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Genetic Research: Ethical and Legal Aspects

Daria M. Kovba* and Yan Yu. Moiseenko

Institute of Philosophy and Law of the Ural Branch of the Russian Academy of Sciences Ekaterinburg, Russian Federation

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Abstract. The present paper discusses ethical and socio-political aspects of genetic research and technologies; the readiness of the international legislation to regulate genetic interference is also within the remit of the discussion. Research methods include a discursive approach, a chronological method, as well as a number of methods applied in legal science. The paper also highlights the problems of genetics inherited from eugenics (such as reductionism and a balance between private and public spheres) and raises the problem of discrimination on genetic grounds, which requires specific laws to protect the rights in the considered area. The analysis of international legislation has shown its central ideas to be respect for human dignity, rights and freedoms, the principle of autonomy. Bioethics proves to have made a great contribution to the development of ethical principles in the field of genetic research, while the standard-setting role here belongs to UNESCO. The declarations developed by this organization have a number of weaknesses (non-binding nature, lack of practical recommendations, etc.). Despite this, the authors argue in favor of continuing the work of bioethics committees.

Keywords: genetic research, human rights, personal dignity, discrimination, ethics, eugenics, legal regulation.

Research area: law.

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^{*} Corresponding author E-mail address: daria_kovba@mail.ru

Генетические исследования: этические и правовые аспекты

Д.М. Ковба, Я.Ю. Моисеенко

Институт философии и права Уральского отделения Российской академии наук Российская Федерация, Екатеринбург

Аннотация. Статья посвящена изучению этических и социально-политических аспектов генетических исследований и технологий, а также оценке того, в какой степени международная правовая сфера в состоянии их регулировать. Методологической основой исследования выступают дискурсивный подход, хронологический метод, а также ряд методов, присущих правовой науке. Анализ научной литературы позволил выделить проблемы генетики, унаследованные ею от евгеники (редукционизм и установление баланса между частным и общественным), а также исследовать проблему дискриминации граждан по генетическим признакам. Доказано, что большой вклад в развитие этических принципов в области генетических исследований внесли представители биоэтики, именно они рассматривались как точки отсчёта при разработке международного законодательства. Одна из ведущих нормотворческих ролей в области биоэтики по праву принадлежит ЮНЕСКО. В то же время отмечено, что декларации, выработанные этой организацией, имеют слабые стороны (необязательный характер, отсутствие практических рекомендаций и др.). Несмотря на это, приведены аргументы в пользу продолжения работы комитетов по биоэтике.

Ключевые слова: генетические исследования, права человека, личное достоинство, дискриминация, этика, евгеника, правовое регулирование.

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Introduction

In recent years, the rapid development of new technologies in the field of genetic research and genome editing has become the topic of considerable scientific interest. Numerous works have been devoted to studying the role of genes in determining the healthy life of an individual, as well as how the expression of genes can be influenced by the environment (Wastell, White, 2007: xii). A major contribution to scientific knowledge in this field was made by the Human Genome Project (HGP, 1990–2003), the world's largest genetic research project, whose most notable result was the creation of a human genetic map (NIH, 2020).

One of the reasons for the recent explosion of interest in genetic research is due to its apparent applicability for solving actual human health problems. For example, prenatal screening methods are used to identify hereditary fetal pathology in the early stages of a pregnancy. Moreover, the developing field of gene therapy involves the introduction of engineered genetic constructs into a body to restore or replace a gene identified as defective.

In addition to healthcare fields, genetic research is increasingly applicable in various legal and social contexts, e.g. to determine the biological relationship between two potentially related individuals or to discover the identity of an unknown corpse. There is a continuing strong demand for breakthroughs in therapeutic applications that could be of benefit in overcoming immune diseases, as well as prolonging life and improving its quality.

Theoretical bioethical framework

Due to having significant potential consequences for human beings, it is generally accepted that medical applications of genetic technologies must be governed according to bioethical criteria. The interdisciplinary field of bioethics, which focuses on the moral implications of human activity in medicine and biology, has been actively developing at the intersection of law, ethics and natural sciences since the 1970s.

