; 2023. 164 p. (In Russian).

[6] Постановленные Правительства Российской Федерации от 27 декабря 2024 г. № 1940 "О программе государственных гарантий бесплатного оказания гражданам медицинской помощи на 2025 год и на плановый период 2026 и 2027 годов" (в редакции от 04.09.2025) [Decree of the Government of the Russian Federation No. 1940 of December 27, 2024, "On the Program of State Guarantees for the Provision of Free Medical Care to Citizens for 2025 and the Planned Period of 2026 and 2027" (as amended on September 04, 2025)] (in Russian). Accessed 24.11.2025. http://pravo.gov.ru/proxy/ips/?docbody=&nd=608201774

[7] Трудовой кодекс Российской Федерации от 30.12.2001 № 197-ФЗ (в редакции от 29 сентября 2025) [Labor Code of the Russian Federation dated December 30, 2001, No. 197-FZ (as amended on September 29, 2025)] (in Russian). Accessed 24.11.2025. http://pravo.gov.ru/proxy/ips/?docbody=&nd=102074279/

FIG. 4. Program-targeted management of medical care provision to the population at the regional level



Note: MC – Medical Care; MS – Medical Service; MO – Medical Organization; PSG – The program of state guarantees of free medical care to citizens; TPSG – Territorial program of state guarantees of free medical care to citizens; SA – State Assignment.

of preventive medical examinations and medical check-ups for certain groups of the adult population as much as possible, actively introducing and using lean technologies in practical healthcare, organizing patient routing to allow preventive measures to be carried out in the shortest possible time, and providing the opportunity to undergo medical examinations and check-ups in the evenings and on weekends.

Digitalization and technological innovation

Digitalization is one of the priority areas for the development of the healthcare system [5, 6]. Over the past few years, the domestic healthcare system has come a long way from disparate medical information systems in individual medical organizations to the creation of a Unified State Information System in the healthcare sector, which provides information for the methodological and organizational support of healthcare system participants. Currently, medical organizations maintain medical records in the form of electronic documents, online appointments scheduling, and issue electronic sick leave certificates and prescriptions for medications. Some of the main strategic trends in the technological development of the healthcare system in the near future are the use of medical decision support systems and artificial intelligence in healthcare, remote patient monitoring, digital twins in healthcare, robotics and automation, and cybersecurity in healthcare [6–8].

Conclusion

Thus, the current healthcare model of the Russian Federation system is based on the principles of the Semashko healthcare system. This is supplemented by innovative digital and organizational technologies that ensure an optimal level of accessibility and quality of medical care for the population of the Russian Federation, taking into account the needs and state social guarantees, as well as ensuring the achievement of the National Development Goal of preserving the population, strengthening health, and improving the well-being of people.

The federal principle of state structure and the vast territory of the country necessitate the adaptation of regional healthcare systems, taking into account the specific characteristics of each constituent entity of the Russian Federation and the actual healthcare needs of the population, which has been successfully implemented in the current model.

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REVIEW

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Health systems in the BRICS context: institutional characteristics and contemporary challenges in Brazil, China, and Russia

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ABSTRACT

Health systems in emerging economies face the dual challenge of expanding access while ensuring equity, quality, and financial sustainability amid demographic, epidemiological, and geopolitical changes. This article analyzes the health systems of Brazil, China, and Russia, three key members of the BRICS group with large populations and diverse institutional paths. Using policy documents, official statistics, and secondary literature, we examine their historical foundations, governance structures, financing mechanisms, service delivery models, and recent reforms. Despite differing political, economic, and administrative traditions, these countries share a strong state role in stewardship and a formal commitment to universal access. Brazil's tax-funded Unified Health System is rooted in constitutional rights, decentralization, and social participation. China has achieved near-universal insurance coverage through consolidated social health insurance schemes under strengthened central regulation, alongside ongoing payment and disease-control reforms. Russia maintains universal coverage through mandatory health insurance within a territorially organized, hierarchical delivery system rooted in the Semashko model. Major challenges include regional inequalities, hospital-centered care patterns, fiscal pressures, demographic ageing, and the rising burden of chronic diseases. The comparative analysis reveals multiple institutional pathways toward universal health coverage and highlights the strategic importance of public stewardship, primary health care, and domestic production capacity. These findings contribute to debates on health system strengthening and South–South cooperation within BRICS and the broader global health agenda.

Key Words: BRICS, Brazil's health system; China's health system; Russia's health system; public health; global health; health cooperation

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Introduction

Over the past decades, health systems have become central arenas for addressing structural inequalities, demographic transitions, epidemiological changes, and global health emergencies. In this context, middle-income and emerging economies face the dual challenge of expanding access to health services while ensuring equity, financial protection, and system sustainability. Advancing the development of people-centered and resilient health systems is essential to reducing avoidable mortality and mitigating substantial economic losses. As argued by Kruk et al. (2018) [1], poor-quality health systems are responsible for more than 8 million deaths annually in low- and middle-income countries, generating economic welfare losses estimated at US $6 trillion. These findings underscore that expanding coverage alone is insufficient; improving quality, safety, and responsiveness is critical to ensuring that health systems effectively translate access into meaningful health gains and social protection.

The BRICS countries – Brazil, Russia, India, China, South Africa, Egypt, Ethiopia, Indonesia, Iran, Saudi Arabia and the United Arab Emirates, – occupy a strategic position in this debate, combining large populations and significant internal heterogeneity, and increasingly positioning themselves as a bloc capable of influencing global health governance.

Since the early 2010s, the BRICS has explicitly prioritized health, emphasizing principles such as universal access, equity, solidarity, and South-South cooperation. Health ministerial declarations and joint initiatives have highlighted the importance of strengthening national health systems, enhancing public health and disease control capacities, promoting access to medicines and technologies, and fostering collaborative research[1].

Brazil assumed the BRICS Chairship on January 1, 2025 under the theme “Strengthening Global South Cooperation for More Inclusive and Sustainable Governance.” Brazil’s Presidency focused on two priorities: the Global South Cooperation and BRICS Partnerships for Social, Economic and Environmental Development. In this context, the BRICS Health Ministers’ Declaration recommended an unprecedented partnership aimed at eliminating socially determined diseases, reinforcing joint actions to promote health among member states and partner countries[2]. The issues debated within the BRICS framework include the burden of chronic non-communicable diseases; the modernization of health systems; the promotion of digital health and innovation; improved access to vaccines, medicines, diagnostics, and other essential health technologies; the reduction of maternal and child mortality; the strengthening of Primary Health Care (PHC); the control of communicable diseases; preparedness for and response to public health emergencies; adaptation to the health impacts of climate change; and the promotion of healthy diets and nutrition.

Health cooperation within the BRICS framework can influence debates on equity, universality, and South-South health collaboration. In this sense, the development of institutionalized cooperation mechanisms and coordinated initiatives can contribute to more consistent and sustainable outcomes across PHC, disease control, health technologies, and workforce development. Expanding engagement

[1] BRICS. BRICS Health Ministers Declaration, 2011–2024. Accessed 09.12.2025. https://brics.br/en/documents/collection-of-previous-presidencies/health-ministerial-declarations

[2] BRICS. Declaration of the XV BRICS Health Ministers’ Meeting. June 17, 2025. Accessed 09.12.2025. https://brics.br/pt-br/assets/final-brics-health-declaration-17-06-25rev.pdf

beyond governmental channels – through academic collaboration, research networks, professional associations, and dialogue with civil society – can also help diversify perspectives and foster innovation [2].

Analyses of BRICS health systems may contribute not only to academic knowledge but also to policy learning and international cooperation. Brazil, China, and Russia represent relevant cases within the BRICS group. Despite distinct political trajectories, institutional arrangements, and historical legacies, the three countries share a strong role of the State in health system governance and a constitutional or legal commitment to universal access to health care. At the same time, each system reflects specific responses to national contexts marked by territorial vastness, regional inequalities, demographic ageing, and changing disease profiles.

Brazil's Unified Health System (Sistema Único de Saúde, SUS) is grounded in a rights-based approach established by the 1988 Constitution, combining universality, comprehensiveness, decentralization, and social participation[3]. China's health system has undergone profound reforms over the past four decades, evolving from a fragmented, out-of-pocket model to a broad system of social health insurance (SHI) and expanding public health infrastructure under strong state stewardship [3]. Russia's health system, rooted in the Semashko tradition, ensures universal coverage through mandatory health insurance and a multilevel service delivery structure adapted to its vast and diverse territory[4].

The objective of this article is to explore the main characteristics of the health systems of Brazil, China, and Russia, considering their historical foundations, organizational structures, financing arrangements and governance models. The analysis was based on policy documents, official statistics, and secondary literature to provide a deeper understanding of how different institutional designs can shape health system performance and equity outcomes. By highlighting both convergences and divergences between the countries, the study seeks to contribute to the literature on comparative health systems and to inform ongoing discussions on health system strengthening and cooperation within the BRICS framework. Moreover, it sheds light on the potential contributions of BRICS countries to global health debates at a time when multilateral cooperation faces growing tensions and uncertainties.

Health system characteristics in Brazil, China, and Russia

Brazilian unified health system: public, universal and comprehensive

Brazil is a Latin American country with over 200 million residents, a vast territory, and diverse biomes, peoples, and cultures. Politically and institutionally, it functions as a presidential and federal democratic republic composed of three levels of government: the Union, 26 states, and the Federal District, along with 5570 municipalities, all sharing responsibilities for public policies, including health.

[3] Brasil. Lei No. 8.080, de 19 de setembro de 1990. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências.[Brazil. Law No. 8,080 of September 19, 1990. It provides for the conditions for the promotion, protection and recovery of Health, the organization and functioning of the corresponding services and makes other arrangements] (In Portuguese). Accessed 09.12.2025. https://www2.camara.leg.br/legin/fed/lei/1990/lei-8080-19-setembro-1990-365093-publicacaooriginal-1-pl.html

[4] Федеральный закон от 21.11.2011 г. № 323-ФЗ. Об основах охраны здоровья граждан в Российской Федерации [Russian Federation. Federal Law No. 323-FZ of November 21, 2011. On the Fundamentals of Citizens' Health Protection in the Russian Federation] (in Russian). Accessed 09.12.2025. http://government.ru/docs/all/100186/

Historically, the nation has been marked by deep inequalities rooted in the colonial era and worsened by capitalist modernization, which concentrated wealth and failed to distribute it fairly. Structural inequalities take various forms – spatial, economic, social, ethnic-racial, and gender – affecting public health policies and conditions.

Health policies in Brazil, like in other Latin American countries, expanded throughout the 20th century into two main branches [4]. One branch focused on healthcare for workers in the formal sector, linked to a social insurance system supported by financial contributions. This branch was characterized by high client segmentation, institutional fragmentation, centralized decision-making, a focus on hospital care, and limited effectiveness in improving health outcomes. It also had limited coverage, excluding informal workers, rural workers, and the unemployed. The other branch consisted of vertical public health programs, mostly aimed at controlling specific infectious diseases. Despite incremental reforms and occasional efforts to expand access, this institutional duality persisted for decades. Additionally, from the 1960s onward, the private health sector expanded, supported by state subsidies, marked by a notable increase in private hospitals and the rise of the private insurance sector [5].

In the 1980s, the process of democratization in the country led to intense social mobilization in favour of expanding rights. In this context, the movement for Brazilian health reform [6, 7] succeeded in influencing the 1988 Constitution, which recognized health as a right for all and a duty of the State, based on a broad view of Social Security. This Constitution established the SUS, which became one of the largest and most complex public health systems in the world, providing universal, free health care to all. The main principles of SUS include universality, comprehensiveness, equality, political-administrative decentralization, and social participation.

The SUS includes comprehensive health policies and guarantees healthcare as a right for every Brazilian citizen. It covers health promotion and surveillance strategies; primary, secondary, and high-complexity care; emergency and urgent services; pharmaceutical care; technological development, production, and distribution of strategic health supplies like vaccines, drugs, and diagnostic tests; health education and professional training efforts; and preparedness to respond to public health emergencies.

The adoption of a broad view of social determination of health also entails efforts to coordinate the SUS with other social and economic policies that influence living conditions and population health. Macroeconomic policies influence social conditions, depending on their redistributive effects, and are also crucial in defining public budget priorities [8]. Labor, social security, and social assistance policies play a key role in preventing poverty and ensuring decent living conditions for workers, older adults, and vulnerable groups. Sanitation and environmental policies are crucial for ensuring healthy living environments and preventing many infectious diseases. Scientific and industrial development policies are vital for enabling the domestic production of strategic health inputs such as vaccines and medicines, ensuring universal access and the sustainability of the health system.

Regarding financing, the SUS is tax-funded, non-contributory, and free of charge. The three levels of government must allocate resources to fund the SUS, with specific legislation setting minimum criteria for the distribution of government revenues to health at each level. In 2022, federal funding accounted for about 38% of public

expenditures, while states and municipalities accounted for 28% and 34%, respectively[5]. A large portion of the federal health budget is transferred to municipalities, which are responsible for providing health care services at the local level.

