# SOCIOCULTURAL ASPECTS OF PRECONCEPTION GENETIC TESTING

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Preconception genetic testing for carrier diseases (PGT(C)) became a noticeable sociocultural phenomenon that raised various ethical issues with the individual and society. The issue of informing patients about the risks of giving birth to children with genetic abnormalities includes a range of questions about the probabilistic nature of genetic data, determinism, and cost and quality of medical and genetic counseling. Preventive tasks of genetics inevitably raise a question about the borders of a patient's autonomy and mutual responsibility of the individual and society. In this article, ethical and philosophical analysis of sociocultural aspects of PGT(C) has been presented, including neoeugenic prevention traits, hubris and genetic fatalism.

**Key words**: preconception genetic testing, medical and genetic counseling, ethics, ethical problems of genetics, sociocultural aspects of genetics

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# СОЦИОКУЛЬТУРНЫЕ АСПЕКТЫ ПРЕКОНЦЕПЦИОННОГО ГЕНЕТИЧЕСКОГО ТЕСТИРОВАНИЯ

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Преконцепционное генетическое тестирование на носительство (ПГТ(Н)) стало заметным социокультурным явлением, поставив перед индивидом и обществом различные этические вопросы. Проблема информирования пациента касательно рисков рождения детей с генетическими патологиями включает в себя спектр вопросов, касающихся вероятностного характера генетических данных, проблемы детерминизма, а также стоимости и качества медико-генетического консультирования. Профилактические задачи генетики неизбежно ставят вопрос о границах автономии пациента и взаимной ответственности индивида и общества. В статье приведен этико-философский анализ социокультурных аспектов ПГТ(Н), включающих в себя неоевгенические черты профилактики, проблемы гибриса и генетического фатализма.

**Ключевые слова**: преконцепционное генетическое тестирование, медико-генетическое консультирование, этика, этические проблемы генетики, социокультурные аспекты генетики

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Different types of genetic testing became an essential part of modern life. They gave birth to a number of social phenomena built in the culture at various worldview levels.

The next-generation sequencing (NGS) methods, which appeared in 2008, enabled rapid sequencing of DNA, RNA nucleotide sequence and other biopolymeric molecules. NGS methods are not costly (the cost of DNA sequencing reduced 100 thousand times during 15 years) and highly accurate as compared with previously used technologies. Due to that, genetic testing is accessible to clinicians of different specialties and to a wide range of patients. To determine the risks of diseases and sports-related injuries, predisposition to obesity and other metabolic disorders, drug sensitivity and prediction of reproductive capabilities, new health protecting practices associated with genetic testing have emerged. Moreover, an economically stimulated desire to find out something new and interesting about oneself resulted in the development of consumer genetics. It is an area of research, which goals are far from applied tasks of medicine and are rather intended for entertainment. For instance, a test for ethnicity, search of relatives, selection of cosmetic and skincare products. Anyone now can use genetic testing without sticking to doctor's recommendations, as genetic laboratories come into direct contact with a consumer by providing new insights into genetic information. Customary hierarchical medical algorithms are broken [1], genetics goes beyond the healthcare frames and becomes part of the modern society and important sector of the economy.

Thus, new genomics has turned into a large-scale social phenomenon and a new challenge for the individual and society.

Preconception genetic testing for carrier diseases (PGT(C)) raised a very serious question about the ratio of prevention and patient's reproductive autonomy and also some ethical controversies. Successful experience of using the PGT(C) programs became popular and raised such ethical issues as the forced selection or moral obligation in relation to future children based on the cultural ideas of health, well-being and happiness.

These valuable constructs, on the one hand, and the individual's freedom along with the right to medical resources, on the other hand, make up a complex ethical choice. This choice is shifted toward the interests of an individual in some cases and society in other cases. For instance, in case of prevention, the interests of the society prevail.

In pursuit of good intentions to prevent severe diseases, medical genetics has expanded a specter of values well beyond the limits of biological comprehension of health. A wish to improve the population health threatened the individual freedom. With development of genetic technologies and consumer genomics, the patient's autonomy became more vulnerable and dependent.

Moral dilemmas of the 'proper choice' are built in the social tissue in the context of medicalization at the level of prognostic and therapeutic decisions. Every such decision grows on the sociocultural soil. In the context of PGT(C), the reproductive autonomy acquires specific traits, which are important to be analyzed from the point of view of modern bioethics.