While the ethical consequences of applied genetic technologies comprise the proper domain of specialists working in the fields of bioethics and clinical studies, the involvement of a wider circle of disciplines (e.g. philosophy, sociology, etc.) should also be assumed due to the significant implications for future human society. Thus, the present paper will focus on the considerable interest generated by investigations into the ethical aspects of genetic technologies in relation to eugenics (Ricci, 2009; CH G., & B A., 2008; Newman, 2010) and transhumanism (Vvedenskaya, 2014; Kovba, Gribovod, 2019), as well as the consequences of emerging governmental and business practices that arise in response to advances in genetic technology (Salardi, 2014; Khen, 2003; Anomaly, 2018).

Problem statement

The rapid development of new technologies in the field of genetics poses numerous challenges both for the international community and individual nation states in terms of their regulation. Since many of these technologies have not previously been tested or widely implemented, the immediate and long-term consequences of their use remain controversial. Thus, for example, significant contemporary concern is aroused by genetic experiments on human embryos. In 2018, experiments conducted by the Chinese scientist He Jiankui, in which embryos subjected to genetic modification resulted in the birth of twins, were broadly discussed in the media and by the scientific community (Mironov, 2019). The ambivalence of the scientific and public response to this research project and its results demonstrates the current incapacity of the legal system, as well as the wider community, to arrive at a general consensus regarding genetic research.

At the same time, due to the increasingly widespread availability of such technologies, the risk of such genetic experiments leading to dangerous consequences can only be expected to increase. In addition, ethical problems arise concerning the provision of equitable access to genetic services, as well as the protection of genetic information.

Thus, the broad development of new genetic technologies, especially those involving experiments on humans, has already attracted significant attention to the possible consequences of their unregulated application. For this reason, the following objectives are formulated:

1. highlight the main ethical challenges posed by genetic research and inherited from eugenics (reductionism, balance between private and public), as well as the related problem of discrimination on genetic grounds;

2. consider the ethical problem of genome editing in terms of the present "liberal" or transhumanistic trend as against a proposed, more balanced bioethical approach;

3. summarize the historical development and contemporary state of international legislation in the field of genetic research.

Methods

The present paper discusses both Russian and foreign literature sources concerning ethical, socio-political and legal aspects of genetic research, which were selected on the basis of their transparency and examined according to a number of perspectival contexts. Among these, a discursive approach was chosen in order to study the family of ideas having developed around eugenics and genetics over the course of time. A lack of consistency revealed by the research process is addressed by taking a chronological approach to investigation of the legislation in the field of genetics, starting with the Nuremberg Code 1947 and continuing until the acts of the present day.

Discussion

1. Weaknesses of genetics: reductionism, government control and discrimination

A quick glance through post-WWII literature reminds us that one of the chief fears

still associated with the tragic events of the 20th century concerns the possibility that advances in genetic engineering will invoke the same issues that discredited the ideology and practice of eugenics. At the Third International Congress of Eugenics (New York, 1932), eugenics was defined as a "biological metascience of man, combining distinctly different disciplines like population statistics, genetics, anthropology, psychometric analysis, history and religion, into a form of preventive medicine that endeavours to define and eradicate inherited illnesses" (Ricci, 2009: 11). A number of eugenicists, such as Charles Davenport, Harry L. Laughlin and Henry G. Goddard, believed that inherited traits included not only genetic diseases, but also social vices, such as the tendency to commit crime or even simply to live in poverty (Chousou D., et. al., 2019: 145). During the early 20th century, eugenics departments were opened in prestigious universities such as University College London and Harvard. Eugenics societies founded by prominent scientists like Karl Pearson and Charles Davenport found enthusiastic worldwide support (Allen, 2011:314). However, it was under Nazi rule when the most notorious examples of eugenic practices were carried out. Fortunately, their ideas have been consistently condemned and discredited following the defeat of Nazi Germany in 1945.

Since then many of the concepts developed in such discourses appear to have been carried over into genetics (CH & B, 2008: 22). For example, from the mid-1940s onwards, the practice of genetic counseling, initially based on genealogical data, but subsequently supported by DNA analysis, became widespread. Following the 1953 discovery of the double helix DNA structure by Francis Crick and his colleagues, other breakthroughs, such as the development of an effective method for in-vitro fertilization (IVF), stimulated public interest in the wide possibilities offered by genetic science, reopening discussions about the possibilities of "improving" human beings (Kovba, 2020, p. 13). Nevertheless, some critics argue that conveniently forgotten coercive practices carried out under the banner of eugenics have been surreptitiously reintroduced under the

cover of the ostensibly voluntary nature of personal genetic testing (Newman, 2010: 33).

