

PRE-BIRTH PHARMACOGENETICS: PERSONALIZED PHARMACOTHERAPY, THE BURDEN OF KNOWLEDGE AND ETHICS OF A PARENTAL DECISION

Demarina SM , Usolkin AA, Balashova YD, Tikhomirova SV

Yaroslavl State Medical University, Yaroslavl, Russia

This review examines the ethical and legal implications of creating pharmacogenetic passports during the preconception (prior to conception) and prenatal (intrauterine) periods. The work is based on a methodological differentiation between the stages of genetic testing.. Preconception screening aims to assess carrier status in prospective parents and ensure their reproductive freedom, while prenatal testing provides fetus-related data, raising bioethical issues regarding the protection of interests and self-determination of the future child. The technologies of non-invasive prenatal testing (NIPT), preimplantation genetic testing (PGT), and prospects for intrauterine pharmacotherapy in severe congenital abnormalities are discussed. Special attention is given to ethical conflicts such as a conflict between the right to health and the right not to know, limits of parental proxy, and risk of genetic stigmatization. Normative approaches are suggested to address the identified ethical tensions (minimum intervention, clinical benefit, and deferred choice). The analysis of the Russian legislation and international instruments (Oviedo Convention, the GINA Act, the GDPR) yields recommendations for the healthcare system and legal regulation.

Keywords: pharmacogenetics, pharmacogenetic passport, prenatal testing, preconception screening, parental proxy, genetic discrimination, intrauterine pharmacotherapy, bioethics, personalized medicine

Author contribution: Demarina SM — literature selection and analysis; writing and editing the manuscript; Usolkin AA — literature selection and analysis; writing the manuscript; Balashova YD — literature selection and analysis; writing the manuscript; Tikhomirova SV — manuscript editing.

✉ **Correspondence should be addressed:** Svetlana M Demarina
Revolyutsionnaya St, 5, Yaroslavl, 150000, Russia; chugsm@yandex.ru

Received: 19.03.2026 **Accepted:** 17.04.2026 **Published online:** 23.05.2026

DOI: 10.24075/medet.2026.012

Copyright: © 2026 by the authors. **Licensee:** Pirogov University. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (<https://creativecommons.org/licenses/by/4.0/>).

ФАРМАКОГЕНЕТИКА ДО РОЖДЕНИЯ: ПЕРСОНАЛИЗИРОВАННАЯ ФАРМАКОТЕРАПИЯ, БРЕМЯ ЗНАНИЯ И ЭТИКА РОДИТЕЛЬСКОГО РЕШЕНИЯ

С. М. Демарина , А. А. Усолкин, Ю. Д. Балашова, С. В. Тихомирова

Ярославский государственный медицинский университет, Ярославль, Россия

В настоящем обзоре рассматриваются этические и правовые аспекты формирования фармакогенетического паспорта на прекоцепционном (до зачатия) и пренатальном (внутриутробном) периодах. Методологическое разграничение этапов генетического тестирования положено в основу работы. Прекоцепционный скрининг направлен на оценку статуса носительства у будущих родителей и обеспечения их репродуктивной свободы, тогда как пренатальное исследование предоставляет данные о плоде, ставя биоэтические вопросы о защите интересов и самоопределении ребенка в будущем. Обсуждаются технологии неинвазивного пренатального тестирования (НИПТ) и преимплантационной генетической диагностики (ПГД) и перспективы использования внутриутробной фармакотерапии при тяжелых врожденных аномалиях. Особое внимание уделяется этическим конфликтам: дилеммой между «правом на здоровье» и «правом на незнание», границам родительского решения и риском генетической стигматизации. Предложены нормативные подходы для баланса выявленных противоречий (минимальное вмешательство, клиническая польза, отложенный выбор). В результате анализа российского законодательства и международных документов (Конвенция Овьедо, Закон GINA, Регламент GDPR) сформулированы рекомендации для системы здравоохранения и правового регулирования.