According to the Brazilian federation's institutional design, health policies are developed and carried out through cooperation among the federal, state, and municipal governments. Since the early 1990s, each government level has a single health authority – the Ministry of Health, the state secretaries, and the municipal secretaries – responsible for creating and implementing health policies within their respective jurisdictions, in collaboration with other actors. This marked a significant shift from the institutional configuration prior to the SUS, where responsibilities for public health and healthcare strategies were divided among different ministries and official departments.

Federative coordination is maintained through intergovernmental commissions at the national and state levels, which are strategic arenas for technical and political dialogue, negotiations and agreements on the health policy's agenda and implementation strategies. Even amid political and administrative decentralization of responsibilities, resources, and services, federal regulations and financial transfers remained potent mechanisms for advancing the implementation of national priorities [9]. The articulation between political-administrative decentralization and regionalization remain a structural challenge for the SUS [10].

Another key feature of the SUS is social participation, which aligns with the democratic values that supported health reform in Brazil. Society's involvement in health policies is ensured by the regular operation of participatory health councils at the three levels of government. These councils are deliberative and include representatives from government, service providers, health professionals, and system users, with the latter group holding half of the seats [11]. Additionally, every four years, health conferences are held at the municipal, state, and national levels, with hundreds of thousands of people across the country participating to help shape the strategic direction of health policies for the upcoming four years.

Over more than 35 years of implementation, the SUS has facilitated the expansion of public health actions and services nationwide and improved various health indicators[5]. Significant progress has been made in transforming PHC through the Family Health Strategy, which includes multidisciplinary teams and has achieved nationwide coverage. Moreover, PHC is expected to be adapted to community needs and to adopt coordination mechanisms to ensure continuity of care across higher levels of complexity. Another achievement was the development of internationally recognized comprehensive health policies, such as those for tobacco control and HIV (Human immunodeficiency viruses)/AIDS (acquired immunodeficiency syndrome) prevention, which coordinate actions from health promotion and prevention to complex treatments. There have also been notable advances in women's health and in mental health care – replacing psychiatric hospitals with community-based services and more appropriate approaches – among other examples.

In health surveillance, a field with a long history in Brazilian public health, SUS has led to significant progress [12, 13]. The first was increased institutional presence in the area, achieved through the creation of new structures at the federal level, followed by state and municipal bodies, and organizational rules that reinforced the systemic and federative

[5] Instituto de Pesquisa Econômica Aplicada (IPEA). Data from the Beneficiômetro da Seguridade Social. [Institute for Applied Economic Research (IPEA). Data from the Social Security Beneficiometer.] (In Portuguese). Accessed 09.12.2025. https://www.ipea.gov.br/portal/beneficiometro/beneficiometro-artigos/saude/gasto-publico-em-saude

approach. The second was expanding the scope from traditional infectious disease surveillance to include health promotion, environmental surveillance, violence prevention, and the management of non-communicable chronic diseases. The third involved establishing service networks and training professionals to identify, prepare for, and respond to health emergencies. Lastly, initiatives were introduced to coordinate surveillance efforts with PHC. In health regulation, there were also institutional advances, such as creating a new national regulatory agency and developing strategies for regulating technology adoption and ensuring quality control of health services, products, and inputs [14].

In the context of the economic-industrial health complex, in addition to some capacity to produce health supplies through private industry, Brazil also has public producers of vaccines, such as Fiocruz and the Butantan Institute, as well as medicines through the Oswaldo Cruz Foundation (Fiocruz) and state producers. This national production capacity is a strategic asset for ensuring the supply of inputs to the SUS, aligned with national priorities [15]. However, the country remains heavily reliant on imports of health products and lacks sufficient investment in science and technology that would bolster national sovereignty in health. In this regard, South-South cooperation is vital for fostering partnerships that improve the availability and accessibility of strategic health supplies for the entire population.

Despite significant progress over the last 35 years, important challenges to consolidating the SUS remain: health funding is insufficient, health infrastructure needs improvement, and health services and the health workforce are unevenly distributed nationwide. Regarding strategic health supplies such as medicines and vaccines, additional investment is vital to strengthen national capacity in science, technology, and production, and to ensure universal access and sustainability in an asymmetric global context. Finally, it is crucial to regulate and reduce state subsidies to the private health sector, whose growth and dynamics hinder the consolidation of the SUS [12].

China's health system

Over the past four decades, China has transformed its health system from a fragmented, largely out-of-pocket model into one of the world's largest systems of universal health coverage. Major reforms since 2009 reaffirmed the government's stewardship role in financing, regulation, and delivery, aiming to ensure essential service access, improve quality, and provide financial protection [3]. Enrolment in basic medical insurance has remained above 95%, while life expectancy rose to 79 years in 2024[6]. These gains reflect sustained investments in public health infrastructure, expansion of SHI, and strengthened service delivery capacity. However, challenges remain, including demographic ageing, persistent regional inequalities, rising burden of chronic diseases, and the need to further enhance primary care and disease-control capacities.

China operates a unified, state-led SHI system that has progressively consolidated and expanded coverage since the 2009 health reform. The Urban Employee Basic Medical Insurance, financed mainly through payroll contributions, covers employees in the formal sector, while the Urban–Rural Resident Basic Medical Insurance pools together the former urban resident and rural cooperative schemes and is funded primarily through government-subsidised premiums. Complementing these schemes, the Medical Assistance program provides additional financial support for low-income and vulnerable groups. Since 2018, the National Healthcare

[6] Gao Z. China's average life expectancy rises to 79 years in 2024. State Council Information Office; 2025. Accessed 09.12.2025. http://english.scio.gov.cn

Security Administration (NHSA) has overseen SHI administration, drug and device price negotiation, reimbursement policy, and payment reform, reducing fragmentation and strengthening equity and strategic purchasing across the system [16, 17].

Service delivery in China is organised through a three-tier system – primary health-care institutions, secondary hospitals, and tertiary hospitals – with public hospitals providing most of the medical care. Although private hospitals now constitute a significant portion of healthcare providers, public institutions still handle most of the service volume. Influenced by patient preferences and different diagnostic capabilities, hospitals often serve as the first point of access. Data from 2021 to 2024 highlights a divergent trend within this system: primary care institutions have shown resilience by absorbing a massive rebound in outpatient visits, but their role in inpatient care has levelled off. Meanwhile, tertiary hospitals have experienced steady growth in both outpatient and inpatient volumes, reinforcing a centralized model. This concentration poses ongoing challenges for resource allocation and the continuity of care required for chronic disease management, suggesting that although primary access is expanding, the systemic shift toward a fully integrated, prevention-led hierarchy remains in progress [17].

China's health-care infrastructure has continued to expand. By 2024, the country had 7.3 hospital beds, 3.6 licensed (assistant) physicians, and 4.1 registered nurses per 1,000 population, reflecting steady improvements in service capacity[7]. Nevertheless, significant regional and structural disparities persist. Eastern provinces maintain markedly higher densities of health workers, more advanced equipment, and stronger fiscal capacity than central and western regions. Moreover, despite overall resource growth, high-quality medical resources – such as tertiary specialists, advanced diagnostics, and high-performing hospitals – remain unevenly distributed, contributing to persistent cross-regional patient flows and overcrowding in major urban centres.

China maintains a four-tier CDC (Centers for Disease Control and Prevention) system and, since COVID-19, has advanced comprehensive reforms to modernize its disease-control capacity. Following the establishment of the National Disease Control and Prevention Administration in 2021, reforms have clarified the functions of the CDC across administrative tiers, strengthened governance structures, and enhanced the core capacity for infectious disease prevention and control. The 2024 roadmap priorities upgrading real-time surveillance and early warning systems, enhancing laboratory and emergency-response capacity, and establishing national and regional public-health centers to support integrated command and resource sharing. The agenda also promotes closer alignment between prevention and clinical care through cross-training, data integration, and clearer public-health roles for hospitals. Multisectoral collaboration, community engagement, and strengthened workforce development are supported by newly established Academies of Preventive Medicine [18]. Traditional Chinese Medicine remains integrated across primary care, rehabilitation, and chronic disease management.

China's total health expenditure has continued to rise alongside broader health-system reforms. By 2023, the country's health spending reached 7.2% of gross domestic product, reflecting sustained government prioritization of health investment. Public financing – including government budgets and SHI – remains the dominant funding source, while out-of-pocket expenditure fell to 27.3%, a substantial decline from 59% in 2000,

[7] National Bureau of Statistics of China. Official statistics. 2025 (In Chinese). Accessed 09.12.2025. https://www.stats.gov.cn/

driven by expanded insurance coverage, equalization of public-health services, and strengthened pharmaceutical governance [19].

Since the establishment of the NHSA in 2018, strategic purchasing and payment reforms have accelerated. A key priority has been reducing dependence on fee-for-service, previously associated with cost escalation and provider-induced demand. National roll-out of diagnosis-related groups, diagnosis-intervention packet payments, global budgets, and capitation for primary care is underway, aiming to align provider incentives with efficiency, quality, and value. Complementary reforms in public hospitals – including strengthened performance evaluation, centralized procurement of medicines and high-value consumables, and elimination of profit-linked drug mark-ups – seek to curb cost growth and enhance accountability [20, 21]. These combined financing and governance reforms form the core of China's shift toward a more equitable, efficient, and sustainable health system.

Russia's health system

The Russian Federation, with over 17 million km^2 of territory and approximately 146 million inhabitants[8], spans eleven time zones and encompasses a wide range of climatic, geographic, and socio-economic conditions. To serve its entire population, Russia has built a multilayered healthcare system – from medical outposts in remote villages to federal research institutes in major cities – ensuring universal access.

Under the Constitution of the Russian Federation, every citizen has the right to health protection and medical care[9]. Additionally, it specifies that "medical care rendered in state or municipal healthcare institutions shall be provided free of charge to all citizens, financed through corresponding budgets, insurance payments, and additional revenue sources."

The constitutional guarantee of accessible medical care for Russian citizens is further reinforced by the Mandatory Health Insurance System. This system serves as the cornerstone for securing universal coverage of healthcare services nationwide. According to Federal Law No. 323-FZ (2011), citizens are entitled to receive medical care free of charge within the scope defined by the State Program for Guaranteed Free Medical Care. This encompasses a wide spectrum of care options, ranging from PHC services to highly specialized treatments and cutting-edge medical procedures[10].

Federal Law No. 323-FZ delineates the institutional framework for establishing state-backed guarantees that ensure the availability of free medical care for all citizens. It mandates the formulation of Regional Programs of State Guarantees, thereby operationalizing these commitments at the subnational levels across Russia[11]. The organizational structure of the healthcare system in the Russian Federation consists of three tiers. This division reflects differentiation based on accessibility and complexity of medical services provided to the population.

The origins of PHC in Russia can be traced to Nikolai Semashko, regarded as the architect of the first state-run health protection system. Through his efforts, he created a new healthcare model focused

[8] Russian Federal State Statistics Service. Population (01.01.2025) resident population estimate. Accessed 09.12.2025. https://eng.rosstat.gov.ru/

[9] Russian Federation. Constitution of the Russian Federation. Accessed 09.12.2025. https://mid.ru/upload/medialibrary/fa3/xwhwumdwunawy9iprvhcxdqds1lzxqdx/CONSTITUTION-Eng.pdf

[10] Федеральный закон от 21.11.2011 г. № 323-ФЗ. Об основах охраны здоровья граждан в Российской Федерации [Russian Federation. Federal Law No. 323-FZ of November 21, 2011. On the Fundamentals of Citizens' Health Protection in the Russian Federation] (in Russian). Accessed 09.12.2025. http://government.ru/docs/all/100186/

[11] Ibid.

on safeguarding public health, extending lifespan, and preventing diseases. The principles formulated by N.A. Semashko in 1918 remain applicable in many countries today [22]. Key elements include universal accessibility and free-of-charge medical aid of all types, priority attention given to childhood and maternity, preventive focus in health protection, elimination of social roots of illness, unity between medical science and practice, prevention and treatment, public character of healthcare, continuity in rendering medical care.

These principles formed the basis of the Alma-Ata Declaration adopted on September 12, 1978, during the International Conference on PHC conducted by World Health Organization[12]. The Alma-Ata Declaration was a landmark event in the history of public health in the twentieth century, defining PHC as the cornerstone for achieving the global objective of "Health for All" and emphasizing its importance as the foundation of global healthcare systems.

Today's healthcare model builds upon historical experiences and multilevel characteristics adapted to the territorial peculiarities of different regions. Thus, the current system incorporates several distinctive traits: provision of PHC characterized by comprehensiveness and implemented via polyclinics, rural health posts, and family doctors; emphasis on disease prevention, early diagnosis, and continuous medical care; reinforcement of outpatient services, home visits, and digital technologies to enhance accessibility and efficiency.