In general, critiques of genetic research problems inherited from eugenics are focused on two specific issues:

1) reductionism and biological determinism;

2) a disbalance between private and public spheres in terms of the possibility of state intervention in the regulation of genetic selection.

Critics of the reductionism common to both eugenics and genetics generally object to the use of a set of methodological principles according to which complex phenomena can be explained in terms of observable laws applying to simpler phenomena (Ricci, 2009, p. 22). For such critics, both disciplines tend to reduce the value of a human to his or her genetic makeup by ignoring other relevant factors, e.g., cultural, emotional, spiritual or educational. Such reductionism seems to be associated with a strong desire to determine the significant parameters of human nature once and for all.

However, according to the legal framework of universal human rights, there are precedents that militate against the use of genetic information to determine the legal basis of a person. Commonly cited examples of historical mistakes feature "constitutive rules to punish individuals not for their actions, but for what they are: the punishment of witches in the Middle Ages, the penal sanctions of heretics, the persecution of Jews" (Salardi, 2014: 200).

In terms of government regulation and control, it is generally accepted in contemporary Western societies that genetic services are to be provided solely on a voluntary, properly informed and individual basis. This contrasts with eugenic practices, where coercive (or conditionally coercive) decisions to select a person for testing are taken by civil authorities. Nevertheless, issues associated with state interventions justified in terms of the health and safety of populations remain quite acute today. Thus, Jonathan Anomaly argues that "the state may (in some cases) require us to act in ways that promote social welfare when we find ourselves in collective action problems in which each of us has an incentive to act one way, but most of us are better off if most people act in another way" (Anomaly, 2018: 29).

Although such arguments in favour of modern "liberal eugenics" remain controversial, Anomaly's opinions are not necessarily anomalous (pun intended). In the context of the rapid development of genetic technologies, the temptation to interfere with human genes in order to regulate human reproduction is likely to become irresistible due to the ease with which such actions may be justified in terms of the interests of society as a whole. It may therefore be concluded that only a fully developed civil society having adequate laws for protecting the legal status of individual citizens is capable of maintaining the necessary balance between individual and collective interests. In the absence of such laws, not only authoritarian, but also democratic states are likely to increase measures to control and coerce their citizens in order to achieve collective goals.

The issue of state control over the genetic structure of the population gains additional significance when discussing problems associated with passportisation carried out on the basis of genetic screening. Not a long time ago debates on this topic were opened in Russia following the signing of decree No. 97 in March 2019, according to which it is proposed to "carry out genetic certification of the population, taking into account the legal basis for the protection of data on the personal genome and the formation of a genetic profile of the population" (Kremlin, 2019). In this regard, a number of problems arise: (1) since there is no existing definition of a genetic passport in Russian normative acts, it is not clear what information the passport should include (Abrosimova, 2020: 137); (2) an algorithm for the secure communication and storage of genetic information is yet to be developed; (3) the high cost of such a passport raises serious doubts that this idea will be implemented in practice within the next five years (ibid: 140).

As seen from the above, both populationbased genetic projects currently being implemented are reliant on the voluntary provision of genetic data. As screening procedures become more available and affordable, this practice will likely be introduced in many developed countries. However, public reception to the widely-discussed notion of introducing genetic passports is more ambiguous. For example, the Scientific Institute of Public Health in Belgium, called Sciensano, conducted a public opinion survey on the possibility of introducing a genetic passport for all citizens in 2019-2020. Among positive aspects, respondents identified the following: (1) a genetic passport will provide an understanding of human health, improve individual diagnosis, treatment and prevention; (2) more efficient patient management, since healthcare providers would access all relevant health, medical and genetic information of patients more directly; (3) wider use of genomic information for forensic purposes (e.g., in identifying criminals) (Mayeur, Saelaert, Van Hoof, 2021: 6).

At the same time, respondents who are suspicious of the idea of introducing genetic passports, or who categorically reject such a proposal, make the following objections: (1) a genetic passport would strengthen official control over the population, limiting individual freedom of action; (2) the centralization of genomic information increases the risk that educational institutions, banks, insurers, commercial companies will be able to use this information to discriminate against the population (Mayeur, Saelaert, Van Hoof, 2021: 7). The researchers note that, in order to ensure public confidence in the implementation of such a policy, health sector leaders and experts need to take into account the feelings expressed by the survey respondents (insecurity and vulnerability from government and other organizations having access to all data about a person) (ibid .: 8). It's also highly necessary to create both national and international legal frameworks for ensuring personal data protection in order to reduce the risk of discrimination based on genetic characteristics. In particular, such risk may increase in the remit of health insurance and employment.