Ключевые слова: фармакогенетика, фармакогенетический паспорт, пренатальное тестирование, прекоцепционный скрининг, родительское представительство, генетическая дискриминация, внутриутробная фармакотерапия, биоэтика, персонализированная медицина

Вклад авторов: С. М. Демарина — подбор и анализ литературы, написание и редактирование текста рукописи; А. А. Усолкин — подбор и анализ литературы, написание текста рукописи; Ю. Д. Балашова — подбор и анализ литературы, написание текста рукописи; С. В. Тихомирова — редактирование текста рукописи.

✉ **Для корреспонденции:** Светлана Михайловна Демарина
ул. Революционная, д. 5, г. Ярославль, 150000, Россия; chugsm@yandex.ru

Статья поступила: 19.03.2026 **Статья принята к печати:** 17.04.2026 **Опубликована онлайн:** 23.05.2026

DOI: 10.24075/medet.2026.012

Авторские права: © 2026 принадлежат авторам. **Лицензиат:** РНИМУ им. Н. И. Пирогова. Статья размещена в открытом доступе и распространяется на условиях лицензии Creative Commons Attribution (CC BY) (<https://creativecommons.org/licenses/by/4.0/>).

Modern medicine is shifting from reactive, post-manifestation care toward a predictive and anticipatory model that prioritizes forecasting and active prevention [1–3]. Key

focus areas of these changes are preconception testing (at the stage of pregnancy planning), prenatal testing (during pregnancy), and pharmacogenetic testing for expanded

prevention, early diagnosis, and personalized therapy selection [4, 5].

Preconception and prenatal stages should be differentiated from a methodological point of view. During the preconception stage, parental genetic screening identifies potential recessive disorders, respecting the autonomy of adult individuals who make informed reproductive decisions. Conversely, prenatal diagnosis obtains information directly about the fetus, which lacks legal capacity, and it is the parents who decide on the child's future. The central focus is thus shifted to parental proxy and protection of the child's future autonomy, which fundamentally alters the ethical landscape [6–8].

This review aims to critically examine the ethical and legal implications of creating pharmacogenetic passports during pre-conception and prenatal care. It includes a comparative analysis of international and Russian regulatory frameworks and development of normative models that balance between the child's "right to health" and the "right not to know".

LITERATURE SEARCH METHODOLOGY

A comprehensive search of the PubMed/MEDLINE, Scopus, eLibrary.ru and Google Scholar databases was conducted from January 2023 to March 2026. The following search queries were employed (both in English and Russian): "preconception carrier screening ethics", "prenatal pharmacogenomics", "fetal pharmacotherapy ethics", "right not to know genetic information", "pharmacogenetic passport", "genetic discrimination GINA", "Oviedo Convention genetics", "noninvasive prenatal testing", "pharmacogenetic passport", "right not to know". Inclusion criteria: peer-reviewed original and review articles, monographs, regulatory legal acts, international conventions, and professional society guidelines, published primarily in 2009–2026, and devoted to ethical, legal, and clinical aspects of genetic testing at pre- and perinatal stages, and pharmacokinetics. Exclusion criteria: unreviewed materials, not directly relevant to the review topic, and duplicate sources. Twenty-five sources were included in the final list.

PRECONCEPTION SCREENING: POSSIBILITIES AND ETHICAL RISKS

At the preconception stage, genetic testing assessing the genetic profile of parents or prospective parents prior to pregnancy. Academic sources define clear clinical guidelines for testing carriers of genetic mutations, focusing mainly on autosomal recessive conditions. It enables prospective parents to identify risks of transmitting severe inherited monogenic conditions before pregnancy [6, 9]. This technology is particularly relevant for populations with a high frequency of pathogenic variants. According to the European Society of Human Genetics (ESHG), Expanded Carrier Screening (ECS) is currently being offered to an increasingly wider range of couples, regardless of their ethnic background or personal history [10]. Preconception diagnostics expands reproductive autonomy. Thus, genetic information makes it possible for couples to consciously select among natural conception, assisted reproductive technologies (ART), donation, or choosing to be childfree [9, 11]. Nevertheless, broad-scale genetic screening is associated with the risks of establishing standards for a "normal genome" and increasing marginalization of individuals with disabilities, as well as applying moral pressure on parents whose reproductive