In this article, the cultural factors of shaping social ideas of health in the context of genetic testing are reviewed, and social phenomena generated by the PGT(C) technologies are analyzed.

## 1. PRECONCEPTION GENETIC TESTING AS A NEW CHALLENGE FACED BY THE SOCIETY

### 1.1. Social tendencies of genetic testing for carrier diseases in Russia

In spite of the relative novelty, the services of genetic diagnostics are gaining more popularity among the citizens of Russia. According to experts, the market of genetic testing is growing.

By using the method of content analysis of mass media in this article, we noticed that DNA testing gained popularity among population.

According to the data published in the report of Smart Consult marketing company, it has been revealed during the secondary data analysis that there was growing demand for manufacturer's services in 2021. While analyzing the data it has been found out that the Russian market of genetic testing has an annual average growth by 15% with DNA testing expenses reaching 5 billion RUB by 2025 [2].

In report of Genetico Center for Genetics and Reproductive Medicine for 2020, a 10% decline has been noticed for the profit as compared with 2019 [3]. The authors note that a decreased demand for genetic testing was associated with the COVID-19 pandemic. During the period, citizens were limited in movement and were less likely to turn to medical and diagnostic aid not related to prevention and treatment of coronavirus.

Manufacturers of genetic testing interviewed during the research by Forbes noted that in 2021, demand for their products significantly increased as compared with 2020. Russian Genotek has reported in the survey that the demand for their services has been increased 2.5 times annually [4].

The results of such studies and reviews enable to determine the economic role of genetic testing and its demand for the population, which in turn points to social significance as well.

The key contribution into the increased demand for genetic testing was made by the widespread propaganda and popularization of a healthy way of life. In spite of a higher cost of genetic testing in Russia as compared with the U.S. (2 or 3 times) [5], genetic testing is more frequently used by people with average income as well. However, the people of today are more interested not in the birth of healthy children, but in current personal problems associated with excessive weight, muscle mass, risk of severe cardiovascular diseases, diabetes mellitus, etc. [6].

Thus, based on the research at the Endocrinology National Medical Research Center, the demand for genetic testing in Russia was significantly increased in 2021. It was 16% more than in 2020. The authors referred to Mokrysheva NG and noted as follows: 'genetics is becoming increasingly popular in modern medicine based on four basic directions in science, including prenatal diagnostics, predictive medicine and various screenings' [7].

With reference to the expert's opinion, Logacheva MD and Pushkareva VS confirm [8] that the cost of genetic testing will be gradually reduced. The reduced cost can also produce a positive effect on the demand for testing among population and scaling of the service, including PGT(C), at the state level.

While analyzing the legal risks associated with genetic discrimination, Bogdanova EE states directly that the society request for DNA data has increased dramatically. The 'significance of genetic data contained in the human DNA' has increased as well [9].

Revazyan KZ analyzed foreign experience in psychosocial, ethical and other aspects of genetic testing and mentioned as follows: 'after obtaining information on the advantages of genetic carrier testing for monogenic recessive diseases, a positive attitude is formed in the majority of people even without an aggravated history' [10]. The authors mention the research that was held in the U.S. in 2019. Its participants obtained screening data. 'The majority of the patients reported a positive (45.2%) or neutral (48.2%) attitude. They also believed that screening should be offered to all pregnant women. However, among those who were asked about their wish to have a carrier screening, only 34.2% provided a positive response, 51% were not ready, whereas others had doubts. There were no statistically significant differences in the investigated groups of patients. Unwillingness of screening was explained by the lack of time, lack of readiness to change their reproduction-related plans when the carrier is detected, financial limitations, as participants did not consider it necessary to spend money on the 'hypothetical possibility of carrier'. This again displays the necessity in better educated population' [11].

Literacy of recipients (patients) and medical professionals contributes to the demand for the service among population.

### 1.2. Information sharing

Information sharing is one of the most complex ethical issues in genetics, as it is where the conflict of interests between an individual and society arises.

The particular character of the genetic data reported to the patient consists in its probabilistic nature and complexity of data interpretation.