2. Bioethical perspectives

on interference with the human genome

In terms of the level of interference considered permissible, debates around the ethical aspects of genetic interventions vary considerably depending on the basic approach. Generally enthusiastic attitudes presented in transhumanist discourses contrast with the strong criticism or outright categorical rejection expressed by many religious commentators. After briefly considering these diametrically opposed positions, we will dwell in more detail on the more balanced and cautious approach taken by bioethics that falls within the scope of our research.

In Russian transhumanist discourses, it has been claimed that interference with the human genome is *a priori* a moral action since the natural needs of a human being include improving his/her biological characteristics (Gerasimov, 2019: 64). Furthermore, genetic research is asserted to be ethical due to being concomitant with the "desire to create" (ibid.). Proceeding in such an attitude of scientific optimism (or blind faith in progress), researchers associated with the transhumanist movement tend to minimize concerns about the dangerous uncertainty inherent in human genome editing as present in all innovative processes. According to this ideological position, the universal aim of selfimprovement should include selective tweaking of both physical and intellectual characteristics. Here, it is important to acknowledge a key distinction between eugenics and transhumanism: while eugenics envisaged the development and implementation of state-controlled programmes for improving the health and "quality" of entire populations, transhumanism is generally based on the concept of individual choice (Kovba, Gribovod, 2019, p. 43). Transhumanist ideas concerning the possibility of genetic improvements might seem to correspond to the contemporary liberal-democratic value system, in which citizens are encouraged to develop their individuality along with their personal prosperity.

Although many transhumanists (e.g. Bostrom, 2003: 504) endorse the use of both somatic and germ-line gene therapies (at least those that are medically justified), there is a significant ethical distinction between treating an individual patient's genetic disorders and changing the genome of his or her descendants (Vvedenskaia, 2014, p. 36). This may explain why the ideas of transhumanists have gained so little support in Russia. Even among young people, the social category most inclined to take risks and accept novelties, there is a tendency to reject such ideas. For example, according to an opinion poll carried out in 2016–2017, only 33.3 % of young people supported the idea of artificial reproduction, while an even smaller proportion approved more radically ambitious projects such as transferring a human mind to a computer or overcoming a person's basic biological limits (Davydov, 2018: 43).

According to the bioethical approach, gene therapy for somatic cells is generally considered to be unobjectionable if carried out in accordance with the ethical standards developed by the Council of Europe (Convention on Human Rights and Biomedicine, 1996) and UNESCO (The Universal Declaration on the Human Genome and Human Rights, 1997). However, since "some phases of the normal development of the embryo can be disturbed with severe negative consequences, and these disturbances can be passed on to subsequent generations", bioethicists typically draw the line when it comes to interventions in the germ-line (Vvedenskaia, 2014, p. 37) or programmes aimed at creating "designer babies" having genetically tweaked mental and physical parameters.

The basic principles of bioethics, which assert the autonomy, dignity, integrity and essential vulnerability of the individual human being, have been discussed by Jacob Dahl Rendtorff and Peter Kemp in terms of providing "a normative framework for the protection of the human person in biomedical development" (Rendtorff, 2002: 235). For example, the concept of autonomy corresponds with the capacity of an individual to have ideas and life goals, gain insights, make decisions and take personal responsibility for his or her actions. The principle of dignity expresses the intrinsic value of a person and fundamental equality of all people. However, according to Rendtorff, the idea of integrity is paramount due to its association with the private personal sphere, which should not be subjected to external violation. Finally, the concept of vulnerability is asserted in terms of a necessary balance "between this logic of the struggle for immortality and the finitude

of the earthly presence of human suffering" (Rendtorff, 2002: 237).

Further research on this topic has resulted in a comprehensive consideration and interpretation of these principles, as well as the proposal of additional concepts pertaining to bioethics. In particular, human dignity has been asserted as the broadest concept of human rights applying to the biotechnological context (Francioni, 2006: 14).

Despite the principles of autonomy, dignity, integrity and vulnerability being generally shared by the European community, these tenets are reflected differently in the legislation of individual EU states. In other parts of the world, the contrasts become even more striking. However, regardless of any prejudice against non-European countries, with the gathering pace of globalization, a consensus about what is considered to be normal and what should be prevented is starting to form. If this were not so, He Jiankui's announcement of the birth of genetically-modified human twins might really have demonstrated the People's Republic of China to be "a wild land where bioethics matters little" (The Hastings Center, 2018). However, almost immediately following the announcement of He's results, 122 Chinese scientists signed a public statement condemning his actions (ibid.).