choices diverge from societal expectations [10, 12]. Provision of a full informed consent while detecting variants of uncertain significance (VUS) remains a principal problem [6, 9]. Religious and worldview aspects that make parents feel social pressure even within the framework of voluntary programs add extra tensions [6, 9].

PRENATAL DIAGNOSTICS AND PHARMACOGENETIC FETAL PROFILE

Prenatal diagnostics involves invasive methods (chorionic villus sampling, amniocentesis) and non-invasive prenatal testing (NIPT) using cell-free fetal DNA in maternal blood. NIPT enables the detection of detect chromosomal abnormalities with up to 99% sensitivity for trisomy 21 and over 96% for trisomy 18 and 13 [12], and a series of monogenic disorders. Preimplantation genetic testing (PGT) makes it possible to select embryos without detected genetic defects before they are transferred into the uterus [6]. In Russia, NIPT has been included into clinical recommendations on perinatal diagnostics since 2012–2013, whereas the current procedure for providing obstetric-gynecological care is established by Order of the Ministry of Health No. 1130H as of 20.10.2020 [13]. Experts are still debating its widespread inclusion in the state guarantee system [14, 15].

Expanding prenatal diagnostics into a full-fledged fetal pharmacogenetic (PGx) profile is a promising area in medicine. Pharmacogenetics studies the impact of genotype on pharmacokinetics and pharmacodynamics of drugs: polymorphisms of the *CYP2D6*, *CYP2C19*, *SLCO1B1*, *ABCG2*, and other genes determine the risk of adverse reactions and the variability of therapeutic response in cardiology, oncology, psychiatry, and other specialties. According to data from the Clinical Pharmacogenetics Implementation Consortium (CPIC), clinically significant pharmacogenetic variants are identified in 85–95% of the population [16].

The pharmacogenetic profile of the fetus allows for the adjustment of maternal medication therapy based on the child's metabolic characteristics, reducing the risks of teratogenic effects and adverse reactions through the placenta [16]. In cases of severe congenital disorders such as congenital adrenal hyperplasia, hemolytic disease of the fetus or several metabolic disorders, intrauterine pharmacotherapy is increasingly gaining real clinical significance, and the fetal pharmacogenetic passport is becoming a tool for selecting safe and effective treatment regimens [17, 18]. Given that technological advancements are significantly outpacing the regulatory response, an ethical and legal examination of the limitations for such interventions is urgently required [17].

REGULATING GENETIC INFORMATION: RUSSIAN LEGISLATION AND INTERNATIONAL STANDARDS

Within the Russian Federation, genetic information is classified as a category of biometric personal data subject to stringent regulatory oversight under Federal Law No. 152-FZ "On Personal Data". The Law requires informed consent, strict purpose limitation, and robust data protection measures. Presidential Decree No. 680 of November 28, 2018 "On the Development of Genetic Technologies in the Russian Federation" accelerates genetic research in Russia and states that genetic data rigorous control and security measures are

required. Federal Law No. 323-FZ “On the Basics of Health Protection of Citizens in the Russian Federation” serves as the foundational legal framework governing patient rights, access to medical information, and medical confidentiality, encompassing matters relating to genetic testing. The prospects for developing predictive medicine within the current normative context are extensively discussed in Russian literature [19].

Domestic rules, however, are significantly less comprehensive than international standards. The European Convention on Human Rights and Biomedicine, commonly known as the Oviedo Convention (1997), is recognized as the first legally binding international instrument in the biomedical field. Specifically, Article 11 prohibits genetic discrimination, Article 12 states that genetic testing is allowed exclusively for medical purposes or health-related scientific research, whereas Specifically, Article 10 establishes both the right to access and the right to refuse genetic information [7]. Russia has not ratified the Oviedo Convention, which creates a gap in the legal protection of citizens regarding the use of genomic technologies.