Contemporary Russian healthcare operates along a three-tier structure [23]. At the first tier are medical organizations primarily offering PHC, including primary specialized medical assistance: Central District Hospitals, district hospitals, clinic-hospitals, ambulatory clinics, city hospitals, urban polyclinics. These establishments play a vital role in preventing diseases, diagnosing, and treating most illnesses at early stages. Regular check-ups, vaccinations, treatment of minor illnesses, and referrals to specialists when needed are part of their routine activities.

Second-tier institutions provide mainly specialized medical care, housing either inter-municipal divisions or centers, as well as district and city dispensaries, multi-profile city hospitals. Equipped with appropriate technology, these entities enable diagnostics and treatment for a broad range of conditions, additionally offering consultations with narrow-specialized physicians.

Third-tier facilities deliver specialized medical care alongside those providing high-technology medical services, including regional (oblast, krai, republican) hospitals, children's hospitals, research institutes, and university clinics. Specializing in highly qualified and technologically advanced medical care, these institutions treat severe illnesses and perform unique operations using cutting-edge techniques and equipment. Thus, the three-tier healthcare system operating at the regional level allows for optimal allocation of resources and services depending on patient disease severity. Each tier interacts continuously, providing comprehensive medical assistance to every citizen.

The Russian Federation ensures universal access to medical services for its entire population, which is supported by a multifaceted governance structure, where different levels of administration fulfil distinct yet complementary roles in organizing and supervising healthcare delivery[13].

At the helm of this system sits the Ministry of Health of the Russian Federation, charged with crafting and implementing the national

[12] World Health Organization. Declaration of Alma-Ata. 1978. Accessed 09.12.2025. https://cdn.who.int/media/docs/default-source/documents/almaata-declaration-en.pdf

[13] Федеральный закон от 21.11.2011 г. № 323-ФЗ. Об основах охраны здоровья граждан в Российской Федерации [Russian Federation. Federal Law No. 323-FZ of November 21, 2011. On the Fundamentals of Citizens' Health Protection in the Russian Federation] (in Russian). Accessed 09.12.2025. http://government.ru/docs/all/100186/

healthcare policy. The Ministry of Health sets industry-wide standards for medical services and coordinates the nationwide operations of healthcare institutions. Importantly, at the federal level, national medical research centers, top-ranked medical universities, and the Federal Biomedical Agency play integral roles. These institutions provide expert guidance, drive medical innovation, formulate clinical recommendations, and conduct training for healthcare professionals.

Underpinning the system is the Mandatory Health Insurance Scheme, administered by the Federal Mandatory Health Insurance Fund. This fund shoulders the financial burden of medical care, ensuring that Russian citizens do not face additional costs when accessing healthcare.

Ensuring quality in medical services falls under the purview of Roszdravnadzor, the Federal Service for Healthcare Oversight. This agency rigorously monitors compliance with healthcare standards, performs inspections of medical institutions, and introduces innovative measures to enhance service quality.

Executive authorities in the healthcare sector of Russia's 89 constituent entities or regions assume responsibility for organizing and delivering medical services at the regional level. These authorities must implement federal healthcare policies, customizing them to match regional realities, coordinate the work of local medical institutions, secure citizens' access to medical services, and enforce compliance with established standards. Operating in close collaboration with federal agencies, regional authorities contribute to a cohesive and comprehensive governance framework.

The Ministry of Health charts the national policy and strategic direction, while regional authorities are tasked with executing healthcare services locally. This dual structure ensures alignment with national objectives while accommodating regional variations in healthcare needs.

Final considerations

The comparative analysis of the health systems of Brazil, China, and Russia highlights both shared foundations and significant institutional diversity, reflecting distinct historical trajectories, political economies, and governance arrangements. Despite these differences, the three countries converge around a strong role of the State in health system organization and a formal commitment to universal access to health care.

A key similarity lies in recognizing health as a public responsibility, anchored in constitutional or legal frameworks that guarantee access to a defined set of services. In all three countries, public authorities play a central role in financing, regulating, and coordinating health systems, even as mixed provision and private actors coexist to varying degrees. Moreover, Brazil, China, and Russia have invested in nationwide service delivery networks, large-scale public health infrastructures, and mechanisms to expand population coverage, reflecting an understanding of health systems as strategic components of social protection and national development.

At the same time, important differences emerge in institutional design and policy orientation. SUS is distinctive for its rights-based foundation, high degree of political-administrative decentralization, and institutionalized mechanisms of social participation, which embed democratic governance into health policymaking. China's health system stands out for its strong central steering capacity, rapid scaling of SHI coverage, and recent advances in strategic purchasing, digital health, and disease-control system reform, although persistent regional inequalities and hospital-centered care remain challenges. Russia's

system, shaped by the Semashko legacy, combines universal coverage through mandatory health insurance with a hierarchical, territorially organized service delivery model, that emphasizes continuity of care, prevention, and state-led coordination across vast and heterogeneous regions.

These differences illustrate multiple pathways toward universal health systems strengthening, challenging linear or prescriptive models. They also underscore how historical legacies, state capacity, territorial characteristics, and political priorities shape the balance between centralization and decentralization, preventive and curative care, and public and private roles within health systems.

From a global health perspective, the experiences of Brazil, China, and Russia offer important lessons at a time of increasing uncertainty in multilateral governance and renewed emphasis on national health system resilience. The COVID-19 pandemic reinforced the strategic importance of robust public health capacities, coordinated governance, domestic production of essential health technologies, and integrated surveillance and response systems – areas in which BRICS countries have accumulated relevant, though uneven, experience.

In this context, cooperation among BRICS health systems holds significant potential. Comparative findings reinforce the strategic importance of structured cooperation among BRICS countries in areas such as pharmaceutical production, digital health governance, workforce training, and strengthening PHC. Research collaboration and policy dialogue within BRICS networks can further support the exchange of institutional innovations and context-sensitive solutions, reinforcing South – South cooperation in health.

Ultimately, the cases of Brazil, China, and Russia demonstrate that strengthening health systems in the Global South requires not only technical solutions but also political commitment to universality, equity, and public stewardship. By fostering cooperation grounded in shared challenges and diverse institutional experiences, BRICS countries can contribute to advancing alternative approaches to health system development and to reshaping global health debates in favor of more inclusive, solidarity-based models.

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REVIEW

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From global experience to the Russian future: strategic vectors for the development of pediatric hematology and oncology

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The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.
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ABSTRACT

The article focuses on the analysis of current issues and challenges facing pediatric oncology and hematology. Data on cancer incidence in children at the level of economic development of the state, relative to the healthcare model are provided. The main characteristics of oncological care systems in economically developed countries and in developing countries around the world are identified, and the features of the Russian model are emphasized. Particular attention is paid to recent technologies and development vectors of molecular-targeted, cell therapy, precision surgery. The role of information technology and digital transformations in increasing the efficiency of healthcare models for providing oncological care to children in Russia is shown. National and foreign experience convincingly proves that a breakthrough in pediatric oncology is possible only with a systematic approach combining scientific innovations with access to medical care. Russia, being at a unique stage of development, demonstrates both significant successes in the field of high technologies and persistent structural problems. Thus, the key vector of development is not only the introduction of individual innovations but also solving

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fundamental tasks of standardization, overcoming regional inequality, and developing personnel potential, which will allow fully realizing the accumulated scientific and clinical potential.

Key Words: pediatric oncology; oncohematology; healthcare system; model challenges; medical technologies; molecular and cellular treatment methods; oncosurgery; prospects

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Introduction

Pediatric oncology and hematology remain one of the most rapidly developing fields in modern medicine. Despite the achievements of recent decades, malignant neoplasms (MN) in children continue to be a leading cause of mortality from non-communicable diseases. A key challenge is the pronounced inequality in survival rates: in high-income countries (HICs), the 5-year survival rate exceeds 80%, while in resource-limited countries it does not reach 30%.

Modern systems of care for children with oncohematological diseases are directly dependent on the level of infrastructure, availability of highly qualified personnel, and innovative technologies. In the modern world, progress is driven by the standardization of therapy protocols, initiation and participation in multicenter studies, and the implementation of precision and personalized medicine. Persistent barriers, found almost everywhere, are primarily related to late diagnosis and a shortage of qualified specialists. Russia currently occupies a unique position: on one hand, major federal centers have accumulated extensive experience in hematopoietic stem cell transplantation (HSCT), gradual digitalization is occurring, and new treatment methods are being introduced; on the other hand, disparities in the quality of care between federal centers and regions have not yet been fully overcome, and charitable organizations continue to play a significant role in financing medical care. Prospects for development in this area are associated with accelerating the pace of technological transformation of the industry, digitalization, the establishment of national registries, the development of genomic technologies, and expanding access to targeted and cellular therapies.

The international landscape of pediatric hematology and oncology: achievements and challenges

Modern pediatric oncology and hematology represent a field of medicine where scientific achievements stand in sharp contrast to global inequality in access to healthcare. On one hand, it is a story of triumph: thanks to decades of international collaboration and systematic clinical research, in HICs, the 5-year survival rate for children with cancer has exceeded 80%, especially for acute lymphoblastic leukemia (ALL) (Table 1) [1, 2]. On the other hand, these successes remain virtually inaccessible to the vast majority of the world's children living in low- and middle-income countries (LMICs). This disparity is due not so much to tumor biology

Table 1. Evolution of overall survival in children with acute lymphoblastic leukemia [1, 2, 4]

Protocol	Number of patients	5-year survival, %
BFM-90	469	68%±3%
MB-91	460	72%±2%
MB-2002	1544	76%±1%
MB-2008	3466	86%±1%

Note: 5-year survival is represented as mean ± standard deviation. BFM – international clinical protocol of treatment patients with acute lymphoblastic leukemia The Berlin–Frankfurt–Münster consortium; MB – International clinical protocol of treatment patients with acute lymphoblastic leukemia Moscow–Berlin.

as to fundamental differences in the organization, funding, and functioning of national healthcare systems [3].

The high-income countries model

Healthcare delivery systems in HICs (North America, Western Europe, Australia) are characterized by several key principles that have enabled therapeutic breakthroughs:

- Large research groups and standardization of therapy protocols. The foundation of success has been the creation of cooperative groups (e.g., Children's Oncology Group in the United States of America, the Berlin–Frankfurt–Münster consortium in Europe, the Moscow–Berlin protocol in Russia), which has allowed for large-scale randomized clinical trials, rapid data accumulation, protocol standardization, and finding effective solutions even for rare tumors [5, 6].
- Patient risk stratification. Modern treatment is based on the principle of therapy individualization depending on various clinical and molecular-genetic parameters. Using high-precision methods, including genetic techniques and minimal residual disease assessment, patients are stratified into risk groups. This allows for reducing therapy intensity and subsequent toxicity for patients with a favorable prognosis and, conversely, applying more aggressive approaches for high-risk patients, thereby increasing the chances of cure [7].
- Reduction of therapy toxicity. As overall survival has increased, the system has faced a new challenge – the "cost of cure." Aggressive therapy in the 1970s–80s led to a high frequency of severe adverse reactions (secondary tumors, cardiomyopathies), resulting in reduced quality of life and increased mortality among survivors. Analysis of these long-term consequences within studies such as the Childhood Cancer Survivor Study became the basis for revising protocols and modifying therapy. Targeted reduction of doses, the volume of radiation therapy, and cumulative doses of anthracyclines led to a statistically significant reduction in mortality among patients treated in the 1990s compared to the 1970s [7].
- Funding. Treatment is typically covered by national or private health insurance systems, ensuring a high level of access to expensive drugs and technologies [3].

The main challenge for systems in HICs today, and Russia is no exception, is the treatment of complex cases (early relapses, as well as refractory tumors) and further personalization of therapy (Table 2).

The low- and middle-income countries model

In most countries of Asia, Africa, and Latin America, the care system is fragmented and faces barriers at every stage of the "treatment cascade."