To summarize this section, a number of ethical problems have been inherited by genetics from eugenics. Firstly, we can observe a trend towards reductionism and biological determinism, which implies the valuation of a person in accordance with the quality of his/ her genes. Secondly, both eugenics and genetics rely on knowledge concerning the hereditary characteristics and health of individual persons, which can in principle be used to discriminate against them. In terms of affecting private life, such interventions can take various forms, including reproductive control and selection, as well as the imposition of genetic passportization, the use of genetic testing when hiring employees, etc. In reaction to this tendency, we can observe a growing concern that discrimination against individuals may disrupt the healthy balance between individual and collective interests. Thus, the contribution of

bioethics to the development of principles and laws that ensure the legal status of individual citizens is significant in maintaining such a balance. In what follows, we will highlight procedural issues associated with the development of international legislation governing genetic research and manipulation.

3. The historical development and contemporary state of international legislation

The primacy of individual interests over those of science and collective society was notably asserted in the Nuremberg Code (Iudin, 1998). In the context of the present work, it is important to acknowledge its central importance, since it was here that the need for informed consent in order to protect human rights was first stated. According to researchers, the main value of the code consists in its synthesis of Hippocratic ethics and the protection of human rights (Shuster, 1997, p. 1439).

For a long time, this document was applied only to the crimes committed by the Nazis, whose excesses of brutality are widely considered to have gone beyond the bounds of all reason. However, issues concerning the health and dignity of subjects participating in medical research have frequently been ignored since the Code's publication. Nevertheless, in response to the questions raised therein, attitudes towards the conduct of medical experiments on humans started to change, especially during the mid-60s. The concept of human rights featured centrally in laws governing experimentation on human beings passed by many countries towards the end of 20th century. National laws concerning medical research are typically based on the Declaration of Helsinki (1964, by the World Medical Association, WMA; regularly updated) (Talantov, 2019: 246). Although this declaration has no legal force, it serves as a normative ethical guide. There are numerous international agreements following on the matter of genetic research, but no specific provisions appear in these documents, which may be explained in terms of the underdeveloped state of the applicable technologies at the time of their signing.

In addition, the Human Genome Project has been vigorously challenged in the scientific community since its launch in 1990 on the basis of the risks of certain negative consequences to humanity that it represents. For example, Shawn Harmon points out that scientific progress has contributed to "man, for the first time, [having] the power to transform living matter in a programmed and selective manner" (Harmon, 2005: 23). This situation prompted UNE-SCO to start developing an international bioethics instrument specifically concerned with human rights and genetics (ibid). The following important documents (UNESCO, n.d.) have set a high bioethical standard:

• Universal Declaration on the Human Genome and Human Rights (1997);

• International Declaration on Human Genetic Data (2003);

• Universal Declaration on Bioethics and Human Rights (2005).

Among the most important provisions of the Universal Declaration on the Human Genome and Human Rights, the following should be noted: the human genome is recognized as "the heritage of humanity" (Art. 1); any procedures affecting an individual's genome should be carried out only "after rigorous and prior assessment of the potential risks and benefits" (Art. 5); no-one "shall be subjected to discrimination" on the basis of his/her genetic characteristics (Art. 6); reproductive cloning of human beings "shall not be permitted", being contrary to human dignity (Art. 11).

Having analyzed the provisions of the Declaration, it became clear this document appeals to the principles of autonomy, equality and solidarity, along with related rights including non-discrimination, consent and confidentiality, while related obligations consist in avoiding dangerous practices and providing full information. Scholarly assessments of the provisions include "the Declaration is not a failure, but an equivocal success" (Harmon, 2005: 45) and "the most thorough global initiative to date addressing the need to protect human rights with respect to genetic advances" (Taylor, 1999: 509). However, the presence of several lacunae can be noted. For example, the Declaration can be criticised for failing to cover important issues of human embryo research, high-tech genetic methods for selecting the sex of a child, the choice of abortion for various genetic disorders or restrictions on state interference in the process of making reproductive decisions. Nevertheless, despite such criticism, UNESCO has succeeded in identifying shortterm and long-term problems associated with genetic research, as well as stimulating scientific and public debate crucial for the development of bioethical thought.