The increasing complexity of informing a patient during genetic testing creates specific requirements to the forms of voluntary informed consent, which includes educational and explanatory tasks. 'The patients have to be explained a set of various aspects about the probabilistic, predictive and family-related specifics of genetic data, possibility to change the interpretation of results in the future, and attaching special importance to clarity and readability of VIC forms. <… > Presentation of general information is aimed to avoid useless and even potentially harmful information sharing effects, with simultaneous submission of the data, which are necessary to take decisions. The patient should be aware of genetic data specifics, understand its value for close relatives and dependence on continuously changing genome bases' [12].

During a consultation, a genetic scientist obtains a massive amount of data, the clinical significance of which can vary depending on DNA sequence variants.

Izhevskaya VL and Baranova EE subdivide them into three groups:

'– variants, which were related to the disease earlier, making it possible to confirm the diagnosis;
– variants, which can be related to human health, but not to the primary goal of testing (secondary or unexpected findings);
– variants of undetermined significance with an unconfirmed relation to the pathology until now.

It can be difficult to interpret the discovered genetic variants due to the lack of knowledge on their pathogenicity or purity (the so-called variants of undetermined significance). It can be changed over time with accumulation of scientific knowledge or clinical observations. Whenever some genetic variants are found, a disease can be predicted with a high probability in the context of medical or family anamnesis of the respective disease only' [13].

The preconception genetic testing submits data about the possible birth of a child with abnormalities. Though the percentage is low, the probability raises serious concern and gives birth to various behavior patterns including refusal from reproduction or intentional avoidance of genetic testing. For instance, preventive activities to fight thalassemia in Cyprus in 1970 led to enormous fears of giving birth to a sick child, decline in the birth rate and increased number of abortions. People who had one healthy baby did not want to try their fate and take a risk as they were satisfied with what they had; people with a sick child were not eager to go through the same traumatic experience, avoiding childbearing as well. P. Rabinow, an American anthropologist, calls the self-limitation 'the genetic nocebo' [14].

The information obtained by patients during a consultation helps them to take decisions about their future, on the one hand, and is often in conflict with their cultural and educational background. This results in a false image of a disease, which can sometimes be superficial and too optimistic, or negative and depressing. The information can be predominant for representatives of traditional cultures (conservative jews) due to their responsibility before the future generation and danger of accidental disclosure of confidential information within a small community, where people know one another.

Comprehension of genetic information during consultation is superimposed on a patient's available expectations. The preliminary ideas can vary from complete uncertainty to a rather clear and well explained model. According to Macleod R [15], patients were still looking for the hereditary causality, even if it was lacking based on research results. The attempts to analyze the reason for the disease were slightly biased.

It is not understood what the genetic counseling will imply. Though many patients had some experience in genetics at the preclinical stage, the information obtained during the consultation did not seem unexpected to them. The main question for a genetic scientist was the one, which provided the maximum certainty (yes/no questions). It was mainly about heredity, patient- and family-related risks, and an ability to influence those. The possibilities are more frequently delegated over a doctor making a patient feel safe [15].

The genetic counselling research that occurred in Canada in 2013 has shown that the basic problem included the low level of awareness about genetic diseases within the entire society. Patients hope to obtain more information with their psychoemotional condition depending on the counseling [16].

Protection of personal data during genetic counseling for carrier diseases is also pressing. Though the program of Tay-Sachs prevention within Dor Yeshorim is confidential, a small group of followers who underwent PGT(C) was vulnerable. The so-called 'community genetics' enables to build the mechanisms of prevention due to traditions, but is, according to A. Ratz, at the same time associated with the risk of accidental information disclosure. Within a small community people can be aware of the reasons of disengagement due to indirect reasons and discriminate the carrier and the family.

Thus, the prognostic pattern requires to change the mode of 'doctor-patient' relations by deeply understanding both the risks and benefits for the patient, the cultural belonging and psychoemotional condition.

Provision of information is not just about obtaining the VIC, but also about obtaining information [17], and consultation on the issues of disposition to hereditary disorders [18].

Due to poor family awareness of the methods of diagnostics and medical technologies, Sultanaeva ZM et al. conducted sociological research of women's attitude to methods of genetic counseling and genetic education among 698 women of reproductive age.