Table 2. Key characteristics of medical care models for children with malignant neoplasms worldwide

Parameter	HICs (USA, Europe, Canada), incl. Russia	LMICs (Asia, Africa, Latin America)	"Hybrids" (India, Latin America, Africa)
System organization	Integrated, multicenter networks (cooperative groups), standardized protocols	Fragmented systems, weak routing, infrastructure deficit	Centers of "excellence hubs," public-private partnerships, twinning programs
Diagnostics	Access to modern molecular and genetic diagnostics, minimal residual disease assessment	Access to molecular-genetic diagnostics is limited	Modern diagnostics available in major centers
Funding	Government or insurance coverage, access to expensive therapy	Lack of universal insurance, out-of-pocket expenses (up to 60%)	Mixed: government programs + NGOs + international grants (St. Jude, GFAOP, foundations)
Quality of therapy	Risk-stratified therapy, access to transplantation, CAR-T	Lack of standard protocols, personnel shortage, high mortality	Some protocols adapted, staff training, improving quality in pilot centers
5-year overall survival	>80–90% (for ALL in leading centers)	<30-40% on average, with wide variation (<25% in Africa)	In successful centers, approaches HIC levels
Main challenges	Complex cases, integration of costly innovations, minimizing late complications	Late diagnosis, treatment abandonment, drug shortages, personnel deficit	Scaling up experience, expanding coverage, sustainable government funding
Successful examples	COG (USA), BFM (Europe), CCSS, MB (Russia)	Tata Memorial (India), hospitals in Africa with limited support	Renaci Foundation (Paraguay), Fundación Ayúdame a Vivir (El Salvador), PhilHealth (Philippines), GFAOP (Africa)

Note: HICs – high-income countries; LMICs – low- and middle-income countries; NGOs – non-governmental organizations; GFAOP – Franco-African Pediatric Oncology Group; CAR-T – chimeric antigen receptor T-cells; ALL – acute lymphoblastic leukemia; COG – Children's Oncology Group; BFM – international clinical protocol of treatment patients with acute lymphoblastic leukemia The Berlin–Frankfurt–Münster consortium; CCSS – Childhood Cancer Survivor Study; MB – international clinical protocol of treatment patients with ALL Moscow–Berlin.

Problems and challenges:

- Large-scale of "under-diagnosis". According to models presented in the Lancet Oncology Commission report, up to 44% of all childhood MN cases worldwide remain undiagnosed. In low-income countries, this figure can exceed 55%. This means that for every child diagnosed, there is another who dies without a correct diagnosis and adequate care [3].
- Funding and treatment abandonment. Funding systems in LMICs are extremely heterogeneous. In most, government insurance is absent or covers a small portion of costs. This forces patient families to bear catastrophic out-of-pocket expenditures, which are the main reason for the high rate of treatment abandonment. In some regions, treatment abandonment is the leading cause of death, affecting up to 60% of patients [3, 8, 9].
- Resource deficits and low quality of care. Even if a child reaches a specialized center, they face problems such as: a) a shortage of highly qualified personnel, especially nurses, pathologists, and pediatric oncologists; b) a lack of supportive therapy in the form of safe blood components and drugs, basic antibiotics; and c) a high prevalence of nutritional deficiency (up to 50–70% of patients), which collectively leads to high mortality from toxicity and infections [3, 8].
- Limited access to high technologies: Many countries experience shortages of basic chemotherapy drugs. Access to radiation therapy and qualified surgery is extremely limited; for example, 80% of the African population lacks access to radiation therapy [8, 9].

International experience shows that successful strategies are built on the adaptation and creation of hybrid models based on interaction between major centers and international partners.

The model of "centers of excellence" and the role of partnerships can be illustrated by the examples of African and South Asian countries (India). In countries with huge populations and a deficit of government funding, care has historically developed around individual large centers (e.g.,

Tata Memorial Hospital in India). These centers, often with the support of international partners (twinning programs), achieve good and quality results. The experience of the "My Child Matters" program showed that even local projects focused on training medical personnel, improving diagnostic methods, or organizing palliative care can serve as catalysts for larger-scale changes. Thus, the creation of the African School of Pediatric Oncology was a good and quality response to the personnel deficit; the implementation of this program has trained many highly qualified specialists in pediatric oncology.

Latin American countries: the model of public-private partnership and "network" interaction

The experience of this region demonstrates the high effectiveness of public-private partnerships. In El Salvador and Guatemala, services were created through the cooperation of public hospitals, local foundations, and international partners. A unique example of a solution is the national care network in Paraguay (Renaci Foundation), which united the country's three disparate healthcare systems. The creation of satellite clinics allowed for the decentralization of care and reduced the rate of treatment abandonment for ALL from 17.5% to 0%[1] [3, 9].

Analysis of international experience, summarized in the Lancet Oncology Commission report, showed that modifying the oncology care system could not only prevent over 6 million childhood deaths by 2050 but also bring colossal benefits to the global economy: every dollar invested returns three dollars through the future contribution of surviving patients.

The care system in the Russian Federation: current state and main challenges

Currently, the healthcare system of the Russian Federation faces both traditional, historically established tasks and new ones dictated by modernity. According to expert assessment, the issue of developing and expanding primary medical care remains relevant [10, 11]. A comparative 20-year analysis of the healthcare system in the European Union and the Russian Federation showed that inpatient care still predominates in our country, and the expansion of primary care occurs through hiring new staff rather than expanding their authority. At the same time, researchers note significant growth in preventive measures and successes in early disease diagnosis, as well as a reduction in hospital bed capacity and a decrease in the average length of patient hospital stay. Forming a unified preventive environment requires active state participation, additional funding, and the development of regional programs to combat MN, taking into account local characteristics.

Funding for medical care for children with oncological and onco-hematological diseases in the Russian Federation today is a complex, multi-level ecosystem based on the principle of segmented financial responsibility. This model is not monolithic but consists of four key, complementary elements:

(1) the compulsory medical insurance (CMI) system, covering basic and specialized medical care;
(2) direct budgetary funding from the federal and regional budgets for providing high-tech medical care (HTMC);
(3) the state fund "Krug Dobra" (Circle of Kindness), ensuring access to innovative and orphan drugs, unique medical care technologies;

[1] Gupta S, Howard SC, Hunger SP, et al. Treating childhood cancer in low- and middle-income countries. In: Gelband H, Jha P, Sankaranarayanan R, Horton S, eds. Cancer: Disease Control Priorities, Third Edition (Volume 3). The International Bank for Reconstruction and Development / The World Bank; 2015. Accessed 20.11.2025. https://openknowledge.worldbank.org/server/api/core/bitstreams/62c36567-a0c0-52c4-9720-85b1dfcbbd69/content

(4) the non-governmental sector represented by charitable foundations, compensating for systemic gaps and providing non-medical support.

The foundational document securing citizens' right to free medical care is the Constitution of the Russian Federation. Federal Law No. 323-FZ of November 21, 2011, "On the Fundamentals of Protecting the Health of Citizens in the Russian Federation," establishes constitutional guarantees in the field of healthcare and serves as the legal basis for all subsequent programs and funding mechanisms. The relevance of the regulatory framework is maintained by regular amendments; the latest changes, clarifying, in particular, the concept of clinical recommendations, were introduced into the law in July 2025. It is this act that defines the state's guarantee of medical care for neoplasms, creating a legal obligation realized through specific financial instruments discussed below.

An analysis of the four main elements of funding shows that they function not as isolated structures but as elements of a single, albeit complex, integrated ecosystem.

To illustrate their interaction, consider a hypothetical patient pathway:

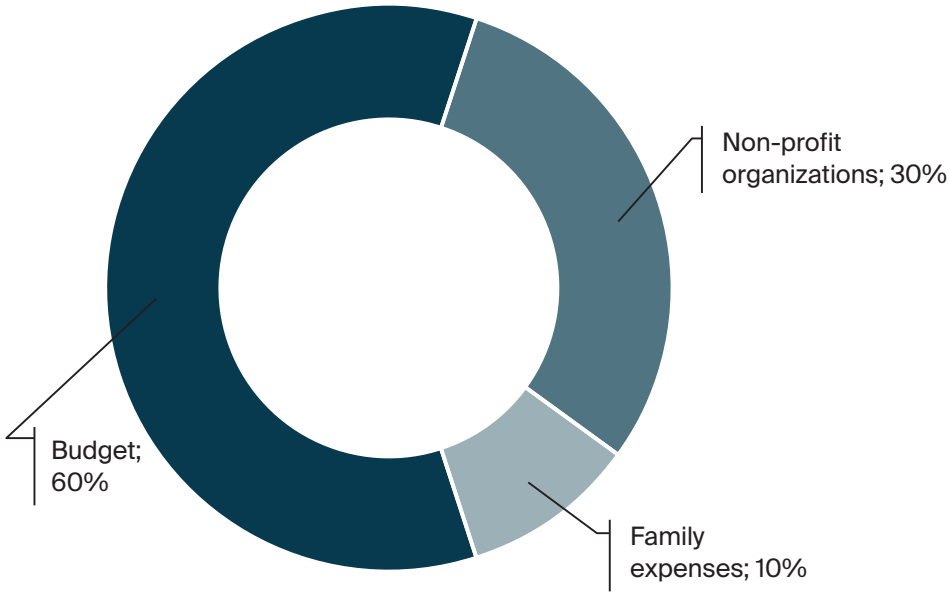
(1) CMI: Primary diagnosis, standard chemotherapy courses, hospitalization, and stay of a legal representative in the ward are paid for from CMI funds according to relevant clinical-statistical groups.
(2) "Krug Dobra": During treatment, it is determined that standard therapy is ineffective, and a medical council prescribes an innovative targeted drug not registered in Russia. An application is sent to the "Krug Dobra" fund, which organizes the purchase and delivery of the drug.
(3) HTMC (Budget): Treatment leads to remission, but its consolidation requires a bone marrow transplant from an unrelated donor. This type of care falls under HTMC, not included in the basic CMI program, and is funded directly from the federal budget.
(4) Charitable Foundations: The family lives in a remote region. A charitable foundation pays for air tickets to the federal center where the transplant will be performed and provides accommodation outside the hospital for the period of post-transplant outpatient observation.

This example demonstrates that all four funding channels may be involved for the successful treatment of one child. The strength of this model is its multi-level nature and ability to provide a comprehensive approach, from basic care to the most advanced technologies and social support. Figure and Table 3 present the structure and volumes of funding for medical care for children with MN.

According to external assessments, our country has noted a necessary focus on the performance indicators of the World Health Organization, which helps identify weaknesses and adjust management decisions. A deficit of motivation and knowledge among pediatricians, as well as their insufficient awareness of MN prevention and early diagnosis, has been identified [12]. This is confirmed by the fact that over 30% of physicians participating in surveys had an insufficient level of knowledge about MN. Also, to reduce mortality and improve treatment outcomes, it is necessary to improve the material and technical base and introduce modern standards of diagnosis and treatment into the regions [13].

Order No. 55n of the Russian Ministry of Health dated 05.02.2021 establishes a three-level system of medical care. It regulates that medical care must be provided in accordance with clinical recommendations and standards. To date, unified standards and professional standards for physicians have been developed and are being implemented, allowing for the unification of approaches to diagnosis and treatment. This is the result of the joint work of the Russian Society of Pediatric Oncologists and Hematologists, Dmitry Rogachev National Medical Research Center

FIG. Structure and volumes of funding for medical care for children with malignant neoplasms



of Pediatric Hematology, Oncology and Immunology, and other federal centers with the support of the National Medical Chamber [14]. The start time for specialized care for oncological diseases should not exceed 14 calendar days, which is an important step in combating the problem of late diagnosis [15].

In modern Russian pediatric oncology and hematology, there is a clear trend towards the formation of multidisciplinary teams, which is essential for treating complex cases. This approach is one of the key components of success through the exchange of accumulated experience, along with the interaction of national centers with leading professional societies both within our country and abroad.

According to the standardized incidence rate of MN among children (0–14 years), the Russian Federation ranks 42nd in the world, with this indicator being 44.7% higher than the global average [16]. Using the Northwestern Federal District as an example, a decrease in mortality and an increase in survival rates are noted [17]. In the period 2005–2010, the 5-year survival rate of adolescents with MN (15–17 years) was 68.1%, and in 2011–2020 it was already 73.4%. This demonstrates a positive trend in the system of pediatric oncology care. Nevertheless, despite improvements in diagnostics, the problem of late detection of MN remains;

Table 3. Funding sources and volumes for pediatric oncology care in the Russian Federation (estimated)

Funding source	Funding volume	Note
Compulsory medical insurance (oncology part)	389.9 billion rubles	Targeted budget within CMI for all oncology care (adult and pediatric)
“Krug Dobra” fund	218.9 billion rubles	Total fund budget for 106 severe and orphan diseases, including oncological
High technology medical care (HTMC, oncology part)	~32.7+ billion rubles (estimated)	Estimation is based on 2024 data (32.7 billion rubles) considering general HTMC budget increase in 2025
Non-governmental funds	> 2.2 billion rubles (estimated)	Estimation is based on annual expenses of the largest specialized fund “Podari Zhizn” (Give Life) in 2024

Note: CMI – compulsory medical insurance; HTMC – high-tech medical care.

the rate of active detection is 4.7–7.9% (compared to over 20% in the adult population). This dictates the need to make efforts to improve the system of early screening and increase oncological alertness among physicians.