In the USA, it is the Genetic Information Nondiscrimination Act (GINA, 2008) that provides protection against discrimination on the basis of genetic information. The Act prohibits insurers and employers from using genetic data when making decisions about insurance coverage and hiring [7]. The EU General Data Protection Regulation (GDPR, 2018) classifies genetic data as special categories requiring enhanced legal protection and explicit consent from the data subject. The domestic legislator will have to develop mechanisms ensuring a comparable level of guarantees, including those related to pharmacogenetic data obtained in the prenatal period [19, 20]. The establishment of centralized genomic databases exacerbates the tension between individual confidentiality and governmental imperatives, necessitating a tailored legal framework [20, 21].

THE PHARMACOGENETIC PASSPORT: FROM POSTNATAL TO PRENATAL PERSONALIZED MEDICINE

In clinical practice, the concept of a “pharmacogenetic patient passport”, which is a structured document containing information on genetic variants that are clinically significant for drug therapy, is actively developing. It includes data on polymorphisms of genes encoding xenobiotic metabolism enzymes (CYP family), transport proteins, and molecular targets of drugs, including anticoagulants, statins, and psychotropic agents, which allows for the customization of drug selection and dosage [8, 16, 22, 23]. By 2025, the Clinical Pharmacogenetics Implementation Consortium (CPIC) has developed guidelines for more than 34 genes and 164 drugs, covering the most critical therapeutic areas [16]. Pharmacogenetic data retain their predictive value throughout the patient's life and are relevant for biological relatives.

A fundamentally new approach is the transitioning from the postnatal application of this approach to the pre-birth creation of an individual pharmacogenetic passport. The prospects for development of postnatal pharmacotherapy in pediatrics and perinatal treatment are expanded. Correction of maternal therapy regimens has become possible, taking into account the pharmacokinetic characteristics of the fetus, along with direct intrauterine therapy when clinically justified [17, 18]. The focus is shifting from the diagnosis of monogenic hereditary diseases to the creation of an expanded pharmacogenetic

profile, which increases the clinical significance of prenatal testing while simultaneously complicating its ethical and legal regulation [5, 21].

ETHICAL AND LEGAL DIFFICULTIES OF PRENATAL PHARMACOGENETICS

The implementation of pharmacogenetic data into medical practice and their development from the prenatal period raise a number of fundamental legal and ethical issues.

Confidentiality and secondary use. Pharmacogenetic data have a dual predictive value: not only do these elements delineate the individual's metabolic state, but they can also serve as latent precursors to future medical conditions. This creates a threat of discrimination by insurance companies or employers, a vulnerability that the US GINA and EU GDPR were specifically enacted to prevent, whereas Russian legislation does not yet provide for a similar mechanism [7, 21]. Pharmacogenetic records necessitate legally mandated safeguards as restricted, highly classified medical information.

Informed consent under conditions of uncertainty. As genetic science continuously advances, informed consent must be treated as a fluid, evolving dialogue rather than a singular agreement that encompasses the patient's prerogative to be updated as scientific discoveries emerge [6, 24]. The emergence of variants of uncertain clinical significance (VUS) dramatically complicates this process, especially in the prenatal context [14, 15, 24].

Parental proxy and fetal rights. Prenatal or preconception testing affects the interests of a person not yet possessing legal capacity. According to the ethical principles formulated by V. S. Baranov, prenatal creation of a genetic profile is permissible exclusively when there is direct clinical benefit for the child at an early age and must be accompanied by mandatory genetic counseling. This approach is consistent with the position of the European Society of Human Genetics (ESHG) [10, 11] regarding the prohibition of screening children for conditions that manifest in adulthood.