The results showed that the majority of participants (70.5%) stressed the importance of knowledge and information related to hereditary diseases. The respondents were asked whether the medical and genetic counseling was required. Thus, 38.4%, 47.9% and 24.2% of those interviewed believed the testing was necessary while 'getting married, in case of pregnancy and only among people with hereditary diseases', respectively.

It should be noted that some interviewed respondents (25.7%) said that the decision about the prenatal diagnostics should be taken by a physician.

Within the abovementioned interview the participants were offered to provide an answer about the consent form for DNA testing. 32.2% of them believe that oral agreement is enough for the procedure, '28.5% opt for a written agreement with the signature of the person being examined, 38.5% need obligatory written informed consent signed both by the doctor, and the patient' [19].

### 1.3. Prevention and reproductive autonomy

The basic goals of PGT(C) include the reduced risk of giving birth to children with pathologies and obtaining health-related data.

According to western preventive programs, the focus needs to be shifted from the individual's interests to the interest of the society. It raises the question about the patient's autonomy borders. The idea of prevention consists of certain decisions, which do not always coincide with the patient's expectations or life values.

Honesty is the ethical basis for 'doctor-patient' relations. It represents the 'right to know', or getting complete and true information, which can be used to take a decision. The decision should be taken independently and with no external influence. Then the principle of autonomy can be followed.

The autonomous decisions are interpreted in different ways. On the one hand, they are part of practical health care. On the other hand, they represent a responsible attitude to parenthood, and a wish to give children a better future. Nevertheless, the rhetoric of 'ethical obligation' to the society is built on the sense of responsibility and duty. 'Why give birth to a disabled person? Why should the child be put through sufferings?' — this is what friends, relatives, citizens keep asking. Social expectations created as dreams about the ideal healthy society are not somewhat utopian in nature. They make the reproductive human choice dependent on the surroundings and values of

the society. Genetic data turn into the tool of control and power, giving birth to the so-called 'genetic discrimination'. During the pandemic of coronavirus, hospitals of Washington and Alabama were accused of discrimination and sorting of patients who were deprived of ventilators based on genetic pathology such as chronic diseases or mental abnormalities [20].

In the society where families with disabled children are condemned and consumer genomics acquires an increasing effect, fear becomes the tool of promotional speculations, whereas a patient's decisions are taken in stressful situations.

Statement by I. Lebedev, deputy of the State Duma, about a disabled girl ('why are the children allowed to be born?! It is torture, not a life. Modern medicine can discover a pathology beforehand') led to a stormy discussion in mass media and social networks in 2017 [21].

According to the research, stigmatization results in social isolation of parents from the family and society, burnout, and suicidal thoughts.

Genetic counseling is a solution. Thus, M. Watanabe offers two solutions of dealing with interpersonal relations within a family [22].

Possible treatment of a diagnosed disease is another aspect of the autonomous decision. However, 95% of genetic pathologies can't be treated today.

Thus, being informed of the carrier, the patient faces superimposition, when there is a choice, but at the same time there is not.

The patient's autonomy and preventive tasks of healthcare are interwoven into a complex picture of biosociality, which can be described as a set of human ideas about themselves as life forms based on sociocultural ideas of health and possibilities to influence it.

Speculating about the relations between the mechanisms of the modern society, P. Rabinow describes the paradigm of social reality, which strives to construct and alter the nature in accordance with the cultural ideas. He traces the historical shift from construction of the society based on the models of nature to construction of nature based on the models of culture. This is a system of social practices developed on the basis of novel genomics.

With reference to R. Castel (Risk Management, 1981), Rabinow describes the change in social technologies, which '… reduces the direct therapeutic intervention and replaces it with stronger preventive administration management using the groups of population within the risky area'.

Attempts to overcome the discrepancies between the nature and culture result in the projection of values both from nature to culture, and from culture to nature.

Bruno Latour, a French philosopher and sociologist, assigns properties of agency not only to the individuals, but also to objects, ideas, and technologies. In actor-network theory of his, technologies acquire the status of a privileged object. Following the ideas of the Paris school of semiotics, Latour states that 'the scientific fact is set up between the society and nature when heterogenous subjects/objects interact' [23]. Interpreting the sociocultural effects of PGT(C) using Latour's theory it can be asserted that the competencies of the society are delegated to genetics. Following the same logics, a person is treated not as a passive social subject, but as a complex ensemble of natural and social aspects, which is a hybrid actor system within itself.