The current agenda in pediatric oncology and hematology in Russia is closely linked to the implementation of the National Project "Healthcare," specifically the federal project "Combating Oncological Diseases" [18]. Initially, pediatric oncology was not explicitly highlighted in this project, but a decision was later made to include it, which allowed for significant funding from 2021. From 2025, new federal projects are taking over, particularly "Family" and "Long and Active Life," which, within the framework of the "Protection of Motherhood and Childhood" program, are designed to ensure the further development of high-tech medical care for children. Thus, national projects serve as a key tool for the systemic development of pediatric oncology and hematology in Russia, providing its funding and infrastructure renewal.

Having analyzed the models, from integrated systems in HICs to fragmented approaches in LMICs, it is important to determine Russia's place in this global landscape. The domestic healthcare system combines features of both models: the presence of powerful federal "centers of excellence" comparable to the best world centers, and systemic challenges characteristic of resource-limited countries, especially at the regional level. Let's examine these features in detail.

Vectors of transformation in pediatric oncology and hematology: from innovative therapy to digitalization

Innovative approaches in therapy

Russia is actively introducing new, as well as modernizing and improving existing approaches to therapy in pediatric oncology and hematology. Among the main therapeutic directions, targeted drugs, immunotherapeutic and transplantation approaches stand out, allowing for a significant improvement in prognosis even for the most complex patient categories.

Targeted and immunotherapy

Among cases of malignant diseases, there are frequent instances where standard therapy approaches based solely on chemotherapy are powerless, which necessitates the search for new methods. Thus, following foreign experience, the inclusion of rituximab in the standard protocol for the treatment of relapsed B-cell non-Hodgkin lymphomas in our country has increased the 10-year event-free survival to 93.8% [19]. Similarly, blinatumomab is actively used for the treatment of relapsed acute lymphoblastic leukemia (ALL), serving as a "bridge" to HSCT and allowing the achievement of remission in the majority of patients. Early inclusion of blinatumomab in the ALL-REZ 2016 protocol showed an increase in event-free survival by more than 2 times compared to the ALL-REZ 2014 protocol.

Modern, highly effective approaches to the treatment of relapsed and refractory forms of Hodgkin's lymphoma (HL) are also successfully applied. The use of the GVD (gemcitabine, vinorelbine, pegylated liposomal doxorubicin) protocol in combination with pembrolizumab showed high efficacy, allowing more than 2/3 of patients with HL relapse to achieve a complete metabolic response [20]. The possibility of applying personalized therapy is based on the rapid development of molecular-genetic and cytogenetic research methods, thanks to which

"targets" characteristic of the tumor in a particular patient become clear to physicians. Thanks to this, a system for early prediction of Ewing sarcoma progression, based on clinical, laboratory, and molecular-genetic indicators, has been developed and successfully tested in Russia. This system allows for dividing patients into groups with different risks of progression, enabling treatment personalization [21].

Transplantation technologies

Hematopoietic stem cell transplantation, where healthy, fully functional hematopoietic cells from a donor are transplanted to a recipient, replacing "pathological" hematopoiesis, remains the main method of treating many onco-hematological diseases. In Russia, this method is being actively modernized to achieve a balance between the graft-versus-leukemia effect and graft-versus-host disease. At Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, a platform for HSCT with $\alpha\beta$-T-lymphocyte depletion has been developed and successfully tested, allowing for significant time savings and the use of haploidentical parents as donors. This approach reduced transplant mortality to 2% (compared to 13% in a historical cohort) and accelerated immune reconstitution (recovery of the immune system) [22]. A reduced-toxicity conditioning regimen based on thiotepa and treosulfan for patients with primary immunodeficiencies has also been developed and successfully tested, thanks to which the period after HSCT proceeds with fewer side effects [23].

In the treatment of resistant neuroblastoma at Raisa Gorbacheva Memorial Research Institute for Pediatric Oncology, Hematology and Transplantation (Saint Petersburg), combined RIST (rapamycin, irinotecan, sunitinib, temozolomide) therapy followed by haploidentical HSCT is successfully used, achieving a long-term response in 20% of patients [24]. For consolidation of remission in patients with high-risk solid MNs, tandem HSCT is used. The two-year overall survival in this group is 53.8%, and event-free survival is 46.2%, which is comparable to world data [25].

Cellular technologies

Chimeric antigen receptor T-cells (CAR-T) therapy continues to be actively introduced into clinical practice. This method of cellular therapy is aimed at producing special lymphocytes that recognize and eliminate malignant cells from the patient's body. Experts emphasize its high efficacy in the treatment of relapsed and refractory forms of B-cell ALL.

An important step in solving organizational problems related to the legal aspects of the production and implementation of biomedical cellular products (BMCP) and high-tech medicinal products (HTMP) was the Decree of the Government of the Russian Federation dated December 13, 2024, No. 3736-r [26]. This document approves the list of medical organizations that receive the right to manufacture and apply biomedical cellular products for individual medical use. The list includes 11 institutions, demonstrating strategic support for the development of a local "academic" model of CAR-T production.

The list includes leading research centers located not only in Moscow and St. Petersburg but also in the regions (Novosibirsk, Tomsk, Kazan, Vladivostok). This fact indicates a targeted creation of regional biotechnological clusters. This is a practical response to the need for local production capacities and may become the basis for the further development and expansion of access to cellular therapy in the country.

In the Russian Federation, research and development of CAR-T therapy are conducted in several large scientific and clinical centers.

A distributed network of research and clinical centers working on the implementation and improvement of CAR-T therapy is being formed in Russia, reflecting the strategic importance of this technology for healthcare.

Russia is conducting its own clinical trials of CAR-T (Table 4) [27, 28].

These examples show that pediatric onco-hematology is one of the priority areas in the development of CAR-T therapy in the Russian Federation. The focus on a comprehensive safety assessment demonstrates the responsible approach of Russian scientists to translating CAR-T technologies into clinical practice, which is critically important for patient protection.

High-tech and reconstructive surgery

Surgery in pediatric oncology in Russia goes beyond simple tumor removal, turning into a high-tech direction focused on preserving quality of life. A number of the most dynamically developing oncological surgical vectors can be identified:

- Complex oncological surgery. Russian centers successfully perform the most complex operations for rare tumors, such as calcifying nested stromal-epithelial tumor of the liver. Radical tumor removal through mesohepatectomy and anatomical liver resection is the only effective treatment method, and its successful performance without complications demonstrates the high level of qualification of surgeons [29].
- Minimally invasive methods. Minimally invasive surgical methods, such as laparoscopy and thoracoscopy, are being actively introduced. They allow reducing the trauma of operations, shortening the postoperative period, and ensuring rapid patient rehabilitation. For example, minimally invasive nephrectomies for kidney tumors comply with all principles of oncological surgery and have a number of advantages over open operations.
- Organ-sparing operations. In the treatment of renal cell carcinoma, the possibility of performing organ-sparing operations without worsening the prognosis is indicated, which allows preserving kidney function, especially in patients with bilateral tumors or a single kidney.
- Reconstructive surgery. Separate attention is paid to reconstructive surgery, including the use of additive technologies, which allows restoring aesthetic and functional characteristics after radical tumor removal, optimizing the organizational model of medical care for this category of patients. The successful application of precision prosthetics technologies based on individual prototyping, “growing” prostheses, and new materials has opened a new chapter in pediatric oncological orthopedics and maxillofacial oncological surgery [30].

Table 4. Clinical trials of CAR-T conducted in the Russian Federation

Study / drug	Organization	Description	Patient groups
MB-CAR-T 19.1	Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology	Academic production of anti-CD19 CAR-T lymphocytes	Pediatric patients with relapsed or refractory B-cell ALL
In-house production and therapy	FSBI “NMRCO named after N.N. Blokhin” of the Ministry of Health of Russia	Academic production of CAR-T lymphocytes	Planned application in pediatric cohort
Utzhefra drug development	FSBI “NMRCH” of the Ministry of Health of Russia	Production of HTMP	Adult patients with B-cell ALL

Note: CD – cluster of differentiation; CAR-T – chimeric antigen receptor T-cells; ALL – acute lymphoblastic leukemia; HTMP – high-tech medicinal products.

Improvement of supportive therapy and rehabilitation

Improvement of supportive therapy and rehabilitation is an integral part of clinical success in the treatment of MN in children. According to modern concepts, it is often properly conducted supportive therapy and the fight against complications that can guarantee a positive outcome of therapy. Here it is also important to highlight a number of areas:

- Nutritional Support. A particularly important subject of observation is the full enteral nutrition of the patient; not always do children retain their previous appetite after such aggressive treatment, and the placement of a nasogastric tube in some cases can represent serious psychological discomfort. Percutaneous endoscopic gastrostomy is successfully used as a minimally invasive and effective method of long-term nutritional support in children with oncological diseases, improving their quality of life and reducing risks associated with other feeding methods.
- Complication Management. Russian centers are developing and implementing methods for treating rare and severe therapy complications: for example, the use of daratumumab has shown high efficacy in the treatment of partial red cell aplasia after HSCT. The drug romiplostim is successfully used to treat severe resistant immune thrombocytopenia in children, allowing to avoid long-term immunosuppressive therapy. The course of infectious complications during periods after chemo- and immunotherapy are frequent but no less dangerous complications that pose a mortal danger to oncological and hematological patients. An important achievement is the introduction of strict protocols for infection control and prevention of infectious complications, which is crucial for the safety and survival of immunocompromised children.
- Psychological Support. For the first time in Russia, a prospective study of the quality of life and subjective well-being of families of patients receiving HSCT was conducted. The results show that the most psychologically difficult stage is the preparation for transplantation, which justifies the need for early and active psychological support. It is noted that a family approach in support is key to successful rehabilitation [31].

Digital transformation

The digital transformation of the healthcare system is one of the strategic priorities of the state policy of the Russian Federation. Unlike the market-oriented model of the United States of America or the decentralized European one, the domestic approach is characterized by the construction of a unified, vertically integrated system with a leading role of the state. A key tool for these changes has been the federal project “Creating a Unified Digital Circuit in healthcare based on the Unified State Information System in Healthcare (EGISZ).” Its goal is to form a holistic digital environment to improve management efficiency, as well as the quality and accessibility of medical care, which is of particular importance for such a complex and high-tech field as pediatric oncology and hematology.

“Unified digital circuit” and telemedicine

The basis of digitalization is the Unified State Information System in Healthcare platform, designed to unite medical organizations of all levels. For pediatric oncology, where treatment lasts for years and often requires the participation of both regional clinics and federal centers, creating a unified information space based on electronic medical records

is critically important for ensuring continuity of therapy. However, a key barrier on this path is the lack of a single standard for medical information systems. The historically established diversity of regional and hospital medical information systems, often incompatible with each other, creates significant difficulties for data aggregation and exchange. For a child with acute leukemia, this may mean that detailed information about conducted chemotherapy courses, results of minimal residual disease monitoring, or arising complications will not be "seamlessly" transferred from the regional dispensary to the federal center, complicating decision-making and increasing risks. The situation is exacerbated by the different levels of technical equipment in the regions.

Against this background, telemedicine consultations in the "doctor–doctor" format are developing most successfully. Leading federal institutions, such as the Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, actively use this tool to maintain communication with regional clinics. Through telemedicine, consultations on complex clinical cases are conducted to correct diagnostic and therapeutic tactics. The potential of "doctor-patient" consultations can be used for discussing control examinations after the main stages of therapy, for dynamic monitoring of children with orphan hematological diseases.

Application of artificial intelligence

Russia demonstrates continuity in mastering technologies based on artificial intelligence, primarily in the analysis of medical images. The Moscow experiment on the use of artificial intelligence for the analysis of radiological studies showed high diagnostic efficacy [32]. In perspective, such technologies can be adapted for the needs of pediatric hematology/oncology, for example, for the primary diagnosis of onco-hematological diseases through the analysis of bone marrow or peripheral blood smears, using computer vision for the analysis of magnetic resonance and computed tomography images.

However, scaling up such programs is limited by two main problems:

(1) Quantitative and qualitative data deficit: Hematological and oncological diseases in children are rare, which makes it difficult to collect sufficient data for training artificial intelligence models. It is also appropriate to mention registry filling; mainly, the attending physician is responsible for filling out registries, but given the high workload on physicians in federal centers, registry filling does not always occur with quality and regularity. In this regard, the creation of representative national datasets requires centralized efforts to collect information.

(2) Lack of specialists in related fields: There is an acute shortage of specialists with competencies at the intersection of pediatric hematology, oncology, and data science, which are necessary for the development and clinical validation of such complex systems.

National registries: potential and risks

The next stage in the development of the patient accounting system was the creation of vertically integrated medical information systems (VIMIS), in particular, for the "Oncology" profile, which includes pediatric patients. VIMIS are complex analytical tools for collecting clinical data in real-time.

The potential of VIMIS for pediatric oncology is enormous; the accumulated anonymized data ("Big Data") can become the basis for conducting quality multicenter research, allowing for the assessment of protocol effectiveness, analysis of various outcomes, and the formation

of patient cohorts for studying the long-term consequences of therapy, by analogy with international studies.