Thus, the Declaration should be seen not as the final expression of an international consensus on advances in genetics, but only as a first step towards such international cooperation.

The expansion of genetic testing practices has presented the international community with the daunting challenge of protecting human genome data due to the significant amounts of such data that have already been accumulated. As a result, the 2003 UN General Conference adopted the International Declaration on Human Genetic Data. In particular, this document consolidated the special status of human genetic data (Article 4) and asserted the necessity of proper measures ensuring "accuracy, reliability, quality and security" of this data (Article 15). However, some commentators object that this document is weak in terms of its normative force and effectiveness: "the drafters of the text have carefully avoided to frame the Declaration in terms of rights of individuals (patients), except in relation to the right to decide (not) to be informed about research results (article 10)" (Abbing, 2004: 93). The 2005 Universal Declaration on Bioethics and Human Rights considers the relationship of science, freedom and ethics in terms of "how far can we possibly go in scientific research?" (UNESCO, 2005). This document appears to respond to the urgent need to establish universal standards in the field of bioethics, taking the concepts of human dignity and human rights into consideration.

Even if only 29 of them subsequently ratified it to incorporate its principles into their national legislation, the 1997 signing of the Convention for the Protection of Human Rights and Dignity by a total of 35 states (including Russia) was a significant step in the history of genetic research legislation. According to the terms of the Convention, the interests of the individual are given priority over those of a particular society or science (Article 2): no medical intervention must be carried out until the individual patient has given his or her free and informed consent (Article 5); any form of discrimination on the grounds of genetic heritage is prohibited (Article 11); no intervention in a human genome may be undertaken other than for preventive, diagnostic and therapeutic purposes (Article 13); the creation of human embryos for research purposes is prohibited (Article 18).

Having analysed the above mentioned documents, we found their main principles to be based on respect for human dignity, rights and freedoms, as well as upholding the principle of autonomy. Since the genetic data of a person is confidential, it cannot be used as grounds for discrimination. In other words, the main ethical standards governing biomedical research are to incorporate principles of fairness, mercy and respect.

Conclusion

In this article, we have focused primarily on the ethical and socio-political issues involved in contemporary genetic research, as well as the state of the current international legislation for their regulation. The analysis has shown that some of the ethical problems faced by genetics (danger of discrimination against citizens based on genetic characteristics, genetic reductionism and determinism, dubious balance between public and personal interests) were inherited from eugenics. In this regard, we conclude that, when regulating research that entails changes in human nature, it is necessary to navigate somewhat closer to the Scylla of stifling regulation than the Charybdis of baby designing. That is, while restrictive and protective measures are needed in the form of laws, and an absolute prohibition on genomic research is not very practicable since it would impair the development of science. Our analysis has shown that such a balanced position is characteristic of bioethics discourses. The principles of individual autonomy, dignity, integrity and vulnerability proposed by bioethics became the starting point for the development of basic international norms. As genetic manipulation technology has developed over time, this set of principles has been refined and expanded.

From our study of existing legislation in the field of genomic research, we identified a continuity between earlier legal documents (1948–1949) and those that developed later. Although the earlier documents did not contain provisions directly regulating genomic research, it is there that the legal basis for the protection of human rights and non-discrimination was first laid down. It can be stated that the leading positions in establishing norms in the field of bioethics were exercised by European countries and UNESCO, the latter organization having convened an intellectual forum aimed at solving ethical problems in areas of genetic research. However, critical analysis of UNESCO documents carried out by a number of researchers has drawn attention to their normative weakness, non-binding nature, lack of practical recommendations, as well as some lacunae when it comes to certain novel genetic technologies.

Despite all this criticism, there are several reasons for defending the activities of bioethical committees. Firstly, the detailed regulation of particular activities lies outside the remit of international documents. Such specific issues are left to national legislatures, where general principles are open for interpretation due to their expression in specific laws depending on many factors such as cultural differences, market conditions, available genetic technologies, etc. If a particular state decides to adopt an international declaration or convention at the national level, it may result in the transition from soft law to binding law. Secondly, since it is not always possible to foresee the emergence of new technologies emerging from scientific research, it is quite rational to limit the purview of such declarations to general ethical principles. Thirdly, such ethics committees contribute to an emerging social consensus on complex issues to provide for the longer term influence of norms to be later enshrined in national legislation.

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