Moreover, even genetic pathologies manifested through the phenotype can be perceived not as a total failure and pathetic cheerless existence, but as a specific way of life. These examples are given by Assael BM in his 'The Devil's Gene': 'I recollect the fate of Michel Petrucciani, the genius of music, who had imperfect osteogenesis and died prematurely due to the complicated pathology. Who can say that his life was not worth living for? Michel decided to continue the line, though he was aware of the high possibility of giving birth to a sick baby. He, however, perceived his condition as a phenomenon, not as a disease' [24].

Numerous patient organizations only confirm the opinion and tend to prove that anyone can live with dignity and realize his potential within a civilized community irrespective of the congenital pathology.

Thus, the patient's autonomy can be implemented within the system of social ideas of health where conventional values are fused with hopes and concerns in relation to modern biomedical technologies. Meanwhile, dreamy focus on the ideal life, which can be predicted and constructed, is pragmatically balanced with social reality and its individual mental perception.

## 2. CULTURAL LANDSCAPES AS VIEWED BY ETHICS

### 2.1 Neoeugenic traits of PGT(C)

Until the 1980s of the XX century, genetic counseling was preventive. However, numerous questions about social justice and neoeugenic trends in genomics changed the vector of information sharing in favor of non-directive provision of health information. If the healthcare system informs couples of the carrier without reducing a number of sick children, the focus shifts to distribution of social and economic state resources.

Creation of 'an ideal healthy child' may have faded into the mosaic of collective hopes and expectations based on the Human Genome Project discoveries. In new genomics, we see numerous eugenic traits, which, though not associated with physical annihilation of autonomous live organisms, still raise many questions about the ethical part of genetic technologies.

Neoeugenic traits in genetics are manifested through various scenarios. First, prenatal diagnostics (NIPT and invasive methods). Though it can't be called selective, the possibility of abortion due to medical indications creates moral tension. It is suggested that during the examination a pathology should be prevented with the help of an abortion. The scenario is stressful for a family expecting a wanted child or not accepting abortions because of personal reasons. Perinatal palliative aid can be an alternative when a patient's autonomy is respected. The system supports the natural course of events and having the experience of parenthood even in case of the most unfavorable prognosis. The practice of such foreign countries as the Netherlands, U.S. and Canada shows that the programs of palliative care allow to have less stress when a child with severe pathology is born and died.

Another ethical aspect of prenatal genetic diagnostics is the non-medical nature of prediction. While dealing with such non-life-threatening abnormalities as Down syndrome, the prognosis is based not on the threat for a maternal life or severe disability of a child, but on the ideas of life quality. The prediction is not deprived of stigmatization both on the part of the society, and medical professionals.

The second scenario of genetic testing is preimplantation diagnostics and selection of healthy embryos during in vitro fertilization (IVF). Looking at the legal and moral status of an embryo as a subject of moral attitude, selection of healthy volunteers and annihilation of abnormal ones raises a question regarding a greater value of some people as compared with others.

Neoeugenic traits are built in the idea of population prevention, giving birth to bioethical discussion about justice within the society under the conditions of geneticization. The urgency of this discussion is decreased when the main tasks of genetic

counseling shift from prevention to information sharing, when prevention is free, but not urged selection of a patient. Thus, information sharing is the basis for the reproductive selection.

At the same time, if taking a patient's decision is treated as a completely autonomous and free from the external pressure of the state prevention policy, it is not clear what the society should do if parents will use the possibilities of consumer genomics and choose the hereditary signs not just by exclusion of severe diseases, but also by subjective presentations, for instance, tendency to corpulence or eye color. Should the society assess these phenomena or leave the decisions as they are?

From the point of view of bioethics, it can be assumed that healthy balance of patient pragmatism should be determined based not only on 'desirable' and 'undesirable' signs, but also on the moral values of the individual or a couple together with the measures of social and medical support.

### 2.2. Genomics as Pygmalion. Hubris as an essential feature of preventive prognoses

The image of Pygmalion, who was in love with his own creation, became a vivid metaphor of humanitarian genetic research (Lucas J. Matthews, Ruth Ottman, Paul S. Appelbaum, Cleaver JE, Vuksanovic L.) [25]. It is true that prognostic hopes and utopianism are implicitly related to the high level of emotional involvement of discourse participants. A wish to reach the ideal is totally sincere, whereas preventive purposes are ethically and economically justified.