However, the main challenge for the effectiveness of VIMIS is ensuring the completeness and quality of primary data. The high administrative burden on physicians combined with their different levels of digital literacy creates a risk of entering incomplete or heterogeneous information. In pediatric hematology/oncology, where treatment protocols are multi-stage, poor-quality registry filling can completely devalue the record for subsequent analysis, posing risks of distorting conclusions both in the managerial and scientific spheres.

Conclusion

National and foreign experience convincingly proves that a breakthrough in pediatric oncology is possible only with a systematic approach combining scientific innovations with access to medical care. Russia, being at a unique stage of development, demonstrates both significant successes in the field of high technologies (HSCT, CAR-T) and persistent structural problems. Thus, the key vector of development is not only the introduction of individual innovations but also solving fundamental tasks of standardization, overcoming regional inequality, and developing personnel potential, which will allow fully realizing the accumulated scientific and clinical potential.

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MEETING REPORT

Rare diseases as a global priority: the CIS Orphan Forum and the path toward collaboration with BRICS

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ABSTRACT

The Second Orphan Forum of the Commonwealth of Independent States, held in Moscow on June 26–27, 2025, served as a platform to translate World Health Assembly Resolution 78.11 on rare diseases into coordinated policy action. The Forum convened delegates from eight Commonwealth of Independent States members and representatives from India, the United Arab Emirates, South Africa, and Oman, advancing interregional cooperation.

Participants highlighted shared challenges: lack of national strategies and harmonized definitions of rare diseases, gaps in diagnostics and care infrastructure, limited registries, shortages of trained specialists, and unstable funding. The adopted Resolution set four priority domains for joint work: policy and regulatory development; organization of care

and workforce capacity; pharmaceutical provision and health technology assessment; and international collaboration.
Country presentations showed progress alongside persistent gaps. Priorities include expanding screening, establishing centers of expertise, improving patient pathways, extending reimbursement, introducing accelerated regulatory procedures, and updating clinical guidelines. Recommendations emphasize integrated care, continuity from pediatric to adult services, stronger health technology assessment for orphan medicines, real-world data collection, and managed entry and risk-sharing agreements.
The Forum also concluded that closer cooperation on rare diseases is needed within BRICS, especially to improve the efficiency of orphan medicine development, manufacturing, and procurement through coordinated approaches, demand aggregation, and joint price negotiations.

Key Words: orphan diseases, CIS Orphan Consortium, reimbursement policy, joint procurement, orphan medicines, regulatory harmonization

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Introduction

Rare diseases comprise a heterogeneous group of over 6,000 conditions, most of which are genetic in origin and manifest during childhood. Although each disease is rare (on average 1 case per 2,000 people), collectively they affect between 3.5 and 5.9 percent of the world's population (more than 450 million individuals) [1]. Effective therapies exist for fewer than 5% of these conditions, while the annual cost of treatment often exceeds 300,000–400,000 US dollars (USD) per patient [2]. Diagnostic delays, insufficient clinical expertise, and lack of integrated social support make rare diseases not only a medical but also a socioeconomic challenge.

In May 2025[1], the World Health Assembly (WHA) adopted Resolution WHA 78.11, officially elevating rare diseases to a global health priority. The Resolution emphasized the need to integrate rare diseases into national health strategies, expand screening programs, establish centers of excellence, national and regional registries, and innovative ways of funding. It lays the foundation for the ten-year World Health Organization (WHO) Global Action Plan on Rare Diseases, aimed at embedding rare diseases policy within Universal Health Coverage.

For the Commonwealth of Independent States (CIS) region, these priorities are of particular relevance. Despite growing interest, most states still lack comprehensive national strategies, legal definitions, or long-term funding models [3]. In 2024, the CIS Orphan Consortium was

[1] World Health Organization. Rare diseases: A global health priority for equity and inclusion. Accessed 11.12.2025. https://apps.who.int/gb/ebwha/pdf_files/WHA78/A78_R11-en.pdf

established as a multi-country platform bringing together experts, patient organizations, and regulators to coordinate policies and act as the WHO's regional partner in shaping the WHO Global Action Plan.

The II CIS Orphan Forum (Moscow, June 26–27, 2025) became the first regional event focused on implementing the WHA Resolution and strengthening collaboration with BRICS. Delegations from eight CIS countries (Republic of Azerbaijan, Republic of Armenia, Republic of Belarus, Republic of Kazakhstan, Kyrgyz Republic, Russian Federation, Republic of Tajikistan, Republic of Uzbekistan) participated alongside partners from India, the United Arab Emirates (UAE), South Africa, and Oman, creating a CIS–BRICS interregional dimension.

Opening the Forum, Ulrike Schwerdtfeger (Figure 1), Technical Lead for Rare Diseases at the WHO, presented the key priorities of Resolution WHA 78.11, the first-ever resolution on rare diseases discussed and adopted by the WHA.

Among the matters of high importance for WHO Member States as reflected in the resolution are the need for integration of rare diseases into national health systems including in national health policies and programmes; the urgent need for cross-sector collaboration to foster innovation in research and innovative diagnosis and treatment; the establishment of national, regional and international centers of excellence as specialized hubs for care, research and training for rare diseases, human resource capacity; the use of interoperable codification systems for rare diseases; the establishment of national and regional registries; patient engagement mechanisms and the adoption of innovative ways of funding and resource mobilization.

She also announced that WHO, in consultation with its Member States and other stakeholders, including patient organizations, will develop a draft 10-Year WHO Global Action Plan on Rare Diseases.

FIG. 1. Ulrike Schwerdtfeger, Technical Lead Rare Diseases at the WHO, presenting online

Note: Alexander Rumyantsev, President of CIS Orphan Consortium, President of the Federal State Budgetary Institution "Dmitry Rogachev National Medical Research Center for Pediatric Hematology and Oncology" of the Ministry of Health of the Russian Federation, Academician of the Russian Academy of Sciences and Elena Shamal, Advisor to the Department for Cooperation in Political, Humanitarian and Social Spheres of the CIS Executive Committee, Secretary of the Council for Cooperation in Healthcare of the CIS co-chairing the plenary session.

In preparation for the development of the Global Action Plan, WHO will map existing WHO standards, guidelines and protocols relating to rare diseases, and identify technological innovation opportunities (including e-health, m-health, digital and artificial intelligence solutions) to centralize clinical health information for diagnostics and treatment. To support improved access to diagnosis and care, WHO will also identify centers of excellence around the world able to cluster clinical work in rare disease groups and to act as hubs to exchange experience and clinical knowledge and provide peer-to-peer medical advice, including across borders[2].

Thus, the Forum became a pivotal mechanism for translating WHO's global principles into regional practice. Its agenda, ranging from national policy and regulatory frameworks to health technology assessment (HTA), real-world data (RWD)/real-world evidence (RWE), and financing, defined the contours of the future rare disease care ecosystem in the CIS and BRICS regions as an integral part of implementing Resolution WHA 78.11.

Plenary session I. Rare diseases in the focus of national strategy: coordination of efforts and development priorities

The first plenary session of the II CIS Orphan Forum opened a central discussion on the practical implementation of the WHA Resolution WHA 78.11. The session gathered representatives of the World Health Organization, ministries of health of CIS member states, the CIS Executive Committee, and international partners.

In the welcoming address, the Minister of Health of the Russian Federation, Mikhail Murashko, emphasized that the adoption of the WHA Resolution marks a new stage in consolidating global responsibility for rare diseases and reinforces the moral and political commitment of national health systems to ensure equal access to care for all patients.

Academician Alexander Rumyantsev, President of the CIS Orphan Consortium, recalled that the first Forum in 2024 initiated the creation of the Consortium, which now unites more than 20 leading medical centers and patient organizations. He stressed that the 2025 Forum had evolved into an interregional platform where the CIS and BRICS act as a unified area of shared responsibility for patients with rare diseases.

Delegates from CIS member states presented reports on the current status of medical care for patients with rare diseases. Kazakhstan demonstrated the country's transition from fragmented measures to a systemic model: 56 clinical protocols for diagnosis and treatment have been approved, national screening programs implemented, and a Republican Coordination Center and national patient registry established.

The Russian Federation's report underlined that Russia is building a comprehensive, multi-level system of care for rare disease patients from neonatal screening and federal expert centers to centralized pharmaceutical supply and the "Circle of Kindness" Foundation, which ensures equitable access to therapy for all children in the country.

[2] Schwerdtfeger U. World Health Assembly Resolution WHA78.11: Rare Diseases – A Priority for Global Health Equity and Inclusion [Online presentation]. II Forum of CIS Countries on Orphan Diseases. CIS Orphan Consortium. Accessed 11.12.2025. https://en.orphan-cis.net/events/92/

The representative of Uzbekistan highlighted the importance of multidisciplinary teams and integration with social services, while Kyrgyzstan emphasized the need to legally define the national list of rare diseases and establish its own regulatory framework in this field.

Plenary session II. The future of rare disease therapy: new technologies, accessibility, and partnership across the CIS, BRICS, and the Middle East

The second plenary session became the central international segment of the Forum and the first platform where the rare disease agenda was discussed within the context of the global technological and economic trends of the BRICS countries. The session focused on developing a joint sustainable model of access to innovative therapies, using instruments such as HTA, RWD/RWE, multi-criteria decision analysis (MCDA), centralized price negotiations and procurement, and mechanisms for collaborative research.

India

Prasanna Kumar Shirol (Figure 2), Co-Founder and Executive Director of the Organization for Rare Diseases India (ORDI), presented India's evolving experience in shaping a comprehensive national policy for rare diseases and the potential for extending this framework through cooperation within BRICS. Drawing on his dual perspective as both an advocate and a parent of India's first Pompe disease patient, Shirol described how patient-led activism in India has become a catalyst for policy reform, infrastructure development, and public awareness.

He outlined the main pillars of India's National Policy for Rare Diseases (2021), which established a network of Centres of Excellence, created a national registry under the Indian Council of Medical Research, and introduced state-supported treatment for 63 prioritized conditions. This policy, together with judicial advocacy and parliamentary oversight, has ensured a gradual increase in national funding for rare diseases – from pilot grants to a sustained budget line under the Ministry of Health. These developments have been described in prior policy analyses [4, 5]. The Production-Linked Incentive scheme and customs duty exemptions have further encouraged domestic production of orphan drugs and medical devices, reducing dependency on imports and aligning industrial incentives with patient needs.

Shirol emphasized the importance of integrating research, innovation, and access, noting recent initiatives such as the National Consortium for Research and Development on therapeutics for Rare Diseases and a newly announced 1 million USD government prize for the development of a drug for sickle-cell disease. He stressed that India's combination of robust pharmaceutical manufacturing, digital health infrastructure, and active civil society provides a scalable foundation for cross-border collaboration.

In his strategic proposal titled "Rare BRICS: A Collaborative Framework for Rare Diseases," Shirol called for the establishment of a BRICS-wide alliance bringing together regulators, clinicians, researchers, and patient organizations. The initiative would aim to:

- harmonize definitions and orphan-drug designations;
- develop a joint research and manufacturing consortium to focus on priority conditions;

FIG. 2. Prasanna Kumar Shirol, Co-Founder and Executive Director of the Organization for Rare Diseases India

- coordinate Good Clinical Practice standards and facilitate fast-track approval of orphan drugs recognized by any BRICS regulatory agency;
- explore joint procurement and price-negotiation models using existing mechanisms such as Russia's "Circle of Kindness" as templates for sustainable financing;
- advance telehealth, artificial intelligence-based genetic diagnostics, and cross-border training programs to build shared capacity.

Shirol concluded by underscoring that with 40% of the world's population residing in BRICS countries, the bloc has the demographic scale and technological capacity to redefine access to orphan therapies. Coordinated action among BRICS members, he argued, could transform the region into a global innovation hub for rare disease research, development, and equitable care[3].

United Arab Emirates

Dr. Ayman El-Hattab (Figure 3), consultant in clinical genetics and director of the Genetics and Rare Disease Center at Burjeel Medical City (Abu Dhabi), professor at the University of Sharjah

[3] Shirol P. K. BRICS – Way to collaborate. [Online presentation]. II Forum of CIS Countries on Orphan Diseases. CIS Orphan Consortium. Accessed 11.12.2025. https://en.orphan-cis.net/events/92/

and president of the Middle East and North Africa (MENA) Congress for Rare Diseases, outlined the broader context of rare diseases across the MENA region. Although the region is home to more than 600 million people across 24 countries, rare diseases remain under-recognized in public health policy. The majority of conditions are genetic, largely due to high consanguinity rates and large family size, yet registries are scarce, and diagnostic delays are common. Competing health priorities and limited data on prevalence and costs continue to hinder policy development [6, 7].