THE RIGHT NOT TO KNOW WITHIN THE CONTEXT OF A CHILD'S PHARMACOGENETIC PASSPORT

The concept of the “right not to know” one's own genetic information holds a significant place in modern bioethics. The right is understood as the manifestation of personal autonomy when a person has the right to remain uninformed to protect themselves from psychological harm and preserve their freedom of choice [21]. At the international level, this right is enshrined in Article 10 of the Oviedo Convention, which recognizes both the right to know and the right not to know information about one's own health [7]. In the context of Russian jurisprudence, this concept lacks definitive statutory recognition, although a number of researchers believe that it is firmly grounded in the constitutional right to privacy and the broader principle of personal inviolability [21].

At the same time, the right to absolute ignorance is not absolute. When genetic information yields immense clinical significance and makes it possible to prevent a serious disease, an ethical obligation to know arises both in relation to oneself and to biological relatives [7, 21]. Scientific discussion indicates that the “right not to know” conflicts with the duty of healthcare professionals to inform the

patient, as well as with the interests of third parties, family members who may share a similar genetic risk [21, 25]. The problem is particularly acute in the era of expanding genomic databases: an individual patient's choice has consequences for others.

PRENATAL PARENTAL DECISIONS: PROXY LIMITS

If a pharmacogenetic profile is created before birth, the decision to perform testing and its scope is made by the parents or legal representatives. Within the framework of pediatric ethics, it is assumed that parents have the right to use available medical technologies to prevent harm and ensure the optimal development of the child [6, 7]. However, the collection and long-term storage of genetic information without the possibility for the child to subsequently refuse its use can be qualified as a violation of their right to future autonomy [7, 21].

The problem becomes particularly acute when a pharmacogenetic passport includes data not only with immediate clinical significance in childhood, but also information on late-onset, potentially incurable diseases. Such information can influence the development of a young person's identity [7, 25]. In pediatric genomics, the concept of the "right to an open future" is widely applied: a child should have the opportunity to make decisions about their own genetic information upon reaching maturity. For this reason it is standard practice to restrict prenatal genetic testing to conditions where early detection allows for treatment and prevention during childhood [7]. Simulating the child's future retrospective perspective helps define the ethical dilemma. In the first scenario, an adult retrospectively criticizes their parents' decision to create a genetic passport, viewing it as a violation of the right to choose and perceiving this document as a psychological burden. In the second scenario, by contrast, the absence of personalized pharmacogenetic profiling is interpreted as a missed opportunity if a person has experienced severe, preventable adverse drug reactions. In certain situations, the right to health makes medicine act: if the harm is predictable and preventable, the healthcare system cannot remain passive. It means that the right to not to know is not absolute as in clinically significant cases it may be reasonably restricted in the patient's best interest [5, 21].

NORMATIVE MODELS OF BALANCING THE RIGHTS AND INTERESTS

Based on literature analysis, the conflict between the child's "right to health" and the "right not to know" regarding a pharmacogenetic passport can be resolved through three main normative approaches.

The minimal intervention model limits prenatal and early childhood genetic testing to data which are significant for prevention and treatment in childhood. Advanced testing is deferred until the individual reaches the age of majority and is able to provide independent informed consent. This approach most fully protects the future adult's autonomy; however, it entails the risk of missed clinical benefit.

The clinical utility model is based on a simple principle: if genetic information helps to prevent a disease or select treatment, it is acceptable to disclose and use it for medical purposes. It is a strict requirement to ensure secure protection of the data against insurers, employers, and third parties [21].

In practice, the model is applied when an identified genetic variant changes the treatment strategy. For instance, it can indicate intolerance to a specific drug or a high risk of a severe adverse reaction.

The deferred choice model involves creating an enhanced pharmacogenetic passport with differentiated access. Critical health-related data are made available to clinicians and parents, whereas supplementary information remains inaccessible until the individual decides to access it. This model preserves the patient's future autonomy without forgoing clinically significant preventive benefits..