Risk management makes masters of fate out of actors of medical and genetic interaction (genetic researchers, clinician doctors and patients) who wish to reduce the risks with the best of intentions. Prediction of happy future becomes a meta-task of a responsible medical professional and reasonable patient. This is about an autonomous decision about birth/no birth. Heuristic value of preconception genetic testing for carrier diseases and formulated high goals have an increased value. But what are the goals?

They are certainly global. According to P. Rabinow, care for the country and humanity in general is built 'in the social tissue at the microlevel due to numerous biopolitical practices and discourses' [26]. They constitute a powerful force in relation to the change within the society, which is even more powerful than revolution in physics.

These purposes rest upon overconfidence and arrogance or, in other words, hubris, or a trait of people who have great power or believe to have it. The concept of hubris can be applied to the issues of bioethics.

Hubris is a combination of such traits as overconfidence, harsh criticism of another opinion and disassociation from reality. It should be noted that these properties are typical of some cultural attitudes to PGT(C). Desire not of prediction only, but also of prevention of problematic issues at the personal and population levels turns the healthcare system into the master of destiny, whereas an individual (patient) acts like Creator who constructs reality in accordance with the intention.

The sociocultural motives of taking decisions by representatives of various cultures can go their separate ways. For some, it is commitment to the clan, community and God; for others, it is a rational way that prevents risks following the idea of patient pragmatism.

The axiological basis is formed by the management of own destiny based on irrationality. It is the illusory sense of being able to control the fate that turns the novel genomics into the mythical creator of the future generations similar to mythical Galathea, which becomes alive in the hands of a master.

According to the authors, the issue of hubris in the ethical aspect of PGT(C) can be solved in case of the proper 'doctor-patient' relation based on the competent non-directive information sharing, patient feedback, taking into account the patient's cultural level and values.

### 2.3. Genetic fatalism and values of the modern society

Influencing the reproductive choice is still a pressing issue in the context of comprehension of personal freedom and responsibility. Fighting a disease of the population using genetic literacy was effective: in 1950s, a large-scale program of fighting thalassemia in Italy covered about 20% of the population. A complex approach and state support were extremely successful in elimination of the disease. Prevention consisted in provision of information to the juvenile carrier who could influence the future reproductive solutions.

Under which conditions the solutions are taken? Is freedom of choice being implemented? Or does a man become an information hostage?

Speculations about the freedom and responsibility for the reproductive destiny (and destiny in general) are closely interrelated with the issue of genetic determinism. Such a philosophical issue as 'fate' is interpreted not as inevitability, destiny, ontological givenness, but as a complex of scientific determinants resting on cultural values.

An attempt to make freedom look rational acquires new meanings, reducing the notion of freedom to such conditional oppositions as 'health/disease', 'well-being/ill-being', 'accident/choice', 'benefit/risk'.

Bryzgalyna EV, a Russian researcher, takes the formation of genetic determinism and resulting fatalism as processes involving various social transformations. 'References to genetics as a science in the public consciousness make value judgements in relation to destiny dependance essential. On the one hand, it is an effect of genetic judgements produced on the ideas about the human life dependence; on the other hand, interpretations of genetic data adjust to the cultural ideas of the accidental/necessary and hereditary/environmental ratio. This occurs within the context of medicalization and geneticization that transform different spheres of social relations and have various manifestations' [27].

It can be concluded that the correlation of personal and public benefit is seen through the tendency of genetic determinism, which gives birth to rational and irrational motivations when the patient is taking decisions.

## CONCLUSION

Preconception genetic testing for carrier diseases became a new challenge for the society that build its own culture-based ideas of health and well-being.

Ethical and sociocultural aspects of actively developed medical and consumer genomics were of particular relevance. The internal logics of a patient's decision has been formed under the influence of various factors. On one hand, it is based on concerns and fears; on the other hand, it rests with the confidence in biomedicine achievements and wish to control and predict the life. In particular, the fate and well-being of future children are consistent with the patient's personal plans and depend on culture-based values and education.

A great effect of genetic determinism and hope to control the health of future generations becomes a specific feature of PGT(C), bringing ethical matters of concern before the state and society.

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