Focusing on the UAE, Dr. El-Hattab emphasized that the country has emerged as a regional leader in rare-disease policy and an active participant in the evolving BRICS health agenda. The UAE has introduced accelerated orphan-drug registration pathways based on European Medicines Agency and Food and Drug Administration approvals and implemented flexible managed-entry agreements negotiated among the Ministry of Health, Abu Dhabi public healthcare provider SEHA and the Dubai Health Authority [8]. These contracts, mainly financial, with growing use of outcome-based models, address the high cost of orphan

FIG. 3. Dr. Ayman El-Hattab, consultant in clinical genetics and director of the Genetics and Rare Disease Center at Burjeel Medical City (Abu Dhabi), professor at the University of Sharjah and president of the Middle East and North Africa Congress for Rare Diseases

drugs, which remain several times more expensive than conventional therapies. Among key national achievements are the Emirati Genome Project, launched in 2019 to sequence one million citizens; the Genetics and Rare Disease Center at Burjeel Medical City, offering integrated clinical and research services; and the Abu Dhabi Rare Disease Registry, embedded in the Malaffi electronic-health-record system to link clinical and genomic data for policy and research use. Preliminary results from this program have been partially reported [9].

Dr. El-Hattab concluded that the UAE is now entering a phase of "sustainable access," prioritizing national guidelines for orphan-drug designation, cost-effectiveness thresholds for ultra-rare diseases, and joint procurement mechanisms across the region. As a new member of BRICS, the UAE can serve as a bridge between the Middle East, the CIS and other BRICS countries, facilitating alignment of regulatory standards, collaborative clinical trials and equitable access to orphan therapies[4].

South Africa

Dr. Helen Malherbe (Figure 4), Associate Professor at the Centre for Human Metabolomics at North-West University (Potchefstroom), presented South Africa's efforts towards developing a rare-disease framework and its potential role within the BRICS health agenda.

With a population of about 63 million, the country faces a dual burden of communicable and non-communicable diseases, while rare conditions remain largely unrecorded in health statistics. More than 90 percent of congenital disorders go underreported, leaving an estimated 4.2 million people affected by rare diseases alone, with the average diagnostic delay exceeding 5 years, if diagnosed at all [10]. Treatments are scarce and often unaffordable in the public sector. Although South Africa has a strong legislative foundation, including the National Health

FIG. 4. Online presentation by Dr. Helen Malherbe, Associate Professor at the Centre for Human Metabolomics at North-West University (Potchefstroom)

[4] El-Hattab A. W. Rare Diseases in the MENA region. [Online presentation]. II Forum of CIS Countries on Orphan Diseases. CIS Orphan Consortium. Accessed 11.12.2025. https://en.orphan-cis.net/events/92/

Act, the Medicines Act, and the National Health Insurance Act (2023), implementation of rare-disease policy remains fragmented.

Dr. Malherbe noted that the national capacity for medical genetics and counselling remains insufficient, but recent initiatives are beginning to address this gap [11]. Ongoing efforts include the drafting of a National Rare Diseases Framework, work by the established South African Rare Diseases Access Initiative, and active civil-society engagement through Rare Diseases South Africa. Among near-term priorities are completing a rare disease national strategy for implementation by 2027, creating a patient-initiated rare disease population registry and newborn-screening roadmap, extending access to genetic services across all provinces, and embedding rare-disease education into medical curricula.

In her concluding remarks, Dr. Malherbe underscored the importance of strengthening BRICS–CIS collaboration through context-specific approaches rather than importing European models. She proposed creating a joint BRICS–CIS registry platform, coordinated workforce training through virtual fellowships and hospital partnerships, and an open-access policy toolkit for shared strategic planning. South Africa, she argued, could serve as a pilot site for integrated rare-disease services in resource-limited contexts, drawing on its experience in congenital-disorder policy and universal-health-coverage reform. Aligning national actions with the forthcoming WHO Global Action Plan on Rare Diseases would allow South Africa to contribute regional expertise to global progress while advancing equitable access and capacity-building across the BRICS partnership[5].

The plenary discussions also featured contributions from the Sultanate of Oman, which, although not a BRICS member, plays an increasingly important role in linking the CIS and Gulf regions. Dr. Ahmed Al Saidi, former Minister of Health of Oman, outlined the country's healthcare transformation within the framework of Oman Vision 2040 [12]. He explained that the national system, while achieving significant progress in primary and preventive care, continues to face challenges typical for small and mid-income states: limited genetic-diagnostic capacity, high dependence on imported medicines, and the rising cost of treatment for chronic and rare conditions [13]. To address these issues, Oman is expanding regional partnerships in the pharmaceutical and biotechnology sectors, aiming to localize production of essential and high-cost drugs, attract investment, and strengthen quality-control and regulatory capacity. The Ministry of Health also promotes the creation of joint supply chains and pooled procurement initiatives with Gulf and Asian partners to improve affordability and ensure continuity of access. This approach is supported by Dubois et al. (2021), who analyzed pooled procurement procedures for medicines in low- and middle-income countries, including Oman [14]. Dr. Al Saidi emphasized that closer scientific and industrial cooperation between Oman, the CIS and BRICS countries could enhance efficiency, support technology transfer, and increase the sustainability of rare-disease care across the wider Eurasian and Middle Eastern region[6].

Overall, the plenary discussions showed that the CIS and BRICS countries face comparable challenges in organizing care and ensuring access to effective therapies for rare diseases. At the same time, participants proposed practical measures for closer cooperation, including the harmonization of drug registration requirements,

[5] Malherbe, H. Rare diseases in South Africa [Online presentation]. II Forum of CIS Countries on Orphan Diseases. CIS Orphan Consortium. Accessed 11.12.2025. https://en.orphan-cis.net/events/92/

[6] Al Saidi A. II Forum of CIS countries on Orphan Diseases. Transforming Healthcare, Innovations and Challenges In Modern Medicine. [Online presentation]. II Forum of CIS Countries on Orphan Diseases. CIS Orphan Consortium. Accessed 11.12.2025. https://en.orphan-cis.net/events/92/

the development of shared mechanisms for joint procurement, and the exchange of clinical knowledge and professional expertise. The Forum thus marked a transition from fragmented national actions to coordinated regional dialogue, outlining the foundations for a BRICS–CIS Alliance for Rare Diseases aimed at improving availability and equity of treatment across regions.

Nosological and thematic sessions: identified barriers and directions for solutions

The thematic and disease-specific sessions of the second day of the Forum (Figure 5) provided an in-depth analysis of how the challenges of organizing care and ensuring access for patients with rare diseases are reflected across different medical and institutional contexts. Despite diverse national systems, countries of the CIS region demonstrated a shared pattern of fragmentation, limited data, and gaps in continuity of care. The sessions also produced a number of common proposals that were subsequently incorporated into the Resolution of the II CIS Orphan Forum[7].

FIG. 5. Participants of Nosological and thematic sessions 2 days of the II CIS Orphan Forum

[7] Резолюция по итогам II Орфанного форума стран СНГ. Москва, Россия [CIS Orphan Consortium. Resolution of the II Orphan Forum of CIS Countries. Moscow, Russian Federation] (In Russian). Accessed 11.12.2025. https://orphan-cis.net/upload/iblock/ de6/7a5sp3cwz18lq67u6tb4py5r4xo8rudm/Rezolyutsiya_rus.pdf

Bleeding disorders

The session on bleeding disorders served as a model for identifying typical clinical and organizational challenges in rare-disease management. Experts from Russia, Kazakhstan, Tajikistan, Azerbaijan, and Kyrgyzstan emphasized the fragmented referral systems and shortage of specialized centers for hemophilia and other coagulopathies. Key problems include the absence of national registries, unequal access to medicines, and lack of continuity in adult care. Participants called for a transition from on-demand to preventive therapy, the establishment of multidisciplinary teams, and advanced training for hematologists, surgeons, and orthopedists to manage patients receiving modern therapies.

Rare tumors

The session on rare tumors brought together heads of pediatric oncology centers from Russia, Kazakhstan, Belarus, and Uzbekistan. Discussions focused on rare childhood cancers as one of the most complex segments of rare diseases. The main barriers identified were the absence of national registries, diagnostic errors reaching up to 20%, and insufficient laboratory capacity for molecular and morphological verification. Participants underlined the importance of establishing reference centers, developing biobanks, expanding the use of CAR-T therapies, and building interstate expert networks for the joint development of clinical recommendations.

Spinal muscular atrophy

The session on spinal muscular atrophy showcased successful examples of multisectoral collaboration. Russia reported neonatal screening coverage reaching 98 percent, while Kazakhstan and Uzbekistan presented national programs combining state and charitable funding [15]. Persistent problems include weak coordination during transition from pediatric to adult care, the absence of long-term reimbursement mechanisms, and limited registries for outcome monitoring. These challenges correspond to clauses 1.2, 1.4, and 1.12 of the Forum Resolution, which call for the institutionalization of centers, expansion of screening programs, and sustainable sources of financing.

Integration of care for rare diseases: multidisciplinarity and continuity at all stages of life

This session emphasized that rare diseases are inherently complex, often involving multiple organ systems and requiring the participation of specialists from different disciplines. Ensuring integration of care therefore entails several dimensions: interdisciplinary coordination among physicians and allied professionals, vertical integration between levels of care (from primary and specialized outpatient to inpatient services), and horizontal integration between regions and institutions to reduce territorial disparities.

Participants agreed that the most critical challenge lies in maintaining continuity of treatment during the transition from pediatric to adult care. Differences in drug-provision systems and organizational models of medical assistance frequently result in therapy interruptions, undermining the progress and investments achieved during childhood. In the past, few patients with rare diseases survived into adulthood, but earlier diagnosis and effective therapies have changed this trajectory. As the number of adult patients continues to grow, establishing integrated and continuous care pathways has

become a top priority to preserve treatment outcomes and quality of life throughout the patient's lifespan.

Organization of the system of care for rare diseases: orphan centers, regional and national coordinators

Participants from Kazakhstan, Russia, Belarus, Uzbekistan, and Kyrgyzstan confirmed that most CIS countries still lack a formalized network of orphan centers and legally defined responsibilities for coordinators. Problems of patient routing, insufficient staffing, and weak links between medical, rehabilitation, and social services cause loss of continuity and exacerbate regional inequalities. The Resolution recommends establishing national and regional centers, securing their legal status and funding, incorporating rare-disease topics into medical education, and developing telemedicine cooperation among CIS countries.

Medicines reimbursement and health technology assessment

The session gathered experts from various CIS countries who discussed the use of HTA to support decision-making on innovative therapies for rare diseases. While HTA practices exist across the region, they are formally institutionalized only in Belarus, Kazakhstan, and Russia. Speakers pointed to the high level of uncertainty in clinical and economic evidence and the lack of RWD and RWE, particularly for gene and cell therapies, as key limitations. These gaps hinder robust evaluation and make conventional cost-effectiveness thresholds inadequate for rare diseases.

Participants highlighted the need to implement managed entry agreements as a way to combine early access with evidence generation. However, existing regulatory frameworks prevent most CIS countries from using such mechanisms. Belarus remains the only country with practical experience in managed entry agreements for high-cost orphan medicines, while others are exploring similar approaches but require legal reform. The session concluded that regional cooperation should focus on enabling performance-based reimbursement, improving data systems, and advancing toward joint clinical assessments within the Eurasian Economic Union (EAEU) and joint procurement initiatives across the CIS and BRICS frameworks to enhance affordability and access.

Pharmaceutical policy for rare diseases: challenges, approaches, perspectives

This session addressed the absence of harmonized definitions of rare diseases and registration procedures for orphan drugs across the EAEU. Experts noted that the lack of a unified recognition process leads to duplication of evaluations and delays in patient access to therapy. It was proposed to introduce a shared mechanism for granting orphan-drug status at the EAEU level and to include a dedicated chapter on rare diseases in the CIS Model Law on Pharmaceutical Provision.

Role of patient organizations and charitable foundations

The final session underlined the evolution of patient and charitable organizations from advocacy movements to recognized policy partners. Representatives from Russia, Kazakhstan, Kyrgyzstan, and Uzbekistan showed that patient associations are instrumental in monitoring therapy access and promoting expansion of screening programs. The Resolution calls for the institutional support of such organizations and for their involvement in planning and evaluating national rare-disease strategies.

It can be noted that patient organizations for rare diseases in the CIS countries are gaining a level of influence in specific decision-making processes comparable to that in Europe [16, 17].

In summary, the nosological and thematic sessions revealed a unified pattern of systemic challenges across the CIS region: the absence of comprehensive national strategies, legal definitions, and registries; a shortage of specialized personnel; fragmented financing; and weak inter-country coordination. These findings provide the foundation for the next section of the article, which analyzes the systemic barriers outlined in the Resolution of the II CIS Orphan Forum as a roadmap for strengthening regional collaboration on rare-disease policy.