The deferred choice model involves creating an enhanced pharmacogenetic passport with differentiated access. Critical health-related data are made available to clinicians and parents, whereas supplementary information remains inaccessible until the individual decides to access it. This model preserves the patient's future autonomy without forgoing clinically significant preventive benefits. [7, 21]. A similar approach is implemented through the recommendations of ESHG related to enhanced preconception screening [10] and of ESHG-ESHRE concerning the practice of enhanced carrier screening in reproductive centers [11].

CONCLUSIONS

1. The preconception and prenatal stages require strict differentiation: the former involves parental autonomy, while the latter concerns the autonomy and rights of the future child. Conflating these stages leads to errors in ethical analysis.
2. A pharmacogenetic (PGx) passport created before birth offers significant clinical advantages, ranging from the optimization of postnatal therapy to, under sound indications, intrauterine pharmacotherapy. These possibilities necessitate specialized ethical and legal safeguards.
3. The right not to know one's genetic status is anchored in the Oviedo Convention as an element of personal autonomy. This right may be reasonably restricted in the interest of the patient's health when the timely use of genetic information can genuinely prevent harm.
4. Russian legislation requires specialized regulation of pharmacogenetic data including mechanisms for differentiated, data retention periods, rights of patients to correct and erase data, and protect from genetic discrimination similar to GINA and GDPR.
5. The ethically most balanced approach is the deferred choice model, which ensures access to clinically significant data during childhood while preserving the adult's right to independently decide on the disclosure of the remaining genetic information.
6. It is recommended as follows: a) to conduct prenatal and neonatal genetic testing exclusively for those conditions that can be prevented and treated in childhood; b) to ensure mandatory genetic counseling when creating a fetal pharmacogenetic passport; c) to consolidate the "right not to know" within the Russian law as a mechanism to protect patient information autonomy.

Thus, establishing a prenatal pharmacogenetic passport demands structured procedural guidelines rather than restrictive bans. It requires clearly specifying exactly which information is available, to whom, and at what stage while strictly prioritizing the welfare of the unborn child.