Systemic problems identified following the II CIS Orphan Forum

An analysis of the Forum discussions and the adopted Resolution made it possible to systematize the main barriers hindering the development of effective rare-disease care systems in CIS countries. These challenges are grouped into four categories – regulatory and legal, organizational and infrastructural, pharmaceutical and economic, and analytical and methodological, in accordance with Section II of the Resolution.

Regulatory and legal problems

A clear and predictable regulatory and legal framework is the foundation of rare disease policy: it defines eligibility, establishes official lists and care pathways, and sets rules for funding, access, and accountability. Clear rules matter for every stakeholder: patients gain transparent and equitable access criteria, industry gains predictable requirements and planning horizons for launch and evidence generation, and health systems gain the ability to budget, negotiate, and manage resources more efficiently. In the CIS context, the Forum discussions highlighted several regulatory gaps that prevent rare disease care from developing into a sustainable system:

- Lack of national strategies and action plans for rare diseases. None of the countries in the region has yet approved a comprehensive strategy covering diagnosis, pharmaceutical provision, social support, and workforce development. Policies remain fragmented, decisions ad hoc and short-term, preventing systemic planning and evaluation.
- Inconsistency in definitions and lists of rare diseases. No unified definition or national lists exist. In Armenia, Azerbaijan, Kyrgyzstan, Tajikistan, and Uzbekistan, the regulatory framework is only being developed; in other countries, criteria differ, making statistical comparison difficult and hindering reimbursement-policy design.
- Non-harmonized procedures for determining orphan-drug status. Within the EAEU, orphan status is assigned at the national level, which delays registration and limits access to therapy. The lack of a single procedure reduces the efficiency of the common market and excludes some states from mutual recognition.
- Absence of sustainable financing mechanisms. Funding relies on regional or short-term programs without long-term commitments, creating inequity in access, particularly during transition from pediatric to adult care.
- Inability to implement flexible pharmaceutical-access models. There is no legal framework for managed-entry agreements, conditional reimbursement, or outcome-based payment. Post-marketing monitoring and review of funding decisions are not legislatively secured.

Organization of care and human resources

Rare disease care depends on coordinated service delivery: timely diagnosis, referral to specialized teams, long-term follow-up, and continuity across life stages. Because expertise is scarce and cases are complex, systems typically rely on defined networks of centers, standardized care pathways, and structured workforce development. The Forum discussions showed that in many CIS countries these elements remain informal or fragmented, which directly affects diagnostic delays, treatment continuity, and patient outcomes. The main points of the discussions included:

- Absence of an institutionalized network of orphan centers. In most countries, no legally recognized centers of competence with uniform standards, criteria, and financing exist. Care is delivered through isolated institutions without coordination or patient routing.
- Discontinuity between pediatric and adult services. Transitions occur unsystematically; mechanisms for communication and data transfer are lacking, leading to loss of follow-up and interruption of therapy.
- Workforce shortages and lack of training programs. Rare-disease topics are not included in medical curricula; no standardized postgraduate training or professional standards exist, limiting diagnostic and treatment quality.
- Insufficient cross-sectoral integration. Coordination between medical, social, educational, and rehabilitation services remains informal, and patient pathways often depend on individual initiative rather than institutional design.

Pharmaceutical access and health technology assessment

Access to orphan therapies requires balancing clinical need with financial sustainability under high uncertainty – small trials, limited comparators, and rapidly evolving evidence. HTA and related decision mechanisms help systems make transparent choices, structure price negotiations, and design adaptive access models (including monitoring and reassessment). The Forum discussions underlined that without institutional HTA capacity and real-world monitoring infrastructure, CIS countries struggle to implement consistent, value-oriented access policies for rare disease medicines. The raised concerns were as follows:

- High therapy costs and limited evidence base. Orphan drugs are expensive and supported by limited clinical data, complicating financing decisions in resource-constrained settings.
- Absence of institutionalized HTA structures. In Azerbaijan, Armenia, Kyrgyzstan, Tajikistan, and Uzbekistan, no official HTA agencies or units exist, preventing consistent evaluation and transparency.
- Methodological limitations of existing HTA systems. Even where HTA is operational (Russia, Kazakhstan, Belarus), methods are not adapted to orphan technologies.
- Lack of RWD/RWE systems. All CIS countries experience shortages of patient registries and monitoring mechanisms, making it impossible to review funding decisions dynamically or to use outcome-based models.
- Lack of HTA coordination across CIS countries. No unified methodologies or mutual recognition mechanisms exist, leading to duplicated work, higher costs, and reduced comparability.
- Underutilization of joint-procurement potential. Each country negotiates with manufacturers separately, losing economies of scale. The absence of consolidated negotiation platforms leads to higher prices.

Cross-country cooperation and data

For rare diseases, cross-country collaboration is not an “extra” but a practical necessity: patient populations are small, evidence generation requires pooling data, and negotiating power increases when countries coordinate. Shared registries, aligned regulatory/HTA approaches, and joint initiatives can reduce duplication, accelerate learning, and improve affordability. The Forum discussions highlighted that limited coordination and weak data ecosystems remain major constraints for both CIS and broader international cooperation. The particlural issues mentioned were:

- Lack of coordination and harmonization in regulation and HTA. Most CIS and BRICS countries still lack stable mechanisms for coordinating regulatory, assessment processes.
- Low participation in international research and registries. Countries in the region are underrepresented in global research networks, limiting access to advanced practices and international collaboration.
- Absence of joint initiatives for research and development (R&D) and local manufacturing. Despite existing industrial potential, there are no systemic projects for coordinated planning, registration, or production of orphan drugs.
- Insufficient use of joint-procurement opportunities. The lack of consolidated purchasing mechanisms within the CIS and BRICS reduces efficiency and limits therapy affordability.
- Deficit of reliable data and transparency. Many countries lack open patient registries and data on treatment outcomes, which hinders both management and international cooperation.

The combination of these problems demonstrates that CIS health systems are not yet fully ready to implement coordinated rare disease policy. To address these barriers, the Forum participants formulated a detailed set of recommendations – a regional “roadmap” for implementing the global rare-disease agenda presented in Section III of the Resolution.

Recommendations of the II CIS Orphan Forum

The outcomes of the II CIS Orphan Forum define a consistent framework for developing rare-disease policy across the CIS and BRICS regions. The recommendations cover four complementary dimensions: national policy and regulation, organization of care and human resources, analytical and methodological development, and international collaboration.

At the level of state policy, the Forum identified the adoption of national strategies and long-term action plans on rare diseases as a fundamental step. These documents should formalize priorities in diagnosis, screening, treatment, and rehabilitation, and provide a sustainable financial basis for patient care. Harmonization of definitions and criteria for rare diseases, as well as the establishment of a unified procedure for granting orphan-drug status within the EAEU, would improve coherence of regulation and accelerate patient access to therapy. The strengthening of legal and methodological frameworks is also necessary for the introduction of flexible reimbursement mechanisms, including managed entry agreements and risk-sharing models. Expanding neonatal and selective screening programs, and incorporating rare-disease topics into medical and postgraduate education, are integral elements of these reforms.

In the organization of care, the establishment of a structured network of national and regional orphan centers is identified as a key priority. These centers should serve as reference institutions responsible for patient routing, coordination of diagnostics and treatment, methodological

guidance, and professional training. Their institutionalization will ensure uniform standards of care and improve access to expertise across the region.

Equally important is the need to strengthen continuity of care between pediatric and adult services. The absence of established transition mechanisms often leads to treatment interruption when patients move from children's to adult healthcare systems. To preserve therapeutic outcomes and ensure lifelong management, countries should develop unified protocols for transition, aligned drug-provision schemes, and coordination between inpatient, outpatient, and social-support services.

Systematic workforce development through training, internships, and coordinated educational programs across the CIS will help overcome existing human-resource shortages. Cross-border telemedicine and cooperation among orphan centers can ensure a more uniform level of expertise and continuity of care throughout the patient's life.

In the analytical and methodological dimension, the Forum emphasized the need to establish institutionalized HTA systems across the CIS countries, integrated into reimbursement and pricing decisions. The further development of HTA methodologies for orphan medicines should be informed by international experience and adapted to the specific features of rare diseases, with greater use of flexible evaluation criteria, differentiated willingness-to-pay thresholds, and patient-reported outcomes. Building national and regional registries and databases for RWD and RWE is essential to inform outcome-based models. The introduction of horizon scanning is required to anticipate emerging technologies and to plan for orphan-drug demand, enabling more sustainable and data-driven decision-making in healthcare budgeting and procurement. Centralization of procurement and the creation of joint price negotiations mechanisms could improve efficiency and ensure predictable pricing.

Finally, the Forum underscored the importance of international collaboration. Within the CIS, EAEU, and BRICS frameworks, coordinated demand forecasting, R&D coordination, shared data platforms, and joint price negotiations for orphan medicines would enhance sustainability and access.

The CIS Orphan Consortium is expected to continue serving as a key coordination platform for policy monitoring, comparative analysis, and the creation of an integrated information portal covering patients, centers, medicines, and treatment outcomes.

Taken together, these recommendations outline a regional roadmap for the formation of a sustainable and equitable system of care for patients with rare diseases. Their implementation will strengthen the emerging CIS–BRICS Alliance for Rare Diseases and contribute to achieving the goals of the WHO Global Action Plan on Rare Diseases.

Conclusion

The II CIS Orphan Forum confirmed that rare diseases have become an integral part of the global health agenda and a new area for consolidating the efforts of CIS and BRICS countries. The outcomes of the Forum and its adopted Resolution demonstrate the region's readiness to move from fragmented initiatives to a coordinated, long-term policy based on solidarity, knowledge exchange, and equitable access to innovative therapies.

The discussions and initiatives launched during the Forum laid the foundation for the creation of a CIS–BRICS Alliance for Rare Diseases – a multilateral platform uniting regulatory authorities, expert centers,

and patient organizations to coordinate research, harmonize regulatory requirements, and promote joint R&D and access to orphan medicines. This Alliance is envisioned as a mechanism for sustained collaboration between CIS and BRICS countries.

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LETTER TO THE EDITOR

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Letter to the Editor Regarding "Five years of the Genomas Brasil Program: advancing genomics and precision health within Brazil's unified health system"

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To the Editor

The Human Genome Project (HGP) was the largest international biological project. It laid the foundations for our modern understanding of human genetic diversity and enabled us to completely decode the human genome by 2022. The HGP also allowed us to identify genes associated with thousands of diseases, develop personalized medicine and pharmacogenomics, create molecular diagnostic tools and make major advances in bioinformatics.

The success of the HGP stimulated the emergence of national initiatives, including the 100,000 Genomes Project (United Kingdom), All of Us (USA), the Qatar Genome Programme and the Chinese Millionome Database Project, to name a few. These initiatives established an integrated ecosystem of technologies, data and ethical frameworks that helped to translate genomic research from fundamental science into clinical practice and public health [1].

Brazil's state policy in the field of genomics has become a key driver of healthcare innovation, promoting equity and the modernization of the health system. This article analyzes the implementation of Brazil's National Genomics and Precision Medicine Program (GenBR) over a five-year period, examining the prerequisites for launching the program, its institutional structure and governance mechanisms, and quantitative indicators such as funding, the number of projects and sequencing volumes. It also considers the outcomes achieved and the challenges that remain [2].

The GenBR program is still constrained by several structural issues. These include a marked concentration of projects in the Southeast region, indicating limited territorial decentralization, and persistent technological obstacles to scaling up the production of Advanced Therapy Medicinal Products to full Good Manufacturing Practice compliance. Other issues include complex ethical and regulatory requirements relating to the implementation of the Brazilian General Data Protection Law and the safeguarding of genomic data, as well as concerns about long-term sustainability given the program's dependence on public funding and the potential impact of changing political priorities on program continuity [3, 4].

As part of Russia's Federal Scientific and Technical Program for the Development of Genetic Technologies (2019–2030), the large-scale "100,000+ Me" project is being implemented. By June 2025, over 100,000 Russian citizens' genomes had been collected, around 80,000 of which had been sequenced. This has been accompanied by the development of infrastructure, research projects and specialist training through residency and master's programs in genetics. While the GenBR program also highlights workforce development, its measures appear less extensive as it does not include specialist training pathways comparable to Russian residency or master's programs in genetics.

Both initiatives share the overarching goal of advancing genomic research, integrating it into healthcare systems and strengthening national technological sovereignty. Exchanging information between the GenBR and the "100,000+ Me" programs could significantly amplify this effect. This cooperation could focus on three areas:

- Data and methodology exchange, including a unified platform for joint genomic data analysis that considers Brazilian genetic heterogeneity and the Russian genetic profile.
- Joint research on rare diseases, focusing on shared and unique genetic markers.
- Personnel exchange, including training placements for specialists at genetic centers in both countries, with an emphasis on residency and master's programs.

This collaboration could also increase the global value of large-scale genomic consortia by improving the representation of Brazilian and Russian populations in international genomic databases, enabling more inclusive discoveries with direct implications for public health.

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