References

1. Baranov VS. Polimorfizm genov, ekogeneticheskiye bolezni i geneticheskiy pasport. *Ekologicheskaya Genetika*. 2011; 9(3): 3–14. Russian
2. Baranov VS. Genomika na puti k prediktivnoy meditsine. *Acta Naturae*. 2009; 1(3): 77–88. Russian.
3. Baranov VS, ed. *Geneticheskiy pasport — osnova individual'noy i prediktivnoy meditsiny*. Saint Petersburg. Izd-vo N-L. 2009; 528 p. Russian
4. Solomon BD, Jack BW, Feero WG. The clinical content of preconception care: genetics and genomics. *Am J Obstet Gynecol*. 2008; 199(6 Suppl 2): S340–S344.
5. Raymond M, Critchlow J, Rice SM, et al. Fetal pharmacogenomics: a promising addition to complex neonatal care. *Mol Genet Metab*. 2022; 137(1–2): 140–145.
6. Kihlborn U. Ethical issues in preconception genetic carrier screening. *Ups J Med Sci*. 2016; 121(4): 295–298.
7. Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo Convention). Oviedo; 1997. Available from: <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164> (accessed: 18.03.2026).
8. Kaye DK. Addressing ethical issues related to prenatal diagnostic procedures. *Matern Health Neonatol Perinatol*. 2023; 9(1): 1.
9. De Wert GM, Dondorp WJ, Knoppers BM. Preconception care and genetic risk: ethical issues. *J Community Genet*. 2012; 3(3): 221–228.
10. Henneman L, Borry P, Chokoshvili D, et al. Responsible implementation of expanded carrier screening. *Eur J Hum Genet*. 2016; 24(6): e1–e12.
11. Capalbo A, Ramos-Alcalá L, Cimadomo D, et al. ESHG-ESHRE survey on the current practice of expanded carrier screening in European MAR centres. *Hum Reprod*. 2024; 39(8): 1844–1855.
12. De Jong A, Dondorp WJ, de Die-Smulders CE, et al. Non-invasive prenatal testing: ethical issues explored. *Eur J Hum Genet*. 2010; 18(3): 272–277.
13. Ministry of Health of the Russian Federation. Order No. 1130n of 20.10.2020 on the procedure for providing medical care in obstetrics and gynaecology [Ob utverzhdenii Poryadka okazaniya meditsinskoy pomoshchi po profilu «akusherstvo i ginekologiya»]. Available from: https://www.consultant.ru/document/cons_doc_LAW_367763/ (accessed: 18.03.2026). Russian.
14. Baranova EE, Izhevskaya VL, Efremova EE. Eticheskiye aspekty neinvazivnogo prenatal'nogo testirovaniya: avtonomiya i informirovannyi vybor. *Meditsinskaya Genetika*. 2024; 23(3): 12–20. Russian.
15. Potapov AA, Kaplanova MT, Galaktionova AM, et al. Eticheskiye aspekty primeneniya polnogenomnogo neinvazivnogo prenatal'nogo testirovaniya. *Meditsinskaya Genetika*. 2023; 22(11): 3–12. Russian.
16. Rim JH, Kim JH, Park JH, et al. Clinical pharmacogenetic testing and application: a guideline update. *Ann Lab Med*. 2024; 44(6): 494–512.
17. Meslin EM, Kant C, Mazzuri S, Knoppers BM. Prenatal therapies: a Points to Consider framework for responsible innovation. *BMC Med Genomics*. 2025; 18(1): 191.
18. Lynn AY, Farmer DL. The technical and ethical framework of fetal therapy. *Curr Opin Pediatr*. 2024; 36(3): 367–373.
19. Aseyev MV, Baranov VS, Baranova EV, et al., eds. *Evolutsiya prediktivnoy meditsiny Saint Petersburg*. Eko-Vektor. 2021; 359 p. Russian.
20. Baranov VS. Genomika i prediktivnaya meditsina. *Sibirskiy zhurnal klinicheskoy i eksperimental'noy meditsiny*. 2021; 36(4): 14–28. Russian.
21. Kurskaya SA. Pravo ne znat' geneticheskuyu informatsiyu o sebe: imeyet li mesto v rossiyskom zakonodatel'stve. *Yuridicheskiy mir*. 2025; (4): 32–35. Russian.
22. Guan ZW, Wu KJ, Bian HJ, et al. Pharmacogenetics of statins treatment: efficacy and safety. *J Clin Pharm Ther*. 2019; 44(6): 858–867.
23. Raymond J, Dooley M, Singl N, et al. Pharmacogenetics of direct oral anticoagulants: a systematic review. *J Pers Med*. 2021; 11(1): 37.
24. Muflih S, Al-Husein BA, Karasneh R, et al. Physicians' attitudes and ethical obligations to pharmacogenetic testing. *J Multidiscip Healthc*. 2020; 13: 249–258.
25. Greene BL, Nichols K, Parsons DW. Ethical considerations of genetic and genomic testing in pediatric oncology. *CA Cancer J Clin*. 2026; 76(2): e70005.

Литература

1. Баранов В. С. Полиморфизм генов, экогенетические болезни и генетический паспорт. *Экологическая генетика*. 2011; 9(3): 3–14.
2. Баранов В. С. Геномика на пути к предиктивной медицине. *Acta Naturae*. 2009; 1(3): 77–88.
3. Баранов В. С. Генетический паспорт — основа индивидуальной и предиктивной медицины. Под ред. В. С. Баранова. СПб. Изд-во Н-Л. 2009; 528 с.
4. Solomon BD, Jack BW, Feero WG. The clinical content of preconception care: genetics and genomics. *Am J Obstet Gynecol*. 2008; 199(6 Suppl 2): S340–S344.
5. Raymond M, Critchlow J, Rice SM, et al. Fetal pharmacogenomics: a promising addition to complex neonatal care. *Mol Genet Metab*. 2022; 137(1–2): 140–145.
6. Kihlborn U. Ethical issues in preconception genetic carrier screening. *Ups J Med Sci*. 2016; 121(4): 295–298.
7. Совет Европы. Конвенция о защите прав человека и человеческого достоинства в связи с применением биологии и медицины (Конвенция Овьедо). Овьедо; 1997. Режим доступа: <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164> (дата обращения: 18.03.2026).
8. Kaye DK. Addressing ethical issues related to prenatal diagnostic procedures. *Matern Health Neonatol Perinatol*. 2023; 9(1): 1.
9. De Wert GM, Dondorp WJ, Knoppers BM. Preconception care and genetic risk: ethical issues. *J Community Genet*. 2012; 3(3): 221–228.
10. Henneman L, Borry P, Chokoshvili D, et al. Responsible implementation of expanded carrier screening. *Eur J Hum Genet*. 2016; 24(6): e1–e12.
11. Capalbo A, Ramos-Alcalá L, Cimadomo D, et al. ESHG-ESHRE survey on the current practice of expanded carrier screening in European MAR centres. *Hum Reprod*. 2024; 39(8): 1844–1855.
12. De Jong A, Dondorp WJ, de Die-Smulders CE, et al. Non-invasive prenatal testing: ethical issues explored. *Eur J Hum Genet*. 2010; 18(3): 272–277.
13. Об утверждении Порядка оказания медицинской помощи по профилю «акушерство и гинекология»: приказ Минздрава России от 20.10.2020 № 1130н. Режим доступа: https://www.consultant.ru/document/cons_doc_LAW_367763/ (дата обращения: 18.03.2026).
14. Баранова Е. Е., Ижевская В. Л., Ефремова Е. Е. Этические аспекты неинвазивного пренатального тестирования: автономия и информированный выбор. *Медицинская генетика*. 2024; 23(3): 12–20.
15. Потапов А. А., Капланова М. Т., Галактионова А. М. и др. Этические аспекты применения полногеномного неинвазивного пренатального тестирования. *Медицинская генетика*. 2023; 22(11): 3–12.

16. Rim JH, Kim JH, Park JH, et al. Clinical pharmacogenetic testing and application: a guideline update. *Ann Lab Med*. 2024; 44(6): 494–512.
17. Meslin EM, Kant C, Mazzuri S, Knoppers BM. Prenatal therapies: a Points to Consider framework for responsible innovation. *BMC Med Genomics*. 2025; 18(1): 191.
18. Lynn AY, Farmer DL. The technical and ethical framework of fetal therapy. *Curr Opin Pediatr*. 2024; 36(3): 367–373.
19. М. В. Асеев, В. С. Баранов, Е. В. Баранова и др. Эволюция предиктивной медицины. Под ред. М. В. Асеева СПб. Эко-Вектор. 2021; 359 с.
20. Баранов В. С. Геномика и предиктивная медицина. Сибирский журнал клинической и экспериментальной медицины. 2021; 36(4): 14–28.
21. Курская С. А. Право не знать генетическую информацию о себе: имеет ли место в российском законодательстве? *Юридический мир*. 2025; (4): 32–35.
22. Guan ZW, Wu KJ, Bian HJ, et al. Pharmacogenetics of statins treatment: efficacy and safety. *J Clin Pharm Ther*. 2019; 44(6): 858–867.
23. Raymond J, Dooley M, Singl N, et al. Pharmacogenetics of direct oral anticoagulants: a systematic review. *J Pers Med*. 2021; 11(1): 37.
24. Muflih S, Al-Husein BA, Karasneh R, et al. Physicians' attitudes and ethical obligations to pharmacogenetic testing. *J Multidiscip Healthc*. 2020; 13: 249–258.
25. Greene BL, Nichols K, Parsons DW. Ethical considerations of genetic and genomic testing in pediatric oncology. *CA Cancer J Clin*. 2026; 76(2): e70005.